

AoA Caregiver Listserv: Caregiver Education, Training, and Counseling

July 31-August 10, 2001
Prepared by The Lewin Group

INTRODUCTION

The fourth Administration on Aging (AoA) caregiver listserv session, “Caregiver Education, Training, and Counseling,” took place from July 31-August 10, 2001. The listserv session provided the aging network participants an opportunity to share information and ideas regarding the need for caregiver education, training, and counseling, as well as issues around the implementation of services and programs to support these needs. Ron Toseland, Ph.D., Professor and Director of the Institute of Gerontology at SUNY Albany, served as the research resource for this session.

BACKGROUND RESEARCH

The listserv session began with a background paper authored by Ron Toseland and Tamara Smith (Research Associate at the Institute of Gerontology at SUNY Albany) entitled, “Supporting Caregivers Through Education and Training.” The paper underscores the need for caregiver education, training, and counseling programs to support caregivers and ease the negative effects that caregivers often experience such as social isolation, financial worries, family conflict, and changing emotional health. An important consideration in designing and planning these services is to identify what population the program is being designed to serve: a broad population of caregivers or a specific subpopulation of caregivers. Although a program targeted to a broad population has the advantage of reaching a wide audience, it does not allow for the dissemination of specialized information and knowledge useful for specific subpopulations. Toseland suggests that programs designed to serve specific populations can be targeted based on: the nature and extent of care recipient disability, the relationship of the caregiver to the care recipient, the gender of the caregiver, and the race or ethnicity of the caregiver. In addition, programs can be designed to target special caregiving populations such as grandparent caregivers.

Toseland describes the various types of training and education models as follows:

- **Community workshops and forums.** Often single session educational events, these programs focus on community resources, caregiving skills, and psychological and social issues. Sessions are often held at health fairs and senior expos and range in length from one hour to one day.
- **Lecture series followed by discussion.** For a lecture series, a leading clinician speaks on a specific topic of interest, e.g. a pharmacist may be brought in to discuss prescription drug

management. This presentation is followed by a question and answer period, or small or large group discussions.

- **Psycho-educational, skills building, and support groups.** Often small group sessions, these programs range from long-term unstructured support groups to short-term structured groups. Long-term groups usually aim to educate members through information sharing and encouraging reciprocal help and self-help among members. Short-term groups frequently aim to educate members about caregiving resources, and teach problem solving and coping skills.
- **Individual counseling and training.** Individual counseling is often done within a health or human service organization or in the caregiver's or care recipient's home. The focus of the counseling includes diverse topics such as: emotional reactions to chronic illness, family conflict resolution, personal care skills, problem solving skills, behavior management skills, information about caregiving resources and services, and care coordination and care management skills.
- **Family counseling.** Practitioners in various health and human services counsel families on how to sustain their loved ones in both community and institutional settings and how to interact with formal care providers.
- **Care coordination and management.** Care coordinators and managers educate caregivers on ways of performing their roles as caregivers more effectively. In addition, they teach caregivers how to interface with formal caregivers.
- **Technology-based interventions.** Technology assisted education and training methods include telephone-mediated groups, computer-mediated groups, and video-conferencing. These programs allow caregivers in rural areas, as well as those unable to leave the care recipient long enough to attend traditional education sessions, the opportunity to gain knowledge regarding their role as caregiver.

Although there is a lack of definitive evidence as to which types of caregiver education and training models are the most efficacious, current research suggests that multi-component programs are more effective than single-component programs. In addition, individual training sessions are helpful for caregivers dealing with emotional problems whereas group training sessions are useful in building social support. Both individual and group sessions have been shown to decrease caregiver stress.

In planning and implementing caregiver education and training programs, it is important to consider strategies of recruiting participants. Some frequently used recruitment methods include direct contact with the caregiver, mailed and posted announcements, television and radio announcements and programs, and press releases. Although direct contact is one of the most effective methods, it can be expensive; however, a feature newspaper story is often an effective and inexpensive way of recruiting caregivers.

In addition, program planners must also make specific efforts to target minority caregivers given the history of low minority utilization of services and participation in intervention studies. Several steps can be taken to reach out to minority caregivers including: recognizing minority caregivers' need for assistance; hiring providers with an ethnic and linguistic background similar to the caregivers being served; working with health, human service, civic, and religious organizations known and trusted by the caregivers being served; and presenting material in a culturally sensitive manner.

It is also suggested that implementation of these services should be monitored through the use of audio-taping or video-taping group sessions. These tapes can then be used by the trainers to help improve their program implementation skills. Furthermore, it is recommended that evaluation of education and training programs be guided by the goals of the program. At a minimum, caregivers should evaluate the instructor and usefulness of the program, as well as the least and most helpful aspects of the program, and what issues were not covered that should be covered in future programs.

*The full paper as it appeared in this listserv session, including a list of recommended resources on caregiver education and training, can be accessed through the AoA webpage, Implementing the National Family Caregiver Support Information, at:

<http://www.aoa.gov/carenetwork> (Click on “Program Development Issue Briefs”)

AGING NETWORK RESPONSES

Listserv participants responded enthusiastically to this paper, stating that “it was the most comprehensive and useful summary of the topic” seen to date and that it “read like a how-to for those of us struggling with development of our NFCSP systems.” Participants pointed out that offering different types of education and training models provides the opportunity for caregivers to choose a program that matches their learning style. One participant noted that effective recruitment strategies are essential because many spouses do not recognize themselves as caregivers, and thus do not seek supportive services. An inquiry was made as to whether other states had a job description for hiring a Family Caregiver Support Coordinator to provide caregiver care management. A Washington AAA representative responded that they have three such individuals. For a job description, the representative suggested contacting them at jjohnson@crisisclinic.org, catharinewu@kinon.org, or eileenM@seniorservices.org.

Several representatives shared their state and local plans for developing caregiver education and training programs. A representative from Alaska noted that the Alaska Commission on Aging (the State Unit on Aging in Alaska) issued a Request for Proposals (RFP) on Family Caregiver Outreach and Support Program Development. The RFP can be accessed at <http://www.alaskaaging.org>. A representative from Louisiana stated that they were in the process of developing a RFP that would use Toseland’s recommended guidelines for the education and training components. In response to a participant’s inquiry if there are any specific questions that should be used in evaluating these services in rural areas, Toseland recommended that evaluation questions should be driven by the program goals.

A participant from New Jersey shared her AAA’s plan for developing a unique technology-based intervention. For this program, “telehealth” technology will be used to link caregivers to support networks, educational presentations, and, in the case of long distance caregivers, directly to the care recipient. A partnership has been established with a local hospital and the VNA to help locate caregivers that are most in need of this type of support to participate in this innovative

program. The AAA is beginning to design outcome measures that will be incorporated into the overall program planning and implementation.

Representatives from Washington and Illinois shared plans to use a program called, *Taking Care of You: Powerful Tools for Caregiving*, developed by Vicki Schmall of Legacy Health Systems in Portland, Oregon. The program is designed to provide caregivers with tools to increase their self-care and confidence in handling difficult situations, emotions, and decision making. The program was modeled after “Chronic Disease Self-Management Programs,” developed by Dr. Kate Lorig at Stanford University. An Illinois AAA awarded a one-time grant for FY 2002 to a provider to use the “Taking Care of You: Powerful Tools for Caregiving” model and awarded two additional grants to caregiver training programs that will use different models. In King County (Seattle area), the AAA contracted with two local organizations to provide the program. Respite services will be available for caregivers to enable them to attend the training sessions. The providers can be contacted at jlrosby@prninc.net and marianneL@seniorservices.org for more information.

The Seattle-King County AAA representative noted that they have now contracted their NFCSP dollars out to the community providers and have also allocated \$122,000 of NFCSP dollars to their existing State Respite program. The following is a description of the specific project descriptions:

NATIONAL FAMILY CAREGIVING SERVICES		
AGENCY (For services, please contact the Agency web site.)	PROJECT DESCRIPTION	CONTACT (For program information, please use this contact.)
Senior Services www.seniorservices.org	<p>Provide the main entry point for Caregivers who are caring for adults with disabilities and who are age 60 or older; as well as, Kinship Caregivers who are age 60 or older and caring for children under age 19. Information, Referral and Assistance Services through the Senior Information & Assistance call centers. Extend the access hours for I & A calls. Provide the lead coordination for all the Caregiver providers in King County, including hosting the NFCSP kick-off event for King County. Develop a comprehensive media campaign and a community outreach effort in collaboration with the Healthy Aging Partnership (HAP), which uses the easy-to-remember 1-888-4Elders. Outreach will be conducted primarily through 40 congregate meal sites, 35 Senior Rights Assistance sites and 9 Senior Centers, countywide.</p> <p>Caregiver Specialists will:</p> <ul style="list-style-type: none"> • Identify caregivers through community outreach, education and coordination with other providers. • Cross train Outreach and Information Specialists who in turn will • Provide direct service to caregivers on site. • Use laptop computers to access the comprehensive resource database in order to assist caregivers in accessing services, etc. • Provide limited in-home assistance. • Conduct community and workplace educational workshops for caregivers. <p>Develop additional Caregiver components for the Senior I & A library. Enhance the Caregiver web site. Develop an interactive web page: " Caregiver Journal Exchange" . Provide a range of " Supplemental Services" such as</p>	Eileen Murphy eileenM@seniorservices.org

	Transportation, home modifications, assistive devices, medical equipment, financial help for non-covered prescription costs, etc.	
<p>Crisis Clinic www.crisisclinic.org <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i></p>	<p>Provide the main entry point for Caregivers caring for adults with disabilities, age 18 or older. Information, Referral and Assistance Services through the Community Information Line (CIL), 24-hour access, seven days a week.</p> <p>Caregiver Program Specialist will:</p> <ul style="list-style-type: none"> • Trains all the " I & R" specialists regarding Caregiver needs and services. • Provides in-person Caregiver Support. • Arranges for Emergency Respite Care, when necessary. <p>Develop and maintain a Caregiver website. Provide callback telephone support to caregivers. Continue Caregiver outreach and publicity.</p>	<p>Julie Johnson jjohnson@crisisclinic.org</p>
<p>Kin On Family Support Center www.kinon.org <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i></p>	<p>Expand the outreach to community groups, Chinese religious groups, and other gatekeepers. Train volunteer caregivers recruited through Care Team ministries in basic caregiving techniques, how to access services, and support of family caregivers. Develop a training manual for Chinese Caregivers. Evening and Weekend coverage for Kin On supervisors Available to caregivers and service providers (8:30 AM - 9:00 PM, seven days a week). Develop a bilingual Caregiver's web site (Chinese & English). Collaborate with City of Bellevue, Overlake Hospital and other Eastside providers to organize an Asian Caregivers Health Awareness Conference. Initiate an Asian Caregiver Alliance for King County that will plan a Caregiver Conference, develop Caregiver training curriculum and advocate for needs of Caregivers.</p>	<p>Catharine Wu catharinewu@kinon.org</p>
<p>Chinese Information Service Ctr. www.cisc-seattle.org</p>	<p>Outreach to potential Chinese caregivers through home visits, meetings with Chinese Associations, business and church groups. Special outreach efforts will be made in East King County. Care management support. Respite Promotion and Placement.</p>	<p>Stephen Lam stephen@teleport.com</p>
<p>Overlake Hospital www.overlakehospital.org</p>	<p>Outreach to informal support networks through the Eastside churches. Expand distribution of Caregiver materials developed for the Eastside. In-home counseling to family caregivers in Bellevue, Redmond, Mercer Island, Issaquah, Sno-Valley and North Bend. Develop a Bellevue-based Caregiver support group</p>	<p>Debbie Anderson danderso@overlakehospital.org</p>
<p>Alzheimer's Association www.alzwa.org</p>	<p>Outreach to unpaid caregivers of persons with Alzheimer's. A " Care Consultant" will establish a relationship with families caring for a person with Alzheimer's and develop a needs assessment. Develop a " care plan" with both short and long term goals, and provide on-going problem solving and follow-up with families.</p>	<p>Mark Buckley mark.buckley@alz.org</p>
<p>Professional Registry of Nursing www.prninc.net</p>	<p>Provide training for unpaid caregivers, when slots are available, for each of the Training programs available to paid caregivers. Provide special training for unpaid caregivers through the " Taking Care of You: Powerful Tools for Caregiving" .</p>	<p>Jerry Crosby jlcrosby@prninc.net</p>
<p>Interfaith Volunteer Caregivers www.providencemarianwo</p>	<p>Recruit and Train new Volunteer Caregivers in order to increase the number of community residents who may be served.</p>	<p>Sally Farrell sfarrell2@providence.org</p>

od.org	Trained Volunteers will provide assistance with Transportation, shopping, errands, light housekeeping, companionship, short respite care and yard work.	
Eastside Adult Day Services www.eadsdayhealth.org	Develop a support group for caregivers in the Greater Issaquah and Sammamish Plateau communities. Develop a caregiver resource center at the Sammamish Plateau site, which can be used independently or with consultation from a trained staff member.	Paula Hardy pdhardy@serve.net
Evergreen HealthCare www.evergreenhealthcare.org	The Geriatric Regional Assessment Team (GRAT) will provide therapy services, (one to five sessions between 45 and 75 minutes) to isolated caregivers that are unable to access mental health services elsewhere. They will focus on high stress, depression, abuse or domestic violence, grief from the loss or decline of loved ones.	Karen Kent kkent@evergreenhealthcare.org
Northshore Senior Center www.halcyon.com/senior	Expand current support groups to include the Kirkland Senior Center. Extend the Health Enhancement Program (HEP) to caregivers in order to increase support for caregivers. Caregiver training: two series of six week classes on "Taking Care of You: Powerful Tools for Caregiving" Counseling and emergency consultation for caregivers in a state of chronic or acute distress.	Marianne LoGerfo marianneL@seniorservices.org
King County Housing Authority www.kcha.org <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Coordinated Caregiver services for residents and caregivers in the 23 King County Public Housing residences. Individual consultations, including assistance with problem solving and decision making related to caregiving roles. Provided by the Support Services coordinators, including referrals to support groups, respite care and the Community Information Line (CIL) at Crisis Clinic, which provides 24-hour access to caregivers. Meetings at each of the 23 KCHA residences for caregivers; informational and resource mailings provided in all the major languages including Russian, Vietnamese and Korean.	Cassandra Miller CassandraM@KCHA.org
KINSHIP CAREGIVING <i>(Grandparents and other relatives, age 60 or older, caring for grandchildren)</i>		
Children's Services of Sno-Valley www.cssv.org	Develop a local media campaign, brochure to do outreach and recruitment in the Snoqualmie Valley, North Bend and Duvall areas of King Co. Assess the needs of current and new participants. Assist in accessing information, referrals to professional services such as legal. Assist with funds for individual family needs; i.e., summer camp, school break activities, supplies, athletic costs. Provide Kinship Caregiver support groups. Provide Child support groups.	Nancy Whitaker nwhitaker@cssv.org
Southeast Youth & Family Serv. www.scn.org/civic/seoyouth	Provide an evening support group. Workshops on a variety of specific topics unique to Kinship Care providers, such as Finance and Budget, Respite and Child Care, Child Development, Raising mixed race children, health, legal, nutrition, domestic violence, signs and symptoms of drug use, stress management, etc. Outreach and care management to assist kinship caregivers in accessing necessary services. Referrals to counseling, medical, housing, etc.	Jeri White jrwhiteseyfs@swest.net
Atlantic Street Center www.atlanticstreet.org	Provide professionally facilitated therapeutic adult support groups and children's social skill groups. Educational workshops on adoption; custody and guardianship; healthcare and nutrition; economic and	Tamsen Spengler tamsens@atlanticstreet.org

	financial concerns; navigating the school systems; parenting issues unique to kinship care providers.	
Public Health - Seattle & King Co. www.metrokc.gov/health	Identify and expand services to grandparents and other kin. Provide individual counseling for grandparents, with Special emphasis on mental health issues and learning Disabilities. Provide " system navigation" assistance for barriers in the health, education and TANF ("welfare") systems.	Abbey Moon-Jordan abigail.moon-jordan@metrokc.gov
MINI-GRANTS		
U. of Washington Alzheimer Satellite. <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Organize and facilitate two (2) discussion groups for Chinese-American caregivers on shared experiences and needs to determine the desired services as well as the barriers experienced by these caregivers in accessing services.	Judy Cashman judym@u.washington.edu
Providence Mount Saint Vincent www.providence.org/the mount <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Plan and sponsor a one-day workshop for up to 150 unpaid caregivers of functionally disabled adults 18 years and older. It will provide life-enhancing strategies and information to improve the caregiver's quality of life.	Carol Collins cscollins@providence.org
Magnolia Adult Day Center <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Provide additional counseling and support to caregivers.	Vanessa Harrold 206-283-0233
Korean Women's Association www.kwaonline.com <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Plan and sponsor two educational seminars for unpaid Korean caregivers in the Federal Way, Auburn and Kent areas. The focus will be on alternative ways to strengthen the quality of caregiving for elders and adults with a disability.	Faaluaina Pritchard luaprkwa@nwlink.com
Mt. Si Senior Center/Snoqualmie Valley <i>Both State and Federal funding enables them to serve Caregivers who care for persons, age 18 or older.</i>	Produce a brochure featuring local service providers who assist unpaid caregivers of adults with disabilities. It will be widely distributed, including the Snoqualmie Valley Caregivers Fair.	Ruth Tolmasoff tolmas@accessone.com