Medicaid Disability Managed Care Collaborative Meeting with the National Quality Forum – May 22, 2012

Medicaid Disability Managed Care Collaborative attendees:

Maureen Fitzgerald - the Arc
Denise Rozell - Easter Seals
Laura Summer - Georgetown University on behalf of Easter Seals
Sita Diehl - NAMI (National Alliance on Mental Illness)
Clarke Ross - AAHD (American Association on Health and Disability)

NQF Staff Attendees

Helen Burstin, M.D., M.P.H., Senior Vice President, Performance Measures
Angela Franklin, J.D., Senior Director, Performance Measures (Behavioral Health Project)
Connie Hwang, M.D., M.P.H., Vice President, Measure Application Partnership
Sarah Lash, M.S., Senior Program Director, Strategic Partnerships (Dual Eligible Beneficiaries Work Group)
Karen Pace, Senior Director, Performance Measures (Patient Reported Outcomes and Home Health)

Collaborative Agenda

1. Introductions:
   Quick round robin introductions (all)
   Purpose for meeting:
      Exploratory, informal
      Introduce Medicaid Inventory idea
      Discuss **possible cross-disability** quality measures
   Introduce our organizations, our missions
   The people we serve in context of overall population
   Bring some stories to illustrate: only offer if there is an appropriate place to personalize
   Offer our group as a resource for cross-disability perspective
   NQF introduce their mission and needs regarding populations with disabilities

2. Medicaid Inventory concept: Sita
   Describe need across disability populations

3. Initial quality measures: Clarke
   Identify performance measures for services to disability populations

4. Next steps?

Medicaid Disability Managed Care Collaborative Areas of Priority:

1. What do consumers and families want to see from any program or system including Medicaid?

2. What metrics would systematically measure effects of supports and services on health, well-being and independence for individuals with disabilities?
3. What is CMS telling NQF about home and community based services for persons with disabilities?
4. What information is NQF looking for from us?

Proposed Consumer and Family Measures:

1. **Consumer choice:**
   % with self-defined plan of care, (how to ensure self-defined?)
   % making key life decisions
   Where Money Follows the Person program participants spend their money

   "Participant-Directed Services" allow program participants to exercise choice and control over the LTSS that they need to live as independently as possible at home. Participants can hire/fire and manage individual paid workers (such home health aides, personal care attendants, homemaker/chore workers, and other paid worker) of their choosing, rather than being assigned workers from an agency. Participants may also be given a set budget allowance to pay personal aides and purchase goods and services such as assistive technologies, home modifications, personal care supplies, transportation, and other supports recognized as serving to meet disability-related functional needs. The first approach is called the "employer authority" and the second approach is called the "budget authority."

   Money Follows the Person State Option - track where people choose to spend service dollars. Participant-directed options allow, at minimum, the individual to manage monetary allowances roughly equivalent to what would be spent for traditional home and community-based services. These allowances would be used to hire and fire personal attendants and aides and/or purchase goods and services (such as assistive technologies, transportation, home modifications). Enrollees may alternatively choose agency delivered services. As of November 2011, there were 298 Participant-Directed Services programs in the U.S., with at least one program in every state. Total enrollment was 810,000 people with 59% of participants in California. Arkansas Department of Human Services was the first program of its type in the nation. See Arkansas, Doty, NRCPDS - below

   See NASDDDS-HSRI NCI below. In 2009-2010, only 41% of consumers with intellectual and developmental disabilities chose where they live; only 37% chose their roommates; and 45% had "no" input into selecting their case managers.

2. **Satisfaction:** Person experience of care

   As part of its Medicaid managed mental health initiatives, Massachusetts and Philadelphia, Pennsylvania financed third party, independent, consumer and family directed consumer satisfaction monitoring teams. The teams focus on documented dis-satisfaction and regularly meet with health plans to resolve areas of dis-satisfaction.

[NAMI Advocate 1998-1999 and Ross edited-Aspen Publishers textbook on managed behavioral health, 2001]

3. **Integrated primary and specialty care**
   We can provide examples of existing integrated programs but we do not have performance data.

   See NASDDS-HSRI NCI below. Data is presented on the proportion of consumers who received preventive health services. NASMHPD (see below) also is piloting preventive screening for persons with serious mental illness.

4. **Access to timely and appropriate care**
   Training in early warning signs, early in-home behavioral intervention
   Crisis intervention where they live
   Recidivism to institutional settings, preventable hospitalization
   Trans-institutionalization: jails/prisons, homelessness
   While hospitalization, emergency room use, and hospital readmission are priority tracking areas, no standardized national data base that we know track these by disability.

5. **% in employment or meaningful day**
   Employment/avocation continuum

   See NASDDS-HSRI NCI below. In 2009-2010, employment data are presented. Only 52% of employed individuals with intellectual and developmental disabilities earned at or above the state's minimum wage.

   Individual Placement and Support (IPS) supported employment helps people with severe mental illness work at regular jobs of their choosing. Although variations of supported employment exist, IPS refers to the evidence-based practice of supported employment. Dartmouth University has an IPS center and is coordinating sites around the country. http://www.dartmouth.edu/~ips/. Site data is available but routine data are tracked.

   U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. Federal Financing of Supported Employment and Customized Employment for People with Mental Illnesses: Final Report. February 2011. Four states were analyzed for their recent success and experience with implementing supported employment (SE) programs, partially financed with Medicaid. The states were Illinois, Kansas, Maryland, and Washington. The rehabilitation and targeted case management Medicaid options and the Section 1915 HCBS options finance individual supports that are partially related to employment goals. No routine data are tracked.

6. **% in independent housing,** housing appropriateness, stability. Consumer choice. Stability. Need operational definition of "independent," and "appropriateness."

See NASDDDS-HSRI NCI below. In 2009-2010, only 41% of consumers with intellectual and developmental disabilities chose where they live and only 37% chose their roommates.

From: Helen Burstin [mailto:hburstin@qualityforum.org]
Sent: Wednesday, May 23, 2012 10:49 AM
To: Sarah Lash; clarkeross10@comcast.net; Sita Diehl (sdiehl@nami.org); Maureen Fitzgerald; Denise Rozell (drozell@easterseals.com); Laura Summer (lls6@georgetown.edu)
Cc: Connie Hwang; Angela J. Franklin; Karen Pace
Subject: RE: Follow-Up to Medicaid Disability Managed Care Collaborative Meeting

Thanks, Sarah. I have also attached the final Multiple Chronic Conditions Framework.

Karen Pace is the lead for the meeting on Patient Reported Outcomes on July 30-31. Please let us know if someone could serve as a reactor for the meeting. Some information is available on the project page.

http://www.qualityforum.org/Projects/n-r/Patient-Reported_Outcomes/Patient-Reported_Outcomes.aspx

Please let me know if you would like me to send an introductory email to Nancy Wilson at AHRQ. Her email is nancy.wilson@ahrq.hhs.gov.

Best,

Helen

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From: Sarah Lash
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Cc: Connie Hwang; Helen Burstin; Angela J. Franklin; Karen Pace
Subject: Follow-Up to Medicaid Disability Managed Care Collaborative Meeting

Clarke, Sita, Maureen, Denise, and Laura –

Thank you for such a lively discussion yesterday. As promised, I am attaching many resources related to quality measurement in disability populations. I apologize in advance for the information overload, but as I said yesterday we did a very thorough scan for potential measures.

Given our approach, many of these resources are focused on the healthcare aspects of quality of life.

- Attachments
  - Presentation on PEONIES – used by State of Wisconsin for Quality Monitoring
  - uSPEQ / CARF resources
  - Medicare Health Outcomes Survey (HOS)
  - Mental Health Process Measures Toolkit
  - Presentation by DEB Potter on Performance Measures in FFS Medicaid
  - 2 presentations by Palsbo/Mastal on developing measures so people with activity limitations can rate their health care/insurance
- Online Measure Databases
  - AHRQ National Quality Measures Clearinghouse
  - NQF Quality Positioning System
- Other resources
  - AHRQ's Care Coordination Measures Atlas
  - AHRQ's HCBS Quality Measure Compendium
  - SF-12 Survey
  - CAHPS Surveys
  - National Balancing Indicators
  - Long-Term Care Quality Alliance
  - AARP / SCAN Foundation / Commonwealth Foundation LTSS Scorecard
  - National Core Indicators

Regards,

Sarah

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From: Clarke Ross [mailto:clarkeross10@comcast.net]
Sent: Wednesday, May 23, 2012 4:12 PM
To: response to e-mail group
Subject: RE: Follow-Up to Medicaid Disability Managed Care Collaborative Meeting

Dear Helen, Sarah, Connie, Angela, and Karen:

Thank you again for your openness-sharing-giving-and collaboration.

Yes, we will discuss and recommend an appropriate reactor on the Patient Reported Outcomes expert panel July meeting. We greatly appreciate this. We did not make a point of this at yesterday's meeting, but persons with disabilities requiring a variety of services and supports, do "not" appreciate being called "patients." The term "patient" conveys a "medical model," and

thus a negative reaction by persons with disabilities. In our handout, there is the National Resource Center on "Participant" Directed Services. In a separate e-mail, I will introduce you all to Kevin Mahoney, executive director, NRCPDS.

Yes, please introduce us to Nancy Wilson at AHRQ.

I attach an updated summary of our meeting – it inserts NQF attendees and inserts our e-mail exchanges.

RE: your suggestion that we contact Dr. Charlie Lakin, NIDRR Director: I will contact Charlie.

RE: your suggestion that we contact Dr. Lisa Iezzoni, M.D., Harvard University. I do not know Dr. Iezzoni but will contact her through the American Association on Health and Disability (AAHD). Attached is the editorial board list from AAHD's Disability and Health Journal. Dr. Iezzoni serves on the editorial board and is involved in a proposed AAHD-CDC application project. I will separately send NQF folks information on the AAHD Journal. This is something you should subscribe to!

FYI: AAHD is partially funded by CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD). The NCBDDD disability branch leadership has asked me for an orientation to our dialogue with NQF and future work with the duals workgroup. I will share the attached meeting summary with the NCBDDD folks – as my orientation script. I will also share the duals power points that Sarah previously sent.

I attach four, decade old, attachments that might be of interest to Angela. In 2001, Aspen Publishers (since sold to Jones Bartlett) published a textbook on managed behavioral healthcare that I edited. I attach:

1. Chapter 10 – Performance, Quality, and Outcomes, by presidents of the American College of Mental Health Administrators (ACMHA) – John Morris and Neal Adams. I can put you in touch with John Morris. Attached is the final pre-published Word version of the chapter.
2. Chapter 11 – Consumer Satisfaction Teams and Other Third-Party Independent Accountability Entities. I was the author. Attached is the final pre-published Word version of the chapter.
3. The Aspen Publishers flyer on the textbook.
4. Also attached, NAMI Advocate article on Independent, 3rd Party, Consumer and Family Satisfaction Teams. This concept was recently endorsed by the Consortium for Citizens with Disabilities (CCD) "Principles and Recommendations for Transitioning People with Disabilities into Medicaid Managed Care." Maureen is a co-chair of the CCD Task Force on Long Term Services and Supports. Let me know if you would like a copy of the CCD principles.

Maureen and I look forward to participating in the June 5 NQF duals webinar-call.

Thanks again,

Clarke

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Medicaid Disability Managed Care Collaborative Resource Handouts at the Meeting

MACPAC, Report to the Congress on Medicaid and CHIP, March 2012. Page 10
"The Secretary (of HHS) and the states should accelerate the development of program innovations that support high-quality, cost-effective care for persons with disabilities, particularly those with Medicaid-only coverage. Priority should be given to innovations that promote coordination of physical, behavioral, and community support services and the development of payment approaches that foster their cost-effective service delivery. Best practices regarding these programs should be actively disseminated."

Existing Disability Measures:

Arkansas Department of Human Services. Independent Choices: Final Report. December 1998-March 2008.

CAHPS – Consumer Assessment of Healthcare Providers and Systems

Centers for Medicare and Medicaid. CHIPRA Quality Measures. Letter to State Officials. February 14, 2011. There are no disability-specific measures. One measure – access to primary care practitioners – does not track by diagnosis.

Commonwealth Fund. Recommended Core Measures for Evaluating the Patient-Centered Medical Home: Cost, Utilization, and Clinical Quality. May 2012 Data Brief. And, May 16, 2012 webinar – Measuring the Success of the Patient-Centered Medical Home. Non-disability measures that include, but do not separately track disability, include:
Emergency department visits
Hospitalizations
Hospital Readmissions
Continuity of Care
Comprehensiveness of Care
Coordination and Integration
Whole Person Orientation
Patient-Provider Communication

Team Based Care

Disability-Specific measures include:
Anti-depressant medication management – HEDIS source
Follow-up care for children with ADHD after medication prescription – HEDIS source
Follow-up after hospitalization for mental illness – HEDIS source

Department of Health and Human Services. Office of the Secretary. Medicaid Program: Initial Core Set of Health Quality Measures for Medicaid Eligible Adults. In: Federal Register. December 30, 2010. Pages 82397-82399. Disability-specific measures include, not related to other health conditions:
Alcohol Misuse: Screening, Brief Intervention, Referral for Treatment – RAND source
Follow-up After Hospitalization for Mental Illness – NCQA source
Anti-depressant medication management – NCQA source
Bi-polar disorder - % treated with appropriate medication – RAND source
Schizophrenia - % treated with appropriate medication – RAND source
Availability of mental health services – utilization data – NCQA source

Doty, Pamela; Kevin Mahoney, and Mark Sciegai. "New State Strategies To Meet Long-Term Care Needs." In: Health Affairs. 29 (1), 2010, 49-56

Doty, Pamela; Kevin Mahoney; Lori Simon-Rusimowitz; Mark Sciegai; Isaac Selkow; and Dawn Loughlin. "Cash and Counseling's Role in the Growth of Participant-Directed Service." Unpublished.

HEDIS – Healthcare Effectiveness Data and Information Set
See disability measures summarized in MACPAC, below

MACPAC, Report to the Congress on Medicaid and CHIP, March 2012. Pages 65-66
Draft CMS Required Measures for **CMS-Approved Medicaid Health Homes**, 2011, include the following disability measures, not related to other health conditions:

Care Transition – transition record transmitted to health care professional – NQMC: NQF source
Follow-up after hospitalization for mental illness – HEDIS source
Screening for clinical depression and follow-up plan – NQF source
Initiation and engagement of alcohol and other drug dependence treatment – HEDIS source
Selected Recommended Measures for **California Medi-Cal Dashboard**, 2011. Include the following disability measures, not related to other health conditions:
Risk-adjusted average length of hospital stay – NQF source
Medication possession ratio
Antidepressant medication management – HEDIS source
Follow-up after hospitalization for mental illness – HEDIS source
Initiation and engagement of alcohol and other drug dependence treatment – HEDIS source
Waiver waiting lists
Services in community vs institutions
Getting care quickly – CAHPS source

Getting needed care – CAHPS source
NAMI – National Alliance on Mental Illness. "Consumer-Staffed Monitoring Teams in Managed Care Assessment." NAMI Advocate. December/January 1998-1999. See consumer satisfaction item, above.

National Association of State Directors of Developmental Disabilities Services (NASDDS)-Human Services Research Institute (HSRI) National Core Indicators (NCI) Program. 2009-2010
Voluntary program launched in 1997. Currently, 25 states, 4 sub-state entities, and DC participate. 100 indicators are assessed in 5 domains. The 5 domains are:

Individual outcomes
Family Outcomes
Health, Welfare, and Rights
Staff Stability and Competency
System Performance

The program uses annual face-to-face surveys of a random sample of 400 individuals per state and mail surveys of families and guardians. In 2009-2010, 11,599 consumer and family surveys were completed in 16 states, DC, and one sub-state entity.

National Association of State Mental Health Program Directors. Measurement of Health Status for People with Serious Mental Illness. October 16, 2008.
10 measures are proposed. 9 are screening for other chronic illnesses. One is the availability of "social supports." NASMHPD is field testing pilots.

NCQA – National Committee for Quality Assurance
Draft measures for persons with mental illness include:
Continuity of care for anti-psychotic medications
Follow-up after inpatient psychiatric care
Access to primary care for certain chronic health conditions

National Quality Forum – National Quality Strategy – Table 3 – Alignment of Nursing Home Compare Measures and Home Health Compare Measures with the Core Measures Concepts

Nursing Homes
% of residents who need help with activities of daily living
% of residents with depressive symptoms
% of residents who were physically restrained

Home Health
Improvement in selective activities of daily living (ambulation; bathing; bed transferring)
Depression assessment conducted
CAHPS consumer assessment of care
Transition of care – timely initiation of care

Affordable hospitalizations and emergency room use

National Quality Forum – National Quality Strategy – Use of NQF-Endorsed Measures in Federal Programs by NQS Priority and Setting. The endorsed measures and NQS priorities are:

Safer Care
Effective Care Coordination
Prevention and Treatment of Leading Causes of Mortality and Morbidity
Person and Family Centered Care
Supporting Better Health in Communities
Making Care More Affordable

Can these measures be targeted to disability? To categories of disability?

National Resource Center for Participant-Directed Services. "Inventory of Publicly Funded Participant-Directed Supportive Care Programs." April 11, 2012. Prepared for CMS.

National Resource Center for Participant-Directed Services. "issue Brief: What Impact Does The Ability To Purchase Goods and Services Have On Participants in Cash and Counseling Programs." March 2009.

Ross, E. Clarke. "Chapter 11: Consumer Satisfaction Teams, and Other Third Party Independent Accountability Entities." In: **Managed Behavioral Health Care Handbook**. E. Clarke Ross, editor. Aspen Publishers, 2001. See consumer satisfaction item, above.