Information and Assistance for Caregivers

AoA Caregiver Listserv Summary

Submitted to:

U.S. Administration on Aging

Submitted by:

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INTRODUCTION

The third Administration on Aging (AoA) caregiver listserv session, "Information and Assistance to Caregivers," was held from June 4-June 15, 2001. The listserv session was an opportunity for the aging network participants to exchange information and ideas related to the information and assistance needs of caregivers, system components, and ways of enhancing information and assistance services under the National Family Caregiver Support Program (NFCSP). Cheryll Schramm, Director of the Atlanta Regional Commission (AAA), served as the research resource for this session.

BACKGROUND RESEARCH

Cheryll Schramm authored the background paper, "Information and Assistance: Where We Are...And We Can and Should Be," which was distributed to listserv participants to begin the online discussion. The paper stressed information and assistance (I&A) as a fundamental resource that needs to be expanded and enhanced to meet a diverse range of caregiver need. The value of I&A was described as: providing up to date information on opportunities and services available to caregivers; assessing problems faced by caregivers and their emotional, physical, and financial capacities; linking caregivers to available services; and ensuring individuals are receiving needed services and are aware of opportunities available to them through adequate follow-up. Schramm's experience in developing I&A services in the Atlanta region has provided her with much insight and she offered the following recommendations to enhance I&A development:

- **Recognize caregivers as clients with different needs from those of the care recipient.** Because caregivers often do not recognize their own role and needs as a caregiver, this may be a difficult; however, it is essential for meeting caregiver needs.
- **Implement the use of a caregiver assessment instrument.** This will allow caregivers an opportunity to voice their concerns and let their needs be known. In Georgia, caregiver information is collected in a structured interview that takes place during the screening process. Questions that are asked include: who is the primary caregiver? are they physically/emotionally overburdened? and, are their needs being met? They are exploring the use of other instruments that better measure caregiver stress, including one that is used by the Greater Georgia Alzheimer's Association in its caregiver voucher program.
- **Include information relevant to caregivers in I&A systems mailings**. Such materials could include caregiver tip sheets or articles that reaffirm the role of the caregiver.
- **Hire a staff person to provide caregiving consultation as their primary role.** This individual could help the caregiver explore solutions to caregiving problems**,** discuss day-to-day management of behaviors, discuss management of medications, etc. In Atlanta, this new caregiving consultation position is being filled by a RN with clinical experience who is knowledgeable about many of the health issues surrounding caregivers; however, a medical social worker could also fill the position.

- **Explore I&A system building.** A coordinated statewide I&A system that recognizes the unique characteristics of caregivers as well as the diversity among them is essential to meeting the broad array of caregiver needs. This system should be available to the business community and health and social service organizations in order to have the greatest impact.
- **Identify new and innovative ways to serve caregivers through the Internet.** Aside from regional or statewide I&A websites, the aging network should include links to national organizations with vast information resources, including AoA, NASUA, NAAAA, and AARP. This expanded use of technology will allow the aging network to reach a larger number of caregivers, including working caregivers, and will provide these caregivers with information at their fingertips.
- **Work with human resource offices in the business community to provide information to employees who are caregivers.** Making businesses aware of caregiving issues is the first step of this process, after which the provision of information is critical. Business policies and benefits have the ability to ease caregiver burden, but they must first be informed of the problem. One example of a business working to assist caregiving employees is AT&T, which over the past year convened focus groups to discuss possible ways the company could assist caregivers in their caregiving role.
- **Explore new methods of outreach.** In California, Caregiver Resource Centers were developed across the state to provide easier access, and in Wisconsin, the Community Options Program integrates caregiver support within the regular long-term care service system. AAAs are also pursuing innovative outreach strategies. A Southwest Missouri AAA is initiating a two-year outreach program in which a staff member is provided with a van equipped with caregiver material to be distributed in a very isolated geographic region with no electricity or running water. In Georgia, a quarterly magazine featuring caregiving issues will be distributed through doctor's offices, pharmacies and other places frequented by urban and rural caregivers. In addition, just outside Fairbanks, Alaska, a boat is being equipped with service and public benefit information to reach individuals in isolated communities that can be accessed only by the Yukon River.
- **Involve caregivers.** Listening to caregivers will give the aging network the opportunity to discover what needs are being met and which needs are still unmet. In addition, caregivers can provide crucial insight into how to adjust service systems to better meet the diverse range of caregivers needs. For example, Georgia and Minnesota have used caregiver focus groups to help direct program design and implementation.

*The full paper as it appeared in this listserv session can be accessed through the AoA Caregiver Resources for the Aging Network website at:

http://www.aoa.gov/carenetwork/default.htm

AGING NETWORK RESPONSES

Participants echoed Schramm's emphasis on the value of expanding and enhancing caregiver I&A services. They believe that the NFSCP offers an opportunity to take on this effort. Several aging network representatives questioned the division of "Information" and "Assistance" as defined in the Act. Representatives also were curious as to what information should be collected

on the caregiver and the care receiver. In response, AoA offered program guidance that is summarized at the end of this synopsis. In addition, several participants shared their own plans for I&A services around these topic areas:

Use of the Internet

State representatives agreed that the Internet offers an excellent opportunity to reach a wide range of caregivers while simultaneously providing vast amounts of information and resources. The development of online databases will offer comprehensive data which the caregiver can access when he/she is "information ready", be it day or night. A NASUA representative stressed the importance of incorporating special services into these databases, including pharmacies and grocery stores that deliver, and veterinarians who pick up pets. Furthermore, the representative stressed that information and resources on legal, financial, housing, and pension matters be included, as well as for profit providers for those who can afford it. These databases can be seen as "self-serve" I&A, and thus it is important to examine existing database terminology to verify that terms are consumer friendly.

Several aging network representatives discussed their states' goal of developing a statewide database to ensure a seamless array of services. As a representative in North Carolina stated, the development of a statewide database will resolve the issue of smaller AAAs not having the funding for technology development efforts. Until this goal is achieved in North Carolina, a webpage is set up that connects caregivers and older adults to all of the available directories in the state.

In addition to database development, states are pursuing other uses of the Internet to enhance I&A services. A participant from Wisconsin shared how one rural county in the state is encouraging the use of a caregiver chat room with a RN moderator. Computers donated by businesses are repaired at a local computer store, and the RN then sets up the computer in the caregiver's home and provides instruction on how to use the computer and access the Internet. While at the house, the RN has the opportunity to do an assessment, talk about caregiver issues, and inquire as to whether or not the caregiver is linked to any other services. It was noted that this person-to-person interaction with the chat room moderator usually allows the caregiver to be comfortable interacting over the computer. In addition, there is a bulletin board for those who are not comfortable with the chat room format.

Although Schramm agreed that these efforts should enhance I&A services, she stressed the importance of also developing more traditional I&A services for those individuals who do not have access to the Internet or are reluctant to use it. Furthermore, she stressed the importance of regularly collecting and updating service provider information for these databases. Websites must emphasize a variety of options and allow for easy consultation via email, chat rooms, and phone calls. Many caregivers start looking for information on a nursing home for their loved one, and through consultation find other alternative services that are better suited to their desires. This consultation must be available and easy to access.

Coordination with the Business Community and Community Organizations

Participants agreed that working with the corporate community to provide information to caregivers is an important component of I&A; however, they also stressed that coordination with various other organizations would be beneficial to caregivers. A representative from Connecticut emphasized that faith-based organizations and places of worship offer ideal places to connect with caregivers across racial and economic lines. In addition, a NASUA representative stressed the importance of coordinating with other I&A systems. For example, there should be a link between aging I&A systems and the I&A systems serving grandparents caring for grandchildren and older individuals caring for children with disabilities. All of these systems need to be aware of each other's services to ensure that the caregiver's information and assistance needs are being met.

It was recommended that coordination exist between NFCSP I&A and other aging programs that have I&A components, such as the LTC ombudsman and SHIP. For caregivers entering the long-term care system through one of these other programs, it is essential that staff are aware of I&A under NFSCP. In addition, linking with other organizations such as United Way 211 can enhance a program's capacity to reach as many caregivers as possible. A representative from Minnesota explained the value of the 211 initiative as it relates to caregivers in the following way: many caregivers are not expecting to become caregivers—it happens by chance as a result of an acute illness or an ever increasing disability or chronic illness—and thus, it is difficult to market an 800 number to caregivers. They are not expecting to need it, so they do not remember it. However, remembering 211 is easy and thus people will remember it just as they remember 911.

Schramm agreed that the 211 initiative can serve as an important means of connecting with caregivers. However, she also stressed that it should not replace aging and long-term care information services. She stated that in the state of Georgia, 211 is a long-distance number and thus eliminating the aging 800 number would place a financial hardship on many caregivers. They would thus be less inclined to access services. Currently, the Georgia AAAs and the United Way have a written agreement in which most aging-related 211 calls are automatically transferred to an aging information specialist. This agreement provides the aging network with multiple ways of connecting with caregivers.

Use of a Caregiver Assessment Tool

A NASUA representative stressed the need to collect information from the caregiver. She noted that the goal for initial data collection, satisfaction surveys, and evaluation activities is to gain a better understanding of caregivers' needs and of how these needs are being met. This understanding should be the basis for modification of I&A services and planning. In addition, input gained from these efforts should inform the training of personnel and determine systems advocacy issues. She stated that "integrated client tracking systems—designed for both the caregiver, as well as the care recipient—and computerized caregiver assessment tools that link to the I&R database may need to be developed or current systems may need to be redesigned."

Representatives from Wisconsin and Pennsylvania explained that in their states' programs, the care recipient is screened in addition to the caregiver in some cases. In Wisconsin, the "functional screen" employed by nutrition providers to determine ADLs for home-delivered

meals may be used to determine eligibility for respite and supplemental services. In Pennsylvania, care receivers in the FCSP are assessed "in a manner that is clinically identical to what we do for Medicaid Waiver consumers."

Information and Assistance: Definitional Issues

Several state representatives expressed confusion around the separation Information and Assistance as two distinct categories of service under the NFCSP. State representatives wondered where Information ended and Assistance began and offered different interpretations of how their states viewed the law.

One participant stated that in Wisconsin, an AoA technical assistance piece was used to help inform their definitions of Information and Assistance. They have concluded that Information is provided in group settings and includes outreach, while Assistance is one-on-one I&A and case management. However, in the states of North Carolina and Washington, both Information and Assistance are defined as services provided on an individual basis, as opposed to group activities or outreach. The North Carolina state representative shared the current definition of Information to mean "informing people about programs and services, identifying types of assistance they need and connecting them to appropriate service providers." The state's definition of Case Assistance implies a more intensive service that assists in the negotiation with the service delivery system. It may involve referral, follow-up, advocacy, and a home visit to more clearly identify a client's need or develop a care plan. A representative from Washington shared their definition of Information to mean the provision of up to date information regarding services and benefits to older adults and their caregivers for the client's own action. This interaction can take place over the phone, in person, or via the Internet. Similar to North Carolina, Assistance is considered to be a more intense service in which the client is assisted in obtaining a needed service or accomplish a necessary task that he/she is unable to perform. The provision of Assistance can take place over the phone, in the office, or during a home visit. For Assistance services in Washington, staff conduct a needs assessment, open a client file, collect demographic data, contact the referral agency, provide advocacy and follow-up, and close the case when the need is met. However, no demographic data is collected and follow-up is rare for Information services. Furthermore, individuals who participate in group presentations are not counted as Information contacts, nor are individuals who receive brochures through mass distribution.

In response to definitional questions and reporting requirements, AoA issued NFCSP guidance for states around expected data collection efforts:

- The caregiver is the client for the NFCSP and thus data should be reported for the caregiver, not the care recipient
- The five categories of service include:
  1. **Information**: Group services, such as public education
  2. **Assistance Management**: Individual one-on-one contact, such as case management or I&A
  3. **Counseling/Support Groups/Training**: Provision of advice, guidance and instruction to caregivers on an individual or group basis

4. **Respite**: Temporary, substitute supports or living arrangements to provide a brief period of relief or rest, such as in-home respite, adult day care or institutional respite on an intermittent, occasional or emergency basis
5. **Supplemental Services**: Other services, as defined by states, to support the needs of caregivers

- The three data elements include:
    1. Expenditures
    2. Units of Service
    3. Number of persons served in each of the five service categories
- Data should be reported to AoA in the aggregate by category not by individual services
- Units of measurement have not been defined for the NFCSP. States are encouraged to use NAPIS definitions where appropriate
- The separation of information and assistance into two distinct categories applies only to the NFCSP
- Over the next 15 months, AoA, in partnership with state and area agencies on aging, will revise data collection requirements.