



PA CareKit

Long-Term Services and Supports (LTSS) Subcommittee Meeting
August 06, 2025

Presenter: Nathan Lampenfeld, Special Assistant to the Secretary of Aging



Pennsylvania
Department of Aging



PA CareKit

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”
- Rosalyn Carter



Pennsylvania
Department of Aging



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Aging Our Way, PA

A Plan for Lifelong Independence

Aging Our Way, PA

Context: Pennsylvanians Are Aging, We Are Preparing

- Older adult demographics are changing
- Multisector Plans for Aging (MPAs) are a national movement

Development: A Gold Standard in Record Time

- Over 20,000 Pennsylvanians contributed input to the Plan
- Thirty state agencies are committed to the Plan, including partners outside the Governor's jurisdiction

Content: A 10-Year Roadmap to Aging Transformation

- Five high-level priorities, 36 strategic approaches, 163 actionable tactics

Tactic #128:

- Develop a statewide Caregiver Toolkit, including information on supports and resources and a caregiver screening tool.

PA CareKit



A collection of tools, information, and support



Supports caregivers through key challenges in the caregiving journey



Personal, practical, and ready for all kinds of caregivers



Options available digitally and in print

Project Tasks

Task 1 Project Launch & Visioning

- Stakeholder Engagement
- Vision Development
- Research

Task 2 Content Development & Review

- Subject & Topics
- Tools
- Language Accessibility

Task 3 Platform Development & Review

- *Understanding Your Needs* Quiz
- Site Organization

Task 4 Launch & Outreach

- Rollout
- Marketing & Media Campaign

Content Development Survey

- The Pennsylvania Department of Aging (PDA) launched a survey to inform the development of the toolkit and received 243 responses
- Eighty-eight percent of respondents identified as family or friend caregivers
- Key themes included:
 - Low Awareness of Resources
 - High Levels of Stress
 - Unrealistic Expectations and Progressive Challenges
 - Navigation Challenges
 - Considerations for Support

Survey Findings

- **Low Awareness of Resources**

- The onset of caregiving is associated with a steep learning curve.
- Caregivers are often unaware of programs that may support them and struggle to understand specific programs, benefits, and entitlements.
- Effective communication and widespread awareness are essential to ensuring that caregivers know about and can access the resources available to them.

- **High Level of Stress**

- Caregiving is an emotionally complex journey that reshapes relationships and requires compassion for oneself and others.
- Caregiving is often too difficult for one person to handle and building a supportive family network early in the journey is crucial to prevent burnout.

Survey Findings (cont.)

- **Unrealistic Expectations and Progressive Challenges**

- Starting caregiving can feel overwhelming, but knowing where to find resources, tools, and support can make the journey more manageable.
- Caregivers feel unprepared for the decline of care recipients and the progression of caregiver commitment.
- Caregivers face severe financial challenges, struggling with high care costs, limited financial support, and insufficient assistance for middle-income families.
- The financial strain of caregiving is overwhelming and unexpected, especially for families who do not qualify for income-restricted programs.
- Caregivers need proactive education and guidance to navigate the evolving and unpredictable demands of caregiving, especially when they are new to the role.

Survey Findings (cont.)

- **Navigation Challenges**

- A critical gap in caregiving is the lack of accessible and reliable resources, leaving caregivers overwhelmed and unsupported.
- Caregivers face significant challenges due to the lack of communication, coordination, and information-sharing within the healthcare and social care systems.
- Navigation challenges leave caregivers overwhelmed, financially strained, and emotionally isolated.
- Many caregivers express a frustration with automated systems and online resources that lack human interaction.

Survey Findings (cont.)

- **Considerations for Support Options**

- The Toolkit should centralize resources into a single, easy-to-navigate platform, reducing the time and effort caregivers spend searching for help.
- Effective communication is essential in caregiving to ensure that the care recipient and their family feel understood and supported.
- Caregivers would benefit from sharing experiences with a peer community to navigate the challenges of caregiving effectively.
- The Toolkit should be adaptable to diverse caregiving situations, acknowledging the unique needs of caregivers from different backgrounds and experiences.
- Caregivers benefit from practical tools to manage tasks, stay organized, and reduce stress during crisis periods.
- The Toolkit should be practical and understandable. Caregivers often struggle with complex documentation and confusing systems that exacerbates stress and frustration.

Key Design Elements

**Visible &
Convenient**

**Realistic &
Encouraging**

Clear & Practical

**Up to Date &
Accurate**

**Comprehensive &
Inclusive**

**Proactive &
Targeted**

Key Messaging

PA CareKit

Personal, practical, and ready when you are.

No two caregiving journeys are the same. One day, you're simply helping out. The next day, you're just holding everything together.

PA CareKit is a collection of tools, information, and support to help you learn more, plan ahead, or catch your breath.

It's here to support your role, your time, and your needs – because caregiving rarely comes with instructions.

A place to find answers you didn't know you needed. A place to find resources that make sense. A place that sees you as more than just a caregiver.

Support starts with a simple truth: You don't have to do this alone. Thank you for stepping up to care.

Thank You!

The PDA Executive and
Program Staff

Angie Bixler, PDA

Meredith Hughes, NAMI

Margaret Barajas, Ombudsman

Jamie Rose, Ombudsman

Quentin Burchfield, P4A

Lisa Scaffer, P4A

Carin Tinney, P4A

Denise Deiter, P4A

Holly Kyle, P4A

Karen Leonovich, P4A

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Stephanie Meyers, DHS

Candi Walton, DHS

Maria Dispenziere, DOH

Andrew Zechman, DOH

Melissa Myers, DOH

Melissa Hawk, DLI

Caroline Boehm, PID

Sandy Ykema, PID

Travis Davis, DMVA

Amanda Wolfe, DDAP

Danielle Spila, PennDOT

Thank You!

Charlotte McDaniel, PCOA
Jennifer Patten-Rudolph, PCOA
Debra Isenberger, PCOA
Janyce Collier, PCOA
Jennifer Drake, PCOA
Nancy Hodgson, LTCC
Shona Eakin, LTCC
Mark Gusek, LTCC
Mia Haney, LTCC
The Governor's Commissions

Melanie Smith, Alzheimer's
Association
Sara Murphy, Alzheimer's
Association
Stacie Bonenberger, JHF
Annelise Perry, JHF
Lisa George, JHF
Teresa Osborne, AARP
Janette Bisbee, HAP
Katie Noss, PACHC
ADvancing States

PHI
National Alliance for Caregiving
Family Caregiver Alliance
Tia-Maria Smith, KinConnector



Questions?

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