

**Alzheimer's Association Comments on National Quality Forum's Interim Report on Measure Gaps in Home- and Community-Based Services (HCBS)**

**FINAL**

**(submitted through online format)**

**Definition of "HCBS" and/or its proposed characteristics (3,000 character limit; currently at 1,696)**

The Alzheimer's Association appreciates the opportunity to comment on NQF's Interim Report on Measure Gaps in Home- and Community-Based Services (HCBS). While we offer more detailed comment below, we note here that the report generally implies that all persons receiving HCBS have normal cognitive function and can clearly articulate their needs and preferences. For example, the committee includes "a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals (e.g., employment, enjoying life)," and "[e]ngages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance" as characteristics of high-quality HCBS. Similarly, the committee provides that "[it should] be a principle of high-quality HCBS that the system maximizes individual autonomy and self-determination. This 'dignity of risk' is fundamental in a person-centered system." While the Association agrees with these characteristics, the committee does not seem to account for the perspective of persons with cognitive impairment or their caregivers. Dementia is a degenerative condition that impairs judgement and eventually robs a person of his ability to make decisions and his capacity to assume risk. Many persons with dementia and their caregivers rely on HCBS, so this framework must accommodate the perspective of this population alongside those individuals who will be able to remain independent in their homes and communities. The committee must recognize this, particularly as it considers the definitions of "integrated" and "full community inclusion." We discuss this in further detail under the "Full Community Inclusion" domain.

**Proposed domains and subdomains (3,000 character limit; currently at 2,243)**

The Association offers comments on the following domains and subdomains:

"Full Community Inclusion:" The Association cautions the committee as it considers the definition of this term. Some persons with dementia are at risk for wandering and live in facilities with effective methods of deterring wandering while keeping residents engaged, healthy, and safe. Some individuals, however, do not view these facilities as providing the opportunity for "full community inclusion" or "full integration." We appreciate and support the committee's acknowledgment of the importance of safety and an individualized approach to safety supports. Safety supports must be available and the quality of those supports must be measured. We also commend the committee's inclusion of "choice of setting" as a subdomain and remind the committee that settings must meet a person's preferences *and* needs.

"Service Delivery:" Because the needs of a person with dementia and her caregiver change with the progression of the disease, we applaud the committee's acknowledgement that services must be sufficient to meet both current and future demands.

"Health and Well-Being:" For reasons noted above, we encourage the committee to include "safety and risk as defined by the consumer *and caregivers*."

"Caregiver support:" We applaud the committee's recognition of the importance of caregivers and the many supports they need. We respectfully suggest that the committee add a caregiver satisfaction subdomain to ensure that they are receiving the right supports at the right time.

"Choice and Control:" Similarly, we encourage the committee to include a consumer satisfaction subdomain. We also suggest that the committee include identifying and documenting caregivers as a subdomain and note the caregiver's role in supporting person-centered decision-making. Persons with

dementia will eventually lose their ability to make informed choices and understand consequences. Their wishes, however, can be fulfilled by including caregivers in planning and decision-making.

Finally, we suggest that the committee add “Safety” as a domain. Persons using HCBS are frail and vulnerable in many different ways and the safety of settings should be assessed, evaluated, and improved.

### **Illustration of proposed framework**

N/A

### **General comments (3,000 character limit; currently at 539)**

The committee notes that the core users of HCBS are older adults, people with multiple chronic conditions, and people with disabilities. As the project proceeds, we encourage the committee and NQF to look closely at which of these populations use particular services and in what settings to better inform and shape quality measures. For example, measures in certain domains (e.g., Consumer Voice, Choice and Control, Full Community Inclusion) should be constructed to reflect HCBS residents who have cognitive impairment and safety needs.