pennsylvania
DEPARTMENT OF AGING

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Good morning Chairwoman Ward, Chairwoman Collett, members of the Senate Aging and Youth Committee, and staff. On behalf of the Pennsylvania Department of Aging (PDA), we would like to thank you for the opportunity to provide information on the Department's Caregiver Support Program and some proposed legislative changes that are being recommended to Act 112 of 2011 to improve utilization and administration of the program. As the state unit on Aging, PDA is formally charged by the federal Older Americans Act (OAA) and the Pennsylvania General Assembly with representing and advocating for the interests of older Pennsylvanians throughout the Commonwealth. PDA recognizes the significant role caregivers play in helping individuals age in their homes and communities. While unpaid, informal caregivers often find caring for their loved ones or others to be a meaningful and rewarding experience, the demands of being a primary caregiver is stressful and overwhelming physically, emotionally, and financially.

According to AARP's *Valuing the Invaluable: 2019 Update - Charting a Path Forward*, there are approximately 1.6 million family caregivers in Pennsylvania who provide an estimated 1.3 billion hours of unpaid care and other related services valued at more than $18 billion. Of those caregivers, over 90,000 are grandparents and other older relative caregivers, primarily responsible for caring for the needs of approximately 195,000 children, which accounts for nearly 8% of children residing in the state. Approximately 60 percent of caregivers are shouldering the responsibility of caring for a loved one while also maintaining part-time or full-time employment. And over 20% are living below the poverty level.

There are a myriad of challenges that caregivers face as they seek to provide care and support to their care receivers such as access to information about available benefits and resources, lack of adequate education and training, and financial assistance to help defray the costs of caregiving-related expenses, to name a few. Pennsylvania's Caregiver Support Program provides resources and assistance to individuals who assume primary responsibly for the provision of care in order to help alleviate the stresses associated with caregiving and support the caregiving relationship by focusing on the caregiver's well-being.

## History of the Caregiver Support Program

The Pennsylvania General Assembly established the Family Caregiver Support Program in 1990 to assist individuals who assume primary responsibility for the provision of care for older adults with functional deficits and adults with Alzheimer's Disease or other chronic dementia. This was one of the first family caregiver programs in the country. The goal of the program was to provide assistance and support to caregivers in an effort to enhance their well-being, reduce stress and strengthen their caregiving relationship. As one of the trailblazers in providing supportive services to caregivers, Pennsylvania implemented its Family Caregiver Support Program nearly a decade before the National Family Caregiver Support Act was enacted by Congress in November of 2000 as part of the reauthorization of the OAA.

With each reauthorization of the OAA since 2000, the National Family Caregiver Support Program has evolved to become more inclusive of caregivers that can be served through the program. This includes expanding eligibility to family members and other informal caregivers, age 18 and older, who provide care to individuals 60 and older and to individuals of any age with Alzheimer's disease or related disorders, as well as older relatives (not parents) age 55 and older who provide care to children under the age of 18 and older relatives, including parents, age 55 and older who provide care to adults ages 18-59 with disabilities.

Similarly, the passage of Act 112 of 2011 by the Pennsylvania General Assembly contained a significant revision which changed the state program name from the "Pennsylvania Family Caregiver Support Program" to the "Pennsylvania Caregiver Support Program". This important milestone paved the way for primary caregivers who were not related to their care receivers to participate in the program, thereby expanding program access and increasing utilization of benefits.

Pennsylvania is fortunate to have a state and federally funded Caregiver Support Program; however, the state and federal requirements are not completely in alignment with one another. Changes to the state statute are needed to better align the state and federal programs, remove barriers to utilizing the program, and provide more flexibility to effectively administer the program. These proposed changes will be discussed later in the testimony.

## Program Overview

The Department's Caregiver Support Program served approximately 4,500 caregivers in FY 2019-2020 and is funded by both federal and state dollars and administered by a network of 52 AAAs. To be eligible for the Program, all caregivers and their care receivers must be residents of Pennsylvania to participate in the Caregiver Support Program. Additionally, caregivers who are enrolled in the program must meet one of the following eligibility categories:

1) An individual age 18 and older who is the primary caregiver for a functionally dependent older adult age 60 or older, or an individual of any age who has a diagnosis of Alzheimer's Disease or other chronic dementia. The caregiver and care receiver in this category are not required to be related nor live in the same residence.

2) An individual age 55 and older who is the primary caregiver for a dependent child under the age of 18, and related by blood, marriage, or adoption. The caregiver cannot be the biological parent of the child, and the caregiver and care receiver in this category are required to live in the same residence.
3) An individual age 55 or older who is the primary caregiver for an individual age 18-59 who has a disability, and is related by blood, marriage, or adoption. The caregiver can be the biological parent of the child, and the caregiver and care receiver in this category are required to live in the same residence.

Caregivers are <u>not</u> eligible for the program when one or more of the following occur:

- The caregiver or their care receiver receives Medical Assistance Long-Term Services and Supports (MA LTSS);
- The caregiver has been convicted of a crime relating to abuse, neglect, exploitation, or abandonment;
- The caregiver has been found civilly liable for abuse, neglect, exploitation, or abandonment, or
- The caregiver has been notified that he/she is an alleged perpetrator in a substantiated report of need for protective services.

Caregivers who desire to be enrolled in the Caregiver Support Program are assigned a Care Manager from their local AAA. The Care Manager will conduct a comprehensive assessment with both the caregiver and care receiver to determine the needs of the caregiver, provide support, and work to develop a person-centered plan of services. Services available in the Caregiver Support Program include:

1. **Care Management** – Care management is the identification of a caregiver's needs and the timely delivery of services and supports to meet those needs. Care Management-related services include assessment, development of a person-centered care plan, and ongoing support and follow-up. All caregivers in the program receive care management.
2. **Benefits Counseling** – Benefits counseling provides information about available services and programs that caregivers and their care receivers may be eligible to receive. This includes individualized counseling and support, as well as assistance with applying for federal, state, and local benefits, if needed.
3. **Caregiver Education and Training** – Caregiver education and training provides educational curriculum and resources designed to help caregivers strengthen caregiving skills, foster healthy coping skills, and develop effective stress-reduction strategies. These interventions are provided and arranged by the AAA and include, but are not limited to, access to caregiver support groups, distribution of printed materials, referrals to web-based training, and other caregiving-related training opportunities.
4. **Caregiver Reimbursement** – Caregiver reimbursement is financial assistance to help defray the costs associated with approved, caregiving-related expenses such as respite care, consumable supplies, supportive services, supplemental services, home modifications and assistive devices. Caregiver reimbursement is the highest utilized service in the program.

There is neither a financial eligibility requirement nor asset test to receive services through the Caregiver Support Program; however, the reimbursement amount received by caregivers enrolled in the program is determined using a sliding scale that covers a range of income from

200% to 380% of the Federal Poverty Level and is updated annually. The standard monthly care plan cost cap is $200 but may be increased up to $500 when there is a justified need. However, the current state statute stipulates a AAA's aggregate, average monthly reimbursement may not exceed $300 across its entire caregiver support program caseload.

Of the individuals served in the Caregiver Support Program, 62% of the caregivers are over age 60 themselves. The majority of caregivers, approximately 71%, are women. Eighty-five percent of caregivers are white, non-Hispanic, 12.5% are African American, and 2% are Hispanic. Over 26% of caregivers are caring for someone with Alzheimer's Disease or related dementia. In FY 2019-2020, the Caregiver Support Program served approximately 680 Grandparents/Older Relative Caregivers caring for approximately 724 children.

## Proposed Changes to the Caregiver Support Program

Factors exist within the current state statute that prevent caregivers from fully benefiting from the program and impedes PDA's and the AAAs' ability to effectively administer the program to caregivers most in need. Over the past two years, PDA surveyed the AAA network and received feedback regarding some of the obstacles and programmatic challenges within the Caregiver Support Program. Based on that feedback, an analysis of data, and the need to update terminology and requirements to be consistent with the OAA, PDA has determined that revisions to Act 112 of 2011 are critically needed to remove barriers to utilizing the program, provide more flexibility to effectively administer the program, and better align the state and federal program requirements.

The Department of Aging has proposed the following revisions to Act 112 of 2011:

1. **Proposal:** Remove specific dollar amounts in the maximum monthly reimbursement rate to qualified primary caregivers and replace with language allowing the amounts to be established by the Department.

   **Justification:** The maximum monthly reimbursement amount, also referred to as the monthly care plan cost cap, has not been increased since the inception of the program in 1993, and the costs associated with caregiver and the financial impacts to caregivers have steadily risen over the past 26 years. The current standard monthly care plan cost cap of $200 per month, when coupled with the caregiver's determined reimbursement percentage, is not adequate to cover the costs of caregiving-related supplies and expenses and often serves as a disincentive to many potential program participants. The removal of specific monetary references will enable PDA to be more responsive to economic and programmatic trends and to manage the monthly care plan cap in a timely and efficient manner, which could not occur if dollar amounts are specified in statute.

2. **Proposal:** Remove specific dollar amounts in the maximum lifetime amount available to qualified primary caregivers for Home Modifications and Assistive Devices and replace with language allowing the amounts to be established by the Department.

   **Justification:** The maximum lifetime limit for Home Modifications and Assistive Devices has not been increased since the inception of the program in 1993, and the costs associated with home modifications and assistive devices and the financial impacts to caregivers have steadily risen over the past 27 years. The current lifetime limit of $2,000 is not adequate to cover the increasing costs of contractor fees, building materials, equipment or devices, or even the cost associated with renting equipment such as a portable ramp or stair glide. This limit can hinder caregivers from home modifications or purchasing the equipment or devices needed by their care receiver to ensure they can navigate safely and remain in their homes. The removal of specific monetary references will enable PDA to be more responsive to economic and programmatic trends and to manage the lifetime limit amount in a timely and efficient manner, which could not occur if dollar amounts are specified in statute.

3. **Proposal:** Remove the $300 monthly aggregate average reimbursement limit across a AAA's entire Caregiver Support Program caseload.

   **Justification:** The $300 aggregate average requirement has hampered the AAAs' efforts to provide more comprehensive financial reimbursement to current program participants as well as the ability to serve a greater number of potential caregivers. This is particularly true for AAAs with a small Caregiver Support Program caseload where the average monthly reimbursement can quickly rise over $300 with just one or two larger care plans. If the $300 aggregate were removed, AAAs would be able to better serve caregivers and provide adequate reimbursement, unhindered by the requirement to keep the average caseload below $300.

4. **Proposal:** Expand the definitions of primary caregiver and care receiver to be inclusive of all individuals this program is permitted to serve according to the Older Americans Act and to better align the state and federal programs. This includes adding references to caregivers age 18 and older who provide care to individuals of any age with Alzheimer's disease or related disorders, older relative caregivers (not parents) age 55 and older who provide care to children under the age of 18, and older relative caregivers, including parents, age 55 and older who provide care to adults ages 18-59 with disabilities.

**Justification:** Pennsylvania's Family Caregiver Support Act was enacted 30 years ago to only assist caregivers of functionally dependent older adults age 60 and older and adults age 18 and over with chronic dementia. Since then, Pennsylvania has seen a dramatic rise in the number of grandparents and other older relatives who are assuming the primary responsibility of raising children, as well as older adults who struggle to continue to be the primary caregivers of their disabled adult children. PDA wants to align the language in the state and federal statutes in an effort to create one comprehensive, unified Caregiver Support Program for Pennsylvania.

5. **Proposal:** Revise key definitions and language throughout the statute to reflect current terminology and consistency with the OAA.

   **Justification:** Examples of revisions include changing references to "adults with chronic dementia" to "adults with Alzheimer's Disease or Related Disorders" to mirror language in the OAA and align with Pennsylvania's State Plan on Alzheimer's Disease and Related Disorders, and changing references to labeling people as being "victims" of chronic dementia to "those living with Alzheimer's Disease or a related disorder".

In summary, Pennsylvania's Caregiver Support Program is a vital resource that helps caregivers alleviate the stresses associated with caregiving and manage the challenges associated with caring for a loved one or other individual. Again, thank you for the opportunity to speak with you today about the Caregiver Support Program. PDA looks forward to working with the legislature to update the current statute to maximize the support and assistance provided to caregivers through the Caregiver Support Program.