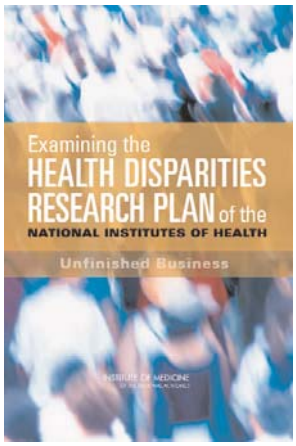
EXAMINING THE HEALTH DISPARITIES RESEARCH PLAN OF THE NATIONAL INSTITUTES OF HEALTH: UNFINISHED BUSINESS



David Satcher, the former U.S. Surgeon General, has observed "With the diversity of our population, it's in our interests as a nation to make sure that all of our people are as healthy as they can be." However, the country is far from achieving this goal. Evidence shows that African-Americans are disproportionately likely to struggle with diabetes, Hispanics are more likely to die of AIDS and American Indians face a higher risk of dying in infancy. Poor and rural populations are also disproportionately affected by poor health. An aggressive research agenda must be at the heart of any campaign to eliminate these health disparities among U.S. populations. As the nation's foremost research agency, the National Institutes of Health (NIH) naturally has a leading role in this effort.

In 2000, Congress passed a law to enhance NIH's work in this area—the Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525). This legislation established the NIH National Center on Minority Health and Health Disparities (NCMHD) to administer special grant programs, coordinate minority health disparities research across NIH and lead the development of an NIH-wide Strategic Plan on health disparities. A primary goal of the law was to ensure that NIH health disparities research is conducted as an integrated and inclusive field of study, rather than as an aggregate of independent research activities occurring in separate research domains.

In *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*, the Institute of Medicine assesses NIH's response to the 2000 law, focusing on the development and implementation of the Strategic Plan across NIH Institutes and Centers. The report examines the Strategic Plan for fiscal years 2002-2006 and the as-yet-unapproved Plan for 2004-2008.

Twenty-seven Institutes and Centers (ICs), along with two NIH Offices developed individual plans as part of the 2002-2006 NIH-wide Strategic Plan. These units are conducting and planning valuable health disparities research. At the same time, the impact of this work is being mitigated by a lack of coordination and limited strategic planning. In short, when it comes to addressing health disparities and fulfilling the promise of the 2000 law, NIH's business is unfinished.

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KEY FINDINGS

Minority health and health disparities are the focus of a great deal of energy and concern at the National Institutes of Health. The individual strategic plans of the Institutes and Centers contain an impressive array of planned activities. In fact, NIH ranks health disparities third among its top five organizational priorities. Despite these encouraging signs, many areas of NIH's work are still ripe for improvement.

Planning

The 2000 law stipulated that the NIH-wide Strategic Plan would be revised and updated annually. Six years later, only the Strategic Plan for 2002-2006 has been approved. The Plan for fiscal years 2004-2008, which incorporates many useful improvements on the original Plan, is still not official.

Coordination

The Strategic Plan was envisioned as a mechanism for coordinating NIH's activities regarding health disparities and leveraging their impact. However, there is not strong evidence that the extensive programs initiated by the ICs and Offices are centrally coordinated, appropriately assessed regarding priorities and outcomes, or otherwise viewed as part of an overall NIH strategy. In other words, the level of trans-NIH coordination needed to effectively *implement* the strategic plan has not been evident.

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Comprehensiveness

The Strategic Plan was supposed to ensure that needed areas of research are not neglected. Unfortunately, gaps remain regarding social and behavioral determinants of health and their interaction with biological factors; the characteristics of populations affected by poor health; the relationship between population disparities in health care and differences in health status; and causes of disparities in health care.

Funding

The 2000 law authorized up to $100 million in additional annual funding for minority health and health disparities research. This funding was not allocated, effectively making the Strategic Plan an unfunded mandate. In addition, complete, standardized, approved budget information was not available from the Strategic Plan. The absence of such information calls into question the validity and efficacy of the Plan.

RECOMMENDATIONS

Carrying out the mandate of the 2000 legislation is no easy task. The breadth and complexity of the health disparities Strategic Plan presents an extraordinary management challenge. And the NIH ICs and Offices already face multiple preexisting commitments, mandates and priorities. In order to overcome these challenges and maximize the impact of NIH's research on health disparities, the IOM's recommendations include the following:

- NIH, through NCMHD and the ICs and, when appropriate, collaborating agencies, should undertake research to further refine and develop the conceptual, definitional, and methodological issues involved in health disparities research and to further the understanding of the causes of disparities.
- The NIH director should assure that the Strategic Plan is reviewed and revised annually using an established, trans-NIH process subject to timely review, approval, and dissemination.

- The Strategic Plan research objectives should promote more integration of research on the multifactorial nature of health disparities, including nonbiological factors; population research to further the understanding of the presence, prevalence, trends, and other elements of health disparity conditions; and, when the opportunity exists, an understanding of the causes of disparities in health care.
- The Strategic Plan should include measurable targets and time periods for the research capacity objectives. NIH, through NCMHD's oversight, should develop methods of measuring, analyzing and monitoring the results of programs that address research capacity, including workforce, institutional, infrastructure, and community-based participatory health disparity research objectives.
- The Strategic Plan's communication programs should be organized as a specific trans-NIH effort with centralized coordination, with particular attention to the strategic planning, design, prioritization, implementation, and evaluation of efforts across NIH. The initiative should be informed by advisory expertise; develop a surveillance system to identify information needs and availability, sources, behaviors, and use patterns; and promote attention to the issue of inequalities in health communication.
- The development of updated Strategic Plans should include assessments of the appropriateness of the individual strategic plans of the ICs, including whether they adequately reflect the overall goals and objectives of the NIH Strategic Plan. Objectives should be time-based and targeted with measurable outcomes.
- NCMHD should consider the designation of additional health disparity groups based on an informed process and developed criteria. It should promote development of, and access to, a registry of diseases and conditions for which disparities exist with regard to race, ethnicity, socioeconomic status, geographic locale, and other designated health disparity populations.
- Within NIH, a clear and timely budget process should be linked to the Strategic Plan, and it should be updated in a timely manner. Annual budgets should include information for NIH as a whole, and for each involved IC and Office, and should detail allocations for the Strategic Plan goal areas and each objective. Trans-NIH budget information on efforts made in the major categories of research, research capacity, and communication also should be made available.
- The NIH director should review and assess the administrative staffing of NCMHD to assure that it is sufficient to attend to the Center's responsibilities. Increasing the science leadership and presence within NCMHD should be pursued by the NIH and NCMHD directors. This entails the appointment of additional eminent scientists, recognized in the areas of minority health and health disparities, and the establishment by NCMHD of committees and panels with relevant expertise from within and outside NIH.
- The NIH director, through the established authority of the NCMHD director, should assure continuous, effective coordination of the health disparities research program across the NIH.

CONCLUSION

NIH has appropriately identified minority health disparities as one of its five highest priorities. This report should serve as a guide to help NIH conduct the strategic planning necessary to ensure progress toward the goal of eliminating these injustices.

The breadth and complexity of the health disparities Strategic Plan presents an extraordinary management challenge.

FOR MORE INFORMATION...

Copies of *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business* are available from the National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, http://www.nap.edu. The full text of this report is available at http://www.nap.edu.

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COMMITTEE ON THE REVIEW AND ASSESSMENT OF THE NIH'S STRATEGIC RESEARCH PLAN AND BUDGET TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES

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