



Information for State Health Policy

An RWJF national program

SUMMARY

Information for State Health Policy was a Robert Wood Johnson Foundation (RWJF) national program charged with improving the capacity of state health statistics systems to support policymaking, as well as aiding in program development and management.

Projects funded under this program:

- Assessed states' health policy needs.
- Established plans and set priorities to meet those needs.
- Improved the states' health statistics infrastructure.

The national program funded projects in 10 states for 18-month Phase I planning grants; seven of those states received Phase II implementation grants that extended over four years through 1997. See the [Project List](#) to link to reports on the projects and evaluation.

Key Findings

Mathematica Policy Research, Washington conducted an evaluation of the program. It includes these findings:

- All states made concrete improvements in the data available to support policymaking, though the breadth and depth of progress varied across the states as did the closeness of the link between data enhancements and policy deliberations.
- Generally, states launched four types of projects:
 - Building system capacity via new data systems or links among existing systems.
 - Developing population-based survey capacity.
 - Conducting geographic and other issue-targeted analysis.
 - Building dissemination vehicles.
- All states made progress toward achieving their original goals, although none met all.

- States were more successful in making concrete improvements in their data and in shifting the orientation of their staff than in establishing formal structures to maintain an inter-agency process.
- All but one of the Phase II states succeeded in extending the *Information for State Health Policy* entity, or at least key staff and functions, beyond the RWJF grant.

Program Management

The program operated under the leadership of a national program office at the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, Department of Environmental and Community Medicine, Piscataway, N.J.

Until October 1993, it was co-directed by Ruth Hanft at George Washington University.

Funding

RWJF's Board of Trustees authorized \$7.3 million for the national program for five years beginning February 1991.

The Phase I awards were made to: Arkansas, California, Connecticut, Mississippi, Montana, New York, North Carolina, South Carolina, West Virginia and Wisconsin.

Connecticut, West Virginia, and Montana did not receive implementation funding.

THE PROBLEM

To make informed health policy decisions, those responsible for state health programs and policies need appropriate tools, including data collection and analytic capability.

Yet, the quality and sophistication of these tools vary from state to state, with even the most advanced states showing weaknesses in health statistics.

In most states, data collection agencies lack the human and technological resources necessary to provide high quality, quick responses to the broad spectrum of questions posed by those who must formulate policy.

Furthermore, in many states, agencies responsible for data systems do not coordinate with those responsible for policy development and program management.

For health care data to be of real meaning and value to persons working in the health field, it must be transformed from data to information. Converting data to information becomes easier when health policy leaders collaborate with health information specialists in a process of sharing and interpreting data.

CONTEXT

As early as 1986, the Robert Wood Johnson Foundation's (RWJF) Board of Trustees raised serious concerns about the timeliness and accuracy of health data then available to RWJF for its program development and grant-making activities.

In response to those concerns, RWJF staff undertook an examination of existing national and state health data systems. Their report to the Board in July 1988 made clear that the problems of both federal and state health data systems could not be sufficiently addressed by a single RWJF initiative.

In particular, RWJF staff found that state health systems were particularly vulnerable to political factors specific to individual states.

During 1989, RWJF's program on health data and statistical analysis found that state-level health data infrastructures were not adequate to support the information needs of state policymakers and program managers.

A few states, by maintaining relatively constant proportions of their health budgets in support of health statistics, continued to be leaders in the use of health data for policy analysis and decision-making.

Some states had allowed their data collection and analysis capabilities to atrophy. Others focused their efforts on specific improvements in narrow policy areas.

It was clear from this survey that in cases in which decision-makers trusted their data agencies to provide unbiased, nonpartisan data in a timely manner, major data systems became well insulated from political attacks.

RWJF program staff concluded that, in most states, data collection agencies lacked the analytical expertise and technological capacity to provide high quality, quick responses to questions posed by decision-makers.

Also, in many states there was a fragmentation between the agencies responsible for data collection and those responsible for policy development and program management.

Further, the program staff concluded that RWJF could play a role in building a more appropriate health statistics infrastructure by assisting states to examine their health statistics systems and take steps to improve them.

PROGRAM DESIGN

The Board of Trustees of the Robert Wood Johnson Foundation authorized \$7.3 million for the *Information for State Health Policy* program for five years beginning February 1991.

Projects funded under this program were designed to address the issues identified in prior efforts by:

- Assessing states' health policy needs.
- Establishing plans and set priorities to meet those needs.
- Improving the states' health statistics infrastructure.

THE PROGRAM

National Program Office

The national program office was originally housed at George Washington University under the direction of Ruth Hanft.

In November 1991, the national program office was moved to the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, Department of Environmental and Community Medicine, Piscataway, N.J.

Ira Kaufman, Clinical Associate Professor, Department of Environmental and Community Medicine, became the program's director. Denise Davis was appointed as the deputy director.

Ruth Hanft served as a program co-director through October 1993, when the national program office at George Washington closed.

The University of Medicine and Dentistry of New Jersey national program office closed in December 1998.

The national program office's responsibilities included:

- Identifying innovations in health data information and sharing these innovations with the projects.
- Providing technical assistance to the program's state health-data projects, directly or through consultants.
- Monitoring the financial and programmatic progress of grantees.
- Convening annual meetings of program grantees; and disseminating program results.

The Planning Phase

To receive funding, projects were required to have a lead agency designated by the governor was charged with convening an interagency working group to prepare a plan for comprehensive health-statistics system improvements.

The interagency working group could include active participation from:

- State agencies and the legislature.
- State health program managers.
- Health data agency representatives.
- Representatives from private sector organizations and consumer groups.
- Local health agency representatives.
- University-based analysts.

The working group could be a new commission, an ad hoc committee, or a pre-existing entity.

The lead agency and the interagency working group were required to:

- Conduct a comprehensive review of state information needs for health policy development and program management.
- Set priorities among those needs.
- Establish short-term and long-term plans for meeting the needs identified.
- Develop a specific, detailed proposal for enhancing an existing data system(s) or for creating a new one(s) to meet high priority information needs.

The national program office solicited proposals for planning grants from state agencies across the country in 1992 and received 42 proposals. Projects in 10 states received funding for an 18-month Phase I planning period.

The Phase I awards were made to:

- Arkansas
- California
- Connecticut
- Mississippi
- Montana
- New York
- North Carolina
- South Carolina
- West Virginia
- Wisconsin

The Implementation Phase

In Phase II implementation the interagency working group remained in place to assure appropriate integration with the activities of policy and program agencies, as well as to continue their long-range planning efforts.

The implementation phase funding was directed at:

- Developing and testing the planned data system improvement(s).
- Collecting and processing data.
- Training personnel.
- Analyzing and disseminating data.

Seven of the 10 states were funded for a Phase II implementation period of up to four years.

Connecticut, West Virginia, and Montana did not receive implementation funding.

National Advisory Committee

The national program office's activities were assisted by two advisory committees. The national advisory committee (see [Appendix 1](#)) was formed from a Technical Review Committee that helped the national program office review proposals in the planning phase, and helped maintain continuity between the two phases.

The Federal Advisory Committee (see [Appendix 2](#)):

- Acted as a liaison with federal agencies and coordinated grant programs.
- Shared information on data and information agendas.
- Identified common activities.
- Shared information on emerging issues.

Communications

The national program office conducted five national meetings of the Phase II states and additional invited states. More than 175 attended the final meeting, including representatives from 8 federal agencies and 37 states.

The national program office also conducted technical group consultations on measuring access to health care and produced a regular publication, *Health Policy on Target*, which provided in-depth articles on the activities of the projects to more than 7,000 individuals at the state and federal levels.

The national program office posted a website (no longer available). Local projects also produced reports and each state developed or was in the process of developing an Internet site on their state activities.

Reports produced by local sites are listed in their own bibliographies. The publications and dissemination activities of the national program office are listed in the [Bibliography](#) at the end of this report.

EVALUATION

The *Information for State Health Policy* Program was evaluated by [Mathematica Policy Research, Inc.](#), Washington, D.C. The project director for the evaluation was Marsha Gold, Sc.D.

The evaluation looked at the program's record in Phase I planning and to inform ongoing implementation, the first two years of Phase II implementation.

RWJF later commissioned Mathematica to undertake a more limited follow-up evaluation of the program at its completion. In addition, Mathematica did a 50-state survey comparing the program states to states without the program.

OVERALL PROGRAM RESULTS

The final evaluation by Mathematica includes the following findings. For more detailed results, see the [Program Results Report](#) on the evaluation.

- **All states made some concrete improvements in the data available to support policymaking, though the breadth and depth of progress varied across the states as did the closeness of the link between data enhancements and policy deliberations.** See the [Project List](#) for links to reports on the projects.
- **Generally, states launched four types of projects:**
 - Building system capacity via new data systems or linkages among existing systems.
 - Developing population-based survey capacity.
 - Conducting geographic and other issue-targeted analysis.
 - Building dissemination vehicles.
- **All states made progress toward achieving their original goals, although none met all.** Some of the factors that impeded progress were not under the control of the states.
- **States were more successful in making concrete improvements in their data and in shifting the orientation of their staff than in establishing formal structures to maintain an inter-agency process.**

- **All but one of the Phase II states succeeded in extending the *Information for State Health Policy Entity*, or at least key staff and functions, beyond the RWJF grant.** At least some of the concrete improvements made under the national program will be maintained in each of the states.
- **While states may have accomplished some capacity building in the absence of the national program, it contributed in important ways to the results.**
- **The evaluators identified six factors critical to the development of partnerships and the establishment of a plan for the data enhancements required to support health policy decision-making.** These factors are:
 - Active policy champions.
 - High-level staff with effective entrepreneurial and bridging skills.
 - A strategy tailored to the data demands unique to each state.
 - Support of key constituencies.
 - A strategic location for the health data initiative.
 - The ability to capitalize on short-term policy windows while pursuing longer-term capacity building.

Prepared by: Robert Mahon

Edited by: Karin Gillespie and Marian Bass

Reviewed by: Molly McKaughan

Program Officer: James Knickman

APPENDIX 1

National Advisory Committee

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Alan B. Cohen, Sc.D.

Professor of Health Policy and Management
Director, Health Care Management Program
Boston University
Waltham, Mass.

Allan Noonan, M.D.

Regional Health Administrator
United States Public Health Service, Region V
Harrisburg, Pa.

Ralph A. Desonia

Director, Health Policy Studies
National Governors' Association
Washington, D.C.

Charles J. Rothwell

Associate Director
Data Processing and Services
National Center for Health Statistics
Hyattsville, Md.

Nelda McCall

President
Laguana Research Associates
San Francisco, Calif.

Sarah C. Shuptrine

President
Sarah Shuptrine and Associates
President
The Southern Institute on Children and
Families
Columbia, S.C.

M. Susan Marquis, Ph.D.

Staff Member
Economics Department
RAND Corporation
Washington, D.C.

Gloria R. Smith, Ph.D.

Coordinator and Program Director
Health Programming
WK Kellogg Foundation
Battle Creek, Mich.

Jeffrey C. Miller

Associate Dean
Administration and Planning
Northwestern University Medical School
Chicago, Ill.

Steven L. Taylor, D.S.W.

Chief Program Officer
Department of Management
The American Red Cross of Greater New York
New York, N.Y.

APPENDIX 2

Federal Advisory Committee

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

Agency for Health Care Policy Research
Centers for Disease Control and Prevention
Health Care Financing Administration
Health Research Services Administration
National Center for Health Statistics
Office of the Assistant Secretary of Health
Office of the Assistant Secretary of Planning and Evaluation
Substance Abuse and Mental Health Administration
Women, Infants, and Children's Program

BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Reports

Miss or Match: How Well do State Data Systems Meet State Health Policy Needs?

Billings, John, M.D. *Monitoring Access within Political and Market Boundaries.*

Overview of Primary Care Access Issues.

Using Administrative Data Sets to Measure Barriers to Care.

Analyzing Primary Care Access: The Role of Providers.

Legislative Survey Report, 1997.

Tools for Analyzing Primary Care Issues at the State and Local Level, 1994.

Kaufman, Ira A.; Davis, Denise. *Building Better State Health Data Systems: Outcomes of the Information for State Health Policy Program.* Piscataway, NJ.

Newsletters

Health Policy on Target, five issues published: August 1994; April 1995; October 1995; April 1997; October 1997.

Focus, "Advocacy, Interest Groups and the Wisconsin Initiative," October 1995.

Focus, "Institutional Providers and the New York Initiative," March 1995.

Focus, "A Governor, and the South Carolina Initiative," August 1994.

Sponsored Conferences

National Meeting held with the National Association of Health Data Organizations and the American Hospital Association, 1993.

Presentations and Testimony

"The Secrets of Information for State Health Policy and Practice," Atlanta. October 15–17, 1997.

"Year 2000 Initiative," presentation at the Centers for Disease Control and Prevention Meeting, 1996.

"1115 Demonstration Waivers," presentation at the Federal-State Partnerships for State Health Reform Meeting, 1996.

"Developing Information Systems for Managed Care," presentation at the Medicaid Director's Meeting 1996.

"Information Systems and Health Applications," presentation at the National Library of Medicine Meeting, 1996.

Presentation at the National Academy for State Health Policy Meeting, 1996.

Presentation at the American Public Health Association Annual Meeting, 1996.

"Medicaid and Medigrants," presentation at the National Governor's Association Meeting, 1996.

Presentation at the National Association for Health Data Organizations annual meeting on information needs, 1996.

"Medicaid and Medigrants," presentation National Council of State Legislatures Meeting, 1996.

"Medicaid and Medigrants," presentation Maternal and Child Health Bureau Meeting, 1996.

"Developing Information Systems for Managed Care," presentation at the Medicaid Director's Meeting, 1996.

"Information Systems and Health Applications," presentation at the National Library of Medicine Meeting, 1996.

Presentation at the National Academy for State Health Policy Meeting, 1996.

"Year 2000 Initiative," presentation at the Centers for Disease Control and Prevention Meeting, 1995.

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"Medicaid and Medigrants," presentation at the National Governor's Association Meeting, 1995.

"Medicaid and Medigrants," presentation National Council of State Legislatures Meeting, 1995.

"Medicaid and Medigrants," presentation Maternal and Child Health Bureau Meeting, 1995.

Presentation at the National Center for Health Statistics Minority Health Conference, 1994.

Presentation at the National Association of Health Data Organizations, 1993.

News Conferences and Briefings

Health Care Financing Administration, Office of Medicaid Managed Care, 1996.

Health Care Financing Administration, Office of Research and Development, 1996.

Health Care Financing Administration, The Bureau of Medicaid, 1996.

American Public Welfare Association, 1996.

Centers for Disease Control and Prevention, 1996.

Health Care Financing Administration, Office of Medicaid Managed Care, 1995.

Health Care Financing Administration, Office of Research and Development, 1995.

Health Care Financing Administration, The Bureau of Medicaid, 1995.

American Public Welfare Association, 1995.

National Governors' Association, 1994.

Council of Governors' Policy Advisors, 1993.

National Governors' Association, 1993.

Council of Governors' Policy Advisors, 1993.

American Hospital Association, 1993.

Grantee Websites

www2.umdnj.edu/ishppweb (no longer available) was the website of the national program office.

PROJECT LIST

Reports on the projects managed under this National Program are listed below. Click on a project's title to see the complete report, which typically includes a summary, description of the project's objectives, its results or findings, post grant activities and a list of key products.

Evaluation Projects

- ['Information for State Health Policy Program' Gives Policy-Makers Helpful Data](#) (Grant ID# PC390, etc., May 1999)

Implementation Projects

- [California Improves Usefulness of Health Data](#) (Grant ID# 22865, etc., May 1999)
- [Linking Data in South Carolina Enables Analyses Across Health Care Settings](#) (Grant ID# 22869, etc., May 1999)
- [Mississippi Enhances Health Data Systems](#) (Grant ID# 22867, etc., May 1999)
- [New York Builds System to Analyze Health Data by Region](#) (Grant ID# 22866, etc., May 1999)
- [North Carolina Creates Links Among Health Data, Markets Findings](#) (Grant ID# 22868, etc., May 1999)
- [State of Arkansas Collects, Disseminates New Health Data](#) (Grant ID# 22864, etc., May 1999)
- [Wisconsin Creates Health Profiles of Pregnant Women and Infants, Children, People with Chronic Conditions](#) (Grant ID# 22870, etc., May 1999)

Phase I Planning Projects

- [Connecticut Highlights Need for Data on Maternal and Child Health](#) (Grant ID# 19742, May 1999)
- [Montana Merges Health Data Sources to Provide Better Services for Minorities](#) (Grant ID# 19744, May 1999)
- [West Virginia Assesses 85 Health Databases, Recommends Changes](#) (Grant ID# 19748, May 1999)