

**Lynn Friss Feinberg, MSW**, is Deputy Director of the National Center on Caregiving at the San Francisco-based Family Caregiver Alliance. She was director and first author of a recently completed 50-state survey, funded by the U.S. Administration on Aging, to profile the "State of the States in Family Caregiver Support." In recent years her research has focused on choice and decision-making for persons with cognitive impairment and their families, and she is co-investigator of a longitudinal study of caregiver mental health. She has served on numerous national advisory committees and panels addressing long-term care issues and is an author on over 40 publications. Ms. Feinberg holds a master's degree in social welfare and gerontology from the University of California at Berkeley.



# Family Caregivers: The Backbone of Long Term Care

**Lynn Friss Feinberg, National Center on Caregiving**

## The Issue

When we think of long-term care, we usually picture an elderly person in a nursing home; however, families provide the vast majority of support and direct care to frail elderly and persons with disabilities.<sup>1</sup> As Figure 1 shows:

**Family caregiving has enormous economic value.**

- 78% of adults (18 and older) receiving long-term care rely **solely** on informal help, most often provided by family members (e.g., wives and adult daughters)
- 14% receive a combination of family care and paid assistance
- Only 8% rely exclusively on formal care.<sup>1</sup>

Family caregiving has enormous economic value (see Figure 2):

- With an estimated value of \$257 billion nationally (2000 dollars), it surpasses costs of home health care (\$32 billion) and nursing home care (\$92 billion) combined.<sup>2</sup>

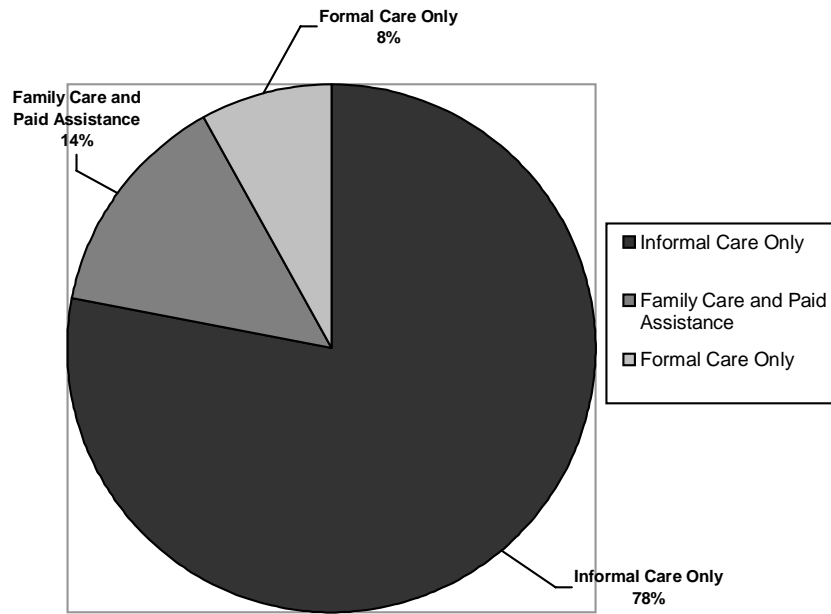
**Federal and state policymakers are now recognizing the important role family caregivers play in easing the burden on the more expensive formal long-term care system.**

Until recently public policy has neither acknowledged nor supported service needs of family members in their caregiving role. However, federal and state policymakers are now recognizing the important role family caregivers play in easing the burden on the more expensive formal long-term care system. Indeed, the availability of family and informal caregivers is often the deciding factor in determining whether an individual can remain at home or must turn to more costly nursing home care.<sup>3</sup>

Although the federal government has increased its role in financing caregiver support for older people through the National Family Caregiver Support Program (NFCSP), states still lead the effort in recognizing and supporting the family caregiver. Because little was known about the experiences of states in providing caregiver support, the Family Caregiver Alliance, with funding from the U.S. Department of Health and Human Services Administration on Aging, undertook two studies to learn more about how states are implementing caregiver support.<sup>4 5 6</sup> This report is a brief summary of findings from those and other studies of state initiatives [Feinberg, Hunt, et al., 2004].

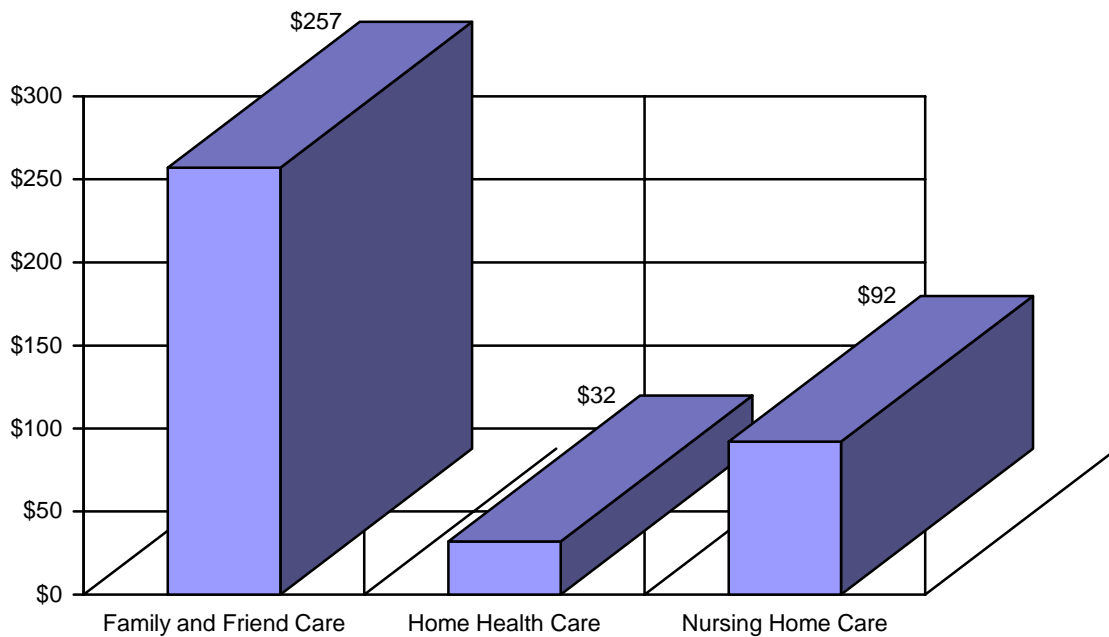
*1. Informal care is provided by a family member, friend or volunteer and consists of assistance with a range of activities, including hands-on help with personal care needs; running errands or assisting with transportation; helping to educate the consumer about their health and long-term care needs; arranging and/or providing financial assistance for health and long-term care needs such as medications, doctor visits, and formal care. Formal care consists of assistance from paid providers, often paraprofessionals such as personal assistants or home care aides; this care can be provided in-home or in a facility such as an adult day care center.*

**Figure 1: Type of Care Received**



Source: Thompson, L. (2004, March). *Long-term care: Support for family caregivers* (Issue Brief). Washington, DC: Georgetown University, Long-term Care Financing Project.

**Figure 2: Value of Family Caregiving**



Source: Arno, P.S (February 2002). "The Economic Value of Informal Caregiving," updated figures presented at the American Association for Geriatric Psychiatry meeting, Orlando, FL

## What Strategies Are States Using to Support Family Caregivers?

**Family caregiver support programs are part of a larger configuration of services, known as home and community-based services (HCBS), whose goal is to maintain frail elderly and disabled persons in their own homes as an alternative to institutional placement.**

**Most states face a difficult balancing act between sufficient flexibility to encourage individualized options and the need to set statewide standards.**

**States are using federal and state funding streams to support family caregivers.**

Family caregiver support programs are part of a larger configuration of services, known as home and community-based services (HCBS), whose goal is to maintain frail elderly and disabled persons in their own homes as an alternative to institutional placement. Most services are targeted directly toward the elderly or disabled person; family caregiver services are one component of this system of HCBS. In general, these programs are administered by the local Area Agencies on Aging (AAAs).

States are using four main approaches to caregiver support:

- Enhanced Direct Services
- Consumer-Directed Options and Financial Compensation
- Tax Incentives
- Workplace and Family Leave Policies

[For a summary of Michigan programs, see chapter 3 page 26.]

### **Strategy 1: Bolster direct services**

States vary widely in how services are organized and integrated into service systems. Two states (California and Pennsylvania) have comprehensive programs that were started using state general funds. Most states face a difficult balancing act between giving local Area Agencies on Aging (AAAs) sufficient flexibility to encourage individualized options and the need to set statewide standards for uniformity of core services. In the majority of states, caregivers in different parts of the state cannot access the same package of services.

The following services are offered by most states:

- **Respite care** (temporary alternative care) is the service most typically funded by states. The definition of “respite” and eligibility criteria vary widely across states; the number of available services varies within states. [In **Michigan**, respite care is offered through state- and federally-funded programs; adult day services and in-home care are available.]
- **Supplemental services** (e.g., assistive devices, consumable supplies, home modifications) are seen as another high priority need of family caregivers. [**Michigan** funds some supplemental services through its two programs receiving federal funds, MI Choice and the Family Caregiver Support Program].

### **How are states funding expanded services?**

States are using federal and state funding streams to support family caregivers. Major sources include:

- **The National Family Caregiver Support Program (NFCSP)**. This federal program was authorized by the Older Americans Act of 2000 to support the important role that family caregivers play by offering states the opportunity to provide for caregiver needs directly. It allocates formula grants to states based on population and in FY 2005 \$163 million (including \$6 million for Native American caregivers) was allocated to the program – a \$4 million increase over the prior year. While there are no income eligibility requirements for the NFCSP, states are required to give priority consideration to persons in greatest social and economic need, with

particular attention to low-income, minority individuals. The NFCSP allows states to provide to family caregivers:

- Information to about available services
- Assistance in gaining access to supportive services
- Individual counseling, support groups, and training
- Respite care to temporarily relieve caregivers
- Supplemental services on a limited basis to complement family care
- **Home and Community Based Medicaid Waivers [MI Choice in Michigan].** These waivers allow states to provide certain home-based services to low-income persons who otherwise would be eligible for institutional care. Services provided under Medicaid waivers must be directed toward the recipient rather than the family system. However, waivers allow states to offer support indirectly to family caregivers by:
  - Paying for respite care
  - Purchasing supplementary services, such as home modifications, education, and training
  - Expanding eligibility to include individuals with incomes up to 300% of standard Medicaid eligibility [In Michigan individuals with disabilities are eligible for Medicaid if they receive Supplemental Security Income; elderly persons are eligible if their income is more than 100% of the Federal Poverty Level]
- **Tobacco settlement money.** Several states<sup>11</sup> are using portions of their tobacco settlement funds in programs for family caregivers. [Michigan funds a caregiver respite program with tobacco settlement funds].
- **State general funds.** The NFCSP requires a 25% match, which states generally meet using some combination of state general funds, local funds and in-kind contributions.<sup>111</sup> In addition, states such as California, Pennsylvania and Washington commit significant state general funds for explicit caregiver support programs providing a range of services (e.g., caregiver assessment, family education and training, individual/family counseling, respite care and/or cash grants or reimbursements for services) to family caregivers in their state. [Michigan uses Blue Cross/Blue Shield Escheat funds to support respite care.]

***Home and Community Based Medicaid Waivers allow states to provide certain home-based services to low-income persons who otherwise would be eligible for institutional care.***

## **Strategy 2: Promote Consumer Direction and Direct Financial Compensation to Caregivers**

“Consumer direction” describes a range of approaches that offer choice and control for people who use services to help with daily living. These programs offer families maximum control of how, when, and by whom respite is provided and/or give families the option of purchasing goods or services directly, rather than receiving them through an agency providing the services. Popular consumer-directed options include:

- Vouchers that family and informal caregivers can use to purchase supplemental services
- A variety of respite service options
- Direct payments to family caregivers

***“Consumer direction” describes a range of approaches that offer choice and control for people who use services to help with daily living.***

11. Florida, Georgia, Iowa, Michigan, Nebraska, Nevada, Pennsylvania

111. A state may use other funds currently used for related programs to match the federal NFCSP so long as such monies are not from other federal sources, e.g., Medicaid, and are not used to match other programs.

States vary widely in the extent to which family caregivers have consumer-directed options:

- **Illinois** allows AAAs to offer vouchers (averaging \$1,000 per year) to family caregivers for goods or services ranging from home modifications to lawn care.
- **Georgia** is involved in a demonstration project to develop self-directed care projects for elderly in rural areas who are not eligible for Medicaid.
- **North Dakota** is addressing a **shortage of direct-care workers in rural areas** by allowing payments of up to \$700 per month to eligible spouses or other family members who provide care to individuals who might otherwise be eligible for nursing home admission. Costs are far less than the estimated \$3,200 per month for nursing home care.
- **Arkansas, Florida, and New Jersey** initiated a program called **Cash and Counseling**, which pays cash allowances, coupled with information services, directly to consumers to purchase services. Begun as a demonstration project funded by the Robert Wood Johnson Foundation and the U.S. Dept of Health and Human Services, it has expanded to 10 states because of early success.<sup>7</sup> [Michigan has a Cash and Counseling program that was initiated in 2004.]
- **Michigan** has a voucher program and allows consumer choice in respite options.

**Arkansas, Florida, and New Jersey initiated a program called Cash and Counseling, which pays cash allowances, coupled with information services, directly to consumers to purchase services.**

### **Strategy 3: Expand Tax Incentives**

State tax incentives include tax credits and tax deductions. Twenty-six states and the District of Columbia offer state income tax deductions for expenses, usually up to \$2,400, or tax credits of \$500 to \$1,000. **Tax credits** are the most popular option because they generally benefit lower-income taxpayers and are often viewed as a more equitable way of providing tax incentives. [Michigan has no state tax deductions or tax credits for caregiver services.]

### **Strategy 4: Expand Workplace and Family & Medical Leave Policies**

For workers in businesses with more than 50 employees, the federal Family and Medical Leave Act of 1993 (FMLA) guaranteed 12 weeks of unpaid leave to care for a new child or ill family member without risking their job. By expanding FMLA, states can help caregivers balance work and family roles. However, since the duration of caregiving averages 4.3 years and for Alzheimer's patients can last up to 20 years, the amount of leave allowed by FMLA falls short of addressing the realities that many caregivers face.

States have expanded the scope of the federal FMLA in several ways:

- Allowing leave in workplaces with less than 50 employees (Oregon, Vermont)
- Expanding the range of needs that fall under the law (Maine, Massachusetts, and Vermont)
- Expanding the definition of "family" (Hawaii, Oregon, Rhode Island, Vermont)
- Extending leave periods (California, Connecticut, Louisiana, Oregon, Rhode Island, Tennessee)
- Offering paid leave (California)

The **California leave program**, which began offering benefits July 1, 2004, is the most comprehensive in the nation. It has the following provisions:

- Provides up to six weeks of paid leave each year by expanding the state disability insurance program to allow workers to care for an ill child, spouse, parent or domestic partner
- Replaces workers' wages at the level of 55-60% of wage, up to \$728 per week
- Is 100% funded by an employee tax at an average cost of \$27 per year per worker

[At this time, Michigan has not expanded upon the federal minimum under the FMLA.]

## Key Findings from the 50-state Survey of Family Caregiver Support Programs

A recent survey of programs in all 50 states<sup>5</sup> illuminated the large role that states play in support of family caregivers of frail elderly and persons with disabilities. Key findings of the survey are discussed below.

- **Publicly funded services are increasing, but access is uneven within and across states**  
  
State administrators identified a lack of adequate resources to meet the range of caregiver needs as the top unmet need. This lack leads to gaps in services and limited options for some, depending on where they live.
- **NFCSP is emerging as a key program to enhance the scope of services, but is inadequately funded**  
  
Compared to Medicaid and other Home and Community Based Services (HCBSs), the current funding level for the NFCSP is too low to support the multifaceted needs of all family caregivers. However, it does fill a gap by providing some support to low- to moderate-income families who are not eligible for Medicaid.
- **Broad recognition of the value of uniform caregiver assessment exists; however, approaches vary greatly.**  
  
Good assessment of needs is crucial to maintaining quality services. Although a few states uniformly assess what caregivers need to sustain caregiving, the majority of state-funded and Medicaid waiver programs assess only the recipient of services. Systematic assessment of caregiver needs is central to improving policy and practice in HCBS.
- **States have different perspectives on approaches to system development, the importance of caregiver services within home and community-based care, and integration of family caregiving programs into HCBS.**  
  
Recognizing family caregivers as legitimate "consumers" is a new concept for states,<sup>4</sup> and administrators lacked agreement about how and to what extent service integration with other support programs for elderly and disabled persons should take place.

Because our current HCBS system relies heavily on family and informal caregivers, families will need more help as they struggle to balance competing demands of work, family and caregiving. A family-centered rather than client-centered approach to assessment and services should be considered as states pursue the goal of strengthening integrated systems of home and community-based care.

What Can States Do to Promote Caregiver Support?

**Recommendation 1: Pursue federal Systems Change Grants to promote a “family systems approach” to HCBS.**

In January 2001 the Centers for Medicare and Medicaid Services (CMS) announced a new grant program for Real Choice Systems Change grants to help states improve community long-term support systems for people with disabilities and their families. These grants present opportunities for aging, disability, and family advocates to shape state policy to strengthen caregiver supports.

[In 2001, the **Michigan Department of Community Health** was awarded a 3-year Real Choice Systems Change grant by CMS. The goals of the grant were to develop quality indicators across all long-term care settings; include consumers on HCBS site monitoring teams; develop web-based options to determine eligibility and to obtain and manage services; and develop models for consumers’ and families’ collective control of resources for community living. In 2001, Michigan was also awarded a Nursing Family Transitions grant and a Community Integrated Personal Assistance Services and Support grant under the Systems Change program.]

**Recommendation 2: Adopt a uniform assessment of caregiver needs in all HCBS programs in the state that provide caregiver support, and advocate for uniform national assessment standards.**

Presently, only five states using a uniform assessment tool include assessment of caregiver needs (not including Michigan). Identifying and meeting the needs of family caregivers is often the deciding factor in whether an individual can remain in the home, so understanding and addressing caregiver needs is critical to keeping individuals out of more expensive institutional care.

**Recommendation 3: Advocate for improved, uniform data collection and reporting standards in the NFCSP and other caregiver support programs.**

Accountability is key to success of the NFCSP and other caregiver support programs. However, state program administrators currently use a range of definitions and data collection methods to track expenditures, service delivery and outcomes. Uniform reporting will provide better data, which supports better decision-making and higher quality of care. Without uniform data across all programs, it is not possible to assess the quality or outcome of services.

**Recommendation 4: Conduct a statewide public awareness campaign on family caregiving or participate in national campaigns.**

The recent 50-state survey found that recurring themes were lack of public awareness about caregiver issues and the notion that caregivers do not self-identify with the term “caregiver.” Outreach to informal caregivers specifically, and to the public in general, is crucial to ensuring that families and friends have access to information and support services early in the caregiving process.

**Recommendation 5: Invest in staff training and technical assistance.**

States want to learn from the successes and challenges experienced by other states. Over 90% of survey respondents identified 5 training topics as most likely to benefit staff: 1) best practices in service delivery; 2) culturally/ethnically appropriate services; 3) program evaluation/outcome measures; 4) outreach/public awareness; and 5) caregiver assessment. State administrators expressed an interest in program design to provide a broader array of services, develop greater consumer direction and choice, and use technology to access hard-to-reach caregivers.

States can take a range of approaches to training and technical assistance. States can use federal funds from the aforementioned Real Choices grant program to develop uniform assessment instruments that include a caregiver component; implement program evaluation/outcome measures for use in programs across their state's HCBS system; and establish single points of entry. NFCSP funds could be used in a range of areas, including developing marketing and other materials to facilitate outreach and public awareness; develop best practices; and focus on delivering culturally/ethnically appropriate services. Policymakers and program administrators can build on successful models used in other states.