Quality Indicators
for Nursing Home and Community-Based Long Term Care:
Current Systems and Trends in Indicator Development

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by

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Introduction

Under the Global Waiver recently approved by CMS and the RI state legislature, RI residents applying to Medicaid for long term care services will be classified into one of three levels of care, and those classified as most needy will be triaged to the least restrictive setting possible, including to an array of community-based services and supports. This unprecedented emphasis on community-based care, including the expansion of existing services and development of new services, requires careful monitoring to ensure that the health and well-being of the Medicaid population with disabilities are not compromised by this policy shift, and that the goals for the population affected by the rebalancing initiative are met. An important aspect of quality assurance, as described in the CMS Home and Community-based Service Quality Framework, is the development and use of data indicators to identify problems in care processes and unmet needs specific to population subgroups (see http://www.cms.hhs.gov/HCBS/downloads/qualityframework.pdf).

It is important to differentiate long term care quality indicators from acute care quality indicators. The Healthcare Effectiveness Data and Information Set (HEDIS) measures developed by the National Committee for Quality Assurance (NCQA), for example, are designed to measure health care system performance on important dimensions of care to ensure the delivery of quality medical care (see http://www.ncqa.org/tabid/187/Default.aspx). While HEDIS indicators focus on processes of care, Prevention Quality Indicators (PQIs; also referred to as ambulatory care sensitive (ACS) conditions) developed by the Agency for Healthcare Research and Quality (AHRQ) are designed to identify care outcomes, specifically, hospital admissions that evidence suggests could have been avoided with high quality outpatient care (see http://www.qualityindicators.ahrq.gov/index.htm).

In contrast, long term care quality of care indicators are intended to reflect the quality of care provided to residents of nursing homes and recipients of community-based long term care services, and generally include both processes and outcomes of care. In addition, there are newer trends toward monitoring the quality of life of people whose health conditions and impairments have made them vulnerable to loss of autonomy and decrements in a variety of aspects of well-being. While quality of care indicators are generally derived from administrative data, quality of life indicators are generally based on resident/client (or report from a proxy for the resident/client), via survey interviews.

The purpose of this report is to provide an overview of state of science quality indicators currently in use in monitoring the quality of long term care, and to describe current efforts to develop indicators pertinent to nursing home residents' and HCBS clients' quality of life. This review is not intended to be all-inclusive, since there are currently numerous quality indicator initiatives in various stages of development and testing by a variety of federal and state agencies, as well as by private entities, as described in a recent Medicaid HCBS measure environmental scan (Galantowicz et al., 2008). Only indicator sets or systems that have been scientifically validated and in use nationally or by at least several states are presented in this report.

Quality of care indicators based on comprehensive resident/client assessment data are first presented, for both nursing home and community-based long term care (Table 1). Next, quality of life indicators that are typically based on data from interviews with facility residents or clients of HCBS, or their proxies, are presented, for frail elderly and physically disabled populations (Table 2), as well as those developed for populations with cognitive disabilities (Table 3).

Methods

This report is based on a review of the published literature as well as relevant policy websites. Online research data bases such as Pubmed and CINAHL, as well as government (e.g., AHRQ, CMS) and non-government data bases (e.g., Center for Health Care Strategies, Commonwealth) were searched with relevant keywords. In addition, the Google search engine was used to attempt to identify policy reports available on state-specific data bases to capture the current and recent efforts of states who are engaged in similar rebalancing initiatives. Finally, a compendium of tools and measures identified in a Medicaid HCBS measure scan served as a useful resource to ensure that all key indicator sets and trends relevant to the goals of the RI Medicaid program were included (Galantowicz et al., 2008).

Results

Table 1: Long Term Care Quality Indicators for Adults in Institutional and Community-Based Settings

The indicator systems best known and validated for use in institutional and community long term care are presented in Table 1. All three indicator systems are based on comprehensive assessment instruments from which data elements generally agreed upon by experts in the field to reflect the quality of care provided to individuals with chronic conditions and impairments are extracted. Indicators are generally of two types: process measures and outcome measures. *Process measures* indicate evidence of care processes that are to be avoided when possible (and thus a high prevalence of such indicators at the aggregate level is evidence of poor quality care, e.g., use of restraints) or of care processes that are beneficial to the individual (and thus a high prevalence of such indicators at the aggregate level is evidence of high quality of care (e.g., receipt of pneumonia vaccinations).

In addition to process indicators, the indicator systems displayed in Table 1 contain *outcome indicators*, which, like process indicators, may be evidence of the impact of both poor (e.g., urinary tract infections) or high (e.g., ADL improvement) quality care. While Table 1 presents quality of care domains, the specific indicators selected and the way in which they are operationalized within these domains may be different from system to system, as discussed below.

Not all indicators are relevant to all residents/clients for whom the indicator system is designed. For example, an indicator of "adequate pain control" is only relevant for residents or clients who report pain on their most recent assessment. Therefore, the *denominators* of individual indicators may vary.

Finally, it is important to understand that many quality indicators that are suggestive of poor quality care may, in fact, be unavoidable for some resident/client groups, depending on the "casemix" of people served in a given nursing facility or by a particular home health agency, for example. Because these indicators are often considered to reflect the "performance" of one institution relative to another, it is important that they be *case-mix adjusted*, that is, the acuity level of the population under care (and thus the inherent risk of negative outcomes associated with particular health and functional conditions) is taken into account in determining the prevalence of quality indicators before they are reported.

A. MDS Nursing Home Quality Indicators

Legislation passed by Congress as part of the Federal Nursing Home Reform Act of 1987 (OBRA 87) mandated the use of the Resident Assessment Instrument (RAI) for the purposes of care planning in all nursing homes nationally. Assessments are required at initial entry into a nursing home and annually thereafter. In addition, assessments are required when there is a major change in a resident's health status, and abbreviated versions of the full assessment are completed quarterly. All data is entered into a computer and files are uploaded to CMS. CMS then creates state level and national level files for analysis. The data elements of the assessment are collectively titled the Minimum Data Set (MDS), and the nursing home resident assessment instrument is now commonly termed the MDS.

The mandated universal use of an assessment instrument provided an opportunity to develop indicators of quality of care that could be used in nursing home quality assurance efforts (Hawes et al, 1997). A set of MDS quality indicators were initially developed by a team of researchers at the Center for Health Systems Research and Analysis (CHSRA) at the University of Wisconsin-Madison as part of a national demonstration by CMS to develop and test both a payment system and quality monitoring system based on the MDA resident data. CHSRA's development process resulted in an initial 24 quality indicators covering 12 domains of care which were tested and found to be reliable and valid in the sense that they are at risk for losing control of their lives due to their impairments, and may suffer (Zimmerman, 2003).

In 2002, a revised set of quality indicators was developed for use by the general public in selecting nursing facilities for their own or a loved one's placement. These indicators are posted for all nursing facilities in the nation on the CMS website *Nursing Home Compare* (see http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteriaNEW.asp). The revised MDS-NH indicator set includes several new indicators and more sophisticated case-mix adjustment than the initial set, and was developed by a research team headed by John Morris, PhD of Hebrew Rehabilitation Centre for the Aged, and Vincent Mor, PhD of Brown University under contract to CMS (e.g., Mor, 2004).

MDS quality indicators are expressed as the prevalence of a process or outcome that occurred over a defined time period that varies according to the indicator in question. An example of a process indicator is: “Percent of residents who were physically restrained in the past 7 days”; similarly, an example of an outcome measure is: “Percent of residents with a urinary tract infection in the past 30 days.” There are 14 indicators relevant to long-stay nursing home residents, i.e., those residents who have been in the nursing home for long periods of time and/or who are not expected to return to the community, and five indicators relevant to short-stay residents, i.e., people needing short-term skilled nursing care or rehabilitation services following a hospital stay, who are expected to return home. Four of the five short stay indicators are also long stay indicators, with the one exception being “percent of short stay residents with delirium in the past seven days.” The domains covered by these indicators are presented in Table 1, and “snap shot” definitions that describe the numerator, denominator, exclusions and covariates involved in the creation of these indicators from MDS data are included Appendix A of the National Nursing Home Quality Measures: Users Guide (see http://www.cms.hhs.gov/NursingHomeQualityInits/downloads/NHQIQMUsersManual.pdf)

B. MDS Home Care Quality Indicators

The MDS home care quality indicators presented in Table 1 are based upon a comprehensive assessment instrument developed for home care users, the MDS-HC. The MDS-HC is part of a suite of 12 instruments, with other instruments defined for unique populations and/or settings, including, for example, an assessment for residents of assisted living, and for persons with developmental disabilities who live in the community (http://www.interrai.org/section/view/). The MDS-HC is modeled after the MDS-NH and has many measures in common with the MDS-HC, thus allowing comparisons across institutional and community-based settings. Both the MDS-HC instrument and the associated MDS-HC quality indicators were developed by *interRAI,* a 30 country nonprofit network of researchers and clinicians. Today the MDS-HC is used in 11 states in the US, in Canada, and in several countries within both Europe and Asia for a variety of purposes including level of care determination and assessment. Three states are also using or intending to use the quality indicators derived from the MDS-HC.

In total, there are 22 MDS-HC quality indicators, 16 of which are prevalence indicators, i.e., the percent of a defined population who meet the criteria for a particular indicator (e.g., the percent of home care clients who have pain and are receiving inadequate pain control), and 6 of which are failure to improve OR incidence indicators (e.g., the percent of home care clients who had skin ulcer on previous assessment who did not improve OR had new ulcer at current assessment).

Like the MDS-NH quality indicators, the MDS-HC indicators refer to both process and outcomes of care. Unlike the MDS-NH indicators, indications of poor quality care are not necessarily attributable to the quality of care provided by home care agency personnel. Home care clients by definition live within their own homes; thus, problems with care may be attributable to care provided by (or not provided by) visiting nurses and home health aides, but also by physicians, private pay nurses, family members, and other parties involved in an individual's care. For example, family members may not be able or willing to provide nutritious meals.

Like the MDS-NH, a substantial amount of work has been done to risk-adjust MDS-HC indicators (Dalby et al., 2005). A listing of the MDS-HC indicators together with the definitions (unadjusted for acuity) of individual indicator's numerators and denominators are included in a paper published by members of the *inter-RAI* team (Hirdes et al., 2004).

C. OASIS Home Care Quality Indicators

The third set of indicators presented in Table 3 is based on the Outcomes and Assessment Information Set (OASIS), a comprehensive assessment for adult home care patients. Data elements from this assessment form the basis for measuring patient outcomes for purposes of outcome-based quality improvement. All home health agencies providing skilled services to patients covered by Medicare and/or Medicaid are required to assess these patients at the start of care (SOC), every 60 days thereafter, and at discharge from care, transfer to another facility, or death. Quality indicator data based on the OASIS assessments are available to the general public nationally on all Medicare certified home health agencies on the CMS website Home Health Compare (see http://www.medicare.gov/HHCompare/Home.asp)

It is important to note that *these indicators refer to skilled care only*, not supportive care such as that provided by homemaker services. Like MDS nursing home assessment data, data collected from OASIS assessments are computerized by home health agencies and transmitted to CMS. There are currently 41 home health quality indicators derived from OASIS data (http://www.cms.hhs.gov/OASIS/09b_hhareports.asp?qtr=15&isSubmitted=hhaqi412). Indicators cover five broad domains, including Activities of Daily Living (ambulation, dressing upper body, dressing lower body, grooming, bathing, toileting, transferring, eating), Instrumental Activities of Daily Living (management of oral medications, light meal preparation, laundry, housekeeping, shopping, telephone use), Physiological (pain, number of surgical wounds, status of surgical wounds, dyspnea, urinary tract infections, urinary incontinence, bowel incontinence, speech or language), Behavioral (anxiety, behavior problems), Cognitive (confusion, cognitive functioning), and Utilization (hospitalized, received emergent care, discharged to community).

The MDS-HC indicator system does not include process indicators; all indicators refer to patient outcomes. With the exception of the three utilization indicators, the indicators within domains refer to Improvement, e.g., Improved in grooming, and Stabilization, e.g., stabilized in grooming. No indicators refer to deterioration or decline (Shaughnessy et al., 2002).

Table 2: Long Term Care Quality of Life Indicators for Adults in Institutional and Community-Based Settings

Recognizing that the exclusive focus on quality of care inherent in indicator systems presented in Table 1 exclude the "resident (or client) voice," new trends in indicator system development for nursing home and community-based care focus on quality of *life* rather than quality of *care* (Kane 2003; Kane et al, 2003). While quality of care indicators derive from comprehensive assessments completed by health care professionals (ostensibly with input from residents/patients and their family members), quality of life indicators are reported by the resident or patient him/herself, or by a proxy for the individual.

Most quality of life indicators implemented or under development today are based on the work of Rosalie Kane and her colleagues at the University of Minnesota, a team of researchers contracted by CMS to develop QOL measures that reflected psychosocial domains that were either omitted from or not directly emphasized in the MDS to counterbalance that assessment's focus on quality of care. The final quality of life scale included 41 items contained in 10 domains (see Table 2; also, see Kane et al., 2003, for a listing of abbreviated items within domains). This scale forms the basis of many Nursing Home Satisfaction Scales administered by states to nursing home residents and families, including a RI survey administered by the RI

Department of Health (RI DOH, 2006). Similarities in items across state surveys allow for state comparisons, and also for facility by facility comparisons within states. In addition, a number of items related to autonomy and privacy, in particular, are included in the newest version of the MDS-NH (MDS 3.0, which is still in a testing phase).

Kane and colleagues' work is also evident in a series of tools developed by the MEDSTAT group under contract from CMS to be used by states to solicit feedback directly from waiver participants about the services and supports they received under the Medicaid Home and Community-Based Waiver Program. To date, versions of the *Participant Experience Surveys* (PES) have been designed for the frail elderly and physically disabled populations, for populations with mental retardation and developmentally disabilities, and for the population of adults with acquired brain injuries. Four domains are represented in the PES (see Table 2): Access to Care (sample question from Elderly/Disabled survey: Are you sometimes unable to get groceries when you need them?); Choice and Control (sample question from Elderly/Disabled survey: Do you help pick the people who help you?); Respect/Dignity (sample question from Elderly/Disabled survey: Do the people paid to help you treat you respectfully in your home?) and Community Integration/Inclusion (sample question from Elderly/Disabled survey: Is there anything you want to do outside your home that you don't do now?) The complete survey is available at http://www.cms.hhs.gov/HCBS/downloads/4_PESUG_ED.pdf**.**

Unlike the MDS-HC and OASIS, states are not mandated to use Participant Experience Surveys; rather they are intended for use by state Medicaid programs voluntarily to identify gaps and problems for remediation. At least 12 states nationwide are reported to have administered Elderly and Disabled versions of the Participant Experience Survey (Galantowicz et al, 2008).

Table 3: Long Term Care Quality of Life Indicators for Populations with Cognitive Disabilities

The *National Core Indicators (NCI)* is an extensive indicator system including approximately 100 consumer, family, and system outcomes that are important to understanding the overall health of public developmental disabilities agencies. The development of this system was by collaboration among participating National Association of State Directors of Developmental Disability Services member state agencies and the Human Services Research Institute. A total of 29 states, including Rhode Island (RI MHRH, 2004), were participating in NCI as of 9/1/08, and many of these states use NCI as a key component within their quality assurance systems.

The major domains covered in the NCI are presented in Table 3. As is evident, indicators relate to the quality of life of consumers as well as the performance of agencies whose mission is to ensure the health and well-being of this population. The source for the majority of indicators is data from consumers and families; other data sources are provider surveys and state administrative data. A complete listing of 2008-09 NCI indicators and their associated data sources can be found at http://www.hsri.org/nci/.

A second indicator system designed to monitor quality of life and the degree to which organizations individualize supports to facilitate outcomes for consumers with intellectual and developmental disabilities is based on the *Personal Outcome Measure Survey*, developed by the Council on Quality and Leadership, a non-profit international organization whose mission is to advance the quality of life for persons with intellectual and developmental disabilities. This system includes 21 outcome indicators, many of which tap domains that are also included in the

NCI, and is currently in use in approximately 10 states (see http://www.thecouncil.org/Personal_Outcome_Measures.aspx).

Similar to the Elderly/Physically Disabled version of the *Personal Experience Survey* instrument (see table 2) the *Participant Experience Survey-MRDD* was designed as a 97 item face to face survey, from which 51 indicators are derived covering domains of Access, Unmet-Need, Choice and Control, Health and Welfare. Approximately 5 states are considering or preparing to use this survey,

Fewer quality of life instruments were identified for severely and persistently mentally ill populations than for the MR/DD population. However, an SPMI consumer survey was developed by the Mental Health Statistics Improvement Program, supported by the Center for Mental Health Services (CMHS) and SAMHSA, to evaluate state progress in the improvement of mental health services. Version 1.2 of the survey contains 36 items/indicators and is called the *Mental Health Statistics Improvement Program Uniform Reporting System*. All states are required to submit data from this survey to CMHS as part of the Community Mental Health Block Grant Requirements, thus allowing for tracking of individual state performance as well as a picture of the national mental health service system. HCBS domains covered include general service satisfaction, service quality, access, service effectiveness, social functioning and relationships (see http://www.mhsip.org/surveylink.htm).

States' Efforts to Monitor Quality of Care and Quality of Life of Medicaid Populations

Based on the Medicaid HCBS measures scan compiled by Thomson Healthcare under contract from the US agency for Healthcare Quality and Research, states have engaged in a variety of efforts to identify quality of life of HCBS clients and their satisfaction with the service systems available to them (Galantowicz et al, 2008). Data sources are often varied and include state administrative data, but most often data is collected through surveys of samples of specific populations. It is not clear how many states collect survey data on a regular basis to determine change in quality of life indicators over time; many surveys appear to be developed with grant funding (often through CMS *Real* initiatives (CMS, 2008)) and administered on a single occasion. Consumer surveys include overlapping domains across states, and can be roughly classified to fall into two broad categories, as mentioned above: personal QOL as a community member, and satisfaction with services. Among the most common individual domains are those reported in Tables 2 and 3, particularly access, autonomy, safety, efficiency and timeliness of services, unmet need, equity, and health and welfare.

While a number of states have collected and reported the results of quality of life and satisfaction surveys of consumers residing in institutional as well as community-based settings, it is more difficult for states to systematically track quality of care indicators based upon comprehensive assessment data. While "report card" indicator are presented at the state and individual nursing home facility/home health agency level based on MDS-NH data and OASIS data respectively, states typically do not have the resources to analyze state level MDS-NH files to monitor specific Medicaid populations. Further, OASIS indicators apply to skilled care only. With the exception of Michigan, the expenses associated with computerization and data analyses prohibit even those states who have implemented the MDS-HC assessment for Medicaid home care from using this data to develop and monitor indicators on an ongoing basis.

However, several states have used MDS nursing home indicators, surveys and administrative data sources for quality monitoring, as well as to provide state residents with enhanced information regarding their options for nursing home facilities. Below, we highlight

Minnesota, which in many ways is ahead of the curve in designing a quality assurance system that allows for problem discovery as well as the impact of remediation efforts.

Minnesota: Exemplar State in Monitoring the Quality of Nursing Home Care and the Quality of Life of Nursing Home Residents.

The Minnesota Nursing Home Report Card is one of the most comprehensive in the nation (see (www.health.state.mn.us/nhreportcard). Indicators of resident quality of life and satisfaction have been tracked annually from 2006-2008 based on annual face-to-face surveys of a representative sample of residents in all Medicaid certified nursing homes, and are posted for viewing by the general public along with 16 MDS-NH quality of care indicators risk adjusted to account for differences in resident populations by facility.

In three years of active monitoring, the majority of indicators have shown small to modest improvement, with gains of 1%-4% in quality of life indicators, and more substantial gains (5-9% improvement) in the quality of care domains of pain control, continence care, reversal of pressure ulcers, and appropriate use of antipsychotic medication (MN DHS, 2008). Thus, for the state of Minnesota, indicator tracking appears to be an effective quality assurance mechanism for Medicaid certified nursing homes, and also makes available ample information for consumers facing the daunting prospect of choosing a nursing home for themselves or their loved ones.

Summary and Conclusion

While federally mandated comprehensive resident/client assessments have facilitated the development of quality of care indicator systems for nursing homes (MDS-NH) and post-acute home care services (OASIS), the development of quality of care indicators for Medicaid HCBS lags far behind. Particularly in this area of scarce resources, and despite the gains made under federal grants such as the Real Choice Systems Change initiative, many states are currently challenged by budget deficits and still lack the information technology capabilities required to implement and computerize comprehensive assessments across HCBS agencies.

The emergence and continued development of consumer surveys as a basis for tracking quality of life indicators in Medicaid population subgroups has been relatively widespread among states in recent years although it is not clear that the current environment will allow for annual implementation, as is optimal in a quality indicator monitoring system.

In the meantime, state efforts to "rebalance" long term care continue, and current state budget deficits may hasten this process. In RI, the timetable for the development of expanded community options for the Medicaid population with disabilities has moved forward with the approval of the Medicaid Global Waiver. Now more than ever, it is essential that mechanisms are in place to monitor both the quality of care *and* quality of life of Medicaid populations with disabilities, to ensure that the health and well-being of RIs most vulnerable citizens are not adversely affected by policy change.

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