

## REPORT ON THE MARYLAND COMMISSION ON CAREGIVING MARYLAND DEPARTMENT OF HUMAN SERVICES

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

DATE: October 1, 2022

### REPORT REQUIREMENT

This report is hereby submitted in response to the following reporting requirements 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).

### BACKGROUND

The Maryland Commission on Caregiving (MCC) is Maryland's formal voice for the informal caregiver. An informal caregiver provides a family member, friend, or neighbor with supportive care when that person is unable to care for themselves. Activities the informal caregiver may offer include personal care, housekeeping, medication assistance, coordination of services, and assistance in accessing the community for various reasons. The purpose of the MCC is to coordinate statewide planning, development, and implementation of family caregiver support services for all ages, especially respite care. The MCC was created during the 2017 session of the General Assembly, established through legislation enacted in Senate Bill 215/HB 769 and signed into law by Governor Larry Hogan on April 11, 2017. The new Commission took effect on October 1, 2017 and includes 19 commissioners including a legislator from the House of Delegates and one from the State Senate. In addition, five commissioners are appointed as family caregivers/consumers to ensure that the "Voice of the Caregiver" is fully represented.

### ACTIVITIES

The MCC is pleased to provide this annual report covering the activities of July 1, 2021 through June 30, 2022. The MCC continues with the ongoing review of the 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.

The MCC held ten (10) meetings this year (the Commission did not meet in July 2021, or January 2022). At each meeting, Commissioners and community partners joined together to hear and network with speakers, discuss Commission matters and activities, learn about how proposed legislation may impact the caregiving community, and exchange information on community events and funding opportunities.

Meeting speakers this year included:

- Katie Gandy, State Coordinator for Autism Strategy at the Governor's Office of Community Initiatives
- Megan Rusciano, Managing Attorney at Disability Rights Maryland speaking about Supported Decision Making
- Beth Morrow and Myles Hickee from the Time to Care Coalition speaking about the Time to Care Act which passed in the 2022 Legislative Session

All of the speakers provided essential knowledge to MCC, caregivers, and partners and contributed to a valuable network of resources

## OUTREACH

The MCC continues to focus on information sharing through both an email distribution list containing approximately 140 committed partners and through its monthly meetings. Through the partnership distribution list, the MCC has been instrumental in cross-sharing of information relevant to caregivers and the organizations supporting them.

Conferences, funding opportunities, legislative efforts, and state and national reports are disseminated to an email distribution group of 140 recipients. This establishes the MCC as a central repository of information pertinent to families and organizations.

The MCC has also developed state-specific materials for distribution which includes information collected from various sources as they pertain to family caregiving. Additionally, the monthly meetings are open to the public which allows for new community partners and caregivers to join and participate. The monthly meetings also encourage partner sharing as outside entities come to present and exchange information.

In February 2021, the National Academy for State Health Policy (NASHP) invited the State of Maryland to participate in its State Medicaid Policy Institute on Family Caregiving. The Institute engaged up to five teams of state leaders to develop and/or strengthen health policies and strategies that support family caregivers, with a particular focus on home and community-based approaches for older adults. This year-long project was slated to run from March 2021 to February 2022, but Maryland received an extension in spending and activities beyond FY22. Participation in the collaborative provided states with \$40,000 to cover the cost of project activities plus technical support from the NASHP team. Members of Maryland's team included representatives from the Departments of Disabilities, Aging, Health, and Human Services in

addition to Medicaid as well as collaboration and partnership with the MD Technology Assistance Program (MDTAP) and Easter Seals.

Some of the accomplishments of the NASHP learning collaborative include:

- Creation of a revised logo for the MCC (see Appendix B)
- Purchase of \$5,000 of assistive technology available for loan through the Technology Assistance loan program which includes items that substitute for human assistance that can supplement care provided by a person
- A 3-part recorded webinar series from MDTAP with corresponding fact sheets (see Appendix C)
- A caregiver campaign video highlighting the parents of a young man caring for their son with a traumatic brain injury
- Five videos highlighting the caregiver and respite programs and resources available through the Departments of Aging, Disabilities, Human Services, and Health, including the National Family Caregiver Support Program, Technology Assistance Program, the Respite Care Program, Low Intensity Support Services (Developmental Disabilities Administration), and the Adolescent Respite Care Program (Behavioral Health Administration)
- Revision and reformatting of 11 Medicaid waiver and state plan fact sheets available through the MD Medicaid program

#### PRIORITIES FOR 2021-2022

An informal discussion during a regularly scheduled Commission meeting sought to identify priorities for Commission activities for FY2022. Some of the members identified the following topics of interest to them:

- Multi-generational caregiving and dynamics among family members
- Best practices for caregiver supports in other states
- Developing and disseminating surveys
- Identify and make public social media handles (Instagram, TikTok, Facebook, YouTube) on caregiving issues (ex. Teepa Snow)
- Improving dissemination of information to caregivers who need it (ex. disseminating information via SMS text messaging)
- Ascertaining one's level of caregiving: where are they in the journey
- Resilience and its role in caregiving; identifying a caregiver's wellness needs
- "Certified caregiving coaches", Care Years Academy
- Environmental scan and assessment of peer to peer models

Following that Commission meeting, a poll was disseminated to members and partners to provide more guidance and feedback to drive activities. The results of the poll can be seen in Appendix D. The conclusion of the poll and corresponding discussion revealed that members were most interested in developing and disseminating a survey for MD caregivers similar to what was conducted in 2014.

A caregiver survey workgroup was formed as a result. See Appendix D for results.

## PRIORITIES 2022-2023

### Survey

With the support from the caregiver survey workgroup, the MCC plans to distribute a survey in early Spring 2023 to assess the prevalence of MD family and informal caregivers, who the care recipients are, the types of assistance needed, the level of awareness and utilization of available resources, and the burden experienced by caregivers. Using the 2014 survey as a guide, the workgroup will crosswalk AARP's national survey on caregivers to ensure the 2023 MCC survey is comprehensive and asks relevant questions across a variety of caregiving topics.

Most importantly, the workgroup wants to ensure that the survey respondents complete the survey and are triaged to a list of resources applicable to them based on their circumstances and needs. This requires the MCC to revise the webpage within the Department of Human Services and ensure it reflects the most current information and that it includes the tools and resources that emerged from the NASHP caregiver collaborative.

With remaining funding from the NASHP caregiver collaborative, the MCC will identify an entity to perform analysis on the data collected from the survey and employ a graphic designer to organize the information into fact sheets for distribution. It is the hope of the MCC that the survey can lead to policy recommendations that relevant state Departments can adopt or that lawmakers can introduce in subsequent legislative sessions. Partners can use the survey results to provide effective interventions for their stakeholders or for resource and program development.

### National Family Caregiver Month

National Family Caregiver Month is recognized every November. Since the COVID-19 pandemic, the MCC has coordinated webinars or promoted webinars and events from its partner organizations to its email network. This year, the MCC hopes to sponsor one webinar and identify an inspirational caregiver who can speak about their caregiving journey. Funding has also been set aside through the NASHP project to create a caregiver campaign video which will accompany a Governor's proclamation.

### Partnership Development

The MCC would like to establish better connections with external advocacy organizations such as AARP and the Time to Care Act Coalition. There is also an awareness of the research institutions within the state of MD that are focused on caregivers. The MCC would appreciate the opportunity to leverage the research being conducted to better inform policy and interventions to support family and informal caregivers.

## Appendix A - MD Commission on Caregiving Members

Chair

Jennifer Eastman

Maryland Department of Disabilities

Director, Community Living Policy

Commissioners

Larry Bram

Senior Vice President, Innovation & Program Development

Easter Seals Serving DC/MD/VA

Florence C. Harvey

Program Administrator I

Office for Genetics and People with Special Health Care Needs

MD Department of Health

Mary Anne Kane-Breschi, Director of Family Supports

Developmental Disabilities Administration

Maryland Department of Health

Chalarra A. Sessoms, LCSW-C

Chief, Rural Health and School Based Programs

Child, Adolescent and Young Adult Services Division

Behavioral Health Administration

Maryland Department of Health

Yetunde Olobatuyi

Respite Program Administrator, Office of Adult Services

Maryland Department of Human Services

Trina Townsend

Kinship Navigator, Social Services Administration

Maryland Department of Human Services

Maryland Department of Aging - vacant

Delegate Karen Lewis Young

Health and Government Operations Committee

Representative of the State Senate - vacant

Area Agency on Aging representation - vacant

Maryland Respite Care Coalition representative - vacant

Ann Squire, Family Caregiver

Patricia Morris, Family Caregiver

Theresa Robertson, Family Caregiver

Esther Ward, Family Caregiver

Terri Johnson, Family caregiver

Commission Staff

Greg Sesek, ex-officio

Director, Office of Adult Services

Social Services Administration

Maryland Department of Human Services

Commission Executive Director

Shalini Arora, LCSW-C

Assistant Director, Office of Adult Services

Maryland Department of Human Services

Appendix B - MD Commission on Caregiving Logos

Horizontal Logos



Vertical Logos

MCC



MARYLAND  
COMMISSION  
ON CAREGIVING



MARYLAND  
COMMISSION  
ON CAREGIVING



MCC

## Appendix C - Caregiver Collaborative Series Videos/Tip Sheets

▶ Caregiver Collaborative Series Episode 1: Remote Supports, Monitoring, and ECU's.

<https://www.youtube.com/watch?v=yKlv15FjfE0&t=448s>

▶ Caregiver Collaborative Series Episode 2: Health Management

<https://www.youtube.com/watch?v=10MC8UMj9iw&t=544s>

▶ Caregiver Collaborative Series Episode 3: Independent Living Aids Final

<https://www.youtube.com/watch?v=blymnRcraTA&t=2509s>



## Appendix D: MD Commission on Caregiving Priorities Poll

4/7/22

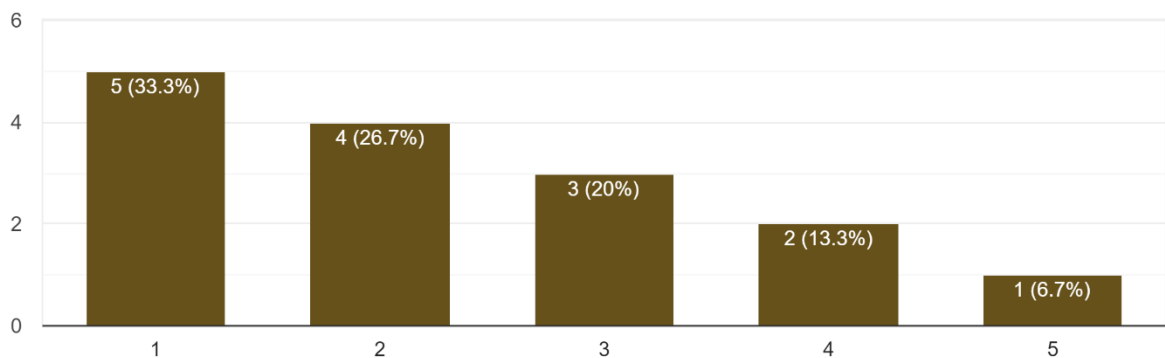
What caregiving population are you most interested in? Ex: dementia caregivers, parents of people with intellectual and/or developmental disabilities, TBI caregivers, intergenerational caregivers, minority caregivers, etc. 15 responses

- minority caregivers, parents of people with intellectual and mental health challenges
- dementia caregivers
- Caregivers of children birth through three with special needs, medically fragile, etc.
- Dementia Caregivers
- Caregivers to older adults including dementia
- Caregivers providing social and other support to individuals with mental illness - all demographics.
- Parents of people with id/dd, particularly aging parents.
- Cancer caregiving across the lifespan
- All of the above
- Early childhood
- All of the above, but work with a lot of dementia caregivers, spouses and adult children
- TBI/Caregivers/Aging
- All caregivers I hear more from minority caregivers
- Parents of people with I/DD
- Intergenerational Caregivers, Minority Caregivers

The following is a list of topics or actions that members and their partners shared as being important for the Commission to focus on in the short term. Please indicate your level of interest on each item.

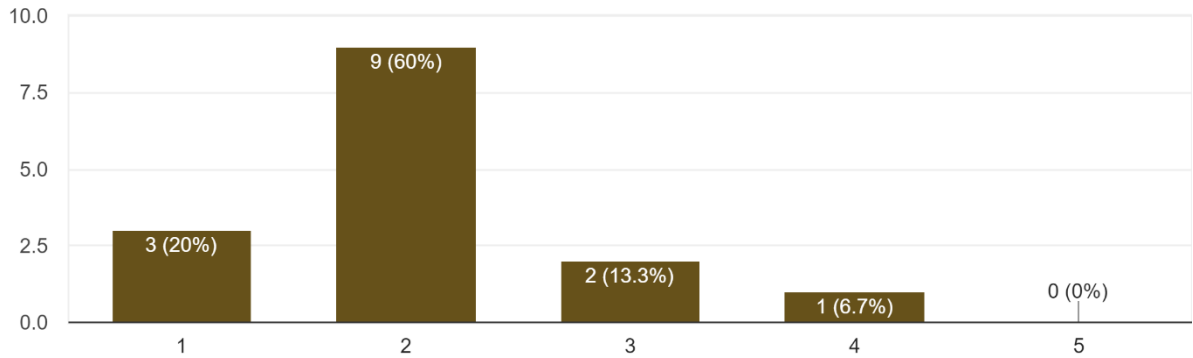
### Multi-generational caregiving and dynamics among family members

15 responses



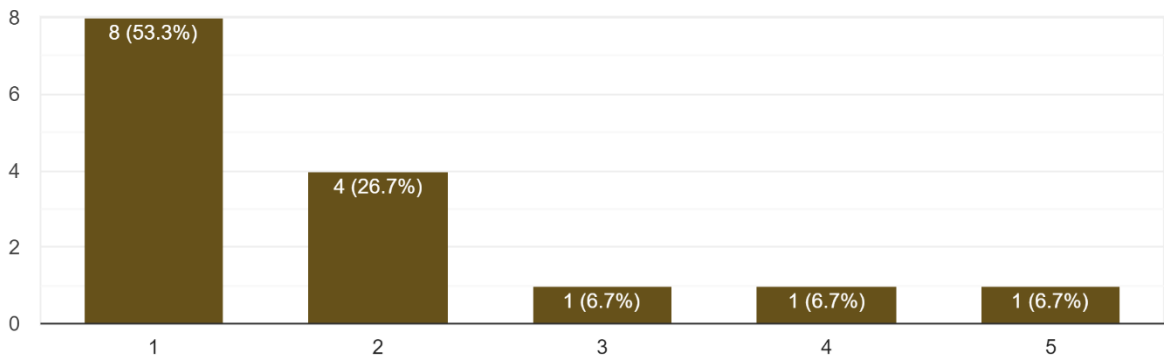
### Researching and identifying best practices for caregiver supports in other states

15 responses



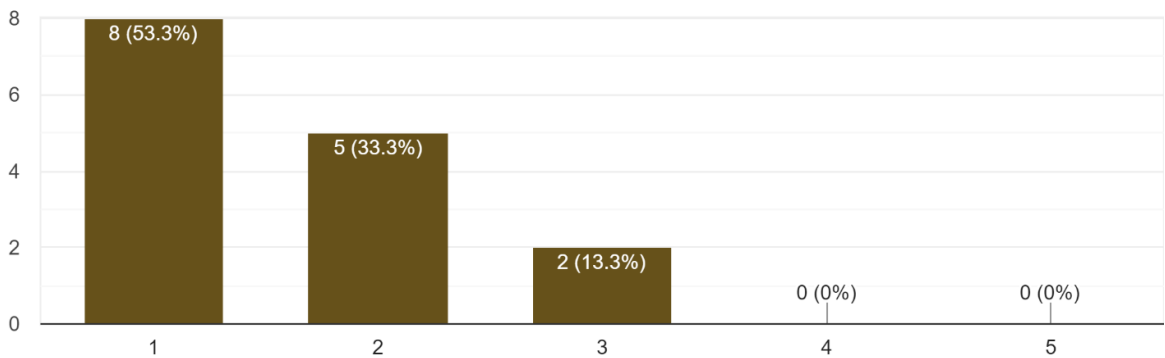
### Developing and disseminating surveys to gather the concerns of the caregiver

15 responses



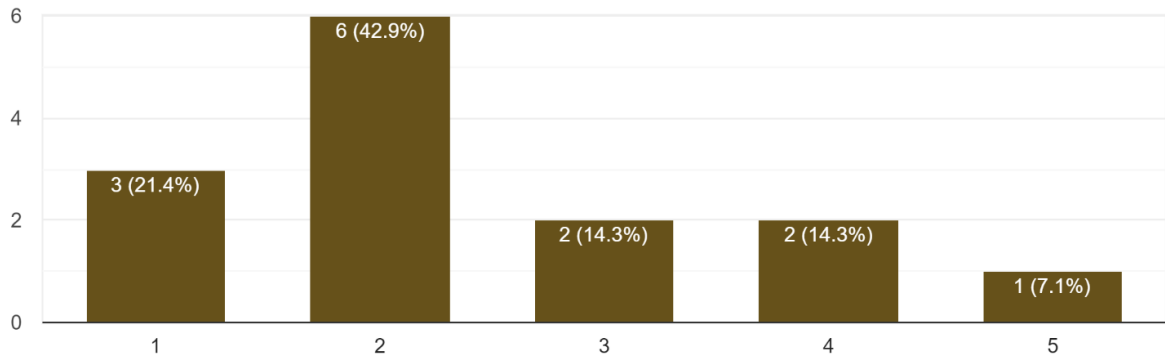
### Developing strategies and identifying relevant information to communicate to caregivers (SMS messaging, promoting social media handles, prioritizing Caregiver Commission website)

15 responses



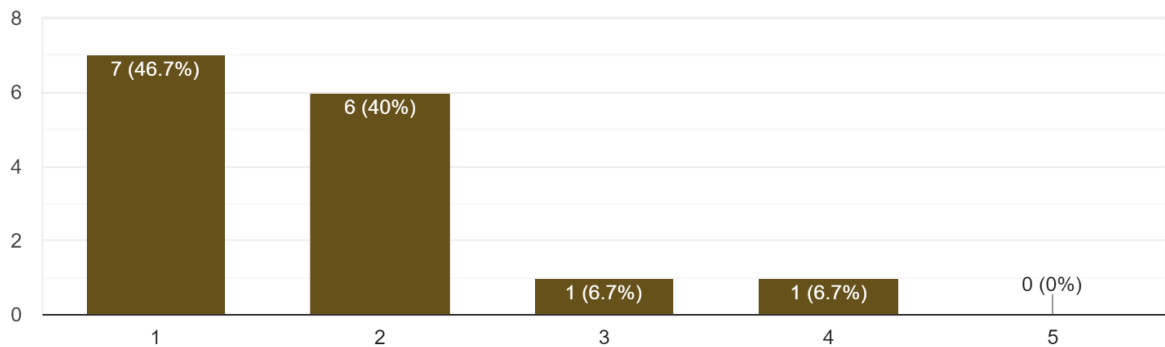
Researching and evaluating peer to peer models in caregiving: where is it and who uses it?

14 responses



Caregiver wellness and resilience; personal development opportunities (certified caregiving coaches)

15 responses



Priority/Topic/Issue(s) not mentioned: 3 responses

- Advocacy for caregivers
- Educating the provider community on the necessity/value of caregivers if given the support and education they need; effective communication and support tools
- Respite services and affordable caregivers services when needed

These specifically relate to administering a survey:

If the Commission were to develop a survey, what questions do you want to ask and/or what data points are you wanting to collect about your specific caregiving population? Or the caregiving population as a whole? 14 responses

- How can the Commission help caregivers?

- What are your pressing needs as it relates to caring for an infant/toddler with special needs? What supports or resources would be most beneficial to you? What services are available at no cost or low cost?
- What is the best way to communicate with you? Email, SMS, social media, phone?
- Where do they look for resources/information/advice?
- We have done extensive surveys about the caregivers in our population, though not all are rigorous or evaluated. That said, I would want to know whether they felt adequately supported by the professionals/provider community, how they would improve communication and inclusion in treatment planning, what they need to support their own well-being (from \$ to respite to training) and what they know of current services and programs to support them.
- Inclusion of questions on what works for caregivers. If it is possible to have subsections included easily for different populations it would be helpful.
- Time lost from work due to caregiving responsibilities; Whether caregivers feel their own health has diminished as a result of caregiving
- What supports do you need?
- How they find out about early intervention and other resources
- Their self-care supports, level of burden (particularly how CG affects their health), financial supports and future plans.
- Caregiver perception of how easy/challenging it is to navigate the system to identify supports for themselves and their loved ones.
- What is your greatest need as a caregiver? What challenge is facing you now as a caregiver
- Age of caregiver, diagnosis/challenges of person cared for, location of residence, greatest challenges i.e. money, time, lack knowledge personal knowledge of systems and resources, lack of energy, isolation, caregiver burnout, med equipment, respite, technology, life planning - what happens to my family member when I'm no longer here?
- Level of experience , percentage of time and level of training

What would you hope to accomplish with the information you're requesting above? How can that knowledge translate into action? 13 responses

- Further the path toward more direct services for caregivers
- Be able to link families to available resources. Link families to a system of supports inclusive of emotional well-being.
- I want to identify the easiest way to get information into the hands of caregivers
- Learn where to best communicate our resources
- I assume that results could help spur collection and/or development of resources (educational, outreach, even funding.) We have developed resource materials and even programs after our less scientific surveys, including training for providers on how to effectively communicate and support family caregivers and self care planning for family caregivers. Of course funding is always an issue. We would be pleased to use these survey results to educate various audiences.

- Understanding the most pressing and prevalent difficulties of caregivers will enable better and more targeted support to them. Learning coping strategies and which government programs work best from the caregivers perspective is of benefit well.
- Statistics to prove the needs of employers and legislators for respite or other supports.
- Develop policy according to needs.
- We want to better serve the caregiver and how their duties affect them and help them look ahead so we can enrich their lives.
- Systems change/modification, making changes based on stakeholder input
- That my concerns would be heard and acted upon and to get caregivers more involved, hear directly from the caregiver)
- Identify caregivers not known to DD systems. Gain a better understanding of and prioritize their challenges in an effort to improve access and the obtaining of resources, support and services. Perhaps even develop new services to meet their needs.
- A needed for Peer to Peer groups, Identify barriers, information sharing and needed training

#### Anything else you'd like to add? 5 responses

- Just a thanks for all you do!
- Thanks . (and glad I reviewed before submitting- I somehow had reversed the 1-5 so that 5 was most important. I fixed my answers.
- Grateful for this survey!
- No
- Encourage and provide opportunities for life and future planning utilizing PCT, and CtLC.