Literature Review

Quality Management and Improvement Practices for Home and Community-Based Care

January 10, 2002

Maureen Booth
Julie Fralich
Sue Nonemaker

Edmund S. Muskie School of Public Service
96 Falmouth Street
PO Box 9300
Portland, ME 04104-9300
207-780-4851

This product was produced for the Centers for Medicare and Medicaid Services under Order No. CMS-01-00328.

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I. Purpose and Scope of the Project

The Centers for Medicare and Medicaid Services (CMS) have contracted with the Muskie School of Public Service to develop a technical assistance guide for use by states and CMS regional offices to assess and improve the quality of home and community-based care (HCBC) to Medicaid beneficiaries. [1] The project will identify tools, measures, standards, and oversight mechanisms for performance measurement and quality improvement of long term care services delivered under federal and state-funded HCBC programs, exclusive of consumer-directed services. In addition to highlighting promising state practices, the project will describe the opportunities and challenges of applying advancements in the field of quality management, so broadly used in other sectors of health care, to improve the quality of HCBC services.

This paper reviews published literature and provides a summary of major CMS initiatives in the area of quality measurement and improvement over the last five years. In conducting this review, a wide lens was applied to identify quality strategies in settings of care and delivery systems both within and outside long term care. This paper will serve as background for a meeting with federal and state policymakers and quality experts to assess the relevance and limitations of identified methods to improve the quality of services and outcomes in HCBC programs. Based on findings from the meeting and additional structured interviews with stakeholders, a technical assistance guide will be prepared.

II. Statement of the Problem

The unprecedented growth in expenditures and the vulnerability of clients served heighten the imperative for states to closely examine the quality of HCBC services. However, the diversity and complexity of care needs, multiple and sometimes conflicting definitions of quality, the reliance on a diffused and often unsupervised network of providers, and the absence of a focal point for accountability all combine to make HCBC services a difficult environment for quality oversight (Katz, Kane and Mezey, 1991; Feder, Komisar and Niefeld, 2000; and Kane, Kane, Illston, et al., 1994).

UNPRECEDENTED GROWTH AND EXPENDITURES IN HCBC SERVICES

The quantity and diversity of HCBC services has increased dramatically over the past decade. This growth has been fueled by abbreviated hospital stays, an expansion of services and procedures performed on an outpatient basis, advances in medical technology, and a desire to provide services in the most cost-effective manner possible (Feder, Komisar and Niefeld, 2000). As importantly, individuals needing care overwhelmingly prefer to remain in their homes and have lobbied for alternatives to institutional care (Kane and Kane, 2001).

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[1] For purposes of this project, home and community based long term care includes an array of home health care, non-medical personal care, care management, and other supportive services provided to older adults, children, and adults with disabilities in non-institutional settings, including assisted living facilities and board and care homes.

The net result of these trends has been a doubling of public funding for HCBC services in the past 10 years (Lutzky, Alecxih, Duffy et al., 2000). Specifically, expenditures in Medicaid 1915(c) home and community-based waiver programs grew from $3.8 million in 1982 to more than $8.1 billion in 1997, making up more than 14.4 percent of Medicaid long-term care expenditures (Miller, Ramsland and Harrington, 1999). The 1915(c) waiver program has come to dominate Medicaid home and community-based spending, with such programs making up almost two-thirds of state home care funding in 1999 (Lutzky, Alecxih, Duffy et al., 2000).

The Social Services Block Grant, the Older Americans Act, and state general revenues contribute the remaining source of funds for HCBC services. State-funded programs, in particular, provide the flexibility to cover persons whose incomes exceed Medicaid limits or whose impairments are less severe than those required to meet Medicaid eligibility requirements (Kassner and Williams, 1997). In 1996, 39 states reported having one or more state-funded HCBC services, ranging from personal care services, care management to nutritional services (Kassner and Williams, 1997).

Home and community based services are expected to expand even further, given the Supreme Court's 1999 Olmstead decision. This decision requires states to develop comprehensive plans "to strengthen community service systems and serve people with disabilities in the most integrated setting appropriate to their needs" (HCFA letter to all Medicaid directors dated January 14, 2000). The major premise of Olmstead is that failing to serve persons with disabilities in the most integrated setting appropriate to their needs is a form of discrimination under the Adults with Disabilities Act.

DIVERSITY OF CLIENTS SERVED BY HCBC SERVICES

Slightly over half of all HCBC service users are elderly (IOM, 1996). As federal waiver programs expand options for persons to live independently in the community, HCBC services extended their reach to serve persons with mental retardation and developmental disabilities, children with special health needs, adults and children with AIDS, and people with traumatic brain injuries. An estimated 560,000 persons received federally-funded HCBC services in 1997, more than double that of 1992. The greatest growth in HCBC services has been in the number of persons with mental retardation and developmental disabilities, which quadrupled between 1992 and 1997 compared to a doubling of all HCBS waiver enrollees during the same time period (Lutzky, Alecxih, Duffy et al., 2000).

The needs of HCBC users vary significantly. Most clients require services to assist with activities of daily living (eating, bathing, using the toilet, dressing, and transfer) and/or instrumental activities of daily living (cooking, cleaning, laundry, household maintenance, transportation, money management). In addition, many need care related to an underlying chronic disease or disability and case management services to assure that clients' needs are being met. Some require only occasional help while others may require assistance on a 24-hour basis (Kinney, Freedman, and Loveland Cook, 1994).

MULTIPLE AND SOMETIMES CONFLICTING DEFINITIONS OF QUALITY

Unlike medical care where nationally recognized standards of care set the benchmark for assessing clinical quality, the goals and outcomes of HCBC services are highly personalized and are often judged by the client's own assessment of how the care process impacts daily life, a sense of autonomy, and personal wellbeing (IOM, 1996; Riley, Fortinsky, and Coburn, 1992). In addition to overseeing the technical appropriateness of care delivery, a quality oversight system for HCBC services must depend on regular client feedback mechanisms to assure responsiveness to the more personalized aspects of care. (Kane, Kane, Illston et al., 1994; Applebaum and Phillips, 1990).

There are often multiple and conflicting goals in home care, some of which are difficult to balance. A 1990 series of stakeholder panels identified issues of most importance to consumers. These included freedom from exploitation, satisfaction with care, physical safety, affordability, and physical functioning (Kane, Kane, Illston et al., 1994). Much of the literature regarding the consumer's perception of home care quality indicates the importance of self-direction, the psychosocial characteristics of the home care worker, and the interpersonal relationship established between the client and worker (Lutzky, Alecxih, Duffy et al., 2000; and Tilly, Wiener and Cueller, 2000).

Consumer emphasis on quality of life is not always compatible with how providers or regulators define quality of care. Regulatory protections that enhance consumer safety in the home may end up decreasing consumer choice and autonomy (Kane, Kane, Illston et al., 1994). Both providers and consumers value safety but focus on different aspects. Consumers place value on the sense of safety in their living situation and with their care worker. Providers look to minimize risk and professional liability (Kane, Kane, Illston et al., 1994).

DIFFUSED NETWORK OF HCBC PROVIDERS

Approximately two-thirds of HCBC services are provided by informal caregivers, including family and friends. Another 19 percent is estimated to come from a mix of informal and formal caregivers, with the remaining 14 percent from formal caregivers (IOM, 1996). Persons providing attendant and housekeeping services make up the bulk of caregivers. These workers may be employed by an agency, listed in a referral registry or, most often, are hired directly by the consumer. Home health agencies are the principal vendor for home health aides while Area Agencies on Aging (AAA) offer personal care services, transportation and home-delivered meals (IOM, 1996).

Most HCBC workers who provide direct care are unskilled, with limited education or training. Supervision may come directly from the client or through a disparate group of case managers or employment arrangements. Nurses or social workers, often in the role of case managers, may oversee treatment plans but provide only limited direct care themselves (Kinney, Freedman and Loveland Cook, 1994). The unskilled nature of the workforce and the uncontrolled venue of the home as the delivery site place vulnerable clients at risk. Service quality in this context is highly dependent on the respectfulness, reliability, trustworthiness, and competence of the worker (Kinney, Freedman and Loveland Cook, 1994). Quality oversight systems must provide easy outlets for clients to address their complaints and to give feedback on a regular basis about their care experience. Mechanisms must be adapted to assure that the care provided to those with severe disabilities and cognitive impairments is consistent with a client's values and preferences.

LACK OF UNIFORM DATA

States are not required to use a uniform assessment instrument for determining program eligibility, assessing care or service needs, or developing service plans (GAO, 1996). Each state uses its own assessment instrument, the protocols for addressing care needs based upon an assessment are not uniform or consistent, and few states have automated such information. This hampers the ability to use consumer-level assessment information to measure consumer outcomes of care – particularly outcomes that measure change in functioning, cognition, behavior or other clinical indicators. The currently available sources of potential information for constructing outcome measures include claims data (i.e. Medicaid, Medicare or state-based claims) and possibly assessment data from the Medicare OASIS system. Claims data present many challenges. Many people covered by HCBS programs are also eligible for Medicare. To get a full picture of a person's service use and cost, it is desirable to have both Medicaid and Medicare claims data. Furthermore, many people covered by HCBS programs are also accessing state-funded programs. The other source of uniform, standardized assessment information is the Medicare OASIS assessment instrument. Home health agencies must collect OASIS data on all Medicaid and Medicare beneficiaries who are receiving skilled nursing services. Most people on HCBS or state funded home care programs are receiving personal care or attendant services and not skilled level services. The lack of uniform, consistent, automated assessment data is a major barrier to the development of quality improvement programs and the construction of care outcome measures.

ABSENCE OF A FOCAL POINT FOR ACCOUNTABILITY

HCBC services differ from other types of health care in that there is rarely a single entity that can be held accountable for the overall quality of care.[2] More often, the care process is spread across a broad spectrum of independent agencies and workers with no one entity or program fully in charge of the outcome. Each agency or vendor has a defined scope of responsibility that influences and can be influenced by the effectiveness of other caregivers. This "silo" aspect of care delivery impedes a state's ability to look systemically at how well an HCBC program is working and, as importantly, to create system changes when outcomes are less than desirable (Feder, Komisar, and Niefeld, 2000; Lutzky, Alecxih, Duffy et al., 2000; and Macro Systems, 1989).

Oversight at the state level is similarly decentralized and involves numerous parties. Medicaid provides the majority of funding for HCBC services through federally approved 1915(c) waivers. As a condition of waiver approval, a state must provide assurances that it will protect the health and welfare of clients. Medicaid may delegate the administration of the waiver program to state units on aging, mental health departments, or other state agencies with primary jurisdiction for a specific population or service**.** These agencies may contract with local networks (e.g., Area

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[2] Exceptions include arrangements where a state may contract with a single entity to provide the entire array of services to HCBC, most often on a capitated basis.

Agencies on Aging, centers of independent living, mental health centers, or county agencies**)** to provide or arrange for the provision of HCBC services. State licensing agencies regulate some HCBC services, such as residential care facilities or home health agencies. Some services may be certified through private accreditation organizations or operate under the terms of a contract with a state agency. Home health agencies that participate in the Medicare program must meet Conditions of Participation. Many non-medical services are funded through the Older Americans Act, Social Security Block grants, or state supplemental programs. Each of these programs defines requirements that HCBC agencies or vendors must meet to assure quality (Kinney, Freedman and Loveland Cook, 1994). The scope and enforcement of these quality assurance requirements vary. While each entity is looking after its "piece of the pie", no single entity has ultimate authority and accountability for overseeing and improving the outcome of care to clients. Furthermore, a "regulatory hole" exists with the provision of non-skilled long term care services which make up the majority of HCBC services (Kinney, Freedman and Loveland Cook, 1994).

III. Organization of the Report

This literature review is organized to correspond to the basic components of a quality assessment and improvement process. Section IV discusses a broad conceptual model of quality assessment and improvement: infrastructure, performance measurement, quality improvement, and re-measurement. This model serves as the organizing framework for reviewing the literature and CMS initiatives in subsequent sections. Section V discusses the varying ways program goals are defined for HCBC services and how those differences affect the quality assessment and improvement process. Section VI describes the underlying infrastructure necessary to support quality of care. This section draws heavily from a federal *Protocol* that establishes the safeguards a state must demonstrate are in place as a condition of 1915(c) HCBS waiver approval.[3] Section VII examines approaches for measuring the performance of HCBC providers and their effect on the health status and well-being of clients. The multi-dimensional nature of quality in HCBC is discussed as well as methods for translating concepts of quality into objective measures for monitoring purposes. The task of analyzing performance measurement data, selecting priorities and developing improvement strategies is reviewed in Section VIII. This section discusses the challenges of creating a quality improvement system for HCBC and the lessons that may be learned from other settings of care and initiatives. Finally, Section IX reviews the lessons and issues of improving HCBC services and implications for the Quality Guide.

IV. Framework for HCBC Quality Assessment and Improvement

Figure 1 presents a generic framework for conceptualizing the quality assessment and improvement process. Components of the process include:

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[3] Health Care Financing Administration, *HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community Based Services Waiver Programs,* Version 1.2, 2000.

HCBC goals: a state's vision for the ideal HCBC system of care. Goals articulate the populations to be served under the program, the services to be offered, and the outcomes to be achieved.

Enabling requirements: this term is used to describe the organizational, structural and procedural requirements of a care delivery system. They are prospective safeguards that increase the probability of providing good quality. The area of *Enabling Requirements* is shaded in Figure 1 since it is outside the scope of this literature review but will be referenced to show its relationship to other components of the quality assessment and improvement process. This process addresses whether the basic service infrastructure is in place and operating as expected ("structure*" or "*compliance" review). Indicators used to assess the "structure" of HCBS services are outside the scope of this literature review but will be discussed within the context of CMS requirements for 1915(c) waiver approval.[4]

Performance measurement: the activities necessary to credibly assess whether the service delivery system is meeting a state's goals. This process determines whether the delivery of care is consistent with accepted practices (process of care) or improves client outcomes.

Quality improvement: the systematic analysis of performance measurement data to identify opportunities for improvement and to implement improvement strategies.

Re-measurement: the cycle of activities necessary to continually assess whether quality is improving or that optimal performance is sustained.

Each component will be discussed in later sections, with emphasis on how the literature and experience can inform the design of a quality assessment process for HCBC services.

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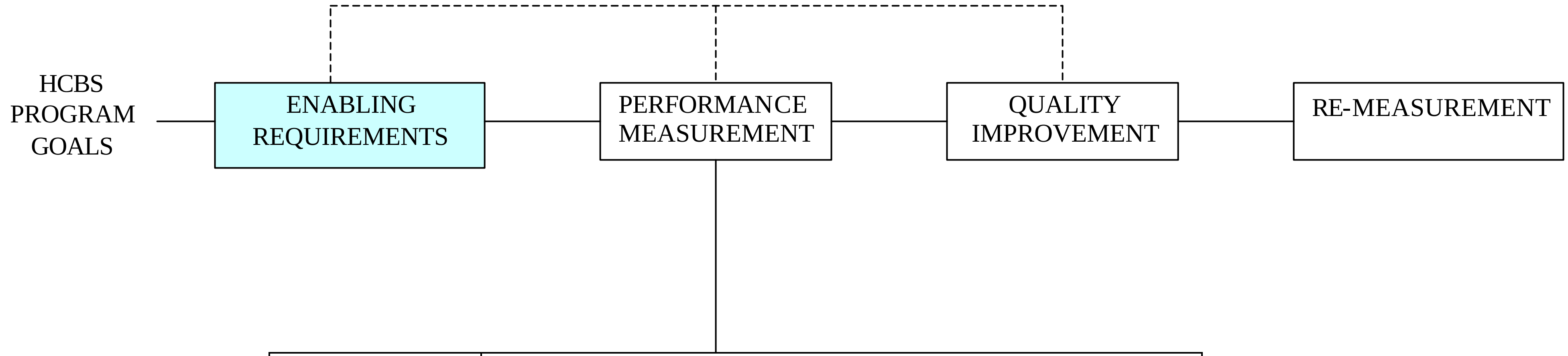
[4] Health Care Financing Administration, *HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community Based Services Waiver Programs,* Version 1.2, 2000.

FIGURE 1
HCBS QUALITY IMPROVEMENT FRAMEWORK



DOMAIN	QUALITY MEASURES		
	STRUCTURE	**PROCESS**	**OUTCOME**
Aspects of care: - Safety - Effectiveness - Client-centeredness - Timeliness	*Resources & operational practices*: - Type/# of providers - Staff training - Equipment - Complaint system - Policies and procedures - Systems information - Quality mgmt system - Client protections - Document req'mts	*Activities/procedures in providing care:* -Technical quality - Interpersonal characteristics	*Results of the care process:* - Health status - Functional status - Mortality - Consumer well-being

V. Defining HCBC Goals

There may be multiple goals for a state's HCBC program and goals may vary by individual program. Goals are influenced by the characteristics of the population, state and federal policy, the investment that can be made to support the goals, and by the political process that engages stakeholders.

The basic goal of HCBC services is to prevent premature institutionalization of clients.[5] Within that very broad goal, Kane et al suggest further classification of HCBC programs based on specific program goals (Kane, Kane, Illston et al., 1994):

Convalescence from acute illness: goals focus on stabilizing medical conditions; enhancing patient and family ability to manage conditions; limiting complications; and reducing re-hospitalizations.

Rehabilitation: goals emphasize physical functioning; self-care skills; communication skills; and compensation for disabilities.

Terminal care: goals stress pain control, patient and family well-being, patient control; and death with dignity.

In-home maintenance: goals focus on reducing the rate of deterioration; detection and attention to changes in health status; safety and security; patient satisfaction; and reducing admission to nursing facilities.

Respite care: goals focus on sustaining family caregivers in their roles; and reducing use of nursing facilities.

Tensions may exist among the goals for HCBC programs. Most obvious is the tension between safety versus choice and control (Kane and Kane, 2001). Since most HCBC services are non-medical and are designed to assist consumers conduct activities of daily living, goals are often articulated in terms of satisfying consumer values and preferences not meeting uniform professional standards (Benjamin, 2001; and Kinney, Freedman and Loveland Cook, 1994). Although one-third of seniors prefer choice over safety (Kane and Kane, 2001), this response may not be as straightforward as it initially seems. Most consumers also assume that licensed agencies or professionals already control for safety and provide technically competent care (Kane and Kane, 2001). Thus, even a consumer-driven model must be concerned with technical quality of care and safety as well as addressing consumer quality of life and choice (Kane and Kane, 2001; and Katz, Kane and Mezey,1991).

Over the past decade, many publicly funded programs have made consumer direction an explicit goal for their HCBC programs. Consumer-direction allows consumers to shape and direct their supportive services and to have greater control over how they live their lives.

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[5] 42 U.S.C. §1396, 3001(4).

Although outside the scope of this paper, consumer-directed models offer particular challenges to quality oversight system. Unlike traditional models where the state depends on licensed or certified providers to assume responsibility for the quality of care, responsibility rests with the individual consumer under a self-directed model (Benjamin, 2001).

VI. Enabling Requirements

The design and operation of a program are indicative of the probability of good care and, according to Donabedian, can be "the most important means of protecting and promoting the quality of care" (Donabedian, 1996). The term "enabling requirements" includes structural and operational standards that set forth the physical characteristics of an agency or service (e.g., equipment), staff characteristics (e.g., number and type of staff, criminal background checks) and procedures (e.g., complaint system, staff supervision) that impact the processes and outcomes of care (Campbell, Roland and Buetow, 2000). These are prospective safeguards that, although not guaranteeing quality, are generally believed to be prerequisite to good care.

Regulatory, certification and accreditation bodies use mostly structural and operational standards to evaluate whether conditions are favorable for good care. Debates persist about the value and research evidence of the link between structural standards and quality of care (O'Laughlin and Phillips, 1988; Applebaum, Regan, and Woodruff, 1993; Brook, McGlynn, and Shekelle, 2000; and Kane and Kane, 1988;). However, given that outcome standards can only be measured after the provision of care, structural and operational standards provide an imperfect yet essential safeguard to the public in advance of care being provided. An analysis of the effect of regulation on the quality of care in board and care homes found that regulation (e.g., structure and process standards) generally prevents very poor performance as well as promotes better performance when compared to homes that are not licensed (Hawes, Mor, Wildfire et al., 1995). Despite the prominence of structural standards, public and private agencies are looking for ways to combine process and outcome measures with structural standards once programs become operational (Applebaum, Mollica and Tilly, 1998).

HCBC programs and individual providers are subject to different sets of structural and operational standards or, as defined in this report, "enabling requirements":

- HCBC services established under Section 1915(c) of the Social Security Act must provide assurances to CMS as a condition of waiver approval and renewal. Effective January 1, 2001, the terms of approval are delineated in the *HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs* (HCFA, 2000). The *Protocol* lays out structural and operational standards for use by CMS regional offices to determine whether state programs are designed and operated to assure quality of care.

- The National Association of State Medicaid Directors (NASMD) published the *Home and Community-Based Quality Assurance Guide for States* to serve as a companion to the federal Regional Office *Protocol.* The *Guide* provides guidance to states on meeting federal standards for waiver approval and renewal (The National Association for State Medicaid Directors, 2001).

- Home health agencies wishing to receive payment from Medicare must meet certification standards established by the federal government. Standards specify the organization and administration of services, requirements for professional staff, assessment of client needs, provision of services, documentation of medical records, and evaluation. Certification standards have been criticized for focusing too much on structural measures and relying on "paper compliance" without sufficient direct observation of care (Katz, Kane and Mezey, 1991).

- Most states require home health agencies that provide skilled nursing services to be licensed as a condition of operation. Licensure standards vary substantially across states and many of these standards are believed to be weak and alone are felt not to assure quality (Katz, Kane and Mezey, 1991).

- Home care providers may seek private, voluntary accreditation of their programs. The National League for Nursing's Community Health Accreditation Program, the Joint Commission on the Accreditation of Health Care Organizations, and the National Home Caring Council review programs and certify that structural and procedural standards have been satisfied.

The above standards may differ in both major and minor ways but almost all focus on structural standards and, to a lesser degree, on the process of care or outcomes. Also, almost all regulatory activity is targeted to the provision of skilled services, leaving a major gap in the regulation of non-professional care which comprises the bulk of HCBC services (Kinney, Freedman and Loveland Cook,1994).

VII. Performance Measurement

DEFINING QUALITY

The purpose of this section of this report is to outline the key components of performance measurement and to discuss their relevance and potential use in HCBC services. The major activities involved in the design of a performance measurement system are: (1) to define the purpose of quality measures including their intended audiences and uses; (2) to identify the major domains of quality; (3) to specify the types of measures of interest (e.g., structure, process and outcome); (4) to select a set of measures; (5) to identify data sources; (6) to define the method for computing quality measures; and (7) to set standards for evaluating and using measures.

The Institute of Medicine defines health care quality "as the degree to which health services for individuals and populations increase the likelihood of desired outcomes and are consistent with professional knowledge" (Institute of Medicine (IOM, 2001b). The definition of quality for HCBC also needs to include the concepts of consumer-centered services and quality of life. Consumer centered care "focuses on the needs, circumstances, and preferences of people using care and their families, and involves them, to the extent possible, in planning, delivering, and evaluating long term care"(IOM, 2001c). Quality of life reflects "subjective or objective judgment concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic, and spiritual aspects"(Gold et al., 1996).

Measuring quality in the context of HCBC services is a complex task. Many of the outcomes of interest in long term care (overall health status, presence or absence of specific conditions, social and psychological well-being and satisfaction with care) relate to care provided by a multitude of professionals, non-professionals, family members and consumers. Unlike acute care, where successful outcomes often mean restoring a person to their level of functioning before the onset of illness, in long term care, successful outcomes are measured based on maximizing quality of life and physical function in the presence of permanent and sometimes worsening impairment (IOM, 2001c).

PURPOSE OF MEASUREMENT

Quality measurement is an essential feature of quality improvement. Valid, reliable and timely data about the care provided, consumer experience with care, and those providing care are fundamental to all strategies for monitoring and improving the quality of long term care. This information is important to many constituencies including consumers, providers, regulators and purchasers of services (IOM, 2001c).

Information on quality can help consumers make informed choices. Most consumers know little about the technical proficiencies of the medical and social services system. Some ask friends for advice. Some choose providers based on limited information. Information on quality can help consumers decide where and from whom to get care. (Schuster, McGlynn and Brook, 1997). Studies have shown that comparative information is more likely to be useful and used by consumers when it is presented in a meaningful format rather than in a comparative format. This means presenting information in a way that provides a context for understanding the information (e.g. labeling care as good, fair or poor, rather than just providing comparative information) (IOM, 2001b).

Providers can use quality measures to improve care provided in their own organizations. Information can be used to select areas for monitoring or investigation, to evaluate internal care processes and to develop action plans for quality improvement. Such information can also be used to identify best practices across providers and to focus educational needs and activities. Quality indicators for nursing facilities and residential care facilities have been used to compare outcomes across providers and among peers. Outcome-based Quality Improvement (OBQI) reports are also being developed for home health agencies to identify areas for improvement and to monitor and evaluate changes in care outcomes.

Regulators use data from a variety of sources to identify quality problems, to target monitoring and enforcement processes and confirm corrective actions. This information can be used to schedule oversight and enforcement activities, to select cases for review, and to assign staff for site visits.

Purchasers of health care, such as Medicare, Medicaid and other state agencies use quality information to select providers or agencies with whom to contract, to identify system level areas for improvement or education, to identify areas where policy changes may be needed and to evaluate the impact of new policies and systems.

Purchasers and other organizations also use information as part of ongoing quality improvement activities. In the business sector, the developers of the Balanced Score Card for the health care sector noted that –"Measurement Matters – if you can't measure it, you can't manage it. An organization's measurement system strongly affects the behavior of people both inside and outside the organization" (Kaplan and Norton, 1996).

Quality improvement involves a cycle of activities that is repeated continuously to produce ongoing improvements in practice and care. Reliable, valid and timely data provide the tools for establishing baseline measures and monitoring those measures either over time or in relation to established benchmarks or standards.

Throughout this section, reference is made to existing quality measurement sets and initiatives related to their development. Table 1.0 provides a summary of some of the sets of quality indicators and quality measures that have been developed or are in development in long term care and their intended audience and use. Appendix A provides a brief description of various quality initiatives and selected sets of quality indicators that are in development and/or in use.

DOMAINS OF QUALITY

The purpose of this section is to identify the major ways in which quality has been categorized in general and for HCBC services in particular. This includes an examination of the domains and subdomains that have been used to define the key attributes or components of care and consumer perspectives on care.

Health care quality and the quality of HCBC services in particular is a multi-dimensional and dynamic construct. It is multi-dimensional in the sense that the attributes or components of quality include multiple levels of inputs, processes and outcomes. There are a myriad of organizing schemes for defining the dimensions of quality and there are hundreds of variables that can be used to measure the various attributes of quality. The challenge in developing a performance measurement set is to find a way to define and organize the major dimensions of quality, to identify measures that provide a balanced representation of the various domains, and to assure that the measures are accurate, reliable, interpretable and actionable.

Table 1.0
Examples of Sets of Quality Measures for Long Term Care and Home and Community Based-Care Systems

Appendix[6]	Indicator Set	Purpose	Audience	Data Source	Use	Developer
	Home Care Indicators					
C-1	OASIS Adverse Event and Outcome-Based Quality Improvement Reports (OBQI)	For internal quality improvement for agencies (initially)	▪ Home Health Agencies	OASIS data set for Medicare home health services	National	Univ. of Colorado CHSPR/CMS
C-2	ORYX Home Care Measures	To target accreditation surveys For performance monitoring For quality improvement	▪ Hospital ▪ Long Term Care ▪ Home Care ▪ Behavioral health care programs	Various data sets	JCAHO organizations	JCAHO
C-3	*inter*RAI MDS-HC Quality Indicators for Home Care	For quality improvement for agencies (initially)	▪ State Medicaid and Aging agencies ▪ Provider agencies	MDS-HC	Selected states	*inter*RAI
C-4	CHSRA Quality Indicators for Home Care	For quality improvement for agencies	▪ Provider agencies	OASIS data Or MDS-HC	Selected agencies –for ORYX	Univ. of Wisconsin CHSRA
C-5	VA Quality Measures for Home Care Programs	Quality Assurance	▪ Veteran's Administration	Sample of Medical records	VA system	Veterans Admin.
	Quality Indicators for Developmental Disabilities					
C-6	Core Indicators For Developmental Disabilities	To benchmark performance of the service system	▪ State DD Departments	Consumer/Family Surveys State-level data	In use by selected states	HSRI and NASDDS
N/A	Quality Indicators for Developmental Disabilities	For internal quality improvement For regulatory monitoring of ICF/MRs To inform consumers	▪ Providers ▪ Reulatory Agencies ▪ Consumers	In development	In development	Univ. of Wisconsin CHSRA/CMS
	Home Care Satisfaction/Consumer Outcomes					
	Satisfaction with Home Care (Developed by Scott Geron et al)	Measure client satisfaction with home care use	▪ State agencies ▪ Provider agencies	Interview questionnaire	Selected states and programs	Geron, et al
	Waiver Consumer Experience Survey (MEDSTAT)	Measure consumer experience with services	▪ State Waiver agencies	Interview Questionnaire	In testing in selected states	MEDSTAT/CMS
	Nursing Facility Indicators					
C-7	Quality Indicators for Nursing Facilities	To select facilities/cases for review For quality improvement To Inform decision making	▪ State survey agencies ▪ Providers ▪ General Public	MDS 2.0	National (required by CMS)	Univ. of Wisconsin CHSRA/CMS
	Residential Care Indicators					
C-8	Quality Indicators for Residential Care	To select facilities/cases for review For quality improvement To Inform decision making	▪ State survey agencies ▪ Providers ▪ General Public	RAI-AL	In Maine; in development for other states	Texas A&M and Muskie School/ AHRQ
	Observable Quality Indicators	Quality Improvement Inform Decision-making	▪ Providers ▪ Consumers	Observable Indicator Survey	In development	University of Missouri

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[6] A brief description of each of these sets of quality measures is included in Appendix B. The actual quality indicators are included in Appendix C. The consumer surveys (by Greon et al and in development by the MEDSTAT Group) and the survey instruments associated with Observable Quality Indicators are not included in the Appendices.

Identifying the major domains of quality is an approach that has been used by many to organize the way one thinks about quality and to provide a foundation for quality measurement, data collection and reporting (IOM, 2001b). The Institute of Medicine explains that a framework (of domains) "provides durable dimensions and categories of measurement that outlast any specific measures. In essence, it lays down an enduring way of specifying what should be measured while allowing for variation in how it is measured over time" (IOM, 2001b).

The literature on health care quality is replete with ways to define, organize and measure quality. There is very little consensus on the domains to use to define the major attributes of quality or the subcomponents of quality. An attribute that may be considered a "major domain" by one author is a subdomain by another.

For purposes of this paper, the review of the literature on quality domains has been organized into three major categories: (1) general health care; (2) home and community based services; and (3) institutional long term care services.

Appendix B provides a comparison of the major domains that have been identified for health care quality in general, for home and community-based services, institutional long term care services and for measuring consumer outcomes, satisfaction and experience with care. Appendix C includes selected sets of long term care quality indicators.

Domains of Health Care Quality in General

Institute of Medicine Two recent reports of the Institute of Medicine include recommendations for the goals of a quality health care system. In its report, Crossing the Quality Chasm, the IOM recommends that:

All health care organizations, professional groups, and private and public purchasers should pursue six major aims; specifically health care should be safe, effective, patient-centered, timely, and equitable. (IOM, 2001a).

This IOM report outlines the major reasons for the gap in quality in the health care system including the growing complexity of science and technology, poorly organized delivery systems, the increase in chronic conditions and constraints on effectively using information technology. For those people who are living with chronic conditions, the need for a well organized, reliable, and personal health care system is particularly important. Some of the elements that have been identified as prerequisites for a quality health care system, particularly for people with chronic conditions, include: (1) evidence based, planned care; (2) reorganization of practices to provide more time, a broad array of services and closer follow-up; (3) systematic attention to patients' needs for information and behavioral change; (4) ready access to clinical expertise; and (5) supportive information systems (Wagner et al., 1996).

Another report by the Institute of Medicine, Envisioning the National Health Care Quality Report, proposes two main dimensions of health care quality. The first dimension consists of **components of health care quality** and the second dimension encompasses **consumer**

perspectives on health care needs. The components of health care quality include the domains of *safety, effectiveness, patient centeredness and timeliness*. The consumer perspectives dimension reflects the life cycle of people's involvement with the health care system or their reasons for seeking care at any particular time." This dimension builds on the work of the Foundation for Accountability and includes the domains of *staying healthy, getting better, living with illness or disability, and coping with end of life* (IOM, 2001b).

The definitions that are used for the **components of health care quality** (IOM, 2001b) are listed below.

Safety	refers to "avoiding injury to patients from care that is intended to help them" (IOM 2001a).
Effectiveness	refers to "providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit (avoiding overuse and under-use)(IOM2001a).
Patient centeredness	refers to health care that establishes a partnership among practitioners, patients and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.
Timeliness	refers to obtaining needed care and minimizing unnecessary delays in getting that care.

The second major dimension, **consumer perspectives on health care needs**, represents the most important reasons why people seek care and reflect the life cycle of their involvement with the health care system. The relative importance of people's health care needs change over time and over the life span of an individual. Furthermore, an individual may experience several health care needs simultaneously. For example, a person may seek advice on managing diabetes (living with illness) and at the same time seek care to get an immunization (staying healthy)(IOM, 2001b). The definitions of these consumer perspectives on health care needs are as follows:

Staying Healthy	refers to getting help to avoid illness.
Getting Better	refers to getting help to recover from an illness or injury.
Living with illness or disability	refers to getting help with managing an ongoing, chronic condition or dealing with a disability that affects function.
Coping with the end of life	refers to getting help to deal with terminal illness.

The Institute of Medicine uses a matrix as a way to visualize the framework and how various aspects of the framework work together.

CONSUMER PERSPECTIVE ON HEALTH CARE NEEDS	**COMPONENTS OF HEALTH CARE QUALITY**			
	Safety	Effectiveness	Patient Centeredness	Timeliness
Staying Healthy				
Getting Better				
Living with illness or disability				
Coping with end of life				

In addition to these domains of quality, the Institute of Medicine reports identified two other important areas related to quality – equity and efficiency. Equity is a cross cutting issue that may influence system performance and the quality of health care. It can be assessed across all components of quality by examining disparities among groups by race, ethnicity, gender, age, income location or economic status. Efficiency is defined as "avoiding waste, including waste of equipment, supplies, ideas and energy" (IOM, 2001a). Although efficiency was acknowledged as clearly related to quality of care, it was not identified as a domain area that was within the scope of the IOM report.

Appendix B-1 provides a summary of the major domains and subdomains that were identified in the Institute of Medicine Report (IOM, 2001b). For purposes of this report, we have used these domains as the frame of reference for examining other domains of quality that have been identified in the literature or are being used in the development of various sets of quality indicators. This is not to suggest that one set of domains is better or worse than another. However, given the potential confusion in taxonomy and nomenclature associated with domains, the domains proposed by the Institute of Medicine provide a useful framework and common language for organizing and categorizing quality measures.

***Foundation for Accountability* (FACCT)** In 1997, CMS (formerly HCFA) contracted with the Foundation for Accountability to develop model and draft language for communicating information to consumers and to recommend a way to combine measures into conceptual groups and to weight and score these combined measures (FACCT 1997). FACCT's goals for the project were to identify high-level conceptual categories of interest for consumer reporting, to provide context language for use in beneficiary materials and to provide a scoring algorithm for combining and weighting individual measurement scores. FACCT conducted 12 focus groups, 8 cognitive groups and surveyed numerous experts. As a result of this work, FACCT identified five general consumer-reporting categories and mapped the FACCT, HEDIS and CAHPS measures into these groups. The five groups included: (1) the Basics, (2) Staying Healthy, (3) Getting Better, (4) Living with illness, and (5) Changing Needs.

Subcomponents of quality for each high-level category were also identified. Four of the five high-level categories became the basis of the domain, *consumer perspectives on health care quality*, in the Institute of Medicine Report, Envisioning a National Health Care Quality Report. The category, *The Basics*, was not included although many of the concepts in that category are captured in the other IOM domains. In addition, the IOM report uses coping with end of life as its fourth consumer category. The domains and subdomains that were developed by FACCT are included in Appendix B-1.

Other Quality Domains Many authors have discussed and proposed ways to define and categorize the attributes of quality. Donabedian provided an extensive review of previous work on this subject and suggested that the attributes of quality be classified into the categories of accessibility (both physical and socio-organizational); technical management; management of the inter-personal process; and continuity. Each of these major categories was also cross tabulated with ways to assess quality using structure, process and outcome measures (Donabedian, 1980). Others have continued to use many, although not exactly the same categorization schemes. Campbell and colleagues propose two primary dimensions of quality: access and effectiveness. Access refers to whether people who need care, get care. Effectiveness includes both clinical effectiveness and effectiveness of inter-personal care (Campbell, Rolan, and Buetow, 2000). McGlynn and Brook propose a conceptual framework for quality assessment that identifies the major attributes of quality according the Donabedian's structure, process and outcome framework. In their model, process quality includes technical excellence (whether care is appropriate and effective) and inter-personal excellence (whether care is patient-centered and responsive). Outcomes include clinical status, functional status, satisfaction and mortality (McGlynn and Brook, 2001a).

Quality domains in home and community-based care

The Institute of Medicine Report, Improving the Quality of Long Term Care, includes a number of guiding principles for improving the quality of long term care (IOM, 2001c). Among those that are particularly relevant for this paper are that long term care should be consumer-centered, the system of long term care should be structured to serve people with diverse characteristics and preferences, and measures of the quality of long term care should incorporate many dimensions of quality, especially quality of life (IOM, 2001c).

Consumer-centered care is care that is responsive to patients' wants, needs and preferences. Provider needs are still considered important but secondary to the consumer. Elements of consumer-centered care include individualized care planning and delivery of services, participation of the consumer in the care planning process, consideration of consumer values, culture, experiences and preferences and recognition and support of consumer self-care capabilities. Consumer-directed services go beyond consumer centeredness to include capacity of individuals to assess their own needs, select, train and supervise caregivers and providers and monitor quality of care.

In the mental health system, there has been increasing emphasis on patient values, a focus on community rather than hospital care, the inclusion of broadened measurements of outcomes that encompass not only symptom reduction but functional status and quality of life. Efforts to define outcome domains from the perspective of mental health consumers has led to a suggested list of core consumer outcome indicators including self-help outcomes, well-being and personhood outcomes, empowerment outcomes, recovery outcomes, iatrogenic effects and negative outcomes, measures of satisfaction and dissatisfaction and other outcomes (Campbell, 1998).

Quality of life is considered by some as the sum of all the domains of quality including physical health, cognitive status, functional status, as well as psychosocial, social, spiritual and economic well-being. It has a subjective component, that requires input directly from the persons concerned regarding what components of quality are most important and how they should be weighted (IOM, 2001c). Measuring quality of life is a complicated and difficult task particularly for people who are vulnerable or have cognitive impairments. A number of quality of life instruments have been developed for people with mental illness and for older people (Lehman, 1988; and Lawton, 1999). Work on the development of quality of life assessments for people with mental illness has also been extended to quality of life outcome assessments for people with disabling medical disorders (Lehman, 1995).

A number of articles have examined what older people want from long term care and the attributes of quality that are important to various groups, including consumers, providers and regulators. Most recently, Kane and Kane reviewed the literature on the preferences of older people needing long term care (Kane and Kane, 2001). According to their review, older consumers value interpersonal qualities (the caregiver liking and caring about them, being compatible with the caregiver), reliability (caregiver showing up on time, staying the expected time and being trustworthy), task competence (the caregiver doing housekeeping and care tasks that the older person likes) and adequacy in the amount of care and help received. Consumers valued physical, social and psychosocial outcomes as well as attributes such as reliability, honesty and kindness. Older and younger people approach long term care differently. Younger people seek control and flexibility while older people emphasize safety and protection.

In an earlier article, Kane and colleagues report on the results of six structured panel discussions to identify the most salient outcomes of home care as perceived by six different constituencies: (1) users of home care, (2) consumer representatives, (3) home care providers, (4) paraprofessional personnel, (5) payors and insurers of home, and (6) regulators, accrediting bodies, and government officials. Participants were asked to rate the importance of 21 home care outcomes by assigning a score from 0 to 100. Five goals were consistently reported to be important: freedom from exploitation and abuse; satisfaction with care; physical safety, affordability, and maintenance or improvement of physical functioning. Affordability was also highly ranked as a goal by a number of the panels. Among the other 16 goals that panel members were asked to rank, there was less consensus on the importance or ranking of the outcomes.

In addition to identifying the most highly ranked goals of quality in home care, the article identified a number of themes that emerged across the groups. These themes included: (1) the interpersonal component of home care, (2) normalization, (3) balancing quality of life with safety, (4) flexible, negotiated care plans, (5) affordability, (6) appropriateness, (7) case management, (8) accountability, and (9) insurers and payors.

This article is relevant to this discussion because it attempts to elicit from the perspectives of various groups, the elements of quality and quality outcomes that are most important to each group. Two of the weaknesses that were identified with respect to outcome measurement were: the providers believed that they had incomplete control over outcomes; and the concern that outcome measures may not identify care of questionable quality until it is too late.

Others have examined other aspects of home care quality. One study examined the relationship between objective measures of home care adequacy based on clinical standards and measures based on self-reports of unmet needs. This study concluded that the perspectives of both consumers and professionals should be included in the definition of quality and any quality enhancement approaches. This study confirmed the need for a multi-dimensional approach to quality measurement. The health and functioning levels over time, quality of life, and satisfaction with care are determined by different aspects of the process of care and the context of the care delivery (Capitman, Abrahams and Ritter, 1997).

Appendix B-2 provides a comparison of the quality domains that have been used in selected HCBC quality initiatives and quality indicator systems. Appendix B-3 provides a comparison of various domains that have been used to categorize consumer outcomes and consumer experience with care.

Quality in institutional long term care

Nursing Facilities While the focus of this paper is on the quality of home care services, an examination of the literature and review of some of the reforms and advances that have been made in the regulation of nursing homes and the measurement of long term care outcomes are potentially relevant to HCBC services. In a comprehensive review of the literature, Sainfort et al found at least twenty-four models of nursing facility quality measurement with attributes that encompass a range of process, outcome and structural variables including health status, psychosocial well-being, environmental factors, medical care, services, resident activities, nutrition, staffing, resources and facility characteristics (Sainfort et al., 1995).

In response to years of scandals and studies of the inadequacies of care and the ineffectiveness of the nursing home regulations, Congress passed the Omnibus Reconciliation Act of 1987. The OBRA statute provided for new standards of care, a resident-focused approach to care planning, an outcome-oriented survey process and a range of federal enforcement remedies. Among the new standards was the requirement that all Medicare and Medicaid certified nursing facilities use a standardized, reproducible, comprehensive functional assessment tool to assess all residents and guide the development of individualized care plans. Previous studies had found widespread deficiencies in the process quality of nursing homes. Assessment information was often inaccurate, incomplete, and unrelated to the plan of care. Poor care practices were common including the use of restraints, inappropriate use of medications, overuse of catheters, inattention to nutritional problems, inadequate psychosocial interventions and management. (Hawes, Mor, Phillips et al., 1997).

As a result of OBRA'87, a core functional assessment instrument was developed, the resident assessment instrument (RAI). The purpose of the assessment instrument is to identify a resident's strengths, preferences and needs in key areas and provide a holistic and comprehensive picture of the resident's functional status (Hawes, Mor, Phillips et al., 1997). One of the other major advances that grew out of OBRA'87 and the implementation of the RAI, was the development of a set of nursing home quality indicators (QIs) and a quality monitoring system for internal and external quality review and improvement. (Zimmerman 1997-1998; Karon and Zimmerman 1996; and Zimmerman, Karon, Arling, et al., 1995). The QIs were developed through a process of clinical input, empirical analysis and field testing. Clinical panels were convened representing the major disciplines in the provision of nursing home care. An initial set of 175 QIs was developed and after further analysis and testing, a final list of 24 indicators in 11 domains was developed. These QIs have been adopted by CMS for use in the state survey process and by nursing homes for quality assurance and quality improvement activities. The QIs are also available for viewing on the HCFA website (http://medicare/gov/nhcompare/home.asp).

Residential Care Research by Rosalie Kane of the University of Minnesota identifies three dimensions of care in residential care settings: 1) the extent to which the environment is homelike, 2) the philosophy of consumer choice and control, and 3) the capacity to deliver routine and recurring services (Mollica, 2000). In some of the earliest work on residential care settings, Moos and Lemke identified nine dimensions of physical and architectural features that affect the behavior and functioning of elderly people (Moos and Lemke, 1980). These included physical amenities, social-recreational aids, prosthetic aids, orientational aids, safety features, space availability, staff facilities and community accessibility. These were subsequently included in a conceptual framework that included a set of objective characteristics and a set of personal factors that combine to influence the quality of a program's social climate, a resident's coping responses and their adaptations (Moos and Lemke 1996).

These themes are consistent with the themes that emerged from focus groups that were conducted with families of residents in assisted living facilities (Hawes, Green, Wood et al., 1997). In these focus groups, comments about quality were grouped into four major topic areas: staffing levels, services, environmental features and facility policies. (Greene, Hawes, Wood et al., 1997-1998). Furthermore, it was found that what constitutes quality for family members depends on a number of factors including: 1) their knowledge base and level of experience, 2) the level of cognitive impairment of the person in the facility, and 3) what the family can afford. Finally, as a resident's needs change, the quality of the staff and the quality of the actual care the resident receives become more important for the family members than the environmental features that were initially a major aspect of quality.

Another area of research related to quality in nursing and residential care settings is work done by Marilyn Rantz at the University of Missouri to develop "Observable Indicators of Quality." Rantz et al have proposed a conceptual model to guide nursing home quality research and the development of instruments to measure quality (Rantz, Mehr, Zwygart-Stauffacher et al., 1998). In a series of focus groups with key stakeholders, Rantz et al identified seven dimensions of quality in nursing homes. These include: (1) interaction; (2) milieu; (3) environment; (4) individualized care; (5) staff; (6) safety and (7) central focus on residents and families. These core concepts were originally identified as quality domains for nursing homes and used to develop a measurement tool to identify "Observable Indicators of Nursing Home Quality". They have also been modified and are being tested for use in residential care settings.

TYPES OF MEASURES

Quality measures are generally categorized as structure, process or outcome measures. Structural measures refer to the organizational or stable elements of the health care delivery system. This includes characteristics of the community, health care organization characteristics (e.g. hospital beds per capita), provider characteristics (e.g. mix of specialists or types of facilities), and population characteristics (e.g. demographics) (McGlynn and Brook 2001). Structural characteristics can also include governance and management structure, the qualifications of staff, the mix of professional and nonprofessional staff, record keeping systems, and other internal quality review activities of an organization. (Donabedian,1980; McGlynn and Brook, 2001).

Although structural measures of quality tend to be the easiest and most commonly used measures, the research is mixed with respect to the relationship between structural measures and outcomes of care (McGlynn and Brook 2001).

Process of care refers to the interaction between the consumer or user of care and the health care system. Process is usually divided into the technical component and the interpersonal component of the process. The technical component refers to the application of clinical knowledge to a health problem (Donabedian 1980). Technical excellence means that the intervention was appropriate (e.g. the health benefit exceeded the health risk to an individual) and that it was skillfully provided (McGlynn and Brook 2001). Examples of process quality include appropriateness of care and services provided, including assessment, care planning and care provision; timeliness/delay in seeking care and adherence to practice guidelines (Hawes, Mor, Phillips, 1997; Donabedian, 1980).

The interpersonal component includes the management of the social and psychosocial interaction between the practitioner and the person. This includes the experience with care including providing care with concern, courtesy, and respect (Donabedian 1980). A number of skills underlie good interpersonal skills including communication, trust, understanding and empathy, and ability to show humanism, sensitivity and responsiveness (Campbell et al., 2000).

Outcomes are consequences of care. They are the results of efforts to prevent, diagnose and treat health problems. Outcomes have been categorized as health related outcomes and user evaluation of care. Health status outcomes include changes in functional status, cognitive status, clinical status, and mortality. Other measures of outcomes include consumer satisfaction and enablement. Although outcomes are viewed as one of the best ways to measure quality, they also are technically and methodologically difficult to use. Two of the primary challenges with outcome measures are (1) the need to adjust for differences in risk and severity of the populations being measured and (2) the difficulty of attributing an outcome to a particular provider or service (McGlynn and Brook, 2001).

SELECTION OF MEASURES

Selecting a set of quality measures is a complex process that includes identifying candidate measures and obtaining input from experts and end users on the number, importance and presentation of the measures. This includes identifying individual measures that meet certain criteria, identifying measures that are both positive and negative, and developing a set of measures that are balanced, comprehensive and robust. The selection of measures also needs to involve technical experts, consumers, providers, policy makers and academia (IOM, 2001b).

The Institute of Medicine recommends the following criteria be considered when selecting quality measures (IOM 2001b):

Importance of what is being measured Different stakeholders will have varying perspectives on the weight or degree of importance to assign any single measure or set of measures. This will also vary depending on the context and the time at which a measure is being considered. Providing ways to get input into the selection of measures and refining those measures on an ongoing basis is an important part of the process. As part of the Quality Enhancement Research Initiative (QUERI) of the Veterans Health Administration, six steps were identified as part of a quality improvement process. The first step involved the selection of areas to be targeted. The QUERI group identified those conditions that were targeted to provide the greatest possible impact on veterans. This involved the identification of high risk/high volume diseases and conditions (Demakis, McQueen, Kizer et al., 2000).

Impact on health The IOM recommends that the measures address important health priorities such as issues related to care or specific conditions or problems that significantly affect morbidity, disability, functional status, mortality or overall health (IOM, 2001b). For people receiving home and community-based services, quality of life needs to be considered in addition to impact on health. These issues are particularly important for people who are living with a chronic illness or are coping with the end of life.

Meaningfulness Measures should be easily understood by policymakers and consumers and refer to something that matters to them. People should be able to interpret what the measures mean and be able to act on the measures, if necessary (IOM, 2001b). Particular attention should be paid to making information useful for consumers and to present the information in a way that clarifies the relevance of the measure to the consumer (Schuster et al., 1997).

Susceptibility to influence by the health care system The measures should reflect aspects of care that policymakers or the intended audience or user of the information can influence. For policymakers or providers, this would mean measures where it is possible to take specific actions in response to the measures (IOM, 2001b). This is particularly challenging for home and community-based services since so often many different people may be involved in providing care.

Scientific Soundness Assuring the scientific soundness of a measure is particularly important in assuring the credibility of the measure among the provider community and others. Use of measures that do not meet these criteria can create major setbacks in efforts to report on and use quality information.

Validity. A measure should make logical and clinical sense, it should correlate with other measures and it should capture meaningful aspects of quality (IOM, 2001b). One of the most important issues underlying validity is whether there is a basis for asserting that certain processes lead to certain outcomes, or that any given outcome is the consequence of specified antecedent processes (Donabedian, 1980). Outcome quality measures, for example, are most useful when we know the specific process of care that produce them. If we do not know how an outcome relates to processes of care, we will not know what to do to improve the outcome (Schuster el al, 1997).

Reliability. The measure should produce consistent results when repeated with different groups and when assessed by different people at different times. This is particularly important when a measure is being reported on an ongoing basis. Changes over time should reflect real changes in the measure and not ones that are an artifact of the data collection, time frame or other factors (IOM, 2001b).

Explicitness of the evidence base. The measure should have a documented foundation of evidence in the literature. This could mean that there is some other specific, formal process by which the measure has been accepted as a valid marker for quality, such as a review by an expert panel (IOM, 2001b).

Feasibility Feasibility refers to the ability to implement the measure, the cost to collect the data, and whether the measure can be used to compare different groups. Measures that are considered important and scientifically sound, but not feasible, at least in the short term might still be included in an initial set of potential measures and maintained for consideration as the measure set is updated (IOM, 2001b).

Existence of measure prototypes. Ideally, the measure should be one that has been tested, applied and is in use. It should also include understandable procedures for data collection, definitions, and methods of computation.

Availability of data across the system. Given the paucity of uniform and standardized data for home and community-based services, this may be a difficult criterion to meet. However, there are efforts to develop instruments (survey and assessment instruments) that can be used across the long term care system or across states.

Cost or burden of measurement. The cost of ongoing and continuous data collection is a major issue. Conducting interviews of consumers can be very costly and time consuming. Collecting information on a sample of people is one way to reduce costs but it also limits some of the analysis that can be done (at a regional or sub-population level) and must be done consistently from year to year.

Capacity of data to support subgroup analysis. It is helpful to have a sufficiently large database to be able to examine characteristics of subgroups of the population.

DATA SOURCES

The availability of valid and reliable data is key to the construction of quality measures. Some of the desirable attributes for evaluating sources of data are: 1) the credibility and validity of the data 2) the potential to provide state-level detail 3) the availability and consistency of the data over time and across sources 4) the timeliness of the data 5) the ability to support subgroup and condition specific analysis and 6) public accessibility of data (IOM, 2001b).

The following is a brief description of the various sources of data available to state Medicaid programs.

Administrative Data Administrative data are maintained as part of the ongoing operations of the agency or program. This could include provider related data, grievance and complaint data, enrollment or utilization data, data from survey and licensure activities, and claims related data. CMS has developed the Quality Improvement and Evaluation System (QIES) to support the state level survey process. This involves the integration of the licensing and survey systems into a new platform, the Aspen Central Office (ACO). This system is a database system that includes core structural and licensure information on facilities and agencies licensed by the state. It is also designed to be integrated into the workflow of the survey and certification process. Core information includes information on the facility name, address, bed count, census, licensure status, ownership, staffing, administrator status, deficiency information, review dates, meeting summaries etc.

Claims Data Claims data provide one source of quality measurement information for people who are receiving home and community based services under Medicaid and/or for people receiving state funded services. This can include information such as hospitalization rates for people with certain conditions, costs per member per month, and cost or utilization patterns by region or provider. Some states are also using Medicare data in conjunction with Medicaid data to examine cost and utilization patterns. It is also possible to use state specific claims data for programs that are not covered by Medicaid or Medicare. This could include, for example, pharmacy claims data (if a state has a pharmacy benefit) or claims for state funded programs. Some of the limitations of claims data are: 1) timeliness of the data, 2) completeness of the data (e.g. many people are receiving services under a variety of program and funding sources), 3) lack of clinical detail regarding functional or cognitive impairments, and 4) cost of analyzing claims data for quality measurement purposes.

Assessment Data The measurement of quality in Medicaid home and community-based care is hampered by the lack of a consistent, standardized approach to assessing individuals, evaluating service or care needs or determining program eligibility (GAO, 1996). Every state uses its own assessment instrument for determining eligibility and developing care or service plans. The data elements, definitions and process for conducting these activities vary from state to state. They may also vary from program to program within a state.

A number of states are starting to use the RAI-HC to assess home care clients. The RAI-HC is a comprehensive, standardized instrument for evaluating the needs, strengths and preferences of elderly clients of home care agencies. It has been designed to be compatible with other *inter*RAI assessment instruments including the MDS 2.0 for nursing homes and the assessment instrument for assisted living. It is meant to be a usable, useful client assessment system that will inform and guide comprehensive care planning in the current home care environment (Morris, Bernabei, Ikegami et al., 1999). The instrument is currently being implemented as part of the Veterans Administration home care system.

Michigan and Georgia have been using the RAI-HC for several years. Rhode Island, Massachusetts, Utah and New Jersey are moving toward implementation of the instrument. New York and Texas have are implementing the instrument as part of a research project. Maine has been using a modified version of the RAI-HC since 1995. Michigan, Georgia and Maine have electronic submission of their instruments in place. The other states are moving toward electronic submission (Personal communication from Brant Fries, University of Michigan, December 21, 2001).

OASIS Data Medicare requires the use of the OASIS[7] assessment instrument for Medicare certified home health agencies. The OASIS is a group of data elements that represent core items of a comprehensive assessment for an adult home care patient and that form the basis for measuring patient outcomes for purposes of outcome-based quality improvement (OBQI). OASIS data have three areas of use: patient assessment and care planning; agency level case mix reports; and internal performance improvement of home health agencies. As a condition of Medicare participation, all home health agencies are required to collect and electronically submit OASIS data on all Medicare and Medicaid beneficiaries who are receiving skilled nursing services. The OASIS is not required for people who are receiving personal care services or chore or homemaker services (www.hcfa.gov.medicaid.oasis.hhoview.htm).

OASIS data items encompass sociodemographic, environmental, support system, health status, and functional status attributes of adult patients. The OASIS data are currently available on an agency-specific basis and reports are generated for each agency that compares the performance of the agency with a reference group. The reference group is from a national OASIS database and is not, at this time, developed on a state-specific basis.

The OASIS OBQI system was initially implemented in 2001 with the introduction of the case mix and adverse event reports. In 2002, agencies will start to receive and use the outcome reports. Eventually, these reports will also be used by survey agencies to focus their review activities.

Although many people who are receiving home and community-based services are also receiving Medicare services, this does not represent the full population of people or full range or services of HCBC beneficiaries. While the OASIS data have potential for supporting Medicaid focused quality improvement activities in the future, its use at this time is limited.

Survey and Interview Data Information on consumer choice, control, respect, dignity and other areas of interest to consumers are usually captured through consumer surveys or interviews. A number of surveys have been developed (Geron, Smith, Tennstedt et al., 2000) or are being developed (by the MEDSTAT Group) to capture consumer experience with care. Geron and colleagues developed the home care satisfaction instrument which measures the satisfaction of frail elderly persons who receive any of several common home care services. The responses to questions on the instrument are scored and an overall home care satisfaction score is computed as well as subscale scores for the five areas. The instrument was tested for validity and reliability and its design was based on consumer-defined notions of satisfaction including those of various ethnic minorities (Geron, Smith, Tennstedt et al., 2000).

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[7] Outcome and Assessment Information Set.

Another instrument is also being developed by the MEDSTAT Group to develop and test a Consumer Experience Survey for the Medicaid HCBS waiver programs. The goal of the project is to develop a short survey that generates information related to: 1) choice/empowerment, 2) satisfaction with care, 3) access to care/services, 4) respect/dignity, and 5) community integration/inclusion.

Although surveys provide an important way to capture information on consumer satisfaction and experience with care, there are a number of challenges associated with the collection of such data. These include: (1) the cost of interviewing people, (2) the need to trade-off cost with sample size (i.e. the size of the sample may be sufficient for statewide reporting but not for sub-population or program-specific reporting), and (3) the need for standardized interview instruments and a reference database for comparison purposes.

Medical Records Patient medical records or care plan records are a source of quality information. Medical record information is usually maintained at an individual agency. Information from the medical record is usually abstracted for a particular purpose as part of a review of records on ongoing quality assurance activity. Compiling information from medical records in a large database for purposes of constructing quality measures is a time consuming and costly activity.

CONSTRUCTION OF MEASURES

This section reviews both the unit of analysis of the measure as well as adjusting measures for risk or severity of illness.

Unit of Analysis

Quality measurements are usually constructed as a rate with a numerator and a denominator. The selection of the appropriate observations for the denominator include specification of the data source, the method for selecting a sample, if appropriate, the time frame for data collection or aggregation, and the method for ongoing data collection. Quality measurements can be aggregated in the following ways:

- population (older adults, people with physical disabilities, mental illness, children, etc)
- setting (home, residential, institution, hospital)
- geographic area (population-based, region)
- provider
- condition (disease or other condition)
- payor/program area (Medicaid, Medicare, state-funded, or private)

The way in which a measure is defined and constructed depends in part on the audience, the end use of the measure and the availability of data. Identifying disease-specific conditions is one way to define an initial set of quality indicators. Focusing on selected conditions is in line with both consumer and policymaker perspectives on care and the importance of making the indicators specific to conditions that affect consumers and their families. Disease-specific indicators also allow for study of the relationships between the specific processes of care and outcomes of care for specific conditions (IOM, 2001b). Specific conditions can be prioritized using a number of methods including using national lists of priority conditions, importance of the condition and prevalence. In its development of categories for reporting quality information to consumers, FACCT found that the use of condition-specific measures mapped well with its consumer categories of staying healthy, getting better, living with illness and changing needs (FACCT, 1997).

Thus, the construction of any measure is linked with the purpose and end use of the measure. Other considerations include the ongoing availability of data, the availability of other data for comparative purposes and the reliability of the data.

Risk Adjustment

Once a quality measure is computed, the next challenge is to develop an appropriate methodology for risk adjusting the measure. Risk adjustment is a way of minimizing the possibility that differences in outcomes between comparison groups are due to factors other than the care provided by the agency or organization (Department of Health and Human Services, 2002). Without some way to adjust for the characteristics of the population, the progression of disease and the aging process, it is difficult to interpret particular outcomes as indicators of quality. Ideally, a risk adjustment should account for factors that affect the probability of outcome but cannot be controlled by the provider (Mukamel, 1997).

Risk can be adjusted for in a number of ways. One method is to use the standard epidemiological method and create a single risk-adjusted rate for each QI. Using this approach, an expected rate or QI occurrence is computed, given the presence of risk factors. The difference between the observed rate and the expected rate, expressed as a ratio, becomes the quality measure. Facilities or agencies with a ratio greater than 1.0 would be presumed to have a potential problem (Mukamel 1997; Zimmerman,1995).

In constructing risk adjusted Quality Indicators (QIs) for Nursing homes, Zimmerman used a more direct approach that took into consideration the end users of the quality indicators -- the surveyors, facilities and consumers. This approach allows surveyors and others to see the detail that goes into constructing the index (the numerator and denominator, for example) and provides a way to tie a resident-level report to the construction of the quality indicator.

Some of the NF quality indicators are risk adjusted. The indicators include three measures: an unadjusted indicator, a high risk and a low risk indicator. For example, one unadjusted quality indicator is the prevalence of bladder or bowel incontinence. This indicator is further divided into those who are high risk of bladder or bowel incontinence and those who are not. Thus, the NF QIs include a high risk and low risk quality indicator for prevalence of bowel and bladder incontinence. For the high risk quality indicator, the denominator includes all those people who are considered at high risk for bladder or bowel incontinence (e.g. have severe cognitive impairment or are totally dependent in mobility.) The denominator of the low risk QI includes all those people in the nursing facility who do not have a risk for bladder or bowel incontinence. This approach was desirable for a number of reasons. First, it allowed the surveyors and the facilities to determine the relative sizes of the populations, to identify whether there was a potential problem for either group, and to set different thresholds for each group (Zimmerman, Karon, Arling et al., 1995).

For purposes of the OBQI indicators that are being developed for home health agencies, a different approach was taken to adjust for risk. The OBQI indicators are adjusted for risk using a logistic regression technique. This involves developing a predictive formula for a specific outcome using a reference group of patients. The predictive model is applied to obtain an expected agency-level outcome rate, which is then compared to the agency's actual outcome to determine whether care was superior or inferior relative to the reference sample. This provides a way to take into account the patient characteristics and risk factors most closely associated with the specific outcome. Each outcome measure in the OBQI System has its own risk model and this risk model is re-estimated each time outcome reports are produced which means that the current characteristics of the reference sample are always considered (Centers for Medicare and Medicaid Services, 2002).

STANDARD SETTING

Once quality measures have been constructed, they can be used in conjunction with established standards or norms. Absolute standards include identification of a normative or threshold value for each quality indicator. Sentinel events, thresholds set by professional consensus or quality indicator "flags" represent absolute standards. Relative standards can also be established that provide comparative rankings of providers or measure longitudinal change in performance.

Sentinel events A sentinel event is usually an adverse event that is likely to be associated with poor quality of care and tracks the frequency with which the event occurs. Examples of sentinel events or adverse outcomes include mortality, early readmission to a hospital, surgical complications, nosocomial infections or adverse drug reactions (McGlynn and Brook, 2001). In nursing facilities, a sentinel event is a rare but serious condition that few if any residents would show. Sentinel events in nursing facilities include dehydration, fecal impaction and pressure ulcers in low risk populations. Because sentinel events are important and unacceptable occurrences, they are events that facilities should address as soon as the problem appears (Karon et al., 1999).

Percentile Ranking and Quality Indicator "Flags" Percentile ranking is a method for comparing the performance of an organization relative to its peers. Using this method, the quality indicator of an organization is computed and the rank order of the indicator is displayed relative to a peer group. The nursing facility quality indicator reports identify those instances where the quality indicator of a facility exceeds a certain threshold and hence the indicator is "flagged". This provides a prompt for the facility (or the survey team) to examine the indicator and to identify whether there is a problem with is area of care. For purposes of the nursing facility quality indicators, the 75th percentile is used to establish a flag for review. This may be a trigger for review by a survey agency or for internal quality improvement.

Thresholds by Expert Panels Another way to establish a standard is through the use of an expert panel. For some, this approach is more appropriate than using relative standards or statewide means (Rantz, Petroski, Madsen et al., 2000). If a group mean reflects a systemic problem with care in an area, the use of relative standards will fail to identify problems. Alternatively, if a group consistently has a high quality of care, the group means may penalize facilities that are outside the thresholds even though quality is acceptable. For this reason, Rantz and colleagues convened an expert panel to review Nursing Facility Quality Indicators and reset the thresholds for interpreting scores. In this study in Missouri, nursing homes found that staff were better able to use data in their quality improvement activities when the data was displayed with meaningful thresholds (Rantz et al., 2000).

Other Relative Performance Standards It is often the case that external standards or thresholds are not available. Another method for monitoring quality performance is to examine changes in the performance indicators over time. This method is useful in the development of quality improvement programs. It provides an opportunity for an organization to assess its own performance, identify areas where improvement may be needed and to monitor the impact of actions taken. One of the difficulties, however, is that it is not always easy to judge whether the difference in an indicator between two time periods is a result of changes or actions taken, or is a result of other randomly occurring effects.

Reference Sample (OBQI) The OBQI reports developed for home health agencies uses a risk adjusted reference sample as a way to compare an agency's performance with a national standard. Using a multi-variate modeling technique, each outcome measure is risk adjusted based on a predictive model that has been developed for that measure. The OBQI reports provide a comparison of an individual agency's outcome measures with the same outcomes of a risk adjusted reference group. The agency outcome is then compared with the reference group outcome and a measure of statistical significance is computed. In those instances where the difference is statistically significant, it is so noted and provides a prompt to the agency investigate further (Centers for Medicare and Medicaid, 2002).

VIII. Quality Management and Improvement

This section of the report reviews activities that detect quality problems and improve the outcomes of care to HCBC clients. The literature in this area predominantly focuses on studies, practice guidelines and interventions to detect, treat and improve the outcomes of persons with specific chronic illnesses or physical disabilities living in the community. Most of these findings are written from a clinical perspective and/or from the vantage point of a delivery system that manages all aspects of the care process. Much less is written and understood about state oversight of highly fragmented systems of care where providers have less influence on the outcome or where there is diffusion of responsibility among multiple caregivers. Furthermore, quality improvement from a consumer value-based perspective is relatively new although emergent models offer encouraging insights into how these concepts can be structured into quality management programs for HCBC services.

This section of the report distinguishes quality improvement from the traditional quality assurance function. In the past, quality was assessed with respect to how well a program, service or individual practitioner satisfied structural and process standards. Quality problems were viewed as the product of "bad apples" or incompetence. Licensure, accreditation and certification programs focused on ridding the system of these negative influences or raising compliance to minimum acceptable thresholds (IOM, 1996). While still the mainstay of many regulatory functions, quality assurance is gradually being replaced or augmented by a continuous quality improvement (CQI) approach which emphasizes outcomes of care provided by entire systems, not individual providers. Quality problems in these models are more often the product of failed systems, not individuals (IOM, 1996; National Chronic Care Consortium, 2001).

The quality oversight chain links back to structure and process standards but does not end there under a CQI model. The *Enabling Requirements*, as discussed in Section VI, establish the structure and process for care and provide a "good housekeeping seal of approval" from state, federal and accrediting bodies that conditions are favorable for good quality. Quality management and improvement is the method for assessing how well structures and processes actually work in achieving the desired outcomes or expectations of care. In Section VII, *Performance Measurement*, we discussed the development and use of indicators to assess how well a delivery system is performing. When outcomes do not meet anticipated levels, the CQI process examines factors that may contribute to poor performance (or, conversely, identifies factors which promote positive outcomes) and implements appropriate interventions. Under CQI, the effectiveness of structure and process is not gauged by "paper compliance" to standards but rather through their capacity to impact desired outcomes or performance goals (National Chronic Care Consortium, 2001).

Traditional Quality Assurance Approaches in HCBC Services

The movement away from quality assurance toward a quality management and improvement model poses significant challenges to HCBC services. In this section, we review the historical role of quality assurance and the issues affecting the trend toward an outcomes-based CQI approach.

In 1989, Macro Systems reviewed state quality assurance programs for home care and found that mechanisms varied widely but generally could be grouped into three categories:

- *The use of standards for providers*, particularly worker training, worker certification, licensing and provider approval.
- *Monitoring* of home care to assure that standards have been met. These activities were commonly conducted through supervision of workers, supervisory home visits, client assessments and evaluations, care planning, case management, contract reviews and provider surveys.
- *Enforcement activities* when there is a failure to comply with standards (Macro Systems, 1989).

In 1993, the Health Care Financing Administration (now CMS) conducted a similar study that found interesting variations although some similarities to the earlier Macro Systems study (HCFA, 1993). HCFA classified state QI activities into four categories, including:

- *Case management activities* that allowed for close observation of the individual care encounter and the implementation of the care plan in accordance with client preferences and needs.
- *Training requirements* for workers and agencies, including certification.
- *Program monitoring* that assessed performance across providers, including the development of quality assurance teams and the implementation of provider review visits.
- *Client involvement*, including the participation of clients in the development of care plans, client surveys, and complaint systems or "hot lines."

The Ohio Quality Assurance Project, a two-year demonstration to develop a model quality assurance system for in-home supportive services, revealed the dilemma of using uniform standards to measure quality given "the critical importance of clients' autonomy in assessing quality" (Applebaum, Regan, and Woodruff, 1993). Study findings stressed that quality assurance must "come from the bottom up rather than the top down" with individuals delivering care assuming front-line responsibility for quality monitoring. The study, however, did not resolve the apparent conflict of creating a quality assurance system where the assessors themselves may be the focus of potential quality problems. In his review of consumer-directed services at home, Benjamin reiterated the failure of uniform professional standards to serve as an accurate indication of quality. Citing the work of Kane, Kane et al, he argued that where personal services in the home are involved, values and preferences are likely to vary with respect to what is considered appropriate, adequate, comfortable, and secure. The client is in the best position to define quality and to measure and monitor performance (Benjamin, 2001; Kane, Kane, Illston et al., 1994).

A more systematic and comprehensive review of quality oversight was conducted in 1997 of three states believed to have "strong commitment to homecare quality" (Applebaum, Mollica, and Tilly, 1998). Experts interviewed state officials, case management agencies, and direct providers in Massachusetts, South Carolina and Washington and found that, despite very different models of service delivery, QI activities could be broadly grouped into those conducted by the state agency, case management agency and at the local provider level. Table 2 presents the range of activities found in this three-state study.

Table 2
Levels of Quality Assurance Activities

Type of QI Activity	Level of Activity		
	State Agency	**Case Mgmt. Agency**	**Local Provider Agency**
Structural	Licensing and standards Training curriculum Quality assurance unit Criminal background checks	Quality management initiatives	Training and recruitment Supervision
Process	Case management/provider audits Peer review	Peer review systems Provider audits	Monitoring
Outcome	Performance measures Satisfaction surveys	Consumer surveys Nurse oversight visits	Consumer surveys Random verification calls to clients

Source: (Applebaum, Mollica, and Tilly, 1998)

This study also identified factors that were believed to affect the quality of home care. First, low reimbursement and wages resulted in a workforce with low education and training. Workers were given significant responsibility for care oftentimes beyond their ability. Second, provisions that allow a consumer to choose his or her provider are weakened by the general lack of information on the quality of providers or services that can lead to an informed choice. Finally, the rise in the use of independent providers raised issues about their effect on the quality of care.

Applebaum et al stressed the need to evaluate the merits of state quality assurance activities to assess whether they make a difference in client outcomes. While states continue to invest time and resources into their monitoring functions, there is little evidence to suggest that they are necessarily looking at the right things or know how to accurately measure quality (Applebaum, Mollica, and Tilly, 1998; Kane, Kane, Illston et al., 1994). This problem is exacerbated by the lack of information-sharing across states that could suggest best practices in this area (Applebaum, Mollica, and Tilly, 1998).

States have no regulatory directive to improve the quality of care to HCBC clients. The HCFA Regional Office *Protocol* for determining compliance to federal home and community based waiver assurances acknowledges that quality improvement activities are beyond the basic assurances and are not required under any current regulatory authority. While recognizing the absence of regulatory control, HCFA included “quality enhancing activities” within the *Protocol* to encourage states to move in a CQI direction (HCFA, 2000).

Trends in Quality Management and Improvement

Over the past five years, there has been a flurry of activity to identify outcome measures relevant to the HCBC population. These approaches have been fully discussed in the previous section on

Performance Measurement. While the movement to develop and use performance measures has been widely embraced, there is less clarity and uniformity on how measures are incorporated into a state's quality management and improvement system for HCBC services. Several recent federal and private initiatives can be illustrative in helping to establish a vision for how quality management and improvement is likely to be applied to HCBC services in the future.

In formulating new rules to redesign and improve care, the *IOM* described the changes needed to overcome the old approach to health care quality indicated in the table below.

Table 3
Rules for the 21st Century Health Care System

Current Approach	New Rule
Care is based primarily on visits	Care is based on continuous healing relationships
Professional autonomy drives variability	Care is customized according to patient needs
Professional controls care	The patient is the source of control
Information is a record	Knowledge is shared & information flows freely
Decisions are based on training & experience	Decision making is evidence-based
Do no harm is an individual responsibility	Safety is a system property
Secrecy is necessary	Transparency is necessary
The system reacts to needs	Needs are anticipated
Cost reduction is sought	Waste is continuously decreased
Preference is given to professional roles over the system	Cooperation among clinicians is a priority.

Source: (IOM, 2001a)

With support from the Robert Wood Johnson Foundation, the *Chronic Care Model or CCM* was developed in response to growing evidence that traditional care delivery systems fail to provide the clinical, psychological, physical and social demands of the chronically ill population (Wagner, Austin, Davis et al., 2001). The CCM operationalized the tenets put forth by the IOM (see Table 3), especially those relating to continuous relationships, the individualization of care according to a person's needs and values, the anticipation of a person's needs, services based on evidence, and cooperation among clinicians. The model depicts what a care delivery system would look like if based on these principles.

The quality improvement component of the CCM emphasizes "rapid system changes" in response to identified problems that provide enhancements to the organization and its practices in ways that improve client outcomes. Client outcomes are optimized through four essential interactions that: (1) elicit and review data concerning clients' perspectives and other critical information about the course and management of the condition; (2) help clients set goals and solve problems for improved self-management; (3) apply clinical and behavioral interventions that prevent complications and optimize client well-being; and (4) ensure continuous follow-up.

Although data are collected at the client level under CCM, they are examined from the perspective of system improvements that can affect positive change across an entire population. Quality improvement interventions tend to cluster into six areas:

- *The health care organization* including the ability to remove barriers to quality improvement, such as financial disincentives or lack of resources. For purposes of our discussion, "health care organization" may also extend to a state Medicaid agency.
- *Community resources* that expand the capacity of an organization through linkages with relevant agencies and services.
- *Self management support* that shifts the focus from "patient education" to encouragement and support for more effective self management.
- *Delivery system design* that facilitates coordinated actions among multiple caregivers.
- *Decision support* that enhances provider and caregiver knowledge in ways that are woven into the care process, not supplemental to it.
- *Clinical information systems* that use simple database software to aid in the care of clients, such as disease registries populated through claims or assessment data.

The CCM is primarily a medical model but offers an approach for managing the care of a diverse population across multiple caregivers, much like the HCBC service environment. As importantly, it speaks to the complexity of the interactions within an organization or delivery system that can affect the outcome of care.

The *Accreditation Council on Services for People with Disabilitie*s laid out their principles which signal "a new focus and offers a new challenge to the traditional assessment of quality in human services." Their *Outcome Based Performance Measures* are the core of a new system for quality improvement that emphasizes "responsiveness to individual needs rather than traditional compliance with established standards" (Accreditation Council, 1995).

OASIS established a system of outcome measures for use by Medicare participating home health agencies in their patient assessment and care planning as well as internal performance improvement." The OASIS data system was designed as a means to achieve outcome based measurement and quality improvement. The OBCQI approach includes a two stage process, outcome analysis, and outcome enhancement. The outcome analysis stage includes the collection and electronic submission of the OASIS data and the creation of risk adjusted outcome reports. The second stage, outcome enhancement, includes selecting target outcomes for enhancement, evaluating care for target outcomes and developing plans of action for change. The impact of the activities is determined with the next outcome report and assessing whether the target outcomes are actually enhanced. The OBCQI outcome management framework includes OASIS, outcome evaluation, outcome management, resource management and ultimately cost-effective, quality care (Center for Medicare and Medicaid Services, 2002).

Another OASIS-related project is the development of an outcome-based continuous quality improvement system and core outcome and comprehensive assessment data set (*OBCQI/COCOA*) for the Program for All-Inclusive Care for the Elderly (Pace). This includes selecting target outcomes for review "after which plans of action are documented and implemented to change or reinforce care behaviors" (Center for Health Services Research, 2001).

A project to develop a performance measure set for the evaluation of Medicaid services to people with mental retardation or developmental disabilities residing in *ICF/MR* facilities includes a beta test to assess how the measurement set can be used for quality monitoring, quality improvement and consumer information.

Advancements in the design and collection of performance measurements offer many opportunities for improving HCBC services. Measurement, however, can also serve as a distraction if not incorporated into a quality management system that uses findings to target quality problems and to assess and address the factors leading to poor outcomes. Despite major developments in measurement, there has not been comparable activity on how information can be used and managed to facilitate effective decision-making at the state and program levels.

Classic quality improvement approaches have been developed under an acute care model where the goal is to bring practice into alignment with accepted professional standards of care. Under these models, data are reviewed to determine where discrepancies in care are the greatest and where the greatest possible impact can be achieved. Performance in each focus area is reviewed to determine where it varies with professional guidelines or practice protocols. Interventions are implemented in accordance with evidence-based research on factors or practices that improve given outcomes. After a cycle of interventions, data are reviewed again to determine the effects of the intervention (Chassin, 1996; Demakis, McQueen, Kizer et al., 2000). This neat and tidy approach to quality oversight does not easily lend itself to HCBC services where there may be an inherent conflict between standardized definitions of quality and the preferences of clients (Applebaum, Mollica, and Tilly, 1998; Brook and McGlynn, 1996; Campbell, Roland, and Buetow, 2000).

In other sectors of long term care, protocols have been developed that translate research into practice guidelines. In nursing facilities, the Resident Assessment Protocols (RAPS) are used as part of the assessment and care planning process. The protocols are used to alert the assessor to a client's potential problems or needs and to provide guidelines for evaluating triggered conditions. The RAP guidelines provide guidance on how to synthesize assessment information within a comprehensive assessment and provide support to facility staff on how to evaluate conditions and how to address those conditions in the care plan. The RAP guidelines supplement clinical judgment and stimulate critical thinking in attempting to understand or resolve confusing symptoms and their causes. Surveyors review the RAP problem areas and the care planning decision associated with the triggered conditions (Morris, Murphy et al., 1995). Client Assessment Protocols (CAPs) have also been developed for use with MDS-HC, the home care assessment instrument. Like the RAPS, the CAPs are designed to inform and supplement the clinical process. The CAP guidelines focus attention on the causal factors of a condition and ways in which the problem is being experienced and why it is present. They then provide guidance on next steps and what should be addressed (Morris, Bernabei, Ikegami et al., 1999). Similar protocols are also being developed for residential care facilities and assisted living facilities.

One can look to other initiatives and settings of care to anticipate how to reconcile or incorporate client-centered outcomes into an overall strategy for quality improvement of HCBC services. Of particular interest is the movement to link outcome and client-based measures to the survey and licensure process. Quality indicators, based on information collected from client assessment instruments in nursing homes, are used by state survey agencies to target and focus reviews in areas where the data suggest potential problems (e.g., high incidence of falls). Many states recognize the value of these reports for internal quality improvement purposes and regularly share with nursing facilities their performance on these indicators compared to peer groups. Software is available to link performance to individual residents and to possible interventions or protocols to address the specified condition. Similar indicators are also being developed for resident care facilities and the VA home care system although they have yet to be incorporated into the licensure or survey process.

Some states are moving on their own to revamp their quality assurance activities to more outcomes-oriented quality improvement   Connecticut, Iowa and Minnesota have each included consumer feedback as a criterion for evaluating provider or agency requests for licensure or renewal. While not abandoning structure and process standards as an aspect of the process, these states have acknowledged that the consumer voice must be heard in determining the continuing status of a provider.

What is less clear in these cases is how consumer perceptions influence quality improvement within a given program, service or agency. On an individual level, it is relatively easy to accommodate individual needs and preferences, at least within the constraints of an agency's resources, authority and defined service scope. The challenge in HCBC services is to translate individual experience to collective knowledge and action about system design and practices that facilitate client empowerment and well-being.

Campbell, Roland and Beutow describe the distinction between individual care planning and aggregate quality improvement. Whereas individual perceptions and autonomy matter most at the individual level, they propose that quality improvement at the aggregate level relates more to issues of equity, efficiency and cost (Campbell, Roland, and Buetow, 2000). In combination with structure and process standards discussed in Section IV, *Enabling Requirements,* these concepts may suggest a means for designing a quality improvement and oversight system that gives sufficient weight to values and preferences at the individual level while being alert to the need for accountable, effective and responsive systems of care at the agency and program level.

IX.   Lessons and Implications for HCBC Quality Guide

The literature review was prepared to inform states and CMS about the current state of the art in the area of quality improvement and their implications for HCBC services. The work has identified opportunities and challenges that states will face in creating viable and useful quality oversight systems. Several findings from the literature review stand out as particularly relevant for consideration in the development of the HCBC Quality Guide.

- ***Relationship of the Guide to CMS Initiatives.*** The Guide has been conceived as a tool for states to use in establishing quality oversight systems for HCBC services. CMS also has a number of HCBC quality initiatives in development. The relationship of the Guide to state responsibilities in meeting the terms of the HCFA *Protocol* and other CMS initiatives must be more explicitly understood. The literature review stressed the importance of linking structure and process standards (such as those included within the *Protocol*) to outcomes-based performance measurement. At the time of initial licensure, contracting or certification, states and CMS are dependent on structure and process standards to determine that safeguards are in place to provide quality care. However, once services are initiated and performance measures collected, it is incumbent to use this data to assess the effectiveness of a program's structure and process and to make changes where they are found to be lacking. Establishing the link between the *Protocol* and a state's quality oversight system will be an important message to convey within the Guide so that the quality improvement process is not seen as an isolated function.

- ***Scope of the Guide.*** The Guide should reflect the multiple roles that states assume in fulfilling their quality oversight functions. Quality oversight begins with the specification of clear goals for HCBC services and the establishment of an infrastructure within the state Medicaid agency as well as within contracting providers to measure and achieve those goals. The Guide should address both of these components in addition to the complex task of collecting, analyzing and acting upon performance measurement data.

- ***Building blocks.*** The literature review confirmed that quality oversight of HCBC services represents a new frontier without a standardized model for proceeding. The Guide should lay out an incremental approach to building capacity within states and provider agencies for quality management and improvement. The availability of reliable, comparable data will be an important first step that most states have yet to achieve. Creating consensus around a small but meaningful number of performance measures will be another milestone. Developing the expertise to collect, analyze and report performance data in ways that are useful to consumers, providers, agencies and state policymakers is a major step. The establishment of forums to assess data for quality implications and to execute effective interventions will require that states build coalitions and credibility for action. The Guide should provide tools and practical lessons in each of these areas so that a state can build its quality oversight system for HCBC services at the pace and within the scope of its capacities.

- ***Hearing the consumer's voice.*** So much of the literature stressed the need to give priority to the consumer's values, preferences and perceptions when defining and evaluating the quality of HCBC services. Finding ways to hear the voice of consumers with vulnerabilities and cognitive impairments will be challenging. The Guide should help states reconcile potential tensions between consumer perceptions of quality and professional standards for safe and effective HCBC services.

The next phase of this project is to conduct interviews with state policy makers and other experts to better understand the practical implications of designing and implementing a quality management and improvement system for HCBC services. Following these interviews, a meeting with state and federal policymakers will be held to determine the general scope, content and format of the Guide for states. This literature review will help inform these efforts and provide an important reference to states as they develop their oversight systems.

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Appendix A

APPENDIX A

SUMMARIES OF SELECTED QUALITY INITIATIVES

HCBS Inventory CMS has contracted with the MEDSTAT GROUP who has subcontracted with the National Association of State DD Directors and National Association of State Units on Aging to conduct a national inventory of quality improvement activities within state HCBS programs. The purpose of this project is to establish a framework/description of relevant quality domains that will facilitate a common dialogue, identify relevant strategies that states might use to monitor and improve quality within those domains and conduct research to establish state of the art for state QA/QI systems for information sharing and planning purposes. We have reviewed a preliminary draft of the proposed domains as of 11/14/2001. Seven major domains have been identified and a desired outcome for each domain has been developed. Sub domains and the outcomes of each sub domain have also been identified.The domains and sub domains are mapped against the domains of the IoM report in Appendix B-2.

Home Care Quality Indicators Home care quality indicators have been developed for use by Medicare home health agencies, for use with the MDS-HC instrument, by the Veteran's Administration and by the Joint Commission of Healthcare Organizations (JCAHO). A brief description of each of these sets of indicators follows. Appendix B-2 provides a comparison of the domains that are used with these indicators (when available) in comparison with the domains of the IOM report.

Outcome Based Quality Indicators (OBCQIs) CMS developed the Outcome Assessment Information Set(OASIS) system[8], which is a clinical data set design specifically to develop outcome based quality indicators (OBQI) for home health (www.hcfa.gov/quality/10b.htm -- accessed 12-14-01). The OBQM monitoring system includes 3 reports: the Case Mix Report, the Adverse Outcome Report and the Outcome Report. The Case Mix Report profiles the demographic and other patient characteristics of a home health agency with a national reference sample. The Adverse Outcome report displays incidence rates for untoward events (or outcomes) comparing one HHA's patients to similar patients in the OASIS national repository for the same time period. The Outcome Report includes two types of measures: end-result outcomes and utilization outcomes. End-result outcomes include a variety of health status outcomes including physiologic, functional, cognitive, and emotional status. Utilization outcomes relate to use of health care resulting from a change in patient health status. The case mix and adverse event reports were made available in 2001. The Outcome-Based Quality Improvement Reports will be available in 2002. Similar quality indicators are also being developed for use with the PACE program. Appendix C-1 provides a list of the OBCQI indicators.

ORYX Performance Measures of JCAHO The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) announced the ORYX initiative, intended to integrate outcomes and other performance measurement data into the accreditation process, in February 1997. Use of ORYX performance measures were introduced in the hospital, long term care,

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[8] The OASIS system was derived in the context of a HCFA-funded national research project (co-funded by the Robert Wood Johnson Foundation) to develop a system of measures for home health care. This system was developed by the Center for Health Services and Policy Research, Denver, CO.

home care and behavioral health care programs to target accreditation surveys; allow continuous monitoring of performance; and to guide provider quality improvement activities. In the case of home care, agencies with an average monthly census of 10 or more patients are required to select a minimum of 6 measures from performance measurement systems approved by JCAHO, and to collect data on the selected measures. Data is then reported to the provider's chosen performance measurement system, which periodically transmits data to JCAHO (http://jcprdwl.jcaho.org/perfmeas/nextevol.html). The Joint Commission plans to specify "core measures" for home health agencies derived from OASIS data elements by the end of 2001 (*http://jcprdwl.jcaho.org/news/hcb111200.html)*.

A comprehensive listing of possible ORYX home care measures can be obtained from the Joint Commission. One possible set of measures developed by the Association of Maryland Hospitals and Health Systems is found in C-2. (www.qiproject.org/ORYX/HomeORYX.asp). A number of companies have entered the market to provide home care agencies with the tools necessary to support the ORYX initiative.[9]

MDS-HC Indicators Quality Indicators for home care have been developed for use with the MDS-HC. In 1999, *inter*Rai, a not for profit organization that seeks to improve the care of the elderly world-wide through the adoption of standardized assessment methods, developed the MDS-Home Care or MDS-HC. In addition to the assessment instrument, *inter*Rai developed an initial set of proposed quality indicators for home care and classified these indicators into domains. The MDS-HC quality indicators are included in Appendix C-3. The University of Wisconsin, Center for Health Systems Research and Analysis have also developed a set of quality indicators using the MDS-HC. There are 23 indicators categorized in 9 domains.(see Appendix C-4).

Veterans Administration The scope of home care provided by the Veterans Administration (VA) has recently expanded as a result of the Veterans Millineum Health Act, which required the VA to make home care, hospice, and respite services mandatory benefits. The Act also required the VA to conduct several long term care and assisted living pilots, one using the PACE model. All VA nursing homes implemented the MDS by April 2001, and the VA is in the process of implementing the MDS-HC for their home care program. The VA is also in the process of implementing a standardized screen, known as VA-Choice, for any veteran needing extended care[10] (personal communication, Marcia Goodwin, Acting Chief Consultant, Geriatrics and Extended Care, Veterans Administration (Central Office), August 2001).

The VA has a national Performance Measurement Workgroup that defines quality measures for each provider type. Data is collected by a contractor on a sample of patient's medical records. Many of the data elements collected for the VA's internal quality assurance program are also ORYX measures (required as a term of accreditation by the Joint Commission) (personal communication, Christine Shehee, Director, Quality Programs, Veterans Administration (Central

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[9] For example, Creative Healthcare Strategies, Inc. (CHSI) was organized in 1995 to "develop, license and support software tools for home care that will achieve the highest levels of quality and customer satisfaction." Its software was "designed to provide OASIS and ORYX compliance and ongoing outcome measurement at an affordable cost" (http://www.chsidata.com/about.html).

[10] The VA-Choice is an expanded version of the MI-Choice screen used in Michigan. It is expected that the MDS-HC will be fully implemented by the end of FY 2002.

Office), September 2001). The various quality measures used in the VA's home based primary care program are listed in Appendix C-5.

Quality Indicators for Developmental Disabilities A number of organizations are working on quality indicators for people with developmental disabilities. These are discussed briefly below.

Core Indicators The core indicators project is a joint effort between the National Association of State Directors of Developmental Disabilities Services (NASDDS) and the Human Services Research Institute. The purpose of the project is to develop nationally recognized performance and outcome indicators that will enable developmentally disabilities policy makers to benchmark the performance of their state against the performance of other states. This is a collaboration among participating state agencies and HSRI with the goal of developing a systematic approach to performance and outcome measurement. Phase I of the project covered three main activities: (1) the selection of 60 candidate indicators organized by areas of common concern as identified by participating states (2) development of data collection protocols including a consumer survey and a survey of families with an adult member living at home and the field testing of data collection tools. Phase II entailed a refinement of the core indicators and the addition of another collection tool – the family/guardian survey. Phase III includes 15 states and some of these states will employ the children/family survey to assess the experiences and outcomes for families and family members under 21 years of age. (www.hsri.org) (See Appendix C-6 for a list of indicators).

Quality Indicators for Developmental Disabilities – University of Wisconsin This CMS-funded study began in 1999 for the purpose of developing measures that could be used in provider quality improvement projects; help inform States' regulatory monitoring of Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program; and provide consumers with quality-related information. Conducted by the University of Wisconsin's Center for Health Systems Research and Analysis (CHSRA), the project was tasked with reviewing existing quality indicators and recommending some for use in CMS programs. Upon review, the project team did not find any of the existing indicators "ready" for use, feeling that most lacked specific definitions and instructions for data collection. Additionally, none of the indicators developed to date had been intended for use in regulatory programs.

After a period of redefining the goals of the project in light of the changing needs of new CMS management, the research team is presently beginning to operationalize several of the most-promising existing measures (e.g., developing definitions and data collection approaches). About 33 indicators were identified as conceptually important and comprehensive during the project's Stakeholders' Group meeting in January 2000. These domains include: person-centered services/supports; integration/inclusion; relationships/social connections; self-determination; rights; health; safety; interpersonal relationships; dignity; and respect for cultural/linguistic differences. Through the process of reviewing and selecting indicators, another domain was added to include structural indicators.

The measures may be ready for preliminary field testing by summer 2002 in ICF/MRs and group homes in which individuals receive services through HCBS waiver programs. A larger beta test will also be designed under the auspices of the current contract (personal communication and correspondence, Sara Karon, Principal Investigator, CHSRA, September 2001).

Quality of Life

Quality of Life in Nursing Homes Another area of research in long term care is the area of quality of life. CMS is currently funding a project that is being conducted by the University of Minnesota and the Philadelphia Geriatric Center to develop quality of life indicators for nursing facilities. One of the main purposes of the project is to develop and test measures of quality of life of older nursing home residents, emphasizing psychological and social aspects of life. Eleven domains of quality have been identified. This project is still in development but the main domains of quality of life have been identified. (See Table B-4).

Consumer Outcomes and Experience

Consumer Experience Survey CMS has funded the MEDSTAT Group to develop and test a Consumer Experience Survey for the Medicaid HCBS waiver programs and once developed to make this instrument available to the States. The goal of the project is to develop a short survey that generates information in the following domains. Five major areas have been identified: choice/empowerment; satisfaction with care; access to care/services; respect/dignity and community integration/inclusion.

Home Care Satisfaction Measure Geron and colleagues developed the home care satisfaction instrument, which measures the satisfaction of frail elderly persons who receive any of several common home care services. The responses to questions on the instrument are scored and an overall home care satisfaction score is computed as well as subscale scores for the five areas. The instrument was tested for validity and reliability and its design was based on consumer-defined notions of satisfaction including those of various ethnic minorities (Geron, Smith, Tennstedt et al., 2000).

Council on Leadership The Council on Quality and Leadership is an international organization dedicated to improving the quality of services and supports to individuals with MR/DD. The Council provides leadership for greater accountability, responsiveness and quality performance in human and social organizations and systems. The Council works collaboratively to develop quality measures, performance indicators and evaluation method that are person centered and provides access to the latest information, developments and best practices to consumers, their families, support and service organizations and governmental organizations. The National Center on Outcomes Resources is a division of the Coucil and provides leadership in outcomes, analysis, and dissemination. [11]

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[11] Recent publications from the Council include the 2000 Edition of Personal Outcome Measures, Personal Outcome Measures for Children and Youth, Personal Outcome Measures in Consumer-Directed Behavioral Health, and Personal Outcome Measures for Families with Young Children. Recent publications from the National Center on Outcomes Resources include Practice Guidelines for Delivering Outcomes in Service Coordination, A Guide to Exploring Satisfaction with Services, Community and Quality: A Guide to Incident Management and Quality of Life Outcomes. (www.accredcouncil.org/pombk.htm)

Nursing Facility Quality Indicators

Nursing Facility Quality Indicators were developed by the University of Wisconsin Center for Health Services Research and Analysis. There are 24 indicators in 11 domains. The quality indicators are presented in a Facility Indicator Profile Report that is used by the survey and certification agency to target facilities for review, to plan protocols for site visits and to identify areas for improvement. The Facility Indicator Profile report also compares an individual facility's performance with a comparison group (usually a state wide mean) and displays the percentile rank for that indicator. A facility with an indicator percentage that is above a certain percentile rank is flagged for closer review by the facility and the survey agency. The quality indicators are also presented in a consumer friendly format on the CMS Nursing Home Compare website. (see Appendix C-7 for a list of the quality indicators).

Residential Care Quality Indicators

The Agency for Healthcare Research and Quality is funding a project to develop meaningful quality measures for vulnerable individuals living in residential care and assisted living facilities. The project includes the development of quality improvement protocols that translate research into practice guidelines, quality indicators to be used in external quality assurance systems, a prototype consumer report card and a performance feedback system for providers and a case mix classification and payment model. This work is being conducted by the University of Texas A&M and the Muskie School of Public Service. The Maine Department of Human Services is currently using quality indicators for residential care facilities. Appendix C-8 includes a list of the Maine residential care quality indicators.

Appendix B

Appendix B-1
Comparison of Quality Domains[12]

Institute of Medicine[13]	FACCT[14]
Safety Diagnosis Treatment Health Care Environment	
Effectiveness Preventive Care Acute, chronic and end of life care Appropriateness of procedures	Technical Quality/Coordination/Continuity**
Patient Centeredness Experience of care Effective partnerships	Communication/Involvement** Global Evaluation**
Timeliness Access to the system of care Timeliness in getting care Timeliness within and across episodes of care	Access** Plan Administration/ Hassles/Responsiveness**
Staying Healthy	**Staying Healthy** Reduction in health risks Early detection and monitoring Avoiding health problems in at risk populations Health status
Getting Better	**Getting Better** Getting appropriate treatment and follow-up care Recovery from illness, injuries, infections
Living with illness or disability	**Living with Illness** Functional status Quality of life
Coping with end of life	**Changing needs** End of life care Caregiver burden Care for disabilities Care for the frail elderly

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[12] The authors have arbitrarily mapped the domains and subdomains of these two reports for illustration purposes. In many instances, there is not a clear and consistent match between the domains and subdomains.

[13] Institute of Medicine, Envisioning the National Health Care Quality Report, 2001

[14] FACCT, 1997

** Considered under the domain, "The Basics" by FACCT.

Appendix B-2[15]

Comparison of Domains for Selected HCBS Quality Initiatives and Quality Indictors

Institute of Medicine[16]	National Inventory of Quality Improvement Strategies[17]	OBCQI[18]	Oryx Indicators (Maryland Hospital Association)	interRai MDS-HC
Safety Diagnosis Treatment Health care environment	**Participant Safeguards** Abuse, neglect and exploitation Major and unusual incidents Housing and environment Behavior Interventions Medication management Personal safety and security Natural disasters and other public emergencies	**Adverse Events**		**Safety**
Effectiveness Preventive care Acute,chronic,and end of life care Appropriateness of procedures	**Participant Outcomes and Satisfaction**	Improvement/Stabilization in ADLS and IADLs and selected other areas of cognition, functioning and behavior	Unscheduled Transfers to Inpatient Acute Care Use of Emergent Care Services Discharge to Nursing Home Care Acquired Infections	**Nutrition** **Medication** **Ulcers** **Physical Function** **Cognitive Function** **Pain** **Other**
Patient Centeredness Experience of care Effective partnerships	**Patient-centered service planning and delivery**			
Timeliness Access to the system of care Timeliness in getting care Timeliness within / across episodes of care				
OTHER	**Provider Capabilities** Provider networks and availability Provider qualifications Provider monitoring			
	System Performance System performance appraisal Continuous quality improvement Cultural compentency Participant and stakeholder involvement Financial integrity			

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[15] The authors have arbitrarily mapped the domains and subdomains of these quality indicator sets for illustration purposes. In many instances, there is not a clear or consistent match between the IOM domains and the domains of the quality indicator sets.

[16] Institute of Medicine, 2001b

[17] Based on domains identified as part of the National Inventory of HCBS Quality Initiatives – draft as of 11-14-01.

[18] OBCQIs do not have defined domains. The OBCQI indicators have been categorized into topic areas for purposes of this comparative chart only.

Appendix B-3[19]

Comparison of Quality Domains for Consumer Outcomes and Perspectives

Institute of Medicine[20]	Core Indicators developed by HSRI and NASDDS	Consumer Experience Survey in development by the MEDSTAT GROUP	Home Care Satisfaction Measure developed by Geron et al., 21
Safety Diagnosis Treatment Health Care Environment	**Health, Welfare and Rights** Safety Health Respect/Rights		
Effectiveness Preventive Care Acute,chronic,and end of life care Appropriateness of Procedures	**Consumer Outcomes** Work Community Inclusion Choice and Decision-making Supporting Families Family Involvement Relationships Satisfaction	Satisfaction with Care	Competency
Patient Centeredness Experience of care Effective partnerships		Choice/Empowerment Respect/Dignity Community Integration/Inclusion	Positive interpersonal Negative Interpersonal Service Choice
Timeliness Access to the system of care Timeliness in getting care Timeliness within and across episodes of care		Access to Care/Services	
OTHER	**System Performance** Service Coordination Utilization and Expenditures Access		System adequacy System dependability Service Convenience
	Service Delivery System Strength and Stability Acceptability Stability Staff Qualifications/ Competency		

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[19] The authors have arbitrarily mapped the domains and subdomains of these quality indicator sets for illustration purposes. In many instances, there is not an clear or consistent match between the IOM domains and the domains of the quality indicator sets.

[20] Institute of Medicine, 2001b

[21] The Home Care Satisfaction Measure identifies a number of dimensions associated with the services, homemaker, home health aids, care management, home-delivered meals and grocery. The categories of quality care included here are the dimensions identified by Greon et al.

Appendix B-4[22]
Comparison of Quality Domains for Institutional Long Term Care

Institute of Medicine[23]	Nursing Facility Quality Indicators	Nursing Facility Quality of Life[24]	Residential Care Observable Quality Indicators [25]
Safety Diagnosis Treatment Health Care Environment	Accidents	Safety, security, order	Safety
Effectiveness Preventive Care Acute,chronic,and end of life care Appropriateness of Procedures	Behavioral/Emotional Patterns Cognitive Patterns Elimination/Incontinence Infection Control Nutrition/Eating Physical Functioning Psychotropic Drug Use Skin Care	Functional Competence	
Patient Centeredness Experience of care Effective partnerships	Quality of Life	Physical Comfort Privacy Autonomy Dignity Meaningful Activity Food Enjoyment Individuality Relationships Spiritual well-being	Interaction Milieu Environment Individualized Care Central focus on residents and families Staff interaction
Timeliness Access to the system of care Timeliness in getting care Timeliness within and across episodes of care			

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[22] The authors have arbitrarily mapped the domains and subdomains of these quality indicator sets for illustration purposes. In many instances, there is not a clear or consistent match between the IOM domains and the domains of the quality indicator sets.

[23] Institute of Medicine, 2001b.

[24] CMS funded initiative being conducted by the University of Minnesota.

[25] Developed by the University of Missouri

Appendix C

Appendix C-1a

Outcome Based Quality Improvement (OBQI) System[26] (OASIS-derived Quality Indicators)

Improvement in grooming	Improvement in speech and language
Stabilization in grooming	Stabilization in speech and language
Improvement in dressing upper body	Improvement in pain interfering with activity
Improvement in dressing lower body	Improvement in number of surgical wounds
Improvement in bathing	Improvement in status of surgical wounds
Stabilization in bathing	Improvement in dyspnea
Improvement in toileting	Improvement in urinary tract infection
Improvement in transferring	Improvement in urinary incontinence
Stabilization in transferring	Improvement in bowel incontinence
Improvement in ambulation/locomotion	Improvement in cognitive functioning
Improvement in eating	Stabilization in cognitive functioning
Improvement in light meal preparation	Improvement in confusion frequency
Stabilization in light meal preparation	Improvement in anxiety level
Improvement in laundry	Stabilization in anxiety level
Stabilization in laundry	Improvement in behavioral problem frequency
Improvement in housekeeping	
Stabilization in housekeeping	
Improvement in shopping	**Utilization Outcomes**
Stabilization in shopping	Any emergent care provided
Improvement in phone use	Discharged to community
Stabilization in phone use	Acute care hospitalization
Improvement in management of oral meds	
Stabilization in management of oral meds	

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[26] Center for Health Services and Policy Research, Denver, CO, 2002.

Appendix C-1b

Outcome Based Quality Improvement System[27]

Adverse Event Outcomes
Emergent care for injury caused by fall or accident at home
Emergent care for wound infections, deteriorating wound status
Emergent care for improper medication administration, medication side effects
Emergent care for hypo/hyperglycemia
Development of urinary tract infection
Increase in number of pressure ulcers
Substantial decline in 3 or more activities of daily living
Substantial decline in management of oral medications
Unexpected nursing home admission
Discharged to the community needing wound care or medication assistance
Discharged to the community needing toileting assistance
Discharged to the community with behavioral problems
Unexpected death

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[27] Center for Health Services and Policy Research, Denver, CO, 2002.

Appendix C-2

ORYX Home Care Measures
Developed by the Association of Maryland Hospitals and Health Systems[28]

Domain	Indicator
Indicator HC-1: Unscheduled Transfers to Inpatient Acute Care	***Unscheduled Transfers due to:*** ▪ Respiratory Problems ▪ Gastrointestinal Problems ▪ Catheter-Related Urinary Tract Infections ▪ Medication Problems ▪ Injuries ▪ Cardiac Problems ▪ Endocrine Problems
Indicator HC-2: Use of Emergent Care Services	▪ Patients Experiencing Emergent Care Visits ▪ Emergent Care Visits to Emergency Room ▪ Emergent Care Visits to Outpatient Departments ▪ Emergent Care Visits to Doctor’s Office/House Calls
Indicator HC-3: Discharge to Nursing Home Care	▪ Discharge to Nursing Home Care for Therapy Services ▪ Discharge to Nursing Home Care Because Unsafe for Care at Home
Indicator HC-4: Acquired Infections	▪ Surgical Wound Infection ▪ Symptomatic UTI/Patients with Indwelling Catheters ▪ Symptomatic UTI/Patients with Indwelling Catheters—Age<75 ▪ Symptomatic UTI/Patients with Indwelling Catheters—Age>75 ▪ TPN Patients with Sepsis ▪ Infusion Site Infections

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[28] Association of Maryland Hospitals and Health Systems, 2000.

Appendix C-3

interRAI Home Care Quality Indicators (HCQI) for MDS-HC Version 2.0[29]

Domain	Indicator
Nutrition	▪ Prevalence of inadequate meals ▪ Prevalence of weight loss ▪ Prevalence of dehydration
Medication	▪ Prevalence of not receiving a medication review by a physician ▪ Failure to improve/incidence of bladder incontinence
Ulcers	▪ Failure to improve/incidence of skin ulcers
Physical Function	▪ Prevalence of no assistive device among clients with difficulty in locomotion ▪ Prevalence of ADL/rehabilitation potential and no therapies ▪ Failure to improve/incidence of decline on ADL long form ▪ Failure to improve/incidence of impaired locomotion in the home ▪ Prevalence of falls
Cognitive Function	▪ Prevalence of social isolation ▪ Failure to improve/incidence of cognitive decline ▪ Prevalence of delirium ▪ Prevalence of negative mood ▪ Failure to improve/incidence of difficulty in communication
Pain	▪ Prevalence of disruptive or intense daily pain ▪ Prevalence of inadequate pain control among those with pain
Safety	▪ Prevalence of neglect/abuse ▪ Prevalence of any injuries
Other	▪ Prevalence of not receiving influenza vaccine ▪ Prevalence of hospitalization

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[29] Developed by John Hirdes,Ph.D, Brant Fries, Ph.D.,John Morris, Ph.d; Naoki Ikagami, M.D., Ph.D; Zimmerman, Ph.D ;Dawn Dalby,M.Sc.; Pabo Aliaga, M.A.; Suzanne Hammer,M.A.; Richard Jones, Ph.D

Appendix C-4

Home Care Quality Indicators
Developed by the Center for Health Systems Research and Analysis, University of Wisconsin

Domain	Indicator (Prevalence of)
Accidents	▪ Any Injuries
Cognitive Patterns	▪ 9 or More Scheduled Medications ▪ Delirium ▪ Cognitive Impairment
Elimination/Continence	▪ Bladder or Bowel Incontinence
Emotional Well-being	▪ Depression
Pain	▪ Pain
Physical Functioning	▪ Dependence in Late-Loss ADLs ▪ Dependence in Select IADLs ▪ Respiratory Impairment
Skin Integrity	▪ Stage 1-4 Pressure Ulcers ▪ Wounds that are not healing

Appendix C-5

Quality Measures Used In Veterans Administration Home Care Programs

Percent of patients:

- Receiving pneumovax vaccine
- Receiving influenza vaccine
- Screened for depression
- Receiving Quality of Life planning, which consists of 7 subscales:
  - Advanced directives
  - Pain assessment/management
  - Dyspnea management
  - Nutrition/hydration
  - Psychosocial
  - Depression
  - Discharge planning

- Receiving alcohol screening
- Counseled for smoking use/cessation
- Assessed using a 0-10 pain scale

Appendix C-6

Core Indicators Project: Phase II Indicators (Version 2.0)
Developed by the Human Services Research Institute[30]

Domain	Subdomains and Indicators
Consumer Outcomes	**Work**
	1. Average monthly wage of people who receive work supports. 2. Average number of hours worked per month during the previous year. 3. Percent of people earning at or above the state minimum wage. 4. Percent of people who were continuously employed in community based settings during the previous year. 5. Proportion of all individuals who receive daytime supports of any type who are engaged in community integrated employment.
	Community Inclusion
	Proportion of people who participate in integrated activities in their communities, including: shopping, using public services, attending religious events, playing sports, attending arts/entertainment events, and dining out.
	Choice and Decision-making
	1. Proportion of people who make choices about important life decisions, including: housing, roommates, daily routines, support staff or providers, and social activities. 2. Proportion of people reporting that their service plan includes or is about things that are important to them. 3. Proportion of people reporting that they control their own spending money (i.e., have access to it and choose what to buy with it).
	Supporting Families
	Percentage of families with an adult family member living in the home who report satisfaction with the following areas: supports received by the family and the family member, information, choices/planning, access, linkages to supports, service coordination, and crisis response.
	Family Involvement
	Proportion of families/guardians of individuals NOT living at home who report (a) satisfaction with the services and supports their family member receives; and (b) the extent to which the system supports continuing family involvement.
	Relationships
	1. Proportion of people who report having friends and caring relationships with people other than support staff and family members. 2. Proportion of people who report having a close friend, someone they can talk to about private matters. 3. Proportion of people who are able to see their families and friends when they want to. 4. Proportion of people reporting feeling lonely.

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[30] Human Services Research Institute, Retrieved November, 2001.

Consumer Outcomes (cont.)	**Satisfaction**
	1. Proportion of people who report satisfaction with where they live. 2. Proportion of people reporting satisfaction with their job or day program. 3. Proportion of people reporting that they work as many hours as they want to.
System Performance	**Service Coordination**
	1. Proportion of people reporting that service coordinators help them get what they need. 2. Proportion of people who are able to contact their service coordinators when they want to. 3. Proportion of people who report that they participated in the development of their service plan.
	Utilization and Expenditures
	1. The average annual expenditure per person overall, by living arrangement, type of service and category of support. 2. The annual expenditure for each living arrangement, type of service and category of support, as a percent of total expenditures. 3. The range of annual per person expenditures, by living arrangement, type of service and category of support.
	Access
	1. The number of persons receiving services and supports, by age and by type of service and category of support. 2. The proportion of people served, by race and ethnicity, relative to proportions in the general population of the service area. 3. The number of persons (unduplicated count), age-adjusted, receiving one or more services or supports. 4. The number of persons (unduplicated count), age-adjusted, in service per 100,000 general population. 5. The number of persons waiting for services/supports relative to the total service population. 6. The proportion of families reporting that consumers have access to adaptive equipment, environmental modifications, and assistive communication devices. 7. The proportion of people reporting that they received support to learn or do something new in the past year. 8. The proportion of people who report having adequate transportation when they want to go somewhere. 9. The rate at which people report that “needed” services were not available.

Health, Welfare and Rights	**Safety**	1. The mortality rate of the MR/DD population compared to the general area population, by age, by cause of death (natural or medico-legal), and by MR or DD diagnosis. 2. The incidence of serious injuries reported among people with MR/DD in the course of service provision, during the past year. 3. The proportion of people who were victims of selected crimes reported to a law enforcement agency during the past year, by type of crime (rape, personal robbery, aggravated assault, burglary, and theft). 4. The proportion of people who report that they feel safe in their home and neighborhood.
	Health	1. The proportion of people who have had a physical exam in the past year. 2. The proportion of women who have had an OB/GYN exam in the past year. 3. The proportion of people who have had a routine dental exam in the past six months. 4. The number of days in the past month people report that their normal routines were interrupted due to illness. 5. The proportion of people receiving psychotropic medications. 6. The incidence of chemical or physical restraints reported in the past year, by type of restraint and reason for use.
	Respect/Rights	1. The proportion of people reporting that they have an “advocate” or someone who speaks on their behalf. 2. The proportion of people who report that their basic rights are respected by others. 3. The proportion of people who have participated in activities of self-advocacy groups or other groups that address rights. 4. The proportion of people reporting satisfaction with the amount of privacy they have.
Service Delivery System Strength and Stability	**Acceptability**	1. The proportion of voting members on provider agency boards of directors who are primary consumers. 2. The proportion of voting members on provider agency boards of directors who are family members of primary consumers. 3. The proportion of families who are satisfied with the grievance process. 4. The proportion of people indicating that most support staff treat them with respect. 5. The proportion of people who have changed residences more than once in the past year.

Service Delivery System Strength and Stability (cont.)	**Stability**
	1. The crude separation rate, defined as the proportion of direct contact staff separated in the past year. 2. Average length of service for all direct contact staff who separated in the past year, and for all currently employed direct contact staff. 3. The vacancy rate, defined as the proportion of direct contact positions that were vacant as of a specified date. 4. The proportion of direct contact hours paid in overtime hours. 5. The capability of community service organizations to meet their near-term financial obligations (as measured by (a) the ratio of current assets to current liabilities; and (b) months of reserve funds on hand). 6. Community service organizations exhibit financial strength, stability, and long term solvency (as measured by (a) the ratio of total assets to total liabilities; (b) total assets (including depreciated assets) to total liabilities; and (c) total liabilities to net worth). 7. The extent to which community services organizations attract private contributions to strengthen their operations (as measured by the ratio of private revenue to total revenue).
	Staff Qualifications/Competency
	The proportion of families reporting that staff is available to communicate with individuals who use modes of communication other than spoken English.

Appendix C-7

Quality Indicators for Nursing Facilities Developed by CHSRA at the University of Wisconsin

Domain	Indicator
Accidents	▪ Incidence of new fractures ▪ Prevalence of falls
Behavior/Emotional Patterns	▪ Prevalence of behavioral symptoms affecting others (high risk/low risk) ▪ Prevalence of symptoms of depression ▪ Prevalence of symptoms of depression without antidepressant therapy
Clinical Management	▪ Use of 9 or more different medications
Cognitive Patterns	▪ Incidence of cognitive impairment
Elimination/Incontinence	▪ Prevalence of bladder or bowel incontinence (high risk/low risk) ▪ Prevalence of occasional or frequent bladder or bowel incontinence without a toileting plan ▪ Prevalence of indwelling catheter ▪ Prevalence of fecal impaction
Infection Control	▪ Prevalence of urinary tract infections
Nutrition/Eating	▪ Prevalence of weight loss ▪ Prevalence of tube feeding ▪ Prevalence of dehydration
Physical Functioning	▪ Prevalence of bedfast residents ▪ Incidence of decline in late loss ADLs ▪ Incidence of decline in ROM
Psychotropic Drug Use	▪ Prevalence of antipsychotic use, in the absence of psychotic or related conditions ▪ Prevalence of antianxiety/hypnotic use ▪ Prevalence of hypnotic use more than two times in last week
Quality of Life	▪ Prevalence of daily physical restraints ▪ Prevalence of little or no activity
Skin Care	▪ Prevalence of stage 1-4 pressure ulcers (high risk/low risk)

Appendix C-8
Maine Department of Human Services
Residential Care Quality Indicators
(January 2002)

Indicators

Prevalence of:

- Percent high case mix index
- Decline in early loss ADLs
- Any pain
- Pain interfering with no pain management
- Need for monitoring
- Medication management and non-compliant
- Use of anti-psychotic meds in absence of DX
- Lack of preventative health
- Ulcers due to any cause
- Fecal impaction
- Unsettled relationships (revised one)
- Improvement in late loss ADLs
- Improvement in early loss ADLs
- Bladder incontinence (high)
- Bladder incontinence (low)
- Bowel incontinence (high)
- Bladder incontinence without scheduled toileting Plan

Occurrence of:

- Injury
- Falls

Prevalence of:

- Behavioral symptoms
- Behavioral symptoms without behavior management

Resident using 9 or more scheduled medications in the last 7 days including PRNs

Resident using 9 or more scheduled medications in the last 7 days

Prevalence of:

- Cognitive impairment
- Cognitive impairment – modified
- Little or no activity
- Anti-psychotic drugs
- Awake at night
- Communication difficulties
- Signs of distress or sad/anxious mood
- Unsettled relationships

Incidence of:

- Decline in late loss ADLs
- Decline in late loss ADLs – high risk
- Decline in late loss ADLs – low risk

Prevalence of:

- Emergency room visits w/o overnight stay in last 6 months
- Psychiatric hospital stays in last six months
- Hospital stays in last six months
- Weight loss
- Wheelchair as primary mode of locomotion
- Advanced directives
- Responsible party other than self
- Responsible party other than self + CPS
- Responsible party other than self + MH
- Therapy