

Disability inclusion in the National Quality Forum

by Clarke Ross, D.P.A.

The National Quality Forum (NQF), a nonprofit membership organization created to develop and implement a national strategy for health care quality measurement and reporting, builds consensus on national priorities and goals for performance improvement. Under contract with the U.S. Department of Health and Human Services (HHS), the NQF Measure Applications Partnership (MAP) establishes a portfolio of quality measures to report and improve healthcare quality in all U.S. Department of Health and Human Services-funded programs.

Nearly 9 million people, including 5.5 million low-income seniors and 3.4 million people with disabilities under the age of 65, are dually eligible for and enrolled in both Medicare and Medicaid. Sixty-six percent of the beneficiaries have three or more chronic conditions; 61 percent have a cognitive or mental impairment; and 86 percent of these persons have incomes below 150 percentage of poverty. These persons have complex but highly varied needs.

The Consortium for Citizens with Disabilities (CCD) is concerned with persons with disabilities, many of whose disability is over their life span and many of whom have severe disabilities. Consistent with the Olmstead U.S. Supreme Court decision, CCD supports and advocates community involvement, engagement, and participation and personal preference and individual self-direction. This is a cross-disability effort that includes persons with mental illness.

The disability movement endorses an "independent living" paradigm and philosophy, rather than a "medical model" paradigm and philosophy. To date, NQF has been focused on the "medical model." The "medical model" sees people as "patients." Patient implies a focus on episode of care, episode of illness, and reliance on medical professionals. The "independent living" movement and model (as contrasted with the "medical model") focuses on services and supports, many by non-medical professionals and many by families and peers, that encourage and support community-based living and consumer choice and self-direction for persons with disabilities.

CCD has identified six gaps in existing quality

standards as they directly relate to persons with disabilities. These are consumer and family-centered measure areas. They are not intended to reflect all important measures to disability. The six consumer and family measure areas are:

1. Consumer choice and participant-directed service.
2. Satisfaction: Individual experience with services and supports.
3. Percentage in employment or meaningful day activity.
4. Percentage in independent housing: Consumer choice, housing appropriateness, and stability.
5. Integrated primary and specialty care.
6. Access to timely and appropriate care.

In addition to existing measures, there are successful models of third-party, independent, consumer and family-operated monitoring teams to assist in determining individual experience with services and supports. Payers — public payers and health plans — finance these teams. These programs are operational in Maryland, Massachusetts, Pennsylvania, and Wisconsin in the area of mental illness. The process for engaging consumers and their families and obtaining program and system feedback is as important as the actual measures themselves.

The Olmstead U.S. Supreme Court decision codifies the aspirations of persons with severe disabilities to live an active and meaningful life in the community of their choice. The six measure areas above would significantly improve and enhance the daily lives of persons with the most severe disabilities. In the area of mental illness and fundamental to the independent living movement are peer-delivered services and supports.

Clarke Ross, D.P.A., is a member of the National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid (www.qualityforum.org), a representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (www.c-c-d.org), and a policy associate for the American Association on Health and Disability (www.aahd.us).

FROM THE FIELD...

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The DOJ began investigating the state hospital, the Delaware Psychiatric Center, and subsequently modified the scope of the investiga-

tion in 2010 to focus on the state's violations of the ADA through the mental health system. The DOJ found that the state's current mental health system fails to provide ser-

vices to individuals with mental illness in the most integrated setting appropriate to their needs, as required by the ADA.

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