Person-Centered Quality Measurement for Individuals Using Long-Term Services and Supports

December 11, 2012

For audio, dial: 1-888-600-4866; Passcode 837161
CHCS Mission

To improve health care access and quality for low-income children and adults, people with chronic illnesses and disabilities, frail elders, and racially and ethnically diverse populations experiencing disparities in care.

► Our Priorities

- Enhancing access to coverage and services
- Improving quality and reducing racial and ethnic disparities
- Integrating care for people with complex and special needs
- Building Medicaid leadership and capacity
Presentation Agenda

- Introduction
- Survey Overview and Goals
- Domains and Constructs
- 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**
  - Telephone and in-person modes

- **Alignment with existing CAHPS® tools**
  - 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
  - Patient 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
Survey Domains (con.)

- 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

- **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
CAHPS

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

- 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
  - Consulting expertise from Julie Brown, RAND Corporation

- CAHPS provides alignment with other CMS measurement initiatives

- 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.
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 “bank” 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

- Shoshanna Sofaer, PhD serves as the TEP facilitator

- 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
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 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: 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
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

Margarita Hurtado, PhD serves as a consultant on testing and translation

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

- Draft instrument and field testing proposal currently with OMB for review and approval to conduct large-scale, national data collection

- Training materials and protocols for survey vendors and interviewers under development

- Data collection will potentially 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

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National Core Indicators

A Multi-State Initiative to Measure the Performance of State Developmental Disabilities Systems

Mary Lee Fay, NASDDDS
Valerie Bradley, HSRI
Center for Health Care Strategies, Inc.
December 11, 2012
What Will We Cover?

• History and Purpose of NCI
• Data collection and outcome indicators
• Selected findings from the consumer and family surveys
• How have states used the data
The Emergence of National Core Indicators

Background and Rationale
Purpose of NCI

• To support a multi-state collaboration among ID/DD agencies interested in measuring the performance of state systems of support
• To allow for state to state comparisons
• To provide data at the systems level on outcomes
• To assist states to improve the quality of services and supports
Premise of NCI

• Improving performance starts with measuring performance – if you don’t measure it, no guarantee that it will happen

• NCI helps states to measure performance:
  ▪ Over time (change from baseline)
  ▪ Against multi-state benchmarks (our performance compared to performance elsewhere)
Evolution of NCI

Fifteen Years of Growth
Overview of NCI

• Launched in 1997 in 13 participating states; collaboration between the National Association of State Directors of Developmental Disabilities and the Human Services Research Institute

• Currently 35 states, the District of Columbia and 25 sub-state regions (including all CA Regional Centers)

• Unparalleled 15-year database on over 12,000 individuals

• Recent grant from AIDD will take NCI nationwide

• Valid and reliable consumer survey that has been recently up-dated

NASUAD Waiver Conference
NCI State Participation 2012-13

*Includes Clearwater Council of Governments and the Mid-East Ohio Regional Council

Orange states denote first year participation funded by ADD
NCI System Performance Measures

Individual Outcomes
- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

Family Outcomes
- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections
- Response

Health, Welfare, System
- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability
National Core Indicators Design

**Valid**
- Measure what is intended to be measured

**Reliable**
- Provide consistent results over time

**Risk Adjusted**
- Provide a national perspective and permit multiple state comparisons
What are the data sources?

• Consumer Quality of Life Survey
  ▪ Face to face interview
  ▪ Random sample
  ▪ Adults only

• Family Survey
  ▪ Adult Family Survey (at home, 18+)
  ▪ Family Guardian Survey (out-of-home)
  ▪ Children Family Survey (at home, <18)

• System Indicators
  ▪ Specific protocols for reporting turnover, mortality and incidents
Use of Data to Identify Specific Policy Issues

Review of Selected Findings from the 2010-2011
Other Disabilities

- **33% Dual Diagnosis**

Bar chart showing percentages of various disabilities:
- Psych. Diag: 33%
- ASD: 10%
- CP: 15%
- Brain Inj: 3%
- Seizure Dis: 26%
- Sensory: 11%
- Phys Dis: 10%
- Comm Dis: 8%
- Alzheimer's: 2%
- Down Syndrome: 9%
- Prader Willi: 1%
- Other: 23%
### Where People Live

<table>
<thead>
<tr>
<th>Housing Type</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Specialized Institutional facility</td>
<td>6%</td>
</tr>
<tr>
<td>Group Home</td>
<td>27%</td>
</tr>
<tr>
<td>Apartment Program</td>
<td>4%</td>
</tr>
<tr>
<td>Independent Home/ Apt</td>
<td>17%</td>
</tr>
<tr>
<td>Parent or Relative's home</td>
<td>34%</td>
</tr>
<tr>
<td>Foster care/ Host home</td>
<td>6%</td>
</tr>
<tr>
<td>Nursing Facility</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
</tr>
<tr>
<td>Don't know</td>
<td>0%</td>
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Choice

<table>
<thead>
<tr>
<th>Choice</th>
<th>Percentage</th>
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<td>Chose where lives</td>
<td>50%</td>
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<tr>
<td>Chose roommates</td>
<td>45%</td>
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<td>Chose home staff</td>
<td>64%</td>
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<tr>
<td>Chose place of work</td>
<td>80%</td>
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<tr>
<td>Chose work staff</td>
<td>60%</td>
</tr>
<tr>
<td>Chose day program/activity</td>
<td>60%</td>
</tr>
<tr>
<td>Chose day staff</td>
<td>58%</td>
</tr>
<tr>
<td>Chose case manager</td>
<td>59%</td>
</tr>
</tbody>
</table>
What Do People Do During the Day Differs by Residence

- **Institution**: 55% Paid Community Job, 40% Paid Facility-based Job, 8% Unpaid Community Activity, 2% Unpaid Facility-based Activity
- **Group Home/Agency**: 22% Paid Community Job, 27% Paid Facility-based Job, 15% Unpaid Community Activity, 2% Unpaid Facility-based Activity
- **Independent Home/Apartment**: 24% Paid Community Job, 22% Paid Facility-based Job, 20% Unpaid Community Activity, 17% Unpaid Facility-based Activity
- **Parents/Relatives Home**: 24% Paid Community Job, 22% Paid Facility-based Job, 24% Unpaid Community Activity, 17% Unpaid Facility-based Activity
For People with a job, How Are They Employed?

- 38% Competitive
- 38% Individually-supported
- 24% Group-supported
Basic Exams & Screenings

- Higher percentages in provider-based settings
- Lowest for people living in parent/relative home
- Similar trend across indicators
At Least One Psychotropic Medication by Living Arrangement

- Institution: 53%
- Community-based residence: 68%
- Independent home/apt: 53%
- Parents/relatives home: 36%
Use of Psychotropic Medications and Obesity
Selected Findings from the 2010-2011 Adult and Child Family Surveys

Families with Adults with ID/DD Living at Home
The Majority of Care Givers are Older

64% over 55 years of age

Caregiver Age

- Under 35
- 35-54
- 55-74
- 75 and over

Under 35 35-54 55-74 75 and over

60%
50%
40%
30%
20%
10%
0%
Family Income

Child Family Survey

- 18% Below $15,000
- 24% $15,001-$25,000
- 16% $25,001-$50,000
- 24% $50,001-$75,000
- 18% Over $75,000

Adult Family Survey

- 12% Below $15,000
- 13% $15,001-$25,000
- 28% $25,001-$50,000
- 19% $50,001-$75,000
- 27% Over $75,000

2011 HHS Poverty Guidelines for a Family of Four: $22,350
Crisis/Emergency

Crisis Supports Provided if Requested (past year)

![Bar chart showing percentage of clients who did not receive crisis services by family type.]

- Adult Family: 65% received, 35% did not.
- Child Family: 71% received, 29% did not.
How States Have Used NCI Data
Strengthening Service Delivery and Quality System-Wide

- Providing NCI survey findings to state and regional quality councils for review, analysis and feedback
- Identifying quality concerns and prioritizing service improvement activities
- Comparing the state’s performance against that of other states
- Targeting areas for remediation and improvement at the state and system levels in line with CMS requirements
NCI Website

• State Reports
• Annual Reports
• Data Briefs
• Articles
• National data
• Chart function
• Technical reports
Core Indicators
Drive Improvement

The core indicators are the foundation of the effort. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety indicators.

Participating states pool their resources and knowledge to create performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results in order to understand the overall health of public developmental disabilities agencies.

Featured Core Indicators
Understanding the overall health of public developmental disabilities agencies

Indicator Name or Description
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Integer a sollicitudin nisl in Massachusetts.
Suspendisse quis nunc sapien. Fusce erat elit, scelerisque a faucibus a, pharetra non eros. Varrus etiam diam, phellipiseque non lobortis ac, vissma ac eros. Eism sagittis metus ac aule sodales et sagittae magna estrem.

NCI Data Used by Self-Advocates and Families
by Josh Engler

HSRI and NASDDDS staff were in the beautiful state of Washington last week to observe Lisa Weber and the rest of the WA NCI team in action. Part of the agenda included attending a CCC Council focus group meeting. This meeting was made up of self-advocates, family members of children with developmental disabilities, and...

Participating NCI States
Select a participating state to view it's profile

November 2010
Report Released: National Core Indicators (NCI) 2008-09 Annual Summary Report
HSRI and NASDDDS are pleased to announce the release of the National Core Indicators 2008-09 Annual Summary Report. This Annual Summary Report highlights selected aggregate results from several of the NCI data sources...

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NASDDDS

Human Services Research Institute
Questions?

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Your questions will be viewable only to CHCS staff and the panelists.

Answers to questions that cannot be addressed due to time constraints will be posted online after the webinar.
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