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Quality Improvement for Individuals with Intellectual & Developmental Disabilities

A Proposed Framework

To date, there has been little consensus from the federal government and state Medicaid agencies around which quality measures are most appropriate for monitoring the care delivered to complex populations such as individuals with intellectual disabilities and developmental disabilities (ID/DD). Work related to consistently measuring the quality of services provided to individuals with ID/DD has been slow to develop and expand. These populations rely heavily upon unique social and health care services to meet their highly individualized needs complicating the ability to develop standard quality measures because traditional approaches do not measure for non-traditional health care services and interventions.

As states begin to analyze opportunities to transition individuals with ID/DD into Medicaid managed care, it is imperative that the federal government, states, stakeholders, beneficiaries and insurers collaborate to determine the most appropriate measures for this complex and diverse population. UnitedHealthcare Community & State, along with our National Advisory Board, has developed a quality framework which highlights a small subset of key elements that are important to begin to more meaningfully measure the quality of care provided to individuals with ID/DD. Recommended measures are intended to advance the discussion and highlight the need for more rapid agreement among key stakeholders to adopt the most appropriate measures for this population.

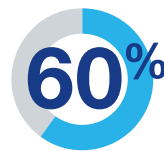
It is critical that the primary goals of any quality framework focused on services for individuals with ID/DD are to both serve the members and reduce their burden of participating in data collection. The key measurements that are highlighted in this paper were selected through a lens focused on the needs of these vulnerable populations.

We understand that there are key differences in the nature of the conditions, characteristics and needs for individuals with ID and those with DD. The care delivery model is also unique to each group. We recognize that creating a single framework for quality measurement that collectively addresses both groups will not fully address the needs of each group. However, the quality framework presented in this paper is intended for state policymakers and stakeholders to adopt in their managed care programs serving these populations. As most state programs and related waivers serving these two groups leverage a single eligibility category of individuals with ID/DD, this framework was created to be implemented within that structure. This framework can and should evolve with any programmatic changes that impact the collective eligibility designations individuals with ID and those with DD.

Unique Characteristics and Needs of Individuals with ID/DD

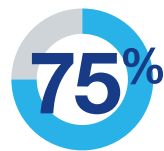
UnitedHealthcare Community & State currently serves individuals with ID/DD through managed care programs with several state partners. Serving beneficiaries in these states has provided us with insight to better understand service needs, quality of care goals and overall population characteristics.

There are nearly 5 million individuals in the US with ID/DD.¹



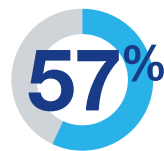
Approximately 60 percent of these individuals **rely on Medicaid** for their health insurance coverage.²

Almost **35,000 individuals** with ID/DD are in Medicaid managed care.³



Roughly 75 percent of these individuals **live in the community** either with their families, roommates, or on their own.⁴

Approximately **640,000 adults over the age of 60** have ID/DD and this number is expected to exceed **1.2 million adults in 30 years**. However, the majority of individuals with ID/DD are under the age of 60.⁵ It is important to note that many older adults have intellectual disabilities but **do not have developmental disabilities** due to brain injury, Alzheimer's or stroke acquired post age 22.



About 57 percent of individuals with ID/DD **have three or more chronic conditions**.⁶

These beneficiaries often rely on specialty providers to address multiple complex conditions and use a network of community supports to live and work in the community. The needs of individuals with ID/DD evolve as they prepare for and transition through life phases (i.e., diagnosis in childhood, adulthood, end of life planning).⁷ They also have limitations in both functioning (e.g., reasoning, learning, problem solving) and adaptive behavior (i.e., every day social and practical skills).⁸

Even though individuals with ID/DD are often discussed together as a group, there are nuances to each condition that are important to differentiate.

- Individuals with **intellectual disabilities** have impaired cognitive ability caused by injury, genetic disorder, or neurological challenges. They also have adaptive limitations such as difficulties with self-care and communication.
- Individuals with **developmental disabilities** have impaired mental, sensory, and/or physical ability and functional limitations in three or more areas (e.g., language, mobility, learning, and self-care), which likely require long-term services and supports (LTSS) or home and community-based services (HCBS).⁹ It is important to note that many people considered to have developmental disability have no cognitive impairment, often times experiencing conditions such as blindness, spinal cord injury, cerebral palsy, etc.

Because of their often-complex health needs, individuals with ID/DD have unique service utilization patterns that differ significantly from the general and Medicaid-specific populations. Among individuals with ID/DD the prevalence of a mental health diagnosis is 30 percent to 35 percent,¹⁰ significantly higher than the Medicaid enrollee population nationwide, which is approximately 20 percent.¹¹ In addition, individuals with ID/DD are more likely to become obese or develop diabetes.¹² Almost half of these individuals have three or more chronic conditions, making tracking co-occurring disabilities critical.¹³ Many individuals with ID/DD are impacted by trauma. Children with intellectual disabilities may be three to six times more likely to suffer abuse than non-disabled children and one out of three will be sexually abused before the age of 18.¹⁴

Given that their health care needs are so diverse and specific, Medicaid beneficiaries with ID/DD and their families and caregivers have developed extensive experience navigating a complex system of supports and specialty providers needed to help them live their lives. They rely on a specific team of care

providers, caregivers, HCBS and facilities (not institutions) to help them meet their needs. These health and functional needs, as well as service utilization characteristics, are important differentiators from other populations and should be considered when developing effective and appropriate ways to assess quality of life and monitor the quality of care received. Equally important as this “medical model” is the “social model”, which considers individual preferences for where to live, education, employment, recreation, and more.

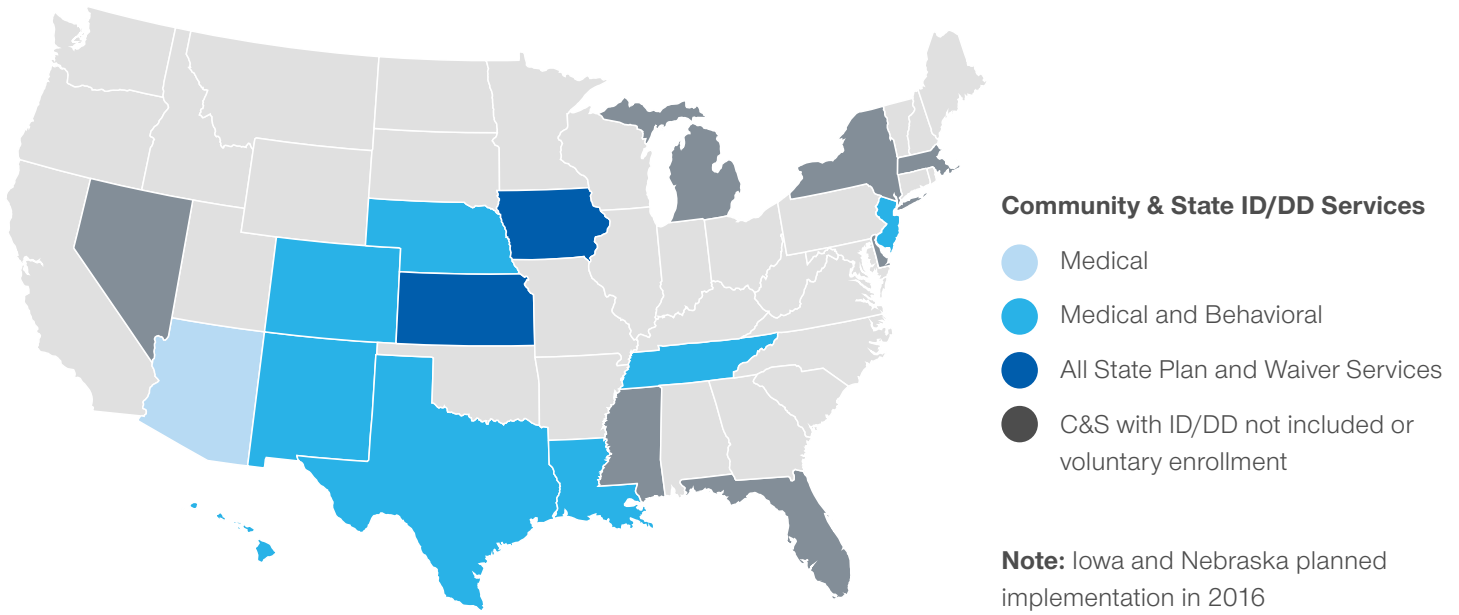
Serving Individuals with ID/DD in Managed Care Settings

Historically, Medicaid services provided to individuals with ID/DD have been delivered through fee-for-service (FFS) with little historic reliance upon managed care. The FFS delivery system poses several distinctive challenges for complex populations, such as those with ID/DD:

- Fee-for-service does not present as many rich opportunities for data collection and analysis, as compared to managed care.
- Many providers of these unique, but critical services are smaller, locally based entities that have not had the mechanisms and resources to collect and report quality data for ID/DD and other complex populations.
- The collection of quality data as a whole, in the FFS environment across all populations, is not as rigorous as that of Medicaid managed care due to the lack of comparable federal and state requirements in the FFS Medicaid environment.

Only a handful of states have truly carved-in individuals with ID/DD into Medicaid managed care for all benefits. In several states, individuals with ID/DD receive some or all of their Medicaid services through a managed care arrangement. Frequently, individuals with ID/DD receive physical health and behavioral health services within Medicaid managed care.

UnitedHealthcare Community & State manages either physical or behavioral health, and in some cases both of these benefits, for the ID/DD populations in Tennessee, New Mexico, Hawaii, Louisiana, New Jersey, Texas and soon in Nebraska (2016). Additionally, we have experience in Kansas where we manage a comprehensive set of Medicaid benefits inclusive of waiver services for individuals with ID/DD. We are preparing to implement the full set of Medicaid state plan and waiver benefits in Iowa in 2016. The following map details UnitedHealthcare Community & State ID/DD experience.



The Realities of Quality Measurement Today

While the federal government has endorsed a core set of HCBS quality metrics, they are not required for states. They are also not specific to the complex needs required for individuals with ID/DD. A separate core set of measures has been defined for Medicare-Medicaid enrollees (MMEs) participating in the Financial Alignment Demonstration, to more closely integrate care for beneficiaries navigating between these two programs; however, these measures are more focused on acute care as opposed to LTSS (key supports for the ID/DD population).

Given the lack of a consistent national approach, states are starting to pave their own way for determining how best to monitor quality of care for Medicaid beneficiaries with ID/DD. There are inherent challenges with adapting quality measures for this population beyond the lack of consensus on core measures.

- Current quality measures widely used with other Medicaid populations do not easily translate and address the more complex health care and social needs of individuals with ID/DD.
- Current Medicaid quality measures are generally focused on structure and process and are not more widely focused on individual outcomes and personal experiences, which are the basis for specialized services such as LTSS.
- Quality of life and individual experience perspectives are difficult to quantify consistently given the need to gather

data through interviews, surveys, etc. and the subjectivity involved with topics such as quality of life.

- Goals, outcomes of care, and supportive services are personalized and can mean different things to individuals with complex conditions, which makes the use of standardized metrics and tools challenging.
- Depending on the state and Medicaid program, HCBS and behavioral health services may be covered under different arrangements through either FFS, primary care case management (PCCM), or managed care. This makes data collection difficult since federal government data-collection requirements for MCOs are more robust than FFS. Data collection requirements are foundational to MCO contracts, whereas there is limited to no infrastructure for collecting quality data from providers in Medicaid FFS and PCCM.
- There are also varying degrees of coverage under Medicaid for HCBS. States have significant flexibility in determining the eligibility for individuals to be served as well as the benefits for which they are eligible. Beyond traditional, required Medicaid services, there is no defined set of core benefits that must be provided to individuals with complex conditions to ensure coverage of key support services. Additionally, in many states, waiver waitlists often result in individuals experiencing extensive wait times to receive HCBS services.

As an increasing number of states are moving away from FFS and are considering the transition of individuals with ID/DD into Medicaid managed care, there are key policy and service delivery issues that must be addressed to ensure that individuals have the most appropriate access to care in these types of settings. MCOs must adhere to Olmstead and the Americans with Disability Act (ADA) requirements to ensure that all individuals receive services in the most integrated setting. It is important that individuals have adequate access to LTSS and HCBS services that aim to preserve existing, established provider relationships in the most integrated setting. There has been increased activity by advocates, stakeholders, and industry groups over the last several years to outline how individuals can best receive the most appropriate access to care in these types of settings.

To monitor the appropriateness of care delivery and access to services, it is essential that appropriate quality metrics unique to the ID/DD population be defined and implemented.

Overview of Current Data Collection Methodologies

Despite the challenges noted above, there has been significant, targeted work to date to determine the most appropriate measures for gauging the care of complex populations that use unique services such as HCBS. While not all of these efforts are specifically geared toward ID/DD, some of them may have broad applicability with advancing quality of care discussions for this population.

- **The National Quality Forum (NQF)** has established a workgroup focused on defining a core set of measures for monitoring the quality of care delivered to individuals who are eligible for Medicare and Medicaid. While not specific to the ID/DD population, several of these measures focus on the delivery of HCBS, which are frequently used by the ID/DD population. The workgroup's final recommendations concluded earlier this year and included a defined group of core metrics that support quality of care monitoring for HCBS. CMS has not yet formally endorsed these metrics, which leaves a void for tailoring more specific individualized measures of care for individuals with ID/DD.
- CMS is working to test a **HCBS Experience of Care Survey** for Medicaid programs. The survey will ultimately receive CAHPS certification. It is geared toward state FFS and managed long-term services and supports (MLTSS) programs that serve individuals who are frail and elderly,

adults with disabilities, and individuals with ID/DD. It aims to gauge individuals' experiences (not satisfaction) with HCBS. It can be administered using a combination of phone or face-to-face interviews. Tennessee is currently participating in testing the new survey.¹⁵

A group of experts, including representatives from advocacy groups, Medicaid agencies, state associations, federal agencies, and researchers convened to provide feedback on the development and testing of the survey.¹⁶ Certain elements of the survey may prove useful in determining the effectiveness of HCBS in serving the ID/DD population. Survey domains that highlight areas of critical importance to individuals with ID/DD receiving care include the following:

- Getting needed services from personal assistant and behavioral health staff
 - How well personal assistant and behavioral health staff communicate and treat you
 - Getting needed services from homemakers
 - How well homemakers communicate and treat you
 - Your case manager
 - Choosing your services
 - Transportation
 - Personal safety
 - Community inclusion and empowerment
 - Employment
- **The CMS MR/DD Patient Experience Survey (PES)** examines various domains of an individual's environment and care. It captures feedback from individuals about the supports and services they receive through HCBS waiver services. This data can be used by states to monitor waiver programs that serve individuals with ID/DD.¹⁷ While the survey is meant to be administered to individuals with ID/DD via face-to-face contact; it has key domains that are important for framing quality measurement. The survey domains include the following:
 - Choice and control (regarding living arrangements, support staff, personal habits, case manager or support coordinator, job/day program/volunteer work)
 - Respect/dignity
 - Access to care
 - Community integration/inclusion

- **The National Core Indicator (NCI) Set** is a promising tool developed through collaboration between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Human Services Research Institute (HSRI), and more than 25 participating states. The indicators help states manage the quality of DD services and create a platform to allow state-to-state comparisons against the indicators. The NCIs focus on outcomes related to health, wellness, medications, consumer and family outcomes, and system performance outcomes. There has been recent discussion on ways to possibly integrate the NCIs into mainstream DD quality monitoring across all states.

- The Council on Quality and Leadership (CQL) created a set of **Personal Outcome Measures (POMs)** in 1991. These measures have been refined over time to capture individual quality of life outcomes and emphasize choice and self-determination. Measures are specifically geared toward individuals with disabilities and individuals with mental illness. The three key domains of the POMs include, My Self, My World, and My Dreams. Some states, such as New York, are beginning to incorporate the three domains with 21 specific POMs into their work with individuals with disabilities to ensure that services are meeting key quality of life desires and outcomes of the population.

- The State of Wisconsin uses a state-specific interview/survey tool called **PEONIES**. It is used to compare the quality of life experiences of people served by various state long-term care programs and across different target population groups including people with DD, physical disabilities, and those eligible as a result of age-related impairments. Survey data provides information on outcomes most important to individuals, the status of outcomes with regard to achievement and support, and the types and sources of supports that are needed.

PEONIES identifies outcomes in 12 distinct quality of life domains, however not all areas are equally important because members may not identify outcomes in all 12 areas.

1. I decide where and with whom I live.
2. I make decisions regarding my supports and services.
3. I decide how I spend my day.
4. I have relationships with family and friends I care about.
5. I do things that are important to me.

6. I am involved in my community.
7. My life is stable.
8. I am respected and treated fairly.
9. I have privacy.
10. I have the best possible health.
11. I feel safe.
12. I am free from abuse and neglect.

- **The Mental Health Statistics Improvement Program (MHSIP)**, developed by the Substance Abuse and Mental Health Services Administration (SAMHSA), is a 28-item consumer-satisfaction survey tool that focuses on improving the quality of life and recovery for people with mental illness. Several states use the tool to monitor the quality of services provided by state mental health agencies to consumers. Survey elements may link into behavioral health services received by individuals with ID/DD.

- **Healthy People 2020** is a science-based initiative led by the US Department of Health and Human Services with the goal of improving health for all Americans.¹⁸ Healthy People 2020 identifies the following priorities for action to address disability and health, based upon the World Health Organization principles of action for addressing health determinants and the International Classification of Functioning, Disability and Health. Although the initiative examines disability broadly, several measures address developmental disability specifically.

- Improve the conditions of daily life by:
 - Encouraging communities to be accessible so all can live in, move through, and interact with their environment
 - Encouraging community living
 - Removing barriers in the environment using both physical universal design concepts and operational policy shifts
- Address the inequitable distribution of resources among people with disabilities and those without disabilities by increasing:
 - Appropriate health care for people with disabilities
 - Education and work opportunities
 - Social participation
 - Access to needed technologies and assistive supports

Healthy People 2020 also highlights awareness of other issues for individuals with disabilities including the expansion of disability and health training opportunities for health care professionals, inclusion of the population in public health data collection across the lifespan, and inclusion of the population in health promotion activities.

- **The Patient-Centered Outcomes Research Institute (PCORI)** notes, “improving the care continuum for individuals with disabilities” as a research priority.¹⁹ PCORI is placing a specific focus on the effectiveness of interventions to improve the continuum of care for community dwelling for nonelderly adults with disabilities; interventions include access to care, care coordination, and quality of care. The independent living community closely follows this initiative.
- **The Agency for Healthcare Research and Quality (AHRQ)** notes disability as a priority population for improving health disparities through improved cultural competency.²⁰ The agency’s research focuses on both children and adults with disabilities and considers provider attitudes and training, patient intermediate outcomes (such as access barriers and perceptions of care), final health outcomes, patient-centered health outcomes (with a particular focus on mental health, substance abuse, preventive care use and medical outcomes), and negative consequences or unintended consequence of interventions.
- The **President’s Committee for People with Intellectual Disabilities** prepared a report on MLTSS which outlines recommendations in the following key areas for transitioning individuals with ID into managed care:
 - Disability stakeholder engagement
 - Choice and self-determination
 - Consumer protections and rights
 - Quality measurement, data collection, and research

The report also highlights the importance of quality measurement and monitoring activities for this population in an MLTSS environment to:

- Ensure consumer protections, identify problems, and enhance plan performance
- Provide consumers with information to make choices about plan selection

- Align payments, incentives, and penalties to meet desired goals, such as promoting options for self-direction, rebalancing, community employment, or strengthening the direct support professional workforce.”²¹

Challenges and Considerations in Selecting Measures

Disability can be viewed on a continuum, much like health. This brings about challenges requiring that quality measures and initiatives uphold a person-centered approach that considers individual needs and goals while understanding generalities are necessary to facilitate a population-specific quality program. Because of this, longitudinal data collection on quality of care is critical.

Assistant secretary Kathy Greenlee, Administration on Community Living, has noted the complexity in determining the appropriate quality measures for disability and has stated that quality should arise from the values deemed important by the individuals served. However, individuals and interested parties (i.e., advocacy groups) may advance competing initiatives and various value statements, making consensus difficult. Other challenges include the following:

- Monitoring and regulatory requirements in various states and settings affect the development of quality measures that address quality of life versus traditional provider performance (i.e., group home regulations). Policy and advocacy stakeholders note the need for a shift to quality-of-life driven quality programs for ID/DD.
- Numerous factors (e.g., age, disorder/diagnosis, co-morbid/co-occurring conditions, placement or setting, and gender) affect the specific quality measures appropriate for sub-populations within the broad ID/DD population and increase the complexity of determining and tracking the appropriate grouping or denominator for each measure. Grouping by functional needs can lessen differences and result in more direct comparisons.
- The example measure from the National Core Indicators, “of the consumers without paid jobs that do want one, what percentage has a job goal in their ISP (individual support plan),” illustrates the potential operational complexities in blending consumer perceptions of quality with performance measures. For annual performance measures, the cohort of “individuals wanting a job” could change numerous times throughout the year as consumer desires change.

Core Quality Elements and Recommendations

As an organization, UnitedHealthcare Community & State engaged the expertise of a National Advisory Board (NAB) to assist in the understanding of the special needs of the ID/DD population to determine appropriate measures to assess the quality and effectiveness of care. The NAB serves as an independent advisory council that provides input to UnitedHealthcare in actively engaging members, providers, advocacy groups, and other key stakeholders in the design and delivery system supporting individuals with special health care needs. The NAB makes recommendations, develops and champions innovations and advises on member engagement strategies that support clinical approaches. NAB is comprised of leading experts and aging and disability advocates as well as a UnitedHealthcare Community Plan member, a direct care worker, and family member of a child with special health care needs.

In 2015, NAB initiated a yearlong project to identify the subset of the most critical measures for any state monitoring the quality of services delivered to individuals with ID/DD in a managed care setting. The board surveyed the landscape of leading quality measurement tools and recommended frameworks, including the NCI, state-specific measures, and federal regulations.

It was crucial to UnitedHealthcare Community & State that the key measures ultimately identified represent the most meaningful and impactful areas for the aging and disabled

population in terms of services sought, services used, and overall quality of life including experience and perceptions ranging from relationships, independence, to meaningful employment.

The result of the board's efforts is a list of quality measures that apply to the complex needs of the individuals with ID/DD, focus on outcomes, and are immediately actionable in a managed ID/DD program. UnitedHealthcare Community & State endorses these measures as part of a strong quality framework for any state implementing managed services for the ID/DD population in its Medicaid program. National Association of Councils for Developmental Disabilities, the National Alliance for Caregiving, and the National Council on Independent Living, among other recognized national leaders in intellectual and developmental disability have endorsed our quality measurement framework.

Measures are segmented into key domains and include the existing source from which the information can be obtained:

- Health Status/Medical Care
- Community-Based Employment/Other Day Activities
- Living Independently/Choice and Decision-Making
- Service Coordination

Domain	Element/Metric	Source
Health Status / Medical Care	Emergency room visits, advocate based upon specific population	CDC ²²
	Percentage of people hospitalized for potentially preventable conditions	HEDIS
	Percent of individuals who report having a dental exam within the past six months	NCI
	How quickly individuals receive services following initial requests (critical-immediate response, urgent-72 hours, non-urgent-15 days)	State-specific
	Follow-up visit within seven days of discharge after hospitalization for mental illness	HEDIS
	Look for potentially avoidable inpatient services for psych patients by ensuring preventative out-patient services	State-specific
	Percent of participants that have a plan of care (POC) that is adequate and appropriate to address needs (including health care needs) as indicated in assessment	State-specific

Domain	Element/Metric	Source
Health Status / Medical Care	Percent of participants that have a POC that is adequate and appropriate and includes strategies to address safety risks as indicated in assessment	State-specific
	Percent of POCs that address goals as indicated in participants' assessments	State-specific
	Percent of participants that receive services as specified in the POC	State-specific
	Percent of individuals that have service plans that address functional needs during service year	State-specific
	Percent of individuals that have service plans that address health and safety risk factors during service year	State-specific
	Percent of individuals that have service plans that address personal goals during the service year	State-specific
	Percent of sample participants that receive services in the type, scope, and frequency identified in service plan	State-specific
Community-Based Employment /Other Day Activities	Number of individuals who are working at minimum wage or above	State-specific
	Percentage of people with developmental or physical disabilities, or with significant mental health treatment needs, that maintain competitive and integrated employment over a personally significant period of time	State-specific
	Individuals participated in an unpaid activity in a community-based setting during the past month, if appropriate given the capacity of the consumer. (Flexibility with services so that personal attendant can take the individual out for socialization and/or help connect with community group) Needs to align with POC	State-specific
Living Independently / Choice and	Chose where they live	NCI
	Chose whom they live with – to the extent that it impacts their safety	NCI
Decision-Making	Chose who helps them at home	NCI
	People choose personal goals	POM
	People realize personal goals	POM
	Had access to transportation when they needed it	NCI
	Received needed services, including access to care managers when needed	NCI
	People paid to help person at home are respectful	NCI
	People paid to help person at day program are respectful	NCI
	People paid to help person with transportation are respectful	NCI
	Participated in self-advocacy	NCI
	Wanted to participate in self-advocacy	NCI
	People experience continuity and security	POM

Domain	Element/Metric	Source
Service Coordination	Service coordinator is accessible	NCI
	Person met or could name their case manager or service coordinator	NCI
	Person could talk to their case manager or service coordinator when needed	NCI
	Service coordinator is responsive	NCI
	When person asked, case manager or service coordinator got person what they needed	NCI
	Person got special equipment or home modification after talking to service coordinator	NCI
	Service coordinator supports the person's participation in planning their services	NCI
	Case manager or service coordinator asked about the person's preferences	NCI
	Services and supports addressed health and well being	NCI
	Services and supports helped people achieve their personal goals	NCI
	Information about services, including consumer-directed services, is available	NCI
	In the last six months, how often did your providers give you all the information you wanted about your health?	State-specific
	In the last six months, how often did your providers encourage you to talk about all your health questions or concerns?	State-specific
	In the last six months, how often did your providers ask you to describe how you were going to follow instructions?	State-specific
	In the last six months, how often were instructions about how to take your medicines easy to understand?	State-specific

A Call to Action for States, Advocates, and Consumers

This paper has laid out the challenges states and health plans face in implementing a strong, consistent quality framework for managing the services for individuals with ID/DD. As noted above, due to these challenges, there is currently no consistent, national approach for quality measurement for these types of programs.

As a result, frameworks used across states are inconsistent and disjointed, making it challenging to measure quality across state lines and to identify opportunities for programmatic or delivery improvement to ultimately improve outcomes for the ID/DD population. Additionally, because the metrics and

frameworks deployed often evolve from procurement to procurement, measuring quality longitudinally is also a challenge.

As more states move toward managing the benefits for individuals with ID/DD within Medicaid managed care arrangements, it has become crucial that states begin to measure quality consistently across their programs. We are encouraging states to adopt a nationally endorsed baseline framework of quality metrics for long-term services and supports. Of critical importance is ensuring that the metrics states adopt focus on outcomes and include measures that

states, health plans, and stakeholders can track to identify areas to improve quality of care and experience. The measures recommended by the NAB and endorsed by UnitedHealthcare Community & State provide an expertly vetted, person-centered, outcomes-focused, comprehensive baseline for a quality framework that can be used by all states administering a managed care program for individuals with ID/DD. Furthermore, these recommended metrics reflect areas that can and should be influenced and supported by managed care organizations to improve the lives of the individuals they serve and carefully omits metrics for which managed care organizations would have limited to no ability to effectively influence.

By implementing this quality framework, states are better positioned to:

- Measure progress on outcomes that matter most to individuals served in such programs
- Ground policy and program design decisions in data
- Compare the state's program to other states and national trends

If multiple states implement the same baseline framework and measures, nationally all stakeholders will experience a greater understanding of the impacts of delivery system and benefit design considerations and their impacts on outcomes.

States

States interested in progressing toward advance accountability, evidence-based decision making, and quality should consider taking the following steps:

- Review the framework and determine what, if any, steps need to be made to implement the quality framework.
- Share with stakeholders the rationale for a consistent quality framework.
- Work with the local provider, health plan, consumer, and advocacy communities to evaluate any state-specific measures that the state should track in addition to (not in lieu of) the baseline framework.
- In upcoming requests for proposals, require that bidding health plans leverage a specific set of universal quality measures as a condition for being selected as a plan to manage the services for individuals with ID/DD.

Advocates

Organizations and individuals advocating for quality, person-centered care for individuals with ID/DD are critical partners in advancing progress toward consistent, outcomes-focused quality measurement. Advocates invested in this effort should consider taking the following steps:

- Leverage your organization's platforms to publicize the challenges caused by inconsistent quality measurement and endorse this quality framework as the first step toward consistency and accountability in decision-making for managed ID/DD programs.
- Launch letter-writing campaigns, author op-eds, and conduct other outreach to state and federal officials to encourage adoption of a consistent quality framework across states.
- Encourage partner organizations to join the effort to advance the quality framework.
- Work with the local provider, health plan, and consumer communities to evaluate any state-specific measures that a specific state should track in addition to (not in lieu of) the baseline framework.

Consumers

Individuals with ID/DD, as well as their family members and caregivers, are vital to the advancement of a consistent quality framework for managed ID/DD programs across states.

Lending your voices to this effort provides policymakers with the understanding of how an outcomes-based, person-centered quality framework directly impacts the quality of ID/DD services. Consumers interested in advancing this effort should consider the following steps:

- Reach out to state officials, through letters or calls to state offices, outlining the challenges posed to individuals with ID/DD and the critical need for a consistent framework to improve quality of care provided within MLTSS programs.
- Actively participate in public meetings regarding ID/DD services or Medicaid, advancing the call to state leaders to adopt the consistent quality framework.
- Encourage members of your community to join the effort to advance the quality framework.
- Select an advocacy organization in which to join and become an active participant.

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- ²⁰ Agency for Healthcare Quality and Research: Improving Cultural Competency to Reduce Health Disparities in Priority Populations. Jul 8 2014.
- ²¹ Managed Long-Term Services and Supports. 2012 Report to the President. President's Committee for People with Intellectual Disabilities.
- ²² US Surveillance of Health of People with Intellectual Disabilities. A White Paper. CDC. National Center on Birth Defects and Developmental Disabilities (NCBDDD) Health Surveillance Work Group. September 2009.

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