



Educating & Advocating

Fiscal Year 2014/2015 Family Caregiver Needs Assessment Report

“Keep your focus on the quality of human interactions for both you and the one you are caring for. The medical service system of today is consumed by measurement, efficiency, liability avoidance, and regulatory compliance and has little institutional focus on simple humanness.

Both for your sake and the one you are caring for you have to protect (your) humanity.”

-Family Caregiver Survey Participant

Executive Summary:

The Older Americans Act funds services for Family Caregivers through Title III E, which is locally administered by the Marin County Area Agency on Aging (AAA). Every four years, the AAA issues a Request for Proposal (RFP) to award contracts to qualified home-and community-based agencies. To inform allocation of resources for the 2015 – 2019 contracts, a needs assessment of family caregivers—defined as people who provide unpaid care for a friend, spouse, or other relatives—was conducted by the Planning Committee of the Marin County Commission on Aging.

Background:

In 2013, 40% of American adults identified as being a caregiver, in comparison to 30% in 2010.¹ The U.S. Department of Finance has estimated that older adults, persons ages 60 and over, will represent 27% of the population in 2015 and 30% in 2019.² With age, there is often a decline in health, which requires additional care. In 2015, persons over the age of 75 comprised 28% of all older adults in 2015 and will increase slightly to 30% in 2019.³ Marin County has the longest life expectancy for women in the United States, and ranks fifth among males.⁴ With the increased number of older adults and associated longevity, there will be an increased demand for the time of family caregivers, who nationally provide at least \$450 billion in unpaid hours per year.⁵ These caregivers are often drained of financial, emotional, and physical resources and

¹ Pew Research Center, “Family Caregivers are Wired for Health.” Available at: <http://pewinternet.org/Reports/2013/Family-Caregivers.aspx>. Accessed 12/9/2014.

² State of California, Department of Finance, Demographic Research Unit. State and County Population Projections by Race/Ethnicity and Age (5-Year Increments) 2010-2060 (as of July 1) Report P-2. Available at: <http://www.dof.ca.gov/research/demographic/reports/projections/P-2/>. Accessed 12/10/14.

³ Ibid.

⁴ Wang H, et al. “Left behind: widening disparities for males and females in US county life expectancy, 1985-2010.” *Population Health Metrics*. 2013; 11:8.

⁵ L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, the Growing Contributions and Costs of Family Caregiving*, AARP Public Policy Institute Insight on the Issues 51 (Washington, DC: AARP, June 2011).

health. The need for services offering support to these unpaid workers is imperative in our health care system and community.

The role of family caregiving cuts across all demographics. Majority of current caregivers are between the ages of 35-64, but the number of younger people assuming this role is also growing. It is a role shared equally between men and women.⁶ Many are still in the workforce and have other familial obligations. In a national study, of those who identified as family caregivers, at least 40% are utilizing the internet to search for information and resources.⁷

Methodology:

To assess the needs of family caregivers in Marin County, members of the Commission on Aging (COA) were asked to complete Family Caregiver Surveys from 10/2014 – 12/2014. Commissioners utilized a seven open-ended question survey to be administered to family caregivers that they knew personally or family caregivers located through related events and/ or organizations. Of the 23 members of the Commission, 75% collected surveys, with an average of 4 surveys each. A total of 74 surveys were collected. Survey results were entered by hand into SurveyMonkey. Survey analysis was conducted by Area Agency on Aging staff in conjunction with a member of the COA Planning Committee, who created response driven categories to sort results. In the charts below, “N” represents the number of persons who responded to a question. Response percentages are based on total number of individual responses; if one listed five areas, this would be counted five times in the baseline.

Summary of Results:

The average time respondents have spent in a caregiving role was 5 years, with a range of less than 1 year to 27 years. A constant theme among respondents was feeling overwhelmed, as if there was no time to gather information or to perform any kind of self-care. Those that did maintain care of themselves were able to do so by taking breaks for enjoyable activities and, when possible, a vacation away. People felt that there was a lack of qualified paid caregivers and a means for vetting them. There was a recognized need for a centralized place or “one stop shop” to acquire information and resources online, via phone, and in person. Across questions, caregivers reported finding resources via the internet. Respondents mentioned the need to create a network of support, be it though groups, peers, or family. Many mentioned the need to maintain love and tolerance both towards oneself and the person receiving the care. For more descriptive analysis, please see charts below.

Pew Research Center, “Family Caregivers are Wired for Health.” Available at: <http://pewinternet.org/Reports/2013/Family-Caregivers.aspx>. Accessed 12/9/2014.

⁷ IBID

Recommendations:

The frequent mention of a “one stop shop” requires allocations to Information and Assistance. Stakeholders should commit to creating/ maintaining a centralized source of information. There should be an emphasis on the need to keep up-to-date resources online. Any organizations applying for funds must work in partnership with new AAA Information and Assistance Unit to share information, offer trainings, and create a strong network of support. The frequent mention of the necessity of breaks from caregiving indicates the continued need for respite services.

Caregiver respondents indicated the need to talk to someone familiar with their concerns, as well as difficulty in managing stress and the physical demands of caregiving. There should be specific funds allocated towards Peer Counseling. Training funds should be used to include classes on body mechanics and stress reduction. Respite services should be available during caregiver trainings.

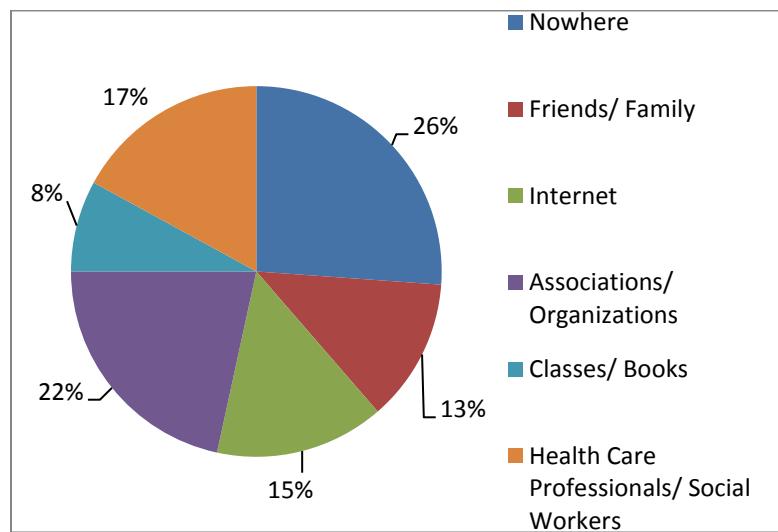
There was a demand for qualified paid caregivers to provide intermittent care. RFP should stipulate that bidders work with existing registry services, provided by both for-profit and non-profit agencies.

Data Analysis

Where are you seeking (or did seek) information to prepare for this role?

Approximately 25% of respondents did not seek information to prepare and be informed about their role as family caregiver. Some felt they had no time in which to do so and others did not feel it necessary. Many did their own research utilizing the internet, attending seminars, and reading books. A caregiver comments, “There seems to be no easy place to access resources except by searching the internet.” Another says, “I am reading everything I can on the internet.”

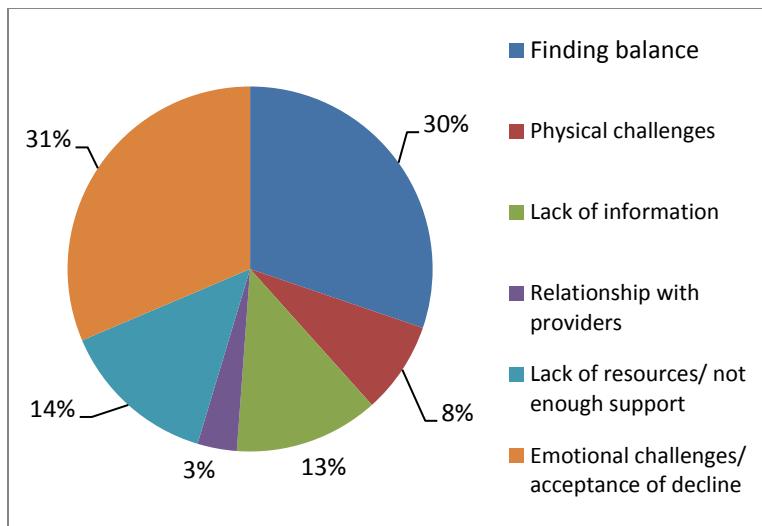
Others sought information from organizations and associations, the most frequently cited being the Alzheimer’s Association (N=9). Other organizations mentioned were: Marin Center for Independent Living (N=2), Marin County (N=1), Veterans Administration (N=2), Whistlestop (N=3), Living Well (N=1), The Redwoods (N=1), Institute on Aging (N=1), Jewish Family and Children’s Services (N=1), and Marin Villages (N=1).



What challenges did you face as a caregiver? (N=71)

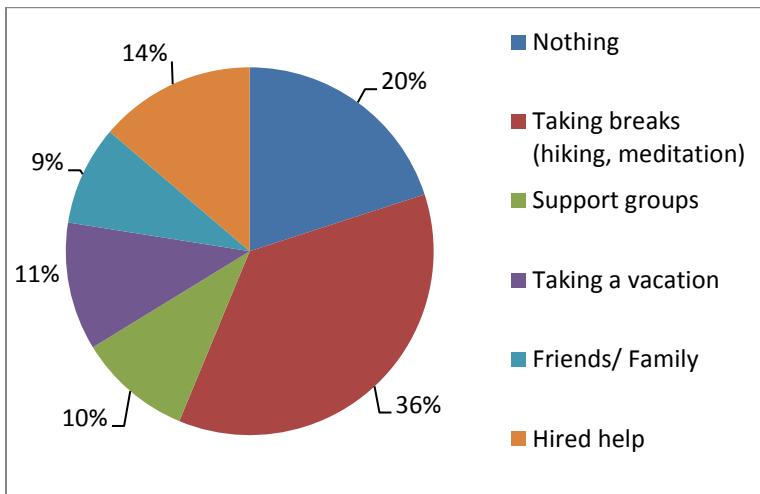
The most frequently cited challenges facing caregivers was the need to find a balance in life with their role as a caregiver and maintaining self-care. Also expressed was the need to accept the health and decline of the patient and subsequent emotional challenges, such as depression.

There was a need for additional information and resources quickly. Caregiver comments include: "It all happened so fast I had no time to research or investigate choices." "My primary challenges are learning about Alzheimer's disease and assembling the support I am going to need as the disease progresses."



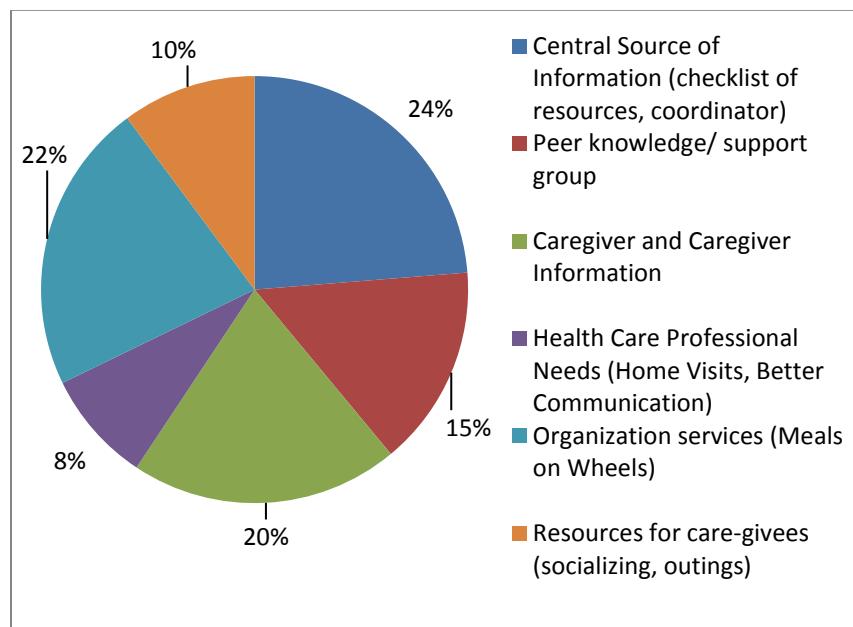
What did you do to take care of your own health and well-being? (N=69)

The most frequent way respondents practiced self-care was to take frequent breaks to do things they enjoyed, including walking, birding, yoga, and going to a beautician. The second most frequently cited response that people did nothing as they felt overwhelmed and that there was not sufficient time for self-care. Others cited the need to hire outside paid help. People also took care of themselves by seeking support from groups, friends, and family.



What services do you think would be (or would have been) most helpful to you? (N=59)

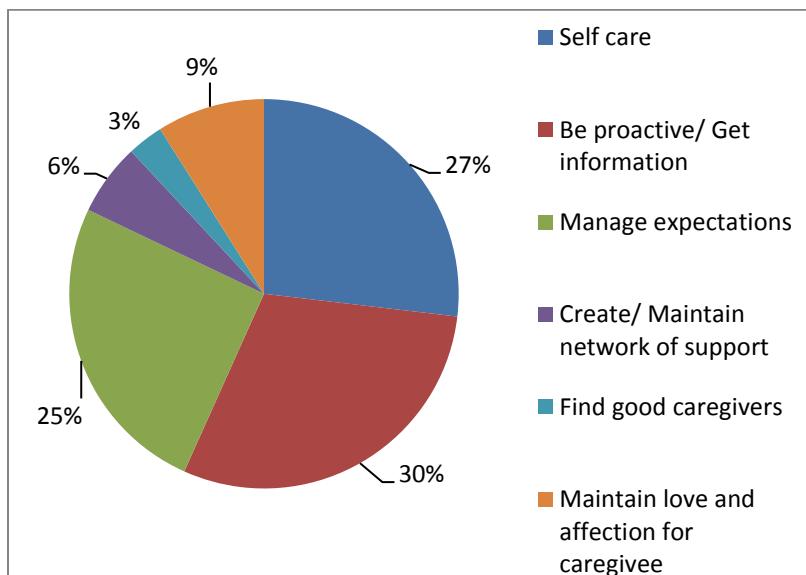
Among those who responded, the most commonly cited response was a need for centralized information. “If I just knew there was one place to call or a how-to binder with local services.” Also noted was the need for caregiver information and vetting, including “home health care workers to lighten the ordinary tasks that don’t rewire continual or knowledge base skills.” Caregivers received support from organizational services, especially Hospice. There was a need to “talk to someone who had been down this road before” through support groups or peer conversation.



What advice might you have for other caregivers or those who may be in a caregiving role in the future? (N=67)

The majority of respondents recommended that new caregivers be proactive in getting information and resources. “Educate yourself about the disease, resources, trajectory. Create the support team as soon as possible,” advises a respondent. “Contact every agency at the county and state. Be a squeaky wheel,” Says another. Also noted was the need to maintain good self-care in taking breaks and creating time for oneself. Being aware of one’s own needs, desires, and health was mentioned. Many comments were based around managing expectations by being “prepared for things to go badly.” There were also mentions of the importance of maintaining tenderness, love, and affection.

“Stay focused, give and take love from the individual you are caring for, you will remember the best times, the bad times fade quickly.”



Demographics of caregivers (all)⁸

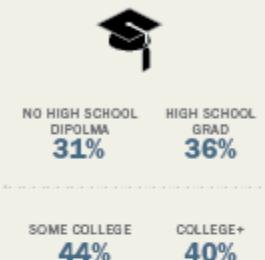
Who Are Caregivers?

Among all adults, the percent within each group who care for someone.

All adults ages 18+



Educational Attainment



Household Income



Household Size



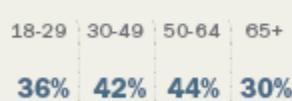
Race/ethnicity



Parent of Minor



Age



Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults. See Appendix for further details.

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⁸ Pew Research Center, “Family Caregivers are Wired for Health.” Available at: <http://pewinternet.org/Reports/2013/Family-Caregivers.aspx>. Accessed 12/9/2014.