



Martin O'Malley
Governor

Anthony Brown
Lt. Governor

Theodore Dallas
Secretary

Elizabeth Weglein, Chair
Maryland Respite Care
Coalition, Inc.

Carol Allenza
Maryland Coalition of Families
for Children's Mental Health

Kelli Meginnis Cummings
Maryland Department of
Disabilities

Felicia French
Maryland Department of Aging

**Laleh Alemzadeh
Hancock**
Caregiver

Mary Johnson
Maryland Department of
Health and Mental Hygiene

Brooke Kaiser
Easter Seals Greater
Washington-Baltimore Region

Connie Marth
Delmarva Community Services

Ginger Miller
Caregiver

April Seitz
Maryland Department of
Human Resources

Joan Smith
Maryland Department of
Health and Mental Hygiene

Merle Smith
Maryland Department of
Human Resources

Patricia Sollock
Caregiver

Sequaya Tasker
Maryland Department of
Health and Mental Hygiene

Lynn Hewitt Towle
Caregiver

Carolyn True
Frederick County Department
of Aging

Rhonda Ulmer
Caregiver

Staff:
Dorinda A. Adams
Maryland Department of
Human Resources

February 15, 2012

The Honorable Martin O'Malley
Governor of the State of Maryland
State House
Annapolis, Maryland 21401-1991

The Honorable Thomas V. Mike Miller, Jr.
State House, H-107
Annapolis, MD 21401-1991

The Honorable Michael E. Busch
State House, H-101
Annapolis, MD 21401-1991

RE: MSAR #6510, Human Services Article §7-305, Maryland Caregivers Support
Coordinating Council Annual Report, 2011

Dear Gentlemen,

The Maryland Caregivers Support Coordinating Council respectfully submits their 2011
Annual Reports pursuant to the Human Services Article §7-305 of the Maryland
Annotated Code, which requires that the Maryland Caregivers Support Coordinating
Council report annually on its activities to the Governor and the General Assembly.

The Council is the state's formal voice for all caregivers throughout our state created
during the 2001 session of the 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.

We appreciate your support of our initiatives and thank you for your time and
consideration. If you require additional information, please contact Dorinda Adams,
Department of Human Resources staff to the Council, at 410-767-7323.

Most sincerely,

Elizabeth Weglein
Chair, Maryland Caregivers Support
Coordinating Council

cc: Secretary Theodore Dallas
Carnitra White

Maryland Caregivers Support Coordinating Council

2011 Annual Report

WHO ARE THE CAREGIVERS?

Family Caregiver's are the backbone of Maryland's long-term care system. Family Caregivers are represented by people of all ages, genders, races and ethnicities, income levels, living arrangements, and levels of health and well being. In testimony before the Senate Special Committee on Aging, former first lady Rosalynn Carter said, "There are only four kinds of people in the world; those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who will need caregivers." (September 10, 1998).

According to a 2011 report by AARP Public Policy Institute, family caregivers provided care valued at \$450 billion nationally in 2009. In Maryland the estimate is \$8.1 billion. A Fact Sheet with details of this report is attached.

HIGHLIGHTS

○ *Caregiver Stories Video*

The Council, in partnership with the Maryland Respite Care Coalition and Easter Seals Greater Washington Baltimore Region, produced and developed a caregiver stories video to educate legislators, policy makers, decision makers and families concerning family caregiving. The unedited video was screened at the Maryland Respite Care Coalition's Annual Respite Awareness Day Conference. The final version will be released in 2012. The Council envisions the video as a means to promote an awareness of Family Caregiving and its many facets from the perspective of personal caregiver stories.

○ *Maryland Access Point, MAP*

The Council met with the Maryland Department of Aging, which is developing and implementing the federally and state funded Maryland Access Point (Maryland's Aging and Disability Resource Center). The Council conveyed that caregivers need to be fully represented in the MAP system at all levels and as a lifespan issue. MAP staff met with the Council on a several subsequent occasions and agreed to partner with the Council to ensure that caregivers are properly and fully represented within the MAP program across the state. The Council will continue its relationship and work with MAP staff into 2012.

○ *Aging Caregiver Initiative*

Department of Health and Mental Hygiene Secretary Joshua Sharfstein asked that the Council consider the issue of the aging family caregiver and the trauma to those needing care when an emergency, such as hospitalization or even sudden death of the caregiver, occurs. Often the family member needing care has not been part of any type of service system and is left without any care. The Council agrees that this is a critical concern and will be a priority project in 2012.

- ***Speakers Series***

The monthly Council meetings feature key state leadership and caregiving experts. The meetings are open to the public. Meetings goals are to remain advised of the current research, program trends and data pertaining to Family Caregiving across the lifespan and how it may be utilized to support the needs and priorities of all family caregivers.

Department of Human Resources Secretary Theodore Dallas spoke at a monthly meeting. The Department is responsible for staffing the Council and oversees programs and funding in support of lifespan caregiving issues throughout the state.

- ***Partnering with Statewide Advocates***

The Council successfully partnered with the Maryland Respite Care Coalition on two occasions in 2011 for the caregiver stories video and the Caregiver Issues and Trends Forum. The Council also partnered with the Maryland Gerontological Association for the Caregiver Issues and Trends Forum offering educational CEU's to nurses and social workers. Future statewide partnerships and events will be conducted in 2012.

- ***Veterans***

The Council reached out to the Lt. Governor's Office and requested his recommendation for a family caregiver of a veteran to serve on the Council. The Department of Veterans Affairs assisted in this recommendation and the Council now has the voice of a person who is not only the primary caregiver of a veteran but is also a veteran.

- ***Community Outreach***

The Council participated in statewide and community activities promoting caregivers and the Council throughout the year. Attached is calendar of the Council's outreach activities for 2011.

OBSTACLES

Although the Department of Human Resources provides staffing to the Council, there is a need for a dedicated part-time staff position to coordinate the activities and requirements mandated by statute. The volunteer Council is limited in its time and abilities to properly execute the responsibilities of the Council without dedicated staff.

2012 GOALS

- ***Website***

The Council will expand its website presence with additional resources to support Family Caregivers across the lifespan. The Council is currently working with the Department of Human Resources to enhance the website presence and make information more accessible to Maryland citizens.

- ***Advocacy and Policy***

Under the new Affordable Care Act, there are many new caregiving programs under home- and community-based initiatives that directly affect caregivers in our state. The Council will continue to advocate for caregivers across disciplines to ensure they are an important part of the planning and execution of these programs. The Council will be directly involved in these activities in 2012.

MEMBERSHIP & ATTENDANCE

Council membership is composed of Governor appointees representing state agencies, caregivers, consumers, service providers, and advocacy groups. The Department of Human Resources provides staff to the Council. The Council meets the first Thursday of every month in Annapolis from 10:30 am to 12:30 pm. Meetings are open to the public.

Membership attendance is required and recorded. Several members are currently on leave from the Council due to their own caregiving needs and priorities.

ATTACHMENTS

Valuing the Invaluable: 2011 Update
The Economic Value of Family Caregiving in 2009
AARP Public Policy Institute

MCSCC Outreach Calendar 2011

Maryland Caregiver's Support Coordinating Council Outreach Calendar 2011

Month	Name of Event	Location	Target Population	No. of Attendees (est.)	Council Representative
January	No Activity				
February	No Activity				
March	23 rd - 25 th Annual Conference on Pediatric Health Care	National	Pediatric nurses, physicians	4,500 plus	Mary Johnson
April	Reproductive Health Update	Statewide	School Health nurses, health departments	400	Mary Johnson
May (Women's Health Month)	Frankford Improvement Association	Local	Community	300	Mary Johnson
	FASD National Conference	National	Caregivers, state representatives, state agencies	500	Mary Johnson
	STD Annual Meeting	Statewide	Nurses, case managers	500 plus	Mary Johnson
June	Radio Interview WOLB 1010 AM	Baltimore Metropolitan	General Public	Unknown	Felicia French Dorinda Adams
July	Morgan State University 8 th Gerontology Conference	Statewide	Caregiving women, partners, leaders, human service workers, physicians, administrators, policymakers	200 plus	Ginger Miller
August (Breastfeeding Month)	Breastfeeding Month Display	Statewide	State workers and community	800 plus	Mary Johnson
	MACO				Carolyn True
September (Fetal Alcohol Spectrum Disorders) FASD Week	FASD Display	Statewide	State workers and community	800 plus	Mary Johnson
	Back To School Jam	East Baltimore	Families and community leaders	2500	Mary Johnson

October Child Health Month	Child Health Display	Statewide	State workers and community	800 plus	Mary Johnson
	Maryland 14 th Annual Respite Awareness Day	Statewide	Caregivers, community leaders, government agencies/private agencies	175	Mary Johnson and Council Members * Caregiver Video Screened, Ginger Miller and Joan Smith presented workshops
November	2 nd Annual Women's Veterans Day & Celebration	Washington, DC	Veteran families, policymakers	400 plus	Ginger Miller, Maryland State Ambassador and Statewide Coordinator of "Women Veterans ROCK"
	Maryland Cancer Control Conference	Statewide	State agencies, survivors, community leaders	300 plus	Mary Johnson
December	Caregiver Issues/Trends Forum - Partnership with MRCC and MGA	Statewide	State and local agencies, private agencies, volunteers, family caregivers	85	Gail Hunt, National Alliance on Caregiving, Michael Marcus, Weinberg Foundation, Jill Kagan, National Respite Coalition, Ginger Miller, MCSCC, Elizabeth Weglein, MCSCC Chair

Valuing the Invaluable: 2011 Update The Economic Value of Family Caregiving in 2009

This Fact Sheet presents highlights from the AARP Public Policy Institute Report *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*, by Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula. For a detailed discussion of these contributions and costs, methodology, and source data, please see the full report at <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>.

Family Caregivers Provided Care Valued at \$450 billion in 2009

Family support is a key driver in remaining in one's home and in the community, but it comes at substantial costs to the caregivers themselves, to their families, and to society. If family caregivers were no longer available, the economic cost to the U.S. health care and long-term services and supports (LTSS) systems would increase astronomically.

This report, part of the Valuing the Invaluable series on the economic value of family caregiving, updates national and individual state estimates of the economic value of family care using the most current available data. It finds that—

In 2009, about 42.1 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time, and about 61.6 million provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion in 2009, up from an estimated \$375 billion in 2007.

The \$450 billion figure is based on 42.1 million caregivers age 18 or older providing an average of 18.4 hours of care per week to recipients age 18 or older, at

an average value of \$11.16 per hour. Some benchmarks can help to put this figure into meaningful context. The estimated \$450 billion is—

- More than total Medicaid spending in 2009, including both federal and state contributions for both health care and LTSS (\$361 billion)¹
- Nearly four times Medicaid LTSS spending in 2009 (\$119 billion)²
- More than twice total paid LTSS, regardless of payer source, in 2009 (\$203 billion)³
- As much as the total sales of the world's largest companies, including Wal-Mart (\$408 billion in 2009, the most of any company) and the three largest publicly held auto companies combined (Toyota, Ford, Daimler: total \$439 billion)⁴
- Approaching total 2009 expenditures for the Medicare program (\$509 billion)⁵
- Almost \$1,500 for every person in the United States (307 million people as of July 1, 2009)⁶
- About 3.2 percent of the 2009 U.S. gross domestic product (\$14.1 trillion)⁷
- Almost as much as the 2009 gross domestic product of Belgium, the 20th largest economy in the world (\$471 billion)⁸

State Estimates of the Economic Value of Family Caregiving

The most important factor in determining the number of caregivers in each state is population. However, caregiving prevalence also varies among states, reflecting differences in the age structure of the population, rates of disability and chronic health conditions, and cultural and economic factors. There is also significant variation in economic value per hour among states. Table 1 presents estimates of the number of caregivers, economic value per hour, hours of care provided, and total economic value of caregiving in every state and the District of Columbia.

Table 2 compares the total economic value of caregiving to three measures in each state: total Medicaid, LTSS, and home and community-based services (HCBS) spending.⁹ Medicaid LTSS spending includes the cost of nursing home care, as

well as payments for home care and services provided in assisted living. State-to-state variation in these ratios is mostly due to variation in state Medicaid spending.

Total Medicaid spending ranges from less than \$500 per capita in Nevada and Utah to more than \$2,500 per capita in New York and the District of Columbia.

States differ even more dramatically in Medicaid spending for LTSS, from about \$125 to more than \$1,000 per capita, and in spending for HCBS, from about \$60 to almost \$500 per capita.

The economic value of caregiving exceeded total Medicaid LTSS spending in all states, and was more than three times as high in 42 states.

Compared to Medicaid HCBS spending, the economic value of family caregiving was at least twice as high in all states, and more than six times as high in 40 states.

Endnotes

¹ S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Long Term Care Expenditures FY 2009* (Cambridge, MA: Thomson Reuters, 2010). <http://www.hcbs.org/moreInfo.php/doc/3325>.

² J. Kasten, S. Eiken, and B. Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures*. (Cambridge, MA: Thomson Reuters, 2011), <http://www.hcbs.org/moreInfo.php/doc/3584>.

³ C. O'Shaughnessy, "National Spending for Long-Term Services and Supports (LTSS)," *National Health Policy Forum*, March 15, 2011.

⁴ Forbes.com, *Special Report: The Global 2000*, http://www.forbes.com/lists/2010/18/global-2000-10_The-Global-2000_Sales.html. Sales figures are actually for the most recent 12 months, as of spring 2010.

⁵ Center for Medicare and Medicaid Services, *2010 Medicare Trustees Report*. <https://www.cms.gov/ReportsTrustFunds/downloads/tr2010.pdf>.

⁶ U.S. Census Bureau, *Population Estimates Program, Annual Estimates of the Resident Population for the United States, Regions, States, and Puerto Rico: April 1, 2000 to July 1, 2009* (NST-EST2009-01), <http://www.census.gov/popest/states/NST-ann-est.html>.

⁷ U.S. Department of Commerce, Bureau of Economic Analysis, NIPA table 1.1.5, 2009-A. <http://www.bea.gov/national/nipaweb/TableView.asp?SelectedTable=5&ViewSeries=NO&Java=no&Request3Place=N&3Place=N&FromView=YES&Freq=Year&FirstYear=2009&LastYear=2009&3Place=N&Update=Update&JavaBox=no#Mid>

⁸ The World Bank, <http://data.worldbank.org/indicator/NY.GDP.MKTP.CD?> Accessed May 4, 2011.

⁹ Eiken, Sredl, Burwell, and Gold, *Medicaid Long Term Care Expenditures FY 2009*; Kasten, Eiken, and Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures*. In this report, LTSS and HCBS spending includes home health services.

Fact Sheet 229, June, 2011

AARP Public Policy Institute,
601 E Street, NW, Washington, DC 20049
www.aarp.org/ppi
202-434-3890, ppi@aarp.org
© 2011, AARP.
Reprinting with permission only.

Table 1
Number of Caregivers and the Economic Value of Caregiving, by State, 2009

State	Total State Population	Number of Caregivers		Total Hours of Care (millions)	Economic Value/ Hour	Total Value (millions)
		At any given time	At any time during the year			
Alabama	4,710,000	818,000	1,200,000	783	\$9.37	\$7,300
Alaska	698,000	88,000	128,000	84	\$13.10	\$1,100
Arizona	6,600,000	855,000	1,250,000	818	\$11.50	\$9,400
Arkansas	2,890,000	478,000	698,000	457	\$9.87	\$4,500
California	37,000,000	4,020,000	5,880,000	3,850	\$12.17	\$47,000
Colorado	5,020,000	576,000	843,000	551	\$11.93	\$6,600
Connecticut	3,520,000	486,000	711,000	465	\$12.50	\$5,800
Delaware	885,000	138,000	202,000	132	\$11.77	\$1,560
District of Columbia	600,000	68,000	99,000	65	\$11.70	\$760
Florida	18,500,000	2,780,000	4,060,000	2,660	\$10.88	\$29,000
Georgia	9,830,000	1,360,000	2,000,000	1,310	\$10.03	\$13,100
Hawaii	1,300,000	169,000	247,000	162	\$12.33	\$1,990
Idaho	1,550,000	210,000	307,000	201	\$10.03	\$2,000
Illinois	12,900,000	1,660,000	2,430,000	1,590	\$11.83	\$18,800
Indiana	6,420,000	916,000	1,340,000	877	\$10.70	\$9,400
Iowa	3,010,000	369,000	540,000	353	\$11.66	\$4,100
Kansas	2,820,000	414,000	605,000	396	\$10.41	\$4,100
Kentucky	4,310,000	735,000	1,080,000	704	\$10.03	\$7,100
Louisiana	4,490,000	627,000	917,000	600	\$9.53	\$5,700
Maine	1,320,000	191,000	279,000	182	\$12.50	\$2,300
Maryland	5,700,000	769,000	1,120,000	735	\$11.03	\$8,100
Massachusetts	6,590,000	858,000	1,260,000	821	\$13.33	\$10,900
Michigan	9,970,000	1,440,000	2,110,000	1,380	\$11.23	\$15,500
Minnesota	5,270,000	679,000	993,000	649	\$12.70	\$8,200
Mississippi	2,950,000	565,000	826,000	540	\$9.70	\$5,200
Missouri	5,990,000	865,000	1,270,000	828	\$10.70	\$8,900
Montana	975,000	131,000	191,000	125	\$11.16	\$1,390
Nebraska	1,800,000	219,000	320,000	210	\$10.70	\$2,200
Nevada	2,640,000	364,000	532,000	348	\$11.48	\$4,000
New Hampshire	1,320,000	183,000	268,000	175	\$12.67	\$2,200
New Jersey	8,710,000	1,190,000	1,750,000	1,140	\$11.59	\$13,200
New Mexico	2,010,000	287,000	419,000	274	\$11.25	\$3,100
New York	19,500,000	2,800,000	4,100,000	2,680	\$11.85	\$32,000
North Carolina	9,380,000	1,180,000	1,730,000	1,130	\$10.37	\$11,700
North Dakota	647,000	75,000	109,000	71	\$11.68	\$830
Ohio	11,500,000	1,660,000	2,430,000	1,590	\$11.03	\$17,500
Oklahoma	3,690,000	596,000	872,000	570	\$10.44	\$6,000
Oregon	3,830,000	463,000	678,000	443	\$12.43	\$5,500
Pennsylvania	12,600,000	1,850,000	2,700,000	1,770	\$11.27	\$19,900
Rhode Island	1,050,000	148,000	217,000	142	\$13.27	\$1,880
South Carolina	4,560,000	770,000	1,130,000	737	\$10.04	\$7,400
South Dakota	812,000	101,000	147,000	96	\$10.70	\$1,030
Tennessee	6,300,000	1,130,000	1,650,000	1,080	\$10.20	\$11,000
Texas	24,800,000	3,420,000	5,010,000	3,270	\$10.35	\$34,000
Utah	2,780,000	382,000	559,000	365	\$11.37	\$4,200
Vermont	622,000	83,000	122,000	80	\$12.37	\$990
Virginia	7,880,000	1,180,000	1,720,000	1,130	\$10.37	\$11,700
Washington	6,660,000	854,000	1,250,000	817	\$12.94	\$10,600
West Virginia	1,820,000	303,000	443,000	290	\$9.67	\$2,800
Wisconsin	5,650,000	524,000	766,000	501	\$11.49	\$5,800
Wyoming	544,000	72,000	106,000	69	\$9.87	\$680
USA	307,000,000	42,100,000	61,600,000	40,300	\$11.16	\$450,000

Source: Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*, Insight on the Issues #51 (Washington, DC: AARP Public Policy Institute, June 2011).

Table 2**Ratio of Economic Value of Caregiving to Medicaid Spending, by State, 2009**

State	Ratio of Economic Value of Caregiving to		
	Total Medicaid Spending	Medicaid LTSS Spending	Medicaid HCBS Spending
Alabama	1.66	5.2	16.7
Alaska	1.03	2.9	4.4
Arizona	1.12	6.3	9.2
Arkansas	1.30	4.2	12.3
California	1.25	4.1	7.2
Colorado	1.85	4.8	8.2
Connecticut	0.97	1.8	3.8
Delaware	1.29	4.7	13.0
District of Columbia	0.47	1.4	2.7
Florida	1.91	6.8	19.3
Georgia	1.70	6.6	17.5
Hawaii	1.50	7.9	14.3
Idaho	1.56	4.9	10.3
Illinois	1.47	6.1	20.5
Indiana	1.49	4.1	12.7
Iowa	1.39	3.2	7.7
Kansas	1.67	4.0	7.1
Kentucky	1.32	5.1	15.4
Louisiana	0.88	2.9	7.5
Maine	0.91	3.2	5.6
Maryland	1.21	4.3	10.3
Massachusetts	0.87	2.9	6.2
Michigan	1.47	6.5	18.5
Minnesota	1.12	2.4	3.5
Mississippi	1.37	4.4	29.3
Missouri	1.16	4.7	10.2
Montana	1.59	4.1	8.4
Nebraska	1.39	3.4	8.2
Nevada	2.89	11.9	25.4
New Hampshire	1.67	3.9	8.9
New Jersey	1.34	3.5	11.6
New Mexico	0.94	3.3	3.9
New York	0.65	1.5	3.1
North Carolina	1.02	3.5	7.6
North Dakota	1.41	2.3	7.7
Ohio	1.31	3.5	9.7
Oklahoma	1.51	5.0	11.0
Oregon	1.50	4.2	5.7
Pennsylvania	1.17	3.1	8.9
Rhode Island	1.00	3.3	7.1
South Carolina	1.45	6.3	15.1
South Dakota	1.44	3.7	8.9
Tennessee	1.49	5.1	12.0
Texas	1.47	5.6	11.4
Utah	2.54	10.7	23.4
Vermont	0.87	3.1	4.5
Virginia	2.02	6.0	13.2
Washington	1.60	4.8	7.3
West Virginia	1.15	3.1	7.1
Wisconsin	0.79	1.9	3.6
Wyoming	1.30	3.2	5.5
USA	1.25	3.8	8.2

Spending data are from S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Long Term Care Expenditures FY 2009* (Cambridge, MA: Thomson Reuters, 2010); and J. Kasten, S. Eiken, and B. Burwell, *Medicaid Managed Long-Term Services and Supports Expenditures* (Cambridge, MA: Thomson Reuters, 2011). In these calculations, LTSS and HCBS spending includes home health services.