Development and Dissemination of Information for the Aging Network

Technical Advisory Group Summary Report

November 30, 2000

ATTENDEES

The first Administration on Aging (AoA) Caregiver Technical Advisory Group meeting was held on 11/17/00 from 1:00pm to 4:00pm at the Hubert Humphrey Building in Washington, DC. Attendees included:

- **TAG Members**
  Dolores Gallagher-Thompson (via conference call); *Veteran Affairs Medical Center*
  Lisa Gwyther; *Director, Family Support Program, Duke University Center for Aging*
  Rhonda Montgomery; *Director, Gerontology Center, University of Kansas*
  Richard Browdie; *Secretary, Pennsylvania Department of Aging*
  Neetu-Dhawan Gray; *Executive Director, Baltimore City Commission on Aging and Retirement Education*
  Cheryll Schramm; *Chief, Aging Services Division, Atlanta Regional Commission*
  Virginia Dize; *National Association of State Units on Aging*
  Angela Heath; *National Association of Area Agencies on Aging*
  Donna McDowell (not in attendance); *Director, Wisconsin Bureau of Aging and LTC Services*

- **AoA**
  Jeanette Takamura; *Assistant Secretary for Aging*
  Diane Justice; *Deputy Assistant Secretary*
  Edwin Walker; *Director, Office of Program Operations and Development*
  Jim Steen; *Aging Services Specialist, Office of Program Operations and Development*
  Melanie Stearns; *Project Officer, Alzheimer's Disease Demonstration Grants to States*
- **The Lewin Group**
  Karen Linkins and Sharon Zeruld

I.   INTRODUCTORY REMARKS

A. Background

Jeanette Takamura welcomed the participants and marked the passing of the National Family Caregiver Support Program as an historic opportunity. On 11/13/00, President Clinton signed the bill into law as part of the reauthorization of the Older Americans Act. AoA is awaiting the appropriation of funds. A budget request of $125 million has been made to initiate the program.

B. Purpose of Meeting

Aging network representatives and caregiver experts were requested to assist AoA in prioritizing the initial steps toward the implementation of the National Family Caregiver Support Program (NFCSP) with a focus on identifying the information and knowledge most needed by the network to develop and improve family caregiver support programs. AoA officials expressed the desire to apply three tools in shaping the NFCSP:

1) evidence-based knowledge; 2) experienced-based knowledge; and 3) general hindsight. Diligence in implementing the program is important since future appropriations are dependent upon how the program is implemented now.

C. Provisions of the NFCSP Legislation

In addition to reviewing the main components of the legislation, Ms. Takamura noted the following:

- Grandparents are included in the legislation as a caregiver population, but there is a limitation that a State cannot use more than 10% of the total Federal and non-Federal share available to provide support services to grandparents and older individuals who are relative caregivers.
- The term "Family Caregiver" is broadly defined and does not necessarily mean blood-related.
- Low-income individuals and older individuals providing care and support to people with mental retardation and related developmental disabilities shall be given priority.
- Developing performance measures is very important.

D. GPRA Caregiver Performance Outcome Measures Project

In partnership with the National Association of State Units on Aging and the National Association of Area Agencies on Aging, AoA has begun the Performance Measures Project to develop and field-test performance outcome measures for possible use by the Aging Network. One of the performance goals of this project is to improve caregiver support services. AoA will measure the satisfaction of caregivers with the caregiver support services that are available to them.

States and AAAs are currently field-testing the performance survey and measures. AoA hopes to glean the most salient questions to ask caregivers and other types of information that are needed. It is intended that the information gained from this project will be incorporated into the design and implementation of the NFCSP.

II.   OPEN DISCUSSION

Part 1: Information Needed to Implement NFCSP

- **It is important to consider that states will be starting at different points**. States that do not have programs will need to build infrastructure, whereas states that already have programs in place will not want to be burdened with administrative requirements. Guidance around implementation, therefore, should reflect the current level of development among states and not cause undue burden on states that have existing programs.

- **Planning should be conducted on a statewide basis.** A caregiver does not recognize the artificial boundaries in which the Aging Network currently operates.

The planning process must consider the needs of caregivers in the entire state, not simply the catchment area of the AAA. This is particularly the case for information and assistance efforts.

- **Decisions around cost sharing and what level of variability will be tolerated need to be made.** An important aspect of implementation is deciding the mechanisms for cost sharing and the level of variability across and within states. The network would benefit from guidance around cost-sharing practices and what variability, if at all, is allowable. In Pennsylvania, for example, cost-sharing policies are the same throughout the state. It was noted that mandated policies are difficult to implement.

- **Partnerships will become increasingly important and a key factor in implementation.** Reaching out to the welfare and social service communities (e.g., developmentally disabled and child welfare) will be necessary, but could prove to be a challenge. States and AAAs would benefit from guidance around how and with whom to network and establish alliances in the community. The experience of Pennsylvania working with the Alzheimer's Association showed that although the AA initially felt that their turf was being invaded, the collaboration was ultimately viewed as a valuable effort. It was suggested to consider what public image the network would want to project in their communities.

  Other partners that were identified include the Eldercare Locator, housing, Medicaid Waiver, home extension service, the legal community, HCFA, end-of-life programs, and the business community. It was suggested that the Network reach out to the business community (e.g., Human Resources) to reach caregivers in the workforce. A potential avenue with the business community is through Employee Assistance Programs.

  Partners, including caregiver representatives, will need to be involved in the planning and implementation process to build bridges from existing knowledge and to avoid backlash and alienation.

- **Identifying and serving underserved populations is a great challenge but must be considered during the planning stages.** In California, for example, three major issues of concern regarding the non-Caucasian population were cited: 1) access to services; 2) barriers to services (e.g., language barriers); and 3) cohorts that are not documented for or not deemed citizens but have significant needs. The needs of other populations that have not traditionally been served by the Aging Network, such as grandchildren and MR/DD, must also be considered. Methods for conducting outreach and developing programs that are accessible by underserved populations would be a valuable topic for experts to share their experiences and suggest best practices.

- **Public communication strategies should be cognizant of existing service terminology.** It was suggested that AoA develop a uniform message that caregivers can easily digest. It should contain similar terminology and reflect what caregivers understand (i.e., self-identifying issues). The network will also need to be aware of

public image and how the new legislation relates to current knowledge of caregiver experience and services. In guiding the network, it should be emphasized that caregiver support comprises many things, not just respite. In addition, current programs may have experience with a particular type of support but refer to it as something else. Communication to the Aging Network should therefore be built on common terminology and recognize product variation among programs.

- **Website use is a key mechanism for many potential and current consumers.** It was suggested that there be a multilevel website approach (i.e., federal, state, local) that builds from similar basic information and common terminology. The network should develop interactive websites that are consumer-focused and cater to the caregivers that access the Internet during the day (particularly around lunch time). In developing the sites, the network would benefit from technical assistance around website structure, design, and use as a vehicle to reach caregivers—particularly caregivers in the workforce.

- **The Network has an opportunity to reinvent itself and marketing leadership will be critical in this pursuit.** The network will not be marketing to its existing market but rather, should seize the opportunity to reinvent itself in terms of a new audience (i.e., caregivers). An opportunity exists for AoA to launch a new campaign to greatly influence public knowledge and opinion about caregiving issues and for that message to be clear, recognizable (i.e., branding), and transferable to local levels. A national campaign should be generalizable but persistent to shift public thinking about caregiving.

  Marketing efforts should also be built around common terminology and be consumer-focused. Marketing principles should be applied to the information and assistance arena in understanding why certain people resist services. In doing so, it was suggested that audiences be segmented—e.g., spousal caregiver needs versus adult children caregiver needs.

- **Information and Assistance (I & A) is a key program feature and devising standards and triage methods should be given attention at this time.** I & A is considered the first point of entry and is a critical stage in getting people engaged in caregiver support. Standards, training, and system integration around information and assistance is therefore a top priority for the implementation of the NFCSP.

  Standards must be established for the entity involved in resource dissemination, including the type of skills I & A staff must have, training content, and language capabilities. A new training program for I & A should be established that teaches the staff how to ask the right questions. Training should focus on what information the staff are obtaining from contacts and how to make the connection between information, needs, and service delivery. Staff needs to be savvy about when to refer contacts, when to counsel contacts and whether this should be conducted over the telephone or in person. Lisa Gwyther discussed the I & A training packet that she is preparing for the North Carolina Aging Network. One of the greatest needs identified is how to communicate with families, particularly those resistant to service use. The

information and link to resources must be consumer driven rather than industry driven. An important piece to I & A is recognizing the difference between *service seekers* and *information seekers* and developing modes to accommodate various consumer needs.

- **Research about population segmentation shows that the service options should not be limited by the definition.** Person-centered, culturally sensitive planning should drive programs so that what works for the caregiver and individual in need becomes the service provided. Rhonda Montgomery commented that "respite," for example, is the *purpose* of the service not the *definition*. Respite should be thought of in a broad context such as, "ways in which one can do things for an older person to provide support and give the family a break." Another example is that "day care" is most often used by adult children who desire to continue participating in the workforce as compared to the Brookdale model, which caters to spousal services. The approach taken in Pennsylvania, which allows the definition of caregiver need to drive the type of service, was highlighted as one effective model. It was advised that the benefits of particular resources be defined and presented to caregivers rather than simply listing services. This approach might allow the caregiver to more easily understand the connection between one's needs at a given time and potential support options. Caregivers could be presented with decision-tree logic to think and navigate through their options. It was noted, however, that the desire to build flexibility into the program would have to be balanced with the need to categorize services since some categorization is necessary to capture outcomes for receiving future appropriation.

  Dolores Gallagher-Thompson recommended that terms be explained in a culturally appropriate manner. Ms. Gallagher-Thompson is willing to share the definitions that California uses (e.g., Alzheimer's disease, dementia) and also commented that other efforts to define terms are underway, such as that of the National Alzheimer's Association, and it would be advisable to collaborate with them rather than reinventing the wheel.

- **The issue of locus of service delivery in relation to the caregiver location must be further explored, especially with regard to funding.** States would benefit from an exchange of ideas around funding decisions so that the method of funding does not restrict caregiver access to needed support programs and services. Instead of funding from top down within the state, one should be sensitive to caregivers that live in one place, work elsewhere, and care for loved ones living elsewhere. One solution might be to fund regional service areas. Another option is to offer interstate vouchers to caregivers who can then access services across borders. It was noted that the vast majority of direct services would most likely be consumed where the caregiver lives.

- **Support to caregivers must include, but extend beyond the traditional paradigm of serving the Alzheimer's disease population.** There needs to be a proactive step at the national level to avert the association of caregiver support with specific diseases. Rather than emphasizing support in a long-term care context (e.g., ADLs), it was proffered that support programs could be designed in a chronic disease context.

A paradigm shift from "long-term care" to "chronic diseases" might better serve non-AD afflicted families (e.g., stroke, arthritis). Caregivers will require training and education around the disabling condition itself. Angela Heath commented that the National Association of Black Caregivers is currently looking at this issue of caregiver need across illnesses. Some major drawbacks of using the chronic disease approach were identified including that it takes on a medical association and it does not account for co-morbidities. For these reasons, it is advisable not to design a program that is disease-specific. One suggestion is to focus on certain caregiver types such as "daughters caring for aging parents." Caregiver needs might best be assessed for the purposes of starting this program in an ADL context with the concept of chronic illnesses blended in.

Part 2: Vehicles for Program Implementation

Diane Justice provided an overview of information development and dissemination options that AoA is considering with regard to the NFCSP. A discussion of AoA's contract with The Lewin Group followed detailing the activities within the contract that support this aspect of the caregiver project (i.e. assistance with setting up a moderated listserv and improving the existing aging network caregiver web page).

A. Listserv

- **A moderated listserv will be a valuable tool and should run for an adequate period to get a full response.** The length of each listserv session should allow participants adequate time to respond. It was expressed that a two-week response period would enable participants, particularly AAA representatives, to obtain input from colleagues across the state. After consideration of the intent of the listserv however, it is recommended that one-week sessions be conducted to capitalize on the immediacy and interactive nature of the listserv. Participants will be encouraged to consult with colleagues about the topics but should not feel that they have to represent all the concerns of their SUA or state AAAs.

- **Several ideas for kickoff listserv topics:**
  ‣ Targeting support services to caregivers (i.e., the Network will need to reconceptualize how to deliver services now that the client/consumer is considered the caregiver).
  ‣ Defining terms (e.g., "what is respite?")
  ‣ Status of State/ AAA information and assistance and the direction entities should take in enhancing these services and incorporating standards.
  ‣ Networking with other communities and partners (especially with those that are not traditionally part of the aging network).
  ‣ Formulating and delivering caregiver assessments. It was suggested that the caregiver be the driver of assessments rather than focusing on the clinical aspects (e.g., use a quick, consumer-driven tool similar to that used in the MetLife study that can be used across groups—faith-based, Human Resources, etc.).

B. Caregiver Web page

- **Relevant research should remain accessible through the web page but be presented in a manner that is easy to digest**. The quantity and format of caregiver research that currently appears on the page is too dense for administrators' uses. Users from the Aging Network would benefit from displays of research highlights and major findings. The University of Kansas Elder Law website (KELN) offers a rich collection of annotated bibliographies.

- **Offer a package of marketing and outreach tools on the website.** The Network could view various options that others have had experience with and determine what method might work best for them.

- **Include a section concerning assessment tools.** Information about tools that have been developed, innovations, and methods for capturing data across various contexts would be very beneficial.

- **The content of the monographs should be targeted and applicable to members of the aging network at certain stages of program development.** Information from targeted research could be presented in a multilayered format: program structure for newcomers (i.e., how to begin structuring a new initiative); how states carry out this structure and; how to integrate this into existing structures. An example is how to initiate, structure, and manage a respite voucher program.

C. National Caregiver Conference

- **Holding a conference serves the dual purpose of launching public information and building support from the Network.** It was suggested to have one national conference and have round table discussions to share best practices. Regional meetings could follow the national conference once states and AAAs are further in the process.

E. Research and Demonstrations Ideas

There is a need to develop new knowledge about caregiver supports and the new Older Americans Act provides authority to carry out national innovation projects. The following suggestions were made about possible content areas for any new funding solicitations:

‣ ⬜Issue RFPs around the new components (e.g., grandparents as caregivers and effective outreach with this population).
‣ ⬜Direct RFPs to particular priority areas and leave open opportunity for other innovative ideas.
‣ ⬜Emphasize information and assistance and how to more effectively integrate it with the larger support system.

III.   Future TAG Meeting and Follow-up

The Caregiver TAG will reconvene for its second and final meeting in the spring of 2001. TAG members are interested in assisting with the national conference and suggested arranging a conference call around this in the coming months.