Developing Questions to Identify Adults with Long-Term Services and Supports Needs

Office of the Assistant Secretary for Planning and Evaluation
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Technical Instructions

• All participants are muted upon entry

• **You can access closed captioning** and Webex assistance at the lower left of the window

• There will be a **Question/Comment** session at the end of the webinar
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• Please contact **Derek Mitchell** (Host) through the Q&A panel with any **webinar platform issues**

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How to Submit a Question

Use the Q&A panel to submit questions and comments

- To submit a question or comment, click the Q&A panel and select “All Panelists” in the “Ask” field.

- Type your question in the text box and click “Send”
  - Note: Only the presentation team will be able to see your questions and comments; your questions will be read out for all participants to hear both the question and the discussion.

- For webinar platform issues, select “Host” in the “Ask” menu.
Agenda

• Welcome and introductions
• Background on long-term services and supports (LTSS)
• Overview of ASPE LTSS question development project
• Developing question set
• Next steps
• Questions and comments
Introductions

• Tisamarie Sherry, MD, PhD
  ◦ Deputy Assistant Secretary, ASPE Office of Behavioral Health, Disability, and Aging Policy
• Nikkilyn Morrison, MPPA
  ◦ Survey Researcher, Mathematica
• ASPE leads:
  ◦ Judy Dey, PhD
  ◦ Bill Marton, PhD
  ◦ Helen Lamont, PhD
Background
Long-Term Services and Supports (LTSS)

• LTSS includes a range of assistance to address people’s health, personal needs, or both over an extended period

• Most LTSS is not medical care but rather assistance with basic activities of daily living, such as bathing, dressing, toileting, and eating

• Medicaid and unpaid family care form the core of the LTSS system in the United States, with a small portion of Americans using private long-term care insurance

• While LTSS need may increase with age, more than half (56%) of Medicaid enrollees who use LTSS are younger than age 65*

Federal Reform Efforts

• Community Living Assistance Services and Supports (CLASS) Act
  ◦ Self-funded and voluntary long-term care insurance choice
  ◦ Established in 2010 as part of Affordable Care Act; repealed in 2013 because it is not economically viable

• Well-Being Insurance for Seniors to be at Home (WISH) Act
  ◦ Proposed a social insurance trust fund to cover long periods of LTSS needs
  ◦ Federal bill proposed in 2021; did not pass

• Build Back Better Act
  ◦ Proposed to increase Medicaid coverage for home and community-based services (HCBS) for seniors and people with disabilities
  ◦ Federal bill proposed in 2021 and replaced with Inflation Reduction Act of 2022 that excluded home care funding
Data on Need for LTSS Is Crucial

- Policymakers need data on need for LTSS to:
  - Assess demand for LTSS reform
  - Explore feasibility of LTSS reform proposals and changes to Medicaid
  - Understand burden on unpaid caregivers
  - Make projections about demand for workers
  - Understand what happens when people do not get the LTSS they need
Data Challenges: Defining LTSS Need

• There is no consistent definition of LTSS need
  ◦ Qualification for services under tax-qualified private long-term care insurance defined in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) include:
    - Inability to perform (without substantial human assistance) at least two activities of daily living (ADLs) for at least 90 days
    - Severe cognitive impairment requiring substantial supervision
  ◦ State Medicaid agencies use various functional assessment instruments to determine eligibility for Medicaid LTSS*
    - Some states include assessment of instrumental ADLs (IADLs) (for example, taking medications, managing money, food preparation, using transportation) in addition to ADLs

Data Challenges: Population Coverage

• Existing national population-based surveys that measure adults’ functioning and need for LTSS:
  ◦ Focus on adults ages 50 and older
  ◦ Do not align with Medicaid LTSS eligibility criteria

• No comprehensive federal data collection among adults ages 18 to 64 to understand the need for and receipt of LTSS
Overview of ASPE LTSS Question Development Project
Overview

• Goal: Ability to document prevalence and types of LTSS needs and consequences of unmet needs among adults to inform LTSS program design and policy changes

• Draft short (<15 minute) set of survey questions to measure:
  ◦ Need for LTSS
  ◦ Use of paid and unpaid LTSS
  ◦ Unmet needs
  ◦ Outcomes and consequences if needs are not adequately met
Population of Interest

- Noninstitutionalized adults (age 18+)
- Have a need for LTSS
  - Could qualify for Medicaid LTSS or private long-term care insurance based on functional limitations
  - Criteria based on:
    - Need for assistance to perform ADLs (for example, bathing, eating, toileting)
    - Severe cognitive impairment
    - Need for assistance to perform IADLs (for example, taking medications, managing money, food preparation, using transportation)
    - Other?
Timeline

• Conduct virtual stakeholder meeting (today)
  ◦ Solicit high-level feedback on plan

• Develop brief (<15 minutes) question set and data collection strategy (Summer 2024)
  ◦ Drawing on existing validated items whenever possible

• Convene technical expert panel (TEP) to further refine survey questions and potential data collection strategies (Summer/Fall 2024)

• Evaluate survey questions for validity and reliability (post-TEP)
Developing Question Set
Proposed Question Set Content

• Need for LTSS
  ◦ Need for assistance with ADLs and IADLs
  ◦ Cognitive impairments
  ◦ Length of time the needs are expected to last

• Receipt of LTSS/how needs are met
  ◦ Who provides assistance (unpaid family/friend, paid worker)
  ◦ Sources of payment (self/out-of-pocket, Medicaid, private long-term care insurance, unpaid, other)
Proposed Question Set Content (continued)

• Unmet needs
  ◦ Need for more assistance than what is received
  ◦ Types of additional assistance needed (for example, personal care, housekeeping, medication management)
  ◦ Barriers to assistance (for example, financial, helper availability, not qualifying for public programs)

• Consequences of unmet needs
  ◦ For example, missing work, missing meals, not bathing for more than three days, injury or bodily harm
What the Questions Will Not Cover

• Every state’s unique Medicaid eligibility criteria
• Specific diagnoses and conditions (though this may be covered in other parts of host survey)
• Past LTSS needs or timing of onset of LTSS needs
• Detailed functional or cognitive assessments
• Cost or affordability of LTSS
• Satisfaction with LTSS
Next Steps

• Draft survey questions
• Convene TEP
• Test questions and revise, as needed
• Explore data collection options
Questions and Comments
Possible Feedback Topics

• Will all populations with LTSS needs be captured by considering ADLs and IADLs? Do we need to explicitly ask about cognitive impairment or some other questions about functioning?
  ◦ If we need to ask about cognitive impairment, how should a measure of cognitive impairment requiring substantial supervision be structured to inform policy or program development?

• What is important to you with respect to a host survey or sampling strategy?

• Any feedback on the proposed survey domains:
  ◦ Need for LTSS (including functional abilities, cognitive impairments, length of time the needs are expected to last)
  ◦ Receipt of LTSS/how needs are met (including who provides assistance and sources of payment)
  ◦ Unmet needs in past month (including need for more assistance than what is received, type of assistance needed, and barriers to getting more help)
  ◦ Consequences of unmet needs in past month

To submit a question, send Q&A to “All Panelists”
Resources and More Information

• For questions about ASPE’s efforts to improve data collection on LTSS needs, email Helen Lamont at helen.lamont@hhs.gov

• To provide additional feedback on this question set development, please respond to the post-webinar survey