

IX. NONTRADITIONAL APPROACHES

Assistant Secretary, Josefina G. Carbonell, elaborated her vision for the National Family Caregiver Support Program (NFCSP) at the national Administration on Aging (AoA) conference, calling for the aging network to learn from other programs and, at the same time, recognize that every state, community, and family is different. Carbonell also emphasized the need under the NFCSP to create optimum flexibility, maximize consumer choice, and communicate directly with caregivers. This chapter highlights several innovative strategies and approaches the network can consider to enhance support to caregivers through: 1) consumer direction for caregivers, 2) caregiver self-advocacy, 3) volunteer models, and 4) technology applications.

CONSUMER DIRECTION

Parts of the following section are drawn from Carol Whitlatch's issue brief *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*.¹

The notion that individual preferences and freedoms should drive health care delivery has become commonly characterized as consumer direction. In the broadest sense, consumer direction provides opportunities for persons to make meaningful choices regarding their care or the care they are providing.² It is also based on the premise that "individuals with long-term care needs should be empowered to make decisions about the care they receive, including having primary control over the nature of the services and who, when, and how the services are delivered."³

Consumer-directed services were originally developed to meet the needs of younger people with disabilities. The consumer direction movement emerged from the push by the younger physically disabled population for alternatives to institutionalization and evolved during the 1990s to imply greater consumer control and decision-making around care. The National Institute of Consumer-Directed Long Term Care Services has established several key principles of consumer direction, as illustrated in *Exhibit IX.1*.

¹ Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

² Sciegaj, M. (2001). *Elder Preferences for Consumer Direction*. Paper presented at *Consumer Voice and Choice*, Scripps Gerontology Center, Fourth Conference on Long-Term Care. October 18, 2001, Columbus, OH.

³ Stone, R.I. (2001). *Long Term Care Workforce Shortages: Impact on Families* (Executive Summary No. 3). San Francisco, CA: Family Caregiver Alliance.

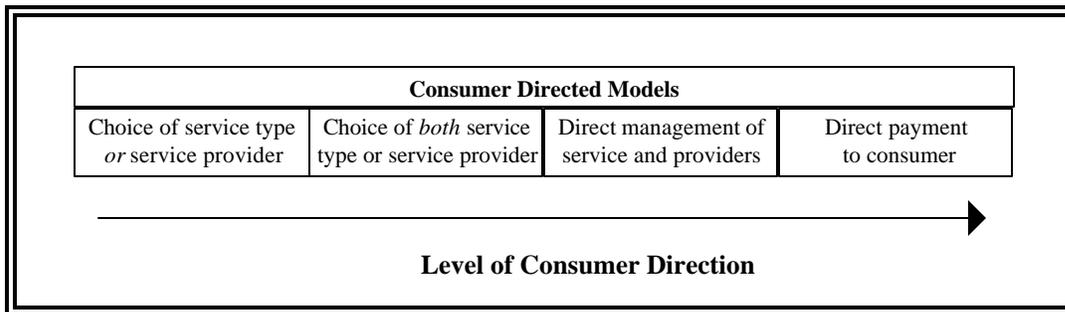
Exhibit IX.1 Principles of Consumer Direction

- Systems should be based on the presumption that consumers are the experts of their service needs.
- Different types of services warrant different levels of professional involvement.
- Choice and control can be introduced into all service delivery environments.
- Consumer-directed service systems support the dignity of people requiring assistance as well as cost less when properly designed.
- Consumer direction should be available regardless of payer.

Source: The National Institute of Consumer-Directed Long Term Care Services.

The services that constitute “consumer-directed care” represent a range of delivery and financing models that support varying degrees of individual choice, autonomy, and self-determination. For example, on the more conservative end of the spectrum are consumer-directed models that allow caregivers to choose between a variety of agency-selected home health or chore service providers rather than appointing a specific provider or worker. On the more flexible end of the spectrum are consumer-directed programs that provide direct payments to consumers so individuals can determine how they would like to use the funding allocation. Area Agencies on Aging (AAAs) should keep in mind that the spirit of consumer-directed care lies in the practice of assuring that the consumer retains choice and control. *Exhibit IX.2* presents the range of service approaches for providing consumer-directed care.

Exhibit IX.2 Range of Consumer-Directed Approaches



Many federally and state-funded consumer-directed models have been established for the *care recipient*, but few states have developed consumer-directed programs that focus on the *caregiver*. Some consumer-directed programs designed for care recipients, however, have also benefited caregivers. For example, under the Cash and Counseling Model, funded by the Robert Wood Johnson (RWJ) Foundation and the Office of the Assistant Secretary of Health and Human Services, *care recipients* are offered a choice between receiving traditional agency-delivered personal assistance services listed in their care plans or managing cash allowances to obtain these services themselves. Medicaid Home and Community-Based Waivers (HCBW) approved by the federal Centers for Medicare and Medicaid Services permit direct cash payments to Medicaid consumers receiving

personal assistance services. Payments are available to care recipients to pay for nontraditional services and *to employ family members as caregivers*.

Although this model benefits both care recipients and caregivers, it is important to distinguish that the care recipient, rather than the caregiver, is the individual with ultimate decision-making power. The aging network must recognize the interdependence of the caregiver and the care recipient in designing and delivering consumer-directed services, but the network also should make a deliberate effort to move beyond consumer-directed program options that address the needs of caregivers solely in the context of care recipients. For example, a program that makes direct payments to caregivers to obtain a needed service, such as respite care, is clearly a consumer-directed caregiver program.

The NFCSP presents an opportunity for the aging network to create consumer-directed models specifically aimed at offering caregivers the flexibility to select services that will benefit them directly. Well-designed consumer-directed programs for caregivers should:

- Empower the caregiver to serve as the decision-maker;
- Provide multiple approaches for caregivers and their families to obtain services, training opportunities (e.g., information on how to hire, train, and manage service providers), and peer and advocacy support programs; and
- Incorporate flexible designs to ensure individual needs and preferences are met.

Strategies and Program Examples

This section presents concepts and approaches drawn from consumer-directed models for both care recipients and caregivers. Program examples, however, strictly reflect models that have been specifically designed for caregivers and allow the caregiver to be the key decision-maker.

Provide Staff Education and Training on Consumer Direction for Caregivers. Because intake and eligibility staff across a range of aging and non-aging providers are likely the first representatives caregivers encounter, training on caregiver consumer direction for these people is essential. The information that intake and eligibility staff routinely give consumers about aging network services could include a description of the ways either the SUA or specific AAAs accommodate consumers' individual needs and preferences. AAA staff must understand and support principles of consumer direction, incorporate consumer direction principles into service planning, and support consumers who want to exercise varying degrees of choice and control.⁴

Provide Flexibility and Maximize Caregivers' Opportunities to Make Choices. No single consumer direction model will be useful in all settings; thus, flexible designs in consumer direction are crucial and more apt to meet the individual needs of caregivers. A

⁴ National Institute on Consumer-Directed Long-Term Services. 1996. Principles of Consumer-Directed Home- and Community-Based Services. Washington, DC: National Council on Aging.

consumer-directed NFCSP offers more than one consumer-directed option, giving caregivers numerous choices, ranging from traditional service models to programs that offer consumers cash or vouchers to purchase services for themselves. At a minimum, a caregiver program should be flexible enough to:

- Give consumers a range of choices regarding service types, providers, service delivery models, and financing mechanisms, etc.;
- Consider development of services and options identified by consumers as important;
- Allow consumers to choose the level of responsibility they will assume in making decisions about services; and
- Offer an acceptable reimbursement rate for services to attract a variety of providers from which consumers can choose.

Whitlatch also emphasizes the importance of recognizing that some consumers do not want to use consumer-directed service options. The program example in *Exhibit IX.3* highlights Michigan's effort to allow caregivers to select respite services from a menu of service options identified by Michigan's Adult Well-Being Service agency.

Exhibit IX.3 Respite Care Self-Determination Model

Title: Respite Care Self-Determination Model

Affiliation: Adult Well-Being Service (AWBS) and Detroit AAA, Detroit, Michigan

Status: Operational

Target Population: Family caregivers

Approach: AWBS, a community-based, nonprofit organization, has launched an initiative to offer respite services to caregivers unlikely to seek services on their own. Respite services for caregivers are being advertised and promoted through the news media (e.g., newspaper articles, radio talk shows). When a caregiver contacts or is referred to AWBS, a social worker conducts an assessment at the caregiver's home. Based on the assessment, the social worker presents several appropriate options for receiving respite services. AWBS has developed working agreements with multiple respite agencies so caregivers can choose the type of respite they would like to receive, including: 1) in-home one-on-one respite offered during non-traditional hours, 2) adult day services for the care recipient, and 3) overnight respite or 4) use of an independent respite worker chosen by the caregiver (family member not living in care recipient's home, friend, or neighbor). Caregivers can receive up to 80 hours of respite per year. Approximately 100 families per year are served.

Costs/Funds: The program's funding sources and approximate amount include: 1) \$75,000 from the NFCSP, 2) \$50,000 from tobacco settlement dollars, 3) \$50,000 from a federal program earmarking dollars to serve low-income neighborhoods, and 4) United Way funds.

Contact Information: Darlene Racz, Director of Aging, Adult Well-Being Service, at dracz@awbs.org or (313) 825-2505.

Direct Payment Options to Caregivers. Concepts of consumer direction for care recipients have been tested under the Cash and Counseling Model in several states, including Arkansas, Florida, and New Jersey. This concept has also been applied to caregiver programs in California, Georgia, and Pennsylvania, which offer caregivers the option of receiving direct payment to purchase and select needed services. Georgia and Pennsylvania require the caregiver to choose a formal provider; however, California allows consumers to hire and manage their own respite workers, including family or friends. In Georgia, caregivers enjoy the option of using funds to receive direct services (e.g., respite) from a list of providers that contract with the AAA or to receive services for care recipients. In Pennsylvania, caregivers can receive any type of service from a formal provider that will help “prolong, improve, or enhance their relationship with the care recipient.” *Exhibit IX.4* highlights the California, Georgia, and Pennsylvania consumer-directed caregiver program examples.

Exhibit IX.4 Direct Payments to Caregivers for Needed Services

Title: Caregiver Resource Center System

Affiliation: Caregiver Resource Center, California Department of Mental Health

Status: Operational

Target Population: Caregivers of persons with adult-onset brain diseases and disorders

Approach: This model system of 11 Caregiver Resource Centers (CRCs) serves families and caregivers of persons with adult-onset brain diseases and disorders (e.g., Alzheimer's Disease, Parkinson's Disease, stroke, traumatic brain injury). CRCs provide a range of support services, including specialized information and assistance (I&A), family consultation and care planning, support groups, legal and financial consultations with attorneys, education, training, and subsidized respite care. In-home respite, the most sought after service within the CRC system, is delivered through two mechanisms: 1) the vendor in-home respite (agency based) in which caregivers are offered vouchers to purchase service hours from home care agencies subcontracting with a CRC and 2) the direct pay or consumer-directed program whereby family caregivers are offered vouchers to hire and manage their own respite workers, including family or friends.

Costs/Funds: A sliding scale copayment schedule, uniform for all CRCs, is used for respite services and takes into account both family income and household size.

Contact Information: Wailing Rosello, Associate Mental Health Specialist, Caregiver Resource Center, at wrosello@dmhhq.state.ca or (916) 654-2629.

Title: Legacy Express

Affiliation: Legacy Link AAA, Gainesville, Georgia

Status: Operational

Target Population: Family caregivers

Approach: Legacy Express promotes caregiver participation in the planning and management of services they receive. Caregivers receive vouchers totaling \$500 (the AAA has varied the amount available) and can elect to spend the money on either: 1) services that will directly benefit the caregiver (e.g., respite) or 2) services for that might reduce some of the burden on the caregiver (e.g., prescriptions, day care services, homemakers services, home modifications, emergency response systems). The program issues to caregivers a handbook of approved providers willing to accept voucher payments.

Contact Information: Cliff Burt, Alzheimer's Program Director, Georgia Division of Aging Services, at gcburt@dhr.state.ga.us or (404) 657-5336.

Exhibit IX.4
Direct Payments to Caregivers
for Needed Services, continued

Title: Pennsylvania Family Caregiver Support Program in Bucks County

Affiliation: Bucks County AAA, Pennsylvania

Status: Operational

Target Population: Family caregivers

Approach: Under the “voucher system,” the AAA supplies the caregiver in need of service with a list of contracted providers. The caregiver contacts a contracted AAA provider and the provider verifies authorization with the AAA fiscal department. After the service is provided, the provider bills the AAA for the authorized AAA percentage and bills the caregiver for the caregiver percentage, if any. Under the “reimbursement system,” if a caregiver purchases from a noncontracted provider (e.g., neighbor or drugstore), the caregiver pays the entire cost and sends the receipt to the AAA, who then reimburses the caregiver for their percentage. Unused amounts from the previous six months are automatically “banked,” but caregivers must receive prior approval in order to use funds from this “savings.”

Cost/Funding: Caregivers eligible for the FCSP can receive reimbursement for their percentage of the first \$200 per month that they spend on necessary care expenses for the older relative. Caregivers eligible for the NFCSP can receive reimbursement for their percentage of up to \$500 per month in some instances.

Contact Information: JoLynn Mokos, FCSP Program Supervisor, Bucks County AAA, at [jlmokos@co.bucks.pa.us](mailto:jl Mokos@co.bucks.pa.us) or (215) 348-0510.

Balance the Needs of the Caregiver with the Needs of the Care Recipient. Whitlatch emphasizes that one of the key challenges for the aging network in building caregiver consumer-directed models is balancing the needs and preferences of caregivers with those of the care recipients.⁵ For example, a care recipient with impaired capacity for planning and judgment might perceive adult day services as a threat to his or her level of independence. In contrast, a caregiver might view adult day services as an opportunity to receive respite from the day-to-day responsibilities of caregiving. Increased understanding of the preferences of the person with cognitive or physical impairments and the needs of the family caregiver will improve the decision-making process, lead to more informed decisions, and reduce the strain on family caregivers and associated health costs.

Support Caregivers Who Choose Consumer Direction. To make a caregiver consumer-directed program work, caregivers must have more than decision-making authority—they must also receive necessary support and information to enable them to decide whether they need staff support and how to manage their service providers. Although individual caregivers will vary in the amount of information and support they need, NFCSPs should make training and counseling available to all caregivers.

⁵ Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

The range and scope of consumer-directed programs vary greatly according to funding source and amount, population served, and organizational capacity. As more consumer-directed programs are developed and implemented specifically for caregivers, Whitlatch notes the importance of remembering several critical issues:⁶

- Only some caregivers will use consumer-directed models.
- Caregivers must be presented with tools to explore and understand what the care recipient's preferences are.
- In systems of care, provider agencies' focus shifts from *providing* services to *supporting* provision of services.
- Contrary to myths about consumer-directed services, states with experience in this arena have found little or no abuse of program funds; however, they included mechanisms to ensure appropriate use of program funding.
- Consumer-directed programs must be thoroughly evaluated, modified, and re-evaluated if they are to be efficient and effective.
- The results of program evaluations must be disseminated widely to ensure the continuation and replication of effective consumer-directed programs.

SELF-ADVOCACY

One of the most effective methods for promoting consumer preference can be through AAA support of caregivers interested in serving in advocacy roles. With resources and innovation under the NFCSP, caregivers can play an integral role in advocating supports for themselves at the individual, program, and state levels. Similar to the niche that other consumers (e.g., individuals with developmental disabilities and individuals with behavioral health problems) have created in various segments of the health care system, SUAs and AAAs have the opportunity to help caregivers make an imprint on the evolving system of care for this population. *Exhibit IX.5* presents specific mechanisms caregivers might use to advocate change at the individual, program, and system levels.

⁶ Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

**Exhibit IX.5
Multiple Levels of Self-Advocacy**

Individual Level	Program Level	System Level
<ul style="list-style-type: none"> ▪ Self-identify as a caregiver. ▪ Determine and communicate needs through consumer-directed models. ▪ Establish an individual sense of empowerment. 	<ul style="list-style-type: none"> ▪ Help AAAs conduct outreach to caregivers who have yet to self-identify. ▪ Establish self-help/peer groups, and educate and train other caregivers. 	<ul style="list-style-type: none"> ▪ Participate in planning, implementation, and evaluation efforts.

Strategies and Program Examples at the Program Level

Several key approaches can help AAAs with successful mobilization of caregivers interested in serving as advocates. However, involving caregivers in a way that minimizes disruption to caregiving is critical for AAAs.

Use Caregivers as Resources for Reaching Other Caregivers. A major challenge in implementing the NFCSP is overcoming barriers to reaching the caregiver population. Individuals who have yet to self-identify as caregivers often fall through the cracks and either receive no needed services at all or receive inappropriate services. The term “caregiver” is unfamiliar to many people—caregivers identify themselves as wife, husband, daughter, son, or friend. Many individuals also have concerns with the term caregiver redefining the relationship with the person to whom they provide care. Some caregivers are also less apt to respond to outreach efforts that emphasize change is needed to help them, primarily because caregivers believe the focus should be on the care recipient. The aging network must solicit advice from caregivers on how best to help others self-identify as caregivers. Caregivers can help AAAs create outreach strategies by identifying areas of “hidden” caregivers, or those who have yet to self-identify, and crafting messages that will attract the attention of this difficult-to-reach population.

Encourage Caregivers to Provide Peer-to-Peer Assistance. The use of caregivers to reach, educate, train, and support other caregivers represents an important strategy for AAAs. Peer support and caregiver mentors have been shown to be effective methods in supporting caregivers and appear to increase the likelihood of their receiving additional assistance. Some AAAs face challenges in piquing interest about support groups for caregivers; however, using caregivers to facilitate discussions provides an entirely different perspective to the group. Support groups can cover a range of topics, including changing relationships with a spouse, navigating the support system, options for respite care, and how to provide self-care. Recognizing that “support group” might fail to resonate with caregivers who desire “a break” and “peers to talk to” is important.

Create Volunteer or Paid Caregiver Specialist Positions in AAA Offices. As mentioned throughout this guide, SUAs and AAAs must re-conceptualize how services are delivered for the caregiver population. Some agencies are planning to or have already created caregiver specialist positions to support and advocate, rather than directly provide or

manage, services for caregivers. Many states, such as North Carolina, are placing a priority on recruiting caregivers to serve in this capacity, as *Exhibit IX.6* explains.

**Exhibit IX.6
Caregivers Serving as Caregiver Specialists**

Title: North Carolina Regional Caregiver Specialists

Affiliation: North Carolina Department of Aging and AAA

Status: Operational

Target Population: Caregivers

Approach: Seventeen of the State’s AAAs hired a regional caregiver specialist (RCS) responsible for building program and community relations and functioning in an advocacy role as a primary spokesperson in the region on the FCSP and the needs of family caregivers. The RCS collaborates with a wide array of individuals and groups to develop community resources and coordinate care for the caregiver population.

Contact Information: Program information and job descriptions are available upon request from North Carolina. Chris Urso, Family Caregiver Specialists, North Carolina Department of Health and Human Services, Division on Aging, at chris.urso@ncmail.net or (919) 733-8400. For more information on the credentials of the specialists, please visit: <http://www.dhhs.state.nc.us/aging/fcaregr/fcjobs.htm>

Strategies and Program Examples at the System Level

Invite Caregivers to Participate in the Program Design Process. A fundamental step in employing caregivers to serve as advocates is ensuring that they are given many opportunities to play an active role in guiding system design. Barriers that prevent or discourage caregiver involvement should be identified to facilitate increased consumer participation in developing, designing, administrating, and evaluating caregiver programs. Both formal (e.g., public hearings) and informal opportunities (e.g., community forums, public meetings) to provide input should be made available to consumers. Caregivers can also play an ongoing advisory role in delivery and evaluation of caregiver services.

Recruit and Train Caregivers to Serve on Planning Counsels in States. As the goals of providing long-term care have evolved, an increasing number of care recipients and caregivers have assumed advocacy functions. The Oklahoma AAA initiative provides valuable examples of involving caregivers in advocacy roles. *Exhibit IX.7* showcases Oklahoma Aging Services Division efforts to establish a program for training and developing volunteers, including caregivers, to become informed leaders on issues affecting caregivers and care recipients.

Exhibit IX.7 Development of Advocates

<p>Title: Oklahoma Aging Advocacy Leadership Academy</p> <p>Affiliation: Oklahoma Aging Services Division (SUA)</p> <p>Status: Operational</p> <p>Target Population: Volunteers persons of all ages, including caregiver volunteers, interested in aging issues</p> <p>Approach: The Oklahoma Aging Advocacy Leadership Academy (OAALA) identifies and trains volunteer persons interested in becoming leaders and advocates on issues related to aging. Selected applicants participate in the OAALA, a 10-month program convening one weekend per month that prepares individuals for serving on local and state boards and councils assisting the aging in Oklahoma. Strategies focus on issues related to aging. Topics addressed during the course of the training include: caregiver issues; demographics of aging; aging issues in society, legislative advocacy, mental health and aging, organizing social change, diversity of the aging population, self-protection in negotiations, and medical relations. Participants in the OAALA represent business, nonprofit organizations, communities, and individuals.</p> <p>Cost/Funding: The Department of Human Services, Aging Services Division, sponsors the Academy, which was developed through a grant from the Oklahoma Developmental Disabilities Council. Southwestern Bell Telephone, Oklahoma Gas and Electric, and Sooner Management Consultants have joined as corporate sponsors, as well, and further corporate sponsorship is being sought throughout the state.</p> <p>Contact Information: Judy Leitner, Director of Community Relations, Oklahoma Aging Services Division, at judy.leitner@okdhs.org</p>

VOLUNTEER MODELS

Volunteers serve as critical partners to the aging network through a range of administrative and direct service activities. Despite the large number of people who share their time and talents, however, the needs of local communities and the nation as a whole continue to outpace the number of volunteers. AAAs will have to create effective strategies to recruit additional volunteers to provide support to caregivers.

SUA and AAAs can employ a number of strategies to use volunteers as a resource for supporting caregivers, such as conducting outreach campaigns targeting volunteers, establishing volunteer databases, creating non-financial incentives for volunteers (e.g., having volunteers provide respite to one another), and training new and existing volunteers. Several programs across the country, including programs in Minnesota, North Carolina and Kentucky, have efforts under way to recruit and train volunteers for providing respite and other services to caregivers, as *Exhibit IX.8* illustrates.

Exhibit IX.8 Recruitment and Training of Volunteers Providing Respite

Title: Project ROSE (Reaching Out to Support Elders)

Affiliation: Serving as the Project ROSE Coordinator in Mankata, Minnesota, Region Nine partners with eight nonprofit agencies: Interfaith Volunteer Caregivers, CARE Project, Chippewa County Interfaith Caregiver Program, Waseca Faith in Action Program, Community Response Effort Service Team, Volunteer Interfaith Network Effort, Mid Minnesota AAA, and Upper Minnesota Valley AAA.

Status: Operational

Target Population: Family caregivers

Approach: Project ROSE provides community-based volunteer respite care and informal caregiver support services for caregivers. The program comprises nine nonprofit entities in the south central region of the state that provide respite services to a 20-county area. Volunteers provide respite for caregivers so they can spend time accomplishing other tasks, such as attending medical and dental appointments, running errands and shopping, meeting friends, and enjoying relaxation time. Respite volunteers receive professional training and commit to a regular schedule (usually 2 to 4 hours per week). Caregivers also receive information and assistance services, have access to lending libraries of books and video tapes specific to caregiving issues, and can attend caregiver education and support group activities.

Costs/Funding: A Minnesota Department of Human Services grant, and Robert Wood Johnson Foundation grants have provided funding for these services. NFCSP funds will be utilized to expand these services into additional counties.

Contact Information: Elaine Spain, Project ROSE Coordinator, Region Nine AAA, at (507) 389-8860.

Title: Volunteer Respite Services

Affiliation: Region J AAA, including seven county area, in North Carolina

Status: Operational

Target Population: Family caregivers

Approach: The region's seven counties recruit volunteers to provide respite services for caregivers. Several counties served by the AAA have seed volunteer respite programs newly in place. One of the longest-standing county programs has 400 volunteers serving 300 families. The counties are working with United Way, RSVP, and other volunteer organizations to expand their volunteer base.

Costs/Funding: The funding for the services for the last six months of Fiscal Year 2001-2002 totals \$204,217. Costs include: outreach, staff time, recruitment, screening and supervision of volunteers, assessment of caregiver family situations, matching of clients with volunteers, and program promotion. The program is funded primarily through the NFCSP.

Contact Information: Ellison Jones, Family Caregiver Specialist, Region J AAA, at ejones@tjcog.org or (919) 558-9391.

Exhibit IX.8
Recruitment and Training of Volunteers
Providing Respite, continued

Title: Dementia-specific Volunteer Caregivers Program (VCP)

Affiliation: University of Louisville School of Nursing, Alzheimer's Disease Chapter

Status: Operational

Approach: This program is an outgrowth of the Volunteer Interfaith Caregivers of Kentucky. The idea for this support program began when representatives from various religious congregations and a local Alzheimer's Disease chapter joined together and developed a vision to train volunteers to provide in-home respite to keep caregivers connected to their support groups. Since 1994, the VCP has provided support services to more than 100 caregivers at no charge. Program services include assessment, care planning, education, evaluation, information and assistance, and volunteer support. The VCP also provides free public services such as memory screening and community education programs.

Contact: Karen Robinson, RN, Ph.D., FAAN, University of Louisville School of Nursing, at kmrobi01@louisville.edu or (502) 852-8512.

Other AAAs have established service banks to encourage volunteers to provide in-home services and respite care for homebound people with disabilities and their caregivers. When a volunteer or family member needs similar services, he or she may draw on, at no cost, services credits earned for time volunteered.

Under the Retired and Senior Volunteer Program (RSVP), volunteers serve from a few to more than forty hours a week in a range of organizations. RSVP involves individuals age 55 and older who volunteer to provide services that typically match their personal interest and make use of their skills and lifelong experiences. Some states, including Washington, partner with RSVP to provide specialized training to volunteers interested in serving as peer counselors to caregivers. Caregiver peer counseling differs from professional counseling in several ways, such as allowing for a more equal relationship and less intimidation. *Exhibit IX.9* highlights Washington's Olympic Area Agency on Aging's initiative to provide specialized training for RSVP volunteers to serve as peer counselors.

Exhibit IX.9 Building on RSVP Activities to Support Caregivers

<p>Title: RSVP Caregiver Peer Counseling Program</p> <p>Affiliation: Olympic Area Agency on Aging, Washington</p> <p>Status: Operational</p> <p>Target Population: Volunteers</p> <p>Approach: Olympic AAA is building on its relationship with RSVP to train volunteers to work with caregivers. RSVP trains individuals to serve as caregiver peer counselors who offer emotional support, guidance and empathy to peers who are providing ongoing caregiving. Peer counselors make visits to caregiver homes to assess needs, assist in accessing supportive services, and provide informal counseling/problem-solving assistance. Training includes instruction, role-playing, group discussions, and training materials.</p> <p>Cost/Funding: One training session for 10 volunteers is budgeted at \$2,000. Additional costs are minimal because volunteers staff the program.</p> <p>Contact Information: Sheryl Lowe, Senior Planner, Olympic AAA, at loweshj@dshs.wa.gov or 360-452-3221 ex.103.</p>

TECHNOLOGY APPLICATIONS FOR CAREGIVERS

The following section draws on Frank Worts’ issue brief *Technology and Applications for Caregivers*.⁷ Individuals in the age range 50 to 64 and older, a group extremely apt to represent caregivers, are three time more likely to access the Internet than the 65 and older population, according to a study conducted by the Pew Internet and American Life Project in 2000. This section presents strategies for SUAs and AAAs to share information with caregivers and to support caregiver efforts to obtain information through technology applications, including Web sites, email, listservs, and real-time communication.

Strategies and Program Examples

Establish and Maintain AAA Web Sites That Include Caregiver-Specific Information and Links to Other Critical Caregiver Web Sites. Many AAAs are creating and designing information for their Web sites that specifically targets the caregiver population. The Web provides caregivers with the opportunity to efficiently find and contact needed resources such as a list of services provided under the NFCSP or approaches for providing services selected by consumers; a list of statewide resources (e.g., information and available services) for caregivers; agendas and materials for upcoming caregiver seminars, conferences, or both; and links to other caregiver-related Web sites and online caregiver support groups. Providing current and accurate information on AAA Web sites can prove extremely valuable to caregivers as well as to staff assisting caregivers in community organizations across the state.

⁷ Worts, F. (2001). *Technology and Applications for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

Provide Training to Caregivers in Using Technology-Based Resources and Educate Caregivers on the Benefits of Using Different Applications. The Web can serve as a valuable information source for caregivers and care recipients; however, because of the variability in the quality of information, SUAs and AAAs should provide guidance (e.g., providing linkages on the AAA Web site) and training to caregivers on how to find useful, reliable, and authoritative sources. Often, individuals are directed to a specific Web site for information. In other cases, finding specific information can be a formidable task. The following list includes key types of information that might be useful to caregivers and are easily accessible on the Web.

- Health services and resources
- Social service resources
- University services and resources
- Virtual libraries
- Online support groups
- Newspaper clipping services
- Full-text reports and articles from experts
- Government reports
- Expert advice
- Medication availability, uses, and side effects
- Stress reduction strategies
- Assisted technology equipment

Email can facilitate communication among: 1) caregivers and care recipients, 2) caregivers in different locations and households providing care to the same care recipient, and 3) caregivers and service providers. At times, the primary caregiver has to make important decisions concerning the family member, and the caregiver feels that all family members should take part in the decision-making process. Email can enhance this process by providing an opportunity for sharing information with all significant family members to reach a consensus.

Caregivers can connect with service providers working with their relative to communicate about shifts in care recipient need, resources available, and suggestions for care. They can remain informed about the elder's status and issues. Email can also help in planning caregiving tasks. Caregivers can send themselves email reminders about appointments and activities needing attention at specific intervals.

Real-time communication, also referred to as *chat*, is an extension and refinement of email. The advantage of chat is that individuals communicate in real time, so the information shared, the questions asked, the opinions given are addressed immediately. No waiting occurs, and in most cases, the interaction is much more personal. Chat takes place in three formats: text, audio, and audio/video. When audio and video are used, the communication approaches in-person communication.

People providing distance caregiving have difficulty communicating with service providers as well as other caregivers and their family members. Caregivers using real-time communications can participate in care planning conferences for their family member in a creative way. This technology offers the opportunity for the family member to present his or her preferences, share medical and other information, and be involved in the decision making process.

Costs, except for equipment purchase, are contained in the monthly Internet service provider fees. The most difficult issue with real-time chat relates to software set up. AAAs can help caregivers locate the appropriate support to configure the software and hardware. When adding equipment to an existing computer, individuals would benefit, in most instances, from professional installation.

Typically, *discussion forums* are organized by topic. The forums are real-time text-oriented mechanisms that give individuals a chance to communicate around a certain topic in real time. Many Web sites offer support for people with similar problems or situations. Caregivers can communicate with other caregivers to support each other. They can also invite professionals to log on to their site to provide advice and information for assisting their caregiving efforts. Professionals working with specific client types can communicate with each other about best professional practices.

*Listserve*s enable caregivers to participate in discussion forums. Subscribers to a listserve usually receive information that addresses state-of-the-art and recent developments in a specific topic area. Because they provide an easy way to keep up with a given field and provide information that is forwarded frequently and automatically, listserve are useful and convenient. Caregivers can post questions to the list, receive helpful responses, and join and leave a listserve at any time. A number of listserve cover a range of topics on aging, health, social service, government funding, and other issues of interest to the aging network. For a comprehensive directory of listserve, visit <http://www.list.com>. **Exhibit IX.10** provides an example of an SUA that employs a Web page and listserve to facilitate information sharing for caregiver specialists.

Exhibit IX.10 Caregiver Specialist Listserv and Web Page

Title: Family Caregiver Specialist Listserv and Webpage

Affiliation: North Carolina Department of Aging (SUA)

Status: Operational

Target Population: Family caregivers and staff supporting family caregivers

Approach: The state created a Yahoo Web site for caregiver specialists and a listserv for staff at the SUA and AAAs involved in the NFCSP initiative. The Web site provides: 1) NFCSP development information, 2) a list of statewide resources for caregivers, 3) a list of AAA caregiver specialists and their credentials, 4) summaries of issues addressed during AAA caregiver listserv discussions, and 5) a snapshot of support services available for caregivers in North Carolina. Furthermore, the North Carolina SUA is developing a common list of keywords that will be used across the State to ensure that each AAA is using common terms in categorizing their services. The listserv provides a mechanism for staff to exchange information across the state regarding available resources for caregivers. In addition to information exchange opportunities, it also allows staff to provide support to one another in addressing questions and concerns related to the NFCSP.

Contact Information: Chris Urso, Family Caregiver Specialist, North Carolina Department of Health and Human Services Division on Aging, at chris.urso@ncmail.net or (919) 733-8400.

Title: TeleCare Connections

Affiliation: The Office of Aging (AAA), New Jersey

Status: Developmental (implementation expected May 2002)

Target Population: Long-distance caregivers

Approach: The Office of Aging (OOA) is in the final stages of developing a program that allows caregivers and care recipients to use interactive Web-based television for communication between care recipient and caregivers. The AAA, a local hospital, and the local Visiting Nurses Association are working together to locate individuals interested in participating in the program. The program also involves the use of outcome measurements.

Costs/Funding: Funding sources include grants from the NFCSP, the New Jersey Department of Health and Senior Services, the Administration on Aging, and Verizon.

Contact Information: Jill Smith, Program Coordinator, The Office of Aging, at jcsmith@shore.co.monmouth.jn.us or (732) 431-7450.

Facilitate Online Support Groups or Refer Caregivers to Support Group Web Sites. AAAs should consider hosting online support groups for caregivers or referring individuals to known caregiver support groups. Caregiver support groups, which currently are available 24 hours a day, provide the information needed to cope with day-to-day caregiving situations. The groups offer support in that participants recognize immediately that their situation is far from unique. Logging on to a discussion group could be one way to relieve tension and gain support and advice. Participants can use discussion groups in the following ways:

- Receive information on almost any topic.
- Pose questions and receive answers from people with varying information and experience.
- Follow trends and state-of-the-art development in any area of interest.
- Become part of a network where their experience and expertise could help others.
- Discuss their situation and receive support and feedback.

This chapter presented strategies, including the use of models that emphasize individual consumer needs and preferences as the focal point, and state program examples familiar to the aging network. Challenges for the aging network in this venue are twofold. First, no single, universally applicable model exists that constitutes self-determination for either care recipients or caregivers. Models in each state are shaped by unique political, geographic, demographic, and systemic characteristics as well as differing levels of available resources. Second, although self-determination models have been used for many developmentally disabled individuals and can be adapted for adults caring for children with developmental disabilities under the NFCSP, self-determination models for older individuals likely will require different types of approaches (e.g., more intense support from staff to help elders manage the service system). Regardless of the age of the individual served through the NFCSP, a clear consensus exists that program planners must strive to promote choice and foster independence among caregivers. SUAs and AAAs must remain informed about consumer-directed programs that have been evaluated and respond to lessons learned from evaluations by being willing to modify programs as needed.

The network also is especially aware of the need to maximize important resources, such as volunteers and technology. Recruiting and training volunteers and supporting caregivers in their efforts to access relevant information through technological applications requires SUAs and AAAs to look beyond the initial investment of staff resources. Rather, the network must recognize and envision the potential long-term value of establishing informative AAA Web sites and other Internet resources.