Standardizing LTSS Assessments for State Initiatives

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Today's emphasis on person-centered systems is changing the way we think about addressing individuals' needs for both health care and long term service and supports (LTSS). A person-centered approach focuses holistically on a persons' needs, arranging services and settings that can meet those needs, rather than focusing on the various silo-ed service delivery systems and cobbling together services from across these systems.   The person-centered approach assumes that organizing services and supports for the range of a person's health care and LTSS needs will improve their health outcomes and quality of life; contribute to better population health; and reduce aggregate care costs by reducing the potential for expensive adverse medical events. The capacity to communicate and share information across settings and service delivery systems is essential for care planning, care coordination, and accountability for outcomes. At the core of a person-centered approach are communication tools that provide a common language, allow information to be transferred easily, and eliminate duplication of effort and redundancy of information, while protecting individual privacy.   The effort to standardize assessment approaches is aimed at collecting the information needed for multiple programs to determine eligibility, consider level of need, and identify appropriate services without duplication of assessment interviews and redundancy of data collection.

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.

This paper is the second of two papers[1] intended to provide background information for a roundtable discussion among a selected group of organizations and experts addressing person-centered care initiatives. The roundtable is intended to share information, discuss the current state of standardized assessment, and develop recommendations for steps needed to advance progress toward common core assessment domains, concepts, and items that could form the basis for person-centered assessment, care planning, and care coordination.

This paper is based on an analysis of existing assessment instruments.[2] The paper reviews state and federal activity in standardizing assessment tools, identifies common domains, and

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[1] The first paper is: G.L. Atkins and B. Gage. The Need to Standardize Assessment Items for Persons in Need of LTSS. Long-Term Quality Alliance. April 29, 2014.

[2] LTQA collected 66 assessment instruments from 48 states using state websites and other sources. LTQA compared instruments and conducted a detailed review of items, reviewed secondary documents, and interviewed experts.

discusses considerations and implications for state standardization of items that would contribute significantly to better integration.

New Initiatives from the Affordable Care Act

A number of provisions of the Affordable Care Act (ACA) have given new momentum to the nation's wide-ranging efforts to develop more person-centered systems. ACA provisions aimed at improving coordination of health care and social support services to better meet individual needs and preferences in the Medicaid and Medicare programs include:

- A new office at the Centers for Medicare & Medicaid Services (CMS) focused on integrating Medicare and Medicaid services for dually-eligible beneficiaries (the Medicare-Medicaid Coordination Office or MMCO);
- A broader definition of LTSS that includes a range of services from home health and rehabilitation to more traditional social support services, including those provided under state plans and under the various waivers.
- New programs to help states build the systems needed to rebalance LTSS, such as the Balancing Incentives Program (BIP) which provides Federal funds to states that still have a high reliance on institutional services for their LTSS populations. The BIP provides funding to help states establish stronger community-based programs with "no wrong door" approaches, standardized assessment systems to support them, and conflict-free case management to improve coordination.
- An expanded Medicaid Managed LTSS program to move more dually-eligible Medicare/Medicaid populations into integrated managed LTSS programs.
- Transition Grants from the Administration for Community Living (ACL) to improve service coordination across the health and social spectrum for aged and disabled populations.

Central to all these initiatives is the ability to coordinate resources and information to better meet the needs of the individual receiving services. As part of this effort, the Office of the National Coordinator (ONC) offered grants to support the development of data exchangeability across different systems of care. These grants have funded the establishment of interoperability standards within the health information technology (HIT) community that will allow the transfer of content as determined by the program communities. ONC grants have also been funding the establishment and diffusion of ways to exchange data across entities in states with and without health information exchanges, or IT superhighways. In addition, ONC has been working with the long term and post-acute care communities to develop interoperability standards for the mandated assessment items currently used in nursing facilities and home health agencies (e.g., the MDS 3.0 and the OASIS-C, respectively).

Medicare Standardization Efforts

The traditional, fee-for-service Medicare program also has been moving towards greater data and measurement standardization. The Deficit Reduction Act of 2005 directed CMS to standardize assessment items across the three federally mandated, public domain assessment tools: the Minimum Data Set (MDS) required on all Medicare and Medicaid populations in nursing facilities (NF), the OASIS required for all Medicare and Medicaid populations receiving Home Health Agency (HHA) services, and the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI) required for all Medicare admissions to inpatient rehabilitation facilities (IRFs). CMS has been working across program offices to standardize items in the medical, functional, cognitive, and social support domains and to develop e-specifications to allow exchangeability options in the public domain.

This standardization initiative included extensive stakeholder input from the professional communities working with these populations in the acute hospitals, SNFs, HHAs, IRFs, and long term care hospitals (LTCHs). The standardization began with a review of the existing Federal and commercial assessment tools, and with input from the communities working with these populations, a set of the "best in class" items were identified to be tested across populations. This effort resulted in the Continuity Assessment Record and Evaluation (CARE) tool. The CARE tool was used to collect standardized items in each type of setting and test them for reliability with each type of population and across different types of caregivers. From this, the best performing items across different levels of patient complexity were selected to use in subsequent quality reporting programs.

These standardized items were selected based on their ability to explain differences in individual resource needs, minimize provider burden, and be reliable within and across settings. Cross-population, cross-discipline analyses then identified a subset of the medical, functional, and cognitive items that could be substituted in the existing forms to allow standardization across the MDS, the OASIS, and the IRF-PAI as well as to develop an assessment tool for use in long-term care hospitals. The items were reliable when used by a range of professionals including nurses, therapists, and social workers. A subset of these items is currently being used in the Bundled Payment Initiatives to allow cross-setting measurement of medical, functional, cognitive, and social support factors.

Currently, CMS is developing an assessment item library that contains the "best in class" assessment items, including those from the MDS, OASIS, IRF-PAI, and standardized CARE item set for cross-walking the common medical, functional, cognitive, and social support domains and identifying the electronic specifications to allow data exchangeability. A driving goal in the CMS item library is to make available to providers, vendors, states, and others a repository of electronically exchangeable items that have proven reliability across populations, can be used

to develop reliable quality measures independent of settings, and can be used to set equitable payment rates for similar service components.[3] Current work at CMS is beginning to examine the types of additional items needed in the standardized item library to assess LTSS populations for determining eligibility and service needs.[4]

These standardized items in the CARE item set serve as the core of several initiatives to expand the Federal standardized items beyond the medical, functional, cognitive, and social support domains. CMS has funded subsequent work to test the items with healthier populations receiving therapy services in the community and more impaired populations in a nursing facility. These items were tested in the community version of the CARE item set (CARE-C) and the nursing facility version (CARE-F). These item sets included the same core items from the medical, functional, and cognitive domains but dropped items that were not relevant to community-based residents. These item sets also added items to test for reliability, including self-report function items from the short form of the Activity Measures for Post-Acute Care (AM-PAC). These items were developed to measure the person's perspective on their abilities and are consistent with the additional domains of social participation that the World Health Organization put forth for persons with disabilities. These items were tested in addition to the professional assessment in the basic CARE items.

Additional modules are also being developed for the LTSS populations under the Testing Experience and Functional Tools (TEFT) grants program sponsored by CMS. The grants are designed to test quality measurement tools and demonstrate e-health in Medicaid community-based long term services and supports (LTSS). The CARE item set is being modified to to identify additional domains, such as social and environmental factors that are important for LTSS population information but were not included in the earlier standardization efforts. This work includes a review of existing state Medicaid assessment instruments and input from the stakeholders.

Federal quality reporting programs are also pursuing item standardization to allow comparison of outcomes associated with different types of services, such as those in nursing facilities relative to those provided by a home health agency. For example, the items underlying "changes in pressure ulcers" have been standardized across the Federal assessment tools so that everyone tracking pressure ulcers is using the same language and standards. CMS currently has work underway to develop standardized measures of function. This standardized

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[3] 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.
[4] See TEFT program announcements, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/TEFT-Program-.html

measurement is key to allowing comparability across settings and creating electronic information transfers across people and organizations.

State Activity in Standardized Assessments

States are also undertaking standardized assessment initiatives. Several provisions of the Affordable Care Act (ACA) allow for Medicaid funding for initiatives to standardize assessments for LTSS populations. The legislation broadly defined LTSS services to include home and community-based services (HCBS) under 1915 (c or d) or 1115 waivers; state plan services for home health, personal care, and optional rehabilitation services, PACE, home and community care under section 1929(a), self-directed personal assistance services under 1915(j), services under 1915(i), community-based, private duty nursing under section 1905 (a)(8), state options for health homes for enrollees with chronic conditions, and Community First Choice Option as defined under ACA section 2401, 1915(k).[5]

Standardized assessment efforts are in different stages of development. Some states have older systems that were put in place to meet the OBRA '87 requirements to improve quality. Many of these states rely on MDS-related tools such as the InterRAI-Home Care instrument. Other states, like Minnesota, have developed their own approaches for coordinating assessments across multiple state programs to increase their programs' efficiency or are considering testing the LTSS CARE items developed under the TEFT program tool to improve their ability to report to CMS and their Medicaid agencies.

Managed Long Term Services and Supports (MLTSS) - More recently, with the establishment of the Managed LTSS demonstrations under CMS' MMCO, managed care plans are trying to establish more standardized approaches for assessing their enrolled populations across states that meet state-specific assessment requirements in those states that have them.

As of April 2014, 19 states had moved to integrate LTSS and medical care in either their Medicaid-only or dual-eligible programs[6] . These efforts are designed to improve outcomes, enhance experience, reduce costs, and streamline program administration. They typically have a care coordinator who assesses the consumer's need and preferences, works with the primary care physician (PCP) and others to plan, authorize, and coordinate services, monitors the service plan, follows the consumer across services and through transitions, and facilitates information transfers across multiple parties, including the consumer, family, social worker,

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[5] Mission Analytics Group. The Balancing Incentives Program Implementation Manual. February 2013. Pp. 22-24.
[6] Saucier, Paul, State Approaches to Integrating Care, LTQA/NCHC Capital Hill Forum, April 2014

PCP, specialists, pharmacy consultants, state/county social services, community-based organizations, and others. The focus is on person-centered planning although the details vary across these programs.

Balancing Incentives Program (BIP) - BIP is one of the largest ACA initiatives for LTSS populations. It provides additional Federal Matches to states with low proportions of their LTSS spending in non-institutional settings as incentive payments to rebalance their LTSS systems. In exchange for the increased federal matches, BIP participants must ensure their state systems have three components:

- **No Wrong Door/Single Entry Point (SEP)** to all LTSS programs that includes functional and financial assessment eligibility determination
- **Conflict-Free Case Management** where case management, eligibility, and funding level decisions are not provided by the entity providing direct services. Further, assessments and plans of care cannot be conducted by family members of the individual or their caregivers.
- **Core Standardized Assessment Instruments** for determining eligibility for LTSS; need for support services, support training, medical care, transportation, and other services; and to develop an individual service plan to address these needs. Five core domains are required, including activities of daily living (ADL), instrumental activities of daily living (IADL), medical diagnoses/conditions, information.

Currently, 19 states are participating in the BIP including Arkansas, Connecticut, Georgia, Illinois, Indiana, Iowa, Kentucky, Louisiana, Ohio, Maine, Massachusetts, Missouri, Mississippi, Maryland, New York, New Jersey, Nevada, New Hampshire, and Texas. These participants must establish core uniform assessments similar to those in the Federal tools for measuring medical conditions, functional status (ADLs/IADLs), cognitive status (including functioning and learning), behavioral concerns, and financial and employment information. These data will be used in "no wrong door" eligibility determination for LTSS, as well as to develop care plans. The BIPs technical assistance team also recommended using the information to predict expected level of care needs for setting individual budgets.

Aging Disability Resource Centers (ADRCs) - Resources, such as the Aging Disability Resource Centers (ADRCs) found in each state, are excellent sources of information on the various state initiatives. However, this information is dispersed across different venues and is difficult to compile. A better understanding of what different states are doing on assessment is needed as the level and diversity of state activity on uniform assessment increases with growth in the

number of states receiving funding requiring uniform assessment or participating in managed Duals programs.

Common Domains in State LTSS Assessment Tools

To better understand the current variability of state assessment tools and the potential for developing a common core of standardized items, the team collected and reviewed a wide array of state assessment tools for LTSS populations to identify the common concepts currently included in state program assessments.[7] The assessment forms all supported state programs but varied in whether they were tied to specific Medicaid waivers or other state programs for LTSS. Many of them include the same domains as in the federally-mandated assessment forms, such as the MDS and the OASIS. These domains include items measuring medical conditions and complications, functional status, cognitive status, and social support factors but they vary in the items used.

Few states currently have comprehensive assessment approaches that meet all six domains identified in the BIP definition of core assessment requirements. Components may be found in different assessment tools used by parts of the LTSS system but most are not exchangeable across systems to allow caregivers to see the complete information that may affect determination of person's overall support needs. Where concepts may be common within a state across programs, the items may still differ. The most commonly collected concepts are Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), which are frequently used for determining eligibility in nursing home transition programs. Payment amounts are often set relative to impairment thresholds, but these payments are typically for purchasing support services. With the expansion of the LTSS definition to also include rehabilitation and home health services, more specific information may be needed to predict expected level of need for these populations. For example, if the state programs are each using the standard assessment items, the programs covering therapy services may need more information on level of impairment than number of ADL limitations.

The assessment tools varied in the number and types of ADL items collected in their state programs. The RAI tool provides a set of items consistent with the Federal MDS tool but inconsistent with the OASIS assessment required by participating home health agencies. The therapy community varies even more in terms of the items they use to estimate service need based on their measures of ambulation and self-care (ADLs). IADL items used in each tool varied by state.

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[7] Assessment forms were collected from state websites, review of secondary documents, and based on discussions with individuals working in this area.

Other commonly collected concepts include memory and cognition. Almost all assessment tools that measure memory and cognition collect information on short term memory, such as the items used in the MDS and included in CMS' standardized item set.

Other concepts that are highly common include communication impairments, home environments and environmental safety, behavioral symptoms and medical and mental health symptoms, medications management, adherence, and types. Many also collect information on transportation needs, social networks, and economic status. A longer comparison of the differences in individual items used in each assessment will be provided at the meeting. Few of the assessment tools collected focused specifically on subpopulation factors, with the exception of the preadmission screening and resident review (PASRR) screening tools for developmentally-disabled eligibility determinations.

Many of the Medicaid waivers for HCBS apply to specific subpopulations, such as those with traumatic brain injuries or HIV/AIDs. These programs may require additional information unique to the subpopulation or the waiver, and may incorporate domains and items that have been traditionally used to measure complexity of needs and document service provision. For specific cognitively and physically disabled subpopulations, it may be both clinically necessary and cost-effective to use the "best in class" traditionally-used measures to determine appropriate service levels and measure outcomes and effectiveness of services consistently across state and federal funding.   These measures could be supplemental to a common core of items used for all populations. The communities serving the developmentally disabled populations have been working on these issues and can contribute items they find useful for these purposes.

Considerations for Standardizing Assessment Tools

These directives to create more standardized assessment approaches raise many issues.   First, most state assessment processes have been designed to meet their respective needs. Many have been in use for a long time and their state information systems have incorporated these items as they were developed and refined. Changes to these systems can be costly. However, many of these systems prohibit coordination across state programs as needed by the "no wrong door" initiatives and supported by many states legislatures attempting to improve the efficiency and effectiveness of their state-funded programs.

Second, items that will be used across different programs to determine eligibility, level of service needs, and manage the person's needs in a holistic manner must be scientifically valid

and reliable. Meeting these types of scientific standards is important for ensuring the items perform consistently across different users, especially in programs where users may have different types of backgrounds. Although CMS has shown that training can improve inter-rater reliability as with the on-going MDS and OASIS training they provide, the items themselves must be reliable to ensure fair and equitable application. For example, an item may have been in use for years but its wording may be so broad that it measures more than one concept, and therefore, its application inadvertently covers more people than intended, or when used to estimate cost allocation, could result in very different service estimations. For example, toileting items that include transferring abilities may identify someone who has difficulty toileting or difficulty transferring to the toilet. One task can be accomplished with the assistance of a lower cost aide while the other suggests the need for higher cost skilled therapy to either strengthen or train the person in mobility functions.

Response scales are also important to consider. The possible answers to an item must be mutually exclusive so only one answer is correct. And they should use language that is simple enough to be clear without requiring extensive, detailed training. For example, some of the ADL scales use response codes that ask the assessor to rate the person's abilities in terms of the percent of their independence – 25 percent, 50 percent, 75 percent or total independence or dependence. Determining which quartile a person belongs in can be difficult and misleading – giving a sense of specificity despite the subjectivity of the rating and the potential for inaccuracy. Where scales are used, the specificity should be granular enough to determine expected service needs. For example, the standardized function items in the CARE set distinguish between whether someone needs assistance with more than half or less than half an activity. If the person needs assistance with less than half the activity, can materials be set up and the person be safely left alone to complete the task or does someone need to remain for cueing or supervising purposes? If the person cannot do half the task themselves, does the caregiver perform the entire task or is the person able to do part of the task?

A third consideration in thinking about standardization is determining which items would be beneficial to standardize. While one could argue that using the same method for recording any item would be beneficial to data exchangeability across program systems, these efforts can be costly for states that have already invested in their current disparate systems. Prioritizing the types of items that need to be standardized will allow those states to incrementally move to standardization. Identifying those items that are key to determining eligibility in multiple state programs would be an early consideration. One of the key reasons to standardize is to meet the "no wrong door" goal which provides opportunity to collect the data once to identify the range of benefits for which the person may qualify. Common elements are activities of daily living, instrumental activities of daily living, mobility status, medical conditions that require

nursing services, such as skin conditions, caregiver ability, and social support networks. In addition, one of the key areas under the person-centered approach is incorporating information on the person's and family's goals. State nursing home transition programs may offer a standardized item which may be important for building person-centered systems.

A fourth consideration may be to determine how widely standardized your items should be. Across what range of programs and activities is it necessary to develop consistency? There are several possible levels:

- State-funded programs to allow "no wrong door" eligibility determination and comparative reporting for people qualifying for more than one benefit. This could allow comparability of outcomes for people who qualify for nursing home use but receive home and community-based services under one of the LTSS benefits.
- State and federal services to compare medical or functional status for people receiving home health benefits who transfer to Medicaid-covered benefits at the end of an episode and who may ping-pong between benefits due to chronic illness or impairments. This would also apply to people moving between Medicare and Medicaid covered nursing facility benefits.
- Regional or cross-state comparisons to determine whether there are systematic differences in outcomes across state lines for similar types of populations or services.

A fifth consideration may be the level of IT sophistication among your LTSS community participants. Are your community-based service providers or intermediaries or other key players already using a technology that allows them to transfer information across transitions? If so, are these systems program-specific or are they using interoperable data standards that would allow exchange with other types of IT systems? Some systems are designed as a suite of forms and the data can be shared across system users while other systems may use "electronic envelopes" allowing transfer of commonly defined items across systems.

Implications for State Standardization

As we move forward with discussions about the needs of LTSS *populations*, instead of the issues around LTSS service management, it may be useful to think about how to capitalize on existing resources to create state-wide efficiencies in building person-centered systems. The move toward person-centered care and accountability to increase efficiency is increasing the number and types of resources available to build these systems and create efficiencies.

Some states are leading the way to developing uniform assessments across their programs. Their ability to electronically transfer the data varies but they are addressing issues of identifying the concepts important to them for payment, quality, or coordination. Other states are just beginning this process.

One opportunity for the less advanced states may be to decide which concepts they feel are important to their stakeholders and then use the assessment data standardization efforts occurring at the Federal level to pull in items that have been identified as valid and reliable measures of a specific concept. Using the Federal items would also have the benefit of the data exchangeability standards to all allow data transfers among programs without a large investment on the state's part. This would be consistent with state goals in allowing the data to be collected once at the "no wrong door" assessment and be transferred around the state. Alternatively, commercial products have been developed to address the needs of the LTSS providers. These systems often offer exchangeability within their commercial system but not necessarily with the other systems used by the state or federal programs.

Conclusions

Standardizing the assessment items improves program efficiencies as data can be collected once but used multiple times, improves transitions of care because of better communications, and allows data to be transferred electronically across services, allowing comparisons of outcomes associated with each type of service. Collecting the data once and using it across programs reduces both the provider burden for data collection and the individual and family burden in repeating information previously given to their team. While data need to be updated as individual status changes, information on prior functioning, utilization, and social supports can be readily transferred across users. This may also improve the accuracy of the information as it changes over time.

This paper provides background information to allow the beginning of a national discussion on LTSS item standardization. The benefits have been widely noted.[8] The question is: how far can we go and how far do we need to go in developing a common core of assessment domains, concepts, and items needed to support person-centered health care and LTSS? Where do the benefits of a uniform assessment, single care plan, care coordination and quality measurement tool outweigh the costs and complexity of developing and implementing a common core assessment? How broadly should the common core apply – within the state and across states?

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

What are the steps necessary to take the very significant progress that has been made with standardized assessment in Medicare, BIP, CMS's Item Library, and within several states and apply the results of this progress or develop it further for other programs and in other states?