

Irma T. Elo, Ph.D., Chair Associate Professor

Department of Sociology University of Pennsylvania

Ronald J Angel, Ph.D.

Professor Department of Sociology The University of Texas at Austin

Lvnn A. Blewett, Ph.D.

Associate Professor Division of Health Policy and Management University of Minnesota

Llewellyn Cornelius, Ph.D.

Professor School of Social Work University of Maryland

Jose Escarce, M.D., Ph.D.

Professor of Medicine David Geffen School of Medicine at UCLA & Senior Natural Scientist at RAND

Kathleen Mullan Harris, Ph.D.

James Haar Distinguished Professor Department of Sociology University of North Carolina

Holly Hedegaard, M.D., M.S.P.H.

Colorado Department of Public Health and Environment

Donald J. Hernandez, Ph.D.

Professor Department of Sociology University of Albany, SUNY

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Executive Secretary



Board of Scientific Counselors National Center for Health Statistics Centers for Disease Control and Prevention

October 9, 2009

Edward J. Sondik, Ph.D. Director, National Center for Health Statistics Centers for Disease Control and Prevention 3311 Toledo Road, Room 7209 Hyattsville, Maryland 20782

Dear Dr. Sondik:

As part of an on-going program review process, the Board of Scientific Counselors (BSC) of the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) commissioned a panel to review the Long-Term Care Statistics Program (LTCSP) and to report its findings to the BSC. The Long-Term Care Statistics Program is administered by the Long-Term Care Statistics Branch (LTCSB) in the Division of Health Care Statistics (DHCS), NCHS. The attached panel report summarizes the review process; examines the diverse and changing longterm care (LTC) sector and resulting data implications; describes the LTCSB, its surveys, the data produced, and the users and uses of those data; outlines the issues and challenges facing the LTCSB; and presents a series of recommendations.

Dr. Penny H. Feldman, Ph.D., of Visiting Nurse Service of NY, was the chair of the panel. The other panel members are listed in Attachment 1of the report. The BSC commends Dr. Feldman and her fellow panel members for an outstanding review and report, and forwards the report to you for action.

NCHS is well-positioned to address the nation's future data needs to inform long-term care policies. Already a significant component of health care, long-term care will become even more important as the population ages. Public programs pay for a substantial share of LTC services. Having a coordinated and well designed data system providing state-of-the-art data and analysis to help guide those programs is essential. The nature of long-term care with its diverse and evolving types of services means current data sources provide only fragmentary and not fully representative information. To meet the looming challenges of the changing LTC environment moving forward, NCHS and the LTCSB will need to provide more regular, frequent data on a wider range of LTC provider types and issues.

The panel's report contains two overarching recommendations:

1. Develop a strategic plan to define NCHS's role in the collection of long-term care data to meet future policy needs. This strategic plan should be based on a thorough and comprehensive assessment of:



- a. How long-term care is currently provided and financed
- b. The data needed to inform policy decisions regarding long-term care
- c. The data on long-term care provision and financing currently collected by NCHS and other public and private entities (e.g., Centers for Medicare and Medicaid Services, National Institute on Aging)
- d. The gaps in currently available data for policy purposes
- e. Currently collected data that are no longer a priority or that require modifications to increase their usefulness
- f. The priorities and strategies for addressing data gaps including new provider-based or person-based surveys or a combination
- 2. Integrate all existing and future long-term care provider surveys into a unified set of surveys—the National Long-Term Care Provider Surveys (NLTCPS)—with coordinated sampling frames across the spectrum of long-term care providers, a common set of core data elements and the capacity to add topical modules to respond to evolving policy issues.

The Board of Scientific Counselors endorses these panel recommendations and urges NCHS to go even farther. The provision of long term care has a significant impact on a wide range of departmental priorities from the Center for Medicare and Medicaid Services' stewardship of the Medicare and Medicaid programs to the Administration on Aging's efforts to improve the health and well-being of seniors in their local communities. If these programs are to run efficiently and effectively, they require the best and most rigorous data to inform policy. The NCHS should be at the forefront of a department-wide effort to develop and maintain the data systems needed to provide these data.

The panel also made a number of specific recommendations the Board endorses and highlights for your consideration:

- 1. Engage policymakers, providers and other users to understand their needs and increase the surveys' value to them.
- 2. Establish a regular process for expert review of methods, content and relevance of the long-term care surveys that extends beyond the initial design and implementation of the surveys.
- 3. Develop a unified strategy and inclusive set of sampling frames for the NLTCPS.
- 4. Review and develop core content for all types of providers in the NLTCPS.
- 5. Develop a strategy for linking administrative records data to the NLTCPS to enhance the analytical potential of findings from the surveys reduce duplication and increase efficiency in survey operations.
- 6. Fill an important gap in the existing provider surveys by fielding the NSRCF as soon as feasible and reconsider the decision not to collect resident-level data supporting data linkages.
- 7. Evaluate, consider, and test changes in data collection methodology that have the potential to increase the efficiency and the response rates of current and future surveys.

8. Explore the possibility of sharing the NLTCPS sampling frames with states and researchers

We hope that you will take the review panel's full set of recommendations into consideration in view of the challenging issues NCHS faces today. We welcome your response and continued dialogue on how the BSC can assist in implementing the recommendations of the LTCSP review panel.

On behalf of the Board of Scientific Counselors, I respectfully submit the enclosed report.

Sincerely,

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Irma T. Elo, PhD Chair, Board of Scientific Counselors of the National Center for Health Statistics