U.S. Department of Health and Human Services
Administration on Aging

Promising Practices

in the Field of Caregiving

28 National Innovations Programs

11 Projects of National Significance

Message from the Assistant Secretary

Currently there are more than 23 million family and informal caregivers nationwide, and that number is only increasing. Most (85%) have no outside paid help, and 72% of caregivers are women. There are 4.5 million children in grandparent-headed households, and 1.5 million children in other relative-headed households. 480,000 adults with developmental disabilities live with parents over age 60. These elderly Americans need our help.

On behalf of the Administration on Aging it is my pleasure to give to you this publication highlighting some of our grantees under the National Family Caregiver Support Program. In fiscal year 2001, AoA was entrusted by Congress under the Older Americans Act with discretionary funds to support grants on a competitive basis. The Act provided authorization for three years of funding to support and foster the development and testing of new approaches to sustaining the efforts of families and other informal caregivers of older individuals. The following 11 Projects of National Significance and 28 National Innovations Programs should be viewed as promising practices in the field of caregiving.

This booklet is designed to give a brief overview of the projects AoA is funding, and some insight into the grant's goals and objectives. Further information can be obtained by contacting the project director or primary contact, which has been listed for your reference above each project description.

I hope that the lessons learned from these projects can be replicated at the local level. These grants will be showcased on our website, so please visit www.aoa.gov for more information.

Josefina G. Carbonell
Assistant Secretary for Aging

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Caregiver Coalitions Research Project

AARP Foundation

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The Project will develop and implement a training program to encourage the formation of coalitions, and to strengthen family caregiver coalitions developed because of this project. The training intervention will be based on the experiences and best practices of existing caregiver coalitions. An experimental design will be used to test whether the training intervention achieves its desired outcomes.

Goals/Objectives

- Research the benefits of forming caregiver coalitions to determine if they are a viable option to promote caregiver services
- Research information on successful coalitions
- Conduct focus groups and in-depth interviews with coalition leaders
- Develop training design and materials based on research findings
- Develop and test the training for those who want to establish family caregiver coalitions

Target Audience

Individuals and groups who are interested in developing family caregiver coalitions that serve the needs of caregivers of either older family members or grandchildren

Caregivers in Crisis/Caregiver Assistance Network (CAN)

The Alliance for Aging, Inc.

9500 South Dadeland Boulevard
Suite 400
Miami, FL 33156

Primary Contact
Michael M. Weston
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CAN is a special program now available to caregivers in crisis. The demands of caregiving become so great that the caregiver needs a break before they break. The Alliance for Aging now has a Family Caregiver Support Specialist who can arrange for services to assist and support these caregivers who are in a heightened state of need. An additional facet of response is the acknowledgement that an increasing number of grandparents and other older relatives have been thrust into the role of parent again needing to raise children that are not their own. The CAN system goes beyond traditional business hours and is staffed to respond to immediate requests for assistance after hours and through the weekend.

Goals/Objectives

- Mitigate the circumstances that have thrust a caregiver into crisis or intervene early enough to diffuse what could become a crisis, if left unchecked

Target Audience

Caregivers responsible for someone over the age of 60 or caregivers that are 60 or over and now have to raise a child

C.A.R.E.-Pro (Caregiving Awareness through Resources and Education for Professionals)

American Society on Aging

833 Market Street, Suite 511
San Francisco, CA 94103

Primary Contact
Therese McNamee
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theresem@asaging.org

The American Society on Aging (ASA) is collaborating with the American Nurses Association (ANA), the American Occupational Therapy Association (AOTA) and the National Association of Social Workers (NASW), to increase the skills and knowledge of professionals providing needed services to family caregivers. ASA will utilize two distance learning approaches. One, a web-based, multimedia, self-study curriculum, with an alternative version on CD-ROM, and two, the use of a combination of teleconferencing and delivery of graphics over the Web, which will be referred to as an "e-seminar."

Goals/Objectives

- Have a minimum of 10,000 professionals from social work, occupational therapy and nursing professions demonstrate increased competence in identifying the needs of family caregivers in their day-to-day practice
- Have these professionals demonstrate increased competence and knowledge of the resources available to caregiver through the aging network and the National Family Caregiver Support Program (NFCSP)
- Increase the awareness of the NFCSP among members of the partner associations from under 18% to over 50%

Target Audience

Healthcare professionals (specifically social workers, occupational therapists and nurses)

Applying the National Family Caregiver Support Program to Persons with Developmental Disabilities

The Arc of the United States

Richardson Hall 280
135 Western Avenue
Albany, NY 12222

Primary Contact
Sharon Davis
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davis@thearc.org

The Arc project will work to build service capacity to aging network constituents and disability provider organizations through cooperative planning, coordinating and supportive services to older caregivers of children and adults with intellectual and developmental disabilities. This will be accomplished through a national technical assistance and training program provided across the United States in collaboration with receptive aging and disability-based organizations and the development and dissemination of technical resource materials. The Arc will also assess state aging agency practices as they relate to implementing these provisions by recommending efficiencies or improvements to local aging network outreach strategies to organizations and families.

Goals/Objectives

- Enhance the awareness and build the capacity of State Units on Aging (SUA), Area Agencies on Aging (AAA) and local provider organizations to provide National Family Caregiver Support Program (NFCSP) services to grandparents and related older caregivers of children and adults with intellectual and developmental disabilities
- Provide technical assistance
- Encourage adoption of culturally-sensitive outreach and service delivery approaches when targeting areas with diverse language and ethnic populations
- Identify key aspects of best practice approaches to delivering services in support of older caregivers

Target Audience

Aging Constituents with local AAA, SUA and local provider organizations to provide services to persons with developmental disabilities in 12 geographically diverse sites in regions across the United States

Lifelong Learning & Wellness Program at Asian Community Center

Asian Community Center of Sacramento Valley, Inc.

7375 Park City Drive
Sacramento, CA 95831

Primary Contact
Donna L. Yee
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dly@accsv.org

The Asian Community Center of Sacramento Valley, Incorporated intends to build capacity in a multi-cultural community through small group and community-level interventions that foster involvement in service-oriented activities. The organization assists Asian American and Pacific Islander (AAPI) caregivers by developing culturally appropriate caregiver support resources that responds to individual needs, and incorporates feedback efforts to assure ongoing quality assurance and community responsiveness.

Goals/Objectives

- Participation of AAPI family caregivers in new lifelong learning and wellness programs, such as tai chi, line dancing, introduction to computers, origami, Ikebana, Chinese calligraphy, and cooking demonstrations
- Use these lifelong learning and wellness programs as a way to engage daughters, wives and friends in respite and wellness activities
- Use social periods during and after classes to provide information and assistance, and recruit participants to assist with service projects that benefit caregiver like themselves

Target Audience

Asian American and Pacific Islander family caregivers living in the Sacramento area, but serves all older persons and family caregivers in the neighborhood

PACT (Providing Assistance to Caregivers in Transition)

Case Management Division, Aging and Adult Services, Employment and Human Services of Contra Costa County

Aging and Adult Services
2530 Arnold Drive #300
Martinez, CA 94553

Primary Contact
Bette Wilgus
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The PACT approach is multidisciplinary. When caregivers are referred to the program, a caseworker vists them at their home to assess the home setting and their ability to provide care. The public health nurse meets with the care recipient at the skilled nursing home facility to assess their needs. The nurse and caseworker then conference to determine the feasibility of the transition to home. If transition to home is not recommended, an Ombudsman staff member works with the caregivers to assist them in advocating for quality care for the care recipient.

Goals/Objectives

- Identify and remove barriers whenever possible to successfully transition a person from a nursing home institution to home for both the caregiver and care recipient
- Assist caregivers in advocating for quality care within the nursing home when transition is not possible

Target Audience

Caregivers

Kinship Care Resource Network

Catholic Family Center

87 North Clinton Avenue
Rochester, NY 14604

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Through the Catholic Family Center, the Kinship Care Resource Network is a collaborative effort designed to create an accessible, comprehensive continuum of services for Kinship Care Families. A wide range of services are provided from a single entry point. Catholic Family Center's service partners for this project are the Family Resource Centers of Rochester, Community Place of Greater Rochester, Brookdale Grandparent Caregiver Law Center, Monroe County Legal Assistance Corporation, the University of Rochester, Catholic Youth Organization and the Urban League.

Goals/Objectives

- Increase community awareness of available services through community education and outreach
- Increase family stability, adjustment and emotional well-being
- Improve knowledge and skills of kinship caregivers/families and the professionals who work with them

Target Audience

Kinship caregivers (especially Grandparents who are raising their Grandchildren)

A Multi-State Family Caregiver Mediation Project

The Center for Social Gerontology, Inc.

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Ann Arbor, MI 48103

Primary Contact
Penelope A. Hommel
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phommel@tcsg.org

The project is testing a highly innovative approach — mediation — to assist older persons and family caregivers in addressing problems and disputes that often arise when they face the physical emotional and financial demands of providing ongoing care to a family member. The long term goal is to make mediation a part of mainstream caregiver support services. Mediation is a means of promoting informed, person- and family-centered care decisions. It identifies the needs and issues of all parties, along with exploring options available to meet those needs, thereby enhancing the autonomy and well-being of older persons and family caregivers.

Goals/Objectives

- Design, plan and organize a demonstration project overall and in three distinct sites: Michigan, Georgia and Vermont
- Operationalize- train mediators, conduct mediations and institutionalize mediation into the caregiver support systems in the three sites
- Gather information and evaluate both the organizational/operational aspects of the demonstration programs and the impact/outcome of the mediations
- Create and disseminate a replication guide and offer technical assistance to other states/areas wanting to initiate family caregiver mediation

Target Audience

For program set-up and referrals, the target audience is the broad aging/caregiver support network, the courts and elder law advocates, the mediation community, and other groups that can help reach under-served populations such as communities of color, low-income, etc; for service delivery. The target audience is the consumers, who are older care recipients and their family caregivers, and older caregivers who are caring for dependent adult children or grandchildren.

COALA Informal Caregiving Training and Support

Council on Aging of Southwestern Ohio

644 Linn Street, Suite 1100
Cincinnati, OH 45203

Primary Contact
Cynthia K. Fischer
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cfischer@help4seniors.org

The Council on Aging of Southwestern Ohio and the Area Agency on Aging District 7 are collaborating to expand their formal caregiver training program of Home Health Aides, and develop a new program to provide in-home training of informal caregivers. Between the two agencies the project will be able to serve both urban and rural areas and a population that is ethnically, racially and economically diverse. A manual produced for the informal caregiver will include: assessing the care-recipient and caregiver's situation, balancing caregiving and personal responsibilities, forming an organized plan for meeting the needs of the recipient and caregiver, financial concerns, mental and physical health of the caregiver, planning for the future, community resources (including support groups), and internet and literary resources on caregiving.

Goals/Objectives

- Demonstrate that informal caregivers will show higher levels of knowledge and skills required to properly care for an older adult
- Show that informal caregivers will report fewer injuries resulting from improper transfers, lower levels of stress and depression, and more confidence in the care they are providing

Target Audience

The caregiver over the age of 60, or the caregiver under the age of 60 and providing care to a care recipient over the age of 60

Transportation Solutions for Caregivers

Easter Seals

230 West Monroe Avenue, Suite 1800
Chicago, IL 60606

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Lisa Peters-Beumer
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Transportation Solutions for Caregivers intends to increase the capacity of the aging network to provide meaningful solutions to the concerns and questions of caregivers about transporting the older adults in their care. This will be accomplished by providing support in three key areas known to reduce the transportation burden on caregivers: safety, community-based alternatives and education on accessing existing resources and services. Easter Seals has produced a caregiver transportation toolkit, "Transportation Solutions for Caregivers: A Starting Point," which includes a video, informational booklet and a list of helpful products and resources for family caregivers. Issues addressed in the toolkit include difficulty getting into and out of a vehicle, providing physical assistance (wheelchair transfers, proper body mechanics, etc.) and both preventing and dealing with dementia-related behaviors.

Goals/Objectives

- Reduce caregiver burden in the area of transportation
- Increase the capacity of the aging network to provide meaningful solutions to the concerns and questions of caregivers about transporting the older adults in their care
- Provide support in three key areas known to reduce the transportation burden on caregivers: safety, community-based alternatives, and education on accessing existing resources and services
- Enhance the expertise of the aging network through tools, training, and technical assistance
- Produce a Transportation Toolkit

Target Audience

Caregivers of older adults with cognitive and/or physical impairments and the aging network who serves them

Maine Primary Partners in Caregiving (MPPC)

Eastern Area Agency on Aging

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Bangor, ME 04401

Primary Contact
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redowney@eaaa.org

Maine Primary Partners in Caregiving will demonstrate that primary health care is an effective and efficient point of caregiver intervention in a rural setting. MPPC has forged creative partnerships with primary care practices, area agencies on aging and a university center on aging in four rural Maine counties. It is felt that caregivers will be more likely to utilize information, support and training when it is validated by a trusted health care provider and assistance can be tailored to an individual's needs. A brief survey/screening tool is administered during routine health care visits which identifies patients burdened with caregiving responsibilities. Caregiver specialists then assess and respond to caregiver needs with customized services including education and training resources and a statewide hotline.

Goals/Objectives

- Demonstrate that rural primary health care practices are an effective point of early intervention for individuals who are caring for older persons
- Show that caregivers will accept/utilize information, support and training when the need is identified or validated by their personal physician or other health care staff
- Demonstrate that the combination of information, support and training by MPPC caregiver specialists will be successful in improving the multiple risks of rural caregiving
- Show that a productive community service partnership among primary care practitioners, AAA's and a university center can be established and sustained in service to family caregivers

Target Audience

Persons 18 and older providing care for persons 60 and older

The State of the States in Family Caregiver Support

Family Caregiver Alliance, National Center on Caregiving

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The Family Caregiver Alliance will complete a 50-state survey of federal and state-funded caregiver support programs, including the National Family Caregiver Support Program (NFCSP), state general funds, Medicaid waivers, systems change grants and other state funding streams. There will also be a 50-state legislative trend analysis of new and expanded caregiver support programs and state appropriations. Finally, a 50-state database to construct state-by-state profiles will be developed.

Goals/Objectives

- Stimulate the development of public policies and programs that support family and informal caregivers of the elderly and persons with disabilities
- Increase understanding of the scope of federal and state-funded caregiver support policies and programs in each of the 50 states and across states
- Assist the aging network in areas of program development and promising practices that can improve the quality and effectiveness of the NFCSP and its coordination with other caregiver policy initiatives

Target Audience

Legislators, policymakers, program administrators and other members of the aging network

National Center on Grandparents and Other Relatives Raising Children

Generations United

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Suite 820
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Primary Contact
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With the National Center on Grandparents and Other Relatives Raising Grandchildren, Generations United continues to support grandparents and other relatives raising children through their inclusion in the National Family Caregiver Support Program (NFCSP). The goal of the Center is to provide training and technical assistance to the aging network, via a National Network of Experts on this subject. The Center will build on its efforts to compliment the work of the Administration on Aging (AoA) and link experts and model programs to the aging network by collaborating with various partners, including the National Association of Area Agencies on Aging (n4a) and the National Association of State Units on Aging (NASUA).

Goals/Objectives

- Increase the ability of service providers in the aging network to institute models of support for grandparents and other relatives raising children through the NFCSP
- Conduct a national survey of the Aging Network to determine training needs on issues pertaining to grandparents and other relatives raising grandchildren
- Expand the Center's current Network of Experts from 18 to 25 and to provide 24 national, state and local trainings in year one and 30 in year two
- Provide comprehensive and responsive technical assistance through responses to 150 individual requests in year one and 200 in year two; quarterly online chats; comprehensive website resources

Target Audience

The aging network and other community service agencies with which they collaborate

Self-Directed Care Project

Georgia Division of Aging Services

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Suite 9398
Atlanta, GA 30303

Primary Contact
Cliff Burt
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The aging community has increasingly become interested in self-directed care as an option designed to maximize consumer choice and enhance empowerment. Recent self-directed care projects have focused primarily on the developmentally disabled with Medicaid and foundation funding. The Georgia Division of Aging Services proposes to increase service options by developing five self-directed voucher care projects for the non-Medicaid elderly in rural areas that can be replicated in other states. They will evaluate the effects of self-directed care by adapting and administering to caregivers participating in voucher programs the Caregiver Support and Satisfaction Survey.

Goals/Objectives

- Evaluate the effects of self-directed care by adapting and administering to caregivers participating in this program the Caregiver Support and Satisfaction Survey
- Produce two products:
    1) Replication manual developed in Year 2, and field-tested during Year 3, incorporating additional informationfrom Georgia's aging network
    2) A professional evaluation of caregiver support and satisfaction, comparing responses of caregivers participating in self-directed care with caregivers receiving traditional services
- Assist policymakers and program administrators in developing new options for service delivery

Target Audience

Caregivers of persons aged 60 and older

CARESS
(Caregivers Assistance Registry & Enhanced Support System)

Healthcare Consortium of Illinois

1350 East Sibley, Suite 401
Dolton, IL 60419

Primary Contact
J. Diane Adams-Alsberry
1-877-CARESS-1 (1-877-227-3771)
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The mission of CARESS is to develop systems that will enhance access to support services for seniors and their caregivers through planning, collaboration and coordination. Under this grant, the Healthcare Consortium of Illinois (HCI) partnered with the Metropolitan Family Services (Metro) of Chicago, Illinois to expand and enhance the support system for caregivers of seniors living in four target communities in the city of Chicago. This project is intended to create a systematic process for meeting the needs of caregivers through three activities: 1) enhance coordination and collaboration because the programs that are in place are not systematically linked, 2) improve identification and support of caregivers, and 3) expand access to in-home respite services.

Goals/Objectives

- Develop a Caregivers Coordination Council
- Develop a Caregiver Registry that will identify who the caregivers are, what their needs are, and how they will receive services
- Establish a faith-based volunteer program, and volunteers will make referrals to the Caregiver Registry

Target Audience

Caregivers of individuals aged 60 and older (with assets less than $10,000 annually) that live within five neighborhoods in the Chicago area

Caregiving at Life's End

The Hospice of the Florida Suncoast

300 East Bay Drive
Largo, FL 33770

Primary Contact
Kathy Egan
(727) 586-4432
kathyegan@thehospice.org

Caregiving at Life's End has been created in response to the lack of specialized training for family caregivers providing care for persons near life's end. The purpose of this multi-faceted family caregiver training project is to assess family caregiver needs and then to design, implement, and evaluate Caregiving at Life's End Train-the-Trainer Program so that hospice palliative care, elder care, and social services professionals can be prepared to provide training and resources to caregivers in their community. The intensive five-day train-the-trainer workshop will be free to qualified participants. Each participant will be expected to return to their community to train a minimum of fifty family caregivers.

Goals/Objectives

- Assess the needs of family caregivers with regards to end-of-life caregiving issues
- Provide training and resources to professionals nationally through a train-the-trainer program
- Evaluate the impact of the Caregiving at Life's End program on family caregiver participants

Target Audience

Professionals in end-of-life care, palliative/hospice care, care of the elderly or caregiving training

Servicing Senior Caregivers and Their Adult Family Members with Developmental Disabilities

Illinois Department on Aging

421 East Capitol Avenue, Suite 100
Springfield, IL 62701

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The project targets the elderly family caregivers of adult family members with developmental disabilities, building on existing home and community-based service programs and intergenerational programs. The Illinois Department on Aging, the Department of Human Services, the Illinois Council on Developmental Disabilities, and researchers at the University of Illinois, Chicago, will collaborate with local service providers to identify families to outreach through health service agencies, community agencies and churches. The Illinois Department on Aging will also increase the number of families receiving training on planning for the future. Famlies will also receive community and home-based services and case management to assist caregivers with current and future needs, including participation in peer support groups. Work products will include training materials for staff, adult caregivers, and adults with developmental disabilities.

Goals/Objectives

- Identify senior caregivers of adult family members with developmental disabilities through outreach to health service agencies, community agencies and faith-based organizations and these families on planning for the future through Family Futures Planning Training Sessions
- Assist the adult family member with developmental disabilities in maximizing future independence
- Better prepare the families for changes which can be expected as a result of increasing age, as well as provide important information on methods to serve these families, both now and as age-related changes occur
- Set up an advisory council and peer support groups/chat groups
- Coordinate work with agency-supported services through waivers to provide unduplicated resources/services which in turn creates cost-cutting results

Target Audience

Elderly family caregivers of adult family members with developmental disabilities

Caregiver Resource Center for Deaf, Late Deafened, and Hard of Hearing Elders: A Demonstration Project

Massachusetts Executive Office of Elder Affairs

One Ashburn Place, Room 517
Boston, MA 02108

Primary Contact
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(617) 222-7477
Michael.Banville@state.ma.us

This project has two components. One: the Social Day Program for Deaf and Late Deafened Adults, which operates weekdays and provides family caregivers with respite from caregiving. Two: the Caregiver Resource Center that provides information, referral, and hands-on demonstration/training regarding assistive listening devices and technology; equipment available for activities of daily living; communication techniques for caregivers of individuals with hearing loss, and adaptive technology for low vision and blindness.

Goals/Objectives

- Provide caregivers with the information, knowledge and skills with which to appropriately care for deaf and hard of hearing elders
- Provide family caregiver training that reduces stress on families and other caregivers that may result from caring for deaf elders
- Preserve the independence and quality of life for deaf and hard of hearing elders as cost-effectively as possible
- Provide a community-based solution to the problem of providing appropriate social day care for deaf and hard of hearing elders
- Reduce de facto segregation of deaf and hard of hearing elders which may occur because of their condition
- Encourage deaf and hard of hearing elders to communicate appropriately with caregivers and participate in decisions involving their care
- Provide cross-training to Area Agencies on Aging and Councils on Aging for case managers and other professional caregivers

Target Audience

Family caregivers of those who are age 60 and over and deaf, late deafened or hard-of-hearing

Powerful Tools for Caregivers

Mather LifeWays

1603 Orrington Avenue
Suite 1800
Evanston, IL 60201

Primary Contact
Daniel Kuhn
(847) 492-6810
dkuhn@matherlifeways.com

This is a "train-the-trainer" model whereby Master Trainers teach a six-part course about self-care skills to professionals from healthcare and social service agencies who, in turn, teach family caregivers in groups at dozens of sites throughout northeastern Illinois. Professionals are first taught in groups of twenty through a four-day intensive training program. Working in pairs, they receive a variety of materials necessary to become Class Leaders and teach the course in their local communities.

Goals/Objectives

- Train a total of 120 Class Leaders have 2,400 family caregivers will complete this course
- Comprehensive evaluation of caregivers at four points in time: pre-course, post-course, 6 months post-course and 12 months post-course
- Comprehensive evaluation of class leaders through self-evaluation, observation by Master Trainers, and caregiver evaluations

Target Audience

Health care and social service professionals, and family caregivers

Adult Day Services Plus

Mid-County Senior Services

22 Media Line Road
Newton Square, PA 19073

Primary Contact
Karen E. Reever
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reeverk@mlhs.org

Adult Day Services Plus (ADS Plus) is a model of care management with family caregivers using adult day services. ADS Plus adds care management to adult day services and evaluates its impact. It includes developing and integrating care management tools into ADS that target where caregiver support is needed, care planning with the caregiver to maximize support for the caregiver, and delivering support in ways that match the caregiver preferences. ADS Plus is offered to half of the caregivers enrolling their care receivers in ADS. All new ADS caregivers will be evaluated at enrollment, 3, 6 and 12 months using interview tools that measure caregiving strain, burden, self-efficacy, depression and healthy behaviors.

Goals/Objectives

- Provide care management to 50 caregivers annually
- Demonstrate its impact by comparing ADS caregivers who receive management with those who get traditional ADS
- Nationally disseminate the ADS Plus model

Target Audience

Family caregivers using adult day services

Making the Link: Connecting Caregivers with Services through Physicians

National Association of Area Agencies on Aging

927 15th Street, N.W.
Suite 600
Washington, D.C. 20005

Primary Contact
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The National Association of Area Agencies on Aging's (n4a) *Making the Link* will bring together two distinct but complementary systems- the aging network and health care providers- for the benefit of family caregivers across the country. Project activities are geared towards raising awareness among physicians of three key issues: one, caregiving can take a toll on the health of caregivers; two, caregivers are an important part of the health care team; and three, services are available in the local community through Area Agencies on Aging (AAAs) and Title VI- Native American aging programs (Title VI grantees) to help ease caregiver burden. To accomplish this, approximately 120 AAAs and Title VI grantees will provide information about caregivers and caregiver services to their local physicians, armed with strategies and materials developed by n4a based on input from an Advisory Board comprised of major medical associations, agencies with an interest in public health and caregiver advocates. A national awareness campaign will also be conducted with the support of the organizations represented on the Advisory Board and other national awareness campaign partners.

Goals/Objectives

- Strengthen the ability of AAAs and Title VI grantees to serve family caregivers through a local, state and national campaign to actively involve physicians in identifying caregivers and referring them to National Family Carergiver Support Program (NFCSP) services
- Promote within the medical community the concept that caregiving is a public health issue and increase awareness among physicians of the important health care role of family caregivers

Target Audience

AAAs and Title VI grantees, and medical practices

Promoting Systemic Development of State Family Caregiver Support Programs

National Association of State Units on Aging

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Washington, D.C. 20005

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NASUA's project will build on a previous one-year project funded by the Administration on Aging, under which guidance was developed regarding three of the key components: the service package, coordination and service continuity. The current project will focus on the remaining key components: quality and program effectiveness. A deliberative process will be utilized to engage multi-disciplinary panels of aging and caregiver support experts for the purpose of generating new knowledge and identifying relevant research and promising practices. The information gathered will be synthesized into system development guides, research briefs and executive summaries, to be disseminated throughout the aging network. Two sets of national teleconferences will be convened with states, resulting in the development of state experience guides. A state self-assessment tool will be developed to enable states to determine their progress in developing the NFCSP and to identify areas needing further systemic development.

Goals/Objectives

- Facilitate states' application of a systemic approach to the development of the NFCSP so that programs are integrated, accessible, flexible, consumer-directed and culturally competent
- Generate new knowledge about effective approaches for enhancing the design and operation of family caregiver support programs
- Foster the application of recommended systems development approaches by state family caregiver support programs

Target Audience

State Units on Aging are the primary target audience; however, this project will also support Area Agencies on Aging and local providers in the community

Communicating Effectively with Healthcare Professionals

National Family Caregivers Association

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Suite 500
Kensington, MD 20895

Primary Contact
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Communicating Effectively with Healthcare Professionals empowers family caregivers to advocate more persuasively on behalf of their loved ones with the healthcare professionals providing treatment. By improving the specific communications skills that the family caregiver uses in health care settings, the program enables the caregiver to function as a member of the healthcare team, thus assuring better continuity of care and better access to the healthcare resources needed by the care recipient and the caregiver. The project design calls for training 500 workshop leaders to present a three-hour, interactive workshop to 15,000 family caregivers. The workshop can be expanded to a six-hour session by including related topics and additional skills practice exercises. The workshop emphasizes a philosophy of collaboration and teamwork among health care professionals and family caregivers.

Goals/Objectives

- Help family caregivers gain the knowledge and skills they need to interact more effectively with both health professionals and the healthcare system
- Train a network of 500 workshop leaders, primarily professionals from within the aging network, to use the Communicating Effectively With Healthcare Professionals curriculum
- Use innovative technologies to provide on-going support for trained workshop leaders in the implementation of local workshops to reach a minimum of 15,000 family caregivers
- Expand the geographic reach of the curriculum to all 50 states and the District of Columbia

Target Audience

Family caregivers whose care recipients have frequent contact with healthcare professionals

New Jersey EASE for Caregivers

New Jersey Department of Health and Senior Services, Division of Senior Affairs

P.O. Box 807
Trenton, NJ 08625

Primary Contact
Barbara Fuller
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NJ EASE for Caregivers will broaden the focus of the existing NJ EASE single entry system for senior services to include the needs of caregivers. This will be achieved through development of uniform caregiver screening, assessment and care planning tools; piloting staff caregiver training; modification and creation of state policies to integrate federal and state-funded caregiver services; development of critical pathways for caregiver decision making and service coordination protocols to guide worker actions; establishment of caregiver service standards; and development of a caregiver website. The development of culturally and linguistically competent staff will be emphasized in all program components.

Goals/Objectives

- Integrate caregivers into New Jersey's established single entry system for senior services, emphasizing access for caregivers from diverse communities
- Pilot and promote innovative, multifaceted approaches to caregiver services
- Enhance worker knowledge of caregivers' concerns, needs, and preferences
- Establish uniform mechanisms to identify, assess and plan for caregivers' needs
- Increase statewide caregiver education and support programs, including the development of a caregiver website
- Establish standards for delivering care management for caregivers

Target Audience

Caregivers caring for individuals 60 years of age and older; caregivers, 60 years and over, caring for children 18 years and under

Care Team Model

Normandale Ministry for Healing and Wholeness

6100 Normandale Road
Edina, MN 55436

Primary Contact
Jean Sigford
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jean@normluth.org

This project will offer services including caregiver training, respite and resource counseling. This will be accomplished through a delivery model referred to as Care Team. The Care Team model will have four components: Each caregiver will be matched with a Care Team. The Team, made up of 2-3 trained volunteers, will provide respite, grocery shopping, transportation, friendly visits, meal preparation, social activities, rides to appointments and other services as needed. One-to-one counseling will be designed to assist caregivers in navigating the system of resources and arranging for community services as needed. The model will offer training through the American Red Cross which will prepare caregivers to provide the physical aspects of care. The project will seek to partner with government, social services and other faith communities to replicate the Care Team model.

Goals/Objectives

- Improve quality of life for caregivers, decrease caregiver burden, and decrease stress
- Increase knowledge of caregiving resources in the community and the utilization of these resources
- Reduce the rate of injury among caregivers, due to improper body mechanics
- Assist 100+ caregivers with one or more of the services offered through the Care Team Model
- Present information about the model to 30 other organizations through presentations, consultations, newsletters and reports

Target Audience

Caregivers caring for elderly family members in the community

An Outcome Based Project for Assessing the Quality of Caregiver Support Services

Ohio Department of Aging

50 West Broad Street, 9th Floor
Columbus, OH 43215

Primary Contact
Richard R. LeBlanc
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The quality monitoring system will be developed with input from caregivers, older consumers, the aging network, and service providers, and will be designed to give primary emphasis on the needs of the caregiver. The principles and standards for quality of service will be based on outcomes identified by all of these stakeholders. The Ohio Department of Aging will work in close partnership with the Scripps Gerontology Center during the development, implementation, and testing of the quality assessment system. The resulting system will be evaluated for effectiveness and feasibility. Recommendations based on caregiver and stakeholder input, and results of the evaluation will be developed. These recommendations will be used to develop a guide for states, area agencies, and providers interested in improving the quality of caregiver support services delivered through the aging network.

Goals/Objectives

- Put the needs and desires of the caregiver first by shifting the paradigm to concentrate on the results, "through the caregiver's eyes"
- Produce outcome-based measurements that take effect on a provider-to-caregiver level
- Assist the Aging Network by producing a resource to help adapt and implement this practice

Target Audience

Area Agencies on Aging and service providers of caregiver support services

Elder Caregivers of Adults with Disabilities

Pennsylvania Department on Aging

Bureau of Home and Community Based Services
Division of Managed Care
555 Walnut Street
Harrisburg, PA 17110

Primary Contact
Joan Dougherty
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jdougherty@state.pa.us

The project provides a support system for primary caregivers, age 60 and older, who are caregivers of relative adult children, age 19 to 59, with mental retardation and/or developmental disabilities, who live in the same household. This project looks to reach this particular target population which is not specifically addressed in many service systems. Older parents of children with disabilities have traditionally isolated themselves, providing needed care at home without accessing community services. Services provided by the project are: specialized information and referral, assessment, family consultation/care planning, care management, benefits counseling, legal consultation, access to support groups and caregiver education and training. Reimbursement based on total household income is provided for services and supplies e.g., respite, emergency response, home modifications, assistive technology and any other goods and services that can be justified as being directly related to the caregiving. It is a very flexible service package and care plans are individually tailored to meet the specific needs of each family served in the project.

Goals/Objectives

- Provide needed care at home without accessing community services

Target Audience

Caregivers age 60 and older caring for relative adult children age 19 to 59 with mental retardation and/or developmental disabilities who live in the same household

Early Diagnosis of Dementia: Dyadic Counseling for Family Caregivers and Patients

The Pennsylvania State University, Gerontology Center, University Park

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This project, Early Diagnosis Dyadic Intervention (EDDI), provides a structured, time-limited program of dyadic counseling to family caregivers and their care recipients who are in the early diagnosed stages of dementia. This work is done in collaboration with the Benjamin Rose Institute, Cleveland, OH. The goals of this intervention, called Project PLAN, are to develop positive communication patterns between the caregiver and care recipient, increase knowledge and understanding about available services, preferences for care, and care values, and increase the care recipients' active participation in his/her care plan. The program is delivered by trained counselors who meet with the dyad for 9 sessions over a 4-month period. Sixty caregiver-care recipient dyads who meet the eligibility criteria and are interested in participating will be randomly assigned to either Project PLAN or treatment as usual. The expected outcomes in the Project PLAN group as compared to treatment as usual are: (1) an increased understanding of the care recipients' preferences and values; (2) increased agreement between caregivers' and care recipients' preferences for care, (3) an increase in the dyad's knowledge of available services; and (4) improved well-being, self-esteem and self-efficacy in managing the consequences of dementia among caregivers and their care recipients.

Goals/Objectives

- YEAR 1 — Create and pilot the Project PLAN treatment, treatment manual, and research instruments, and train all staff
- YEAR 2 — Recruit and randomly assign 30 dyads to participate in Project PLAN and 30 dyads to participate in the usual treatment
- YEAR 3 — Complete data collection and analysis, complete final report and disseminate findings

Target Audience

Caregivers and care recipients in the early stages of Alzheimer's disease

Supporting Older African American Caregivers: Assessing Needs, Building Skills and Maintaining Health

Philadelphia Corporation for Aging

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Two hundred daughter and daughter-in-law caregivers are being enrolled in the study, (split between 100 African American and 100 Caucasian). Each caregiver is randomly assigned to an experimental group or a control group. The caregivers in the experimental group receive 4-5 visits from a nurse practioner over a 3-month time frame. The initail visit includes a basic evaluation using a Caregiver Health Interview tool, a health exam, and a plan for heath care and health education. Caregivers then receive 3-4 additional visits where the care plan is acted on. At the final visit, the nurse practitioner reviews what has been done and completes the same Caregiver Health Interview tool as was done in the initial visit. The evaluation tools (from the first and last visits) are reviewed to ensure all data is collected and removal of any identifying information. It is then sent to data entry. Caregivers in the control group receive two visits from a registered nurse over a 3-month time frame. For both visits, the same basic evaluation tool as in the experimental group is used.

Goals/Objectives

- Improvement and/or maintenance of caregiver's health
- Emphasize preventive care
- Management of chronic illness
- Enhance/teach performance of caregiving tasks
- Decrease caregiver stress
- Enhance quality of life

Target Audience

Social service providers, health care professionals and caregivers

Cuidando con Confianza (Caring with Confidence)

Pima Council on Aging

8467 East Broadway
Tuscon, AZ 85710

Primary Contact
Donna Wagner
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ccc@pcoa.org

This project is being conducted to develop, test and implement an effective, culturally appropriate, and acceptable family caregiver support model for culturally defined communities. The methodology that is employed to develop this model will be documented and available as the final product of the project. This will serve to assist other culturally defined communities on the best methods for community engagement strategies, recruitment and retention strategies, evaluation strategies, sample materials and measurement instruments. The project design utilizes focus groups that define the needs of community caregivers, develop program literature, develop program activities, and serve to advise program staff on culturally appropriate methods of service provision. In addition to focus groups, the project provides services that have been defined by the caregivers. These services include peer support groups, workshops and training on caregiving techniques, community resources, and social activities.

Goals/Objectives

- Develop and test a model of family caregiver support that will be designed by caregivers in South Tucson and implemented in a manner that is culturally acceptable
- Identify the demographic characteristics of Mexican American caregivers and elders in South Tucson
- Produce a replicable model of the methodology employed by community caregivers to establish a culturally appropriate, sustainable model of caregiver support

Target Audience

Mexican American caregivers in the City of South Tuscon

Establishing Community Caregiving Networks (CARE-NETs) and Development of a Community Caregiving Capacity Index (CCCI)

Rosalynn Carter Institute for Human Development

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Americus, GA 31709

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The project is designed to establish a network of caregiving communities, CARE-NETs, within each of six Georgia Area Agencies on Aging, and to develop a new caregiving metric. The new metric, the Community Caregiving Capacity Index (CCCI), is designed to help communities assess their caregiving strengths and needs in order to help them develop action plans for a coordinated, community-wide response to improve caregiving services. Four primary products will be produced. First, A Practical Guide to Establishing Community Caregiving Networks, CARE-NETs, will be developed. Second, the Community Caregiving Capacity Index (CCCI) will be developed. Third, A User's Guide for the CCCI will be developed. Fourth, an Action Planning Guide for addressing caregiver needs will be developed; this document will be a companion to the CCCI for communities wishing to increase their caregiving capacity.

Goals/Objectives

- Involve community members in a collaborative network, CARE-NET, to study a community's caregiver needs and proceed to find the ways and means of addressing those needs
- Develop a CARE-NET Implementation Guide
- Develop a Community Caregiving Capacity Index to assess a community's caregiver needs

Target Audience

Leaders of the professional and family caregiving community

Caring Workplace

St. Andrew's At-Home Services

6633 Delmar Boulevard
St. Louis, MO 63011

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abannes@standrews1.com

The Caring Workplace provides eldercare management and support services to corporation for their employees. The overarching goal is to improve cost effectiveness and allow the employee to remain productive and committed employees. This comprehensive approach to eldercare management includes in-home assessments, education, consultation, counseling, resource/referral information, coordination of services, and caregiver evaluation. A website that provides education and direct access to staff is also available for all employees. The Caring Workplace contains three main components: demonstration project at ten local companies, establishment of a business advisory council, and a business education campaign to raise awareness of the need for workplace eldercare management programs.

Goals/Objectives

- Support an ongoing partnership of corporate and organizational advocacy for eldercare services in the St. Louis region
- Develop, implement, refine, package, and disseminate a model workplace eldercare program
- Increase employers' awareness and understanding of workplace eldercare issues and their willingness to implement workplace-based services for their employed caregivers

Target Audience

The employed caregivers of the eleven businesses in the pilot program

Telephone Support Groups for Caregivers

Senior Service Centers of the Albany Area, Inc.

25 Delaware Avenue
Albany, NY 12210

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Senior Service Centers of the Albany Area, Inc. in partnership with the University at Albany Institute of Gerontology, runs this project, which consists of developing, running and evaluating Telephone Support Groups for family caregivers of the frail elderly. Support Group members attend 12 weekly semi-structured meetings via conference calls, and meetings will focus on emotional support, problem-solving, taking care of yourself, stress reduction, coping strategies and community resources. Groups include up to 8 individuals who are all caring for a spouse or all caring for a parent and the MSW level group leader. Participants are screened, interviewed (pre-test) and are randomly selected to either be part of the next Telephone Support Group or be placed on a waiting list for future group participation (control group). A second interview (post-test) is completed with participants at the conclusion of their Support Group or their waiting period. This design enables comparison, between caregivers who have been in a Support Group with those who have not, on measures of health, emotional well-being, use of social support, feelings of burden, problems of caregiving, and knowledge and use of community resources.

Goals/Objectives

- Caregivers in Telephone Support Groups will experience statistically significant improvements in perceived health status, emotional well-being, social support, subjective caregiving burden, pressing problems associated with caregiving and knowledge and use of community resources
- A manual for leading Telephone Support Groups for caregivers will be refined and made available at cost to other organizations wishing to conduct Telephone Caregiver Support Groups
- A companion workbook for group participants will similarly be refined and made available

Target Audience

Adult children or spouses caring for a frail elderly parent or spouse who are unable to attend face-to-face groups

Caregiver Marketing and Information Campaign (Circle of Caregiving Campaign)

Ten County Aging Board, Inc.

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Wichita, KS 67206

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sboot1@cox.net

The Circle of Caregiving campaign approach, in the first year of the grant, consisted of a statewide paid media campaign, providing caregiver tips and resources. The media campaign utilized Television (1/2 hr. shows, commercials, news segments), radio, and billboards. The half-hour television shows focused on the different types of caregivers: spousal caregiving in the home; spousal caregiving in a facility setting/support groups; sandwich generation caregivers; long-distance caregivers; and friend caregivers. A different campaign commercial ran each month covering such topics as caregiver depression; safety proofing the home; printed guides available for caregivers; legal and financial issues; caring for the caregiver and self-identification. A 1-800 Caregiver Information and Assistance line was advertised in all campaign components.

Goals/Objectives

- Increase public awareness of caregiving and the resources available to assist caregivers
- Increase self-identification by caregivers and to make the public aware of the term "caregiver" and the important role caregivers play in keeping older Kansans in their homes

Target Audience

Adults age 35 and adults who are current or potential caregivers

Project ACE (Aging Caregivers and Exceptional Children)

United Cerebral Palsy of Southern Arizona

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Tuscon, AZ 85711

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Project ACE was designed to assess access to service systems for older caregivers (grandparents and older caregivers) of children with developmental disabilities (children with special needs under their primary care). Following the assessment, tools will be put in place to increase knowledge about and access to services.

Goals/Objectives

- Identify barriers to access and acceptance of services by aging caregivers in order to assist them in their commitment to obtain services for the children with special needs under their care

Target Audience

Grandparents and other older caregivers who are raising children with developmental disabilities

Strengthening the Care Process: A Care-Receiver Efficacy Intervention (CREI)

University of Denver Institute of Gerontology

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Denver, CO 80208

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The overall goal of this project is to demonstrate two models (small group and individual) of an empowerment-oriented care-receiver efficacy intervention that addresses key concerns of caregivers including care-receiver knowledge, attitudes and behaviors that affect the care process. This intervention which is designed to reduce the sense of powerlessness and increase the sense of efficacy of care-receivers by increasing knowledge and skills of care-receivers as partners in their care process. As a result of the intervention, care-receivers are better able to overcome the challenges of care-receiving and assist their caregivers.

Goals/Objectives

- Increase attention to the critical importance of the care-receiver role in the care process
- Demonstrate the interventions and provide materials that allow for replication of the interventions
- Increase knowledge and skills in self-care
- Teach care receivers how to better deal with increased dependence
- Assist with communication with personal and professional caregivers
- Develop and maintain new networks of social support

Target Audience

Persons aged 60 and older who require caregiving services

End-of-Life Planning for Multi-Ethnic Caregivers (ECHO)

University of Hawaii at Manoa
Center on Aging, John A. Burns School of Medicine

Biomedical Building C-106
University of Hawaii at Manoa
1960 East West Road
Honolulu, HI 96822

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The ECHO is a project designed to explore the impact of group-targeted messages and individually tailored support on end-of-life planning by multi-ethnic caregivers of elders receiving long-term care (LTC) services in Hawaii. Six hundred multi-ethnic family caregivers are being recruited through partner agencies that provide home care services and institutional long-term care (LTC) services and also via conferences and brochures. Under the project, a series of 4 booklets has been developed to enhance knowledge about the end-of-life care planning. Besides the distribution of the booklets, 3 supplemental supports—by telephone, caregiver training, and trained case manager/volunteer are being provided.

Goals/Objectives

- Increase the number of older adults who die in the place of their choice, relatively free of pain, and are treated according to their beliefs and values by improving end-of-life knowledge, attitudes, and behaviors through the provision of targeted messages and tailored supplemental supports to multi-ethnic caregivers
- By the end of the first two quarters, produce 4 targeted message booklets and refine the 3 supplemental support strategies, and train 30-50 service providers in the intervention
- Starting in the third quarter, identify 100 caregivers and invite their participation, collect baseline data from caregivers who agree to participate, and provide booklets, along with supplemental support chosen by caregivers

Target Audience

600 multi-ethnic family caregivers on the islands of Oahu and Hawaii

Caregiver Adaptations to Reduce Environmental Stress (CARES)

University of Southern California Andrus Gerontology Center
National Resource Center on Supportive Housing and Home Modification

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Los Angeles, CA 90089

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The CARES project consists of four stages. In Stage One, Area Agencies on Aging (AAAs) will be surveyed to determine the extent to which ECS are incorporated in their Family Caregiver Support Program (3 months). Stage Two (9 months) will involve the creation and administration of an 8-week online training and technical assistance course on CARES that will be offered twice to 30 AAA staff members each time. Stage Three involves a six month Plan of Action implementation period, during which CARES staff will be available for guidance and technical assistance. In Stage Four, (6 months) CARES project staff will survey the AAAs to assess the success and impact of their efforts following implementation.

Goals/Objectives

- Create and stimulate improved systems of supportive services that increase utilization of environmental coping strategies by caregivers
- Assess aging network knowledge and strategies designed to assist caregivers in utilizing ECS in their own homes or in the homes of care recipients
- Educate aging network service providers on how to effect systems change in delivering home modification and assistive devices
- Stimulate aging network activities that address physical caregiver burdens and stresses, including working with other key entities such as Centers for Independent Living

Target Audience

Caregivers and care recipients, State Units on Aging, State Independent Living Councils, State Technology Assistance Programs, AAAs, Centers for Independent Living, policymakers, and affiliated organizations that support caregivers

Outreach and Support for Male Caregivers

Virginia Department for the Aging

1600 Forest Avenue
Richmond, VA 23229

Primary Contact
William H. Peterson
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whpeterson@vdh.state.va.us

This project will provide outreach to male caregivers and provide a support system that will help them continue in their caregiving role.

Goals/Objectives

- Provide information on caregiving and any respite or other supportive care that is provided to the caregiver that will allow him to continue to perform as an effective care provider
- Identify and provide support to male caregivers who may have become depressed and desperate in their care providing role
- Provide information, counseling, and support services to allow the male caregivers to continue in their role as effective care providers
- Disseminate information about caregiving and respite care to diverse community and civic groups

Target Audience

Male caregivers who are retired military and in rural settings

Notes

Notes

U.S. Department of Health and Human Services

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Website: www.aoa.gov