

What Matters Most: Essential Attributes of a High-Quality System of Care for Adults with Complex Care Needs (Full Report)

*The SCAN Foundation thanks the Alliance for Health Reform,
specifically Sarah Dash, Kelly Appenzeller, and Katie Rubinger.*

*The SCAN Foundation also thanks Health Management Associates,
specifically Sarah Barth and Kristan McIntosh.*

[The Alliance for Health Reform](#) is an independent not-for-profit organization that facilitated the working group process.

[Health Management Associates](#) is an independent, national research, and consulting firm in the health care industry that provided technical assistance and drafted the working group products.

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INTRODUCTION

Currently, adults with complex care needs are often served by a number of providers and systems that do not talk to each other or coordinate efforts, making it difficult for individuals to receive high-quality care. Efforts to transform delivery systems and associated quality measurements for this vulnerable population are also fragmented across multiple organizations and institutions, as well as state and federal governments.*

As various health systems move toward streamlining services and care for adults with complex care needs, a number of critical goals must be met. The individuals served and their family/caregivers must be at the center of system evolution. Delivery systems must work together as a simplified, easy to navigate, cohesive whole. Health care and supportive services should be tailored to each individual's unique circumstances, preferences, and goals for living a full and meaningful life. Health and well-being, including living independently, are essential and need to encompass the social, non-medical components of home- and community-based services.† Quality measurement across payers and delivery systems needs to capture the effectiveness of services that help with function, independence, and assure the receipt of necessary and desired supportive services in the least restrictive setting possible.

In pursuit of these goals, The SCAN Foundation (Foundation) convened a working group of diverse experts representing the interests of adults with complex care needs. Federal officials working on relevant programs participated as ex-officio members, as did representatives from other foundations with related interests. (*See Appendix A – Working Group and Ex-Officio Participant List*)

Multiple frameworks exist or are in development, but there is currently no single statement of what a delivery system must have to effectively serve adults with complex care needs. The working group

The goal of the working group was to develop consensus on the Essential Attributes of a high-quality system of care that supports system transformation and evaluation, and is from the vantage point of adults with complex care needs.

* Efforts to align delivery systems, for example, Medicaid and Medicare, have been in the form of federal-state demonstrations such as the Financial Alignment Demonstrations, state innovation projects, and individual state efforts to build delivery system integration platforms.

† Home- and community-based services include: homemaker/home health aide/personal care; adult day health; home-delivered meals; habilitation; supported employment support; respite; day treatment/partial hospitalization; psychosocial rehabilitation; transportation; extended home health and supported housing.

recognized the need to address this gap and identify what matters most for quality systems supporting this vulnerable population. Through a consensus process, the group developed an overarching goal statement:

Individuals are able to live their lives with services and supports reflecting their values and preferences in the least restrictive, most independent setting possible with access to a delivery system that respects and supports their choices and decisions.

The working group also developed four Essential Attributes of a high-quality system of care that supports system transformation and evaluation, as well as core elements in the functioning of such a system. These Essential Attributes build on a large body of existing expert frameworks and are intended to help guide future efforts to transform delivery systems and develop quality measures capturing individuals' goals, preferences, and desired outcomes.

The Essential Attributes aim to inform and support the diverse array of stakeholders working to improve care for adults with complex care needs. These include the individual, their family/caregivers, quality measurement organizations, state and federal policymakers and organizations, advocacy and consumer groups, service providers, health plans and delivery systems, and others that are part of and have an interest in health care and long-term services and supports (LTSS) delivery systems for this population.

At the outset, the working group recognized several issues and concerns. The group identified the need to address the structure of health care, LTSS, and social service delivery systems in order to comprehensively provide quality support. There was consensus that fragmented systems and funding streams need to be seamless, offering flexibility in benefit design so that those with complex care needs can have those needs met by a quality system designed around the individual. The group highlighted that family/caregivers are major providers of LTSS to individuals with complex care needs, and therefore delivery systems should acknowledge their unique role while assessing and addressing their needs with appropriate information, training, respite care, and other supportive services tailored to their values and preferences.

However, while the working group recognized that adults with complex care needs belong to many distinct subpopulations, this paper does not define these subpopulations. Instead, it identifies what matters most to individuals and their family/caregivers: the Essential Attributes of a high-quality system. In addition, while the group realized that resources and sustainability (including the ability of delivery systems to be discerning in how they deploy available resources) are important, these issues were not the focus of this effort, since other public- and private-sector entities are currently addressing them through other initiatives.

METHODOLOGY

Project Components and Working Group

This project consisted of three main components. First, a comprehensive literature review was conducted, in which the large body of ongoing work by many organizations, collaborations, and governments was examined, and quality frameworks and measurements for serving people with complex care needs were identified (along with related gray literature).[‡] Next, three meetings of the working group were held, with ex-officio members participating. In addition, individual interviews with all working group members and selected ex-officio members were conducted.

Table 1: Papers Contained in Abbreviated Literature Review of Existing Frameworks (Appendix B)[¶]

Organization	Paper Title	Year
AARP Public Policy Institute	Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers	2014
American Geriatrics Society	Person-Centered Care: A Definition and Essential Elements	2015
Center for Health Care Strategies (CHCS)	Opportunities to Improve Models of Care for People with Complex Needs	2015
Centers for Medicare & Medicaid Services (CMS)	Medicare-Medicaid Plan Quality Ratings Strategy	2015
CMS	CMS Quality Strategy	2013
Long Term Quality Alliance (LTQA)	Measurement Opportunities & Gaps: Transitional Care Processes and Outcomes Among Adult Recipients of Long-Term Services and Supports	2011
National Association of States United for Aging and Disabilities (NASUAD)	National Core Indicators—Aging and Disabilities	2015
National Committee for Quality Assurance (NCQA)	Integrated Care for People with Medicare and Medicaid: A Roadmap for Quality	2013
National Quality Forum (NQF)	Multiple Chronic Conditions Measurement Framework: Final Report	2012
NQF	Person- and Family-Centered Care: Final Report - Phase I	2015
NQF	Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps in Person-Centered Care and Outcomes	2014
Substance Abuse and Mental Health Services Administration (SAMHSA)	National Behavioral Health Quality Framework	2014
U.S. Department of Health and Human Services (U.S.HHS)	Multiple Chronic Conditions (MCC): A Strategic Framework	2013
U.S. HHS	National Strategy for Quality Improvement in Health Care	2015

[‡] The comprehensive literature review included 79 publications.

[¶] The working group identified the Essential Attributes by referencing the content contained in the comprehensive literature review and extensive group discussions.

The working group drew program and quality expertise from quality measurement organizations, state governments, and consumer advocates, and there was representation of health plans. A selection of leaders from the federal government and health care foundations, serving as ex-officio members, provided input into the working group process and product. The Foundation also commissioned expert facilitation and technical assistance from the Alliance for Health Reform and Health Management Associates.

Process

The literature review, working group consensus process, and interviews identified existing definitions of “complex needs populations” and other terms used by state and federal governments for publicly financed health care as well as by health care institutions, health plans, and consumer organizations. Review of “person-centered care,” “family-centered care,” and “quality of life” definitions informed the working group effort to focus on individuals with complex needs and their goals, preferences, and choices.

The literature review and interviews identified the importance of developing and formalizing approaches to considering the needs of family/caregivers as essential people who support and self-activate adults with complex care needs. Family members/caregivers enable such individuals to remain stable and connected to community, family, and friends. Support for family/caregivers is now recognized as a key component of a high-performing LTSS system. Further review and discussion emphasized identifying the social determinants of health (e.g., housing, transportation, income, health literacy, nutrition) and the role and responsibility of the health care system in addressing them. Utilizing all of this rich content through an iterative process, the working group articulated the Essential Attributes.

“In an ideal system, flexibility in benefit design, not just methods of service delivery, makes services available to people with complex needs that are dictated by the needs of each individual.”

-Tim Engelhardt
Ex-Officio Member

Existing Definitions of Adults with Complex Needs

Various definitions of adults with complex needs are employed and applied differently across contexts. Table 2 provides selected definitions in use today and shows their variability. For articulating the Essential Attributes, the working group considered all of these to create a single definition of adults with complex care needs.

Table 2: Selected Definitions of Adults with Complex Needs

Organization	Definition
CHCS ¹	Individuals with complex needs often face multiple medical, behavioral health, and social challenges, which contribute to their largely ineffective and costly interactions with the health care system. Patients with complex physical and behavioral health needs typically require more intensive, ongoing treatment models than the fragmented care available in emergency department and primary care settings.
The Commonwealth Fund ²	<p>Individuals with complex health needs:</p> <ul style="list-style-type: none"> • Account for a disproportionate share of health care spending or may be at risk of incurring high spending in the near future; • Typically suffer from multiple chronic health conditions and/or functional limitations; • Have health care needs that may be exacerbated by unmet social needs; and • Are often poorly served by current health care delivery and financing arrangements that fail to adequately coordinate care across different service providers and care settings.
NQF ³	Persons with multiple chronic conditions are defined as having two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex health care management, decision-making, or coordination.
Robert Wood Johnson Foundation ⁴	High utilizers are patients with many chronic conditions who require more care than most patients and thus consume a higher proportion of total costs. Super-utilizers are high-cost health care users with complex health and social issues who have high rates of emergency department use and hospitalization. They may be divided into several different categories—from patients with chronic conditions to those who struggle with behavioral health needs that impede their ability to engage in self-care, to frail elderly patients.

ESSENTIAL ATTRIBUTES OF A HIGH-QUALITY SYSTEM FOR ADULTS WITH COMPLEX CARE NEEDS

The working group articulated four Essential Attributes of a high-quality delivery system serving and supporting adults with complex care needs. Collectively, these Essential Attributes represent the milestones that, when regularly monitored and measured, can track progress toward the overarching goal. They are intended to help guide future efforts to transform delivery systems and develop quality measures that capture individuals' goals, preferences, and desired outcomes. Figure 1 (see page 10) depicts the connected continuum of the four Essential Attributes around the individual and the care and supports they receive. Key definitions precede Figure 1 and the detailed elements of each Essential Attribute.⁵

Key Definitions

The following two definitions were developed to guide the working group consensus process:

- Adults with complex care needs: Individuals having two or more mental and/or physical chronic conditions, and additional functional limitations that collectively have an effect on health status and quality of life.
- Essential Attribute: A feature regarded as a characteristic or inherent part of care delivery by providers serving adults with complex care needs, which affects its success or failure.

Below are definitions for terms used in Figure 1, which are drawn from existing sources:

- Behavioral health care: Refers to services that encompass prevention and promotion of emotional health; prevention of mental and substance use disorders, substance use, and related problems; treatments and services for mental and substance use disorders; and recovery support.⁶
- Community and social supports: Refers to services and supports that are not LTSS that promote independence, well-being, self-determination, social connectedness and community inclusion in meaningful, desired activities of individuals with complex needs, supporting each individual to remain in his/her home and/or community.⁷ Community and social supports include items such as housing, transportation, employment, and education.

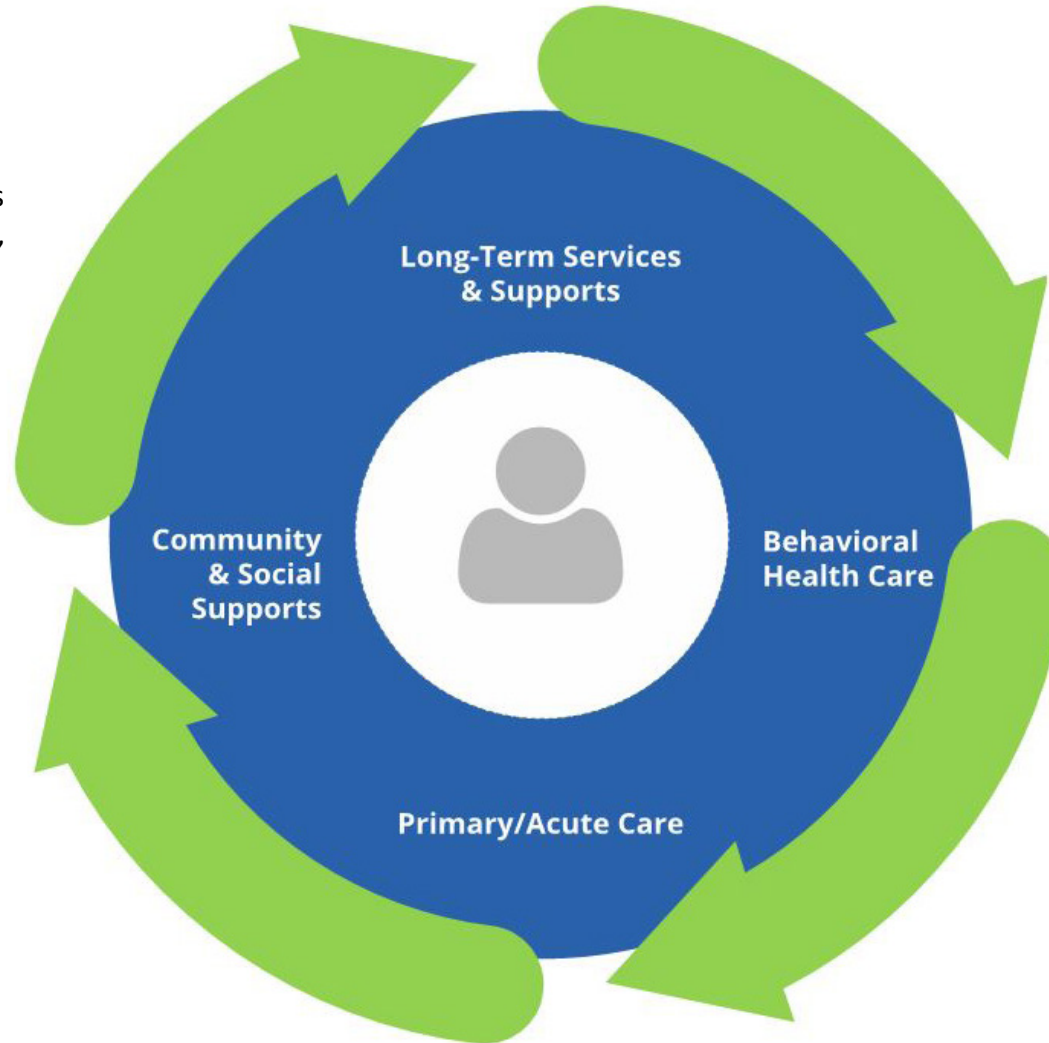
- Family/caregiver: Broadly defined, refers to any relative, partner, friend or neighbor, as well as paid caregivers, who has a significant personal relationship with, and who provides a broad range of assistance for an adult with complex care needs.^{8,9}
- LTSS: Refers to assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) provided in homes, community residences, or institutional settings to people with complex needs who cannot perform these activities on their own due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time, typically 90 days or more. LTSS also include supports provided to family members and other unpaid caregivers.¹⁰
- Primary/acute care: Primary care refers to care provided by physicians, nurse practitioners, physician assistants or other qualified health professionals specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern. Primary care services include health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses.¹¹ Acute care refers to a type of primary care that includes all promotive, preventive, curative, rehabilitative, or palliative actions whose primary purpose is to improve health and whose effectiveness largely depends on time-sensitive and, frequently, rapid intervention.¹²

FIGURE 1: HIGH-QUALITY SYSTEM FOR ADULTS WITH COMPLEX CARE NEEDS

Individuals are able to live their lives with services and supports reflecting their values and preferences in the least restrictive, most independent setting possible with access to a delivery system that respects and supports their choices and decisions.

Attribute 1:

Each individual's range of needs and goals, both medical and non-medical, as well as for family/caregivers, are identified and re-evaluated on an ongoing basis to drive care plans.



Attribute 2:

Each individual's needs are addressed in a compassionate, meaningful, and person-focused way and incorporated into a care plan that is tailored, safe, and timely.

Attribute 4:

Individuals and their family/caregivers continually inform the way the delivery system is structured to ensure that it is addressing their needs and providing resources tailored to them.

Attribute 3:

Individuals have a cohesive, easily navigable delivery system so that they can get the services and information they want by themselves or with support when needed, and avoid the services they do not need or want.

ATTRIBUTE 1: *Each individual's range of needs and goals, both medical and non-medical, as well as for family/caregivers, are identified and re-evaluated on an ongoing basis to drive care plans.*

Delivery systems:

- Appropriately and adequately identify adults with complex care needs;
- Assess each individual's needs in a comprehensive and holistic way, to the extent desired by the individual;
- Identify each individual's goals, preferences, strengths, and values by a care team member with whom the individual and family/caregiver feel comfortable;
- Share information about the individual's goals, preferences, strengths, and values with the individual's entire care team;
- Use assessment approaches that take into account an individual's entire history, its impact on his/her health, and support well-being and strengths (i.e., recovery-oriented and trauma-informed);
- Promote community integration, social supports, and care coordination, including opportunities for self-directed care to the greatest extent feasible; and
- Identify family/caregivers' needs and the natural supports and home- and community-based resources that enable them to provide assistance aligned with the individual's needs and preferences, and ensure they get the training/support they require.

ATTRIBUTE 2: *Each individual's needs are addressed in a compassionate, meaningful, and person-focused way and incorporated into a care plan that is tailored, safe, and timely.*

Delivery systems:

- Support the individual and his/her family/caregivers to guide the care plan to the greatest extent feasible;
- Use a collaborative partnership approach to decision-making with the individual and his/her family/caregivers;

- Develop care plans that address daily living needs;
- Empower each individual with tools and strategies to promote his/her strengths and self-management of care within the care plan; and
- Use individual choice and priorities to help guide the most appropriate medical and social support strategy that is accessible and aligned with both the individual's values and the family/caregivers' needs.

ATTRIBUTE 3: *Individuals have a cohesive, easily navigable delivery system so that they can get the services and information they want by themselves or with support when needed, and avoid the services they do not need or want.*

Delivery systems:

- Ensure high-quality, coordinated, integrated, and accessible services that meet an individual's full set of care needs (including, primary care, behavioral health care and substance use disorder treatment, LTSS, and technological assistance) in the most appropriate setting;
- Provide timely information on the benefits, costs, and risks of care and service options that individuals and their family/caregivers can understand and evaluate alongside their needs, values, and preferences in order to make decisions;
- Ensure that the individual is at the center of decision-making regarding care and services, and a full partner with their entire care team;
- Support timely, uninterrupted care and service delivery via an accountable primary point of contact who understands the complete picture of the individual's needs and has the authority and services and supports to connect the individual and family/caregivers to needs and services, as well as grievances and appeals processes across settings and systems;
- Ensure that care teams effectively communicate with the individual, family/caregivers, and each other to support continuous, coordinated, and integrated care;
- Acknowledge that circumstances and environment affect individuals' ability to navigate care and services, and tailor support to reflect these circumstances; and

- Provide culturally competent care and services tailored to each individual, as well as their family/caregiver, and the individual’s strengths, health literacy, language proficiency, and social/environmental circumstances.

ATTRIBUTE 4: *Individuals and their family/caregivers continually inform the way the delivery system is structured to ensure that it is addressing their needs and providing resources tailored to them.*

Delivery systems:

- Solicit and are responsive to ongoing collective input from individuals and the family/caregivers served;
- Provide ways for individuals and their family/caregivers to raise issues outside of the delivery system’s formal grievance and appeal channels (i.e., hold regular local forums to solicit input);
- Support meaningful input by individuals and their family/caregivers for continuous improvement; and
- Evolve based on individuals’ and family/caregivers’ input into design, implementation, and evaluation to ensure the system is responsive to all individuals being served and their family/caregivers.

ESSENTIAL ATTRIBUTES CONTEXT

While not explicitly referenced in the Essential Attributes, the following aspects of systems are prevalent in the literature and of note when considering a high-quality system.

- *Affordability:* Systems must be affordable in order to be accessible by individuals and their family/caregivers. The attributes do not directly address this issue, but note that “accessibility” includes affordability.

- *Publicly-financed health system fiscal constraints*: Literature and working group members noted the cost and difficulty of creating expectations that may be in conflict with fiscal realities for publicly-financed health care.
- *Social determinants of health*: Spectrums of viewpoints exist regarding which determinants the health care system should address and prioritize. Within the working group, consensus existed that the health system should be identifying certain determinants (e.g., housing, nutrition, transportation, financial well-being, education, health literacy) and taking them into consideration when addressing and supporting individual's needs, goals, and preferences. A divide exists as to what the health care system should be held accountable for addressing, what it is responsible for, and to what extent. The working group relayed that fiscal constraints must be considered and there is need to clearly delineate the responsibilities of the health care system versus other social service systems.
- *Person-centered care*: In order to be very specific about what is essential, based on feedback from working group members the attributes did not use the term "person-centered care," or "person- and family-centered care." Instead, more explicit words are used to describe what a person-focused system should seek to achieve from the perspective of an adult with complex care needs and their family/caregivers, where appropriate.
- *Quality of life*: In order to be specific about what is essential, based on feedback from working group members the attributes did not use the term "quality of life." Instead, the attributes more specifically describe what adults with complex care needs seek and prefer in order to live their lives according to their choices.

SUMMARY REFLECTIONS

The consensus of the working group and resulting Essential Attributes articulate what matters most for high-quality care from the perspective of an adult with complex care needs. The Essential Attributes seek to describe critical quality elements of a system regardless of the specific subpopulation being served. The working group expressed that models of care and interventions must be tailored to the individuals living with complex care needs and system elements must work together as a seamless – and to the greatest extent possible – single delivery system that is easy to understand and navigate. The Essential Attributes are intended to help guide future efforts to develop quality measures that capture the goals, preferences, and desired life outcomes of adults with complex care needs.

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APPENDIX A - WORKING GROUP AND EX-OFFICIO PARTICIPANT LIST

WORKING GROUP MEMBERS

G. Lawrence Atkins

Executive Director
Long Term Quality Alliance

Melanie Bella

Independent Consultant

Rich Bringewatt

Co-Founder and CEO
National Health Policy Group

Co-Founder and Chair
SNP Alliance

Helen Burstin

Chief Scientific Officer
National Quality Forum

Jennifer Dexter

Assistant Vice President, Government Relations
Easterseals

Lynn Friss Feinberg

Senior Strategic Policy Advisor
AARP Public Policy Institute

Allison Hamblin

Vice President for Strategic Planning
Center for Health Care Strategies, Inc.

Jennifer Goldberg

Directing Attorney
Justice in Aging

Alice Lind

Manager
Grants and Program Development
Washington State Health Care Authority

Debra Lipson

Senior Fellow
Mathematica Policy Research

Deidre Gifford

Director of State Policy and Programs
National Association of Medicaid Directors

Margaret E. O’Kane

President
National Committee for Quality Assurance

Pam Parker

Medicare-Medicaid Integration Consultant
Minnesota Department of Human Services

Carol Regan

Senior Advisor
Community Catalyst, Center for Consumer
Engagement in Health Innovation

EX-OFFICIO PARTICIPANTS

Federal

Eliza Navarro Bangit

Director
Office of Policy Analysis and Development
Administration for Community Living
Department of Health and Human Services

Stephen Cha

Director
State Innovations Group
Centers for Medicare & Medicaid Services

Tim Engelhardt

Director
Medicare-Medicaid Coordination Office
Centers for Medicare & Medicaid Services

Lisa Patton

Division Director
Center for Behavioral Health Statistics and
Quality
Substance Abuse and Mental Health
Services Administration

Nidhi Singh Shah

Health Policy Analyst
CMS/Center for Clinical Standards and Quality

Additional Participants

Stephanie Gibbs

Senior Program Officer
Center for Health Care Strategies, Inc.

Erin Giovanetti

Research Scientist, Performance Management
National Committee for Quality Assurance

Ann Hwang

Director
Community Catalyst
Center for Consumer Engagement in Health
Innovation

Foundations

Gretchen Alkema

Vice President of Policy and Communications
The SCAN Foundation

Bruce Chernof

President and CEO
The SCAN Foundation

Marcus Escobedo

Senior Program Officer
The John A. Hartford Foundation

Susan Mende

Senior Program Officer
Robert Wood Johnson Foundation

MaryBeth Musumeci

Associate Director
Kaiser Commission on Medicaid and the
Uninsured

Wally Patawaran

Program Officer
The John A. Hartford Foundation

Kali Peterson

Program Officer
The SCAN Foundation

Diane Rowland

Executive Vice President
Kaiser Family Foundation

Executive Director

Kaiser Commission on Medicaid and the
Uninsured

René Seidel

Vice President of Programs and Operations
The SCAN Foundation

Emily Zyborowicz

Manager, Research and Identification
Peterson Center on Healthcare

Complex Population of Focus	Domains/Measure Concepts	Identified Measurement Challenges
<p>AARP Public Policy Institute. Reinhard, S.C., Kassner, E., Houser, A., Ujvari, K., Mollica, R., & Hendrickson, L. (2014). Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf</p>		
<p>Older adults and individuals with disabilities</p>	<p>The AARP Scorecard is designed to measure the LTSS system performance across five key dimensions:</p> <ol style="list-style-type: none"> (1) Affordability and access (2) Choice of setting and provider (3) Quality of life and quality of care (4) Support for family caregivers (5) Effective transitions 	<p>Despite the looming care gap created by the increasing numbers of older adults and people with disabilities, which will place new demands on the LTSS systems across the nation, there is no national solution to providing LTSS. There are very large differences across states in how they operate their LTSS system, and national solutions are needed.</p>
<p>American Geriatrics Society. Goodwin, C. (2015). Person-Centered Care: A Definition and Essential Elements. http://geriatricscareonline.org/ProductAbstract/person-centered-care-a-definition-and-essential-elements/CL020</p>		
<p>Older adults with multiple chronic conditions and/or functional limitations</p>	<p>Essential elements of person-centered care include:</p> <ul style="list-style-type: none"> • An individualized, goal-oriented care plan based on the person’s preferences; • Ongoing review of the person’s goals and care plan; • Care supported by an inter-professional team in which the person is an integral team member; • One primary or lead point of contact on the health care team; • Active coordination among all health care and supportive service providers; • Continued information sharing and integrated communication; • Education and training for providers, and when appropriate, the person and those important to the person; and • Performance measurement and quality improvement using feedback from the person and caregivers. 	<p>Improving health care safety, quality, and coordination, as well as quality of life, are important aims of caring for older adults with multiple chronic conditions and/or functional limitations. Person-centered care is an approach to meeting these aims, but there are no standardized, agreed upon definition, parameters for delivering such care, or measures for assessing quality of such care.</p>

Complex Population of Focus	Domains/Measure Concepts	Identified Measurement Challenges
<p>Center for Health Care Strategies (CHCS). Thomas-Henkel, C., Hamblin, A., & Hendricks, T. (2015). Opportunities to Improve Models of Care for People with Complex Needs. http://www.chcs.org/resource/opportunities-to-improve-models-of-care-people-with-complex-needs/</p>		
<p>Individuals with complex needs</p>	<p>Through a series of interviews and a small group consultation with expert stakeholders across the United States, combined with a literature review of peer-reviewed and other relevant resources, CHCS organized current projects related to improving care for complex populations across six domains:</p> <ul style="list-style-type: none"> • Care model enhancements • Policy and advocacy • Governance and operations • Workforce development • Data and analytics • Financing and accountability 	<p>Despite recent progress, significant gaps in understanding remain—including how to identify and engage individuals; segment populations into meaningful subgroups with tailored interventions; measure quality outcomes; and align financial incentives across systems.</p> <p>There is currently no standard definition for what constitutes “super-utilization,” and although there is substantial variation across the high-needs population, programs often do not differentiate. One or more consistent, consensus-based definitions would enable more accurate comparisons of approaches and outcomes across programs, and also help advance the policy agenda by enabling more objective and uniform evaluation of new models of care.</p>
<p>Centers for Medicare and Medicaid Services (CMS). (2015). Medicare-Medicaid Plan Quality Ratings Strategy. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/FinalMMPQualityRatingsStrategy110615.pdf</p>		
<p>Dual-eligible individuals enrolled in both Medicare and Medicaid</p>	<p>The Medicare-Medicaid Plan (MMP) star rating system, at maturity, will be based on the following domains:</p> <ul style="list-style-type: none"> • Community integration/LTSS • Management of chronic conditions/health outcomes • Prevention • Safety of care provided • Member experiences with health plan and care providers • Plan performance on administrative measures 	<p>Despite recent and renewed emphasis on measures of care coordination and LTSS, gaps exist for tested, endorsed, actionable, and outcome-oriented measures in these areas for Medicare-Medicaid enrollees.</p>

Complex Population of Focus	Domains/Measure Concepts	Identified Measurement Challenges
<p>Centers for Medicare and Medicaid Services (CMS). (2013). CMS Quality Strategy. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf</p>		
<p>All individuals who access publicly funded health care (i.e., Medicare and Medicaid)</p>	<p>The CMS Quality Strategy is built on four main goals:</p> <ul style="list-style-type: none"> • Better care and lower costs • Prevention and population health • Expanded health care coverage • Enterprise excellence 	<p>N/A</p>
<p>Long Term Quality Alliance. Young, H.M., Kurtzman, E., Roes, M., Toles, M. & Ammerman, A. (2011). Measurement Opportunities & Gaps: Transitional Care Processes and Outcomes Among Adult Recipients of Long-Term Services and Supports. http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//TransitionalCare_Final_122311.pdf</p>		
<p>Older adults who access LTSS</p>	<p>A broad scan of existing measures coupled with a scan of the transitional care literature yielded key domains for measuring transitional care processes and outcomes among older adults receiving LTSS:</p> <ul style="list-style-type: none"> • Person- and family-centered care: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions • Transitional care processes: A broad range of time-limited services designed to ensure health care continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care to another or from one type of setting to another • Performance outcomes: Measurable endpoints of LTSS with a particular emphasis on economic, utilization, and clinical complications 	<p>A major challenge in measuring care transitions is the lack of common terms, definitions, and uniform data sets from which performance measures can be constructed as well as the absence of a national data repository to which all LTSS providers and settings contribute. While performance measurement, public reporting, and quality improvement within discrete settings has advanced, measurement across LTSS settings lags.</p> <p>Existing measures do not assess the care for older adults who appear in emergency departments and hospitals for treatment of chronic health conditions, then return home with no follow-up care for Medicare-covered services, or who are never admitted to the hospital and are sent home from an emergency department. This is an overlooked population subset that would benefit greatly from person-centered care planning.</p>

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<p>National Association of States United for Aging and Disability. (2015). National Core Indicators—Aging and Disabilities. http://www.nasuad.org/initiatives/national-core-indicators-aging-and-disabilities</p>		
<p>Older adults, individuals with physical disabilities, and caregivers</p>	<p>The National Core Indicators-Aging and Disabilities assess:</p> <ul style="list-style-type: none"> • Quality of life, including: <ul style="list-style-type: none"> • Wellness • Access to needed care • Rights and respect • Self-direction of care • Employment • Everyday living • Planning for the future • Functional competence • Community integration, including: <ul style="list-style-type: none"> • Community participation • Choice and decision-making • Relationships • Satisfaction with living arrangements & services • Person-centered services, including: <ul style="list-style-type: none"> • Coordination of care • Preventive health care 	<p>N/A</p>

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<p>National Committee for Quality Assurance (NCQA). (2013). Integrated Care for People with Medicare and Medicaid: A Roadmap for Quality. http://www.ncqa.org/portals/0/public%20policy/NCQAWhitePaper-IntegratedCareforPeoplewithMedicareandMedicaid.pdf</p>		
<p>Dual-eligible individuals enrolled in both Medicare and Medicaid</p>	<p>NCQA’s Domains for recommended structure and process measures for integrated care include:</p> <ul style="list-style-type: none"> • Comprehensive assessment • Individualized care plan • Coordinated care delivery • Population health management and health information technology • Quality measurement and improvement • Beneficiary engagement and rights 	<p>Existing measures do not fully address the complex characteristics of people with Medicare and Medicaid (i.e., use of LTSS, functional decline, frailty, multiple coexisting conditions) nor do they address critical indicators of quality improvement through the provision of integrated care. Current measures do not capture coordination of care across medical and LTSS or outcomes when enrollees may have different goals.</p> <p>Quality measures have not crossed disciplines or service areas, but fall into silos, being collected within a particular setting and for particular diseases. For example, measuring HbA1c for diabetes is more straightforward than measuring good, person-centered care and the quality of the communication among providers.</p>
<p>National Quality Forum (NQF). (2012). Multiple Chronic Conditions Measurement Framework. Final Report. http://www.qualityforum.org/Publications/2012/05/MCC_Measurement_Framework_Final_Report.aspx</p>		
<p>Adults with two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex health care management, decision-making, or coordination.</p>	<p>A comprehensive picture of the quality of care provided to individuals with MCCs should include measures that address:</p> <ul style="list-style-type: none"> • Patient- and family-level outcomes • Communication • Care coordination • Safety • Processes of care • Essential structures • Integration • Costs and resource use 	<p>Strict adherence to disease-specific measures for patients with MCCs may lead to the unintended consequence of delivering inappropriate care that is not aligned with an individuals’ goals and preferences. Additionally, applying numerous measures targeting a variety of diseases could impose potential harm; lead to high measurement burden, often without attaining better outcomes; and consume resources that might otherwise be used more judiciously and effectively to provide high-quality care.</p>

Complex Population of Focus	Domains/Measure Concepts	Identified Measurement Challenges
<p>National Quality Forum (NQF). (2015). Person- and Family-Centered Care Final Report—Phase 1. http://www.qualityforum.org/Publications/2015/03/Person- and Family-Centered_Care_Final_Report_-_Phase_1.aspx</p>		
<p>Individuals receiving care from the publicly funded system</p>	<p>Currently, NQF’s portfolio of person- and family-centered care measures includes measures in the following categories:</p> <ul style="list-style-type: none"> • Experience with care • Functional status • Health-related quality of life • Symptoms/symptom burden (pain) • Other miscellaneous measures of language communication, culture, and staff surveys 	<ul style="list-style-type: none"> • Measures and related surveys must be relevant and inclusive of populations that speak languages other than English. • Measures should be developed for other care settings, including rehabilitation facilities. • A need exists to better understand commonly excluded populations and how their “voices” may not be heard across surveys (e.g., pediatrics, maternity, behavioral health).

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<p>National Quality Forum (NQF). (2014). Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps in Person-Centered Care and Outcomes. http://www.qualityforum.org/Publications/2014/08/Priority_Setting_for_Healthcare_Performance_Measurement_Addressing_Performance_Measure_Gaps_in_Person-Centered_Care_and_Outcomes.aspx</p>		
<p>All individuals who access publicly funded health care</p>	<p>The Measure Applications Partnership (MAP) identified priority areas for measuring person- and family-centered care, which include:</p> <ul style="list-style-type: none"> • Interpersonal relationships • Patient and family engagement • Care planning and delivery • Access to support • Quality of life, including measures of physical and cognitive functioning, symptom and symptom burden (e.g., pain, fatigue), and treatment burden (e.g., patients, families, caregivers, siblings) <p>In addition, Person-Reported Outcomes of Care domains were identified as:</p> <ul style="list-style-type: none"> • Health-related quality of life/functional status • Symptom/symptom burden • Experience with care (including engagement and shared decision-making), and health-related behaviors (e.g., smoking) 	<p>The current health care system is fragmented and not conducive to person- and family-centered care, so it is important to first envision person- and family-centered care in an ideal system and then consider recommendations in the context of moving from the present to the ideal.</p>

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<p>Substance Abuse and Mental Health Services Administration (SAMHSA). (2014). National Behavioral Health Quality Framework. http://www.samhsa.gov/data/national-behavioral-health-quality-framework</p>		
<p>Individuals with behavioral health conditions</p>	<p>The six framework domains for which SAMHSA has developed goals related to the development of quality measures include:</p> <ul style="list-style-type: none"> • Evidence-based practices • Person-centered care • Coordinated care • Healthy living for communities • Reduction of adverse events • Cost reductions 	<p>N/A</p>
<p>U.S. Department of Health and Human Services (HHS). (2010). Multiple Chronic Conditions (MCC): A Strategic Framework. http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf?_sm_au=iVVPnFJcrHSQ8q7M</p>		
<p>Adults with multiple chronic conditions</p>	<p>The framework comprises these four overarching goals:</p> <ul style="list-style-type: none"> • Foster health care and public health system changes to improve the health of individuals with multiple chronic conditions; • Maximize the use of proven self-care management and other services by individuals with multiple chronic conditions; • Provide better tools and information to health care, public health, and social services workers who deliver care to individuals with multiple chronic conditions; and • Facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with multiple chronic conditions. 	<p>The MCC population is characterized by clinical heterogeneity, and substantially varies in the number of chronic conditions, the severity of illness and functional limitations, and the clustering of conditions.</p>

Complex Population of Focus	Domains/Measure Concepts	Identified Measurement Challenges
<p>U.S. Department of Health and Human Services (HHS). (2015). National Strategy for Quality Improvement in Health Care. http://www.ahrq.gov/workingforquality/reports/annual-reports/nqs2015annlrpt.htm</p>		
<p>All individuals who access publicly funded health care (e.g., Medicare, Medicaid)</p>	<p>Focuses on person- and family-centered care.</p> <p>Establishes three aims:</p> <ul style="list-style-type: none"> • Better care • Healthy people/healthy communities—address behavioral, social, and environmental determinants of health • Affordable care <p>The strategy is across six priorities:</p> <ul style="list-style-type: none"> • Making care safer by reducing harm caused in the delivery of care • Ensuring that each person and family are engaged as partners in their care • Promoting effective communication and coordination of care • Promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease • Working with communities to promote wide use of best practices to enable healthy living • Making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models <p>Which cross nine levels:</p> <ul style="list-style-type: none"> • Measurement and feedback • Public reporting • Learning and technical assistance • Certification, accreditation, and regulation • Consumer incentives and benefit designs • Payment • Health information technology • Innovation and diffusion • Workforce development 	<p>N/A</p>