



Attn: Anne Marie Costello
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016
Via electronic submission at HCBSMeasuresRFI@cms.hhs.gov

Re: Request for Information - Recommended Measure Set for Medicaid-Funded Home and Community- Based Services

November 6, 2020

Dear Director Costello,

On behalf of the American Network of Community Options and Resources (ANCOR), thank you for the opportunity to provide comment on the recently released RFI on a proposed voluntary quality outcomes measures set for home and community based services. ANCOR is a national trade association representing more than 1,600 private providers of community living and employment services for people with intellectual and developmental disabilities (I/DD) as well as fifty-five state provider associations.

ANCOR greatly supports the identification of standardized measures which evaluate the quality of services and quality of life outcomes for individuals with intellectual and developmental disabilities. We appreciate CMS's leadership on issues of quality measurement, and CMS's interest in obtaining public input on this complex area. ANCOR is pleased to partner with you on its development. At ANCOR, we believe that all people with I/DD are entitled to a meaningful life with equal access to all of life's opportunities, satisfactions, and risks as every other person. The commitment to establishing widely agreed upon outcome measures is a good first step in ensuring access and evaluating the effectiveness of publicly funded services. As states move toward greater use of value-based payment methods, it is essential that the metrics which will be used to determine provider success are aligned with key outcomes and that the base set measures are funded appropriately.

Key comments include:

- An endorsed measure set needs to be more strongly focused on person-centeredness, the use of person first language, and focused on assessing the individual's personal satisfaction and general quality of life within the core measures set.
 - The measures presented lean heavily on those items which reflect the health of the system and not on recommended measures like autonomy, sense of belonging, and self-determination.
- The current version of the measure set does not reflect the needs and preferences of people with I/DD and are not I/DD specific.

- As CMS and states move toward greater use of value based payment approaches, they must ensure that base payments are sufficient, and that payment incentives do not substitute for adequate base rates.
- The number of measures identified is extensive. Is it the recommendation of CMS that states adopt all the measures identified, or is this intended to serve as a “menu” of possible measure from which states can choose?
 - Measures should minimize reporting burdens on providers.
 - Measures should consider variation in providers’ ability to report.
- Recommendation of a pilot project to incorporate and test life-satisfaction and personal outcome measures.
- Move toward a small but mandatory set of core measures and afford states the ability to customize extended measures to suit their service culture and stakeholders’ needs.

Upon review of the Request for Information, we appreciate the value of measures that evaluate the health of a given state system and we support the use of the NQF domains as the overall framework for these outcomes. Additionally, many of the identified measures within those domains are appropriate, yet we would like to see more person-centered metrics be incorporated. **We believe that any endorsed measures set needs to be more strongly focused on person-centeredness, the use of person first language, and focused on assessing the individual’s personal satisfaction and general quality of life within the base measures set.** The sector of HCBS and LTSS centered on supporting people with intellectual and developmental disabilities has, for decades, been built on advancing and supporting people to envision the life they desire, communicate those wishes to their natural and paid supports, and be supported in achieving those goals. We do not find these foundational supports to be adequately represented in the proposed quality measures set. Particularly in consideration of other CMS regulatory requirements like the HCBS Community Settings Rule, which is keenly focused on individual choice, control, and autonomy. This proposed set provides CMS an opportunity to place its focus on the quality and preferences of a specific customer group, and to prompt states and service providers to participate in the same. It is our hope that eventually the set of quality indicators will be reflective of the community-based, inclusive, and autonomous lives desired by people with I/DD with an eye to holding their service providers accountable for such.

We support the principle of measuring outcomes of services for people with I/DD. **As people with I/DD have a unique set of needs, we recommend moving toward an I/DD specific measurement set over the long term.** Measuring the quality of HCBS services across the diverse populations that Medicaid programs serve will mask important differences in these populations, the services they receive, and potentially the outcomes of these services. Specifically, the final recommended measures set must consider that the very nature of home and community based services are life-long and not episodic in nature, and that the population of people with I/DD are highly diverse and not easily comparable with other LTSS recipients. These measures must focus on what happens for and with the person once they are receiving HCBS services: are they getting what they want, and are those services supporting them to be as autonomous and self-determined as possible. The work to advance a standard measures set is an opportunity to ensure measures are customizable to reflect customer preferences and consider the unique needs of this subset of people receiving HCBS. Additionally, most measurement scales focus on measures at a point in time and do not gather outcomes reflective of the individual’s life span. Specifically, the goals of a twenty-five year old with Autism vary significantly from

the goals and needs of a fifty year old or a seventy-five year old person. Our measurement of satisfaction must be reflective of not only the unique needs of people with I/DD but also of where a person is in his/her life span. The measures set should be able to accommodate these variations.

This RFI is leaning heavily on those measures which reflect the health of the system and not on our recommended measures like autonomy, sense of belonging, and self-determination as stated above. For example, in the proposed set there are numerous references to “access to transportation”, which is fine on the surface, but meaningless if the person has nowhere to go. We agree that the final set of measures must include some process measures, like ensuring basic rights and access to services, but we need a hard shift toward outcome measures that are consistent with what payors want to accomplish and what individuals value in their lives.

When considering the intersection of quality measures in the context of CMS’s recent Medicaid Directors’ Letter on value-based care, we see the impending evolution of value-based payment models for I/DD long term supports and services. The linkage of any quality measures to payment incentives for providers needs to be discussed with people with I/DD, their family members, providers, and payers, prior to implementation. **While ANCOR supports initiatives on pay-for-performance, we have an overriding concern that such VBP will be tied to base measures and core service provision.** It is essential that basic service qualifications are funded and achievable. States and CMS must recognize the actual costs of providing services and ensure that providers are reimbursed appropriately. We most strongly advocate that after base costs are met, only then is outcome-based reimbursement appropriate and applied to the extended set of measures. The notion that payment enhancements have any value when the base payment is insufficient is faulty and we would not support a system that withholds or claws back payment from an insufficient base. In long term supports and services such as those provided to the most vulnerable Medicaid recipients, providers should not be penalized after the service is delivered. VBP must be additive, not reductive, and should be reserved for the extended measures set. Additionally, we believe transparency is essential in establishing base costs particularly as we look to the future of value-based contracts. To establish a base level of funding, we would also recommend that CMS adopt a national, uniform cost reporting process that builds on Generally Accepted Accounting Principles and specifically recognizes the historical cost of the service and assures all reasonable and customary costs of service delivery are captured, while striving for full disclosure.

To develop a set of measures that is more appropriate to the needs of the I/DD population, **ANCOR proposes a pilot project.** We recognize the need to build consensus among stakeholders and test measures that more directly speak to individual autonomy, belonging and self-determination. We envision a plan that starts small with a pilot in a willing state where proposed measures can be tested, adjusted and modified along the way. The pilots would develop and expedite additional measures that are specific to the needs of people with I/DD. We see this as an opportunity to test out new measures that will focus on the outcomes identified herein. We recognize that there are established processes for testing new measures however, these processes take years to complete. While the current process is thorough, it moves slowly and we would like to see CMS develop new measures via the proposed pilot, collect and analyze data, and use the results to deploy new measures. This pilot can inform initial voluntary use of measures that with time and experience become mandatory.

The reference to the CMS’ Measures Management System Blueprint is concerning as it defines a “quality measure” as a “numeric quantification of healthcare quality for a designated accountable

healthcare entity, such as hospital, health plan, nursing home, or clinician” and specifically links healthcare performance measures to HCBS services. We understand CMS’ interest in aligning HCBS quality measures with broader CMS measurement initiatives, however **the use of healthcare and system measures are appropriate and valuable for certain metrics but applying health care measures to a set of services that are designed to foster a lifetime of independence and community integration is counterproductive.** Any measures used must reflect the heart of the outcomes we strive for in community-based long term supports and services and align with the HCBS Settings Rule. We are concerned that in using this framework, we will not have measures that evaluate satisfaction, autonomy, and self-determination which is of stated importance to people with I/DD.

From a logistics perspective, we agree that a set of valid and reliable measures should eventually be achieved but not at the exclusion of more person-centered measures. **We recommend that people with disabilities, their families and other stakeholders should be involved in the identification of pertinent measures and that the measures be written in person-first language** and communicated in a manner easily understood by people with I/DD, their family members, and DSPs. As we have stated our agreement on the need for valid and reliable measures, we support the need for a routine review or update of the measures at least every five years.

Lastly, **we cannot overstate our recommendation that over time CMS work toward eventually making the measures set mandatory in HCBS for people with I/DD.** A handful of core measures should be required of states, plans, and payers who then can adapt or modify additional measures relative to their stakeholders’ preferences and cultural differences. We do not think the base set should be left to a state-by-state decision and we are concerned that without all states tracking the same data, we will not achieve a critical mass thereby allowing payers and stakeholders the ability to compare outcomes across the sector. Our subset of Medicaid and HCBS services are frequently criticized for the percent of spending versus the number of people served. It is our hope that through uniform accountability, we as a provider cohort will be better able to demonstrate the outcomes we foster and demonstrate the inherent value of the services provided.

Sincerely,



Shannon McCracken
VP for Government Relations