ANNOTATED BIBLIOGRAPHY FOR

Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Synthesis of Evidence and Environmental Scan

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Adler NE, Stead WW. Patients in context – HER capture of social and behavioral determinants of health. *New Engl J Med.* 2015;372(8):698-701.	This article describes the social and behavioral factors influencing health and the need for providers to attend to these factors. A new set of standard measures for social and behavioral health determinants were delineated by the IOM and were expected to catalyze action. The use of standardized measures offers the opportunity to efficiently identify conditions that modify diagnoses and treatment plans rendering the information usable by various systems for various purposes (Table on page 3). Furthermore, this measure set can be implemented into EHRs and used to improve patient care by: 1. Promoting greater precision in diagnoses/improved treatment; 2. Facilitating more effective decisionmaking 3. Helping clinicians to identify risk factors 4. Prompting clinical teams to refer a patient to a public health department or community agency for social supports 5. Using information on social/behavioral factors to expand health systems' capacity to tailor services to meet the needs of the population 6. Broadening patient context available to researchers for EHRs which would store standard measures of social conditions/behavioral risk alongside conventional clinical data.	High	High	High
Agency for Healthcare Research and Quality (AHRQ). Environmental scan of measures for Medicaid Title XIX home and community-based services final report website. http://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/hcbsreport/index.html. Last accessed November 2015.	This online resource outlines the findings of the 2007 environmental scan for measures for Medicaid Title XIX. AHRQ was asked to develop measures in the domains of client functioning, client satisfaction, and program performance in order to assess the quality of Medicaid HCBS programs nationwide. In addition, AHRQ is tasked with publishing best practices information as a result of comparative analyses. To lay the groundwork for meeting these requirements, AHRQ is releasing this environmental scan of existing and potential measures. The measure scan was AHRQ's first step in fulfilling the directive, through documentation of the available science to support measure development and use.	High	High	High

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AHRQ. Assessing the health and welfare of the HCBS population website. http://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/hcbsfindings/hcbsfind1.html. Last accessed November 2015.	This report describes outcome indicators for the health and welfare of the HCBS population. The analysis was based on the 2005 Medicaid population as captured in the Medicaid Analytic extract dataset. The investigators described the Medicaid HCBS population for each state, and they report outcome indicators and their relationship to individual, area, and State policy attributes only nationally. This report is organized into five sections: (1) The approach to defining the HCBS population and four main subpopulations, followed by findings in terms of characteristics of HCBS recipients; (2) availability and use of Medicaid HCBS services, including both State plan and waiver services; (3) hospital admission outcome indicators used in this report to assess the health and well-being of the HCBS population; (4) rates of outcome indicators for the HCBS population by various personal and policy contextual attributes of potential interest, including by HCBS subpopulation, demographics, service availability and use, State Medicaid policy environment, area-level age and race, socioeconomic status, supply of healthcare providers, and area-level health characteristics of the population and (5) conclusions.	High	High	High
Algood CL, Hong JS, Gourdine RM, et al. Maltreatment of children with developmental disabilities: an ecological systems analysis. *Child Youth Serv Rev.* 2011;33:1142-1148.	The purpose of this review is to understand the risk factors for maltreatment of children with developmental disabilities. Using the Bronfrenbrenner's (1976, 1977) ecological systems framework, the authors examine how sociodemographic characteristics (age, gender, and special education), micro- (parent-child relationship and domestic violence), exo- (parenting stress, parents' social support, and area of residence), and macrosystems level (culturally defined parenting practices) factors influence or inhibit maltreatment of children with disabilities. The authors highlight major implications for practice and policy for maltreated children with disabilities.	Medium	High	Low
Allen KG. Long-Term Care Implications of Supreme Court's Olmstead Decision Are Still Unfolding. Testimony to the Special Committee on Aging, U.S. Senate; September 24, 2001.	This report examines the setting in which a person with disabilities receives care. It describes the extent to which the Olmstead decision will dictate major shifts from institutional care to HCBS.	High	High	High

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American Elder Care Research Organization. Minnesota Medicaid elderly waiver (EWA) program: qualifications and services website. http://www.payingforseniorcare.com/medicaid-waivers/mn-elderly-waiver.html. Last accessed November 2015.	This website is maintained by the American Elder Care Research Organization to assist individuals in locating federal and state services and public and private programs available for long-term senior care across the U.S. Among the information and interactive tools available on the website are the following: finding financial assistance for care; understanding health insurance coverage; finding quality, affordable care; and qualifying for Medicaid. Among the programs featured is the Minnesota Medicaid's Elderly Waiver program, that pays for home and community-based services for people age 65 years or older who require the level of medical care provided in a nursing home but choose to reside in the community. The website provides information about the waiver description, eligibility guidelines, benefits and services, and how to apply and learn more.	High	High	High
Arizona Strategic Enterprise Technology (ASET) Office. Arizona Health Information Exchange (HIE) Unconnected Providers Program. Arizona HIE Environmental Scan and Community Interviews. Phoenix, AZ: ASET; 2012. Available at http://hie.az.gov/docs/app_plans/Arizona_HIE_Environmental_Scan_and_Community_Interviews.pdf. Last accessed October 2015.	This report presents a series of interviews and an HIE environmental scan to better understand the adoption and use of health information technology, and health information exchange, in Arizona. The focus of the interviews was on four specific healthcare segments: behavioral health, rural providers, rural hospitals, and long-term care providers. The interviews highlighted barriers to adopting health information technology, drivers of participation and assistance needed for adopting HIT/HIE.	Medium	Medium	High

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Aron L, Honberg R, Duckworth K, et al. Grading the States 2009. A Report on America's Health Care System for Adults with Serious Mental Illness. Arlington, VA: National Alliance on Mental Illness; 2009. Available at http://www.nami.org/grades09/. Last accessed November 2015.	Although mental illness is the leading cause of disability in America, the mental healthcare system remains fragile, fragmented, and inadequate. The National Alliance on Mental Illness (NAMI) first published Grading the States: A Report on America's Health Care System for Serious Mental Illness in 2006. This second report builds on the first; it measures each state's progress in providing evidence-based, cost-effective, recovery-oriented services for adults living with serious mental illnesses. The report finds the national average to be the same as in 2006: A grade of D. The information was gathered though a survey of state mental health agencies, based on 65 criteria, with each state being measured and graded across four categories: health promotion and management, financing and core treatment/recovery services, consumer and family empowerment, and community integration and social inclusion. Many states are trying to improve systems and promote recovery, despite rising demand and inadequate resources. To improve the mental health care system, governments must: 1. increase public funding for mental health care services; 2. improve data collection, outcomes measurement, and accountability; 3. integrate mental and physical health care; 4. promote recovery and respect; and 5. increase services for people with serious mental illnesses who are most at risk.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Bazinsky K, Bailit M. The Significant Lack of Alignment across State and Regional Health Measure Sets. Needham, MA: Bailit Health Purchasing LLC; 2013. Available at http://www.bailit-health.com/articles/091113_bhp_measuresbrief.pdf. Last accessed October 2015.	This report presents an analysis of a broad array of state-organized measure sets. Forty-eight measure sets were gathered that represent different program types, designed for different purposes, across twenty-five different states and three regional collaboratives. The goal of the analysis was to provide basic summary information to describe the 48 measure sets and assess the extent of alignment across the measure sets. Key Findings: • There are many/regional performance measures for providers in use today • There is little alignment across measure sets • Nonalignment persists despite preference for standard measures • Most programs modify a portion of their measures, which also contributes to a lack of alignment • Measures are not aligned • Many programs create their own measures • Most home grown measures are not innovative • There is a need for new standardized measures in the areas of self-management, cost, and care management and coordination	High	High	High
Bipartisan Policy Center. America's Long-Term Care Crisis: Challenges in Financing and Delivery. Washington, DC: 2014. Available at http://bipartisanpolicy.org/wp-content/uploads/2014/03/BPC-Long-Term-Care-Initiative.pdf. Last accessed October 2015.	The objectives of this work were to: (1) identify the most pressing problems associated with the current system of providing LTSS in the United States; (2) identify the barriers to finding a sustainable means of financing and delivering LTSS; and (3) outline some of the more critical policy questions that will guide this kind of work in the future.	High	High	High
Black BS, Johnston D, Morrison A, et al. Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Qual Life Res.* 2012;21(8):1379-1389.	This study identifies the relationship between self-rated and caregiver-rated quality of life (QOL) in community-residing persons with dementia (PWD) for intervention development. Researchers used cross-sectional data of 254 PWD and their caregivers participating in a clinical trial derived from in-home assessments. Self-rated QOL was measured with the QOL-Alzheimer Disease scale, and the caregiver-rated QOL was measured using the QOL-AD and Alzheimer Disease Related QOL scales. The results of this study found that self-rated QOL was related significantly to participant race, unmet needs, depression, and total medications. Caregiver-rated QOL-AD scores were significantly associated with participant function, unmet needs, depression, and health problems and with caregiver burden and self-rated health. The researchers concluded that correlates of QOL in community-residing PWD depend on who rates the PWD's QOL and which measure is used.	Medium	Medium	Medium

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Bogart V, de Jung T, Farrell L. New York's 2012 Managed Long Term Care Report: An Incomplete Picture. New York, NY: Coalition to Protect the Rights of New York's Dually Eligible; 2013. Available at http://nylag.org/wp-content/uploads/2012/01/CPRNYDE-Response-to-the-2012-DOH-Report-April-5-2013.pdf. Last accessed October 2015.	This paper presents suggestions from the Coalition to Protect the Rights of New York's Dually Eligible for the inclusion of additional information in the annual Managed Long-Term Care Report. The coalition suggests improvement in the following areas of the report: enrollee satisfaction, service utilization of data, enrollment data, continuity of care, and comparisons between plans. The coalition requested that a supplemental report be prepared and new quality and consumer survey measures be employed per their recommendations.	Medium	High	Medium
Bohl A, Firucane M, Ross J, et al. Proposed Methods for Developing and Testing Risk- and Reliability-Adjustment Models for HCBS Composite Measures. Cambridge, MA: Mathematica Policy Research; 2015. Available at http://www.mathematica-mpr.com/~/media/publications/pdfs/health/hcbscompositeriskadjustment.pdf. Last accessed November 2015.	The Agency for Healthcare Research and Quality indicators for HCBS programs serving Medicaid beneficiaries include three composite measures (Ambulatory Care Sensitive Condition (ACSC) Chronic Conditions, ASCS Acute Conditions, ACSC Overall Conditions). The original specifications for these measures did not account for case-mix differences or statistical uncertainty. This report describes the methods and processes to develop and test the risk-adjusted HCBS composites, with the ultimate goal of the finalized HCBS composites being to compare state-level rates for selected HCBS populations to relevant benchmarks. The authors provide information about the selection and testing of person-level risk factors, reliability-adjustment validation, and comparison of state-level results. Development of the measures was anticipated to be finalized by September 2015.	High	High	High
Bohl A, Ross J, Ayele D. Risk Adjustment of HCBS Composite Measures, Volume 1. Cambridge, MA: Mathematica Policy Research; 2015. Available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/downloads/risk-adjust-hcbs-composite-vol1.pdf. Last accessed November 2015.	This is the first of two reports describing the development of risk-adjusted HCBS composite measures. This report describes the methods used to account for differences in the health and case-mix when comparing HCBS composite rates across states or populations. The ultimate goal of the finalized HCBS composites is to compare state-level rates for selected HCBS populations to relevant benchmarks. The authors provide information regarding the final risk-adjusted models; the data, methods, and approach to developing the risk-adjusted models; model development process; descriptive statistics on HCBS composite events; and the risk-adjusted HCBS composite rates at the state level with supporting validity information. The second report should be available October 2015 and will discuss how to utilize the final HCBS risk-adjusted measures. It is important to continue to follow risk adjustment as this work is relevant to HCBS measures and populations. Most of these populations risk adjusted to hospitalization using claims data.	High	High	High

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Bohl A, Schurrer J, Lim W, et al. The Changing Medical and Long-Term Care Expenditures of People who Transition from Institutional Care to Home- and Community-Based Services. Cambridge, MA: Mathematica Policy Research; 2014. Available at http://www.mathematica-mpr.com/our-publications-and-findings/publications/the-changing-medical-and-long-term-care-expenditures-of-people-who-transition. Last accessed November 2015.	This report focuses on the medical and long-term care expenditures for Medicaid beneficiaries who transition from institutional to community-based LTSS and how those expenditures change after the transition. The results of this study found that total Medicaid and Medicare expenditures decline during the first 12 months after someone transitions from institutional care to HCBS. Results also found that in most instances, the post-transition total expenditures of MFP participants are similar to those of a matched sample of others who transition without the benefit of MFP (with the exception of those with mental illness). Overall, the evidence suggests that MFP programs are effective in improving participant health outcomes and reducing acute care episodes that could lead to a return to institutional care.	High	High	High
Bonomi AE, Patrick DL, Bushnell DM, et al. Validation of the United States' version of the World Health Organization Quality of Life (WHOQOL) instrument. *J Clin Epidemiol.* 2000;53(1):1-12.	The objective of this study was to evaluate the WHOQOL-100 (The World Health Organization Quality of Life instrument) in the U.S., one of the original 15 participating countries. The WHOQOL is a 100-item self-report instrument consisting of 24 subscales within six domains: Physical, Psychological, Independence, Social, Environment, and Spiritual. Four additional items pertain to overall QOL/health. The investigators concluded that the WHOQOL measurement system is suitable for evaluating the QOL of adults in the U.S. While this survey was validated, it is very long at 100 items making it difficult to use. (MT)	High	Medium	High
Borck R, Irvin CV, Lim W. Transitions from Medicare-Only to Medicare-Medicaid Enrollment. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/MMTransV1.pdf. Last accessed August 2015.	The objectives of this study were to provide up-to-date national statistics on these transitions, learn more about the extent to which transitions are associated with long-term care (LTC) use, and examine variations in MME entry across states. A Medicare beneficiary's transition from Medicare-only coverage to Medicare-Medicaid enrollment (MME) often results from the combination of need for medical care not covered by Medicare and very low income and resources. The report highlights several recommendations on care coordination for policymakers.	High	High	Medium

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Braddock D, Hemp R, Rizzolo MC, et al. The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession. Washington, DC: The American Association on Intellectual and Developmental Disabilities; 2014.	The primary purpose of this study is to measure the impact of the Great Recession and its aftermath on services and supports for people with Intellectual and Developmental Disabilities (I/DD) and their families in the United States. During the Great Recession, aggregate inflation-adjusted state general funds fell 6.1 percent in 2009 and 6.4 percent in 2010 before recovering to 0.6 percent growth in 2011 and 1.6 percent growth in 2012. State general fund expenditures are critical to the provision of I/DD LTSS. They match federal Medicaid reimbursement for HCBS waivers and other community Medicaid programs. Overall, the report highlights the lack of appropriate resources to address the formidable challenges faced by people with I/DD.	High	High	Medium

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Bruner-Canholo L, McGaffigan E, Quach E, et al. Quality Framework for Frail Elder Home and Community-Based Services. Shrewsbury, MA: University of Massachusetts Center for Health Policy and Research; 2007.	The Executive Office of Elder Affairs (Elder Affairs) in Massachusetts oversees a wide array of supportive services for adults over 60. The Aging Services Access Points (ASAPs) coordinate the Medicaid 1915(c) frail elder waiver program and the state-funded Home Care program under which the supportive services are organized. Elder Affairs and the ASAPs have instituted measures and processes to identify and address quality concerns, but measures vary across ASAPs, making it difficult to generate reliable aggregate data. The endorsement of the HCBS Quality Framework by CMS and the early implementation of the Senior Information Management System (SIMS) at Elder Affairs have created an opportunity to standardize and strengthen quality monitoring and reporting. To meet these goals, Elder Affairs tasked a workgroup to (1) scan the ASAPs for current quality management practices, (2) identify a set of measures with which Elder Affairs can gather key quality information, and (3) recommend implementation strategies for these measures. This report summarizes the workgroup's findings and implementation recommendations. ASAPs currently use participant file data, written and oral feedback, and document on care providers to monitor quality outcomes. The workgroup identified measures related to access; person-centered planning and delivery; provider capacity and qualifications; safeguards; rights and responsibilities; satisfaction and outcomes; and system performance. The working group recommends a pilot test that specifies and operationalizes the measures; clarifies data collection, analysis, and reporting guidelines; implements the measures for a sample of ASAPs, and evaluates and refines the measures and guidelines based on results. The report also identifies recommendations from the Center for Health Policy and Research on additional measures that could be incorporated into the quality management system. These measures include measures related to participant-reported outcomes and satisfaction and other measures that were deferred during the process of developing consensus on the initial set of measures.	High	High	High
Burke-Miller JK, Swarbrick MA, Carter TM, et al. Promoting self-determination and financial security through innovative asset building approaches. *Psychiatr Rehabil J.* 2010;34(2):104-112.	The purpose of this article is to increase the use of Individual Development Accounts (IDAs) to enhance self-determination and recovery for people with psychiatric disabilities. The investigators discuss the use of self-determination among people with psychiatric disabilities, along with barriers and future directions.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Burt M, Wilkins C, Locke G. Medicaid and Permanent Supportive Housing for Chronically Homeless Individuals: Emerging Practices from the Field. Washington, DC: HHS Office of Disability, Aging and Long-Term Care; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/EmergPrac.pdf. Last accessed August 2015.	This report presents the findings of a study that examined the complexities of chronic homelessness and the role that the Federal government can play in providing for people who have experienced chronic homelessness. This study examined the intersection of three areas that can end chronic homelessness: 1) chronic homelessness itself; 2) permanent supportive housing; and 3) Medicaid's potential to fund health-related services for people experiencing chronic homelessness or living in Permanent Supportive Housing (PSH). Current gaps in services include the need for more flexibility in services to address substance use disorders, alone and in the context of co-occurring medical and mental health conditions; and the need to address challenges in serving dual eligibles. The report highlights seven key examples of innovations that led to a reduction of chronic homelessness across several states: (1) early expansion of eligibility based on Affordable Care Act income rules; (2) Medicaid waivers to create coverage for low-income people through new types of health plans that offer a "bridge" to the expanded coverage available under the Affordable Care Act; (3) linking Medicaid-covered mental health and behavioral health services to housing assistance to create PSH; (4) expanding the types of services covered by Medicaid; (5) involving Health Centers; (6) expanding the role of managed care; and (7) developing entirely new structures for integrating physical and behavioral healthcare with links to housing. This report also describes the use of integrated EHR systems to facilitate information sharing that can be used for quality assurance and outcome measurement. It also mentions measuring clinicians who work with the chronically homeless and productivity rates.	High	High	High

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Caldwell J. Consumer-directed supports: economic, health, and social outcomes for families. *Ment Retard.* 2006;44(6):405-417.	This article describes the impact of a consumer-directed support program on family caregivers of adults with developmental disabilities. Economic, health, and social outcomes were compared between families in the program and families on the waiting list for the program. The authors argued that control over services, particularly respite, could improve social and leisure outcomes for caregivers. Thus, specific research questions were addressed during the study including: does participation in a consumer-directed support program improve economic outcomes (greater employment and fewer out-of-pocket disability expenses), health outcomes (better physical health, mental health, and access to healthcare), and social outcomes (greater social participation and leisure satisfaction) for family caregivers; and are there greater benefits for lower income families on these outcomes? The results of this study found that caregivers of adults in the program reported fewer out-of-pocket disability expenses, greater access to healthcare, engagement in more social activities, and greater leisure satisfaction. There also appeared to be greater impacts on lower income families; these caregivers reported better mental health and access to healthcare than did similar caregivers on the waiting list.	Medium	Medium	Medium
Callahan CM, Boustani MA, Schmid AA, et al. Alzheimer's disease multiple intervention trial (ADMIT): study protocol for a randomized controlled clinical trial. *Trials.* 2012;13:92.	This study analyzes whether best practices primary care plus home-based OT delays functional decline among patients with AD compared to subjects treated in the control group. This study was designed as a parallel randomized controlled clinical trial with 1:1 allocation. This study does not have conclusions and is still ongoing at the time this journal was published.	High	High	High

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CDC. National Center for Health Statistics website. http://www.cdc.gov/nchs/. Last accessed August 2015.	This report presents descriptive results from the first wave of the National Study of Long-Term Care Providers, which was conducted by the CDC's National Center for Health Statistics. The report provides information on the supply, organizational characteristics, staffing, and services offered by providers of long-term care; and the demographic, health, and functional composition of users of these services. The major sectors of paid, long-term care services providers now also include adult day services centers, assisted living and similar residential care communities, home health agencies, and hospices. Key Findings: • In 2012, about 58,000 paid, regulated long-term care services providers served about 8 million people in the United States. Provider sectors differed in ownership, and average size and supply varied by region. • Provider sectors differed in their nursing staff levels, use of social workers, and variety of services offered. • Rates of use of long-term care services varied by sector and state users of long-term care services varied by sector in their demographic and health characteristics and functional status. • The survey findings in this report provide a current national picture of providers and users of five major sectors of paid, regulated long-term care services in the U.S. This report does not include the state providers and services provided by personal care and support staff provided by these organizational entities.	Medium	High	Medium
Center for Health Care Strategies, Inc. (CHCS). Medicaid Accountable Care Organizations: Program Characteristics in Leading-Edge States. Technical Assistance Tool. Hamilton, NJ: CHCS; 2014. Available at http://www.chcs.org/media/ACO_Design-Matrix-053014.pdf. Last accessed October 2015.	This resource presents key features and requirements for Accountable Care Organizations in seven states: Colorado, Maine, Massachusetts, Minnesota, New Jersey, Oregon, and Vermont. This multistate initiative is supporting several states in designing and implementing Medicaid ACO programs.	High	High	High
Centers for Disease Control and Prevention (CDC). National study of long-term care provider's website. http://www.cdc.gov/nchs/nsltcp.htm. Last accessed August 2015.	This webpage links to the biennial National Study of Long Term Care Providers (NSLTCP). This study is a groundbreaking initiative to monitor trends in the major sectors of paid, regulated LTC services providers. This page links to the data used for surveys of residential care communities and adult day services centers to support testing. This webpage also links to additional downloadable PDFs providing overviews of NSLTCP survey data and results.	High	High	High

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Centers for Medicare & Medicaid Services (CMS). About home health care (CAHPS) website. https://homehealthcahps.org/GeneralInformation/AboutHomeHealthCareCAHPSSurvey.aspx. Last accessed November 2015.	This webpage describes the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program, a program of the U.S. Agency for Healthcare Research and Quality (AHRQ), and the CAHPS surveys. The surveys ask consumers and patients to report on and evaluate their experiences with healthcare. The CAHPS surveys focus on aspects of quality that consumers are best qualified to assess such as provider communication skills and ease of access to services. The webpage links to more information about the CAHPS program, principles underlying the CAHPS surveys, the CAHPS User Network, a bibliography listing articles that discuss the development and use of CAHPS surveys, frequently asked questions, and a glossary.	Medium	Low	Medium
Centers for Medicare & Medicaid Services (CMS). Consumer assessment of healthcare providers and systems (CAHPS) hospice survey website. http://www.hospicecahpssurvey.org/content/homepage.aspx. Last accessed November 2015.	This website is the homepage of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey. The CAHPS Hospice Survey was designed to measure and assess the experiences of patients who died while receiving hospice care, and the experiences of their informal primary caregivers. The website features Frequently Asked Questions (FAQs) about the CAHPS Hospice Survey and makes the survey materials and quality assurance guidelines available for download. This website also provides links to the Hospital Quality Reporting Program, the Hospital Experience of Care Survey Development and Field Test Report, and the FY2016 Hospice Final Rule. The CAHPS Hospice Survey Fact Sheet from April 2015, available as a link from this website, identifies quality measures and constituent items from the survey. Composite measures include hospice team communication, getting timely care, treating family members with respect, providing emotional support, getting help for symptoms, and getting hospice care training. Single item measures include providing support for religious and spiritual beliefs, information continuity, and understanding the side effects of pain medication. Two global measures are included: overall rating of hospice and recommend hospice.	High	High	Medium
Centers for Medicare & Medicaid Services (CMS). Hospice item set (HIS) website. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Hospice-Item-Set-HIS.html. Last accessed November 2015.	The Hospice Item Set (HIS) webpage provides updates, announcements, and resources specific to the HIS. On this page you will find direct links to the HIS, the HIS manual, factsheets, and training materials. Announcements related to HIS activities (such as trainings and OMB approval) are posted here. Descriptive information about the measures included in the Hospice Quality Reporting system are available here. There are seven process measures currently endorsed by NQF and in use in the program.	High	High	High

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Centers for Medicare & Medicaid Services (CMS). Outcome and assessment information set (OASIS) website. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/OASIS/index.html. Last accessed November 2015.	The purpose of this website is to store and disseminate policy and technical information related to the Outcome and Assessment Information Set (OASIS) data set for use in home health agencies (HHAs), State agencies, software vendors, professional associations and other Federal agencies in implementing and maintaining OASIS. OASIS is a group of data elements that: (1) Represent core items of a comprehensive assessment for an adult home care patient; and (2) form the basis for measuring patient outcomes for purposes of outcome-based quality improvement (OBQI). Overall, the OASIS items have utility for outcome monitoring, clinical assessment, care planning, and other internal agency-level applications. The website links to background information, regulations, jHAVEN software, data set, data specifications, OASIS user manuals, educational and automation coordinators, prospective payment system (PPS), frequently asked questions, and training.	High	High	Medium
Centers for Medicare and Medicaid Services (CMS). The Home and Community-Based Service (HCBS) Experience Survey Part A Justification and Supporting Statement. Baltimore, MD: CMS; 2012. CMS-10389. Available at https://www.ncoa.org/wp-content/uploads/508Supporting-Statement-Part-A-HCBS-11-Mar-2012.pdf. Last accessed August 2015.	The goal of this survey is to provide standard performance metrics for HCBS programs that are applicable to all populations served by these programs, including people with physical disabilities, cognitive disabilities, intellectual impairments, and/or disabilities due to mental illness. The assessment will enable HCBS programs to identify areas in which quality can be improved and provide CMS, CHIP and Survey Certification (CMCSC), state Medicaid programs, consumers and their families, consumer advocacy organizations, and other stakeholders with comparisons across HCBS programs. This survey is intended to gather direct feedback from participants in Medicaid HCBS programs, operated by individual states, about their experiences with services and supports. This report does not include the assessment items.	High	High	High
Claes C, Van Hove G, Vndevelde S, et al. Person-centered planning: analysis of research and effectiveness. *Intellect Dev Disabil.* 2010;46(6):432-453.	The purpose of this study was to (a) review the current status of effectiveness research; (b) describe its effectiveness in terms of outcomes or results; and (c) discuss the effectiveness of person-centered planning in relation to evidence-based practices. Analyzed studies suggest that, overall, this planning has a positive, but moderate, impact on personal outcomes for people with intellectual and developmental disabilities. The body of evidence provided in this review is weak with regard to criteria for evidence-based research.	Medium	Medium	Medium

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		Impact	Improvability	Inclusiveness
CMS. Pioneer ACO model website. http://innovation.cms.gov/initiatives/Pioneer-ACO-Model/. Last accessed August 2015.	This report describes the Pioneer ACO Model which is designed for health care organizations and providers that are already experienced in coordinating care for patients across care settings. It allows these provider groups to move more rapidly from a shared savings payment model to a population-based payment model on a track consistent with, but separate from, the Medicare Shared Services Program. The report also describes how healthcare organizations can apply for these programs and discusses the quality measures used to assess performance in both programs.	High	Medium	High
CMS. Analytic reports and data resources website. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Analytics.html. Last accessed August 2015.	CMS conducted a study to determine the prevalence of diagnosed physical/medical health conditions and comorbidity rates among FFS Medicare-Medicaid dually enrolled beneficiaries, overall, and by state. The study population consisted of 5.3 million dual enrollees with a minimum six months with Medicare Parts A and B or Medicaid FFS in CY 2008. Individuals enrolled in either a Medicare Managed Care plan or a Medicaid comprehensive risk based or behavioral health managed care program at any time during CY 2008 were excluded from the study. Physical and mental health condition indicators were derived from 2008 Medicare-Medicaid claims data using Medicare-Medicaid Linked Enrollee Analytic Data Source (MMLEADS) that is a component of the CMS Chronic Condition Warehouse (CCW). The key findings of this study indicated that 60 percent of Medicare-Medicaid FFS enrollee's had diagnoses across at least three of the physical and mental health categorical condition groups; 25 percent had diagnoses spanning five or more condition groups; 75 percent had at least one heart related condition diagnosis; and 41 percent had one or more mental health condition (excluding substance use disorders). In addition, subgroup analyses found highest condition prevalence among those with one or more stays in an LTC facility. Analyses also found that high condition prevalence among those with depressive disorders to be roughly double of those who had no nursing home stay in the same year. The prevalence of reported depression was also found to escalate sharply within the first few months of beneficiaries' time in a nursing home. The study also found high expenditures for those beneficiaries with high condition prevalence. According to the study, beneficiaries with no physical/mental conditions incurred $875 per member per month (PMPM); beneficiaries with diagnoses across two comorbid conditions incurred $1628 PMPM; and beneficiaries with five or more comorbid conditions incurred $3940 PMPM.	Medium	Medium	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
CMS. CARE item set and B-CARE website. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/CARE-Item-Set-and-B-CARE.html. Last accessed August 2015.	The CARE Item Set is designed to standardize assessment of patients' medical, functional, cognitive, and social support status across acute- and post-acute settings, including long-term care hospitals (LTCHs), inpatient rehabilitation facilities (IRFs), skilled nursing facilities (SNFs), and home health agencies (HHAs). The tool is meant to standardize the items used in each of the existing assessment tools while posing minimal administrative burden to providers. The CARE Item Set builds on prior research and incorporates lessons learned from clinicians treating the continuum of patients seen in all settings. The CARE Item Set targets a range of measures that document variations in a patient's level of care needs including factors related to treatment and staffing patterns such as predictors of physician, nursing, and therapy intensity. The CARE Item Set includes two types of items: 1) core items which are asked of every patient in that setting, regardless of condition; and 2) supplemental items which are only asked if patients having a specific condition. The supplemental items measure severity or degree of need for those who have a condition. This demonstration provided standardized information on patient health and functional status, independent of site of care, and examined resources and outcomes associated with treatment in each type of setting. The study provided information on resource use within each setting which helped to understand differences in patient treatment, outcomes, and costs of care in order to create appropriate payment reform recommendations.	High	High	High
CMS. CMS Quality Strategy 2013 – Beyond. Available at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf. Last accessed August 2015.	The CMS Quality Strategy is a public and private partnership to support the delivery of consistent, high-quality care, promote efficient outcomes in our health system, and ensure affordable health coverage. The CMS QS has laid out goals, objectives, and intended outcomes to guide action to realize six broad and interrelated goals that reflect the six priorities of the National Quality Strategy. These goals include eliminating ethnic/racial disparities, strengthening infrastructure and data systems, enabling local innovations, and fostering learning organizations.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
CMS. Core Measures in FFS Duals. MMCO-MFFS-Guidance 4-17-13. Baltimore, MD: CMS; 2013. Available at https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_MFFS_Guidance_4_17_13.pdf. Last accessed August 2015.	This report describes the managed care fee-for-service model (MFFS) which is intended to encourage and support state investment in models to better align service delivery and financing for Medicaid and Medicare enrollees across the two programs and integrate primary, acute, behavioral health, and long-term supports and services. Under the MFFS model, CMS has agreed to make retrospective performance payments to a state if that state qualifies by meeting certain quality or savings criteria. The report contains the quality measures (i.e. model core measures, state-specific process measures and state specific demonstration measures) that states must to report on each year. This report also discussed a CAHPS survey as another quality measure to include.	High	High	High
CMS. Core Set of Health Care Quality Measures for Medicaid Health Home Programs. Technical Specifications and Resource Manual for Federal Fiscal Year 2013 Reporting. Baltimore, MD: CMS; 2014. Available at http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Downloads/Health-home-core-set-manual.pdf. Last accessed August 2015.	This CMS report identifies the core set of healthcare quality measures for the Medicaid Health Home Programs for FFY 2013 reporting. This includes data collection and reporting of the home health core set, technical specifications for the home health core set measures, and technical specifications for the home health utilization measures.	High	High	High
CMS. Home health quality initiative website. Available at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/index.html. Last accessed August 2015.	This website describes CMS' home health quality initiative which is covered under the Medicare Part A benefit. It consists of part-time, medically necessary skilled care (nursing, physical therapy, occupational therapy, and speech-language therapy) that is ordered by a physician. The instrument/data collection tool used to collect and report performance data by home health agencies is called the Outcome and Assessment Information Set (OASIS). Since 1999, CMS has required Medicare-certified home health agencies to collect and transmit OASIS data for all adult patients whose care is reimbursed by Medicare and Medicaid with the exception of patients receiving pre- or postnatal services only. OASIS data are used for multiple purposes including calculating several types of quality reports which are provided to home health agencies to help guide quality and performance improvement efforts. This website links to a general list of home health outcome and process measures as well as specific measures for potentially avoidable events. Star ratings are also now on the Home Health Compare Website. VBP demonstration will begin 2016. Some IMPACT measures will begin collection in 2016.	High	High	High

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CMS. IMPACT Act of 2014 & cross setting measures website. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/IMPACT-Act-of-2014-and-Cross-Setting-Measures.html. Last accessed August 2015.	This website describes the IMPACT act which requires the submission of standardized data by Long-Term Care Hospitals (LTCHs), Skilled Nursing Facilities (SNFs), Home Health Agencies (HHAs) and Inpatient Rehabilitation Facilities (IRFs). Specifically, the IMPACT Act requires, among other significant activities, the reporting of standardized patient assessment data with regard to quality measures, resource use, and other measures. It further specifies that the data [elements] "… be standardized and interoperable so as to allow for the exchange of such data among post-acute care providers and other providers and the use by such providers of such data that has been so exchanged, including by using common standards and definitions in order to provide access to longitudinal information for such providers to facilitate coordinated care and improved Medicare beneficiary outcomes…." The website is continuously updated with new information on how the Act is being implemented. Its latest update mentions several NQF-endorsed measures that may be used for implementation.	High	High	High
CMS. Independence at Home Demonstration Solicitation. Baltimore, MD: CMS. Available at https://www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts/Downloads/IAH_Solicitation.pdf Last accessed August 2015.	This report describes the Independence at Home Demonstration Project which tests a service delivery and payment incentive model that uses home-based primary care teams designed to improve health outcomes and reduce expenditures for Medicare beneficiaries with multiple chronic conditions. The Independence at Home Demonstration awards incentive payments to healthcare providers who succeed in reducing Medicare expenditures and meet designated quality measures. The report includes quality measures for the identification of goals for the patient and family caregiver; screenings/assessments conducted, including depression, home safety evaluation, risk of falling, cognitive deficits; symptom management (e.g., pain, shortness of breath, cognitive deficits, fatigue, sleep disturbances); medication management; caregiver stress; voluntary disenrollment rate; and referrals made to home health, community/social services, hospice as well as satisfaction.	High	High	High

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CMS. Medicaid.gov. Home & community-based services website. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html. Last accessed November 2015.	This website is a Medicaid resource on home and community-based services (HCBS). HCBS provide opportunities for Medicaid beneficiaries to receive services in their homes or community. The website features the Final Regulation: 1915(i) State Plan HCBS, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) HCBS Waivers, including an informational bulletin, press release, and factsheets on the overview of the regulation, changes to the 1915(c) waiver program, key provisions in 1915(i) and the HCBS Settings Final Rule, a webinar, and Q&A. The website also includes the Settings Requirements Compliance Toolkit to assist states develop Home and Community-Based 1915(c) waiver and 1915(i) SPA amendment or renewal application(s) to comply with new requirements in HCBS regulations.	High	High	High
CMS. Medicare-Medicaid Capitated Financial Alignment Model Reporting Requirements. Baltimore, MD: CMS; 2014. Available at https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/Downloads/FinalCY2014CoreReportingRequirements.pdf. Last accessed August 2015.	This report describes the Medicare-Medicaid financial alignment initiative which tested innovative models to better align Medicare and Medicaid financing and services provided to Medicare and Medicaid enrollees. The purpose of the report is to provide Medicare-Medicaid Plans (MMP) with the reporting requirements for the capitated financial alignment model. An MMP is a managed care plan that is entered into as a three-way contract with CMS and the State in which the plan will operate. This report provides technical specifications for these measures to ensure a common understanding of the data to be reported by MMPs, to assist MMPs in preparing and submitting datasets, and to ensure a high level of accuracy in the data reported to CMS. The measures included in this report focus on access, care coordination, enrollee protections, organizational structure and staffing, performance, provider networks, systems and utilization, etc.	High	High	Medium
CMS. Medicare-Medicaid enrollee state profiles website. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/StateProfiles.html. Last accessed August 2015.	The CMS Chronic Conditions Data Warehouse (CCW) provides researchers with Medicare and Medicaid beneficiary, claims, and assessment data linked by beneficiary across the continuum of care. The CCW is a research database designed to make Medicare, Medicaid, Assessments, and Part D Prescription Drug Event data more readily available to support research designed to improve the quality of care and reduce costs and utilization.	Low	Low	Low

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CMS. Report to Congress: The Centers for Medicare & Medicaid Services' Evaluation of Community-based Wellness and Prevention Programs under Section 4202 (b) of the Affordable Care Act. Baltimore, MD: CMS; 2014. Available at http://innovation.cms.gov/Files/reports/CommunityWellnessRTC.pdf. Last accessed August 2015.	This report presents findings from the examination of programs focused on increasing physical activity, reducing obesity, improving diet and nutrition, reducing falls, promoting chronic disease management, and better management of mental health issues for Medicare beneficiaries. The project team conducted an environmental scan, evidence review, and pilot evaluation of the Chronic Disease Self-Management Program (a nationally disseminated chronic disease management intervention developed and administered by Stanford University). The pilot evaluation tested methodologies for linking program participants to Medicare administrative records and assessing claims-based outcomes. They then conducted a retrospective analysis of a select group of wellness and prevention programs and studied the effects of how community-based wellness and prevention programs affect Medicare beneficiaries. The report presents results from the first two phases of the project. The study evaluated outcomes including utilization of healthcare and mortality based on participation in some of the programs.	High	High	Medium
CMS. State innovation models initiative: model test awards round one website. http://innovation.cms.gov/initiatives/State-Innovations-Model-Testing/index.html. Last accessed August 2015.	This website presents the State Health Care Innovation Plan which is a proposal that describes a state's strategy to use all of the levers available to it to transform its healthcare delivery system through multipayer payment reform and other state-led initiatives. Currently, six states are participating and they each have different plans to improve care delivery. A total of $250 million has been awarded by CMS for these new models. Important information on how each of these models improve both nonmedical HCBS and Medical HCBS.	High	High	High
CMS. State survey agency guidance emergency preparedness for every emergency website. https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertEmergPrep/StateAgencyGuidance.html. Last accessed August 2015.	These documents include approved amendments to 1915(k), 1915(c), and emergency preparedness programs by state.	Medium	Low	Medium
CMS. Waiver applications website. https://wms-mmdl.cdsvdc.com/WMS/faces/portal.jsp. Last accessed August 2015.	This website describes the 1915(c) waiver program. It also links to a private webpage where states can request to operate a managed care program [under waiver 1915(b)]. Some pages list services available in these waiver programs.	Medium	Medium	Medium

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Community Living Policy Center (CLPC). Conceptual Framework for Quality and Outcome Measurement in Long-Term Services and Supports. San Francisco, CA: University of California; 2014.	This source provides a conceptual framework for quality and outcome measurement in LTSS. A diagram of the conceptual relationships among the various LTSS components (system, consumer, resources) is provided. A list of quality domains in seven different areas are listed including: program characteristics, system responsiveness, paid and unpaid providers, supportive environment, LTSS received, and consumer outcomes.	High	High	High
Conroy JW. Personal Life Quality Protocol. Short, Reliable Outcome Measurement Tools for Quality Tracking in Developmental Disabilities Systems. Havertown, PA: Center for Outcome Analysis (COA); 2014. Available at http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/PLQ-COA-OnePageQualityModules-V38.doc. Last accessed October 2015.	This scale, taken from the Harris poll of Americans with and without disabilities, measures how often people “go out” to visit with friends, go shopping, go to a place of worship, engage in recreation, etc. It was used in the National Consumer Survey of 1990. The scale measures productivity, autonomy, quality of life, individual planning, individual goals, relationships as well as demographics, legal status, and disability.	High	High	High
Conroy JW. Personal Life Quality Protocol. Short, Reliable Outcome Measurement Tools for Quality Tracking in Developmental Disabilities Systems. Havertown, PA: Center for Outcome Analysis (COA); 2014. Available at http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/PLQ-COA-OnePageQualityModules-V38.doc. Last accessed October 2015.	This presentation outlines key points from the HCBS Final Rule of January 2014. It highlights the importance of individual outcomes in the new rule (person-centered planning, self-direction, integration, inclusion and relationships). It provides examples of several kinds of measures for HCBS and presents measurement initiatives such as the National Core Indicators, InterRAI, SIS, and ongoing work at AHRQ and PCORI.	High	High	High
Cooper C, Manela M, Katona C, et al. Screening for elder abuse in dementia in the LASER-AD study: prevalence, correlates and validation of instruments. *Int J Geriatr Psychiatry.* 2008;23(3):283-288.	This study examines the scientific acceptability of the Modified Conflict Tactics Scale (MCTS). The sample consisted of 86 people with Alzheimer’s Disease and their family caregivers. Researchers asked about acceptability of the MCTS and investigated its validity by comparing scores to the Minimum Data Set (MDS) abuse screen (objective measure) and tested the hypothesis that MCTS score would correlate with the COPE dysfunction coping scale but not career education. The MCTS was acceptable and had convergent and discriminant validity for measuring career abuse. The MDS failed to identify cases of abuse.	High	High	High
Cooper E, O’Hara A, Singer N, et al. Priced Out in 2012: The Housing Crisis for People for Disabilities. Boston, MA: Technical Assistance Collaborative, Inc; Washington, DC: Consortium for Citizens with Disabilities, Housing Task Force; 2013. Available at http://www.tacinc.org/media/33368/PricedOut2012.pdf. Last accessed November 2015.	This report describes a national study of the complexities of the housing crisis for persons with disabilities. The key findings in this report indicate that it is nearly impossible for people with disabilities who rely on SSI to obtain decent, safe, affordable, and accessible housing in the community without a permanent subsidy.	Medium	Medium	Medium

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Crist JD, Velazquez H, Durnan I, et al. Instrument development of the confidence in home care services questionnaire for use with elders and caregivers of Mexican descent. *Public Health Nurs.* 2006;23(3):284-291.	This study describes the results of qualitative interviews conducted with Mexican American elders and their caregivers. The Community Service Attitude Inventory was used to determine whether lack of confidence in home care services is an indication of utilizing services less than their non-Hispanic counterparts.	Medium	Medium	Medium
Croke EE, Thompson AB. Person centered planning in a transition program for Bronx youth with disabilities. *Child Youth Serv Rev.* 2011;33(6):810-819.	This federally funded research and demonstration project was designed to help transition-age youth with disabilities receiving Supplemental Security Income (SSI) achieve maximum self-sufficiency. More than 400 youth living in the high-poverty county of Bronx, NY, were enrolled in a treatment group and offered a series of interventions, including Person-Centered Planning (PCP). Quantitative and qualitative research methods show that this process was linked to improved educational and employment outcomes for youth. Sixty-five percent of youth enrolled in the project participated in at least one PCP session. Youth from lower-income families were less likely to participate in PCP, as were youth with mood disorders. Youth who did participate in PCP were more likely to hold at least one paid job. Youth focused on relationships, personal strengths, and goals during these sessions, which proved an important part of their transition process. Recommendations for educators, service providers and policymakers are included for professionals seeking to implement collaborative transition services for youth and their families.	Medium	High	Medium
Dale S, Brown R, Phillips B, et al. How do hired workers fare under consumer-directed personal care? *Gerontologist.* 2005;45(5):583-592.	This journal article describes the results of a study of the experiences of workers hired under consumer direction. Medicaid beneficiaries in the Cash and Counseling demonstration program were randomly assigned to the treatment group. Additionally, paid workers for both groups were surveyed about 10 month's post-demonstration enrollment. The results of this study indicated that directly hired workers for the treatment group were mostly consumers' friends or relatives vs. those in the control group who were mostly consumers in agency care. The two groups received similar wages, and both were highly satisfied with their working conditions/supervision. Compared to agency workers, directly hired workers who lived with or were related to the consumer were more likely to report emotional strain and a desire for more respect from the consumers' family. This study implies that the Cash and Counseling model does not appear to cause adverse consequences for the hired workers.	High	High	High

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Deutsch A, Kline T, Kelleher C, et al. Analysis of Crosscutting Medicare Functional Status Quality Metrics Using the Continuity and Assessment Record and Evaluation (CARE) Item Set Final Report. Washington, DC: HHS Office of Assistant Secretary for Planning and Evaluation (ASPE); 2012. Available at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Post-Acute-Care-Quality-Initiatives/Downloads/ASPE-Report-Analysis-of-Crosscutting-Medicare-Functional-Status-Quality-Metrics-Using-the-Continuity-and-Assessment-Record-and-Evaluation-CARE-Item-Set-Final-Report.pdf. Last accessed August 2015.	The purpose of this work was to provide ASPHE/HP and CMS with recommendations for functional status quality metrics to be used across acute and post-acute care providers, including inpatient rehabilitation facilities, long-term care hospitals, skilled nursing facilities, and home health agencies. RTI used CARE data to explore the development of risk-adjusted, facility-level functional status outcome measures that are applicable across the different types of providers. This report presents RTI's environmental scan of quality measures for motor functional status and communication, problem solving, and memory. Through this scan they identified key analytic issues pertinent to functional status quality measure development, conducted data analysis to address these analytic issues, and convened a technical expert panel (TEP). This report summarizes the work, including a summary of the environmental scan and a discussion about each of the key analytic issues, and details the comments and perspectives of members of the TEP members. This is one summary document of four from RTI on Care Tool and functional status measures.	High	High	Medium
Disability Rights Education and Defense Fund (DREDF), National Senior Citizens Law Center (NSCLC). Identifying and Selecting Long-Term Services and Supports Outcome Measures. Berkeley, CA: DREDF; 2013. Available at http://dredf.org/2013-documents/Guide-LTSS-Outcome-Measures.pdf. Last accessed August 2015.	This paper provides resources to help state advocates identify measures that can help determine if the identified needs and goals of people with disabilities and seniors are being met. The writers focus primarily on identification of LTSS outcome measures that examine individual experience, whether that individual is the beneficiary receiving services, the beneficiary's family caregiver, or a paid personal assistant, rather than measures that relate to structural elements or processes. The paper outlines the factors that have spurred the increase in states' enrollment of Medicaid beneficiaries with disabilities into managed LTSS/HCBS and explains why measuring individual outcomes is so important as these changes are implemented. It presents core principles and criteria for selection of LTSS outcome measures and possible sources of data that could be used to respond to specific questions related to quality as well as key report topics that will generate information needed for quality improvement. The paper concludes with suggested action steps and resources for advocates who are working with states, MCOs, community-based service organizations, disability and senior groups and other stakeholders as states launch managed LTSS and HCBS initiatives. Excellent report and summary of some of the work and reports on outcome measures and surveys.	High	High	High

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Diskey P, Hatton C, Dagnan D. The Equity Perception Scale – Intellectual Disability Services (EPS-IDS): evaluating the reliability and validity of a new measure. *J Intellect Dev Disabil.* 2013;38(4):292-300.	The purpose of this study was to determine the reliability and validity of the Equity Perception Scale - Intellectual Disability Services (EPS-IDS) used as a measure of staff equity perceptions in services for people with ID. This tool contains three relationship indices that assess staff relationships with their employing organizations, colleagues, and service users. Researchers distributed postal questionnaires to collect quantitative data from a purposive sample of ID service staff. Results of this study indicated good internal consistency of reliability and validity (with the exception of test-retest reliability and co-worker relationship index). Overall, the findings from this study indicated that the EPS-IDS shows promise as a measure of the equity perceptions of ID service staff but will need further refinements to the relationship indices.	High	High	High
Dougherty M, Williams M, Millenson M, et al. EHR Payment Incentives for Providers Ineligible for Payment Incentives and Other Funding Study. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/sites/default/files/pdf/76706/EHRPI.pdf. Last accessed August 2015.	This report describes a study conducted in response to a requirement in the Health Information for Economic and Clinical Health Act (HITECH) of the American Recovery and Reinvestment Act of 2009 (ARRA). It presents the findings of the study indicating that many healthcare providers not eligible for the Medicare and Medicaid EHR Incentive Programs, such as Long-term Care and Post-Acute Care (LTPAC) and Behavioral Health providers, have a frequent need to exchange health information on behalf of their patients, who are among the most vulnerable and costly in our society. Advancing the adoption of certified EHR technology solutions by providers not eligible for the EHR Incentive Programs may support the realization of the goals associated with implementing a national health IT infrastructure. In addition, filling gaps in standards is essential to support the interoperable exchange of health information of vulnerable groups receiving care services. This report connects to the need to develop and support clinical quality measures using EHR data.	High	High	High
Dowler DL, Solovieva TI, Walls RT. Personal assistance services in the workplace: a literature review. *Disabil Health J.* 2011;4(4):201-208.	This literature review explored the professional literature on the use of Personal Assistance Services (PAS) in the workplace. The studies found uncovered issues related to (a) recruiting, training, and retaining personal assistants, (b) employer concerns, (c) costs and benefits of workplace PAS, (d) wages and incentives for personal assistants, and (e) sources for financing PAS as a workplace accommodation. The findings reveal the value and benefits of effective PAS on the job. PAS can lead to successful employment of people with disabilities when other accommodations cannot provide adequate workplace support. Additionally, the evolution of workplace PAS is dependent on development of realistic PAS policy and funding options.	Low	Medium	Low

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Dynek C, Johnson M, Mardon R, et al. Clinical-Community Relationships Measures Atlas. Rockville, MD: Agency for Healthcare Research and Quality (AHRQ); 2013. AHRQ Publication No. 13-00334-EF. Available at http://www.ahrq.gov/sites/default/files/publications/files/ccrmatlas.pdf. Last accessed November 2015.	Clinical-community partnerships are a potentially powerful mechanism by which the delivery of preventative services can be enhanced. Measures are important for fostering these relationships as they help to identify vital relationship components as well as help link these relationships to health outcomes of interest. The purpose of the Atlas is to: 1. Provide a framework for understanding measurement of clinical-community relationships; 2. Provide a list of existing measures for clinical-community relationships; 3. Align existing measures with the framework; 4. Provide further details on existing measures. The Atlas proposes a Measurement Framework consisting of two dimensions — Elements (clinic/clinician; patient; community resource) and Relationships (clinic/clinician-patient; clinic-clinician community-resource; patient-community resource) — and three categorizing domains — Structure, Process and Outcome. The elements of the model identify key players in the clinical-community relationships, and the relationships identify the various interactions between these key players. The measure map cross-references 22 measures with the Framework's elements and categorizing domains and provides measurement specifications for each reviewed measure. The review contains measures used in, or that have the potential to be used in, primary care practices since this setting is viewed as the point of origin for preventative activities. Patient health outcomes are excluded. Primary care practices may have relationships with agencies or providers who fall within the umbrella of HCBS meaning these measures may be applicable, particularly in terms of whether and to what extent HCBS providers are engaged in preventative health care activities.	Medium	Medium	High
Egbert N, Dellmann-Jenkins M, Smith GC, et al. The emotional needs of care recipients and the psychological well-being of informal caregivers. Implications for home care clinicians. *Home Health Nurs.* 2008;26(1):50-57.	This study describes the results of a phone interview of 77 informal caregivers of older persons in Ohio. Participants were surveyed on their perceived difficulty providing emotional and physical care, perceived quality of care, and demographic items including caregivers' health status and measures of their psychological wellbeing. Study findings suggest that psychological well-being of informal caregivers is diminished when they experience greater difficulty meeting the care recipients' emotional needs, are in poorer health, or are older. This study also provides suggestions for clinical implications and future research based on results.	Medium	Medium	Medium

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Eiken S, Burwell B, Gold L, et al. Medicaid Expenditures for Section 1915(c) Waiver Programs in FFY 2012. Baltimore, MD: CMS; 2014. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/1915-C-Expenditures-Report.pdf. Last accessed August 2015.	This report summarizes the Medicaid Section 1915 (c) expenditures, a subset of overall Medicaid LTSS spending, and provides the number of programs by target population. Section 1915(c) waivers targeting people with developmental disabilities comprise the largest number of programs and greatest share of spending across all LTSS population groups. Other populations most commonly targeted include older adults and people with physical disabilities. Less common are programs for people with brain injuries, medically fragile children, people with HIV/AIDS, and people with serious mental health conditions.	High	High	High
Eiken S, Sredl K, Burwell B, et al. Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services were a Majority of LTSS Spending. Ann Arbor, MI: Truven Health Analytics; 2015. Available at http://medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf. Last accessed November 2015.	This report provides in-depth information on the annual Medicaid LTSS expenditure reports compiled primarily from CMS-64 reports used by states to claim federal matching funds for their Medicaid expenditures. This report summarizes and describes national trends regarding the HCBS portion of Medicaid LTSS expenditures, the rate of increase in Medicaid LTSS expenditures, the percentage of total Medicaid spending used for LTSS, variation by state, variation by targeted population group, the use of managed care for LTSS, and changes in federal authority used to deliver LTSS over time. This report also includes numerous data tables that provide expenditures by service category and state.	High	High	High
Eiken S, Sredl K, Gold L, et al. Medicaid Expenditures for Long-Term Services and Supports in FFY 2012. Baltimore, MD: CMS; 2014. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/LTSS-Expenditures-2012.pdf. Last accessed August 2015.	This report summarizes the expenditure data of long-term services and supports (LTSS) and describes the following national trends: the rate of increase in Medicaid LTSS expenditures, the percentage of total Medicaid spending used for LTSS, the HCBS portion of Medicaid LTSS expenditures, variation by state, variation by targeted population group, and changes in federal authorities used to deliver LTSS over time. This report includes numerous data tables that detail expenditures by service category and state.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Eiken S, Sredl K, Gold L, et al. Medicaid Expenditures for Long-Term Services and Supports in FFY 2012. Baltimore, MD: CMS; 2014. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/LTSS-Expenditures-2012.pdf. Last accessed October 2015.	This report provides a detailed overview of trends in total LTSS expenditures from 1995-2012. This report breaks down LTSS as a percent of Medicaid, HCBS as a percent of total LTSS, variation by population, and changes in program authorities authorizing LTSS. The findings in this report state that LTSS has increased as a percentage of total Medicaid spending in 2012 due to a decrease in total Medicaid spending overall. LTSS expenditure trends demonstrate federal and state initiatives have begun to shift the balance of costs from institutional services to HCBS. HCBS accounted for 70 percent of spending in programs targeting people with developmental disabilities, 39 percent of spending in programs targeting older people or people with physical disabilities, and 35 percent of spending in programs targeting people with serious mental illness or serious emotional disturbance. The majority of HCBS funding has been attributable to the Section 1915(c) waiver programs.	High	High	High
Eldercare Workforce Alliance. Advanced direct care worker: a role to improve quality and efficiency of care for older adults and strengthen career ladders for home care workers. *Ann Longterm Care.* 2014;22(12):30-34.	In response to a growing number of older adults (many expected to age in home- and community-based settings) and the need to stabilize the eldercare workforce, this brief by the Eldercare Workforce Alliance (EWA) proposes fostering advanced roles for direct care workers within the home setting, to improve the quality of person- and family-centered care and address demands for a high-functioning eldercare workforce. Currently, 75 percent of paid, hands-on care is provided by direct care workers. The Alliance believes that with the appropriate training, supervision, and support, some home care workers can play an enhanced role, with more responsibility for improving the safety and quality of care for older adults and their family caregivers. The brief details findings from a series of roundtable discussions between EWA-convened interdisciplinary teams over a three-year period. Findings include the need for improved respect, engagement, and training for all direct care workers, and the many roles that the advanced direct care workers can fill towards providing comprehensive older-adult care.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Eldercare Workforce Alliance. Quality Care through a Quality Workforce. A Toolkit for Advocates of Older Adults who are Dually Eligible for Medicare and Medicaid. Washington, DC: Eldercare Workforce Alliance; 2014. Available at http://www.eldercareworkforce.org/files/DUALS/EWA_Duals_Tookit_-_FINAL_v1_-_October_2014.pdf. Last accessed November 2015.	This purpose of this toolkit is to provide advocates of dually eligible older adults with the knowledge, information and tools to effectively advocate for high-quality, coordinated, person- and family-centered healthcare and LTSS. The toolkit is particularly focused on ensuring that the eldercare workforce is trained in gerontology and geriatrics. The toolkit includes: national and state-specific information on older adults who are dually eligible for both Medicare and Medicaid; background on how a well-trained and supported eldercare workforce can impact the quality of care, services and supports being delivered; and specific tools, checklists, and resources for advocacy efforts. The toolkit was designed by the Eldercare Workforce Alliance — a coalition of 30 national organizations tasked to address the workforce crisis in caring for older Americans and their families — to "help advocates ensure that older adults are receiving coordinated, person- and family-centered care, services and supports" from the eldercare workforce (including family caregivers).	High	Medium	Medium
Electronic Long-Term Services & Supports Initiative Glossary. Available at https://view.officeapps.live.com/op/view.aspx?src=http%3A%2F%2Fwiki.siframework.org%2Ffile%2Fview%2FeLTSS%2520Glossary%252022DEC14.docx%2F539861068%2FeLTSS%2520Glossary%252022DEC14.docx. Last accessed November 2015.	The term "long-term services and supports" is not easily defined and encompasses a multitude of concepts and government programs. The purpose of this document is to provide descriptions of some of those concepts and programs as well links to the website from which the descriptions are derived. Key concepts that are described include long-term services and supports, home and community-based services (HCBS), person-centered planning, and plan of care versus care plan. A single definition for HCBS is not proposed, but rather, many are presented. Key government programs described include Section 1915(c) of SSA, Section 2402 (a) of ACA, State Plan HCBS and the eLTSS Initiative. These concepts and programs are commonly referenced when discussing HCBS so the document provides a resource for becoming familiar with the general ideas encompassed by these terms. Specific measures of these concepts and for these programs were not included.	Low	Low	High
Environmental Scan of Assessment and Care Planning Quality Measures. Assessment and Care Planning Appendix 2.	This report describes the purpose and process of the environmental scan of assessment and care planning quality measures. The purpose of this project was to develop a set of performance measures that can be used to evaluate the processes of assessment and care planning for individuals receiving MLTSS. This report references NQF's 2012 report titled Measuring Healthcare Quality for the Dual Eligible Beneficiary Population on developing person- and family-centered measures.	High	High	High

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Fernandes R, Braun KL, Ozawa J, et al. Home-based palliative care services for underserved populations. *J Palliat Med.* 2010;13(4):413-419.	The study measures symptom relief and quality of life, resource utilization, and satisfaction with home-based palliative care (HBPC) in Kakua Kalihi Valley. This area is one of the first federally qualified community health centers offering such services to low-income immigrant populations from Asia/Pacific Islands whose end-of-life needs are rarely addressed. This prospective study collected data from the Missoula-Vitas QOL Index, Edmonton Symptom Assessment Scale, and the Palliative Performance Scale. This study found that more than half of participants had chronic neurodegenerative conditions. However, data on outcomes and quality indicators of HBPC programs are scantily available particularly among Asian/Pacific Islander populations.	Medium	Medium	Medium
Field MJ, Jette AM. The Future of Disability in America. Washington, DC: National Academies Press; 2007. Available at http://www.nap.edu/catalog/11898/the-future-of-disability-in-america. Last accessed October 2015.	This IOM report provides an in depth understanding of disability in the United States through an assessment of the current situation. It also provides recommendations for improvement. The committee reviewed the developments since two previous IOM reports on disability, analyzed a number of shortcomings in the nation's disability policies and programs, and raised serious questions about how individuals and society will cope with the challenges of disability. This report concludes that immediate action is essential for the nation to avoid harm and to help people with disabilities lead independent and productive lives.	High	High	Medium
Firman C. Measuring Systems Change and Consumer Outcomes. Recommendations for Developing Performance Metrics for State Lifespan Respite Programs. Chapel Hill, NC: National Respite Network and Resource Center (ARCH); 2014. Available at http://archrespite.org/images/docs/2014_Guidebooks/PerformanceMeasurmentGuide_web.pdf. Last accessed November 2015.	This document provides a roadmap with tools and step-by-step suggestions for developing a performance measurement plan for determining success among the Lifespan Respite Programs grantees. The goal of the Lifespan Respite Care Program is to improve the delivery and quality of respite services by supporting, expanding, and streamlining coordinated systems of community-based respite for all family caregivers across the disability and age spectrum. The report provides and overview of what defines performance measurement including specific issues to consider when developing, implementing and evaluating measures for Lifespan Respite Programs. A menu of measures and indicators reflecting systems change and caregiver/consumer change is provided as well as links to the original sources for each measure or indicator. Many of the measures were provided by Lifespan Respite grantees.	High	High	High

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Flanagan S, Howard J, Urdapilleta O, et al. National Balancing Indicators Project Implementation Options Report. Baltimore, MD: CMS; 2014.	This report incorporates findings from the Final NBI Final Report (NBIC), Crosswalk Report, Indicator Refinements and Expansions Report, and findings from the online 2012 state self-assessment survey. The final Implementation Options Report was used as a guide for CMS in deciding on the final set of NBIs, data collection requirements, data infrastructure development, and other aspects of developing a balanced LTSS system consistent with CMS' vision.	High	High	High
Flanagan S, Howard J, Urdapilleta O, et al. National Balancing Indicators Project Measure Additions and Refinement Final Report. Baltimore, MD: CMS; 2014.	The purpose of the National Balancing Indicators project was to develop a conceptual framework for LTSS balancing and to develop and test the feasibility of implementing a set of National Balancing Indicators (NBIs) that States could use to measure federal and state efforts towards attaining and maintaining balanced, person-driven LTSS systems. The NBIP Team has integrated comments and recommendations on the NBIC indicators from stakeholders into the NBI Additions and Refinements Report. As part of the indicator review, modification, and addition activities, the NBIP conducted background research on the proposed set of updated NBI indicators, NBI developmental indicators, and new, additional indicators identified.	High	High	High
Gagnon M, Hebert R, Dube M, et al. Development and validation of an instrument measuring individual empowerment in relation to personal health care: the Health Care Empowerment Questionnaire (HCEQ). *Am J Health Promot.* 2006;20(6):429-435.	This study describes the purpose of developing and validating a questionnaire that measures the degree of individual empowerment in relation to personal healthcare services. The Health Care Empowerment Questionnaire (HCEQ) was developed using individual empowerment indicators, literature review, and pretesting the tool with older persons participating in the Program of Research to Integrate Services for Maintenance Autonomy (PRISMA) in Canada. This study included 873 subjects and described the multidimensional nature of the concept of individual empowerment. These findings are potentially useful in advancing knowledge about individual empowerment in relation to personal healthcare services.	High	High	High
Galantowicz S. Implementing Continuous Quality Improvement (CQI) in Medicaid HCBS Programs. Baltimore, MD: CMS; 2010.	This report presents the continuous quality improvement (CQI) efforts for state HCBS waiver programs. It describes the design-discovery-remediation-improvement (DDRI) model and variation in the ways this model has been implemented across states. The report also provides a case study to assist readers in understanding how the model is typically used.	High	High	High

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GAO. Adults with Severe Disabilities Federal and State Approaches for Personal Care and Other Services. Washington, DC: GAO; 1999. Available at http://www.gao.gov/assets/230/227309.pdf. Last accessed August 2015.	The report provides estimates for the number and characteristics of adults with severe disabilities; quantifies the federal assistance available to such individuals; describes Medicaid coverage of personal care and related services; and discusses how a sample of selected states have implemented Medicaid policies that allow consumers to select their own caregivers, an approach called consumer direction.	High	High	High
GAO. Long-Term Care Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened. Washington, DC: GAO; 2003. Available at http://www.gao.gov/new.items/d03576.pdf. Last accessed August 2015.	This report presented findings from the GAO's task to review (1) trends in states' use of Medicaid home and community-based service (HCBS) waivers, particularly for the elderly, (2) state quality assurance approaches, including available data on the quality of care provided to elderly individuals through waivers, and (3) the adequacy of federal oversight of state waivers. The GAO recommended that the Administrator of CMS take steps to (1) better ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries, and (2) strengthen federal oversight of the growing HCBS waiver programs. Although CMS raised certain concerns about aspects of the report, such as the respective state and federal roles in quality assurance and the potential need for additional federal oversight resources, CMS generally concurred with the recommendations.	High	High	High
GAO. Medicaid Home and Community-Based Waivers CMS Should Encourage States to Conduct Mortality Reviews for Individuals with Developmental Disabilities. Washington, DC: GAO; 2008. Available at http://www.gao.gov/new.items/d03576.pdf. Last accessed August 2015.	This report contains recommendations to CMS that include (1) encouraging states to conduct mortality reviews or broaden processes for such reviews and (2) establishing an expectation for reporting deaths to state protection and advocacy agencies. HHS stated that CMS concurred with the first recommendation. However, the agency did not fully address it. HHS did not state whether CMS agreed or disagreed with the second recommendation.	Medium	High	Medium
GAO. Medicaid States' Plans to Pursue New and Revised Options for Home- and Community-Based Services. Washington, DC: GAO; 2012. Available at http://www.gao.gov/assets/600/591560.pdf. Last accessed August 2015.	This report outlines the key findings from the GAO's work to assess the implementation status of the four Medicaid HCBS options in PPACA. GAO assessed (1) how the four options are structured to increase the availability of services, (2) what is known about states' plans to use the options, and (3) factors affecting states' decisions regarding implementing the options. To determine the structure of the options, GAO reviewed federal statutes and regulations and interviewed officials at CMS. To determine what is known about states' plans, GAO obtained copies of states' grant applications and state plan amendments. To understand factors affecting states' decisions, GAO conducted interviews with officials in 10 states. The states were selected to reflect a range of state Medicaid spending for HCBS as a percentage of total Medicaid expenditures for long-term services and supports.	High	High	High

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GAO. Older Americans Act: More Should Be Done to Measure the Extent of Unmet Need for Services. Washington, DC: GAO; 2011. Available at http://www.gao.gov/new.items/d11237.pdf. Last accessed August 2015.	The report highlights the GAO's request to find (1) what is known about the need for home- and community-based services like those funded by OAA and the potential unmet need for these services; (2) how have agencies used their funds, including Recovery Act funds, to meet program objectives, and (3) how government and local agencies measured need and unmet need. To do this, GAO analyzed national self-reported data; surveyed a random sample of 125 local agencies; reviewed agency documents; and spoke with officials from the Administration on Aging (AoA) and state and local agencies. GAO recommended that the Department of Health and Human Services study the effectiveness of cost-sharing and definitions and measurement procedures for need and unmet need. The agency expressed that they would explore options for implementing the recommendations.	High	High	High
Geron SM, Smith K, Tennstedt S, et al. The home care satisfaction measure: a client-centered approach to assessing the satisfaction of frail older adults with home care services. *J Gerontol B Psychol Sci Soc Sci.* 2000;55(5):S259-S270.	The Home Care Satisfaction Measure (HCSM) is a tool based on consumer definitions of satisfaction, including perspective of ethnic minorities. HCSM provides an overall home care satisfaction score and subscale scores (0-100) for five common services. Researchers conducted focus groups with various minority populations. The instrument was also field tested with 228 frail, low-income, older home care recipients. The results of this study showed high internal consistency reliabilities, scores were not associated with gender, race, or age but was negatively associated with physical disability. In addition, significant social desirability effects were found.	High	High	High
Gervey R, Gao Ni, Tillman D, et al. Person-centered employment planning teams: a demonstration project to enhance employment and training outcomes for persons with disabilities accessing the One-Stop Career Center System. *J Rehabil.* 2009;75(2):43-49.	The article describes the method and findings of the employment and training trajectory of a self-selected sample of the One-Stop customers with psychiatric disabilities. The One-Stop center was created as a result of the 1998 Workforce Investment Act that combined a fragmented federal, state, and local employment training system. The primary population for the Person-Centered Employment Planning Team (PCEPT) project included persons willing to disclose the presence of a psychiatric disability and participate in an interview designed to assess the functional limitations of their disability and need for intensive support services. The study found that 65 percent were ultimately placed in a job or training program. Thus, the PCEPT process appears to fill an important gap for a minority of individuals with severe disabilities seeking services within the One-Stop system.	Medium	Medium	Low

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Ghosh A, Orfield C, Schmitz R. Evaluating PACE: A Review of the Literature. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/PACELitRev.pdf. Last accessed August 2015.	This paper brings together available evidence on the effect of PACE on several key outcomes of interest—Medicare and Medicaid costs; hospital and NH utilization; quality of care, satisfaction and quality of life; and mortality. The investigators summarize findings from past studies and assess their methodological approach. Both published articles as well as research reports are included in this review. Several key findings emerged from this literature review regarding the design and methodological approaches of prior PACE evaluations as well as on the effectiveness of PACE in controlling spending, reducing hospitalizations and NH use, and improving quality of care and satisfaction.	High	High	Medium
Gitlin LN, Winter L, Dennis MP, et al. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA.* 2010;304(9):983-991.	This study is a prospective 2-group randomized trial involving patients with Dementia (COPE) and family caregivers. The purpose of the study was to test nonpharmacologic intervention realigning environmental demands with patient capabilities. The results of this study found that COPE patients had less functional dependence and less dependence in instrumental activities of daily living.	High	High	High
Gottlieb BH, Bergen AE. Social support concepts and measures. *J Psychosom Res.* 2010;69(5):511-520.	This article makes distinctions among concepts and approaches to assessing social supports as well as reviews published general and specialized measures of social supports. Observational and self-reported measures of support are presented, along with brief and extensive measures. A final set of three support measures is highlighted, including their psychometric properties. This report provides variety of measures and measure concepts in this topic area.	High	High	High
Government Accountability Office (GAO). Older Adults. Federal Strategy Needed to Help Ensure Efficient and Effective Delivery of Home and Community-Based Services and Supports. Washington, DC: GAO; 2015. Available at http://www.gao.gov/assets/680/670306.pdf. Last accessed November 2015.	This report describes a GAO study that addresses federal programs that fund HCBS services for older adults, how they were planned and delivered in selected localities, and agencies' efforts to promote a coordinated federal system. GAO reviewed federal program documents, interviewed federal officials, and visited programs in various areas across three states. These states were selected based on efforts made to enhance their system of HCBS and supports, recommendations from federal agencies and experts, varied governmental jurisdiction, and geographic dispersion. As a result of this study, the GAO recommends that HHS facilitate development of a cross-agency federal strategy to ensure efficient and effective use of federal resources for HCBS. HHS concurred and HUD, DOT, and USDA did not comment.	High	Medium	Low

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Gray DB, Hollingsworth HH, Stark SL, et al. Participation survey/mobility: psychometric properties of a measure of participation for people with mobility impairments and limitations. *Arch Phys Med Rehabil.* 2006;87(2):189-197.	This article describes the development and psychometric properties of the Participation Survey/Mobility (PARTS/M), a self-report survey of participation by people with mobility limitations. Researchers conducted interviews and focus groups to develop items of the PARTS/M as well as collected demographics and measures of disability, health, and functioning. This test was administered twice to a sample of 604 people with mobility limitations including SCI, MS, CP, stroke, or postpoliomyelitis. This survey is composed of 20 major life activities across six domains used in the International Classification of Functioning, Disability, and Health and was found to have good internal consistency. Researchers concluded that the PARTS/M was a reliable measure of some aspects of participation in major life activities for people with mobility impairments and limitations in community settings.	High	High	High
Groschl S. Presumed incapable: exploring the validity of negative judgments about persons with disabilities and their employability in hotel operations. *Cornell Hospital Quart.* 2012;54(2):114-123.	Research has found that managers in the hotel industry have a very negative perception of persons with disabilities in the workplace suggesting that they are unable to meet industry specific work requirements and are too costly to employ. The findings of this study offer a counterargument to such perceptions. Based on interviews with 49 managers, employers, and guests, with and without disabilities, and nine days of observations, researchers found very positive attributes associated with employees with disabilities in relation to the workplace. These findings indicate that maintaining an open and tolerant atmosphere is essential to the integration of persons with disabilities in the workplace.	Low	Low	Low
Guo J, Konetzka T, Magett E, et al. Quantifying long-term care preferences. *Med Decis Making.* 2015;35(1):106-113.	This study quantifies LTC preference between different delivery modes based on previous studies indicating that the shift to home care is not as cost efficient. In this study, users' LTC preferences are measured as differential utilities between alternative LTC options for each health state. For the same health state, respondents significantly preferred home care over institutional care, except for the most impaired health state. The preference for home care depends significantly on levels of disability and was weaker once the need for help became greater.	Medium	Medium	Medium

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Hagner D, Kurtz A, Cloutier H, et al. Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus Autism Other Dev Disabl.* 2012;27(1):42-50.	This article describes the results of a study conducted to determine the outcomes of a family-centered transition process for students along the ASD using a three-component intervention plan. The study consisted of 47 young individuals with ASD ages 16-19. Participants were randomly assigned to two groups. Year 1: group received a transition planning intervention consisting of group training sessions for families in the transition process, person-centered planning meetings facilitated by project staff, and follow-up assistance with career exploration and plan implementation. Year 2: group began receiving services following the second data collection point. The results of this study found that the Year 1 group reported statistically significant increases in all four measured variables, whereas the Year 2 group showed no significant changes. Implications for redesigning transition services for this population are discussed.	High	High	Low
Harrow M, Jobe TH, Faull RN. Does treatment of schizophrenia with antipsychotic medications eliminate or reduce psychosis? A 20-year multi-follow-up study. *Psychol Med.* 2014;44(14):3007-3016.	This study assesses whether multiyear treatment with antipsychotic medications reduces or eliminates psychosis in schizophrenia. This is a 20-year longitudinal study on the frequency and severity of psychotic activity in samples of SZ patients treated versus those not treated with antipsychotic medications. The study included 139 early young SZ and mood-disordered patients assessed at index hospitalization and then reassessed six times over 20 years for psychosis and other major variables. The results of this study found that at each follow-up assessment a large percentage of SZ patients treated with antipsychotic medication experienced more psychotic activity compared to SZ patients not prescribed medication. This study concludes that antipsychotic medications do not eliminate or reduce the frequency of psychosis in schizophrenia, or reduce the severity of post-acute psychosis.	Low	Medium	Low

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Harrow M, Jobe TH. Factors involved in outcome and recovery in schizophrenia patients not on antipsychotic medications: a 15-year multifollow-up study. *J Nerv Ment Dis.* 2007;195(5):406-414.	This article provided an overview of the prospective longitudinal 15-year multi-follow-up research study on whether unmedicated patients with schizophrenia can function as well as schizophrenia patients on antipsychotic medications. The study showed that a larger percent of schizophrenia patients not on antipsychotics had periods of recovery and better global functioning (p .001). The longitudinal data identified a subgroup of schizophrenia patients who do not immediately relapse while off antipsychotics and experience intervals of recovery. Their more favorable outcome is associated with internal characteristics of the patients, including better premorbid developmental achievements, favorable personality and attitudinal approaches, less vulnerability, greater resilience, and favorable prognostic factors. The current longitudinal data suggest not all schizophrenia patients need to use antipsychotic medications continuously throughout their lives. This article mentions the locus of control (LOC) and self-esteem measure concepts. The early prognostic potential and developmental achievements utilized two widely used measures including the Zigler-Phillips scale, an index of earlier developmental achievements, is based on patients' work history, education, marital status, age at onset and IQ; and, the other is a composite index of prognostic potential.	Low	Medium	Low
Harvard Joint Center for Housing Studies, AARP Foundation. Housing America's Older Adults – Meeting the Needs of an Aging Population. Cambridge, MA: 2014. Available at. http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/jchs-housing_americas_older_adults_2014.pdf. Last accessed October 2015.	This report provides an in-depth overview of the current demographics in an aging America, housing and financial security, accessibility needs and the existing stock, social connection and community support, linking housing and LTSS, and housing for an aging society.	High	High	High
Hatton C, Wigham S, Craig J. Developing measures of job performance for support staff in housing services for people with intellectual disabilities. *J Appl Res Intellect Disabil.* 2009;22(1):54-64.	This research study employed a worker-oriented job analysis method to develop four short job performance measures (self-report questionnaires) for direct housing support staff, from the perspective of people with intellectual disabilities, family members, support staff, and service managers. All four measures demonstrated adequate internal and test-retest reliability and showed very few associations with staff and resident characteristics, although there were no associations between the job performance measures. The service user and manager-rated job performance measures showed the widest range of associations with aspects of staff well-being, service quality and service user choice, and satisfaction with life, and showed the most promise as short, practical measures of the job performance of direct housing support workers.	Medium	Medium	Low

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Health IT Policy Committee. PowerPoint presentation to the Quality Measures Workgroup: Recommendations to HITPC; May 1, 2014. Available at http://www.healthit.gov/facas/sites/faca/files/HITPC_QMWG_LTPAC_BH_Rec_2014-05-06_0.pdf. Last accessed August 2015.	This presentation details the work of the Health IT Policy Committee. They were tasked with identifying the infrastructure needed to support quality measurement in the LTPAC/BH settings. They set out to identify the foundational capabilities/minimum functions that EHR systems need to perform quality measurement; certification of minimal data elements or assessment tools needed; and gaps that need to be addressed and/or barriers. The presentation provides information on EHR use in long-term and post-acute care.	High	High	Medium
HealthIT.gov. Program initiatives HIT trailblazer states website. http://www.healthit.gov/policy-researchers-implementers/hit-trailblazer-states. Last accessed August 2015.	This website describes the HIT Trailblazer States. This initiative began to support the alignment of state-level HIT activities and other efforts to transform the healthcare delivery system. The initiative was supported by the Office of the National Coordinator for Health Information Technology (ONC), the National Academy for State Health Policy (NASHP), Research Triangle Institute (RTI), and Deloitte Consulting LLP. The Trailblazer States initiative has included two phases to date. The website describes the phases of the project. It includes two briefs that discuss the results of the in-person meetings. This source is peripherally relevant.	High	Medium	High
Herman M, Ensslin B. Innovations in Integration: State Approaches to Improving Care for Medicare-Medicaid Enrollees. Hamilton, NJ: Center for Health Care Strategies (CHCS); 2013. Available at http://www.chcs.org/media/Innovations_in_Integration_022213_2.pdf. Last accessed October 2015.	This policy brief summarizes select state plans for financial alignment initiatives and examines some of the innovative design approaches that have been proposed. This information and a discussion of common issues in creating integrated programs is meant to be a resource for other states considering similar programs for this high-need, high-cost population.	High	Medium	Medium
HHS Administration on Aging (AoA). National family caregiver support program (OAA Title IIIE). http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/index.aspx. Last accessed November 2015.	This website highlights services and supports available for caregivers. • Information to caregivers about available services, • assistance to caregivers in gaining access to the services, • individual counseling, organization of support groups, and caregiver training, • respite care, and • supplemental services, on a limited basis.	High	Medium	Medium

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HHS, Administration on Aging (AoA). National survey of Older Americans Act participants website. https://aoasurvey.org/default.asp. Last accessed November 2015.	The Administration for Community Living (ACL) oversees Administration on Aging (AoA) programs and conducts the National Survey of Older Americans Act (OAA) Participants. This is a national sample survey of programs on aging funded by Title III of the Older Americans Act. The purpose of this survey is to provide ACL/AoA with an effective method for collecting data on Title III programs. The results of this study help ACL/AoA meet its accountability requirements to the President. The results also demonstrate to Congress how well programs are achieving their legislative goals.	High	Medium	Medium
HHS, Administration on Aging (AoA). Technical assistance exchange website. http://www.adrc-tae.acl.gov/tiki-index.php?page=HomePage. Last accessed November 2015.	This website provides a forum to allow a diverse community of stakeholders involved in making changes to their long-term services system to exchange ideas, knowledge, and best practices. The U.S. Administration for Community Living, which includes the Administration on Aging, sponsors this Exchange to make information and resources available to states and community organizations. ACL is committed to supporting states' efforts to develop and sustain a person-centered, self-directed national long-term supports and services system.	High	Medium	Medium
HHS, CMS. Principles and Strategy for Accelerating Health Information Exchange (HIE). Washington, DC: Office of the National Coordinator for Health Information Technology; 2013. Available at https://www.healthit.gov/sites/default/files/acceleratinghieprinciples_strategy.pdf. Last accessed October 2015.	This report describes the need for interoperability among health information exchanges (HIE). HIEs must be able to exchange information and use the information that has been exchanged. It cites that although there has been widespread adoption of EHRs throughout the U.S., there is very little HIE involving post-acute and institutional long-term care. The report goes on to outline the various supports that CMS is offering to develop their HIE infrastructure.	High	High	High
HHS. 2014 Annual Report on the Quality of Care for Children in Medicaid and CHIP. Washington, DC: HHS; 2014. Available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/downloads/2014-child-sec-rept.pdf. Last accessed August 2015.	This report provides a detailed overview of CMS' collaboration with states on reporting of Child Core Set measures and presents information on key activities CMS undertook to ensure accurate updates on the quality of care children receive in Medicaid/CHIP. This report also provides findings on state-specific quality and access in Medicaid and CHIP. It describes quality measurement using the Core Set of Children's Health Care Quality Measures as well as changes in state reporting of the Child Core Set for FFY 2013.	High	High	High

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		Impact	Improvability	Inclusiveness
HHS. 2014 Annual Report on the Quality of Health Care for Adults Enrolled in Medicaid. Washington, DC: HHS; 2014. Available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/downloads/2014-adult-sec-rept.pdf. Last accessed August 2015.	This report summarizes information on the quality of healthcare furnished to adults covered by Medicaid. To promote a better understanding of healthcare quality efforts targeting adults enrolled in Medicaid, this report discusses the status of quality measurement and reporting efforts using the Medicaid Adult Core Set and summarizes information on managed care performance measures and performance improvement projects (PIPs) reported in external quality review (EQR) technical reports submitted to CMS by states. The report also describes performance improvement projects in 2013-14. It includes 2013 Core Set of Health Care Quality Measures for Adults enrolled in Medicaid.	High	Medium	Medium
HHS. Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure. Washington, DC: Office of the National Coordinator Health Information Technology; 2014. Available at https://www.healthit.gov/sites/default/files/ONC10yearInteroperabilityConceptPaper.pdf. Last accessed October 2015.	This report describes HHS's mission to protect the health of all Americans and provide essential human services, especially for those who are least able to help themselves. It stresses that achieving this goal will only be possible with a strong, flexible health IT ecosystem that can appropriately support transparency and decisionmaking, reduce redundancy, inform payment reform, and help to transform care into an model that enhances access and truly addresses health beyond the confines of the healthcare system. The report describes HHS's vision for the future of HIT, guiding principles upon which to realize that vision and a specific 3-, 6-, and 10-year agenda.	High	High	High
HHS. HCBS Waiver Assurances and Sub-Assurances. Available at http://dhhs.ne.gov/Documents/HCBS%20Waiver%20Sub-Assurances.pdf. Last accessed November 2015.	This document provides a brief outline of HCBS Waiver Assurances and Sub-Assurances including administrative authority, level of care, qualified providers, and service plans.	Medium	Low	Low
HHS. Health IT in Long-Term and Post-Acute Care Issue Brief. Washington, DC: Office of the National Coordinator for Health Information Technology; 2013. Available at https://www.healthit.gov/sites/default/files/pdf/HIT_LTPAC_IssueBrief031513.pdf. Last accessed October 2015.	This issue brief provides an overview of the opportunities for long-term and post-acute care (LTPAC) providers to use health information technology (IT) to improve care delivery and health outcomes while reducing total cost of care. The first section defines the issue. The second section provides background information on the current landscape of health IT in LTPAC and an overview of the challenges and opportunities to improve care coordination and patient outcomes through the use of health IT in LTPAC settings. The third section highlights promising examples of how health IT tools and standards-based health information exchange (HIE) are enabling patient-centered care. The fourth section summarizes many healthcare transformation programs that represent opportunities for LTPAC providers to be integrated into health IT-enabled healthcare delivery and payment programs. The fifth section summarizes the key considerations for the LTPAC community today in deciding how to use health IT to transform care and the sixth and final section provides suggestions for additional resources to aid the LTPAC community as providers implement tools and standards-based HIE.	High	High	High

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HHS. Homelessness website. http://www.hhs.gov/programs/social-services/homelessness/index.html. Last accessed November 2015.	This government resource page provides a brief overview of homelessness as well as the supportive services available by government and community organizations. This webpage leads to other links to information on grants, research, additional resources, and federal links.	High	High	High
HHS. Multiple Chronic Conditions – A Strategic Framework: Optimum Health and Quality of Life for Individuals with Multiple Chronic Conditions. Washington, DC: HHS; 2010. Available at http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf. Last accessed August 2015.	This report presents the strategic framework for the U.S. Department of Health and Human Services (HHS) to improve the health status of individuals with multiple chronic conditions. This framework contains a vision statement, goals, objectives, and strategies to guide the department in coordinating its efforts internally and collaborating with stakeholders externally. The framework is designed to address the spectrum of all population groups with multiple chronic conditions. The report also describes the role of HCBS in enabling individuals with MCCs to live and work successfully in their communities.	High	Medium	High
HHS. National Plan to Address Alzheimer's Disease: 2013 Update. Washington, DC: Assistant Secretary for Planning and Evaluation; 2013. Available at http://aspe.hhs.gov/daltcp/napa/natlplan.pdf. Last accessed August 2015.	This report describes the coordination and integration of LTSS for individuals living with AD. It presents the National Alzheimer's Project objectives which seek to: • Create and maintain an integrated national plan to overcome Alzheimer's disease. • Coordinate Alzheimer's disease research and services across all federal agencies. • Accelerate the development of treatments that would prevent, halt, or reverse the course of Alzheimer's disease. • Improve early diagnosis and coordination of care and treatment of Alzheimer's disease. • Improve outcomes for ethnic and racial minority populations that are at higher risk for Alzheimer's disease. • Coordinate with international bodies to fight Alzheimer's globally.	High	High	Medium
HHS. Substance Abuse and Mental Health Services Administration. SAMHSA's National Registry of Evidence-based Programs and Practices website. http://www.nrepp.samhsa.gov/. Last accessed November 2015.	NREPP is a searchable online registry of more than 350 substance abuse and mental health interventions. NREPP was developed to help the public learn more about evidence-based interventions that are available for implementation. There are some assessment tools that have been tested and are considered valid and reliable in evaluating patient response to treatments.	High	High	High

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Higgins A, Veselovskiy G, McKown L. Provider performance measures in private and public programs: achieving meaningful alignment with flexibility to innovate. *Health Aff.* 2013;32(8):1453-1461.	The article describes a study of 23 health plans with 121 million enrollees to characterize the use of performance measures by private payers as well as compare the use of these measures among selected private and public programs. The health plans reported using 546 distinct performance measures; however, there was much variation between private and public payment and care delivery programs despite common areas of focus (i.e. CV, diabetes, and preventive services). Researchers concluded that policymakers/stakeholders who seek less variability in the use of performance measures to increase consistency should balance the need for flexibility to meet the needs for specific populations and promote innovation.	High	High	High
Home & Community Based Services Clearinghouse (NCBS.org). Participant experience survey (PES) tools website. http://www.nasuad.org/hcbs/article/participant-experience-survey-pes-tools. Last accessed August 2015.	The Participant Experience Surveys (PES) solicit feedback directly from waiver participants about the services and supports they receive under the Medicaid Home and Community-Based Services (HCBS) waiver program. States can use these data to calculate performance indicators for monitoring quality within their waiver programs, to guide quality improvement projects, and to use in conjunction with other quality management strategies. The PES instruments were developed by The MEDSTAT Group, Inc. (Medstat) under contract to the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (DHHS). This survey style—asking what participants want and then determining if they receive it—is along the lines of an experience survey but with some different approaches. The categories or domains could serve to help structure other surveys for HCBS.	High	High	High
Houser A, Fox-Grage W, Ujvari K. Across the States 2012: Profiles of Long-Term Services and Supports. Washington, DC: AARP Public Policy Institute; 2012. Available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf. Last accessed October 2015.	This report was developed to help inform policy among public and private sector leaders in long-term services and supports throughout the United States. It presents comparable state-level data and national data for more than 140 indicators, drawn together from a wide variety of sources into a single reference.	High	High	High

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Howard J, Zuckerman I, Woodcock C, et al. National Balancing Indicators (NBI) Final Summary Report. Baltimore, MD: CMS; 2014.	The Final Summary Report will incorporate all updates made to the National Balancing Indicators (NBI) indicators, the NBIC developmental indicators and any new, additional indicators resulting from NBI project activities, (such as the DSW indicators). Upon completion of all major project activities (such as indicator data collection and analysis, data infrastructure report, indicator reliability and validity study), the NBI project team will provide the results and findings along with final recommendations for implementation of the final set of NBIs.	High	High	High
Howard J. National Balancing Indicators Fact Sheet. Baltimore, MD: CMS; 2014	The document outlines the seven National Balancing Indicators Project principles field tested in efforts to explore state progress in designing, implementing, and maintaining person-driven and balanced community-based LTSS systems. This effort was commissioned by CMS. The seven NBIP principles include Sustainability, Self-Determination/Person-Centeredness, Shared Accountability, Community Integration and Inclusion, Coordination and Transparency, Prevention, and Cultural and Linguistic Competency.	High	Medium	Medium
Howard J. Selected National Balancing Indicators Project Reports. Baltimore, MD: CMS; 2013.	This document is an annotated bibliography of four reports. The first report is a final summary and next steps of the National Balancing Indicators. The second report describes the implementation options of NBI; the third report describes the additions and refinements report of measures; and the fourth report is a crosswalk of LTSS balancing indicators compared all efforts within the Federal Government and other organizations developing and implementing LTSS indicators.	Low	Low	Low
Hsieh CM. Using client satisfaction to improve case management services for the elderly. *Res Soc Work Pract.* 2006;16(6):605-612.	This article describes the use of a client-centered approach to developing a client satisfaction measure for a case management setting, Client Satisfaction: Case Management (CSAT-CM). This tool is meant to overcome major limitations related to prior client satisfaction studies and can be used to collect client satisfaction data for improved case management services by providers. Preliminary results of this study found the CSAT-CM has desirable psychometric properties and this method has the potential to be adopted by other types of social service agencies.	High	High	High
HUD. Section 811 supportive housing for persons with disabilities program website. http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/grants/section811pt. Last accessed August 2015.	This website describes the purpose of the Supportive Housing for Persons with Disabilities Program. HUD provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities. The Section 811 program allows persons with disabilities to live as independently as possible in the community by subsidizing rental housing opportunities which provide access to appropriate supportive services.	High	Medium	High

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Hughes C, Avoke SK. The elephant in the room: poverty, disability, and employment. *Res Pract Persons Severe Disabil.* 2010;35(1-2):5-14.	This article describes the prevalence and complexities of poverty in the U.S. as it relates to disability and employment. The article describes disability as both a cause and effect of poverty, affecting employment and quality of life of people with severe disabilities particularly those who are racially and ethnically diverse. Researchers propose strategies to address the challenges caused by the intersection of poverty, disability, and employment and efforts to improve the adult lives of people with severe disabilities.	Medium	Medium	Medium
Iezzoni LI. Developing Quality of Care Measures for People with Disabilities: Summary of Expert Meeting. Rockville, MD: Agency for Healthcare Research and Quality (AHRQ); 2010. AHRQ Publication No. 10-0103. Available at http://archive.ahrq.gov/research/findings/final-reports/devqmdis/devqmdis.pdf. Last accessed August 2015.	The purpose of this meeting was to develop an action plan for creating quality-of-care measures for persons with disabilities, which could be derived from existing data. The focus was explicitly methodological with the goal of developing a research agenda for AHRQ concerning healthcare quality metrics for persons with disabilities. The attendees also set out to provide an operational definition of "disability". They discussed several topics such as, priority areas for measurement, data issues, eMeasures, etc.	High	High	Medium
ILRU. IL History and philosophy: orientation for IL staff website. http://www.ilru.org/il-history-and-philosophy-orientation-for-il-staff. Last accessed November 2015.	ILRU (Independent Living Research Utilization) program. A four-part video series with accompanying study guide and descriptive narratives in English and Spanish. This website provides orientation of the IL history and philosophy. There are four modules: 1. One brief history of disability 2. Emergence of independent living 3. Codification of independent living - it's the law 4. Disability policy framework and advocacy	Medium	Medium	Medium
IMPAQ International. National Balancing Indicator Project (NBIP) to Conduct Research, Development, and Technical Assistance on Long-Term Support System Balancing Indicators. Baltimore, CMS; 2014. Available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-incentive-program.html. Last accessed November 2015.	This report describes measure additions/refinements in LTSS provided by input from an expert committee. This Technical Assistance Guide (TAG) by the National Balancing Indicators is used to facilitate CMS/state examination of progress in offering person driven and balanced LTSS systems. This report provides additional guidance/resources for states to collect the necessary measurement information.	High	High	High

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Iris M, Conrad KJ, Ridings J. Observational measure of elder self-neglect. *J Elder Abuse Negl.* 2014;26(4):365-397.	This article describes a study to improve measurement of elder self-neglect by testing the psychometric properties of the Elder Self Neglect Assessment (ESNA). Various health professionals including social workers, case managers, and adult protective services providers from 13 Illinois agencies completed a 77-item assessment for 215 clients experiencing self-neglect. Researchers used the Rasch item response theory and traditional validation approaches to test for dimensionality, model fit, and additional construct validation resulting in a 62-item assessment. Analysis found that the ESNA as well a 25-item short form met the Rasch criteria with internal consistency, item reliability, and construct validity. The results of this study found that ESNA indicators of self-neglect align into two broad categories (behavioral characteristics and environmental factors). Theoretical refinements developed using the empirically generated item hierarchy may help to improve assessment and intervention.	High	High	High
Irvin CV, Denny-Brown N, Bohl A, et al. Money Follows the Person 2013 Annual Evaluation Report. Cambridge, MA: Mathematica Policy Research; 2015. Available at http://www.mathematica-mpr.com/our-publications-and-findings/publications/money-follows-the-person-2013-annual-evaluation-report. Last accessed November 2015.	This report describes Mathematica's national evaluation of the MFP demonstration program from inception through December 31, 13 including how states are progressing on the their transition and HCBS expenditure goals, assessment of how expenditures and utilization of select medical care services change when someone transitions, and the HCBS that participants receive while in the program.	High	High	High
Jackson B, Rivard P, Seibert J, et al. Quality in managed long-term services and supports programs. Washington, DC: HHS, Office of Disablity, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/LTSSqual.pdf. Last accessed August 2015.	This report compares and contrasts how 8 out of 16 states in 2012 established quality oversight in their MLTSS programs for Medicaid beneficiaries. CMS issued regulations requiring MLTSS MCOs to perform certain quality activities, and through a combination regulation and policy guidance, CMS has also specified what federal Medicaid expects from states with respect to quality oversight of MCOs. The study found 2 out of 8 states heavily leveraged the oversight infrastructure already in place to monitor medical services provided by the participating MCOs; 6 states established relatively free-look MLTSS oversight infrastructures.	High	High	High
Johnson RW, Park JS. Who Purchases Long-Term Care Insurance? Washington, DC: Urban Institute Program on Retirement Policy; 2011. Available at http://www.urban.org/sites/default/files/alfresco/publication-pdfs/412324-Who-Purchases-Long-Term-Care-Insurance-.PDF. Last accessed November 2015.	This paper describes the population of Americans who purchase long-term care (LTC) insurance. The authors define LTC to encompass a wide range of services for people who need regular assistance because of chronic illness or physical or mental disabilities. Primary assistance is usually with basic activities of daily living and with tasks necessary for independent living. This paper also details the scope of need for LTC, cost of LTC, describes private LTC insurance, and identifies who has private LTC insurance.	Medium	Medium	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Kasper JD, Freedman VA, Spillman BC. Disability and Care Needs of Older Americans by Dementia Status: An Analysis of the 2011 National Health and Aging Trends Study. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DS.pdf. Last accessed August 2015.	This report uses the National Health and Aging Trends Study (NHATS), to describe late-life disability and care needs of older adults with dementia. The results of this study highlight the disabling effects of dementia and its substantial role in late-life disability and caregiving to older people. This report references disability measures from NHATS and a measure developed for NHATS that classifies persons as probable, possible, and no dementia. Measures examine variation by dementia status for several topics: activity limitations and assistance; demographic characteristics and residence; caregiving resources; and support available to or sought by caregivers to individuals with dementia.	High	High	Medium
Kassner E. Home and Community-Based Long-Term Services and Supports for Older People. Fact Sheet. Washington, DC: AARP Public Policy Institute; 2011. Available at http://assets.aarp.org/rgcenter/ppi/ltc/fs222-health.pdf. Last accessed November 2015	More than 5 million older adults need services and support to remain living in their homes and communities. This factsheet provides an overview of home and community-based long-term services and supports (HCBS) for older adults and people with disabilities. The factsheet defines HCBS as assistance with daily activities that generally helps older adults and people with disabilities to remain in their homes. It provides examples of activities of daily living (ADLs) and instrumental activities of daily living (IADLs), services, and settings. The factsheet provides an estimate of 10 million Americans living in the community and needing long-term services and supports in 2009. A brief overview of federal and state funding is provided. Finally, the facesheet outlines four expanded HCBS options: assisted living, adult foster care, subsidized rental housing for older adults, and consumer-directed services.	Medium	Low	Medium
Kasten J, Saucier P, Burwell B. How Have Long-Term Services and Supports Providers Fared in the Transition to Medicaid Managed Care? A Study of Three States. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/sites/default/files/pdf/73196/3LTSStrans.pdf. Last accessed August 2015.	This report describes an in-depth qualitative study of the impact of MLTSS on traditional FFS LTSS providers in three states: Delaware, Minnesota, and Tennessee. The study had several findings. 1) Most HCBS providers were able to manage the transition to MLTSS however, experience increased administrative and cash management pressures (i.e., billing). 2) Some MCOs changed their network adequacy requirements. 3) Traditional case management providers became obsolete in states where MCOs decided to perform the function internally. 4) The volume of Medicaid nursing home days decreased. All three study states are seeking payment reform in partnership with MCOs and providers. In two of the study states (Delaware and Tennessee), the implementation of MLTSS programs has led, deliberately, to the increased use of participant-directed services. This report lists performance measures based on data from the three study states.	High	High	High

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Katz PP, Morris A. Use of accommodations for valued life activities: prevalence and effects on disability scores. *Arthritis Rheum.* 2007;57(5):730-737.	This study aimed to describe the prevalence of using behavioral accommodations to perform valued life activities (VLA), and to examine the impact of accounting for these accommodations on VLA disability scores. The researchers examined telephone interview data from 467 individuals with rheumatoid arthritis (RA). VLA disability was assessed using a 29-item scale, rating difficulty performing each activity and asking whether the participant used: (1) assistive devices, (2) personal assistance, and (3) limits on the amount or kinds of activities, and/or (4) taking more time to perform activities. The study found that individuals with RA used behavioral accommodations, particularly limits and taking more time. Adjusting for use of accommodations resulted in substantial increases in disability scores. The study identified that the Health Assessment Questionnaire (HAQ) which is most commonly used to measure functioning for individuals with RA does not include the accommodations of limits or taking more time. In order to provide a more comprehensive view of how disability affects daily functioning, assessments should include a broader range of accommodations. This study employs the VLA disability scale and contrasts it with the HAQ.	Medium	Low	Low

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		Impact	Improvability	Inclusiveness
Kaye HS, Harrington C, LaPlante MP. Long-term care: who gets it, who provides it, who pays, and how much? *Health Aff.* 2010;29(1):11-21.	Long-term care services are essential to the well-being of many elderly and nonelderly people who need help with activities of daily living (ADL). This paper explores the size and characteristics of the U.S. population needing help with ADLs, the nature of unpaid and paid providers of long-term care, sources of payment, and spending for those services, on an individual and on a national level. The authors analyzed data sets from five nationally representative federal surveys containing questions about ADLs, instrumental activities of daily living (IADLs), need for help from others, and difficulty performing activities. The study found that there are two main population groups needing long-term care services: (1) community residents and (2) institutional residents. Within the community resident population, the authors identified three tiers of need: (1) the broadly defined population that needs help with one or more ADLs or IADLs; (2) the intermediate population that needs help with ADLs; and (3) the narrowly defined population that needs help with two or more ADLs. The study found that family members are the principal providers of assistance to the long-term care population living in households. Additionally, Medicare and Medicaid are the primary payers of community-based long-term care services; nursing home stays are primarily paid by Medicaid plus out-of-pocket expenditures. Per-person expenditures are five times as high, and national expenditures are three times as high for nursing home residents compared to community residents. One critical piece of missing evidence is the extent to which long-term care needs are met or unmet. Study findings suggest that a redistribution of spending across care settings and from agency to independent providers may result in savings and service expansion.	High	Medium	High
Kaye HS. Gradual rebalancing of Medicaid long-term services and supports saves money and serves more people, statistical model shows. *Health Aff.* 2012;31(6):1195-1203	This article describes the importance of rebalancing spending for LTSS. An analysis of 15 years of state expenditure data was used to develop a model indicating that gradual rebalancing, by roughly two percentage points annually, can reduce spending by about 15 percent over 10 years.	High	High	Medium

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Kaye HS. Measuring quality in home- and community-based services. Gerontol. 2015 (unpublished).	There is no consensus on the aspects of HCBS that are needed to improve quality; compare service delivery models, settings, or providers; or ensure equity in service provision. This article summarizes the historical development of HCBS quality measures, prior conceptual work, and the principal quality tools being used and developed. The article proposes a conceptual framework for HCBS quality and maps the principal quality tools to the framework. The article identifies measures found in studies focused on older adults or adults with physical disabilities related to quality of care, quality of life, quality of circumstances, unmet need for services, the impact of services on caregivers, consumer or family satisfaction (pp. 3-4). The article identifies current tools for HCBS quality measurement including five principal consumer survey instruments: (1) National Core Indicators Adult consumer Survey; (2) Personal Experience Survey; (3) Money Follows the Person Quality of Life Survey; (4) National Core Indicators - Aging and Disability Survey; and (5) HCBS Experience of Care Survey. Four additional tools include the Council of Quality and Leadership Personal Outcome Measures; the interRAI Home Care Quality Indicators; the National Committee for Quality Assurance Structure and Process Measures for Integrated Care; and the LTSS Scorecard. The conceptual framework proposes six high-level domains of quality. At the center are *services received* and *consumer outcome*; above those are *paid and unpaid providers* and *a supportive environment*. At the top and bottom are *program characteristics* and *system responsiveness*. The author argues that the conceptual framework can be used to help establish priorities for measuring quality in HCBS.	High	High	High
Kaye HS. Selected Inventory of Quality-of-Life Measures for Long-Term Services and Supports Participant Experience Surveys. San Francisco, CA: University of California at San Francisco, Center for Personal Assistance Services; 2012. Available at http://dredf.org/Personal-experience-domains-and-items.pdf. Last accessed October 2015.	This paper stresses the importance of not only monitoring outcomes specifically related to LTSS received, but also measures of consumers' personal experiences/quality of life. It presents the "independent living perspective," meaning, a high quality of life is equally possible regardless of disability status. The paper uses the Personal Experiences Outcomes Integrated Interview and Evaluation System (PEONIES), as an example of an existing conceptual framework for quality of life. The paper also presents a list of measures that is meant to provide advocates and administrators with ideas as to what existing measures might be used or adapted to construct concise surveys useful for monitoring particular programs.	High	High	High

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Kaye HS. Toward a model long-term services and supports system: state policy elements. *Gerontol.* 2014;54(5):754-761.	This commentary discusses an array of policies and practices that have the potential to improve long-term services and supports (LTSS) provisions by shifting from institutional to Home and Community-Based Services (HCBS), increasing equity across populations, offering consumers more choice and control, improving conditions for workers and caregivers, and promoting improved consumer outcomes. Policy conditions apply to programs and managed care organizations. Policy areas discussed include: • Access to publicly funded LTSS • Support for consumer direction • Workforce development • Caregiver support • Transition from institutions to the community • Diversion from institutional placement • Quality and outcome measurement • Financial risk and capitation rates • Enrollment strategies • Assessment • Outcomes monitoring • Care coordination, • Support for independent living goals The commentary recognizes that previous LTSS assessment efforts often focus on expenditures on institutional services versus HCBS, number of program participants, amount of services received, and existing policies rather than on quality and outcome measures such as adequacy and appropriateness of care and the consumers' level of integration, control, participation, and quality of life. The author identifies initiatives to develop measures in these areas including: the Measure Applications Partnership (NQF, 2012) identified LTSS quality measures, the Agency for Healthcare Research and Quality (AHRQ, 2010) identified HCBS quality measures, the Centers for Medicare & Medicaid Services (2012) funded the development of "personal experience surveys" for use by HCBS programs, including measures of met and unmet need for LTSS, choice of and satisfaction with services, and community participation, and Wisconsin's Personal Experience Outcomes Integrated Interview and Evaluation System (PEONIES) identified domains of a conceptual framework for HCBS outcomes, rather than actual measures (DREDF & NSCLC, 2013). The author concludes that strengthening the LTSS system involves expanding HCBS offerings to better meet demands by simplifying the numerous programs, standardizing eligibility requirements, providing enrollment assistance, empowering consumers' and stabilizing the LTSS workforce.	High	High	High

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Kaye SH, Harrington C. Long-term services and supports in the community: toward a research agenda. *Disabil Health J.* 2015;8(1):3-8.	Long-term services and supports (LTSS) comprise the personal assistance, technology, and healthcare-related services needed by people who are unable to perform routine daily activities without assistance. Despite increasing attention to LTSS research, there are gaps in knowledge about the need for LTSS; access to HCBS programs; LTSS costs, quality, and outcomes; and the workforce providing HCBS. To identify gaps in knowledge and the research needed to fill those gaps, the Center for Personal Assistance Services at the University of California San Francisco convened a conference to focus on LTSS provided in community settings. This article presents a synopsis of the conference material and discussion on important issues in community-based LTSS that have not been adequately studied or understood. Based on the conference discussions, the authors identified the following as the most pressing LTSS research needs: 1. Research on the transition from fee-for-service to managed LTSS, in particular the shift of dual eligibles into an integrated acute-care and LTSS system. 2. Identifying LTSS outcome measures that focus on quality of services and the consumer's experiences, quality of life, community integration, and social participation. 3. More and better data collection and availability on LTSS need, unmet need, programs and services, and workforce. 4. Research on how to maintain and promote consumer focused, consumer-directed services in the face of rapid changes to the LTSS system. 5. Research on equity or disparities by disability type, age, gender, race, and ethnicity in LTSS utilization, unmet needs, and family caregiver responsibilities and needs.	High	High	High
Kehn M, Lipson D. The Real Choice Systems Change Grant: Building Sustainable Partnerships for Housing. Final Report. Cambridge, MA: Mathematica Policy Research; 2014. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Downloads/Final-RCSC-Report.pdf. Last accessed November 2015.	This report describes Mathematica's assessment of the extent to which six grantee states accomplished the goals of the RCSC grant program. It also describes how each grantee used the RCSC funds to achieve program goals and identifies major outcomes as well as efforts to sustain these activities beyond the life of the grant. State progress reports were used to develop this report including major challenges hindering state efforts to maintain and expand permanent and affordable rental housing to low income people with disabilities receiving MLTSS in the community.	Medium	Medium	Medium

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Komisar HL. Characteristics of a High-Performing Long-Term Care System. Baltimore, MD: The Hilltop Institute, University of Maryland Baltimore County; 2010.	The purpose of this work was to describe the characteristics of a high-performing long-term care system to assist the AARP Public Policy Institute's State LTC Scorecard project in developing a framework to guide in the selection of specific indicators that can be used to assess state LTC systems.	High	High	Medium
Krause N, Borawski-Clark E. Social class differences in social support among older adults. *Gerontol.* 1995;35(4):498-508.	A number of research studies suggest that social supports may play a critical role in improving and maintaining physical and mental health. However, not everyone may have access to the benefits of social support. The purpose of the study was to test for social class differences in social support among older adults. Using data on social support measures provided by a nationwide sample of older adults (65 years old and older), the study indicated that social class standing is indeed related to social support in later life. Older adults in the upper income and education categories had more contact with friends, provided more support to others, and were more satisfied with support received from social network members. There were no significant differences for all other social support measures (i.e., contact with family, support received, and negative interaction). Social support may be useful for explaining the greater vulnerability of those lower in social class; however, more research is needed to understand how the broader social context shapes the daily encounters of older adults.	Medium	Medium	Medium
L&M Policy Research, LLC. Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD. Baltimore, MD: CMS; 2014. HHSM-500-2006-00009I/HHSM-500-T0002. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf. Last accessed November 2015.	This paper captures information about services for people with Autism Spectrum Disorders (ASD) across all federal and state level agencies/offices that could serve as a useful tool as well as identify gaps in data. This report includes responses to what states and/or local governments are doing to provide services for people with ASD, the types of services and supports that a person with ASD can access, and how these services and supports are funded. This report includes an appendix of 1915(c) ASD specific waivers.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
L&M Policy Research. Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD. Baltimore, MD: CMS; 2014. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf. Last accessed August 2015.	In 2009, CMS contracted with L&M Policy Research and partners, Truven Health Analytics, and the National Association of State Directors of Developmental Disabilities Services to address the growing need among federal and state policymakers to compile accurate and comprehensive information regarding available services and supports for people with Autism Spectrum Disorders (ASD). This report stemmed from the Interagency Autism Coordinating Committee's 2010 and 2011 Strategic Plans. Currently, there is no comprehensive, nationwide summary of state services and policies related to people with ASD. The overall goal of this project was to capture information about services for people with ASD across all federal- and state-level agencies as well as identify gaps in data that could serve as a useful tool and be updated on an as needed basis. The L&M Policy Research team was tasked with collecting data on existing programs and policies in all 50 states and DC to compile this report with three questions in mind: 1) What are states and local governments doing to provide services for people with ASD? 2) What are the types of services and supports that a person with ASD can access? 3) How are these supports and services funded? This report provides a state by state analysis of the types and quality of services provide to those with ASD at the local and federal policy level.	High	High	Medium
Lamberton CM, Leana CR, Williams JM. Measuring empathetic care: development and validation of a self-report scale. J Appl Gerontol. 2015:34(8):1028-1053.	This article describes the development and implementation results of a self-reported survey measure of empathetic care. The authors define empathetic care as caregiving that supports clients' socio-emotional capabilities and addresses their emotional needs. Researchers conducted a literature review, structured interviews, and focus groups. This information was used to identify three dimensions of empathetic care: extra role behavior, emotional support, and rational richness. A large pool of items and versions of the survey were developed. The results of this study suggested that ECS has desirable psychometric properties and evidence of convergent and discriminant validity. Additionally, future samples demonstrated acceptable levels of test-retest reliability and no social desirability bias.	Medium	Medium	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Lamont H. Long-Term Services and Supports: An Overview. Slides presented at: HHS Office of Disability, Aging and Long-Term Care Advisory Council on Alzheimer's Research, Care and Services; April 28, 2015, Washington, DC. http://aspe.hhs.gov/daltcp/napa/042815/Mtg16-Slides2.pdf. Last accessed August 2015.	This presentation provides an overview of LTSS, users and providers, types of services, the need for LTSS, impact of caregivers (informal and paid), sources of payment and out-of-pocket costs, Medicaid and Medicare LTSS, long-term care insurance, the aging network, and recent trends and development. It also presents statistics on the impact of informal caregivers on the LTSS system.	High	High	High
LaPlante MP. The classic measure of disability in activities of daily living is biased by age but an expanded IADL/ADL measure is not. *J Gerontol B Psychol Sci Soc Sci.* 2010;65(6):720-732.	Activities of daily living (ADL) consist of bathing, dressing, toileting, transferring, continence, and eating. The index of ADL, the classic measure of how severe a person's need for personal assistance services and long-term services and supports (LTSS) is, counts the number of ADL a person needs help with. A complementary index based on needing assistance with eight instrumental activities of daily living (IADL) is used to measure less severe levels of disability. The eight IADLS are using the phone, grocery shopping, meal preparation, housekeeping, doing laundry, using transportation, taking medications, and managing finances. This study evaluates, by age, the performance of two disability measures based on needing help: (1) using five ADL and (2) using 14 activities including IADL, ADL, walking, and getting outside (IADL/ADL). This study employed the Guttman and item response theory (IRT) scaling and found that Guttman scalability of the ADL items increases with age, reaching a high level at 75 years and older; the IADL/ADL items also increase with age but are lower than the ADL. The study concludes that the IADL/ADL scale measuring need for help is hierarchical, unidimensional, and unbiased by age. The expanded IADL/ADL scale is more useful than ADL as it has greater content validity for measuring need for help in the community and is more sensitive to age than the class ADL measure.	High	Medium	High
Larson S, Hallas-Muchow L, Hewitt A, et al. In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012. Minneapolis, MN: University of Minnesota Research and Training Center on Community Living, Institute on Community Integration; 2014. Available at http://rtc.umn.edu/risp/docs/RISP_FINAL_2012.pdf. Last accessed October 2015.	This report describes the status of and trends in long-term supports and services (LTSS) for people with intellectual or developmental disabilities (IDD) in the United States on June 30, 2012 based on annual surveys of directors of state IDD agencies and large state residential facilities.	High	High	Medium

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Larson SA, Hewitt AS. Staff Recruitment, Retention, & Training Strategies for Community Human Services Organizations. Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota; 2012: 293-300. Available at http://www.rtc.umn.edu/docs/Larson_and_Hewitt_Staff_rrt_book_U_of_MN_reprint_2012.pdf. Last accessed November 2015.	This book provides an overview of the challenges associated with recruitment, retention, and training of direct care support workers. It also provides practical strategies that agencies can use to assess and successfully address workforce challenges with detailed implementation plans, illustrative worksheets, and strategies to gain buy-in from stakeholders.	Medium	High	High
Laudet AB. The case for considering quality of life in addiction research and clinical practice. *Addict Sci Clin Pract.* 2011;6(1):;44-55.	As substance use disorders are increasingly viewed and treated as chronic conditions, treatment for addiction aims for the goal of abstinence and improved quality of life. However, the concept of quality of life in addiction is relatively undeveloped. This article reviews the evidence for the relevance of the concept of quality of life in substance use disorder treatment and recovery. Two types of quality of life (QOL) are discussed: health-related QOL (HRQOL) and overall QOL (OQOL). HRQOL is the patient's perception of how his or her health affects well-being, while OQOL encompasses the patient's overall satisfaction with life. The article summarizes these concepts and includes instruments to measure QOL, the SF-36 and SF-12 which assess limitations in functioning due to disease, and the WHOQOL-100 and WHOQOL-BREF which assess objective functioning and satisfaction with functioning. Evidence suggests that quality of life is generally poor among active substance abusers and treatment seekers. Treatment is associated with improvement. Substance abuse was found to have a negative impact on nearly all quality-of-life domains such as physical, mental, social health, and living environment (e.g., housing, finances, safety, access to care). The study suggests the goals of clinical and recovery-oriented services should include improvements on the quality-of-life domains.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Leff B, Carlson CM, Sliba D, et al. The invisible homebound setting quality-of-care standards for home-based primary and palliative care. *Health Aff.* 2015;34(1):21-29.	Home-based medical care can improve outcomes and reduce healthcare costs, but there is currently no quality-of-care framework or set of nationally recognized and widely used quality measures. The aims of this article are to describe the unique characteristics of homebound older adults, existing models of home-based medical care, the deficits of existing quality measures for homebound older adults who are cared for at home, and the development of quality framework for this population. The article presents the VA Home-Based Primary Care Program and the House Call Program at MedStar Washington Hospital Center as two high performing home-based medical practices. The article highlights the cost savings, reduction in readmission rates, and improved consumer and caregiver satisfaction associated with these programs. The article describes a literature review and a set of semi-structured interviews both conducted by the National Home-Based Primary and Palliative Care Network to identify relevant quality domains and standards, and measurement gap areas (p. 27). The network identified a set of 20 quality indicators that are being field tested for feasibility and validity. Ten indicators fell in the domain of assessment: assessment for pain, constipation, depression, functional status, alcohol use, preferred spoken language for healthcare, vision and hearing status, abuse and neglect, and risk of falls. Three indicators were in the safety domain: reviewing the drug regimen, addressing medications in the context of new cognitive decline, and reconciling medication changes after a hospital discharge. Two indicators were in the quality-of-life domain: offering treatment for depression and providing the flu vaccine. Two indicators were in the patient and caregiver experience domain: provider ability to be caring, and his/her ability to inspire trust. In the domain of access, a quality indicator focused on timely hospice referral; in goal attainment, an indicator focused on discussion of preferences for life-sustaining treatment; and in care coordination, an indicator assessed timely follow-up after hospital discharge.	High	High	High

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Lewis S. Person-centered planning and self-direction: HHS issues new guidance on implementing section 2402(a) of the Affordable Care Act. Administration for Community Living blog. July 1, 2015. http://www.acl.gov/NewsRoom/blog/2014/2014_07_09.aspx. Last accessed August 2015.	This report highlights the discussion of a workgroup commissioned by HHS through a cross agency effort. The workgroup met regularly over the course of two years as members considered a range of options and strategies for implementing section 2402(a) of the ACA. In addition to implementation strategies, the workgroup discussed key focus areas including PCP, SD, workforce competency and adequacy, quality of life, and a definition for HCBS. The workgroup developed concept papers, conducted interviews with subject matter experts, and engaged in outreach to key stakeholders including advocacy groups, state associations, people with disabilities and older adults, providers, and other federal departments and agencies. The report also includes the elements of a person-centered/self-directed plan.	High	High	High
Li H, Kyrouac GA, McManus DQ, et al. Unmet home care service needs of rural older adults with Alzheimer's disease: a perspective of informal caregivers. *J Gerontol Soc Work.* 2012;55(5):409-425.	This study provides an assessment of the unmet service needs of rural older adults with Alzheimer's disease (AD) as well as identified factors that were related to these needs. Researchers collected data collected from 109 informal caregivers of AD patients. Findings included that over half of the patients experienced unmet service needs in one or more areas of activities of daily functioning and were associated with informal caregiver burden, patient's gender, and functional status. In addition, patients' use of formal services was marginally related to their unmet service needs. Researchers concluded that to better address patients' service needs, a comprehensive needs assessment should be conducted with both patients and their caregivers.	Medium	Medium	Medium
Li LW, Conwell Y. Effects of changes in depressive symptoms and cognitive functioning on physical disability in home care elders. *J Gerontol A Biol Sci Med Sci.* 2009;69(2):230-236.	Research studies on population-based aging have reported that depression is disabling, however the effect of depression on disability may be less pronounced in older adults with disabilities. This study aimed to investigate: (1) the effect of changes in depression status on physical disability in older adults receiving home care, (2) whether the effect is a result of concurrent changes in cognition, and (3) whether affective state and cognitive ability interact to influence physical disability. The study employed multilevel analyses on longitudinal data from older adults in Michigan's community-based long-term care programs. The study found that worsening of depression and cognitive abilities independently predicts a subsequent increase in severity of disability of older adults using home care. This study includes measures of physical disability, depressive symptoms, and cognitive functioning.	Medium	Medium	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Libersky J, Lipson D, Liao K. Hand in Hand: Enhancing the Synergy between Money Follows the Person and Managed Long-Term Services and Supports. Reports from the Field #17. Washington, DC: Mathematical Policy Research; 2015. Available at http://www.mathematica-mpr.com/~/media/publications/pdfs/health/mfpfieldrpt17.pdf. Last accessed November 2015.	This report describes the interaction between MFP and MLTSS in seven states including Hawaii, Massachusetts, Minnesota, New Jersey, Tennessee, Texas, and Wisconsin; provides updates on enrolled populations, covered services, and transition coordination; details payment strategies and performance and quality measures used to align incentives for achieving goals of MFP/MLTSS; and identifies opportunities for further alignment. This report indicates that states which linked MFP and MLTSS offered more supportive services than would be available under either stand-alone program. The experiences of these seven states are used as examples for other states trying to develop MLTSS and provide incentives for transitioning people from institutional care to community based care.	High	High	High
Lind A. Measuring Quality for Complex Medicaid Beneficiaries in New York. New York, NY: Medicaid Institute at United Hospital Fund; 2011. Available at http://www.medicaidinstitute.org/assets/1357. Last accessed November 2015.	This report provides essential information on the importance of quality measurement in the context of NY state policy. The report describes the characteristics of quality measurement, quality measurement for care of multiple chronic conditions, behavioral healthcare, and long-term care, as well as key issues for New York State implementation.	High	High	High
Lind A. Quality Measurement in Integrated Care for Medicare-Medicaid Enrollees. Technical Assistance Brief. Hamilton, NJ: Center for Health Care Strategies, Inc. (CHCS); 2013. Available at http://www.chcs.org/media/Quality_Measurement_in_Integrated_Care.pdf. Last accessed October 2015.	This brief summarizes efforts to develop quality-of-care measures for Medicare-Medicaid enrollees. It provides guidance to states in developing measurement approaches for proposed integrated programs, including assessment of quality in specific domains of integrated care such as long-term services and supports and behavioral health services. It also describes how performance measures can be shaped by stakeholder input.	High	Medium	Medium

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Lipson DJ, Libersky J, Machta R, et al. Keeping Watch: Building State Capacity to Oversee Medicaid Managed Long-Term Services and Supports. Washington, DC: AARP Public Policy Institute; 2012. Available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/keeping-watch-building-state-capacity-to-oversee-medicaid-managed-ltss-AARP-ppi-health.pdf. Last accessed October 2015.	This study was conducted to determine the specific capacities that state Medicaid agencies need to monitor the performance of managed LTSS (MLTSS) programs. It sought to identify promising practices in state oversight as well as the monitoring capacities that should be in place when states begin to implement new or expanded MLTSS programs. Lessons were drawn from oversight practices in eight states that have many years of experience operating and overseeing MLTSS: Arizona, Massachusetts, Minnesota, New Mexico, New York, Tennessee, Texas, and Wisconsin. **Findings:** State MLTSS programs vary along several dimensions Over time, most of the states had gradually consolidated contract monitoring functions for MLTSS with other Medicaid managed care operations. The authors call this the integrated oversight model. All of the states used the skills and resources of many other organizations to enhance or strengthen their MLTSS oversight capacity. State capacity to oversee MLTSS program performance requires staff with the right mix of skills and experience, as well as information system expertise. The states differed in how they carried out core MLTSS oversight functions. Room to build capacity in all states.	Medium	High	Medium

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Low LF, Yap M, Brodaty H. A systematic review of different models of home and community care services for older persons. *BMC Health Serv Res.* 2011;11:93	Care has been shifting from institutions to home and community for older adults as a result of costs and consumer preferences. This systematic review aimed to evaluate the outcomes of case-managed, integrated, or consumer-directed home and community care for older adults, including those with dementia. The authors searched MEDLINE, PsycINFO, CINAHL, AgeLine, Scopus, and PubMed for papers related to nonmedical home and community care services for frail older adults published between 1994 and May 2009. The review includes 25 papers. The highest quality evidence was on case management. Randomized controlled trials showed that case management improves function and appropriate medication use, increases use of community services, and reduces admissions to nursing homes. Evidence on integrated care was mainly from nonrandomized studies. These papers showed increases in service use when integrated care was the care model, but the few randomized controlled trials found that integrated care does not improve clinical outcomes. Evidence for consumer-directed care was the lowest quality. Consumer-directed care appears to increase consumer satisfaction with care and community service use, but has little effect on clinical outcomes. The studies reviewed used different methodologies and had inconsistent results. The authors conclude that outcomes for different models of home and community care depend on the focus on the model: case management focuses on consumer care, integrated care on an efficient system, and consumer-directed care on giving control to the consumer. An ideal home and community care model could combine the successful features of all three models to maximize outcomes. The article presents a table of the studies reviewed including the outcome measures for the studies.	High	High	High
Lynn J, McKethan A, Jha AK. Value-based payments require valuing what matters to patients. *JAMA.* 2015;314(14):1445-1446.	This editorial discusses the importance creating a value-based payment system that emphasizes positive health outcomes of the population served. The authors also discuss the need to develop measurement schemes in various clinical/health outcome related areas.	Medium	Medium	Medium

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Malley JN, Towers AM, Netten AP, et al. An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people. *Health Qual Life Outcomes.* 2012;10:21.	This article aims to demonstrate the construct validity of the Adult Social Care Outcomes Toolkit (ASCOT) attributes. This toolkit includes a preference-weighted measure of social care-related quality of life for use in economic evaluations and consists of eight attributes: personal cleanliness and comfort, food and drink, control over daily life, personal safety, accommodation, cleanliness and comfort, social participation and involvement, occupation and dignity. Researchers surveyed 301 older people receiving publicly funded home care services in several locations across England. This study provides some evidence for the construct validity of the ASCOT attributes and therefore support for ASCOT's use in economic evaluation. It also demonstrated the feasibility of its use among older people.	High	High	High
Mann C. Letter to State Medicaid Director regarding health home core quality measures. January 15, 2013. SMD#13-001 ACA#23. Available at http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/SMD-13-001.pdf. Last accessed August 2015.	This letter contains the CMS-recommended core set of healthcare quality measures for assessing the health home service delivery model. This letter was sent to state Medicaid directors to give states time to share information with their healthcare providers, which is important, because health home providers will be required to report healthcare quality measures in order to receive payment. These recommended health home measures are an integral part of a larger payment and care delivery effort that focuses on quality outcomes for beneficiaries. The letter expresses CMS' intention to provide technical assistance on the implementation of these recommended health home measures and to release guidance on when states should begin reporting on the measures. Recommended health home core measures are: Adult Body Mass Index (BMI) Assessment, Ambulatory Care - Sensitive Condition Admission, Care Transition – Transition Record Transmitted to Health Care Professional, Follow-up After Hospitalization for Mental Illness, Plan All Cause Readmission, Screening for Clinical Depression and Follow-up Plan, Initiation and Engagement of Alcohol Other Drug Dependence Treatment, Controlling High Blood Pressure.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Marek KD, Popejoy L, Petroski G, et al. Nurse care coordination in community-based long-term care. *J Nurs Scholarsh.* 2006;38(1):80-86.	To prevent unnecessary exacerbations of chronic illness, individuals, including frail older adults, need a program where they are closely monitored in their home environments for changes in their ability to comply with their plan of care. This study was designed to evaluate the clinical outcomes of a nurse care coordination program for people receiving services from a state-funded home and community-based waiver program. The study employed quasi-experimental design to compare clients who received nurse care coordination and clients who received services with no nurse care coordination. The program consists of assigning a registered nurse who provides home care services. The Minimum Data Set (MDS) for resident care and planning and the Outcome Assessment Instrument and Data Set (OASIS) were collected. The Cochran-Mantel-Haenszel (CMH) method was used to test the association between the nurse care coordination intervention and clinical outcomes. The study found that after 12 months in the waiver program, individuals who received nurse care coordination had statistically significant better clinical outcomes of pain, dyspnea, and ADLs.	High	High	High
Maxwell CJ, Kang J, Walker JD, et al. Sex differences in the relative contribution of social and clinical factors to the Health Utilities Index Mark 2 measure of health-related quality of life in older home care clients. *Health Qual Life Outcomes.* 2009;7:80.	Health-related quality of life (HRQL) is an important construct to help understand the health status and outcomes of older consumers of home care and the cost-effectiveness of home and community-based services. Measuring HRQL allows for the comparison of diverse populations through a single measure that captures capacity in multiple domains of health that are relevant to older adults. The heterogeneity of consumers highlights the need to better understand the clinical and social determinants of HRQL indices and of the potential sex-differences in these determinants. This study examined how social and clinical factors contribute to HRQL of older consumers and explored whether any associations varied by sex. The study used the Minimum Data Set for Home Care to obtain data on sociodemographic, health, and clinical characteristics; the Health Utilities Index Mark 2 (HUI2) to measure self-reported HRQL; and multivariable linear regression models. The study found that women had a significantly lower mean HUI2 score than men. Consumers with distressed caregivers and poor self-rated health exhibited significantly lower HRQL scores after adjusting for clinical conditions. HRQL scores were negatively associated with conditions predictive or indicative of disability, and with markers of psychosocial stress.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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McDonald MK, Schultz E, Albin L, et al. Care Coordination Measures Atlas. Version 4. Rockville, MD: Agency for Healthcare Research and Quality (AHRQ); 2014. AHRQ Publication No. 14-0037-EF. Available at http://www.ahrq.gov/sites/default/files/publications/files/ccm_atlas.pdf. Last accessed November 2015.	Most reviews of care coordination focus on clinical and utilization measures rather than structures, processes, or intermediate outcomes related to coordination. This is thought to be a result of the paucity of care-coordination-specific measures that capture the extent to which care coordination is or is not occurring. The purpose of the Atlas is to help evaluators identify appropriate measures for assessing care coordination interventions in research studies and demonstration projects, particularly those measures focused on care coordination in ambulatory care. The Atlas proposes a Care Coordination Measurement Framework identifying the major measurement domains as “Coordination Activities” and “Broad Approaches” and three potential data sources – Patient/Family, Health Care Professional, and System Representative. The measure map cross-references 80 measures with the Framework’s domain and data sources as well as provides measurement specifications for each. Types of measures include structural, process, intermediate outcomes but not common endpoints (e.g., ER visits, readmission). A special review of the issues surrounding the use of EHR and Social Network Analysis-based measures is also provided. The review is focused on measures primarily related to care provided in ambulatory and primary care settings. As such, these measures may not be appropriate for inclusion as measures for home and community-based services but may provide guidance and/or inspiration for care coordination measures within HCBS programs.	High	Medium	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
McGinnis T, Crawford M, Somers SA. A State Policy Framework for Integrating Health and Social Services. Issue Brief. Washington, DC: The Commonwealth Fund; 2014. Available at http://www.commonwealthfund.org/~/media/files/publications/issue-brief/2014/jul/1757_mcginnis_state_policy_framework_ib.pdf. Last accessed November 2015.	Recognizing that health is determined by various interrelated factors, states are exploring health delivery models that connect health care, public health, and social services to improve population health and care, and reduce costs. This issue brief describes three essential components for integrating health and social services: 1. a coordinating mechanism 2. quality measurement and data-sharing tools 3. aligned financing and payment. It also presents a five-step policy framework to help states move beyond isolated pilot efforts and establish the infrastructure necessary to support ongoing integration efforts particularly for Medicaid beneficiaries. The five planning steps include: 1. Establish goals 2. Identify gaps and opportunities 3. Prioritize opportunities for integration 4. Establish an implementation roadmap 5. Create a measurement strategy The brief identifies examples of metrics that reflect realistic quality and accountability goals, emphasizing that it may take decades to fully influence outcomes. Metrics of population health include: life expectancy, condition-specific life expectancy changes, and self-reported levels of health.	Medium	High	Medium
McKillop JM. Occupational satisfaction, strain, and intention to quit among direct care providers assisting individuals with developmental disabilities. *J Dev Disabil.* 2011;17(1):7-14.	This paper describes the results of a study that addressed employment variables that may predict intention to quit among direct care providers assisting individuals with developmental disabilities. This study included a sample of 96 direct care providers who completed a brief questionnaire that measured specific occupational characteristics of providers, frequency of adaptive and maladaptive behaviors displayed by clients, the quality of providers' workgroup, and providers' level of occupational strain and job satisfaction. The results of the questionnaire indicated that direct care providers with lower job satisfaction exhibited greater intentions to leave their employment influenced by occupational strain, workgroup dysfunction and years of education. Researchers conclude that reducing employment strain among direct care providers and increasing workgroup cohesion may be beneficial to both providers and agencies that assist individuals with developmental disabilities.	High	High	High

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Medicaid gov. 1915(c) Home & community-based waivers website. http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/home-and-community-based-1915-c-waivers.html. Last accessed August 2015.	This webpage provides resource information on the 1915(c) HCBS Waivers for each state, the waiver application, technical guidance, and modifications to quality measures and reporting in HCBS waivers.	High	High	High

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Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers; Final Rule. 79 (11) Fed Regist; January 16, 2014.	This final rule amends Medicaid regulations consistent with the requirements of the Affordable Care Act (ACA), which added section 1915(h)(2) to provide authority for a 5-year duration for certain demonstration projects or waivers, at the discretion of the Secretary, when they provide medical assistance to individuals who are dually eligible for Medicaid and Medicare. This final rule provides additional limited exception to the general requirement that payment for services under a state plan must be made directly to the individual practitioner providing a service when the Medicaid program is the primary source of reimbursement for a class of individual practitioners. This exception allows payments to be made to other parties to benefit the providers by ensuring workforce stability, health and welfare, and trainings, and provide added flexibility to the state. This final rule amends Medicaid regulations to provide home and community-based setting requirements related to the ACA for the Community First Choice State plan option. This final rule further amends the Medicaid regulations to define and describe state plan home and community-based services (HCBS). This regulation outlines the optional state plan benefit to furnish state plan HCBS and draw federal matching funds. As a result, states will be able to design and tailor Medicaid services to better accommodate individual needs. This may result in improved consumer outcomes and satisfaction, while enabling states to effectively manage their Medicaid resources. This final rule also revises the regulations implementing Medicaid HCBS waivers under the Social Security Act by providing states the option to combine the existing three waiver targeting groups. This final rule includes other changes to the HCBS waiver provisions to: 1. convey expectations regarding person-centered care plans, 2. provide characteristics of settings that are home and community-based as well as settings that may not be home and community-based, 3. clarify the timing of amendments and public input requirements when states propose modifications to HCBS waiver programs and service rates, and 4. describe additional strategies for CMS to ensure state compliance with the statutory provisions of the Social Security Act. The final rule also includes requirements for person-centered care plans that document, among other things, a person's choice of setting from among options that meet the person's needs.	Medium	Low	High

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Medicaid.gov. Balancing incentive program website. http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-incentive-program.html. Last accessed August 2015.	This website provides an overview of the Balancing Incentive Program, created by the ACA, which authorizes grants to States to increase access to noninstitutional LTSS as of October 1, 2011. It is meant to help states transform their long-term care systems by lowering costs, creating tools to help consumers with care planning and assessment, and improving quality measurement and oversight. This program in keeping with the integration mandate of the Americans with Disabilities Act (ADA), as required by the Olmstead decision. This website offers additional information on how this program is financed, federal funding for state programs, and program guidelines.	High	High	Medium
Medicaid.gov. Guide to Medicaid health home design and implementation. Health home background resources website. http://www.medicaid.gov/State-Resource-Center/Medicaid-State-Technical-Assistance/Health-Homes-Technical-Assistance/Guide-to-Health-Homes-Design-and-Implementation.html. Last accessed August 2015.	This letter provides preliminary guidance to States on the implementation of section 2703 of the Affordable Care Act, entitled "State Option to Provide Health Homes for Enrollees with Chronic Conditions." This guidance outlines expectations for states' successful implementation of the health home model of service delivery and presents important aspects of health home provision. The health home service delivery model is an important option for providing enrollees access to an interdisciplinary array of medical care, behavioral healthcare, and community-based social services and supports for both children and adults with chronic conditions. This letter provides service definitions, payment methodologies, an explanation of provider standards, quality measure reporting requirements, etc. It also outlines the level of support the federal government will provide states in this endeavor. It includes the following health home services to be provided by designated health home providers or health teams: comprehensive care management; care coordination and health promotion; comprehensive transitional care from inpatient to other settings including appropriate follow-up individual and family support, which includes authorized representatives; referral to community and social support services, if relevant; and the use of health information technology to link services, as feasible and appropriate.	High	High	High

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Medicaid.gov. Health homes website. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Integrating-Care/Health-Homes/Health-Homes.html. Last accessed August 2015.	This technical manual describes the core set of healthcare quality measures for the ongoing assessment of the effectiveness of the Health Home Model. These measures reflect key priority areas such as behavioral health and preventative care, and they align with the core set of healthcare quality measures for adults enrolled in Medicaid. The measures are based on the Core Set of healthcare quality measures for Medicaid-eligible adults. The model details how the data used for these measures are collected and reported. It also includes the technical specifications for the health home core set and for the health home utilization measures. The eight measures are BMI (NCQA/HEDIS), Screening for Clinical Depression and follow-up (CMS), All-cause readmission rate (NCQA/HEDIS), Follow-up hospitalization after hospitalization for Mental Illness (NCQA/HEDIS), Controlling HP (NCQA/HEDIS), Care transition- timely transmission of transition record (AMA/physician consortium for PI), Initiation and engagement of other Drug Dependence treatment (NCQA/HEDIS), chronic condition hospital admission composite (AHRQ). These measures are detailed throughout the report.	High	High	Medium
Medicaid.gov. Long term services & supports website. http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/long-term-services-and-supports.html. Last accessed November 2015.	This government website provides a host of resources on LTSS including institutional long-term care and community-based LTSS. This website links to many other resources including the demonstration grant for TEFT, ACL/CMS/VHA funding opportunity announcements for planning grants, ASD state report, ASD final report on environmental scan, LTSS annual expenditures, Medicaid expenditures for Section 1915(c) waiver program in FFY 2011, and the Medicaid Beneficiaries Receive Long-Term Services and Supports Report.	High	High	High
Medicaid.gov. Medicaid innovation accelerator program (IAP) website. http://www.medicaid.gov/state-resource-center/innovation-accelerator-program/innovation-accelerator-program.html. Last accessed August 2015.	This website describes the Medicaid Innovation Accelerator Program (IAP) with the goal of improving states' efforts to accelerate new payment and delivery reforms. The IAP provides additional federal tools and resources to support states. These resources include the Child Core and Adult Core Measure Sets. The website also links to the technical specifications for health home measures. It also includes measures for substance abuse, complex medical care, preventive and Maternal and child care.	High	High	High
Medicaid.gov. Program of all-inclusive care for the elderly (PACE) website. http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/integrating-care/program-of-all-inclusive-care-for-the-elderly-pace/program-of-all-inclusive-care-for-the-elderly-pace.html. Last accessed August 2015.	This website describes the Programs for All-Inclusive Care for the Elderly (PACE) which provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals, most of whom are dually eligible for Medicare and Medicaid benefits. The website details eligibility requirements and marketing guidelines. It also contains links to other relevant information.	High	High	Medium

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Medicaid.gov. Quality of care website. http://www.medicaid.gov/medicaid-chip-program-information/by-topics/quality-of-care/quality-of-care.html. Last accessed August 2015.	This webpage provides an overview of quality of care as a partnership between CMS and CHIP Services (CMCS) and states to share best practices to provide technical assistance to improve care. This page links to the CMS Quality Strategy, the National Quality Strategy and many other links to expand upon multiple efforts to improve care quality. This page also provides links to various core sets of performance measures (e.g., Adult Core Set and Health Homes Core Set), quality improvement initiatives, Medicaid Managed Care resources, and releases and announcements.	High	High	High
Medicaid.gov. Testing experience and functional tools (TEFT) website. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/TEFT-Program.html. Last accessed August 2015.	This website provides information on the Testing Experience and Functional Tools (TEFT) grant. This grant is designed to field test an experience survey and a set of functional assessment items, demonstrate personal health records, and create a standard electronic LTSS record. A table with more specific information on the nine awarded states is provided as well.	High	High	High
Morris E, Medeiros M, Denny-Brown N, et al. Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2014. Cambridge, MA: Mathematica Policy Research; 2015. Available at http://www.mathematica-mpr.com/our-publications-and-findings/publications/money-follows-the-person-demonstration-overview-of-state-grantee-progress-january-to-december-2014. Last accessed November 2015.	This report summarizes the implementation progress of the MFP demonstration in the 44 grantee states that were actively transitioning participants from January 1-December 31, 2014 (aka reporting period). This report compares performance data during 2014 to the previous year and in some cases to five-year annual trends. Key indicators of progress, including the number of transitions to the community, states' progress toward 2014 transition goals, HCBS expenditure levels, rates of self-direction and re-institutionalization among MFP participants, types of qualified housing for new enrollees, and employment supports and services for MFP participants are presented as well.	High	High	High

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Morris JN, Fries BE, Frijters D, et al. interRAI home care quality indicators. *BMC Geriatr.* 2013;13:127.	This paper describes the development of the second generation InterRAI home care quality indicators (HC-QI). This version was derived from two widely used community assessments including the Community Health Assessment and the Home Care Assessment. Researchers reviewed both client level and home site level data from Europe, Canada, and the U.S. in order to identify potential HC-QIs (both prevalence and change measures). The analyses found the set of risk-adjusted HC-QIs to be multidimensional in scope including measures of function, clinical complexity, social life, distress, and services used. Two factors were identified: (1) a set of 11 measures that revolve around the absence of decline (scale on functional independence and engagement); (2) return to clinical balance based on 9 functional improvement HC-QIs referenced positively. In conclusion, 23 risk-adjusted HC-QIs are described in this paper. Two new summary HC-QI scales including Independence Quality Scale and the Clinical Balance Quality Scale are derived which can be useful in providing a macro view of local performance, offering a way for a home care agency to understand its performance and offering more opportunities to improve.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Moseley C, Walker PD, Cichocki B, et al. Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community. National Council on Disability (NCD), National Association of State Directors of Development Disabilities Services (NASDDDS). Washington, DC: National Council on Disabilities; 2015. Available at http://www.ncd.gov/rawmedia_repository/HCBS%20Report_FINAL.pdf. Last accessed November 2015.	The shift in service delivery for people with disabilities from traditional congregate settings to community settings continues to challenge policymakers, providers, and other stakeholders. This report examines the research on the impact of the size and types of community settings on the individual and service-related outcomes of people with disabilities who live in those settings. Findings support the conclusion that smaller, more dispersed, and individualized community settings further integration and positive outcomes for individuals with disabilities. Factors such as greater individual choice, satisfaction, housing stability, and higher levels of adaptive behavior and community participation are associated with living in residential settings of smaller size. Most studies focused on people with intellectual and developmental disabilities and adults with mental health disabilities, but the findings are considered applicable to the wider population of individuals with disabilities as well as to all entities receiving federal funding for the provision of home and community-based services. The report concludes with a series of recommendations. At the federal level: (1) full regulatory implementation; (2) identifying and sharing promising practices; (3) making toolkit sources useful for effective regulatory compliance; (4) self-assessment by federal fund administrators; (5) effective federal monitoring and enforcement; and (6) establishing definitions and requiring measurement of service and support quality. At the state level: (1) limiting residence setting size; (2) quality management; (3) financial alignment across current funding, resource, and rate setting, setting of system goals, the current HCBS regulations; 4) assuring stakeholder engagement throughout the planning and implementation of plans, processes, and programs; 5) oversight that enhances provider expectations about qualifications, training, and giving necessary services and supports; (6) expansion of opportunities that promote self-determination and consumer control in living alternatives across the broad array of people with disabilities receiving federal benefits. Performance measurement is identified as an area in need of further work, but specific measures are not identified or reviewed.	High	Medium	Medium
Napili A, Colello KJ. Funding for the Older Americans Act and Other Aging Services Programs. Washington, DC: Congressional Research Service (CRS); 2013. Available at http://fas.org/sgp/crs/misc/RL33880.pdf. Last accessed November 2015.	This report details the findings from fiscal year 2011, 2012, and 2013 funding for the Older Americans Act authorized activities as well as other aging services programs administered by the Administration for Community Living under other statutory authorities.	High	High	High

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National Association of States United for Aging and Disabilities (NASUAD). National core indicators – aging and disabilities website. http://www.nasuad.org/initiatives/national-core-indicators-aging-and-disabilities. Last accessed November 2015.	This is the website of the National Core Indicators (NCI) program. The purpose of NCI is **“**to support member agencies of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks.**”** NCI is a voluntary effort by public developmental disabilities agencies (42 states) to measure and track their own performance. The NCI indicator domains are: individual outcomes; health, welfare, and rights; system performance; staff stability; and family indicators, with subdomains under each indicator. Individual outcomes subdomains are work, relationships, satisfaction, choice and decisionmaking, self-determination, and community inclusion. These indicators address how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain prove how satisfied individuals are with services and supports. Health, Welfare, and Rights subdomains are safety, health medications, wellness, restraints, and respect/rights. System Performance indicators address service coordination; family and individual participation in provider-level decisions; the utilization of and outlays for various types of services and support; cultural competency; and access to services. Staff stability addresses provider staff stability and competence of direct contact staff. Finally, family indicators address how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decisionmaking, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports, and how supports have affected their lives. The subdomains for Family Indicators are satisfaction, family involvement, community connections, access and support delivery, information and planning, choice and control, and family outcomes. Measures for the subdomains can be accessed by clicking the appropriate subdomain link under the Indicators tab. The website features the core indicators (standard measures used across participating states) and interactive charts that show current rates on the measures/indicators, by year, state, SDS factors and health conditions. There are also links to states participating in NCI, resources such as technical reports, data briefs, and presentations, and a blog and news section.	High	High	High

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National Association of States United for Aging and Disabilities (NASUAD). Results of February 2012 Survey on Medicaid Funded Long Term Services and Supports. Assessments, Reassessments and Care Plans. 2012. Washington, DC: NASUAD; 2012. Available at http://www.nasuad.org/documentation/Surveys/Assessment%20%20Care%20Planning.pdf. Last accessed November 2015.	In 2012, the National Association of States United for Aging and Disability (NASUAD) surveyed all states using an online survey with 30 questions on consumer directed services and related processes; assessments, reassessments, and care plans; and case management. These articles provide an overview of the results from the survey. Sixteen states provided information about 27 programs. Five trends in assessment emerged: 1. Almost two-thirds of programs contract out the assessment, reassessment, or care plan change process. Monitoring methods and rates for this work vary. 2. More than half of the programs allow HCBS providers to do assessments, reassessments and care plan changes. 3. Almost every program uses a standardized assessment instrument. 4. Most programs rely on a team, including the consumer, to develop the care plan. 5. Over two-thirds of programs do not categorize HCBS participants by levels of service. For case management, four trends emerged: 1. State programs often pay for case management as a service rather than an administrative cost. 2. Reimbursement rates for case management vary. 3. There are more state programs that do not limit the amount of case management than programs that do. 4. Programs have not encountered barriers to shifting from funding case management as an administrative cost to funding it as a service. Finally, there were four overall trends related to Consumer Directed Personal Care: 1. It is more often provided through waivers, but half of the responding programs are paid by the Medicaid State Plan. 2. Consumers are typically considered the employer of record. 3. Providing Financial Management Services (FMS) varies, with 44 percent of respondents providing this as a waiver service. 4. 4 There is a variety of approaches to and amounts for reimbursing Information and Referral and Supports Brokerage Services.	Medium	Medium	High

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National Committee for Quality Assurance (NCQA). Integrated Care for People with Medicare and Medicaid. Washington, DC: NCQA; 2013. Available at http://store.ncqa.org/index.php/other-products/white-papers.html. Last accessed November 2015.	Better care for people who have Medicare and Medicaid has the potential to improve outcomes and reduce costs. This paper describes the dual eligible population and prior integration efforts, identifies a model for integrated entities and a framework for assessing and promoting quality of integrated care, and discusses the challenges of implementing and achieving person-centered and integrated care for the dual eligible population. It groups integrated care's key functions into three steps: screening and assessment, care planning, and coordinated service delivery. The report provides examples of structure, process, and performance measures to evaluate integrated care entities (pp.15-17). These measures set expectations for key functions and capabilities of integrated care, and create the foundation for developing and applying outcome measures. The report calls for more person-centered performance measures that provide robust information about the process and eventually the outcomes of the Medicaid/Medicare population served—such as experience of care, functional status, quality of life, and health outcomes.	High	High	High
National Quality Forum (NQF). Measure Applications Partnership. Process and Approach for MAP-Pre-Rulemaking Deliberations, 2015. Final Report. Washington, DC: 2015. Available at http://www.qualityforum.org/Publications/2015/01/Process_and_Approach_for_MAP_Pre-Rulemaking_Deliberations_2015.aspx. Last accessed December 2015.	This NQF report provides the process and approach for the Measure Applications Pre-Rulemaking deliberations of 2015 for the Hospital, Clinician, Post-Acute Care and Long-Term Care setting-specific areas. For each setting-specific area, cross cutting challenges facing measurement are described along with MAP guidance as well recommendations for implementing measures into federal programs.	High	High	High
National Quality Forum (NQF). Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer's Disease. Washington, DC: NQF; 2014. Available at http://www.qualityforum.org/prioritizing_measures/. Last accessed August 2015.	This NQF report highlights the findings for an environmental scan for existing dementia-specific performance measures, a conceptual measurement framework and recommended priorities for future performance measurement development focusing on persons with dementia and their family caregivers. The report also includes measurement ideas/concepts.	High	High	Medium
Neely-Barnes S, Marcenko M, Weber L. Does choice influence quality of life for people with mild intellectual disabilities? *Intellect Dev Disabil.* 2008;46(1):12-26.	The purpose of this study was to assess the relationship between consumer choice and three quality-of-life indicators: community inclusion, rights, and opportunities for relationships. This study analyzed data from Washington state's Division of Developmental Disabilities 2002 National Core Indicators study including 224 consumers with mild IDD. Researchers used a structural equation model to assess the influence of type of living arrangement and choice on QoL indicators.	High	High	High

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New York State Department of Health. 2012 Managed Long-Term Care Report. Albany, NY: 2012. Available at http://www.health.ny.gov/publications/3391.pdf. Last accessed November 2015.	Managed long-term care (MLTC) plans assist chronically ill or disabled individuals who need health and long-term care services. This report describes 2011 data on enrollment, quality performance over time, utilization, and consumer satisfaction from New York's 30 approved MLTC partial capitation, PACE organizations, and Medicaid Advantage Plus plans. Enrollment in the MLTC plans have been steadily increasing. The domains of quality performance in this report are based on a semiannual assessment of consumer health and functional status: (1) Measures of performance based on the most recent assessment, such as the percentage of consumers who received a flu shot; and (2) Measures that track performance over time such as the percentage of individuals whose overall functioning remained stable or improved over time. The report shows the percentage of consumers who were admitted to a nursing home for permanent placement or a hospital one or more times in a six-month period. Finally, the report provides results from a consumer satisfaction survey. This report outlines use of the SAAM Index to establish clinical eligibility for the MLTC program. It contains measures related to overall functioning and/or activities of daily living (p. 17); incontinence and neurological/emotional/behavioral status (p. 20); living arrangements and sensory/emotional status (p. 22), and quality of life/effectiveness of care/hospital emergent care (p. 25). The report describes outcome measures that are calculated as performance over time with respect to: (1) Activities of Daily Living (p. 28); (2) Incontinence (p. 31); and (3) Quality of life/effectiveness of care (p. 33). The report also contains three risk-adjusted measures (p. 35), patient safety and system utilization measures (p. 37), and measures on consumer satisfaction with the experience of care (p. 40). A description of all of the measures contained in the report is available in Appendix C on page 47.	High	High	High
Ng T, Harrington C, Musumeci MB, et al. Medicaid Home and Community-Based Services Programs: 2011 Data Update. Washington, DC: Kaiser Family Foundation: 2014. Available at http://files.kff.org/attachment/report-medicaid-home-and-community-based-services-programs-2011-data-update. Last accessed November 2015.	This report provides information and analysis on healthcare coverage and access for the low-income population with a special focus on Medicaid's role and coverage of the uninsured. A summary of the key national trends to emerge from the latest 2011 participant and expenditure data for the three main Medicaid HCBS programs is also provided. This includes the mandatory home health services state benefit plan, the optional personal care services state benefit, and the optional 1915(c) HCBS waivers. This report also briefly discusses the provision of Medicaid HCBS participants eligibility, enrollment, and spending for MFP 1915(I) HCBS State Plan Option, BIP or Community First Choice State Plan Option.	High	High	High

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NQF. Advancing Person-Centered Care for Dual Eligible Beneficiaries through Performance Measurement: 2015 Recommendations from the Measure Applications Partnership. Washington, DC: NQF; 2015. Available at http://www.qualityforum.org/Publications/2015/08/Advancing_Person-Centered_Care_for_Dual_Eligible_Beneficiaries_through_Performance_Measurement.aspx. Last accessed November 2015.	This NQF report describes the process and deliberations of the MAP Dual Eligible Beneficiaries Workgroup on the use of performance measures to assess and improve healthcare for people eligible for both Medicare and Medicaid. This report builds upon previous work and includes a list of updated measures aligned with programs that serve this population. This report contains feedback from stakeholders about the use and utility of the measures including recommendations to remove nonessential measurement, attestation, and regulatory requirements to allow for innovative measure development.	High	High	High

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NQF. Appendix A; Unmet Need Causal Factor Identification Tool. Washington, DC: NQF; 2015.	The presence of older adults on waitlists for services has historically been the sentinel indicator of unmet needs. However, waitlist data do not sufficiently capture whether the needs of older adults are being met. The purpose of this report is to identify and document the extent and impact of unmet needs among older adults in a region in Michigan, develop a strategy to quantify the levels of unmet needs, and recommend methods for capturing unmet need information to use in program management, accountability, and advocacy. The report identifies personal, social, environmental, and political factors that influence the existence of unmet needs and barriers to meeting the needs of older adults. The report describes a matrix of unmet needs causal factors that identifies root causes of unmet needs, provides for measurement of underserving and identified unmet needs, and fosters the monetization of unmet needs so that program managers and policymakers can assess the cost and resources needed to fully alleviate the unmet needs. The causal factors are rationing, prioritizing, suitability, deferral, denial, deprivation, misaligned incentives, and prohibition. The report concludes with five recommendations: 1. Michigan's Aging Network programs should increase the number and scope of unmet need indicators that are being monitored and reported. 2. The recommended increase in unmet need indicator reporting should be concurrent with an analysis of existing reporting requirements, with the goal of reducing the overall number of measures reported and/or reducing the frequency at which measures must be reported. 3. The Area Agency on Aging (AAA) 1-B departments of Community and Business Development and Research, Policy Development, and Advocacy should collaborate in developing a unified set of programmatic performance, outcome, and need/unmet need requirements and guidelines for the FY 2016-2018 multiyear planning and contracting cycle. 4. The Michigan Office of Services to the Aging should further refine its definition of underserving, and extend the reporting requirement for this indicator to other in-home and community services. 5. The AAA 1-B should offer training to promote the use of the AAA 1-B Matrix of Unmet Need Causal Factors in identifying unmet needs for aging programs, establishing indicators of unmet needs for data collection and reporting purposes, presenting unmet needs for program management and advocacy purposes, and calculating a price for eliminating selected unmet needs.	High	High	High

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NQF. Behavioral health measures website. http://www.qualityforum.org/Behavioral_Health_Endorsement_Maintenance.aspx. Last accessed August 2015.	This multiphase NQF project sought to endorse measures for improving the delivery of behavioral health services, achieving better behavioral health outcomes, and improving the behavioral health of the U.S. population, especially those with mental illness and substance abuse. The endorsed measures were not specific to LTSS or HCBS.	High	High	High
NQF. Multiple Chronic Conditions Measurement Framework. Washington, DC: NQF; 2012. Available at http://www.qualityforum.org/Publications/2012/05/MCC_Measurement_Framework_Final_Report.aspx. Last accessed August 2015.	This NQF report presents a measurement framework for individuals with MCCs. Following endorsement through NQF's consensus development process, this framework is meant to serve as a guide for future NQF-endorsement decisions for measures that address this population. More broadly, the framework seeks to: • Align initiatives targeting individuals with MCCs; • Identify measure gaps; • Guide selection of measures for public reporting and payment; • Suggest a roadmap for new delivery models (e.g., accountable care organizations, patient-centered medical homes); and • Inform and stimulate research.	High	High	High
NQF. Patient Reported Outcomes (PROs) in Performance Measurement. Washington, DC: NQF; 2013. Available at http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx. Last accessed August 2015.	This NQF report presents recommendations from the Patient Reported Outcomes in Performance Measurement project in which the project goals were to: • Identify key characteristics for selecting PROMs to be used in PRO-PMs; • Identify any unique considerations for evaluating PRO-PMs for NQF endorsement and use in accountability or performance improvement applications; and • Lay out the pathway to move from PROs to NQF-endorsed PRO-PMs. NQF designed this project to bring together a diverse set of stakeholders who could facilitate the groundwork for developing, testing, endorsing and implementing PRO-PMs.	Medium	High	High
O'Day B, Blyler C, Collins A, et al. Improving Employment Outcomes for People with Psychiatric Disorders and Other Disabilities. Washington DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/EmpOut.pdf. Last accessed August 2015.	This report details the Improving Employment Outcomes for People with Psychiatric Disorders and Other Disabilities Project. The purpose of this project is to identify policy measures that prohibit or facilitate employment opportunities among people with psychiatric disorders and identify improvements in healthcare and human services programs, in a post-ACA environment, that are likely to reduce these barriers. ASPE was particularly interested in knowing what supports will assist people with psychiatric disorders. This report also provides a table of statistics with definitions of employment, income, and program participation (Appendix D).	High	High	High

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O'Keeffe J, Saucier P, Jackson B, et al. Understanding Medicaid Home and Community Services: A Primer. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2010. Available at http://aspe.hhs.gov/daltcp/reports/2010/primer10.pdf. Last accessed August 2015.	This Primer Edition was designed specifically to explain how the Medicaid program can be used to expand access to a broad range of HCBS and supports for people of all ages with disabilities and to promote consumer authority and control over their services. It was also designed to encourage a fundamental approach to the support of people with disabilities that minimizes reliance on institutions and maximizes community integration in the most cost-effective manner. This has been updated with the relevant statutory, regulatory, and policy changes that have occurred in the last 10 years. This report also discusses a variety of performance measures pertaining to the Medicaid HCBS population.	High	High	High
Office of the National Corodinator for Health Information Technology (ONC) and the Centers for Medicare & Medicaid Services (CMS). Electronic Long-Term Services and Supports (eLTSS) website. http://wiki.siframework.org/electronic+Long-Term+Services+and+Supports+%28eLTSS%. Last accessed November 2015.	This report details the utilization of an eLTSS use case to describe the following: • The operational context for the sharing and exchange of LTSS data • Stakeholders with an interest in the use case • The information flows that must be supported by the data exchange • The types of data and their specifications required in the data exchange The eLTSS use case serves as the foundation for identifying and specifying the standards required to support the data exchange and developing reference implementations and tools to ensure consistent and reliable adoption of the data exchange standards. The initiative will identify key domains that will inform the creation of a structured, longitudinal, person-centered eLTSS plan designed to be shared electronically in community and health settings.	High	High	High

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Ottomanelli L, Barnett SD, Goetz LL. A prospective examination of the impact of a supported employment program of employment on health-related quality of life, handicap, and disability among Veterans with SCI. *Qual Life Res.* 2013;22(8):2133-2141.	The paper describes the results of a prospective randomized controlled multisite trial of supported employment (SE) versus treatment as usual (TAU) for vocational issues. The study subjects included 157 veterans. The purpose of this study was to investigate the impact of participation in a SE program as well as the impact of employment on health-related QOL, disability, and handicap among veterans with spinal cord injuries (SCI). Outcomes in terms of types of vocational treatment and whether competitive employment was obtained as well as HRQOL were examined by the Veterans RAND 36-item health survey (VR-36), handicap as measured by the Craig Handicap Assessment and Reporting Technique (CHART), and disability as measured by the Functional Independence Measure (FIM). Subjects were assessed at baseline and at 3, 6, 9, and 12 months. The results found no significant difference between veterans who participated in SE compared to TAU in the study measures. Participants obtaining competitive employment demonstrated significantly higher scores on the social integration, mobility, and occupation dimensions of the chart. There were no observed differences in VR-36 scores or FIM scores for those obtaining competitive employment. This study suggests that employment has a positive effect on an individuals' ability to participate in social relationships, move about home/community, and spend time in productive roles. The inability to detect difference across other domains of handicap or any changes in HRQOL may have been due to several factors including levels of intensity of employment, insufficient follow-up period, or measurement limitations.	High	High	High
Palmer M. Disability and poverty: a conceptual review. *J Disabil Pol Stud.* 2015;21(4):210-218.	People with disabilities are increasingly being mainstreamed into national poverty reduction strategies. Despite the acknowledged links between disability and poverty, the relationship is not comprehensively documented. This article outlines the basic needs, capability, and economic resources approaches to defining poverty. Next, the article examines these approaches with an application to disability. It presents empirical evidence from high-income and low/middle-income countries on disability and poverty. Finally, it provides recommendations for future research and policy implications. In the review of empirical evidence, this article identifies other studies which have measured various aspects of poverty and its relationship to disability.	Medium	Medium	Medium

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Peebles V, Bohl A. The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services. *Medicaid Policy Brief.* 2013;19:1-12. Available at https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/Downloads/MAX_IB19_Taxonomy.pdf. Last accessed August 2015.	This brief describes the HCBS taxonomy and presents findings on HCBS expenditures and users by type of service for the 28 states using MAX data files. The taxonomy is meant to improve the identification of state-level variation for HCBS. It also provided more detailed information on what home and community-based services entail as well as the costs associated with specific services (e.g., round-the-clock, home-based, and day services). The results of the study presented in this brief found that among the 28 states, nearly 80 percent of the total $23.6 billion spent on 1915(c) waiver services was for round-the-clock, home-based, and day services. According to this brief, CMS plans to implement the HCBS taxonomy in other Medicaid systems in efforts to improve reporting of HCBS as well as increase standardization of HCBS service definition across states.	High	High	High
Peebles V, Kehn M. Innovations in Home- and Community-Based Services: Highlights from a Review of Services Available to Money Follows the Person Participants. Cambridge, MA: Mathematica Policy Research; 2014. Available at http://www.mathematica-mpr.com/our-publications-and-findings/publications/mfp-innovations-in-home-and-community-based-services. Last accessed November 2015.	This report highlights select qualified demonstration and supplemental services that were deemed particularly innovative and promising. Where possible, data on utilization and spending were included. This report does not include an exhaustive list of innovative services but rather illustrative examples of how states using the MFP demonstration grant are doing while testing and developing various types of HCBS. This report can be a useful resource for policymakers on people's needs for a successful transition from LTC to community living.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Petry K, Maes B, Vlaskamp C. Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *J Appl Res Intellect Disabil.* 2005;18(1):35-46.	The concept of quality of life is increasingly being applied to people with intellectual disabilities. Using interview methods, this study explored: 1) whether the five basic domains in the Felce & Perry (1995) theoretical model of quality of life are valid and relevant for people with profound multiple disabilities, according to parents and direct support staff; 2) how parents and direct support staff operationalize quality of life domains for people with profound disabilities; and 3) the effect of support setting and age on this operationalization. More than half of respondents spontaneously identified all five of the basic domains — i) physical well-being; ii) material well-being; iii) social well-being iv) development and activity; and v) emotional well-being — as being important for the quality of life of people with profound disabilities. Parents and support staff operationalized these domains by identifying indicators or subdomains for each. For example, respondents identified mobility, health, hygiene, nourishment, and rest as indicators of physical well-being. The authors found that neither age nor support setting had a significant effect on operationalization of the domains. Study results support the multidimensionality of quality of life and the validity of the basic domains for people with profound multiple disabilities. However, the operationalization of these domains differ for people with profound multiple disabilities given their dependence on others for meeting their needs. This study does not contain measures, but identifies domains, subdomains, and indicators of quality of life.	High	High	High
Radwany SM, Hazelett SE, Allen KR, et al. Results of the Promoting Effective Advance Care Planning for Elders (PEACE) randomized pilot study. *Pop Health Manag.* 2014;17(2):106-111.	This paper describes the feasibility of a fully powered study to test the effectiveness of an in-home geriatrics/palliative care interdisciplinary care management intervention for improving measures of utilization, quality of care, and QOL in enrollee's of Ohio's community based LTC Medicaid Waiver Program PASSPORT. This randomized pilot study consisted of 40 new enrollee's aged 60 years and older into the PASSPORT program. This study included an interdisciplinary chronic illness care management intervention by PASSPORT care managers collaborating with a hospital-based geriatrics/palliative care specialist team and the consumers' PCPs. Primary outcomes measured symptom control, mood, decisionmaking, spirituality, and quality of life. However, utilization favored the enrollees. At 12 months, the enrollees had fewer hospital visits and nursing facility admissions. This study found that using hospital-based specialists to interface with a community agency to provide a team-based approach to care of consumers with chronic illnesses was feasible.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Raetzman S, Jackson B. Draft Home and Community Based Services Experience Survey. Baltimore, MD: CMS; 2015. HCBS Experience Survey CMS-10389.	This HCBS Survey is used for field testing and measures the progress of HCBS outcomes. This document is a draft and has not yet been field tested.	High	High	High
Redfoot DL, Houser A, Gibson MJ. Trends in Disability, Community Living and Caregiving: Analysis of Data from the National Long-Term Care Survey. In Brief 186. Washington, DC: AARP Public Policy Institute; 2010. Available at http://assets.aarp.org/rgcenter/ppi/ltc/inb186-trends.pdf. Last accessed November 2015.	This In-Brief summarizes two new AARP Public Policy Institute research reports that draw data from the 2004 National Long Term Care Survey results. It also provides comparable data from previous years to determine important trends in disability, institutional use, community living, family caregiving, and paid home care. The major findings of this report are summarized by seven trends. The top three trends relate to the overarching changes in the older population regarding disability, institutional use, and living in the community with disabilities. The last four trends explore in greater detail how these overarching trends have played out among different subgroups in the older population by gender, marital status, living arrangements, and economic status.	Medium	Medium	Medium
Reinhard SC, Kassner E, Houser A, et al. Raising Expectations 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. Washington, DC: AARP Public Policy Institute; 2014. Available at http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf. Last accessed October 2015.	The State Long-Term Services and Supports (LTSS) Scorecard is a multidimensional approach to measure state-level performance of LTSS systems that assist older people, adults with disabilities, and their family caregivers. This second edition of the State LTSS Scorecard measures LTSS system performance across five key dimensions: (1) affordability and access, (2) choice of setting and provider, (3) quality of life and quality of care, (4) support for family caregivers, and (5) effective transitions. Performance varies tremendously across the states, with LTSS systems in leading states having markedly different characteristics than those in lagging states. LTSS performance is gradually improving, both nationally and in most states. Progress is notable in many areas where public policy has a direct impact, including performance of the Medicaid safety net and legal and system supports for family caregivers.	High	High	High

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Rivard P, Jackson B, Rachel J, et al. Environment Scan of MLTSS Quality Requirements in MCO Contracts. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/MCOcontr.pdf. Last accessed August 2015.	This report describes the findings of a scan of MLTSS quality requirements in 17 states with contracts with MCOs. The results of this scan found wide diversity in some instances and more convergence in others. For example, in some states, the quality element requirements may be very specific and prescriptive whereas in other states the detail of implementing the requirement may be left to MCO discretion. This report includes required LTSS performance measures that focus on the processes for response time to respond to referrals, timeliness of receipt of covered services, timeliness of care plan implementation, process for handling critical incidents, and process for coordination of services. Several contracts also specified outcomes related to community retention rate, rate of preventable hospital admissions, rates of nursing facility and chronic hospital admission. This report also describes required performance improvement projects that focus on clinical and nonclinical areas.	High	High	High
Rivard P, Jackson B, Stokes T. Addressing Critical Incidents in the MLTSS Environment. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/CritIncidRB.pdf. Last accessed August 2015.	This brief emphasizes the importance of having a critical incident reporting and management system to ensure the health and welfare of Medicaid enrollees are safeguarded in the MLTSS environment. Ways in which some established MLTSS programs managed critical incidents where MCOs play a key role are discussed. Various examples of the approaches some states have taken to address the occurrence of critical incidents are provided. CMS provides guidance about essential aspects of a well-conceived incident system with the expectation that they are incorporated into new/existing MLTSS Programs. These criteria will also be used to review/approve programs using the 1115 or 1915(c) waivers for MLTSS. This brief provides links to articles on performance measures in MLTSS programs and environmental scans.	High	High	High
Rivard P, Jackson B, Stokes T. Performance Measures in MLTSS Programs. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/PerfMeaRB.pdf. Last accessed August 2015.	This brief provides an overview of the performance measures that some of the more established managed LTSS (MLTSS) programs are using to monitor the services provided to beneficiaries and to improve overall quality in MLTSS. Examples of process and outcome measures that states use to assess MTLSS programs are provided. These performance measures must demonstrate that the state meets the 1915(c) assurances that federal law requires, several of which are directly related to quality. The brief also mentions member surveys that are used to measure person-centered outcomes.	High	High	High

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Robertson J, Emerson E, Hatton C, et al. Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities. *J Intellect Disabil Res.* 2007;51(3):232-243.	Person-centered planning (PCP) can have a positive impact on lifestyle-related outcomes for individuals with intellectual disabilities, but its effect is not uniform across individuals. The purpose of this study was to identify factors associated with the probability of an individual receiving a person-centered plan as well as factors associated with improvements in the areas associated with PCP. • Factors significantly associated with having a PCP were: being involved with the study for longer and having a keyworker at baseline. • Factors associated with a PCP effect on lifestyle-related outcomes were: Having an improved social network (i.e., size of social network at baseline) and index of deprivation Increased community involvement (i.e., lower Index of Community Involvement score at baseline), increased scheduled day activities (i.e., lower total score on LDCS challenging behavior scale, having less scheduled day service hours at baseline), improved contact with friends (i.e., having more health problems relative to other participants at baseline, lower scores on the SDQ hyperactivity subscale, higher scores on the SDQ pro-social subscale, and improved or no contact with the family, improved choice (i.e, fewer facilitator-reported staff barriers) PCP is considered an important process within HCBS and assessing its occurrence and effect on outcomes important. The measures utilized in this study were either survey or frequency data.	Medium	High	Low
Robertson J, Emerson E, Pinkney L, et al. Treatment and management of challenging behaviours in congregate and noncongregate community-based supported accommodation. *J Intellect Disabil Res.* 2005;49(1):63-72.	The expression of challenging behaviors is associated with an increased risk of exposure to negative outcomes including physical injury; social exclusion, isolation, and neglect; abuse from caregivers; exposure to restrictive treatment and management practices; increased caregiver burden; and increase cost of service provision. This study used a longitudinal matched groups design to compare the nature and prevalence of the use of procedures to treat and manage challenging behaviors across two approaches to providing community-based supported accommodation for people with intellectual disabilities (ID) and severe challenging behavior: (1) no congregate settings where the minority of residents have challenging behavior, and 2) congregate settings where the majority of residents have challenging behavior. The study found that both types of settings were associated with low prevalence of use of behavioral technologies for the reduction of challenging behavior. High proportions of participants received antipsychotic medication in both settings. Congregate settings were associated with increased use of physical restraints as a reactive management strategy. This study contains structural and process measures related to challenging behaviors and treatment and management procedures.	High	High	Low

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Rosenfeld P, Russell D. A review of factors influencing utilization of home and community-based long-term care: trends and implications to the nursing workforce. *Policy Polit Nurs Pract.* 2012;13(2):72-80.	This article describes the developments of U.S. health care policy that have resulted in the increased demand for and utilization of HCBS. Through a descriptive analysis of data, the authors present significant differences between nurses employed in HCBS and hospital settings as well as the health workforce response to the increase demand for nurses in HCBS.	High	High	High
RTI International. Support and Services at Home (SASH) Evaluation: First Annual Report. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/SASH1.pdf. Last accessed August 2015.	This report describes implementation challenges and early impacts of the SASH program intended to improve health and decrease healthcare expenditures among elderly residents of affordable housing developments. The SASH program connects residents with community-based services and promotes coordination of healthcare. Findings of the SASH evaluation showed that although participants had higher rates of hospitalizations and ER visits relative to non-SASH/MAPCP Demonstration beneficiaries, the early SASH panels were associated with lower rates of growth in Medicare expenditures relative to a comparison group.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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RTI International. Support and Services at Home (SASH) Evaluation: First Annual Report. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/sites/default/files/pdf/77171/SASH1.pdf. Last accessed November 2015.	The TEFT project was launched in 2013 by the Disabled and Elderly Health Programs Group (DEHPG), and comprises four components, the second of which is focused on adapting a subset of CARE items for appropriate standardized assessment of community-based, long-term services and supports (CB-LTSS) programs beneficiaries (referred to as the HCBS CARE project). With the basis for the HCBS CARE project being standardized assessment in LTSS, it adapted existing CARE items (originally developed for post-acute care) so they are appropriate for the HCBS population (HCBS CARE Item Set). The HCBS Care project thus formed the need for this report, which details the results of an environmental scan and literature review of HCBS instruments and quality measures. The review focused on: • Tools currently used or that are needed to conduct functional assessments of HCBS population • Appropriateness of the tools identified • Qualifications of entities/providers conducting the HCBS assessments (proper training, background, etc.) • HCBS quality measures currently used and measure gaps • Actions to ensure successful exchange of HCBS CARE items Findings include: • three types of modifications (where appropriate) are needed on existing CARE items: trivial, nontrivial, and substantive • new items needed for development center around assistive technologies, behavioral symptoms, cognitive impairment, employment, home ownership/living arrangement, home safety and abuse, informal caregiver support, mobility, preferences and goals, pressure ulcer/skin condition, sensory perception and communication, significant change in status, and transportation • identified 13 key initiatives in the public and private sectors that focused on HCBS performance measures; findings are detailed in the report • there is variation by state in required qualifications for people conducting assessments, majority of states requiring them to be registered nurses or social workers. This report contains a scan of HCBS quality measure initiatives and analysis highlighting client-focused process or outcome measures that have been tested for validity and reliability. Quality measures, by program, for the ten most common measure domain/construct themes are reported in Appendix C.	High	High	High

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RTI. Draft Specifications for the Functional Status Quality Measures for Long-Term Care Hospitals. Public Comment Document. Baltimore, MD: CMS; 2014. Available at: http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Public-Comment-Functional-Specs.zip. Last accessed August 2015.	These two reports describe functional status measures taken from the CARE item set for inpatient rehabilitation facilities and long-term care hospitals. CMS solicits public comments on these measures to support ongoing measure development and implementation for the CMS IRF Quality Reporting Program. Specifically, these six quality measures focus on self-care and mobility activities. The report also includes the reliability and validity testing for these measures.	High	High	Low
S&I Framework. Electronic long-term services and supports (eLTSS) website. http://wiki.siframework.org/electronic+Long-Term+Services+and+Supports+%28eLTSS%29. Last accessed November 2015.	This website provides an overview of the eLTSS Initiative in partnership with ONC and CMS. This initiative will focus on identifying and harmonizing electronic standards and interoperability of health records for use in HCBS. The goal is to improve the coordination of health and social services that support an individual's mental and physical health. This initiative is driven by the requirements of the CMS TEFT in CB-LTSS Planning and Demonstration Grant Program created in the ACA. This website also provides information on weekly meeting schedules, homework assignments, announcements, and timeline details on eLTSS as well as contact information on CMS staff.	High	High	High
SAMHSA. SAMHSA's Working Definition of Recovery. Rockville, MD: SAMHSA; 2012. HHS Publication No. PEP12-RECDEF. Available at http://store.samhsa.gov/product/SAMHSA-s-Working-Definition-of-Recovery/PEP12-RECDEF. Last accessed October 2015.	This report outlines SAMHSA's working definition and set of principles for recovery. This work is meant to create a unified operational definition that will help advance recovery opportunities for all Americans, and help to clarify these concepts for peers, families, funders, providers, and others.	Low	Low	Low

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Samuel PS, Lacey KK, Giertz C, et al. Benefits and quality of life outcomes from transportation voucher use by adults with disabilities. *J Pol Pract Intellect Disabil.* 2013;10(4):277-288.	Access to transportation is a substantial barrier to community participation and an improved quality of life for individuals with disabilities. This study examined the perceived benefits of participating in a transportation voucher program in Michigan. Cross-sectional survey data collected from a convenience sample of 73 participants of the voucher program were analyzed. Participation outcomes were differentiated by age, sex, employment status, and type of disability using multivariate logistic regression analysis. More than two-thirds (70 percent) of participants reported that their emotional well-being and community participation had improved, and 54 percent of participants indicated that participation in the voucher program had resulted in better overall quality of life. The type of disability was an important factor in determining the degree of gain experienced, particularly in terms of community participation and overall quality of life. Findings suggest that resources spent on developing voucher programs have the potential to enrich the lives of persons with disabilities and their families. However, future longitudinal research along with a comparison group may be necessary to validate these preliminary findings on the benefits of vouchers. This study contains measures concepts of transportation, participation outcomes, and quality of life outcomes.	Medium	Medium	High
Saucier P, Kasten J, Burwell B, et al. The Growth of Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 Update. Baltimore, MD: CMS; 2012. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf. Last accessed August 2015.	In 2012, Truven Health Analytics conducted an environmental scan of Medicaid managed LTSS for disabled and elderly health program groups at CMS. The scan included an inventory of all MLTSS programs that had been implemented as of June 2012 and a projection of future programs through January 2014. This study found that Medicaid managed LTSS has grown significantly since 2004 and is expected to spread across more states in the next two years with an increasing number of programs and enrollees. In 2012, the number of states with MLTSS doubled from 8 to 16 and the number of persons receiving LTSS increased from 105,000 to 389,000. Although the development of the MLTSS market was originally hampered by a very limited supply of organizations willing and able to provide services, compared to traditional FFS delivery of care, MLTSS has become a significant part of the system in several states. In the absence of a set of national LTSS performance measures, states have implemented their own unique approaches to measuring quality. These include system measures (e.g., progress on rebalancing), and person level measures around use of institutional services, community inclusion, experience and satisfaction. Since each state has developed its own unique approach to measuring quality in MLTSS, there is currently no clear method to compare the quality of LTSS series across MLTSS programs.	High	High	High

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Schalock RL, Verdugo MA. A conceptual and measurement framework to guide policy development and systems change. *J Policy Pract Intellect Disabil.* 2012;9(1):63-72.	This article describes a conceptual and measurement framework that serves as a guide for policy development and systems change. The framework is built on the concepts of vertical and horizontal alignment, system-level processes, and organization-level practices. The framework helps identify significant disconnects between and among system-level processes and organization-level practices in order to improve alignment in policy and streamline system changes. The article discusses change-oriented principles (vision of the future, simple communication, leadership, empowering, immediate feedback and reinforcement, organization's culture) and guidelines (pace the change process, reallocate and restructure resources, alignment processed, partnerships, continuous quality improvement framework, system and organization-level outputs, innovation, performance-based evaluation and management system) that address significant challenges faced by intellectual and developmental disabilities organizations and systems. This article offers measure concepts, domains, subdomains, and levels of analysis.	Low	Low	Medium
Schmidt S, Muhlan H, Power M. The EUROHIS-QOL 8-item index: psychometric results of a cross-cultural field study. *Eur J Pub Health.* 2005;16(4):420-428.	The purpose of this study was to perform psychometric testing on the EUROHIS-QOL 8-item index, an adaptation of the WHOQOL-100 and the WHOQOL-BREF. The authors surveyed 4849 European adults across 10 countries. Survey respondents were also investigated with a chronic condition checklist, measures on general health perception, mental health, healthcare utilization, and social support. Study findings indicated good internal consistencies across most countries, with acceptable convergent validity with physical and mental health measures. The measure discriminates well between individuals that report having a chronic condition and healthy individuals across all countries. The authors conclude that the EUROHIS-QOL 8-item index can be recommended for use in public health research, and recommend testing it for sensitivity in multinational clinical studies. This article contains a patient-reported outcome measure on quality of life.	Medium	High	High
Schultz E, Davies SM, McDonald KM. Development of Quality Indicators for Home and Community-Based Services Population: Technical Report. Rockville, MD: AHRQ; 2012. Available at http://www.qualityindicators.ahrq.gov/Downloads/Resources/Publications/2012/HCBS_QI_Technical_Report.pdf. Last accessed August 2015.	Purpose of report: These quality indicators (QIs) are intended to reflect the health and well-being of beneficiaries receiving home and community-based services (HCBS) through state Medicaid programs. The indicators focus on the well-being of HCBS beneficiaries as reflected by potentially preventable hospitalizations. These include hospitalizations for specific conditions associated with chronic disease exacerbation and progression as well as poor access to care and support services.	Medium	Medium	High

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Sciegaj M, Crip S, DeLuca C, et al. Participant-Directed Services in Managed Long-Term Services and Supports Programs: A Five State Comparison. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/sites/default/files/pdf/76751/5LTSS.pdf. Last accessed August 2015.	This report describes an in-depth examination of participant-directed MLTSS (PD-MLTSS) programs in five states: Arizona, Massachusetts, New Mexico, Tennessee, and Texas. The findings include a description of state requirements for PD-MLTSS, how PD-MLTSS programs are developed and managed, the number of participants enrolled in PD-MLTSS, how PD-MLTSS quality is monitored, the roles and functions of financial management service agencies. The implications of this five-state examination are also described: states play a major role in how PD-MLTSS is operationalized; there are examples of how the principles of managed care and participant direction can be integrated; training for MCO service coordinators is vital; how PD-MLTSS is presented to participants is critical; PD-MLTSS would benefit from clarity in the roles and responsibilities of the different PD-MLTSS Supports; FMS is a key PD-MLTSS support element; and MCOs would benefit from increased engagement from participants. This report lists enrollment targets and PD-MLTSS performance measures and performance indicators for Tennessee.	High	High	High

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Seekins T, Ravesloot C, Katz M, et al. Nursing home emancipation: a preliminary study of efforts by centers for independent living in urban and rural areas. *Disabil Health J.* 2011;4(4):245-253.	Centers for independent living (CILs) and other disability advocacy organizations have initiated a variety of efforts to transition adults with disabilities from undesired nursing home placements to the community. The purpose of this paper is to establish a baseline of nursing home transition services provided by CILs in the US. The paper describes research to assess: (1) the levels of nursing home emancipation services and barriers to transitions, including the role of secondary health condition, and (2) transition policies and procedures. Researchers surveyed 165 CILs operating nursing home emancipation programs. They received the written transition policy and procedures of 28 CILs from 14 states. Survey respondents reported transitioning 61 percent (2389) of individuals from nursing homes to the community in the previous year, with only 4 percent returning to a nursing home for any reason. The study identified six categories of barriers to emancipation: 1. concerns about pain management; 2. fear of social isolation; 3. access to appropriate services; 4. guardian or third-party interference issues such as difficultly working with nursing home staff; 5. financial resources; and 6. instrumental barriers to participation such as access to transportation and appropriate equipment. Policy and procedure review found there is growing consensus on what is important to implementing nursing home transition programs. However, the extent to which policies reflected the standard components varied widely. Study findings suggest the need to expand established emancipation programs to build evidence-based practices. This study contains process measures on care transitions.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Shih RA, Concannon TW, Liu JL, et al. Improving Dementia Long-Term Care: A Policy Blueprint. Santa Monica, CA: Rand Corporation; 2014. Available at http://www.rand.org/content/dam/rand/pubs/research_reports/RR500/RR597/RAND_RR597.pdf. Last accessed November 2015.	The number of older Americans requiring dementia-related long-term services and supports (LTSS) is increasing. This national report focuses on policy options at the intersection of dementia and LTSS and aims to provide a foundation for consensus-building on prioritization and sequencing of policy recommendations. The authors undertook five major tasks that resulted in a prioritized list of policy options and research directions to help decisionmakers improve the dementia LTSS delivery system, workforce, and financing. These were to: (1) Identify weaknesses in the LTSS system that may be particularly severe for persons with dementia; (2) Review national and state strategies addressing dementia or LTSS policy; (3) Identify policy options from the perspective of a diverse group of stakeholders; (4) Evaluate the policy options; and (5) Prioritize policy options by impact and feasibility. Stakeholders identified 38 policy options. RAND researchers independently evaluated these options against prespecified criteria, settling on 25 priority options. These policy options can be summarized into five objectives for the dementia LTSS system: (1) Increase public awareness of dementia to reduce stigma and promote earlier detection; (2) Improve access to and use of LTSS; (3) Promote high-quality, person- and caregiver-centered care; (4) Provide better support for family caregivers of people with dementia; and (5) Reduce the burden of dementia LTSS costs on individuals and families. The authors identify examples of key performance indicators of LTSS system performance for persons affected by dementia in order to monitor progressive improvements on the five overarching objectives (pp. 33-34). They also identify possible process metrics.	Medium	High	Medium
Sloan M, Irvin C. Money Follows the Person Quality of Life Survey. Baltimore, MD: CMS, Cambridge, MA: Mathematica Policy Research; 2007. Available at http://www.mathematica-mpr.com/~/media/publications/PDFs/health/MFP_QoL_Survey.pdf. Last accessed August 2015.	This document includes an overview of the Money Follows the Person QoL survey as well as the actual survey itself. This survey was designed to measure QoL in seven domains including: living situation, choice and control, access to personal care, respect/dignity, community integration/inclusion, overall life satisfaction, and health status. The target population for the survey includes people with disabilities and long-term illnesses who are transitioning from institutionalized care to a care setting in the community. The survey is to be administered to all participants at three points in time—just prior to transition, about 11 months after transition, and about 24 months after transition.	Medium	Medium	Medium
Smith D, Lakin KC, Larson S, et al. Changes in residential arrangements of persons with intellectual and developmental disabilities in the decade following the Olmstead decision of 1999. *Intellect Dev Disabil.* 2011;49(1):53-56.	This report describes changes in residential arrangements of persons with IDD in the decade following the Olmstead decision of 1999. It includes statistics on individuals with IDD receiving residential specific services up to 2009. These statistics indicate a reduction in people living in institutional settings as well as a shift toward community health living.	Medium	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
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Spillman BC, Wolff J, Freedman VA et al. Informal Caregiving for Older Americans" An Analysis of the 2011 National Study of Caregiving. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/NHATS-IC.pdf. Last accessed August 2015.	This report examines the role and experiences of informal caregivers for older adults (65+ years) using the National Survey of Caregiving (NSOC). The data collected in this study allows for the examination of how gains/burdens differ by caregiver, care recipient characteristics and by the intensity of care provided. Results found that in 2011, 18 million informal caregivers provided 1.3 billion hours of care monthly to more than 9 million older adults beyond traditional household and self-care activities of daily living.	High	High	High
Standards and Interoperability (S&I) Framework. HealthIT website. http://www.siframework.org/. Last accessed August 2015.	This website describes the Standards and Interoperability Framework (S&I). The S&I Framework is a collaborative community of participants from the public and private sectors who are focused on providing the tools, services, and guidance to facilitate the functional exchange of health information. The S&I Framework uses a set of integrated functions, processes, and tools that enable execution of specific value-creating initiatives. Each S&I Initiative tackles a critical interoperability challenge through a rigorous process that typically includes: • Development of clinically oriented user stories and robust use cases • Harmonization of interoperability specifications and implementation guidance • Provision of real-world experience and implementer support through new initiatives, workgroups, and pilot projects • Mechanisms for feedback and testing of implementations, often in conjunction with ONC partners such as NIST	High	High	High

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Stanek M. Quality Measurement to Support Value-Based Purchasing: Aligning Federal and State Efforts. Portland ME: National Academy for State Health Policy; 2014. Available at http://www.nashp.org/sites/default/files/Quality.Measurement.Support.ValueBasedPurchasing.pdf. Last accessed November 2015.	Improvements in infrastructure, legislative reform, and national policies are driving an increased focus on accurate and reliable quality measurement in healthcare. This report details the current quality measurement landscape and federal and state initiatives to incorporate robust quality measurement into value-based purchasing strategies, including discussion results from a meeting of federal and state leaders convened by the National Academy of State Health Policy (NASHP) in November 2013 to: 1. give state participants the opportunity to learn about and discuss new opportunities and promising practices for measuring quality under value-based purchasing approaches with their peers; 2. give states the chance to learn about new federal opportunities they can leverage to support quality measurement; and 3. 3 give federal participants the opportunity to learn about state approaches to quality measurement and identify potential federal policy changes that can support state activities or better align federal strategies with state approaches. The report enumerates opportunities for policy improvement to achieve a greater degree of alignment between federal and state initiatives, along with flexibility necessary to help states and the federal government find the best path to achieve such goal. Four key themes emerged: 1. Federal and state partners have multiple options for aligning strategies, from using identical metrics to agreeing on a shared policy direction for value-based purchasing. 2. In quality domains that have an excess of measures available, measures can be aligned across programs to reduce provider burdens. 3. In areas of measure selection and development that suffer from a dearth of available measures, as well as in the ongoing development of the information technology infrastructure to support measurement, experimentation is necessary to identify promising paths forward. 4. Measurement strategies should incorporate flexibility to accommodate changing needs and circumstances, as well as state-level variations in technical capacity and public health priorities. There was also agreement that both levels of government need to learn from each other and to focus policy on a goal of broadly supporting each other's initiatives by avoiding misalignment rather than the narrower goal of choosing identical quality measure.	Low	Low	Low

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Steger MF, Frazier P, Oishi S, et al. The meaning in life questionnaire: assessing the presence of and search for meaning in life. *J Couns Psychol.* 2006;53(17):80-93.	This article provides evidence from three studies on the internal consistency, temporal stability, factor structure, and validity of the Meaning in Life Questionnaire (MLQ), a new 10-item measure of the presence of, and the search for, meaning in life. According to this study, research has supported a proposed link between lack of meaning and psychological distress. The results of this study conclude that accurate measurement is essential to psychological research and can significantly improve positive human functioning. The MLQ Search subscale can effectively gauge the extent to which clients seek greater purpose and meaning as part of this growth process.	High	High	High
Stokes T, Jackson B, Rivard P. Did they or didn't they: a brief review of service delivery verification in MLTSS. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/verifyRB.pdf. Last accessed August 2015.	This brief addresses how states and MCOs verify that providers deliver the MLTSS specified in member service plans. A review of service delivery verification in MLTSS found that states rely on a variety of approaches for monitoring services including whether members receive services/supports, organization of timely action when service gaps do occur, and ensuring safeguarding of member health and well-being. This report provides links to other reports on the study of Medicaid MLTSS and lessons learned. It also links to another research brief on performance measures in MLTSS programs.	High	High	High
Substance Abuse and Mental Health Services Administration (SAMHSA). Leading Change 2.0: Advancing the Behavioral Health of the Nation 2015-2018. Rockville, MD: SAMHSA; 2014. HHS Publication No. (PEP) 14-LEADCHANGE2. Available at http://store.samhsa.gov/shin/content/PEP14-LEADCHANGE2/PEP14-LEADCHANGE2.pdf. Last accessed October 2015.	This report outlines SAMHSA's strategic plan 2015-2018, Leading Change 2.0: Advancing the Behavioral Health of the Nation (Leading Change 2.0). It highlights six key strategic initiatives that SAMHSA will employ to meet new and existing goals, deliver on its mission, and realize its vision moving forward. This source is peripherally relevant as it focuses on certain types of HCBS.	Medium	Medium	Low
Support Development Associates (SDA) website. http://sdaus.com/. Last accessed November 2015.	This is a YouTube Series on Person Centered Thinking and Planning. This link leads to a multiseries of short videos by Michael Smull on: 1. The history of essential lifestyle planning and the learning community; 2. A rock in the pond. Why training is not enough and what managers need to do. 3. Definitions. What is meant by person-centered approaches, thinking, and planning? 4. Creating person centered plans that make a difference. 5. Making person centered planning mainstream. How to get started.	Medium	Medium	Medium

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Support Development Associates (SDA). Powerpoint presentation to the Administration for Community Living; Putting the person at the center: integrating plans for long-term services and supports and health care delivery through health IT; October 16, 2014.	This website provides information on the "Putting the Person at the Center: Integrating Plans for Long-Term Services and Supports and Health Care Delivery through Health Information Technology" town-hall style public workshop. ACL and the ONC sought input from stakeholders and experts on the use of health information technology (HIT) to enable a person-centered approach for planning and delivering both long-term services and supports and healthcare, including how to improve communication and collaboration among community-based organizations and healthcare partners. The topics discussed include care planning, technology and integration; key opportunities and challenges; and delivery and payment reform policy levers.	Low	High	High
Tang WR. Hospice family caregivers' quality of life. *J Clin Nurs.* 2009;18(18):2563-2572.	This cross-sectional correlational study describes the quality of life and it interlinks among family caregivers of terminally ill patients receiving in-home hospice care. Researchers received self-report data from 60 caregivers using the Caregiver QOL Index-Cancer, Spiritual Well-Being Scale, American Pain Society Patient Outcomes Questionnaire, Easter Cooperative Oncology Group Performance Status Rating, and Medical Outcome Study Social Support Survey to measure their QOL, spirituality, health status, and social support. The results of this study found that caregivers with higher education, better physical health status, greater spirituality, and more qualitative and quantitative social support had a significantly better QOL. Researchers concluded that the QOL for this sample of hospice caregivers was significantly predicted only by physical health status and spirituality, likely because of collinearity among the independent variables. Additional research is needed to explore the factors that sustain or promote caregivers' QOL over time.	High	High	High
Taylor EF, Lake T, Nysenbaum J, et al. Coordinating Care in the Medical Neighborhood: Critical Components and Available Mechanisms. Rockville, MD; AHRQ; 2011. AHRQ Publication No. 11-0064. Available at http://pcmh.ahrq.gov/sites/default/files/attachments/Coordinating%20Care%20in%20the%20Medical%20Neighborhood.pdf. Last accessed August 2015.	This paper examines the various "neighbors" in the medical neighborhood and how these neighbors could work together better, thus allowing the PCMH to reach its full potential to improve patient outcomes. Specifically, the paper addresses (1) key components of the medical neighborhood and how the PCMH is situated within it; (2) existing barriers to achieving a well-functioning medical neighborhood; and (3) the approaches and tools available to achieve a well-functioning neighborhood, and the strengths and weaknesses of each.	High	High	High

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Tennessee Department of Intellectual and Developmental Disabilities (DID). Person-centered excellence network accreditation website. http://tn.gov/didd/topic/network-accreditation. Last accessed November 2015.	The State of Tennessee government website featuring the Department of Intellectual and Developmental Disabilities (DIDD), a Council on Quality and Leadership (CQL)-accredited Person-Centered Excellence network. The Person-Centered Excellence accreditation process is designed to assess the quality of services and supports delivered by the department and its contracted providers, resulting to the DIDD's better understanding of how their consumers define quality of life. The department is using that information to guide a systemic change to improve quality of life.	High	High	Medium
The Center for Self-Determination. Principles of self-determination website. http://www.centerforself-determination.com/. Last accessed November 2015.	This website presents the five principles of self-determination which are freedom, authority, support, responsibility, and confirmation. It also links to several articles related to mental health, self-determination, aging, quality, guardianship, and employment.	Medium	Medium	High
The Council on Quality and Leadership. Personal outcome measures. http://www.c-q-l.org/the-cql-difference/personal-outcome-measures. Last accessed November 2015.	This website provides a description of personal outcome measures. It describes three domains for which measures can be organized: my self, my world, my dreams. The Personal Outcome Measures tool contains 21 items that define quality from the individual's perspective. These are the key indicators and experiences that people and their families have said are most important to them.	High	High	High
The Kaiser Commission on Medicaid and the Uninsured. Measuring Long-Term Services and Supports Rebalancing. Fact Sheet. Washington, DC: Kaiser Family Foundation; 2015. Available at http://files.kff.org/attachment/fact-sheet-measuring-long-term-services-and-supports-rebalancing. Last accessed November 2015.	The Medicaid Health Home State Plan Option, authorized under the Affordable Care Act, allows states to design health homes to provide comprehensive care coordination for Medicaid beneficiaries with chronic conditions. The Health Home Information Resource Center was established by the Centers for Medicare & Medicaid Services (CMS) to help states develop these new models to coordinate the full range of medical, behavioral health, and long-term services and supports needed by Medicaid beneficiaries with chronic health needs. The resource center offers various technical assistance services and a resource library to help guide state health home development and implementation. The website links to Health Home Technical Assistance Pages: Approved Health Home State Plan Amendments, Guide to Medicaid Health Home Design and Implementation, Request Health Home Planning Funds, Request Health Home Technical Assistance, and Health Home Technical Assistance Learning Forums. It contains a link to a resource manual on Health Home Care Set of Quality Measures. The linked Approved Health Home State Plan Amendments page contains PDFs for amendments for 19 states. Many of these PDFs contain goal-based quality measures related to clinical outcomes, experience of care, and quality of care.	Medium	High	Medium

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The Kaiser Commission on Medicaid and the Uninsured. Measuring Long-Term Services and Supports Rebalancing. Fact Sheet. Washington, DC: Kaiser Family Foundation; 2015. Available at http://files.kff.org/attachment/fact-sheet-measuring-long-term-services-and-supports-rebalancing. Last accessed November 2015.	A growing number of states report that the structure of their managed LTSS programs is expected to increase beneficiary access to HCBS and thus contribute to rebalancing of state LTSS systems. This factsheet provides an overview of quality measures related to LTSS rebalancing. The two major categories of measures reviewed are (1) extent of community integration (e.g., The National Core Indicators) and (2) quality measures from States' capitated financial alignment demonstrations (e.g., number or percent of beneficiaries living in institutional or community-based settings or experiencing decreases in personal care hour authorizations). Two tables provide detail about each rebalancing measure. The authors conclude that as more states start to utilize managed LTSS programs, tracking the effect of these programs on LTSS rebalancing is important and that measures must not only assess whether services are provided in the community but also to what extent these services are adequate to support the individual beneficiary.	High	High	High
The Lewin Group. The "Value Added" of Linking Publicly Assisted Housing for Low-Income Older Adults with Enhanced Services: A Literature Synthesis and Environmental Scan. Washington, DC: HHS Office of Disability, Aging and Long-Term Care; 2012. Available at http://aspe.hhs.gov/daltcp/reports/2012/ValueAdd.pdf. Last accessed August 2015.	This report describes the findings of design options for a demonstration of publicly assisted rental housing coordinated with health and LTSS for low-income older adults. These findings suggest that housing with services can help meet many of the federal policy objectives outlined in the report and improve population outcomes. There are many innovative strategies being developed to address the challenges to expanding publicly assisted housing with enhanced service programs. This report also describes research gaps and discusses measure concepts to identify ways to measure program success, health and well-being measures, need for services for difficulties with ADL, and measures of mental health.	Medium	High	Medium
The Lewin Group. Picture of Housing and Health: Medicare and Medicaid Use Among Older Adults in HUD-Assisted Housing. Washington, DC: HHS Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/HUDpic.pdf. Last accessed August 2015.	This report explores the potential for publicly subsidized senior housing to serve as a platform for efficiently managing the population health of low-income older adults with various levels of physical and mental health risks. The design of a new demonstration piloted with a new dataset linking HUD tenant and Medicare/Medicaid claims data is described. The purpose of the demonstration was to determine the extent to which this resource could track health and housing outcomes, and whether this approach could reliably support future research and policy analysis. This study demonstrates the feasibility and utility of linking HUD tenant data to CMS administrative data. The results of this study highlight key areas for future analysis to better understand the health and healthcare utilization of HUD assisted elderly individuals enrolled in Medicare	High	High	Medium

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Tracy EM, Laudet AB, Min MO, et al. Prospective patterns and correlates of quality of life among women in substance abuse treatment. Drug Alcohol Depend. 2012:124(3):242-249.	This article examines the patterns and predictors of QoL at 1 and 6 months post treatment intake among 240 women enrolled in substance abuse treatment using the WHOQOL-BREF measure to assess physical, psychological, social, and environmental domains. The results of this study found that all QoL domains across follow-up time points improved significantly; however, scores across domains remained below those of healthy population norms. This suggests that the WHOQOL measure was a useful indicator of functioning in substance abusing populations. Overall, QoL measures can be used to supplement more objective symptom measures, identify specific service needs, and document changes in functioning that are associated with substance use patterns.	Medium	Medium	Low
Truven Health Analytics. Population Groups Enrolled in Managed Long Term Services and Supports. Baltimore, MD: CMS; 2012. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSS-Populations.pdf. Last accessed August 2015.	This report provides a listing of current and future population groups included in managed long-term services and support programs.	Low	Low	Low
U.S. Census Bureau. Disability website. http://www.census.gov/people/disability/. Last accessed August 2015.	This link provides an overview of disability data and where it was collected in the United States. The U.S. Census Bureau collected disability data primarily through the American Community Survey and Survey of Income and Program Participation. This website provides links to latest releases of reports, presentations, definitions, and population data.	High	High	High
U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR). 2013 Annual Disability Statistics Compendium. Durham, NH: University of New Hampshire Institute on Disability; 2013. Available at http://www.disabilitycompendium.org/docs/default-source/2013-compendium/download-the-2013-compendium.pdf?sfvrsn=0. Last accessed November 2015	This report is a publication of statistics about the populations with disabilities and the government programs that serve them. The report is designed to serve as a reference guide to government publications. Topics covered in this report include population size, prevalence of disability, labor force participation, unemployment and employment, poverty, earnings from work, enrollment in education, educational attainment, self-reported health status, health behaviors, healthcare coverages, Supplemental Security Income, Social Security Disability Insurance, special education, and vocational rehabilitation.	Low	Low	Low

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U.S. Department of Housing and Urban Development (HUD). American housing survey website. http://www.huduser.org/portal/datasets/ahs.html. Last accessed August 2015.	This website contains research reports based on the American Housing Survey. The American Housing Survey provides up-to-date information on the size and composition of the housing inventory in the United States. As the country grows, so does the demand for housing. There is a great need for information about the types of homes in which people are now living and the characteristics of these homes, as well as the costs of running and maintaining them. This information can be useful when determining the suitability of homes for certain types of services.	Medium	Medium	Low
U.S. General Accounting Office (GAO). Long-Term Care Status of Quality Assurance and Measurement in Home and Community-Based Services. Washington, DC: GAO; 1994. Available at http://www.gao.gov/assets/220/219369.pdf. Last accessed August 2015.	This report explored the status of quality assurance and measurement in home and community-based services pertaining to long-term care.	High	High	High
U.S. Senate Commission on Long-Term Care. Report to the Congress. Washington, DC: Government Printing Office; 2013. Available at http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf. Last accessed August 2015.	This report written to Congress contains a call to action to create a more extensive and deliberative effort to build momentum towards confronting and preparing for the LTSS challenge the U.S. faces. The Commission recommends further steps to expand the national dialogue and move forward on the development and implementation of a better and more comprehensive LTSS system. The report contains a number of recommendations, but the Commission specifically refers to the importance of focusing on quality across settings of LTSS—with particular attention to home and community-based services. The Commission recommends increasing resources and accelerating the time frame for activities currently underway to develop quality measurement tools for use in home and community-based settings; develop appropriate procedures and mechanisms for applying quality measures to ensure quality and appropriateness of services in these settings; and develop measures on family experience of care, especially when caring for people with Alzheimer's disease or other cognitive or intellectual disabilities. The Commission also recommends working with states to establish a system to publish quality measures that will be understandable to consumers, develop payment incentives and value-based purchasing of services based on quality after testing in pilot projects, and develop provider accreditation and certification based on quality. Important sections include services delivery, workforce, and financing.	High	High	High

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Umberson D, Montez JK. Social relationships and health: a flashpoint for health policy. *J Health Soc Behav.* 2010;51(Suppl):S54-S66.	This paper describes the impact of social relationships on mental, behavioral, physical health, and mortality risk. Studies show that social relationships have short- and long-term effects on health that can be positive or negative and often begin in childhood and continue throughout a person's life. The findings in this paper indicate that there is an urgency in developing policy solutions for improving social relationships in relation to health outcomes.	Medium	Medium	Medium
Van Durme T, Macq J, Jeanmart C, et al. Tools for measuring the impact of informal caregiving of the elderly: a literature review. *Int J Nurs Stud.* 2012;49(4):490-504.	This article has three major objectives including: to describe available tools to assess the impact of informal caregiving of home dwelling elderly, to identify an acceptable/appropriate tool to evaluate the impact of innovative projects for care/support of care for elderly in the home, on their informal caregiver, and determine an appropriate definition of "main informal caregiver. Researchers conducted a large literature search using specific keywords to retrieve articles and identified 105 scales assessing the impact of informal caregiving of the elderly. Most scales were intended to measure the impact of caregiving on caregivers' health for those who care for the elderly with dementia, overall elderly, cancer patients, chronically ill patients, psychiatric patients, and stroke patients. The impact was classified as either positive, negative, or neither consequence on the informal caregivers' health using a 200-question scale. The review yielded a large number of scales that can be used to assess the impact of caregiving via different dimensions. In particular, the Zarit Burden Interview was a useful tool due to its validity and international use, making comparisons between groups possible. Many tools captured in this article were created and tested prior to the year 2000.	High	High	High
Venkatesh A, Goodrich K, Conway PH. Opportunities for quality measurement to improve the value of care for patients with multiple chronic conditions. *Ann Intern Med.* 2014;161(10 Suppl):S76-S80.	This article offers guidelines and recommendations for quality measurement opportunities to improve the value of care for patients with multiple chronic conditions (MCC). It highlights 3 emerging policy opportunities for CMS to guide public and private quality measurement efforts for patients with MCCs: (1) infusing an MCC framework into measure development to promote patient-centered, as opposed to single-disease-specific, performance measurement; (2) importance of using common performance measures for individual clinicians, hospitals, and communities to accelerate meaningful improvement in the prevention and management of chronic conditions across local populations; (3) need for longitudinal measurement as a foundation for sustained quality improvement is presented.	High	High	High

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Walsh PN, Emerson E, Lobb C, et al. Supported accommodation for people with intellectual disabilities and quality of life: an overview. *J Policy Pract Intellect Disabil.* 2010;7(2):137-142.	This article presents the findings of a review of select published research from 1995-2005 studies (67 studies from 86 articles) on quality of life, deinstitutionalization, and post-deinstitutionalization of adults with intellectual and developmental disabilities (IDD). Outcomes, outcomes instruments, and the cost and benefits of supported accommodation models were reviewed. Deinstitutionalization is the term given to the policy of moving individuals with IDD out of large mental institutions into family- or community-based settings. The review of deinstitutionalization studies found that there was consistent evidence of greater choice and self-determination, participation in social networks or relationships, and community-based activities, and personal satisfaction in community-based settings. Post-deinstitutionalization studies provided consistent evidence for greater choice, self-determination, and participation in community-based activities in smaller settings, but no evidence for greater physical health or material well-being, and little evidence for a relationship between type of setting and employment. The review also identified 3 quality-of-life domains missing from conducted studies so far, such as poverty and income, organizational culture, and geographical variation. These domains are suggested for future research as they have been shown as vital determinants of quality in supported accommodation services.	High	High	Medium
Weinstock J. Protecting personal care services from fraud and abuse: OIG's concerns regarding vulnerabilities in Medicaid personal care services. Presentation at National Home and Community Based Services Conference; September 11, 2013. Available at http://www.nasuad.org/documentation/HCBS_2013/Presentations/9.11%204.00-5.15%20Washington.pdf. Last accessed August 2015.	This presentation describes the outputs of the work the Office of Inspector General on Medicaid personal care services and criminal and civil investigation/fraud. This information was presented at the National Home and Community-Based Services Conference in 2013.	Medium	High	Medium

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Wenzlow A, Borck R, Miller D, et al. An Investigation of Interstate Variation in Medicaid Long-Term Care Use and Expenditures Across 40 States in 2006. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2013. Available at http://aspe.hhs.gov/daltcp/reports/2013/40State.pdf. Last accessed August 2015.	This report explores interstate variations in LTC expenditure and service use patterns, not only in terms of institutional and noninstitutional services, but also by Medicaid LTC users' age and type of disability (e.g., intellectual and developmental disabilities [ID/DD] or other adult onset disabilities). Some states have re-oriented more toward HCBS than others. It also well known that greater progress has been made in serving certain subgroups within the LTC population in the community (those with ID/DD) compared to others and that reliance on institutional care remains greatest among the elderly, although here again there are interstate variations. This report seeks to quantify the magnitude of such differences.	Medium	Medium	High
Wheeler PN, Sardi I, Davies R, et al. Person-centred planning: a mixed-methods study of the experiences of people with intellectual disabilities and their carers. *Psychol Health.* 2009;24(Suppl 1):413.	This document is a 350-page compilation of over 270 abstracts of the poster and oral presentations presented and conducted at the 2009 European Health Psychology Society (EHPS) Conference in Pisa, Italy. The conference theme was *Health Psychology: from Knowledge to Interventions.* The presentations centered on health behavior interventions, health promotion, healthcare, and health policy related to variety of ages and conditions.	Low	Medium	High
WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med.* 1998;28(3):551-558.	The paper reports on the development of the WHOQOL-BREF, an abbreviated version of the WHOQOL-100 quality of life assessment. The data collected produces scores for physical health, psychological, social relationships and environment. The results of this assessment find that domain scores produced by the WHOQOL-BREF correlate highly (0±89 or above) with WHOQOL-100 domain scores (calculated on a four-domain structure). WHOQOL-BREF domain scores demonstrated good discriminant validity, content validity, internal consistency, and test-retest reliability. These data suggest that the WHOQOL-BREF provides a valid and reliable alternative to the assessment of domain profiles using the WHOQOL-100.	High	High	High

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Wiener JM, Anderson WL, Khatutsky G. Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontol.* 2007;47(6):763-774.	This article describes a study analyzing the effect of consumer-directed vs. agency-directed home care on satisfaction with paid personal assistance services among Medicaid beneficiaries in Washington State. A survey of 513 Medicaid beneficiaries receiving HCBS was analyzed. Additionally, researchers developed an eight-item Satisfaction with Paid Personal Assistance Scale as the measure of satisfaction. This study found that among the older population, beneficiaries receiving consumer-directed services were more satisfied than individuals receiving agency-directed care. This was not the case with younger individuals with disabilities. Evidence did not show that quality of care was less with consumer-directed services. Overall, satisfaction levels with paid home care were very high. Researchers conclude that consumer satisfaction is an important measure of quality and underlines the fact this service option is relevant for the older population.	High	High	High
Wilkins C, Burt M, Locke G. A Primer on Using Medicaid for People Experiencing Chronic Homelessness and Tenants in Permanent Supportive Housing. Washington, DC: HHS, Office of Disability, Aging and Long-Term Care Policy; 2014. Available at http://aspe.hhs.gov/daltcp/reports/2014/PSHprimer.pdf. Last accessed August 2015.	This report discusses approaches to integrated and cost-effective care for people experiencing chronic homelessness among the Medicaid eligible population. There are several gaps in services (e.g., outreach and engagement, collateral contacts, and services that explicitly focus on helping people get and keep housing as a social determinant of health and a driver of healthcare utilization and costs) that need to be filled. This report also describes measures of vulnerability or chronic homelessness used to determine the severity of chronic health conditions, performance measures that require health plans to reduce hospital readmissions for homeless patients, and cost and quality measures.	High	High	Medium
Williams AM, Wang L, Kitchen P. Differential impacts of care-giving across three caregiver groups in Canada: end-of-life care, long-term care and short-term care. *Health Soc Care Community.* 2014;22(2):187-196.	This study provides a comparative analysis of care-giving across three caregiver types including end-of-life (EOL) care, long-term care, and short-term care. It also provides an understanding of some of the health-related characteristics of caregivers. Evidence suggests that end-of-life care is the most intense form of care-giving, potentially causing the greatest burden compared to long-term and short-term care giving. This is shown through the greater negative impacts experience by the EOL when compared to the short term and long term caregivers.	Medium	Medium	Medium

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Wisconsin Department of Health and Family Services. Personal experience outcomes integrated interview and evaluation system (PEONIES) website. http://www.chsra.wisc.edu/peonies/PEONIES_Index.html. Last accessed November 2015.	This is the official website for the PEONIES project. PEONIES stands for Personal Experience Outcomes Integrated Interview and Evaluation System. The official name of the project is "Development of Methods and Training for Assessing Personal Experience Outcomes for Adults with Developmental or Physical Disabilities and Frail Elders in Wisconsin's Medicaid-Funded HCBS And Managed Long-Term Care Programs." It is funded by the Wisconsin Department of Health and Family Services with the purpose to develop a way of measuring and using the 12 Personal Experience Outcomes (listed on the website) for people receiving long-term care services in the community. So far, the project has developed and disseminated tools into the community that capture the consumers, family members, care managers, quality reviewers, policymakers and other stakeholders' needs and perspectives.	High	High	High
World Health Organization (WHO). International classification of functioning, disability and health (ICF) website. http://www.who.int/classifications/icf/en/. Last accessed November 2015.	This page on the World Health Organization (WHO) website features the International Classification of Functioning, Disability and Health or ICF — a classification of health and health-related domains. ICF is the WHO framework for describing and measuring health and disability at both individual and population levels, endorsed by all 191 WHO Member States as the international standard to describe and measure health and disability. The framework is currently used in both international and national health and disability reporting and in clinical settings for functional status assessment, goal setting and treatment planning, monitoring, and outcome measurement.	High	High	High
Wunderink L, Nieboer RM, Wiersma D, et al. Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose of reduction/discontinuation or maintenance treatment strategy. Long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiatr.* 2013;70(9):913-920.	This article presents the findings of a seven-year follow-up of a two-year open randomized clinical trial comparing maintenance treatment (MT) versus dose reduction/discontinuation (DT) treatment strategies in patients with remitted first-episode psychosis (FEP). 128 patients were recruited from the original 257 patients, completed the trial, and consented to follow-up. They were interviewed five years later about the course and outcome of psychosis. The DT patients experienced twice the recovery rate of the MT patients, attributed to higher functional remission rates in the DR group. Functional remission implies proper social functioning in the main domains of everyday life. Domains from the Groningen Social Disability Schedule (GSDS), a semistructured investigator-based interview measuring disabilities in social functioning in eight domains (seven included in this study): self-care, housekeeping, family relationships partner relationships, relationships with peers, community integration, and vocational functioning. There was no significant difference in symptom remission rate between the groups. The study concludes that schizophrenia treatment strategy trials should include recovery or functional remission rates as their primary outcome and should also include long-term follow-up.	Medium	Medium	Low

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Wysocki A, Bohl A, Fleming C, et al. Development of an HCBS Pressure Ulcer Measure, Volume 1. Cambridge, MA: Mathematica Policy Research; 2015. Available at http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/downloads/hcbs-pressure-ulcer-report-vol-1.pdf. Last accessed November 2015.	This report is one of two that describes the iterative development of an HCBS pressure ulcer measure to address potentially avoidable hospitalizations due to pressure ulcers among MFFS beneficiaries using HCBS. This measure is intended to assess the quality of care for HCBS recipients under a shared accountability framework. Numerator Specification: includes inpatient hospital admissions where a severe (stage III, IV, or unstageable) pressure ulcer is noted in any diagnosis code field on inpatient hospital claims. Exclusions: On claims where POA information is available (i.e., those paid by Medicare), the pressure ulcer measure will exclude pressure ulcers that are acquired during the hospital stay. Any hospitalization where the date of admission is outside of a month of HCBS use or enrollment will be excluded from the numerator. The numerator excludes pressure ulcers that occur during months when a Medicaid beneficiary is using hospice care. Denominator Criteria: The pressure ulcer denominator counts each month of HCBS use or enrollment in a given calendar year (or within the observation period of interest). Like the numerator, the denominator excludes months of HCBS use or enrollment when a Medicaid beneficiary is using hospice care.	High	High	High
Wysocki A, Butler M, Kane RL, et al. Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care. Rockville, MD: AGRQ; 2012. AHRQ Publication No. 12(13):-EHC134-EF. Available at http://www.ncbi.nlm.nih.gov/books/NBK114863/pdf/Bookshelf_NBK114863.pdf. Last accessed August 2015.	The objective of this systematic review was to compare long-term care (LTC) for older adults delivered through Home and Community-Based Services (HCBS) with care provided in nursing homes (NHs) by evaluating (1) the characteristics of older adults served through HCBS and in NHs; (2) the impact of HCBS and NH care on outcome trajectories of older adults; and (3) the per person costs of HCBS and NH care, costs for other services such as acute care, and family burden. Investigators found that determining whether and how the delivery of LTC through HCBS versus NHs affects outcome trajectories of older adults is difficult due to scant evidence and the methodological limitations of studies reviewed. More and better research is needed to draw robust conclusions about how the setting of care delivery influences the outcomes and costs of LTC for older adults.	High	High	Medium

Formatted Citation	Annotation	Evaluation Criteria Rating		
		Impact	Improvability	Inclusiveness
Young HM, Kurtzman E, Roes M, et al. Measurement Opportunities & Gaps. Quality Measurement Workgroup Report. Washington, DC: Long-Term Quality Alliance (LTQA); 2011. Available at http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images/TransitionalCare_Final_122311.pdf. Last accessed November 2015.	The Long-Term Quality Alliance (LTQA) is a member organization committed to improving the effectiveness and efficiency of long-term services and supports (LTSS). LTQA aims to promote effective transitions, improve health and quality of life, and reduce healthcare costs for adults receiving LTSS. This report summarizes the work of the LTQA's Quality Measurement Workgroup which was charged with addressing these goals. Using an iterative consensus process including a literature scan and surveys, the Workgroup achieved consensus on domains for measurement of transitional care in LTSS and their definitions. The domains are: • person- and family-centeredness, • transitional care processes, and • performance outcomes. They also identified and recommended 12 transitional care measures: Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS); Client Perceptions of Coordination Questionnaire (CPCQ); 3-Item Care Transition Measure (CTM-3); Percentage of patients age 65 years and older with a history of falls who had a plan of care for falls documented within 12 months; Percentage of Medicare members age 65 years and older who received at least two different high-risk medications; Percent of discharges from Jan 1 to Dec 1 of the measurement year for members 66 years of age and older for whom medications were reconciled on or within 30 days of discharge; Mean change score in basic mobility of patient in a post-acute care setting assessed; Mean change score in daily activity of patient in a post-acute care setting assessed; Percent of patients who need urgent, unplanned medical care; Percentage of patients discharged from an inpatient facility to home/any other site of care from whom a transition record was transmitted to the facility/primary physical/other healthcare professional for follow-up care within 24 hours of discharge; advanced care plan; and all-cause readmission (risk-adjusted) (see p.2). Identified measurement gaps relevant to transitional care include person- and family-centeredness measures that assess family caregivers' roles and experiences, personal experience with transitional care, palliative care during transitions, assessment of the care for older adults seen in hospital and return home with no follow-up care, measures that capture the unique needs, care processes, and outcomes for populations with health disparities, with cognitive impairment, and at the end of life/receiving hospice, measures that assess care for older adults who receive ambulatory care for chronic conditions, testing the recommended measure set to determine whether it yields meaningful information for quality improvement and consumer choice.	High	High	High

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Young J, Corea C, Kimani J, et al. Autism Spectrum Disorders (ASDs) Services Final Report on Environmental Scan. Baltimore, MD; CMS; 2010. Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf. Last accessed August 2015.	This report addresses the need for information on the most effective services for individuals with autism spectrum disorders (ASD). The report highlights key findings from an environmental scan of the scientific evidence regarding the efficacy, effectiveness, safety, and availability of ASD-related psychosocial services and supports for children, transitioning youth, and adults with ASD. It also describes the findings from the literature review, including data on the evidence base for interventions for individuals with autism across the age span as well as data on the significant costs associated with caring for individuals with autism.	Medium	Medium	Low
Zimmerman S, Allen J, Cohen LW, et al. A measure of person-centered practices in assisted living: the PC-PAL. *J Am Med Dir Assoc.* 2015;16(2):132-137.	This report describes the development and implementation of self-administered questionnaires of person-centeredness by residents and staff in assisted living (AL) residences. This study consisted of a consortium of 11 stakeholder organizations, literature review, item generation, and reduction, cognitive testing, and additional testing analyses. The setting was two assisted living residences, and field testing was conducted in 19 diverse, stratified AL residences in six states including eight residents/staff participating in cognitive testing, and 228 residents and 123 staff participating in field testing. This study measured the feasibility and psychometric testing of draft questionnaires that included 75 items (resident version) and 102 items (staff version), with parallel items on both versions as appropriate. The results of this study found that staff ranked person-centeredness higher than did the residents, indicating differences in perspectives/experiences.	High	High	High
Zimmerman S, Cohen L, Reed D, et al. Toolkit for Person-Centeredness in Assisted Living. Informational Guide and Questionnaires of Person-Centered Practices in Assisted Living (PC-PAL). Chapel Hill, NC: University of North Carolina Cecil G. Sheps Center for Health Services Research, Center for Excellence in Assisted Living (CEAL); 2014. Available at http://www.shepscenter.unc.edu/wp-content/uploads/2014/06/Person-Centered-Toolkit-for-Assisted-Living-Final.pdf. Last accessed October 2015.	This Toolkit includes an in-depth framework of person-centered structures, processes, and outcomes along with numerous examples that clarify the "what" of person-centeredness. In also includes several questionnaires of person-centered practices in assisted living. The five domains of the survey are: Workplace practices, social connectedness, individualized care and services, atmosphere, caregiver-resident relationship (MT).	High	Medium	Medium

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Zimmerman S, Cohen L. Environmental scan material for discussion at panel. Correspondence to Long-Term Care Advisory Panel. Chapel Hill, NC: University of North Carolina Cecil G. Sheps Center for Health Services Research; September 24, 2015.	This memo describes a project identifying and evaluating evidence-based measures of person-centered care, medication management, care coordination/transitions, workforce, and resident/patient quality outcomes that have been implemented in AL and other health and LTC settings used for quality improvement. This memo includes a table of five domains of the environmental scan and related key areas, literature search, and key words. Appendix III includes titles of identified measures by domain.	High	High	Medium