

## **2023 ANNUAL REPORT OF THE MARYLAND COMMISSION ON CAREGIVING**

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MARYLAND DEPARTMENT OF HUMAN SERVICES

*Completed in accordance with Human Services Article § 7-305(b)*

October 4, 2023

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## REPORT REQUIREMENT

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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).

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## BACKGROUND

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The Maryland Commission on Caregiving (MCC) serves as Maryland's official advocate for informal caregivers. Informal caregivers are individuals who provide supportive care to family members, friends, or neighbors unable to care for themselves due to illness, injury, or disability. Their support may encompass a range of activities such as personal care, housekeeping, medication assistance, coordinating services, and facilitating access to the community for various needs.

The MCC was created during the 2017 Legislative Session of the Maryland General Assembly, through Senate Bill 215/House Bill 769 and signed into law on April 11, 2017. The Commission took effect on October 1, 2017 and includes 17 Commissioners, including a legislator from the House of Delegates and one from the Senate of Maryland. In addition, seven Commissioners are appointed as family caregivers/consumers 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 present its annual report, covering the period from July 1, 2022, to June 30, 2023. During this time, the MCC diligently continued its commitment to fulfilling legislative mandates, which include:

1. Gathering and addressing caregiver concerns.
2. Developing and distributing a handbook of current respite care and other available family caregiver services in the State.
3. Reviewing successful respite care programs in other states.
4. Creating a model family caregiver support program incorporating best practices from existing programs.
5. Coordinating activities among existing and proposed family caregiver support services at both the state and local levels.
6. Researching available funding sources and exploring opportunities for additional funds.
7. Identifying unmet needs and priorities for additional funding.
8. Providing ongoing analysis of best practices in family caregiver support programs in Maryland and other states.
9. Monitoring the implementation of the Commission's recommendations.

Throughout the year, the MCC held a total of 11 meetings. The Commission did not convene in July 2022. These monthly Commission meetings were conducted both in-person and virtually. These gatherings were attended by Commissioners and community partners, with the primary aim of coordinating caregiver support throughout Maryland. This coordination involved the review of existing programs, solicitation of feedback from family caregivers to identify service gaps, and the examination of proposed legislation. The Commission also frequently extended invitations to guest speakers who provided valuable insights and information on various supports and services.

Meeting speakers this year included:

Speaker	Date	Topic
Senator Karen Lewis-Young, Maryland State Senator	August 2022	Vacancies and recruitment continued efforts
Peter Rosenberger, Author and Radio Host, Hope for the Caregiver Yetunde Olobatuyi, Respite Program Administrator, Department of Human Services	November 2022	Lived experience as a caregiver State programs for vulnerable adults and caregivers
Eric Colchamiro, Alzheimer’s Association of Maryland Shalini Arora, Deputy Director, Office of Adult Services, Department of Human Services	January 2023	Legislation and Budget in relation to Alzheimer and Dementia Emergency Respite Program
Dorinda Adams, Government Affairs Liaison, Department of Human Services Lynn Phan, Alzheimer’s Association of Maryland Trina Townsend, Kinship Care Navigator, Department of Human Services Esther Ward, Caregiver and a commissioner Yetunde Olobatuyi, Respite Program Administrator, Department of Human Services	February 2023	Kinship Navigator Program Lived experience as a caregiver State programs for vulnerable adults and caregivers
Patricia Morris, Founder, Hands of Hope Caregivers Foundation	March 2023	Lived experience as a caregiver
Pam Luby, Guardianship Program Administrator, Department of Human Services Ilene Rosenthal, Alzheimer’s Association of Maryland	May 2023	Legislative Updates Awareness on Alzheimer
Shalini Arora, Deputy Director, Office of Adult Services, Department of Human Services	June 2023	Emergency Respite Program and Elderly Abuse

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## OUTREACH

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The MCC continues to focus on information sharing through both an email distribution list to Commissioners and partners, and through its monthly meetings. Through the email distribution list, the MCC has been instrumental in cross-sharing of information relevant to caregivers and the organizations supporting them. This includes conferences, funding opportunities, legislative efforts, and state and national reports.

In an effort to streamline communication, a dedicated email address, [dhs.mcc@maryland.gov](mailto:dhs.mcc@maryland.gov), was developed for the business of the Commission. The [Commission website](#) was updated with the following important information:

1. Training resources for caregivers
2. Caring for the caregivers
3. Meeting dates
4. Members of the Commission
5. Annual Reports
6. Resources
7. Contact us

Yetunde Olobatuyi, Commissioner, participated in the Kennedy Krieger annual Resource Fair and Vaccine Clinic, held in October 2022, where she shared information about respite services to the attendees.

Patricia Morris, Commissioner, and CEO of Hands of Hope, extended an invitation to Ms. Yetunde Olobatuyi for her annual caregivers' conference, which was held virtually on November 22, 2022 and benefited approximately 100 attendees. Hands of Hope focuses on supporting the African American caregiver community in Prince George's County. During the conference, Ms. Olobatuyi provided information about state respite services and highlighted a federal grant awarded to DHS for the provision of Emergency Respite.

Jennifer Eastman, MCC Chair, received an invitation from the Alzheimer's Association of Maryland to speak during their Legislative Awareness Day, which took place on February 16, 2023, at the Stanton Community Center in Annapolis. During her address, Ms. Eastman discussed the state and federal efforts to support caregivers, as well as the resources available through various programs and services. The event saw an attendance of approximately 100 people. Additionally, Ms. Eastman dedicated a portion of her allotted time to gathering feedback from caregivers about their needs and ways in which the state can enhance its support for them.

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## NATIONAL ACADEMY FOR STATE HEALTH POLICY LEARNING COLLABORATIVE

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In February 2021, the National Academy for State Health Policy (NASHP) extended an invitation to the State of Maryland to participate in its State Medicaid Policy Institute on Family Caregiving. This Institute engaged five teams of state leaders in the development and strengthening of health policies and strategies that support family caregivers, with a specific emphasis on home and community-based

approaches for older adults. Originally, this year-long project was scheduled to run from March 2021 to February 2022, but Maryland was granted an extension, allowing it to continue activities beyond 2022. States participating in the collaborative initiative were allocated \$40,000 to cover the expenses related to project activities, along with receiving technical support from the NASHP team.

Maryland's team included representatives from various state Departments, including Disabilities, Aging, Health, and Human Services, as well as Medicaid. Collaboration and partnership were established with the MD Technology Assistance Program (MDTAP) and Easter Seals as part of this initiative.

Some of the accomplishments of the NASHP learning collaborative included:

- Creation of a revised MCC logo (Appendix B).
- Purchase of \$5,000 of assistive technology available for loan through the Maryland Department of Disabilities' 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.
- A caregiver campaign video highlighting the parents of a young man caring for their son with a traumatic brain injury. The video can be located [here](#).
- 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). The videos can be located through this [link](#).
- Compensating a nationally recognized caregiver and motivational speaker, Peter Rosenberger, to address MD's family caregivers during a virtual event for National Family Caregiving Month.

Jennifer Eastman, MCC Chair, represented the MCC at the NASHP National Conference in September 2022 in Seattle, WA. She highlighted some of the work that had been accomplished as a result of the learning collaborative.

The remaining funds from the learning collaborative were allocated to the administration of National Alliance on Mental Illness (NAMI) MD's caregiver support pilot program. This program was conducted virtually in a single 4-hour session and aimed to offer participants information on practicing self-care and creating a personalized self-care plan. Although the participants were primarily caregivers of individuals with mental health diagnoses, the program can be readily adopted by caregivers in any context.

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#### LEGISLATIVE EFFORTS

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In the 2023 General Assembly Session, the MCC achieved notable progress in offering input on legislation pertinent to family caregivers. The MCC identified and flagged 32 pieces of legislation, submitted written testimony for 8, and had 4 Commissioners provide oral testimony, 3 of whom were family caregivers.

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## **PRIORITIES FOR 2022-2023**

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Last year, Commissioners voted to prioritize the development and dissemination of a survey to better understand the needs of family and informal caregivers. The objective was to assess the prevalence of family and informal caregivers across the state, identify care recipients, determine the types of assistance required, gauge the level of awareness and utilization of available resources, and evaluate the burden experienced by caregivers. Using AARP's Family Caregiving Survey as a guide and building upon the previously administered 2014 survey, the newly formed workgroup ensured that the 2023 MCC survey was comprehensive and included relevant questions on various caregiving topics.

Utilizing the remaining funding from the NASHP caregiver collaborative and partnering with the University of Maryland's School of Social Work (UMD SSW), the caregiver survey will be disseminated in late 2023. The MCC aims to present preliminary findings to legislators during the 2024 legislative session. The goal of the survey is to assist the MCC in meeting its mandate to gather the needs of caregivers and recommend policies to support services.

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## **NATIONAL FAMILY CAREGIVER MONTH**

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National Family Caregiver Month is observed every November. Since the onset of the COVID-19 pandemic, the MCC has been actively involved in coordinating webinars and promoting webinars and events from its partner organizations to its email network. In the current year, the MCC organized a virtual caregiver webinar, which was open to the public. For this webinar, the MCC invited a nationally recognized guest speaker, Peter Rosenberger, who has been a caregiver for his wife for over 30 years. Peter shared insights from his personal caregiving journey and provided valuable information on caring for loved ones. You can find a recording of Mr. Rosenberger's presentation [here](#).

Additionally, the MCC utilized funds from the learning collaborative to engage the services of Lasser Media, which produced a concise caregiver awareness campaign video. This video was launched in November 2022 during National Family Caregiver Month and can be accessed via this [link](#).

Lastly, throughout the month of November, the MCC coordinated the dissemination of social media messages, videos, and resource information. This outreach effort was conducted through the Department of Human Services' social media accounts.

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## **PARTNERSHIP DEVELOPMENT**

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The MCC has a strong partnership network and benefits from the valuable investment of time and resources from numerous partner organizations, extending well beyond its membership. Organizations such as the Alzheimer's Association Greater MD Chapter, the Arc of Howard County, the Arc of the Northern Chesapeake Region, NAMI, and various representatives from the Area Agencies on Aging have all shown interest in the Commission's work. They have actively participated in meetings and contributed valuable feedback during discussions.

MCC's collaboration with the Alzheimer's Association extends to community outreach and legislative efforts, including the successful passage of Senate Bill 228/House Bill 614 in 2023. This legislation established a long-term care and dementia care navigation program, enabling seniors and caregivers to access essential services. Partnering with the Arcs has broadened MCC's reach to caregivers of individuals with intellectual disabilities, facilitating information sharing and participation in community events. Furthermore, having representatives from NAMI as Commissioner adds valuable expertise in navigating mental health resources and services.

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### **NEEDS**

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The MCC would greatly benefit from having a full-time Executive Director based within DHS to effectively fulfill its nine legislative mandates. Currently, this role is held by the Deputy Director of the Office of Adult Services, who must balance it alongside other duties, including the provision of adult protective services for a vulnerable population across the state. Establishing a full-time Executive Director position would bring the Commission on Caregiving to a level similar to that of the Commission for Women, which has both a full-time Executive Director and a full-time Management Associate providing administrative support.

A full-time Executive Director could manage various essential tasks, such as planning monthly meetings, organizing guest speaker invitations, and documenting meeting minutes. More importantly, they could actively engage with the caregiving community, with particular focus on areas and populations that are often excluded and overlooked. Additionally, the Executive Director could work towards fostering collaborative partnerships with state agencies to better coordinate caregiver services and collaborate with community-based organizations and foundations.

Furthermore, having an operating budget would enable the Commission to plan effectively for the annual National Caregivers Month in November.

According to the Baltimore City Health Department, there are over 770,000 caregivers providing vital support to loved ones, enabling them to stay in their homes. The role of caregivers has grown in significance, and the need for their support has intensified. This is evident at the federal level, where the 2022 [National Strategy to Support Family Caregivers](#) outlines 150 actions that states and communities can take to better support family caregivers.

It is imperative for Maryland to have the necessary resources and human capital to meet its mandates effectively. Therefore, the Commission must address these needs and develop an action plan. The current all-volunteer structure, without a funding mechanism, hinders growth and sustainability.

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### **TESTIMONY FROM MEMBERS**

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As the "Voice of the Caregiver" the MCC is committed to providing a forum for caregivers and its members to share their experiences of caregiving and on serving on the Commission.

“I would like to share a brief thought about the Commission on Caregiving for the State of Maryland. The Commission on Caregiving is a wonderful organization. I have had the opportunity to work with an awesome group of people representing agencies and organizations throughout the State of Maryland. I have learned a lot from each of them, which has helped me to share information with my group of caregivers in Prince George's County. The journey being a caregiver is stressful. Thanks to all of the members and Chair Jennifer Eastman for helping me to help others.”

-Patricia Morris.



## 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

MD Department of Health - Vacant

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

Representative of the House - vacant

Representative of the State Senate - vacant

Kathy Wehr  
Caregiver Support Program Manager  
Howard County Office on Aging and Independence

Area Agency on Aging representative  
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 Seseck, 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=yKiv15FjfE0&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

**This poll was used to inform work throughout 2022-2023.**

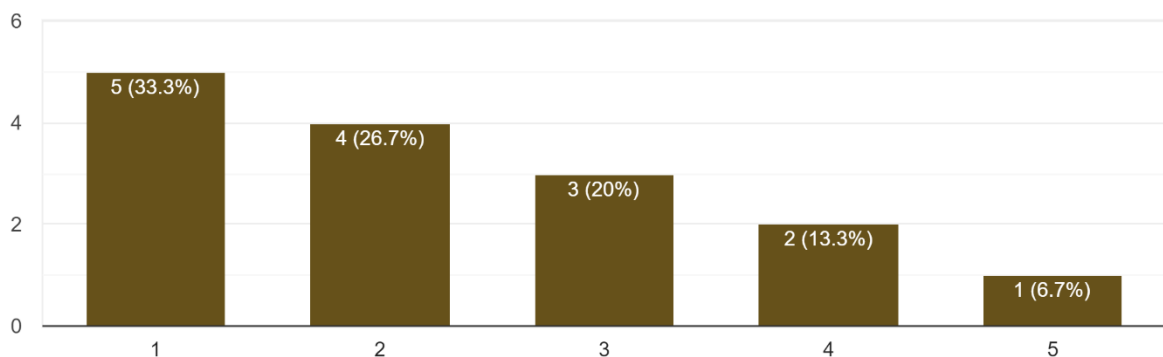
What caregiving population are you most interested in? Ex: dementia caregivers, parents of people with intellectual and/or developmental disabilities, TBI caregivers, intergenerational caregivers, minority caregivers, etc. 15 responses

- minority caregivers, parents of people with intellectual and mental health challenges
- dementia caregivers
- Caregivers of children born through three with special needs, medically fragile, etc.
- Dementia Caregivers
- Caregivers to older adults including dementia
- Caregivers provide 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.

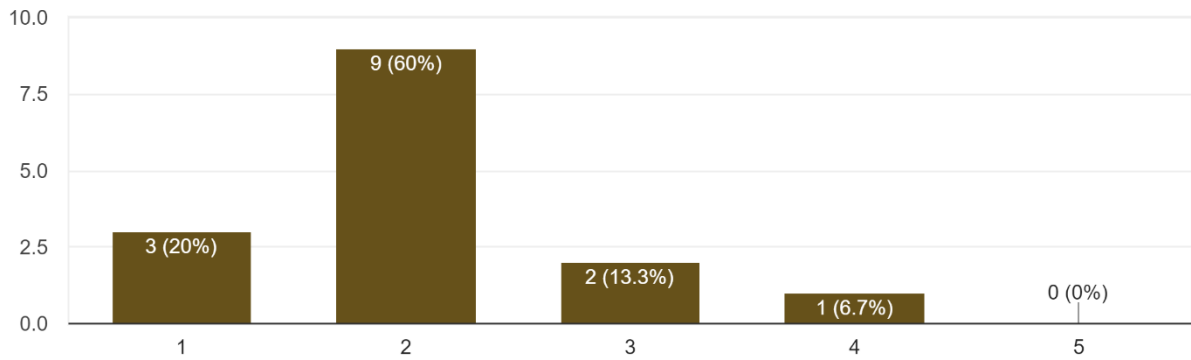
Multi-generational caregiving and dynamics among family members

15 responses



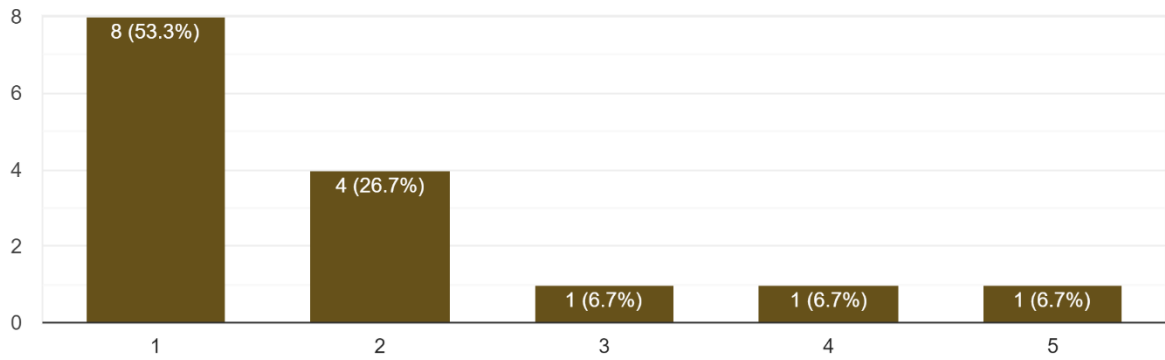
### Researching and identifying best practices for caregiver supports in other states

15 responses



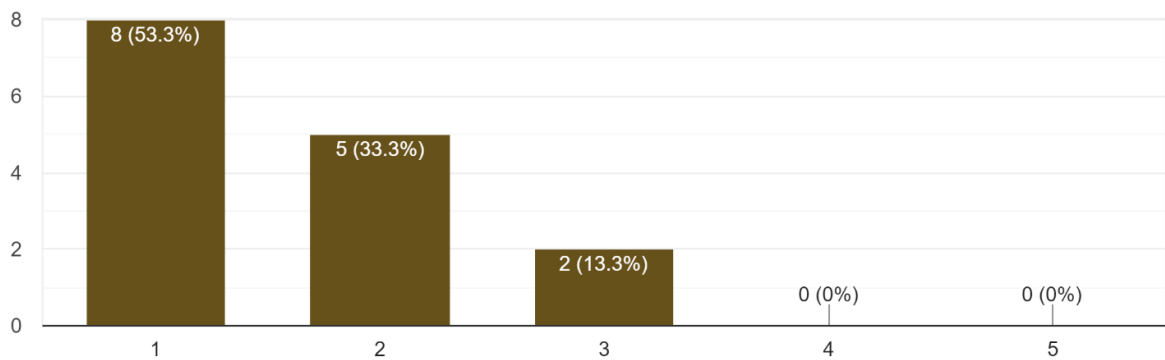
### Developing and disseminating surveys to gather the concerns of the caregiver

15 responses



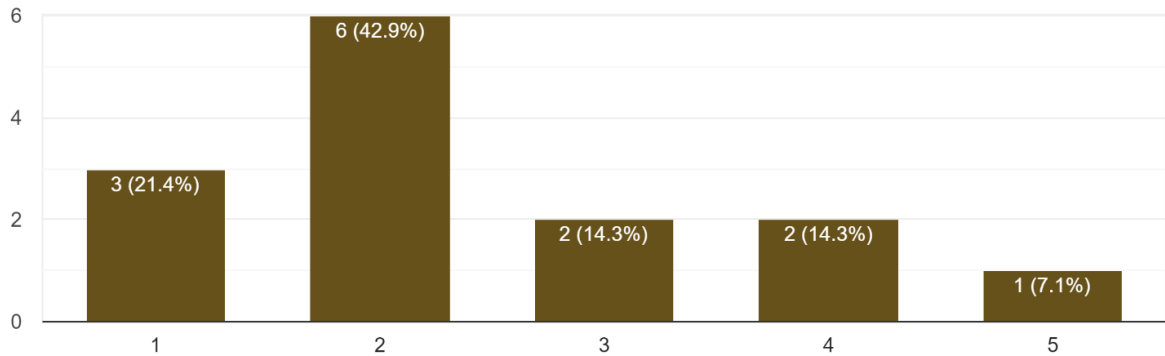
### Developing strategies and identifying relevant information to communicate to caregivers (SMS messaging, promoting social media handles, prioritizing Caregiver Commission website)

15 responses



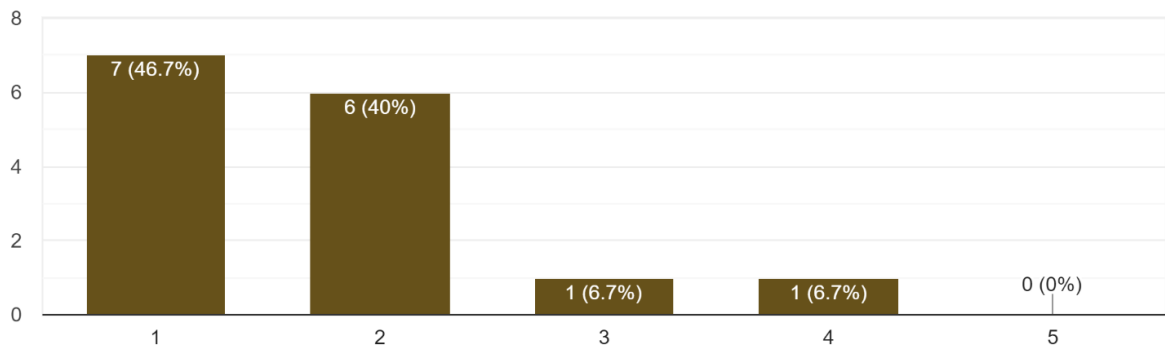
### Researching and evaluating peer to peer models in caregiving: where is it and who uses it?

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 support 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 support 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 support 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 support.



- 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.