Developing Questions to Identify Adults with Long-Term Services and Supports Needs
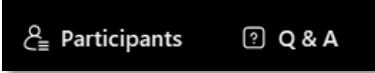
Office of the Assistant Secretary for Planning and Evaluation

June 17, 2024

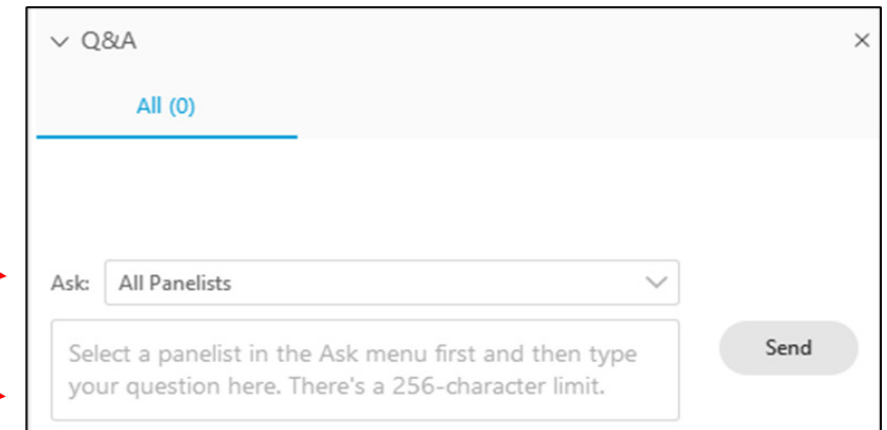U.S. Department of Health and Human Services

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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- A **recording** of the meeting and slides will be available after the webinar
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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.

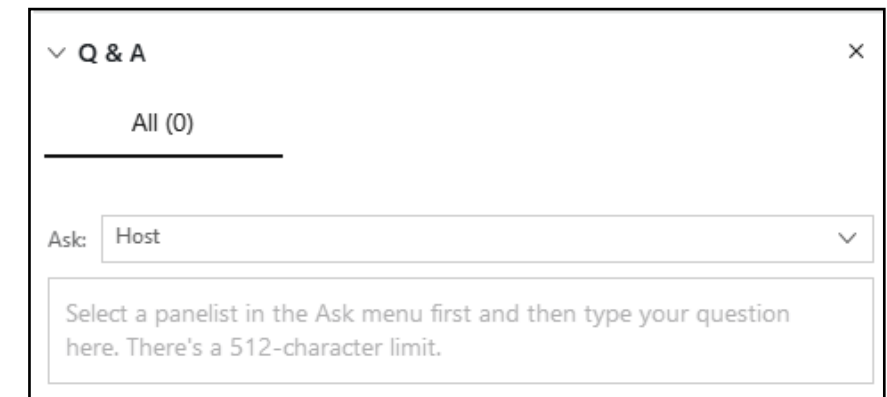- For webinar platform issues, select "**Host**" in the "Ask" menu

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*

* KFF. "Who Uses Medicaid LTSS?" 2023. https://www.kff.org/medicaid/issue-brief/who-uses-medicaid-long-term-services-and-supports/

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

* MACPAC. "Report to Congress, June 2016, Chapter 4." 2016.
https://www.macpac.gov/publication/functional-assessments-for-long-term-services-and-supports/

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