



February 23, 2017

The Honorable Thomas V. Mike Miller, Jr.
President of Senate
State House, H-107
100 State Circle
Annapolis, MD 21401

The Honorable Michael E. Busch
Speaker of the House
State House, H101
100 State Circle
Annapolis, MD 21401

RE: Maryland Caregivers Support Coordinating Council 2016 Report – MSAR # 6510

Dear President Miller and Speaker Busch:

The Department of Human Resources (DHR) is required to issue an annual report on the activities of the Maryland Caregivers Support Coordinating Council to the Governor of Maryland and the Maryland General Assembly. This requirement is stated in Senate Bill 567, Chapter 400 (cross filed with House Bill 513) which was passed and signed into law in 2001.

As always, if there are any questions regarding this report, or if additional information is needed, please contact Rebecca Jones Gaston, Executive Director for the Social Services Administration at 410-767-8939.

Sincerely,

Lourdes R. Padilla
Secretary

The Maryland Caregivers Support Coordinating Council

2016 Annual Report

- Disseminated state regulatory concerns and provider needs of Maryland caregivers from the Governor's Executive Order on the Health Care Workforce, and from each of the 24 local jurisdictions.
- Promoted widespread use of caregiver support services through collective outreach efforts that focused on caregivers across the lifespan.
- Collaborated with key stakeholders to apply for the Lifespan Respite Care Grant through the U.S. Administration on Community Living to establish a Lifespan Respite Care Program in Maryland facilities.*
- Received available funding sources to expand statewide respite care capacity, including successful effort securing state agencies and partners.
- Enhanced caregiver support systems for effectiveness and accessibility, toward creating better care systems, including participation in the Task Force on Family Caregivers and Long-Term Supports (HHR 2017- enacted in 2018, Chapter 153)

Footer

The Council disseminated data from a Maryland-specific family caregiver survey to inform Council policy recommendations. Analysis of the survey data, statistical comparisons of survey findings to national data (see Addendum A), and commentary to data from national caregivers supported the Council's legislative advisement from a wide range of stakeholders including members of the recommendations in the Final Report of the Task Force on Family Caregivers and Long-Term Supports.

http://data.maryland.gov/publications/records/R29331055_2015.pdf

- Acquired CSR 716 legislation: Designation of Long-Term Caregivers (the CARE Act) - Part of a broader agenda the Council supported that legislation regarding the definition of the term "respite care in hospital in-ride and a non-disruptive discharge protocol."

Council Activities/Subjects in 2016:

- Assisted in the application and design of the federal Lifespan Respite Care Grant through the U.S. Administration on Community Living to provide knowledge and resources to families caring for individuals across the lifespan and disability spectrum (see Addendum B)
- Developed a local user-to-user network and business model to implementing the Lifespan Respite Care Project.
- Supported the Task Force on Family Caregivers and Long-Term Supports recommendations to strengthen the Council's current statutory authority to coordinate and disseminate information to the public.

- Supported passage of the Maryland CARE Act which ensures inclusion of family caregivers when their loved ones are hospitalized or are transitioning home from the hospital.
- Distributed information on current available caregiver services through at least 10 community outreach events. (See Addendum C)

2017 Goals

- Continue collection, analysis, and dissemination of up-to-date data on the characteristics and unmet needs of Maryland's family caregivers.
- Advisory role for the implementation of the Lifespan Respite Care project. (See Addendum D)
- Coordination and enhancement of media and social media presence, including a new Council website that will be developed through a public/private partnership and Facebook page.
- Continue to work with partners on implementation of CARE Act.



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

The Administration for Community Living's
2016 Lifespan Respite Care Program Grant

Awarded To
The Department of Human Resources (DHR),
Through the Social Services Administration's (SSA),
Office of Adult Services (OAS)

Grant Purpose: To implement the requirements of the Lifespan Respite Care Act of 2006

Maryland's Goal: 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.

Objectives of the **Lifespan Respite Care Program** are:

- **Impact the existing respite care system by increasing access to Emergency Respite Care to families in need of immediate assistance across the lifespan.**
- **Establish a Consortium that will work toward increasing training and social opportunities for Caregivers and their loved ones across the state.**
- **Partner with Faith-based organizations and postsecondary education programs to foster the development of well-qualified respite care providers and expand capacity of volunteer options.**
- **Improve access to Respite Care information through a partnership with Maryland Access Point and the development of a Universal Application for Respite Care**

Be a part of creating enhanced services to family caregivers and their loved ones across the Lifespan. Together we can make it happen.

For Additional Information Contact:
Kathleen Ward
At - 410-767-7422 or Kathleen.Ward@maryland.gov
Department of Human Resources
Social Services Administration
Office of Adult Services
311 W Saratoga St.
Baltimore MD 21201



Maryland Caregivers Support Coordinating Council

Caregiver Outreach & Community Events

2016

Month	Name of Event	Type of Event	Council Members Present	Location	Population	Number of People who Attended
JANUARY						
FEBRUARY						
MARCH						
APRIL	13 th Annual Aging in Worcester Conference	Conference Presenter	Dorinda Adams	Ocean City, MD	Aging Professionals on Eastern Shore	200
MAY						
JUNE	Talbot County Aging Summit	Conference Presenter	April Seitz	Talbot County Community Center	Citizens and Aging Professionals	40

JULY						
AUGUST	3 rd /4 th School Health Interdisciplinary Program (SHIP) Conference	Conference presenter	Mary Price and Angela Sittler	Radisson Hotel in Timonium, MD	Schools	300
	6 th Mt. Moriah Baptist Church Back to School Jam	Exhibitor	Mary Price	Mt. Moriah Baptist Church (Baltimore)	Community	250
	13 th Set the Captives Free School Event	Exhibitor	Mary Price	Woodlawn, MD	Community	300
	25 th United Health Care – Community Advisory Board	Advisory Board	Mary Price	Columbia, MD	Community and UHC staff	60
SEPTEMBER (FASD Month)	15 th Baltimore City Health Department Division of Aging & CARE Service's 5 th Annual Grandparents Conference	Conference Panelist	Tina Bullock	Morgan State University	Grandparents and their families	About 200
	17 th Maryland State Sickle Cell Picnic	Table	Mary Price	Druid Hill Park	Community	200
	20 th -22 nd National Respite Conference <i>Elevate Respite!</i>	Presenter	Mary Chaput, Dorinda Adams & Elizabeth Waglein	Denver, CO	Respite professionals	20
	27 th Health and Government Operations Briefing: Taskforce on	House committee briefing	D. Adams, Senator Kelley, (more Council members	House Office Building	Health and Government Operations House Committee	23 Delegates, About 10 in audience

	Family Caregiving and Long Term Supports Final Report		present)			
	27 th Cumberland LHD	Attendee?	Mary Price	Cumberland, MD	Staff	30
OCTOBER (Child Health Month)	14 th Baltimore County Exhibit	Exhibitor	Mary Price	Oregon Ridge	Community	250
	15 th Montgomery County Health Fair	Exhibitor	Mary Price	Takoma Park, MD	Community	200
	22 nd Baltimore Parent Empowerment Conference	Presenter	Mary Price	Family Life Center at Gospel Tabernacle Baptist Church	Community	150
NOVEMBER (National Caregiver's Month)	3 rd Maryland Caregiver Forum Legislative and Programmatic Accomplishments (MCSCC in partnership with AARP)	Presenters	D. Adams, G. Sesek, K. Ward, R. Frederickson, C. Marth, N. Sweeney, T. Bullock, J. Eastman, A. Sittler, A. Seitz, J. Smith, A. Jackson, B. Jones, C. Keller	Inn at Chesapeake Bay Beach Club (Kent Island, MD)	MCSCC, AARP members, Senator Mathias, Other caregiver advocates	About 50
	9 th Social Security Administration Work-Life Fair	Info table	Greg Sesek	SSA Headquarters in Woodlawn, MD	SSA Employees	200
DECEMBER						

The Social Services Administration's (SSA), Office of Adult Services (OAS) 2016 Lifespan Respite Care Project Grant

Committees

In order for this project to be successful, we are looking for groups of people willing to work cooperatively to accomplish a common mission using their knowledge, experience, talents and gifts in the context of mutual accountability.

Below is a list of four committees and some of the functions the committees may include.

Training

- Assist in the development of a consortium of Maryland Caregivers, Recipients and Professional that will design and deliver a respite Info-social model of training and activities
- Support the enhanced training of qualified caregivers and professionals assuring the inclusion of diverse target populations
- Assist in the development of opportunities to access information on topics of interest that will increase skills for caregivers and lower stress levels
- Identify professionals willing and able to share their expertise with potential respite care workers, family caregivers, care recipients and the general public to increase the community's knowledge and awareness of caregiving issues.

Volunteer Development

- Assist in the development of volunteer training programs
- Partner with Maryland's Higher Educational System to recruit and train qualified students studying in health and disability related fields and offer internships or volunteer respite opportunities to assist families caring for children and adults with special needs
- Work in identifying faith-based congregations to develop volunteer training programs for participating congregations willing to address the needs of caregivers in their communities

Access

- Identify existing respite care programs and services, waitlists, and target population to be served by this project
- Assist in the development of a central repository for provider information.
- Identify ways to streamline access to information
- Assist in the creation of a universal application

Outreach and Expansion

- Identify ways to offer support and information about respite issues and services to a wider population across the state
- Identify gaps in the current array of services
- Seek avenues to build and expand respite capacity and improve services across the Lifespan
- Advocate for caregivers and recipients of care across the state of Maryland



Maryland Caregivers Support Coordinating Council

MEMBERS

July 1, 2016 – June 30, 2019

1. Tina Bullock

Family Centered Practice Supervisor
Training & Organizational Development
Social Services Administration
Department of Human Resources
Represents- DHR

2. Mary Chaput

Program Director
Respite Care Referral & Family Caregiver
Represents- Area Agencies on Aging

3. Kevin Dougherty

Vice President, Programs & Services
National Multiple Sclerosis Society
Represents- Agency with Respite
Experience

4. Jennifer Eastman

Director of Community Living Policy
Maryland Department of Disabilities
Represents-Department of Disabilities

5. Dr. Renée S. Fredericksen

Represents- Family Caregiver

6. Anthony Jackson

Constituent Services Coordinator
DHMH
Developmental Disabilities Administration
Represents- DHMH

7. Angela Sittler

Department Health and Mental Hygiene
Center for Maternal and Child Health
Represents – DHMH

8. Betty Jones

Represents- Family Caregiver

9. Brooke Kaiser

Respite Services Director
Easter Seals Greater Washington-Baltimore
Region
Represents – Agency with Respite
Experience

10. Connie Marth

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

11. Cynthia Peterman

Represents- Family Caregiver

12. April V. Seitz, L.C.S.W.-C

Director, Office of Adult Services
Social Services Administration
Department of Human Resources
Represents- DHR

13. Joan Smith

Child and Adolescent Division
Behavioral Health Administration
Represents- DHMH

14. Ann Squire

Represents- Family Caregiver

15. Nate Sweeney

Represents- Family Caregiver

16. Elizabeth Weglein, Council Chair

Represents- Maryland Respite Care
Coalition, Inc. (MRCC)

17. Vacant

MDoA - Program Manager - Caregivers
Support - Elder Abuse
Represents- MDoA

Council Staff – Dorinda A. Adams, LGSW,
Senior Staff to the Council
Greg Seseck, Staff to the Council