Friday Morning Collaborative Webinar

Development of the Home and Community Based Services Experience Survey

December 18, 2012
Friday Morning Collaborative

With support from The SCAN Foundation, NCOA leads a coalition of national aging and disability organizations working to protect and strengthen Home and Community-Based Services.

For more information about The SCAN Foundation visit: www.TheSCANFoundation.org
Friday Morning Collaborative

- American Association on Health and Disability
- American Association of People with Disabilities
- AARP
- Alliance for Retired Americans
- American Network of Community Options and Resources
- The Arc of the United States
- Association of University Centers on Disabilities
- Alzheimer’s Association
- Balezon Center for Mental Health Law
- Community Catalyst
- Direct Care Alliance
- Disability Rights Education & Defense Fund
- Easter Seals
- Families USA
- Leading Age
- Lutheran Services in America
- National Association of Area Agencies on Aging
- National Association for Home Care and Hospice
- National Committee to Preserve Social Security and Medicare
- National Council on Aging
- National Council on Independent Living
- National Consumer Voice for Quality Long-Term Care
- National Disability Rights Network
- National Domestic Workers Alliance
- National Health Law Program
- National PACE Association
- National Senior Citizens Law Center
- Paralyzed Veterans of America
- Paraprofessional Healthcare Institute
- Service Employees International Union
- United Spinal Association
- VNAA – Visiting Nurse Associations of America
Webinar Overview

• Introduction
  – Joe Caldwell (National Council on Aging)

• Speakers
  – Anita Yuskauskas (Disabled and Elderly Health Programs, CMS)
  – Julie Hayes Seibert, (Truven Health Analytics)
  – Elizabeth Frentzel (American Institutes for Research)

• Questions and Answers
  – 20 – 30 minutes
Questions and Comments

All Lines Will Be Muted During the Call
To Ask A Question Use the Chat Function

We Will Take Live Questions at the End
Information Follows the Person: Advancing LTSS Measures & Integrated Electronic Records

Anita Yuskauskas, Ph.D.
Technical Director, HCBS Quality
DEMONSTRATION GRANT FOR TESTING EXPERIENCE AND FUNCTIONAL TOOLS (TEFT) IN MEDICAID LONG TERM SERVICES AND SUPPORTS
TEFT INITIATIVE DESCRIPTION:
$64 MILLION INITIATIVE

❖ Ten + Grants
❖ Four Contracts
  • EoC Testing
  • CARE Testing
  • Technical Assistance
  • Evaluation
❖ Two Federal Interagency Agreements
  • ONC – Standards Development
  • DoD – PHR/EHR
FOUR COMPONENTS OF TEFT

- Test and Experience of Care Survey
- Test a set of CARE Functional Assessment Measures
- Develop Standards for e-LTSS Records
- Demonstrate Personal health Records
WHY TEFT?
THE “THREE-PART AIM”

Better Health for the Population

Better Care for Individuals

Lower Cost Through Improvement
Adult Quality Measures: The Affordable Care Act of 2010

- Development of a Core Set of Health Care Quality Measures for Adults Eligible for Benefits Under Medicaid
  - Includes Individuals with LTSS Needs
  - 5% Using 55% Resources
  - Lack of National Measures
Meaningful Use:
The American Recovery & Reinvestment Act of 2009

- Provides Incentives to targeted “eligible professionals” for using Electronic Health Technology
- Targeted Professionals in Medicaid include:
  - Physicians, certified nurse midwife, nurse practitioner, physician assistant practicing in a FQHC or RHC led by a Physician Assistant
  - May not be based in an inpatient hospital or emergency room of a hospital
WHAT’S MISSING IN THIS PICTURE??
WHERE IS LONG TERM CARE???
5% DRIVE 55% OF MEDICAID EXPENDITURES

Source: CMS Analysis of MSIS data FY2008
LONG-TERM CARE EXPENDITURES DOMINATE TOP 5%

Source: CMS Analysis of MSIS data FY2008
LTC EXPENDITURES BY PAYER: UNITED STATES, 2005

Medicaid 48.9%
Medicare 20.4%
Out-of-Pocket 18.1%
Private Insurance 7.2%
Other Private 2.7%
Other Public 2.6%

Source: Georgetown University Long-Term Care Financing Project
MEDICAID INSTITUTIONAL AND COMMUNITY-BASED EXPENDITURES IN 2005 DOLLARS: FFY 1980-2005

Source: CMS Form 64 Reports, adjusted for price increases based on the Skilled Nursing Facility Input Price Index.
Figure 3: Non-Institutional LTSS as a Percentage of Total Medicaid LTSS, 1995–2009
The E-Health Connected Medicaid Health System

- Hospital Care Coordination
- Diagnostics
- Specialist Referral
- Primary Care Medical Home Provider
- Order Entry Lab Result Reporting
- E-Prescribing
- Remote Patient Self Monitoring
- MCO Medical Medical Mgmt.
- Research
COMPLICATING FACTORS IN LTSS

- Wide Range Of Settings
- Wide Range Of Service Provider Types And Qualifications
- Wide Range of Measurement Sets: No Standardization
- Wide Variety Of Diagnostic Categories in LTC
- No Standard “Treatment Intervention”, i.e., service definitions & service delivery models
- Personal & social outcomes versus illness or disease outcomes
THE CENTRAL LAW OF IMPROVEMENT:

“Every system is perfectly designed to achieve exactly the results it gets.”
WHAT IS CB-LTSS SYSTEM DESIGNED TO DO?

- Flexibility
- Person Centered
- Portable
- Customized Services
- Customized Providers: licensed and non-licensed
- Vehicle to improve QoL and Healthcare.
MESSY!
WHAT ARE THE THREE MAIN COMPONENTS OF MEANINGFUL USE?

The Recovery Act specifies the following 3 components of Meaningful Use:

1. Use of certified EHR in a meaningful manner (e.g., e-prescribing)

2. Use of certified EHR technology for electronic exchange of health information to improve quality of health care

3. Use of certified EHR technology to submit clinical quality measures (CQM) and other such measures selected by the Secretary
A CONCEPTUAL APPROACH TO MEANINGFUL USE

Data capture and sharing

Advanced clinical processes

Improved outcomes
SYSTEM OF LTSS NEEDS TO PARTICIPATE IN MU

1. Standards
2. Personal Health Records
3. Trained Providers
4. Measures
# CURRENT & DEVELOPING MEASURES

## CURRENT

- Quality of Life Surveys
- Assurance-Process/System Performance
- Avoidable Hospitalization Composite
- Avoidable Incident Composite

## DEVELOPING

- Access
- Care/Service Coordination
- Experience Survey (CAHPS trademark)
- Functional Assessment (CARE)
- Evidence-based Practices
- Disparity
Presentation Agenda

- Introduction
- Survey Overview and Goals
- Domains and Constructs
- Survey Questions
- Development and Testing
- Questions and Suggestions
The HCBS Experience Survey

- Goal of the survey is to gather feedback on individuals’ experience with Medicaid home and community-based services (HCBS)
  - All program authorities

- HCBS programs, not providers, are the unit of analysis

- Self-report
  - Designed to maximize individual response and avoid proxies

- Funded by CMS
  - Developed by Truven Health Analytics, in partnership with the American Institutes for Research
    - Other consultants provide additional support
Key Survey Features

- **Cross-disability**
  - All disability populations receiving Medicaid-funded HCBS
  - Physical, cognitive and behavioral disabilities

- **Focus on experience, not satisfaction**
  - Actionable results

- **Address quality of life issues**
  - Includes domains and measures valued by program participants

- **Interviewer-administered**
  - In-person and telephone modes

- **Alignment with existing CAHPS® tools**
  - Consumer Assessment of Healthcare Providers and Systems surveys
  - Allow for benchmarking and comparisons between programs, states, and across the life span
  - Draft tool includes several standard CAHPS constructs
Policy Context

- Affordable Care Act, Section 2701: Adult Quality Measures
  - Legislative authority

- AHRQ DRA measure scan findings
  - Paucity of tested, cross-disability measures for HCBS in key domains

- National Quality Strategy
  - Individual experience is a key component

- CMS long-standing use of the CAHPS family of instruments

- Select survey items relate to statutory requirements for Medicaid 1915c waivers
  - Primary authority for Medicaid HCBS
Survey Domains

- Getting Needed Services from Personal Assistant and Behavioral Health Staff
- How Well Personal Assistant and Behavioral Health Staff Communicate and Treat You
- Getting Needed Services from Homemakers
- How Well Homemakers Communicate and Treat You
- Your Case Manager
- Choosing Your Services
- Transportation
- Personal Safety
- Community Inclusion and Empowerment
- Employment
  - Supplemental module
Examples of Constructs

- **Getting Needed Services from Personal Assistant and Behavioral Health Staff**
  - Unmet need in toileting
  - Unmet need in taking medication

- **How Well Homemakers Communicate and Treat You**
  - Individualized/responsive treatment by homemaker staff
  - Homemaker staff listen carefully

- **Your Case Manager**
  - Case manager responsive to service requests
### Choosing Your Services
- Service plan includes what is important to participant

### Personal Safety
- Assistance addressing physical abuse by paid staff

### Community Inclusion and Empowerment
- Able to get together with friends when want
Sometimes people need help taking their medicines, such as reminders, help pouring them, or setting up their pills. Do you need help from {personal assistance/behavioral health staff} to take your medicines? Yes/No

Do you **always** take your medicine when you are supposed to? Yes/No

[If No] Is this because there are no {personal assistance/behavioral health staff} to help you? Yes/No
Questions - How Well Homemakers Communicate and Treat You

- How often are {personal assistance/behavioral health staff} nice and polite to you? Would you say . . .
  - Never,
  - Sometimes,
  - Usually, or
  - Always?
  - DON’T KNOW
  - REFUSED
  - UNCLEAR RESPONSE
Questions - Your Case Manager

- Do you know who your \{case manager\} is?
  - YES
  - NO
  - DON’T KNOW
  - REFUSED
  - UNCLEAR RESPONSE
Questions - Your Case Manager

- Can you contact this {case manager} when you need to?
  - YES
  - NO
  - DON’T KNOW
  - REFUSED
  - UNCLEAR RESPONSE
How would you rate the help you get from the {case manager}? Would you say . . .

- Excellent
- Very good
- Good
- Fair
- Poor
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
Questions – Choosing Your Services

- A *program-specific term for “service plan”*—sometimes called a care plan, goals, or service plan—lists the services you need and who will provide them. Did you work with someone to develop your *program-specific term for “service plan”*?
  - YES
  - NO
  - DON’T KNOW
  - REFUSED
  - UNCLEAR RESPONSE
Questions - Personal Safety

- Is there a person you can talk to if someone hurts you or does something to you that you don’t like?
  - YES
  - NO
  - DON’T KNOW
  - REFUSED
  - UNCLEAR RESPONSE
When you want to, how often can you do things in the community that you like, such as shopping or going out to eat? Would you say . . .

- Never
- Sometimes
- Usually, or
- Always?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
Alternate Version: When you want to, can you do things in the community that you like, such as shopping or going out to eat? Would you say . . .

- Mostly yes, or
- Mostly no?
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
CAHPS

- Tool is being developed and tested according to the principles of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) initiative

- CAHPS provides alignment with other CMS measurement initiatives

- Seeking CAHPS Consortium approval
  - Preliminary application in 2011
  - Formal review and feedback
  - Consulting expertise from Julie Brown, RAND Corporation

- Final application will be submitted after field testing
CAHPS Principles

- CAHPS surveys ask about aspects of care for which the recipient is the best or only source of information.

- CAHPS surveys ask about aspects of care that recipients say are most important and relevant to them.

- CAHPS surveys are developed with an understanding of how the data will be reported.

- All CAHPS products, including surveys, are in the public domain and free of charge.

- CAHPS surveys ask recipients to report on and rate the services they receive.

- CAHPS surveys consist of a common core set of measures that are administered to all respondents in a standardized manner to enable meaningful comparisons of providers.
CAHPS Principles

- Results on CAHPS survey items are summarized into composite measures, primarily for reporting purposes.

- CAHPS surveys are designed so that only respondents who have had an experience are asked to report on it.

- CAHPS surveys provide an explicit time or event reference for respondents.

- CAHPS surveys use frequency-based response sets for reporting.

- CAHPS surveys include an explicit reference to the provider that the respondent is asked to report on or rate.

- A broad spectrum of stakeholders is consulted.
CAHPS Principles

- CAHPS surveys build on existing research and available tools.
- CAHPS surveys undergo iterative rounds of cognitive testing.
- CAHPS surveys undergo field testing.
- CAHPS surveys are developed in both English and Spanish and, where feasible, are tested in these two languages.
- CAHPS surveys employ multiple modes of data collection to enhance the representativeness of respondents.
Survey Development Process

- Literature Review
- Interviews
- Expert Input
- Draft Survey

Formative Research

Test Survey
- Cognitive Testing
- Expert Input
- Field Test

Functional Survey
- Analyze Field Data
- Expert Input

Finalize Survey
Phase I: Formative Research

- Literature review and collection of extant survey tools potentially relevant to HCBS services and populations

- Development of an 1,100 item library of potential survey items culled from extant tools

- Formative research interviews and focus groups with a range of HCBS recipients (all disability types) in several states
  - Determine which services are used and how
  - Identify and rank potential quality domains and constructs
  - Identify common terms and titles for services and providers
  - 24 total participants

- Formative interviews revealed common quality domains and values across disability groups
Technical Expert Panel

- Technical Expert panel convened to provide input on survey development and testing. Representatives from:
  - Advocacy groups (e.g. SABE, NAMI, AARP, and ADAPT)
  - State Medicaid and Operating Agencies
  - State Associations (e.g. NASUAD, NASDDDS, and NASMHPD)
  - Federal Agencies
  - Researchers and survey development professionals

- Three TEP meetings held to date
  - Provision of project overview and sought input on survey domains and data collection modes
  - Presentation of preliminary cognitive testing results
  - Present draft instrument and field test methodology
Formative Research Demographics

- Lower education
- Variation in disability types
- Other demographics
  - Mixed ages (18+)
  - Mostly female (71%)
  - Mostly white (58%)

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<tr>
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<tr>
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<tr>
<td>Age-related</td>
<td>7</td>
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Phase II: Cognitive Testing

- Drafted survey to reflect formative research findings and CAHPS principles

- Conducted three rounds of cognitive testing interviews with HCBS recipients
  - In-person Interviews to assess content, comprehension, recall, flow
  - All disability groups
  - 6 states total

- Conducted experiments with types of question responses
  - Frequency
  - Rating
  - Time references
Cognitive Testing Demographics

- Lower education
- Variation in disability types
- Other demographics
  - Mixed ages (18+)
  - Equally female/male (52%/48%)
  - Mostly white (73%)
  - Some Hispanic (20%)

### Education

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### Disability type

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<td>Physical</td>
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<td>Mental health</td>
<td>10</td>
<td>23%</td>
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Cognitive Testing: Findings

- Alternate response options needed for some respondents
  - Frequency: Never/Sometimes/Usually/Always
  - Dichotomous: Mostly Yes/Mostly No

- Items should be set in the general present
  - Explicit time reference (e.g. last six months) did not work for some respondents
  - Asking questions in the present worked across all respondents

- Titles of staff (PCA, assistant, etc.) varied significantly
- Responses using words (excellent, very good…) worked better compared to responses with numbers (0 to 10).
Frequency Scale Findings

Frequency scales worked well for some, not all:

- Q: [How often] do staff work as long as they are supposed to?

  “I like [never, sometimes, usually always response pattern] because it is more direct.” —respondent with a physical disability

  “This one [mostly yes/mostly no] is easier to understand.” —respondent with an intellectual disability
Overall Rating Findings

Ordinal scales were challenging to interpret for individuals with cognitive impairments.

“I think the first one (excellent-poor) really forces you to think if they are doing a good job or not. I don’t like the numbering system.” —Respondent with a brain injury

Would a 7 be better or worse than a 5? “A seven would be worse.” —Respondent with a cognitive impairment
Survey and interviewing protocol translated into Spanish
- Two certified translators conducted independent, simultaneous translation
- Meet with senior translator to reconcile any differences

One round of cognitive interviews with Spanish-speaking HCBS recipients and/or proxies
- Texas and Florida

Final survey draft reconciled English and Spanish translation issues
Phase III: Field Testing

- Draft instrument and field testing descriptions have undergone preliminary testing
- Training materials and protocols for survey vendors and interviewers under development
- Data collection will be conducted under the TEFT demonstration
  - Up to 10 states
  - 2 or more programs per state
- Sampling design to yield composites at the program level
- Goals
  - Compare the ability of disability groups to respond
  - Conduct psychometric analyses of field test data to evaluate reliability and validity
  - Evaluate survey administration logistics
Mode Test

- Field test includes mode test
  - In-person interviews via computer-assisted personal interview (CAPI)
    - 80% of sample
  - Telephone interviews via computer-assisted telephone interview (CATI)
    - 20% of sample

- Hypothesis is that CATI will not work well for some disability groups
  - Individuals with intellectual impairments
  - Individuals with dementia
  - Individuals with auditory or speech impairments

- However, CATI is less resource-intensive
Phase IV: Reporting Composites and Tool Endorsement

- Field test data will be used to modify items and create final version of survey
- Factor analysis to guide development of reporting composites and to determine which items to retain
- Draft templates for public reporting back to field test states
- Final CAHPS submission package following field test, to seek trademark
- Application to the National Quality Forum for endorsement
Comments and Questions

- Contacts

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Questions
Join to discuss what you learned today!

www.NCOACrossroads.org/HCBS

• Online community with over 300 aging and disability advocates across country interested in home and community-based services
  – Listserv and message board functions
  – Share information and resources with others
  – Post questions and discuss issues

• Please complete follow up survey