VA CAREGIVER SUPPORT
Assistance and Support for Family Caregivers

NATIONAL HOME AND COMMUNITY BASED SERVICES CONFERENCE
CARE MANAGEMENT AND SOCIAL WORK/ MARGARET CAMPBELL-KOTLER MPH,RN

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Comprehensive Caregiver Support Services

- Allow Veterans to remain at home in the community
- Address specific needs of family caregivers with a menu of programs and services
- Promote Veteran and caregiver health and well-being
- Provide one location to obtain needed information
- Provide training and information on common conditions
- Reduce isolation with professional and peer support
- Provide respite care options to give caregivers a break
- Sensitize health care providers to the caregivers’ role
Menu of VA Services

**In-Home Care**
- Skilled Nursing
- Home Health Aide
- Home Based Primary Care
- Veteran Directed Home & Community Based Care

**Respite Care**

**Services to Address**
- Equipment
- Home Modification
- Automobile Modification

**Education and Training**

**Financial Support**
- Aid and Attendance
- Caregiver Stipend (Post 9-11)

**Information and Referral**
- Caregiver Web site: [www.caregiver.va.gov](http://www.caregiver.va.gov)
- Caregiver Support Line

**Caregiver Support**
- Support Groups
- Caregiver Support Coordinators
- Interactive Website
- Peer Mentoring Program

VETERANS HEALTH ADMINISTRATION
All **General Caregivers** Receive:

- In person education
- Interactive website
- Telehealth training
- Teaching techniques, strategies, and skills for caring
- Counseling and other services under § 1782
  - Respite care under §1720B
  - Information on all available services

**Family Caregivers** Additionally Receive:

*Post 9-11 Only*

- Appropriate instruction and training
- Travel, lodging, and per diem for training
- Lodging and subsistence for appointments
  - Respite care during training
  - Ongoing technical support
  - Counseling

**Primary Family Caregiver** Additionally Receive:

*Post 9-11 Only*

- Monthly caregiver stipend
- Appropriate Mental health services
- Respite care not less than 30 days/yr
  - Health care coverage
Current vs. New Caregiver Benefits

Current Benefits
Available to Veterans of All Eras

World War II
Korean
Vietnam
Gulf War
Post-9/11

- Education and Training
- Family Support Services
- In-Home Care
- 30 Days of Respite Care
- Aid and Attendance
- Additional Benefits

Additional Benefits under P.L. 111-163
Available to subset of post-9/11 Veterans and Servicemembers

Primary Caregivers Receive:
- Stipend
- Health care (if not otherwise available)
- Mental health services
- Family Caregiver Benefits

Family Caregivers Receive:
- Travel, lodging and per diem for training
- Respite care during training
- Lodging and subsistence for Veteran’s VA appointments
- Appropriate instruction and training
- Counseling
Eligibility Criteria - A Snapshot

Veteran (or Servicemember undergoing medical discharge) incurred or aggravated a serious injury in the line of duty on or after September 11, 2001 (includes Traumatic Brain Injury, psychological trauma or other mental disorders).

Requires on-going assistance from a Caregiver for a minimum of 6 months to:

*Support the Veteran or Servicemember’s health and well-being;
*Perform personal functions required in everyday living; and
*Ensure the Veteran or Servicemember remains safe from hazards or dangers incident to his or her daily environment.
Application Process for Caregiver Support Program

- Veteran and Family Caregiver complete the Program application form 1010CG.
- Application can be processed online, by mail, or in person at local VAMC.
- Assistance is available online (24/7 live chat), by toll free phone (24/7 HRC 600+ staffing), or in person with Caregiver Support Coordinator at VAMC.
- Additional assistance by phone at National Caregiver Support Line (staffed 24/7).
- Completed application form submitted to Health Eligibility Center or local CSC.
- VA determines administrative eligibility for Veteran (must include LOD serious injury incurred or aggravated post 9/11 – to include TBI or other mental disorders).
Caregiver Education and Training

Standardized Core Curriculum
- Developed in collaboration with Easter Seals
- In-person, home or web-based
- Convenient and easily accessible
- Well received by caregivers
- Nearly 1500 Family Caregivers have been trained

“Two Thumbs Up,” “Very Enlightening,” “Knowledgeable Presenters,” and “The Networks You Need – Important to Be with other Caregivers.”

Specific Training to Individual Veteran Needs
- In-home return demonstration
- Additional training to ensure success
Home Visit – Support to Veteran and Caregiver

• In-Home Initial Visit within 10 days of Training completion
• Well-being checks every 90 days
• Home visits are supportive and instructive
• Evaluation of Veteran and caregiver’s physical and emotional state
• Recommendations for additional training, support, equipment, etc
The Home Visit and Assistive Devices

- Important Adjunct to In-Patient and Out–Patient Care in Assuring Veteran and Caregiver have needed Assistive Devices
  - Greater Comfort in Familiar Surroundings
  - Able to cue into personal situation and express needs more completely
  - Clinician assesses environmental barriers on the spot
  - Assistive Devices ordered immediately or PT/OT evaluations arranged

Examples
Veteran with great pain from lumbosacral/cervical strain was unable to bend, reach or transfer without assistance. Expressed distress about his inability to put on his own socks – clinician ordered a sock aid as well as raised toilet seat frame and grab bars to provide as much independence in self-care as possible.
A “health buddy” used by VA tele-health to assist with chronic disease self-management was recommended for a Veteran with chronic pain.

- Identified need for more stable ramp at a Veteran’s home.
- Monthly alarming pill dispenser.
- Grab bars, shower chairs, raised toilet seats are routinely provided.

- Very basic but extraordinary interventions with meaningful application to accomplishing basic tasks which were important to the Veteran.
Additional Caregiver Support Program Services

- Caregiver Support Coordinator in every VA Medical Center

- Dedicated Web Site:
  - [www.caregiver.va.gov](http://www.caregiver.va.gov)

- National Caregiver Support Line:
  - 1-855-260-3274
  - Staffed by licensed clinical social workers
  - Averaging 150 calls per day

- Additional evidence-based support services for Family Caregivers
Caregiver Support Program To-Date

- Caregiver Support Line – has received 16,000 calls since February 1, 2011

- As of September 8, 2011, more than 2,000 applications for the Caregiver Support Program are in process

- 1,111 Family Caregivers have been approved for the stipend and 216 Family Caregivers now have health insurance coverage under CHAMPVA

- Average monthly stipend varies based on Veteran’s level of personal care needs and the geographic location of new applicants averages $1,600 - $1,800/ month
Questions

Margaret Campbell-Kotler MPH RN
Director, Caregiver Education and Training
202-461-6085
margaret.campbell-kotler@va.gov
Aging in Place
Better Living at Home:
A Person-Environment-Task Framework

September 13, 2011

Mary Becker, MS, OTR/L
Howard County Office on Aging
Columbia, MD
OVERVIEW

- Program Services (Howard County, MD)
- Case Example
- Research & Evaluation (Univ. of Maryland)
  - 43% reduction in HCBS hours
  - Estimated cost savings of $7,000 per each $1,000 spent
- Future Business Model
AIP/Better Living at Home Program Services

- Area Agency on Aging
- Innovative Person-Centered Approach
- In-Home Assessments & Interventions
  - Home Modifications
  - Assistive Devices
- Team: Occupational Therapists, Social Workers, Nurses
- Person-Environment Fit
PERSON-ENVIRONMENT-OCCUPATIONAL MODEL

ADL, IADL, Leisure, Social Participation Education, Work, Play

Person
Occupation
Environment

PERSON-ENVIRONMENT-OCCUPATIONAL MODEL

Cognitive Skills
Motor Skills
Communication
Body Functions
Body Structures
Habits
Routines
Roles

Person

Occupation

Environment

PERSON-ENVIRONMENT-OCCUPATIONAL MODEL

Person

Occupation

Environment

Cultural, Physical, Social, Personal, Spiritual, Virtual
Typical Referral Request

- Consult for County funded services
- Increase Independence
  - Perform Home Modifications
  - Provide Assistive Technology
- Assess/Increase Client Safety
- Decrease caregiver burden
Assessment

“Show me please!”
CASE EXAMPLE
CASE EXAMPLE IN FRAMEWORK

Person
- Cognition, Diabetes, Low Vision, Arthritis
- Neuropathy, Mobility, Anxiety, Useful Habits

Occupation
- Toilet hygiene, Showering, Health Management, Financial management, Home Management, Leisure

Environment
- Tub Shower, low commode, low contrast, poor lighting
EVALUATION

- Collaboration with Chava Sheffield & University of Maryland

- Randomized experimental design
  - Sample: community dwelling older adults
  - Validated instruments
  - Cost effectiveness perspective
  - Lower dosage variant of ABLE intervention proposed by Laura Gitlin
STUDY DESIGN

Pre-test / Assessment

Randomization

Experimental

OT Intervention

3 month post-test

Control

OT Evaluation (no intervention)

3 month re-assessment

6 month post-test
RESULTS

- 43% reduction in hours of HCBS
- Improved functional independence & safety
- Increase in QOL
- Decreased Fear of Falling
- Estimated program savings of $7,000 per each $1,000 spent on intervention
IMPLICATIONS

- Cost effectiveness
  - Dosage
  - Helping people do for themselves

- Translation of research – *lessons learned*
  - “Champions” / Top Down Approach
  - Big & small picture
    - “Show” efficacy
    - Training
Business Model

- Local Fee for Service
- Web Based Professional Continuing Education Program
  - Allied Health
  - Front-Line Staff
- General Public
FOR ADDITIONAL INFORMATION

Mary Becker, MS, OTR/L
Howard County Office on Aging
6751 Columbia Gateway Drive
Columbia, MD 21046
410-313-6494
mbecker@howardcountymd.gov

Charles A. Smith, PhD, LCSW
Montgomery County Health & Human Services
401 Hungerford Drive, 4th floor
Rockville, MD 20850
240-777-1231
charles.smith@montgomerycountymd.gov
Expanding the Use of Assistive Technologies and Home Modifications

Kathleen Kelly, MPA, Executive Director
Family Caregiver Alliance
180 Montgomery Street Ste 900
San Francisco CA 94104
415.434.3388
caregiver.org
kkelly@caregiver.org
Overview of Presentation

• Caregivers - particularly the target baby boomer women - use the Internet to find information and make connections with others. Current survey trends.
• Caregivers are using the Internet to find and use information about assistive technologies - online survey highlights
Change in internet use by age, 2000-2010

- Teens 12-17*: 93%
- All adults 18 and older: 79%
- Adults 18-29: 95%
- Adults 30-49: 87%
- Adults 50-64: 78%
- Adults 65 and older: 42%

* Teens data is from Sept-09.
Demographics

- No difference in gender
- White (non Hispanic), Asian and Hispanic (English-Speaking) show no difference (80+%) 
- Black non-Hispanic 71%
- Income disparities: less than $30,000 (63%); above $30,000 84-95%
- Educational attainment key: less than high school (52%) and high school (67%)
- Rural 67% while urban/suburban (80%)
Home Broadband Adoption, 2000-2010

Source: Pew Internet & American Life Project surveys 2000-2010. Based on all American adults 18 and older.
The New Digital Divide Issues

• Broadband access: rural communities at a disadvantage
• Adults living with chronic disease are significantly less likely than healthy adults to have Internet access (62% vs 81%)
• Adults managing with multiple chronic disease are less likely to have Internet access than those adults with only one chronic impairment (52% vs 68%)
Digital Divide, cont.

- Those living with a chronic disease are more likely to be involved with blogging and online health discussions or support groups
- Those living with a chronic disease are more likely to say that health information found on the Internet had an impact on their own care or care of others
Social networking use continues to grow among older users

The percentage of adult internet users who use social networking sites in each age group

Source: Pew Research Center's Internet & American Life Project Surveys, September 2005 - May, 2010. All surveys are of adults 18 and older.
Use of Social Networking

- 37% of those with a chronic disease have read an online news group, blog or website
- 25% have consulted ranking of medical facilities
- 25% have consulted rankings of health professionals
- 22% have signed up for news feeds
- 8% of adults with chronic disease have signed up with an online group
Summary

- The digital divide is most striking when considering those with chronic impairments
- Those with broadband access will more likely be “power” Internet users
- Caregivers are looking to technology to make their lives easier and stay connected with others
- The Internet is a major source for health information and comparison shopping
Survey of Family Caregivers on Technology and Changes to the Home

• Survey developed by Lewin, et al, to determine trend information on what types of assistive technologies are used to:
  – maintain independence
  – make life easier for the caregiver
  – determine what technologies have been used
  – determine who pays for technologies
  – information about the caregiver
Survey of Family Caregivers on Technology and Changes to the Home

• Survey fielded online over 3+ months
• Self selected sample
• 340 surveys were completed
• Basic demographic profile of survey participants:
  – 87.5% female
  – average age: 57
  – average age of person you care for: 73
Survey of Family Caregivers on Technology and Changes to the Home

• What technologies (personal care) have you used....mobility aids (92%), bathing aids (87%), medication aids (76%), toileting aids (71%), dressing aids (48%)  (n=184)

• What technologies (smart tech) have you used... medical emergency tech (83%), online cgr calendars/communication (31%), health monitoring devices (30%)  (n=129)

• Who pays for the assistive technologies....myself or other family (63%), family member (51%), Medicare (44%), private insurance (24%)  (n=177)

• Did it help...75% yes
Survey of Family Caregivers on Technology and Changes to the Home

• If you have never used assistive technologies, why...not aware of assistive technology (59%), never been a need or never thought about it (29%), cost (23%) (n=110)

• What home modifications have you used...home mods such as ramps, chair glides, bath mods, etc (63%), repair for safety (38%), never had a modification (29%) (n=278)

• Who paid for the modifications...myself or family member (64%), family member (45%), other organization (9%) (n=196)
Survey of Family Caregivers on Technology and Changes to the Home

• Has home modification helped...yes (76%)
• If no modifications, why...no need (39%), cost (30%), renters (18%) (n=72)
• Have you or your family member ever have training in using devices or techniques to minimize injury...no (59%) (n=258)
• If you need information about technologies, where would you go....Internet (67%), health care provider (47%), AAA (41%), family/friend (28%), other orgs (23%) (n=242)
Survey of Family Caregivers on Technology and Changes to the Home

• How much physical strain is caregiving...moderate to heavy (57%) (n=260)

• Which services do you feel you need more help/info...assistive tech (68%), training (51%), home mod (40%) (n=216)

• In addition to tech and home mod, what other issue do you need more help...managing emotional stress (74%), finding personal time (71%), keeping the person safe (56%), help in dealing with agencies (49%) (n=252)
Survey of Family Caregivers on Technology and Changes to the Home

• Caregiver comment:
  – “I practically turned into an occupational therapist trying to find ways to accomplish all the various activities of daily living which changed, and changed, and changed again throughout my mother’s decline. I did a great deal of research online to educate myself and come up with practical solutions.”
Take Aways

• Internet gaining in functionality as a major provider of information and training for family caregivers

• Policy implications of broadband access is imperative for rural communities as a health access issue

• As chronic conditions increase, online access decreases

• Home modifications are the major activity but “smart technologies” are increasing

• Payment for technologies comes from family members

• Large numbers of caregivers not aware of technologies

• Large numbers of caregivers are not getting training

• Physical strain of caregiving is great - and emotional
Expanding the Use of Assistive Technologies and Home Modifications

2011 HCBS Conference
Presenters

- Lisa Alecxih, Vice President, The Lewin Group
- Pam Doty, Project Officer, Assistant Secretary for Planning and Evaluation
- Mary Becker, Program Manager, Aging in Place, Howard County Office on Aging
- Margaret Campbell-Kotler, Caregiver Training and Education, Office of Care Management and Social Work, Veteran’s Affairs
- Kathleen Kelly, Executive Director, Family Caregiver Alliance, National Center on Caregiving
<table>
<thead>
<tr>
<th>Agenda</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductions/Overview</td>
</tr>
<tr>
<td>Project’s Inception/National Family Caregiver Support Program (NFCSP)</td>
</tr>
<tr>
<td>A Unique Model/Making a Business Case for AT/HM Assessment</td>
</tr>
<tr>
<td>Veteran’s Administration Caregiver Program</td>
</tr>
<tr>
<td>AT/HM Via Computer/Internet</td>
</tr>
<tr>
<td>Question and Answer</td>
</tr>
</tbody>
</table>
Purpose of the Project

- Provide a means to mitigate caregiver stress related to physical strain (few studies have focused on the use of assistive technologies and home modifications (AT/HM) to help reduce physical strain).

- Promote the independence of older adults with disabilities living at home.

- Lay the groundwork for advancing the use of AT/HM to reduce physical strain among family caregivers supporting elders with disabilities in the elders' or the caregivers' homes.

- Promote increased awareness and use of appropriate AT/HM for individuals receiving services from the National Family Caregiver Support Program (NFCSP).

- Increase knowledge to identify and leverage other funding streams for AT/HM.
Project Activities (some complete)

- Conduct a systematic literature review to understand which AT/HM could reduce physical strain among family caregivers and effective strategies for accelerating their use.
- Solicit guidance and feedback from a panel of key AT/HM technical experts through a technical expert panel (TEP).
- Seek guidance and input from a family caregiver advisory panel (CAP).
- Conduct site visits (n=9) with state and local level representatives from select NFCSP sites to provide a contextual framework for issues identified in the literature review to develop an effective strategy to disseminate AT/HM to family caregivers through FCSPs.
- Convene a 1 ½ day working meeting of the TEP and CAP in Washington, DC;
- Final product: Report on recommendations for accelerating AT/HM.
The focus of this study is on reducing physical strain—we are considering any device/training/modification that achieves this end.

Please think broadly and consider interventions that increase the ability of individuals to function independently or with less difficulty.
Causes of Caregiver Physical Strain

- Assisting with lifting/transferring: 25% of family caregivers are required to lift the care recipient AND they experience difficulty doing so.
- Communication problems/misunderstandings with person with dementia (e.g., care recipient becomes resistant to being transferred due to confusion, distractions).
- Risk factors (overweight, history of back problems, providing long hours of care to person with high level of impairment, home not well designed/arranged for caregiving) - Fact: Almost half of all caregivers are over age 50, making them more vulnerable to a decline in their own health, and one-third describe their own health as fair to poor.
Similarities and Differences among Family Caregivers and Paid Caregivers in Homes/Facilities

- Most long-term care is provided by family caregivers
  - 80% of chronically disabled elders live in the community, not institutions
  - On average, 75% of functional assistance is from family caregivers

- Rates of physical injuries/strain
  - Nursing aides, orderlies, and attendants have highest musculoskeletal disorder rate of any U.S. occupation (BLS, 2010)
  - Research has shown that caregiving exacts a heavy emotional, physical, and financial toll on family caregivers. Nearly 1/3 report caregiving is a physical strain (Spillman & Long, 2009).
  - High stress among family caregivers is the single most powerful predictor of long-stay nursing home admission among chronically disabled elders who had been receiving care at home (Spillman & Black, 2007).
Similarities and Differences Among Family and Paid Caregivers in Homes/Facilities

- **Work hours**
  - Unlike a paid worker, a live-in family caregiver is “on call” 24 hours a day. Many family caregivers also work at paid jobs.
    - 22% are assisting 2 individuals
    - 8% are caring for 3 or more
  - Many professional caregivers work multiple jobs. Many also have family members they care for, in addition to their paid caregiving jobs.

- **Education on safety/injury prevention**
  - Family caregivers often do not think about how to protect themselves from injury. Family caregivers may find it difficult to find training when they need it.
  - Training for paid caregivers is widely recognized as inadequate, especially in home care.
Similarities and Differences Among Family and Paid Caregivers in Homes/Facilities

- Caregiving environment and availability of assistive equipment
  - Institutions are more likely to have assistive equipment (e.g., ceiling lifts, portable lifts, back belts). Nine states have safe patient handling legislation; OSHA has developed safe patient handling guidelines for NHs. However, equipment is not always available in all facilities, and workers may not always use it due to high workloads, understaffing, lack of training on injury prevention, or other factors.
  - Many homes are not designed or arranged to support safety and independence for people with physical or cognitive impairment or to support caregiving in the home.
Limited Coverage of Assistive Technologies

- Medicare provides coverage for durable medical equipment (DME). However, many assistive technologies do not qualify as Medicare-covered DME.

- Example: Medicare will not cover a bed lift unless the patient required a “two-person transfer” and would otherwise be bed bound.

- Other public programs have greater flexibility to facilitate access to appropriate technologies to address physical strain among family caregivers (e.g., NFCSP, ADRCs); however, the amount of funding is often very limited/restricted.
The National Family Caregiver Support Program (NFCSP) was established in 2000 as part of the reauthorization of the Older Americans Act (OAA).

- Title III E (NFCSP)
- Title VI C (Native American Caregiver Support Program)

2006 Reauthorization of the OAA

- Refined targeting criteria
- Modified age requirements
National Family Caregiver Support Program (Populations Served)

- Family Caregivers (18+)
  - Caring for those 60+
  - Caring for those of any age with Alzheimer’s disease or related dementia*

- Grandparent/Relative Caregivers (55+)*
  - Caring for children under age 18
  - Caring for adults age 18 to 59 with disabilities

*Changed with the 2006 reauthorization of the OAA
National Family Caregiver Support Program (Allowable Services)

- Information about services
- Assistance with access to services
- Individual counseling; support group establishment; caregiver training
- Respite
- Supplemental services (on a limited basis)

*Changed with the 2006 reauthorization of the OAA*
NFCSP Supplemental Services

- Services are available on a “limited basis”
- Complements care provided by caregivers
- Considerable flexibility
  - Home modifications
  - Transportation
  - Durable goods
  - Consumable medical supplies
  - Others