Future Directions for Community-Based Long-Term Care Health Services Research

Expert Meeting Summary
June 20-21, 2000

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Suggested Citation:

Spector WD, Shaffer TJ, Hodlewsky RT, et al. *Future Directions for Community-Based Long-Term Care Health Services Research*. [Expert Meeting Summary, June 20-21, 2000]. Rockville, MD: Agency for Healthcare Research and Quality; 2002. AHRQ Publication No. 02-0022.

Executive Summary

In June 2000, the Agency for Healthcare Research and Quality (AHRQ) sponsored "Future Directions for Community-Based Long-Term Care Health Services Research." This meeting of long-term care experts was convened by AHRQ's Center for Organization and Delivery Studies and Center for Cost and Financing Studies to help guide the Agency in developing its long-term care agenda. Participants were asked to provide advice on research priorities, identify quality measures and data gaps, and develop strategies on how to reduce these gaps.

The 2-day discussion was based on experts' responses to a series of questions collected prior to the meeting. The questions focused on research priorities, quality indicators, and adequacy of existing national databases.

On the first day of the meeting, participants listed their top research priorities concerning community-based long-term care. Their responses reflected a number of concerns in six major categories: organization and delivery, equity/access, financial and market incentives, consumer issues, quality, and methodology.

Three distinct populations of community-based long-term care users were identified: children with special health care needs, adults with disabilities, and elderly. Each of these populations has unique concerns – from dedicated disability measures for children to workplace issues for the adults with disabilities.

Four topics emerged as high priorities during the discussion:

- *Outcomes* – More research on risk-adjusted outcome measures is needed. Improved identification of important patient risk factors is seen as fundamental.

- *Workforce issues* – Evidence-based approaches to recruitment and retention of qualified staff and workforce training is seen as essential.

- *Family decisionmaking* – More research on how families make decisions to meet long-term care needs is needed.

- *Children with special health care needs* – Experts noted the dearth of even descriptive data regarding this population and their long-term care needs, utilization, and patterns of caregiving.

The afternoon session focused on a discussion and recommendations for measuring quality of community-based services. The discussion had three goals: 1) to determine how quality concerns in community-based long-term care differed from residential long-term care; 2) to determine if quality concerns differed for the three long-term care subpopulations; and 3) to get advice about specific long-term care quality measures that could be achieved with existing data.

Specific quality measure recommendations were hampered by the shortage of existing validated measures. No service-specific quality measures were provided other than a general recommendation to develop measures of satisfaction.

Participants recommended a number of global measures such as the percentage of persons who are institutionalized, the degree of unmet functional need, and percentage of caregivers expressing high levels of burden or stress. However, they emphasized the limitations of global measures because they are not directly linked to specific services provided. It is thus difficult to attribute changes in these measures to service delivery.

On the second day of the meeting, presenters highlighted major features of national long-term care surveys and administrative data

systems and discussed data gaps and strategies for reducing them. During the afternoon, participants discussed other data topics. These included measuring unmet need in activities of daily living and instrumental activities of daily living, the collection of State-level data, and capturing transitions.

Experts provided many recommendations for filling research and national data gaps. The following list highlights these recommendations:

- National long-term care data on persons living in the community have focused mainly on the elderly; more data on the patterns of service delivery are needed about the nonelderly.
- Periodic collection of data is important to monitor changes in the service delivery system.
- Sample sizes in national data need to be increased to better study subpopulations.
- Disability measures for children should be improved.
- Data on informal caregivers need to be expanded to better capture influence on caregivers' lives, including influence on work and social, psychological, and physical burden.

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Introduction

On June 20-21, 2000, the Agency for Healthcare Research and Quality (AHRQ) sponsored "Future Directions for Community-Based Long-Term Care Health Services Research." This meeting of long-term care experts was convened by AHRQ's Center for Organization and Delivery Studies (CODS) and Center for Cost and Financing Studies (CCFS) to help guide the Agency in developing its long-term care agenda. This was the second of two AHRQ-sponsored meetings on long-term care health services research. (See Appendix 1 for the meeting agenda.)

The first meeting, "Future Directions for Residential Long-Term Care Health Services Research, was held in October 1999.[1] That meeting focused on residential long-term care , which included both assisted living and nursing home care. The scope of the second meeting was community-based long-term care, including both formal and informal care.

Community-based long-term care services were defined as services that help maintain community living, maximize independence, enable social integration, and provide supports for instrumental activities of daily living (IADLs) and activities of daily living (ADLs). IADLs include activities such as shopping, help with taking medicines, and help with light housework; ADLs include

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[1] Spector WD, Potter DEB, De La Mare J. Future Directions for Residential Long-Term Care Health Services Research. Expert Meeting Summary, October 14-15, 1999. Rockville, MD: Agency for Healthcare Research and Quality; 2000. AHRQ Pub. No. 01-0007.

help with activities such as bathing, dressing, and eating. The meeting focused on community-based services including service-enhanced housing settings, such as group homes and personal care homes. Assisted living was discussed as part of the first meeting on residential care.

Specifically, the goals of the meeting were to:
- Identify the highest research priorities for community-based long-term care.
- Identify the most important quality indicators and identify measurement needs to help set priorities for the future development of quality measures.
- Assess the capability of current survey and administrative data to answer priority research questions.
- Get advice on data strategies to identify and reduce data gaps.

The 2-day meeting was based on experts' responses to a series of questions asked of the participants prior to the meeting. (See Appendix 2 for a list of the meeting participants.) The questions focused on research priorities, quality indicators, and adequacy of existing national databases.

DAY 1

Long-Term Care Research Priorities

Before the meeting, participants were asked to list their top five research and policy questions concerning cost, quality, and outcomes of community-based long-term care

(see Appendix 3). Respondents were asked to focus on the age group best corresponding to their primary field of expertise: children with special health care needs (CSHCN), adults with disabilities, or the elderly.

Although we were interested in high priority topics, their combined responses covered an expansive range of issues, which we assigned into six categories: organization and delivery, equity/access, financial and market incentives, consumer issues, quality, and methodology. In some cases topics overlapped these categories, but assignment was made to only one category based on the major focus of the topic. (See Table 1 for a summary of these dimensions.)

Quality Dimension Categories

Organization and Delivery

Participants identified a number of priorities related to organization and delivery issues. The major concerns were the impacts of organizational factors and program design on cost and outcomes. Some respondents wanted more evaluation of models of care that integrate long-term care and acute care, while others stressed the need to evaluate new models (e.g., care being provided in existing housing arrangements or neighborhood-based designs).

There was also interest in the impact of other aspects of community care such as consumer-directed care and case management. The appropriate roles of clinicians in providing care were also a concern (e.g., physicians vs. nurses, nurses vs. aides).

Equity/Access

Respondents believed that issues related to access and equity were important. Included in the equity/access category were research on racial and ethnic disparities in access to community care, the need to develop models of care sensitive to cultural differences, and

the need to better understand how financing influences access. When focusing on care for children, respondents emphasized the need to assure that long-term care services were integrated with educational services.

Financial and Market Incentives

Many respondents emphasized the need to study the overall impact of Medicare home health prospective payment. Others were concerned about how the aging of the population would affect financing of long-term care. An additional concern was to better understand the changing market place for long-term care, especially the implications of the growth of managed care, the decrease in Medicare home health spending, and the expanding assisted living market.

Consumer Issues

There were three main themes promoted by respondents concerning consumer issues. First, they recommended evaluation of models of care that are sensitive to consumer preferences and expand consumer choices. Second, they were concerned about family caregiving and understanding the costs and burdens of that care. There was interest in a number of topics including the decisionmaking process that determines the mix of formal and informal care, prevention of caregiver health problems, and the prevention of elder abuse. For children and adults with disabilities, there was concern that we have insufficient data to currently describe basic patterns of care and caregiver burdens. Third, there was interest in improving ways to provide information to families such as quality report cards and approaches to promoting self-directed care.

Quality

Many respondents included research on quality as a high priority. For some, this meant monitoring certain aspects of quality,

such as quality of life, unmet needs, and safety of the home environment. Also, there was concern about how regulatory approaches and the mix of informal and formal care affect the overall quality of care provided. There was also interest in improving care guidelines for long-term care. Because patients frequently move from one level of care to another, there was interest in decisionmaking that results in care transitions and the appropriateness of care settings. Finally there was great interest in being able to understand what were the best staffing patterns for long-term care, including the amount of staff and the skill mix. Because of the apparent shortage of staff throughout the long-term care spectrum, there was interest in improving ways to hire and retain staff. A final area of concern was medication management.

Methodology

The final category of priorities was methodology. The main methodological priority for participants was the improvement of measures. Two areas for improved measures were consumer satisfaction and processes of care. Specialized areas mentioned were satisfaction measures for the cognitively impaired and measures to assess the burden of informal care. For children, there was interest in better measuring functional limitations. Finally, there was interest expressed in improving projections of long-term care needs.

Immediate Research Priorities

The combined list of research questions was narrowed to a shorter list of immediate priorities during the course of the discussion. Three priority topics emerged as especially high priorities: outcome studies, workforce issues, and family decisionmaking. Basic information about needs and utilization for children and adults with disabilities was also a very high priority.

Outcomes

Participants suggested that one of the highest priorities would be a focus on outcomes in community-based care. Once important patient risk factors were identified, the influences of care provision, health system, and market factors could be studied. Participants noted, however, the need for more research on risk-adjusted outcome measures. Areas for which measures remain lacking are social outcomes, access to care, and family caregiving.

Participants stressed the need for evaluations of services to include cost. A focus on the amount of care needed − or dose-response − was emphasized as very important. Some participants also noted the importance of impact of new technologies in long-term care.

Participants noted that the need for research on evaluation of outcomes applies to each of the three age groups of long-term care users (CSHCN, adults with disabilities, elderly), but outcomes may need to be defined differently for each population. For example, standard measures of functional and cognitive status for the elderly are inadequate for children, whose long-term care goals must be integrated with developmental and educational goals. Long-term care outcomes for adults with disabilities must include employment goals as well as other social goals. It was also noted that outcomes may be viewed differently by recipients of care than by the families of recipients.

Workforce Issues

Participants suggested that the recruitment and retention of qualified staff appears to be in crisis across the spectrum of long-term care. Participants emphasized the need for research on the development, preparation, and maintenance of the workforce; approaches to monitoring staff quality; and the effectiveness of recruitment and retention strategies. Research should include the development of

new approaches to meeting consumer preferences in staffing and the study of existing approaches such as self-directed care. Approaches to increasing the supply of informal caregivers and assuring the quality of their care should also be studied.

Family Decisionmaking

Participants expressed the importance of more research on how families make decisions about meeting long-term care needs. This was viewed as important for all three age groups: CSHCN, adults with disabilities, and the elderly. It is important to determine where families receive information and what people know about options for care. Research should include an analysis of the incentives provided by different State programs and reimbursement systems and their effect on choice of care setting. Experts also expressed strong interest in transition decisions, the appropriateness of transfers from one setting to another, and the quality of care provided during transition periods.

Special Concerns Regarding Children and Adults With Disabilities

Unlike long-term care for the elderly population, for which there are a variety of data sources, respondents declared that very little is known about long-term care for children and adults with disabilities. Experts lamented the dearth of data even at a very basic descriptive level, including long-term care needs and utilization by age and by disability. Trajectories and projections of need/use would also be helpful. For these groups, participants believed there was a need for basic descriptive data that could give direction to subsequent research on the appropriateness of care in various settings and the effect of those settings on outcomes.

Participants raised a number of issues that specifically concerned children or adults with disabilities, including the following:

- Little information exists about the effectiveness of therapies and home health care, especially for children.

- Transitions in care have not been studied for children; it is especially important to study transitions from home to school and hospital to home.

- Information about parental caregiving for children is insufficient. Participants stressed that informal care should not be confused with the normal care provided as part of parenting and that the two are difficult to separate in practice. This is similar to separating out normal tasks provided in the role of spouse from caregiving for a disabled spouse, but it may be more difficult.

- AHRQ's Medical Expenditure Panel Survey (MEPS) was seen as an ideal survey to add questions about one's experience with the long-term care system and to incorporate subjective judgments about the quality of care from both the children's and their families' viewpoints.

- MEPS is the only national data set that has longitudinal information about children's health services and has good health status data.

- MEPS was seen as important in describing caregiving arrangements and the relationship between informal and formal care, and caregiver burden. It remains the only source of caregiving information for these populations.

- Health status measures, in general, need improving. More developmental work is needed to adapt ADL and IADL measures for children. Measuring outcomes for children is difficult because of the particular diversity of conditions they may have.

Table 1. Summary of quality dimensions

Organization and delivery	Equity/access	Financial and market issues	Consumer issues	Quality	Methodology
Assess the effect of organizational factors on home care use. Assess the role of physicians, nurses, and other providers in community care. **Assess the costs and benefits of existing models** • Consumer-directed care • Program of All Inclusive Care for the Elderly (PACE) • Social health maintenance organizations (SHMOs) • Continuing care retirement communities (CCRCs) • Family care • Home care • Hospice care • Adult day care • Chronic care for children **Develop new models** • Housing/neighborhood-based care • Team-based care **Assess the effect of long-term care program design** • Eligibility • Resource allocation • Financing/caps • Consumer-directed • Case management	Measure and reduce disparities across race, ethnicity, and gender. Understand different cultural models of care. Study the integration of long-term care with educational services for children. Monitor State long-term care program variations and assess impact on access to care. Monitor variations in scope and intensity of children's services. Assess access to affordable housing and transportation for adults with disabilities. **Influence of financing on equity/access** Monitor distribution of home care expenditures across payment sources (Medicare, Medicaid, private pay, out-of-pocket). Reduce barriers to services created by categorical funding. Assess influence of insurance coverage on access to services. **Barriers to access for children** Assess impact of "medically needy" rules. Identify additional barriers to services for low-income children.	**Financing of care** Evaluate the impact of aging of population on approaches to financing long-term care. Impact of Medicare home care prospective payment on: • Access use, quality, and cost • Acute care, informal care, and community services **Market issues** Monitor changes resulting from growth in managed care and assisted living.	Evaluate models of care that expand consumer choices and incorporate consumer preferences. **Family caregiving** Monitor trends in caregiving especially for children and adults with disabilities. Assess factors influencing decisionmaking, especially effect of formal care on informal care. Assess caregiver burden and evaluate approaches to burden reduction. Assess and reduce elder abuse. Identify approaches to preventing caregiver health problems. **Support for families** Improve quality information to consumers (e.g., report cards). Develop services to promote self-directed care.	Develop nonregulatory-based approaches to quality assurance. Understand "dose-response" in home care. **Assessment** Develop standards of care for long-term care. Monitor safety of care and home environment. Monitor patient's quality of life. Evaluate quality of care for board-and-care facilities. Evaluate impact of informal caregiving on quality of care. Assess unmet needs. **Care transitions** Assess transition decisions. Evaluate the costs and benefits of care settings. **Care provision** Determine staffing and skill mix. Identify best approaches to retaining long-term care staffing and assuring adequate training. Evaluate medication management.	**Develop measures of:** • Consumer satisfaction specific to home care, adult day care, and other services/settings • Risk-adjusted outcomes • Processes of care • Functioning for children • Long-term care needs among children • Quality for cognitively impaired • Quality for informal care • Projections of long-term care needs

Quality Measurement

In the afternoon of day 1, the participants discussed quality issues related to community-based long-term care. The discussion had three goals: 1) to determine how quality concerns in community-based, long-term care differed from residential long-term care; 2) to determine if quality concerns differed for the three long-term care subpopulations; and 3) to get advice about specific long-term care quality measures that could be achieved with existing data, especially measures that would be appropriate for an annual national quality report that has been mandated by Congress. (The purpose of that report is to describe the changing state of quality in the health care system over time.)

Determining the Scope of Quality Concerns in Community-Based Long-Term Care

Prior to the meeting, the participants were shown a table that specified the scope of quality concerns associated with residential care that was an outgrowth of the October 1999 meeting on residential care. They were asked to add to this table so that it would reflect concerns of both institutional and community-based long-term care. They were asked also to think about the three populations of long-term care users and to focus on the population in which they were most expert. Table 2 presents the revised and expanded table of quality dimensions.

The most obvious addition to the table was the inclusion of informal caregiving concerns. Table 2 responses are categorized into three dimensions of care: caregiving, quality of (formal) care, and quality of life. Caregiving bridges both quality of care and quality of life. With respect to caregiving, there are concerns about the technical skills and interpersonal skills of caregivers, but there is also a concern that the quality of life of the

caregiver can be detrimentally affected by caregiving responsibilities. These dimensions were further classified as process and structure or outcome (see Table 2).

When discussing informal caregiving, respondents were concerned with the adequacy of informal caregiver training, caregiver burden and stress, negative impacts on the physical health of caregivers, and the economic impact of caregiving – especially impact on work.

In the areas of quality of care and quality of life, respondents added a number of measures that reflected the fact that a community-based care population is less disabled than a residential care population and includes more children and working-aged adults. Additions included: IADLs, concerns about social integration into the community, ability to engage in productive activities, mental and social development for children, prevention of institutionalization, prevention of accidents during transportation, achieving a high level of autonomy and control, and assuring care is provided in the least restrictive environment.

In addition, respondents added other items that extended the scope of quality concerns (e.g., fears about physical or financial harm, unmet needs, adequacy of care plans, aspects of the home environment, and elapsed time to receive services). In some cases these were concerns that are more important for a community population; and in other cases, respondents suggested aspects of long-term care that were not stressed in the prior meeting but are applicable to all long-term care populations.

Attendees were asked to discuss any other items that should be included in the table as well as other related concerns. The following are some issues that were raised:

- The importance of quality-of-life measures such as control, autonomy, choice, respect, and dignity. Participants believed these were difficult to measure.

- Importance of assessing the housing and community environments.
- The difficulty of measuring satisfaction with care for cognitively impaired persons. Participants believed this information could be provided, although imperfectly, by family members. Research about what can be measured by self-report from cognitively impaired persons is an area for future research.
- Concern that different clinical disciplines have difficulty communicating with each other while providing care, which sometimes results in clinical errors.

Defining a Quality Indicator

Participants discussed the meaning of the term "quality indicator" and described at least two common uses of the term. One definition is often referred to as a "red flag." A red flag is a value of a measure that triggers concerns that indicates quality problems first, but it is not a direct indicator of a quality problem. A red flag usually leads to reviews of processes of care to determine if care problems exist. Quality indicators being designed by the Centers for Medicare & Medicaid Services (CMS) for use in the home health survey and certification process and for nursing homes are examples of red flag indicators.

Knowledge of red flags for a particular facility may affect how surveyors spend their time in a facility when reviewing potential quality problems. These indicators also can be used by facilities to monitor potential quality problems throughout the year.

Risk-adjusted outcome measures of quality are also examples of red flag indicators. For most outcomes there is no specific value that would necessarily suggest poor quality. Typically the expected value of the outcome would depend on the case mix of the patients being treated. One approach is to account for the mix of patients and compare mean outcomes for a risk group with what would be

expected if care were adequate (or average). Since it is difficult to perfectly risk-adjust, this approach may not adequately differentiate poor or good quality. Therefore, risk-adjusted outcome measures are typically recommended as part of a quality assurance process rather than indicators of quality per se.

A second definition is a measure that in itself indicates unacceptable care. An example is a measure based on a care guideline if there is strong evidence that the guideline improves outcomes. An illustration would be turning patients every 2 hours, which is a standard for good care to prevent pressure ulcers. Any immobile resident who is not turned at least every 2 hours would be viewed as not receiving adequate care. Another example may be outcomes that should not happen if care meets current practice – for example, stage-four pressure ulcers or residents dying of malnutrition. Even in these cases it may be difficult to set the standard at no incidents because there may be unusual circumstances that would make some small prevalence possible without the existence of a quality problem.

Other Conceptual Issues

When discussing quality, the participants spent extensive amounts of time on conceptual issues. It was agreed that in order to think about specific outcome measures, it was necessary to attribute the outcome to specific services. Participants also stressed the importance of controlling for the health risks of the populations when making comparisons of service-outcome relationships. Some pointed out the importance of accounting for consumer preferences in some way.

The scope of quality concerns depends on the type of services being considered. In adult day care, quality-of-life issues may be very important; examples include comfort of furniture, noisiness of common areas,

Table 2. Priority long-term care quality concerns

	Process and structure			**Outcome**	
Caregiving	**Caregiver training**		**Caregiver health**	Burden Stress Physical decline	
			Economic impact	Impact on employment	
Quality of care	**Clinical care**	Skin care Periodic turning Range of motion exercises Medications Toilet training Use of restraints	**Mental health**	Cognition Mood	
			Disability	ADLs and IADLs Unmet functional needs Mobility Strength, balance, and endurance Social integration Ability to engage in productive activity Social development (children)	
	Care planning	Adequacy of care plan	**Infections**	Tooth and gum decay and loss Pneumonia Septicemia Urinary tract infections	
	Staffing	Turnover Staff ratios and composition Training Compensation	**Geriatric syndromes**	Pressure ulcers Incontinence Contractures Sleep disturbances Bruises	
	Responsiveness	Elapsed time to receive services	**Satisfaction**		
			Discomfort	Pain	
			Preventable outcomes	Falls Transportation accidents Unnecessarily restrictive environment Inappropriate hospitalizations, emergency department use	
			Nutrition	Weight loss Dehydration	
Quality of life	**Home environment**	Noisiness in common areas Furnishings Safety features	**Personal/internal**	Autonomy Dignity Privacy	
	Organized activities		**Personal/social**	Social interaction Locus of control	
			External/societal	Safety Abuse and neglect Financial harm	

usability of the library, and ability to choose from a variety of organized activities. In addition, clinical concerns include staff competency and the ability to meet the needs of persons with dementia. For home care, the measures should be more clinically focused and include indicators such as the responsiveness of caregivers, staff turnover, technical competence of the clinical care, and the quality of caregiver-patient interactions.

Quality concerns also may vary by type of long-term care population. For adults with disabilities, some services would have the goal of social integration into the community or attainment of employment. Children may be receiving services to improve mental or physical development to reach age-appropriate developmental goals.

Goals may also depend on the level of disability. An elderly person who is on a ventilator and receiving skilled care from a home health agency may have extensive clinical and functional needs. In contrast, a person with mild cognitive impairment and few physical disabilities who needs help with medicines and transportation may have few clinical issues but may want to be involved in care management decisions.

A final point discussed was the potential for outcomes to conflict and the willingness of people to accept tradeoffs of goals. For example, some patients may be willing to accept less safety to increase physical activity, autonomy, or control. They may prefer a caregiver whom they know personally and trust but who has less training than a stranger from a certified agency. Therefore, the need to incorporate preferences in quality measurement was seen as important. However, few specifics on how this should be accomplished were provided.

Measuring Outcomes in Home Health Care: OASIS

The Outcome and Assessment Information Set (OASIS) refers to a collection of outcomes and associated risk factors developed for home health care. It is currently being used to assess home health care by CMS. Because it is a potentially important source of quality outcome measures, it was discussed extensively throughout the meeting. This section highlights the discussion.

In OASIS, outcome measures are at the patient level and reflect changes in health over two points in time (every 60 days, admission to discharge). Measures are dichotomous, defined as either stabilization or improvement vs. other. Negative outcomes also include hospital readmissions and emergency room use. There are 40 outcomes covering standard domains: functional, physical, cognitive, and emotional. It is now part of the assessment process for home health agencies; 19 items are also used in the Medicare prospective payment system. Data are transmitted for all Medicare and Medicaid residents who receive skilled care. The goal is to compare risk-adjusted outcomes to a reference group or to performance in the prior year. The system will be used similarly to the Minimum Data Set system to flag potential indicators of poor quality and then to follow up with more intensive review to assess ways to improve processes of care.

The discussion of OASIS focused on its perceived limitations and strengths:

- It was viewed as an important model for outcome measurement; but since it is limited to home health and is very clinically oriented, it may not be applicable to other home care services.
- There was concern about using OASIS data for research because it may not be possible to follow all home health "users"

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over time. For non-Medicaid, non-Medicare persons, or those not receiving skilled care, identifiers are masked, making it impossible to follow persons or link to other data.

- Its strengths are the uniformity of the data across home health agencies, its integration into the agency assessment process, its use for quality measurement and payment, and the fact that risk-adjusted measures have been developed.

The University of Colorado group is currently developing an OASIS-like set of measures for personal care services in New York State.

Recommendations About Specific Quality Measures

Participants were somewhat reluctant to recommend specific quality indicators. To some extent, this is a reflection of the dearth of peer-reviewed literature on quality indicators. They focused more on what should not be used than what should. The discussion remained at a fairly conceptual level most of the time. Some examples of possible measures were suggested, but without consensus. In some cases, the limitations of the measures were discussed more than the strengths. The discussion focused primarily on indicators that would in themselves indicate a quality problem.

Participants discussed two types of measures: those that evaluate the long-term care system globally and those that might be used to evaluate specific services or settings. A few highlights from the discussion are summarized below.

Global Measures

- Participants suggested considering measures such as the percent of persons who are institutionalized. They considered viewing it as a possible measure because of the belief that persons

prefer to be in the least restricted setting; therefore, remaining in the community is a goal in itself. Following this logic, evidence of a reduction in the rate of nursing home use among those with long-term care needs may be seen at a system level as an improvement in the quality of care provided.

- A second measure was unmet functional need. The argument is that one of the major goals of the long-term care system is to meet functional needs. In all but rare cases, unmet need would suggest a failure of the underlying care system. Unmet need in IADLs and ADLs can be constructed from some data, such as the National Long-Term Care Survey. Questions were raised about the psychometric properties of these measures, and it was noted that more development work is necessary. An alternative to measuring unmet need in ADLs and IADLs is measuring greater than expected declines in ADLs and IADLs. Expected declines would need to be adjusted for important health risk factors.

- Participants suggested another global measure – the percent of informal caregivers expressing high levels of stress or burden. They did not recommend preferred measures of stress or burden.

- Participants discussed the limitations of global measures. Global measures, by their nature, are not closely linked to specific services, resulting in potential attribution problems. Changes in these measures may not reflect changes in the quality of care in the system; rather, they may reflect other factors such as changes in health behavior or changes in the level of disability of the population. For example, if the long-term care population continues to become more disabled, the system quality may unfairly appear to be declining because we would likely

observe increases in the percentage of persons in nursing homes and more unmet needs among the long-term care population. One approach to minimizing this effect is to adjust expected outcomes for changes in the disability level of the population.

Service-Specific Measures

- Participants did not recommend any specific measures of satisfaction, although there was a discussion about the need to narrowly define the services received. It was reported that the Administration on Aging is developing satisfaction measures to be used by State Agencies on Aging. Instruments include measures designed by Scott Geron at Boston University. CMS and AHRQ, as part of the nursing home Consumer Assessment of Health Plans (CAHPS®) project, are attempting to develop satisfaction measures; but this project is limited to nursing homes.

- Beyond OASIS, participants did not establish consensus on specific outcome, process, or structural measures that go beyond the detail of Table 2. They emphasized several times that because OASIS is designed for home health care, it is very clinical and does not capture many of the social and quality-of-life dimensions of home care and other community-based care.

- Participants emphasized that more investment in needed in the development of measures of quality for community-based care. It was felt that AHRQ could play an important role in stimulating research in this area.

Data Presentations

The goal of day 2 was to present a summary of the most important data sources that contain community-based long-term care information and query attendees about their use of these data, inviting any suggestions they had about possible improvements. The morning session included five informal presentations of six data sets, followed by an afternoon discussion of data gaps and a concluding discussion on how to fill these gaps.

The presentations included the following data sets:
- Medical Expenditure Panel Survey
- Medicare Current Beneficiary Survey
- Health and Retirement Study
- Health Dynamics Among the Oldest Old
- National Long-Term Care Survey
- National Home and Hospice Care Survey

Medical Expenditure Panel Survey (MEPS)

The MEPS is an ongoing, nationally representative survey designed to capture various aspects of medical care for the noninstitutionalized U.S. population. The MEPS consists of four survey components: Household, Medical Provider, Insurance, and Nursing Home (1996 only). The Household Component collects data on families and individuals across the Nation and is drawn from a nationally representative subsample of households that participated in the prior year's National Center for Health Statistics (NCHS) National Health Interview Survey. AHRQ began fielding MEPS in March 1996. AHRQ conducts MEPS in conjunction with NCHS and through contracts with Westat, a survey research firm located in Rockville, MD.

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MEPS is the most recent in a series of medical expenditure surveys that began in 1977 as the National Medical Care Expenditure Survey and later became the National Medical Expenditure Survey. The purpose of these surveys is to provide nationally representative estimates of health care use, expenditures, sources of payments, and insurance coverage for the U.S. noninstitutionalized population.

Community-Based Variables

Utilization of community-based long-term care can be identified from the Household Component of the MEPS with variables specific to adults and children.

Variables available to identify chronic illness and disability for adults include the following:

- Conditions and impairments associated with use of health care services
- Work, school, or housework limitations
- Functional limitations (e.g., walking, bending)
- Receipt of help with ADLs or IADLs (one question for each category)
- Social role limitations
- Assistive devices
- Hearing, vision, and cognitive limitations

Variables available to measure disability for children include the following:

- For children ages 4 and under
  - Limitations in any activities
  - Limitations in play activities
  - Participation in special programs or early intervention services
- For children over age 4
  - Interpersonal problems
  - Limitations in school attendance
  - Enrolled in special education or related services
  - Limited in activities other than school

Home Health Care

Home health data have been collected for every year between 1996 to present; data for 1996-99 have been released. Sample sizes may be small for particular subpopulations but are expected to increase in the future**.**

Home health care data are collected each round and identify all sources of help including family, neighbors, friends, and paid care. Agency-based providers are identified and caregivers from agencies are tracked on a monthly basis. The survey respondent provides estimates of the number of visits per month and average length of time per visit.

Details captured about visits include type of provider, nature of help, expenditures for care, and sources of payment. Additionally, the type of health problem associated with the receipt of care is captured.

Supplements

A long-term care supplement was fielded in 1996, 1997, and 1998. Persons were screened into the supplement if they were flagged for any of the following in any round: ADL or IADL deficits, use of special equipment, functional limitations, work, housework, school limitations, social limitations, cognitive limitations, vision or hearing deficits, or child with limited activities or school attendance limitations. The supplement includes details on ADLs and IADLs, communication limitations, developmental delays, special diets, employment accommodations, transportation, and the condition that is associated with the limitations.

Concurrent with the long-term care supplement, a caregiver supplement was administered in 1996, 1997, and 1998. Persons were screened in using the same criteria as the long-term care supplement. It captured the type of help received at home, time spent by caregiver, and changes in living

arrangements. Potential caregivers outside of the household were also identified.

More information on MEPS can be found at www.meps.ahrq.gov.

Medicare Current Beneficiary Survey (MCBS)

The Medicare Current Beneficiary Survey, sponsored by CMS, has been in the field since 1991. It is an ongoing, nationally representative sample of approximately 12,000 Medicare beneficiaries. The purpose of this survey is to develop reliable information on Medicare-covered and non-Medicare-covered services and costs, to study transitions in beneficiaries' lives, and to monitor the effect of change on the Medicare beneficiary population. Data are collected for beneficiaries living in the community and in health care institutions and are supplemented with Medicare claims data.

There are three rounds of data collection per year. Persons are followed for 4 years, from setting to setting, to capture 3 calendar years' worth of health care use and expenditures and transitions in care. The design is an overlapping panel with an oversample of the disabled and oldest old. Persons are sampled from the Medicare rolls; and, after the first round, questions about cost and use of services are asked for the period since the last interview.

Community-Based Variables

Questions about general health, chronic conditions, and functional limitations (ADLs and IADLs) are asked. Use of health care includes Medicare-covered services, noncovered services, and preventive services. Total payments by source of payment (up to eight sources) are captured. Health status measures include the following:

- General health

- Vision and hearing
- Height and weight
- Presence of chronic conditions
- Continence
- IADLs and ADLs
- Physical functioning and locomotion
- Preventive services: mammogram and Pap smear, flu and pneumonia shots, prostate specific antigen and digital exam

Additional questions about the living arrangements of survey respondents are being planned.

Home Health Care

Home health care questions are limited to a simple acknowledgment of receipt of care at home, type of organization providing care, reasons for not using a home health provider, time per visit, receipt of medical care (e.g., changing dressings, giving shots), help with IADLs or ADLs, receipt of personal care from other nonresident sources, and the type of relationship to respondent. Affiliations with Department of Veterans Affairs facilities or health maintenance organizations are also captured.

Health and Retirement Study (HRS)

The Health and Retirement Study is a nationally representative, longitudinal survey of more than 12,000 persons born during the years 1931 to 1941. The focus of the survey is on health, retirement decisions, and the physical and financial well-being of Americans in later life. It is intended to provide data for researchers, policy analysts, and program planners who are making major policy decisions that affect retirement, health insurance, saving, and economic well-being. The University of Michigan Institute for Social Research conducts the HRS under a cooperative agreement with the National Institute on Aging.

HRS Questionnaire Topics

- Health and cognitive conditions and status
- Retirement plans and perspectives
- Attitudes, preferences, expectations, and subjective probabilities
- Family structure and transfers
- Employment status and job history
- Job demands and requirements
- Disability
- Demographic background
- Housing
- Income and net worth
- Health insurance and pension plans

Wave 1 data collection was completed in February 1994. Wave 2 data collection ended in May 1996. Wave 3 data collection ended in 1998; future waves will largely replicate HRS 1998 in design, format, coverage, structure, and measurement. Wave 4 data collection was fielded as a joint data collection effort with Health Dynamics Among the Oldest Old (see below) and ended in March 1999.

Health Dynamics Among the Oldest Old (AHEAD)

The AHEAD study is a nationally representative, longitudinal survey of more than 7,000 persons over age 70 and provides data to address a broad range of scientific questions focused on the interplay of resources and late life health transitions. Among these issues are the costs of illness borne by the family; differences in how resources are used to offset cognitive, physical, and functional losses; the effectiveness of various care arrangements in preserving function and delaying institutionalization; the extent to which transfers from kin buffer the assets of older persons and slow transitions to late life impoverishment; and the extent of and mechanisms for spending down private assets as well as Medicaid spend-down.

AHEAD Questionnaire Topics

- Cognitive performance
- Physical and functional health
- Economic status (assets and income)
- Claims on transfer programs and contingent claims
- Spend-down and Medicaid eligibility
- Family structure, caregiving, and financial transfers
- Demographic characteristics
- Housing (including access to services)
- Service use (community and nursing home)
- Out-of-pocket costs for all services

Other Variables

Both HRS and AHEAD contain data on utilization of care, health, living arrangements, and economic resources/ behavior. Respondents who reported one or more of 12 physical limitations were asked questions about difficulties in ADLs. All respondents were asked IADL questions. Questions about time spent by helpers, cost, and availability of helpers were asked.

Both surveys include home care use and utilization data in the past 2 years and use of other special services (e.g., adult care center, social worker, outpatient rehabilitation, transportation, and meals). Use and expenditure information was also captured for hospitals, nursing homes, outpatient services, dental care, and prescription drugs.

Health measures include self-ratings and change, disease inventory with some severity measures, pain assessment, cognitive competencies, subjective expectation of life span, and need for nursing care. Living arrangement data include housing, services, ownership, and value. Data about children and parents (if applicable) are also gathered.

More information can be found at www.umich.edu/~hrswww/.

National Long-Term Care Survey (NLTCS)

The National Long-Term Care Survey is a nationally representative survey of Medicare beneficiaries age 65 and over with chronic functional disabilities. Data have been collected for 1982, 1984, and every 5 years since. Persons (in the community and health care institutions) are sampled from the Medicare beneficiary rolls, and those with functional limitations are oversampled.

The NLTCS for 1982, 1984, 1989, and 1994 are designed to measure the point prevalence of chronic (90 days or more) disability in the U.S. elderly Medicare enrolled population and changes (both improvement and incidence) in chronic disability (and institutionalization) over time. Slightly different sampling procedures were utilized for each of the survey years.[2]

For the elderly population with disabilities, the NLTCS provides cross-sectional and longitudinal data on: prevalence and patterns of functional limitations, medical conditions and recent medical problems, use of health services, kinds and amounts of formal and informal long-term care services used, demographic characteristics, public and private expenditures for health services, and housing and neighborhood characteristics.

Community Questionnaire

The community portion of the survey includes information on the following:

- Condition list
- ADL status (detailed questions on six ADLs)
- IADL status (detailed questions on seven IADLs)
- Source, type, and amount of informal help

- Source, type, amount, and payer for formal help
- Questions on range of motion and impairment (Nagi items)
- Activity list
- Nutrition
- Social activities
- Alcohol consumption and smoking
- Other functioning (mental, emotional, behavioral)
- Housing and neighborhood characteristics
- Health insurance
- Medical providers and prescription medicines
- Cognitive functioning
- Military service, ethnicity, income, assets

Informal Caregiver Survey

A separate (but linked) informal caregiver supplement was administered in the surveys for 1982, 1989, and 1999. A caregiver was defined as someone who provided help to a sample member with one or more IADLs or ADLs in the week prior to the sample interview. The caregiver was either a paid or unpaid relative or unpaid nonrelative.

The supplement includes the following information:

- Caregiver name, address, and basic demographics
- Relationship to sample member
- Amount and kinds of help provided
- Information on care provided by others
- Caregiver's living and work situation
- Caregiver's health and functional status
- Caregiver's income and assets

The instruments used for the informal caregiver surveys have not remained static across the life of the NLTCS. The 1982 and 1989 caregiver surveys are similar in content although the 1989 survey was shortened.

The 1999 survey contains detailed caregiver information and includes asking caregivers whether they helped with IADLs, ADLs,

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toileting, medications, and other medical care, as well as the number of times this help was given. Other questions about the amount of time the caregiver can leave the sample person alone and questions on problems and inconveniences experienced by the caregiver also are asked. Sources of and satisfaction with outside help, caregiver experience, living situation, and work situation are other areas covered.

More information can be found at http://cds.duke.edu and aspe.os.dhhs.gov/daltcp/reports/nltcssu2.htm.

National Home and Hospice Care Survey (NHHCS)

The National Home and Hospice Care Survey is a set of surveys of a random sample of home and hospice care agencies in the United States. The survey was been fielded in 1992, 1993, 1994, 1996, and 1998. The survey includes all types of agencies that provide home health and hospice care without regard to whether they are Medicare or Medicaid certified or whether they are licensed. Information is collected about the agency, current patients, and discharges.

All data collected in the NHHCS consist of three files: agency, current patients, and discharged patients. Each record includes a common agency number to allow linkage between them.

Agency Variables

- Type of ownership
- Agency affiliation
- Certification status
- Number of current patients
- Services available: 1993, 1994, 1996, 1998
- 1992 only:
  - Number of full- and part-time staff
  - Part-time staff hours
  - Nonpayroll staff hours

Patient Variables (Current and Discharged)

- Demographics (age, sex, race, marital status)
- Current living arrangements
- Referral source
- Primary caregiver and relationship
- Diagnoses at admission, time of survey, and discharge (if applicable)
- Reason for discharge
- Type of care received
- Living arrangements at discharge
- Aids used
- Vision and hearing status
- Activities of daily living
- Instrumental activities of daily living
- Services provided
- Service providers
- Amount billed for care
- Primary and secondary sources of payment
- Number of visits: 1992, 1993, 1994
- Surgical and diagnostic procedures related to admission: 1996 only
- Dates covered by bill: 1992, 1993, 1994, 1998

More information can be found at www.cdc.gov/nchs/products/catalogs/subject/nhhcs.htm.

Improving Data

Prior to the meeting, participants were asked to comment on ways they would like to see the data sets improved. Highlights from their responses follow:

- National long-term care data on persons living in the community have focused mainly on the elderly; more data are needed about the nonelderly.

- Researchers expressed concern that some rich data sets such as the disability supplement to the National Health Interview Survey are only one-time efforts; thus, trends in care and health status cannot be monitored. As a consequence, we cannot get parallel

information about disability trends for the nonelderly as we get for the elderly from the NLTCS, for example.

- Information on quality of long-term care services provided in the community is lacking.

- Analyses are often limited by small sample sizes, especially when trying to compare subpopulations of the long-term care population, such as children with special needs, adults with disabilities, or persons with specific chronic conditions.

- Combining data to link all care received to an individual is often impossible when care is provided across settings and financed by different payers.

- Data on informal caregivers need to be expanded to better capture influence on caregivers' lives, including influence on work and social, psychological, and physical burden.

- Access to data has become very difficult in some cases because of confidentiality concerns.

- Administrative data such as OASIS should be linkable with national data to reduce the burden of survey data on providers.

- Outcome measures in national data need to be improved to increase the sensitivity of measures to change.

- Information about satisfaction with community-based long-term care services currently is not available in national survey data.

Identifying and Prioritizing Data Gaps

Following the presentation of data sets, a discussion was held to summarize and prioritize the most important data gaps in community-based long-term care. A number of concerns were emphasized:

- Participants agreed that both facility-based and population-based surveys were important. Many stressed that in either type of survey, person-level longitudinal or repeated panel, information is needed to enable the monitoring of changes in quality, outcomes, access, and cost – an important goal for national data. These data can be supplemented periodically with special studies, but a coherent strategy should be put into place.

- Priority should be given to increasing the sample sizes of the long-term care populations so that separate analyses of subpopulations can be made.

- Administrative data should be made more useful by improving data linkages (e.g., improved linkages across payers, common person-based identifiers, and centralized data cleaning). Access should be improved to enable researchers to take advantage of these important data. Participants were sensitive to confidentiality issues, but expressed concerns that confidentiality issues should be balanced by concerns about facilitating research. They expressed concerns about limitations in access and constraints on linking survey data to Social Security Administration, Medicaid, and Medicare administrative data.

- Caregiver data, especially for children and adults with disabilities, need to be collected. More information is needed on how caregiving decisions are made and how caregiving responsibilities are allocated among potential caregivers; estimates are needed about caregiver burden – economic, physical, and psychological.

- Information about service-enhanced housing needs to be improved to better capture long-term care services provided in home-like environments. This would also improve our ability to capture

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transitions from home and across different levels of service-enhanced settings.

- Participants viewed the development of a frame of residential long-term care providers as very important and believed it should include all types of service-enhanced settings, if possible. However, they acknowledged that it is difficult to build a frame when there are many small facilities. This is precisely the nature of the board- and-care market, especially those places serving the nonelderly. These facilities have grown greatly in number but are usually small places serving only a few people.
- Descriptive data on care received should be improved to capture both informal and formal care.
- Disability measures for children should be improved.

Other Data Issues

Measuring Unmet Need in ADLs and IADLs

Some participants advocated for improving the measurement of unmet need. The discussion centered around the NLTCS and whether the low estimates of unmet need in that survey were real or artifacts of measurement. There seemed to be a consensus that the measurement of unmet need in the NLTCS could be improved. To get valid responses, a debate exists about whether one can ask if someone has an unmet need, or if more specific questions should be asked about the consequences of the lack of available help. More specific questions were asked in the Longitudinal Survey on Aging. Estimates of unmet need collected periodically would provide an indication of how the long-term care system is meeting needs over time.

State-Level Data

Participants emphasized that most of community-based long-term care is financed at the State level, and consequently, policy decisions are often made by States, not the Federal Government. There are tremendous differences in the array of government programs that exist across States as well as how States use Medicaid waiver programs. There are no consistent data collection systems for State programs.

Some States are able to monitor their home and community-based services well while others are not. Consequently, it is difficult to compare States on almost all dimensions of service delivery. Participants emphasized that it wasn't enough to mandate the availability of data unless a uniform data system was developed. In addition, most national data sets are not designed to provide State estimates. Some participants believed that an agency of the Federal Government might help stimulate a consistent data collection system. Others discussed the importance of studying a few States in detail or even a few major cities. As an alternative approach, participants discussed developing a State data system that could be linked to national data so that the impact of the variation in programs across States could be studied.

Capturing Transitions

Most participants wanted improved data on transitions in care and health, including capturing the important changes and being able to study transition decisions. Another concern is that the change period captured should be small enough to include important clinical changes. For the Medicare population, the MCBS follows persons across all settings and captures all use and expenditures either from Medicare and Medicare bills or from self-report over a 3-year period. For persons of all ages and all payers, MEPS follows persons for 2 years and

captures all changes in home health on a monthly basis. It only captures changes in functioning three times over the 2 years, allowing only for approximate annual changes in status to be measured. For home health care, the potential for linking OASIS data, which include health changes over a 60-day period, was discussed. National surveys do not currently link to the OASIS data.

Although the MCBS and MEPS follow persons across settings, the sample size is a concern. To understand transition decisions, information needs to be collected at admission or at discharge. Both service and health data need to be collected and linked.

In addition to capturing clinical information inadequately, participants believed that data do not sufficiently capture social transitions. For children with special health care needs, transitions to school are important but are not generally captured in health surveys. For adults with disabilities, transitions in work, family, and other social activities should be captured.

Special Issues Related to CSHCN

For children with special health care needs, participants emphasized concerns about sample size and screening criteria. Because educational services also contribute to health outcomes, the importance of linking educational activities with health care and long-term care arrangements was also stressed. Children with special health care needs comprise the smallest of the three main disability groups, but this population has its own service delivery issues. Therefore, CSHCN must be analyzed separately, which, in turn, makes oversampling this population of paramount importance.

There are plans to oversample CSHCN in the MEPS, but this will depend on future budgets. Also, a common definition of CSHCN is needed. An example of this is the development of a CSHCN screener that is

being incorporated into the MEPS by the Child and Adolescent Health Measurement Initiative's Living with Illness Task Force.

Measuring Home Care Quality and Staffing

Participants believed that it was important to include quality measures for long-term care even in national surveys and that home care outcome measures could be broadened. The importance of better capturing consumer satisfaction and the staffing profile in home care agencies was stressed. Information should be collected on staff ratios, training, and wages, whether the staff are independent providers or affiliated with an agency, and whether they are directly hired by the patients.

Related to staffing for home care is the need for better information about long-term care management. Care management is difficult to measure because there are no common definitions, financial incentives vary, and care intensity varies. Participants recommended collecting a measure of case load, services provided, and professional training. Clients may receive care from more than one care manager, which should also be captured in some way.

Conclusions

This meeting provided AHRQ with a broad view of the data needs and research priorities for community-based long-term care research. Participants communicated a number of important messages. The following recommendations summarize the next steps that are needed to enhance information about community-based long-term care.

- Improve basic information about the caregiving patterns and service use of persons of all ages, but especially for those under age 65.

- Evaluate new models and financing mechanisms for improving outcomes from community-based care.
- Evaluate models to improve methods to encourage the hiring and retention of new staff.
- Expand our ability to measure quality beyond home health including less clinical forms of home care.
- Develop outcome measures that are sensitive to the differing goals of the three long-term care populations: CSHCN, adults with disabilities, and the elderly.
- Develop better measures of satisfaction, quality of life, and community and housing environments.
- Improve data about State long-term care programs to assess the large variation in access to care.
- Increase national samples to enable separate analyses of the major subpopulations of long-term care users who have very different goals and needs.
- Increase information about services provided in service-enhanced housing.
- Capture important transitions in health, levels of care, and social roles to improve our understanding of how decisions are made at transition points.
- Facilitate access to administrative data and linkages between national surveys and administrative data.

Appendix 1. Meeting Agenda

U.S. Department of Health and Human Services
Agency for Healthcare Research and Quality

Presents

Future Directions for Community-Based, Long-Term Care Health Services Research

AHRQ Conference Center
Rockville, Maryland
June 20-21, 2000

Agenda

Tuesday, June 20, 2000

10:00 am   **Welcome, Meeting Overview and Goals**
                  John Eisenberg, M.D., M.B.A. – Agency for Healthcare Research and Quality
                  Irene Fraser, Ph.D. – Agency for Healthcare Research and Quality
                  Steven B. Cohen, Ph.D. – Agency for Healthcare Research and Quality
                  Lawrence Bartlett, Ph.D. – Health Systems Research, Inc.

10:20 a.m.   Overview of Priority Research and Policy Questions
                  William D. Spector, Ph.D. - Agency for Healthcare Research and Quality

                  Discussion on Priorities for Policy and Research with Focus on
                  Differences with respect to Children, Adults with Disabilities, and
                  Elderly

12:30 p.m.   **Lunch**

1:30 p.m.   Presentation/Discussion of Compiled Information on Quality
                  Dimensions from Participants
                  William D. Spector, Ph.D.

2:30 p.m.   Discussion on Quality Indicators Specific to Children, Adults with
                  Disabilities, and Elderly

5:00 p.m.   **Adjourn**

Appendix 1. Meeting Agenda (continued)

Wednesday, June 21, 2000

8:45 a.m.	Overview of the Day's Agenda
9:00 a.m.	Presentation of Current National Community-Based Long-Term Care Data Collection Efforts

Medical Expenditure Panel Survey – Household Component
Barbara Altman - Agency for Healthcare Research and Quality

Medicare Current Beneficiary Survey
Frank Eppig – Health Care Financing Administration

National Home and Hospice Care Survey
Genevieve Strahan – National Center for Health Statistics

Health and Retirement Study and Health Dynamics Among the Oldest Old
Timothy Waidmann – The Urban Institute

National Long Term Care Survey
Larry Corder – Duke University, Center for Demographic Studies

10:15 a.m.	**Break**
10:30 a.m.	Identifying Data Gaps and Strategies for Addressing Them
Noon	**Lunch**
1:00 p.m.	Identifying Data Gaps and Strategies for Addressing Them (continued)
2:15 p.m.	**Break**
2:30 p.m.	Summary of Recommendations and Implications for Data Collection Efforts to Meet Research and Policy Needs
3:00 p.m.	**Adjourn**

Appendix 2. List of Meeting Participants

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Appendix 2. List of Meeting Participants (continued)

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Appendix 3. Participant Information and Pre-Meeting Questionnaire

May 5, 2000

To: Participants, Community-Based Long-Term Care Meeting
From: William Spector, Ph.D. and Jeffrey Rhoades, Ph.D.
          Agency for Healthcare Research and Quality

Thank you for agreeing to participate in the June 20-21 expert meeting, "The Future Directions of Health Services Research in Community-Based Long-Term Care." We are writing to provide further information on the context and goals of the meeting and to solicit important input from you in advance of the meeting.

This meeting follows up on the Agency for Healthcare Research and Quality's (AHRQ) Fall 1999 meeting that focused on persons living in residential care settings (i.e., nursing home care, assisted living and other residential care). In that meeting, we identified research priorities and data gaps, and discussed strategies for collecting survey data and using administrative data to fill these gaps. We also discussed ways to measure quality and monitor outcomes.

The focus of the upcoming June meeting will be community-based long-term care. Later in the year, the Agency is planning an additional meeting that will focus on the medical care needs of disabled persons, including such services as hospital care and medical rehabilitation. Because the content of these three meetings potentially overlap, it is important to avoid duplication where possible. For this reason, we would like to establish beforehand the intended content of this meeting. The goal of the meeting is to focus on *community-based long-term care services* for adults who have at least one IADL or ADL disability and children with physical and mental limitations**.** These community-based long-term care services include home care, personal assistant services, group homes, other housing with supportive services, and assistive technologies.

For all groups we are interested in services that help maintain community living and maximize independence, enable participation in social activities, and provide the necessary IADL and ADL supports. For children with special care needs, we also would like to discuss school-based services that assure a good education, and for working aged adults, we would like to discuss workplace-related services that improve access to the workplace. We are interested in care provided by agencies, family, and friends, both paid and unpaid.

The research interests of the Agency are very broad. We are the lead Agency within DHHS for supporting research and efforts to improve health care quality. We also are broadly concerned with health issues related to access, cost, quality, and outcomes. Although we are ultimately interested in how the health system serves consumers, we also would like to know how provider and family decisions are made, how the changing market place and public policies affect these decisions, and how these decisions affect the

Appendix 3. Participant Information and Pre-Meeting Questionnaire (continued)

efficiency and quality of the health care system. Although we will place boundaries on the discussion, we are interested in how well community-based long-term care is integrated with residential long-term care and other parts of the health system.

Within this context, we have four goals for this meeting:

1) To identify the priority research and policy questions associated with community-based long-term care;

2) To identify the most important quality measures (outcomes, process, and structural measures) and strategies for collecting these measures;

3) To identify data gaps, especially associated with national data, and establish priorities for filling these gaps; and,

4) To solicit advice on how DHHS can fill data gaps, take advantage of both survey and administrative data, and cost-effectively continue to develop data on community-based long-term care.

This two-day meeting will cover a lot of material. Because we want the sessions to include as much valuable discussion as possible, we are sharing with you the enclosed set of questions and soliciting your responses to them in advance of the meeting so that we will not be starting from scratch. We will use your responses to the pre-meeting questions to develop working documents to be used as the basis for the meeting discussions. We will use the meeting itself to fine tune your ideas and develop recommendations. To this end, we would appreciate you responding to the attached set of questions by May 26.

Again, our thanks. We look forward to seeing you in June.

Appendix 3. Participant Information and Pre-Meeting Questionnaire (continued)

Preliminary Questions for Community-Based Long-term Care Meeting

1. Focusing on community-based long-term care, please provide us with five research or policy questions that you think are the highest priority. Consider issues related to access, cost, quality, and outcomes. Consider consumer, provider, and family caregiving issues. Please focus on the population that you are most expert in: children with special needs, adults with disabilities, or elderly.

2. For those who are currently engaged in research on these topics, please let us know:
   - What data sets you use,
   - Why you have chosen these data sets over others,
   - What are the advantages and disadvantages of these data compared with other data that are available, and
   - What improvements you would like to see made.

3. We are beginning an effort to develop national quality measures for long-term care. We would like your recommendations on what should be measured to develop national quality indicators for community-based long-term care. These measures will be used to monitor trends in the quality of care over time.

   We are interested in outcomes, process and structure measures as well as associated risk factors. Clearly we are interested in the quality of both formal and informal care. For your guidance, we have enclosed the summary of the quality dimensions and risk factors compiled from recommendations for our fall 1999 expert meeting that was focused on nursing home and residential care. We are interested in additional domains and specific examples relevant to community-based care. When making recommendations, please discuss the feasibility of collecting these data as part of national data collection.

   Please focus on the population that you are most expert in: children with special needs, disabled, or elderly disabled.

Given that the participants of this meeting have a broad range of expertise, we understand that some of you will be more able to respond to some questions than others. If you can provide insights into all areas, that is great. Otherwise, please provide us with as much help as you can.

Please respond by May 26. Thank you in advance.