



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

June 27, 2014

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for Medicare and Medicaid

**RE: National Quality Forum: June 13, 2014 draft report of the Workgroup on Persons
Dually Eligible for Medicare and Medicaid**

We are submitting these comments on behalf of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (LTSS). The Consortium for Citizens with Disabilities is a coalition of over 100 national consumer, advocacy, provider, and professional organizations headquartered in Washington, DC. Since 1973, CCD has advocated on behalf of people of all ages with disabilities and their families.

We will submit these comments through the NQF public comment website portal.

General Comments

This is another excellent NQF report that is largely accurate with many important insights and observations.

Most of our comments merely reinforce the insights and observations for moving forward.

We emphasize the importance of the report's observations on person-centeredness, measuring the authentic beneficiary experience, and the high priority measure gaps.

The presentation of the measures is complex and daunting, even for workgroup members. We are concerned with how the general public and stakeholders will understand the presentation. We suggest that measures be ordered into major categories (e.g., community living, prevention of chronic illness, beneficiary choice and self-direction, etc.). Color coding of measures by major category might help in the understanding and presentation.

We suggest that this workgroup report include a quote from the NQF MAP May 30, 2014 draft report - Finding Common Ground for Healthcare Priorities: Families of Measures for Assessing Affordability, Population Health, and Person-and-Family-Centered Care: (page 21) - “one single term cannot apply to all individuals in all situations; in actuality, an individual with many needs may self-identify as a person, client, or patient at a single point in time...The task force agreed to use the word ‘person’ as an over-arching term to encompass the health and healthcare needs of all individuals, regardless of age, setting, or health status.”

Update to Measures

We recommend one deletion and two additions. We propose work group further discussion of one generalized observation made in the draft report.

(pg 13): We recommend deleting from this report UDSMR FIM. They made a brief telephone presentation to the workgroup. They provided no measures. They provided no data. They provided no outcomes. They also expressed an attitude - why is NQF doing this work when the UDSMR FIM exists and no changes are needed. Inclusion of the UDSMR FIM at this point in time is premature. UDSMR FIM could be cited in the list of future topics for the workgroup to consider.

(pg 13): We recommend one addition to the report - Council on Quality and Leadership (CQL) Personal Outcome Measures (POM). They made an in-person meeting presentation. They provided their measures. They provided data. They provided outcomes. This is an existing multiple decade program, previously recognized in NQF reports, that should be recognized again.

(pg 13): We recommend a second addition to the report - acknowledgment of the CMS and AHRQ pilot Medicaid home and community-based services personal experience approach. This could be cited in the list of future topics for the workgroup to consider.

(pg 8): We are delighted to see the emphasis on the need to present the **authentic beneficiary experience** into the quality measurement process. We would like the workgroup to further discuss one observation made in the draft report: “it might be preferable to directly question the people involved in the care planning process to teach their experiences, **but this would be burdensome and subjective.**” The nationwide use of the National Core Indicators (NCI) and the Council on Quality and Leadership (CQL) Personal Outcome Measures (POM) over several decades challenges the assumption that interviewing individual beneficiaries is “burdensome and subjective.” CMS and AHRQ are piloting a Medicaid home and community-based services personal experience approach; thus another example of challenging a generalized statement of burdensome and subjective. Consumer and family advocates believe that the authentic beneficiary experience must be measured. Existing systems do this now. What is left that is meaningful if we don’t measure personal needs, personal perspectives, and personal objectives? The Americans with Disabilities Act (ADA), particularly in implementing the Olmstead Supreme Court decision, requires person centered planning that begins with the beneficiary

experience. The observation on burdensome and subjective was made by some workgroup members but was not a decision or consensus of the workgroup.

Additional Comments on Measures

(pg 5 and Appendix E): We affirm the importance of promoting cross- program alignment

(pg 6): We affirm refining the high priority measure gaps. We affirm the observation – “resources must be devoted to research activities to explore new methodologies for measurement of complex topics, especially non-clinical processes and person- centered outcomes.” We affirm the observation – “the measurement field should do more to address the social issues that affect health outcomes in vulnerable populations.”

(pg 8): We appreciate the discussion of the status and role of the National Committee on Quality Assurance (NCQA) measurement development. We acknowledge –“discussions revealed tensions and differences of opinion as to whether the measures are sufficiently consumer-oriented.” We believe the current NCQA work is **not** sufficiently consumer- oriented.

(pg 8): We appreciate and affirm the observation – “the MAP recognizes the ideal process of developing a shared plan of care to require an ‘authentic’ interpersonal dialogue between the beneficiary, his/her family, and his/her team of medical and non-medical service providers.” We appreciate and affirm the observation – “the care team must focus on the personal needs of the individual beneficiary and that person’s vision of how they would like to live their lives.”

(pg 8) - We affirm the observation – “more groundwork must be provided to support...” “creating patient- reported outcomes measures.” As identified and discussed in the recent MAP draft families of measures report, please use “person” rather than “patient.”

(pg 8) - We agree with the observation, in the current context – “although far from ideal, requirements that care planning activities take place in- person and that agreement with the care plan must be documented with a consumer’s signature are still significant improvements over the current state of practice.” We encourage the workgroup to further discuss the consumer signature situation, believing it isn’t an adequate minimum expectation. Signatures are frequently manipulated by professionals.

(pg 11) - In discussing the concept and approach of “shared accountability,” beneficiary self-direction is a beginning and important element.

Quality of Life Outcomes

(pg 9-12) - We reaffirm the identification and discussion of the quality of life components of person- and- family centered care, team- based care, and shared decision-making.

Stakeholder Feedback Loop and Future Issues for Consideration

(pg 18) - We appreciate the identification of employment as a future consideration topic

(pg 18) - We recommend that the workgroup discuss and analyze again the measurement of “dignity of risk.”

(pg 18) – Person-centeredness is a current popular concept. We recommend that the workgroup learn the skill sets involved in actually doing meaningful person-centered planning, and how to measure the acquisition of these skill sets.

Thank you for your professionalism, integrity, responsiveness, and excellence. We look forward to continuing the work.

Sincerely,

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