



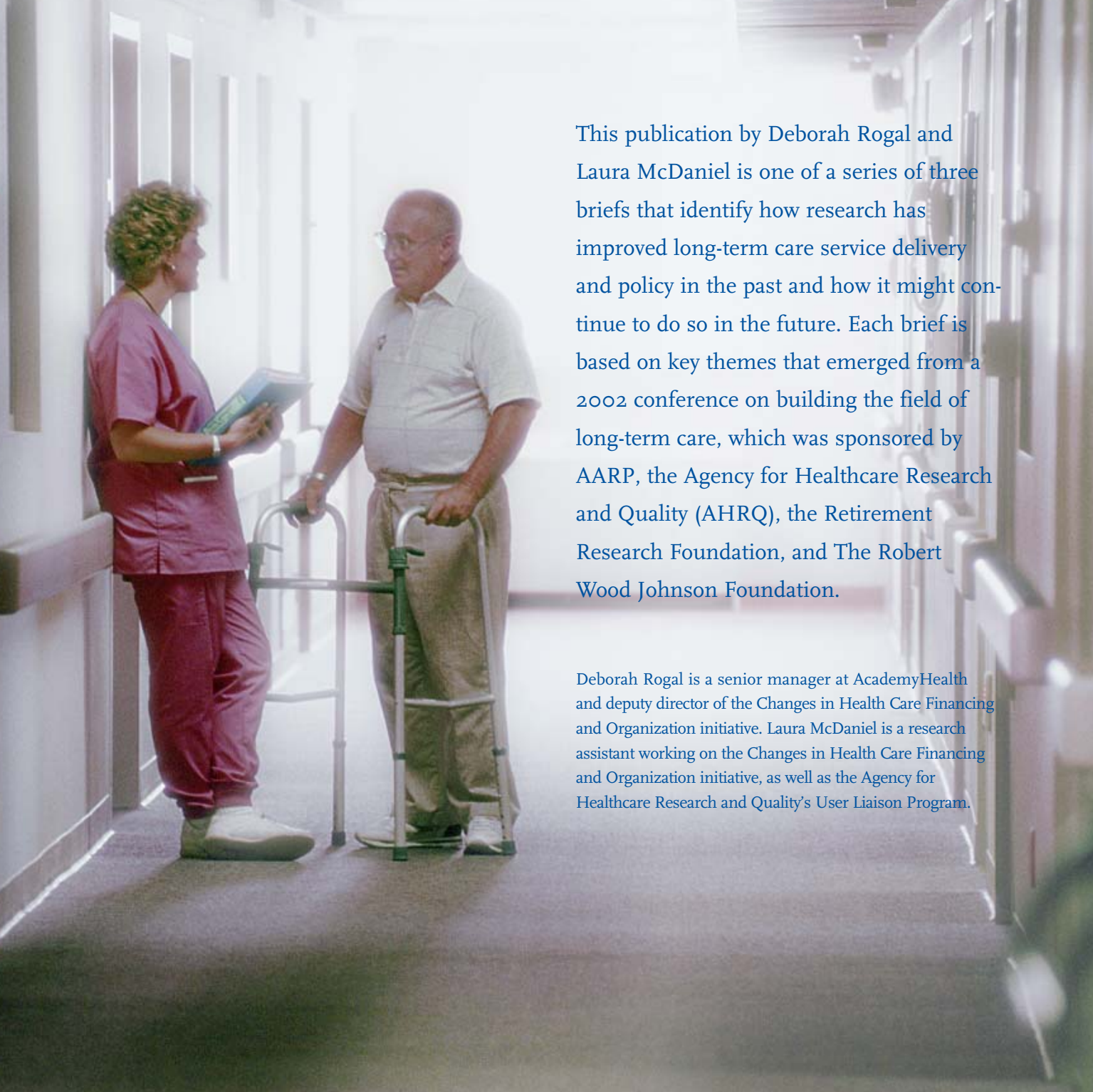
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Advancing Research, Policy and Practice



long-term care

Collaborating for
Solutions



This publication by Deborah Rogal and Laura McDaniel is one of a series of three briefs that identify how research has improved long-term care service delivery and policy in the past and how it might continue to do so in the future. Each brief is based on key themes that emerged from a 2002 conference on building the field of long-term care, which was sponsored by AARP, the Agency for Healthcare Research and Quality (AHRQ), the Retirement Research Foundation, and The Robert Wood Johnson Foundation.

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Several formal collaborations among providers, policymakers, and researchers have been established to improve service delivery, policymaking, and research related to long-term care. Although these collaborations differ in their structure, source of financing, and working relationships, they are all designed to increase understanding of issues that might be addressed by research or policy. They also are intended to ensure that research is applied appropriately to pragmatic day-to-day issues in long-term care delivery and financing.

These arrangements have had considerable influence in improving long-term care delivery and providing specific, policy-oriented research to answer pressing questions. This brief highlights the challenges and achievements of six successful collaborations.¹

Background

Serious concerns exist about the delivery and financing of long-term care in the United States. The aging population, rising health care costs, reductions in retirees' health care coverage benefits, and constraints in state Medicaid budgets have all contributed to uncertainty about how the United States will continue to care for its elderly. In 1960, there were

16.6 million adults over age 65 (9.2 percent of the population) and 2.5 million over age 80 (1.4 percent);² by 2000, those numbers had grown to 34.9 million (13 percent of the population) and 9.3 million (3.4 percent), respectively.³

Some argue that the growth in the elderly population does not necessarily imply a parallel increase in demand for long-term care services, because people are generally healthier now than they were in past decades.⁴ In addition, the elderly may be wealthier in 2030 and therefore better able to handle health-related financial shocks.⁵ However, it seems clear that the number of individuals requiring long-term care services, as well as the costs of providing those services, will continue to rise for the foreseeable future.

Providers, policymakers, and researchers strive for better ways to identify the need for long-term care services and to provide and finance those services. Often, however, they are not able to coordinate their efforts to identify the most important problems or to share the necessary data to develop or evaluate interventions to improve care. Collaborations among providers, policymakers, and researchers provide a vehicle to improve communica-

Environmental Design for Dementia Care

A study by researchers at the former Philadelphia Geriatric Center (PGC), now Abramson Center for Jewish Life, led to the creation of a therapeutic living environment for older people with Alzheimer's disease and other forms of dementia. The Sley Pavilion of the former PGC's Weiss Institute, which opened in 1974, was the nation's first nursing home built for elderly people with dementia. Its design features large central spaces that give residents access to people and activities, as well as gazebos and semi-private bedrooms to accommodate residents' needs for quiet time and privacy.

The model, incorporating homelike settings arranged in clusters with common access to shared activities and services, continues to be a seminal influence on nursing home design. This research also laid the groundwork for architects to specialize in aging and environmental design. Today, Polisher Research Institute scientists are creating a Web-based dictionary of environmental design features to assist long-term care professionals.

Congregate Living Models

Researchers at the Research and Training Institute (RTI) at the Hebrew Rehabilitation Center for Aged (HRCA) undertook several studies to examine home-based long-term care service models, with and without a clinical component. The investigations were funded by the Department of Housing and Urban Development, the Office of the Assistant Secretary of Planning and Evaluation of the Department of Health and Human Services, and the National Institutes of Health. They found that individuals who otherwise would have required nursing home care could live in the community with a modified medical component.

tion among these groups of professionals and ultimately enhance the usefulness of research and improve the quality of long-term care services.

Types of Collaborations

The most common type of collaborative arrangements among researchers, policy-makers, and providers are contractual relationships between states and researchers and research centers within provider organizations. However, there are also less structured relationships (e.g., the Scripps Gerontology Center; see p. 3).

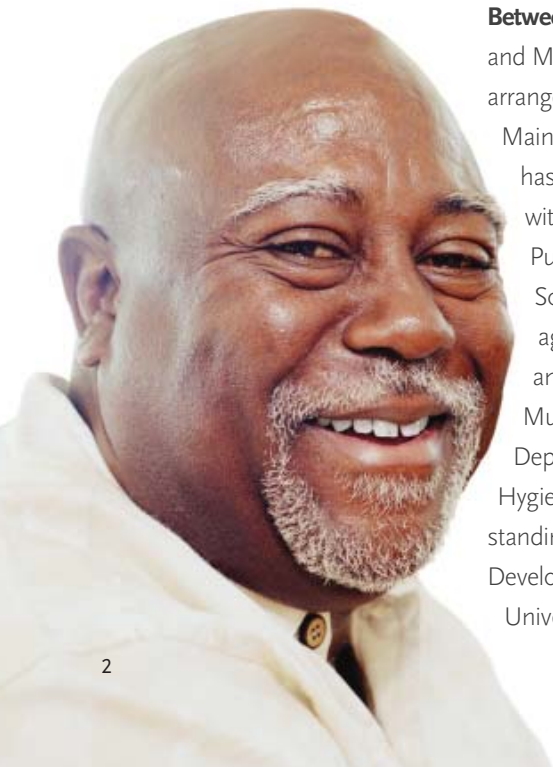
Between States and Researchers: Maine and Maryland have entered into contractual arrangements with university researchers.

MaineCare, the state's Medicaid program, has an omnibus cooperative agreement with the Edmund S. Muskie School of Public Service at the University of Southern Maine. In addition, other state agencies, such as the Bureau of Elder and Adult Services, also contract with the Muskie School. Similarly, the Maryland Department of Health and Mental Hygiene has a memorandum of understanding with the Center for Health Program Development and Management at the University of Maryland.

In addition to conducting research activities designed to connect research, practice, and public policy and improve people's lives, the Muskie School operates the state's internal data infrastructure, including the Minimum Data Set, a federally mandated documentation system that helps nursing home staff gather information on residents' health and needs. The University of Maryland's Center for Health Program Development and Management was created to establish an analytic capability to support the Maryland Department of Health and Mental Hygiene in evaluating its Medicaid program. The Center also conducts requested research on a variety of policy issues that arise throughout the year.

Between Providers and Researchers:

The Center for Home Care Policy and Research of the Visiting Nurse Service of New York (VNSNY) conducts policy-relevant research promoting the delivery of high-quality, cost-effective care to support decision-making by policymakers, providers, and consumers of home and community-based services. The Polisher Research Institute of the Madlyn and Leonard Abramson Center for Jewish Life in Horsham, Pa., is devoted to enhancing the quality of life for older people by providing high-quality care that is strengthened by teaching and research.



The Research and Training Institute (RTI) of the Hebrew Rehabilitation Center for Aged (HRCA) in Boston strives to maximize the functional potential and quality of life of elderly people. Much of its research focuses on gerontology and geriatrics leading to changes in the delivery of elder care in institutional settings.

Each research group functions under the umbrella of the provider organization and attempts to balance its need to meet that organization's goals with a desire to disseminate findings more broadly and contribute to widespread improvements in long-term care. "The Polisher Research Institute is an integral part of the whole," says Frank Podietz, CEO of the Abramson Center, "like a finger on a hand."

Among Researchers, Providers, and

Policymakers: The Scripps Gerontology Center at Miami University of Ohio, whose mission is to contribute knowledge that is essential for meeting the challenges of an aging society, has contracts from both providers and policymakers, allowing it to serve as a "clearinghouse" or "broker" among researchers, policymakers, and providers.⁶ Scripps has long-standing relationships with the Knolls of Oxford, a con-

tinuing care community, and various state agencies in Ohio, including the Department of Aging.

Funding Sources

Collaborative efforts rely on a variety of funding sources, including:

- ▶ state governments;
- ▶ grants from foundations or the federal government; and
- ▶ endowments.

Research centers that operate within non-profit provider organizations often receive direct or in-kind funding from their organizations. Although these collaborations require a financial commitment, they provide value to the parent organization and the field of long-term care. Non-profit organizations, which are required to demonstrate a community benefit, frequently view building the knowledge base through a research center as an integral part of their mission.

The Center for Home Care Policy and Research, with a total annual budget of approximately \$3 million, receives about 20 percent of its funding from VNSNY and the rest from outside grants. Funding for the Polisher Research Institute of the Abramson

Geriatric Assessment Tools

Polisher Research Institute researchers have helped develop some of the most widely used psychological and social geriatric assessment tools, including the Instrumental Activities of Daily Living (IADL), a universally accepted measure of seniors' capacity for self-care. IADL measures have been incorporated into all major aging and disability surveys. Polisher researchers also contributed to the design of the PGC Morale Scale, a tool that measures psychological state, and, more recently, the Observed Emotion Rating Scale, which uses non-verbal cues to assess the emotions of nursing home residents with dementia. To disseminate this tool, the Institute has produced and distributed a training video to teach staff how to recognize and respond to emotions in persons with dementia.

Federal Minimum Data Set

In the late 1980s, a researcher at RTI at the HRCA helped develop the federal government's Minimum Data Set (MDS), a federally mandated documentation system that aids nursing home staff in gathering information on residents' health, needs, and strengths. The MDS is used to identify potential problems during nursing home admissions, annual reviews, and when a resident's condition appears to change. In a recent study that compared health conditions of elderly nursing home residents before and after implementation of MDS, RTI researchers, along with a national team, found a 28 percent decrease in the rate of hospitalization among the frailest nursing home residents, with no increase in death rate, after the MDS was put into operation.⁷

Center has varied substantially over the years, ranging from \$2 million to \$6 million. Roughly 80 percent of the money comes from grants and contracts, and the remaining 20 percent is a combination of operating and endowment funds.

The RTI of the HRCA derives 80 percent of its funding from grants and contracts, primarily through the federal government. About 12 percent of its revenue comes from indirect cost recovery, and the remaining 8 percent represents income on the endowment (4 percent is earmarked for research).

The Muskie School's agreement with MaineCare is currently funded at \$2.2 million from the state. However, the funding level varies from year to year, and the contract covers a wide range of health policy topics in addition to long-term care. The school contracts with other state agencies and has some funding through grants. The Maryland Center is supported primarily by the state budget, but is supplemented by a mix of resources, including direct support from the university and grants. The Scripps Gerontology Center is funded by a combination of endowment funds, university support, and grants for approximately \$1.5 million annually.

Challenges

The major challenges that collaborations face include:

- ▶ maintaining fiscal viability;
- ▶ jointly developing a research agenda that advances the intellectual and publication goals of researchers as well as the pragmatic needs of their partners; and
- ▶ maintaining the integrity and objectivity of research within an organization with vested interests.

Fiscal difficulties are particularly acute for research centers that are not affiliated with universities and, in the current weak economy, for those that depend on state funds. "Everyone wants answers," says one state official, "but no one wants to pay for research." Research centers affiliated with non-profit organizations frequently rely on grants and other "soft money." They cannot count on supplemental funding produced through reimbursement from teaching, as some university researchers can.

The research agenda in collaborations may be jointly developed, but is often driven by investigators in provider-researcher collaborations. The degree to which researchers choose to conduct work that focuses on the needs of their "parent" (provider) agency

varies and is often dependent on available funding and whether that funding comes from outside sources or is part of the provider organization's budget.

Researchers at some centers are affiliated with universities (e.g., most of RTI's faculty at the HRCA have appointments with Harvard). For those that cannot offer university affiliation, it is sometimes difficult to recruit investigators who are dedicated to the research organization's mission. Researchers must maintain the objectivity and integrity of their work, while collaborating closely with those who have a vested interest in their results.

The communication challenges and cultural differences that exist among researchers and policymakers, and researchers and providers are well-documented.⁸ University researchers operate in a "publish or perish" world, in which the publication of research in a peer-reviewed journal is often the prerequisite for success, and the journals, in turn, often require an embargo on the release of findings until the article has appeared in print. Providers or policymakers, on the other hand, have very concrete problems affecting day-to-day operations or fiscal viability, for which they seek immediate answers.

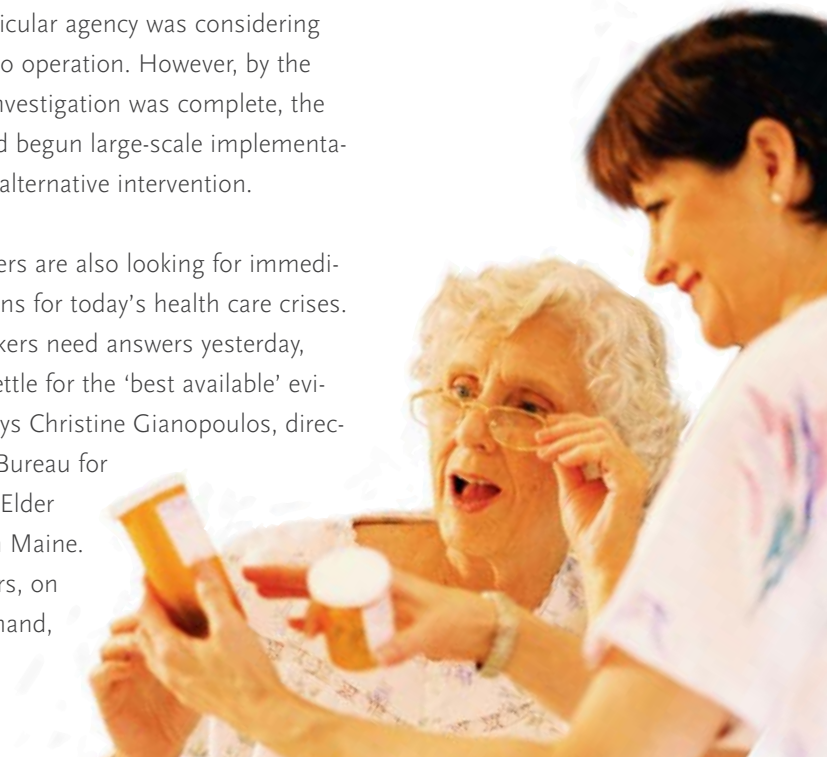
"In the provider setting, information and answers are often needed quickly," says Vicki Freedman, director of the Polisher Research Institute. "But the research frequently takes a year or more." Joan Marren, chief operating officer of the VNSNY, agrees. "Researchers progress along a timeline that is outside of the one in which the service delivery sector is forced to make changes," she says.

Even research that is directly relevant to a provider organization can be difficult to apply. In one case, researchers undertook a rigorous evaluation of an intervention that a particular agency was considering putting into operation. However, by the time the investigation was complete, the agency had begun large-scale implementation of an alternative intervention.

Policymakers are also looking for immediate solutions for today's health care crises. "Policymakers need answers yesterday, and can settle for the 'best available' evidence," says Christine Gianopoulos, director of the Bureau for Adult and Elder Services in Maine. Researchers, on the other hand,

Reducing Medication Errors in Home Health Programs

Researchers at the Center for Home Care Policy and Research at VNSNY conducted one of the first studies to examine medication errors among those receiving home health services. They found that nearly one-third of home-care patients aged 65 and older had usage patterns that signaled "potential" medication errors.⁹ A second study tested a strategy to reduce these errors, and found that a program that includes consultation with a pharmacist can reduce the potential for errors. This intervention could decrease the health care costs that result from adverse events, as well as total drug costs.¹⁰ A free tool-kit to guide implementation is available at www.homemeds.org.



Web Guide to Long-Term Care Services

In 1999, Scripps Gerontology Center coordinated a group of long-term care advocates, nursing home representatives, and state agencies to develop a guide to assist consumers and professionals in identifying long-term care services in Ohio. Researchers at Scripps and the Benjamin Rose Institute designed resident and family satisfaction surveys, which were fielded by Vital Research. The surveys were used to assess 30,000 nursing home residents and their family members. Scripps then created a Web site—www.LTCOhio.org—for consumers, family members, and long-term care professionals. The site contains results from a state survey of nursing homes in Ohio, links to data on nursing homes from the Centers for Medicare and Medicaid Services, and information from the family member and resident surveys.

often strive to reach definitive conclusions about their hypotheses.

Benefits

There is general consensus that the advantages of collaborations outweigh their drawbacks. Benefits of collaborative arrangements include:

- ▶ a sense of purpose and relevancy among researchers;
- ▶ ongoing relationships among researchers, policymakers, and/or providers;
- ▶ a vehicle for payers, particularly Medicaid programs, to make data available to researchers; and
- ▶ added prestige for provider agencies with research centers.

Many researchers involved in formal collaborations indicate that they derive a sense of personal satisfaction from working so closely with provider organizations. “This type of research is gratifying because I work with much stronger confidence that what I’m doing matters and can be implemented,” says Penny Hollander Feldman, vice president for research and evaluation at the VNSNY. “Our close relationship with providers enables us quickly to pinpoint issues where better information would make a

difference,” she says. “Also, because we know VNSNY inside and out, we are better able to structure studies that are feasible in an organization where service delivery must take priority over research.”

One of the most valuable components for state policymakers is the relationships that these collaborations enable them to forge with researchers. “Public universities have tremendous assets that place them in an ideal position to contribute to states’ policy activities,” says John Kaelin, executive director of the Center for Health Program Development and Management at the University of Maryland. “They have the advantages of continuity, since the researchers who work there thoroughly understand the culture of the state.”

According to Elise Bolda, associate professor at the Muskie School, “At a minimum, we are able to provide information so that there is not a dispute over numbers, but instead over the actual policy implications.”

For providers, having a research institute as a part of their organization adds prestige to the agency, and helps them to recruit and retain high-caliber individuals to their workforce and research teams. This type of collaboration invariably leads

to higher quality care because service delivery is under constant scrutiny. Having data on hand also helps organizations move away from making decisions based only on anecdotal evidence.

Conclusion

Collaborations provide an opportunity for researchers to integrate their findings into policy and practice. They also enable policy-makers and providers to easily share their specific information needs with researchers. Although long-term care collaborations face many challenges, particularly in light of current state fiscal crises, their benefits far outweigh their costs. Indeed, these arrangements may be more critical now than ever. “In this time of fiscal challenges, collaborations are even more important because of the need for increased efficiency and quality in service delivery,” says Freedman.

Formal collaborations attempt to bridge the cultural divide among researchers and other players in various ways. Research organizations affiliated with provider groups generally produce “policy or practice briefs” that help synthesize their results for providers in their organization and elsewhere. Moreover, many researchers eventually learn to adapt their findings for use in the provider and policy

worlds. “Communication is not really an issue for us,” says Gianopoulos. “The researchers at the University of Southern Maine have developed an appreciation for the legislative process.” ▶

Further Information

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Collaborations Between States and Researchers

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Continuity of Care in Nursing Homes

There was concern in Maine that individuals were frequently cycling from nursing homes to the community to hospitals because nursing home residents were being discharged prematurely after having lost eligibility for all state-funded long-term care services, including Medicaid. In 1998, researchers at the Edmund S. Muskie School of Public Service, University of Southern Maine, were asked to conduct a study of older adults with chronic conditions, frequent episodes of acute illness, and multiple moves between care settings.

They found that the majority of people who made multiple moves had not lost medical eligibility for nursing facility services during the study period, and that the number of individuals who did cycle through these settings was very small.¹¹ The study supported legislation that gave individuals a “free pass” to a nursing home if they exceeded a certain number of transfers in a year.

Nursing Home Rate Setting

The Center for Health Program Development and Management at the University of Maryland, Baltimore County, collaborated with the Maryland Department of Health and Mental Hygiene to develop an integrated, interactive nursing home rate setting information system. The Center specializes in developing technology solutions to health care financing challenges.

Maryland's initial nursing home rate setting system, developed in the 1980s, evolved in a piecemeal fashion to accommodate new regulations and developments. Over time, rate setting came to require working with different components of the rate-setting system with multiple program languages and databases. This system was cumbersome and did not allow users to analyze the impact of changes in reimbursement policy. Implemented in 2003, the new system integrated all information components into one program language, resulting in quicker, more understandable rate setting and the ability to create predictive scenarios for evaluating policy choices.

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Endnotes

- 1 For a more complete list of major research organizations affiliated with providers who serve the elderly, see the Mather Institute on Aging Benchmarking Survey Final Report, November 1999.
- 2 U.S. Census Bureau. "1980 Census," General Population Characteristics, 1982.
- 3 Population Estimates Program, Population Division, U.S. Census Bureau, "Resident Population Estimates of the United States by Age and Sex: April 1, 1990 to July 1, 1999, with Short-Term Projection to November 1, 2000," January 2, 2001, <http://eire.census.gov/popest/archives/national/nation2/intfile2-1.txt>.
- 4 Knickman, J.R., and E.K. Snell. "The 2030 Problem: Caring for Aging Baby Boomers," *Health Services Research*, Vol. 37, No. 4, August 2002, pp. 849–84.
- 5 Knickman, J.R., et al. "Wealth Patterns among Elderly Americans: Implications for Health Care Affordability," *Health Affairs*, Vol. 22, No. 3, May/June 2003, pp. 168–74.
- 6 Coburn, A.F. "The Role of Health Services Research in Developing State Health Policy," *Health Affairs*, Vol. 17, No. 1, January/February 1998, pp. 139–51.
- 7 Research and Training Institute, "MDS: Developing a Gold Standard for Nursing Home Assessment," www.hebrewrehab.org/mds.htm, March 1, 2003.
- 8 Coburn, A.F. "The Role of Health Services Research in Developing State Health Policy," *Health Affairs*, Vol. 17, No. 1, January/February 1998, pp. 139–51.
- Lomas, J. "Using 'Linkage and Exchange' to Move Research Into Policy at a Canadian Foundation," *Health Affairs*, Vol. 19, No. 1, May/June 2000, pp. 236–40.
- Feldman, P.H., et al. "Improving Communication Between Researchers and Policy Makers in Long-Term Care: Or, Researchers Are from Mars; Policy Makers Are from Venus," *The Gerontologist*, Vol. 41, No. 3, 2001, pp. 312–21.
- 9 Ahrens, J. et al. Center for Home Care Policy & Research Practice Brief, "Preventing Medication Errors in Home Care," Fall 2002.
- 10 Ibid.
- 11 Bolda, E. et al. "Evaluation of Consumer/Resident Transfers: A study of discharges and transfer between various long-term care settings," submitted to the Maine Department of Human Services, January 27, 1998.

Intranet Site for Quality Improvement

The Center for Home Care Policy and Research, in collaboration with the Visiting Nurse Service of New York (VNSNY), developed the VNSNY Outcomes Initiative to provide managers and clinicians with timely information to measure and improve patient outcomes. An intranet site, launched last year, is at the core of the effort. This site permits team managers, for example, to track their patients' satisfaction and outcomes, compare them to quality benchmarks, and monitor the impact of selected quality improvement interventions. In addition, a nurse researcher publishes a newsletter to help nurses sharpen their patient assessment skills.



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