



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

February 18, 2014

The co-chairs of the Consortium for Citizens with Disabilities (CCD) task force on Long-Term Services and Supports (LTSS) are writing to submit comments on the National Quality Forum (NQF) Measure Applications Partnership (MAP): 2014 Interim Report from the Dual Eligible Beneficiaries Workgroup.

We have reviewed and fully support the comments submitted by Clarke Ross of the American Association on Health and Disability (AAHD). On behalf of the CCD LTSS task force, we are writing to endorse the AAHD comments and urge the committee to take those comments into consideration for the final report. The AAHD comments are pasted below for your reference.

The Consortium for Citizens with Disabilities is a coalition of over 100 national consumer, advocacy, provider and professional organizations headquartered in Washington, D.C. Since 1973, the CCD has advocated on behalf of people of all ages with disabilities and their families. CCD works to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

AAHD Comments:

While as a member of the workgroup on persons dually eligible for Medicare and Medicaid, I had input into the report, and while I greatly appreciate the professionalism and responsiveness of the NQF staff, some national disability organizations have expressed a desire to directly comment on the interim report. This letter is intended to assist these organizations in submitting their comments, while sharing my comments directly with NQF. AAHD comments follow:

1. The interim report is a completely accurate and insightful summary of the work group's discussions and deliberations.
2. As stated on page 2: the report sets the stage for continued activities related to quality measurement for dual eligible beneficiaries to be conducted in 2014 and beyond.
3. AAHD acknowledges the page 3 MAP seven properties and particularly commends the property of **"person-centeredness"** – "measures that are meaningful and important to consumers, such as those that focus on engagement, experience, or other individually

reported outcomes. Person-centered care emphasizes access, choice, self-determination, and community integration.”

4. AAHD appreciates the page 4 recognition of the overlap in the **four subgroups** considered. A helpful addition to the interim report would be data on the co-occurrence of disabilities and conditions among the four subgroups.
5. AAHD commends the interim report pages 5-6 identification of the need for new and improved measures to address the **“high priority measure gaps.”** Each of these is of significant importance to persons with disabilities: (a) goal directed, person-centered care planning and implementation; (b) shared decision-making; (c) systems to coordinate healthcare with nonmedical community resources and service providers; (d) beneficiary sense of control, autonomy, self-determination; (e) psychosocial needs; (f) community integration, inclusion, and participation; and (g) optimal functioning.

In spring 2012, the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports identified six gaps in existing quality standards as they directly relate to persons with disabilities, with a focus on home and community-based services and settings, to be pursued within NQF:

Consumer Choice and Participant-Directed Services
Satisfaction: Individual Experience with Services and Supports
% in employment or meaningful day activity
% in independent housing – Consumer choice, housing appropriateness, stability
Integrated primary and specialty care
Access to timely and appropriate care

We remain disappointed that the National Quality Forum has not addressed employment as a performance and quality objective for persons dually eligible for Medicare and Medicaid, particularly given the non-elderly population with disabilities. We request the NQF staff outline the key questions and needed research references in order to effectively bring employment into the discussion.

6. We commend the page 6 effort in discussion to meaningfully address “cross-program alignment.”
7. We commend the report (starting on page 8 and continuing on page 10) recognition and discussion that **“quality of life measurement** tools assess outcomes that are extremely important to care recipients and their families.”

Thank you for the page 12 discussion of the “Money Follows the Person” initiative.

Missing from the pages 12-13 discussion is the importance of self-determination, personal autonomy, and personal direction as “potential domains for measurement of

quality of life.” We appreciate the page 13 observation: “Nearly all structures and processes could do more to promote person-centered delivery with the goal of improving quality of life outcomes.” We agree with the page 13 observation: “Person-centered planning and shared decision-making are two processes that could potentially set the stage for achieving improved quality of life outcomes.” And thank you for the page 13 statement: “an important element of the domain of mental/psychological health is a sense of control or self-determination.”

Thank you for acknowledging:” important principles of this type have recently been formalized in the final rule released by HHS on January 16, 2014 - Medicaid program for state plan home and community-based services final rule. The rule describes numerous requirements for home and community-based settings that will enhance person-centeredness and autonomy in decision-making.” As we have discussed with NQF staff, a few concrete examples from the rule would help illustrate this.

8. We discussed with NQF staff the concept of “**dignity of risk.**” Some of the January home and community-based settings rule addresses “dignity of risk.” As this concept is not addressed in the interim report, it is obvious that the disability community needs to provide more explicit, precise, clear examples and explanations of the concept. This is a task for the disability field to bring forward to NQF.
9. Regarding the page 9 discussion of “**patient-reported outcomes (PROs)**”, we’d like to repeat to observations previously made on several occasions in NQF meetings. (a) the term “patient” connotes a “medical model” managed and dominated by medically credentialed personnel working in medical settings, frequently with paternalistic attitudes. We acknowledge the common use of the word “patient.” But in the disability field, term person and sometimes consumer is a more appropriate term. (b) Previous NQF draft reports have acknowledged the study and replication of independent consumer and family operated monitoring and evaluating organizations. **Independent consumer and family operated monitoring and evaluating organizations** currently function in the mental health system in Maryland, Massachusetts, Pennsylvania, and Wisconsin. We respectfully request such recognition be reinserted into the interim report. An important underlying concept is the idea of “peers” as an important component and partner in delivery of services and supports.
10. Previous NQF draft reports have acknowledged that two quality measurement systems currently operate across the nation, focused on persons with intellectual and other developmental disabilities (ID/DD). These are the **National Core Indicators (NCI) and the Personal Outcome Measures.** We strongly recommend the reinsertion from the July 2013 NQF preliminary findings to CMS acknowledging that these approaches (NCI and POM) “have been proven to accurately assess quality of ID/DD services and individual outcomes.” Expansion of these approaches to other cohorts of persons with disabilities needs to be adapted and piloted, and at least one such three state pilot project is underway.

Thank you again for a comprehensive, very informative, and accurate report. We admire and appreciate the professionalism and responsiveness of the NQF staff. We hope you can make our suggested additions and reinsertions.

Respectfully submitted,

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