

Long-Term Care Research and Policy

Peter Kemper, PhD¹

This article provides a framework for understanding how long-term care (LTC) research contributes to policy, develops a typology of research contributions to policy with examples of each type, and suggests ways to ensure that contributions continue in the future. The article draws on in-depth interviews with LTC experts working at the interface between research and policy, as well as a small, informal Internet survey and the relevant political science and health policy literature. LTC research makes important contributions to policy, but its contributions easily go unrecognized because they are subtle and often depend on research investments made many years before policy is affected. Thus, it is important to consider what investments in LTC research initiatives and infrastructure are needed to ensure the future contributions of research to policy and to identify barriers to funding such investments. A number of steps that researchers can take to enhance the future contribution of research to LTC policy are proposed.

Key Words: Policy research, Nursing home, Home and community-based services, Disability, ADLs

Long-term care (LTC) is an area of current public concern—concern that is certain to grow over time. Already the United States spends a great deal publicly and privately on LTC, and this spending does not take into account the non-monetary cost of the substantial care provided by family and friends (Feder, Komisar, & Niefeld, 2000). People with disabilities who require assistance with personal care and supportive services face difficult challenges in arranging and paying for that care. Their families often have difficulty balancing caregiving with work and other family responsibilities. The populations affected and the associated costs will increase substantially as the baby boom generation ages and chronic diseases, with their associated disability, become more prevalent (U.S. General Accounting Office [GAO], 2002a).

Given the growing LTC policy problem, it is appropriate to ask how research can best contribute to policy. The purpose of this article is to stimulate thinking within the LTC field about the contributions of research to policy and to suggest ways to ensure that contributions continue in the future. (The focus here is on policy, but research plays a similarly important role in practice; see Feldman & Kane, 2003). This article addresses four questions:

1. How does LTC research contribute to policy?
2. What LTC research investments are needed for future policy?
3. What are the barriers to investment in LTC research?
4. What can researchers do to enhance the future contributions of LTC research to policy?

An earlier version of this article was presented at the Academy for Health Services Research and Health Policy invitational conference, *Building the Field of Long Term Care*, held on June 17, 2002, in Chantilly, VA. This article was supported in part by AARP, the Agency for Healthcare Research and Quality, the Retirement Research Foundation, and the Robert Wood Johnson Foundation as part of their support for the conference. I would like to thank Erin Hirschbeck and Louise Meret-Hanke, who assisted with the review of the literature and preparation of the manuscript; Brian Burwell, Catherine Eikel, Penny Feldman, Katie Martin, Debbie Rogal, William Spector, and the conference participants, who provided helpful comments on an earlier version of this article; and the researchers and policy makers listed in Appendix A who generously spent time in telephone interviews for this project. Their insights have contributed greatly to this article. The views expressed, however, are my own.

Address correspondence to Peter Kemper, PhD, Department of Health Policy and Administration, 116 Henderson Building, The Pennsylvania State University, University Park, PA 16802. E-mail: pkemper@psu.edu

¹Department of Health Policy and Administration, The Pennsylvania State University, University Park.

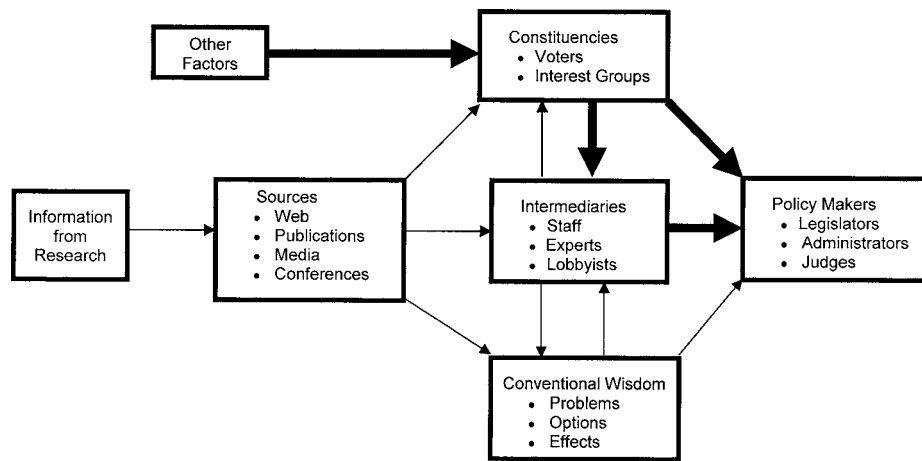


Figure 1. The role of research in policy.

This article is based on in-depth telephone interviews with experts on LTC policy, as well as the relevant health services and political science literature, a small informal Internet survey, and the author's own experience. The author conducted in-depth telephone interviews with 11 LTC experts who are knowledgeable about the role that research plays in policy. They included researchers who have held official policy positions, state policy makers, and academic researchers. (Respondents are listed in Appendix A.) They were asked about the LTC research that has been most useful for policy, how to increase the contributions of research to policy, and the most important research questions for LTC policy over the next decade. Questions were sent to respondents in advance of the telephone interview and served as a guide (see Appendix B). Interviews typically lasted about an hour.

The informal Internet survey also asked a small, convenience sample of researchers, practitioners, and policy makers about the contributions of research to policy and practice. A total of 25 people, mostly researchers, responded. The brief, open-ended survey asked respondents to identify studies that had influenced LTC service delivery and policy, the reasons the studies were influential, and the most important questions to be addressed through research in the next decade.

This article will argue that (a) LTC research makes important contributions to policy; (b) its contributions may not be recognized because they are not easily seen; (c) information that influences policy depends on research investments made many years earlier; (d) investments in LTC research initiatives and infrastructure are needed to ensure the future contributions of research to policy; and (e) LTC faces special barriers to investments in research. The article concludes with steps that researchers can take to ensure the future contributions of LTC research to policy.

The Indirect Route From Research to Policy

The route from research to policy is indirect, making the role of research difficult to identify. The simple framework in Figure 1 depicts how research affects policy. Politics, of course, is the dominant force affecting policy decisions, as indicated by the bold arrows from constituencies to policy makers. ("Policy maker" here refers to elected officials and politically appointed administrators. Judges are also policy makers, but the focus here is not on them.) Occasionally, research can affect the politics surrounding a policy directly or indirectly by influencing constituencies. This can happen, for example, when in response to significant research findings, policy makers become leaders shaping their constituents' views, or when media publicity surrounding a dramatic research finding influences public opinion. But it would be naïve to think that research is the determining factor in policy decisions—policy makers are driven primarily by their constituencies, not information from research. Thus, the assertion that research makes important contributions to policy must be interpreted realistically—recognizing that its contributions are made in the context of powerful political forces driven by other factors.

Research contributions are almost always indirect. Policy makers rarely get their information directly from research articles in journals; the primary route to policy makers is through intermediaries. Policy makers' staff are the most important of these intermediaries. They play the central role in obtaining, digesting, and interpreting research for the policy makers. Both policy makers and staff consult experts directly, hear their testimony or briefings, and rely on expert commissions. Indeed, research creates not only information but also experts. Thus, research plays an important indirect role by developing human capital in the form of expertise and analytic capacity that is difficult to tie

to specific research investments. These staff members and experts are the actors Kingdon (1995) referred to as “hidden participants” who form “communities of specialists” who are influential, particularly in developing policy options.

Lobbyists also are extremely important intermediaries between researchers and policy makers. Research plays an important role for lobbyists as “political ammunition” (Weiss, 1977). Lobbyists can be counted on to bring research favorable to their position to the attention of policy makers and their staff. Policy makers also get information from the media. Investigative reporting brings problems to their attention. Interest groups or their consultants create their own reports focused on specific policy issues.

Bombarded with information from so many sources—each with its own bias—policy makers and their staffs are faced with the challenge of determining what is valid. Objective syntheses, issue briefs, reports of commissions and expert panels, and organized briefings play important roles in sorting through the voluminous and conflicting information. The ultimate source of the credible information often is research, but these digested summaries do not always make that link clear. Again, the route is indirect.

Even when research is identified as the source of relevant information, participants in the political process may not regard research as having *any* effect because it was not the *desired* effect. For advocates of a particular policy position, information that does not support that position is an obstacle to advancing their cause. For better or worse, the findings of research often debunk conventional wisdom or are cautionary with respect to proposed policy changes. When research is cautionary, advocates of change understandably see research as not having made a useful contribution to policy.

The final, important route that research travels to reach policy makers is via changes in conventional wisdom—the generally accepted understanding of LTC policy problems, options, and the effects that policy changes would have. Conventional wisdom typically evolves slowly; the way people think about a problem is rarely changed as a result of a single study. For this reason, conventional wisdom, and changes to it, cannot be traced easily to the research that generated it. Weiss (1977) put it well: “Over time, the gradual accumulation of research results can lead to serious and far-reaching changes in the way people and governments address their problems” (p. 16). This unseen contribution of research to the working assumptions and context in which policy is made is perhaps the most important, if least visible, role that research plays in policy.

Whether information from research traverses a path to policy depends in part on timing. It is extremely difficult to predict when a window of opportunity for putting an issue on the political

agenda will open, but when it does, the information needed for policy and the capacity for analysis must already exist. If it is to influence policy, research cannot wait for an issue to appear on the political agenda because the window of opportunity does not remain open long (Kingdon, 1995). This also is true of expertise. Because it is an outgrowth of conducting research and policy analysis in a specialized area, the development of expertise takes a long time. It is available when policy makers need it only if the issue has already been an area of active research.

Contributions That Research Makes to Policy

LTC research has made important contributions to policy, although its impact is not always easy to identify because of the highly indirect route it takes. (“Research” here is defined broadly to include information based on theory, data, and analysis that is made publicly available through reports, white papers, issue briefs, and Web sites as well as peer-reviewed journals and books. Excluded are technical assistance and policy analyses that are primarily for internal use by government agencies.) Research contributions take a variety of forms. A typology of research contributions to policy is presented below with examples of each type. The intent is to be illustrative, not to be comprehensive or to judge the relative impact of the many research contributions that have been made to policy. The illustrations reflect the author’s own experience, resulting, for example, in an emphasis on older people rather than younger people with disabilities, and federal rather than state policy.

A Typology of Research Contributions

Understanding Problems.—Information from research creates awareness of new problems (present or future), refocuses attention on existing problems, or monitors the successes and failures of current policies. Kingdon (1995) referred to this as “problem recognition.” It is hard to overestimate the importance for policy of simple estimates of the size of a population, projections of its future size, trend data on social or program indicators, or studies documenting adverse policy outcomes. Such research makes the most easily recognized contribution to policy.

For example, research projecting the future need for LTC has played an important role in focusing policy attention on the LTC financing problem (e.g., GAO, 1999; Pepper Commission, 1990; Rivlin & Wiener, 1988). Similarly, studies of quality of care in nursing homes and assisted living have periodically refocused policy attention on quality problems (e.g., GAO, 1999, 2002b).

Research also can provide evidence that a problem is not as serious as generally believed. For example, contrary to the belief of some that family caregiving is declining, research on informal caregiving identified

the extensive amount of LTC that family members not only have provided historically but continue to provide (Spillman & Pezzin, 2000; Stone, Cafferata, & Sangl, 1987; Stone & Kemper, 1989). This is not an isolated example. Wiener and Harris (1990) identified eight important areas in which research has debunked myths about LTC.

Developing Policy Options.—Whether addressing policy innovations or modifications to existing policy, research plays an important role in identifying solutions to policy problems that can be incorporated into proposed legislation or administrative decisions. Kingdon (1995) referred to this as “alternative specification” and argued that researchers’ greatest role in the policy process is in defining policy alternatives.

For example, in response to concerns about the problem of quality of care in nursing homes, the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) commissioned the Institute of Medicine (IOM, 1986) to conduct a major review of ways to improve quality and its regulation. The IOM report with its recommended policy changes is generally credited with precipitating the Nursing Home Reform Act of 1987, which changed the way nursing home quality is regulated. The act led to the development of the standardized Resident Assessment Instrument (RAI) for care management in nursing homes. The RAI has been used to develop outcome measures of quality, improvements in methods for inspecting facilities and enforcing quality regulations, and data systems to disseminate quality information to consumers (Morris, Hawes, & Fries, 1990; Zimmerman et al., 1995). Similarly, in response to concerns about nursing home costs, research on case-mix methods for paying nursing homes has had direct application in Medicaid payment policy in many states (Fries et al., 1994), beginning with a demonstration in the late 1970s sponsored by the National Center for Health Services Research (now the Agency for Healthcare Research and Quality [AHRQ]) and evolving to the current version of Research Utilization Groups (RUGS-III).

Predicting Effects of Policies.—Having identified a reasonable set of options, policy makers ask what the effects of each policy will be. Who will be served? What will it cost? Are unintended consequences likely? Research addresses these questions by predicting the effects of policy alternatives compared with the status quo. Bardach (2000) referred to this as “projecting outcomes” of alternative policies. These projections play an important role in the political debate concerning legislation and are central to sound judgments about regulatory and payment policy. Two important types of research designed to predict effects of policies are (a) demonstration and evaluation research and (b) simulation modeling.

Demonstrations and evaluations undertaken to

test the effect of new policies were mentioned by respondents in the informal Internet survey more often than any other type of research as having influenced policy. Government demonstrations and evaluations have ranged widely, including home and community-based service (HCBS) demonstrations (Kemper, Applebaum, & Harrigan, 1987; Kemper et al., 1988; Weissert, Cready, & Pawelak, 1988), the Program of All-inclusive Care for the Elderly (PACE; White, Abel, & Kidder, 2000), the Social Health Maintenance Organization (S/HMO; Newcomer, Harrington, Manton, & Yordi, 1992; Wooldridge et al., 2001), and EverCare (Kane, Flood, Keckhafer, Bershadsky, & Lum, 2002) to name a few. Although they are most often congressionally mandated and government-financed, demonstrations are also supported by foundations. The Robert Wood Johnson Foundation Public-Private Partnership (McCall, 2001) and the Cash and Counseling Demonstration (Simon-Rusinowitz et al., 2001) are examples. All of these demonstrations, in varying degrees, have provided opportunities to test policy options, develop practical program experience, and establish networks of researchers and committed practitioners who are experts in the area.

Policy simulation models have been developed explicitly to estimate the effect of policy changes, particularly their impact on government expenditures. For example, in the mid-1980s Rivlin and Wiener (1988) developed a microsimulation model to project future need for LTC, its cost, and the distribution of cost among payers under alternative policy options. Later during the Clinton health care reform effort, this LTC financing model provided estimates of the cost of a wide range of options—from subsidizing private LTC insurance to universal public LTC insurance—and played a major role in refining these many options and the ultimate policy proposed.

Analysis of Behavior.—Research on behavior contributes to policy by determining what factors are related to outcomes of interest such as cost and quality. This understanding of behavior helps to identify where and how to intervene with government policy—that is, to identify policy options—and to predict how people will respond to policy changes. For example, a number of studies have investigated the determinants of nursing home use (for reviews, see Miller & Weissert, 2000; Norton, 2000), resulting in a better understanding of the factors that affect nursing home use. This understanding, in turn, has been the basis for developing eligibility criteria for HCBS programs and pre-admission criteria for nursing home care, as well as models of LTC use and cost.

Methodological Research.—Methodology has no immediate payoff for policy but can have significant long-term benefits. Perhaps the best example is the Public Health Service’s investment in the late 1950s

in Katz, Ford, Moskowitz, Jackson, and Jaffe's (1963) work on disability measurement. The resulting measure of ability to perform activities of daily living (ADLs) has been used in eligibility criteria for HCBS programs and nursing home care under Medicaid, requirements for private LTC insurance to qualify for tax deductibility, case-mix payment for nursing homes, and estimating the size of the population needing LTC—not to mention its pervasive importance in practice. The ultimate importance of this research for policy could not possibly have been seen at the time it was funded. It illustrates that investments in basic research with uncertain outcomes can have important unanticipated payoffs for policy decades later.

Data Infrastructure.—Investments in data collection also are without immediate benefit for policy, but national databases have been the foundation for countless contributions to policy. They have been used for analyses of behavior, comparison data for policy interventions, model development, and estimates of the scope of LTC problems. Indeed, any briefing book on LTC policy is certain to draw population estimates from the national LTC data infrastructure. For example, the National Long-Term Care Survey (NLTC), which began in 1982, has been used for all of these purposes. Examples of other significant ongoing national databases that play similarly important roles, each with its own special sample or content, include the Health and Retirement Survey, the National Nursing Home Survey, the Medical Expenditure Panel Survey, the Medicare Current Beneficiary Survey, and Medicare and Medicaid claims databases.

The Importance of Investments in Basic Research

The path from basic research to policy making is especially long, indirect, and difficult to see. Nonetheless, investments in basic research—particularly, methodological research and data infrastructure—well in advance of specific policy needs have important payoffs. For example, as indicated above, the Clinton health care reform effort relied on cost estimates from the LTC financing model. That simulation model was built on the foundation laid by a number of investments in basic research (see Figure 2). Starting with an existing model of income and savings for retirement, the LTC model added the need for LTC, service use, financing, and behavioral assumptions about LTC. This was achieved by drawing data from existing national databases, particularly the NLTC. Measures of need for LTC were drawn from the work of Katz among others. The choice of factors to include in modeling behavior was based on prior research on behavior, for example, the determinants of nursing home use.

Policy makers in the Clinton administration who saw only a table with cost estimates from this model

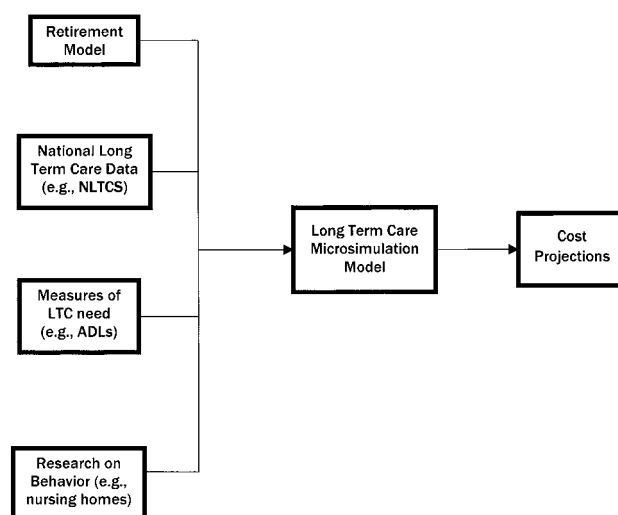


Figure 2. The contribution of basic research to cost estimates.

had no way of knowing about the history of investments in basic research that lay behind the estimates. Yet, investments in nursing home studies over many years, in microsimulation modeling in the mid-1980s, in the NLTC beginning in 1982, and in Katz's development of ADL measures starting in the late 1950s all had payoffs later in the capacity to estimate the cost of policy alternatives in 1993. The LTC financing model would not have been on the shelf when the Clinton administration officials needed it to make cost estimates if the underlying research had not begun decades earlier. In short, research investments must anticipate the needs of policy makers.

Research Needed for Future Policy

Where are research investments needed to inform LTC policy in the future? How can the research infrastructure be strengthened to support the contribution of LTC research to policy? Given the long lead time from investments in research to policy payoffs, these questions should be addressed in advance of the expected growth in demand over the coming decades.

Policy Issues That Call for Research

Eight policy issues for which research is needed are outlined below. In developing the list, the author drew in part on the responses from the in-depth telephone interviews and Internet survey about the most important questions to address in the next decade. Survey responses typically were more specific, and many are incorporated under these policy issues. Given the breadth of LTC and its myriad related policy problems, many potential research initiatives would be useful for future policy, and other research agendas have been articulated (e.g., Binstock & Spector, 1997; Spector, Shaffer, Hodlewsky, De La Mare, & Rhodes, 2002). It is clear

there is no shortage of growing LTC policy problems that call for additional research.

Improving State LTC Policy.—Eligibility, payment, and regulatory policy concerning nursing home, assisted living, and community-based services varies greatly across states. However, we do not know which combinations of policies are the most cost-effective. For example, some states have increased funding for both institutional and community care, whereas others have emphasized community over institutional spending. Similarly, financial eligibility for HCBS programs varies substantially across states. What are the effects of these alternative policies? A research initiative that provides state policy makers with information on which policies are effective might, for example, exploit these state policy variations as natural experiments to determine their effects on cost and outcomes, develop databases to support analysis of state variation, and create a Web repository of current evidence on state policies and what works.

Public Values Concerning LTC.—As acute care gives way to chronic care and people survive with disabilities, *saving life* gives way to *quality of life* as the goal of care. This raises important societal questions. How do we define the LTC problem? What do individuals and their families want? How much are we willing to invest in improving quality of life for persons with disabilities and decreasing levels of stress experienced by their family caregivers? Research is needed to frame the discussion of the LTC policy problem, articulate the goals of LTC, provide information on societal values about LTC, and expand the range of outcomes that are discussed in policy debates. Although LTC policy decisions inevitably are political, research that frames the problem and clarifies societal values has the potential to reorient thinking about the goals of LTC and remove an impediment to policy debate.

Financial Preparedness and Risk Spreading for the Middle Class.—A great deal of LTC policy is focused on people with limited financial resources, but LTC needs are not limited to the poor. At least under current policy, the middle and upper classes must rely on private savings, family caregiving, and private LTC insurance for their care. Indeed, regulation of private LTC insurance and additional tax breaks to encourage people to purchase it are areas of active policy interest. Without objective information on financial preparedness, risk spreading, and performance of the LTC insurance market, however, good policy is not possible. Research is needed to understand the LTC risks that individuals face, the extent of financial preparedness for them, the consequences of not being prepared, and the functioning of the growing private LTC insurance market.

Harnessing Technology to Prevent Disability and Improve Care.—Genetic research and information technology are transforming acute health care at a rapid rate, but technological change in LTC is much slower. This difference in the pace of change arises in part because the incentives that acute care insurance creates to develop new drugs and technology are largely absent in LTC. Policies that speed innovation in LTC could save public and private resources, help address the labor shortage, and improve quality of life. Research is needed in this underdeveloped area of policy to identify the current direction of technological change that affects LTC, explore the untapped potential for innovation, and understand how public policy affects the rate of technological change.

Integrating Acute Care and LTC.—As health care enters an era of increased medical care of chronic conditions, the question of integrating acute and LTC delivery—without subordinating LTC to acute care—becomes critical in care delivery. For policy makers, the question is how payment and regulatory policy can be used to increase the cost-effectiveness of acute and LTC through coordination or integration. Despite research on PACE, S/HMOs, and dual eligibles, much uncertainty remains about their effects and the role of capitation, eligibility criteria, and regulatory requirements on service delivery. Moreover, the range of policies that affect acute-LTC integration is quite broad. For example, policy decisions about risk adjustment for Medicare+Choice, end-of-life care, and the delivery of medical care to people in assisted living all affect the interface between acute care and LTC. Research is needed to identify the relationship between the acute care of chronic disease and LTC (without confusing them); analyze policies that are barriers to effective integration; and assess the effects of alternative policies on cost, quality of life, and family caregivers who manage these dual care needs.

Improving LTC Delivery Systems.—Two decades ago major policy concerns included the institutional bias in public funding for LTC, fragmentation in funding and delivery of community care, and quality of care. Since then, progress has been made, at least in many states. Home and community-based service programs have been expanded, assisted living has grown, and efforts to measure and monitor quality of care have been made. Now the question is how to improve the LTC delivery system's efficiency and quality of care through payment policy, regulation, and consumer information. The list of related policy questions is long, including: Would care payments that followed the individual, regardless of setting, result in delivery of care in the appropriate setting? Can outcome-based payment improve quality of care? How should quality of care in assisted living

and home care be regulated? How can policy encourage better training of LTC aides, increase retention, and increase the supply of workers? A research initiative to begin tackling such questions would help prepare the delivery system to cope with growing demand.

The Local Environment and LTC.—The environment in which people with disabilities live greatly affects their quality of life. If housing is not accessible, they may not be able to live in the community. Transportation affects their ability to get to work or other activities, to shop, or to access health and LTC services. Local government policies concerning transportation infrastructure, zoning, building codes, and planning, as well as funding for transportation and housing, all affect people with LTC needs through their environment. Relatively little is known about the relationship between these aspects of local community policy and LTC. Research directed at these issues is needed to ensure that the transportation, housing, and community environments are prepared for the growing proportion of the population with disabilities.

LTC Issue Awareness.—Projects that increase awareness of LTC problems and options are important for stimulating debate on LTC policy issues. Studies by the Institute of Medicine (e.g., IOM, 1996, 2001) and agenda-building projects (e.g., the Robert Wood Johnson Foundation's Georgetown University Long-Term Care Project and the Picker/Commonwealth Program on Long-Term Care for Frail Elders) are examples of efforts to focus policy makers' attention on LTC. Such issue-awareness projects must be repeated regularly because policy makers and their staffs constantly turn over.

Research Infrastructure

Research contributions to future policy will depend on a sound research infrastructure. Some of those interviewed for this article volunteered their opinion that the LTC field needs revitalization. Research contributions in recent years appear to have slowed compared with the active pace of the 1970s and 1980s. There are exceptions, of course, but the distinct impression is a field less vibrant than a decade or two ago. It is not clear whether this is due to having picked the low-hanging fruit early on, a decline in policy interest, the general decline in policy analysis capability in most parts of federal government, a decline in funding for major research and evaluation initiatives, or something else. But the field appears to be in need of new ideas and new blood.

Although efforts to stimulate fresh thinking in LTC are needed, specific steps toward that goal are not obvious. Creative thinking cannot be decreed, and new researchers cannot be ordered to become

interested in LTC. Undertaking the LTC research initiatives discussed above would certainly contribute, but what additional steps could be taken to increase the supply of new ideas?

More risks could be taken to support innovative projects that would not pass normal research funding processes. Government agency review for practical relevance and political feasibility, foundation review for promise of demonstrable direct impacts in the short run, and the academic peer-review process seeking analytic rigor and promise of publishable results—all can be biased against innovation. Thus, a larger portion of research funding could be devoted to demonstrations of policy options that are not currently considered politically feasible, research whose impact would be indirect or seen only over the long term, and creative research whose initial findings may not be publishable.

Additional investments to develop a cadre of new researchers are needed to bring new blood into the field. The National Institute on Aging (NIA) has supported valuable training grants emphasizing population aging, but fewer opportunities exist for training in the LTC services and policy areas. Expansion of training grants, targeted dissertation grants, and funding for new investigators focused on LTC would help develop a pool of experts to reinvigorate the field.

As indicated, the national data infrastructure is an essential underpinning for policy research. Substantial continued investment in the national surveys is needed to ensure their long-term continuity and to modify and improve them in response to changes in delivery systems, policy questions, measures, and data collection methods. Medicare, Medicaid, and other records data systems must be continually enhanced and made easily available to researchers; information on newer services like assisted living and private case management needs to be added to databases; and local area data systems need to be strengthened. Finally, continued efforts to increase the speed with which data are collected and made publicly available are needed to improve the timeliness of the information available to inform policy.

Finally, the institutions and infrastructure for LTC research need to be strengthened to ensure the vitality of the field. The field needs focal points for LTC research within the federal government, infrastructure to foster collaboration between state policy makers and researchers, and strong LTC interest groups within professional organizations. Institutes for LTC research within research firms, think tanks, and universities also can make important contributions to policy. Finally, establishing collaborative networks of researchers and policy analysts focused on specific policy problems is a highly effective way to develop Kingdon's (1995) "communities of specialists" that are so important to policy. Advances in information technology have

expanded greatly the opportunities to develop effective networks that are geographically dispersed.

Barriers to Investment in LTC Research

Research initiatives and infrastructure needed to inform future policy will require government and foundation investments. There are a number of barriers to increasing funding for LTC research, however. One barrier is common to many policy areas: the difficulty of establishing the contribution of research to policy because the path from research to policy is indirect. Because this contribution is subtle, it is difficult to demonstrate the value of investments in research and make the case for additional investments to policy makers and foundations. All policy areas face this barrier, but LTC has some characteristics that create additional barriers to investing in research.

Enormity of the LTC Problem.—The cost of addressing LTC needs will be great as the baby boom generation ages. Indeed, one of the successes of LTC research has been to identify the future demand for LTC and its associated uninsured cost. But the high cost of addressing the problem makes the issue politically unattractive. And when active policy interest in a problem is absent, policy makers' interest in funding research on the problem wanes.

Complexity of the LTC Problem.—LTC is not just a costly problem, it is also a complex problem. It has many facets, including disability, health, housing, transportation, insurance, saving, and income security. This means that policies also must be multifaceted, and therefore often are difficult to design and understand. The interdisciplinary nature of LTC also makes coordinated advocacy for research funding difficult.

Jurisdictional Fragmentation.—In part because of the multifaceted nature of the problem, jurisdiction over LTC is fragmented at both the federal and state levels. Jurisdiction is dispersed among legislative committees with responsibility for health, income security, tax, housing, and labor. Within the federal executive branch, no unit has responsibility only for LTC policy or research. LTC research funding comes principally from NIA, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, the Centers for Medicare and Medicaid Services, AHRQ, and the Administration on Aging, but none of these has LTC as its primary focus. This fragmentation of legislative and administrative responsibility for LTC policy and research disperses the political energy devoted to the issue and can create competition for funds between and within agencies.

Absence of Dramatic Human Problems With Dramatic Solutions.—Lack of LTC services leads to poor quality of life but in most cases is not immediately life threatening. Nor is there a dramatic cure for disability or alleviation of its effects. This is in sharp contrast with acute care, where diseases are fatal and cures can be miraculous. The broad support for the National Institutes of Health research funding illustrates the political value of the promise of dramatic solutions to dramatic problems—promises that LTC research can seldom make.

Absence of Shared Values About LTC.—Views concerning LTC policy vary widely, and the issues are not often articulated and discussed. For example, is LTC a public or private responsibility? How much responsibility do adult children have? What are the expectations about minimum levels of care and quality of life? Although LTC bears similarities to Social Security and Medicare as policy issues, societal values are articulated less clearly in the LTC arena.

Locus of LTC Policy in the States.—Although LTC is a joint federal-state responsibility, LTC policy is made primarily at the state level. Medicaid, LTC's largest public payer, is administered by the states, which also regulate providers and insurers and run state programs. Thus, many policy questions arise and are answered in different ways in the 50 states. Federal government motivation for funding LTC research is diminished when it does not have specific policy responsibility for LTC. At the same time, states have not had the tradition or the budget to fund substantial amounts of research or policy analysis. Foundations have funded research at the state level, including research that is part of larger cross-state initiatives. However, for foundations, state-by-state research projects are not as visible as national research initiatives.

Ensuring the Future Contribution of LTC Research to Policy

What can researchers do to ensure that LTC research continues to have an impact on policy? They can advocate for the investments required for the future and take steps to enhance the contribution of their own research to policy.

Advocating for Investments in LTC Research

Advocacy must go beyond simply asking for money; it must include targeted marketing of past contributions by making the link between research and policy more visible and articulating future need for LTC research. For most researchers, the natural vehicles for advocacy are their professional associations. Currently, there is no professional focal point or advocacy organization devoted specifically to

LTC research. The three main professional research organizations that include LTC researchers—AcademyHealth (formerly the Association for Health Services Research), The Gerontological Society of America, and the American Public Health Association—have a much broader scope of professional interests, so LTC plays a relatively small role within these organizations. The absence of a professional focal point for LTC research advocacy poses a challenge to the field. Researchers can work through the relevant special interest groups within these professional organizations to encourage them to take a more active role in promoting LTC research.

Researchers also can help by articulating a forward-looking vision of LTC research and working for funding of visible research initiatives that are (a) focused on well-defined problems and (b) substantial enough to have an impact on those problems. A well-defined focus on a specific policy problem avoids the enormity and complexity of the entire LTC problem, the daunting nature of which discourages policy interest. A well-defined focus also makes the research tractable. Large scale is important because large initiatives have greater visibility, which increases their impact. They also develop focal points for research on the problem and networks of researchers who spawn additional research and interest—note the successful network created around the Minimum Data Set for nursing homes. Large initiatives also create the opportunity for senior investigators to pull in junior investigators, who, with sufficient funding over an extended period of time, may develop into a new cadre of LTC researchers. Finally, large initiatives create opportunities for public-private and multi-foundation efforts. These initiatives will make greater contributions if they strive for balance among types of research by including basic as well as applied research.

Beyond the pursuit of research support in general, advocacy should include efforts to build research into specific program legislation. For example, set-asides for program evaluation, monitoring, and development can be included in legislation that establishes new programs or reauthorizes existing ones.

In addition to policy makers, marketing efforts should target interest groups whose constituencies need or provide LTC. Groups that advocate for the aged and groups that advocate for nonelderly persons with disabilities are the most obvious, but it may also be useful to target untapped kindred spirits who have an interest in LTC from a different perspective, such as chronic disease groups and advocates for working women.

Increasing the Contribution of Researchers' Own Research to Policy

How can researchers increase the contribution of their own research to policy? This is not a new

question. Interest in increasing the role of research in policy in general and prescriptions for doing so go back at least three decades (Weiss, 1977). Researchers can take a number of specific steps toward this goal. To start, researchers can understand and explicate the policy importance of their own research. Sometimes researchers do not recognize the importance of their research for policy, particularly if it is basic research or the development of data infrastructure. Once recognized, researchers can make the link more visible by clarifying the contribution of their research to policy in their own writing and presentations.

Researchers can increase their efforts to communicate their results beyond peer-reviewed journals. This has become imperative as the volume of information has exploded and assaults on policy makers' time have increased in sophistication. Fortunately, improving communication with policy makers and intermediaries has received much recent attention (e.g., Feldman, Nadash, & Gursen, 2001; Sorian & Baugh, 2002).

One specific step toward improved communication is to write issue briefs that convey findings in a short, easily understood format. Another is participation in efforts to bring research findings to the busy staff of policy makers. The National Health Policy Forum and the AHRQ User Liaison Program are examples of successful efforts to link researchers and their findings with policy makers at the federal level. Researchers also can release their findings on policy Web sites. Continuing development of Web sites that summarize the latest research increases policy makers' access to up-to-date information. Finally, researchers can write syntheses for policy makers, particularly at the state level, and thereby provide much-needed, thoughtful assessments of what is known about the policy issues that concern them. These will be most useful if researchers first ask policy makers what their questions are and then synthesize the evidence to answer those questions rather than simply providing a comprehensive catalog of the existing literature.

Researchers can increase their impact through more engagement with policy intermediaries and policy makers, not just after the research is done but from its inception. Involvement of users in framing the question and in analysis as the research unfolds increases its usefulness. Research centers at universities can provide the infrastructure to bring researchers and policy makers together on applied research projects. This helps to develop relationships between researchers and policy makers and provide feedback opportunities (Lomas, 2000). A number of successful centers already exist (Coburn, 1998). Researchers also can spend time, for example, on sabbaticals, working in government policy units with similar benefits.

So far, the steps identified are relevant to researchers who conduct applied, policy-directed research and

wish to increase their direct impact. However, one size does not fit all researchers. Nor, given the importance of basic research and the indirect impacts emphasized above, would it be desirable for all researchers to conduct and communicate policy-directed research. Researchers can make essential contributions by identifying and filling substantive gaps in our understanding of LTC and policies that affect it. Indeed, not infrequently, absence of evidence rather than communication has been the reason policy has not been informed by research. For example, finding sufficient LTC research relevant to the needs of state policy makers has been a challenge for the User Liaison Program.

Researchers who collect data can make it available quickly and widely to others. Collecting data is time-consuming, and sharing it has little professional payoff for researchers. The payoff for policy, however, can be great. Unnecessarily slow data collection and stories of researchers who will not share their data, even with government agencies, do little to enhance policy makers' desire to support data collection.

Finally, researchers can work within the research community to ensure that these kinds of efforts to improve the contribution of research to policy are accepted as legitimate activities that are valued in promotion decisions, and faculty can include these skills in graduate training programs.

Conclusion

Researchers and policy makers may perceive research as having little impact on policy. This article has argued to the contrary that research makes an important—albeit often subtle—contribution to improving policy and that its contribution depends on research foundations laid many years in advance of the policy need. The contribution often is invisible, however, because the route from research to policy is indirect. As a consequence, research is sometimes perceived as having little benefit for policy. That perception combined with some unique features of LTC create barriers to investments in LTC research and infrastructure by governments and foundations.

Moreover, because a compelling short-term problem does not exist, policy makers are not currently debating LTC policy issues. Without an active policy debate, interest wanes in research investments. LTC policy issues, however, promise to become compelling over the next several decades as health conditions continue to shift from acute to chronic and as the baby boom generation ages. As LTC demand increases, LTC policy issues will become more difficult to ignore. The challenge for forward-looking leaders in the research, foundation, and government communities is to focus attention on the need for investment in LTC research. That investment is needed now not just to address today's

policy questions but to lay the foundation for addressing LTC issues in the future when windows of opportunity for policy change open.

References

- Bardach, E. (2000). *A practical guide for policy analysis: The eightfold path to more effective problem solving*. New York: Chatham House.
- Binstock, R. H., & Spector, W. D. (1997). Five priority areas for research on long-term care. *Health Services Research, 32*, 715–730.
- Coburn, A. F. (1998). The role of health services research in developing state health policy. *Health Affairs, 17*(1), 139–151.
- Feder, J., Komisar, H. L., & Niefeld, M. (2000). Long-term care in the United States: An overview. *Health Affairs, 19*(3), 40–56.
- Feldman, P. H., & Kane, R. L. (2003). Strengthening research to improve the practice and management of long-term care. *The Milbank Quarterly, 81*, 179–220.
- Feldman, P., Nadash, P., & Gursen, M. (2001). Improving communication between researchers and policy makers in long-term care: Or, researchers are from Mars; policy makers are from Venus. *The Gerontologist, 41*, 312–321.
- Fries, B. E., Schneider, D., Foley, W., Gavazzi, M., Burke, R., & Cornelius, E. (1994). Refining a case-mix measure for nursing homes: Resources utilization groups (Rugs-III). *Medical Care, 32*, 668–685.
- Institute of Medicine. (1986). *Improving the quality of care in nursing homes*. Washington, DC: National Academy Press.
- Institute of Medicine. (1996). *Nursing staff in hospitals and nursing homes: Is it adequate?* Washington, DC: National Academy Press.
- Institute of Medicine. (2001). *Improving the quality of long-term care health care services*. Washington, DC: National Academy Press.
- Kane, R. L., Flood, S., Keckhafer, G., Bershadsky, B., & Lum, Y. S. (2002). Nursing home residents covered by Medicare risk contracts: Early findings from the Evercare evaluation project. *Journal of the American Geriatrics Society, 50*, 719–727.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). The Index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association, 185*, 894–919.
- Kemper, P., Applebaum, R., & Harrigan, M. (1987). Community care demonstrations: What have we learned? *Health Care Financing Review, 8*(4), 87–100.
- Kemper, P., Brown, R. S., Carcagno, G. J., Applebaum, R. A., Christianson, J. B., Corson, W., et al. (1988). The evaluation of the National Long-Term Care Demonstration. *Health Services Research, 23*(1), 1–174.
- Kingdon, J. W. (1995). *Agendas, alternatives, and public policies* (2nd ed.). New York: Addison-Wesley.
- Lomas, J. (2000). Using “linkage and exchange” to move research into policy at a Canadian foundation. *Health Affairs, 19*(3), 236–240.
- McCall, N. (2001). *Who will pay for long-term care? Insights from the Partnership programs*. Chicago: Health Administration Press.
- Miller, E. A., & Weissert, W. G. (2000). Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: A synthesis. *Medical Care Research and Review, 57*, 259–297.
- Morris, J. N., Hawes, C., & Fries, B. E. (1990). Designing the national Resident Assessment Instrument for nursing homes. *The Gerontologist, 30*, 11–14.
- Newcomer, R., Harrington, C., Manton, K., & Yordi, C. (1992). *Second interim report on the Social Health Maintenance Organization demonstration: The first 56 months*. San Francisco: Institute for Health and Aging, University of California San Francisco.
- Norton, E. C. (2000). Long-term care. In A. J. Culyer & J. P. Newhouse (Eds.), *Handbook of health economics* (pp. 956–994). New York: Elsevier.
- Pepper Commission. (1990). *A call for action*. Washington, DC: U.S. Government Printing Office.
- Rivlin, A. M., & Wiener, J. M. (1988). *Caring for the disabled elderly: Who will pay?* Washington, DC: The Brookings Institution.
- Simon-Rusinowitz, L., Mahoney, K. J., Shoop, D. M., Desmond, S. M., Squillace, M. R., & Sowers, J. A. (2001). Consumer and surrogate preferences for a cash option versus traditional services: Florida adults with developmental disabilities. *Mental Retardation, 39*, 87–103.
- Sorian, R., & Baugh, T. (2002). Power of information: Closing the gap between research and policy. *Health Affairs, 21*(2), 264–273.
- Spector, W. D., Shaffer, T. J., Hodlewsky, R. T., De La Mare, J. J., & Rhodes, J. A. (2002). *Future directions for community-based long-term care health services research*. Rockville, MD: Agency for Healthcare Research and Quality.
- Spillman, B. C., & Pezzin, L. E. (2000). Potential and active family caregivers: Changing networks and the “sandwich generation.” *Milbank Quarterly, 78*, 347–374.

- Stone, R. I., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist*, 27, 616-626.
- Stone, R. I., & Kemper, P. (1989). Spouses and children of disabled elders: How large a constituency for long-term care reform? *Milbank Quarterly*, 67, 485-506.
- U. S. General Accounting Office. (1999). *Assisted living: Quality of care and consumer protection issues in four states* (Publication No. HEHS-99-27). Washington, DC: Author.
- U. S. General Accounting Office. (2002a). *Long-term care: Aging baby boom generation will increase demand and burden on federal and state budgets* (Publication No. GAO-02-544T). Washington, DC: Author.
- U. S. General Accounting Office. (2002b). *Nursing homes: More can be done to protect residents from abuse* (Publication No. GAO-02-448T). Washington, DC: Author.
- Weiss, C. H. (1977). *Using social research in public policy making*. Lexington, MA: Lexington Books.
- Weissert, W. G., Cready, C. M., & Pawelak, J. E. (1988). The past and future of home- and community-based long-term care. *Milbank Quarterly*, 66, 309-388.
- White, A. J., Abel, Y., & Kidder, D. (2000). *Evaluation of the Program of All-Inclusive Care for the Elderly demonstration: A comparison of the PACE capitation rates to projected costs in the first year of enrollment*. Boston: Abt Associates.
- Wiener, J. M., & Harris, K. M. (1990). Myths & realities: Why most of what everybody knows about long-term care is wrong. *Brookings Review*, 8(4), 29-34.
- Woodridge, J., Brown, R., Foster, L., Hoag, S., Irvin, C., Kane, R. L., et al. (2001). *Social health maintenance organizations: Transition into the Medicare+Choice program*. Princeton, NJ: Mathematica Policy Research.
- Zimmerman, D. R., Karon, S. L., Arling, G., Clark, B. R., Collins, T., Ross R., et al. (1995). Development and testing of nursing home quality indicators. *Health Care Financing Review*, 16(4), 107-127.

Received September 25, 2002

Accepted April 11, 2003

Decision Editor: Linda S. Noelker, PhD

Appendix A

Respondents and Selected Experience

- Richard Browdie, President and CEO, Benjamin Rose and former Secretary of Aging, Commonwealth of Pennsylvania.
- Judith Feder, Dean of Public Policy, Georgetown University; former Principal Deputy Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; and former Staff Director of the Bipartisan Commission on Comprehensive Health Care (the Pepper Commission).
- Mary Harahan, long-term care consultant; former Work Group Leader, Clinton Health Reform Task Force; and former Deputy to the Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, U.S. Department of Health and Human Services.
- Diane Justice, Senior Research Manager, MEDSTAT and former Deputy Assistant Secretary for Aging, U.S. Department of Health and Human Services.
- Robert Kane, Professor, Minnesota Chair in Long-Term Care and Aging and Professor, Division of Health Services Research and Policy, School of Public Health, University of Minnesota.
- Rosalie A. Kane, Professor, Division of Health Services Research and Policy, School of Public Health, University of Minnesota.
- Barbara Manard, Principal, The Manard Company and independent consultant on state and federal long-term care payment rates and financing.
- Robert Mollica, Senior Program Director, National Academy for State Health Policy and former Assistant Secretary for Policy and Program Development, Massachusetts Executive Office of Elder Affairs.

- William Scanlon, Director of Health Care Issues, U.S. General Accounting Office.
- Robyn Stone, Executive Director, Institute for the Future of Aging Services; former Deputy Assistant Secretary of Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation; and former Assistant Secretary of Aging, U.S. Department of Health and Human Services.
- Joshua Wiener, Principal Research Associate, The Urban Institute and former Work Group Leader, Clinton Health Reform Task Force.

Appendix B

Questions for In-Depth Telephone Interviews

Thank you very much for agreeing to be interviewed. As indicated earlier, the interview will provide input to a paper on contributions of research to long-term care policy and ways of strengthening that contribution. It is part of an effort to assess the role of research in shaping long-term care. This paper and a parallel paper on practice and service delivery will be presented at a conference in June funded by AARP, the Agency for Healthcare Research and Quality, the Retirement Research Foundation, and the Robert Wood Johnson Foundation. The questions I plan to ask are listed below.

- In your view, what information (derived from research) has been most useful for long-term care policy? What impact has it had on policy? Specific examples would be most helpful. We have identified the following types of information but do not be constrained by them:
 - Information on the scope of a problem
 - Projections of the effect of policy changes
 - Methods for administering public programs
 - Identification of policy innovations or policy improvements
- In your view, what types of investments in LTC research have had the largest pay-off for policy? How have they benefited policy making? Specific examples would be most helpful. We have identified the following types of research but do not be constrained by them:
 - Policy research
 - Program administration research
 - Policy analysis and cost estimates
 - Implementation research and program case studies
 - Basic research
 - Data infrastructure
 - Demonstrations and evaluations
 - Analyses of behavior
 - Methodological research
 - Development of microsimulation models
 - Training
 - Dissemination
- What steps should be taken to strengthen the contribution that research makes to policy?
- What investments in long-term care research over the next decade would have the highest payoff for policy?
- What are the most important research questions that should be addressed over the next decade to inform LTC policy making?
- Do you have any other comments or suggestions about what to include in the paper to make it more useful to the audience?