# THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM:

# FROM ENACTMENT TO ACTION

## Highlights from the U.S. Administration on Aging Conference

### Held September 6 – 7, 2001 in Washington, D.C.

ADMINISTRATION ON AGING

**Prepared by The Lewin Group**

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# PREFACE

The Administration on Aging (AoA), with assistance from The Lewin Group, sponsored *The National Family Caregiver Support Program: From Enactment to Action Conference*, held in Washington, D.C., September 6 – 7, 2001. The conference was attended by nearly 700 individuals representing state units on aging, area agencies on aging, tribal organizations, service providers, academic institutions, and national organizations.

The conference was designed to assist the aging network with the early implementation of the National Family Caregiver Support Program (NFCSP) by providing: 1) information on the various ways states are approaching the implementation of the new program and 2) important research and practice knowledge, particularly relating to systems development, service components, and target populations, critical to building new "multi-faceted systems of support" for caregivers. Judging by the conferee evaluations, these outcomes were fully achieved and the conference was a great success.

This report highlights the major issues and themes discussed at the NFCSP conference. The session summaries also are intended to capture key practical information of use for program planning and implementation purposes.

The reader should be aware of the availability of two related resource materials that can be accessed on the NFCSP webpage at www.aoa.gov/carenetwork: 1) the speakers' presentation materials and 2) the Issue Briefs handed out to all conference attendees as background information. Readers are encouraged to review these materials too.

The reader also should know that AoA, with the assistance of The Lewin Group, is developing a *NFCSP Resource Guide* to help the aging network successfully implement the NFCSP. The *Guidebook* is being developed around input from: 1) a technical advisory committee of aging network officials and research experts; 2) issue briefs developed by experts in the field; 3) the AoA Caregiver Listserv; 4) presentations and discussion at the NFCSP Conference; 5) site visits to aging network agencies; and 6) research literature reviews. We expect that the Guide will be available this coming January.

# THE NFCSP AND THE CAREGIVING LANDSCAPE

## Josefina Carbonell, Assistant Secretary for Aging – Working Together to Ensure That Our First Steps Are the Right Steps

Assistant Secretary Josefina G. Carbonell welcomed nearly 700 participants to the first Administration on Aging Technical Assistance Conference for the new National Family Caregiver Support Program. She stressed the importance of this exciting program not only for the growing number of older persons who are and will require help in remaining independent, but also in light of the Olmstead Supreme Court ruling and President George W. Bush's New Freedom Initiative, both of which aim to remove barriers to help those with disabilities maintain their dignity and life in the community. She highlighted the fact that this is the first national program focusing on the needs of caregivers rather than care receivers.

She challenged the network to be flexible, creative, and open to new ideas so that, in the end, the program is effective and consumer-oriented. In doing so, she asked that the network emphasize *family* services, communicate directly with caregivers, learn from other states while recognizing that every state, community, and family is different, and continue to exchange information at the state, regional, and local levels to gain strategies. Secretary Carbonell outlined her vision of the NFCSP:

- To increase access so that every American will know about the NFCSP, particularly the disadvantaged and hard-to-reach families.
- To renew our focus on intergenerational care, thereby promoting efficient and cost-effective services.
- To make home and community-based services available for all older Americans and their families so they can lead productive lives in their communities.
- To partner with and improve access to faith-based and other community-based assistance to enhance support for older Americans and their families.
- To create optimum flexibility and choices for the consumer.

## Rhonda Montgomery, University of Kansas – What the Aging Network Needs to Know About Family Caregivers

In describing the profile of caregivers, Dr. Montgomery reported that most caregivers are women, though they do vary by sex, relationship to care receiver, and ethnicity. Each of these characteristics influences the type of care provided to the caregiver and the length of time an individual maintains his or her caregiving role. Additionally, these characteristics influence the order and timing of what Dr. Montgomery calls the seven markers, a trajectory for viewing the career of a caregiver. The markers include the following: 1) performance of initial caregiving task; 2) self-definition as caregiver; 3) provision of personal care; 4) seeking out or using assistive services; 5) consideration of institutionalization; 6) actual nursing home placement; and 7) termination of the caregiver role. However, timing is dependent on the type of caregiver. For example, spouses tend to seek out or use assistive services later than adult children. The farther along the trajectory a caregiver is without having received supportive services, the more likely the caregiver is to feel burdened. This burden can take various forms including, but not limited to, deteriorating physical health, depression, task overload, lack of privacy, social isolation, and financial burdens. The performance of skilled work, such as changing catheters, that would otherwise require licensing, but that caregivers perform out of their desire to keep their loved one at home, adds to caregiver burden. Additionally, the loss of support previously provided by the care recipient can add to a caregiver's stress.

Caregivers need to receive support services before the burden becomes too great and they reach the point of burnout. Furthermore, the relief provided must be worth the time and physical and emotional energy needed to obtain the support services—the benefit must outweigh all costs. For example, if a daughter needs adult day care for her mother, but it takes one hour to get her mother ready, another hour to drive her mother to the center, and another hour to get to work for a four hour shift, it is likely that the caregiver will not use services because it is too much effort. In order to maximize relief, the optimal combination, timing, quantity, quality, and frequency of services must be provided, which all must be adapted to the type of caregiver.

### Carolyn Johnson, Caregivers in Action – The NFCSP from a Caregivers' Perspective

As the network designs and implements the NFCSP, flexibility and consumer direction will be critical program features to meeting the needs of a wide range of caregivers. Ms. Johnson called for the aging network to start treating caregivers as equal partners, rather than as "informal" caregivers. Caregivers provide the majority of care and it is important that their role is acknowledged and celebrated, not downgraded. The network should be a major advocate for caregivers and design programs that support families for the long term rather than the short term. Efforts need to be focused on increasing the outreach to and monitoring of caregivers, especially those who have not yet self-identified as caregivers and those who are hard to reach. Without this effort, many caregivers will fall through the cracks and will receive inappropriate services or none at all. It is also essential that the quality of care is monitored and continually improved, and that waiting lists are non-existent or very short. If a caregiver cannot use a program or uses a program of less than desirable quality, then the point of the NFCSP is lost. Caregiving is a non-stop job and services will be needed when least expected. Therefore, caregivers need to be able to access the system 24 hours a day, seven days a week via multiple means of connection, including fax, phone, and email.

## HOW THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM FITS WITH MEDICAID AND OTHER DHHS INITIATIVES

### Claude Allen, Deputy Secretary, US Department of Health and Human Service

Claude Allen discussed the Bush Administration's commitment to helping Americans of all ages with disabilities and the part that HHS will play in implementing this commitment. He reported that 33% of the 54 million Americans with disabilities are age 65 and older (this percentage increases to 47% when the 55+ population with disabilities is added). Clearly, the focus needs to be on people who are aging as well as young adults and children with disabilities. Early in his Administration, President Bush unveiled his New Freedom Initiative, a comprehensive set of proposals to assist people with disabilities to live and participate more fully in their communities by: 1) increasing access to assistive and universal design technologies; 2) expanding educational opportunities; 3) providing more employment opportunities; and 4) promoting the use of home and community-based services. The President signed an Executive Order as part of the New Freedom Initiative on June 18, 2001, directing key federal agencies to work closely with states to ensure full compliance with the Supreme Court's ruling in the Olmstead Case and the Americans with Disabilities Act (ADA). The Executive Order charged the Department with several high priority responsibilities, including:

- Conducting a self-evaluation of HHS policies, programs, statutes, and regulations to improve the availability of community-based services for individuals with disabilities.
- Provision of technical guidance to assist states to make more effective use of existing federal resources.
- Coordinating the efforts of other federal agencies and working cooperatively with states and with HHS components to achieve the ADA's goals and implement the Olmstead Decision.

As part of this effort, Deputy Secretary Allen heads the newly formed Interagency Council on Community Living, comprised of ten Federal Departments that have a role in implementing the New Freedom Initiative and the Executive Order. AoA is a vital partner in systems building and an active participant of the HHS' New Freedom Initiative Work Group. He described the NFCSP as an important part of the configuration of services that this country needs to promote community-based alternatives for the large number of older Americans with disabilities. It is the only major program at the federal level that is concerned with the service needs of families and other caregivers. Secretary Tommy Thompson strongly supports the NFCSP and requested an increase in funding for FY 2002, which the President has approved.

The NFCSP, with its emphasis on building "multifaceted systems of support for families and other informal providers," can expand the scope of our long-term care systems at the national, state, and local levels. This is critical in the context of the coordination and coalition building efforts that are needed to implement the Olmstead Decision and the President's Executive Order. Deputy Secretary Allen commended the aging network for its leadership role at the state and local levels, and called for the network to build on the vast experience it has gained in developing and implementing home and community-based services for older persons as it begins to develop and enhance support systems for our nation's caregivers.

### Thomas Hamilton, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, DHHS

Thomas Hamilton also discussed the interrelationship between the NFCSP and other DHHS initiatives. Hamilton stressed the critical role that public programs play in supporting caregivers to decrease unnecessary institutionalization of the elderly and disabled, thereby controlling health care costs and enabling individuals to live in the comfort of their own homes.

Public programs that support elderly and disabled individuals and their families must be considered in light of future needs. In addition to the shortage of direct service workers, the aging network must plan for the aging of the baby boom generation in which the population of those aged 65 and over will double in the next 30 years. This generation possesses different expectations than previous generations: baby boomers are aware that more choices should be available and they want more control of their long-term care.

Although the use of home and community based services has increased dramatically, two-thirds of Medicaid long-term care spending is allocated for nursing home services. In order to reverse this proportion of spending and support families to continue in their caregiving role, better approaches to using formal and informal supports in a mutually supportive way need to be developed. This is particularly critical in relation to President Bush's New Freedom Initiative and the Olmstead ruling. Many states have begun to reassess the placement of institutionalized individuals and prevent unnecessary institutionalization by placing individuals in home and community-based settings whenever possible. Enhancing community infrastructure is a critical pursuit to accommodate the full range of disabilities. For example, the installation of ramps and grab bars in public places and private facilities, might enable a caregiver to continue caring for the care recipient by eliminating the need for personal assistance services or respite care. In addition, it might also decrease the social isolation that the caregiver would otherwise experience if he or she felt unable to take the care recipient out of the house.

Hamilton reported that out-of-pocket and family funds cover three quarters of all long-term care spending, while Medicaid accounts for 17% and Medicare accounts for 4%. However, he adds that even if families can afford institutional care, they cannot buy the support that a family provides. Public programs cannot replace the support of families, but they can provide them with support. Therefore, the NFCSP is a vital foundation that can pave the way for other systems with larger resources, such as Medicaid and Medicare, to create services that support caregivers. The NFCSP will help answer questions such as, if Medicaid enters the caregiver support program picture, will it be seen as having too many rules? Will the woodwork effect occur? Will we be able to assist all those with needs? Hamilton hopes that the NFCSP will lead the way in creating programs to support caregivers...it is just the beginning.

## BUILDING MULTI-FACETED SYSTEMS FOR CAREGIVERS: A VARIETY OF STATE EFFORTS

Two multi-state panels presented their respective state and local approaches to NFCSP implementation and discussed unique aspects of their service systems to show the variety of approaches that states can take in building multi-faceted systems. The five states participating, each represented by a SUA and AAA representative, were Florida, Washington, Minnesota, Oklahoma, and Pennsylvania.

### Themes

- Treat caregivers as partners and customers;
- Build flexibility into the program at the system, program, and consumer levels;
- Reach out to ethnic communities and provide services in a culturally competent manner;
- Create a range of services and recognize the diversity of caregivers and their needs;
- Package the message in a way that can be heard by people who do not yet self-identify as caregivers;

- Train people involved in accessing services as well as policymakers (redefine the importance of caregivers with policymakers and talk about caregiver value);
- Turn over management and direction of care to seniors and their family caregivers;
- Seek ways to integrate various funding sources to create efficiencies and decrease fragmentation;
- Make it easier for seniors, caregivers and providers to "deal" with the network;
- Involve policymakers, legislators, administrators, providers, and consumers in the planning and implementation processes to work toward a common issue; and
- Continue to work together and exchange information at state and local levels.

### Florida: Coordinating the NFCSP with Medicaid, State and Other Funding Streams

Secretary of the Florida Department of Elder Affairs, Gema Hernandez, underscored the importance of including the term "caregiver" in the Department of Elder Affairs' mission statement. It was this addition that enabled the Department to tap into the variety of programs in place to support caregivers. Hernandez stressed that realigning the mission is a critical step to create an umbrella for all funding sources, including federal, state, and local, to be used as part of the caregiver initiative (e.g., Florida uses home and community based waiver funds to support caregivers).

Prior to the NFCSP, Florida's aging network conducted caregiver forums and focus groups to determine the needs of caregivers and identify what needs were not being met. Based on information shared at the public forums and focus groups, the State designed the care planning process to take into account the frailty level of both the care recipient and the caregiver. Though the network may have experience in serving caregivers, the experience of Florida shows that asking the caregivers themselves and providing a voice for families is necessary.

There are several programs supported by the aging network that assist caregivers in Florida, including:

*Home Care for the Elderly*

- Provides stipends averaging $106 per month depending on household income, to assist caregivers in keeping a care recipient in the home.
- The stipend can be used for anything that enables the caregiver to keep the care recipient in the home such as, the purchase of medicine or adult diapers.
- The outcome measurement is whether or not the care recipient is living at home at the end of a six-month period.

*Consumer Directed Care*

- A Medicaid waiver program that allows the elder or the caregiver to choose any provider from which to purchase services. This person can be a neighbor or, if the care recipient desires, it can be the caregiver.
- This approach aims to support consumer choice, ease the burden of the direct worker shortage by tapping into non-traditional workers, and allow services to be provided at a lower cost than would be required for a "formal" provider.

- Creates a legal contract with the caregiver and allows for the payment of Social Security and taxes into the caregiver's account. This is especially important for caregivers under the age of 60 who terminated participation in the workforce to care for their loved one, by ensuring that they will receive Social Security when they reach age 62.
- A cap is established that is based on the care recipient's functioning level and options within that cap are discussed.

The AAA of Pasco-Pinellas is in the process of implementing the Resources, Education, Services, and Training (REST) project. Working with St. Petersburg College through a grant from AoA, the goals of the program are to maximize resources, minimize the stress of caregivers, and create a best practices model for a caregiver support program by developing, testing, and demonstrating methods and products over a three year period.

The program is slated to start at the beginning of October 2001 and is designed to provide a full spectrum of services including: community education, care management, short-term services, caregiver resource centers, an interactive website, a caregiver handbook, I&A, and the recruitment of hard-to-reach caregivers. The AAA's NFCSP three-phase implementation plan consists of: 1) a determination of needs, 2) caregiver forums, and 3) service implementation. The needs assessment phase, conducted largely through a contract with the University of South Florida, includes a review of caregiver literature, interviews with stakeholders, focus groups, public hearings, and an evaluation plan to provide a blueprint for evaluating the effectiveness of implementing the final recommendations. During the next phase, caregiver forums will be held on a variety of topics in order to both provide support to caregivers and to gain feedback concerning their needs. Service implementation will be based on recommendations gleaned from the first two phases to ensure that money and energy are put towards the development of services that caregivers truly need.

### Washington: Developing Service Components for a Comprehensive Caregiver Support Program

Washington State's history of assisting caregivers goes back to the 1980s with the introduction of its statewide respite program. This program introduced the aging network to caregiving and the notion of flexibility related to multiple respite options (e.g., adult day health, home care, residential care, and nursing home care). Although this program was providing great assistance to caregivers, it did not meet the range of caregivers and the spectrum of need. In 1993, a HRSA Alzheimer's Disease demonstration grant supported community efforts to develop innovative ethnic programs. In 1999, the Washington Aging and Adult Services Administration (WAASA) revisited the question of what more is needed to support caregivers. State officials met with representatives from AARP, MR/DD organizations, champions in the Legislature, and others, which led to the passage of a state caregiver program that closely mirrors the federal program.

Dan Murphy, Chief at WAASA, described the state office approach to ensure development of a comprehensive, integrated system was to require the AAAs to do the following five things: 1) work with their communities to develop implementation plans; 2) identify a response to each of the key service components; 3) analyze need and develop priorities; 4) collaborate with other services and quantify the scope using a similar framework; and 5) discuss how the program funds are allowing new and different things to happen.

AASA representatives felt that flexibility is the key to creating a comprehensive system of services but wanted to ensure that funding was allocated across a variety of services. Therefore, AASA provided guidance in several areas. They limited spending on respite to 35% because of the existence of the state respite program and they developed a common language (units of service to track) statewide. Some existing challenges include:

- Developing an extensive program in rural areas with limited resources;
- Marketing to caregivers when demand exceeds supply; and
- Inconsistencies between the state and federal programs (e.g., the federal program's grandparent piece is more restrictive than Washington State's kinship program) that could lead to difficulties in reporting and create administrative burdens.

Victoria Doerper, Director of Northwest Area Agency on Aging, described her agency's local approach: caregivers, providers, and advisory council members were interviewed and a caregiver support taskforce was formed to ensure that caregivers were involved in the implementation process and their needs were heard. Community approaches were matched to core components to ensure that each key service component was considered. After analyzing caregiver need, the AAA decided to develop both quick-and-easy and more complex services so that the full range of need was being met. In addition to the establishment of resource libraries, overnight respite care was added through the coordination with a specialized Alzheimer's Disease boarding house.

Doerper emphasized that it takes time to build trust and work with other programs but that collaboration is essential to addressing all caregivers' needs. The AAA partnered with Community of Faith Outreach, a program that raises the awareness of caregivers' issues with churches and provides recommendations around what they can do to support caregiver member. They also partnered with a kinship care program to help Tribal grandparent caregivers. The federal program money is allowing expansion and enhancements to the I&A system, translation of caregiver information, and opportunities to further work with Tribal organizations.

## Minnesota: Integrating the NFCSP with other Title III programs

Minnesota officials viewed the enactment of the NFCSP as an opportunity to refocus and advocate for system change—to design a system that is more responsive to older Americans and their caregivers. Jim Varpness reported that the State used the NFCSP as a launching pad to change state policy and programs. At the time when the Older Americans Act amendments were re-authorized, the political environment in Minnesota was ripe for long-term care reform initiatives. The Re-balancing Long Term Care Initiative had just come out of the Governor's office, which grew out of a project that began nearly three years ago. They invested much time and grew partners—partnering with business communities, corporation sponsorships, and citizen links. They attempted to involve everyone in the process to encourage buy-in and promote the idea of "ownership." They examined the importance of informal and quasi-formal systems in relation to the state budget, particularly the value that caregivers hold in the system.

Varpness described the planning process as a collaborative effort among the AAAs, counties, a researcher of caregiver issues at the University of Minnesota, providers, health plans, and others. Foremost, the concept that caregivers are partners of the Aging Network and are primary consumers of the services that the Network is providing was emphasized with various stakeholders across the state. A moral mandate to treat caregivers as real *customers* of the system was inculcated. The existing policies and programs (i.e., Waiver, Alternative Care Grant Program, State Caregiver Program which is predominantly respite services, OAA Title IIIB, and community service grants) were reviewed with a caregiver lens to promote changes that forwarded this notion of caregivers as consumers.

Statewide meetings were held to develop policies about the utilization of Title IIIE funding. Minnesota officials advocated for broad-based policy to avoid financing and delivery silos and to build upon the existing programs. Integration of various programs and funding sources was aided by the fact that all of the programs are managed at the state unit; however, the programs do have separate delivery systems. The key strategies that the State used to promote system change included: 1) enhancing the overall access system (giving caregivers access to information about services, information to help caregivers develop skills to cope with their situation and access to specialized assistance), 2) redefining the value of caregivers with policymakers, 3) training Information & Assistance staff, 4) training care management staff and educating families to direct care, 5) incorporating flexibility in program design at both the regional and the individual family caregiver levels, and 6) refocusing marketing strategies to target caregivers in a similar fashion to how businesses sell a product (a new notion of who the customer is).

The new State focus on access is congruent with the Information and Assistance activities already operating through OAA funding and is influencing many of the ideas and proposals on how to use State and NFCSP dollars. The State approach to improving the access system is two-pronged: 1) enhance the Senior LinkAge Line and 2) develop a county-level long-term care consultation service. The State Legislature approved approximately $2 million to build a stronger "on-line" long-term care system, which extends the hours that individuals can access the system and creates an electronic database. The on-line feature to Senior LinkAge, projected to be available in March 2002, is designed to be a comprehensive database to support families and also to provide tools for professionals. In addition to providing descriptive information about available services, the database will introduce quality profiles to enhance consumers' abilities to make informed choices. Minnesota is also in the process of redesigning their former pre-admission and screening program to be a county-level long-term care consultation service. The long-term care consultant's role is to serve as a specialist who is trained to provide information and assistance to families. The legislation requires that there be a link between the new county long-term care consultation system and the AAA I&A system. The state office will be conducting joint training programs in this area. Part of this process involved changing the assessment form to include caregiver elements that they will then be able to use for quality assurance and improvement activities.

Linda Giersdorf of the Region Nine AAA, discussed her agency's local approach to planning caregiver support services. Region Nine AAA officials decided to integrate the NFCSP program with other existing programs to increase efficiency and decrease fragmentation in pursuing a regional caregiver support system. The agency plans to capitalize on the partners' positive relationship with their communities and existing infrastructure to expand the services that they are currently providing. The AAA plans to: 1) build on Project ROSE (Reaching Out to Support Elders)—a caregiver support respite program that began nearly three years ago and that is provided by different funding sources (e.g., offer caregiver access to transportation); 2) expand Senior LinkAge Line (e.g., offer in-person assistance); 3) coordinate referrals between the Senior

LinkAge Line and the county consultation service by developing protocols; and 4) create caregiver consultants who are qualified individuals that will work directly with a caregiver to educate, train, provide emotional or spiritual support, advocate for the caregiver, and link that individual to available services. The AAA worked with the Minnesota Board on Aging to submit a caregiver discretionary grant which, if funded, they hope to pilot the caregiver consultant concept in one county and procure an outside evaluator to look at its effectiveness.

## Oklahoma: Outreach to Rural Caregivers

The State of Oklahoma began working with caregivers about 12 years ago when the aging consortium (state and local government, service agencies and providers) developed the "Caregiver Connection"— a training program that the AAAs used across their planning areas in local communities. The program was deemed successful and further enhancements to caregiver support services were made. The issue of grandparent caregivers emerged and consequently, they conducted a statewide conference for grandparents caring for grandchildren. The conference gave grandparents a voice and increased the understanding among policymakers, legislators, and administrators of the types of issues that this population faces in their roles and their needs. Oklahoma has a statewide respite program and have found that nearly 50% of grandparents caring for grandchildren are in need of these services. As part of the respite program, the State and AAAs worked together to develop a single statewide access point for respite services to decrease consumer confusion.

NFCSP funding was allocated to the providers very promptly. The AAAs had public meetings with family caregivers to hear directly from them about what issues they face and the needs they have. By in large, one of the biggest challenges that both caregivers and the Network face is the limited supply of providers available and interested in delivering caregiver services in rural areas. As a result, the AAAs began to deliver these services directly where needed. In rural Oklahoma, access continues to be a major issue, particularly with respect to transportation. The State Unit on Aging has used its resources to develop materials for the rural area agencies and planning service areas as well as public service announcements and other media outreach. The State is also trying to assist agencies in building adequate infrastructure at the local level.

Nine of the 11 AAAs in Oklahoma are considered rural agencies and are attached to regional councils of government. The SODA AAA (Southern Oklahoma Development Association) is one of the rural AAAs whose planning area consists of 10 counties in South East Oklahoma that serve 47,000 individuals aged 60 and older, two-thirds of which are located in areas that border with Texas. Wes Bowman, Director of SODA, reported that the agency's process of determining caregiver needs included mailed surveys, focus groups and public meetings. The needs of caregivers that were determined include the following, in order of importance: information about services available, training, support groups, and respite. The last topic to come up was counseling—a sensitive service that is not considered culturally "acceptable" among many families. Oklahoma's strategy for outreach to rural caregivers is "personal touch." They work closely with home health agencies, existing caregiver projects, 25 funded nutrition sites, the 52 other senior centers in the area, and the Advantage Waiver program. The AAA administers care management in five counties and independent agencies provide care management in the other five counties. They are setting up a 1-800 line specifically for caregiver services in addition to having the statewide senior information line and county 1-800 numbers. The total area is divided into quadrants and an AAA staff member is assigned to each quadrant to perform monitoring and on-site visits once per quarter at each project site.

## Pennsylvania: Maintaining Flexibility to Better Meet Caregiver Needs

Pennsylvania currently has the fifth largest older adult population in the U.S. and has the largest population of seniors who live in areas designated as rural. They have a locally based AAA system with 52 AAAs planning for 67 counties. Pennsylvania is known to administer a comprehensive and responsible caregiver support program whose extensive network is characterized by flexibility at the local and consumer levels. Richard Browdie, Secretary of the Pennsylvania Department of Aging, discussed the foundation of their current Family Caregiver Support Program (FCSP). The initial planning process reflected the notion that what the family provides is a given in terms of the resource base of the consumer, and it presumed that the family's circumstances would not change. Families advocated that the state go beyond considering the needs of the care recipient (the consumer) in care planning and recognize families as *partners* who need support to sustain their role. The concept of flexibility was supported by early research that suggested if given a flexible pot of money, families will enjoy having choice, they will use resources very prudently, and they will be creative in the types of services they choose to fund. The program began as a successful 3-year pilot project in four regions resulting in state law passed in 1991 that established the FCSP.

Pennsylvania's approach has been to issue policy and guidance at the state level while encouraging flexibility in local implementation. Features of the state program include:

- Engagement of caregivers in the caregivers in the care planning process.
- Baseline assessment of the caregivers' stress levels so that care managers can help caregivers monitor if, when, and how stress levels improve or worsen and so the quality and relative success of the intervention (i.e., the care plan) can be measured.
- Maximization and blending of family and program resources to be able to offer options of "hard" and "soft" services.
- Consumers can receive up to $200 per month for services and supplies in addition to a lifetime maximum of $2,000 for home modification or assistive devices.

The FCSP currently provides about $11 million to AAAs across the state. The NFCSP expanded their capacity by approximately 60%. Differences in the definitions between the State and Federal programs will permit them to do a wider range of activities. For example, the Federal program establishes a more contemporary definition of family than the State program by allowing support to families in which the caregiver and the care recipient do not live in the same residence and for those considered having nontraditional relationships. Because these changes have not taken place in the State program, Pennsylvania is now running two companion programs through the aging network. Pennsylvania's implementation experience shows that there are ways to design flexible programs to make the system less rule-driven and more consumer-driven. The AAAs were already involved with case management and assessment work before the State FCSP, so an infrastructure was in place at the time of implementation. However, the aging network had to realign policies and procedures around assessments and care planning with the notion of families as partners or consumers. As the caregiver program continues to evolve, the State will look for ways to encourage flexibility and support families' needs by allowing families to decide how best to use available resources.

The experience of the AAA in Lancaster County, PA demonstrates the utility of building flexibility into the program that is experienced at the consumer level. The agency allows for a six-month accrual of benefits, which allows consumers to access services based on consumer need. Some caregivers choose to purchase adult briefs or nutritional supplements, others primarily purchase respite services. One example of flexibility that was shared by Jacqueline Burch, Director of the Lancaster County Office of Aging, was a caregiver's wish to purchase deadbolt locks and an alarm to enable that caregiver to sleep in her own bed knowing that her loved one with Alzheimer's Disease would not endanger himself by leaving in the middle of the night. With the NFCSP, flexibility will be further enhanced by expanding eligibility to unrelated, non-residential caregivers, supporting grandparents and older adults caring for children under age 19, and increasing the benefit reimbursement ceiling.

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## SYSTEMS BUILDING CONCURRENT SESSIONS

### Session: Quality Standards and Outcome Measures for Caregiver Supports

#### Themes

- Currently, there is no standard policy or approach for measuring quality and outcomes in caregiver programs.
- Tracking and measuring outcomes can help determine the extent to which a program really makes a difference and enables programs to strengthen and improve existing services.
- To realize the benefits of measuring outcomes, it is important to select the right outcomes that fit the program. Outcomes must be measurable, using data that are readily available or feasible to collect.
- There is a need for replicable models and approaches.

#### Presentation Summary

Dr. David Lindeman presented a framework for thinking about and measuring outcomes that involves four components:

***Inputs*** – resources that are available to or are used by a program, such as funding, staff, facilities, equipment, as well as external constraints such as regulations or program requirements.

***Activities*** – what the program actually does with inputs to achieve a specific programmatic goal, such as conducting caregiver training and providing caregiver support or services.

***Outputs*** – the direct and usually measurable result of program activities, such as number of classes taught, number of hours of service delivered, or number of participants served.

***Outcomes*** – benefits or changes achieved for individuals or populations that participate in the program. These outcomes include such factors as new knowledge gained, increased skill and knowledge levels, changed attitudes or values, modified behavior, or improved condition/status.

Dr. Lindeman pointed out that all too often, programs stop measuring and assessing program activities at the stage of outputs and never actually assess program outcomes. This occurs for a variety of reasons, including a lack of available measures, data, knowledge about how to operationalize outcome measures, and the perception that measuring outcomes requires too much time relative to the value of the information obtained through this activity. However, he stressed that the network should recognize that monitoring program outcomes can affect programs positively by creating an information base about the impact programs are making on target populations. Furthermore, information on program outcomes can be used both internally to continually improve programs and externally to justify resources allocated to programs.

Lynn Feinberg presented a caregiver model that has been developed and is being used in the California Caregiver Resource Centers (RCs), a state-funded support program that is sponsored by the California Department of Mental Health. A central tenet of this approach is the recognition that there is a dynamic relationship between research and service delivery that is critical for continual program improvement and sustainability. The RCs follow a standard set of procedures for assessing and delivering services to caregivers, including: uniform intake, assignment of a Family Consultant, in-home assessment, care plan formulation, service provision, and phone reassessments at 6-month intervals.

Although all of the RCs have a uniform framework (standard procedures) for conducting assessments and delivering services, there is some flexibility allowed for each of the RCs to adapt to local needs. As such, it was important for the RCs to come together to create uniform value statements and goals to ensure uniformity in outcomes achieved and data collected. Ms. Feinberg indicated that this creation of and agreement on value statements and program goals is a step that SUAs and AAAs need to undertake as they move forward in developing and implementing programs.

Ms. Feinberg provided conference participants a detailed overview of the *guiding principles* that the RCs developed for *measuring program outcomes* and related suggestions, including:

- Recognize that deterring nursing home placement may not be a positive outcome for the primary caregiver.
- Recognize that caregivers have multiple needs that change over time.
- Require that outcome measures be relevant to the program.
- Shift from measuring outputs (units of service) to measuring program outcomes.
- Involve clinical and direct services staff in defining and developing these measures to ensure relevance, feasibility, and applicability.

Ms. Feinberg discussed the major *outcome domains* that are used to evaluate the RCs. Each of the domains includes *areas of change* that are anticipated as a result of the program. For example, a goal of the program concerns caregiver education. The expected goal or outcome of this activity is to enhance caregivers' perceptions of competency. The areas of change that can be measured to assess this outcome include: increased knowledge about the disease/disorder; feeling confident and competent in the caregiver role; ability to manage stress; and knowing where and how to get help.

Ken Wilson presented information about the Performance Outcome Measures Project (POMP) that is underway in an AAA in Southwestern Ohio. POMP is a collaborative effort involving AOA, States, AAAs, Westat, and university consultants aimed at helping organizations address GPRA requirements and advocacy needs. Mr. Wilson discussed some of the advantages from this involvement. For one, they see measuring outcomes as an effective and efficient use of resources, which enables better programmatic decision-making, more focus on program goals, program change and innovation, and assessment of these changes. He also pointed out that his program can use the program outcome information to demonstrate the value of the program relative to the resources expended, which helps make the case for leveraging additional resources from funders and decision-makers.

Based on his program's experience, Mr. Wilson discussed the key ingredients for ensuring the success of implementing an outcome measurement effort such as POMP. These include:

1. Establishing buy-in and support with management and staff.
2. Developing a management information system (MIS) with data retrieval ability.
3. Focusing on measuring areas that can be changed.
4. Collecting baseline data to enable comparison over time.

Mr. Wilson described some of the POMP survey implementation challenges, such as respondent burden. The instrument is complex, lengthy, and can induce emotional responses from the caregivers responding to the survey. In addition, there are issues around sampling (e.g., caregiver/client turnover and limited information about the caregiver) and availability (e.g., time and location) to participate in the survey. They were able to overcome these problems by randomly selecting clients receiving specific services and identifying the associated caregivers, and by training case managers to conduct the interview. Mr. Wilson presented findings on some of the outcome indicators, including caregiver demographics, assessment of emotional well being, and perceptions of the role that services received by the care recipient have on the caregiver.

## Additional Resources

### *Program Evaluation and Outcome Measure Sources and Models*

NIA/NINR REACH Initiative: www.edc.gsph.pitt.edu/REACH/
Joint Commission on Accreditation of Healthcare Organizations: www.jcaho.org
National Quality Forum: www.qualityforum.org
United Way: http://national.unitedway.org
Community Tool Box: http://ctb.lsi.ukans.edu/

### *Quality and Assessment Tools and Resources*

POMP Materials: http://www.gpra.net/
AOA Resource Material, PA Assessment tool: http://www.aoa.dhhs.gov/
Improving Care for the End of Life: www.abcd-caring.org

***Professional Contacts***

Nancy Guberman at Guberman.nancy@uqam.ca
Janice Keefe at Janice.keefe@msvu.ca
Administration on Aging – Frank Burns at Frank.Burns@aoa.gov

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## Session: Consumer Directed Services for Caregivers

### Themes

- Contrary to myths about consumer-directed services, states with experience in this arena have not found there to be an abuse of program funds, exploitation by caregivers, declining quality of care or health status to have hampered their programs. However, there are checks in place to make sure that the program funding is used appropriately, caregivers are trained and care recipients are satisfied with their care.
- Consumers are the best judges of their needs and the approach to meet those needs. They should be able to choose their services and who is providing the services.
- The more flexible a delivery package is, the more it will meet individual needs.
- In consumer-directed systems of care, provider agencies' focus shifts from providing services to supporting provision of services.
- Consumer-directed programs should consider including the following four components for caregivers: (1) information on how to hire, fire, manage and train service providers, (2) caregiver training programs, (3) peer support, and (4) financial support and benefits.

### Presentation Summary

Pamela Doty described caregivers as "the invisible welfare state" and spoke about the differential contribution of caregivers—between how many hours informal caregivers put in versus how many hours they are likely to get, if any. She pointed out that 86% of nursing home eligible people living in the community (whether they are Medicaid recipients or not) are living with caregiver family members. Most of the expense of caring for disabled elders in the community is borne by their family members. Thus, the consumer direction philosophy reflects the notion that family caregivers have earned the right to have a system that is responsive to them.

Judith Heumann has defined *consumer direction* as "not doing things by yourself but being in charge of how things are done." The care recipient "controls the *what*, *when*, *how* and *who* of their activities of daily living (ADL)" because they are the best judges of their own preferences.

Donna McDowell discussed the common models of consumer direction: (1) *independent living model* in which individuals get funding directly to hire, set tasks for and supervise a personal care attendant; (2) *self-directed supports* (funded by RWJ) that are mostly found in the disability services field and which the family usually works with a broker whom they have chosen; and (3) *home and community-based waivers* that are targeted, flexible, and individualized in which a care manager authorizes services.

She described the principles of consumer-centered systems of care as:

- Consumer-centered rather than provider-driven.
- The money used in providing services "follows" the individual beneficiary.
- The dignity of living at home may outweigh concerns of safety and hygiene.
- Community-centered.
- Recipients' values and preferences are supported.

In the context of the NFCSP, the network is shifting to a caregiver-centered approach—supporting the caregiver's strengths and choices while responding to the caregiver's values and preferences. McDowell suggested that rather than having service plans, the focus should be to engage in dialogue with caregivers to map the informal support system (i.e., the primary caregiver, the religious affiliation, the neighbors, the other relatives engaged, other supports) and promote planning around the family's needs. With a caregiver-centered approach, the notion of community and family integration is critical. The network should develop family caregiver *support*, not *services,* whereby *support* empowers caregivers to be successful.

How can the aging network provide support and enable caregivers to succeed?

- Make sure caregivers have the knowledge they need. This often begins with knowing more about the older person's condition through the use of a professional assessment.
- Give the caregiver an opportunity to explore and understand what the older person's preferences are.
- Assist the caregiver in defining what the caregiver role is going to be (e.g., setting boundaries around hours, types of care, frequency).
- Allow the caregiver to develop a routine—which formal support should not disrupt.
- Build caring communities for caregivers by looking at the resources across the community to evaluate their utility and how the network can advocate for caregivers to make the communities more responsive.

## Program Examples

### *Arkansas' Independent Choices Program*

Arkansas' consumer direction focus in personal care services developed through a 1996 grant from the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. Formerly named Cash and Counseling, *Independent Choices* allows willing and eligible Medicaid recipients to receive monthly cash allowance payable directly to themselves or an appointed caregiver for purposes of hiring and arranging their own services. The Arkansas program exchanges Medicaid personal care payments made to the provider agency, cashes that out at a reduced amount, and then gives it to the consumer. Suzanne Crisp described that the goal of the program is to identify issues of development, implementation, and management of a consumer-directed intervention and study the impact on care recipients, assistants, and caregivers.

The philosophy of the program is that it is ethically right to pay caregivers. The family unit has changed, calling for a different and more progressive response. Under this model, the roles of caregiver and receiver are formalized, the caregiver is being compensated for his/her work, and the care receiver has dignity in knowing that he/she is not "taking advantage of" or overly reliant on a family member or friend for non reimbursed services. The Cash and Counseling model allows states to select the option to pay spouse caregivers; Arkansas did not take that option which they now regret. The program involves caregiver rights and responsibility counseling, skills training (i.e., hiring, recruiting, training and managing hired individuals), assistance with expenditure planning, monitoring of care, and fiscal support. Sponsoring agencies are required to make two phone contacts with the consumer every month in addition to conducting biannual reassessments. The average monthly allowance paid to participants is $375. Participants can use the allowance for anything tied to personal care needs (e.g., direct assistance, supplies or assistive device, services related to personal care such as adult day care).

Ms. Crisp reported that most participants of Arkansas' Independent Choices program are over the age of 65 (73%) and use their allowance to pay for a personal care assistant. Of those individuals who have hired a personal care assistant, 85% are family members. However, some hired a friend or neighbor (10%) or other person (5%). Sixteen percent of participants chose to spend their money on personal supplies (typically over-the-counter drugs, bathing supplies, home modifications) and 2% purchased assistive devices. Almost every participant chose to have the counseling entity (an organization that employs consumer-directed consultants and bookkeepers) manage the responsibilities of taxes, workers compensation, state and federal reporting, etc. In addition, 44% of the participants chose to have a surrogate (a caregiver representative to advocate and assist the recipient). A survey found that 98% of participants are acquainted with the caregiver and 95% are pleased with their ability to determine and arrange their personal assistance services.

The demonstration project is also being carried out in Florida and New Jersey, and both of these states chose to pay spouse caregivers. Mathematica Policy Research, Inc. is currently evaluating the demonstration programs. Ms. Crisp discussed preliminary results that show increased satisfaction of participants. Another evaluation is being conducted by the Center for Disease Control using a consumer survey designed to compare personal care users to *Independent Choice* users, examine the relationship of the care recipient with the attendant or caregiver, and identify quality issues.

### ***Wisconsin's Aging Services***

In Wisconsin, all elder services programs (Options, Supportive Home Care, Alzheimer's Family Caregiver Support Program, Waiver programs) incorporate consumer direction. Consumer-directed programs may entail training caregivers, providing direct payment to caregivers (under contract), providing allowances or vouchers, establishing a service bank for people who can't afford private services but do not qualify for financial aid, and "cashing out" benefits. In the circumstance when a family member is being paid directly for their care provision, the caregiver must undergo training similar to what an agency would require. This arrangement is considered to be a more formal model in which the family member is now accountable to a *contractual relationship* with the county or state government, as opposed to a *covenant*. Wisconsin uses state funding through the Community Options Program if it is the spouse who wants to be paid, since this is prohibited under Medicaid.

In Wisconsin, half of the Waiver participants require and receive home modification. The system is designed to provide the family with good technical assistance, but allows the family to problem solve and make its own determination. McDowell suggested that caregivers be supported with adequate training and an array of counseling and mediation services. In addition to those aspects of consumer direction already described, a strong information and assistance service is vital to the majority of family caregivers who are private pay customers.

McDowell underscored the importance of the network's role in raising the visibility of caregivers and promoting caregiver recognition. Providing information to caregivers in a "disease organization" such as the Alzheimer's Association, can be useful as they may be more apt to gather together in mutual support in this situation. Community recognition events and award ceremonies are common in Wisconsin—every aging network agency has a volunteer recognition event and recently, they have begun to focus on caregivers. Simple activities like caregiver fairs and recognition in religious circles can help caregivers become aware of support available to them, help them to connect with one another, and expand the network's and the caregivers' visibility.

### Additional Resources

The Mathematica evaluation will be available in 2003/2004. Preliminary findings reported in December 2000 can be found at: http://www.mathematica-mpr.com/PDFs/cashcounisbrark.pdf.

Milwaukee AAA has developed a flexible, consumer-directed model that involves a fiscal intermediary while enabling consumers to spontaneously provide tips and rewards to providers. Please contact the AAA for more information.

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## Session: Caregiver Advocacy

### Themes

- In order to have a successful caregiver advocacy campaign, a message must be developed that caregivers will respond to.
- Advocacy for older caregivers of the developmentally disabled is crucial, especially due to the caregiver's possible need for assistance in caring for him or her.

### Presentation Summary

#### *From Caregivers to Advocates and Activists*

Monette McKinnon outlined the development of the NFCSP to demonstrate the types of considerations and actions that go into the successful mobilization of individuals and ideas. Such efforts can be seen as a series of steps, including:

- Identifying a support network, such as advocacy and caucus groups, special communities, etc.;
- Building support through methods such as circulating "Dear Colleague" letters throughout the Senate and the House, OpEds to numerous editorial directors, human interest stories in Hill testimony, and a toll-free number to Congress throughout the campaign;
- Launching a grassroots campaign by gaining board commitment, appropriating staff, targeting states and districts, and getting the issue out to races and committees; and
- Developing field packets that include a variety of information such as fact sheets, talking points, and sample postcards and letters that can be sent to legislators.

The success of the NFCSP enactment stemmed from various factors including, but not limited to: bi-partisan congressional support, commitment from DHHS and AoA, and support and cooperation of many aging, women and groups representing people with disabilities.

Other current caregiver initiatives at the federal level include:

- The National Family Caregiver Support Program, in which increased funding has already been approved;
- The Long-Term Care and Security Act, which would provide a $3,000 tax credit for family caregivers and an above line tax deduction for insurance premiums;
- The Universal Caregiver Act;
- The Lifespan Respite Act; and
- Early deliberations about a White House Conference and designating a United Nations Year of the Caregiver.

Though the aforementioned acts and deliberations undoubtedly indicate a step toward recognizing caregivers and their needs, Gail Hunt emphasized that the real thrust of the movement lies with the caregivers themselves. Advocacy for this group involves a number of considerations, the foremost being the development of a term and message that caregivers will respond to. Hunt noted that the term "caregiver" does not encourage people to look beyond themselves to others, which is essential to creating activists out of advocates. Many individuals do not like the term "caregiver" because it redefines the relationship with the person who is being cared for. Another example of the importance in terminology and the overall message that the network sends, is that caregivers are less likely to respond to campaigns that say change is needed to help caregivers. Due to the fact that caregivers perceive care recipients as the focus, action must be termed in a way that emphasizes how the introduction of new programs will help caregivers care for others in an improved fashion.

Particular areas of advocacy include increasing access to palliative care, improving communication between discharge planners and caregivers, and assisting caregivers to coordinate efforts and speak out. There are many future opportunities and individuals who seek to organize caregivers; however, it is critical for these individuals to create realistic schedules for responses from caregivers and to design approaches and materials that minimize the effort required to take action and that disrupt caregiving as little as possible.

### *Caregivers of Individuals with Developmental Disabilities*

Matthew Janicki discussed advocacy in relation to caregivers who face the unique difficulties of caring for persons with developmental disabilities. He reported that there are approximately 1.9 million persons with a developmental disability who live at home or with a family caregiver. Some 25% of these caregivers are age 60 or older. A significant portion of in-home supports is being provided by family caregivers who will be aging beyond their capacity to provide care over the next 10 to 20 years. Janicki stressed that older families are an important resource for individuals with lifelong disabilities, especially as the longevity of the developmentally disabled population increases. Support services for these older caregivers are critical due to the fact that they are aging and becoming frailer, and thus, may need the assistance of a caregiver themselves. The main differences between these caregivers and other caregivers is the complexity of the problems that such families often face—the vagaries of financial resources, household composition and relationships, and the type of help these families need in order to face the inevitable end of their caregiving role. Collaboration between aging and disability agencies has the potential to be very productive and should be seriously considered.

## Additional Resources

***Websites***
www.thearc.org
www.ddpc.state.ny.us
www.uic.edu/orgs/rrtcamr
www.brookespublishing.com

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## SERVICE COMPONENTS CONCURRENT SESSIONS

## Session: Information and Assistance

### Themes

- Under the NFCSP, caregivers should be considered as I&A consumers.
- Coordination with other aging and health and human services programs will help reach a larger population of caregivers whom would otherwise fall through the cracks.
- Existing I&A staff should be retrained to gain a full understanding of the NFCSP, types of caregivers and their needs, and reporting requirements.

### Presentation Summary

Theresa Lambert provided a brief history of aging I&A services and also discussed NASUA's vision of a broad-based caregiver I&A system that would empower caregivers. She pointed out that although amendments to the Older Americans Act required states to include aging I&A services in the 1970s, these services most often focus on the *care recipient* as the consumer. With the passage of the NFCSP, State Units on Aging (SUAs) and AAAs are charged with viewing the *caregiver* as an I&A consumer. In order to ensure that caregivers' information and assistance needs are being met, coordination with other programs must exist. This coordination should not only be established with other aging programs, but with other health and human services programs (e.g., 211, other programs serving the disabled, children and youth, and programs tailored to individuals with dementia). Because caregivers often contact these programs in order to gain information about services for the person for whom they are caring, it is essential that these programs are aware of the NFCSP so that they can recognize and refer caregivers to the appropriate I&A service that serves caregivers. This is especially important because many caregivers do not self-identify as caregivers and never receive desperately needed assistance; these staff may be the only way that caregivers will be aware that there are services that can help them.

In addition, the speakers concurred that the development of comprehensive statewide databases that allow for “one-stop shopping” could greatly enhance I&A services for caregivers. In doing so, the database should:

- include nontraditional services, such as grocery and pharmacy delivery services for caregivers who are homebound because they need to care for their loved one;
- offer information about for-profit providers for those who can afford to pay;
- be updated regularly to make certain that the most appropriate and accurate information is provided to the caregiver; and
- be placed on the Internet to allow caregivers to self-serve, which is especially helpful for workforce participants and long-distance caregivers.

The retraining of existing I&A staff is critical to meeting caregivers’ needs. Besides ensuring that staff understand that the caregiver is now also a client of the aging network, staff need to be apprised of NFCSP operations and reporting requirements in order to provide accurate information. Furthermore, the hiring of specialized I&A staff who deal exclusively with caregiver issues could prove to be a valuable resource.

Nancy Day discussed New Jersey’s Easy Access, Single Entry program (EASE) which developed in the early 1990s in response to a highly fragmented state aging system. Under the EASE program, information and services are provided to older adults and their caregivers through all 21 AAAs in the state. Ease program features include:

- A Statewide toll-free number and public awareness campaign for consistency, but counties have the flexibility to adapt the program to best meet their local needs.
- I&A staff are required to attend a three-day mandatory training session.
- Plans to create a statewide website for caregivers.

Day recommended that the network clarify details before launching a public awareness campaign. For example, statewide toll-free numbers should be referred to as “toll-free” numbers rather than “800” numbers. This eliminates confusion if the number is actually an “877” number since some caregivers may not realize that 877 is a toll-free number without it being stated explicitly. In addition, it was recommended to test the toll-free number before publicizing and to continue testing it along the way to ensure its smooth operation so that the aged and their families are able to reach the aging network when they need to without hassle.

Cheryll Schramm discussed her AAA's regional I&A system in that was established in 1982, *Aging Connection*. With the creation of *Aging Connection*, I&A services were brought in-house in all 10 Atlanta-area counties served by the AAA. In 1995, special I&A software was developed called *Elder Services Program*. The AAA also developed the *CONNECT* database and an aging and long-term care taxonomy. Although this taxonomy, which includes 42 categories and 150 services, took a long time to develop, it was essential in organizing the data in a manageable manner. In 1998, the *CONNECT* database went statewide; however, the database continues to be updated on a weekly basis exclusively in Atlanta by three staff members to ensure consistency and maintenance. Schramm pointed out that the statewide database is especially useful for long-distance caregivers because they can now call their local AAA to find out about programs that their loved one can use in another part of the state.

An abbreviated version of the database is available online for caregivers to use themselves, 24 hours a day, thereby increasing I&A accessibility. However, Schramm stressed that although this is beneficial to many caregivers, much more detailed information is available by calling the I&A line because the staff have access to the full database, enabling them to locate services specific to a caregiver's need. Schramm felt that it will be important for I&A staff to be trained and certified, and that their interview skills adapted. In addition, she suggested that mailouts be revised to include information for caregivers.

### Additional Resources

*NASUA's Vision 2010: Toward a Comprehensive Aging Information Resource System for the Next Century*. Information about obtaining a free copy can be found by going to the NASUA webpage: www.nasua.org/bookstore.htm (this publication is under the caption, *Productive Aging)*.

*CONNECT Database* - The abbreviated version of Atlanta's *CONNECT* database can be found at www.agingatlanta.com.

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## Session: Care Management for Caregivers

### Themes

- Caregivers often do not view themselves as such, and thus, do not consider themselves to be a case and do not want to be managed.
- From the caregiver's perspective, situations are constantly in flux and there is no end in sight.
- Care management must: recognize the diversities of the caregiver, the family, and the setting; address the complexities of family care; customize with flexibility, sensitivity and creativity; and help the family find "a new normal."
- Assessments must have relevance to the care manager and the agency to ensure accurate information and consistent use – an assessment avoids assumptions and institutionalizes asking the caregiver.

## Presentation Summary

Lisa Gwyther of the Duke Family Support Program presented an overview of the challenges and opportunities in care management for caregivers. Gwyther discussed how family member roles will drive the types of assistance sought and the need to target care management to the most vulnerable caregivers—frail older caregivers and stressed caregivers—where the care recipient may be at risk.

The following represent the *goals* of caregiver care management:

- To teach by providing timely, appropriate, dosed and relevant information specific to the situation or disability of the care recipient;
- To link to needed resources for both the caregiver and care recipients;
- To support through acknowledgement, absolution, with decision; and
- To prevent further breakdown of the caregiver system.

Care management *outcomes* may include the following:

- caregiver health;
- appropriate, timely use of help;
- reduction of passive neglect, abuse, stress;
- increased effectiveness of care and coping;
- increased satisfaction with preferred level of involvement;
- decreased negative consequences on family; and
- minimized family conflict.

Gwyther discussed several issues to consider in developing a caregiver care plan: 1) service or information seeker; 2) disability of care recipient; 3) caregiver health; 4) relationships; 5) demographic and socio-economic characteristics; 6) values, beliefs, lifestyle, needs, preferences; and 7) age, gender, race of care manager vis a vis caregiver.

David Bass of the Benjamin Rose Institute reviewed items to consider including in an assessment, emphasizing that the knowledge of research about what might be important needs to be combined with the practicality of clinical practice. An organization should pick and choose among available measures and modify them to suit their needs. An assessment aids the care manager in understanding the caregiver's unique situation both in terms of their characteristics and competing demands and the care recipient's characteristics that would influence the caregiving situation (e.g., dementia, disruptive behavior). Assessments, in combination with reassessments, also provide an opportunity to assess service effectiveness. Bass reviewed the common reasons given for not doing or using a caregiver assessment. An assessment should not be a paper exercise because it does neither the care manager nor the caregiver any good. He offered the following tips for designing and implementing an assessment:

- Allow flexibility in the timing of when information is collected;

- Allow flexibility in the method used to collect the information;
- Eliminate redundant information;
- Consider whether answer categories need to be simplified from those used in research;
- Consider the length of the assessment by segmenting and targeting sections as appropriate;
- Consider whether parts can be self-administered;
- Find ways to analyze assessment information and provide results;
- Directly link the assessment, care plan, and reassessment so that information is used to guide service delivery;
- Consider computer applications that streamline the process; and
- Be practical.

## Program Example

### *Pennsylvania FCSP Assessment and Care Planning*

Dan McGuire of the Pennsylvania Department of Aging discussed Pennsylvania's Family Caregiver Support Program (FCSP), which is fully integrated into the State's community-based long-term care system. Key components of care planning in this program include:

- Care planning is conducted by the primary caregiver and the agency care manager acts as a catalyst and guide to services.
- Assessment, care management, benefits counseling and caregiver education and training are considered to be "soft" services and are provided free of charge regardless of income.
- Consumers are not restricted to a pre-set menu of services.
- Reimbursement is provided as long as it can be justified that the service is necessary to preserve, prolong, or enhance the caregiving relationship.
- Payment is for expenses incurred, not services.
- With the exception of a relative, the program will pay anyone – the determination of whether the provider is acceptable is a care manager judgement or a local standard.
- Consumers can reinvent the program on a case-by-case basis by requesting services or products previously unknown to the program.

Pennsylvania's Comprehensive Options Assessment Form (COAF) is used for FCSP and for nursing homes, Medicaid waiver and any other community-based long-term care. The COAF includes a domain on the status of the caregiver, including:

- Amount of care provided;
- Quality of care provided;
- Availability of respite;
- Burden on caregiver (externally evaluated);
- Stress on caregiver (Zarit scale) – caregiver perception;
- Reliability of caregiver; and

- Cognitive status of caregiver (SPMSQ) – optional.

### Additional Resources

Pennsylvania's Comprehensive Options Assessment Form (COAF) is available at www.aoa.gov/carenetwork by clicking on *Resources and Tools*.

## Session: Respite Services

### Themes

- Respite services that are provided in sufficient amounts can provide critical relief for caregivers.
- The aging network should seek ways to provide a range of respite services that offer appropriate options for diverse caregiver circumstances and that are "user-friendly."
- Respite is still often perceived as an outcome rather than a service and respite terminology used by the network is often unfamiliar to many families.
- Local innovation with community partners can be a successful approach to reaching minority and other populations that are isolated from existing respite services.

### Presentation Summary

This session focused on practical implications from the most recent research on respite services and the experiences of respite programs in several states including, New Jersey, California and Washington. Respite was described as a service that provides temporary relief to the primary caregiver. It can be provided through in-home and out-of-home arrangements such as, adult day care, home care, overnight care, and mixed programs that offer two or more types of respite.

Dr. Zarit presented an operational framework for assessing the effects of respite programs, including the extent of benefits to the caregiver. His framework uses three main parameters: 1) the type of care, 2) the type of care recipient, and 3) the type of benefit. Research shows that when respite services are used appropriately (i.e., the right dosage at the right time), they can relieve care-related stress and consequent burnout, thereby producing both physical and psychological benefits for the caregiver. The types of caregivers who have not shown increased benefit from adult day services in the research include, spouses who are caregivers, caregivers with less formal education, caregivers assisting someone with more behavioral-type problems, and caregivers who feel trapped in their role (role captivity). In terms of types of respite, the benefits have been demonstrated most clearly for caregivers using adult day care. The limited research focusing on in-home respite shows positive effects, while there is virtually no evidence around benefits of overnight respite. There is a growing emphasis in research on respite services for individuals caring for loved ones with Alzheimer's Disease and other dementia.

In efforts to enhance respite support for caregivers, Zarit said that the network should realize that many caregivers do not use respite services, use only small amounts of respite, or use it only very late in the care process. He noted that the use of respite services might not affect the caregiver's decision to place the care recipient in an institution and that cost is not often the issue in use of respite. Some barriers to use of respite services include overly bureaucratic rules for assigning families a respite worker, a service delivery time, or for determining financial assistance, and caregivers who do not self-identify early on. Efforts to develop more user-friendly systems that empower consumers may lead to improved utilization. Also, offering different types of services that can be coordinated or packaged (i.e., ADS, in-home, overnight) may increase appropriate use and benefits to the caregiver. It was suggested that the network consider partnering with [local] researchers to better understand the utilization and benefits of respite services so that programs can be shaped efficiently and effectively.

## Program Examples

### *California*

Lynn Friss Feinberg discussed findings from the Family Caregiver Alliance-funded multi-state study that focused on the preferences and use of a consumer-direct "direct pay" model of in-home respite versus an "agency based" model. They found that that the majority of consumers prefer direct pay to agency based. In addition, consumers value safety, quality and reliable in-home respite over the cost and the amount of care. Building from their vast experience, research, and stakeholder input, California's respite program instituted a consumer-oriented focus. California's Caregiver Resource Center provides families with a voucher (up to $425/month per family) to access a range of respite services. The families pay a "share cost" based on their household income. A highly debated issue that other states grapple with, was whether to serve more families with less respite or serve fewer families with richer respite services

### *Washington*

Hilari Hauptman described the state respite program, which currently operates under a budget of $2.7 million and targets primary, unpaid caregivers. Some program features include:

- A diverse range of in-home and out-of-home respite services that target the specific needs of the caregiver.
- The allowable hours per week are determined by a formula used throughout the State.
- A simple screening process is used and if the family is deemed eligible, a care manager makes a home visit to assess both the care recipient and the caregiver.
- Financial eligibility is based on the care recipient's monthly income.
- The State requires 22 hours of training by anyone providing respite services.

In the program's evolution, some of the original restrictions such as, co-residence of the caregiver and care recipient and applying capped hours, have been removed. They have found that nearly two-thirds of respite hours are expended in the home environment and that respite services are more often requested from caregivers that provide care to individuals with Alzheimer's Disease or other dementia. The State never defined "emergency," but this has not been an issue. Some limitations of the State's respite program described by Hauptman include: 1) it does not allow individual providers due to liability issues (though the State allows this in the Waiver program); 2) the home and community services program is separate from the Respite program and so caregivers might not know about respite services if they are not in the program; and 3) the emphasis has been to avoid a waiting list situation resulting in decreased hours available to offer caregivers across the board.

The aging network in Washington also has rich experience in designing and delivering respite services to ethnically and culturally diverse families. Conference participants were shown a video of the Korean Women's Association Alzheimer's Demonstration that took place in Tacoma, WA entitled, *Ethnic Communities and Dementia: Making a Difference*. This demonstration project is an example of how communities can innovate successfully at the local level. Through locally based projects, individuals of various ethnic backgrounds were able to participate in adult day services and interact in a more culturally friendly environment where language, dietary, and religious needs were considered. After the demonstration period ended, these programs continued through the use of Medicaid waiver, State, and private pay funding sources. The panelists emphasized the need for the network to target populations using different marketing strategies, provide multilingual staff, and consider ethnic and culturally appropriate activities and dietary needs when implementing respite services.

### Additional Resources

***Video***

*Ethnic Communities and Dementia: Making a Difference.* Washington State Department of Social and Health Services, AASA. P.O. Box 45600, Olympia, WA 98504-5600. Call (360) 725-2545. Produced by Instructional Broadcast Center – The Seattle Public Schools. Length 20:18.

***Article***

**Title:** Respite programs for caregivers of persons with dementia: a review with practice implications **Author(s):** B. H. Gottlieb; J. Johnson **Source:** Aging and Mental Health **Volume:** 4 **Number:** 2 **Page:** 119 – 129.

This paper critically reviews evidence concerning the role and impact of center-based respite programs for the family caregivers of persons with dementia. It examines the timing, intensity and duration of day program utilization, the expectations the caregivers bring to these programs, and the impacts that derive from program participation, drawing on this information to propose ways of optimizing the role played by this component of the community's long-term system of care.

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## Session: Caregiver Training, Support Groups, and Counseling

### Themes

- Partnering with consumers and other community-based organizations to deliver these services is beneficial for: sustaining collaboration, efficient use of resources, and providing a wider range of options to meet caregivers' varying circumstances.
- These services should be part of an agency's quality assurance and outcome measurement activities.
- The program focus, prevention and/or remediation, should be decided prior to structuring services and targeting caregiver populations.
- The person leading the education session must be able to adapt their training, on the spot, to meet the needs of caregivers and the size of the session.

- Training, support, and counseling sessions should be appropriate to the culture of the population being served.

## Presentation Summary

This session focused on the vital role that education, training, counseling and support groups play in supporting and sustaining family caregiving. The panelists outlined key elements to developing these services and building effective programs. These elements included the importance of determining program structure and goals, developing marketing strategies, and implementing methods to measure outcomes.

### *Defining Goals and Developing Program Structure*

One of the initial steps for the network in implementing the NFCSP is to shift the focus from the care recipient to the caregiver and critically think about what families need to continue caring for their family member(s). Dr. Ronald Toseland suggested that, despite circumstantial differences, caregivers face the following similar difficulties: 1) social isolation, 2) financial constraints, 3) family tensions, and 4) changing emotional health.

Program developers should take into account the nature and extent of the care recipient's disability, the relationship between the caregiver and receiver, gender, race, ethnicity, and socio-economic status, and whether or not the program focus should be on prevention or remediation. In addition, the size of the program should vary depending on the program goals; group sessions are better for social support, whereas individual sessions are needed to deal with deep-seeded psychological problems, such as sibling rivalry. Though identifying one best practice model is difficult, empirical evidence suggests that multi-component programs might be more effective than single-component programs. Thus, providing comprehensive services that address a continuum of needs in an individualized manner is an important consideration for the network in implementing effective support services.

### *Program Examples and Marketing Strategies*

Lisa Durham discussed the Central Ohio Area Agency on Aging's caregiver education demonstration program, which consists of 4 two-hour sessions that address a range of needs:

**Session 1 --** *Caregiving: Is it for You?* covers issues that need to be addressed as a caregiver, including practical, financial, and emotional considerations. It addresses such questions as: What does it mean to be a caregiver? and Will my relationship to the care recipient change?

**Session 2 --** *Moving, Lifting and Transferring an Older Family Member* provides the opportunity for caregivers to practice transferring, a stressful activity for those with little training.

**Session 3 --** *Bringing Services and Assistive Devices into the Home* informs caregivers on accessing a full array of services, from publicly funded programs to private pay services.

**Session 4** -- *Preventing Caregiver Burnout.*

Originally implemented in three of the eight counties served by COAAA, the program is going to be extended to the other five counties. Durham attributed the success of the program to a number of factors, including:

- Effective recruiting and marketing that utilizes numerous resources such as hospitals, libraries, case management staff, discharge planners, and disease-specific organizations;

- Flexible scheduling of workshop times and locations that promote accessibility and consumer choice;
- Highly skilled and informed trainers who know the topics well and are able to quickly adapt presentation style and content to the needs of the audience;
- Well-developed written materials that are easy to read and give the workshop attendee a sense of getting something out of the meeting; and
- Offering CEUs to professionals for attending a free session that gives an overview of all available workshops.

Durham also spoke about reaching out to minority populations and described the collaborative activities between COAAA and the Black Church Network in Columbus, to reach the African American community and inform them about the workshops. COAAA also contracted with a representative from the Community Refugee and Immigration Services to inform the Asian community. In this effort, staff and interpreters go to homes in the community to inform caregivers about the training sessions available to them. In addition, gift certificates are provided at local Asian grocers as an incentive to get Asian caregivers to attend the training sessions. Durham anticipates working with the large Somali population in the near future. COAAA is also working with businesses and the Columbus Employee Assistance Program to take the training workshops to working caregivers.

Margaret Hellie Huyck of the Illinois Institute of Technology, discussed the value of identifying partners in the experience of *Senior Care*—a Metropolitan Family Services Program that serves four communities in Northwest Chicago with large Latino and Polish immigrant communities. Huyck discussed the importance of providing culturally appropriate training material and stressed that printed material and sessions must at least be in the native language of the population that is being served. In addition, terms used must be appropriate to the values of the culture. For example, although "caregiver burden" is a common term used in the United States, it is not culturally appropriate for Latino's to view caregiving as burdensome. Rather, caregiving is supposed to be viewed as supporting a family member through loving actions. Additionally, Huyck emphasized that program developers should assess the existing caregiver support environment and determine what works and what partnerships can be built. From there, programmers can establish needs and focus development efforts.

### *Measuring Outcomes and Improving Program Delivery*

The speakers stressed the importance of assessing the quality of these services. Suggestions of evaluative methods to measure quality and identify areas for improvement included: 1) telephone follow-ups, 2) satisfaction surveys, and 3) sit-in observers whose role is to provide objective feedback. Consistent feedback to staff and trainers is essential to improving the design of education, training, and support workshops. Additionally, it was recommended to continually compare the intent and goals of programs with what is actually delivered and the impact from each session. The panelists reiterated the importance of flexibility in program design and delivery. Caregivers are extremely busy and minimizing inconveniences and effort required to attend a workshop will result in greater turnout.

## Session: Supplemental Services

### Themes

- The speakers emphasized the need for flexibility and creativity to meet caregiver needs.
- Supplemental services can be designed and used to enhance consumer direction.

### Presentation Summary

Gail Schwersenska described some of Wisconsin's aging network initiatives gathered via a listserv request; those specific to supplemental services are outlined in the example section of this summary. Cliff Burt described Georgia's process of soliciting caregiver and provider input through focus groups. Some supplemental services he discussed were: emergency services (back-up for caregivers), home modifications, legal issues (power of attorney, guardianship, donor issues); future planning (financial, funeral, etc.); expanded transportation; financial assistance with medications; and more supervision of services. Margaret Campbell discussed the promise of technology as a caregiver resource by reviewing the promise and reality of the technology revolution as it relates to older persons. Technology can help people with disabilities and their care providers: better monitor their health and nutrition, remain in their own homes, travel more freely about the community, use a telephone and communicate more easily, leave the house without having to rely on the help of another person; take care of personal needs independently, engage in lifelong learning and participate meaningfully in family and community activities. However, many older and disadvantaged persons do not have access to technology for numerous reasons.

### Program Examples

#### *Wisconsin*

Some examples of supplemental services that have been offered through Wisconsin's aging network include: a loan closet for adaptive equipment; home modifications that benefit the caregiver; a contract with a registered nurse to conduct in-home assessments to determine needs; a contract with homemaker services for money management; emergency services, including limited day care transportation, personal care and homemaker services; in-home nutrition counseling and teaching for special diets. Other existing efforts in Wisconsin that might fall under supplemental services include: the purchase of a computer with a large screen monitor for a senior center to provide access to internet info; caregiver survivor kits that include general and resource information (I&A); purchase of caregiver training materials for lending libraries; utilizing an existing "peer counselor" system where the counselors are trained and supervised by a psychiatric social worker from the mental health system to provide in-home caregiver support; and providing friendly visitors for caregivers (counseling/training). In Wisconsin, if a provider will accept the voucher, the county will pay it. Conference participants inquired about liability issues related to lending closets and Wisconsin reported that they run theirs through the county health office and require a physician prescription and a home health aide or RN instruct the individual on how to use the equipment.

### *Georgia*

Georgia has three self-directed care model projects, two nearly started and one more established:

- *Greater Georgia Chapter of Alzheimer Caregivers, Caregiver Time Out Program* – provides up to $100/mo. for in-home services, day care, or overnight respite
- *Elder Connection* (Jewish Family Career Services) – provides up to $1,000 per year to caregivers of limited income and ineligible for other assistance to use as they need, including dietary supplements and vision and hearing aids
- *Legacy Express* (Atlanta Regional Commission) – promotes caregiver participation in planning and managing services in their home; provides a handbook of approved providers (those willing to accept vouchers); vouchers are issues in books of $500 in denominations of $10, $20, and $50; half spent on homemaker services, followed by respite (22%), pharmaceutical (10%), day care (7%), home modifications and emergency response systems (5%); currently no family or friends can be reimbursed, however they are considering this option.

Some types of supplemental services available in Georgia include: assistive technology and home modification, mobile display unit (permits hands on testing at health fairs and other venues) and a lending closet (enables caregivers to try assistive devices before purchasing). If the family is interested in a provider who is unknown to the program, the care manager works with the family to get them listed. Conference participants were interested in knowing how best to categorize and account for supplemental services. In Georgia, the CyberPath elderly services component may provide some guidance because it has a taxonomy of services and definitions. In terms of Title III reporting, each voucher is counted as a unit of service.

Though not specific to supplemental services, other interesting initiatives offered through the aging network in Georgia include:

- Mobile Day Care – staff and materials for day care goes to church or senior center in rural areas a couple of days per week; community development coordinator is a local hire and needs to develop a coalition of community professionals and caregivers; food is provided locally; effective means of providing respite in unserved areas (could also be used in urban areas) and spreading costs between two sites

- Professional In-Home Counseling for the Elderly (PICE) – monthly discussion groups for Georgia caregivers facilitated by a licensed social worker, but also allows for in-home counseling at no cost to the client

## Additional Resources

### *Georgia's CyberPath*

Includes an elderly services component for this I&A database that lists the service name, units of service, whether it is individual or group and definitions. Although it includes respite, the services are not specific to caregivers. For several of the services it distinguishes whether the service was purchased with a voucher.

***Technology and Other Resources***

- Proceedings from White House Office of Science and Technology Policy (OSTP) sponsored conference on "Technologies for Successful Aging" in October 2000 (http://www.vard.org/)
- Newly awarded National Institute on Disability and Rehabilitation Research (NIDRR) Research and Training Center on "Technologies for Successful Aging". This center will stimulate research and development activity in home health and monitoring technologies and personal communication technologies.
- Veteran's Administration "Centers of Excellence" in geriatric rehabilitation (http://www.varrd.emory.edu/) and aging with a disability (http://hoffman.bcm.tmc.edu/)
- National Institute on Aging Centers for Research on Applied Gerontology at http://www.applied-gerontology.org/cag_info.cfm
- John Hopkins University Conference on "Aging and Associated Disability in the Information Age."
- Gerontological Society of America (GSA) formal interest group on Technology and Aging http://www.gsa-tag.org/2001/ for 2001 symposiums and http://www.gsa-tag.org/2000/ for 2000.
- International Conference on Technology and Aging (ICTA) http://www.icta.on.ca/English.

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## TARGET POPULATIONS CONCURRENT SESSIONS

### Session: Barriers to Resources for Socially and Economically Disadvantaged Caregivers

#### Themes

- In communities of color, there often exist a community member or leader that is a focal point in the community and with whom the aging network should develop a relationship to expand networks of care.
- Often, minority and socially disadvantaged communities have experienced discrimination as well as short-term commitments from public programs because the intervention is associated with a grant or study. So these families may have great suspicion with "available services."
- Develop accessible information about basic service definitions that have comparability in other languages and other cultures.
- An important consideration for working with limited or non-English speaking populations, is that bilingual does not necessarily translate into bicultural.
- AAAs have a role in educating its service providers about the caregiver population and the unique needs of certain sub-populations.
- Due to limited resources (including money and staff) in rural communities, the network should consider designing multilevel programs for this caregiver population rather than developing single focus programs.

## Presentation Summary

This session focused on the various caregiver populations who have physical, emotional, and financial barriers to accessing services, the nature of the barriers involved, and strategies that could be employed by the aging network to respond to the needs of these caregivers. Neetu Dhawan-Gray underscored the importance of the network developing a strong presence in the community. The success of caregiver support programs in reaching socially and economically disadvantaged caregivers is directly tied to how the community receives the program message. Target population members need to be active on planning boards and be empowered to communicate their issues with legislators. By giving these caregivers voices, real barriers can be better understood and a stronger connection can be built between the network and those in need of support.

### *Who Faces Barriers to Services?*

Laura Trejo described several sub-populations that have the most difficulty in engaging or accessing service networks and identified specific challenges that they face:

*Women* -- One of the major obstacles that women face is finding time and energy to care for children and older adults. It is estimated that women can expect to spend more time caring for an aging parent than a child. Older women many times do not have the level of disposable income to purchase the level of services that are needed.

*Older Adults* -- This group faces issues related to widowhood, loss, and living alone. Older adults may have low levels of income, substandard housing, limited mobility, employment opportunities, and inadequate health care coverage. Some of the educational material that is developed is not appropriate for the educational level of today's older adults.

*Ethnic and racial minorities* -- Minority populations tend to be more unaware of available services, lack access to culturally appropriate services, have relatively more inflexible job situations, and experience racism and discrimination resulting from rules, regulations, and policies. Limited English speaking groups face additional barriers in accessing information and may require direct assistance to help complete forms.

*Individuals with lower levels of education* -- Low education and literacy levels often result in difficulties with searching for information, reading written materials, using technology, and completing forms without assistance.

*Geographically isolated individuals and families* -- Mobile services are very limited and geographic inequities in service distribution exist. Families and individuals face decreased social support due to isolation and difficulty with finding transportation services.

*Poor and/or disabled persons* -- Persons with low income may have limited choices, social stigma, and inferior health care coverage. This group may have higher levels of risk associated with their jobs resulting in poor health that is only compounded by caring for someone else. Additionally, transportation is a major obstacle.

Rhonda Montgomery discussed rural caregiving issues related to her assessment of the Alzheimer's Disease Demonstrations, in which interviews were conducted with a significant number of consumers and front line service providers. She pointed out that although not all rural barriers are unique, there are three distinguishing qualities of rural communities:

1. *Geographic and social isolation*—accounting for fewer educational opportunities, limited access to medical care and limited range of services. These limitations translate into dependence on the local general practitioner for information, who is not always the most informed provider.
2. *Strong sense of independence*—means that there is a belief in self-reliance ("family comes first"). Strong independence is linked to views of service as welfare, which is further associated with stigma and guilt.
3. *Familiarity*—may imply that there is a concern for privacy. In a small community, word can spread about a family's problems. Familiarity is also related to a suspicion of outsiders (i.e., staff, providers, and researchers) which can impede people from accessing and using services. Lines get drawn in small communities and there is a preference to receive services by "one's own."

Transportation, limited resources, and a lack of economy of scale are also prevalent in rural communities. Retaining qualified *professional staff* is an additional challenge.

### *What are the Possible Solutions?*

The NFCSP provides the network with an opportunity to address system barriers such as, low visibility of caregiver concerns; multiple and, at times, conflicting eligibility criteria; lack of service coordination; lack of trained personnel; and a lack of consensus on "who is the client?" There are several ways to tailor programs to develop quality systems that address the needs of socially and economically disadvantaged caregivers. These center around four factors related to satisfaction: 1) Service expectations, 2) Communication difficulties, 3) Access to services (ease of use, time and days of availability, and the correct amount), and 4) Red tape (waiting to talk to someone, multiple telephone numbers, difficulty in applying for services). The following are strategies that address these four factors:

- Think creatively (e.g., Mobile day care; shared staff between day care, home health agency, and aides; a program that provides caregivers with respite if they work in the thrift shop).
- Be responsive to client need—make concerted efforts to understand each family's situation and difficulties that the various family members face. In doing so, understand the family structure and their belief systems.
- Establish long-distance support groups ("caregiver buddies") over the phone or on the Internet.
- Create clear expectations for care by laying out what services are and are not provided.
- Provide quality care by being intimately involved in *your* service community.
- Build trusting relationships and educate the community by getting to know the culture and the language, becoming knowledgeable of the other resources, and understanding the issues related to the service (socioeconomic, education and employment status).
- Follow through on commitments.

- Develop methods that encourage collaborative service development and planning between staff and families who seek services.
- Use a socializing context for support groups (e.g., potluck dinner, dance).
- Build partnerships with key community providers and organizations. Reach out to the local practitioner to get them linked to critical information about caregivers, particularly the issues faced by dementia caregivers.
- Hire trained personnel who are well versed in caregiving issues and culturally competency.
- Recognize and award excellent staff because they are the most critical link to families.
- Empower families through methods such as educating them about how to ask questions and by requiring nominal co-payments on a sliding scale basis.

The speakers also noted that the network should be cognizant of varying levels of technological sophistication and access, particularly when providing services over the phone or via the Internet. Some people may need more instruction than others, in formats and educational levels that are meaningful to that sub-population.

### Additional Resources

Brochures containing detailed information about the service delivery models of Alzheimer's Demonstration project can be obtained through AoA's website at: http://www.aoa.dhhs.gov/alz/brochures/brochures_main.asp.

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## Session: Ethnically and Culturally Diverse Caregivers

### Themes

- The family is often the unit of caregiving, not an individual. Particularly in minority families, it is important to meet with more than just the primary caregiver.
- It is useful to build upon community services that exist for minority caregivers, rather than trying to create something new.
- Frame caregiving not just in terms of cost, but also in terms of reward.
- Take stock of what the network is already doing and look for missed opportunities in serving a broad range of caregivers.
- Lessons from the REACH projects are a good resource for the network because many of them focused on different parts of community infrastructure and listened to the ways that different communities are expressing their needs.
- Increases in diversity among caregivers are an important trend since many of the caregivers are the network's next care recipients.
- Different ethnic and cultural groups have different needs for intervention but some general principles cut across that can be applied on a large scale.

## Presentation Summary

The process of developing ethnically and culturally sound interventions needs to begin with the involvement of the community. It was recommended that an advisory committee be formed that includes community representatives to help translate what the caregivers express into feasible action in that community. Most caregiving outcome research has focused on Caucasian caregivers and cannot be applied to other groups. However, some general principles should be considered when thinking about how to shape the system: 1) interventions should directly focus on the family (a shift for those used to working with the care recipient or the caregiver one-on-one); 2) caregiver support should be delivered by staff who are bilingual and bicultural and have received training in cultural competence as needed; 3) be respectful of language preferences (e.g., many non Native English speaking individuals are bilingual and prefer to speak in English for certain matters); and 4) translation of materials should translate the *meaning* of the content and not be literal—make them multi-validated (multiple reviewers have given their input so that there is a consensus translation).

Culture plays a large role in a caregiver's outlook and willingness to embrace caregiving. Different ethnic and cultural groups vary in their propensity to provide care directly to an elderly or disabled relative. Compared to 19% of white caregivers, 42% of Asian Americans, 34% of Latinos, and 28% of African Americans provide care to their aging parents, in-laws or other relatives.

Cultural sensitivity must be employed at multiple levels to improve access to services. One way the network can enhance support for these caregivers is by partnering with local ethnic programs and with community members who have the skills and knowledge required in developing ethnically diverse programs.

### *Ethnic and Cultural Issues from REACH*

Dolores Gallagher-Thompson discussed some of the preliminary findings from the 5-year old REACH project, funded by the National Institute on Aging and the National Institute on Nursing Research. It is the largest caregiver intervention study in the country and is specifically designed to evaluate interventions for dementia caregivers that have been tailored at each of six sites for specific ethnic groups. She provided several examples of the different approaches taken. A project involving the African American population in Birmingham, Alabama included:

- Three-hour informational workshop explaining what is dementia and how an intervention can help an African American family caregiver
- Materials for the workshop were tailored for the audience and presented by African American staff in churches and centers known to serve that community.
- The workshop was followed by an in-home, one-on-one skills training program over a period of three months that assisted caregivers in learning techniques in managing difficult behaviors related to dementia and was tailored to that family's particular circumstances.

The interventions developed for Latinos were based in Miami, Florida (serving primarily Cuban Americans) and Palo Alto/Salinas, California (serving primarily Mexican Americans). They found significant differences in serving the different Latino populations. The Cuban Americans preferred a "family systems" approach (i.e., several caregivers being involved simultaneously in the intervention) in which information was tailored to different generations in the family addressing different level of acculturation in the family. In contrast, Mexican Americans preferred a non-stigmatizing, educational approach. The intervention was called, "coping classes, " and was based on cognitive behavioral principles—such as, how to relax in stressful caregiving situations and how to get more help from other family members. They were conducted in the community in small groups to increase the sense of social support and caregivers were reimbursed for travel and sitting expenses.

For Chinese Americans, the intervention emphasized in-home education around behavioral issues, recognizing that many Chinese caregivers do not come to the Chinese language support groups that are conducted by the local chapter of the Alzheimer's Association. The interventions for Japanese American caregivers involved educational programs that focused on wellness and health promotion.

### ***Native American Caregiving***

Cynthia LaCounte, Tribal Chair of the Trenton Indian Service Area, described the Native American population and reported that they constitute the smallest, minority population (2.1 million) in the country. There are approximately 545 federally recognized tribes and about 100 other tribes that are not federally recognized. Most Native Americans live in 34 reservation states in extremely rural areas where basic necessities such as telephone lines, electricity and even transportation are lacking. Access to comprehensive care is a barrier to good health for Native Americans.

The Native American philosophy is that caregiving is one of the highest duties one can perform or be expected to perform. Traditionally, caregiving is a privilege as much as it is a responsibility. Institutionalization is not an option in most cases due to the lack of facilities and lack of resources to pay for such care (there are an estimated 12 nursing homes in Native American country across the nation). Placing an elder in a culturally foreign and off reservation care facility is considered to be a sign of losing them. Native American culture is experiencing a transformation as technology becomes more accessible. As changes take place, values change too. Caregiving agencies do not exist in most Native communities. The Indian Health Service has focused on the young and prevention, which has created a gap in the provision of services. A study of Native American caregiving conducted by Robert John in 1999, indicated that the greatest needs for these caregivers are: training for benefits counseling, more information about problems that caregivers themselves experience, information about disease conditions, techniques for in-home medical care management and preventive health management, information about how to obtain support services, and how to develop personal skills to improve caregiving abilities. In addition, access to legal assistance and how to access public funds that cover the costs of caregiving continues to be a great need.

### ***Hispanic Caregiving***

Marta Sotomayor discussed that in Hispanic and other minority cultures, *family* is the vehicle for providing caregiving, not an individual. Hispanics are most likely to be surrounded by family and value caregiving as a *two-way process*. It is well documented that service utilization rates for Hispanic elderly are very low. Some of the barriers to care that the Hispanic population faces according to Sotomayor include: 1) inability to negotiate the system; 2) uninformed of available services; 3) a mistrust of the federal government, through which many services are funded; 4) a culturally-held notion of family independence; 5) a lack of health insurance (over 1/3 of Hispanics lack insurance); 6) long waiting lists; 7) inadequate outreach and the method for how information is given; and 8) discrimination.

One challenge in serving this population is the culture of migration—the notion that this is a revolving door population due to transparent borders that exist between the U.S. and Latin American countries resulting in *transnational families*. This calls for the network to not only work with the family members residing in the U.S., but to pay attention to their family living outside the border. Attention to the findings from the recent AARP survey of the sandwich generation roles and functions of caregiving may provide helpful insight surrounding the caregiving experience of Hispanic families. Survey results show that family caregiving in Hispanic families is multigenerational. Eleven percent live in three generation households, 6% have extended family arrangements. Thirty-four percent of Hispanics care for their elderly compared to 10% on non-Hispanics whites.

Hispanic caregivers experience high levels of stress because they feel guilty that they do not give enough. In measuring functionality of the family, there has been a movement away from using a Pathology model and toward using a Family Resilience Perspective (looking at a family's capacity to maintain equilibrium as it experiences crisis). This is being seen as an important component of policy reform in which services are not fragmented by age, gender, and other divisions that are currently in place.

### *African American Caregiving*

Sharon Wallace Williams discussed some of the similarities and the differences between African American caregivers and other caregivers. Like other caregivers, the majority of African American caregivers are women. African American caregivers are more likely to be adult children than spouses. These caregivers have multiple roles (e.g., family, work, church, and community). In African American culture, family responsibility plays a large role and it is considered a duty to provide care for the parent. Care is usually provided *within* the family, involving different members of the extended family. The African American adult child caregiver (usually a daughter) is less likely to be married than other caregivers and therefore has less income and support. They typically have jobs that are less flexible than those of other caregivers.

The population that these caregivers are caring for are likely to be older African Americans that are in relatively poor health. The care recipients are also less likely to be married. About 50% of the caregiver and care recipient relationships involve co-residence. Older African Americans are less likely to be institutionalized or use formal support than other individuals. When an African American is placed in an institution, it is usually at a point of complete caregiver burnout. Williams noted that one theoretical framework that is used for this population is based on systems theory to see how the family functions at the system. African American caregivers report more positive outcomes of providing care than other caregivers: they are less depressed, less burdened, don't perceive it as stressful as others, they talk about rewards (a sense of giving back) and providing a model for the younger generation. She pointed out that African American caregivers view their effort as deposits in a support bank—the notion that "if I do this, maybe someone will do this for me." While the literature shows more positive outcomes, Williams stressed that African American caregivers do report being depressed, burdened and strained.

Williams described The Family Caregiving Project—a 3-year study of African American caregivers looking at the structure and outcomes of providing care to older African Americans. Williams and her colleagues just complete the final wave of data collection and have published some preliminary findings. The project involved interviewing up to 3 members of a family—the primary caregiver, the secondary caregiver, and a tertiary caregiver (provided specialized services within the family)—to get a better idea of the *caregiving system.* Information about caregivers' demographics, health status, and role strain were captured. The subsystems were also investigated showing that 20% of the caregivers received support from the church (e.g. prayer, encouragement, visits, help when ill) and 26% received formal help (home health, counseling, legal services). Williams' has found in her research and others that the larger the informal support system, the more likely the African American family is to use formal support. Often, the grandchild provides the critical link to the formal system. Similarly, families that use more church support are more likely to use formal support.

### *Asian American and Pacific Islander Caregiving*

Donna Yee suggested that a strategy to reach and include minority caregivers is to look at what has been developed thus far and borrow from the successes in communities (e.g., working with refugees). When working with minority populations, the network should be sensitive to the many ethnic, language and cultural groups within a minority population.

Yee discussed that Asian Americans are predominantly located in urban areas in a few states, but increasingly locating to other states. One of the major stereotypes of this population is that Asians are self-reliant. In reality, they have a history of little contact with the formal service system, in part because they are not knowledgeable of service options. The message felt by many older Asian Americans and other minorities of color is that the publicly funded system has not been there for them. There are have been many projects and initiatives associated with this population over the last twenty years leading to significant advances. Yee suggested that the network reexamine opportunities that it might have passed by, look at communities that are still underserved, and fine tune the instruments that the network has already. Mapping community resources and examining infrastructure is not a new idea for the network, but figuring out how to understand the structure of community leadership and community institutions in multiple communities (e.g., Thai, Korean, Hmong, Chinese, etc.) is something to strive for. She directed the audience to learn more about one of the Faith in Action programs located in Hawaii that is flavored with Buddhist concepts—giving without an expectation of return (the notion that caregiving is not always about "exchange").

## Additional Resources

- REACH Coordinating Center project abstracts and contact information can be found at http://www.edc.gsph.pitt.edu/reach/abstract.html.
- Florida developed a burden assessment for Hispanic caregivers, contact the state office for more information.

***Native Americans***

- National Resource Center on Native American Aging, University of North Dakota website: http://www.und.nodak.edu/dept/nrcnaa/.
- Selected publications on Native American aging and caregiving issues by Robert John can be found at http://moon.ouhsc.edu/rjohn/maribib1.html.
- Native American Elders Caregiving Grantee list can be found on the AoA website at http://www.aoa.gov/pressroom/Pr2001/naecaregivers.html.
- KELN Bibliography on Native American Elders, Edward Paine, May 1999 found at http://www.keln.org/bibs/paine1.htm.

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## Session: Grandparents and Relative Caregivers

### Themes

- There are 5.4 million children living in grandparent or relative-maintained households in the United States. More than 2 million of these children are being raised solely by their grandparents or other relative caregiver with no parents present.
- Research shows that grandparents and other relative caregivers are at risk for depression, functional limitations, and financial difficulties.
- It is important to develop partnerships and collaborations with other programs and organizations, including public sector programs such as Head Start and Section 8 Housing, local schools and hospitals, and faith based entities.
- Many successful programs have started with small grants from the Brookdale Foundation Group's Relatives as Secondary Parents Program (RAPP).

### Presentation Summary

Dr. Meredith Minkler presented the demographics of grandparents raising grandchildren and emphasized that the typical profile is a white, married woman living slightly above the poverty level. However, African American children are four to five times more likely than non-Hispanic white children to be living in households under the care of grandparents or other relatives. She pointed out that children under the care of grandparents and other relatives is a growing issue; between 1990 and 1998, the number increased by 50%. Some of the major challenges facing grandparent caregivers, include health and health care access, social isolation and alienation, financial vulnerability and limited public assistance, legal issues (e.g., guardianship), and housing.

Dr. Minkler indicated that an important consideration for the earmarked NFCSP funding is to support opportunities to foster leadership in this area around advocacy, as well as to develop comprehensive programs targeting this population. Establishing partnerships and collaborations with local institutions and programs is also a key component to program design and implementation. She noted that a good example of a comprehensive program that accommodates the intergenerational needs of both children and older adults is the Grandfamilies Home in Boston. The program includes support groups, activities for children, and has a task force to promote advocacy on behalf of this population. Replications of this model are underway in eight different locations. And, finally, she encouraged the aging network to maintain open communication with the media and national organizations that focus on policy development. She noted that the Gray Panthers tried, unsuccessfully, to get the National Parents as Teachers (PTA) Organization to change its name to something that would be more inclusive. Nevertheless, she feels like these efforts are important to raise the visibility of this important issue.

Stephanie Noonan described the Grandcare Program that operates in Charlotte, NC, which has been in operation since 1995 and provides an array of services to support grandparents, including support groups, information and referral, respite programs, training in child development, and a "warm line" to homebound seniors. Ms. Noonan emphasized that a major strategy they have used in developing and expanding the Grandcare Program is to think beyond the aging network and consider other sources for funding. In addition, the Program has developed an extensive collaborative network of agencies in the community to meet the needs of their target population, including the family court system, judges, the departments of health, mental health, and social welfare, Boy Scouts, schools, and corporations. The Program is well integrated into and benefits from the other services provided through the Senior Center. For example, the Senior Center sponsors a Title V senior employment program, which has been expanded through funding from the Workforce Investment Act to hire and train older workers to provide in-home respite care for grandparents involved in the Grandcare Program.

Joann Thomas desribed the experience of the Central Illinois Area Agency on Aging in developing their program called "Granparents Raising Grandchildren and other Relatives as Carers." She noted that, from the beginning, the agency recognized that kinship carers are not always grandparents. The program provides support groups to grandparents of all ages, not just those 60 and older. At the local level, they have developed an internship for social work students to work in the grandparent program and plans to expand relationships with the private sector and the faith community. The program began with five support groups which has grown to 81 statewide through the support of the state unit on aging (the initial seed money was through the RAPP program and the SUA also received a grant from the Brookdale Foundation). A Statewide Taskforce was established about 5 years ago to address the grandparent issue at a statewide level. The involvement of a broad range of state agenices, private social service agencies, AARP, universities, and grandparents on the Taskforce has led to a statewide, cross agency effort to mobilize additional funding through state general revenue sources. The Task Force maintains an active speakers bureau, conducts organized advocacy, hold quarterly regional meetings, and a recent initiative has involved the Bar association to develop a training manual for attorneys and child welfare advocates.

## Additional Resources

### *National Organizations*

AARP Grandparent Information Center: www.aarp.org
Child Welfare League of America: www.cwla.org
Generations United: www.gu.org
Brookdale Relatives as Parents Program (RAPP): currently has an RFP for a new round of funding for 15 applicants ($10,000 for 2 years) www.ewol.com/brookdale

## Session: Working and Long Distance Caregivers

### Themes

- Long distance caregivers often do not know where to go to access support services.
- Many long distance caregivers would be comforted by a monitoring service that reports any changes in the health status of the care recipient to them.
- Working caregivers value flexibility in the workplace. This flexibility might allow them to take the individual for whom they are caring to a doctor's appointment or attend to an unexpected emergency with the care recipient in the middle of a workday.
- It is important to provide culturally competent services, especially when working with employers of a large foreign or immigrant workforce.

### Presentation Summary

#### *Long Distance Caregivers*

Angela Heath emphasized that a common concern with long distance caregivers is that they do not know where to start getting information to gain access to services. Rather than contacting an AAA, many of these caregivers turn to neighbors, friends, and doctors for information; these individuals are not as likely to be as informed as the AAA and thus the long distance caregiver continues to have difficulty in getting needed services. She pointed out that the Eldercare Locator is a valuable resource that long distance caregivers need to be informed about. However, one potential problem is that although the Eldercare Locator number is toll-free, long-distance caregivers might still need to pay for the call to the AAA. In response to this problem, a pilot program to be in place within the next year will test a bridging mechanism by transferring callers from the Eldercare Locator directly to the AAA, thereby eliminating the costs incurred as a result of the long-distance phone call. However, even if caregivers are able to contact an AAA, Heath expressed that a major problem is that few agencies are equipped to support the unique needs of long-distance caregivers.

Health discussed several common needs of long-distance caregivers: 1) knowledge of the care recipient's health status, 2) services to help them deal with feelings of guilt (self-imposed and placed by siblings or other relatives providing care closer to the care recipient), and 3) information about end-of-life services. She provided some examples that respond to these needs including, a program implemented by the Los Angeles Alzheimer's Association in which individuals not living in Los Angeles caring for individuals with Alzheimer's living in Los Angeles are informed about the health of their loved on a regular basis. In addition to monitoring services, Heath stressed that the aging network needs to change its mindset and approach to case management for long distance caregivers—case managers need to contact the caregiver rather than waiting for the caregiver to call them. She noted that the Lincoln Trail AAA in Kentucky provides case management to long distance caregivers contracted through an insurance company.

### ***Working Caregivers***

Debbie Phillips and Thomas Otto discussed the needs of working caregivers and ways of working with employers to support working caregivers. With the increase in the number of women and older individuals in the workforce, the difficulties in managing and balancing work and personal responsibilities has become a growing concern. In a survey of working caregivers, Phillips found that working caregivers most often provide emotional support, companionship, financial management, transportation, and household chores to their care recipient. In addition, she found that caregivers want flexibility in the workplace. Although working caregivers are often limited to providing care during mornings, evening, and weekends due to their company's hours, these times do not always coincide with what is needed to provide care to their loved ones. For example, because many doctors' offices are not open on the weekends, caregivers need flexibility to take their care recipient to appointments during the week. Emergency situations arise at unexpected times that can interfere with a caregiver's work schedule. However, Phillips noted that the more flexibility a caregiver has in the workplace, the less support services they will need.

In his discussion, Otto described *Elder Solutions*, an I&A based resource referral product for working caregivers offered by his AAA, CICOA the Access Network (Indianapolis, IN). *Elder Solutions* is targeted toward companies of 100 to 500 employees with pricing based on the number of employees. The premise is that by providing easier access to information and services, the loss of work time due to caregiving responsibilities will decrease, thereby allowing the corporation to increase productivity, and consequently, increase its revenue. In addition to information and assistance, they provide a quarterly newsletter, a dedicated phone line, and an email address for a broad array of questions, and on-site events. These on-site events include staff training, employee consultation, resource kiosks, and seminars on specific caregiving topics. Due to companies' receptivity to this product, *Elder Solutions* now also includes a caregiver/care recipient assessment.

CICOA marketed *Eldercare Solutions* through the use of paid advertisements, articles, brochures, and results from the *Eldercare Survey* completed by employees from five companies. The results of this survey became the most successful marketing tool because it contradicted corporations' belief that caregiver issues were not a problem. Otto reported that companies were slow to come around to the product and utilization is not as much as expected. Although there were more positive responses from companies whose decision-maker had their own eldercare issues, it has been a long process. In addition, he stressed that without philanthropic funds, the cost of developing and marketing the service would not have been feasible.

The panelists emphasized that one of the most important aspects of providing services to working caregivers via employers is the need for culturally competent services. In addition to language barriers, AAAs should be aware that eldercare in other parts of the world is very different than that in the U.S. and should be considered when dealing with companies with a large population of foreign or immigrant employees. For example, when providing services to a large hotel with a largely Mexican workforce, CICOA worked with a Hispanic community center in order to provide information in a culturally appropriate manner.

## Additional Resources

### *Working Caregivers*

Information about CICOA's *Elder Solutions* product for working can be obtained at http://www.cicoa.org/elder/index.htm (there is also an online contact form for more information).

### *Long Distance Caregivers*

Lincoln Trail AAA in Kentucky provides case management to long distance caregivers contracted through an insurance company.

Information about the *Long Distance Caregiver Project*, run through the Alzheimer's Association in Los Angeles, can be found at http://www.alzla.org/. For more information about the Project, please contact Judith Delaney, Clinical Coordinator at judith.delaney@alz.org.

# Conference Presenters

## Greetings

Josefina Carbonell
Assistant Secretary for Aging
U.S. Administration on Aging

## Opening Remarks

Claude A. Allen
Deputy Secretary
U.S. Department of Health and Human Services

## Welcome from the District of Columbia

E. Veronica Pace
Executive Director, District of Columbia Office on Aging

## National Family Caregiver Support Program – From the Caregiver's Perspective

Carolyn Johnson, MA
Founder, Caregivers in Action

## What the Aging Network Needs to Know About Family Caregivers

Rhonda J.V. Montgomery, Ph.D.
Director, Gerontology Center, University of Kansas

## How the National Family Caregiver Support Program Fits with Medicaid and other HHS Initiatives

Thomas E. Hamilton
Director, Disabled and Elderly Health Programs Group,
Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services

## Building Multi-Faceted System for Caregivers: A Variety of State Efforts

**Moderators**

John Wren
Director, Office of Program Development, Administration on Aging

Carol Crecy
Director, Office of State and Community Programs, Administration on Aging

**Panelists**
Gema Hernandez
Secretary, Florida Department of Elder Affairs (FL)

Sally Gronda
Director, Area Agency on Aging Pasco-Pinellas, Inc. (FL)

Dan Murphy
Office Chief, Washington Aging and Adult Services Administration (WA)

Victoria Doerper
Director, Northwest Area Agency on Aging (WA)

Jim Varpness, MPA
Executive Director, Minnesota Board on Aging (MN)

Linda Giersdorf
Director, Region Nine Area Agency on Aging (MN)

Roy Keen
Division Administrator, Oklahoma Aging Services Division (OK)

Wes Bowman
Director, SODA Area Agency on Aging (OK)

Richard Browdie
Secretary, Pennsylvania Department of Aging (PA)

Jacqueline Burch, MSW, LSW
Director, Lancaster County Office of Aging (PA)

## Session: Quality Standards and Outcome Measures for Caregiver Supports

### Moderator

David Lindeman, Ph.D.
Director, Mather Institute on Aging
Dlindeman@matherlifeways.com

### Panelists

Lynn Friss Feinberg, MSW
Manager, Resource and Information Programs, Family Caregiver Alliance
Lfeinberg@caregiver.org

Ken Wilson, MGS
Manager of Planning and Research, Council on Aging of the Cincinnati Area, Inc.
wilson@help4seniors.org

## Session: Consumer Directed Services for Caregivers

**Moderator**

Pamela Doty, Ph.D.
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
pdoty@osaspe.dhhs.gov

**Panelists**

Donna McDowell
Director, Wisconsin Bureau of Aging and LTC Resources
mcdowdb@dhfs.state.wi.us

Suzanne Crisp
Program Manager, Secondary Conditions Grant,
University Affiliated Program of Arkansas
Crispsuzanne@uams.edu

## Session: Caregiver Advocacy

**Moderator**

Richard Browdie
Secretary, Pennsylvania Department of Aging
rbrowdie@state.pa.us

**Panelists**

Gail Hunt
Executive Director, National Alliance for Caregiving
gailhunt.nac@erols.com

Matthew Janicki, Ph.D.
Professor and Researcher, University of Illinois, Chicago
Janickimp@aol.com

Monette McKinnon
Director of Field Communications, National Association of Area Agencies on Aging

## Session: Information and Assistance

**Moderator**

Theresa Lambert
Associate Director, National Association of State Units on Aging
tlambert@nasua.org

**Panelists**

Nancy Day
Director of Community Programs, NJ Division of Senior Affairs
Nancy.day@doh.state.nj.us

Cheryll Schramm
Chief, Aging Services Division, Atlanta Regional Commission (AAA)
cschramm@atlantaregional.com

## Session: Care Management for Caregivers

**Moderator**

Lisa Gwyther, MSW
Director, Family Support Program, Duke University Medical Center on Aging
LPG@geri.duke.edu

**Panelists**

Dan McGuire, MPP
Chief, Division of Managed Care, Pennsylvania Department of Aging
dmcguire@state.pa.us

David Bass, Ph.D.
Director for Research, Margaret Blenkner Research Center, Benjamin Rose Institute
dbass@benrose.org

## Session: Respite Services

**Moderator**

Steven Zarit, Ph.D.
Assistant Director, The Gerontology Center, Pennsylvania State University
z67@psu.edu

**Panelists**

Lynn Friss Feinberg, MSW
Manager, Resource and Information Programs, Family Caregiver Alliance
Lfeinberg@caregiver.org

Hilari Hauptman
Program Manager, Washington Department of Social and Health Services
HauptHP@dshs.wa.gov

## Session: Caregiver Training and Support Groups

**Moderator**

Ronald Toseland, Ph.D.
Director, Ringel Institute of Gerontology, State University of New York at Albany
toseland@csc.albany.edu

**Panelists**

Lisa Durham, MSW
Central Ohio AAA
Durham@coaaa.org

Margaret Hellie Huyck, Ph.D.
Professor, Illinois Institute of Technology
MHHuyck@aol.com

## Session: Supplemental Services

**Moderator**

Cliff Burt, MPA
Alzheimer Caregiver Program Director, Georgia Division of Aging Services
Gcburt@dhr.state.ga.us

**Panelists**

Gail Schwersenska
Section Chief, Wisconsin Bureau of Aging and LTC Resources
schwega@dhfs.state.wi.us

Margaret Campbell, Ph.D.
Program Specialist, NIDRR, US Department of Education
Margaret.Campbell@ed.gov

## Session: Barriers to Resources for Socially and Economically Disadvantaged Caregivers

**Moderator**

Rhonda Montgomery, Ph.D.
Gerontology Center, University of Kansas
Rmontgomery@ukans.edu

**Panelists**

Neetu Dhawan-Gray
Executive Director, Baltimore Commission on Aging and Retirement Education
dhawan@bellatlantic.net

Laura Trejo, MSG, MPA
Program Head, Department of Mental Health, County of Los Angeles
Latrejo@dmh.co.la.ca.us

## Session: Ethnically and Culturally Diverse Caregivers

### Moderator

Dolores Gallagher-Thompson, Ph.D.
Director, Older Adult and Family Research Center, VA Medical Center/ Stanford University
dolorest@leland.stanford.edu

### Panelists

Cynthia LaCounte
Tribal Chair, Trenton Indian Service Area (ND)
Clacounte@nccray.net

Marta Sotomayor, Ph.D.
President and CEO, National Hispanic Council on Aging
nhcoa@worldnet.att.net

Sharon Wallace Williams, Ph.D.
Center on Minority Aging, University of North Carolina- Chapel Hill
Sharon_williams@unc.edu

Donna Yee, Ph.D.
Director, Asian Community Center, Sacramento
Dyee@veriomail.com

## Session: Grandparents and Relative Caregivers

### Moderator

Meredith Minkler, Ph.D.
Professor of Health and Social Behavior, School of Public Health, UC Berkeley
mink@uclink4.berkeley.edu

### Panelists

Stephanie Noonan
Executive Director, Charlotte-Mecklenburg Senior Centers, Inc.
stepnoonan@aol.com

Joann Thomas
Executive Director, Central Illinois Agency on Aging, Inc.
Jthomas@ciaoa.com

## Session: Working and Long Distance Caregivers

### Moderator

Angela Heath, MGS
National Association of Area Agencies on Aging
aheath@n4a.org

### Panelists

Debbie Phillips, Consultant
WFD, Inc.
deb.phillips@wfd.com

Thomas Otto, MPA
Executive Vice President and Chief Operating Officer, CICOA the Access Network
totto@cicoa.org

## Listening Session

Edwin Walker
Director, Office of Program Operations and Development
U.S. Administration on Aging