# ANNUAL REPORT - MARYLAND COMMISSION ON CAREGIVING

MARYLAND DEPARTMENT OF HUMAN SERVICES

Completed pursuant to Human Services Article § 7-305(b)

October 1, 2017

# REPORT REQUIREMENT

This report is hereby submitted in response to the following reporting requirement:

The [Maryland Commission on Caregiving] shall report annually on its activities to the Governor and, subject to § 2-1246 of the State Government Article, the General Assembly.

Source: Human Services Article § 7-305(b)

The Maryland Commission on Caregiving (formerly known as the Maryland Caregivers Support Coordinating Council) is the state's formal voice for the informal caregiver. The Council was created during the 2001 session of the Maryland General Assembly. The purpose of the Council is to coordinate statewide planning, development, and implementation of family caregiver support services for all ages, especially respite care.

Commission membership is comprised of state agencies, caregivers, service providers, and advocacy groups. The Department of Human Services provides staff to the Council.

# BACKGROUND

The Council has provided annual reports on a calendar basis and this report will be an Interim Report covering the activities of January 2017 through June 2017 in order to meet new reporting timelines. The Council has been engaged in Strategic Planning that has required a thorough review of the its legislative mandate (shown below) during this 6 month reporting period:

- Solicit and gather concerns of caregivers
- 2. Develop and distribute to interested parties a handbook of current respite care and other family caregiver services available in the State
- 3. Review successful respite care programs in other states
- 4. Develop a model family caregiver support program that incorporates best practices from existing programs in this and other states
- 5. Coordinate activities of existing and proposed family caregiver support services among State and local units
- 6. Research available funding sources and explore possibilities for additional funds
- 7. Identify unmet needs and priorities for additional funds

As a result of this review of the statute, the Council has refined its focus areas to the following three Action Groups:

Resource Development Evaluation/Data Analysis Communication

The Council is continuing to implement this planning process as a result of its legislative mandate expanding during the 2017 Maryland General Assembly session with the passage of

Senate Bill 216 (Chapter 67) and House Bill 769 (Chapter 68) Maryland Caregivers Support Coordinating Council – Renaming and Altering Membership and Duties. This legislation, which takes effect on October 1, 2017, also requires the addition of two Council members appointed by the President of the Senate and the Speaker of the House of Delegates.

In addition to the Council's name being changed from MCSCC to the Maryland Commission on Caregiving (MCC) and the increased membership, the legislative mandate has expanded to include the following two responsibilities:

- Provide ongoing analysis of best practices in family caregiver support programs in this and other states
- 2. Monitor implementation of the Commission's recommendations

These changes will provide enhanced visibility of the Council and a more defined partnership with the Maryland General Assembly with their participation on the newly formed Commission.

#### **OUTREACH**

MCC has continued to provide a wide array of outreach activities by presenting or exhibiting at 21 events during the reporting period. The total number of attendees for these activities was more then 3,000. MCC partnered with several organizations during their Legislative Outreach during the 2017 General Assembly to expand its ability to address a wider range of Family Caregiver stakeholders (See Outreach and Community Events 2017).

MCC is committed to building partnerships and employing a wide array of outreach techniques to ensure that populations that may not be heard from in traditional outreach methods are invited and encouraged to participate. This is an outcome that has been adopted during the past 6 months of strategic planning.

#### RESEARCH

MCC has continued to utilize the findings from the statewide Family Caregiver Survey conducted from November 2014 through January 2015 to inform their action strategies and overall focus. The Maryland Center for Developmental Disabilities and the University of Maryland School of Social Work have continued to analyze the data from the survey. The most recent report from the survey findings is the qualitative findings of over 500 survey respondents who provided written responses in addition to the survey questions. This additional response was a subset of approximately 30 percent of the total 1,751 participants who completed the entire survey. Their written feedback has provided insights that the quantitative findings, often are unable to describe. (See Addendum B)

MCC has reached out to the Maryland Department of Health's Center for Chronic Disease Prevention, within the Health Promotion Administration as a partner with the Behavioral Risk Factor Surveillance System (BRFSS). This annual survey has an optional Caregiver Module that was part of the 2015 BRFSS Survey. The Council received an overview of the 2015 survey findings and has requested that BRFSS utilize this optional module in future years in order to

begin having an annual data set on Family Caregiving that will assist the mandate of hearing from Family Caregivers.

#### **PARTNERSHIPS**

MCSCC continues to work towards developing new partners and being a partner to already existing collaborative efforts. All Council meetings are open to the public and attendees are encouraged to not only attend the monthly meetings but to participate in the work of the three Focus Area Groups. Two of the three groups are currently being led by partners which demonstrates a commitment beyond attending a meeting.

MCC would not be able to accomplish the mandate that they are legislatively charged without committed partners. The activities that are occurring within this body is demonstrating best practices with a diverse group that includes the public and private sectors, members from across the lifespan of service delivery, and advocacy from grassroots to established national organizations, businesses and volunteers from the faith-based to community organizations. This group is fluid and because of the diversity of members is able to identify other potential partners in this ongoing process of developing an infrastructure of coordination and support of one of the state's most valuable resources, our informal, family Caregivers.

Now that the Council has transitioned to becoming the Maryland Commission on Caregiving and the members of the House of Delegates and the Senate begin to participate in the work, there will be more detailed information about the outcomes from the strategic planning process to report.

# Maryland Commission on Caregiving Outreach & Community Events 2017

Month	Name of Event	Type of Event	Council Members Present	Location	Population	Number of People who Attended
	5 <sup>th</sup> AARP Chapter presentation	Presenter	Renee Fredericksen	Salisbury	Wicomico Chapter of AARP	200
JANUARY	25 <sup>th</sup> United Seniors Advocacy Day	Advocacy Day – presentation and exhibit table	Renee Fredericksen (speaker), Mary Chaput Dorinda Adams and Jennifer Eastman (table)	Senate Building - Annapolis	Maryland General Assembly, staff, public, and family caregivers	400
	2 <sup>nd</sup> Senate Hearing for SB-216.	Testified and others present in audience.	Dorinda Adams, Ann Squire, and Betty Jones testified. At least five other members present.	Senate Building – Annapolis	Senate Finance Committee, Public attendees of hearing	About 40 including Senators
	9 <sup>th</sup> Alzheimer's State Advocacy Day	Presenter and exhibit table	Greg Sesek (speaker), Chloe Keller, Ann Squire, Dorinda Adams Renee Fredericksen	House – Annapolis	State Legislators, Caregivers, Advocates	100
FEBRUARY	9 <sup>th</sup> AARP Legislative Day	Presenter	Dorinda Adams testified. Two staff present.	Annapolis House	AARP members and legislators	
	21 <sup>st</sup> House Hearing for HB-769.	Testified and in audience.	Anthony Jackson, Jennifer Eastman	Building  House – Annapolis	Health & Government Operations Committee, Public attendees of hearing  State Legislators	About 60 including
	23 <sup>rd</sup> DD Council Advocacy Day		Betty Jones, Chloe Keller,		State Senators	Delegates

	26 <sup>th</sup> Presentation to Behavioral Health Administration Respite group	Presenters	Dorinda Adams, Christine Schoenberger	Mitchell Building at Spring Grove	Children Mental Health providers	15
JULY	25 <sup>th</sup> Presentation Before Task to Study Family & Medical Insurance	Presenter	Dorinda Adams	Maryland General Assembly	Legislative Task Force	25
AUGUST	17 <sup>th</sup> Empowering Communities to Age with Dignity sponsored by National Hispanic Council on Aging	Presenter	Dorinda Adams	Silver Spring Civic Center Building	Professionals & Family Caregivers	TBA
SEPTEMBER (FASD Month)						
OCTOBER	11 <sup>th</sup> - 13 <sup>th</sup> National Respite Conference – "Take off with Respite"	Workshop Presenter	Dorinda Adams	Huntsville, AL	Professionals and Family Caregivers	ТВА
(Child Health Month)	Social Security Administration Work-Life Fair	Exhibitor	ТВА	SSA Headquarters Woodlawn	SSA Employees	ТВА
NOVEMBER (National Caregiver's Month)	2 <sup>nd</sup> MCC Annual Meeting			TBA	General Public, Partners, Elected Officials,	ТВА
DECEMBER						

# Understanding Caregiver Needs in Maryland: A Brief Report of Open-Ended Responses

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#### Introduction

The Maryland Commission on Caregiving conducted a state-wide survey in 2014-2015 to understand the most important needs of caregivers in Maryland. This report presents findings from the open-ended responses, to provide more in-depth information to supplement the survey findings.

# Overview of Caregiving in the U.S.

AARP (2015) reports that an estimated 43.5 million adults provide informal care to an adult or child. The average caregiver is female, 49 years old, and caring for a relative. Caregivers spend an average of 24.4 hours per week providing care for their care recipient. While caring for a loved one can be emotionally rewarding, provide the caregiver with a greater sense of purpose, and strengthen the relationship between the caregiver and care recipient, it is often physically, mentally, and emotionally challenging (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). According to AARP (2015), 22% of caregivers report that their health has declined due to caregiving, about one in five caregivers reports experiencing financial strain (18%), one in five caregivers report high levels of physical strain from caregiving, and more than one third report their caregiving situation as emotionally stressful.

While services and information to assist caregivers do exist, caregivers often do not receive such information or they struggle to access services and supports. More than 80% of caregivers report needing more information on caregiving topics, and yet only 1/3 of caregivers report being asked by a health care provider about the needs of the care recipient and the caregiver themselves (AARP, 2015). In addition to not receiving caregiving information, one in four caregivers report difficulty accessing affordable services in their care recipient's community, with nearly half of caregivers already spending over \$5,000 per year out-of-pocket on caregiving (AARP, 2015).

The stress and demands of caregiving can have adverse effects on the caregiver's physical, emotional, spiritual, and social well-being, known as caregiver burden (Zarit, 1986). Caregiver burden can manifest in lower mood, declines in physical health, and decreased coping and self-efficacy. Caregivers who are female, live with the care recipient, have lower educational attainment, spend greater number of hours caregiving, and have a lack of choice in caregiving are at the greatest risk for experiencing caregiver burden (Adelman et al.,2014). The nation's caregivers need greater support, but before caregiver burden can be reduced, the needs and experiences of caregivers must first be understood.

# Overview of the Maryland Caregiver Survey

Between 2014 and 2015 the Maryland Commission on Caregiving conducted the Maryland Caregiver Survey. The purpose of the survey was to identify the needs and concerns of family caregivers across the state of Maryland. The study used a convenience sample identified through public and private organizations. Participants

included caregivers of older adults and children with disabilities. Surveys were distributed statewide and were available in print and online. A total of 1,751 surveys were completed.

Survey respondents were more likely to be female and middle aged. The average age was 57, though approximately half were age 75 or older. Approximately 2/3 of participants work full time and 61% had a college education or above. A little more than half had an annual household income of \$40,000 or more and 1/3 of caregivers had been caregiving for 10+ years. Caregivers who reported a high emotional toll from caregiving spent around 46 hours per week providing care and those reporting a lower burden spend about 30 hours per week. Roughly 1/3 of participants were caring for their mother or mother-in-law, close to a quarter were caring for a child, and 17% were caring for a spouse.

#### Methods

The survey included the following open-ended question, "Please feel free to provide any additional information or suggestions you have regarding your experience as a caregiver that will help inform the discussion on the needs of caregivers such as yourself." Responses to this question were reviewed, and although the question was very open-ended, it provided a lot of useful information about the needs of the caregivers responding to this survey and it was clear that people needed this space to express their experiences of caregiving. Of the 1,751participants, 508 (about 30%) provided a response to this question. Of the 508 responses, three reviews were conducted. During the first review, common themes from the responses were identified, and with each subsequent review the themes were refined. The first author conducted all data analyses, and then the second author reviewed and discussed the findings. This report will discuss the themes that were addressed by at least 20 respondents.

# Caregiver Needs

Many responses described a need for information about existing services and resources, assistance navigating the system, the need for additional or more comprehensive services, or assistance accessing and applying for services. Some examples of responses for this theme include:

"All of the services we've tried have been able to do next to nothing aside giving us the name of another program that "MAY" be able to help. And in the end... none of them do. So, we stopped looking and trying because we've come to the conclusion that our government will do nothing for the elderly and they really don't care what state their people are in." "It would be helpful to have one social worker assigned to provide individualized, full spectrum assistance/information as opposed to the "bits and pieces" approach provided from one agency to the next."

Other responses expressed the need for financial assistance, describing the difficulties caregivers have affording necessary care or services for their loved one,

having to spend down resources, and concerns about not having money leftover for themselves when they may need it. Many of these responses described feeling stuck:

"At this stage I feel I am stuck with the fact that I will be responsible for all additional costs for services needed as this disease progresses with no increase to current income." "I think the most important need that is not met is financial assistance including help for those forced to give up their job to keep their loved one home with them, so that they don't lose their house and some PAID caregiver help would be so appreciated."

Some caregivers described feeling as though they could not adequately care for their loved one in the home without additional in-home care services and supports:

"I was surprised at what I was required to do for my husband. Some training was provided by home nurses and Hospice nurses, but I felt inadequate much of the time. My husband wanted to stay in our home until the end and he died here, but I wonder if my inadequacies hastened his death." "In home help is so essential...I have made it a priority to pay for it myself and also have been grateful for any help I have received from government agencies."

Additional responses expressed a need for self-care or opportunities for social interaction. In these responses, caregivers described being isolated, experiencing declines in their physical or mental health as a result of caregiving, or having to stop working or stop participating in social activities due to the amount of time they spend caregiving.

"Truly overwhelming. I feel I have given up my life. Everything has to be planned from who can cover her care when I 'm working to calling in refill prescriptions. And I feel my health is failing because I cannot attend to my own care needs." "Can't have a job. 24/7 care for mom. Alone and isolated from the entire world. Life as known is totally gone." "I just lost my job because of an emotional outburst at work when I was so tired from caregiving that I just "lost it". I have no time for hobbies and have not seen a doctor myself in 6 years. I am exhausted, physically and emotionally."

Others expressed the need for transportation that can accommodate older adults or adults with disabilities, more reliable transportation, and transportation options that are more affordable for these populations. One caregiver simply summed up this need with response, "Transportation, transportation, transportation!"

Some caregivers expressed concerns that health and human service providers did not have adequate training or education to provide appropriate care or services for their loved ones. These responses also included the need for more reliable providers and better pay to attract higher quality health and human service providers.

"Finding services, dependable services, is difficult. Even private duty nursing agencies have left us hanging in bad weather or with no emergency contact number." "It has always been challenging to find non-family members who are capable of caring for my son, and to be able to pay caregivers a decent wage for their invaluable work."

Additional responses specifically described a need for respite services or just simply for a break from caregiving.

"I no longer can go out when I want or go to dinner with family and friends. Everything has to be scheduled. Sometimes I can't even take a shower without anyone to watch/sit with my mother." "Caregiver retreats would be good for those of us with no means of "vacation" time to decompress. Many are primary caregivers with no true relief for more than a day. The Department of Aging has been an excellent source of one day respite where one can relax knowing loved one is cared for."

Other responses expressed frustration with the system and available supports. These responses included negative feedback regarding specific services or resources, descriptions of the difficulties caregivers have had accessing services or resources, and the frustration with the lack of available and/or appropriate services.

"I feel left on an island. You can apply for services and not hear for years...I apply for something for my disabled daughter and I get entered into a lottery? I could put her into an institution and the state would have to pay tens of thousands of dollars per year for her care." "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? There are many injustices in the world, I realize, and what I'm undergoing is not the worst in the world. But I feel that we're on the cusp of something HUGE that's only getting bigger..."

Some responses were more positive and described the benefits of informal and formal supports. This included feedback on specific services and resources that were beneficial to the caregiver or care recipient, as well as comments on helpful informal support systems that were utilized by the caregiver.

"I attend a monthly support group, but would prefer that it meet more often. I attend as many caregiver conferences and webinars as possible...Education and networking are critical for me." "AA County Department of Aging has been wonderful. My mother (the primary caregiver) and I attended 9 weeks of classes for training caregivers....We also attended a sensory experience that made the Alzheimer's experience real....can't tell you how helpful Department of Aging has been, thank you so very much." "Respite care program has provided several resources to make me a better caregiver. It has also provided opportunities to reduce stress and allow time for a productive life."

Finally, many of the responses simply described the caregiving experience, and included both positive and negative personal experiences of caregiving. Positive experiences described caregiving as rewarding, as a privilege or honor, and an opportunity to spend quality time with their loved one.

"My experience as a caregiver was very much unplanned however when the time came I was so glad I was able to give the support and care for my husband. I worked very hard at continuing our daily life together, keeping life as usual from meeting friends, travel, and quiet time together. Continuing on with life and learning to live in the present moment was my greatest gift to my husband and myself."

Negative experiences described the exhausting, frustrating, stressful, overwhelming, and isolating aspects of caregiving.

"It is a lonely existence. Spending 24/7 with a person who will not ever be well, is emotionally draining. I sometimes feel I cannot go on another day nor another week. In reality, there is no end in sight." "It is a lonely - challenging - unappreciated phase of life that I find myself in."

One respondent only wrote: "ITS KILLING ME."

There were many more themes which were addressed by fewer than 20 respondents, including the need for care recipient social activities, caregiver education and training, dementia-specific supports, employer accommodations, expanded residential options, financial planning and advice, specific supports for child behavioral health, support that is not based on income eligibility, support groups for caregivers, and the experience of caregiving for someone living in a long-term care facility.

# Caregiver Need by Demographic Characteristics

We also analyzed the open-ended responses in terms of the demographic characteristics of the respondents. The demographics examined include caregiver age, caregiver gender, the relationship of care recipient to caregiver, and whether the care recipient lived with the caregiver. Of the 508 participants that provided responses to the open ended question, 2/3 were under the age of 65 and the vast majority were female (89%). Just over 1/3 were providing care to a parent or parent-in-law, close to a quarter were caring for a son or daughter, roughly 17% were providing care for a spouse, and about 16% were caring for a friend or other kin. Over half of the caregivers reported that the care recipient was living with them.

Table 1 provides a breakdown of caregiver demographics for each of the common themes. No statistical analyses were performed and this breakdown is not generalized to other caregivers, but it does provide us with a deeper understanding of which caregivers were expressing which type of needs in the open-ended response of this survey.

# Conclusion

In the U.S. informal caregivers provide an estimated 37 billion hours of care, with an economic value of approximately \$470 billion (Reinhard, Feinberg, Choula & Houser, 2015). The value is informal caregivers are not only financial, but allow individuals to remain at home and in their communities where they want be. To provide the best possible care for their loved ones and themselves, caregivers need greater support. Continued research on caregiving is needed to better identify the needs of caregivers and to develop the policies and programs to more effectively address those needs. In doing so, it will also be important to examine how needs may vary across different types of caregivers and care recipients. It is socially and economically imperative that informal caregivers are provided with increased and more meaningful supports.

DO ANTONIO WO LAND	Caregiver Age	Caregiver Gender	Relationship of Care Recipient to Caregiver	Care Recipient Residence
All Qualitative Responses	Under 65 = 340 65+ = 163	Male = 48 Female = 452	Parent/Parent-in-law = 194 Son/Daughter = 116 Spouse/Partner = 90 Friend/Other Kin = 86	Caregiver home = 293 Other = 192
Need for More Information and Access to Resources (147)	Under 65 = 33.2% (113) 65+ = 20.9% (34)	Male = 18.8% (9) Female = 30.3% (137)	Parent/Parent-in-law = 27.8% (54) Son/Daughter = 25.9% (30) Spouse/Partner = 31.1% (28)	Caregiver home= 29.7% (87) Other = 26.6% (51)
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length of talories and	Judio 6.5 = 11.3% (40)	Value 12.3% (6)	havest Pariet in Los - 13 (% (3.7)	Degreener Condy
Need for Financial Assistance (107)	Under 65 = 25% (85) 65+ = 13.5% (22)	Male = 16.7% (8) Female = 21.7% (98)	Parent/Parent-in-law = 22.2% (43) Son/Daughter = 25.9% (30) Spouse/Partner = 18.9% (17) Friend/Other Kin = 17.4% (15)	Caregiver home= 20.1% (59) Other = 24% (46)
Need for In-Home Care (27)	Under 65 = 5% (17) 65+ = 6.1% (10)	Male = 2.1% (1) Female = 5.8% (26)	Parent/Parent-in-law = 4.6% (9) Son/Daughter = 6.9% (8) Spouse/Partner = 8.9% (8) Friend/Other Kin = 2.3% (2)	Caregiver home= 6.8% (20) Other = 3.6% (7)
Need for Self- Care/Opportunities for Social Interaction (31)	Under 65 = 5.9% (20) 65+ = 6.7% (11)	Male = 2.1% (1) Female = 6.6% (30)	Parent/Parent-in-law = 4.1% (8) Son/Daughter = 8.6% (10) Spouse/Partner = 7.8% (7) Friend/Other Kin = 4.7% (4)	Caregiver home= 7.2% (21) Other = 4.2% (8)
Need for Accessible, Affordable, and/or Available Transportation (27)	Under 65 = 5.3% (18) 65+ = 5.5% (9)	Male = 4.2% (2) Female = 5.5% (25)	Parent/Parent-in-law = 4.1% (8) Son/Daughter = 10.3% (12) Spouse/Partner = 2.2% (2) Friend/Other Kin = 3.5% (3)	Caregiver home= 6.5% (19) Other = 3.1% (6)
Need for a Better Trained	Under 65 = 7.6% (26)	Male = 2.1% (1)	Parent/Parent-in-law = 6.2% (12)	Caregiver home= 7.5% (22)

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# MARYLAND COMMISSION on CAREGIVING MEMBER ROSTER July 1, 2016 – June 30, 2019

Dorinda A. Adams, LGSW, Senior Staff to Council Greg Sesek, Staff to Council

Linda Ramsey
Represents – Maryland Respite Care Coalition

# PUBLIC AGENCIES

Jennifer Eastman, Council Chair Director, Community Living Policy Maryland Department of Disabilities Represents- MDOD

#### Tina Bullock

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#### Joan Smith

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#### **Chris Stewart**

Manager, National Family Caregivers Support Maryland Department of Aging Represents- MDoA

# **FAMILY CAREGIVERS**

Dr. Renée S. Fredericksen, Vice Chair Represents- Family Caregiver

#### **Betty Jones**

Represents- Family Caregiver

### **Ann Squire**

Represents- Family Caregiver

#### **Nate Sweeney**

Represents- Family Caregiver

#### Unfilled

Represents- Family Caregiver

# **PRIVATE AGENCIES**

# **Larry Bram**

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Represents – Agency with Respite Experience

#### Connie Marth

Delmarva Community Services, Inc. Represents- Agency with Respite Experience

# **Christine Schoenberger**

Kennedy Krieger – Maryland Center for Development Disabilities Represents- Agency with Respite Experience