

## Maryland Commission on Caregiving

May 1, 2025

10:30 AM -12:00 PM

### Meeting Minutes

#### I. Meeting Minutes

- A. Commission Member Present: Larry Bram, Mary Anne Kane Breshi, Dawnita Brown, Jennifer Eastman, Patricia Morris, Yetunde Olobatuyi, Theresa Robertson, Greg Sesek, Ann Squire, Trina Townsend, Kathy Wehr, Molly Wisniewski
- B. Guests: Dorinda Adams, Estelle Brooks, Teresa Jetter-Cutting, Pearl Harmon, Terri Johnson, Melissa Karcher, Ruth Kershner, Leslie Smith-Ray, Lynn Phan, Brenda Williams
- C. Approval of April's Meeting Minutes
  - 1. Motion to approve April's meeting Minutes: Yes

#### II. Member Updates

- A. Molly provided a brief administrative update, sharing that recent conversations with Melissa Bender at the Department of Human Services (DHS) indicate support for the Commission's efforts to fill current vacancies. Commissioners were asked to make every effort to attend the June meeting, where administrative topics related to Commission operations will be discussed.
- B. Patricia twice expressed appreciation to the Commission for their warm thoughts and support during a recent health event and recognition award.

#### III. Presentation: Dr. Quincy Samus, Director of the Memory and Aging Services Innovation Center at Johns Hopkins and Mark Tesoro, Cognitive and Behavioral Health Specialist at the Maryland Department of Aging, will present the Johns Hopkins Memory Care Family Checklist Tool. *The Presentation slides will be sent out to the Commission following the meeting.*

- A. Mark Tesoro opened the presentation by discussing efforts to bridge research and practice in Maryland's Aging and Disability Resource Center (ADRC) and Area Agency on Aging (AAA) systems. He emphasized the importance of translating tools developed in research settings into real-world applications for providers, caregivers, and individuals living with dementia.
- B. Key points included:
  - 1. Maryland is legislatively obligated to implement certain evidence-based tools in long-term care and community-based settings.
  - 2. A dementia screening tool developed in partnership with Washington University is currently in use. This tool is designed for use by AAAs, caregivers, and providers to assess cognitive impairment and guide individuals toward appropriate services and supports.

3. As part of long-term care responsibilities, AAAs play a role in supporting navigation to caregiver resources. To do this effectively, a separate Caregiver Needs Assessment Tool was developed.
    - a) This tool is distinct from the dementia screener and is sensitive to the complex and varied domains of caregiving.
    - b) It is designed to be easy to administer, culturally appropriate, and scalable across Maryland.
    - c) Unlike some assessment tools that yield limited actionable data, this tool was specifically developed to provide clear guidance and direction to caregivers and professionals.
  4. The tool aims to keep people living independently at home and aligns with models like “Mind at Home.”
  5. The overarching goal is to better understand caregiver challenges and strengths, enabling providers to offer tailored resources and support that reflect individual needs.
  6. The team believes that the recommended checklist tool offers a practical and scalable solution. They are actively pursuing partnerships to test and implement the tool more broadly across the state.
- C. Dr. Quincy Samus, a gerontologist and epidemiologist with extensive experience in dementia care and family-centered models, presented next. She is affiliated with the Virginia I. Jones Alzheimer’s Disease and Related Disorders Council and contributed to the development of Maryland’s 2022 State Plan, which outlined five strategic goals to strengthen the infrastructure for supporting individuals with dementia and their caregivers.
1. Disclosure: No conflicts of interest reported.
  2. Purpose and Rationale for the Assessment Tool
    - a) The comprehensive needs assessment tool was created to support caregivers of individuals with Alzheimer’s Disease and Related Disorders (ADRD), but is also applicable to other chronic conditions.
    - b) Informal caregivers provide the majority of care for those with ADRDs, and this burden is growing. An estimated 238,000 family caregivers in Maryland are supporting individuals with dementia.
    - c) The tool is designed to identify caregiver challenges, reduce unmet needs, and improve caregiver and care recipient outcomes.
  3. Background and Development

- a) Dementia prevalence is notably high in Baltimore City and Prince George's County, underscoring the urgency for targeted support.
- b) Caregivers often face a wide range of needs—emotional, legal, medical, and environmental—which require a multidimensional assessment approach.
- c) The tool was developed through over 15 prior studies at Johns Hopkins University, with three major iterations leading to the current version.
- d) It is based on a socioeconomic and structural framework, considering lifestyle, caregiving stability, healthcare access, insurance barriers, and structural racism.

#### 4. Tool Features and Applications

- a) The current tool (version 3.0) is a 33-item checklist assessing both the individual living with dementia and their informal care partner.
- b) Areas covered include:
  - (1) Mental health and emotional support
  - (2) Medical care coordination
  - (3) Home safety and fall risk
  - (4) Legal planning
  - (5) Disease education and expectations
  - (6) Meaningful activity and quality of life
- c) The tool is efficient, self-rated, and can be completed in advance of assessments, making it practical for use in multiple settings (e.g., in-home, phone, outpatient clinics).

#### 5. Key Findings from Implementation

- a) Piloted with 646 Maryland families, the tool revealed that the majority of caregivers had at least one unmet need.
- b) Providers, particularly in outpatient settings, were often unaware of critical issues like fall risk or home safety concerns.
- c) Top unmet caregiver needs included:
  - (1) Lack of disease education
  - (2) Uncertainty about legal and financial planning

(3) Mental health and emotional distress

(4) Limited knowledge of available community resources

d) Needs varied by disease stage, with issues like wander management increasing as dementia progresses.

e) Racial disparities were evident:

(1) Black/African American caregivers and care recipients had significantly higher unmet needs, especially around legal issues and daily living support.

(2) Latino and Asian caregivers were not well represented in this sample, though the demographic profile matched the local areas surveyed.

#### 6. Current Use and Future Directions

a) The tool has been used in two randomized controlled trials and is currently being implemented through national models such as the GUIDE (Guiding an Improved Dementia Experience), supported by JHU and nine partner organizations.

b) Adaptations have been made for international use in Brazil, Greece, and Taiwan.

c) The team plans to publish the checklist on the Maryland Access Point (MAP) website, where it will be linked to relevant resources for caregivers and providers. The goal is to evaluate how effectively the online resources meet identified needs.

#### D. Question and Discussion

1. Leslie noted that while the tool was originally developed with a focus on dementia, it serves as a valuable pathway for broader caregiver assessments across agencies, helping ensure that caregivers receive appropriate support and evaluation at all stages of their caregiving journey.
2. Dorinda expressed her appreciation for the project's success, noting that she has followed its progress since its inception.
3. Patricia shared that many caregivers often feel forgotten. She emphasized the importance of creating spaces where caregivers feel comfortable talking about themselves and their needs. "Sometimes, we have to teach caregivers how to speak up," she said, reflecting on her own experience of being told to stay quiet. She noted that learning to express her needs was empowering and highlighted the value of knowing where to go for information and support.

4. Brenda asked how the project is being funded. It was noted that the project is supported through a grant from the Administration for Community Living (ACL).

#### IV. Subcommittee Updates:

##### A. Legislative Subcommittee: Legislative Session Highlights provided by Izzy Shycoff, Director of Policy, Maryland Department of Aging.

1. Paid Family and Medical Leave Implementation Delayed:
  - a) Workers will be eligible to receive up to \$1,000/week for time taken off work to care for a family member.
  - b) Implementation has been delayed; access is now scheduled between January 1, 2027, and January 3, 2028.
2. Caregiving Remains a Key Legislative Topic: A number of caregiver-related bills were introduced, with several passing:
  - a) HB 1478 (Del. Hill): Requires the Maryland Department of Health (MDH) to submit a feasibility report on creating an online directory of local health department directors.
  - b) HB 1843: Establishes a Maryland Interested Parties Advisory Group to ensure adequate access to Home- and Community-Based Services (HCBS) across the state. The goal is to elevate awareness and educate the public on the availability of non-institutional forms of care.
  - c) SB 748 (Sen. Kramer): Focuses on Alzheimer's Disease. Requires MDH to incorporate FDA-approved treatments into state materials and maintain a public website to increase awareness and understanding of these treatments.
3. Bills That Did Not Pass:
  - a) HB 604 / SB (Companion Bill): Addressed theft from senior adults by family caregivers. Highlighted the vulnerability of older adults and concerns over unauthorized control of assets by caregivers.
  - b) SB 104: Proposed a tax credit for elderly residents aged 70+ who resided in Maryland for at least six months during the tax year. Aimed to provide financial relief to caregivers.
  - c) Paid Family Caregiver Compensation: A bill allowing payment to family caregivers passed but implementation has been delayed until 2028.
  - d) SB 202: A caregiving-related tax credit bill passed but was unfunded. Originally filed by a Republican delegate from Frederick, demonstrating that caregiving remains a bipartisan issue. Despite funding gaps, both parties are showing increased interest in supporting caregiver-related legislation.

4. Outlook:
  - a) Izzy noted that the trajectory is improving, and awareness is growing: "Virtually no one is untouched by caregiving anymore—it's becoming real for many people."
5. Commission Member Reflections and Discussion
  - a) Theresa expressed concern that although the trajectory for caregiver support appears positive, there is still a lack of meaningful financial investment. She noted that delays in implementation continue to push action further down the road and emphasized the Commission's responsibility to advocate more strongly for caregivers.
  - b) Patricia inquired about potential actions the Commission could take to influence outcomes. She acknowledged that there are positive developments for caregivers and suggested that upcoming budget meetings present an opportunity for the Commission to have a more active role.
  - c) Leslie observed that many state agencies, including the Commission's subcommittee, are gaining national recognition for their efforts to support caregivers. She noted that this momentum is encouraging and worth building upon.

B. Development of the Caregiver of Youth Survey Subcommittee

1. The subcommittee met on the first Monday in May with key stakeholders, including representatives from the Maryland Coalition for Families, Parents' Place of Maryland, Maryland State Department of Education, Anne Arundel County Area Agency on Aging, and Cecil County Area Agency on Aging to discuss key data points they thought were important to include in the survey.

C. Review of Caregivers of Adults Data

1. The subcommittee met on the second Wednesday in April. Jennifer Eastman provided us with the history of the survey and introduced us to Brittany Wilson at MDH who may be able to provide a presentation on MDH's BRFSS data.

V. Caregiver Ambassador Training Program - Administration for Community Living Grant

- A. This topic discussion will be moved to next month's agenda.

VI. Open Forum for Questions, Concerns, Suggestions, and Announcements

- A. Theresa raised items for future discussion by the Commission. Although there was not sufficient time during the current meeting, these topics will be brought back to ensure they are addressed:
  1. Funding Opportunities to Support Respite
  2. Commission Appointments

VII. Meeting Adjournment

