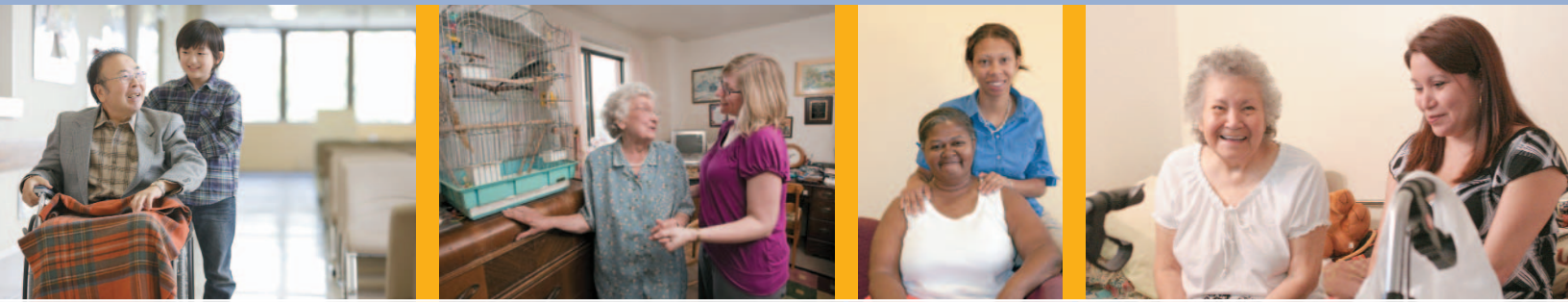


A REPORT BY THE NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING (n4a)

BUILDING CAPACITY

To Support Family Caregivers



Caregiver Support Survey Report on Area Agencies on Aging

OCTOBER 2011



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ACKNOWLEDGEMENTS

In April 2010, the National Association of Area Agencies on Aging (n4a) partnered with Scripps Gerontology Center at Miami University in Oxford, Ohio, under a grant from the U.S. Administration on Aging (AoA), to conduct a survey about caregivers. The purpose of the survey was to obtain a broad understanding of the programs and services provided to caregivers by Area Agencies on Aging (AAAs) nationwide and to identify the training and technical assistance needs of AAAs related to caregiving activities.

Development of the survey, data collection, data analyses and figures presented in this report was conducted by Jane K. Straker, Ph.D.; Abbe E. Lackmeyer, MGS; Suzanne R. Kunkel, Ph.D.; and Emily J. Robbins, Ph.D. from Scripps Gerontology Center,

Miami University in Oxford, Ohio and submitted to n4a as [AAA Caregiving Survey Results](#).^[1] Other contributors to this report include: Abigail Morgan, Sandy Markwood, Helen Eltzeroth, Brian Duke, Sandra Reynolds and Jo Reed.

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Copies of this report, along with other project materials, are available at: www.n4a.org/caregiver_report.pdf and <http://sc.lib.muohio.edu/handle/2374.MIA/4398>

INTRODUCTION

According to a 2009 report on caregivers conducted by the National Alliance for Caregiving (NAC) and AARP, there has been an increase in the proportion of caregivers who say they need help or information. Caregivers are the family, friends, and/or others who provide support and basic assistance for an older adult, outside of government-sponsored or private-pay formal services. One of the main areas they want information on is keeping their care recipients safe at home.^[2] Many older adults in need of care would have difficulty remaining safely in their own homes and communities without the support of their caregivers. These caregivers are vital to the quality of life of countless older adults nationwide. As resources to assist older adults face challenges, the role of the caregiver in the long-term care framework becomes even more critical.

Area Agencies on Aging (AAAs) have been designated to address the needs and concerns of all older Americans and their family caregivers at the regional and local level. As part of the Aging Services Network, these agencies, established under the Older Americans Act (OAA) in 1973, and their service providers deliver a range of home- and community-based services to caregivers and their care recipients. AAAs assist older adults to live with independence and dignity in their own homes and communities for as long as possible, and assist caregivers to address both the concerns of their care recipients and their own concerns. Information and services help support these caregivers as they carry out their important role in providing long-term care to family members and friends. The findings of this AAA survey confirm the commitment that AAAs have to support caregivers through programs and interventions nationwide.

The Survey

In April 2010, the National Association of Area Agencies on Aging (n4a) and Scripps Gerontology Center released a web-based survey to the 629 AAAs nationwide. The goal of the survey was to develop an understanding of the programs and services provided to caregivers by AAAs. The survey was available for approximately three weeks during the month of April. A total of 360 AAAs responded for a response rate of 57.3 percent.

Caregivers Enrolled in Programs

The survey found that caregiver support continues to be an important part of AAA services. In the first three months of 2010, on average, each AAA had 124 new caregivers enrolled in their National Family Caregiver Support Programs and an average of 416 total enrolled caregivers (range: 2 to 9,200 caregivers nationwide). While some agencies reported that their quarterly enrollment was more than usual (15.4 percent) and others that it was less than usual (16.1 percent), two-thirds (68.5 percent) reported that the enrolled numbers were typical. It should be noted that “Some [agencies] provide short-term or one-time services to caregivers so their current enrollment may be lower than the total number served during a quarter.”^[3]

The relatively stable number of caregivers served is in keeping with other research. According to the NAC 2009 study, although the percentage of caregivers assisting those over the age of 85 (the fastest growing segment of the aging population) has increased, the percentage of people who are caregivers to other ages does not appear to have changed significantly since 2004.^[4] With the arrival of the age wave of the Baby Boom generation and increasing life expectancies, however, the number of caregivers will undoubtedly increase in the years ahead.

Characteristics Of AAA Caregiving Programs

How Caregiver Programs are Structured

At most AAAs, caregiver programs are not structured as only one type of service delivery; rather, AAAs develop various approaches to caregiver services. Most commonly, caregiver programs are integrated with other services at the AAA or with another agency (59.6 percent). Structural formats include:

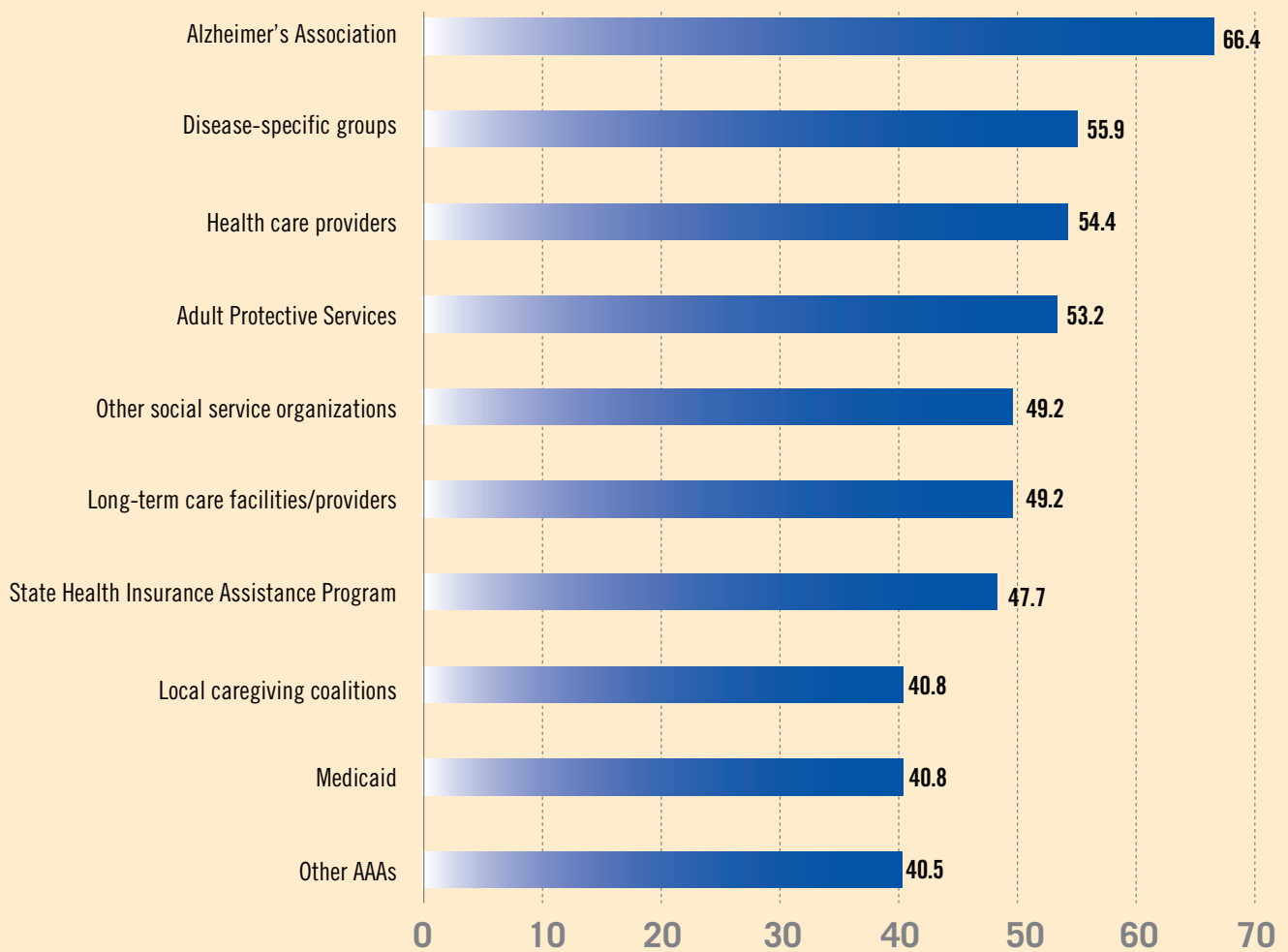
- Contracts with other agencies to provide some services (52.5 percent)
- A specialized caregiver support unit at the AAA (52.0 percent)
- A case management unit at the AAA or other agency (48.9 percent)
- Consumer-directed options of at least some programs (40.7 percent)

All of these formats require the commitment of AAA staff time to implement. “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 percent) 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.”^[5]

Partnerships that Provide Caregiver Support

In order to expand their ability to support caregivers, AAAs have developed well-defined working relationships with other organizations. These partnerships are either formalized with a contract or memorandum of agreement, or are informal. AAAs have, on average, 10 partnerships with other organizations to provide caregiver support. The most common partnerships, identified by over 50 percent of AAAs that responded to the survey, include the Alzheimer’s Association and other disease-specific groups, health care providers and Adult Protective Services. Other partnerships, identified by nearly half of AAAs, include social service organizations, long-term care facilities/providers and State Health Insurance Assistance Programs (SHIPs) (Figure 1). For a complete list of partnerships, see Appendix A.

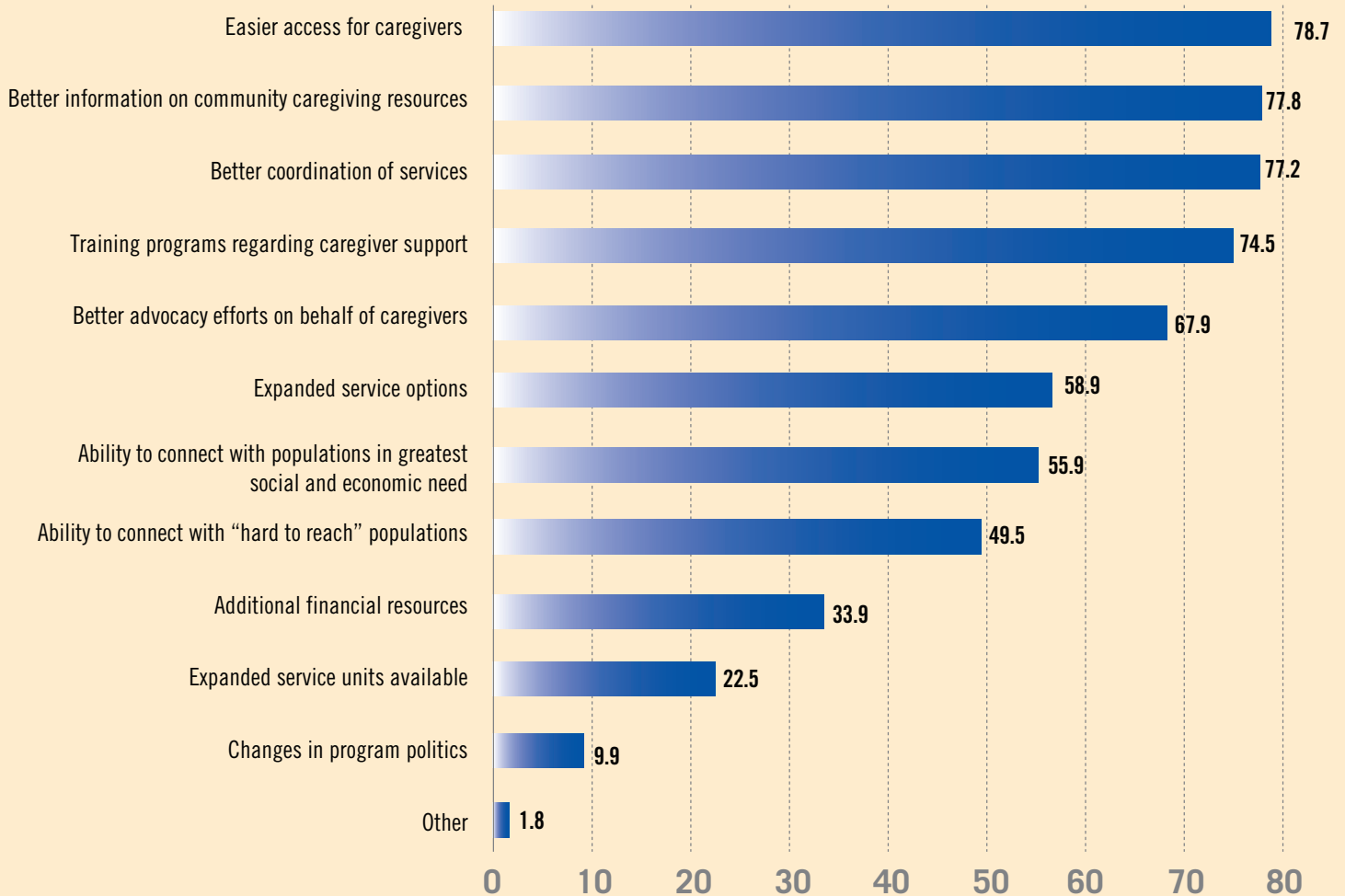
FIGURE 1 | Proportion of AAAs Having Partnerships with Specific Organizations



Source: Straker, Lackmeyer, Kunkel & Robbins, 2010.

AAAs have identified important benefits for caregivers from these partnerships, including providing easier access to programs (78.7 percent), better information on community caregiving resources (77.8 percent), better coordination of services (77.2 percent), and training programs regarding caregiver support (74.5 percent). Other outcomes of the caregiver support partnerships, reported by more than 50 percent of

FIGURE 2 | Proportion of AAAs Identifying Specific Outcomes Achieved by Partnerships



Source: Straker et. al. 2010.

AAA participants, include better advocacy efforts on behalf of caregivers, expanded service options and the ability to connect with populations in greatest social and economic need (Figure 2). Partnerships comprise an important part of AAA outreach and enhance their ability to support caregiver roles.

Funding of Caregiver Programs

Almost all of the participants in this survey (98.3 percent) listed the National Family Caregiver Support Program as their most common funding source for caregiving programs. This particular support program, established under Title III E of the Older Americans Act, ^[6] makes grants available to states to enable AAAs or their contractors to provide specific systems of support services for family caregivers. Services provided under this support program include respite care, counseling, information about and access to services, support groups and caregiver training to assist caregivers in their role as caregivers. Other, less common sources of funding to support caregiving programs come from state revenues (35.9 percent), OAA Title III B funding (supportive services and centers)^[7] (33.7 percent) and local government funding (29.8 percent). For a complete list of funding sources, see Appendix B.

Caregiver Services

Of twenty-two supportive caregiver services listed in the survey, the most commonly provided services include information and referral/assistance (94.2 percent), in-home respite during the day (89.2 percent), support groups (74.7 percent) and education and training on topics related to caregiving (e.g., preventing caregiver burnout, legal issues) (73.3 percent). Less commonly provided services include Internet or web-based monitoring technology (6.4 percent) and corporate eldercare (defined as employer assistance to family caregivers) (8.1 percent).

How Services are Provided

Respondents were asked to identify what type of family caregiving is supported by these services and how services are offered--whether directly by AAA staff or volunteers, through a contract with an agency provider or with a consumer-directed option (one in which people are given maximum choice and oversight of their care providers and services).

For respondents who indicated a consumer-directed option, over three-quarters (78.5 percent) identified the caregiver as the primary consumer (the individual whose directions guide service planning and delivery), while 21.5 percent identified the care recipient. Of those AAAs with consumer-directed options, funding includes cash payments to caregivers (29.2 percent), vouchers (20.8 percent) or both cash and vouchers (5.6 percent). Four out of 10 (44.4 percent) AAAs report not providing either direct cash payments or vouchers (See Table 1).

TABLE 1 | Services, Types of Caregivers and Service Provision Strategies

SERVICE	TYPE OF FAMILY CAREGIVING (% of those who provide each service)									SERVICE PROVISION			
	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 care giving 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

Some programs that AAAs provide are research-tested program models or interventions that have been developed into practical, effective community programs. These evidence-based services can provide health and information benefits to participants and are provided for specific programs such as Alzheimer's disease education/training programs, education/training for hands-on caregiving skills, education/training on other topics and stress management. The most commonly mentioned program used was "Powerful Tools for Caregivers."

Information and Referral Services

Information and Referral (I & R) is the most common service provided to caregivers in this survey (94.2 percent). Although caregivers sometimes neglect their own needs while assisting their care recipients, AAAs report that the majority of caregivers seeking general I & R are looking for services for both themselves and their care recipients (75.8 percent). A much smaller percentage (22.4 percent) seek information only for the care recipient and a very small percentage (1.7 percent) seek caregiver information only for themselves. A large majority of AAAs (90.7 percent) indicate that they routinely ask caregivers who are looking for information for the care recipient about their own needs as a caregiver.

Transportation

Research shows that the percentage of caregivers who have had an outside service provide transportation for care recipients has increased from 17 percent to 30 percent in the last five years.^[8] This increase in outside service use, however, does not mean that caregivers are not accompanying their care recipients on trips. Often caregivers wish or need to go with their care recipients for outings in order to assist during physician appointments, grocery shopping, pharmacy pick-ups, etc.

The majority of AAA participants indicate that the caregiver is able to ride along when the care recipient receives medical and non-medical transportation (94.4 percent and 88.6 percent, respectively). Having transportation for both medical and non-medical outings is an important part of being able to remain independent in community settings; providing this service reinforces the AAAs' strong commitment to, and understanding of, caregiver needs.

Corporate Eldercare Services

Caregivers in the workplace face special challenges. According to the 2009 NAC study, over seven in 10 caregivers were employed at some time when they were caregiving (73 percent); and among them, two-thirds have gone in late, left early or taken time off during the day to deal with caregiving issues (66 percent).^[9] Participants in the 2010 AAA survey report providing corporate eldercare services such as education and training (e.g., seminars, guest speakers) (89.7 percent), access to geriatric care managers (31.0 percent), employee survey on need for caregiving assistance (31.0 percent) and dependent care accounts (3.4 percent). It should also be noted that a 2010 workforce survey completed by AAAs found that one in four of the AAA participants also provide paid parental leave, attesting to the agencies' commitment to assisting their own working caregivers.^[10]

Caregiver Assessment, Tracking And Follow-Up

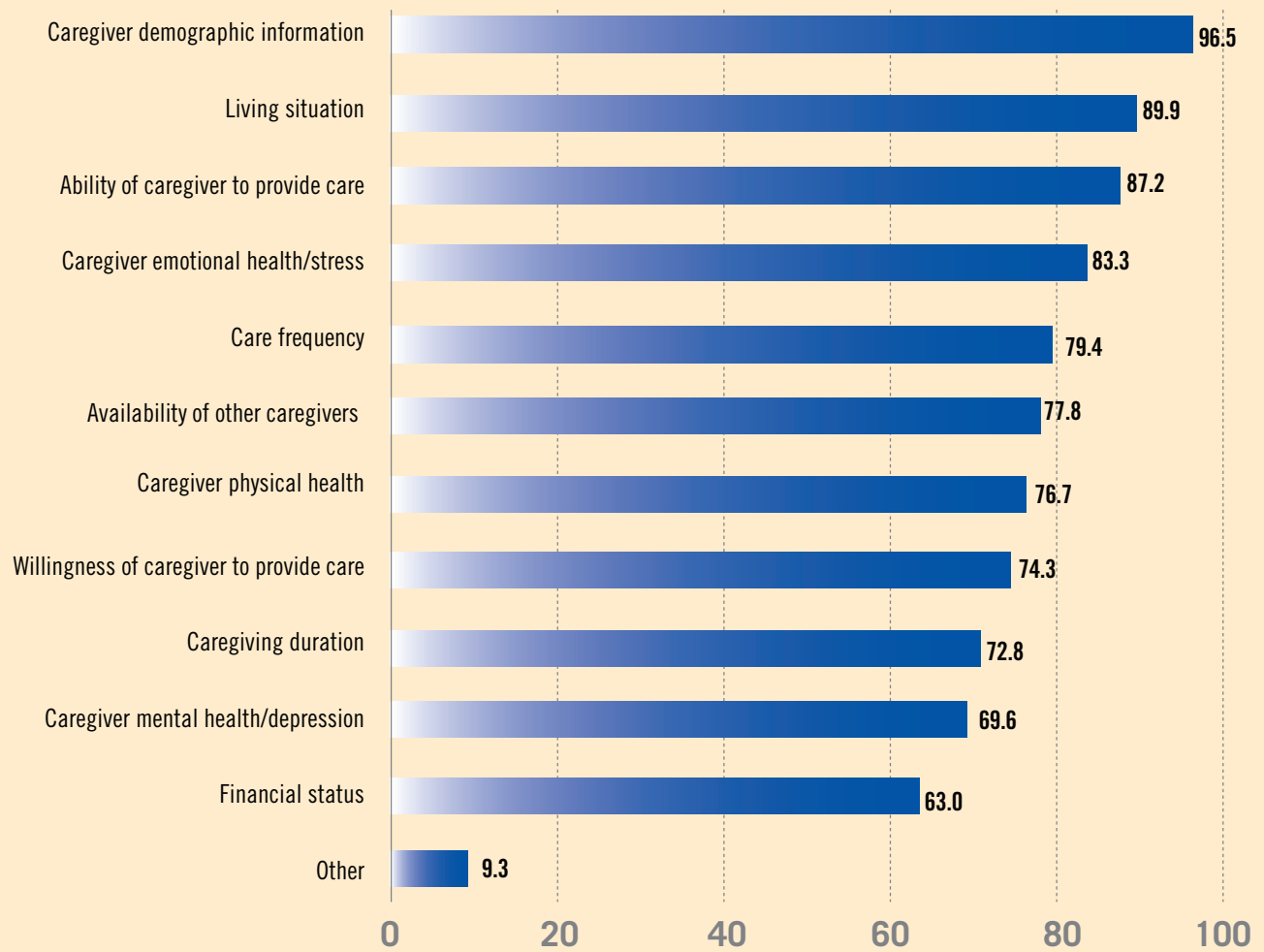
Assessments and Tracking Caregiver Outcomes

Over 70 percent of AAA participants in the survey indicated that they conduct an assessment of caregivers, independent of the care recipient's assessment. Over 80 percent of the AAAs that provide caregiver assessments use a formal assessment tool. Almost two-thirds of AAAs use a tool developed by another organization, primarily provided by their State Unit on Aging. Slightly more than one-third of the AAAs using formal assessment tools indicate that tool was developed in-house. The most common items included on the assessments are caregiver information, living situation and ability of caregiver to provide care (Figure 3).

AAAs use these assessments to help determine and support caregiver needs. Of the participants who responded to the ways in which the caregiver assessments are used, the majority (89.1 percent) indicated that they use them to determine the caregivers' resource and information needs; 68.6 percent develop a formalized care plan, 64.0 percent make a referral to another agency and 62.9 percent make a referral to another service within the agency.

Follow-up with Caregivers

Ongoing contact with caregivers is an important part of AAA services. Many AAA participants or their contract providers who serve caregivers indicate that they track outcomes for caregivers (42.1 percent) in areas such as reduced stress, delayed institutionalization of care recipient and reduced burnout. Once contact with caregivers is established, over a third (36.0 percent) of AAA participants state that their standard for ongoing contact with caregivers is based on the needs of the caregiver. Participants report contact can be monthly (20.4 percent), semi-annually (17.3 percent), other (15.3 percent), more often than monthly (5.9 percent) and annually (5.1 percent).

FIGURE 3 | Proportion of AAAs that Include Specific Items in their Assessment of Caregivers

Source: Straker et, al. 2010.

Training And Technical Assistance Needs

Looking to the future, AAAs are clearly committed to caregiving programs and services. When asked to identify up to five areas of training or assistance they would find most useful to enhance their caregiving programs, the most commonly mentioned areas were:

- Expanding caregiver service options (54.0 percent)
- Developing better outreach strategies to caregivers (53.7 percent)
- Leveraging additional resources (50.7 percent)
- Developing strategies for working with employers to support employed caregivers (43.4 percent), and
- Reaching more diverse caregiver populations (ethnically, geographically) (36.4 percent)

AAAs' vision for the future clearly supports strengthening caregiver support programs, resources and outreach activities. See Appendix C for a complete listing of Training and Technical Assistance Needs.

CONCLUSION

AAAs have long recognized that caregivers both seek and need support, and have made caregiver support an important part of their service delivery and referral services. Agencies across the nation use various strategies to provide such support, including evidence-based service programs, information and referral services, transportation programs that enable caregivers to accompany care recipients, assessments and outcome tracking and follow-up contact with caregivers. Additionally, the extensive use of partnerships allows AAAs to expand their community outreach as well as make more enhanced services available.

It is clear from the findings of this survey that when the majority of caregivers are looking for information on services, both the caregiver and care recipient are in need of services. While the number of caregivers remains relatively stable, with the aging of America and projections that the U.S. population above the age of 65 will increase dramatically in the coming years, the number of caregivers will likely increase concurrently. It will be imperative that AAA caregiver programs remain strong; further, more financial resources will be necessary as the AAAs grow their programs to match increasing demands.

Expanding partnerships will strengthen the position of the AAAs; adding more volunteer programs can help free up staff to develop extended outreach to caregivers, employers and diverse populations, and expand caregiver service options. The partnerships, programs and services in place at AAAs today can provide the framework to meet the needs of the caregivers of tomorrow and support the training and assistance needs that the AAAs have identified in envisioning their future.

Appendix A

PARTNERSHIPS

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

Percent

66.4	Alzheimer’s Association
55.9	Disease-specific groups
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
47.7	State Health Insurance Assistance Program (SHIP)
40.8	Medicaid
40.8	Local caregiving coalitions
40.5	Other AAAs
37.8	Mental health/behavioral health
37.8	Advocacy organizations (e.g., n4a, AARP)
37.5	Faith-based organizations
37.2	Disability service organizations
37.2	Transportation agencies
31.8	Statewide caregiving coalitions
31.5	Charitable organizations (e.g., United Way, Easter Seals, Red Cross)
30.3	Department of Health
29.7	Federal programs (e.g., 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
20.4	Businesses with employees who are caregivers
18.6	Intellectual or developmental disabilities organizations
14.1	Other
10.5	Parks and Recreation
8.1	Managed care/HMO networks
3.9	Tribal organizations or consortiums
1.5	Indian Health Service

Appendix B

FUNDING SOURCES

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

Percent

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
19.8	Consumer co-pay/cost share
18.9	Other charitable donations
18.7	Grant funds
15.0	Medicaid Waiver
12.8	Fundraising, development campaign
12.5	State Health Insurance and Assistance Program (SHIP)
9.5	Other state funding
7.2	Alzheimer’s Association Respite
6.7	Private pay consumers (excluding consumers who share costs for programs)
6.7	Other
5.6	Medicaid
5.3	Transportation funding
4.5	Department of Veterans Affairs
2.8	Businesses/employer caregiver programs
2.8	Faith-based organizations
1.4	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)

Percent

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
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

ENDNOTES

- [¹] Straker, J.K., Lackmeyer, A.E., Kunkel, S.R., and Robbins, E.J. AAA Caregiving Survey Results, June, 2010. <http://sc.lib.muohio.edu/handle/2374.MIA/4398>.
- [²] National Alliance for Caregiving and AARP, November 2009. Caregiving in the U.S.: A Focused Look at Those Caring for Someone Age 50 or Older. Executive Summary. www.caregiving.org
- [³] Straker et al., p. 5.
- [⁴] National Alliance for Caregiving and AARP.
- [⁵] Straker et al., p. 1.
- [⁶] Unofficial Compilation of the Older Americans Act of 1965, as amended in 2006 (Public Law 109-365), www.aoa.gov.
- [⁷] Ibid.
- [⁸] National Alliance for Caregiving and AARP.
- [⁹] Ibid.
- [¹⁰] Morgan, A., Markwood, S., Eltzeroth, H., & Reed, J. Building Capacity Through Our Workforce: Workforce Survey Report on Area Agencies on Aging, May 2010. National Association of Area Agencies on Aging, Washington DC 20036.

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