

**REPORT ON THE MARYLAND COMMISSION ON CAREGIVING**

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MARYLAND DEPARTMENT OF HUMAN SERVICES

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

October 1, 2018

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## REPORT REQUIREMENT

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This report is hereby submitted in response to the following reporting requirement found under Human Services Article § 7-305(b):

*The Maryland Commission on Caregiving shall report annually on its activities and recommendations regarding family caregiver support services to the Governor and, subject to § 2-1246 of the State Government Article, the General Assembly.*

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

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## BACKGROUND

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The Maryland Commission on Caregiving (MCC) is the State's formal voice for the informal caregiver. The purpose of the Commission is to coordinate statewide planning, development, and implementation of family caregiver support services for all ages, especially respite care.

The Commission was created during the 2017 session of the General Assembly, established through legislation enacted in Senate Bill 216/HB 769 and signed into law by Governor Larry Hogan on April 11, 2017. The new Commission took effect on October 1, 2017 and is comprised of 19 commissioners including a legislator from the House of Delegates and one from the State Senate. In addition, three commissioners are appointed as family caregivers to ensure that the "Voice of the Caregiver" is fully represented.

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## ACTIVITIES

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The MCC is pleased to provide this annual report covering the activities of July 1, 2017 through June 30, 2018.

The MCC continued with the Strategic Planning Process which has required a thorough review of the Commission's legislative mandates:

1. 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
8. Provide ongoing analysis of best practices in family caregiver support programs in this and other states
9. Monitor implementation of the Commission's recommendations

As a result of this review of the statute, the MCC achieved foundational milestones needed in order for it to comply with its legislative mandate. The MCC has developed its mission and vision statements and finalized its membership and executive committee.

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## OUTREACH

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The MCC engaged in a wide array of outreach activities during the reporting period. The MCC presented or exhibited at 15 events. The total number of attendees for these events was 1,160. The MCC also partnered with several organizations during their legislative outreach events during the 2018 General Assembly. Please refer to Appendix A (Community and Outreach Events July 2017 to June 2018) for a list of events. The MCC also conducted outreach to legislators by providing a letter of support for HB 1744 “Child Abuse and Neglect-Substance Exposed Newborns-Reporting,” in order to align Maryland’s statutes with federal changes to the Children’s Abuse Prevention and Treatment Act (CAPTA). Please refer to Appendix B (Letter of Support HB 1744).

The MCC focused its efforts on communication and outreach to caregivers through print and digital media. It developed a brochure targeted to caregivers. The brochure serves two important purposes. First, it provides information about programs offered by various State Agencies as well as contact information for Maryland Access Point (MAP).

Second, it raises caregivers’ awareness of their roles and the value they provide to their family members and to the State of Maryland (Refer to Appendix C, MCC Brochure). Several articles written by the MCC were published in the *Star Democrat*. These articles introduced readers to the MCC’s mission, highlighted the types of support caregivers across the lifespan provide to their loved ones, and listed services available to caregivers through various community agencies (Refer to Appendix D, *Star Democrat* Articles).

Finally, the MCC is in the process of developing a standalone website. The goal of the website is two-fold: to provide general information about the MCC (such as its mission, vision, and legislative mandate) and to serve as a medium through which the MCC will provide relevant and timely information to family caregivers, partners, and prospective partners. The website will contain information regarding the MCC’s vision, mission, events and legislative mandate, the definition of a family caregiver, as well as a calendar of events, newsletter and a monthly survey. To assist family caregivers, the website will include reliable and up-to-date information on resources and best practices, using a formal vetting process to ensure that resources are reliable and up-to-date. Moreover, the website will include increased functionality for partners and members. The website will include a repository where MCC partners can share information and record their participation in outreach events and related activities, as well as a resource development tracking database in which potential sources of funding will be housed. The website’s content has been approved, and it is anticipated to launch in 2019.

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## **RESEARCH**

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The MCC is constantly seeking ways in which to obtain “the voice of the caregiver.” During the “Care for All” Town Hall, the MCC gathered input from family caregivers regarding the impact caregiving has had on their lives, the resources they consider most helpful, the resources they need and the ways in which elected officials and the MCC can support family caregivers. To ensure that the opinions of family caregivers across the lifespan and family caregivers of care recipients across a variety of conditions were represented, the questions used in the Town Hall were developed and reviewed by the Maryland Respite Care Coalition, family caregivers, the MCC, and Senator Delores Kelley’s Task Force (Refer to Appendix E, Town Hall Report). Another Town Hall event was planned for September 15, 2018. The opinions of family caregivers are being gathered and analyzed from this event. The forthcoming MCC website will include a monthly survey which will be used to solicit and gather the concerns of caregivers.

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## **PARTNERSHIPS**

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Partnerships will be the focus of the MCC’s Annual Meeting scheduled for November 1, 2018. The Annual Meeting will both celebrate National Caregiver Month and will conduct outreach and strategic planning in order to work more effectively with partners. Town hall events were held in September 2018 to strengthen the MCC’s relationships with partners in Frederick County and on the Eastern Shore.

To facilitate communication with its partners, the MCC created a community outreach database. The database is being used to communicate information about the MCC and its partners’ initiatives and events. Moreover, the MCC’s partnership with the Lifespan Training Committee will benefit the MCC’s website with the inclusion of web-based training programs across the lifespan.

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## **PRIORITIES FOR 2018-2019**

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The MCC has identified three priorities for 2018 -2019:

1. The completion of the MCC website.
2. The identification of new ways to obtain feedback from caregivers who have traditionally been underrepresented and/or hard-to-reach.
3. The development of new strategies to work with partners, per the MCC’s mandate.

# Maryland Commission on Caregiving

## Caregiver Outreach & Community Events

**2018**

<b>Month</b>	<b>Name of Event</b>	<b>Type of Event</b>	<b>Commission Members Present</b>	<b>Location</b>	<b>Population</b>	<b>Number of People who Attended</b>
<b>JULY</b>	<b>25<sup>th</sup></b> Presentation Before Task Force to Study Family & Medical Insurance	Presenter	Dorinda Adams	Maryland General Assembly	Legislative Task Force	25
<b>AUGUST</b>	<b>17<sup>th</sup></b> <i>Empowering Communities to Age with Dignity</i> sponsored by National Hispanic Council on Aging	Presenter	Dorinda Adams, Mary Chaput, Lylie Fisher	Silver Spring Civic Center Building	Professionals & Family Caregivers	100
	<b>30<sup>th</sup></b> National Home & Community-Based Conference	Workshop Presenter	Dorinda Adams, Jennifer Eastman	Baltimore, MD	Professionals	20

<b>Month</b>	<b>Name of Event</b>	<b>Type of Event</b>	<b>Commission Members Present</b>	<b>Location</b>	<b>Population</b>	<b>Number of People who Attended</b>
<b>SEPTEMBER</b> (FASD Month)						
<b>OCTOBER</b> (Child Health Month)	<b>11<sup>th</sup> - 13<sup>th</sup></b> National Respite Conference - "Take off with Respite"	Workshop Presenter	Dorinda Adams	Huntsville, AL	Professionals and Family Caregivers	35
	<b>26<sup>th</sup></b> Maryland Association of Social Services	Presenter	Jennifer Charlton	Annapolis	Human Services Professionals	60
<b>NOVEMBER</b> (National Caregiver's Month)	<b>2<sup>nd</sup></b> MCC Annual Meeting				General Public, Partners, Elected Officials	150
	<b>13<sup>th</sup></b> WYPR Midday Interview for National Caregivers Month	Radio Interview  Presenters	Dorinda Adams  Dorinda Adams, Jennifer Eastman	Baltimore  Linthicum Heights, Hilton BWI Hotel	Radio listeners	NA

<b>Month</b>	<b>Name of Event</b>	<b>Type of Event</b>	<b>Commission Members Present</b>	<b>Location</b>	<b>Population</b>	<b>Number of People who Attended</b>
	<b>14<sup>th</sup></b> AARP Caregiving Celebration "Caring for All"				Family Caregivers, Human Services Professionals, Elected Officials	100
<b>DECEMBER</b>						
<b>JANUARY</b>	<b>17<sup>th</sup></b> United Seniors & AARP State Legislative Day	Exhibitor & Speaker	Jennifer Eastman, Dorinda Adams	Senate Building, Annapolis	State Delegates	150
<b>FEBRUARY</b>	<b>7<sup>th</sup></b> Multiple Sclerosis Legislative Day	Exhibitor	Chandler Johnson	House Building, Annapolis	State Delegates	30
	<b>22<sup>nd</sup></b> NAMI Advocacy Day	Exhibitor	Chandler Johnson	House Building, Annapolis	State Delegates	50
<b>MARCH</b>	<b>14<sup>th</sup></b> Alzheimer's Association Legislative Day (State)	Exhibitor	Chandler Johnson	Senate Building, Annapolis	State Delegates	100

<b>Month</b>	<b>Name of Event</b>	<b>Type of Event</b>	<b>Commission Members Present</b>	<b>Location</b>	<b>Population</b>	<b>Number of People who Attended</b>
<b>APRIL</b>	<b>21<sup>st</sup></b> 26 <sup>th</sup> Annual Anne Arundel County Caregiver Conference	Workshop	Jennifer Eastman, Greg Sesek	Double Tree Hilton Hotel, Annapolis	Family Caregivers	200
	<b>25<sup>th</sup></b> Easter Seals Workshop	Workshop	Larry Bram	Easter Seals, Silver Spring	Family Caregivers	100
<b>MAY</b>	<b>2<sup>nd</sup></b> Social Security Administration Work-Life Fair	Exhibitor	Christine Schoenberger	SSA Headquarters Woodlawn	SSA Employees	40
<b>JUNE</b>						



## Who We Are

**The Maryland Commission on Caregiving** consists of 19 Commissioners, appointed by the Governor of Maryland, to support informal Caregivers as they care for their loved ones across the lifespan.

The Commission serves to:

- Build public awareness and support
- Recommend public policy to support caregiver needs & objectives
- Facilitate development of support systems



## Our Mission

As the "Voice of the Caregiver", the Maryland Commission on Caregiving seeks to recommend policies, address the concerns and acknowledge the contributions of Maryland Caregivers. The Commission will engage communities to empower Caregivers with resources, respite and support.

The following national organizations provide information and guidance to Maryland Family Caregivers



ARCH Respite  
Network  
[archrespite.org](http://archrespite.org)



[AARP.org](http://AARP.org)



Caregiver  
Action  
Network



Family Caregiver  
Alliance  
[caregiver.org](http://caregiver.org)



National Alliance  
for Caregiving  
[caregiving.org](http://caregiving.org)



**MARYLAND  
COMMISSION ON CAREGIVING**

The Voice of the Caregiver

**Jennifer Eastman, Chair**  
**Dorinda Adams, DHS Staff**  
[Dorinda.Adams@maryland.gov](mailto:Dorinda.Adams@maryland.gov)

410-767-7323

Administered by



[DHS.maryland.gov](http://DHS.maryland.gov)



## Who Are Caregivers?

*Caregivers advocate for the physical, emotional and social needs of a family member or loved one, of any age, living with a disability, illness, or chronic condition.*

- **Basic Support** - Medical & social appointments, transportation, aid in managing finances and applying for financial assistance as well as laundry, grocery shopping, and other tasks as needed
- **Medical Care** - Medication reminders, wound care, rehabilitative supports, or other medical treatments
- **Assistance With Activities of Daily Living** - Toileting, bathing, dressing or more complex tasks

*If you are doing any or all of the above activities...you are a Caregiver*

## Did You Know?

- **80% of the care for individuals in the U.S. who need assistance with daily activities is provided by informal, unpaid Caregivers. These Caregivers are the backbone of our long-term care system.**
- **The value of their care and services is:**
  - \$470 billion** per year nationwide
  - \$9.4 billion** per year in Maryland<sup>1</sup>

<sup>1</sup> Reinard, Susan, et al. (July, 2015) **Valuing the Invaluable: 2015 Update.** AARP Public Policy Institute

## Maryland Access Point (MAP)

*MAP Counselors assist Maryland Caregivers - serving loved ones of all ages - to access available long-term care information, support and services.*

For information, call or visit the website

844-627-5465



**MARYLAND ACCESS POINT**  
YOUR LINK TO HEALTH & SUPPORT SERVICES  
[www.marylandaccesspoint.info](http://www.marylandaccesspoint.info)

## Network of Support

*Family Caregivers need a variety of support services depending on the condition, diagnosis, or disability of their loved one. In addition to supportive services for their loved one, caregivers themselves often need back-up support as coverage to maintain employment or to have a much needed break from the daily activities of caregiving.*

*Information and support is available through the following Maryland state agencies.*

### Department of Human Services (DHS)

*Office of Adult Services Respite Care Program  
Kinship Navigator Services*

### Department of Disabilities (DD)

*Attendant Care Program  
Maryland Technology Assistance Program*

### Department of Aging (DOA)

*National Family Caregiver Support Program*

### Department of Health (MDH)

*Child & Adolescent Respite Care Program  
Low Intensity Support Services  
Children & Youth w/Special Health Care Needs  
Resource Locator*



# Maryland Commission on Caregiving

## “The Voice of the Caregiver”

### What is the purpose of the Maryland Commission on Caregiving?

The Commission is charged with looking out for the interests of more than 770,000 unpaid family caregivers throughout Maryland. Informal Caregivers provide nearly \$9.3 billion in unpaid care annually to their family members, loved ones and friends.

In recognition of the important contribution that informal caregivers provide to our families and communities, the Maryland legislature passed Senate Bill 216 during the 2017 legislative session to rename the former Maryland Caregivers Support Coordinating Council to the Maryland Commission on Caregiving. The legislation was signed by Governor Larry Hogan on April 11, 2017, and took effect on October 1, 2017. The Commission consists of 19 members including: legislative members Delegate Karen Lewis Young and Senator James N. Mathias, human service professionals, and three family caregivers to ensure that the “voice of the caregiver” is fully represented.

*(Based on a December 2015 AARP Maryland study of 1,000 Maryland registered voters age 45-plus, the study shows that 58% of Maryland registered voters age 45 and older either are currently family caregivers or have been in the past)*

Each month the Commission will provide highlights of the support being provided by caregivers serving all age groups and disabilities across the mid-shore region. Their stories and testimonials will offer insights and information about services available through various community organizations.

You are a Caregiver if...

You are assisting someone of any age at home for short or long periods of time with:

- housekeeping
- cooking
- shopping
- bathing
- dressing
- mental health/behavioral needs
- medications
- mobility
- medical appointments
- managing households
- managing budgets

**For more information about the Maryland Commission on Caregiving or to locate services and support networks for caregivers, go to:**

**[dhs.maryland.gov/maryland-commission-caregiving](http://dhs.maryland.gov/maryland-commission-caregiving)**

**or call Delmarva Community Services’ Respite Care Service**

**410-943-1106**

**Currently available in 9 Eastern Shore Counties**

### **#1 Most Important Need for Family/Informal Caregivers is Respite Care!**

Respite care, whether on a planned or emergency basis, is simply a break for a caregiver who cares for a child, adult, friend or neighbor of any age with special needs or disabilities. This break from caregiving can be provided in the home of the care receiver, or in an alternate setting, ranging from a quick break for a recharge to an extended vacation for complete renewal.

*(Based on a 2014-2015 Maryland survey conducted by the Council with more than 1,700 respondents)*

For more information about respite care, to attend a meeting, or join the mailing list, please visit:

**[MarylandRespiteCoalition.org](http://MarylandRespiteCoalition.org)**



### **Chesapeake Grove Intergenerational Center in Cambridge**

Based on the St. Ann’s Center in Wisconsin, a shared space, community center model, Delmarva Community Services (DCS) is developing the Chesapeake Grove Intergenerational Center in Cambridge. The new campus/facility is intended to foster genuine and meaningful interactions between seniors, individuals with disabilities and children. The space has been designed to be welcoming, encourage spontaneous interactions, convey a community-like feeling, create new opportunities for senior activities and interests, and encourage a family atmosphere among its staff and visitors.

The Chesapeake Grove Intergenerational Center will provide experiences that enhance the lives of adults and children through shared experiences within the facility and also among the wider community. Programming will offer:

- Interactive programming between daily attendees
- Activities coordinated with school children from local schools within 1 mile
- Natural, spontaneous interactions between attendees within unique physical spaces

The new center will be an intimate, inviting and innovative community center that offers interesting and engaging opportunities with more choices in programs, services, clubs, and classes made available in small group settings.

*In recognition of significant funding provided for this project by the  
Harry and Jeanette Weinberg Foundation  
DCS is proud to announce the new building will be named*

### ***The Harry and Jeanette Weinberg Intergenerational Center***

The center’s programming is framed around four experiences of being human:

- Being Active Together - Being Healthy
- Being Engaged Together - Being Needed
- Being Continual Learners - Being Understood
- Being Happy Together - Being Accepted

The campus will ultimately have 6 buildings including three senior housing buildings with each building having 29 units. The units will offer one and two bedroom layouts with a kitchen in each unit. In response to an identified need for additional senior housing, DCS plans to offer two additional buildings with 15 beds each for those needing a higher level of assistance but not the care of a nursing home.

### **The George B. Todd Fund Matching Grant**

George B. Todd Fund, a fund established in memory of local businessman George Todd, has challenged the community to donate or pledge \$35,000 per year through Dec. 2018. To learn how you can help, please contact:

**Delmarva Community Services (DCS)  
2450 Cambridge Beltway, Cambridge, MD 21613**

**410-221-1900**

**[dcsdct.org](http://dcsdct.org), Facebook & Twitter**

***The Maryland Commission on Caregiving does not provide funding for DCS programs***

**The Maryland Commission on Caregiving  
is supported by the following state agencies:**

Maryland Department of Aging (MDoA), Maryland Department of Disabilities (MDOD),  
Maryland Department of Health (MDH), Maryland Department of Human Services (DHS)

***Our deep appreciation goes to APG Media of Chesapeake for their support and  
commitment to serving those in need throughout the mid-shore!***





# Addendum XX

## Results from Town Hall Facilitated by Senator Delores G. Kelley – District 10 at the “Care for All” Town Hall on November 14, 2017

### RESULTS FROM EVENT-62 returned

<b>Event Title:</b>	<b>AARP MD and the Maryland Commission on Caregiving present Caregiving in Maryland: Care for All</b>	<b>Location:</b>	<b>Linthicum, MD</b>
<b>Guest Speakers and Special Guests</b>	<b>Amy Goyer, Assistant Secretary Lance Robertson, Senator Delores G. Kelley</b>	<b>Date:</b>	<b>November 14, 2017</b>

The purpose of this evaluation is to provide feedback on this event and to assist us in enhancing future events. We appreciate your comments and feedback.

1. Identification: Family/Informal Caregiver-39 Professional-6 Other-7 Both-6 N/A-5

Please place an X in the box that best describes your agreement or disagreement with the following statements:	Strongly Agree	Agree	Disagree	Strongly Disagree	No Answer
1) Overall the event met my expectations.	47	17			
2) Time allotted was sufficient.	42	18	3		
3) Registration for the event was easily accessible.	51	8	1	2	1
4) I enjoyed the guest speakers and thought they had meaningful information in regards to family/informal caregiving.	54	8			1
5) I felt that my voice was heard during the Town Hall.	16	17		1	28
6) The Town Hall questions were meaningful.	23	15			24
7) I am likely to attend future events based on this experience.	49	11			3

**\*please note, answers are recorded verbatim\***

#### **How do you think this event could have been improved?**

- Shorter lunch break, maybe include panel discussion of professionals, talk about federal legislation affecting caregivers.
- Enjoyed the format, great job, very informative, great speaker.
- A list of bills or areas “you” desire us to support “you”...(as the responsible POC/organization).
- Heat, relative children care providers.
- Moderator to keep speakers on schedule or eliminate time noted on program.
- The registration process was extremely frustrating with many calls to the State unit and they made every effort to be accommodating.
- It would be difficult. Amy was both interesting and informative.
- The speaker was interesting but spent a lot of time on her story, but didn’t give us a lot of resources to take home to look at. The room was cold.
- Enjoyed the seminar.
- Tighten up the agenda, lunch was too long. Availability of Amy’s caregiver book.
- Have additional resources/vendors during event to provide information for caregivers and professionals.
- Reduced time for networking, start earlier, invite vendors/resources and move lunch to the end/move town hall to earlier time.

- The event was very informative.
- More concentration on caregivers across the lifespan and kinship caregiving.
- Begin with some type of interactive icebreakers or activity.
- Town hall panel and open questions.
- More caregivers at event.

**I would like to attend events related to (please, be specific as to the topic or content area):**

- Caregiver support systems and resources
- Providing legislation presentations.
- Similar events, yes. Another topic would be “How to interact with difficult family members: how to get them to be a part of the solution”
- More specific information and resources.
- Child disability and young adults with disabilities.
- More practically focused caregiver information, specific items from the MD Commission on Aging findings, and being an executor with a will and grievance power of attorney responsibilities.
- Legal seminars, guardianships, power of attorney, rights of caregivers when there’s no documentation. Medication, nutritional prep.
- Senior housing for seniors who are independent
- Caregiving-ways to reduce costs, alternative living/housing, affordable senior living communities.
- More lifespan caregiving, seemed really focused on older adults.
- Would like to hear from caregivers from other walks of life.
- Informal caregiving, resources available for kinship care providers.
- Funding for caregiving.
- Medicare, Social Security, Respite, Veteran’s benefits.
- Work force development “work capable”
- Elder legal care, estate planning, POA, guardianship.
- Multicultural caregiving through generations, funding resources for aged adults with older homes in need of repairs, mental/behavioral assistance for family caregivers.
- Exercises for caregivers
- Elevation of Alzheimer’s signs and symptoms.
- Dealing with life events that impact caregiving, role reversal, what next?

**Additional comments:**

- Add a portion on AARP website to continue to collect data, improve initiatives.
- Congrats on a successful event.
- Need for caregiver’s to have access to experienced social workers in order to learn how to navigate the community resources to provide appropriately for the patient; assistance in budgeting to supposedly use available financial resources and learning opportunities to thwart the efforts of scammers.
- Excellent lunch, very supportive and wonderful town hall questions.
- Thank you for making me feel like I am not alone.
- Need more time to cover topics from town hall questions.
- Enjoyed slide show, very effective.
- AARP, Dorinda and Senator Kelley are going in the right direction.
- Good location
- Opportunity to purchase Amy’s book

**If you are interested in joining the Maryland Commission on Caregiving email list please provide your**

**email:** \_\_\_\_\_

## ***Addendum XX,***

### **Town Hall facilitated by Senator Delores G. Kelley-District 10 at the “Care for All” on November 14, 2017**

***\*Feel free to complete and leave if you do not want to speak publicly during the Town Hall\****

#### **Town Hall Questions**

1. What has been the single greatest impact your caregiving role has had in your life?
2. What do you love the most about your caregiving role?
3. When you think about your situation as a family caregiver, what are the most important resources you wish you had? What are the greatest barriers you face to accessing these resources?
4. What community based supports and/or resources have been the most helpful in your role as a caregiver?
5. Do you feel Maryland is doing enough to address the needs of family caregivers?
6. What is one thing your elected officials can do to ease the burden on caregivers?
7. Do you see the situation for caregivers in Maryland improving in the next 10 years? Why or why not?

#### **Other questions for consideration (if time permits):**

1. How can the Commission on Caregiving find out what caregivers really need?
2. How can the Commission on Caregiving help caregivers to find the resources they need?
3. How can the Commission on Caregiving use the information from caregivers to fill unmet needs?

**The Maryland Commission on Caregiving thanks all Family/Informal Caregivers for their Participation!**



# Maryland Commission on Caregiving

*“The Voice of the Caregiver”*

APRIL IS

## WORLD AUTISM AWARENESS MONTH



*When I heard my daughter’s diagnosis, at about age 4, it was devastating. I sobbed for hours and my husband took it really hard, but my family encouraged me. Back in the day, before they really understood autism, they blamed the condition on what they termed, “refrigerator mothers”, those who were cold and unfeeling.” -- Jackie Davis*

### Living Life Fully With Autism

*By Jackie Davis, Caregiver for her daughter with Autism*

I was fortunate to be a stay-at-home mom so I immersed myself in research on diets, nutrition, home therapies and living a structured day.

I’ll never forget when, at six years old, we took her to a psychologist. The doctor put a picture on the wall of a cow with brown spots, horns and she was able to name the “udders”. That day she scored about 80 on the IQ. Because of her low IQ the doctor recommended she be put in the Benedictine School in Caroline county (Benschool.org), a school for low functioning children with autism. It’s a wonderful program but I wasn’t sure it was right for my daughter.

On a whim and my gut instinct, I went next door to an educational psychologist for another battery of tests. She told me, **“You need to focus on what she can do versus what she can’t do. Regular activities won’t come naturally so you’ll have to teach her everything through repetition. Structure and order is the key.”** She was a life saver! Over time, once she learned something, I would do it slightly differently to challenge and teach her that life changes and you have to be prepared for change.

*I’ve seen her struggle, I’ve seen her frustrations, I’ve seen her down and out – and – I’ve seen her find her passion in cupcakes and cookies. She is a good, kind, genuine, and sweet person. Today she is an advocate for those living with Autism. I am so very proud of her and who she has become! -- Jackie Davis*

### Autism Spectrum Disorder (ASD) and Parental Stress

*Adapted from “Stress and the Autism Parent” by the Interactive Autism Network at Kennedy Krieger Institute*

Most parents experience stress, but for those raising children with autism, everyday life often brings **Stress** with a capital S. Autism Spectrum Disorder (ASD) is a developmental disorder that affects communication and behavior and often appears in the first two years of life. Parental caregivers on a daily basis manage meltdowns, avoid sights or sounds that overload their child’s senses, address special education needs with teachers, drive to therapists or doctors, and keep their child from running away - all while sleep-deprived.

Studies report that stress experienced by parents of children with autism is more debilitating and causes more physical and mental health concerns, including increased depression and anxiety. One researcher stated, “Chronic stressors can wear down the body, particularly the cardiovascular, immune, and gastrointestinal systems.” Research finds that highly-stressed parents - acting as autism “therapists” at home - tend to focus on their child’s needs and neglect their own health. This can lead to challenges in successfully implementing autism interventions and following their child’s behavioral plans.

**Parent-Led Support Groups** are low-cost solutions for parents of children with autism and other developmental disabilities and offer significant reductions in stress, depression, and anxiety after just six weeks of treatment. Two such therapies are: (1) Mindfulness or (2) Positive Adult Development. In a study at Vanderbilt University, the mindfulness group learned special breathing and relaxation techniques, meditation, and other exercises to improve coping and fared better with anxiety, depression, sleep, and their sense of well-being. Parents in the second group learned how to combat worry, conflict, and pessimism by identifying and using their strengths and abilities and performing exercises involving kindness, optimism, and gratitude.

**Helping Parents Helps the Child.** Sometimes a stressed parent says, “Forget about me. It doesn’t matter how I feel. Just take care of my child.” This sentiment is understandable, but it ignores the fact that the family is a system, and that each person has an impact on the others. Decreasing the stress faced by parents of children with ASD, and promoting their health and ability to cope, is a worthwhile goal. Respite care provides a much needed break for family caregivers and is shown to decrease the psychiatric hospitalization of their loved one with autism.

### Support on the Eastern Shore Through The Kinera Foundation

Kinera Connect offers parents of children with special needs a number of support groups every Tuesday at 5:30 p.m. to gain information for assisting their children and families, learn more about aspects of special needs, and share ideas with others.

**Peace of Mind-Mental Health Services, 8614 Ocean Gateway, Suite #4, Easton.** For more information and upcoming activities, go to [www.kinera.org](http://www.kinera.org).

*The Maryland Commission on Caregiving is an informational resource and does not provide funding for Kinera Foundation’s programs or services*

### **Kinera Connect Parent & Caregiver Meeting**

April 18th @ 6:30 p.m.

Kinera Foundation Hub, 115 Sallitt Dr., Suite C,  
Stevensville

RSVPs are appreciated by April 16.

Go to [Kinera.org](http://Kinera.org) to register

### **Aqua Open Swim & Training For Children with Special Needs & Family Members**

Sunday, April 8 from 2 – 4 p.m.

Fitness RX, 155 Sallitt Dr., Stevensville

Cost is \$5 per person. For more information,  
call Elise Thomson 410-924-6426



Join Kinera Foundation for resources and fun! Local Community Organizations and Businesses will provide info and giveaways on a variety of topics including but not limited to: OT/PT therapy, Youth & Transition Services, Swimming Classes, Pediatric Care, Early Childhood Programs, Support Services, Nutrition, Wellness & Home and More!

- Info & Resources for Families with children /youth with special needs and disabilities and learning differences
- Activities for Children: Cupcake Decorating, Hopscotch, Crafts and Face Painting
- Snacks & Refreshments
- Vote for Vendors with Silliest Spring Hats & Sunglasses

Free event, but Registration required by April 23 at: [www.kinera.org](http://www.kinera.org)  
Questions? Interested in being a display vendor?  
Call 443-249-3126 or email [julie@kinera.org](mailto:julie@kinera.org)



Kinera Foundation - Hub location  
115 Sallitt Dr., Suite C, Stevensville MD

### **The Maryland Commission on Caregiving**

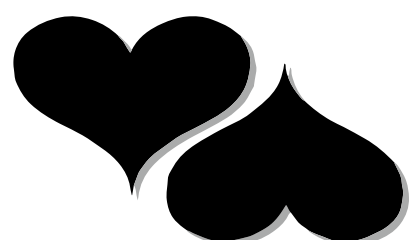
*Supported by the following state agencies:*

**Maryland Department of Aging (MDoA), Maryland Department of Disabilities (MDOD), Maryland Department of Health (MDH), Maryland Department of Human Services (DHS)**

*For more information about caregiving resources go to:*

**[dhs.maryland.gov/maryland-commission-caregiving](http://dhs.maryland.gov/maryland-commission-caregiving)**

*Our deep appreciation goes to APG Media of Chesapeake for their support and commitment to serving those in need throughout the mid-shore!*





# Maryland Commission on Caregiving

## *“The Voice of the Caregiver”*

March 14, 2018

The Honorable Joseph F. Vallario, Jr.  
House Judiciary Committee  
House Office Building, Room 101  
6 Bladen St., Annapolis, MD 21401

Dear Chairman Vallario,

The Maryland Commission on Caregiving is pleased to submit this **letter of support for HB1744** “Child Abuse and Neglect-Substance Exposed Newborns-Reporting”. This bill would amend sections of the Family Law Article as it pertains to substance-exposed newborns by altering the conditions under which a newborn is considered to be substance-exposed and changing reporting requirements, mandating that certain courses of action be taken following a report, and requiring specific data metrics to be collected and shared among the Departments of Health and Human Services.

The passage of HB1744 would align Maryland’s statute as it pertains to substance-exposed newborns with the federal changes made to the Children’s Abuse Prevention and Treatment Act (CAPTA) which provides funding to States in support of childhood abuse prevention, assessment, investigation, prosecution and treatment activities. These funds can be used for training and mutual support programs; improvement of triage procedures, kinship care services (where adult relatives are the preferred placement of children removed from their home); and facilitating linkages among agencies. Such agencies include: child protective services, public health, mental health, substance abuse, developmental disabilities, and domestic violence.

CAPTA was most recently amended by the Comprehensive Addiction and Recovery Act of 2016. Title V, section 503 of the act modified the CAPTA state plan requirement for infants born and identified as being affected by substance abuse or withdrawal symptoms or Fetal Alcohol Spectrum Disorder by adding criteria to state plans to ensure the safety and well-being of infants following the release from the care of health-care providers, to address the health and substance use disorder treatment needs of the infant and affected family or caregiver, and to develop the plans of safe care for infants affected by all substance abuse (not just illegal substance abuse as was the requirement prior to this change).<sup>1</sup> **Without these statutory changes, Maryland would be out of compliance with CAPTA and be ineligible for funding it currently receives and any additional funding that might be available in the future.**

Serving as the ‘voice of the Maryland family caregiver,’ the Maryland Commission on Caregiving (“Commission”) is charged with recommending policies that positively impact family caregivers, soliciting and responding to their concerns and acknowledging their





# Maryland Commission on Caregiving

## *“The Voice of the Caregiver”*

contributions. Family caregivers are responsible for the physical, emotional and financial support of another person regardless of age who is unable to care for him/herself due to illness, injury or disability. As it pertains to this bill, family caregivers include parents and grandparents or other family relatives caring for a child with a disability as a result of being exposed to controlled substances in utero. In 2016, approximately 46,849 Maryland grandparents had primary responsibility caring for their grandchildren.<sup>ii</sup> These caregivers and children they’re providing care for benefit from the support services funded through CAPTA and would be impacted negatively by a loss of such services.

The Commission works alongside the Department of Human Services to ensure that caregivers across the lifespan are equipped with the resources to provide safe care to their loved ones across the state of Maryland. Passage of HB1744 would support such efforts which is why the Commission respectfully urges a favorable report.

Sincerely,

Members of the Maryland Commission on Caregiving

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<sup>i</sup> Child Welfare Information Gateway. (2017). About CAPTA: A legislative history. Washington, DC: U.S. Department of Health and Human Services, Children’s Bureau. Retrieved March 9, 2018 from <https://www.childwelfare.gov/pubPDFs/about.pdf#page=1&view=Introduction>

<sup>ii</sup> U.S. Census Bureau, *2012-2016 American Community Survey 5-Year Estimates, Data Profile. Selected Social Characteristics in the United States*. Retrieved March 9, 2018 from <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>.



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**Member Roster**  
**July 1, 2016 – June 30, 2019**

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Maryland Department of Disabilities  
*Represents -- MDOD*

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Supervisor, Family Centered Practice Office of Systems Improvement  
Social Services Administration  
*Represents- DHS*

**Mary Chaput**

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*Represents- Area Agencies on Aging*

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Director, Office of Adult Services  
Social Services Administration  
*Represents- DHS*

**Angela Sittler**

Parent Resource Coordinator  
Office for Genetics & People w/Special Health Care Needs  
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*Represents – MDH*

**Joan Smith**

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Child, Adolescent, & Young Adult Services  
Behavioral Health Administration  
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**Chris Stewart**

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

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*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**

Easter Seals Serving DC/MD/VA

**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*

**Linda Ramsey**

Maryland Respite Care Coalition

**State Legislators:**

**State Senator James Mathias, District 38**

**State Delegate Karen Lewis Young, District 3A**



# Maryland Commission on Caregiving

*“The Voice of the Caregiver”*

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## **Caregiving for My Wife With Alzheimer’s**

*By Ray Van Horn*

In 2013 our journey into Alzheimer’s began. I noticed my wife’s repetitive questions and lack of memory. We did local testing which she passed because she’s a smart cookie. We decided to go to Johns Hopkins for extensive testing where she received a positive diagnosis for MCI (Mild Cognitive Impairment) with a high likelihood of developing into Alzheimer’s. Our Doctor’s parting comments were that at this point there was no cure and the only course of action was socialization, exercise and information. Thanks to the Alzheimer’s Association we have been able to adjust to our new reality through support groups, the caregiver café and conferences that offer a great deal of resources to family caregivers like me.

### **Adjusting to Our New Reality**

At the time of the diagnosis, we were living in Annapolis and getting very little exercise. Our limited social calendar consisted of one to two events a week and of staying home and eating a meal together in front of the TV.

We researched and visited many options and finally decided to sell our home in Annapolis. We moved to Bayleigh Chase because of the memory clinic and a new life style which better suited our new reality. Their Independent living is very active with two hours of social hour and dining 7 days a week along with a full menu of social activities, trips, exercise programs and equipment.

We were planning our next trip to Florida when my wife asked if we could stay at Bayleigh Chase because all our friends are here. She felt more comfortable staying home and having the support of her friends around her. Now we socialize much more and I truly believe it has increased her longevity and her quality of life.

### **The Biggest Challenge**

As my wife’s caregiver, my biggest hurdle was keeping her engaged in activities throughout the day. I found TV to be non-productive so we searched for more meaningful activities. Our granddaughter gave her a coloring book for Christmas and she loves it! She’s gone from crayons to pencils to flare ink and now to the most challenging - Gel pens. She has become quite an artist and coloring has become her passion.

Walking her best friend, our English Setter, on the grounds of Bayleigh Chase is always an enjoyable outing. When she became disorientated we got her a watch which has GPS for tracking her location. But we still needed something that would keep her safe and engaged throughout the day.

### **Keys for Coping with Dementia or Alzheimer’s:**

*Socialize*

*Exercise*

## Adult Day Care

Dr. Anderson, a Geriatric Psychiatrist, recommended Adult Day Care for dementia patients as an enjoyable experience for the care receiver to be productively engaged. We chose the Serenity Enhancement Center in Centerville, MD.

Over the last eight months the program has exceeded our expectations. After four months her testing recorded some improvement.

### Sundown Syndrome

Behavioral changes that often occur in the late afternoon or evening in people with Alzheimer's disease and similar conditions.

The program is patterned after the book *Alzheimer's Prevention Program*, by Gary Small, MD. Classes take place from 8:30 a.m. to 4:30 p.m. and are limited to 12-15 people. Activities include: exercise, games, conversation, music and crafts that they all do together all day long keeping them active, engaged, and most importantly - happy.

After a full day of activities my wife comes home exhausted and goes to bed early. Fortunately she is able to sleep through the night so she doesn't experience **Sundown Syndrome**.

## Alzheimer's is About Living in the Moment

*"Caregiving for an Alzheimer's patient allows us daily second chances to find the right approach. With Alzheimer's, you don't have a future - you don't have a past - there is only living in the moment and you want that moment to be great."* -- Ray VanHorn, Caregiver

Suggested Resources:

- *Creating Moments of Joy*, by Jolene Brackey
- *The 36-Hour Day*, by Nancy Mace and Peter Rabins
- *Cruising through Caregiving*, by Jennifer Fitz Patrick
- **The Samuel and Alexia Bratton Neurocognitive Clinic**, Easton, MD
- **Alzheimer's Association Support Groups & Conferences**

When Alzheimer's disease touches your life, turn to us.

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS!

**24/7 Helpline: 800.272.3900**

[alz.org/maryland](http://alz.org/maryland) | [facebook.com/maryland](https://facebook.com/maryland)

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## Celebrating Social Workers!

In honor of National Social Work Awareness Month in March, remember to thank a Social Worker for their dedication and commitment to making a difference in the lives of those they serve! Social Workers are professionals who guide family members as they care for loved ones of all ages.

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# Alzheimer's Community Outreach

## 2018 Salisbury Conference for Alzheimer's and Dementia Caregivers

**When:** Tuesday, March 20, 2018

**Time:** 8:30 a.m. - 3:30 p.m.

**Location:** Salisbury University Assembly Hall - 4th Floor  
Guerrieri Academic Commons  
1010 Camden Avenue, Salisbury, MD 21081

*(Park in Lot B - no pass needed)*

Register by March 12, 2018: \$60 Healthcare Professionals, \$20 informal caregivers

<https://www.alz.org/maryland/> (click on education programs)

\*\*\*\*\*

*Save the Date*

## 2018 Talbot Conference for Dementia Caregivers and Professionals

**When:** May 30, 2018

**Time:** 8:30 a.m. - 1:00 p.m.

**Location:** Bayleigh Chase Auditorium  
Dutchman's Lane, Easton, MD 21601

\*\*\*\*\*

## Living with Alzheimer's

**A Three-Part Workshop for Caregivers of People with Early Stage Dementia or Alzheimer's Disease  
Presented by the Alzheimer's Association**

**When:** Thursdays: 4/12, 4/19, 4/26 from 10:00 am to 12:00 noon

## Dementia Simulator Training

**Presented by BrightStar Care**

**When:** Thursday, 5/3 from 10:00 am to 12:00 noon

**Location:** Pleasant Day Adult Medical Center  
2474 Cambridge Beltway, Cambridge, MD 21613

Free to attend, but registration is required.

To register, please email [cprud'homme@alz.org](mailto:cprud'homme@alz.org) or call 1.410.742-0505 x 119

\*\*\*\*\*

The Maryland Commission on Caregiving does not fund the Alzheimer's Association, its programs or services



## **The Maryland Commission on Caregiving**

*Support provided by the following state agencies*

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## **Addendum XX**

### **Trends Identified from Town Hall Facilitated by Senator Delores G. Kelley – District 10 at the “Care for All” Town Hall on November 14, 2017**

**1. What has been the single greatest impact your caregiving role has had in your life?**

*-Negative impacts have been loss of time, social life has diminished, an increase of responsibility and added financial burden.*

*-Positive impacts have been the ability to give back to a loved one, to spend time with them, to give them the proper care to meet their needs.*

**2. What do you love most about your caregiving role?**

*-The most recorded response was all the added time they get to spend with their loved one.*

**3. When you think about your situation as a family caregiver, what are the most important resources you wish you had? What are the greatest barriers you face to accessing these resources?**

*-There is a lack of access in learning about all the resources available.*

*-There is a need for tax breaks for caregivers, or more financial assistance for caregivers.*

**4. What community based supports and/or resources have been most helpful in your role as a caregiver?**

*-Responses included AARP, Department of Aging, Easter Seals, Senior Centers and the Alzheimer’s Association.*

**5. Do you feel Maryland is doing enough to address the needs of family caregivers?**

*-Majority said no or that it wasn’t enough of an effort. Suggestions were around more financial support.*

**6. What is one thing your elected officials can do to ease the burden of caregivers?**

*-The majority stated for lobbying around financial support for caregivers, increase funding for community supports and to ensure that existing resources stay funded.*

**7. Do you see the situation for caregivers in Maryland improving in the next 10 years? Why or why not?**

*-There was a mix of answers for this question. On one side folks said no since there is an entire generation getting older but there are still limited funds. On that same note other folks said since the population of older adults is growing then funds will have to be allocated for more caregiving support.*

*-It was also noted that Maryland was going to improve with the continued advocacy from the Maryland Commission on Caregiving and AARP.*

**8. How can the Commission on Caregiving find out what caregivers really need?**

*-Suggestions included sending out survey's to caregivers, having them in doctor's offices or having a website where folks can go to submit questions and concerns and to keep having events with resources.*

**9. How can the Commission on Caregiving help caregivers find the resources they need?**

*-The majority of responses included having an easily accessible online listing of resources, have questionnaires at service centers, or to directly email caregivers.*

**10. How can the Commission on Caregiving use the information from caregivers to fill unmet needs?**

*-The majority of folks stated they wanted a lot of lobbying around caregiver supports. Also to have counselors available to explain different process around services, to break down the information so it is easily understood.*