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Toward Improved Support for Research
on Delivery of Home- and Community-Based Long-Term Care

Long-Term Care Research Initiative

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Overview. Stronger and more consistent support is needed for research on long-term care. A greater investment in research will strengthen the ability of public and private organizations to provide effective and efficient assistance to people with disabilities and their informal caregivers. This paper provides a rationale for stronger research funding for the field and outlines several options to strengthen research.

Background. The population in need of long-term care is substantial and growing. Most of those needing long-term care live in community settings rather than in institutions. At present, approximately 4.4 million people age 65 and over are in need of help with one or more tasks of daily living. A similar number of people under 65 years of age also have disabilities that make them dependent on others for assistance in daily living tasks. Also heavily affected are the many millions of informal caregivers who provide approximately 80 percent of the long-term care.

The major stakeholders include consumers and informal caregivers, federal and state governments, provider organizations, service professionals and paraprofessional workers, and private insurance companies. The following are examples of the issues that are of major concern to some of the stakeholders:

Federal Government. Central for the federal government are issues of service financing. Since the introduction of the Medicaid and Medicare programs, the federal government has played a major role in financing long-term care. Medicaid is particularly important in financing long-term nursing home care for the medically indigent. Medicaid also plays an important role in financing home care. Medicare finances nursing home care while patients are recovering from acute conditions. Through its home health program, Medicare also plays a significant role in financing home care while beneficiaries are recovering from acute conditions. Medicare's role in financing home health aide services through the home health program grew substantially through most of the 1990s.

A variety of measures to strengthen the role of the federal government in financing long-term care have been proposed over the past 25 years. The various proposals have differed greatly in their emphases. Both the Pepper Commission and the Clinton health care reform plan included major provisions to extend federal financing for home and community-based long-term care (HCLTC). In contrast, the Health Insurance Portability and Accountability Act of 1996 emphasized private responsibility for long-term care financing by providing tax incentives for consumers to purchase private long-term care insurance which could be used to pay for both institutional and home care. More recently, acknowledging the major role played by families as informal sources of long-term care, the Clinton administration proposed a program to provide up to \$3,000 per year in tax relief to informal caregivers. Another initiative to assist informal caregivers is included in the recently reauthorized Older Americans Act.

Containment of its spending on long-term care is an important aspect of the federal government's overall efforts to control health care expenditures. Through provisions of the 1997 Balanced Budget Act, growth rates for Medicare expenditures for both home health services and nursing home care have been cut substantially. The Balanced Budget Act challenges providers to make more efficient use of Medicare resources. The fiscal discipline imposed by the Balanced Budget Act has invited questions about the ability of many providers to remain active, about access of vulnerable people to vital services, and about the quality of care for those who receive services.

The federal government has also been involved in a variety of quality assurance efforts in both nursing homes and home care. On the basis of 1987 OBRA provisions, for example, the federal government initiated a major effort to raise quality standards in nursing homes. Since then, the federal government has initiated similar quality assurance efforts directed at home care.

State Governments. Many of the policy issues in long-term care have a significant impact on states. The Medicaid program provides states with a great deal of discretion in their financing of long-term care services. The Section 2176 Medicaid Waiver program, in particular,

has provided states with encouragement to be creative in offering home- and community-based long-term care services for those who might qualify for institutional long-term care. States face important questions in identifying the populations to be served and the configuration of services to be offered through their Waiver programs.

States face other important long-term care issues. To respond to demand for subsidized HCLTC, some states finance their own programs apart from the Medicaid Section 2176 Waiver programs. In administering these programs, states face persistent issues in establishing eligibility criteria, in defining covered services, and in establishing quality standards.

The role of consumers in directing the publicly-funded HCLTC care that they receive has become a highly visible issue. Proponents of consumer direction are seeking greater control for consumers over how public funds are being spent on their behalf. Their aspirations are reflected in the proposed Medicaid Community Attendant Services Act (MiCASSA), which seeks to make current entitlements more flexible. The legislation would allow an individual who is entitled to institutional services to determine where and how the services are delivered.

Service Providers. The service-delivery issues in long-term care are deceptively complex. A variety of factors contribute to the complexity of service delivery in long-term care: the interplay between what consumers are able to do for themselves, what is done by informal providers, and what is expected of paid services; the complex relationship between personal assistance and health care; the roles of professional case managers and consumers themselves in planning services and supervising workers; the implications of housing environments for formal service requirements; the role of technology (high tech and low tech) in complementing human assistance; the logistics of delivering home care efficiently to consumers who are geographically dispersed; the need to offer culturally sensitive services to members of minority groups; and the challenges of recruiting, training, and supervising a largely entry-level workforce. At the core of long-term care are straightforward services that can be provided by workers with little formal

training and only modest supervision. Further, providers are under overriding pressure to provide high-quality services at modest cost.

Consumers and Their Families. Most long-term care services continue to be provided at home by informal caregivers. However, there is evidence that use of formal services is increasing. In the long run, because of structural changes in the family and the increases that have taken place in the participation of women in paid employment, use of formal services is likely to increase. When consumers seek formal services, their preference is to have a variety of high-quality options available to them. Furthermore, consumers have an interest in being able to obtain sound information about their service options. Some prefer to have case managers available who will help them plan and manage services. Others prefer to have a strong role themselves in planning and managing services. For consumers, the choice of a service setting is a major concern. Many prefer to remain at home but are uncertain whether they can obtain the full range of help that they need on a consistent basis at home. Those who consider moving have a variety of options that include residing with an adult child, independent living in a unit with strong environmental supports, an assisted living facility, and a nursing home.

For those who pay for services themselves, cost and service value are major concerns. Although consumers characteristically prefer to minimize their expenditures, those who pay for their own services have reason to weigh the value they receive from their expenditures against the cost. When consumers finance services from their savings, they also have to be concerned about their capacity to pay for services on a continuing basis.

For many older people and their adult children, anticipation of possible long-term care costs is a major concern. Increasingly, older people with some financial resources consider whether it is advisable to purchase long-term care insurance. Those considering long-term care insurance face important questions about the type and extent of coverage that they should purchase.

Long-Term Care Insurance Industry. In the years to come, private long-term care insurance is likely to play an increasingly important role in financing services. The increasing numbers of people who can afford to purchase long-term care insurance, the greater understanding of the public of the risk of need for long-term care, the lack of political support for long-term care insurance in a social insurance framework, more generous tax incentives for those who purchase policies, and the offering of better designed long-term care policies all contribute to the likelihood that more people will purchase policies. The long-term care insurance industry has varied information needs that include accurate projections of future need for long-term care services, sound projections of future costs of services, the design of policies that offer maximum value to policy holders, and strategies for effective marketing of policies.

Long-Term Care Research. Research has made important contributions to the development of long-term care policy in the United States. In the 1970s federal funds, for example, supported a series of state-level research and demonstration projects that improved our understanding of the link between home care and institutional care. These projects also stimulated the development of a number of state programs providing HCLTC on a continuing basis. The National Long-Term Care channeling initiative contributed greatly to an understanding at a national level of two fundamental service-delivery models: case management and flexible service budgets controlled by professionals. The National Long-Term Care survey and more recently the Assets and Health Dynamics Among the Oldest Old (AHEAD) survey have provided systematic data on the extent of functional disability and patterns of use of formal and informal services that have aided greatly in both conceptualization of legislative options and estimates of service utilization and costs. Federal funds have also supported a number of important demonstrations exploring the links between medical care and home care. Currently, the Cash and Counseling demonstration project, funded jointly by the federal government and The Robert Wood Johnson Foundation, is examining the potential for consumers to play a stronger role in managing their own personal assistance services.

Researchers have also made important contributions to the strengthening of institutional long-term care. An important example is the research that led to the Minimum Data Set (MDS), a clinical protocol that is administered periodically to all nursing home residents. The MDS provides a standardized, structured basis for service planning and monitoring for nursing home patients. Because it can be aggregated, it also provides a basis for facility-level performance evaluation.

Research Funding. Although research has contributed greatly to advancements in long-term care in the past 30 years, the field has been handicapped by the absence of consistent research funding. Historically, the field has depended heavily upon the federal government for long-term care research funding, but federal funding for this research has fluctuated greatly over the years. Funding has most consistently been available for research that addresses the policy concerns of the federal government. Particularly lacking in the past decade has been federal support for investigator-initiated studies of service-delivery issues. The long-term care field is at a disadvantage because no federal agency has a consistent mandate to provide funding for field-initiated research on long-term care. From time to time, the Aging, Disability, and Long-Term Care unit in the Office of the Assistant Secretary for Planning and Evaluations (ASPE) of DHHS, the Administration on Aging (AOA), the Health Care Financing Administration (HCFA), the Agency for Health Research and Quality (AHRQ), the National Institute on Aging (NIA), the National Institute on Mental Health (NIMH), and the National Institute on Disability and Rehabilitation Research (NIDRR) have all supported research on long-term care.

However, missing from the configuration is any one agency that serves HCLTC research needs fully on a consistent basis. No single agency has both a priority concern with service-delivery issues in HCLTC and has a budget to support significant, continuing field-initiated research. ASPE's Disabilities, Aging & Long-Term Care Policy unit addresses the central issues in HCLTC but lacks both a mandate and budget to support field-initiated research. While the AoA in the past supported occasional service demonstrations, it did not provide significant

research funding. AoA currently funds only research and demonstration explicitly mandated by Congress. NIA has supported some research on long-term care but largely in a basic science framework or with an emphasis on health care interventions. NIA has a greater interest in aging processes than in service-delivery systems. NIA does not fund evaluation research. Although long-term care is a current priority for the National Institute for Nursing, the Institute is greatly constrained in its support for the field by its limited budget. HCFA has supported some important long-term care demonstrations and more general service-delivery research. However, its interest in community-based long-term care has been intermittent. HCFA has had reason in recent years to focus its energies on other issues of greater and more immediate implications for health care cost containment. AHRQ has been inconsistent in its attention to community-based long-term care issues. In the past, the agency had an intramural research group with a mandate to address long-term care issues. However, that group no longer exists as such. In its extramural research program, AHRQ is willing to review proposals on community-based long-term care; however, the subject is not a priority. Proposals are likely to be assigned to review panels lacking expertise in community-based long-term care. The NIMH has an interest in the elderly and in service-delivery issues. Although, NIMH's mission to focus on mental health issues restricts its scope in community-based long-term care, its mandate to spend 15 percent of its grant funds on services research is a good model.

A number of national foundations have provided funding for long-term care research and demonstrations, but that support has been intermittent. The Robert Wood Johnson Foundation, the Retirement Research Foundation, the AARP Andrus Foundation, the Commonwealth Fund, and the Pew Charitable Trust are national foundations that have supported initiatives on long-term care.

Some states have taken advantage of an opportunity provided by HCFA to cover costs of some Medicaid-related service delivery research through the Medicaid program. HCFA covers the cost of research to the same extent that it covers the cost of the state's Medicaid services.

Stakeholder Perspectives. The major stakeholders have distinctive needs for research-based information. The stakeholders also vary in their experiences with research. Consumers and their families benefit when research leads to improvements in the quality of services and results in better information for them about how best to make use of services. Consumers and their families rely heavily on information that is generated by stakeholders. Organizations that advocate for consumers rarely have sufficient resources to be able to sponsor research themselves. Consumer organizations may play a useful role in speaking for consumers in shaping research agendas and in interpreting research results for consumers.

For providers, research provides the basis for improving the quality and efficiency of services. Aware of the complexity of the service-delivery issues that confront them and their limited knowledge base, providers are often receptive to participating in research and demonstration efforts. Because service providers rarely have financial resources that would enable them to sponsor research themselves, they depend on government and foundation financing. The persistent shortage of funds for service-delivery research vastly reduces the extent to which new service strategies are designed and tested. A chronic shortage of research funds invites stagnation in the field at a time when its importance is growing and its complexities in the field are increasingly evident.

States enjoy primary responsibility for publicly-funded home and community-based long-term care services. Even though the federal government matches state Medicaid long-term care spending, states enjoy great discretion in the manner in which they design and administer their programs. The 2176 Waiver program explicitly encourages states to be innovative in the services they offer. However, states tend to lack a tradition of sponsoring service-delivery research. Accustomed to making decisions under pressure on the basis of imperfect information, states have tended to settle for “quick and dirty” studies that provide a modicum of guidance to policy development and management. Further, dissemination of research findings is rarely a priority for states when they sponsor service-delivery research. State participation in service-

delivery research has been strongest when the impetus for carefully designed research has been external. The field would benefit greatly if state agencies demanded stronger research data for the refinement of its programs and assumed some responsibility for sharing research findings with other states.

Long-term care insurance companies have reason to seek research data to assist them in designing policies, setting prices for policies, marketing policies, and refining their procedures to respond to claims. Unlike the other stakeholders in long-term care, insurance underwriters should be able to afford to sponsor the research needed by the industry. In fact, large insurance companies may be asked to go further to participate in financing research and demonstration projects that strengthen the field.

A Continuing Need for Research. The need for stronger research on service-delivery issues in long-term care is continuing. Because of growing demand for services, rising consumer expectations for service quality, changing capacity of families to provide care, increasing complexity of the interface with acute health care and rehabilitative services, and technical improvements in environmental supports and communication options, we can anticipate a continuing set of challenges and opportunities involved in service delivery in long-term care. For these reasons, the need for research and demonstration funding to stimulate innovation is continuous. Illustrative of the need for greater emphasis on long-term care research are the recommendations of the Institute of Medicine Committee on Improving Quality in Long-Term Care (Wunderlich & Kohler, 2000). The Committee has recommended funding of a research agenda to investigate the potential quality impact of consumer-centered long-term care services. The Committee has also recommended support for research toward further development of quality assessment instruments that can be used across different long-term care settings and with different population groups.

Productive Research Investments. Like other fields, long-term care needs careful investment of the resources that are available for research. The task of setting sound directions

for research in long-term care is challenging not only because of the complexity and decentralization of the field, but also because of its interrelationship with other fields (especially health), its lack of a distinct identity, and its weak professional traditions. The field needs research that goes beyond meeting immediate needs of policy makers and beyond building basic knowledge with minimal implications for service design and delivery. Rather, the field needs to build a body of knowledge about effective approaches to service delivery that will be disseminated effectively to those who finance, deliver, and consume services. The field, therefore, needs financial support to synthesize research findings, to build carefully upon existing knowledge, and to communicate implications of research to users. The field needs sustained nurturing of research that contributes both to the development of a field with its own body of knowledge and that encourages communication among researchers and other stakeholders in the field.

Need for Investigator-Initiated Research. For state governments, service providers, and consumer advocates, the need for continuing resources to support investigator-initiated research and demonstration projects is particularly important as a stimulus for creativity. Opportunities to permit the development and testing of approaches that arise from the field itself are important to attract and sustain creative, energetic leadership within the field. Knowledge that there are consistent sources of funds for service-delivery research will encourage state agencies, service providers, and consumer organizations to invest in development of research units that will compete for research funding.

Options for improved research funding. Because of the magnitude of the problem, the complexity of the issues, and the decentralization of the field, substantial and sustained research funding is needed. The field will benefit from multiple sources of research funding. Greater investment on the part of the federal government, foundations, and the long-term care industry will be welcome. Particularly useful will be dedicated funding programs that will give continuing support to the field because the advancement of long-term care is their mission.

The potential for stronger federal research support deserves particular consideration. During much of the 1990s, prospects for stronger federal support for long-term care research were bleak. Because of the over-riding effort on the part of the federal government to reduce its expenditures, all proposals for new or expanded federal funding faced severe obstacles during the decade. Long-term care research was not an exception. With the country now in the midst of great prosperity and with the federal government experiencing substantial budget surpluses, the climate may be more favorable for proposals to improve the federal funding base for long-term care research.

Stronger federal support for long-term care research can take a variety of forms. One possibility is for a decentralized approach with expanded funding in some or all of the federal agencies with a history of interest in various aspects of long-term care. Another possibility is the creation of a new entity in the Department of Health and Human Services with a mission to advance long-term care through research. An argument for a new entity is that the long-term field is large enough and different enough to merit sustained attention apart from mainstream health care. Because of the interrelationship of long-term care to other fields, various federal agencies will have reason to fund long-term care research even if there is a new entity dedicated to the subject.

Regardless of the form that expanded federal support for long-term care research may take, it is important that the research advance the development of the field. Stronger research is needed both to address immediate service delivery issues; research is also needed to develop new service approaches that will take advantage of advances in technology, anticipate the expanded demand that will come with the aging of the baby-boomers, and lay the ground work for the higher quality services that will be expected in the future.