The Medicaid HCBS Experience of Care Survey

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PRESENTATION AGENDA

- Introduction
- Survey Overview and Goals
- Domains and Constructs
- Development and Testing
- Preliminary Lessons Learned from Field Test
- Questions and Suggestions
Affordable Care Act: More Than Coverage Expansion

Quality:

... Adult Health Quality Measures in Medicaid

... National Strategy for Quality Improvement in Health Care:

... Other Provisions call for Collection & Reporting of Quality Info: Health Homes, Community First Choice, Balancing Incentives
Adult Quality Measures:
The Affordable Care Act, Sec. 2701

- 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
Demonstration Grant For Testing Experience And Functional Tools (TEFT) In Medicaid Long Term Services And Supports
TEFT Initiative Description:
$60 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 Items
- Develop Standards for e-LTSS Records
- Demonstrate Personal health Records
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
System of LTSS Needs to Participate in MU

1. Standards
2. Personal Health Records
3. Trained Providers
4. Measures
SIX PRIORITIES OF THE NATIONAL QUALITY STRATEGY MAPPED TO DOMAINS FOR QUALITY MEASUREMENT (PROPOSED VBP DOMAINS)

- **Patient and Caregiver experience**
  - CAHPS or equivalent measures for each setting
  - Patient engagement measures

- **Clinical quality of care**
  - HHS primary care and CV quality measures
  - Prevention measures
  - Setting-specific measures
  - Specialty-specific measures

- **Care coordination**
  - Transition of care measures
  - Admission and readmission measures
  - Other measures of care coordination

- **Population/community health**
  - Measures that assess health of the community
  - Measures that reduce health disparities
  - Access to care and equitability measures

- **Efficiency**
  - Spend per beneficiary measures
  - Episode cost measures
  - Quality to cost measures

- **Safety**
  - HCACs

Three-part aim

Greatest overlap of measure concepts across programs
The HCBS Experience Survey
Project Goals

Goal 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
HCBS Experience Survey
Project Goals

- Develop and test a valid and reliable survey to gather participant feedback on experience with Medicaid home and community-based services and supports (HCBS)

- Develop supporting materials and roll-out strategy so states are able to use the survey to improve HCBS program quality if they choose

- Allow survey data to be linked to other administrative data to create a complete picture of program quality

- Obtain Consumer Assessment of Healthcare Providers and Systems (CAHPS) trademark and National Quality Forum endorsement
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.

Survey team collaborating with the Agency for Healthcare Research and Quality (AHRQ) and the CAHPS Consortium to obtain a CAHPS trademark for the final survey tool:
- Preliminary application in 2011
- Formal review and feedback prior to field testing
- Consulting expertise from Julie Brown, RAND Corporation

HCBS Experience Survey -> CAHPS
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 surveys ask about aspects of care

- for which the recipient is the best or only source of information.
- 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.
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.
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**
  - Telephone and in-person 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
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
Sample 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
Sample Constructs

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
Sample 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
Do you know who your {case manager} is?

- YES
- NO
- DON’T KNOW
- REFUSED
- UNCLEAR RESPONSE
Sample 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
Sample 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
Sample Questions - Community Inclusion and Empowerment

- 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
Sample Questions - Community Inclusion and Empowerment

- 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
Survey Development Process

- Literature Review
- Interviews
- Expert Input
- Draft Survey

Formative Research

Test Survey
- Cognitive Testing
- Expert Input
- Field Test

Finalize Survey
- Analyze Field Data
- Expert Input
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
  - In-person meeting with TEP (June 2010) to overview project and seek input on survey domains and data collection modes
  - Presentation of preliminary cognitive testing results to TEP, January 2011
  - Present draft instrument and field test methodology to TEP, April 2012
  - Will have a follow-up TEP meeting in late Fall/early Winter
Formative Research Demographics

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

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Phase II: Cognitive Testing

- Drafted survey to reflect formative research findings and CAHPS principles, including standard CAHPS items where appropriate

- Conducted three rounds of in-depth cognitive testing interviews in English and one round in Spanish with HCBS recipients to assess comprehension and accessibility
  - All disability groups
  - Concurrent probes
  - 6 states total

- Response “experiments” per CAHPS Consortium recommendation to test appropriate item wording response options, with a focus on individuals with cognitive impairments
  - Compared multiple ordinal scales and item formats
    - 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%)

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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 indefinite present
  - Explicit time reference (e.g. last six months) did not work for some respondents

- Need to determine services received by respondent to tailor survey, along with preferred/familiar staff titles

- Adjectival scales and willingness-to-recommend items perform better as ratings and are more accessible than numeric scales
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
Spanish Language Version

- 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 proposal have been approved by OMB and CAHPS consortium for national data collection

- Training materials and protocols for survey vendors and interviewers have been developed, Survey vendor trained

- Data collection is occurring in 2 phases
  - Pilot phase involving TN and LA
  - Additional programs will be included 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
Alternate Response Test

- Pilot field test includes alternate response test
- 50% of sample assigned to standard response and 50% of sample assigned to alternate response regardless of cognitive levels
- Results will help “map” alternate responses to CAHPs responses
  - Will provide information on how to report results when different response options are used across programs
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
Lessons Learned Thus Far ...

- Allow time and plan for appropriate paperwork
  - Business Associates Agreements
  - Data Use Agreements
  - Data Access Forms
  - Institutional Review Boards

- Vet Survey Vendors
  - Experience with CATI and CAPI
  - Experience programming complex surveys
  - Experience with in-person interviews with HCBS population
  - Experience with handling PHI, HIPAA

- Develop a good understanding of HCBS Programs
  - “When you have seen one HCBS program, you have seen one HCBS program.”
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?