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**Ahead of the Curve:  
Emerging Trends and Practices  
in Family Caregiver Support**

**by**

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## Foreword

There is no doubt about it. More and more long-term care is provided at home and in the community rather than in nursing homes. Millions of family caregivers make this possible each day. Against the backdrop of growing numbers of people with disabilities needing long-term services and the fiscal constraints of federal and state governments, reliance on family and other informal caregivers is growing. As a result, caregiver programs are increasingly important in sustaining and strengthening our nation's unpaid caregivers.

Caregiver programs and supports are located in every state in the nation. Some of these programs and supportive services have been in existence for decades, but most are relatively new or are newly expanded, thanks in part to federal funding from the National Family Caregiver Support Program, enacted in 2000.

This paper highlights three “cutting-edge” trends in supporting family caregivers: assessment of caregivers' own needs; consumer direction in family caregiver support services; and collaborations on caregiving between the aging network and health care providers. The purpose of the paper is to provide policymakers, program administrators, and advocates with an overview of these emerging trends; describe state approaches and developing practices; and identify key factors fundamental to successful adoption of these strategies.

Innovation in many states is clearly afoot. This report shines a light on three of these innovations, focusing on what works, why it is important, and what is possible. We hope the ideas put forth in this report stimulate continued development of supports for persons who are the linchpins of our country's long-term care system: family and other informal caregivers.

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## Executive Summary

**Background.** Family caregiving is at the core of what sustains the majority of frail elders and adults with disabilities. Unpaid family and friends (known as informal caregivers) are a vital component of this country's health and long-term care system, but the significance of their role, and their own burdens and compromised health, are often overlooked. Unrelieved caregiver burden, exhaustion, financial concerns, and other care-related strains are major contributing factors to the institutionalization of frail elders and adults with disabilities, often resulting in higher public expenditures for nursing home costs (U.S. Department of Health and Human Services [USDHHS] 2002).

The policy direction in the states toward more home and community-based care as an alternative to institutional care depends greatly on informal caregiving. Policymakers are beginning to realize that a family-centered approach to health care and long-term care is preferred by older persons and may help curb rising costs of care.

The availability, range, and scope of publicly funded caregiver services (e.g., specialized information and assistance, counseling, support groups, education and training, and respite care) vary greatly across the United States. The National Family Caregiver Support Program (NFCSP), enacted under the Older Americans Act Amendments of 2000, along with respite care funded by Medicaid home and community-based services (HCBS) waivers and some state-funded family caregiver support programs, provide the bulk of public financing to support family caregiving.

Some states incorporate caregiver support services into their programs that serve older people or adults with disabilities. Other states view caregiver support as a separate program with distinct eligibility criteria; they seek to ensure explicit recognition of family and informal caregivers as individuals with their own service and support needs. Because states have an increasing responsibility for financing home and community-based services, there is strong interest among policymakers and program administrators in learning more about emerging trends and forward-looking practices in caregiver support that have the potential to bolster caregiving families and improve the quality of care for adults who receive long-term care at home.

**Purpose.** This report highlights three emerging trends that have important implications for increased recognition of and support for addressing the needs of caregiving families: caregiver assessment; consumer direction in family caregiver support services; and collaborations between the aging network and the health care system. The purpose of this report is to provide policymakers, program administrators, and advocates with an overview of these emerging trends, describe state approaches and developing practices, and identify key factors fundamental to successful adoption of these strategies. This report is intended to stimulate continued development and replication of these forward-looking practices to further support and sustain family and informal caregivers.

**Methodology.** This paper draws on findings from a 50-state survey of 150 publicly funded programs, conducted in 2003 by the National Center on Caregiving at Family Caregiver Alliance (FCA) in collaboration with the National Conference of State Legislatures and funded by the U.S. Administration on Aging. The study sought to provide an understanding of the range and

scope of federal and state caregiver support programs in each of the 50 states and across states. Results of the 2003 survey identified two emerging trends in the states to respond to caregivers' needs, which are profiled in this report:

- broad recognition of the value of uniformly assessing caregiver needs and caregiver assessment's central importance to systems change in home and community-based care and health care delivery, and
- emergence of consumer-directed options specifically for family caregivers.

To supplement the findings from the 2003 50-state survey, AARP contracted with FCA's National Center on Caregiving in 2005 to provide more detailed information on these emerging trends and to profile states and specific programs that are developing practices to better recognize and address the needs of caregiving families. Our objective was to select states and programs that represented a range of approaches to identifying family caregivers through assessment practices and developing consumer-directed options for family caregivers.

Based on data from the 2003 50-state caregiving survey, eight states were selected because they demonstrate innovative approaches to developing caregiver support services or integrating caregiver services into broader HCBS programs and show a commitment to experimentation. They also represent diversity on a number of factors: 1) degree of previous involvement in caregiver support services; 2) geographical representation of the United States; and 3) mix of urban and rural populations. The selected states are **Alabama, California, Georgia, Massachusetts, Minnesota, North Carolina, Pennsylvania, and Washington**. FCA's National Center on Caregiving designed a telephone interview guide to collect supplemental information on innovative approaches to these two trends from key contacts in the eight selected states.

Last, a third trend was identified based on a literature review and interviews with leaders in the field: the emergence of collaborations and partnerships between health care practitioners and local area agencies on aging (AAAs) to build programs that better recognize and address the needs of family caregivers. Within this report, we highlight two model programs that demonstrate this trend, one state-based and one national, as innovative ways to integrate the health care system and aging network to better support family caregivers.

### **Emerging Trends**

- **Caregiver Assessment:** Many states are refining their assessment instruments and protocols to streamline eligibility for home and community-based programs, improve care planning and service delivery, and ensure better outcomes. A key to effective outcomes in care settings is not just assessing the frail elder or adult with disabilities (i.e., the care recipient), but the family caregiver as well. The value of systematic assessment of family caregivers' needs in HCBS settings has gained increased attention among policymakers, state program administrators, and practitioners in recent years. This interest stems, in part, from recognition of the fundamental need to strengthen support to sustain caregiving families and help them stay "on the job" (Levine, Reinhard, Feinberg, Albert, & Hart, 2004), and to focus on quality of care. As states pursue approaches to make their long-term care systems more responsive to the needs of different consumer

populations and their families, the concept of a single, universal assessment tool for program clients, including family caregivers, is gaining attention.

- **Consumer Direction in Family Caregiver Support Services:** The emergence of consumer-directed options specifically for family caregivers is taking hold in the states and can be particularly effective in addressing the needs of families in rural areas. Family members can assume a variety of roles within consumer-directed programs, from information-gatherer and coordinator of care, to representative or surrogate decision-maker for persons with cognitive impairment, to the person paid to provide care (Doty, 2004). Several new approaches are being explored throughout the country, funded by the NFCSP. Although states with consumer-directed programs for family caregivers vary in how much choice and control are given to families to manage care, most programs include respite care. Many others include supplemental services (e.g., assistive devices, home modifications) to allow families to purchase whatever goods or services are necessary to help meet their needs and those of the people for whom they provide care.
- **Collaborations on Caregiving between the Aging Network and the Health Care System:** With the emergence of the NFCSP, states and local agencies on aging are pursuing systems development strategies through partnerships and collaborations with health care practitioners. Many people who provide assistance and care to family and friends do not recognize themselves as caregivers, and health care practitioners can help these individuals self-identify as family caregivers so they can access information and services. By proactively identifying family caregivers in primary care physician offices, rather than waiting for caregivers to seek help or continue to brave their situation alone, family caregiver support programs can reach caregivers before they experience adverse effects from caregiving. This support, in turn, may delay institutionalization of the care recipient for as long as possible.

Common themes identified across these three emerging trends and practices in caregiving include a number of success factors: clear commitment to and strong leadership for a family-centered approach in health care and HCBS; involvement of key stakeholders in program design, implementation and evaluation; development of a plan of change to avoid “reinventing the wheel”; continuous education and training of program administrators, service providers, and families; and investment in information technology.

**Summary and Conclusions:** States play a large and growing role in financing and delivering services to support and sustain family and informal caregivers, the backbone of long-term care. These three emerging trends in caregiving taking hold in the states require fundamental changes in the way program administrators and practitioners have traditionally performed their jobs.

The promising directions highlighted in this report can help to promote an exchange of new ideas among states as they pursue the goal of strengthening HCBS to address the broadest needs of the individual and the family. These approaches and innovations hold promise to promote improved caregiver outcomes, better quality of care, integration of caregiver support into HCBS, and increased well-being of both the individual care recipient and the family caregiver.



# **Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support**

## **Introduction**

Family caregiving is at the core of what sustains the majority of frail elders and adults with disabilities. Unpaid family and friends (known as informal caregivers) are a vital component of this country's health and long-term care system, but the significance of their role, and their own burdens and compromised health, are often overlooked.

An estimated 44 million Americans, age 18 years and older, provide unpaid assistance and support to older people and adults with disabilities who live in the community (National Alliance for Caregiving & AARP, 2004). While estimates of the economic value of informal caregiving vary, it is generally recognized that the market value of the unpaid labor of family care is greater than the cost of paid home care assistance. Estimates of the economic value of informal caregiving range from \$168 billion in 1996 (La Plante, Harrington, & Kang, 2002) to \$197 billion in 1997 (Arno, Levine, & Memmott, 1999). In 2000, Arno (2002) updated estimates of the value of unpaid caregiving to \$257 billion per year, greatly surpassing the combined costs of nursing home care (\$92 billion) and home health care (\$32 billion).

The challenges of family care in an aging society are a reality of daily life today for millions of baby boomers, as well as older adults, as they try to locate, access, and provide care for parents, spouses, other relatives, or friends, and as they think about long-term care options for themselves. Contrary to popular belief, most people who need long-term care depend on help from family and friends, not on paid service providers or institutions. The vast majority (78 percent) of adults age 18+ in the United States who receive long-term care at home get *all* their care exclusively from unpaid family and friends, mostly wives and adult daughters. Another 14 percent receive some combination of family care and paid help; only 8 percent rely on formal care alone (Thompson, 2004).

Among older people (age 65+) with a disability living in the community, recent trends in the use of informal and formal care suggest that formal, paid care declined between 1994 and 1999, while sole reliance on family caregivers increased (Spillman & Black, 2005). Using data from the 1999 National Long-Term Care Survey, Spillman and Black (2005) found that most older people with disabilities (66 percent) rely entirely on family and friends. Another 26 percent of older people supplement their informal care with formal care, and 9 percent use paid care only.

Family caregivers may face financial, physical, and emotional hardships while caring for a chronically ill family member or a family member experiencing an acute phase of an illness. Increased family stress and, subsequently, greater demand for health care often translate into higher costs for both families and society. The pressure on the health care system is exacerbated if caregivers seek medical or psychological help for conditions that arise from a lack of support. Unrelieved caregiver burden, exhaustion, financial concerns, and other care-related strains are

major contributing factors to the institutionalization of frail elders and adults with disabilities, often resulting in higher public expenditures for nursing home costs (U.S. Department of Health and Human Services [USDHHS] 2002).

The interests of older people and adults with disabilities in remaining at home converges with policy interests in the states to develop more home and community-based care as an alternative to institutional care. Policymakers are beginning to realize that a family-centered approach to health care and long-term care is preferred by older persons and may help curb rising costs of care. Because states have an increasing responsibility for financing and delivering home and community-based services (HCBS), there is strong interest in sustaining family caregiving and targeting policy and practice to support and strengthen families in this pivotal role. This concept builds on the strong preference of persons who require help with everyday activities to remain at home with their families and in their communities for as long as possible. It also builds on the strengths of families and helps them cope with the strain of caregiving.

This report highlights three emerging trends that are taking hold in the states, and programs within the states, that have important implications for recognizing and addressing the needs of caregiving families:

- caregiver assessment
- consumer direction for family caregivers, and
- collaborations between the aging network and the health care system.

This report seeks to provide policymakers, program administrators, and advocates with an overview of these emerging trends, describe state approaches and developing practices to recognize and address caregivers' needs, and identify key factors fundamental to successful adoption of these strategies. Although formal evaluations of these approaches are not yet available for most programs, states can adopt the innovations and use the lessons learned from these examples and emerging practices to support and strengthen caregiving families and improve quality of care for frail elders and adults with disabilities.

## **Background**

In recent years, demands on family caregivers to locate, access, coordinate, and provide everyday care have grown due to a number of factors. Advances in medical technology have increased the life span and enabled ongoing care at home. Changes in health care delivery, including shorter hospital stays and limited discharge planning, have sent relatives home "sicker and quicker." An inability to locate or pay for paid assistance leaves families with little help with personal care tasks, such as eating, bathing, and dressing. Finally, a highly fragmented and confusing HCBS system makes it very difficult to access support services.

Studies suggest that informal caregivers experience increasing stress from navigating an inefficient and unaffordable health and long-term care system; the lack of coordination and continuity among practitioners and services across care settings; and the increasing complexity of caregiving tasks being required at home with little support or preparation (Coleman & Berenson, 2004; Levine, 2004; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Because treatments for diseases and disorders are now being delivered on an outpatient basis,

family caregivers' responsibilities have expanded far beyond carrying out daily living tasks such as shopping, transportation, and personal care. Family caregivers are also handling more complex medical tasks, including administering medications, performing wound care, and monitoring health symptoms (O'Mara, 2005).

Although family caregiving is usually undertaken willingly and may bring deep personal satisfaction, it frequently takes a heavy emotional, physical, and financial toll on family caregivers themselves. A body of research spanning 25 years shows family caregivers to be a vulnerable, at-risk population that the health care and long-term care systems neglect. Family members face common concerns: health risks, financial pressures, legal quandaries, emotional strain, mental health problems, workplace issues, retirement insecurity, and lost opportunities.

Studies consistently find higher levels of depressive symptoms and other emotional problems among family caregivers than among their noncaregiving peers, particularly when they are caring for relatives with Alzheimer's disease or other dementing illnesses (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995; Gray, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Zarit, Reever, & Bach-Peterson, 1980). Various studies have also linked caregiving with serious health consequences, including increased risk of coronary heart disease; elevated blood pressure and increased risk of developing hypertension; poorer immune function; lower perceived health status; and, among older spouse caregivers, an increased risk of mortality (Kiecolt-Glaser et al., 2003; Lee, Colditz, Berkman, & Kawachi, 2003; Schulz et al., 1997; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlon, 2003).

Research suggests, however, that caregiver support services (e.g., individual and family counseling, respite care, education, and training) can help to reduce the burden, stress, and depression arising from caregiving responsibilities and can improve overall well-being (Knight, Lutzky, & Macofsky-Urban, 1993; Montgomery & Borgatta, 1989; Mittleman, et al., 1995; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Zarit, Stephens, Townsend, & Greene, 1998). Researchers have also shown that providing caregiver support services can delay nursing home placement of persons with Alzheimer's disease (Mittleman, Ferris, Schulman, Steinberg, & Levin, 1996).

Today, family caregiver support services are available in all 50 states through the National Family Caregiver Support Program (NFCSP), enacted under the Older Americans Act Amendments (OAA) of 2000. Federal support of the program was approximately \$155 million in fiscal year 2005. The NFCSP has enabled each state, working in partnership with public or private nonprofit agencies within states that plan, coordinate, and offer services to older adults, known as area agencies on aging (AAAs), and local service providers to provide services explicitly for family caregivers of persons age 60 and older.

Support services are offered to caregivers within five basic categories: 1) information to caregivers about available services; 2) assistance to caregivers in gaining access to supportive services; 3) individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems related to their roles; 4) respite care to provide temporary relief for caregivers from their care responsibilities; and 5) supplemental services (e.g., emergency response systems, home modifications) on a limited basis, to complement the care

provided by caregivers. All income groups are eligible for NFCSP services, but states must give priority to those providing care to older adults in the greatest social or economic need with particular attention to low-income individuals.

States also finance comprehensive caregiver support programs in general, or respite services in particular, using their general revenues. Some states incorporate caregiver support services into their programs that serve older people or adults with disabilities. Others view caregiver support as a separate program with distinct eligibility criteria; they seek to ensure explicit recognition of family and informal caregivers as individuals with their own service and support needs.

A few state-funded caregiver support programs offer services to middle-income families. For example, in California's Caregiver Resource Center (CRC) system, the caregiver or care recipient's income level is not a criterion for eligibility for services. In Pennsylvania, there are no income requirements for the state's core services (e.g., information and assistance, care planning) but income requirements do exist for services such as respite care or consumable supplies. Other states have allowed respite care for family caregivers or caregiver training within Medicaid HCBS waiver programs. Although Medicaid financial eligibility criteria are quite restrictive (Kassner & Williams, 1997), Medicaid HCBS waiver programs allow beneficiaries to have somewhat higher incomes, generally at or below 300 percent of the federal Supplemental Security Income (SSI) level. While there is an increasing, but modest, availability of publicly funded caregiver services, recent research suggests a great unevenness of services and service options for family caregivers across states and within states (Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004).

The three trends in caregiving highlighted in this report (i.e., caregiver assessment; consumer direction for family caregivers; and collaborations between the aging network and the health care system) have important implications for future policy and practice. These trends have emerged because of research on informal caregivers, the aging of the population, the emergence of the NFCSP, and the desire of family care advocates to increase recognition of caregivers and service options in health care and long-term care settings. This report is intended to stimulate continued development and replication of these forward-looking practices to further support and sustain family and informal caregivers.

## **Methodology**

This paper draws on findings from a 50-state survey of 150 publicly funded programs, conducted in 2003 by the National Center on Caregiving at Family Caregiver Alliance (FCA) in collaboration with the National Conference of State Legislatures and funded by the U.S. Administration on Aging (AoA). The study sought to provide an understanding of the range and scope of federal and state caregiver support programs in each of the 50 states and across states. The study also identified cross-cutting themes and issues for the future.

The 50-state study was designed to take a broad focus; researchers collected information to examine policy choices and approaches to caregiver support through state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid waiver programs, and

state-funded programs that either had a caregiver-specific focus or included a family caregiver component (e.g., respite care) in their HCBS program. Data were collected by written survey, supplemented by follow-up, semistructured telephone interviews. The researchers obtained supplemental information from public documents, public agency and research databases, state websites, and a literature review. Results of the 2003 50-state study identified two emerging trends in the states to respond to caregivers' needs, which are profiled in this report:

- broad recognition of the value of uniformly assessing caregiver needs and caregiver assessment's central importance to systems change in home and community-based care and health care delivery, and
- emergence of consumer-directed options specifically for family caregivers.

To supplement the findings from the 2003 50-state survey, AARP contracted with FCA's National Center on Caregiving in 2005 to provide more detailed information on these emerging trends and to profile states and specific programs that are developing practices to better recognize and address the needs of caregiving families. The objective was to select states and programs that represented a range of approaches to identifying family caregivers through assessment practices and development of consumer-directed options for family caregivers.

Many states are developing interesting support programs for caregivers. Among those, we selected eight states to profile because they demonstrate innovative approaches to developing caregiver support programs or integrating caregiver services into broader HCBS programs and show a commitment to experimentation. They also represent diversity on a number of factors: 1) degree of previous involvement in caregiver support services; 2) geographical representation of the United States; and 3) mix of urban and rural populations.

Three states (California, Pennsylvania, and Washington) were selected because of their long history of providing caregiver support services primarily through state general funds and their identification as leaders in caregiver policies and programs. The other five states (Alabama, Georgia, Massachusetts, Minnesota, and North Carolina) were selected because they are relatively new to providing caregiver support services; in these states, explicit support to caregiving families has emerged more recently as a result of enactment of the Older Americans Act's NFCSP in 2000. Yet these states are pioneering approaches to identifying caregivers' needs and preferences and integrating caregiver concerns into a broader home and community-based care framework.

FCA's National Center on Caregiving designed a telephone interview guide to collect supplemental program information on the innovative approaches to these two trends from key contacts in the eight selected states. Before publication, state contacts were given the opportunity to review their program summaries and verify the information.

Last, based on a literature review and interviews with leaders in the field, the authors of this report highlight a third trend: the emergence of partnerships between health care practitioners and AAAs to build programs that better recognize and address the needs of family caregivers. Within this report, two model programs that demonstrate this trend, one state-based

and one national, are highlighted as innovative ways of integrating the health care system and aging network to better support family caregivers.

Five states (California, Massachusetts, Minnesota, Pennsylvania, and Washington) exemplify the first trend to formally recognize and assess the needs of family caregivers. Six states (Alabama, California, Georgia, Minnesota, North Carolina, and Pennsylvania), and programs within those states, are pioneering the second trend toward the emergence of consumer direction in family caregiver support services. Finally, a project in the state of Maine, as well as a national project, represent the third trend of emerging partnerships between health care practitioners and AAAs for improved recognition of and support for family caregivers.

The term “family caregiver” is used broadly in this paper to include care provided by relatives, friends, or neighbors to older persons or adults with physical and /or adult-onset cognitive impairments (e.g., traumatic brain injury, Alzheimer’s disease). The persons giving care may be primary or secondary caregivers, provide full- or part-time help, and live with the individual receiving care or live separately.

The term “care recipient” refers to adults with disabilities or frail elders with long-term care needs. The term “consumer” means individuals receiving support services, either as a caregiver or a care recipient.

Each section of the report is devoted to one of the three emerging trends, and background information and the rationale for each trend’s importance to policymakers and program administrators is discussed. Within each trend, we describe model programs to demonstrate innovative approaches and barriers to program implementation and the key factors of program success.

## **Emerging Trends**

### **Caregiver Assessment**

#### **Introduction**

“Caregiver assessment” is generally used to describe a systematic process of gathering information about a caregiving situation and identifying the particular problems, needs, resources, and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need, and seeks to maintain the caregiver’s own health and well-being. The goal of the caregiver assessment is to develop a care plan that indicates appropriate provision of services and supports for the family caregiver and any measurable outcomes of such services.

The value of systematic assessment of family caregivers’ needs in HCBS settings has gained increased attention in recent years. This interest stems, in part, from recognition of the fundamental need to bolster support to sustain family caregivers, help them stay “on the job” (Levine, Reinhard, Feinberg, Albert, & Hart, 2004), and focus on quality of care for the care recipient.

In long-term care it is of central importance to meet the needs and preserve the dignity and autonomy of the person needing care. It is also important to recognize, respect, and address the needs of the family caregiver that result from the caregiving role. This family-centered approach recognizes the interconnectedness of care recipients and caregivers, facilitates continuity of care, and respects the values and preferences of the individuals assessed. Conducting a systematic caregiver assessment captures information on the caregiving situation and legitimizes the acts of listening to and directly supporting family members (The Lewin Group, 2002).

The success of most care plans, from hospital discharge to everyday care in the home, often rests on the shoulders of the family caregiver. If the caregiver becomes sick or can no longer cope with caregiving tasks, the care recipient suffers. Indeed, identifying and meeting the specific needs of family caregivers is often a deciding factor in determining whether an individual can remain at home rather than enter a nursing home. Ultimately, consistent approaches to caregiver assessment would help service providers better understand family needs and capacities; enable family caregivers to access support, contribute to optimal outcomes for the care recipient, and remain in their caregiving role as long as appropriate; and provide solid information to policymakers and program administrators to improve long-term care service delivery.

Caregiver assessments may determine eligibility for caregiver support services within explicit caregiver support programs, in broader HCBS programs, or in other settings (e.g., physician offices, hospitals). Assessments can be used as a basis for a care plan and services to support family caregivers as well as care recipients, thereby avoiding premature nursing home placement (Feinberg & Newman, 2004). Assessment data also can be used to describe the population being served and changes over time, identify new directions for service or policy

development, and examine caregiver outcomes and assure quality of care. For example, caregiver assessment data can help identify why caregivers do not receive or accept available services and suggest possible program adjustments or innovations to improve the caregiver support system (Maslow, Levine, & Reinhard, 2005).

Although systematic assessment of people with chronic or disabling conditions is now a core element of practice in medical, health, and social service settings, assessment of the family caregiver's situation lags far behind. Health care practitioners and social service providers still do not routinely assess the health risks and well-being of family caregivers, even though the family caregiver's role is generally recognized as physically and emotionally difficult.

States' approaches to collecting information on family caregivers vary greatly as well. In FCA's 50-state study on caregiving, about half of the state administrators (49 percent, 74 programs) said they assess needs, in some way, of both the older person or adult with disabilities and the family caregiver. This family-centered approach was found to be much more common among the NFCSPs (82 percent) than among state-funded (42 percent) or Medicaid waiver (22 percent) programs. Not surprisingly, Medicaid waiver and state-funded programs most commonly assess only the person with disease or disability, focusing solely on the designated client. Eight programs (5 percent) in seven states and the District of Columbia were found to assess only the family caregiver's needs, such as California's state-funded CRCs (Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004). In virtually all states, however, the researchers found that state administrators generally recognized the value of uniformly assessing the caregiver's own needs and the importance of training and technical assistance for care managers and assessors to better recognize and address the needs of family caregivers.

### **Barriers to Conducting Caregiver Assessments**

One of the primary barriers to conducting caregiver assessments is lack of recognition of family caregivers as a "client" population in health care settings and HCBS programs. Most programs and services are based on an assessment of an individual client or patient, not on the family unit. One notable exception is in palliative care. The hospice and palliative care movement has long embraced the key concept of the patient *and* family constituting the "unit of care" (National Consensus Project for Quality Palliative Care, 2004). In home and community-based care, viewing family caregivers as legitimate program clients or consumers of services is a relatively new concept for many state and local public agencies and programs and represents a paradigm shift (Feinberg & Newman, 2004).

A second barrier is the lack of consensus about how to assess family care or what should be included in a uniform caregiver assessment tool. Establishing principles and guidelines for caregiver assessment is a prerequisite for effective development and implementation of systematic assessment protocols and tools across the continuum of care. These principles and guidelines can also assist states and programs within states in adopting consistent practices in this area.

A further challenge is the lack of funding and reimbursement strategies to encourage the adoption of caregiver assessment in health care and in HCBS settings. The lack of financial



incentives creates impediments to integrating caregiver assessment into everyday practice. The absence of management information systems and electronic patient record systems is another obstacle to integrating health care and long-term care systems and hinders continuity of care.

Last, the lack of training that health care practitioners and social service providers need to conduct caregiver assessments and link the information collected to the plan of care is a key barrier. Providers must understand the caregiving process itself and its effects and risks as well as the clinical and communication skills needed to conduct an assessment. Such education and training could target care planning and interventions more appropriately, resulting in optimal outcomes for both the care recipient and the caregiver.

### **New Directions in Implementing Caregiver Assessments**

Many states are refining their assessment protocols and instruments for both care recipients and caregivers to streamline eligibility for HCBS programs, improve care planning and service delivery, and ensure better outcomes for program clients. Currently, there is no universal standard for a state assessment tool or protocol. As a result, states' approaches to assessment vary greatly by the functions performed, populations assessed, level of automation, extent of integration with other systems, funding sources available for services, administration of the assessment, and the areas assessed and questions included (Gillespie, 2005).

States are also using assessment tools to systematically assess care recipients' and caregivers' needs. For example, a caregiver interview may be part of a state's uniform assessment tool for its Medicaid waiver or other HCBS programs for older people and adults with disabilities, as in Washington State and Minnesota. Family caregivers are then connected to support services, if necessary, such as respite care, transportation, counseling, or support groups. Massachusetts is changing its assessment process by testing the use of new assessment components to address various needs and populations, including a new caregiver component. This section identifies the primary family caregiver as a distinct consumer in the HCBS system, a major breakthrough in integrating family caregiver support into a broader systems framework.

Another approach, adopted in Pennsylvania, is to use a uniform assessment process with a caregiver component for *all* publicly funded programs for older people and their families. Caregivers then have access to services that include care management, education and training, counseling, and respite care. California uses a distinct assessment tool within a state-funded caregiver support program to examine the needs and situation of family caregivers to aid in care planning and service development.

The structure of the assessment may differ by state, but all programs require an in-home interview with the caregiver that generally lasts between 90 minutes and three hours. Family caregivers are also reassessed annually or sooner if there is a significant change in the condition or living arrangement of the care recipient. For example, caregivers in California are reassessed by telephone every six months as long as the caregiver receives services. Six-month reassessments are also conducted in Massachusetts. In Pennsylvania, whenever a care recipient is reassessed, the caregiver is also assessed to determine how the situation has changed and what different services the caregiver may need.

Areas assessed vary, but all include some standardized questions to obtain information about basic demographics (e.g., age, employment situation) and caregiver stress, burden, and health status. Areas of assessment that are unique to a particular state assessment tool include the driving status of the care recipient (California); the geographical distance of the caregiver from the care recipient (California, Pennsylvania, Washington); legal, financial, and health insurance status (California, Minnesota); and the amount of consumable caregiving supplies needed (Pennsylvania). The table below outlines the areas of assessment for each tool.

Domains of Caregiver Assessment Tools by State<sup>a</sup>

Caregiver Assessment Area	<u>California<sup>b</sup></u>	<u>Massachusetts<sup>c</sup></u>	<u>Minnesota<sup>d</sup></u>	<u>Pennsylvania<sup>e</sup></u>	<u>Washington<sup>f</sup></u>
Ability to Provide Care		X	X	X	X
Care Duration	X		X	X	X
Care Frequency	X		X	X	
Demographic Information	X	X	X	X	X
Information/Education Needs	X		X		X
Long-Distance Care	X			X	X
Mental Health	X	X		X	
Physical Health	X	X	X	X	X
Social Support	X	X	X		
Strain	X	X		X	X
Willingness to Provide Care		X	X	X	
Other	X		X	X	X

<sup>a</sup> For more information on caregiver measures, see David Bass (2001), *Content and Implementation of a Caregiver Assessment*, NFCSP Issues Brief, Washington, DC, available at [http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/background/program\\_issues/Fin-Bass.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/background/program_issues/Fin-Bass.pdf), and National Center on Caregiving at Family Caregiver Alliance (2002), *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners*, San Francisco, available at [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=470](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=470).

<sup>b</sup> California Caregiver Resource Centers.

<sup>c</sup> Massachusetts Real Choice Functional Assessment Project.

<sup>d</sup> Minnesota Long-Term Care Consultation Services.

<sup>e</sup> Pennsylvania Family Caregiver Support Program.

<sup>f</sup> Washington Home and Community-Based Services.

Most states have automated their assessment systems or are in the process of doing so. Minnesota, Pennsylvania, and Washington have automated systems that can direct data entered off-site on a laptop computer into a centralized database. California is currently working to automate its client tracking system for its 11 CRCs; it will have a web-based client record system in 2006 for customized individual reports that can be generated at each CRC site, so staff can efficiently access the most current information on each family client's situation to improve care planning.

A fundamental element of success in these states' caregiver assessment models is the incorporation of systematic efforts to involve stakeholders (e.g., program administrators, service providers, and others) in the development and implementation of tool and program protocols. California and Massachusetts, for example, show evidence of this, as each state supported the involvement of care managers, social workers, and others in designing, testing, and adapting assessment tools to ensure that they were user-friendly and gathered the necessary information to determine support service needs.

Another key element of a successful assessment process is education and training. For such a process to be successful, it is critical that staff at all levels of an agency appreciate the importance of caregiver assessment (Feinberg, 2004). Each of the states profiled in this paper focused resources on staff training, which typically emphasizes the rationale for and value of caregiver assessment, how the assessment process guides and informs work with the family, and the quality and consistency of data collection. Training also reminds staff of the available services for caregivers and care recipients.

### **Outcomes or Benefits of Conducting Caregiver Assessments**

States have successfully used information collected from caregiver assessment and reassessment data to modify existing programs or develop new programs and services. In Minnesota, for example, a caregiver coach program is currently being developed where an individual "mentor" partners with a caregiver to increase competence of and confidence in the caregiving role. Pennsylvania analyzes assessment data to measure cost effectiveness, service delivery, service pricing, utilization rates, and appropriateness of the overall care delivery. The state also measures health outcomes for both the care recipient and caregiver, such as level of stress.

The California CRCs have also used assessment data for program and policy development and public awareness of caregiving issues. For example, the state has used assessment data to develop an eight-session counseling and suicide prevention protocol to address the needs of family members suffering from depression. In addition, the systematic data have been used to promote expansion of respite options.

Anecdotal reports from California CRCs suggest that family clients appreciate the assessment process and having their situations taken seriously. The information collected during the assessment and reassessment process not only helps families with decision making, it also acknowledges their strengths and the effectiveness of their care plans (Ellano, 1997).

## **Common Themes**

A number of themes are common to these promising approaches to assessment of caregiver needs. Success factors include:

- Creating a clear commitment to increase recognition of the needs of family caregivers by conducting a caregiver assessment
- Using caregiver assessments to legitimize the needs of family caregivers as distinct from but related to the needs of the care recipient
- Involving key stakeholders (e.g., program administrators, service providers, and others) in the development and implementation of assessment tools and protocols
- Exploring valid and reliable caregiver measures before developing an assessment tool
- Incorporating tested measures of caregiver strain and burden for practical application
- Standardizing the assessment process across agencies and programs to maximize consumers' ease of use
- Ensuring reassessment of caregiver needs to identify changes in the caregiver's and care recipient's situation over time
- Linking assessment and reassessments to a plan of care for the caregiver
- Continuous education and training of assessors
- Using information technology, including automation of assessment forms and data, to improve management information systems

Appendix A includes program summaries from five states to highlight approaches to caregiver assessment that assist in tailoring care plans and support services to meet the needs of family caregivers. Included in each program summary are the common elements of and distinguishing features unique to each state model.

## **Consumer Direction in Family Caregiver Support Services**

### **Introduction**

The concept of consumer direction began with younger people with disabilities active in the independent living movements of the 1960s and 1970s (Velgouse & Dize, 2000). Over the past decade, consumer direction in HCBS has increased greatly as older adults with disabilities and their families voice their desire to shape and direct their own community-based options and care.

The distinguishing characteristic of consumer direction as a model of home and community-based care is that it allows individuals to have choice and control over how, when, and from whom they receive supportive services (NASUA/NCOA, 2004). In programs that offer consumer-directed options for caregivers, the caregiver, not the older adult or person with disability, is deemed the “consumer.” Although consumer direction is not appropriate for all people, it does offer choice and control for those caregivers who prefer and are able to direct and manage their own support services.

Consumer-directed models shift the locus of decision-making and control from the traditional service delivery approach, where the provider or payer decides what is needed and covered, to consumers and their families (Benjamin, 2001; Doty, 2004). In some consumer-directed programs, the consumer has total control over how the care dollar is spent (i.e., hiring and paying a relative to provide respite, purchasing goods or other services, etc.). Family members can assume a variety of roles within consumer-directed programs, from information-gatherer and coordinator of care, to representative or surrogate decision-maker for persons with cognitive impairments, to the person paid to provide care (Doty, 2004).

### **Consumer-Directed Services for Family Caregivers**

Most federally and state-funded consumer direction models have been established for the care recipient, while few have focused on the family caregiver (The Lewin Group, 2002). However, some states are expanding the concept of consumer direction to encompass services directed specifically to family caregivers. For example, California’s state-funded CRC system enables caregivers to choose from a broad range of respite options. In-home respite, the most widely used option, allows caregivers to receive a voucher to purchase respite services from an agency under contract with the CRC, or to use the voucher to hire someone privately (such as another family member, friend, or neighbor) to care for their relative.

The availability of consumer-directed approaches for family caregivers varies by state and by programs within states. The Older Americans Act’s NFCSP, Medicaid HCBS waivers, and some state-funded programs permit consumer-directed approaches depending on each state’s rules and regulations. For example, under the NFCSP, states may make direct payments to family caregivers or provide a voucher or budget for goods and services (e.g., grab bars, respite care) to meet their needs and those of the care recipient.

Results of the 2003 50-state study identified 106 of 150 (71 percent) publicly funded programs that offer some kind of consumer-directed option in which family caregivers benefit either directly or indirectly. The researchers found the relatively new state NFCSPs to be facilitating adoption of consumer direction in explicit family caregiving programs. Just seven state NFCSPs (14 percent) reported their service package had no consumer-directed option for family caregivers, compared to 17 Aged/Disabled Medicaid Waiver (35 percent) and 19 state-funded (38 percent) programs (Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004; Feinberg & Newman, 2005).

Consumer-directed approaches to family caregiver support services are a recent development. Hence, much of the research literature on consumer direction focuses on home and community-based programs for people with disabilities. The following sections discuss some of the reasons why consumer-directed programs for both caregivers and care recipients have been expanding as well as some of the barriers to expansion. The inclusion of consumer-directed programs for care recipients is pertinent to this paper's focus on family caregivers because of the close involvement of family members in many of these programs, such as serving as paid providers or as surrogate decision-makers for persons with dementia. In addition, many of the same issues pertain to consumer-directed approaches in general, regardless of who is receiving services.

### **Factors Driving the Expansion of Consumer Direction**

States are grappling with ways to increase consumer choice and improve quality of care and satisfaction with care arrangements. One method of achieving these objectives is to offer options for consumer-directed care. In recent years, consumer direction has become more widespread among older consumers and their families, providers, state administrators, and policymakers for a variety of reasons.

First, some policymakers and administrators view consumer direction as a potential mechanism to control costs through gaining efficiencies in both how resources are allocated and care delivery (Stone, 2000). While there is currently insufficient research to definitively assess the extent to which consumer-directed programs are cost effective, preliminary research indicates these programs may be at least "budget neutral" (Dale, Brown, Phillips, Schore, & Carlson, 2003). Medicaid expenditures for beneficiaries in the Cash and Counseling Demonstration who used consumer-directed personal care services initially increased because budgets were based on the cost of traditional services authorized in care plans, while traditional agencies fell surprisingly short in delivering authorized services. However, within two years these costs were offset by reductions in the use of other Medicaid services—nursing home care, in particular (Dale, Brown, Phillips, Schore, & Carlson, 2003).

Most programs with a consumer-directed option discount the actual dollar amount paid to the consumer relative to the cost of a comparable service package. Savings are also possible through the reduction in administrative overhead costs that would have been accrued in managing a service-package program.

Second, there is a growing shortage of frontline workers to deliver long-term care across all settings, and some view consumer direction as a method to promote more flexibility in hiring workers (including family members), thus expanding the potential pool of caregivers. Families with specific cultural/ethnic needs or those caring for someone with dementia may find that available home health aides are unable to provide culturally appropriate care due to limited language proficiency, or they cannot provide care continuity due to high turnover rates in agencies.

Last, research has shown that when given a choice between agency-based services and the independent provider or “direct pay” model, where family caregivers hire and choose their own service providers, caregivers prefer the latter because they retain control, choice, and flexibility. They also report greater well-being and higher satisfaction rates than do family caregivers receiving agency-based or “traditional” services (Gwyther, 1994; Feinberg & Whitlatch, 1998).

While some program administrators and practitioners contend that older persons are less enthusiastic about the benefits of self-direction than are younger disabled persons, when choices involve daily living, personal assistance services, and home settings, older persons—like their younger counterparts—prefer to have a say in what is done, when, and how (Simon-Rusinowitz et al., 1997; Miller, 1997; Feinberg & Whitlatch, 1998).

It is not surprising therefore that in states that allow consumers to direct their own services, program participants particularly value the freedom to hire a family member, friend, or neighbor (Feinberg & Newman, 2004; Benjamin & Matthias, 2001). In many families, consumer-directed services enable caregivers to extend the time they can provide care in the home, thus avoiding nursing home placement.

### **Barriers to Expansion of Consumer-Directed Programs**

Consumer direction represents a philosophical shift in the way services have traditionally been delivered to older adults and their families. A major barrier to successful implementation of consumer-directed services is incorporating the philosophy of empowerment and choice for the consumer into practice. Consumer direction poses challenges to traditional assumptions held by many practitioners who contend that professional intervention is not only appropriate but required, based on the client’s disability, age, or functional status. Considerable resources must be spent on training clinical staff in how to educate and counsel consumers, rather than assume a paternalistic role.

Another barrier is the concern among some policymakers and providers about greater risk of fraud and abuse and concerns about the safety of and liability and accountability for direct cash payments to consumers (Simon-Rusinowitz, Bochniak, Mahoney, Marks, & Hecht, 2000). Recent research from the first three states to report findings from the Cash and Counseling Demonstration found no major instances of fraud or abuse among Medicaid beneficiaries or their family members when beneficiaries had the opportunity to direct their personal assistance (Foster, Brown, Phillips, Schore, & Carlson, 2003; Dale, Brown, Phillips, Schore, & Carlson, 2003; Phillips et al., 2003).

There is also some controversy specifically about the utility and acceptability of offering direct cash payments to family members. Aside from questions about greater risk and abuse, critics of this approach are concerned about public-private responsibility, increased expenditures of public dollars for services frequently provided for free by families, and quality of care (Blaser, 1998; Linsk, Keigher, Simon-Rusinowitz, & England, 1992). In addition, critics are concerned that family caregivers who are paid to provide care may receive inadequate compensation, lack health care benefits, and have limited job security or career ladders. Proponents argue that paying family caregivers to provide care can be beneficial to both the care recipient and the family caregiver by increasing consumer choice, improving quality of care, expanding the limited direct care worker supply, and sustaining the natural support system (Foster, Brown, Phillips, Schore, & Carlson, 2003; Kunkel, Applebaum, & Nelson, 2004; Simon-Rusinowitz, Mahoney, & Benjamin, 1998).

Finally, the financial administration of consumer-directed programs, including the use of vouchers, fiscal intermediary services, workers' compensation, and tax issues, poses challenges to implementing consumer-directed models (Simon-Rusinowitz, Bochniak, Mahoney, Marks, & Hecht, 2000). Programs offering caregivers consumer-directed options need systematic processes for accessing information and should include training in how to best meet caregivers' needs as well as how to deliver and monitor consumer-directed services.

### **New Directions in Consumer-Directed Services for Family Caregivers**

While most states offer at least one consumer-directed option to family caregivers of older adults or adults with disabilities, considerable variation exists among states and among programs within states in the amount of choice and control they give families to manage care. Most states offering consumer-directed options for caregivers include respite care (i.e., in-home care, adult day care, weekend and overnight stays in a long-term care facility, etc.) and supplemental services (i.e., home modifications, yard work, chore services, assistive devices, etc.). Amounts offered annually for respite vary, from \$500 to \$1,500 in Alabama, up to \$3,500 in Minnesota and \$3,600 in California.

Some states provide a list of approved providers and goods for the caregiver to choose from, while others allow caregivers to hire someone privately; still others provide both options. For example, an AAA in the Northwest Piedmont Triad area of North Carolina prohibits family members and other unlicensed providers from being paid to provide respite services. In California's state-funded CRC system and in several Minnesota AAAs, caregivers may choose to purchase respite services from various home care agencies or hire someone privately, including a family member. In addition, while Alabama's NFCSP and California's state-funded program offer services through a voucher system, several of Minnesota's AAAs and Pennsylvania's NFCSP provide services on a reimbursement basis.

The following table illustrates the various funding, administration, and payment options for caregivers in the highlighted state programs.



## Consumer-Directed Programs for Caregivers

State	Statewide Program	Funding	Administration of Services	Payment
<b>Alabama</b>	Yes	NFCSP	Caregiver may pick from list of providers	Voucher
<b>California</b>	Yes	State-Funded	Caregiver may pick from list of providers; option to hire other family members	Voucher
<b>Georgia</b>	No			
Legacy Express		NFCSP	Caregiver may pick from list of providers	Voucher
SOWEGA <sup>a</sup>		NFCSP	Option to hire other family members	Direct Reimbursement
JFCS <sup>b</sup>		NFCSP	Caregiver may pick from list of providers; option to hire other family members	Voucher
Caregiver Timeout		NFCSP	Caregiver may pick from list of providers; option to hire other family members	Direct Reimbursement
<b>Minnesota<sup>c</sup></b>	No			
Arrowhead AAA		NFCSP	Option to hire other family members	Direct Reimbursement
MN Chippewa Tribe AAA		NFCSP	Option to hire other family members	Direct Reimbursement
<b>North Carolina<sup>d</sup></b>	No			
NWPCOG <sup>e</sup> AAA		NFCSP	Caregiver may pick from list of providers	Voucher
SW Commission AAA		NFCSP	Caregiver may pick from list of providers	Voucher
<b>Pennsylvania</b>	Yes	NFCSP State-Funded	Option to hire friends and neighbors (but not other family members)	Direct Reimbursement

<sup>a</sup> Southwest Georgia Council on Aging.

<sup>b</sup> Jewish Family & Career Services.

<sup>c</sup> There may be other consumer-directed programs for caregivers in Minnesota that are not profiled in this table.

<sup>d</sup> There may be other consumer-directed programs for caregivers in North Carolina that are not profiled in this table.

<sup>e</sup> Northwest Piedmont Council of Governments.

Consumer direction can be especially beneficial for families in rural communities, where caregivers have access to a smaller number and a narrower range of community-based services. In two rural counties in North Carolina, for example, a “restaurant voucher” program is being piloted, in addition to offering consumer-directed respite services and supplemental services for

caregivers. The program seeks to help ease the burden of caregivers by offering up to five meal vouchers per month for themselves and their care recipient that can be redeemed at local participating restaurants.

Aside from programs with a clear commitment to providing direct support services to caregivers, other initiatives that offer consumers the ability to manage their own care, such as The New Freedom Initiative, the federal Systems Change Grants, and expansion of the Medicaid Cash and Counseling Demonstration, may indirectly assist family caregivers in providing care. For example, the national Cash and Counseling Demonstration for Medicaid beneficiaries has expanded to 15 states, including Alabama, Minnesota, and Pennsylvania. This model is helping to fill existing gaps in HCBS by allowing family members to be paid to provide care. For the first time, in 2006, Georgia's Aged/Disabled Medicaid HCBS waiver program permits direct cash payments to Medicaid consumers receiving personal assistance services and allows family members to be paid providers.

States are using innovative approaches to advance consumer direction for family caregivers, beyond just allowing payment to families to provide care. Each of the states profiled here has found that most caregivers want and prefer a flexible approach to service delivery, and increasingly, state public policy and practice are beginning to recognize and meet these needs.

### **Outcomes or Benefits of Consumer-Directed Services for Family Caregivers**

Several states have begun to evaluate their consumer-directed programs for caregivers, and the preliminary findings have been positive. For example, results from research examining the preferences for, and characteristics of, consumer-directed (i.e., direct pay) and professionally managed (i.e., agency-based) respite for family caregivers in California show that caregivers prefer direct payment to agency-based in-home respite by two to one. Compared to the agency-based group, caregivers using the direct-pay option were found to have significantly more choice in and control over decisions related to day-to-day management of their respite workers. Those caregivers who had the most control were also found to be more satisfied with their respite workers. Use of the direct-pay mode was associated with more hours of respite per caregiver and was found to be significantly less costly per hour of service than was use of agency-based respite (Feinberg & Whitlatch, 1998).

In Georgia, one of the goals of the state's consumer-directed programs for caregivers (known as "self-directed care" programs in Georgia) was to evaluate the programs' effectiveness by comparing results to those of consumers receiving services through the traditional service delivery system. Researchers at the Gerontology Institute at Georgia State University have found that consumer direction provided a safety net for many individuals, especially low-income caregivers living in rural areas. Self-directed caregivers reported financial, physical, and emotional relief as well as the ability to provide better care. For example, compared to rural caregivers using traditional services, rural self-directed caregivers were significantly more satisfied with overall services and more often reported that these services enabled them to extend the time they could provide care in the home, thus avoiding nursing home placement (Perkins Lepore, Sambhara, Jackson, & Ball, 2004).

## **Common Themes**

Success factors in developing consumer-directed approaches for family caregivers include:

- Incorporating the philosophy of empowerment and choice for the consumer and family in program design and implementation
- Encouraging options to promote a family-centered approach that benefits the family unit (i.e., caregiver–care recipient dyad)
- Creating partnerships with key stakeholders, including state agencies and provider agencies
- Understanding that policymakers, program administrators, and others must come to agreement on the definition of “consumer direction” (i.e., agency-based options versus direct-pay)
- Providing flexibility in program design to maximize caregivers’ opportunities to make choices
- Providing continuous education and training to service providers on the principles of consumer direction for caregivers and on implementation strategies to promote choice and control
- Conducting program evaluations and analyzing outcomes of existing consumer direction programs

Appendix B includes program summaries from six states to highlight models of consumer-directed care for family caregivers, including common elements and distinguishing features of each state approach.

# **Collaborations on Caregiving between the Aging Network and the Health Care System**

## **Introduction**

With the emergence of the NFCSP, states and local aging agencies are pursuing systems development strategies through partnerships and collaborations with health care practitioners to identify family caregivers and inform them about support services. Many people who provide assistance and care to family and friends do not recognize themselves as caregivers, and health care practitioners can help these individuals self-identify as family caregivers. Research has shown that individuals who identify as caregivers are more prone to seek support than are those who do not recognize themselves in this role (Kaye, Turner, Butler, Downey, & Cotton, 2003). Developing partnerships with health care providers offers aging agencies the opportunity to build a more coordinated and effective system while maximizing resources to support families and increase access to caregiver programs (The Lewin Group, 2002).

For many families across the country, physicians and other primary care practitioners (PCPs) are the entry point into health care delivery and long-term care systems and are often considered the link to care coordination. Research has shown that caregiving has negative health effects on family caregivers. In turn, poor health of the caregiver and other care-related strain increases the likelihood that the care recipient will need to move to a nursing home, which people prefer to avoid and which increases the costs of care. Physicians and PCPs have a unique opportunity to reach caregivers before they experience these adverse effects of caregiving.

Although the negative effects of caregiving are well documented, physicians and other health care practitioners rarely identify and assist their patients who are caregivers or the family members of patients. This is an underrecognized but significant issue in health care today. Screening to identify family caregivers, caregiving-related stress, and other negative health effects is not yet a routine part of primary care practice. However, research suggests that a valuable model for coordination of services uses physicians or PCPs for information gathering and dissemination. Older patients place much trust in health practitioners, who are in a position to survey their caregiver patients smoothly and effectively for symptoms of stress (Kaye, Turner, Butler, Downey, & Cotton, 2003; Fine as cited in Kaye et al., 2003). Furthermore, a caregiver expressing stress and a need for support may feel validated by discussing concerns with a trusted PCP.

## **Barriers to Integration of Aging and Health Care Services**

A primary barrier to promoting partnerships and integration of aging and health care services is the fragmentation of funding sources (e.g., Medicare, Medicaid, Older Americans Act) and the delivery of care. Fragmentation of services can often leave caregivers confused and overwhelmed, posing challenges to finding and using the help they need.

A second obstacle is the lack of training and information for health care practitioners to recognize and address family caregivers' support needs. Health care providers are often unaware of available social services for caregivers in the community. Physicians and their staff may be

unqualified to provide in-depth information, support, or education for caregivers because they traditionally have not performed this role; there is an absence of specialized training; and there are continual time constraints and billable cost impediments (Kaye, Turner, Butler, Downey, & Cotton, 2003). Further, some physicians may not consider it their responsibility to help a family member find information or resources; they may regard this as more the job of a nurse or social worker.

An additional challenge to collaboration is the absence of information management systems and coordinated patient record systems across care settings. Electronic records systems would ease the referral process for health care practitioners and promote better communication with aging and long-term care providers for consumers and their families who may be getting services from both sectors.

### **New Directions in Integrating Aging and Health Care Services**

Two projects highlighted below offer innovative ways to create partnerships on caregiving between two distinct but complementary systems—the aging network and health care providers. The *Maine Primary Partners in Caregiving Project* sought to identify caregivers and targeted caregiver support services through patient visits to local physician offices in a rural setting. The *Making the Link* project, operating on a national scale in rural and urban locales, seeks to raise awareness among physicians of the negative health effects of caregiving, the central role of family members as partners within the health care team, and the importance of identifying and assessing caregivers at risk and referring them to caregiver support services in the community. Each of these programs has strong potential for replication to ensure better integration of the aging network and health care delivery system to improve supports for caregiving families.

#### **Program Name: Maine Primary Partners in Caregiving (MPPC) Project**

**Administering Agency: Eastern Agency on Aging and the University of Maine Center on Aging**

**Program Description:** The MPPC project sought to demonstrate that primary health care is an effective and efficient setting for identifying and supporting rural caregivers. The project forged innovative partnerships among primary care practices, AAAs, and the University of Maine Center on Aging in four rural Maine counties. The project was established in 2001 under a three-year NFCSP innovations grant from the U.S. AoA.

The MPPC project had four main objectives: 1) to demonstrate that rural primary health care practices are an effective point of early intervention for caregivers of older persons; 2) to show that caregivers will accept and use information, support, and training when their personal physician or other health care staff identifies the need for it; 3) to demonstrate that the combination of information, support, and training by MPPC caregiver specialists and field coordination/liaison efforts by a health care provider will be successful in ameliorating the multiple risks of rural caregiving; and 4) to show that a productive community service partnership among primary care practitioners, AAAs, and a university center on aging can be

established and sustained in service to family caregivers (Kaye, Turner, Butler, Downey, & Cotton, 2003).

A brief screening given to patients attending routine health care visits by physician offices' front desk staff identified patients who were caregivers. The *MPCC Brief Patient Screen* was comprised of five yes-or-no questions asked of the patient:

- *Do you help someone 60 years of age or older who is not in good health or is not managing as well as he or she used to?*
- *Is it ever hard to help this person in any way?*
- *Do you ever worry about the health or well-being of this person?*
- *Do you ever feel at all stressed when you are helping this person?*
- *Have you had a major weight change within the past year?*

If a patient who is a caregiver indicated feeling burdened by caregiving responsibilities, an expedited referral pathway to the local AAA's caregiver specialist was subsequently activated. The specialists responded to caregiver needs with customized services, including education and training resources and a statewide hotline (Maine Center on Aging, 2005).

The MPPC project provided education and training to PCPs and to caregivers. Primary care practitioners were educated on techniques for identifying caregivers, the causes of caregiver burden, and the available community resources to address caregiver strain. They were also trained in providing empathetic support and in educating patients who are caregivers about illness and debilitation, safety issues, stress management, and seeking support through a local AAA.

**Outcomes/Benefits:** Over 8,000 caregiver status screenings were completed during routine visits to physicians' offices over the life of the three-year project. Of those, 436 patients (5 percent) identified as caregivers to older adults, and each received at least one contact from a local AAA-based Caregiver Specialist. These caregivers were assessed further to determine appropriate support services and to provide information and referrals. After the initial contact, the caregiving situations of 76 individuals were found to warrant an ongoing relationship in which the Caregiver Specialist customized such services as counseling, referrals, education, and training. These individuals were also invited to enroll in the project research.

The MPPC project was successful in meeting its four objectives. For example, initial evaluation data (Time 1 data taken on intake) showed that higher depression scores among caregivers were associated with lower levels of expressed caregiver competency and confidence, increased perceptions of caregiver burden, a greater sense of social isolation, and smaller social networks. MPPC project data also demonstrated that caregivers who had not previously engaged in efforts to access support services had notable levels of depression and burden. The rate of acceptance of referral by patients who reported feeling caregiver stress, however, was near 100 percent. In addition, while caregiving task frequency and difficulty increased from initial

evaluations (Time 1) to six-month evaluations (Time 2), caregiver levels of depression declined during this period (Kaye, Turner, Butler, Downey, & Cotton, 2003).

Caregiver specialists involved with the MPPC project have also confirmed that most caregivers needed primarily information, rather than intensive interventions like therapeutic counseling, indicating that disseminating information is an effective early intervention strategy to delay more expensive supports. It appears that early intervention of community supports may contribute to a decline in caregiver burnout and could also delay placement of an elderly family member in a long-term care facility (Kaye, Turner, Butler, Downey, & Cotton, 2003).

**Program Name: Making the Link: Connecting Caregivers with Services through Physicians**  
**Administering Agency: National Association of Area Agencies on Aging**

**Program Description:** The National Association of Area Agencies on Aging (n4a) created the *Making the Link* project in 2002 to integrate health care providers and the aging network. The n4a received a two-year NFCSP innovations grant from the U.S. AoA and a third year of funding from MetLife Foundation. The n4a is now maintaining the project, which has already been implemented at the community level by approximately 250 local AAAs and Title VI-Native American aging programs across the country. In addition, several physician and other health care organizations have worked with n4a on a national awareness campaign on the health implications of caregiving.

Through *Making the Link*, local AAAs organize outreach efforts to physician offices to provide local informational and promotional materials. Many physicians learn through office visits that their patients are caregivers and are experiencing caregiver stress, but physicians are often unaware of community resources that are available to support this population. The program allows physicians to easily refer their patients who are caregivers to community resources and support services.

Three main objectives guided this project: 1) provide the strategies and tools for the aging network to collaborate with local physicians to help them identify caregivers and direct them to services; 2) promote within the medical community the concept that caregiving can present a health risk and increase awareness among physicians of the important health care role played by family caregivers; and 3) enhance the ability of physicians to connect caregivers with NFSCP services (National Association of Area Agencies on Aging, n.d.).

**Outcomes/Benefits:** The *Making the Link* program, which received “honorable mention” recognition for best practices by the Archstone Foundation’s 2004 Archstone Award for Excellence in Program Innovation, has shown positive outcomes. Local AAAs have been creative and successful in partnering with area health care practitioners, resulting in numerous caregiver referrals for community services. For example, one agency in New York worked closely with the regional medical society to get informational letters, business cards, and laminated signs to physicians.

Another AAA partnered with the marketing department of a large physician practice and made presentations to various group practices at regular staff meetings, resulting in more than 75

caregiver referrals. The *Making the Link* project is the second biggest source of caregiver referrals for this county. A local AAA serving the Osage Nation Reservation in Oklahoma worked with local doctors and nurses to alert patients of available caregiver resources, which has led to more than 100 referrals to the AAA. In addition, caregivers are reporting to AAAs that they have heard about AAA caregiver services from their physician (Aldrich, 2004).

Collaborations between the Aging Network and the Health Care System: Challenges, Lessons Learned, and Potential for Replication

<u>Project Name</u>	<u>Administering Agency</u>	<u>Challenges</u>	<u>Lessons Learned</u>	<u>Potential for Replication</u>
<b>Maine Primary Partners in Caregiving Project (MPPC)</b>	Eastern Agency on Aging and the University of Maine Center on Aging	<ul style="list-style-type: none"> <li>• Physicians’ time constraints</li> <li>• Overcoming organizational cultures</li> <li>• Changing defined office routines</li> <li>• Maintaining continued participation by office staff in screening patients</li> <li>• Complying with HIPAA regulations</li> </ul>	<ul style="list-style-type: none"> <li>• Emphasize importance of caregiving role to increase participants’ “buy-in”</li> <li>• Create concise caregiver screenings and informational materials</li> <li>• Conduct brief meetings and trainings with physicians and office staff</li> <li>• Maintain routine communication with office staff</li> <li>• Monitor use of project materials</li> </ul>	High— Project materials include a “best practice” manual and model education curricula for rural caregivers and primary care providers <sup>a</sup>
<b>Making the Link: Connecting Caregivers with Services through Physicians</b>	National Association of Area Agencies on Aging (n4a)	<ul style="list-style-type: none"> <li>• AAA staff time and resource constraints to support the project</li> <li>• Physicians’ time constraints</li> </ul>	<ul style="list-style-type: none"> <li>• Enlist staff, advisory board members, associations, and others for assistance with outreach</li> <li>• Design informational materials that are clear, concise, and attention-getting</li> <li>• Conduct brief meetings and trainings with physicians and office staff</li> <li>• Incorporate other appropriate and useful health-related information (e.g., Medicare Prescription Drug Program) when providing materials to physicians’ offices</li> </ul>	High— Project materials include a “promising practices” booklet and several technical assistance presentations <sup>b</sup>

<sup>a</sup> Project materials are available by contacting the University of Maine Center on Aging, or online at: <http://www.umaine.edu/mainecenteronaging/documents/MPPCManFweb.pdf>.

<sup>b</sup> Project materials are available by contacting the National Association of Area Agencies on Aging, or online at: <http://www.n4a.org/makingthelink.cfm>.



## **Common Themes**

There are several common themes in these innovative approaches to creating collaborations between the aging network and health care systems. Success factors include:

- Determining the scope of family caregivers potentially in need in a region to target collaboration efforts appropriately
- Using region-specific resources, such as medical societies or health care practice representatives, to maximize local physician involvement
- Networking with health care professionals to create a base for partnerships and collaborative efforts
- Understanding that health care practitioners may need to adapt to changes in office routines for the program to succeed
- Recognizing the daily time constraints of health care providers and office staff
- Designing collaboration projects (i.e., demonstration programs) that do not affect office workloads significantly
- Educating physician offices about the significant role of family caregivers to increase participation in collaboration projects
- Providing concise information and training for health care providers to recognize and refer patients who are caregivers
- Rewarding partnerships between aging and health care by publicly recognizing individual health care providers

## Summary and Conclusions

States play a large and growing role in financing and delivering services to support and sustain family and informal caregivers, the backbone of the U.S. long-term care system. This report provides new insights into three emerging trends and new directions that promote family-centered care and are taking hold in a number of states:

- **Caregiver Assessment:** It is vital to identify family caregivers and address their own needs for support early to assure quality of care and to minimize caregiver stress and the negative mental and physical health effects caregiving often brings on. A key to effective outcomes in care settings is not just assessing the care recipient, but assessing the family caregiver as well. As states pursue making their long-term care systems more responsive to the needs of different consumer populations and their families, the concept of a single, universal assessment tool for program clients, including family caregivers, is gaining attention. Caregiver assessments assist care managers and other service providers in tailoring support services specifically to meet the needs of the family caregiver and to promote quality of care for the care recipient.
- **Consumer Direction in Family Caregiver Support Services:** Consumer-directed programs that give consumers choice and control over their care decisions and allow them to tailor services and supports to meet their needs and preferences can be effective in supporting caregiving families, particularly those in rural areas. Caregivers using consumer-directed care have also been found to be significantly more satisfied with overall service options that give them choice, control, and flexibility in providing care in the home, and thus avoid premature nursing home placement of the care recipient. It is important that states continue to develop and expand consumer-directed models that are meaningful to consumers and their families and better meet their needs.
- **Collaborations between Aging and Health Care Providers:** By proactively identifying family caregivers in primary care physician offices, rather than waiting for caregivers to seek help or continue to brave their situation alone, family caregiver support programs can reach caregivers before they experience adverse effects from caregiving. This support, in turn, allows family members and friends to remain in the caregiving role for as long as it is appropriate.

The promising directions highlighted in this report can help to promote an exchange of new ideas among states as they pursue the goal of strengthening HCBS to address the broadest needs of the individual and the family. These approaches and innovations hold promise to promote improved caregiver outcomes, better quality of care, integration of caregiver support into HCBS, and increased well-being of both the individual consumer and the family caregiver.

## APPENDIX A

### PROGRAM SUMMARIES—CAREGIVER ASSESSMENT

**Program Name: California Caregiver Resource Centers (CRCs)**

**Administering State Agency: California Department of Mental Health (CA DMH)**

**Overview:** California's CRC system is the country's first state-funded program providing explicit family caregiver support. The CRC system, which serves as a point of entry to caregiver support services, is coordinated by the San Francisco-based Family Caregiver Alliance (FCA), the original CRC and model program, and the state-designated Statewide Resources Consultant (SRC). Under legislation enacted in 1984, 11 nonprofit resource centers were phased in over four years to provide a range of information and support services to families caring for adults with cognitive impairment. The system is unique in that income level is not a criterion for eligibility of services.

**Caregiver Assessment Process:** The initial uniform caregiver assessment tool, developed in consultation with Steven Zarit, Ph.D., was implemented in 1988 and has been revised three times. The purpose of the assessment is to serve as 1) a clinical guide to help service providers assess a caregiver's particular situation and needs, and 2) a data collection tool for policy and service development.

A caregiver contacts a CRC office, and an initial intake assessment is completed over the phone. If a caregiver is eligible for and interested in more help beyond basic information, a social worker, known as a family consultant, conducts a mandatory full assessment, generally in the caregiver's home and lasting an average of 90 minutes. The family or informal caregiver is considered the client in the program, and information is collected from the caregiver's perspective. Telephone reassessments of the caregivers' situation occur every six months as long as they receive services. Currently, all completed caregiver assessment tools are sent to the SRC, where the information is entered into a centralized database. In 2006, the CRC system will implement a web-based client record system for customized individual reports that can be run at each CRC site. Once the assessment process is completed, the CRC staff work with the caregiver to develop a plan of care.

**Caregiving Areas Assessed:** The assessment is designed to obtain specific information about the caregiver and the care recipient to determine aspects of the caregiver's situation that threaten the caregiver's and care recipient's everyday functioning and well-being. The current tool includes items related to caregiver and care recipient demographics, informal support and living situation, functional level of the care recipient, memory and behavioral problems (using an adapted Revised Memory and Behavior Problems Checklist<sup>1</sup>), caregiver health, caregiver strain (using an adapted Zarit Burden Interview<sup>2</sup>), caregiver depression (measured by the Center for

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<sup>1</sup> Teri, L., Traux, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging, 7*, 622–631.

<sup>2</sup> Bedard, M., Mollow, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*, 652–657.

Epidemiological Studies-Depression Scale<sup>3</sup>), information needs, and open-ended questions to elicit the caregiver's view of his or her own situation and a summary section/care plan.

**Consumers Served:** In fiscal year 2004, more than 4,100 caregivers completed full assessments.

**Staff Training:** Staff training is mandated for new and existing staff, emphasizing quality and consistency of data collection throughout the state.

**Outcomes/Benefits:** Caregiver characteristics and measures of well-being (e.g., caregiver physical and mental health) are analyzed and used for program and policy development. For example, CRCs have developed short-term counseling protocols and psychoeducational classes to address caregiver depression and other issues. Anecdotal reports from CRCs suggest that most family clients appreciate the assessment process and view it as an opportunity to express their informal and formal support needs for remaining in the caregiving role, and to have their situation taken seriously. After the assessment process, services are introduced to build caregiver competency and address the strains of caregiving. The assessment process helps to tailor services to best address each caregiver's needs. Caregiver support services include specialized information; family consultation and care planning; individual, group, and family counseling; psychoeducational classes; support groups; legal and financial consultations with attorneys; education and training; and respite assistance.

**Success Factors:** The CA DMH and the SRC both supported social worker involvement in all phases of development, implementation, and refinement of the tool, and assessment protocols and care planning practices, which contribute to the overall success of the program. Staff training is considered key to quality assurance.

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<sup>3</sup> Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.

**Program Name: Massachusetts Real Choice Functional Assessment (RCFA) Project**  
**Administering State Agency: Center for Health Policy and Research (CHPR) in**  
**collaboration with the Massachusetts Executive Office of Elder Affairs**

**Overview:** In 2001, Massachusetts received a Centers for Medicare and Medicaid Services (CMS) Real Choice Systems Change grant to enhance the quality and accessibility of the range of home and community-based long-term supports available to individuals of all ages with disabilities and long-term illnesses. One of the key objectives of this grant was to develop and pilot a uniform assessment tool and process to use across HCBS programs and with different consumer populations, regardless of age, disability, or functional status. The HCBS programs are intended primarily for individuals in the greatest social or economic need, with particular attention to low-income individuals. The assessment tool is currently being piloted in the Real Choice Flexible Supports and Services pilot project. Piloting was initiated in early 2005 and will continue through 2006.

The RCFA project was designed to complement the Minimum Data Set-Home Care (MDS-HC), the standardized assessment tool chosen by the state for use across a number of state-funded programs, such as the Frail Elderly Home and Community-Based Waiver. To ensure that the functional assessment tool being developed met the needs of individuals across all ages and disabilities, Massachusetts built modules for collecting supplemental information to improve service planning and impact outcomes. New modules include family caregiver, employment, support systems, transportation, and nutrition information components. The caregiver component was designed as a separate module to gather accurate and objective information, absent of care recipient influence.

**Caregiver Assessment Process:** The tiered assessment process currently being piloted focuses on a consumer-driven process to seeking information. When a care recipient inquires about potential services, a staff person collects basic core demographic data at intake. If a need for a statewide program is identified, the MDS-HC questions must be answered and completion of additional corresponding modules, including a caregiver interview, can be triggered. Intake assessments can be conducted over the phone, but additional assessments are completed in the clients' homes. As part of the Real Choice pilot project, a reassessment is conducted every six months.

The CHPR currently collects the assessment data for Real Choice pilot participants and maintains the database to understand changes in status of participants and to identify ways to strengthen the assessment tool. Plans are underway to automate the assessment processes so that data collection, analysis, and program evaluation can be better facilitated. Results of the pilot assessment process will inform future implementation of the assessment tool across HCBS programs, including the provision of caregiver support services, in the state.

**Caregiving Areas Assessed:** The caregiver component of the assessment tool addresses willingness and ability to provide care; demographic information; description of caregiver status (i.e., unable to continue caring due to decline in health, not satisfied with support received from

other family and friends, feelings of distress, anger, or depression); measures of self-reported health; and a 13-item Caregiver Strain Index<sup>4</sup>).

**Consumers Served:** The tool is being piloted with 14 consumers in the Real Choice Flexible Supports and Services pilot project in 2005 and 2006.

**Staff Training:** Training is mandatory for assessors administering the RCFA tool. An important component of the pilot project is to gather feedback from assessors using the assessment tool to assist in further refinements and more positive outcomes. A set of standardized questions for staff includes the assessment tool's ease of use, ability to collect intended information, and effectiveness in identifying gaps in the assessment process. Results are forthcoming.

**Outcomes/Benefits:** The pilot project and comprehensive assessment have facilitated collection of information across disabilities and ages, including data on family caregivers, rather than assessing individuals within rigid eligibility criteria related to age or diagnostic category. Inclusion of a caregiver component as part of the uniform assessment process enables staff to identify the primary family caregiver as a distinct consumer, which results in better service delivery and outcomes. Central to this project is the focus on consumer direction and the provision of multiple care options for the family. The state can gather critical functional information as well as measure the support structure and service needs of the family unit. The assessment process guides the caregiver and program staff toward a common understanding of the caregiver's needs, preferences, abilities and capabilities, strengths, and social and environmental barriers. Upon completion of the uniform assessment process, the caregiver has access to a fuller and more innovative range of services, such as respite services, transportation, and homemaker/chore assistance, to sustain family caregiving.

**Success Factors:** The development of a functional assessment tool across age and disability groups requires a strong commitment by stakeholders and the involvement of consumers. Assessor and consumer input on the effectiveness of the system has been a vital component in enhancing access to and delivery of services. Continued success of the assessment process requires agreement on the project's goals and expectations by all participants. Guiding principles, including a discussion of common goals and mission, can facilitate the process.

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<sup>4</sup> Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38, 344–348.

**Program Name: Minnesota Long-Term Care Consultation (LTCC) Services**  
**Administering State Agency: Minnesota Department of Human Services**

**Overview:** Minnesota uses a uniform assessment tool for all HCBS programs for care recipients and their families who wish to access publicly funded, long-term care services. The programs target individuals and families in the greatest social or economic need. Known as the LTCC, the consultation aids care recipients and their families in choosing services and supports that best match their needs and preferences. Legislation enacted in 2001 allowed Minnesota to modify both the assessment tool and the care plan to identify and address caregiver needs.

**Caregiver Assessment Process:** During development of the uniform tool, state officials strongly believed that distinct caregiver questions were an important component of the assessment process. The state also wanted to maximize families' opportunity to attain caregiver support services across different public programs.

Lead agency staff (i.e., social workers or public health nurses), known as long-term care consultants, conduct the assessment in the client's home, which takes an average of two hours to complete. The mandatory core portion of the assessment includes 12 questions that focus on the caregiving situation. There is an optional caregiver interview at the end of the assessment tool.

After completing the caregiver interview, lead agency staff may direct caregivers to other support services in the state, such as services under the Older Americans Act's NFCSP, Senior LinkAge Line (i.e., information and referral), waiver programs, and faith-based or voluntary programs. Caregiver intervention strategies are included in the care recipient's care plan, as appropriate. On an ongoing basis, the care plan may identify changes in caregiver needs, which triggers evaluation of the care situation and the family member's support and service needs. Reassessments occur annually or more frequently if care needs change.

The assessment tool is automated, with the capability of entering data off-site, such as during a home visit, using a laptop computer. However, it is unknown how frequent this function is used because some counties that are more resistant to change still have staff complete paper assessments and enter the data later. Currently, only the 12 mandated caregiver questions are entered into the state's information system; the optional caregiver interview is not yet captured in data reports.

**Caregiving Areas Assessed:** The LTCC tool focuses on availability and capability of informal support; willingness to provide care; care frequency and duration; demographic information; self-reported health; emotional well-being; factors that may limit the caregiver (e.g., limited knowledge to manage care, job restrictions, financial concerns, or the physical burdens of caregiving); one item to rate level of burden; and items related to caregiver exhaustion and/or need for respite or other supports. The tool also includes a question asking if the family member would like to be contacted by a community organization to receive more information and assistance on caregiving.

**Consumers Served:** In fiscal year 2004, more than 81,000 consumer assessments were completed statewide, and approximately 25 percent of consumers were likely to have caregiving needs.

**Staff Training:** Training for new county staff is held every quarter, during which about three hours are devoted to the history and purpose of and processes used to conduct assessments. During the training, there is a concerted effort to promote the needs of caregivers and remind staff of the available services in the state to support the family.

**Outcomes/Benefits:** One of the positive benefits of this mandated assessment process is that it serves as the gateway to all Medicaid waiver services. The caregiver component of the assessment process assists lead agency staff in identifying unmet needs of caregivers so that they may be connected to Medicaid waiver services and Older Americans Act programs, such as the NFCSP, that provide explicit caregiver support services (e.g., counseling, education and training, respite care). The assessment process helps staff to focus on and support caregiver needs in a more uniform fashion, alerts caregivers to the support services that are available to them, and can also lead to the development of new programs.

A random review of assessment records was conducted in 2002, and 50 percent of all narrative case notes identified caregiver support needs. However, the optional caregiver interview was not conducted with family members in the majority of these cases, likely because of time constraints and staff reluctance to interview caregivers in the presence of care recipients. Minnesota is currently evaluating methods to encourage county staff to use the caregiver assessment tool systematically to improve caregiver outcomes and quality of care.

**Success Factors:** Including a caregiver interview within the uniform assessment tool has emphasized to lead agency staff the important role of informal caregivers in HCBS and the need to offer support and services to sustain caregiving families.

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**Program Name: Pennsylvania Family Caregiver Support Program**  
**Administering Agency: Pennsylvania Department of Aging**

**Overview:** Pennsylvania has been in the forefront of caregiver programs and policies to support families in ways specific to their needs and preferences. The state's caregiver program uses state and federal funds to allow family caregivers a choice of goods or services that are most needed to help care for an older relative at home and provide financial assistance with out-of-pocket expenses. There are no income requirements for core services (i.e., support groups, caregiver education and training, etc.), but income requirements do exist for services such as respite and consumable supplies.

The state uses a uniform assessment process and a centralized approach for programs serving older persons and their family caregivers that are administered by the Pennsylvania Department of Aging (PDA). Care managers at AAAs complete an assessment of the older person and the caregiver, using the *Comprehensive OPTIONS Assessment Form* (COAF). The tool was initially developed in 1986; the caregiver component of the COAF was added in 1991 and revised in March 2003.

**Caregiver Assessment Process:** When a consumer (either the care recipient or the family caregiver) requests assistance from one of the state's 52 local AAAs, an AAA care manager conducts the COAF during an in-home visit. On average, the full COAF takes about two hours to complete. During the home visit all information is entered into a laptop, which automatically feeds into the PDA's database. After completing the COAF, the care recipient and caregiver receive a comprehensive menu of services that maximize consumer choice. Care recipients are assessed annually and more frequently if there is a change in residence or care situation. If the care recipient is reassessed, the caregiver is also assessed based on how the situation has changed and what different services may be needed.

**Caregiving Areas Assessed:** The family caregiver components of the COAF focus on the availability and capability of informal support; willingness to provide care; care frequency and duration; demographic information; limitations or caregiver constraints (e.g., poor health, employment status, lack of knowledge/skills); emotional concerns; caregiver strain; availability of consumable supplies (including who pays for supplies and the total average monthly costs); family's preferences for care; and the 22-item Zarit Burden Interview.<sup>5</sup>

**Consumers Served:** In fiscal year 2004, the COAF was administered to 7,400 older persons. Although Pennsylvania does not track the number of caregivers who complete the caregiver assessment component, state officials believe that the majority of caregivers do so.

**Staff Training:** Two days of training are required for all new staff who conduct assessments.

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<sup>5</sup> Zarit, S.H., Reever, K.E., & Back-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of burden. *The Gerontologist*, 20, 649-655.

**Outcomes/Benefits:** The COAF tool is the entry point for obtaining caregiver support services, including information and assistance, care management, counseling, education and training, and respite care. It enables staff to effectively and efficiently identify needs in a holistic manner that includes the care recipient, family, and network of support. Staff are better informed and can use the tool to help trigger important questions that enhance intervention strategies. Five quality assurance staff members, strategically positioned throughout the state, assist the AAAs in measuring and attaining high-quality standards.

The COAF data are used for a wide range of management and planning purposes. Clinical staff and state program administrators review individual assessments and care plans to evaluate outcomes and to measure cost effectiveness, service delivery, service pricing, utilization rates, outcomes (for both the care recipient and the caregiver), and the appropriateness of the overall care delivery. The COAF database also enables the state to compare actual service utilization and outcomes to projected outcome measures.

**Success Factors:** The state has long recognized the importance of caregiver assessment and has been flexible in its design of the COAF tool to accommodate changing caregiver support needs. Staff training has been instrumental in the success of this program.

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**Program Name: Washington Home and Community-Based Services**  
**Administering State Agency: Washington Aging and Disability Services Administration**

**Overview:** Washington State uses a uniform assessment tool for all HCBS programs for older adults and adults with disabilities, including those funded by Medicaid, the Older Americans Act, and state general revenue programs. These programs are intended primarily for individuals with the greatest social or economic need. The mandated *Comprehensive Assessment Reporting Evaluation (CARE)* tool, implemented statewide between April 2003 and February 2004, includes a caregiver component. The automated CARE tool also includes individualized care plans that are based on assessments for all existing clients and a process of reassessments done annually or sooner if there is a significant change in condition.

**Caregiver Assessment Process:** The state Home and Community Services Division is the single point of entry and determines financial and functional eligibility for HCBS statewide. Clients living at home receive ongoing case management services through a local AAA. HCS staff and AAA case managers must conduct an in-person assessment during a home visit, which takes an average of three hours to complete. Case managers complete assessments on laptop computers that automatically feed into a comprehensive database and are linked to an easily accessible resource directory. If a caregiver completes the caregiver status portion of the assessment and shows evidence of stress or requires more assistance, he or she is referred to the state or federally funded Family Caregiver Support Program. A four-page caregiver intake is then completed to determine explicit caregiver support service needs that could be met by family caregiver or other available services. Core information from the initial assessment and future assessments provides a comprehensive picture of care recipients and their needs.

**Caregiving Areas Assessed:** The caregiver component of the CARE tool focuses on ability to provide care; care duration; demographic information; long-distance caregiving; information/education needs; stressors (e.g., decline in emotional or physical health, lack of training or skills, employment status, relationship issues with client/family); and a 12-item Zarit Burden Interview.<sup>6</sup>

**Consumers Served:** In fiscal year 2004, 75,629 consumers completed the CARE tool statewide, and 11,789 family caregivers (16 percent) completed the caregiver assessment component.

**Staff Training:** Staff who conduct assessments must complete five days of training on the assessment tool and protocols, with half of this time devoted to hands-on computer simulations.

**Outcomes/Benefits:** The caregiver component of the CARE tool assists staff in identifying unmet needs of caregivers so they may be connected to programs that provide explicit caregiver support services, including transportation, respite care, and consumable supplies. The caregiver assessment component emphasizes measuring caregiver stress and is sensitive and responsive to the needs of family caregivers, helps staff identify problem areas in the caregiving situation, and triggers referrals to supportive services such as the NFCSP. The automated caregiver screening is

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<sup>6</sup> Zarit, S.H., Reever, K.E., & Back-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of burden. *The Gerontologist*, 20, 649–655.

an important step in systems development and integration to systematically recognize the needs of family caregivers and to deliver appropriate caregiver support services. In the future, caregiver screening will be expanded to capture other pertinent information about the family caregiver and data collection will be streamlined.

**Success Factors:** A key success factor was the Aging and Disability Services Administration's support for case manager involvement in all phases of the CARE project, from content development to user acceptance testing and user interface design. Case managers are more efficient and focused on the needs of the care recipient and caregiver than on data collection and processes. Care recipients and caregivers no longer have to complete multiple, duplicative forms to determine program eligibility.

Historically, Medicaid HCBS programs have focused solely on the Medicaid beneficiary, not on the family caregiver. Washington State's approach begins to address issues from a "family-centered" perspective, rather than a "patient-centered" one, and the state will continue to highlight the central importance of assessing and addressing caregiver needs in HCBS.

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## APPENDIX B

### PROGRAM SUMMARIES—CONSUMER DIRECTION IN FAMILY CAREGIVER SUPPORT SERVICES

**Program Name:** Alabama CARES

**Administering State Agency:** Alabama Department of Senior Services

**Overview:** *Alabama CARES* (Caregiver Assistance with Resources, Education and Services), the state's tagline for the NFCSP, is the first program in Alabama to focus explicitly on the needs of family caregivers. The program seeks to support family caregivers providing care to older individuals in the greatest social or economic need with particular attention to low-income individuals by providing training, assistance, and resources. Alabama CARES strives to keep families together and to allow older adults to age at home instead of in more costly nursing homes. In 2003–2004, *Alabama CARES* directly assisted approximately 25,000 caregivers statewide.

**Consumer-Direction Process:** Alabama CARES makes some elements of consumer direction available through a respite and supplemental services voucher system. All 13 of the state's AAAs subcontract with local providers for respite care through a voucher program, including in-home care, adult day services, overnight care in a facility, and weekend respite options. Family caregivers can choose their own provider from a list of agencies providing respite assistance or supplemental services (e.g., home modifications) and can arrange their own services. Services are provided on a sliding-fee scale where caregivers may receive between \$500 and \$1500 a year for respite and supplemental services based on need and availability of funds. Currently, family caregivers cannot be paid to provide care; however, the program plans to broaden its "provider" network to allow payment of family members, friends, and neighbors.

**Outcomes/Benefits:** Rather than being told by an agency which type of services would help them best and which provider they must use, caregivers are offered choices and have the option to determine what they need as well as their own service providers.

**Challenges:** Limited federal funding curtails the availability of respite and other supports to meet the needs of family caregivers in the state.

**Consumer Direction and State Policy Priorities:** Expanding consumer choice is one of Alabama's four main strategies in delivering services to the state's older population. In October 2004, the Alabama Department of Senior Services received approximately \$1 million to establish a Cash and Counseling program to give Medicaid beneficiaries the opportunity to direct their own personal care services. In addition, the Alabama Department of Senior Services is heading up a statewide initiative to develop a single-entry-point, web-based tool for older adults and their families. The website will give caregivers access to all public and private state health and social services programs, enabling families to make their own choices about services.

**Success Factors:** The Alabama CARES program is flexible and administrators are willing to work with available resources. Families appreciate the opportunity to choose their own providers from the list of voucher home care agencies, and to determine the number of hours of help to best meet their needs.

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**Program Name: California Caregiver Resource Centers (CRCs)**  
**Administering State Agency: California Department of Mental Health**

**Overview:** California's CRC system is the country's first state-funded program providing explicit family caregiver support. The CRC system, which serves as a point of entry to caregiver support services, is coordinated by the San Francisco-based Family Caregiver Alliance (FCA), the original CRC and model program, and the state-designated Statewide Resources Consultant (SRC). Under legislation enacted in 1984, 11 nonprofit resource centers were phased in over four years to provide a range of information and support services to families caring for adults with cognitive impairment. In 2003–2004, the CRC system provided at least one service to 14,993 caregivers. Ten percent of those caregivers (1,454) received in-home respite care, and approximately 40 percent of respite users chose to exercise the consumer-directed option available.

**Consumer-Direction Process:** The CRC respite program offers caregivers flexibility, choice, and consumer control. Families can choose from a broad range of respite options, such as in-home care, adult day services, overnight respite, weekend respite camps, and caregiver retreats. In-home respite, the most widely used respite option, allows caregivers to receive vouchers to purchase respite services from various home care agencies under contract with the CRC (i.e., agency-based), or to receive a voucher to hire someone privately to provide direct care, including family members, friends, or neighbors (i.e., consumer-directed). Currently there is a \$3,600 yearly cap per family for respite.

**Outcomes/Benefits:** Results of a statewide client satisfaction survey conducted in 2004 found that the vast majority (97 percent) of caregiver respondents indicated that they were satisfied with the overall quality of services they received from their CRC. Of those who used respite services, the great majority were satisfied with the type of respite they received, including using a caregiver retreat (94 percent satisfied); adult day care services (94 percent); in-home respite (93 percent); camps for care recipients (89 percent); and out-of-home respite (86 percent).

Results from research examining the preferences for and characteristics of consumer-directed (i.e., direct-pay) and professionally managed (i.e., agency-based) respite for CRC family caregivers show that caregivers prefer direct payment to agency-based in-home respite by two to one. Compared to the agency-based group, CRC caregivers using the direct-pay option were found to have significantly more choice of and control over decisions related to the day-to-day management of their respite workers. Those caregivers who had the most control were also found to be more satisfied with their respite workers. Use of the direct-pay mode was associated with more hours of respite per caregiver and was found to be significantly less costly per hour of service than was use of agency-based respite (Feinberg & Whitlatch, 1998).

**Challenges:** Three of the 11 CRCs do not offer the direct-pay option because of perceived issues of liability surrounding abuse, negligence, or accidents. Without a clear third-party employer, many CRCs fear that, although the family caregiver technically would be the employer and therefore responsible for any misconduct, ultimately the CRC would be liable. One attempt being explored to resolve the issue would be to require private-pay providers to go through California's

In-Home Supportive Services (IHSS) training, thus making the county Public Authority agencies the clear employer.

The need to continually educate staff about the philosophy of empowering families to make their own choices has proved to be challenging. It is a constant struggle for professionals not to dictate which services a family should choose and, instead, allow family members to choose the best outcome for themselves. To address this issue, the basic principles of the consumer-directed CRC model are encompassed in the CRC Program Instruction Manual and staff training, including the core principle, “respect for the needs of the family caregivers and preservation of the dignity and autonomy of the person with cognitive impairment are fundamental to all CRC services.” Staff are educated to respect the family caregiver’s decisions even if they, the service providers, would make a different choice.

**Consumer Direction and State Policy Priorities:** California is pursuing several policy directions to promote expanded consumer direction. The Olmstead Planning Committee is working toward diverting people from moving into skilled nursing facilities and using consumer-directed home and community-based services. State priorities to promote integration among HCBS programs also emphasize consumer-directed approaches through single-entry point systems such as the CRC system and Aging and Disability Resource Centers. The state is also implementing Real Choice grants funded by CMS and AoA where “money follows the person.”

**Success Factors:** CRCs incorporate into practice the philosophy of empowerment and choice for the family caregiver. A guiding tenet of the CRC model is participation of families in planning and overall service delivery. While different types of services warrant different levels of professional staff involvement, choice and control for the family are introduced into all support services. Providers give consumers a range of choices and allow caregivers to make their own decisions, even if they ultimately prove to be bad choices.

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**Program Name: Georgia Self-Determination Program**  
**Administering State Agency: Georgia Division of Aging Services**

**Program Information:** Georgia’s aging network began its first self-directed care program, known as *Legacy Express*, in 1998 with an Alzheimer’s Disease State Demonstration Grant. In 2001, additional consumer-directed programs were developed in the state under the NFCSP. The Georgia Division of Aging Services was awarded a three-year NFCSP innovations grant in 2001 to develop and evaluate five self-directed voucher care projects for the non-Medicaid older population in rural areas of the state.

Currently, there are four consumer-directed programs for family caregivers (known as “self-directed care” programs in Georgia) in 59 counties (37 percent of the state’s counties), representing rural communities, mountain regions, and urban and mid-size cities and serving 432 caregivers. A fifth self-directed care program is planned for 2006 to be offered under the state’s HCBS waiver program, the Community Care Services Program (CCSP).

**Consumer-Direction Process:** The services available from each of the state’s four current programs for family caregivers include respite (i.e., in-home care, adult day care) and supplemental services including but not limited to yard work/chore services, home modifications/repair, consumable supplies, low-tech assistive devices/adaptive equipment, and personal care services (e.g., homemaker services and haircuts). Each program administers the services distinctly:

Program Name	Funding	# of Counties Served	# of Caregivers Served	Voucher/ Reimbursement	Avg. Annual Amount Offered	Can Family Members Be Paid?
Legacy Express	NFCSP	8	84	Voucher	\$1,000	No
Southwest Georgia Council on Aging	NFCSP	6	80	Reimbursement	\$1,750	Yes
Jewish Family & Career Services	NFCSP	10	60	Voucher	\$500–\$1,200	Yes
Caregiver Timeout	NFCSP	35	208	Reimbursement	\$1,200	Yes

**Outcomes/Benefits:** One goal of the state’s self-determination program was to evaluate the program’s effectiveness by comparing results to consumers receiving services through the traditional service delivery system. Research results demonstrate that the consumer-directed program has provided a real safety net, especially for low-income caregivers living in rural areas, where consumers have access to a smaller number and narrower range of community-based services. Caregivers reported financial, physical, and emotional relief; the ability to provide better care; and the ability to keep their older relatives at home and out of institutional settings.

Self-directed caregivers were more likely to report that they were “very satisfied” with services than were caregivers receiving traditional services (82 percent versus 64 percent). The ability to

hire friends, family members, and neighbors may have contributed to self-directed caregivers' increased overall satisfaction with services. A large proportion (81 percent) said they preferred to hire someone they knew rather than hiring a stranger from an agency. In addition, compared to traditional service users who lived in rural areas, rural self-directed caregivers were significantly more satisfied with overall services.<sup>7</sup>

**Challenges:** Georgia encountered conflicting information about whether persons providing unskilled personal care and homemaker/chore services in the home were considered employees or independent contractors. After research and consultation with an expert in the tax code for home care workers, the program was able to overcome this challenge by observing the limits established by the Internal Revenue Service on the amount paid annually to in-home workers. Therefore, the family caregiver did not have to pay federal and state employment taxes on consumer-direction funds.

Another challenge for the programs has been providing consumers with adequate education regarding services, funding, and payment options without making the program seem overly complicated.

**Consumer Direction and State Policy Priorities:** Georgia is continuing a policy to expand self-direction. The Department of Human Resources (DHR), Georgia Division of Mental Health, Developmentally Disabled, and Addictive Diseases (MHDDAD) received a three-year federal Systems Change grant in 2003 from CMS to address barriers to developing and implementing a self-directed home and community-based service delivery system for four consumer populations: older adults, children and adults with developmental disabilities, children and adults with physical disabilities, and adults with traumatic brain injury.

**Success Factors:** Georgia's Self-Determination Program has published a *Self-Directed Guide Book* that details how to develop a consumer-directed program for caregivers. The guidebook can be obtained on the Division's website (<http://aging.dhr.georgia.gov>).

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<sup>7</sup> Perkins, M., Lepore, M., Sambhara, R., Jackson, K., & Ball, M. (2004). *Assessing Georgia's self-directed care program*. Atlanta: Gerontology Institute Georgia State University.

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**Program Name: You Decide Your Help**

**Administering State Agency: Minnesota Department of Human Services**

**Program Information:** *You Decide Your Help* is Minnesota's new consumer-directed community service initiative to maximize choice and control for family caregivers and older adults who want to hire and manage their own workers. Consumer-directed services are available to family caregivers of eligible older adults through a Medicaid HCBS waiver program (Elderly Waiver), the Alternative Care program for older adults funded by state general revenues, and the Older Americans Act's NFCSP. Currently, three of the seven AAAs in Minnesota offer consumer-directed options for caregivers with NFCSP funds, serving a total of 23 caregivers with these options. By the end of 2006, each AAA will have implemented at least one consumer-directed option for caregivers.

**Consumer-Direction Process:** The Arrowhead AAA and the Minnesota Chippewa Tribe AAA offer caregivers consumer-directed respite care and supplemental services and allow family members and others to be paid respite providers. A counselor or support planner is available to work directly with the caregiver to create a spending plan and hire and manage respite workers. The caregiver obtains the funds for a consumer-directed budget (typically \$500–\$3,500 per calendar year) either directly through the AAA or through a fiscal support services provider under a grant or contract with the AAA. The caregiver can opt to be the common law employer of respite workers or use an outside agency to be the employer.

**Outcomes/Benefits:** Consumer-directed services allow caregivers to maximize choice and control to meet their needs. Caregivers with unique needs (i.e., those living in isolated rural areas, those with specific cultural and ethnic needs, or those caring for someone with dementia) or those who are underserved are able to hire the person with whom they feel most comfortable and who best meets their needs. Caregivers are more satisfied when they can hire friends and family members and get the services they really need, when they are needed, which makes the program successful.

Starting in 2004, each AAA began administering a Customer Outcome Survey to assess how the program is helping caregivers to cope and a Customer Satisfaction Survey to assess the quality of the service caregivers are receiving annually. The preliminary results of these surveys are positive.

**Challenges:** The primary challenge with implementing consumer-directed services for family caregivers involves obtaining support for the service model with AAAs and traditional Title III providers. Operating in a "consumer-directed" paradigm is dramatic and difficult for those comfortably grounded in a traditional system that supports professional decision-making and authority. In addition, consumers are often unaware of this option, so there is currently little demand. Additional resources are needed to build community awareness and ensure continuous training and education for AAAs, consumers, and other stakeholders on the merits of allowing consumer choice and control in HCBS.

**Consumer Direction and State Policy Priorities:** Caregiver support and consumer-directed services are two top priorities of Minnesota's Long-Term Care Task Force and have strong

support from the state Governor's Office. These policy directions include maximizing peoples' ability to meet their own long-term care needs by providing them with broader decision-making authority. Minnesota is working to expand support for family caregivers in a variety of ways, including accessible information about services, education and training, and various forms of respite.

In 2004, Minnesota received a three-year Cash and Counseling Demonstration grant to implement consumer-directed community services for older adults across funding streams, with an additional supplement to serve family caregivers.

**Success Factors:** Older adults participating in publicly funded programs are beginning to use the consumer-directed option, *You Decide Your Help*. Throughout the state, providers have received training in and technical assistance for this new approach to pursue the state's policy direction and shift from the traditional service delivery model to consumer-directed approaches. As a result, providers and stakeholders are becoming more familiar with consumer direction and are increasingly helping consumers to access the service.

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**Program Name: North Carolina Family Caregiver Support Program**  
**Administering State Agency: Area Agencies on Aging**

**Program Information:** Before enactment of the NFCSP, there was no comprehensive program for family caregivers in North Carolina. The North Carolina Family Caregiver Support Program has helped fill this gap by making information, supports, and services available as needed and desired by caregivers. The program targets family caregivers providing care to older individuals in the greatest social or economic need, with particular attention to low-income individuals. State-level public and private organizations are partnering to provide information and services to family caregivers and to educate and train professionals who work with them about the needs of family caregivers. Currently two AAAs covering 12 counties in North Carolina offer consumer-directed options for caregivers. In 2004–2005, approximately 341 caregivers were using the consumer-directed options within these programs.

**Consumer-Direction Process:** The Northwest Piedmont Council of Governments (NWPCOG), an AAA serving caregivers in five counties, has voucher programs to assist caregivers in paying for respite, supplemental services, and meals. This AAA contracts with respite agencies and local restaurants to offer caregivers a choice of licensed respite providers (i.e., in-home care, adult day care, and short-term care at a long-term care facility) as well as up to five meals a month for themselves and their care recipient. Supplemental services include counseling, nutritional supplements, incontinence supplies, and emergency response systems. Vouchers (whose annual amounts vary by county) are issued monthly and funding is available for up to one year. In this program, family members cannot be paid to provide respite care. The Southwestern Commission, an AAA that serves seven counties in the state, offers eligible caregivers a \$575 annual letter award (voucher) that is valid for a six-month period. The caregiver coordinates services from a list of options (such as in-home care, adult day care, and group respite) with the administering agency, including hiring private individuals such as friends and neighbors to provide care. Family members may be paid to provide care only if they are not immediate family members. In addition, each county receives \$500 a year for supplemental services to be distributed to caregivers on an as-needed basis.

**Outcomes/Benefits:** The NWPCOG caregiver voucher program and the restaurant voucher program are easy for family caregivers to use. Caregivers do not need to make any monetary transactions and they have a lot of options from which to choose, including types of respite settings and types of meals that best meet their needs. The program empowers caregivers to make their own decisions, giving them control and independence in their service utilization. In addition, the program is cost effective for the AAA because caregivers are responsible for setting up their own services, which saves administrative costs.

One of the benefits of the Southwest Commission's Region A Respite Program is that it allows friends, neighbors, and, in certain circumstances, family members to be paid providers. Caregivers with unique needs (i.e., those living in isolated rural areas, those with specific cultural and ethnic needs, or those caring for someone with dementia) or those who are underserved are able to hire the person they feel most comfortable with and who best meets their needs.

**Challenges:** One challenge the NWPCOG AAA has encountered in administering the consumer-directed options in its program is the limitation in providers that are willing to be reimbursed for respite services. Caregivers have expressed the desire to use family members or to hire someone privately to provide respite; however, the AAA only reimburses for licensed professionals to provide the service.

**Consumer Direction and State Policy Priorities:** In addition to the AAAs that operate self-directed care programs, several other consumer-directed programs are operating in the state. Since 1993 North Carolina's Department of Health and Human Services has administered a consumer-directed respite program for caregivers through an Alzheimer's Disease State Demonstration Grant from the U.S. AoA. In addition, North Carolina received a Real Choice Systems Change grant in 2002 to create a new infrastructure to sustain the service and support system for provision of consumer-directed home and community care to people with disabilities and chronic conditions.

**Success Factors:** Both the NWPCOG and the Southwest Commission note that agencies must be flexible and build flexibility into the program. The NWPCOG monitors the use of vouchers on an ongoing basis by keeping in frequent contact with caregivers and setting monthly expiration dates on all vouchers. The program also requests detailed receipts for supplemental service purchases. In addition, NWPCOG program administrators feel that working with licensed professionals gives structure and validity to the program. Both regions note that, even though the program is consumer-directed, some caregivers still want advice and direction from the agency in determining the services they need.

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**Program Name: Pennsylvania Family Caregiver Support Program (FCSP)**  
**Administering State Agency: Pennsylvania Department of Aging**

**Program Information:** Pennsylvania's FCSP began in 1987 as a pilot project and went statewide in 1991. Since then, Pennsylvania has fully integrated the FCSP into its other long-term care programs for older adults. When the federal NFCSP was enacted, Pennsylvania used the program to supplement and expand access to services under its state-funded FCSP. The program targets family caregivers providing care to older individuals in the greatest social or economic need, with particular attention to low-income individuals. The range of core services provided for family caregivers includes specialized information and referral, assessment of needs, family consultation/care planning, care management, legal consultation, emergency response, support groups, counseling, and caregiver education and training. In addition, the program offers reimbursable services, including respite care, home modification/repair, and financial help to purchase durable goods and related supplies. In 2003–2004, the program served 9,570 families, with an active caseload of 6,655 clients.

**Consumer-Direction Process:** Pennsylvania emphasizes the flexibility of each AAA to meet individual consumer needs. Consumers determine what they need and are then reimbursed for everything from respite care to consumable supplies. Some AAAs provide direct services and others contract out these services. Reimbursement is based on a sliding scale and is typically \$200–\$500 per month. In addition, reimbursements are available for home modifications and assistive technology with a lifetime maximum of \$2,000 (excluding prescription drugs). For respite care, caregivers can purchase services in any setting they choose and can hire friends (but not family members) as providers.

**Outcomes/Benefits:** The program is viewed as one of the most flexible in the state, is well received by families, and is able to target benefits to what the caregiver needs. There is little bureaucratic rigidity, which makes the program adaptable to individual agency needs. The program's popularity has been attributed to its flexibility and its goal of viewing caregivers as consumers who need support services themselves, rather than solely being seen as a resource for the care recipient.

**Challenges:** Before implementing consumer-directed options, most agencies operated using contracts with providers and delivering services in a traditional "agency model" mode. Managing money for clients on a case-by-case basis for respite and supplemental services reimbursement required some training and adjustments for AAA operations; however, challenges have been minimal. Another challenge is to pursue more outreach to culturally diverse populations to increase consumer direction and service delivery to ethnic minorities.

**Consumer Direction and State Policy Priorities:** Pennsylvania is actively practicing and encouraging consumer direction. In addition to the FCSP, the Pennsylvania OPTIONS and Department of Aging Waiver programs offer consumer-directed options. The state recently received a Cash and Counseling demonstration grant to provide consumers the option of controlling their own waiver services, but this program does not target caregivers.

**Success Factors:** The Pennsylvania FCSP uses a family-centered approach to consumer direction by listening to and respecting caregivers' choices, rather than making decisions on their behalf. The program's flexibility limits complex bureaucracy that can frustrate older adults and their family caregivers by allowing providers to respond to caregiver preferences.

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