Public Comment RE: *Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Initial Components of the Conceptual Framework*

First and foremost, the *Coalition for Community Choice* would like to applaud the National Quality Forum for its work to offer measurement goals of high-quality, long term support services that are truly person-centered and ensure the rights of consumers to have choice and control over their Home and Community Based-Supports (HCBS).

The following are suggestions regarding the text of this report influencing NQF work:

A. The text of an operational definition for HCBS should be inclusive of individual preference and right to choose to live with other aging or neurodiverse peers. Thus the draft phrase, "... and that are delivered in the home or other integrated community setting," should be changed to underscore personal choice.

   1. For example: ‘... and that are delivered in their preferred home, workplace, and community.’, or ‘... and that are delivered in the settings that meet the goals and preferences of one’s person-centered plan.’

B. On pages 4 and 5, the report identifies specific types of consumers that receive HCBS. The CCC would like to request that the 5 million HCBS consumers who have an intellectual / developmental disability (I/DD) be explicitly recognized along with the other subpopulations. ‘Individuals with intellectual / developmental disabilities (I/DD)’ is widely used terminology and many states have HCBS waivers that specifically target the needs of individuals with I/DD.
C. Page 4 of the report, which offers statistics to illustrate the demand for home and community based services, should include data that explicitly shows the need for growth of HCBS to serve individuals with I/DD who are at high risk of institutionalization.

1. For example: Nearly one million adults with I/DD are living with a family caregiver over the age of 60. These individuals may soon lose their primary caregiver and potentially their home, yet less than 15% of the almost 5 million adults with I/DD have access to HCBS waivers.¹

D. On page 9, the report describes 13 different characteristics of a high-quality HCBS system. The following suggestions build on the impressive work already done by the committee and aid in the valuable work of establishing a common framework for recognizing high-quality HCBS:

1. Proposed characteristic: “Promotes social connectedness by including people who use HCBS in the community to the same degree as people who do not use HCBS;”

i. As written, the text rhetorically values the relationship of non-HCBS consumers as superior to HCBS consumers, as if the social connectedness of neurodiverse, aging, or other peers with disabilities is not acceptable as high-quality relationships. Many minority populations prefer the relationships to others within their minority, yet access to relationships outside of their minority must not be restricted or limited due to social or physical barriers. This characteristic should be re-evaluated with the goal to identify and reduce barriers to community access.

a. Example of re-written text: ‘Identifies barriers and promotes access to consumers preferred home, workplace, community spaces, and relationships.’

2. Proposed characteristic: “Utilizes and supports a workforce that is trained, adequate, and culturally competent;”
   i. Based on discussions of providers within the CCC, quality of supports are correlated to having dependable, long-term staff that knows an individual’s daily preferences and support needs: how they like their coffee/tea, their unique communication nuances, their favorite music, their favorite type of events, what triggers pain or anxiety, and who they feel can be trusted during difficult physical or emotional trials. Knowing someone in this intimate way takes time, not just training or physically present bodies. Therefore, expansion of the characteristic to include staff retention would bear another important element of measuring quality.
   a. Example of re-written text: ‘Utilizes a workforce development strategy to provide trained, long-term and culturally competent staff;’

3. Proposed characteristic: “Reduces disparities by offering equitable access to and delivery of services;”
   i. It is unclear if this characteristic is addressing disparities regarding access and service delivery of needed consumer HCBS, or if it is addressing the disparities experienced within the greater population of HCBS consumers.

4. Proposed characteristic: “Supplies valid, meaningful, integrated, aligned, and accessible data;”
   i. As the Final Rule relies on outcome-oriented characteristics of HCBS, it should be underscored that outcome-oriented data and emphasis on the consumer voice is absolutely essential to measuring quality of HCBS.
a. Example of re-written text: ‘Supplies valid, meaningful, integrated, outcome-oriented, and accessible data that reflects system effectiveness to influence consumers quality of life;’

E. The CCC would also like to suggest an additional characteristic of high-quality HCBS:

1. There are not enough financial resources to provide paid supports for all who could benefit from HCBS, and many communities need more assistance increasing accessible spaces and attitudes. Public-private community partnerships are essential to develop supports for access to more natural, un-paid, relationships and community integration. This should be addressed when discussing characteristics of service delivery of high-quality HCBS.
   i. Potential text: Maximizes community public-private partnerships to increase access to natural supports and improved community integration.

F. Regarding the illustration of the conceptual framework, arrows should point in both directions as it is essential that individual HCBS consumers are directly represented in informing and participating in the policy/system, not just via services/providers.

G. On page 13, the report lists “high-level domains” and “subdomains” that “highlight the topics for quality measurement in HCBS and begin the process of prioritizing them.” The following are suggestions of additional subdomains within listed domains to be considered:

1. WORKFORCE / PROVIDERS:
   i. The 2012 Disability & Abuse Project survey findings revealed that 70% of people with disabilities report being abused, 57% of these victims said they had experienced abuse on more than 20
occasions, with 46% saying it was too frequent for them to even count. For those that did report, 52.9% said nothing happened and only 9.8% of the cases the perpetrator was arrested. Thus, please consider the addition of measuring accountability of abuse allegations.

ii. Measurement of the influencers of long term staff tenure and reasons for staff self-termination should be considered.

iii. Measurement of the profiles of current workforce for the purpose of understanding what populations may be the future workforce could help with recruitment and career development strategies.

2. CONSUMER VOICE:

i. Of those who reported to be victims of abuse in the above survey, it is important to note that 62.7% did not report the abuse as 58% believed that nothing would happen, 38% had been threatened or were otherwise afraid, and 33% did not know how to or where to report. The need to measure accessibility of assistance for consumers to identify and report abuse, especially individuals who have difficulty communicating verbally, should be considered.

ii. The ability to communicate and be understood by support persons directly influences a HCBS consumers quality of life. Thus, continual assessment of implemented communication strategies should be measured.

3. CHOICE and CONTROL:

i. Measuring HCBS consumers specific barriers to home and community access is important for identifying necessary systemic change.

4. HUMAN and LEGAL RIGHTS:

i. Continual opportunities for HCBS consumers to learn about their rights and changing policy in accessible formats such as plain

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language, video, audio recording, etc. should be measured, especially if a continuing goal of the NQF is HCBS consumer participation.

5. SYSTEM PERFORMANCE:
   i. Flexibility of consumers ability to access different HCBS supports/waivers based on their changing support and service needs is necessary to be measured. A consumer should never have to voluntarily reject supports of an available waiver slot they could use in the present, in hopes of climbing the waitlist ladder to access supports they know they will need in the future.

6. FULL COMMUNITY INCLUSION:
   i. All measures of community integration and inclusion should be based upon an individual's preferred time and extent of participation within the community, not just recorded in terms of hours spent in the community without regard for that individual's life choices.
   ii. Additionally, measuring barriers of access to desired community inclusion is essential.

7. CAREGIVER SUPPORT:
   i. Access to information about basic LTSS structure, access to supports, changing policy, and public comment periods must be measured.
   ii. Measuring what mode of communication delivery is most effective for multiple target populations would also assist in important information dissemination.

8. SERVICE DELIVERY
   i. Identifying and measuring roles and structures within the service delivery system in which conflicts of interests are likely to occur is important for transparency and accountability.
Again, the Coalition for Community Choice applauds the work of the National Quality Forum and looks forward to reading and offering public comment of upcoming reports.

Sincerely,

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