

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

January 19, 2016

Full Comments on the National Quality Forum HCBS Second Interim Draft, Compendium:

Justice in Aging appreciates the opportunity to comment on the National Quality Forum (NQF) Home and Community-Based Services Quality Second Interim Draft.

Justice in Aging, formerly the National Senior Citizens Law Center, believes that seniors and people with disabilities who receive Medicaid should have access to home and community-based services (HCBS) that enable them to live with dignity and independence in their homes. The recent shift in the balance of public spending and services away from institutional care and into the home and community demonstrates important progress toward achieving that goal. As the long-term services and supports (LTSS) delivery system rebalances, NQF's leadership and commitment to identifying quality measure gaps and potential for measure development is timely and important.

We commend NQF's impressive effort in creating the compendium of HCBS measures.¹ The compendium is an excellent resource for states, policymakers, consumer representatives and other LTSS stakeholders working to develop interim HCBS evaluation metrics. While NQF's HCBS work will take time, in the immediate term, we urge states to utilize the HCBS measure compendium to begin evaluating HCBS access and quality at the state level.

As NQF analyzes the findings of the draft report and prepares to prioritize measurement recommendations, we offer suggestions for the final draft. The Second Interim Draft demonstrates NQF is moving in the right direction and highlights growing need for state and federal programs to comprehensively evaluate HCBS. Our suggestions focus on discrete areas where we believe NQF can strengthen the measure domains in the final draft. Overall, we endorse NQF's work on this project.

Project Overview, Purpose and Objectives:

Justice in Aging supports the current NQF HCBS process. We agree that the first step is to identify measures and measure concepts, next identify measure goals, and finally, prioritize and recommend measures. We echo the frustration in the report that the current HCBS framework highlights the fragmented nature of the decentralized HCBS network and lack of measure consensus.² Because of this fragmentation, NQF's leadership in centralizing HCBS measurement is critical and long overdue. We believe the delivery of HCBS is local, and flexibility is needed to meet the variety of beneficiary needs in different states and settings. However, the dearth of centralized and endorsed HCBS measures is not serving any HCBS stakeholders. As the report demonstrates, some states are pioneering effective HCBS measure tools, but overall, most state HCBS quality measurement lags far behind that of medical or institutional quality measurement. NQF's effort to develop a central, endorsed measure set is important to advance the HCBS delivery system.

¹ National Quality Forum, *Addressing Performance Gaps in Home and Community-Based Services to Support Community-Living, Interim Report*, (December 2015).

² NQF Interim Report, pg. 6.

WASHINGTON

1444 Eye Street, NW, Suite 1100
Washington, DC 20005
202-289-6976

LOS ANGELES

3660 Wilshire Boulevard, Suite 718
Los Angeles, CA 90010
213-639-0930

OAKLAND

1330 Broadway, Suite 525
Oakland, CA 94612
510-663-1055

We are concerned, however, that NQF's position on measure concepts may limit measure development. NQF identifies measure concepts as "areas that have a numerator and denominator but have not undergone testing." This limited definition of measure concepts means that important domains such as Caregiving Support, Equity and Consumer Voice, have few, if any, measure concepts. We encourage NQF to explore fully explore all measure concepts and not discount measures that fall outside the current measure concept definition.

Methodology and Results:

NQF has successfully identified the eleven core domains of effective HCBS delivery.³ We suggest the following additions to the subdomains:⁴

Workforce—Dementia Care: We appreciate the example of a dementia training measure in the compendium of workforce measures. (Staff access to dementia-care training measure: Number of staff at care service or facility that receive specific dementia-care training on a regular basis.)⁵ With Alzheimer's disease and related dementias on the rise, it is increasingly important that individuals caring for and encountering people with dementia have training in the special needs of individuals with dementia. Our recent report, *Training to Serve People with Dementia: Is our Health Care System Ready?*,⁶ found most states have few meaningful dementia training requirements for professionals working at home or in the community, particularly compared to institutional and residential staff requirements. We recommend NQF continue to prioritize dementia training measures in the Workforce domain and build upon the example measure in the final draft.

Choice and Control—Supported decision-making: We recommend NQF include measures that evaluate the HCBS system's capacity to protect supported decision-making. The current draft does not identify supported decision making (the process of assisting individuals to understand their choices and make decisions)⁷ as a potential measure gap. In our extensive work with consumers and advocates in state transitions to managed long-term services and supports (MLTSS) and capitated programs for dual eligible individuals under the Financial Alignment Initiative (FAI), we've found states struggle to develop enrollment systems that adequately facilitate supported decision-making. Protecting an individual's right to decide when and how s/he receives care and services falls under the *Choice and Control* domain and requires further exploration in the final draft.

Human and Legal Rights—Nondiscrimination Protections: We are concerned the current Human and Legal Rights domain does not adequately address nondiscrimination protections. The Department of Health and Human Services (HHS) is finalizing regulations to implement Section 1557 of the Affordable Care Act. Section 1557 prohibits health care providers from discriminating against individuals on the basis of sex, gender identity, race, national origin and disability. As health care entities, service providers in the HCBS delivery system are held to these requirements. If nondiscrimination measures exist, we

³ The eleven domains: Service Delivery, System Performance, Effectiveness/Quality of Services, Choice and Control, Health and Well-Being, Workforce, Human and Legal Rights, Community Inclusion, Caregiver Support, Equity, Consumer Voice.

⁴ NQF Interim Report, pg. 33.

⁵ NQF Interim Report, pg. 13.

⁶ Justice in Aging, *Training to Serve People with Dementia: Is our Health Care System Ready?* (November 2014), <http://www.justiceinaging.org/our-work/healthcare/dementia-training-requirements/dementia-training-requirements-state-by-state>.

⁷ Burton Blatt Institute, Syracuse University, *Supported Decision-Making: An Agenda for Action* (February 2014), http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf.

recommend their inclusion in the final draft. If not, they should be included as a subdomain and identified as a measure gap for further measure development.

Equity: We support the inclusion of reducing health and service disparities in the Equity domain. We note the effort to reduce health disparities does not mitigate the requirement to protect against health care discrimination, as noted in the previous Human and Legal Rights discussion.

Service Delivery—Access to Supplemental Services: We support the components in this domain and request the measure also evaluate supplemental service delivery. In our experience with state transitions to MLTSS, particularly with states participating in the FAI, consumers struggle to access supplemental services. These are services that may also be considered nonwaiver services or “flexible benefits,” such as nonmedical transportation or home modifications. Without existing metrics for supplemental service delivery quality and access, stakeholders struggle to identify ways to improve access problems. We strongly suggest NQF prioritize identifying measures to evaluate access to quality supplemental services.

System performance—Effective Management: We support the emphasis on waiting lists and backlogs in the subdomains in this domain. We are concerned about the growing waiting lists for HCBS waiver services. According to the Kaiser Family Foundation, “[i]n 2014, more than 582,000 people were on §1915(c) waiver waiting lists, and the average waiting time exceeded two years.”⁸ Tracking and standardizing data regarding waiting lists for HCBS waivers will help HCBS stakeholders better plan to meet the growing need for HCBS.

We also recommend NQF consider a measure standard from Australia, “effective management.”⁹ The Interim Report describes the expected outcome as “the service provider has effective information management systems in place.” In our public benefit work, we frequently find the barrier to an individual accessing quality services is not a policy problem, but often simply a breakdown in information management systems. State eligibility IT systems, as well as provider payment systems, are frequently cited by consumer advocates as an impediment to service delivery. We strongly recommend NQF’s measure recommendations include standardizing data on the effectiveness of state information management systems.

Caregiver Support—Voluntary Support: We support the prioritization of caregiver support as a core domain, and strongly support the subdomains of caregiver assessment and caregiver compensation. We are increasingly concerned that managed care organizations (MCOs) are relying on uncompensated “natural supports” to provide LTSS. The federal Home and Community Based Services rule clarifies that unpaid natural supports must truly be voluntary¹⁰ and cannot be compelled in a written care plan.¹¹ Despite this protection, there is growing concern that MCOs are taking advantage of natural supports to

⁸ Kaiser Family Foundation, *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers>.

⁹ NQF Interim Report, pg. 20.

¹⁰ 42 C.F.R. §441.301(c)(2)(v).

¹¹ See Justice in Aging, *A Right to Person-Centered Care Planning*, http://justiceinaging.org/wp-content/uploads/2015/04/FINAL_Person-Centered_Apr2015.pdf.

reduce their expenditures.¹² Part of the NQF measure strategy should explore the utilization of natural supports to protect against any abuses.

Next Phase of Project Work:

The Interim Report includes international measures in the environmental scan to illustrate measures in high performing systems; however, these measures were not included in the Measure Compendium. We urge NQF not to overlook the progress achieved by other countries in measure development. Below are measures utilized in other countries that should be adopted in one of the NQF domains, by domain:

- *Caregiving:*
 - The proportion of carers who report they should have been included or consulted in discussion about the person they care for (England)
 - The proportion of people who use services and carers who find it easy to find information and support (England)
- *Service Delivery:*
 - Waiting for personal support services for complex patients:
 - Percentage of home care patients with complex needs who received their first personal support visit within five days of the date they were authorized for personal support services (Canada)
- *Consumer Voice:*
 - Percentage of home care patients with a new problem communicating or existing communication problem that did not improve since their previous assessment (Canada)
- *System Performance:*
 - Effective management: The service provider has effective information management systems in place:
 - Proportion of staff provided with training/education on the policies and procedures (Australia)

Thank you for the opportunity to comment. If there are questions concerning these comments, please contact Fay Gordon, Staff Attorney, fgordon@justiceinaging.org.

¹² See Technical Assistance Brief, ("What are the best strategies to take advantage of family caregiver supports and reduce overall LTSS costs?"), Center for Health Care Strategies, *Developing Capitation Rates for Medicaid Managed Long-Term Services and Supports Programs: State Considerations*, http://www.nasuad.org/sites/nasuad/files/MLTSS-Rate-Setting_Final2.pdf.