



## Understanding Caregiver Needs in Maryland

### Summary of Key Findings: Caregiver Survey Maryland 2015

#### Survey Features

The Maryland Caregivers Support Coordinating Council conducted a state-wide survey in 2014-2015 to understand the most important needs of caregivers in Maryland. More than 1,700 people from across the state responded. Key features of the survey include:

- Examined issues across the lifespan (i.e. all ages)
- Available in print and online
- Spanish language survey available
- Achieved broad geographic representation across the state
- Conducted wide outreach in the community

#### What Did We Learn?

Key issues identified by Maryland respondents reveal themes similar to national survey findings:

- Caregivers are more likely to be female and middle aged
- Approximately half of care recipients are age 75 or over
- Caregivers are likely to be caring for someone with Alzheimer's, dementia, or other memory problems, followed by those with intellectual and developmental disability
- The emotional burden of caregiving is high (40% report high burden), yet
- Awareness and use of services is low
- Respite services (i.e. the need for time off from caregiving duties) is a top need, especially among those spending more than 20 hours a week caregiving
- Of those who use services, the most common form of payment is self-pay – 15-20% of caregivers report great financial strain due to caregiving
- More than half of caregivers are also working full time; among these, most report having to adjust their work schedule in order to give care
- 5-15% of caregivers give up work entirely to fulfill the caregiving role

#### What is the economic value of Caregivers' time and efforts in Maryland?

Maryland family Caregivers provide services valued at \$ 9.4 billion per year\*.

- ✓ 18 average hours spent caregiving each week in Maryland
- ✓ 771,000 caregivers in Maryland
- ✓ 717,000,000 caregiving hours per year in Maryland
- ✓ \$13.09 economic value per hour of caregiving in Maryland

\*Reinhard, Susan et. al. *Valuing the Invaluable 2015 Update*. AARP Public Policy Institute, July 2015.

## Who Did We Hear From?

We primarily heard from middle-aged white women working full-time outside of the home\*

- ✓ 86% Female
- ✓ 70% White
- ✓ 57 average age
- ✓ 65% work full time
- ✓ 1/3 have been caregiving for 10 years or more
- ✓ 61% college or above
- ✓ 53% with total annual household income \$40,000+

This tells us that, even among groups with presumably greater access to resources, caregiver BURDEN IS HIGH.

## For Whom Are They Caring?

Most likely to care for a mother or mother-in-law over the age of 75 with dementia

- ✓ 32% mother or mother-in-law
- ✓ 21% son or daughter
- ✓ 17% spouse
- ✓ 80% require long-term caregiving
- ✓ 36% require constant care (24/7 – 365 days/year)
- ✓ 25% Alzheimer's/Dementia
- ✓ 17% Intellectual or Developmental Disability
- ✓ 15% Chronic Disease
- ✓ 10% Mobility Disability

## What type of care do they provide?

The most common types of activities provided across all respondents were:

- ✓ Manage social/medical responsibilities
- ✓ Transportation
- ✓ Advocacy
- ✓ Manage finances
- ✓ Grocery shopping
- ✓ Light housework
- ✓ Meal prep
- ✓ Help with medicines

## How many hours are spent caregiving in Maryland?

Caregivers reporting a high emotional toll from caregiving duties spend **an average of 46 hours per week** providing care while those reporting lower burden spend 30 hours on average.

*\*Compared to national surveys, Maryland's survey reached a narrower demographic sample.*

*AARP 2015 Caregiving in the U.S. Final Report, profile of American caregivers:*

- 60% Female, 40% Male
- 62% White
- 17% Hispanic/Latino
- 12% African American/Black
- 6% Asian American/Pacific Islander

*Nationally, caregivers spend 24 hours per week on average providing care. Forty percent (40%) report high burden and 25% report great difficulty in finding affordable caregiving services in their area.*

## What is the toll on Caregivers?

Caregiving brings with it a high toll on social/emotional, physical, and financial well-being. Here's how respondents said caregiving directly affects their lives:

- ✓ 76% report less time for family
- ✓ 83% have given up hobbies or vacations
- ✓ 42% have suffered health problems
- ✓ 85% report emotional strain
- ✓ 56% feel isolated from friends
- ✓ 72% have difficulty juggling caregiving duties with school/work
- ✓ 46% report financial difficulties
- ✓ 21% had conflict with employer/teacher
- ✓ 16% experience legal problems
- ✓ 17% have a conflict with school
- ✓ 53% have conflicts with family members

## What kind of public or private services are Caregivers using?

Despite the high burden, most caregivers are NOT (75%) using government services. Those who are using services, primarily **rely on self-pay**. The most common out-of-pocket caregiving expenses include:

- ✓ Housework
- ✓ Respite
- ✓ Home modifications
- ✓ Personal or nursing care
- ✓ Assistive devices/mobility
- ✓ Outside transportation

## Are Caregivers aware of available services?

Low use of services is likely due to low awareness of services. Most caregivers are NOT aware of available services.

- ✓ **83% not aware of Attendant Care program**
- ✓ **76% not aware of Maryland Technology Assistance Program**
- ✓ **80% not aware of Child and Adolescent Respite Care Program**
- ✓ **72% not aware of Low Intensity Support Services**
- ✓ **83% not aware of Kinship Navigator Services**
- ✓ **68% not aware of respite services through local DSS**

## How can state or local government improve services for Caregivers?

Caregivers told us:

- 1. Raise awareness of available services**
- 2. Provide contact information on services**
- 3. Work with government, for-profit, and non-profits and employers toward universal caregiver support options**

## In their own words...Caregiver comments

*It would be helpful to have a website with a list of comprehensive information of senior needs indicated in this survey... There is just a lack of information.*

*When parents just get a diagnosis, they need to be better informed of services and supports out there.*

*Adults with disabilities should be provided the opportunity to live in the community.*

*If caregivers like me are saving the government billions of dollars in care-giving services, is it right that we must sacrifice our own careers, financial situations and even health and well-being to do so?*

*(W)e do not qualify for many of the programs that might be available to others. ... We've had to use credit cards or take out loans to make ends meet.*

*Even when we get the funding for care, we can't find good caregivers.*

*The availability of more trained language and culture specific home aides would be an enormous help. Similarly senior programs and adult day care that can take these issues into consideration will go a long way to alleviate the burden for diverse communities.*

## What is the TOP NEED of Caregivers?

**Free time or a break from caregiving duties** (i.e. Respite Services) was the #1 need reported, followed closely by financial support or tax breaks to cover caregiving expenses. The third most important need reported was information about government services.

## What are the 3 most important information or training topics?

Caregivers were asked to rank, among the types of help they provide, the top 3 for which they would like more information and training.

- 1. Behavior management**
- 2. Exercising power of attorney**
- 3. Advocating for the person they care for**

*Information describing symptoms, behavior, services, and caregiver help MUST be advertised and supported by the governments and agencies.*

*Finding information about elder issues is difficult to find - very fragmented... Lots of programs for the very poor - which is fine, but not much relief for middle-class*

*I support policies and laws that allow family caregivers to receive appropriate compensation from their family member's own health insurance for providing services rather than paying it to an outside agency.*

*We did obtain services in the home for my daughters, but it was a fight to get them and it was just unbelievable what we went through.*

*Please END THE WAITING LIST for respite funds and help other families who desperately need sleep and a break.*

*Other than private pay services, there are no other resources that I am aware of to help people whose income/assets exceed the Long Term Care Medicaid qualification guidelines.*

## **Next Steps**

Information from this survey was used to inform the development of a successful federal grant application for Lifespan Respite Services prepared by the Maryland Department of Human Resources (DHR) and submitted to the Administration on Community Living within the federal Department of Health and Human Services. The two-year project which launched on October 1, 2016, aims to establish a Lifespan Respite Care Program that will provide families caring for individuals across the lifespan and disability spectrum with knowledge and resources to support loved ones and themselves, coupled with improved and timely access to respite care services. More than 30 partner agencies and organizations around the state have committed resources to this important project. A significant portion of these grant funds will be committed to increasing the availability of respite services across the lifespan. DHR also aims to streamline and enhance the navigation of the current system and to increase access to respite information and training.

## **About the Study**

In late 2014 and early 2015, the Maryland Caregivers Support Coordinating Council (MCSCC) conducted a survey of Maryland caregivers in order to create a portrait of Maryland family caregivers, understand the ways in which caregiving has affected their lives, identify caregivers' unmet needs, and explore ways in which local, state, and federal governments can better support family caregivers. Surveys were administered online, in hardcopy form, and were translated into Spanish. To maximize participation, the MCSCC leveraged a convenience sample, conducting outreach to various partners and community organizations such as advocacy groups, the faith community, veterans groups, the business community, government agencies, and health and human services providers. Over a period of 8 weeks, 1,751 surveys were completed. Responses from all Maryland counties were received.

## **About the Department of Human Resources and Maryland Caregiver Support Coordinating Council**

The Maryland Department of Human Resources is Maryland's primary social service provider. The Maryland Caregivers Support Coordinating Council works to identify the needs and challenges faced by informal family caregivers for those across the lifespan, advocating for and empowering through policies that support them, and making recommendations for the coordination of services.

The Council consists of 17 members appointed by the Governor, representing state agencies, family caregivers, service providers, and advocacy groups. The Council's statute requires five family caregiver members. The Department of Human Resources provides staff to the Council.

DHR wishes to acknowledge the efforts of Naomi Duffort, who contributed significantly to the development, administration, and analysis of the survey. Amy Fuhrmann provided additional analysis. DHR also thanks the more than 150 partner organizations that assisted in disseminating the survey statewide. For additional information about the survey results, please contact Dorinda A. Adams, Senior Staff to the Council, Office of Adult Services at the Department at 410-767-7323 or [dorinda.adams@maryland.gov](mailto:dorinda.adams@maryland.gov)