

POLICY APPROACHES TO  
ADVANCING PERSON-CENTERED  
OUTCOME MEASUREMENT

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## **Executive Summary**

Quality of care for people with complex needs begins with a person-centered assessment and care planning process that addresses what is most important to the individual. Better integration can improve care for people with complex needs, but failure to rigorously measure quality could result in cost savings at the expense of quality.

People with complex needs—such as older adults with multiple chronic conditions and functional limitations as well as persons with physical, intellectual or developmental disabilities and/or severe and persistent mental illness—often require combinations of medical care, behavioral health care and long-term services and supports (LTSS). There is broad agreement that person-centered, goal-based, integrated care has the potential to improve health outcomes and reduce the cost of caring for people with complex needs. Quality measurement in health care has long been used to drive improvement and provide accountability of the health care system to consumers and payers. However, quality measures assessing person-centered outcomes are lacking. Our case studies of nine sites shed light on opportunities and barriers to advance person-centered, goal-based care and outcome measurement. The aim of this policy brief is to present our case study findings and policy recommendations for developing the infrastructure necessary to deliver and measure person-centered, goal-based, integrated care to people with complex needs.

***Recommendation 1: Develop and implement models of care that incorporate individuals' goals and preferences in care plans.***

***Recommendation 2: Require organizations responsible for arranging LTSS to demonstrate their capability to provide person-centered, integrated care.***

***Recommendation 3: Explore avenues to eliminate barriers to integration and facilitate collaborative assessment and care planning across disciplines, specialties and care settings.***

***Recommendation 4: Support the development, testing and implementation of quality measures that reflect what is most important to people.***

## Background and Rationale

People with complex needs require a variety of services from multiple providers and care systems. The financing of these services is fragmented, and care and services are often delivered in silos, each functioning well within its specialized sphere, but failing to address the needs of the whole person. Medicare is the primary payer for acute care services for people over 65 and for working-aged people with qualifying disabilities. Behavioral health care for people with severe mental illness is largely paid for by Medicaid. Medicaid is the single largest payer of LTSS, but the specific services covered vary by state. Navigating the maze of services is difficult and can result in suboptimal outcomes and excess expense.

The Affordable Care Act (ACA) and other policy initiatives encourage provision of integrated care in community-based settings to improve health outcomes and reduce the cost of caring for people with complex needs. The Centers for Medicare & Medicaid Services (CMS) has undertaken numerous demonstration projects in an effort to reform and rationalize health care delivery from a system that rewards volume to one that rewards value. States are increasingly moving their complex Medicaid beneficiaries into managed care plans to better control costs and improve quality. Using various waiver authorities and CMS demonstration funding, states are attempting to reduce fragmentation and improve outcomes through integrated care programs emphasizing person-centered, continuous, coordinated and comprehensive care<sup>i</sup>. Models of integrated care include Accountable Care Organizations (ACOs), Comprehensive Managed Care Organizations that provide both medical care and LTSS, Health Homes and Programs for All-Inclusive Care (PACE). Our ability to evaluate the impact of these models is limited<sup>ii iii iv</sup>. In order to effectively implement value-based payment systems, measures of quality and value *relevant to these high-need individuals* are needed. Our case study was intended to inform the development of person-centered, goal-based outcome measures by learning how person-centered care is organized, delivered and integrated, how such care is documented and how it might be measured.

### Cost Drivers

People with complex needs account for the vast majority of health care expenditures in both Medicaid and Medicare. As 19% of the Medicare population, people with dual eligibility represented 34% of aggregate Medicare FFS spending in 2010<sup>v</sup>.

As the population ages and people live longer, this trend is expected to increase. Data show that the cost of care for people with one or more chronic conditions is significantly higher when combined with functional limitations that limit independence<sup>vi</sup>.

- **Multiple chronic conditions:** More than one in four Americans have multiple, concurrent chronic illnesses—conditions lasting a year or more that require ongoing medical attention and/or limit activities of daily living. Per capita spending for Medicare beneficiaries increases with the number of chronic conditions. Beneficiaries with six or more chronic conditions cost 16 times more than beneficiaries with one or no chronic conditions.<sup>vii</sup>
- **Severe mental illness:** Severe mental illnesses are treatable disorders of the brain that include schizophrenia, bipolar disorder and major depression. Mental illness is among the five most costly conditions overall.<sup>viii</sup> The Medicaid Institute at the United Hospital Fund reported that health care spending for Medicaid beneficiaries with mental illness was double that for beneficiaries without mental illness<sup>x</sup>.
- **Disabilities:** People with physical, intellectual or developmental disabilities experience limitations in such activities as bathing, walking, doing basic chores and working. People with chronic conditions in combination with one or more functional limitations experience significantly higher total health care costs than people without functional limitations<sup>x</sup>.

## Quality Drivers

People with complex needs are often poorly served by the specialized health care system that treats one body system at a time. In the United States, people with complex needs are at higher risk for being in poor health, having inadequate access to health care, and experiencing worse health outcomes than other groups<sup>xi,xii</sup>. Fragmented health care delivery is especially problematic for people with complex needs who require medical, behavioral and supportive services to complete activities of daily living (ADL) and instrumental activities of daily living (IADL).

Multiple studies have shown that the number of conditions an individual has directly affects the risk of adverse outcomes including mortality, poor functional status, unnecessary hospitalizations and adverse drug events.<sup>xiii</sup> People with mental illness die 15-25 years earlier than the general population. While suicide is an important cause of death, most premature deaths are due to preventable and treatable medical conditions, led by cardiovascular disease<sup>xiv xv</sup>.

In addition to the variety of causes of their complex needs, people have different preferences for their health and health care. Recently, policy makers and the public alike, have noticed the ways the fragmented health care system fails people with complex needs<sup>xvi xvii xviii xix xx</sup>. Policy makers have focused more on reforms that elevate the individual and their preferences in shaping their care<sup>xxi</sup>, and research across several clinical conditions and populations shows the value and importance of engaging individuals in their care, increasing their autonomy and self-efficacy<sup>xxii</sup>.

## **Case Study Findings**

We visited nine sites that provide various combinations of medical care, behavioral health care and LTSS to people with a variety of complex needs. We observed assessment and care-planning meetings, we interviewed individuals, care managers and organizational leaders, and we reviewed documented care plans. Our findings, summarized here, have implications for quality measurement.

### ***Person-centered care depends on knowing what is most important to people, yet discussion of goals is variable.***

For a care plan and the care it supports to effectively address peoples' priorities, it must capture and document those priorities. However, the processes used for assessment and care planning do not consistently elicit peoples' goals. While care managers commonly use the assessment as a jumping-off point for identifying goals, we observed a variety of approaches to setting goals across sites. For example, at one site, care managers emphasize the individual as the expert who should determine the goal, whereas at another site a care manager described the need to coax people to set more ambitious goals than they initially articulate, reflecting the care manager's priorities to promote well-being. Across sites, documented goals range in breadth. Some goals are broad in focus while others are narrowly tied to problems identified in the assessment.

### ***When discussed, peoples' goals are often not reflected in the documentation, and when captured, the documentation is not sufficient to measure attainment of the goals that people say are most important.***

We initially visited eight sites that had experience providing integrated care to people with complex needs. Of the eight, only two both discussed and documented peoples' goals in their care plans. Other sites documented interventions and services planned, but did not capture peoples' goals. Among sites that routinely document goals in the care plan, we observed a wide variety of goals, but goals most often fell into the categories of

service/care and health and wellness. By contrast, interviews with individuals yielded goals that more often related to lifestyle, such as physical activity or maintaining independence.

***Care is often still delivered in silos, with medical, behavioral and LTSS systems operating independently. Coordination, when it occurs, is idiosyncratic and depends on the efforts of the care coordination/manager, to communicate with all relevant parties and to arrange for information to flow.***

All sites described the use of interdisciplinary care teams. In some cases, the teams were comprised of a registered nurse and social worker, but in most cases, at least for routine care planning, these “teams” were comprised of a care manager (usually a nurse or social worker) in concert with the individual, and consulting individually with physicians and other service providers. Case conferences might be convened to address special circumstances, for example, when an individual’s clinical and social circumstances are particularly complex, or when an individual is hospitalized and multiple disciplines are needed to affect a successful discharge to the community. Few of the case study sites use a single, shared care plan among the various members of the care team. In most cases, a care manager develops an LTSS plan, while other members of the care team develop their own treatment or service plans. Care managers and others readily acknowledged redundancy in assessment and care planning, and often justified it. They said that the assessment process was important in establishing a relationship with the individual, things could have changed since the other assessment was conducted and different assessors were unreliable. They also told us that payment policies required each discipline to conduct its own assessment.

## **Discussion**

People with complex needs account for a disproportionate share of health care spending, and they are not well served by a health care system that is designed to address episodic, acute care needs. Increasingly, states are moving these individuals into managed care. At its best, managed care offers the promise of delivering person-centered care by integrating medical care, behavioral health care and LTSS across providers and settings. At its worst, it could disrupt longstanding relationships (e.g. if individuals’ existing providers are not part of the managed care plan’s network) and create additional barriers to obtaining needed care (e.g., through gatekeeping or coverage restrictions), or “medicalize” the social and functional support systems that people rely on to maintain independence. Our research demonstrates the need to improve organizational capacity to integrate person-centered, goal-based care and to build patient-centered outcome measures.

There is critical need for better quality oversight of organizations responsible for LTSS. Many health plans newly responsible for LTSS are inexperienced with directly providing or coordinating LTSS, and they are unfamiliar with the community based organizations (CBOs) that have been core to organizing and delivering LTSS prior to its move into managed care<sup>xxiii</sup>. CBOs, such as Area Agencies on Aging, Centers for Independent Living, Aging and Disability Resource Centers and local LTSS providers are often small and have limited business experience. As a result, many are not equipped to contract with large managed care plans, particularly on a risk basis. Federal and foundation efforts are under way to support CBOs in making this transition<sup>xxiv xxv</sup>.

Some states have begun to require NCQA Accreditation of their managed LTSS or Medicare-Medicaid health plans. NCQA has also been approached by CBOs asking for an accreditation program to help them demonstrate to health plans their readiness to provide LTSS coordination. While accreditation is a valuable step, accountability does not stop there. Structure, process and outcome measures form a comprehensive approach for assessing organization performance. Accreditation programs typically encompass structure measures, which are important building blocks for quality; they describe the infrastructure and processes needed to support high quality care and to generate the data needed for quality measurement.

Quality measures are also needed to ensure that effective care is systematically provided. Quality measures provide the transparency and accountability to drive change in practice. There are examples, such as the use of Beta blockers after a heart attack, where the introduction of a publically reported quality measure led to improvement in practice and outcomes for patients<sup>xxvi</sup>.

Existing quality measures do not effectively evaluate care for people with LTSS needs because they generally focus on single diseases and do not address the outcomes that are most important to this complex population.

However, outcome measures are challenging in such a heterogeneous population where the best possible care may only help slow an individual's decline. Furthermore, outcome measurement requires that providers and health systems validly and reliably collect and document the data necessary for such measurement.

Thus, as we prepare for the growing number of older adults with LTSS needs and remake our health care system to focus on accountability, there is an urgent need to develop a new comprehensive set of quality measures that guide us to the infrastructure we need and help us see whether we are doing right by these high-need individuals.

#### How to Support Model Development

*CMS, states and philanthropies can help by organizing and funding demonstrations of alternative approaches to embedding individuals' goals into their care plans. Demonstration projects can explore the timing, personnel and techniques that are most effective in eliciting individuals' goals and preferences, and in documenting them for others involved in the individuals' care.*

#### Recommendations

Below we offer a set of policy recommendations to create the conditions needed to develop and implement measures of person-centered, goal-based care.

***Recommendation 1: Develop and implement models of care that incorporate individuals' goals and preferences in care plans.***

Assessment and care planning processes must include a full discussion of peoples' goals. CMS' 2013 Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs<sup>xxvii</sup> suggests states require the use of common assessment instruments that capture personal goals and preferences, and the recent notice of proposed rulemaking (NPRM) carries forward the principle of person-centered processes in assessment and care planning. Models need to be developed for holding these discussions and for documenting the resulting goals in such a way that care plan interventions can be clearly tied to outcomes that individuals prioritize. New models are needed to ensure that person-centered assessment and care planning processes include effective goal-setting discussions and documentation of what individuals identify as their priorities and preferences.

***Recommendation 2: Require organizations responsible for arranging LTSS to demonstrate their capability to provide person-centered, integrated care.***

Managed care plans, ACOs, CBOs and others that assume responsibility for planning and organizing the LTSS for individuals should be required to demonstrate their capacity to provide person-centered, integrated care. These organizations should have the infrastructure needed to plan and organize such care, and they should be able to demonstrate their capabilities.

Several accreditation programs are widely relied upon to indicate organizations' competence at delivering health care services in various environments<sup>xxviii xxix xxx xxxi xxxii</sup>. However, none of these accreditation programs addresses the issues of person-centered, integrated care for people who need LTSS in the context of a comprehensive health care system. Several states and organizations responsible for LTSS are looking to NCQA Accreditation despite its lack of specificity to LTSS or medical-LTSS coordination issues. This is a key gap in accountability and in support for organizations that need to develop and improve their programs.

NCQA is updating its accreditation standards for health plans and case management organizations, to specifically address the structures and processes needed to better integrate care for people with complex needs and to make it more person-centered. These standards will also guide implementation of the infrastructure needed for person-centered outcome measures. With the support of [The SCAN Foundation](#) and the John A. Hartford Foundation, NCQA plans to pilot the updated standards in a learning collaborative comprised of health plans and CBOs. Additional support is needed for widespread implementation.

***Recommendation 3: Explore avenues to eliminate barriers to integration and facilitate collaborative assessment and care planning across disciplines, specialties and care settings.***

This can be done by clarifying accountability for “whole-person” care planning, and building information flows that support collaboration in care planning and interventions to support individuals' goals and preferences. When there are multiple assessments and care plans, each maintained by separate providers, it is difficult to determine which is the appropriate source and the “true north” reflecting the individual's goals. Payment policies requiring assessments could be modified to allow providers to use current assessments conducted by others. A standardized, comprehensive, modular assessment could be used to facilitate cross-discipline sharing. CMS' Testing Experience and Functional Tools (TEFT) program aims to test a common assessment instrument. Concurrently, the Office of the National Coordinator for Health Information Technology (ONC) convenes a public-private collaboration to develop a Standards and Interoperability Framework for the exchange of electronic health information across the health care continuum, including for long-term care coordination. These efforts may provide valuable information about how to streamline the assessment process. This work is being done in PACE plans, duals demonstrations and various isolated pockets, but barriers remain.

**How to Support Organizational Accountability**

*CMS, states and consumers can help to guide the development of independent evaluation programs by commenting on draft standards, and CMS and states can promote implementation through regulatory and purchasing decisions.*

**Recommendation 4: Support the development, testing and implementation of quality measures that reflect what is most important to people.**

Structural requirements, such as accreditation standards, are not sufficient. To drive transformation in health care delivery, structural requirements must be broadly implemented and complemented by a set of quality measures. While methods for delivering person-centered, integrated care are still evolving, quality measures are indispensable for quality improvement. As evidence about best practices emerges, quality measures can be implemented in accountability systems, such as public reporting and value-based payment systems.

New quality measures are needed that go beyond adherence to guideline-based care and outcomes for individual diseases. For people with multiple, complex needs, the success of the health care system may best be measured in relation to their individual outcome goals. Measurement depends on the availability of data. The best source of data about goals and goal attainment come from the assessment process, but only if goals are documented. While various approaches to goal-setting have been used in health care, this is a relatively new and untried approach to quality measurement. NCQA plans to develop and test person-driven outcome measurement embedded in a goal setting and monitoring framework. This measure development work, funded by The SCAN Foundation and the John A. Hartford Foundation, involves designing and testing the workflows needed to assess, document and use individuals' goals for care planning, monitoring and for quality measurement. Once this process has been designed, its feasibility and value must be demonstrated in a variety of organizational settings.

As the health care delivery system becomes increasingly accountable through the expansion of value-based purchasing, payment incentives will play a more important part in driving change. Thus, stakeholders including consumers, researchers, providers, policy makers and purchasers need to work together to ensure incentives are aligned to better address the needs of health care consumers with complex conditions. New quality measures are needed to assess both the infrastructure required to provide person-centered, integrated care, and the effectiveness of that care in helping people to attain their goals.

**How to Support Development of Measures of Goal-Based Care**

CMS, states, researchers and philanthropic organizations can help by collaborating in a larger demonstration of the resulting workflows and quality measures. CMS and states can promote implementation of the measures through regulatory and purchasing decisions.

**How to Facilitate Collaborative Assessment and Care Planning**

CMS can help by identifying and changing payment policies that promote fragmentation. CMS, states and philanthropies can help by convening community-based efforts to organize and integrate multi-disciplinary assessment and care planning processes, and supporting these efforts through health information exchange that includes LTSS and social services.



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*The SCAN Foundation—advancing a coordinated and easily navigated system of high-quality services for older adults that preserve dignity and independence. For more information, visit [www.TheSCANFoundation.org](http://www.TheSCANFoundation.org).*

*The John A. Hartford Foundation, based in New York City, is a private, nonpartisan philanthropy dedicated to improving the care of older adults. For more information, please visit [www.jhartfound.org](http://www.jhartfound.org).*



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