

NAVIGATING  
THE CARE SYSTEM:  
A GUIDE FOR  
PROVIDERS TO HELP  
FAMILY CAREGIVERS

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FAMILY CAREGIVER ALLIANCE®  
*National Center on Caregiving*



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# NAVIGATING THE CARE SYSTEM: A GUIDE FOR PROVIDERS TO HELP FAMILY CAREGIVERS

*“There are now typically, in any given state, over 100 different funding streams, all of which have their own regulations, their own enrollments, their own oversight, and their own programs. I had no idea where to go. And to try to figure it out was more or less impossible. To try to navigate the system was even worse.”*

The Honorable Bruce Bronzan, Assembly member (retired), California State Assembly, at “Who Will Provide Care?” conference sponsored by Family Caregiver Alliance in San Francisco, CA, October 2001.

## INTRODUCTION

Today, millions of Americans with chronic illnesses or disabilities receive help with health and personal care at home rather than in institutional settings such as nursing homes. The vast majority of that help comes from the so-called “informal” (unpaid) support of family and friends. However, family caregivers trying to find medical and personal care services for their loved ones—and help for themselves in their caregiving role—face a daunting task.

The reason: the health and long-term care system in the United States is less a “system” than a patchwork of state and federal programs that differ from state to state in terms of eligibility for services, financing and delivery systems. Trying to find one’s way through these programs without assistance often means that a caregiver will be frustrated in his or her search, spend too much money on the wrong services, or not be able to find quality providers. Caregivers learn that it can be challenging and exhausting to navigate through the network of providers and services to arrange appropriate and affordable care (Reinhard & Scala, 2001).

That’s where the service provider comes in. Service providers are there to help people with disabilities and their families find the assistance they need and to deliver those services. In the process, they also need to support family caregivers to address their own needs. Service providers include publicly funded case workers, private geriatric care managers, nurses, physicians, and other medical practitioners, personal care assistants and many others. As practitioners in the health and long-term care field, providers need to have a good understanding of their local area’s complex array of programs, services, and funding in order to provide constructive and valuable

assistance to older people, persons with disabilities and their family caregivers as well. They need to help knit the pieces together.

It's not an easy job. But a service provider with first-rate skills in navigating the health and long-term care maze is an invaluable asset to a family caregiver, and can help ease the strain on the caregiver *and* the care recipient. The end result will be a web of services and providers that can deliver the best care possible, as seamlessly as possible.

This monograph:

- Traces how the development of health and long-term care in the United States has resulted in such a confusing array of services;
- Describes how a service practitioner can help pull the pieces together;
- Describes challenging situations, such as the problems of employed family caregivers;
- Explains how state single-point-of-entry systems can make the job easier and cites examples from several states; and
- Lists a series of resources for practitioners to tap.

Although this report discusses both health and long-term care because people with disabilities often move between the two, the focus is on long-term care because of its unique, ongoing challenges.

## HISTORY AND BACKGROUND

The disjointed nature of health and long-term care services in the United States arises from decades of public and private programs crafted originally for specific purposes or populations, and then modified and adjusted over the years to fill other needs. **Medicare**, for example, was intended primarily to address the acute care of (mostly medical) conditions. Yet the program's home health benefit today often serves as a *de facto* long-term care service for persons trying to remain in their homes after suffering a disabling event such as a hip injury after a fall.

The joint federal-state **Medicaid** program was originally designed to provide primarily medical care to low-income Americans (O'Keeffe & Smith, 2000). Today, however, Medicaid is also the major source of public funding for long-term services and supports, including nursing homes, and serves many previously middle-income persons, impoverished after paying out-of-pocket for long-term care expenses.

Split federal and state responsibilities and funding further contribute to the crazy quilt of services that has evolved over the years. In the absence of a national long-term care program, states design and administer Medicaid. The states set policies (within broad federal guidelines, particularly in regard to eligibility for Medicaid services), regulate care, and control resources (Coleman, 1998).

Added to the mix are Older Americans Act services, including the **National Family Caregiver Support Program (NFCSP)**, and **state-funded programs**, such as California's **Caregiver Resource Centers**. Additionally, **private initiatives** are available, such as company programs for employees who are family caregivers.

Part of this mix of services and supports is the "**Aging Network**," a name given to the multiplicity of mostly public and nonprofit agencies and organizations. These include the **Area Agencies on Aging (AAAs)**, county services, health-related agencies, and the social services network that includes senior centers, crisis and emergency offices, and adult day centers.

The National Family Caregiver Support Program in particular has come to play a major role in focusing attention on caregiver needs and in providing a range of services to meet those needs since the program was enacted by Congress in the 2000 reauthorization of the Older Americans Act. The value of the NFCSP to service providers lies in its comprehensive approach to caregiver supports through AAAs, located throughout the country. Covered services include information, assistance, individual counseling, training, support groups, respite care and supplemental services. This latter category in particular allows local AAA programs to address specific needs of caregivers in their area. Supplemental services could include home modifications, assistive technology, and emergency assistance, to name but a few. For further information on the NFCSP, see the U.S. Administration on Aging's Fact Sheet on Family Caregiving at [www.aoa.gov/press/oam/May\\_2003/medialfact\\_sheets/National%20Family%20Caregiver%20Support%20Program.pdf](http://www.aoa.gov/press/oam/May_2003/medialfact_sheets/National%20Family%20Caregiver%20Support%20Program.pdf)

## **INTRODUCING THE SERVICE PROVIDER**

The service provider who is trying to help a family caregiver steer through this labyrinth must be knowledgeable, adept and skillful. The first task may be helping family members to identify themselves as caregivers. Although family members perform many care tasks, they do not necessarily define themselves as caregivers (Montgomery & Kosloski, 2001). For example, a wife caring for her husband who has suffered a stroke takes care of his needs as a matter of course, out of love and compassion. She probably does not see herself as in some new and different role that is called "caregiver."

When family caregivers were presented with the name “caregiver” in focus group sessions, for example, they “weren’t especially interested in labeling what they do,” researchers reported. They were “simply too busy filling the role to think about what it is.” Moreover, respondents were so overwhelmed, the researchers said, that many of them “never even thought about options that might be available” (National Family Caregivers Association/National Alliance for Caregiving, 2001). It is only when they *do* embrace the term and the concept that many caregivers are able to avail themselves of services for their family member and themselves.

Researchers have also observed that family members reach a “servable” moment when they are more receptive to supportive services, particularly for themselves (such as respite) at different stages in their caregiving roles. Spouses in particular may seek formal assistance relatively late in the caregiving career. In response, service providers need to offer multiple support services made available in multiple forms (Montgomery & Kosloski, 2001).

Many state and local agencies have launched outreach campaigns and websites to inform family caregivers about their programs. Drawing family caregivers into programs that address *caregiver* needs will also help educate them about available programs for care recipients. Information and assistance is, for instance, one of the five key components of the NFCSP service package that every AAA is expected to offer family caregivers. And information and assistance appropriately directed to the specific needs of each family seeking help can provide choices they may not have known were open to them.

## TAPPING COMMUNITY RESOURCES

Providers need to familiarize themselves with this range of community resources—medical, legal, financial, environmental and emotional. They must identify services and programs for the *care recipient* as well as for the *family caregiver* because services that help the person with disabilities or chronic illnesses are, at the same time, a source of support for the caregiver. Once families have tapped into caregiving services, their needs can be assessed and a care plan developed.

Community resources are available in both public and private agencies, but the major set of connections about which a service provider should be aware includes the Aging Network, the AAAs, social service agencies and state and county services. It is beneficial for service providers who do not work for AAAs to learn about the programs offered by a wide range of organizations. Many AAAs serve as single entry points that enable consumers to access a range

of information and services at one location. (Single points of entry will be discussed in greater detail later in this report.)

Community resources, such as United Way agencies, religious organizations, and social service agencies offer important services to family caregivers. Providers need to increase their knowledge of eligibility rules, services and funding of federal and state programs. Providers in medical settings can be particularly helpful in referring caregivers to local services. Hospital discharge planners, nurses, physicians and other hospital personnel must be able to alert families to the range of community options that can assist not only the patient being released from the hospital, but their family members as well.

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One study reported that none of the caregivers discussing their experiences in a focus group had been referred by health care professionals to community-based agencies for emotional or other kinds of support (Levine, 1998). In another study, home care professionals said they frequently encountered people who were unfamiliar with services and eligibility requirements. Doctors' offices, outpatient clinics, health fairs, bloodmobiles and other locations offer outlets for distributing literature and information about community services.

## LEARNING FROM OTHERS

An important way service providers add to their knowledge of available resources is in interacting with other professionals in the field. A survey of geriatric care managers in 2000 reported that 74 percent worked with physicians, 63 percent with nurses, 62 percent with social workers, 51 percent with other health professionals, and 49 percent with attorneys on behalf of their clients (Stone & Reinhard, 2002). In addition to the knowledge each gains from the other, these contacts help inform a service provider's advice and assistance. For example, a care manager might link the family caregiver to a local financial advisor for help with money issues. She might be able to suggest ways to retrofit a home, a contractor to do the work, and which public or private agencies might be able to help with the finances.

Several national organizations of legal, financial, and accounting professionals can be helpful resources. For example, the American Bar Association ([www.abanet.org](http://www.abanet.org)), the American Institute of Certified Public Accountants ([www.aicpa.org](http://www.aicpa.org)), and the National Association of Personal Financial Advisors whose membership consists of fee-only planners ([www.napfa.org](http://www.napfa.org)) may offer important information regarding long-term caregiving. Legal aid offices are also usually located in most large cities.

## WORKING CAREGIVERS

Another group who could be helped by knowledgeable service providers are working caregivers—those juggling full- or part-time employment and care responsibilities for an ill or elderly loved one. Studies show that by the year 2005, 37 percent of U.S. workers will be more concerned with caring for parents than for a child (National Partnership for Women and Families, 1998). But the price of such care is high both for the employee and the employer. A 1997 MetLife Study of Employer Costs for Working Caregivers found that lost productivity of working caregivers costs employers between \$11 billion to \$29 billion a year (Mature Market Institute, 1997). The causes are increased absenteeism and interruptions incurred by workers caring for a family member, as well as the loss of workers who have had to quit their jobs to provide full-time care.

Working caregivers need access to the same kinds of information as other family caregivers; their circumstances differ mainly in the more limited time that may be available to them to find the answers they need and in the multiple roles they have to perform. Service providers need to find as many shortcuts as possible for these workers, perhaps by suggesting they tap resources within their own companies first, such as employee assistance programs, health fairs or workplace support groups. Other work-based caregiver programs might include education and training, counseling and day care services. Employed caregivers might be encouraged to ask their employers about the possibilities of telecommuting or a flexible work schedule. The Families and Work Institute estimates that one out of four employers with more than 100 employees has a program in place to assist employees with caregiving responsibilities (Wagner, 2003).

Service providers also need to understand the Family and Medical Leave Act (FMLA), which provides up to 12 weeks of unpaid leave a year for employees caring for a seriously ill child, spouse or parent. A 2000 survey reported that employees are using FMLA leave in increasing numbers. These employees generally report that they are satisfied with the leave they took and that it had a positive effect on their own and their families' health and well being (Waldfoegel, 2001).

Service providers also need to understand their own state's FMLA laws, which may go beyond the federal FMLA. For example, as of 2004, California offers partially *paid* family leave. A policy brief available from Family Caregiver Alliance on paid family and medical leave helps identify different state practices in this regard (Bell & Newman, 2003).

Many working caregivers and caregivers in general have another concern: they may live hundreds, even thousands of miles away from a family member who needs help. Long-distance caregiving can present many difficult problems about how to arrange supportive services for your family member. Family Caregiver Alliance's *Handbook for Long-Distance Caregivers* provides both service providers and family caregivers valuable information on steps to be taken and resources available to help (Rosenblatt & Van Steenberg, 2003).

## **MEETING THE NEEDS OF ETHNIC AND RACIAL GROUPS**

Service providers increasingly recognize the importance of dedicating staff, training, outreach, translation and interpreting services to meeting the needs of an ethnically, culturally and racially diverse population of family caregivers. Language and cultural barriers can make it especially difficult for these groups to learn about and understand the services available to them.

An AARP study of multicultural baby boomers coping with family and aging issues reported that the most popular sources of help were spiritual, followed by family members. Forty-three percent of the respondents named doctors as a source of help, but other professionals were much less frequently cited, such as attorneys and accountants (16 percent), government agencies (15 percent), and social workers (13 percent) (AARP, 2001).

Service providers clearly need to find ways to respond to the needs of these diverse populations. Organizing public forums in ethnic neighborhoods, translating materials and broadcasting in the languages of populous groups, and partnering with ethnic community organizations are possibilities. Specialized services to LGBT (lesbian, gay, bisexual and transgender) communities are also available in some communities.

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## PROGRAMS THAT PAY FAMILY CAREGIVERS

In gathering information about services and resources that might assist family caregivers, service providers should also check on the availability of publicly funded programs that pay family members for the personal care services they provide their loved ones. These programs offer several benefits for family caregivers. They:

- relieve them of the pressure of finding qualified workers;
- supplement their incomes when they may be under financial stress; and
- reduce anxiety about strangers caring for their relatives.

Under the Medicaid program, states may pay family members (other than spouses and parents of minor children) for such services. In California's In-Home Supportive Services Program, for example, about 40 percent of consumer-hired personal attendants are related to the Medicaid beneficiary (O'Keeffe & Smith, 2000). Many state-funded home care programs also have this feature, or allow people to use a voucher to access respite care, adult day care, home modification and other support services. These programs give families the chance to choose the services or supplies that are most helpful to their specific situation.

## SINGLE POINT OF ENTRY SYSTEMS

One of the most promising developments for persons with disabilities and their families in recent years has been the creation in many states of "single points of entry" (SEPs) that serve as a means of accessing a state's health and long-term care system. The idea is to provide "one-stop shopping" in a single location where consumers and families can get advice and information about the range of community supports that may be available.

This concept, also called "No Wrong Door" in some states, refers to systems that enable consumers to find services regardless of their specific disability or need. For example, Washington State has a website called "No Wrong Door" that is intended "to guide clients, staff, and partners to resources quickly and easily." The services are offered by the Department of Social and Health Services (see [www.dshs.wa.gov/basicneeds](http://www.dshs.wa.gov/basicneeds)). Given the opportunities these single entry points offer for simplifying the task of finding appropriate services for persons with disabilities, service providers need to become informed about any SEPs in their states and the resources they offer.

A recent national survey reported that 31 states and the District of Columbia were operating 43 SEPs, with 25 of the SEPs serving two or more populations, such as older adults, people with mental

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retardation/developmental disabilities, or people with mental health problems. Most of the SEPs were located in a state agency regional or field office, a community-based nonprofit organization, an AAA, or a county department (health or social service) (Mollica & Gillespie, 2003).

The most comprehensive of these state systems offer consumers an opportunity for an assessment of their needs by competent and trained care managers, and a way to find out if they are eligible for publicly funded programs and services. If they are eligible, a care manager will help guide them through the application process, help them develop a care plan, arrange for the appropriate services, and monitor their care. Even for consumers who may *not* be eligible for publicly funded services, the single entry point agency can provide information and assistance on other community resources.

Following are descriptions of three state programs that provide a comprehensive range of options and supports to diverse populations through a single-entry point system.

### *New Jersey*

New Jersey's statewide program, called NJ EASE (Easy Access, Single Entry), provides one toll-free telephone number for older adults and their families to access medical and social services. When consumers call the toll-free number, they are connected to the agency designated to serve as lead agency in their county. State and county staff are available to answer calls during regular business hours; after hours, calls are picked up by an answering machine. Consumers are given instructions about what to do in an emergency.

Through this program, consumers can access community programs such as case management, transportation, and health insurance counseling. They can learn about in-home services such as home-delivered meals, and home health services, housing and adult day care. Information and assistance specialists provide general information and assess consumers' needs and resources. Consumers who require a home visit or more intense assistance are referred to care managers (Reinhard & Scala, 2001).

### *Washington*

Washington uses six regional offices of the state Aging and Adult Services Administration (AASA) and AAAs throughout the state to channel individuals with disabilities and their family caregivers through the care system. AASA employees in the regional offices assess applicants, create care plans, and authorize services for older adults (65+), adults with disabilities, and persons with mental re-

tardation or developmental disabilities. The AASA staff member acts as the ongoing case manager for any consumer who subsequently receives services in a nursing facility or a nonmedical residential facility. The local AAA takes on the case management function for consumers who remain in their homes (Feinberg, Newman, & Van Steenberg, 2002).

In addition to the Medicaid and Older Americans Act services for people with disabilities, the Washington AAAs also provide specific services for family caregivers through two state-funded programs and the federally funded NFCSP. With the AAAs responsible for all these programs, they can help families learn about the array of assistance that may be available, and integrate those caregivers effectively into the care plan developed for the person with the disability.

### *Indiana*

All community-based long-term care programs in Indiana are integrated and delivered through the 16 AAA across the state. Care managers can arrange services for persons of all ages with disabilities and their families using the state-funded CHOICE (Community and Home Options to Institutional Care for the Elderly and Persons with Disabilities) program, Older Americans Act services, seven Medicaid home and community-based waiver programs, and the Social Services Block Grant funds as well as the NFCSP. Indiana's newest Medicaid waiver, Support Services, includes training for family caregivers.

The consumer can call either a local number or a toll-free number that can be dialed from anywhere in the country, which bounces the call to the local AAA's Call Center. For many of the callers, Information and Assistance (I & A) staff do a brief telephone assessment that includes discussing the caller's problems, personal resources, and potential eligibility for publicly funded services. About two-thirds of calls request basic information about services such as transportation or housing or referrals to local agencies. The other one-third of calls reflect a need for help with home-delivered meals, in-home services or case management.

## Help for Families

The following are descriptions of actual cases of families who received help from CICOA, Aging and In-Home Solutions, an AAA that serves eight counties in and around Indianapolis, Indiana. (Fictitious names have been used to protect the confidentiality of clients and family members.)

The first contact all callers have with the agency is with one of five I & A specialists, all but one of whom are trained social workers. Initial assessments are handled over the telephone, and if a home visit is deemed necessary, it is conducted by the I & A specialist. If a client is on a waiting list, the I & A specialist is responsible for contact and communication with the client and caregivers. Once a funding source is approved, a care manager is assigned and a care plan written.

### ***Mrs. Lamont***

*A social worker at a local hospital referred Mrs. Lamont to the agency, saying that the 90-year-old woman was going to be discharged the next day if she remained stable, but might need to go to a nursing home for the short term if her family could not meet her needs. She had a chronic lung condition and congestive heart condition. She was also short of breath, hard of hearing and forgetful.*

*Mrs. Lamont had not applied for Medicaid. CICOA staff worked with the Medicaid caseworker to access Medicaid benefits for Mrs. Lamont.*

*Mrs. Lamont went home two days after the contact was made with CICOA. A day after that, CICOA staff visited Mrs. Lamont and her daughter at the home to further explain available services and to provide them with a list of home health care providers. A week later, Medicare approved an order for 60 days for physical therapy, occupational therapy, home health care, and the services of a registered nurse. CICOA staff arranged for Attendant Care services to begin through the Aged and Disabled Medicaid waiver program after Medicare services ended. An Emergency Personal Response System was also authorized through the waiver program.*

*Mrs. Lamont was re-admitted to the hospital several weeks later for a stay of six days. CICOA staff followed up once again with a home visit with Mrs. Lamont and her daughter about 12 days later to assist with billing problems. After a couple of months, another meeting was held with the two for a 90-day review. They discussed problems concerning homemaker services, and helped resolve issues. A follow-up call indicated that services had improved.*

## Help for Families (continued)

### **Mrs. Robinson**

*Mrs. Robinson was originally referred to CICOA for pre-admission screening for nursing home placement. She was suffering from dementia and had arthritis and chronic heart disease. After a couple of months in the facility, however, the 89-year-old woman returned to her home because her 70-year-old daughter thought she would be happier in her own home environment. The daughter left her own home to move in with her mother to assist with meal preparation, bathing, medication, housekeeping and shopping.*

*The daughter called CICOA requesting in-home services for her mother. Unfortunately, the state-funded CHOICE program, for which the mother would be eligible, has a two-year waiting list. The mother was placed on the list, but in the interim, the agency's family caregiver program is providing personal hygiene once a week through a home health care agency. The program also provides a companion for two hours two days a month so the daughter can attend church and reconnect with friends.*

## SUMMING UP

Service providers address diverse needs of family caregivers. Circumstances vary from family to family, and not all families can avoid nursing home care for their loved ones, or can make home care work for an indefinite period. One size does not fit all. The service provider also cannot burden the family caregiver with a plethora of choices and services. This will only make the job of navigating through the maze even more difficult. Thus, the development of a care plan is crucial because it can help guide the search for the right setting and the right services. And the family caregiver must be at the center of that plan.

## OTHER RESOURCES

The possible range of resources available in most communities can be extensive. For the service provider who does *not* work for a public local or state agency, investigating available public resources is an important step.

State agencies that serve persons with disabilities (such as persons with developmental disabilities or mental illness) will be listed in the telephone directory in the Government section. Since some of these agencies are divisions or bureaus within a larger umbrella agency, it might be necessary to start with a Department of Human Services or Department of Social Services. State and Area Agencies

on Aging can be found on the U. S. Administration on Aging website, [www.aoa.dhhs.gov](http://www.aoa.dhhs.gov) as a listing under “key topics.”

National organizations have local or state chapters; including:

- **Alzheimer’s Association**, (800) 272-3900, [www.alz.org](http://www.alz.org)
- **American Cancer Society**, (800) 227-2345, [www.cancer.org](http://www.cancer.org)
- **American Heart Association**, (800) 242-8721, [www.americanheart.org](http://www.americanheart.org)
- **National Association for Home Care**, [www.nahc.org](http://www.nahc.org), has a “State Resources” page that may be helpful. For each state, the website lists the name and telephone number for:
  - ▲ the state **Home Care Association** that will have listings for home care agencies that belong to the organization, and
  - ▲ the state **hospice association**.
- **AARP** has an office (sometimes two) in every state, which can be found either in a telephone directory or on the AARP website, [www.aarp.org](http://www.aarp.org).

Other resources include:

- **The Eldercare Locator**, a nationwide, toll-free information and assistance directory and website, identifies community support at (800) 677-1116 or [www.eldercare.gov](http://www.eldercare.gov).
- **Family Caregiver Alliance** operates the **National Center on Caregiving**, which offers families and providers advice and information about care resources. FCA can be reached at (800) 445-8106, email at [info@caregiver.org](mailto:info@caregiver.org), or visit [www.caregiver.org](http://www.caregiver.org)
- **Medicaid**, [www.cms.hhs.gov/medicaid/consumer.asp](http://www.cms.hhs.gov/medicaid/consumer.asp)
- **Medicare**, [www.medicare.gov](http://www.medicare.gov)
- **National Council on Aging Benefits Check Up**, [www.benefitscheckup.org](http://www.benefitscheckup.org)
- **National Academy of Elder Law Attorneys**, [www.naela.org](http://www.naela.org)

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