The Development of Priorities for Health Services Research The National Center, 1974–76

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The priorities published by the National Center for Health Services Research/DHEW in 1975 were the result of more than a year of consultation between federal officials and members of the research community. The process of priority development emerged from an interpretation of the history of the National Center, of health services research as an activity, and of the previous experience of various research agencies. This paper is a combined memoir and intellectual history of the priority development process in the National Center by a participant who, because of his position, was somewhat detached from events.

In September 1975, the National Center for Health Services Research published a statement of research priorities that had been in process for more than a year. Many people in and out of government participated in the discussions that were incorporated into *The Program in Health Services Research* (1975). There are mixed views of the success of the priority-setting process. Although the discussions were broadly consultative, critical decisions were made by the Director of the National Center and his senior staff. Whether these judgments were proper and prudent will be evaluated in a future they will help to shape. What follows is a personal and unauthorized view of the political and intellectual history of the process by which the research priorities were established.[1]

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[1] In 1974–76, I spent several days each week at the National Center, advising the Director on matters pertaining to the academic community. Although I participated in, witnessed, or collected impressions of the events described in this essay, the interpretation is entirely my own. In preparing this account, I benefited from a memoir of the priority-setting experience written by Mr. Dean Farley, now at Princeton University, who served on the staff of the National Center in 1974 and 1975. Gerald Rosenthal, Ph.D., Director, and Donald Goldstone, M.D., Director, Division of Research Strategy, National Center, have discussed the subject of research priority planning with me on numerous occasions.

Priorities for Health Services Research, 1976

The following paragraphs are excerpted from the opening pages of *The Program in Health Services Research* (1975:1–3). The excerpts describe the priority-planning process discussed below and identify the issues given priority for research supported by the National Center. The entire pamphlet is available on request from the National Center, 5600 Fisher's Lane, Rockville, Maryland.

The Program in Health Services Research

> The National Center for Health Services Research was established in accordance with the provisions of Public Law 93–353, the "Health Services Research, Health Statistics, and Medical Libraries Act of 1974." This legislation authorizes the Secretary, acting through the National Center, to undertake a broad range of research, demonstration, and evaluation activities respecting virtually all aspects of health services delivery in this country. The new law resulted from a growing recognition that substantial improvement in the efficiency and effectiveness of health services is most likely to be achieved by expanding our knowledge of provider and consumer behavior and through testing and evaluating new approaches to producing, financing, organizing, and delivering health services. . .
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> A crucial step in the formulation of a health services research program is the identification of those subject areas that ought to be given priority when the decisions about which research projects to support are being made. In general, problems which affect the allocation of substantial resources, which affect the health of a large segment of the population, or which command growing legislative interest would seem to be obvious candidates. Yet, there is no widely accepted scheme for weighting and ordering, in terms of relative importance, the myriad of health care problems that, from time to time, attract the attention of the public as well as those in the field itself.
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> To deal with this situation, the National Center has concluded that it must regularly call upon policy-makers, consumers, health care providers, and program administrators to identify the current and emerging health care issues which they believe to be most pressing. . .
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> The decision on what to study should be based not only on the importance of the issue but also on the likelihood that research will provide information that will contribute substantively to the policymaking process at a micro or macro level. Accordingly, the Center intends to consult with professionals who have been working on

and studying the issues identified. Each major issue selected by the Director as a priority concern as a result of the issue identification process will be submitted for review to an assembled group of experts from within and outside the National Center. . .

To assess the potential social utility of any set of research projects, the Center has identified the following questions, the answers to which will provide a sense of whether these criteria will be met.

1. What is the likelihood that the information derived from the research will still be required when the study is scheduled to be completed?
2. Is the proposed study dependent upon a natural experiment that would preclude the initiation of the research at a later date?
3. Are there political, social, economic or technological considerations that make it unlikely that some action would be taken when the results of the research become available?
4. Is it probable that the research will suggest policy options that would have a significant impact in terms of minimizing or solving the problem being addressed?
5. Are there important externalities associated with the research (e.g., data which may be used for other purposes, methodologies which have other applications) that would in and of themselves justify the expenditure?

The conclusion that a proposal has obvious social utility is a necessary but not a sufficient condition for funding. A set of questions has been developed respecting research methodology, personnel requirements, environment, budget, and time constraints which must be addressed before the funding of any group of research projects will be considered. These questions are as follows:

1. Does the methodology exist to support the analysis required; if not, is it likely that such a methodology can be developed in a timely fashion by the researchers involved?
2. Are researchers with the necessary qualifications available to conduct the research?
3. Is it likely that researchers would be able to get whatever cooperation is required from providers, consumers, and others to conduct the proposed research?
4. Approximately how long would the research effort take?
5. Approximately what resource commitments would be required?

The decisions regarding what research to support must be made by the National Center. Here the interests of the various constituents and the technical information can be synthesized into a scientifically sound, reasonably balanced, and responsible research agenda. The National Center will give priority to those initiatives that appear most likely to generate policy-relevant results.

In describing research directions, no attempt has been made to distinguish between those projects which will be undertaken by the staff of the National Center and those which will be supported by grant or contract. The distribution of projects between the intramural and extramural programs will depend, in part, on the size, backgrounds, and capabilities of the staff acquired to carry out research.

The areas of research identified by the National Center for emphasis are presented here in an issue-oriented framework. Such an approach has been adopted because it makes explicit the relevance of the research for the "users" rather than the "doers." The new format reflects a departure from past practice when projects were distributed by generic categories such as economics, technology, or demonstrations. This system is being abandoned; requests for information are rarely consistent with such a classification scheme, and such generic categories do not provide a sense of the focus, intent, or utility of the set of projects included under a particular rubric.

To date, the National Center has identified seven priority issues for intensive research. Collectively these issues constitute an initial point of departure for the research program of the National Center. The range of issues will be broadened in the future in a manner which is substantive and concordant with the criteria and selection process outlined earlier. The areas currently identified are broadly labeled:

1. Quality of Care;
2. Inflation and Productivity;
3. Health Care and the Disadvantaged;
4. Health Manpower;
5. Health Insurance;
6. Planning and Regulation; and
7. Emergency Medical Services.

The National Center in 1974

The appointment of Gerald Rosenthal as Director in 1974 came at a critical time in the history of the National Center. Few observers believed the agency had succeeded totally in its brief history. Founded in the late 1960s to influence policy and services through research, the National Center had sponsored several notable projects in its early years. Since the early 1970s, however, it had become increasingly passive, responding mainly to initiatives from applicants for grants. Millions of dollars were awarded each year on the basis of exacting standards of scientific adequacy and vague criteria of priority for public policy. This passivity helped to motivate a critical report on health services research in the federal government commissioned by the President's Scientific Advisory Committee in 1972. The report had a wide unofficial circulation and a strong influence on the discussions that led to the Center's first legislative charter, P.L. 93-353, in July of 1974.

The new law authorized the National Center to take a more aggressive role than it had before 1974. The Center was to identify problems of significance and to sponsor research on them through a variety of means: notably a new intramural research investment, a redefined program of research centers and research training, and a more focused program of grants and contracts. Some of the language in the law and in the congressional reports that accompanied it reflected the estrangement that occurred in the early 1970s between the executive and legislative branches of government.

Skepticism about the National Center was the dominant theme in 1974. Congressional staff members who had helped to write the new law doubted the ability of the Center to respond to research questions raised by public officials and the health service community. The Washington health establishment—federal and association officials, lobbyists, instructors, and consultants—was concerned that the bureaucratic location of the Center would impede its ability to respond effectively to pressing issues. Suggestions were made that the Center be moved to the Offices of the Assistant Secretary of Health or the Secretary of HEW.

Rosenthal was also skeptical. The congressional appropriation did not match the promise of the authorization. The Office of Management and the Budget had other priorities than health services research. The process of drafting and publishing regulations to implement the new legislation was, as usual, frustrating to those within the government and baffling to eager grant applicants. The Director was overwhelmed with advice about priorities, much of it conflicting, both within the government and from the research community. The Center had many grants and contracts to manage, reflecting past priorities but significant research in progress.

Priority Setting, 1968–74

By 1974, the National Center had exhausted its original priorities and lacked a broadly accepted mechanism for developing new ones. As the priorities set by the task force that had assisted at the creation of the Center became history, the staff turned inward for most of its ideas. The initial priorities had stimulated major research on, for instance, physicians' extenders, professional services review, and multiphasic screening. These priorities had, to a large extent, emerged from a multidisciplinary planning process similar to the one used in 1974 and 1975. But as these research and development achievements became part of either the conventional wisdom or the critique of health services innovation, became cliche, members of both the research and the Washington health communities assumed that the National Center had lost momentum. The Center was ignored, deplored, or, more frequently, viewed as unimportant by most people concerned with health services.

The Center and, by extension, its research community, was intellectually isolated because it was absent by choice from many major arenas of health politics. The members of the beneficiary constituency were university faculty and advanced students, employees of contractors and several nonprofit research organizations, and the staff of a few professional associations. Few of them had strategic access to major resources in health politics—funds, facilities, patients—in a way similar to constituents of National Institutes of comparable size. Because many social scientists in health are regarded as marginal to the day-to-day activities of health institutions, they have difficulty discriminating between problems which command attention and those which they feel should be emphasized.

This political and intellectual isolation reinforced estrangement from potential users of research. Health services research is applied research, in the oversimple dichotomy that defines some work as basic and neglects the long historical record of research on practical problems leading to major scientific discoveries. But the effectiveness of health services research has never been measured by its impact on those who determine most investment in research results in the health polity: specialists and educators in the major professions, and administrators of large organizations providing and financing health care. Moreover, in the absence of ability to raise hopes about the cure, control, or the treatment of dread disease, to offer ways to satisfy unrequited demand for admission to professional schools, or even to offer findings independent of social and cultural settings, there is little reason for members of the general public to have focused interest in the political economy of research. Even muckraking, especially about excessive costs, attracts only passing attention, confirming citizens' cynicism and sense of helplessness about medical care.

The founding priorities of the National Center were a superb agenda for their time. Most of the pressing questions about health services in the late 1960s appeared to have answers that could be summarized in a word: MORE. Several years of political attention to problems of relative poverty and stigmatized racial and ethnic groups made access the dominant theme of both research and reform in health care. Improved access required more professionals, professions, facilities, entry points, screening, and referral techniques; in sum, more money in the health industry.

As it had in the West for a generation, health policy in the United States in the 1960s focused on problems of equity, on reducing privileged access, rather than on the effectiveness of health care and of those providing it. Language as usual reflected intellectual emphasis: "health care delivery" became code for research and reform activities in all aspects of care that were not biologically based. "Delivery" became the dominant problem, on the transient assumption that production—who does what to whom, why, and with what result—was a secondary problem.

Less than a decade later, these concerns, and the research priorities they stimulated, may appear naive—a result of unavoidable present-mindedness. Research agendas and fashions in any field are a compromise between the concerns of scientists and broader social concerns. Intellectual developments, never simply "caused" by external events, are rarely independent of them.

The original research agenda of the National Center remains vital to many investigators, for reasons rooted in both science and ideology. Rosenthal and his colleagues were trained and began their careers in the years when equity seemed a more important problem than adequacy. They could no more deny the value and legitimacy of their own past than they could leave the determination of health services research priorities to the discretion of colleagues in the academic world and the research industry.

This statement is not intended to be arrogant. Tax-supported research organizations work at the meeting place of science and politics, where "why?" must be followed by "who cares?" The experience of both the National Institutes and the National Center provides convincing evidence that research priorities developed by committees of investigators—study sections, for example—usually and not surprisingly reflect the logic of scientific disciplines more often than emerging issues of public controversy or blur the distinction between the two. Moreover, health services researchers, grounded in diverse disciplines, lack the shared sense of intellectual direction common to most investigators in the biological sciences. Research cannot transcend the state of any art at a particular time. But the National Center, like other federal agencies, is mandated to apply public interest criteria which are defensible to Congress and the administration, as well as to investigators.

Staff determination as an extension of peer review is the most frequent alternative to development of research priorities by nonfederal scientists. This alternative never lacks strong advocates. But expertise in the federal health bureaucracy is not entirely representative of the distribution of interest and ability in the research community. Moreover, staff priority planning cannot avoid efforts to promote individual careers in research management. Staff planning tends to create larger research bureaucracies exploring issues that are safe enough to avoid criticism and pertinent enough to blend with the concerns of superior officials.

Neither staff nor consultant priority planning exists in pure form. Staff always consults, often coopts, and usually gains cooperation from investigators. Advisors who want to be invited back have learned to be solicitous of and dependent on staff. But these adaptations to the models tend to be covert and to be more closely related to peddling preferences than to producing priorities.

Toward "The Program in Health Sciences Research"

Rosenthal chose a planning strategy that involved broad consultation in and out of government, working groups of staff and advisers, and preparation of the final priority statements by staff in his office. This strategy reflected the need for the National Center to generate confidence in the research and health affairs communities, the desirability of preparing staff for the more aggressive role required by the Center's mandate for intramural research, and the absence of an established model for research priority planning in the National Center or elsewhere.

Equally important was the conviction that the problems, methods, and costs of health services research are sufficiently different from those of disciplinary research to justify the exploration of new planning techniques. Health services research may have, and is often expected to have, an impact on the future. For a variety of reasons, moreover, the areas of uncertainty are greater in health services research or in any inquiry that relies on the social sciences than they are in the biological and physical sciences. This uncertainty, particularly when the focus of inquiry is on matters of public concern and welfare, requires that a variety of tools and concepts be focused on any problem—that is, on what are conventionally called multidisciplinary approaches.

The priority planning process began with a series of retreats in the Spring of 1974 and reached a peak of activity in the months during the preparation of the National Center contribution to *The Forward Plan for Health* (1975) in the Spring of 1975. The process continues; new problems are examined and existing research evaluated by a variety of individuals and groups linked to the National Center. Approximately 100 members of the staff of the Center and several hundred non-governmental experts on research (scientists and users) have been involved to date. In addition, conversations were held with colleagues in other federal agencies, foundations, professional associations, and congressional staffs.

The decision to develop the research program around a limited number of themes was discussed so thoroughly that it appeared self-evident in retrospect to many participants. One staff member deeply involved in the planning process, in a memoir of his experiences, first described the "informal discussions and observations" by staff "who somehow internalize their perceptions." Later, unconsciously demonstrating this internalization, he recalled that "most of the issues were identified simply by casual observation of Congressional and Departmental interests." The actual process of selecting issues was more rigorous. In the Fall of 1974, a list of between eight and twelve issues was identified and projects supported by major foundations and other federal agencies were examined in order to compare priorities and levels of commitments of other organizations with the emerging priorities of the National Center. Next, National Center staff classified active projects according to the issues. By January 1975, the list was complete and was circulated widely within HEW.[2]

Meanwhile, work began to specify research questions and projects that followed from the broad statement of each issue. For five issues—quality of care, inflation and productivity, insurance, manpower, and emergency medical services—meetings of consultants and staff were held. There was considerable variation in the number and frequency of meetings, the division of labor between staff and consultants, and the levels of discourse and debate. The other issues—planning and regulation, the disadvantaged, and long-term care—were addressed mainly by staff groups with consultant support. For each issue, investigators from both outside and within the Center participated in developing requests for proposals or prospectuses for grant solicitations, and in reviewing applications. The elaboration of the issues into projects continues.

The program development process was influenced by events outside the Center and the research community. In September 1974, for example, the President's emphasis on inflation led to intense work to assess what was known and needed to be known about the impact of inflation on health care. Fifteen economists participated in this effort: nine from universities and research institutions, four from the National Center; and two from the Office of the Assistant Secretary for Planning in HEW.

Several months later, the National Center convened a meeting to discuss uncertainties about public subsidy for catastrophic costs of illness. The suggestion for this meeting came from policy analysts close to legislative events. Participants included federal and congressional staff and experts from universities and research organizations. Published proceedings circulated widely. A program of research in this area was announced in the Spring of 1976.

The final list of seven issues was elaborated in *The Program in Health Services Research* (1975). No attempt was made to establish an order of importance among the issues themselves. Each issue was the subject of such intense focus on the part of staff and advisors that

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[2] I do not attempt to defend in this essay the choice of priority issues for research. The discussion of each issue in the full text of *The Program in Health Services Research* (1975) will persuade or perplex, depending on the experience, opinions, and discipline of each reader, as well as on psychological and political conditions that can only be conjectured.

nobody noticed until after the first edition of *The Program* was published that the list was in no particular order—either of priority or of alphabet. In the text, the authors summarized the public problems the issue reflected, suggested the range of recent research approaches to the problem, and indicated a number of research initiatives which appeared promising. Although examples of recent research were provided for each issue, questions about what the National Center would support continued to arise after publication. Subsequent editions of the brochure will incorporate summaries of research projects funded by the Center in each substantive area.

The process pained and disappointed some members of the research community. Somebody was not invited to each meeting who felt he or she should have been included. Some investigators are offended by the way the National Center conceives and articulates particular issues.

The research planning process continues to be influenced by events within and outside the relatively small community of health services researchers and those who listen to them. The National Center is affected by fiscal uncertainties and delays in fully implementing the staff reorganization. On the other hand, the growth of the intramural program, staffed by career federal officials, service fellows and visiting scientists, has increased the frequency and thoroughness of discussions about research priorities. The three study sections remain arbiters of scientific integrity. A new small grants program enables the National Center to take reasonable risks on short notice and to fund both the early efforts of newly trained investigators and the syntheses of senior people in the field.

New program areas are being discussed in response to suggestions from within and outside the Center. These areas include research on consumer behavior, on minimal accessible standards for health services and on the effects of professional education on health services. The politics and economy of 1976 will require reconsideration of research priorities.

Health services research is still marginal to health care and health research. Advocates of health services research, in and out of the federal government, require a variety of political and scientific skills to maintain and broaden the occasionally contentious consultation between investigators and research administrators that has occurred in the past two years. Potential users of the results of research need to be more actively involved in setting priorities. These users include physicians and other direct providers, administrators of organizations supplying and paying for health care, legislators, and budget officials. Many of them have not seen sufficient evidence of the findings and utility of the research to date to be convinced of its value. Others suspect that many activities called research mask reform agendas, particularly advocacy for particular versions of national health insurance or modes of organizing medical practice. Most are indifferent to the claims of health services research. Priorities for health services research, in contrast to the agendas of its component disciplines, must be judged by their effects on health and, along the way, by their impact on the organizations and people who provide and pay for health care.

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