



The Need to Standardize Assessment Items for Persons in Need of LTSS

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The Commission on Long-Term Care, in its 2013 report to Congress, called for a delivery system for long-term services and supports (LTSS) “...organized to provide a comprehensive array of person- and family centered, high-quality, financially-sustainable medical and social services and supports that meets the heterogeneous needs, preferences, and values of individuals with cognitive and functional limitations.” The Commission further stated that such a system should provide “integration of LTSS with medical and health-related care, including effective management of transitions between one type or level of care and another.”¹

As part of a foundation for integration, the Commission recommended “...the development and implementation of a standardized assessment tool that can produce a single care plan across care settings for an individual with cognitive or functional limitations.”² Using standardized items³ across a variety of assessment tools makes it possible to share information across settings to support care coordination and develop accountability for ensuring high quality services and outcomes.

However, there are a wide variety of instruments to assess people in need of LTSS and no consensus on the core items needed to support a standardized, person-centered assessment across programs, settings, and populations within states. There is also no agreement on standardized items that should be used across states, beyond those mandated by CMS for Medicare.

The Long-Term Quality Alliance (LTQA), with the support of The SCAN Foundation, is pursuing:

- 1) expert consensus around a core set of standardized items that could be broadly adopted to enable data sharing, care planning, and quality measurement across settings, and
- 2) an action plan for gaining broad adoption of these items in assessment instruments.

¹ Commission on Long-Term Care. Report to the Congress, September 30, 2103. P. 36.

² Commission on Long-Term Care, P. 43.

³ This paper uses three separate terms to define the components of an assessment. A domain is an area of status or activity, such as: communication, functional status, caregiving, socio-economic status, nutrition, social network. A concept is status or activity within a domain. The domain “functional status” may include a number of concepts, including: mobility, activities of daily living (ADLs), and instrumental activities of daily living (IADLs). The domain “socio-economic status” may have a number of concepts including: “employment”, “finances”, “food stamp need.” A concept is measured using one or more items (essentially questions in the questionnaire). The items for measuring ADLs are questions about ability to independently perform daily activities such as bathing, dressing, or eating. The responses to the items are combined into a scale which generates a measure of functional status - a person with 1 ADL will have fewer functional limitations than someone with 3 ADLs. Variation in items includes both differences in the question itself or the phrasing of the question and differences in the number and phrasing of possible responses to the questions.

In May 2014, LTQA is convening a Roundtable of experts from state and federal programs to develop consensus on a core set of items and propose an action plan to gain broad adoption of the core items. LTQA is preparing two background papers to support the discussion.

- This first paper is intended to survey the current status of uniform assessment in state programs and make the case for an effort to standardize assessment items across instruments for persons in need of LTSS. The paper:
 - Reviews the existing variation in assessment instruments and items;
 - Reviews the major standardized assessment instruments that exist and discusses their limitations; and
 - Proposes a stepwise approach to developing consensus on standardized items and gaining adoption of consensus items.
- A second paper, based on an analysis of existing assessment instruments, reviews state and federal activity in standardizing assessment tools, identifies common domains, and discusses considerations and implications for state standardization of items that would contribute significantly to better integration.

State and program differences exist for many reasons, many of them being tied to the historical development of individual state systems. Scientific measurement of these concepts has improved greatly since these programs went into place. Electronic systems to support these public programs have also advanced dramatically. Great gains can be made by starting a discussion across programs, funders, and states to identify commonly collected concepts, examine the reliability of items currently used across these initiatives, and identify areas where the use of common items could strengthen the efficiency of program administration, reduce data collection burden, and allow quality improvement initiatives to be conducted.

Variation in Assessment Instruments and Processes

The assessment instruments and the processes used in determining eligibility and developing care plans vary from state-to-state and within states, from program-to-program.⁴ Often, programs use different assessment instruments and different processes for determining program eligibility and determining service needs.⁵ In most states, assessments of financial eligibility and functional eligibility are conducted separately.⁶

⁴ P. Black and K. Leitch. Analysis of State Approaches to Implementing Standardized Assessments. C.E. Reed and Associates. April 2012. P.2

⁵ C. Shirk. Comprehensive Assessments in Home and Community-Based Services. Baltimore, MD: The Hilltop Institute, UMBC. July 2009. P. 10

⁶ C. Shirk. P. 13

Most of these programs measure the same types of concepts – health status, functional status, social supports, and other factors important to supporting the safe care and treatment of these populations. While the concepts are common, the individual items and instruments to measure a concept across programs within states, and across states within common programs, differ in terms of item definition or response codes. As a result, for an individual served by multiple programs, the same type of data may be collected multiple times with different items. This increases burden on both the participant and the state data systems. Instead of collecting information once and using it multiple times, the data must be collected repeatedly for each program. Further, these differences prohibit the electronic transfer of information across programs and make it difficult to compare populations, relative service use, or outcomes across funding sources or across states.

Medicare and Medicaid mandate that participating nursing facilities use a single assessment instrument (the Minimum Data Set or MDS) for resident assessment. Medicare mandates the use of two other instruments for assessing patients treated in home health or inpatient rehabilitation facilities. Other Medicaid-funded and state-funded programs – including Medicaid home and community-based waiver programs – use individually-designed assessment systems, which can vary from program to program. Seventeen states use a common assessment instrument (interRAI) as the basis for their own instruments.⁷ Often, though, states have multiple instruments that differ for each waiver program. In California, for example, different HCBS waiver programs use different level-of-care criteria, each program’s assessment instrument is different, and federal rules impede sharing of assessments across programs and require individuals transitioning from one waiver program to another to complete a new eligibility and assessment for the new program.⁸ Community LTSS programs funded through other sources can add a further layer of variation and complexity in assessment.

In addition, Medicaid managed LTSS plans in many states develop their own internal assessment instruments, although these plan-specific instruments may incorporate a minimum set of state-required data elements.⁹ For managed LTSS programs, the data from a comprehensive assessment meet a variety of requirements. In addition to individually determining program eligibility, developing a care plan, establishing a budget for service allocation, and identifying high risk members for intervention; the information is useful in the aggregate for establishing capitation rates, producing management reports, and complying with

⁷ L. Ray, et al. Memorandum Comparing Four States’ Comprehensive Assessment Systems. UCLA Borun Center for Gerontological Research. May 9, 2013. P. 24.

⁸ K. Wilber, et al. Memorandum on the Current Assessment Approaches and Domains Used by Three HCBS Program in California. August 12, 2013.

⁹ C. Ingram, A. Lind, and B. Ensslin. Uniform Assessment Practices in Medicaid Managed Long-Term Services and Supports Programs. Center for Health Care Strategies. Technical Assistance Brief. Updated September 2013. P. 2.

CMS quality requirements for HCBS waivers. Standardized concepts and items are needed in these managed LTSS instruments to enable states to aggregate data to meet both state and CMS regulatory requirements.¹⁰

A number of states have developed or are in the process of developing automated standardized assessment tools to apply to multiple programs.¹¹ The Hilltop Institute's 2009 study of 13 states¹² found that:

- 7 of the states used a common assessment instrument for all populations. In many cases, additional modules were used for specific subpopulations. All but one of the states used the same instrument for people applying for institutional care and HCBS.
- 10 of the states used a single assessment for multiple purposes, avoiding redundancy in data collection. However, three of the states used different assessment instruments to determine functional eligibility and to develop the plan of care.

A comparison of the assessment systems in four states showed that while the state assessment instruments all had 8 domains and several topics in common, the structure of the assessment system and of the assessment instruments varied, and each of the states had topics beyond the domains and topics they shared. While the State of Washington had a comprehensive assessment in one instrument, New York collected a core data set in one instrument and, from responses in the core data set, triggered use of a supplemental assessment – functional and/or mental health. Michigan and Pennsylvania used a more limited initial assessment instrument followed by a more comprehensive one.¹³

The use of assessment instruments with topics and items that are compatible with the Minimum Data Set (MDS) has increased the ability, somewhat to aggregate data and activity in community settings with nursing facility and home health data.¹⁴ Further compatibility is possible by building on CMS' efforts to standardize items across the currently mandated MDS, OASIS, and IRF-PAI assessment tools.¹⁵

Use of different assessment instruments for different programs addresses a person's eligibility for each individual program rather than determining which programs would best meet a person's needs. The duplication of assessment activity as individuals move between settings and programs imposes added costs on the system and is a burden for individuals receiving

¹⁰ Black and Leitch p. 6-7.

¹¹ Black and Leitch, P. 10.

¹² C. Shirk. P. 12-16

¹³ L. Ray, et al. P.6-7.

¹⁴ Ibid. p. 3

¹⁵ B. Gage, et al. The Development and Testing of the Continuity Assessment Record and Evaluation (CARE) Item Set: Final Report on the Development of the CARE Item Set, August 2012, CMS Contract No. HHSM-500-2005-00291

services. The lack of comparability of data items across assessment instruments and programs within a state prevents aggregation of individual data across the delivery system, impeding care planning and coordination, measurement of outcomes and quality, and use of the data to analyze population differences or determine reimbursement. Variations in assessment concepts and items between states prevents the accumulation of aggregate data at the national or regional level to monitor program operations, outcomes and quality and to compare the effectiveness of programs across the states.

A few examples of items from state assessment instruments underscore the incompatibility of similar items on different instruments and the impact this has on data exchange and aggregation are:

Mobility: The concept of the assessed person’s mobility is measured through different items and scales in different states and different programs within states. For example, the California Client Development Evaluation Report used in assessing individuals with developmental disabilities measures “walking” separately from “moving in a wheel chair,” while most other states combine these. Some program instruments measure mobility only within the home, while others (e.g., the Colorado ULTC 100.2, used for all LTSS for all populations in the State) include mobility to locations outside the home. The Massachusetts Real Choice Functional Needs Assessment¹⁶ measures “locomotion in the home” (including walking and wheelchair) and has nine possible responses grading from “independent” – no help, setup or oversight – to “unable to perform.” The California CDER¹⁷ measures “walking” separately using a four-point scale ranging from “cannot walk” to “walks alone at least 20 feet with good balance.” The Colorado ULTC 100.2.¹⁸ measures ability to move between locations inside and outside the home with a four-point scale ranging from “independent” to “dependent on others for all mobility.”

Eating: The ability of an assessed person to eat with or without assistance is measured with different scales in different states. The Georgia Determination of Need Functional Assessment Instrument, used for Non-Medicaid Home and Community Based Services,¹⁹ uses a four-point scale (0-3) with “0” representing the least need for assistance and “3” representing the most need. The Florida Form 701B, used by the Department of

¹⁶ Massachusetts Real Choice Functional Needs Assessment

¹⁷ California Client Development Evaluation Report, used by the Department of Developmental Services in assessing the needs of people with developmental disabilities.

¹⁸ Colorado ULTC 100.2. The ULTC-100.2 is the comprehensive assessment form used for all long term care services in Colorado. It is used for all populations, including older adults, persons with physical and cognitive disabilities, and persons with mental illness.

¹⁹ Georgia Determination of Need Functional Assessment Instrument, used for Non-Medicaid Home and Community Based Services.

Elder Affairs,²⁰ uses a five-point scale (0-4) ranging from lowest to highest need for assistance. The California CDER²¹ uses a five-point scale (1-5) with the order reversed: “1” is the highest level of need for assistance and “5” is the lowest level. In each scale, the specific activity measured (e.g., eats with fingers, eats with utensils) is different.

Personal Care/Hygiene: How well someone can perform personal care activities is measured differently in different states. The different items make it impossible to compare assessments across instruments. The California CDER²² combines personal hygiene (combing hair, brushing teeth, shaving, etc.) with bathing and showering, The Massachusetts Real Choice Functional Needs Assessment²³ excludes bathing/showering, and the Wyoming LT101 Assessment²⁴ includes “personal grooming” with dressing.

The emergence of new payment models and pilot projects focused on persons with the most complex care needs has elevated the importance of integrating medical and long-term services and supports to achieve improvements in costs and outcomes. A standardized assessment and single care plan centered on and responsive to the needs, goals, values, and preferences of the person and family are at the core of integrated LTSS. The increased emphasis on integrated care creates a greater imperative to standardize terms and measures for commonly-used concepts and items across care settings. Standard language for measuring commonly-used assessment concepts is necessary to enable electronic exchange of data, development of a single care plan, communication among members of the care team, coordination of care, and measurement of outcomes.

Current Standardized Assessment Instruments

Some parts of the post-acute care and LTSS delivery systems currently employ standardized assessment tools. The design and use of these tools is largely dictated by the unique requirements of each of the various payment systems.

- While Medicare and Medicaid both require the use of a standard national assessment tool for nursing facility residents,²⁵ and Medicare requires standard national assessment

²⁰ Florida Form 701B, Department of Elder Affairs.

²¹ California Client Development Evaluation Report, used by the Department of Developmental Services.

²² California CDER.

²³ Massachusetts Real Choice Functional Needs Assessment.

²⁴ Wyoming LT101 Assessment, which is used for admission to a nursing facility, swing-bed, the Long Term Care and Assisted Living Facility Home and Community Based Waiver Programs and Program of All Inclusive Care for the Elderly.

²⁵ The Federal Nursing Home Reform Act of 1987 established federal minimum standards for care provided in certified Nursing Facilities. The Act required facilities to implement a resident assessment process leading to an individualized care plan. The requirement led to the development of a standardized automated assessment tool: the Minimum Data Set (MDS).

tools for recipients of post-acute home health care²⁶ and inpatient rehabilitation facility residents,²⁷ there is no similar requirement for non-institutional LTSS funded by Medicaid or other payers, and no common, uniform assessment tool that applies across the full range of populations and services within a state.

- Across the country, persons in need of non-institutional LTSS are assessed with different versions of assessment tools in every state. More than half of the states use a standard assessment tool for at least some portion of their LTSS populations,²⁸ but have not been adopted broadly for assessing HCBS need. A number of states use interRAI or a modification of interRAI, a commercial assessment instrument that is based on earlier versions of CMS's MDS. Medicaid assessment requirements and tools - particularly for the Home and Community-Based Services (HCBS) waiver programs - differ in every state, and often vary further among HCBS waiver programs in the same state.
- In States that are integrating LTSS and medical services through expansions of Medicaid managed care to LTSS or through Duals Demonstrations or other initiatives, health plans that are integrating and coordinating LTSS are incorporating assessment tools that span multiple care settings. These tools may apply easily to the full population using LTSS who have cognitive, psychiatric, intellectual and physical impairments.
- A few states are developing or have developed uniform assessment tools for LTSS that apply to the entire LTSS population and can be used to determine eligibility, plan services and supports, and/or monitor quality. States active in this effort include California, Minnesota, and New York. These statewide instruments have not been developed as national assessment tools.
- Two of the Affordable Care Act (ACA) programs expanding HCBS options – the Community First Choice Option Program (CFCO) and the State Balancing Incentives Program (BIP) – set specific national requirements for an assessment of functional needs. CFCO statute directs states to conduct a face-to-face assessment of needs, strengths, preferences, and goals for services and supports. Regulations allow states more latitude and do not prescribe a standardized assessment tool.²⁹ BIP sets specific

²⁶ The Outcome Assessment and Information Set (OASIS) is a national standardized automated assessment tool that Medicare requires for assessing needs of beneficiaries for Medicare Home Health Services.

²⁷ The Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI) is required for residents of inpatient rehabilitation facilities.

²⁸ S. Reinhard, et al. Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. AARP, The Commonwealth Fund, The SCAN Foundation. September 2011.

²⁹ Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services. 42 CFR Part 441 Medicaid Program; Community First Choice Option; Final Rule. 77 Fed Reg 88: 26828-26902. May 7, 2012..

requirements for a statewide standardized assessment of eligibility for non-institutional services and supports that covers five domains: Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), medical conditions, cognitive function and memory/learning difficulties, and behavior difficulties.³⁰

- The Medicare program has been developing standardized assessment items for use across the three Federally mandated assessment tools, as directed by the Deficit Reduction Act of 2005. The Continuity Assessment Record and Evaluation (CARE) item set was developed to meet this mandate. Items were selected from the range of existing assessment instruments, and with input from the medical and social support communities that work with the acute and post-acute populations, a subset of medical, functional, cognitive, and social support items were identified as those to test for reliability when applied to all five populations. Those with high reliability within and across settings are being included in the standardized assessment item library CMS is developing for Federal and state use. Efforts are currently underway to include LTSS items.³¹

Moving to Standardized Assessment Concepts and Items for LTSS

The assessment data that fall within the scope of this discussion are data on persons who need long-term services and supports (LTSS) that are collected in order to plan for and provide services provided in a hospital, post-acute care setting, or long-term institutional, community or home-based setting. In addition to basic demographic and socio-economic information, the data describe the person's physical (including medical) and cognitive functioning, social supports, and environment. The data can be used to determine an individual's eligibility for services and financial assistance, to determine the level of care needed, to determine specific types and amounts of care to be incorporated in a care plan, to establish benchmarks for measuring patient outcomes, and to contribute to aggregated population reports to support planning, resource allocation, and reimbursement decisions.

In a world of integrated, patient-centered care, the common assessment is the cornerstone for building a single care plan which electronically aligns with or incorporates the person's medical record. Electronic exchange of information across sectors enables coordination of care across these sectors, and supports shared accountability by providers and caregivers for a person's

³⁰ Mission Analytics Group. The Balancing Incentives Program Implementation Manual. February 2013. Pp. 22-24.

³¹ B. Gage and S. Mandl. Standardized Assessment Data: Continuity Assessment Record and Evaluation (CARE) Item Set. Presented to Long Term Care Discussion Group. Wednesday, November 6, 2013.

health, satisfaction, and health outcomes resulting from the total array of medical and social services and supports provided.

Much of the variation, redundancy and complexity in assessment instruments results from the variety of program needs, unique statutory and regulatory requirements, and the paths different organizations have taken in modifying requirements, practices, and forms over time. Program needs and requirements will continue to dictate some variation in the contents of program-specific assessment instruments -- a single assessment instrument cannot meet the unique needs of the variety of LTSS programs and populations. However, where different instruments use the same general concepts and items, then it is important the language and interpretation of the concepts and items be the same across instruments to enable consistency in the assessment of the individual and comparability of the assessment and care plan across instruments and to reduce the redundancy in data collected. These issues will become more critical as states strive for greater efficiency and establish interoperable data systems across programs.

The goal for standardizing concepts and items is to develop standard, reliable, inter-operable data items to improve care coordination, data exchangeability, and quality and outcomes measurement. Standardization of concepts and items in core domains are the highest priority. Comparability of the core domains that are not unique to specific programs would enable exchangeability, aggregation, and elimination of redundancy of core data without requiring modification of ancillary domains which contain concepts and items dictated by specific program requirements.

Not all domains are critical for core assessment activities and data exchange. Assessment instruments can start with a standardized core that can serve a wide range of data needs, and add modules to meet individual program requirements. Core concepts and items should be determined with an eye to minimizing the disruption and costs to federal and state assessments and information systems of replacing current concepts and items with standardized concepts and items.

The effort to develop a standardized set of core concepts and items should seek to build on existing instruments that have been widely used and validated. Where possible, the process should identify and select reliable, standardized items – validated items and scales that meet high standards for inter-rater reliability – that can be used in different settings and with different populations.

As a starting point, a process for developing a standardized core set of concepts and items should focus on domains that would be considered fundamental in meeting requirements for key functions or activities that are supported by assessment data.

Step One is to determine which domains, concepts, and items need to be standardized across all assessment instruments for all programs serving individuals in need of LTSS.

The first task is to identify critical care planning and care administration activities that will be supported by assessment data, and establish which of these activities are most important in the care planning and care delivery process. Activities would include:

- Eligibility determination
- Care planning
- Care coordination
- Reimbursement
- Quality and outcomes measurement
- Program evaluation and resource allocation

The second task is to determine which domains are central to these activities. For each of the activities above, which domains below would be considered essential and which would be ancillary? Are there domains that would be essential for all activities?

- Demographics (e.g., age, gender, marital status, language)
- Socio-economic status (e.g., income, employment)
- Health status (e.g., health conditions and therapies, self-reported health, vision/hearing, use of medical care)
- Cognition and communication (e.g., memory, speech)
- Medications (e.g., drug regimens, medication use)
- Functional status (e.g., ADLs and IADLs, mobility)
- Mental health (e.g., depression, problem behaviors, substance use)
- Nutrition (e.g., diet, height/weight, hydration)
- Environment (e.g., residential conditions, pets)
- Social network (e.g., social interaction, outside activities)
- Caregiving (e.g., primary caregiver, caregiver interview)

The third task is to develop the list of essential domains that are necessary for most or all of the activities, and agree on the process for selecting the highest priority domains for standardizing concepts and items.

The fourth task is to articulate a modular approach that would allow incorporation of ancillary domains with unique concepts and items to be incorporated in assessment instruments in addition to the standardized core concepts and items, to serve the unique needs of different programs, populations or activities.

Step Two is to review the cross-state and within-state variation in concepts and items and agree on a process for reconciling differences and developing standardized concepts and items.

The first task is to identify existing validated items and scales and determine the potential for these already validated measures to substitute for items and scales currently used in what would be core domains in assessment instruments.

The second task is to identify and review existing items and scales that are critical for assessment but are not standardized, and develop a process for arriving at a single validated item or scale for use in the core assessment items. For example, ADL and IADL scales are essential to the measurement of functional status, yet there is no single list of ADLs and IADLs and no single approach to scaling ADL or IADL functioning. A process is needed to establish a uniform set of items and responses and a standard approach to producing a numerical measure of ADLs and IADLs.

Step Three is to recommend sets of key standardized concepts and items for each of the core domains.

The first task is to complete the process for developing and agreeing upon recommendations for a single set of validated items and scales for use in a core assessment instrument.

The second task is to assess the impact that modifications in core domain concepts and items will have on existing assessment instruments and the activities that require the assessment data, and the likely obstacles to adoption of a standardized set of concepts and items.

The third task is to recommend a strategy for addressing barriers to adoption and gaining widespread use of the standardized core concepts and items.

Conclusion

Movement toward a more responsive, integrated, high-quality, person-centered, and fiscally sustainable system of services and supports for persons in need of LTSS will depend on our success in creating tools to improve communication, coordination, and accountability across settings and organizations in the service of the individual and family in need of LTSS. Standardized assessment and care planning centered on and responsive to the needs, goals, values, and preferences of the person and family are a fundamental tool in integrated LTSS. The increased emphasis on integrated care creates a greater imperative to standardize terms and measures for commonly-used concepts and items across care settings. Standard language for measuring commonly-used assessment concepts is essential to support the critical activities of integrated care: electronic data exchange, development of a single care plan, communication among members of the care team, coordination of care, and measurement of outcomes.

The papers, the Roundtable, and the conclusions from the Roundtable are intended to serve as a catalyst for expert consensus and widespread adoption of standardized assessment items for persons in need of LTSS. The Roundtable will bring greater alignment among the various federal and state initiatives pursuing standardized assessment. It will produce a plan to accelerate adoption by broadening stakeholder engagement in the discussion and building a network to enable public and private local, state, and national groups to pursue changes in assessment instruments. LTQA will pursue the creation and management of a larger network aimed at implementation of the plan developed from the Roundtable.