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HEALTH MANAGEMENT ASSOCIATES

Access and Adequacy Review for Home and Community-Based Services

PREPARED FOR
AMERICAN NETWORK OF COMMUNITY OPTIONS AND RESOURCES (ANCOR)

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Executive Summary

Section 1902(a)(30)(A) of the Social Security Act requires states to ensure that payment rates in state Medicaid programs are "consistent with efficiency, economy, and quality of care and . . . sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area."

In November of 2015, the Centers for Medicare and Medicaid Services (CMS) issued a final rule (42 CFR 447) regarding access to services and states' compliance, requiring states to submit Access Monitoring Review Plans to CMS that document states' assurances that they meet the requirements of the Act. The plans must include reporting on adequacy of most Medicaid State Plan services. Waiver services, including home and community-based services (HCBS) authorized under 1915(c), and services provided through managed care were not incorporated into the Access Monitoring regulation. Two other recently finalized regulations – the HCBS "settings" rule finalized in January of 2014 and final rule updating regulations regarding Medicaid managed care finalized in May of 2016 – also regulate access and adequacy of services. Additionally, Medicaid regulations at 42 CFR §440.230(b) require each service to be "sufficient in amount, duration, and scope to reasonably achieve its purpose."

This report summarizes the final access rule and related regulations (including relevant stakeholder comments), outlines ANCOR's principles for access to HCBS, and then lays out a framework for access measurement that includes HCBS and maps to CMS's current Access Monitoring review procedures.

ANCOR believes that access, adequacy, and sufficiency standards for HCBS must ensure choice of providers, timely access to services, services in integrated settings, service arrays that meet individuals' assessed needs and person-centered plans, and sufficiency of services such that the purpose of HCBS as a viable alternative to institutional care can be achieved. Reporting must include stakeholder input, workforce measures, and disaggregation of data to reveal service disparities. Finally, access monitoring should ensure HCBS payment rates that are adequate to ensure a range of willing providers who are able to retain a qualified and stable workforce.

Finally, this report outlines a framework for HCBS access, including how these elements could fit into CMS' existing access monitoring system. The elements of an HCBS access and adequacy measurement framework include: beneficiary choice of providers and services, adequate rates, stakeholder engagement and transparency, disaggregation of data, adequate needs assessments, beneficiary experience, workforce measures, population characteristics, availability of providers and services, comparability of access in other programs, and family caregiver measures and input.

HCBS Access and Adequacy – Background

Introduction

On November 2, 2015, CMS published a final rule with comment period, titled "Medicaid Program; Methods for Assuring Access to Covered Medicaid Services." This rule implemented section 1902(a)(30)(A) of the Social Security Act, which requires state plans "to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area."

CMS has clarified that the final access rule applies only to state plan benefits (including HCBS under Section 1915(i) and Section 1915(k), as well as institutional services), excluding services authorized under waivers and demonstrations, such as Section 1915(c) home and community-based services (HCBS) waivers. CMS also clarified that managed care plans are not covered by the access regulation, because CMS views these plans as governed by section 1903(m) rather than by 1902(a)(30)(A), and has established adequacy standards under the Medicaid Managed Care regulation at 42 CFR 438.68, §438.206, and §438.207. In the final rule and Request For Information response to comments about these services, CMS staff pointed to the Medicaid Managed Care rule (finalized on May 6, 2016) and the HCBS Settings rule (finalized in January of 2014) for the most recent standards that apply to services delivered under managed care plans and waiver services, respectively.

In addition to the comment period on the final access rule, CMS also simultaneously issued a Request for Information (42 CFR 447). The RFI sought input on core sets of access measures for services impacted by the rule, setting national thresholds for access to care, and establishing a process for beneficiaries to raise access concerns. The RFI also specifically sought input on measuring access to long-term services and supports (LTSS), including HCBS.

This memo covers three things: the Access to Covered Services rule and RFI issued in 2015, access elements of the Medicaid Managed Care and HCBS Settings final rules, and relevant stakeholder comments from each rulemaking process. This report does not analyze the new RFI published by CMS on November 9, 2016.

The Access Monitoring Process under the Access to Covered Services Rule

The final access rule did not set national standards or thresholds for access but instead mandates a process for states to document that they are ensuring access to care in compliance with the Social Security Act. The rule includes requirements for the Access Monitoring Review Plan (henceforth "the plan") that states must submit to CMS. The plan must be developed in consultation with the state's Medical Care Advisory Committee, be posted for public comment for at least 30 days, and is due to CMS by October 1 of each year, starting in 2016. The rule also requires that a state must include an access review in any state plan amendments that propose provider rate reduction or restructuring.

Access Monitoring Review Plan Requirements:

1. **Required Elements:** The Access Monitoring Analysis must specify elements (data sources, methodologies, baselines, assumptions, trends and factors, and thresholds) that will inform sufficiency determinations. This analysis must consider (and come to conclusions on):
    - the extent to which beneficiary needs are fully met
    - the availability of care in each geographic area, by provider type and site of service
    - characteristics of the beneficiary population
    - actual and estimated levels of provider payment available from other payers
2. **Beneficiary and Provider Input**: The state's conclusion of the sufficiency of access to care must include provider and beneficiary input through:
    - public rate-setting process
    - Medical care advisory committees
    - the ongoing beneficiary and provider input requirements (including hotlines, surveys, ombudsman, review of grievance and appeals data or other equivalent mechanisms) required by the final rule
3. **Comparative payment rate review:** The plan must include a comparison of Medicaid payment rates to other public and private payers for each provider type and site of service.
4. **Standards and methodologies**: The plan must include:
    - specific measures, like time and distance, providers participating in Medicaid, providers accepting new Medicaid patients, service utilization patterns, and provider and beneficiary feedback.
    - procedures to periodically review access for at least three years after a provider rate reduction or restructuring
5. **Service monitoring:** The state must review and report on access to the following specific services at least once every three years:
    - primary care
    - physician specialties
    - behavioral health
    - obstetrics
    - home health
    - services that receive an unusually high number of beneficiary complaints

HCBS in the Access Monitoring Process

As noted above, CMS did not include HCBS provided through 1915(c) waivers in the access review requirements; many commenters disagreed with this decision. The Consortium for Citizens with Disabilities, Easter Seals, United Cerebral Palsy, Community Catalyst, Justice in Aging, the National Health Law Program, and others all urged CMS to include HCBS in access requirements. Many groups also asked about the status of 1915(i) and 1915(k) HCB state plan services. CMS clarified in a new RFI on "Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services," published on November 9, 2016, that 1915(i) and (k) services must be included in access monitoring plans.

In response to the original 2015 RFI, few stakeholder groups had specific recommendations on metrics or methods for analyzing access to HCBS. Most recommended that CMS develop such metrics in a transparent process that engages stakeholders.

Several of those groups also endorsed the comments of the National Health Law Program, which provided an extensive analysis of why 1902(a)(30)(A) should apply beyond strictly state plan benefits. The main points of the analysis are:

1. 1902(a)(30)(A) is a broad Medicaid state plan requirement. When Congress intends to exempt managed care from foundational 1902(a) requirements it does so explicitly, such as section 1932(a)(1)(A) that explicitly exempts managed care from section 1902(a)(23)(A).
2. The authority to waive specific sections of 1902 does not permit HHS to waive general 1902 requirements, including 1902(a)(30)(A). Section 1915(c)(3) sets out specific provisions of 1902 that can be waived by HHS (including 1902(a)(1) and 1902(a)(10(B)), and 1902(a)(30)(A) is not included in that list.
3. Section 1903(m) does not obviate the need for 1902(a)(30)(A) in managed care. 1903(m)(2)(A)(iii) is an actuarial soundness provision, not an access to care provision. 1903(m)(1)(A)(i) requires Medicaid managed care organizations to make services available "to the same extent such services are made accessible" to Medicaid beneficiaries not in managed care. NHeLP argues that (a)(30(A) is a "starting point" for 1903(m) and that managed care access cannot be enforced if (a)(30)(A) is not also enforced.
4. CMS's assertion that the mention of "state plan services" in 1902(a)(30)(A) impedes application to demonstration and waiver programs runs contrary to CMS's interpretation of other sections of 1902. Both 1902(a)(19) and 1902(a)(25) mention services "under the plan" but are interpreted by apply to demonstration and wavier services. CMS's interpretation also runs contrary to language in 1915(c) that describe waiver services as "medical assistance under such [state] plan."
5. Exclusion of 1902(a)(30)(A) requirements from managed care runs contrary to past CMS practice. In 1995, HHS refused to waive 1902(a)(30)(A) as part of the State of Tennessee's 1115 application.

NHeLP also noted that exemption of HCBS waiver programs diverges from CMS's technical guidance. Page 258 of the Instructions, Technical Guide and Review Criteria for 1915(c) applications released in January of 2015 notes, in reference to 1915(c) services, that "1902(a)(30)(A) of the Act requires that payments for Medicaid services be consistent with efficiency, economy, and quality of care."

Medicaid Managed Care Rule

According to the CMS RFI, the "access to care" protections in the Medicaid managed care final rule are the network adequacy standards at §438.68 and availability of services standards at §438.206 and §438.207.

Network Adequacy

With regards to network adequacy for LTSS, §438.68 of the final rule requires states to develop:

1. time and distance standards for LTSS provider types in which an enrollee must travel to receive services
2. standards other than time and distance for provider types in which the provider must travel to the enrollee

States must also consider anticipated enrollment, expected utilization, characteristics and needs of the population, types of providers needed, number of providers accepting new patients, geographic location

of providers, ability of providers to communicate in beneficiaries' preferred language, ability of providers to ensure accessibility and accommodations, and the use of telemedicine. LTSS standards must specifically consider elements that support the beneficiary's choice of provider, strategies that ensure health and welfare and support community integration, and other considerations in the "best interest" of enrollees who use LTSS.

Availability of Services

Availability of services is governed by §438.206 and §438.207of the Medicaid Managed Care rule. The former requires states to "ensure that all services covered under the State plan are available and accessible to enrollees…in a timely manner" and that states comply with §438.68 network adequacy standards. This includes, at §438.206(b)(1), "a network of appropriate providers...to provide adequate access to all services under the contract for all enrollees, including those with…physical or mental disabilities." States must also arrange for out-of-network care at no additional cost to the enrollee if no providers in a network can provide what an enrollee needs. Finally, at §438.206(c)(1)(i), a state must "require network providers to meet state standards for timely access to care and services."

The regulatory language of §438.207 requires plans to document their capacity to fulfill the access requirements of states required above. This includes documentation of an "appropriate range" of providers, including LTSS providers that is "sufficient in number, mix and geographic distribution" to meet the needs of enrollees. Plans must submit this documentation at the beginning of a contract, annually, and after a significant change in services, benefits, service area or payment rates.

In addition, §438.71 requires an independent Beneficiary Support System that is responsible for specific support for LTSS beneficiaries, including "An access point for complaints and concerns about [MCO] enrollment, access to covered services and other related matters" and review and oversight of LTSS program data to guide the State Medicaid Agency on identification, remediation, and resolution of systemic issues.

These standards all must be in place for contracts starting July 1, 2018 or after.

HCBS "Settings" Rule

In the preamble of the final rule, CMS notes that "methods to assure access to care, including payment methodologies, are reviewed in the approval process for Medicaid waiver and demonstration programs (and, when appropriate, may be monitored in the evaluation of a demonstration program)." CMS then points to the HCBS Settings rule finalized in January of 2014.

The settings rule does not include specific access monitoring requirements. However, the regulations regarding person-centered planning at §441.301(c)(2) state that the plan "must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need." Further at §441.301(c)(2)(iii) the regulations require that the plan must "reflect the clinical and support needs as identified through an assessment of functional need."

HCBS Access Measurement and Metrics

Most disability advocacy organizations, while strongly supporting inclusion of HCBS in access monitoring, did not suggest specific metrics.

Mathematica Policy Research submitted comments that did not take a stance on the policy issues at hand, but submitted ideas for a measurement framework that included LTSS. Their proposal built on a "Five A" framework: Availability, Accessibility, Accommodation, Acceptability, Affordability, and Realized Access. LTSS/HCBS measures in each of these areas were included. Some of these are already being collected, others are "aspirational":

- availability: percentage of people who do not use authorized hours or services
- accessibility: measures from HCBS Experience of Care survey
- accommodation: percentage of people eligible for LTSS who use HCBS; percentage of home care workers who show up on time (according to care plan); composite measures from HCBS Experience survey of getting needed services and choice of services
- acceptability: percentage of LTSS users who report that case managers are responsive; composite measures from HCBS Experience survey for how well staff treat beneficiaries
- affordability (no measures proposed)
- realized Access: percentage of beneficiaries each quarter who receive LTSS from the same providers; percentage of intuitional residents who transition to the community and do or do not return to the institution; percentage of institutional residents who are referred to local coordinating agency within 10 days of requesting information on HCBS; percentage of beneficiaries who report that they usually or always receive needed social and emotional support

The National Health Law Program did not suggest specific metrics but did include recommendations on where CMS should develop metrics. Recommended metrics included:

- metrics to evaluate if needed care is being prescribed
- metrics to evaluate if provider capacity is sufficient (network adequacy)
- metrics to evaluate what proportion of prescribed hours is actually being filled
- metrics to evaluate if assessed need is being inappropriately suppressed by extraordinary and unsustainable efforts of family and friends
- methods to stratify data to identify disparities in access

NHeLP also proposed metrics related to workforce adequacy, meant to measure outcomes related to a stable, high-quality workforce:

- comparing service units authorized to those used
- average number of unique participating providers compared to claims
- number of providers licensed to practice in a geographic area
- ratio of unique recipients to unique providers by county

While several groups responded to the original RFI, it is clear that CMS continues to seek additional feedback on how best to measure access and adequacy of home and community-based services.

HCBS Access and Adequacy – Principles and Measures

Introduction

ANCOR believes that access to adequate and sufficient home and community-based services is crucial to the health and wellbeing of Medicaid enrollees with disabilities. All HCBS should be included in the access monitoring required by CMS, regardless of funding authority or financing structure. While adequate rates are a necessary component of ensuring beneficiaries have access to services, this report takes a comprehensive approach to access and sufficiency, including elements of program operation and design that impact access to services.

As CMS noted in the final rule published in November of 2015, the Supreme Court ruling in *Armstrong v. Exceptional Child Center* means that future legal challenges may not be available to supplement CMS review and enforcement of beneficiary access. We agree that CMS should strengthen its review and enforcement capabilities. Further, CMS should be sure to include that HCBS – the services at the issue in the *Armstrong* case and in much of the previous adequacy litigation – are included in access monitoring, review, and enforcement.

We would also be remiss if we did not mention one of the most pressing elements restricting access to services – waiting lists. While waiting lists are beyond the scope of this report, they remain one of the most significant barriers to service access faced by beneficiaries, with some state waiting lists now reaching thousands of beneficiaries and waiting times measured in years or decades. ANCOR encourages states to consider waiting lists as an indicator of the sufficiency of their system.

This section outlines key principles for adequacy and access to HCBS, a framework for access monitoring elements, and potential measures of access. These principles, elements, and measures should be used for current monitoring reports that include section 1915(i) and 1915(k) services and should be used in the future if CMS includes other HCBS authorities, including 1915(c) and 1115. Many of the measures are also applicable in Medicaid Managed Care states, consistent with the MMC regulations.

Principles of Access and Adequacy Standards for Home and Community-Based Services (HCBS):

- Defining adequacy of services means that available services should meet the assessed needs as detailed in the person-centered service plan of each beneficiary.
- All HCBS beneficiaries should have a choice of quality providers for every HCB service offered.
- All HCBS beneficiaries should be able to access services in a timely manner.
- HCBS should be provided in the most integrated setting for beneficiaries, consistent with the *Olmstead* decision and the Americans with Disabilities Act.
- CMS' access monitoring and adequacy standards should incorporate all HCBS in a consistent manner, in both fee-for-service and managed care environments, under both waiver and state plan authorities.
- Measuring access and adequacy should take into account HCBS workforce measures.
- CMS should ensure that states offer adequate rates to ensure a range of willing providers who are able to retain a qualified and stable workforce.

- States' Access Monitoring Review Plans should include the input of stakeholders, including families, providers, and individuals in assessing the adequacy of access to HCBS.
- Reporting on HCBS access and adequacy should disaggregate data by geography and demography, including specific information on access to services for population subgroups: people with I/DD, older adults, younger people with physical disabilities, and people with mental health diagnoses.
- Payment structures that ensure quality and value can improve adequacy, access and sufficiency; while such models may be in their infancy, as innovation occurs, states should develop new measures of these approaches.

Access and Adequacy Measurement Framework

Below we have described the essential elements ANCOR believes CMS should include in measuring the access, adequacy, and sufficiency of HCBS, including potential measures and how each element would fit into CMS' existing Access Monitoring Review Plan requirements. Proposed measures include measures from the National Core Indicators (NCI) for I/DD, NCI for the Aging & Disabled population, measures currently in use in state MLTSS programs, measures required in the Medicaid Managed Care rule that could be used in HCBS fee-for-service, and potential new measures that could be developed.

Workforce

As CMS acknowledged in the Request for Information published on November 9, 2016, the strength of the HCBS workforce has a direct impact on adequacy of and access to services. CMS should require that states incorporate review of significant economic and policy factors in the development of rate methodology and rates, including minimum wage and other state labor laws, unemployment rate, employment vacancy rates, labor regulations, and data from the Bureau of Labor Statistics[1] in Access Monitoring Review Plans. For example, a review of labor costs for direct care workers developed by the Department of Labor for the Administration on Community Living compares the wages, compensation, and annual job openings of direct care workers and personal care aides to occupations with similar entry requirements.[2] It found that direct care occupations tend to pay less than five of the eight occupations analyzed, and in most states there are multiple times the number of annual job openings in higher paid alternative occupations than in direct care occupations. These kinds of measures indicate a higher likelihood of staff turnover, which has a direct impact on quality of services. States should also include workforce metrics for factors that affect the quality of services, like caseload size for case managers, staff longevity, vacancy and no-show rates, and turnover.

Potential measures include:

- staff turnover and longevity rates
- "no show" rates
- NCI measures of Self-Determination[3]
    - proportion of people self-directing whose support workers come when they are supposed to
- NCI measures of System Performance and Service Coordination[4]

[1] For example, http://www.bls.gov/ooh/healthcare/home-health-aides.htm
[2] http://ancor.org/sites/default/files/news/labor_costs_for_direct_care_workers.pdf
[3] http://www.nationalcoreindicators.org/indicators/domain/individual-outcomes/self-determination/
[4] http://www.nationalcoreindicators.org/indicators/domain/system-performance/service-coordination/

    - proportion of people whose support workers come when they are supposed to
    - proportion of people who have met their service coordinators
    - proportion of people who report that their service coordinators call them back right away
- NCI measures on Staff Stability[5]
    - average length of service for all direct contact staff who separated in the past year and for all currently employed direct contact staff
    - the crude separation rate, defined as the proportion of direct contact staff separated in the past year
    - the vacancy rate, defined as the proportion of direct contact positions that were vacant as of a specified date
    - turnover rate, defined as the number of direct contact staff separated in the last 12 months divided by the number of direct contact staff on payroll at the end of that year
- NCI measure of System Performance and Access[6]
    - proportion of people who feel that their staff have been appropriately trained to meet their needs
- percent responding "no" to: Is it difficult for you to find attendant providers for your care? (Arizona EAZI survey)[7]
- percent responding "not very hard" to: How hard was it, overall, for you to find someone to help that you were satisfied with? (Used in evaluation of the Cash & Counseling Demonstration)[8]
- number of home health and personal care aides per 1000 people with self-care and independent living disabilities. (LTSS Scorecard)[9]
- proportion of direct support professionals that meet state-defined competencies (currently in use in NY MLTSS)
- comparison of wages, compensation, and job openings for direct care workers to those of occupations with similar entry requirements in similar geographic locations, including
    - average hourly wages
    - total compensation
    - annual job openings
    - comparison of annual openings in direct care positions to openings in higher paid occupations with similar entry requirements

Beneficiary Choice of Providers and Services

An adequate network of providers will provide true beneficiary choice regarding where and from whom to receive services. CMS should require states to include metrics in Access Monitoring Review Plans that measure the extent of beneficiary choice of HCBS providers and services, including choice of providers within discrete services.

Potential measures include:

- NCI measures of Choice and Decision-Making
    - the proportion of people who make choices about their everyday lives, including:
        - daily schedule

[5] http://www.nationalcoreindicators.org/indicators/domain/staff-stability/staff-stability/
[6] http://www.nationalcoreindicators.org/indicators/domain/system-performance/access/
[7] http://nasuad.org/hcbs/article/quality-improvement-surveys-and-training-materials-arizona
[8] http://mathematica-mpr.com/~/media/publications/PDFs/health/cashcounseling_9month.pdf
[9] http://www.longtermscorecard.org/

        - how to spend free time
        - choice of case manager/service coordinator
        - day activity
        - home
        - roommates
- NCI-AD measures[10]
    - percent responding yes to: can you make changes to your budget/services if you need to?
    - percent responding yes to: can you choose or change what kind of services you get and determine how often and when you get them?
- percent of waiver participants whose record contains documentation indicating a choice of either self-directed or agency-directed care (currently in use in Kansas MLTSS)
- percent of waiver participants whose record contains documentation indicating a choice of service providers under discrete service categories, such as residential, employment, personal care, case management
- measures from Medicaid Managed Care Rule:
    - number of providers accepting new participants
    - standards on the number of providers from which beneficiaries may choose

Adequate Rates

CMS already requires information from the public rate-setting process to be included in the Access Monitoring Review Plan, as well as additional review of any proposal to reduce rates. CMS should also include these elements for HCBS. The Access Monitoring Review Plan should include assurances that the state has set the rates consistent with the following elements:

- workforce statistics for the relevant geographic area, including unemployment rates, wages and compensation, and job openings, both for direct care workers and similar occupations, and a comparison of openings in direct care occupations to openings in higher paid occupations with similar entry requirements
- national, state, and local laws and regulations such as minimum wage and overtime requirements and occupational safety and health requirements
- requirements that the state revisit rate methodology every two years, provide a transparent and public proposal, and receive public input before finalizing the rate methodology
- involvement and encouragement of beneficiary and family participation
- prospective analysis of labor market conditions for direct care workers that includes:
    - average hourly wages, total compensation, and annual job openings
    - comparison of annual openings in direct care positions to openings in higher paid occupations with similar entry requirements

Stakeholder Engagement and Transparency

CMS already requires states to include beneficiary and provider input in the Access Monitoring Review Plan, as obtained through the public rate-setting process, medical care advisory committees, and the mechanisms for ongoing beneficiary and provider input included in the final rule. When incorporating HCBS, CMS should also include information specific to HCBS.

Potential measures include:

[10] http://nci-ad.org/

- NCI Family Indicators under Access and Support Delivery,[11] including
  - the proportion of eligible families who report having access to an adequate array of services and supports
  - the proportion of families reporting that staff or translators are available to provide information, services, and supports in the family/family member's primary language/method of communication
  - the proportion of families who report that service and support staff/providers are available and capable of meeting family needs
  - the proportion of families who report that services/supports are available when needed, even in a crisis
  - the proportion of families who report that services/supports are flexible to meet their changing needs

Disparities and Disaggregation

CMS already requires that Access Monitoring Review Plans include information on availability of care broken down by geography, provider type, and site of service. CMS should further require that plans break down data on demographic lines. This includes disaggregation by disability type – especially pulling out data on people with intellectual and developmental disabilities – and other lines along which people experience access disparities, including racial and ethnic data and access in urban and rural areas.

Potential measures include:

- measures from the Medicaid Managed Care Rule:
  - expected per capita utilization of LTSS by geographic area
  - geographic service area of providers
- measures currently in use in several state MLTSS programs:
  - percent of recipients using each service, compared by eligibility group (MN)
  - community health service utilization data for enrollees, including number of units and units per 1,000 enrollees by age group and gender categories, in the following summary categories: adult day health; home health; group adult foster care; hospice; homemaker, chore, respite and other non-medical residential support services; and personal care attendant. (MA)
  - percent of authorized units paid over time by eligibility group. (MN)

CMS already requires a separate analysis in the Access Monitoring Review Plan for several provider types outlined in the final rule at 447.203(b)(5)(ii). When including HCBS, CMS should also require states to include HCBS providers, including for discrete HCBS provider and service types.

Assessment

The first step in determining whether Medicaid programs are adequately meeting LTSS needs is to ensure that individuals' assessed needs reflect their actual needs. CMS should include measurement of the adequacy of assessment tools in Access Monitoring Review Plans as an element of "the extent to which beneficiary needs are fully met."

Potential measures could include:

[11] http://www.nationalcoreindicators.org/indicators/domain/family-indicators/access-and-support-delivery/

- proportion of beneficiaries whose assessed needs were reduced in the past year relative to the proportion of beneficiaries whose assessed needs were increased
- proportion of beneficiary appeals specifically appealing their level of assessed need
- percent responding "yes" to: Do you believe that the result of your "level of care assessment" identifies your real needs? (New Mexico Waiver Participant Quality Review)[12]
- proportion of beneficiaries who report having input into their assessment
- proportion of beneficiaries who report having the opportunity to review the outcome of their assessment

Beneficiary Experience

Measures of access and adequacy must take into account the experience of the beneficiary in accessing services. Measures should prioritize consumer choice of providers and participant-directed and person-centered services. CMS should require an outlier analysis of complaints, grievances, and appeals related to HCBS in the Access Monitoring Review Plan and investigate states or waivers with unusually high number of complaints, grievances, or appeals. While CMS may not be able to mandate thresholds like maximum lag time between authorization and utilization or maximum caseloads, outlier analysis could indicate to CMS that further investigation is required into that state, waiver, or service, including into rate-setting practices.

Potential measures include:

- measure whether states meet requirement for each person to have an option of a non-disability specific housing opportunity under the HCBS Settings rule
- HCBS Experience Survey or other valid consumer experience or quality of life survey
- measures of community tenure (length of stay in most integrated setting)
- NCI measures of Health, Welfare and Rights, including in the subdomains of
    - Safety[13]
        - the incidence of serious injuries reported among beneficiaries in the course of service provision, during the past year
        - the proportion of people who report having someone to go to for help when they feel afraid
        - the proportion of people who report that they feel safe in their home, neighborhood, workplace, and day program/other daily activity
    - Respect/Rights[14]
        - the proportion of people indicating that most staff treat them with respect
- measures from Medicaid Managed Care Rule
    - ability of providers to communicate in beneficiary's preferred language
    - measures of quality of life, rebalancing, and community integration activities required by the quality assessment and performance review program (§438.330)

Characteristics of the Population

CMS already requires states to include "the characteristics of the beneficiary population (including considerations for care, service and payment variations for pediatric and adult populations and for individuals with disabilities)" in Access Monitoring Review Plans. When including HCBS, CMS should

[12] http://nasuad.org/hcbs/article/participant-experience-survey
[13] http://www.nationalcoreindicators.org/indicators/domain/health-welfare-and-rights/safety/
[14] http://www.nationalcoreindicators.org/indicators/domain/health-welfare-and-rights/respect-rights/

require further breakdown of the population requiring HCBS, including individuals with intellectual/developmental disabilities and physical disabilities, and older people.

Potential measures include:

- measures from the Medicaid Managed Care Rule
    - expected per capita utilization of LTSS
- data on intensity and type of LTSS needed by beneficiaries

Availability of Providers and Services

Measures of access and adequacy should measure the availability of providers to serve beneficiary needs. CMS already requires the Access Monitoring Review Plan to include "availability of care through enrolled provider to beneficiaries in each geographic area, by provider type and site of service." CMS should also include this reporting for HCBS.

Potential measures include:

- average time between authorization and initiation of services.
    - time between request and assessment for services (MI)
    - time between assessment and initiation of services (MI)
- measures used in MLTSS
    - services delivered in accordance with the service plan, including the type, scope, amount, duration, and frequency specified in the plan (NY and HI)
    - percent of waiver individuals who have service plans that are adequate and appropriate to meet their needs and personal goals, as indicated in the assessment (NJ)
    - percent of survey respondents who reported receiving all services as specified in their service plan (KS)
    - the number of service hours delivered minus the number of service hours approved (DE)
- NCI measure of System Performance and Access[15]
    - the rate at which people report that they do not get the services they need in HCBS, including
        - environmental adaptations/home modifications
        - help finding/changing housing
        - help finding/changing jobs
        - respite/family support
        - service coordination/case management
- measures from the Medicaid Managed Care Rule
    - availability of services and providers and assurances of adequate capacity and services (§438.207)

Comparability to Community Standard of Access

Section 1902(a)(30)(A) requires that care and services be available at least to the same extent to which they are available to the general population in the geographic area. While there is a limited private-pay market for intellectual and developmental disabilities services, private-pay markets for personal care and home health services are growing due to the aging of the population. Medicare also has a robust home health benefit for post-acute care. If seeking a comparison group, CMS should compare Medicaid

[15] http://www.nationalcoreindicators.org/indicators/domain/system-performance/access/

HCBS access, adequacy, and provider payment rates to the private pay market and Medicare home health.

Potential measures include:

- comparison of Medicaid payment rates to other public and private payment rates within the geographic area (as currently required in the Access Monitoring Review Plan under §447.203(b)(3))

Family Caregivers

Inappropriate and unsustainable reliance on unpaid family caregivers may reveal adequacy and access problems in an HCBS system. CMS should require states to include measures of caregiver strain.

Potential measures include:

- aggregate themes and trends from the caregiver assessments required in 1915(i)
- percentage of waiver eligible beneficiaries who rely primarily on unpaid care and/or family caregivers to meet their support needs for activities of daily living/instrumental activities of daily living
- NCI Family Indicators under Family Outcomes,[16] including
    - the proportion of eligible families who feel that services and supports have helped them to better care for their family member living at home

Conclusion

Congress sought to ensure that Medicaid beneficiaries have adequate access to services by including section 1902(a)(30)(A) in the Social Security Act, and Medicaid regulations support the notion of sufficiency in order to ensure that services meet their intended purpose. Access to high-quality services is at the heart of Medicaid's role as a safety net and lifeline, and for beneficiaries with disabilities, access to home and community-based services is a crucial component of health and wellbeing. This report has outlined the legal and regulatory framework for ensuring access to HCBS, including the current CMS access monitoring and review system. It encourages CMS to include HCBS in that system by laying out ANCOR's principles for HCBS access and elements of an HCBS access framework that map to the current CMS access monitoring review plans.

[16] http://www.nationalcoreindicators.org/indicators/domain/family-indicators/family-outcomes/