

National Core Indicators® Access Rule Comments

Introduction

National Core Indicators® is a collaboration between our organizations; Human Services Research Institute, National Association of State Directors of Developmental Disabilities Services, and ADvancing States. Together with state developmental disabilities (DD), aging and physical disabilities service systems, and people receiving services, NCI is dedicated to collecting data directly from those with lived experience within service delivery systems. Further, we are committed to ensuring valid and reliable measures are contextualized and used to support quality improvement within service systems. As such, we strongly support the spirit of the proposed Access rule, described as “improving access to care, quality and health outcomes, and better addressing health equity issues....to increase transparency and accountability, standardize data and monitoring, and create opportunities for States to promote active beneficiary engagement” an keeping important focus on “advancing equity in service delivery.” With decades of experience in system-level survey methodology and analysis, administration and technical assistance, and with close partnerships with state systems, we have a unique perspective on the feasibility and implementation considerations of various parts of the proposed rule. In this letter, we detail our questions and concerns. Thank you for the opportunity to comment.

Comments on “Reporting on the Home and Community-Based Services (HCBS) Quality Measure Set”

Timeframe for modifications to Quality Measure Set

From Proposed Rule: We invite comments on whether the timeframes for updating the measures in the HCBS Quality Measure Set and conducting the process for developing and updating the HCBS Quality Measure Set is sufficient, whether we should conduct these activities more frequently (every year) or less frequently (every 3 years), and if an alternate timeframe is recommended, the rationale for that alternate timeframe.

While it is important to continuously evaluate measures used to determine quality in Medicaid-funded services and supports, we believe that potential updates to the Quality Measure Set

every two years (and therefore, measures for reporting) may create undue burden and uncertainty for state quality monitoring and reporting efforts and for measure stewards responsible for maintaining tools to collect this information.

Firstly, we would appreciate clarity as to the intent of this provision in the proposed rule. Does this mean measures will be changed every 2 years, or does this mean there is a process for reviewing measures periodically to ensure measures remain appropriate and align with the values of the field?

Regardless of the intent, it is important to remember that using data to measure quality often requires more than one or two data collection cycles to set benchmarks and understand data trends. For example, one state seeing a high rate of psychotropic medication use in their NCI data implemented new practices to review how medications were prescribed and set initiatives to lower rates of use. They used their NCI data over several years to track progress toward their goal of reducing medication use, which was achieved. If the measures had changed during the measurement period, their efforts to track progress would have been compromised. Another state uses NCI data to regularly monitor and improve employment outcomes for people with IDD across their geographic regions, tracking outcomes over several years to analyze and understand changes. If the measure used to track employment outcomes changes, they will have difficulty understanding whether the differences they see are due to measure change, or actual progress. State policy often takes several years to be implemented, and sometimes even longer for results to impact state-level outcomes data.

In short, the possibility of changes to the recommended measure set every two years will impact the ability of states to focus on targeted areas for improvement over time. Strategic planning and quality improvement often takes multiple years to implement. A stable set of measures over a greater period of time allows states to assess baseline norms, implement new or changing policies/practices for quality improvement, and track progress over time.

NCI surveys currently use a five-year revisions cycle to revise and update survey tools, meaning the surveys do not undergo substantive changes until the revisions cycle is complete. This ensures a longer period with a stable tool with measures that states can use for at least five years to benchmark and track improvement over time – a request directly from states wanting to monitor measures over time. This longer time frame also allows time for robust engagement with states and service users to provide input on direction of revisions, to ensure the tools collect information pertinent to the field, and to test new measures and changes to existing ones. It also allows states to review progress on specific measures over several data cycles. Every other year changes to Quality Measures may impact the ability for tools to stay current with Quality Measures and to ensure that measures perform adequately in the field.

For these reasons, we recommend a frequency of no fewer than every three years for revisiting the Quality Measure Set. A five-year time frame to revisit quality measures would be optimal if possible, with changes decided in year three for implementation in year five.

Sample Stratification

To ensure states collect valid, reliable, and actionable data, NCI program staff provide ongoing technical assistance (TA) to each state in each year of participation. Among other areas, TA includes support to develop sample strategies that meet state individual needs (which may include sample stratification). Additionally, NCI produces detailed annual reports for each survey tool and employs statistical methods (such as weighting) that allow states to compare their results to national norms. TA and reporting provided to states is a critical component of NCI as many states do not have the internal resources, experience, or infrastructure needed to do this on their own. Our experience in assisting states to design sample strategies, provide technical assistance to states to facilitate survey administration, and examine the resulting data give us a unique perspective on the feasibility of sample stratification.

From Proposed Rule: *“Stratified sampling is a method of sampling from a population, in which the sampling can be partitioned into sub-populations, such as by race, ethnicity, sex, age, rural/urban status, disability, language, or such other factors.”*

With these challenges in mind, we propose that stratification by States in reporting of HCBS Quality Measure Set data would be implemented through a phased-in approach in which the Secretary would specify which measures and by which factors States must stratify reported measures.

Secretary will provide States with additional time to report and the amount of additional time. • Inform States how to collect and calculate data on the measures. • Provide a standardized format and reporting schedule for reporting the measures. • Provide procedures that States must follow in reporting the measure data. • Identify specific populations for which States must report the measures

There remain many outstanding questions, including the need for clarification about how CMS is conceptualizing the idea of stratification.

Stratified sampling design?

For example, are states expected to adopt a stratified sampling design whereby the eligible population is partitioned into strata based on the specified demographic factors and samples are drawn from each stratum to yield a required level of statistical power within the stratum? This is implied by the reference to and definition of stratified sampling in the Proposed Rule as cited at the beginning of this section. If this is what is meant by the stratification requirement, it would result in a large number of strata from which to sample, yielding an inordinately large sample for which most states lack the required surveying resources.

Furthermore, considering that some states already stratify their eligible populations by MCO, funding source, region, etc. based on their administrative needs, superimposing additional demographic partitioning on these strata would result in a sampling strategy that is close to impossible to implement. Additionally, some population subgroups would be so small that the

same beneficiaries would need to be surveyed year after year, resulting in burnout and survey fatigue. One state in the NCI-AD group attempted to follow the HCBS Measure Set guidance as set forth in SMDL 22-003, yet despite several meetings with NCI project staff, EQRO staff, and state staff, it was not possible to stratify by more than two factors given the size of the sample.

A stratified sampling design may lead to the same people being sampled year after year. This will undoubtedly lead to survey fatigue, or boredom/exhaustion with repeated surveying year after year. This is a phenomenon we hear about from states administering NCI, surveyors and people being surveyed.

Stratified reporting?

If, on the other hand, the stratification requirement is limited to data reporting by demographics without the expectation that states adopt a stratified sampling strategy by partitioning the eligible population to achieve a sample with sufficient numbers in the required demographic categories, questions remain about the representativeness of the resulting data. While we believe that using these data to begin to explore whether there are differences by demographic and personal characteristics could be valuable and important, we believe it is incumbent on CMS and measure stewards to understand and communicate guidance about the limitations of using data in this way. Using data in this way cannot guarantee accurate representation by each group, especially groups with lower populations, affecting interpretability and usability of results.

These considerations suggest that the language used in the Rule to refer to stratification be clarified to distinguish between stratified sampling strategies (i.e., partitioning the population prior to sampling) and stratified measure reporting.

Demographic Data Source

As noted in the proposed rule, state administrative data sets (which are used as the source for most NCI demographics) do not have consistent demographic information on people being served such as race/ethnicity, language, etc. Further, how demographics categories are defined and collected in those existing administrative data sets varies greatly between states. States will need more specific guidance on the sources for the data required for stratification.

In short, states will need further CMS guidance on what source should be used (for example, to understand urban vs. rural environment); how are categories defined (e.g., what qualifies as “disability”); what are the accepted categories (e.g., what categories may be reported for gender) and more specifics on how the stratification will be implemented.

Stratification Phase-in

We concur that there should be a phase-in period for stratification to alleviate burden for states. However, a phased approach still poses significant effort on the part of measures stewards since each state may choose different timelines for phasing in stratification of different measures. For stewards, for example, the phase in of stratification means extended, detailed,

and close collaboration with all states to support developing, implementing, and reporting their data collection activities with a new, potentially more complex sample. States will need detailed support to pull the sample if there are new stratification requirements. If those requirements are rolled out over time, each new cycle will present the need for new, extended and detailed sampling technical assistance for each state.

States will need extra support to closely track and plan surveying to ensure completion of surveys for the target groups. And states will need support to develop materials and outreach to ensure various populations are aware of the survey and are willing to participate.

A phase-in of different stratification will also complicate reporting to accommodate the various state phase-in timelines. For example, if one state is stratifying for one factor one year but another isn't and the following year more states begin to stratify, the reporting will be complex and unique each year of the phase-in. Measure stewards should be included in decisions on how to collect, calculate, and report measures to best support states to report in a timely manner.

Resources needed for successful data collection and reporting on the Home and Community-Based Services (HCBS) Quality Measure Set

We applaud the goals of this provision of the proposed rule. However, we wish to bring light to the increased effort that will be required on the part of measure stewards as well as for states.

We, as measure stewards, anticipate and are eager to provide additional technical assistance (TA) to states to assist them to successfully report the HCBS recommended measures from NCI. The additional TA described in more detail below, may include developing an appropriate sample strategy, developing infrastructure to better capture uniform demographic information, training and resources to reach out to populations that are typically underrepresented in data, systems to help track progress toward data collection goals, enhanced analysis, and restructured reporting. Many states do not have the internal capacity to do these activities on their own, and we, as stewards, do not currently have the resources to support these activities at scale.

Currently, several NCI states stratify samples to ensure proportional representation for groups of interest (e.g., to ensure that the race and ethnicity breakdown of the final sample mirrors the breakdown of the sample frame) or to reach sample sizes that allow for statistically valid comparisons between groups (e.g., to compare outcomes between waiver programs, or managed care organizations). For states currently stratifying in this way, stratifying the sample means increasing the number of surveys that must be completed. Those states that seek to make statistically valid comparisons between the strata generally require a sample of at least two times the required number of completed surveys. Due to recent feedback from states on the burden and burnout participants faced in completing the surveys, NCI program team often

recommend a sample of three times (or more) of the required number of completed surveys. Many of these states contract with an outside vendor that provides additional support for developing the sample strategy, administering the survey, tracking progress toward goals, and producing sub-group analyses that are not done through standard NCI reporting.

Because states have varying degrees of need in these areas, the NCI program team currently provides tailored technical assistance to help states achieve states' goals to collect valid and reliable data through the NCI program. As the items in the Access Rule come into effect, we expect to provide more targeted TA to support states to meet requirements in the final rule. This will take additional effort on measure stewards to:

- Advise on overall data collection for sub-groups (e.g., record availability);
- Advise on the development and refinement of existing data collection platforms to help track survey completion by strata, and overall data collection progress;
- If representativeness from sub-groups groups are needed, provide individual sampling TA for each state;
- Design appropriate weights: changes to state samples increase complexity for applying appropriate statistical measures such as weights to ensure accurate calculations; and
- Work on a state-to-state basis to understand and include appropriate notations as needed on data limitations.

As states will require additional resources to implement the Access rule to scale, we recommend that states be provided additional funding to support these efforts.

Where additional considerations and guidance is needed:

- How will states report the data for the HCBS Quality Measures? i.e. current 372 reporting process or will a newly developed reporting process be designed/required?
- Do we expect all states to end up on the same two-year reporting cycle? If not and states are allowed to participate every other year, NCI-IDD may struggle to meet the 25-state threshold for the Medicaid Adult Core Set. It is likely NCI-AD will meet the same challenges. Many states collect NCI data each year as part of their ongoing QI process, and we would encourage states to continue annual collection of all NCI measures including those in the HCBS Quality Measure set.
- There are opportunities for alignment/coordination with the Medicaid Adult Core Measure set as this set of measures includes 3 NCI-IDD measures that are also in the HCBS Quality Measure set. We would appreciate consideration of this as the rule is finalized.
- Will demographics for "stratification" phase-in for all states at the same time (e.g., all states will stratify for race and ethnicity year one, add urban/rural year two, and so forth), or will states choose how they phase-in demographics? (assuming samples will need stratification)
- What measures will CMS publish and report on?

- CMS has not yet created guidance for the thresholds for compliance for quality measures. It is worth considering that if a state demonstrates that 80% of service users surveyed through NCI report their service plan includes things that are important to them, is this state considered to be within “quality standards”? From a quality monitoring perspective, a state may be most interested in understanding areas of quality and compliance for which they are doing poorest and allocating their resources to improvement in those areas; in this instance, measurement shouldn’t necessarily be about setting a standard benchmark, but rather creating a metric for amount of improvement/change. Further, the experience of COVID-19 raises questions about how to build in tolerance within standards to account for period or cohort effects that can be expected due to changes in policies, practices, and even public health emergencies.

Comments on HCBS Payment Adequacy

Definition of “direct care workers”

From proposed rule: *“...we propose to require that at least 80 percent of all Medicaid payments, including but not limited to base payments and supplemental payments, with respect to the following services be spent on compensation to direct care workers: homemaker services, home health aide services, and personal care services.*

...We have also focused this requirement on homemaker services, home health aide services, and personal care services because they are services for which we expect that the vast majority of payment should be comprised of compensation for direct care workers.”

We recognize the vital contribution made by those providing homemaker services, home health aide services, and personal care to supporting those receiving HCBS. The workforce plays a crucial role in ensuring those receiving supports are able to live the lives of their choosing and thrive in their communities. The challenges faced by those workforces must be addressed, and we applaud the efforts made in the proposed rule.

However, we are concerned that if the Access Rule includes only these three services by themselves (and not as a component of another service as they do for EVV purposes), the majority of DSPs supporting people with IDD through Medicaid waivers would not be included in this requirement. With a few exceptions, states do not include “homemaker, home health aide or personal care services” as services in their HCBS waivers for people with IDD. Therefore, the majority of DSPs supporting people with IDD may not be included in this provision of the proposed rule.

Although the rule goes further to define “direct care workers” *“to include nurses (registered nurses, licensed practical nurses, nurse practitioners, or clinical nurse specialists) who provide nursing services to Medicaid-eligible individuals receiving HCBS, licensed or certified nursing assistants, direct support professionals, personal care attendants, home health aides, and other individuals who are paid to directly provide services to Medicaid beneficiaries receiving HCBS to address activities of daily living or instrumental activities of daily living, behavioral supports, employment supports, or other services to promote community integration,”* limiting the stipulations of the proposed rule to those providing homemaker services, home health aide services, and personal care will marginalize those workers who provide supports through the DD systems. The proposed rule would potentially exclude DSPs providing supports such as habilitation, job supports, community engagement supports, and other Medicaid-HCBS waiver funded services critical to ensuring that people are able to access their communities. People receiving supports from their state developmental disabilities (DD) systems are heavily reliant on this workforce that supports people in a variety of community settings. Excluding the DSP workforce may push skilled DSPs into other roles and exacerbate the crisis facing the workforce supporting adults with IDD.

The National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) State of the Workforce (SoTW) in 2021 Survey data collected data from 29 states on the Direct Support Professional (DSP) workforce supporting adults through the DD system. Participating states send the survey to all service providers in their state providing supports in residential, in-home and/or non-residential settings to adults with IDD. Of 3,838 responding providers, 12% reported providing exclusively non-residential supports, which are defined as those provided in a day program, community program, or work setting. In total, 65% reported providing non-residential supports only or along with other types of supports. Non-residential supports include adult day services, community supports such as supports provided to assist a person to participate in community activities and employment or vocational services. This can include supports to help people who are looking for work or work supports such as job coaching or employment support. The individual DSPs providing the majority of supports are not included in the payment adequacy stipulations of the proposed rule.

If the rule has the desired effect of ensuring adequate wages for those providing homemaker services, home health aide services, and personal care, this may have the unintended consequence of pushing workers out of other support jobs into those referenced in the proposed rule. This would leave service users, particularly those receiving DD system services, with a smaller workforce to help them work and spend their days.

From the proposed rule: *We included workers with professional degrees, such as nurses, in our proposed definition because of the important roles that direct care workers with professional degrees play in the care and services of people receiving HCBS, and because excluding workers with professional degrees may increase the complexity of reporting, and may unfairly punish States, managed care plans, and providers that disproportionately rely on workers with professional degrees in the delivery of HCBS*

Workers with professional degrees such as nurses, behavioral therapists, occupational therapists, etc., play a critical role in the support of people receiving LTSS. However, their roles and salaries differ significantly from that played by direct care workers. Those with professional degrees provide much more specific, targeted support often of a clinical nature. As such, they are often paid significantly more than direct care workers. Including these workers in the definition of direct care worker, and thus including their compensation in the requirement to use 80% of Medicaid payment for compensation may mean that direct care workers do not see any benefit or compensation increase as a result.

From the proposed rule: *We also request comment on the following options for the minimum percentage of payments that must be spent on compensation to direct care workers for each specific service that this provision should apply if this provision should apply to other services at § 440.180(b): (1) 65 percent; (2) 70 percent; (3) 75 percent; and (4) 80 percent.*

We have concerns that the 80% passthrough requirement will not have the effect of strengthening the DSP workforce. We have heard from providers that current rates for in-home supports offered in IDD systems are not sufficient to allow this pass-through requirement. It is worth considering the typical provider network and the suite of services they provide may require a variation in the overhead costs that are assumed. For all agencies, there are still base costs that must be covered such as payroll services, accounting, human resources, information systems infrastructure and other operational requirements. Smaller agencies, which receive less in total Medicaid payments, pay a larger proportion of their payments to those base costs. In essence, for smaller agencies, more of the 20% of Medicaid payments not going to compensation will be used towards base costs than for larger agencies. Forcing smaller agencies out of the market will disproportionately affect populations that rely on smaller agencies for supports, often rural populations and populations of color. We recommend scaling the percentage based on size of agency or amount of Medicaid payment received.

More detail is needed regarding how this rule will apply to the workforce who are supporting people who are self-directing their supports, as models for self-direction vary significantly by state and even within states. In addition, one of the fundamental characteristics of self-direction is that people with IDD and their supports have flexibility in the wage they pay to their DSP. This requirement could potentially reduce the power of individuals to set wages for the staff they hire.

The National Core Indicators State of the Workforce Surveys

The National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) [State of the Workforce \(SoTW\)](#) Survey and the forthcoming National Core Indicators Aging and Disabilities (NCI-AD) State of the Workforce Survey are currently used by 30 states to assess the stability and quality of the direct support workforce. The NCI-IDD SoTW survey has been in operation since 2015 and has provided state DD systems with critical data on the workforce such as average wage and average starting wages, benefits paid, vacancy rates, turnover and

tenure rates. The surveys also collect information such as demographics of the workforce, gender identity and services provided. The SoTW surveys are separated by population, unlike the data requested by the proposed rule. Also worth noting, the surveys do not collect data on direct care workers who exclusively support people who are self-directing their supports, though we are working to design a survey targeting that workforce.

Because many states have long-standing experience administering the SoTW surveys, we would like to propose a collaboration with CMS to ensure the surveys can be used to collect the requisite data for the proposed rule. The SoTW tools also provide states with data that can be used to develop more targeted recruitment and retention strategies and assess the progress of policy and programs.

Questions and comments regarding the proposed HCBS Payment Adequacy requirements:

We also have a few unanswered questions and comments regarding the proposed requirements under Payment Adequacy:

- 1) Will the state report a statewide total of FFS and managed care payments for HCBS and then a statewide total of how much money is spent on compensation per service, or will it be an average of all services and provider agencies? A statewide total would not provide adequate detail to ensure 80% of all Medicaid payments are being passed along to the DSP workforce.

Quick Note on the Managed Care Rule

It would be beneficial for states to be able to use data collected as part of NCI-IDD and NCI-AD as measures for the beneficiary experience surveys. We support the further evaluation and discussion with CMS and states regarding the possibilities.

Thank you for the opportunity to comment on this important proposed rule.

Sincerely,

The NCI® Measure Stewards

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