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AAA Caregiving Survey Results

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June 2010

Key Findings

- AAAs have, on average, 10 partnerships with other organizations to provide caregiver support.
- Commonly provided caregiver services include information and referral/ assistance (94.2%), in-home respite during normal business hours (89.2%), support groups (74.7%) and education and training on topics such as legal issues, preventing burnout, etc. (73.3%).
- Over 70 percent (72.2%) indicated that they conduct an assessment of caregivers.
- Just over 40 percent (42.1%) of AAAs or their contracted providers track outcomes for caregivers.
- 22.4% of AAAs indicated that caregivers typically seek information regarding the care recipient, 1.7% typically seek caregiver information for themselves, and 75.8% indicated both.

With a grant from the Administration on Aging (AoA), the National Association of Area Agencies on Aging (n4a) partnered with Scripps Gerontology Center to conduct a brief survey to obtain a broad understanding of the programs and services provided to caregives by Area Agencies on Aging (AAA) and to identify the training and technical assistance needs of AAAs related to caregiving activities. The survey was conducted online and was available for approximately three weeks during April 2010. A total of 360 AAAs responded for a response rate of 57.3%. The following information summarizes the results of this survey.

Characteristics of AAA Caregiving Programs

Informal caregivers provide the majority of care to older adults in need of long-term services and supports. Without the assistance of friends and families, many older adults would not be able to remain independent in their communities. Caregiving, however, may often be stressful or burdensome to those providing care. The Aging Network has developed a variety of programs and services to support informal caregivers so that they may continue to provide the care that is essential to maintaining older adults and others with disabilities in their communities.

Structure of Caregiving Programs

Participants were asked to identify how their caregiving programs are organized and/ or structured by the AAA. With the understanding that any given AAA may structure their caregiving program more than one way, these categories are not mutually exclusive. On average, respondents checked 2.6 types of program organization. The most commonly recognized way in which caregiver programs are organized within a AAA is that caregiver programs are integrated with other services at the AAA or with another agency. The following shows the proportion of AAAs indicating how their caregiving programs are structured.

59.6% Integration with other services at the AAA or another agency
52.5% Contracting at least some services to another agency
52.0% A specialized caregiver support unit at the AAA or other service provider
48.9% Case management unit at the AAA or other agency
40.7% Consumer-direction of at least some programs
3.7% Other

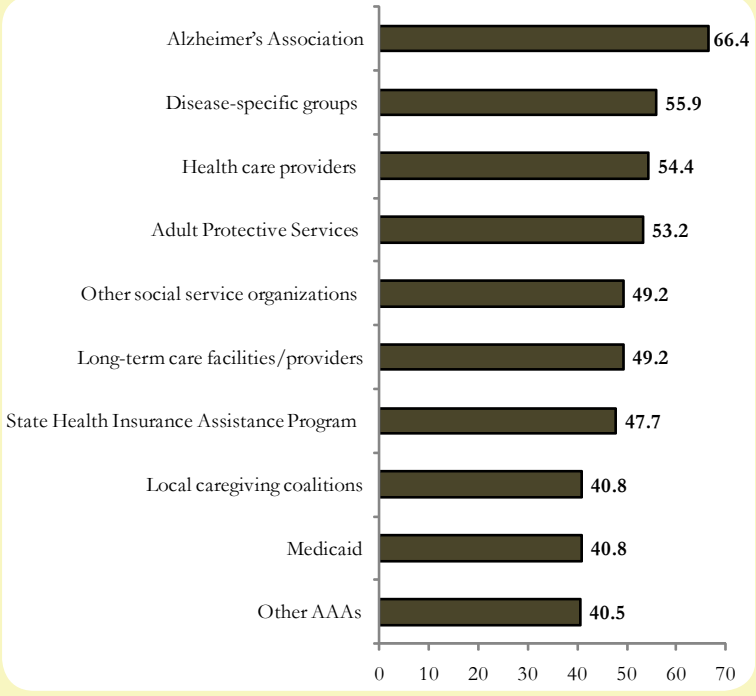
Of those respondents who indicated that their caregiving program is organized through a specialized caregiver support unit at the AAA or other service provider, almost all (95.1%) of respondents indicated that there is a staff member or members who is/are responsible for the caregiving program and services offered by the AAA.

Partnerships

Participants were asked to identify which organizations they partner with in order to provide caregiver support. Partner was defined as a well-defined working relationship with another organization, either formalized with a contract or memorandum of agreement or informal. Of the 30 organizations listed, AAAs have, on average, 10 partnerships with other organizations to provide caregiver support.

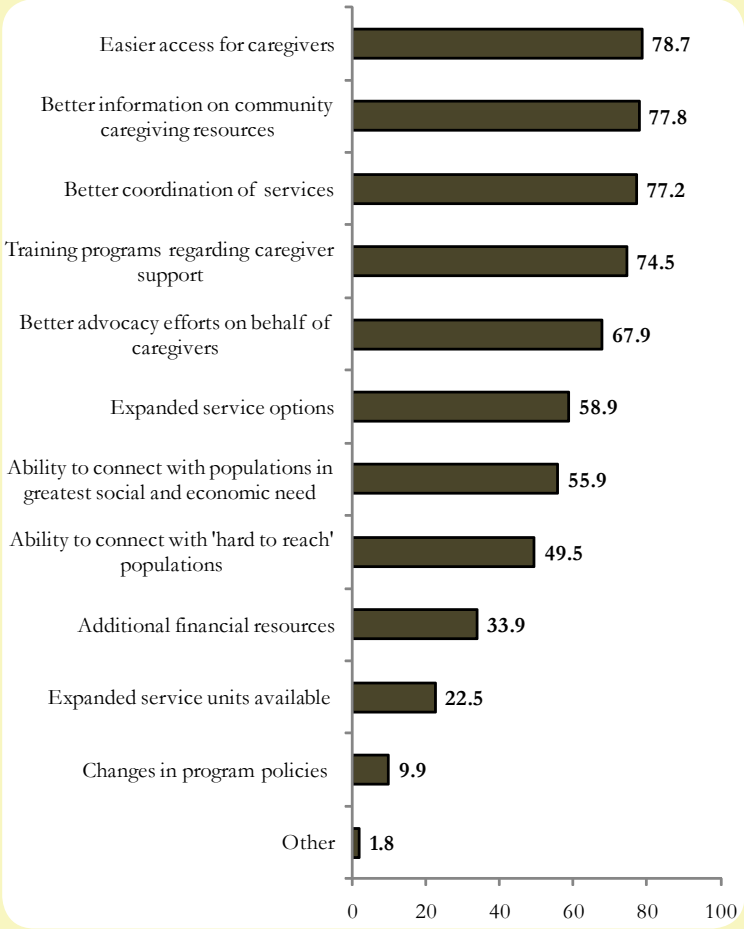
The most common partnerships include those with the Alzheimer's Association, disease-specific groups, health care providers and Adult Protective Services (see Figure 1). For a complete list of partnerships AAAs hold with other organizations to provide caregiver support, please see Appendix A at the end of this report.

Figure 1. Proportion of AAAs Having Partnerships with Specific Organizations



Participants were asked to indicate what outcomes or accomplishments have been achieved as a result of the partnerships they have developed for caregiver support. The most common outcomes include easier access for caregivers, better information on community caregiving resources, better coordination of services and training programs regarding caregiver support (see Figure 2).

Figure 2. Proportion of AAAs Identifying Specfic Outcomes Acheived by Partnerships



Funding

Participants were asked to identify what funding sources are used to fund their caregiving programs. As would be expected, the most common funding source used by AAAs to support their caregiving programs comes from Title III-E funding (National Family Caregiver Support Program) with nearly all (98.3%) of AAAs indicating this source. While less common, other sources of funding to support caregiving programs come from state general revenue (35.9%), Title III-B funding (supportive services and centers) (33.7%) and local funding (city, village, municipal, county funds) (29.8%).

For a complete list of funding sources AAAs use to provide caregiver support, please see Appendix B at the end of this report.

Caregiver Services

Participants were asked to identify which services are provided to support caregivers. From a list of 22, respondents, on average, provided 11 services to assist caregivers. The most commonly provided services include information and referral/assistance (94.2%), in-home respite during normal business hours (89.2%), support groups (74.7%) and education and training on topics such as legal issues, preventing burnout, etc. (73.3%). Less commonly provided services include internet or web-based monitoring technology to support caregiving (6.4%) and corporate eldercare (8.1%).

In addition to the types of services provided, respondents were asked to identify what type of family caregiving these services support and how the service is provided (with a consumer directed option, directly or through a contract with an agency provider). Table 1 shows the proportion of AAAs that provide specific services and of those, who offer each service, the types of family caregivers who receive the service and where applicable, how the service is provided.

Table 1. Services, Types of Caregivers and Service Provision Strategies

			Type of Family Caregiving (% of those who provide each service)							Service Provision			
Service	Proportion offering	Number offering service	Grandparents raising grandchildren	Caregiving for adults over age 60	Caregiving for adults of all ages	Caregiving provided by adults over age 60 regardless of care recipient age	Long-distance caregiving	Caregivers in the workplace	Caregiving for adults with mental disabilities	With a consumer directed option	Directly by AAA staff or volunteers	Through a contract with an agency provider	Through a volunteer program
Information and referral/assistance	94.2	339	-	-	-	-	-	-	-	-	-	-	-
In-home respite - normal business hours	89.2	321	22.7	96.0	21.8	31.8	-	17.4	16.5	41.7	11.5	18.2	14.3
Support groups	74.7	269	59.5	87.0	33.8	43.5	26.0	23.4	26.0	-	-	-	-
Education/training on other topics [1]	73.3	264	56.8	89.8	43.6	49.2	32.2	32.2	25.8	-	-	-	-
Counseling	65.3	235	60.0	95.3	30.6	41.3	41.7	28.5	24.7	-	-	-	-
Assistive devices[2]	64.7	233	28.8	93.6	20.6	33.5	-	16.3	19.7	34.8	34.8	60.0	-
In-home respite during evenings	63.6	229	26.2	94.8	26.2	35.4	-	16.6	19.2	52.8	8.3	75.1	10.9
Adult day services	63.3	228	-	93.4	22.8	31.6	-	18.9	18.4	29.4	11.4	83.8	-
Alzheimer's disease education/training	63.3	228	-	84.6	57.0	51.8	32.0	30.7	27.6	-	-	-	-
Education/training on hands-on caregiving skills[3]	59.4	214	30.8	88.8	41.1	41.1	15.4	18.7	21.0	-	-	-	-
Emergency response systems[4]	53.3	192	9.4	95.3	22.4	29.2	19.3	19.3	15.6	31.8	17.7	78.6	-
In-home respite overnight	49.4	178	25.3	94.4	23.0	33.1	-	15.7	17.8	57.3	5.6	72.4	3.9
Home modification	49.2	177	33.9	97.1	18.6	28.2	-	16.9	19.8	38.4	26.6	72.9	4.5[6]
Institutional respite stays	48.1	173	13.9	96.5	20.8	32.9	-	20.2	17.9	-	-	-	-
Stress management	45.6	164	61.0	92.1	46.3	52.4	36.0	34.1	29.3	-	-	-	-
Financial support	37.8	136	67.6	94.1	22.1	30.1	18.4	19.9	19.9	57.4	36.8	52.2	-
Medical transportation	35.3	127	28.3	96.9	18.1	36.2	15.7	13.4	18.1	31.5	22.0	76.4	-
Emergency respite services	33.3	120	26.7	95.8	25.8	36.7	-	21.7	20.0	42.5	8.3	80.8	6.7
Non-medical transportation	31.7	114	36.0	91.2	23.7	37.7	21.1	17.5	21.9	29.8	30.7	71.9	-
Corporate eldercare[5]	8.1	29	-	-	-	-	-	-	-	13.8	82.8	27.6	24.1[7]
Internet or web-based monitoring technology to support caregiving	6.4	23	52.2	87.0	60.9	56.5	52.2	47.8	52.2	21.7	65.2	43.5	-

[1] Other topics include legal issues, preventing burnout, etc. and training includes conferences and workshops. [2] Assistive devices include grab bars, wheelchairs, walkers, etc. [3] Hands-on caregiving skills include lifting, transferring, care recipient strength building. [4] Emergency response systems include Lifeline, Medical alert for care recipients. [5] Corporate eldercare is defined as employer assistance to family caregivers. [6] Service is provided through a Certified Aging in Place Specialist (CAPS). [7] Service is provided through partnerships with local employers.

Evidence-Based Caregiver Services

For some of the services listed in Table 1, namely, Alzheimer's disease education/training program, education/training for hands on caregiving skills, education/training on other topics, and stress management, respondents were asked whether those services were evidence-based (tested program models or interventions translated into practical, effective community programs that can provide health benefits to participants). The following shows, of those who provide the service, the proportion providing an evidence-based service.

21.0% Alzheimer's disease education/training
16.3% Education/training for hands-on caregiving
15.9% Stress management
11.0% Education/training on other topics (legal issues, prevention burnout)

When asked to name the evidence based program used, the most commonly mentioned program was "Powerful Tools for Caregivers."

Information and Referral Services

As indicated in Table 1, 94.2% of AAAs provide information and referral (I & R) services to support caregiving. Those who provide these services were asked whether caregivers who utilize I & R services are typically looking for caregiver programs and services or seeking information on programs and services for the care recipient. AAAs indicated that 22.4% typically seek information regarding the care recipient, 1.7% typically seek caregiver information for themselves, and 75.8% indicated both.

Of those who are looking for information regarding the care recipient, 90.7% of AAA indicate that caregivers are routinely asked about their needs as a caregiver.

Medical and Non-Medical Transportation

Respondents were asked whether the caregiver was able to ride with the care recipient when they receive transportation services. 94.4% of AAAs indicated that the caregiver is able to ride when the care recipient receives medical transportation and 88.6% said they are able to ride for non-medical transportation.

Corporate Eldercare Services

As shown in Table 1, 8.1% of AAAs provide corporate eldercare services. Of these AAAs, the types of corporate eldercare services provided include education and training (e.g. seminars, guest speakers) (89.7%), access to geriatric care managers (31.0%), employee survey on need for caregiving assistance (31.0%), and dependent care accounts (3.4%).

Consumer Directed Option

For respondents who indicated that one or more of their services were provided with a consumer-directed option, they were asked "for the services provided with this option, who is the primary consumer (e.g. whose directions guide service planning and delivery)?" Over three-quarters (78.5%) identified the caregiver as the primary consumer while 21.5% identified the care recipient. For those agencies that provide at least one service with a consumer-directed option, 29.2% provide cash payments to caregivers, 20.8% provide vouchers to caregivers and 5.6% provide both cash and vouchers. Four out of 10 (44.4%) of AAAs do not provide either direct cash payments or vouchers.

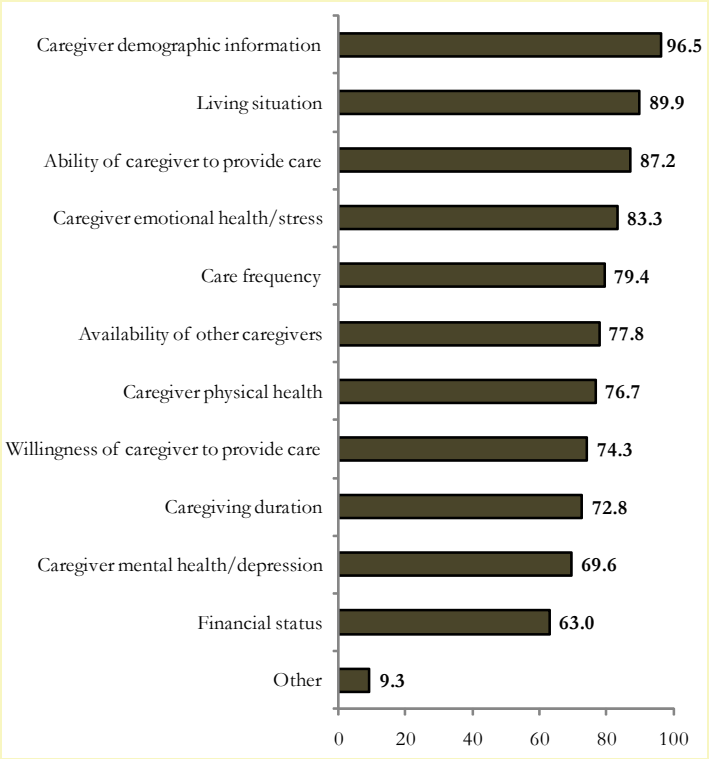
Assessments and Tracking Caregiver Outcomes

Participants were asked whether caregivers receive an assessment, independent of the care recipient's assessment. Over 70 percent (72.2%) indicated that they do conduct an assessment of caregivers. Of those who do, 46.9% indicate the assessment of the caregiver is completed by a staff member, 22.2% indicate that both the caregiver and a staff member conduct the assessment and 3.1% indicate that a self-assessment is completed by the caregiver.

Respondents were asked to identify which items are included in their assessment of caregivers. Caregiver demographic information, living situation and ability of caregiver to provide care are the most common items included on the assessments (see Figure 3).

Over 80 percent (84.8%) of AAAs use a formal assessment tool for their caregiving assessment. Of those who do, 35.1% indicated that their formal assessment tool was developed in-house. Among those agencies that do not have a tool developed in-house, the majority identify the tool as being developed by their state unit on aging.

Figure 3. Proportion of AAAs that Include Specific Items in their Assessment of Caregivers



Of the 175 participants who responded to the ways in which assessments are used, 89.1% determine appropriate information and resource needs, 68.6% develop a formalized care plan, 64.0% make a referral to another agency and 62.9% make a referral to another service within the agency.

When asked about tracking caregiver outcomes, just over 40 percent (42.1%) of AAAs or their contracted providers indicated that they track outcomes for caregivers (e.g., reduced stress, delayed institutionalization of care recipient, reduced burnout).

Contact with Caregivers

When providing services to caregivers, over a third (36.0%) of AAAs state that their requirement or standard for ongoing contact with caregivers is based on the demand of the caregiver, 20.4% monthly, 17.3% semi-anually, 15.3% other, 5.9% more often than monthly and 5.1% annually. Those who checked "other" indicated that they have contact with caregivers on a quarterly basis or develop contact standards based on the needs of the caregivers.

Enrolled Caregivers

Participants were asked for an approximate number of total caregivers enrolled in any of their caregiver programs at the time of the survey (April 2010), regardless of funding. On average, AAAs had 416 caregivers enrolled (median: 124, range 2-9200).

Participants were also asked to provide the number of new family caregivers who were enrolled during the first quarter of 2010 (January - March 2010) into programs funded all or in-part with Title III E (National Family Caregiver Support Program). On average, AAAs enrolled 120 new family caregivers into the program (median: 25, range: 0-4541). Some provide short-term or one-time services to caregivers so their current enrollment may be lower than the total number served during a quarter. When asked if the quarterly enrollment number is more than usual, fewer than usual, or a typical enrollment when compared to other quarters of the year, 68.5% said the numbers were typical, 16.1% said they were less than usual and 15.4% said more than usual.

Training and Technical Assistance

Respondents were asked to identify up to 5 areas of training or assistance most useful for their organization in enhancing their caregiving programs. The most commonly mentioned areas include expanding caregiver service options (54.0%), developing better outreach strategies to caregivers (53.7%), and leveraging additional resources (50.7%). For a complete list of training and technical assistance needs, please see Appendix C at the end of this report.

For More Information
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Funding for this document was made possible (in part) by grant 90AM3126 from the U.S. Administration on Aging. The views expressed in these materials do not necessarily reflect the official policies of the U.S. Department of Health and Human Services, or represent official U.S. Administration on Aging policy.

The project team would like to acknowledge Pamela Marks at Scripps, Sandy Markwood, Abigail Morgan, and Helen Eltzeroth with n4a, Robert Hornyak and Greg Link with AoA, Gail Hunt with the National Alliance for Caregiving and AAA directors Helen Cockrell, Pam Dodge, Brian Duke, Annette Graham and Thelma Watson for their valuable input and assistance in the design of the workforce survey.

Appendix A

Partnerships
(Proportion of AAAs Having Partnerships with Specific Organizations to Provide Support to Caregivers)

%	
66.4	Alzheimer's Association
55.9	Disease-specific groups (Alzheimer's, Parkinson's)
54.4	Health Care Providers (hospital, public health or Indian Health Service clinic, physician office)
53.2	Adult Protective Services (state, tribal or local)
49.2	Long-Term Care Facilities/Providers
49.2	Other Social Service Organizations (e.g., local 211 organization)
47.7	State Health Insurance Assistance Program (SHIP)
40.8	Medicaid (state or local)
40.8	Local caregiving coalitions
40.5	Other AAAs
37.8	Mental Health/Behavioral Health (state, tribal or local)
37.8	Advocacy Organizations (AARP, n4a)
37.5	Faith-based Organizations
37.2	Disability Service Organizations (state, tribal, local, Centers for Independent living)
37.2	Transportation Agencies (state or local)
31.8	Statewide caregiving coalitions
31.5	Charitable Organizations (United Way, Easter Seals, Red Cross)
30.3	Department of Health (state, tribal, or local)
29.7	Federal Programs (i.e. Social Security, Medicare)
27.6	Educational Institutions
25.2	U.S. Department of Veterans Affairs
25.2	Public Housing Authority or Other Housing Programs
22.8	Emergency Preparedness Agencies (state, tribal or local)
20.4	Businesses with employees who are also caregivers (national and local businesses, fiscal intermediaries)
18.6	Intellectual or Developmental Disabilities Organizations (state, tribal or local)
14.1	Other
10.5	Parks and Recreation
8.1	Managed Care/HMO Networks
3.9	Tribal Organization or Consortium
1.5	Indian Health Service

Appendix B

Funding Sources
(Proportion of AAAs Using Specific Funding Sources to Fund Caregiving Programs)

%	
98.3	Title III E funding (National Family Caregiver Support Program)
35.9	State general revenue
33.7	Title III B funding (Supportive Services and Centers)
29.8	Local funding (city, village, municipal, county funds)
19.8	Consumer co-pay/cost share
18.9	Other charitable donations (United Way, service organization grants, private donations)
18.7	Grant funds (including foundations and other federal programs)
15.0	Medicaid Waiver
12.8	Fundraising, development campaign
12.5	State Health Insurance and Assistance Program (SHIP)
9.5	Other state funding (e.g., gaming, lotteries)
7.2	Alzheimer's Association Respite Funding
6.7	Private pay consumers (exclude consumers who share costs for programs)
6.7	Other
5.6	Medicaid
5.3	Transportation funding (federal and/or local)
4.5	Department of Veterans Affairs funding
2.8	Businesses/employer caregiver programs
2.8	Funding from faith-based organizations
1.4	HUD funding (Housing and Urban Development)
1.1	PACE
0.6	Medicare
0.0	Indian Health Service

Appendix C

Training and Technical Assistance Needs
(Proportion of AAAs Identifying Specific Training and Technical Assistance Needs)

%	
54.0	Expanding caregiver service options
53.7	Developing better outreach strategies to caregivers
50.7	Leveraging additional resources
43.4	Developing strategies for working with employers to support employed caregivers
36.4	Reaching more diverse caregiver populations (ethnically, geographically)
35.2	Establishing evidence-based programs for caregivers
32.0	Establishing quality measures for serving caregivers
29.3	Establishing core competencies for staff working with consumers and their family caregivers
22.3	Providing specific training skills, e.g. lifting, transferring techniques
20.8	Implementing promising practices
17.3	Developing partnerships
17.3	Establishing consumer-direction in caregiver programs
16.1	Working with Lifespan Respite Care (serving all ages and disabilities)
2.9	Other