Epidemiology, health systems research, and statistics/data systems / report of an ADAMHA workgroup.

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
Alcohol, Drug Abuse, and Mental Health Administration

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PREFACE

This Workgroup was initiated with an acute awareness of the need for policy-related data on the current state of the alcohol, drug abuse, and mental health (ADM) service delivery system. Congressional, DHEW, and other groups such as the President's Commission on Mental Health (PCMH) have all stressed the immediate need for an improved health care research data base for policy decisions and service planning.

In establishing a Workgroup concerned with improving the health care research data base, Dr. Gerald L. Klerman, Administrator of the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), recognized that such information does not spring de novo from ad hoc studies outside the framework of more basic research fields. Hence, the Workgroup was charged with reviewing and recommending research activities in the three specific fields of epidemiology, health services research, and health statistics/ data systems. These three areas were identified as being most able to provide large-scale public health information on the need for ADM services and on the capability of the existing service delivery system to respond appropriately to ADM service needs.

After Dr. Klerman selected a Chairperson for the Workgroup, the three Institute Directors nominated participants from their epidemiology and health statistics programs. The latter were also asked to represent a limited area of health services research programs (initially labeled "quantitative health services research" and later renamed "health systems research") of their respective Institutes. In addition, two outside consultants were nominated by each Institute Director to complete staffing of subgroups on epidemiology and health systems research/health statistics with six members each.

The actual Workgroup process was initiated February 28, 1978, by ADAMHA staff meetings to define the scope of the programs and research areas to be reviewed. Structured inventory forms were then distributed to every division of the Institutes to obtain descriptive and financial information on all ADAMHA activities within the scope of the Workgroup's purview. Inventory forms were subsequently compiled, and a secondary analysis of this information was performed, as summarized in subsequent sections of the report.

Following an initial presentation of inventory findings to the consultants (3/30 and 4/5), each subgroup had additional meetings with consultants (4/24-26 and 5/31) to discuss problems and major research issues involved in these areas. Initial recommendations emerged from individual consultant reports, subgroup member working papers, and analyses by the Workgroup Chairperson's staff. Preliminary drafts of the report and its recommendations were circulated widely for comments and critique on July 3, 1978.

Comments on the preliminary report underscored the need for a more explicit conceptual framework to organize the Workgroup's findings and recommendations. This need was particularly evident regarding health services research, an area whose diffuse organization within ADAMHA reflected, in part, the poorly defined boundaries of an emerging research field. Hence, we identified a health systems research framework within the context of both the larger field of health services research and the contributing fields of epidemiology and health statistics/data systems.

This framework, as diagrammed on pp. 15-17, has enabled us to focus on research directed at the broad public health policy issues addressed by the Workgroup. It also provides a schema for defining and improving ADAMHA programs in other fundamental areas of health care research: program evaluation, treatment assessment, technology assessment, and health behavior research. The power of this conceptual approach, however, will be determined by its utility in facilitating a more functional linkage of research professionals and a clear administrative delegation of responsibility for developing comprehensive and integrated research programs in these areas.

Within this framework, the Workgroup has documented ADAMHA's current investment in these three study areas, describing the major attendant problems and issues, and recommending appropriate steps for obtaining information to improve the U.S. health care delivery system's ADM services. Appropriate budgetary and administrative recommendations are included to assure that implementation is feasible.

An undertaking of this magnitude requires major contributions of time and energy from many Workgroup participants and staff which are impossible to acknowledge adequately. The expert opinions provided by our consultants were particularly stimulating, considerably increasing our sensitivity to the perspectives of the larger ADM health care research community. Likewise, the ADAMHA Workgroup representatives provided a wide range of program perspectives, attended numerous subgroup meetings, and wrote multiple drafts of their collected material. The collection, presentation, and analysis of so large a mass of information inevitably disrupts the ongoing and often understaffed program activities of the three Institutes. However, the activities associated with this Workgroup were readily and conscientiously undertaken by all members. In the process, new working relationships were forged across Institutes and a better understanding of each program area's unique problems was obtained. In this sense, the implementation of recommendations for improved coordination across Institutes has already begun.

In preparing this final draft, independent reports from the consultants and liberal comments and suggestions by Workgroup participants have been acknowledged and incorporated wherever possible. However, ultimate responsibility for the overall balance and organization of the final report rests with the Chairperson and his staff. We have tried to present a comprehensive yet coherent perspective that will enhance the development and policy applications of epidemiology, health services research, and health statistics programs throughout ADAMHA and the health care research community.

Darrel A. Regier, M.D., M.P.H.
Workgroup Chairperson

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CONTENTS

I. OVERVIEW

A. Background

This report presents results of the first comprehensive review of Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) programs in epidemiology, health systems research, and health statistics/data systems. Such a study could not have occurred at a more propitious time in the Agency's history. With increasing frequency and urgency, these three fields are being reviewed and linked at the Federal level to aid in developing a more informed understanding of our National health care delivery system. Together, they constitute a major portion of the emerging and growing area of health care research.

Federal attention to these fields and their interrelations reflects the confluence of many National concerns as expressed by such groups as the U.S. Congress, the President's Commission on Mental Health (PCMH), the U.S. Public Health Service (PHS), and the Office of Science and Technology Policy (OSTP) in the Executive Office of the President. At the latter's request, the National Academy of Sciences, Institute of Medicine, has recently undertaken a major review of the Federal and private health services research activities. Further, there have been recent legislative efforts to reorganize the National Center for Health Services Research (NCHSR) and the National Center for Health Statistics (NCHS) to create the National Institutes of Health Care Research--encompassing an Institute of Health Policy Research (from NCHSR); an Institute for Health Statistics and Epidemiology (from the NCHS); and a new National Center for the Evaluation of Medical Technology.

The Public Health Service itself has recently reorganized the NCHS and NCHSR under the Deputy Assistant Secretary for Health Policy, Research and Statistics. This reorganization was intended to facilitate a greater degree of coordination among the epidemiological, services research, and statistical activities of these agencies and the health policy applications of research findings.

For the alcohol, drug and mental health (ADM) field, in particular, there could be no clearer note calling for a more rationally developed program of health care research than that sounded by the President's Commission on Mental Health.[1/] The Commission recently reiterated the need for an expanded health care information base, and articulated the consequences of current information limitations:

> Adequate planning cannot be accomplished without reliable information--long-term epidemiological and survey research are necessary to understand the incidence and scope of mental disorders in this country. The need for more precise demographic and socioeconomic

data is urgent if we are to understand and meet the different needs which exist in our society. Data to determine the availability and utilization of services are also insufficient. Without such data, it is difficult to assess needs or to plan for and deliver services.

ADAMHA, as the PHS agency with major responsibility for research and data collection concerning the alcohol, drug and mental health (ADM) service system, must improve its capacity to develop and integrate its health care research programs. Its three Institutes have contributed significantly to understanding of the ADM service system, as one component of the total U.S. health care system. Yet, in view of the pressing information demands required for National health policy development, the current knowledge base about ADM services and clientele is fragmentary at best. There are major gaps in our data on the scope or prevalence of ADM disorders and problems, on the capability of our current service system to address them, and on the costs, efficiency and effectiveness of services.

The lack of such information is felt in many quarters: by State and local health and ADM service planners who need such data to aid in the administration and development of programs; by ADAMHA which needs a knowledge base to guide its service program development and support strategies; and by PHS and Congressional policy makers and planners who require comprehensive data on the existing health care system to shape decisions on forthcoming changes.

Given intense public and professional concern with the cost, quality, equity, accessibility, and efficacy of health care in America, closing these knowledge gaps takes on particular urgency. National health policies and programs are being studied and implemented to address many of these issues. If ADM services are to receive appropriate consideration and structure within this policy framework, data must be available to document how the ADM service system meets the needs of its intended constituency and fits into the larger context of general health services.

In view of the foregoing concerns, the ADAMHA Workgroup on Epidemiology, Health Services Research*, and Statistics/Data Systems was convened by Dr. Klerman as one of four ADAMHA workgroups devoted to key policy-

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* Although the Workgroup's original title has been retained, the scope of its investigation encompasses less than the entire field of health services research. As explained on pages 18-23, its primary focus within that field has been on health <u>systems</u> research.

related areas (the other three examining, respectively, treatment assessment research, manpower and training, and prevention). This Workgroup was charged with providing a comprehensive review of ADAMHA activities bearing on the National scope of ADM service needs and services, and suggesting ways to enhance the further development and application of research findings from these areas. In addition, the Workgroup was to examine the linkage between ADAMHA's research and data collection efforts and those of other State and Federal agencies to assure greater cooperation and data comparability. This report presents the results of that review. It focuses on the three major areas most germane to the Workgroup's charge--epidemiology, health systems research and health statistics--describing these activities in terms of current organizational foci and levels of funding; reviewing the major problems and issues seen from the ADAMHA perspective; and presenting a set of recommendations designed to address them.

B. Major Findings and Issues

Our review of ADAMHA's epidemiology research, health systems research, and health statistics activities revealed a solid programmatic core in all three areas which can serve as an invaluable foundation for future growth (see Figure 1). However, despite the policy and scientific significance of these research areas, our inventory revealed that only three percent ($23 million) of the total ADAMHA expenditures was allocated for epidemiology, health systems research, and data systems for FY 1977.* Approximately 50 percent of this amount was allocated to investigator-initiated grants, with the remaining 50 percent for contracts and in-house data systems. Analyses by each Institute indicate that NIMH expends the greatest absolute amount (e.g., NIMH--$9.3 M; NIDA--$5.7 M; and NIAAA--$6.2 M), but the smallest percentage of its total budget on these areas of health care research (NIMH--2 percent; NIDA--3 percent; and NIAAA--4 percent). More detailed analyses of expenditures in the three health care research fields indicate considerable differences in the attention accorded these areas by the three Institutes.

As shown in Figure 2, current activities are organizationally highly diffuse. Developing a more thorough understanding of the ADM service system and its clientele will require expanded programs in all three areas, as well as greater attention to their overall organization and direction.

Many problems and issues have impeded the development of a comprehensive knowledge base on the ADM service system. Perhaps the most global and characteristic issue is the lack of focused effort at ADAMHA to achieve

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* Inventory totals exclude staff costs, except for data systems.

FIGURE 1 – ADAMHA EXPENDITURES* BY INSTITUTE FOR DATA SYSTEMS, HEALTH SYSTEMS RESEARCH AND EPIDEMIOLOGY RESEARCH, FY77.

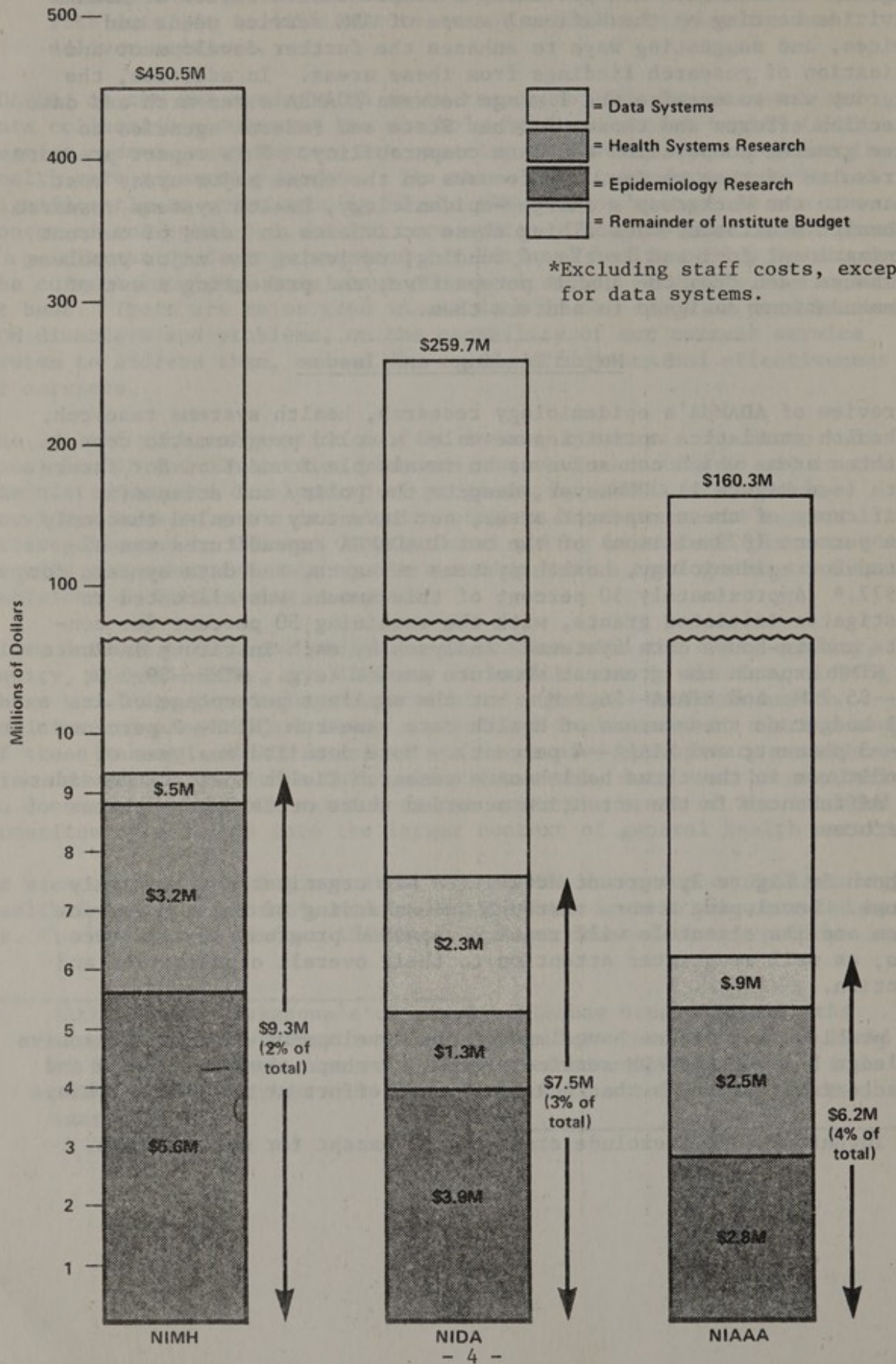
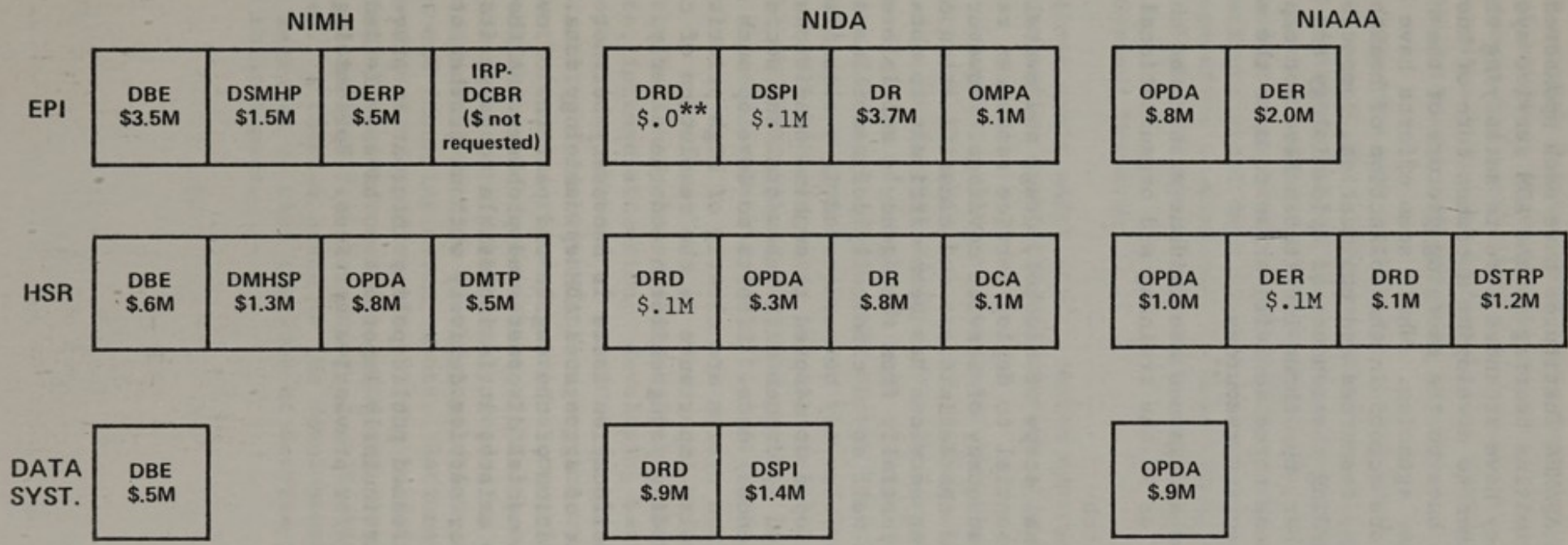


FIGURE 2 – EPIDEMIOLOGY RESEARCH, HEALTH SYSTEMS RESEARCH AND HEALTH STATISTICS DATA SYSTEMS: ADAMHA INSTITUTE DIVISIONAL INVOLVEMENT, FY77.*



DSMHP = Division of Special Mental Health Programs
OPDA = Office of Program Development & Analysis
DBE = Division of Biometry & Epidemiology
DMHSP = Division of Mental Health Service Programs
DERP = Division of Extramural Research Programs
DMTP = Division of Manpower & Training Programs
IRP-DCBR = Intramural Research Program – Division of Clinical & Behavioral Research

OPDA = Office of Program Development & Analysis
DRD = Division of Resource Development
DSPI = Division of Scientific & Program Information
DR = Division of Research
OMPA = Office of Medical & Professional Affairs
DCA = Division of Community Assistance

OPDA = Office of Program Development & Analysis
DER = Division of Extramural Research
DSTRP = Division of Special Treatment & Rehabilitation Programs
DRD = Division of Resource Development

NOTE: Data systems costs include in-house and contract costs; others include only grant and contract costs.

*In millions of dollars. Totals may not agree with Figure 1 due to rounding.
**Greater than zero but less than $50,000.

such a goal. The three ADAMHA Institutes have each sponsored research and data collection activities bearing on the ADM service system and its clientele. However, they have attended more to satisfying their individual information needs than to developing a common core of knowledge, or relating this knowledge base to the emerging picture of the health care system developed by other agencies. While some efforts have been made to develop inter-Institute accord in the collection of health statistics on ADM services, clients, resources and utilization, comparable efforts have not been made regarding the conduct of epidemiology and health systems research. Further, the three Institutes have not capitalized on the commonalities of these three activity areas to make the most efficient use of their respective resources.

More particular problems and issues are evident within the three major areas of study, as well as in the training and organizational spheres.

1. Epidemiology Research

Defining the National scope of alcohol, drug, and mental disorders and problems is essential to deploy service resources rationally and to assess the adequacy of service coverage. However, widespread agreement on the definitions and classification of the ADM conditions requiring services has been difficult to obtain. This situation results partially from the Agency's multiple emphases on social problems as well as on clinically defined illnesses or disorders. This problem may be surmounted if a classification system can be developed or adapted to combine traditional medical data on symptoms and syndromes with behavioral and social (including social consequences) data. Efforts to develop such a "multiaxial" classification system are clearly of high priority for ADAMHA. Of particular importance is the resolution of classification problems regarding young children and the elderly.

Resolving the classification issue is necessary but not sufficient for the development of aggregated ADM epidemiology data. Also needed is clarification of the degree and patterns of overlap among alcohol, drug, and mental disorders and problems. Although it is known that overlap exists, it is impossible to gauge its extent, or its implications for service delivery without further study.

In the face of increased public policy interest in preventive programming, it is particularly important to have well-identified target populations for preventive services. Epidemiological

research on risk factors, involving both longitudinal and cross-sectional studies, is essential to help identify appropriate target groups and controllable risk factors. While some risk factor studies have been undertaken at ADAMHA, these have not been given the intensive support they require.

Epidemiology research activities of the three Institutes have been conducted essentially independently, resulting, in some instances, in less efficient use of their respective resources than is desirable. With greater coordination and cooperation, it may be possible to design and conduct ADAMHA epidemiology surveys so that those of each Institute yield data for the others as well. Exploration of such cooperative studies must be encouraged, as well as greater sharing of methodological approaches and problems.

2. Health Systems Research

Of the three areas under study, health systems research at ADAMHA appears to suffer most from diffuseness of purpose and structure.

Despite the great policy relevance of this research area, it lacks visibility and systematic direction within all three Institutes, and has been characterized more by ad hoc research support than by integrated effort to develop a body of knowledge. All three Institutes have emphasized study of the health care system at the individual and program levels more than in its broad systems aspects. More equitable balance among all aspects of health services research -- at the individual, program, and systems levels -- is clearly needed, as well as better definition of research goals and programs.

Within the health systems research field, three topics require immediate, intense attention: developing better methods of identifying populations in need of services (needs assessment); linking data on service needs with data on service utilization to determine the extent of underservice in various communities and populations; and establishing an adequate base of health economics data. In the latter area, data are particularly needed on utilization and cost for a broad cross-section of the population, across many service settings and financing arrangements. Rational data-based ADM service policies depend on our ability to define quantitatively the public health need for services, and the most cost-effective and organizationally efficient manner of delivering services to meet that need. A related issue is the development of more sophisticated outcome measures so that the cost of service programs can be weighed against their impact.

Although the Workgroup focused on only the health systems research aspect of health services research, it is clear that the broader field of investigation requires the same concerted attention accorded this one facet.

3. Health Statistics/Data Systems

The health statistics area at ADAMHA differs from the other two in several respects. First, it is far less diffuse organizationally within each Institute, falling under the responsibility of one, or at most, two divisions within any Institute. Second, it has already undergone exploratory study designed to achieve greater inter-Institute coordination and data comparability. However, it is essential to see that these efforts materialize as changes in the actual collection of data. The Workgroup has outlined a plan of action which should result in more uniform data collection on ADM service system clients and facilities, and an expanded data base on all relevant service settings. These efforts will not come to fruition, however, unless the plan is carefully implemented, with adequate attention to the cooperative roles and needs of States in this data collection effort.

4. Manpower Development and Technical Assistance

Advancing our understanding of the ADM service system and its clientele requires a cadre of competent researchers to carry out epidemiology and health systems research studies, as well as personnel within service settings and State statistical programs able to develop reliable and useful health statistics data. While the adequacy of these resources was not an explicit topic for Workgroup study, it was a frequently mentioned concern. Greater attention and support is needed to expand the pool of able and interested researchers needed for ADM epidemiology and health service studies, and to provide the technical assistance needed to develop a Federal-State-local cooperative statistical system.

5. Administration

As the previous remarks have indicated, ADAMHA is not optimally organized to make most efficient use of its resources in epidemiology, health systems research, and health statistics. Developing a more extensive and coherent data base on the ADM service system, which will fit in well with other Federal and State health care research and statistical systems, requires several new lines of coordination that link: ADAMHA to other agencies; the ADAMHA

Institutes to one another; and the three activity areas to one another within each Institute. As an interim solution, we have recommended several coordinative and advisory bodies to forge such links. Ultimately, we envision each Institute evolving to the point that each has a critical mass of multidisciplinary personnel working together within a single organization structure --such as a research division--with responsibility for developing a coherent research program spanning all three areas relating to broad National characteristics of the ADM service system.

C. Major Recommendations

The following are the major recommendations* of the ADAMHA Workgroup on Epidemiology, Health Services Research and Statistics:

I. Epidemiology

1. Each Institute should accelerate activities on the definition and multiaxial classification of ADM disorders and related problems. Separate conferences should be conducted to address the unique difficulties in classifying ADM disorders among children and the elderly.

2. Epidemiological surveys of defined population groups should be undertaken by each Institute to assess the incidence and prevalence of specific ADM disorders or problems. Case identification interviews should be used which incorporate the latest state-of-the-art definition and classification criteria and diagnostic/ case detecting techniques.

3. Cooperative, cross-Institute longitudinal epidemiological studies should be initiated to obtain data on the scope and overlap of defined ADM disorders and problems.

4. Studies which assess risk factors associated with ADM disorders must be undertaken to establish a scientific basis for prevention activities.

5. Classifications used in epidemiological studies should be compatible with those derived from clinical, psychopathological, genetic, neurobiological, and sociological research to permit linkage between conditions recognized in clinical practice and those identified in epidemiological surveys.

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* For more detailed discussion of each, see pages 35-37, epidemiology; 45-47, health systems research; 59-60, health statistics; 65, research training and technical assistance; and 69-71, administration.

II. Health Systems Research

1. Each Institute should increase the resources devoted to the cost and financing of care, with immediate priority being given to studies assessing the utilization and cost of ADM services under current health insurance and projected National Health Insurance plans.

2. Studies are essential which link direct measures of need from epidemiological surveys with research findings on services utilization, and with indirect indicators of need for ADM services such as the community sociodemographic profiles used in area health services planning.

3. Additional studies should be initiated on the current and optimal division of responsibility between the general medical and the specialty ADM services sector for the care of patients/clients with ADM disorders and problems.

4. The relative efficacy, effectiveness, and efficiency of alternative ADM treatment settings (e.g., CMHC's private office practice, HMO's) should be studied, with priority given to studies in which outcome measures are applied to patient cohorts.

5. Factors which facilitate or deter the receipt of treatment by people with ADM disorders or problems should be specifically evaluated at all levels of health services research.

6. Manpower studies must be supported which relate data on the supply, distribution, and utilization of ADM service personnel to information on ADM service needs, staffing mix, staffing standards, organization, financing, and practice incentives.

III. Health Statistics/Data Systems

1. Closer integration of the ADAMHA health statistics data systems should be achieved by: (a) developing a common set of client data items for use across all three Institutes; (b) exploring the feasibility of developing a single alcohol and drug abuse client system for use by NIDA and NIAAA; and, (c) exploring the feasibility of developing a common facility/unit inventory for use in all ADM service settings by all three Institutes.

2. The conversion of the routine basic data systems of ADAMHA to a Federal-State-local model, in cooperation with the NCHS Cooperative Health Statistics System, should be accelerated.

3. The comprehensiveness and policy relevance of the ADAMHA data systems should be enhanced, with particular attention given immediately to: (a) filling current data gaps (e.g., obtaining data on patients served in CHMC's, and on patients/clients served in non-ADAMHA sponsored service programs); (b) enhancing the inhouse capacity to analyze existing data.

4. The capacity of each Institute to analyze exising data should be increased by: (a) providing positions for relevant professional disciplines and an organizational structure which allows such positions to be devoted to policy analysis; (b) devoting increased contract money to policy analysis studies which cannot be conducted efficiently by an inhouse staff due to relatively long time frames, or special analytic skill requirements.

IV. Research Training and Technical Assistance

1. The supply of researchers competent to conduct epidemiology and health services studies relevant to ADM problems and services must be increased through an expansion of current ADAMHA research training programs.

2. Research training in epidemiology and health services research must be more closely linked at ADAMHA to research program activities and emphases in these areas.

3. Technical assistance and short-term training programs of the three Institutes regarding their data systems should be reviewed for overlap, relevance to the field, enhancement of ADM course content, and the potential for cost-sharing--among the three ADAMHA Institutes and between ADAMHA and the Applied Statistics Institute program of the National Center for Health Statistics.

V. Administration

1. An Advisory Coordinating Committee on Health Care Research should be established within each Institute, with membership and chair appointed by each Institute Director to include

representation from the areas of epidemiology research, health services research, data systems, and policy development and analysis.

2. An ADAMHA Health Care Research Advisory Committee should be established by the Administrator of ADAMHA, with representation drawn from the three Institute Advisory Coordinating Committees on Health Care Research. This permanent committee should facilitate coordination of health care research activities across the three Institutes and with the rest of the Public Health Service. Its functions should include supervision of the ADAMHA Task Force on Health Services Research (see below).

3. An ADAMHA Task Force on Health Services Research should be established by the Administrator of ADAMHA to study the entire health services research field at ADAMHA, and to recommend better ways to integrate and coordinate health services research activities within the Agency.

4. An urgent goal of intra- and inter-Institute deliberations concerning health care research should be to develop within each Institute a critical mass of epidemiologists, sociologists, demographers, health economists, statisticians, and research clinicians with budgetary and other staff resources for implementing a balanced and comprehensive health care systems research program. Such a program should be placed in an organizational context, such as a research division, where the maximum coordination of related research activities can take place.

II. CONCEPTUAL FRAMEWORK AND SCOPE OF REPORT

Despite the urgent Congressional, PHS, and ADAMHA public health policy needs for more systematic health care research data, there have been conceptual as well as scientific and organizational barriers to developing such information. Clearer conceptualizations of the major relevant fields of inquiry, their contributions, and their interrelationships are needed if useful health care policy data are to emerge. The contributions of many fields and disciplines are necessary for this task, however, three are particularly germane: epidemiology research; that aspect of health services research we have termed "health systems research"; and health statistics/data systems. ADAMHA research and data collection activities in these three fields have therefore formed the focus of this report.

To clarify how we have defined these fields, and to provide a point of reference for discussions to follow, we will present a brief overview of the three fields. Particular attention is given to providing a conceptual framework for health systems research and its relation to the larger field of health services research and the contributing fields of epidemiology and health statistics.

A. Epidemiology Research

The availability of epidemiological data on the prevalence or scope of ADM disorders is prerequisite to the development of any rational ADM health care policy. It is necessary to recognize, however, that the field of epidemiology consists of much more than the application of survey methodologies to population groups.

Epidemiology may be defined as the study of the distribution of disorders and associated problems in space and time, within a population, and of the factors that influence their distribution. An NIH Task Force on Epidemiology[2/] has recently provided a more extensive description of epidemiology research activities as follows:

> Such study involves the identification and analysis of the interactions of the host and the physical, chemical, biological psychological and social factors in the environment. Methodology includes the collection and interpretation of data bearing on the health problem; the development and testing of hypotheses about causes of the health problem; and developing quantitative estimates of risk for subgroups of the population with the goal of disease prevention, control, and health promotion.

Epidemiologic studies may be (a) descriptive regarding the frequency of occurrence of a disease including its characteristics in different population subgroups; (b) analytical to test hypotheses about host and environmental factors which determine or modify the clinical expression of the disease; (c) experimental such as testing whether the frequency of a disease is changed by modifying exposure to a suspected causative agent or through field trials of prophylactic agents or other disease control methodologies; or (d) evaluative such as the evaluation of health services through prospective comparative measurements of utilization, disability, and mortality as they relate to different types or organization of health services systems. Epidemiologic methods may also be employed in clinical trials of new therapeutic agents or techniques although such studies are not necessarily classified as "epidemiologic."

Although such a description is helpful to describe the range of epidemiological research, our Workgroup, following the schema of Morris,[3] has identified and analyzed ADAMHA epidemiology research studies according to four major functional research areas as follows:

1. Studies concerned with the definition, identification and classification of disorders, syndromes, and associated problems. This area of research encompasses the development of case identification techniques, including screening instruments and standardized interviews used in case finding and classification.

2. The use of surveys to determine the incidence and prevalence rates of disorders in population groups. These studies may be used to identify the service needs of population groups and to identify particularly vulnerable groups subject to these disorders. Changes in these rates may be used to monitor the effectiveness of preventive and treatment services.

3. Determination of risk factors associated with the presence of identified disorders, syndromes, and associated problems. the determination of risk factors is essential to the search for causes which elucidate the etiology of these disorders. Etiological studies of this type involve an evaluation of variables associated with the incidence of specific disorders, including sociodemographic, genetic, behavioral, and environmental characteristics of affected persons.

4. Studies of the natural history of disorders, as affected by available treatments, allow an understanding of the course of such disorders from early subclinical through clinical and recuperative stages. These studies are essential to determine whether preventive, treatment, or rehabilitative interventions have been effective.

FIGURE 3. HEALTH SERVICES RESEARCH: COMPONENTS

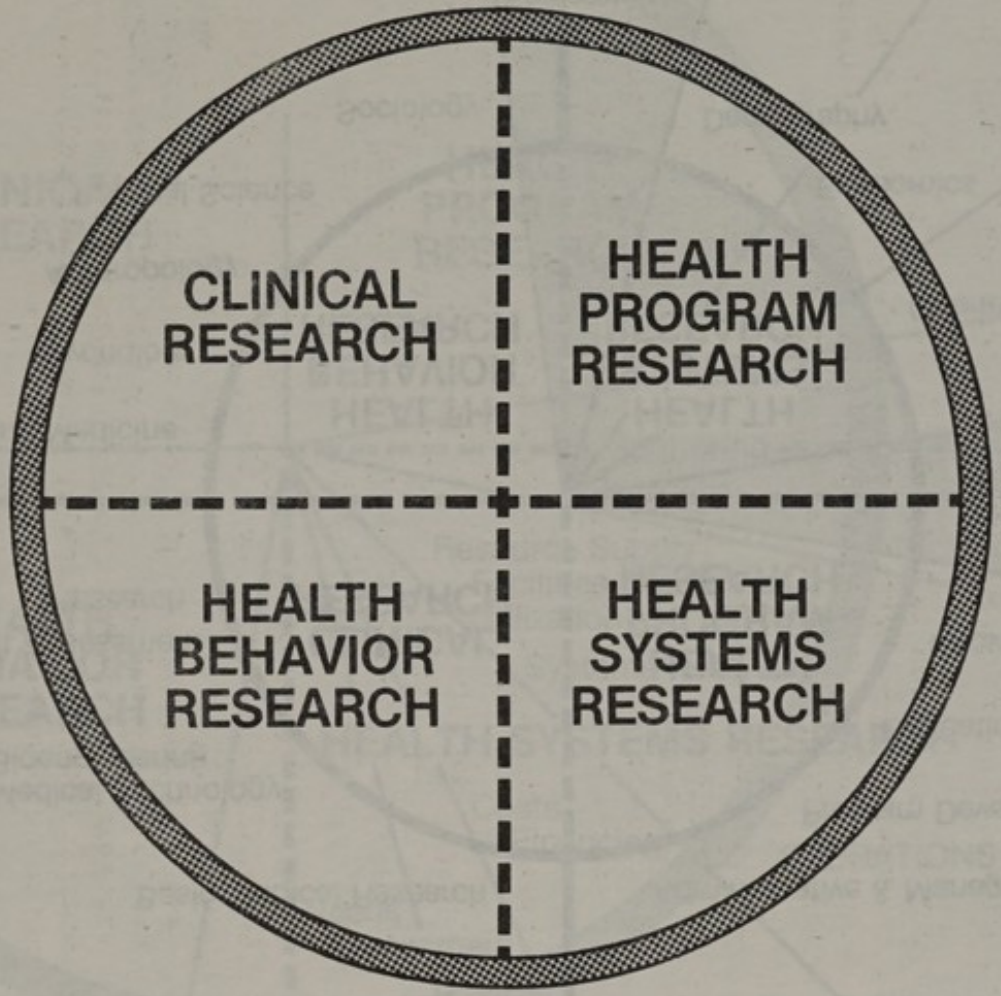


FIGURE 4. HEALTH SERVICES RESEARCH: BOUNDARIES

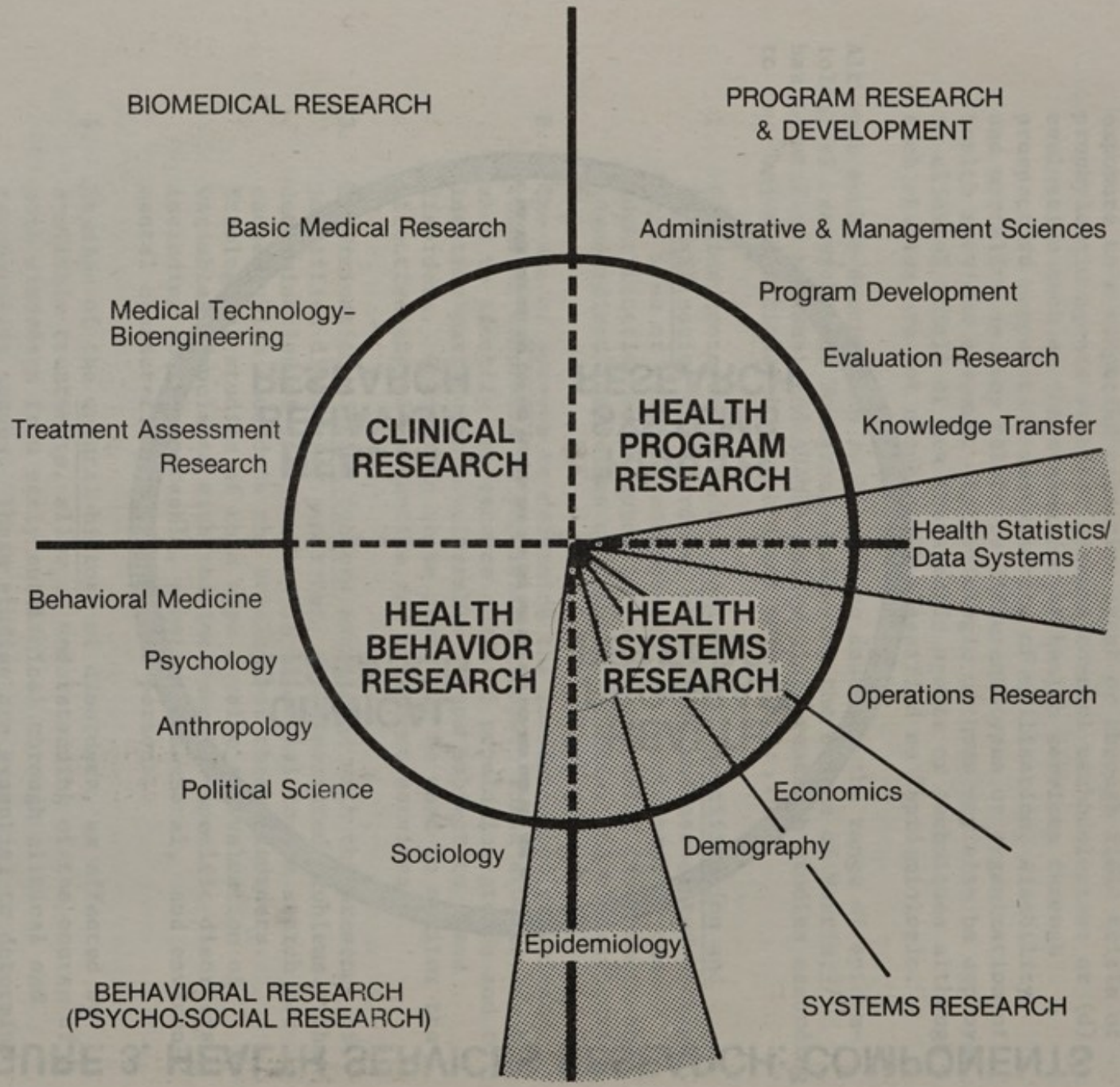
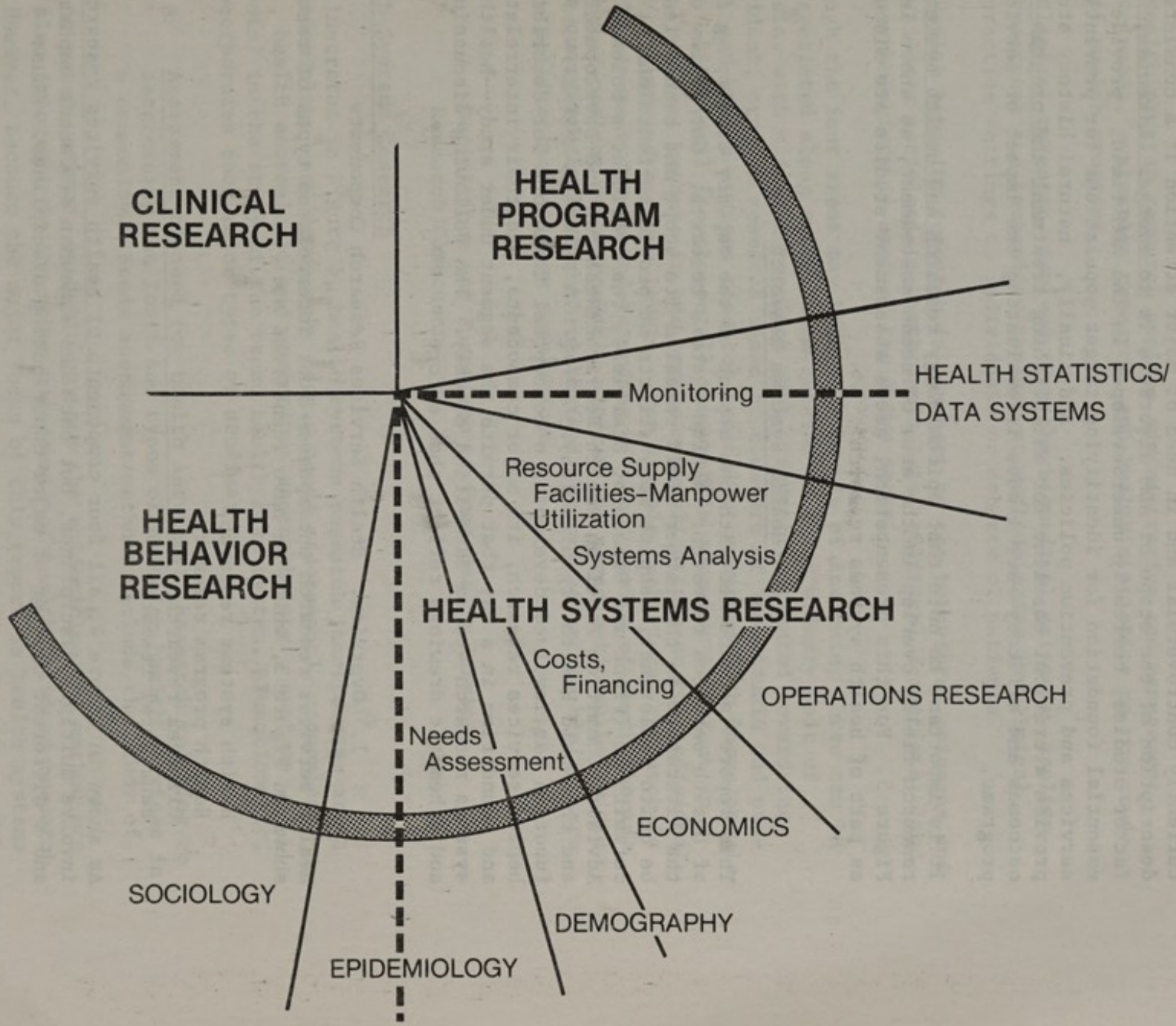


FIGURE 5. HEALTH SYSTEMS RESEARCH



We have examined the entire range of ADAMHA epidemiology research, rather than restricting ourselves to the relatively rare studies of incidence and prevalence. The classification of ADAMHA disorders is currently controversial and in need of major attention if a consistent description of the scope of ADM disorders is to emerge. Likewise, risk factor studies, currently underdeveloped in the ADM field, provide an essential foundation for identifying target populations for preventive services and prevention policies. And finally, natural history studies provide a critical baseline for establishing treatment and program outcomes and efficacy--key issues in evaluating the impact of service programs.

It is important to note that epidemiology research and health systems research fields overlap in the area of needs assessment, as shown in Figure 5. For this presentation, needs assessment studies are discussed as part of health systems research.

B. Health Systems Research

This report is concerned with one aspect of the rapidly developing field of health services research: health systems research. Our review of the literature on the larger field revealed its scope and boundaries to be quite indistinct, despite many efforts at providing functional definitions (Flook and Sanazaro, Starfield, the President's Science Advisory Committee Panel on Health Services Research and Development, and the World Health Organization).4/,5/,6/ A principal Workgroup staff function has involved developing a conceptual framework for describing health services research, its major components, and their interrelations and boundaries in a way that permits the segment under study--health systems research--to be identified clearly. The following discussion and schematic drawings reflect that effort.

1. Overview: Health Services Research Components

Health services research encompasses four interrelated types of research, shown in Figure 3, which we have identified as:

Health systems research
Health program research
Clinical research
Behavioral research

As shown in Figure 4, all four components of health services research involve multiple disciplines, but each has somewhat different emphases, and a different cluster of major contributing disciplines. Thus:

Health systems research incorporates elements of operations research, economics, demography, epidemiology*, and health statistics.

Health program research applies administrative and management sciences, evaluation research, and health statistics to the study of health programs.

Clinical research, derived from the biomedical sciences, applies treatment and technology assessment methodologies in clinical practice settings to individuals or cohorts of patients.

Health behavior research is a subset of the behavioral sciences and utilizes sociologists, anthropologists, political scientists, and psychologists in each of the above areas.

Although the four areas may have many levels of analysis, three can be differentiated along a continuum related to their primary unit of analysis, with clinical research most frequently oriented toward the individual, program research aimed at clusters of individuals and programs, and health systems research typically concerned with large populations. Behavioral (psychosocial) research is somewhat different in focus, however, because it has pervasive applications at the individual, group/program and systems levels. For example, behavioral research is clearly necessary to an understanding of the dynamics of psychotherapy and doctor-patient relationships, program and organizational behavior, and the sociological and anthropological factors affecting health care system utilization by large populations.

2. Definitions and Functions of Four Health Services Research Components

Health Systems Research

As illustrated in Figure 5, health systems research incorporates areas of epidemiology* and demography (e.g., needs assessment), economics (e.g., health economics), and operations research (e.g., systems analysis) in the study of the broad health care system. Functionally, it incorporates four major types of studies:

a. Assessment of need for health services: Research relating to determining the level and types of need for health services in a community. Needs assessment methods include the study of

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* As noted earlier, epidemiology and the epidemiological method are also important in the other components of health services research However, because the major focus of this report is health systems research, we have only indicated the overlap of epidemiology with needs assessment in health systems and health behavior research.

sociodemographic indicators, rates under treatment, key informant interviews, and direct surveys. The latter include epidemiological surveys to determine the prevalence of specific disorders or health-related problems.

b. Assessment of the supply of health resources.

i. Facilities and Services: Research relating to determining the amounts and types of services available and their efficiency, productivity and output; the appropriateness of the services and the relationship of the amount of available service to service need or demand; measurement of service utilization; development of criteria and standards for adequate service levels of different types; and projections of need or demand for services and their supply.

ii. Manpower: Research relating to the supply, demand, production, and utilization of manpower; manpower geographic and disciplinary distribution; the costs and financing of training; and evaluation of training programs, staffing, standards, and related topics.

c. Assessment of costs and financing of care: Research relating to the direct and indirect cost of health problems; the benefits of control programs; returns from investment in education and training; factors influencing the supply, demand, prices and costs of health care; and the financing of care. The latter area involves the assessment of practices such as the use of services by insured vs. the noninsured; the effect of introducing insurance coverage on price, supply, and demand for services; the substitution of services and/or providers; and the impact of differential coverage on the utilization, accessibility, and equity of services. Cost benefit, cost effectiveness, and cost outcome studies are generally included under this rubric.

d. Systems analysis: Research relating to the broad health system, the interaction of its parts, and with its environment, such as: the relation between economies of scale and accessibility of services; the impact of financing mechanisms on the redistribution of services; changes in the mix and composition of services over time; the appropriate balance of care provided in the specialty ADM vs. the general health sector and the social services sector; and the adequacy and amount of care provided in the general health sector for specific ADM disorders.

The remaining three segments of health services research, with which this report deals only tangentially, are: health program research, clinical research, and behavioral research. Brief descriptions follow:

Health Program Research

Health program research encompasses both program development and program evaluation components. Health program development involves the development, demonstration, evaluation, and dissemination of new models of service delivery. The fields of technology transfer and information dissemination research are thus closely allied with program research and development. Health program evaluation is the general process of examining, by objective and systematic methods, the effects of policies and programs on particular targets (individuals, groups, institutions, communities). Evaluation research assesses outcomes (e.g., whether goals are met), and the factors associated with various outcomes. Program evaluation usually occurs as part of organizational management, decision-making, and planning processes as a guide to improving ongoing programs.

Atkisson et al.[7] define program evaluation as a process of making reasonable judgments about program effort, effectiveness, and adequacy based on systematic data collection and analysis designed for use in program management, external accountability, and planning. The evaluation process is equally important, however, to the systems research level, when data from multiple programs must be analyzed to form the basis for large-scale planning and policy decisions. Since systems research often requires the use of small-scale and pilot studies in selected health programs as a basis for generalizing results to the system level, there will undoubtedly be some degree of overlap between evaluation studies at the program and system research levels.

Clinical Research

Clinical research, as a component of health services research, involves the application of biomedical research to the health services field. Clinical research focuses on assessing the impact of biomedical technology and diagnostic, preventive, rehabilitative, and therapeutic interventions on individuals within the health care system. This aspect of health services research includes studies such as clinical trials in various service settings, assessments of the efficacy of preventive interventions in reducing ADM morbidity, and studies of the impact of early diagnosis on individual health. Clinical research overlaps with treatment assessment research in those instances in which both are concerned with assessing how individual patients respond to treatments within clinical settings. Treatment assessment research, however, may also be conducted in more highly controlled environments of specialized research facilities. Finally, the study of patient outcomes, central to clinical research, may also be employed as one approach to outcome assessment.

Health Behavior (Psychosocial) Research

Health behavior research includes studies of the psychosocial aspects of health services and practice, such as individual client, patient, and staff behavior; small group, professional and organizational behavior; and interorganizational relationships in the health arena. Examples of such research include studies of individual and family help-seeking and illness behavior; treatment team interaction; group process in treatment settings; deviant health behavior; cultural barriers to health care; organizational conflict; linkage systems; role negotiation in health institutions; and patient-staff interaction studies. This area of research provides an added and necessary dimension to each of the other three levels of health services research.

C. Health Statistics/Data Systems

The third major area of concern to this Workgroup, health statistics/data systems, includes only systems with some organized, repetetive mechanism for collecting data on the ADM service delivery system. Our particular concern here is with ADAMHA-operated data systems for monitoring, describing, or evaluating the ADM delivery system, including resources (facilities and manpower), utilization, cost, and financing of this system.

In health services research, epidemiology, and other research fields, the modal type of data collection is usually a one-time process specific to a particular hypothesis under study, and does not involve what we have defined here as health statistics/data systems. However, these systems can and should serve an important role in many types of epidemiology and health services research: providing one-time data or trend data which can be used for hypothesis testing; and providing a descriptive foundation concerning service system characteristics and patterns which can guide hypothesis generation for special studies.

Ideally, then, the design, conduct, and analysis of health statistics/data systems should be closely linked to both epidemiology and health systems research programs and strategies to maximize the potential research benefits of ongoing data collection, and to shape it to meet research and policy needs.

D. Scope of Workgroup Report

The data collected by the Workgroup and its recommendations pertain primarily to the shaded area shown in Figure 4, that is, the total field of epidemiology, and the health systems sector of health services research. Within the health systems sector, data systems relevant to

research, data collection, and program monitoring (vs. administrative functions*) have been singled out for special discussion (see pages 48-60) because of their importance in establishing a quantitative description of the current ADM service system.

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* For example, grant administration systems, such as the Community Mental Health Center Management Information Systems of NIMH, have not been included.

III. ADAMHA EPIDEMIOLOGY RESEARCH

A. History, Current Organization, and Research Foci

1. NIMH

a. Historical Background

When NIMH was established in 1949, relatively little research had been undertaken on the epidemiology of mental disorders. World War II had stimulated awareness of mental illness as a National problem, in the face of surprisingly high rates of mental disorder among draftees and servicemen, but the incidence and prevalence of mental disorder for the Nation as a whole were unknown. With the advent of the new Institute, several steps were taken to improve the state of knowledge: research grants were given to support studies on the epidemiology of mental disorders; similar studies were begun by NIMH intramural staff; and the annual census of patients in mental institutions, which had become an NIMH responsibility (see page 48), was used for the systematic development of statistics on the institutionalized mentally ill.

In 1967, the Center for Epidemiologic Studies was established within NIMH as part of the Division of Field Investigations. Among its functions was to staff and manage NIMH field stations across the country which would provide essential data on incidence and prevalence of mental illness and on mental health service operations. Only two field stations were actually funded. In 1968, the Center was transferred to the Division of Extramural Research Programs and in 1975, it became part of the newly established NIMH Division of Biometry and Epidemiology. The Center has gradually built up an epidemiological research and training support program, although the Institute's epidemiology research is by no means centralized within the Center.

The NIMH sponsored several classic epidemiology studies in the late 1950's and early 1960's which reflected both a growing concern with the social causes of mental illness and a commitment to using epidemiological approaches to gain further information on the scope of mental disorders in the population. These studies included the following: (1) the Hollingshead and Redlich study of social class and the treated prevalence of mental disorders; (2) the Sterling County, Nova Scotia studies by the Leightons; (3) the Mid-town Manhattan study

of Srole et al.; and (4) a national sample survey of all U.S. adults by Gurin et al. These surveys utilized the best available instruments at the time, including clinical record diagnoses, screening scales, and structured interviews which allowed determinations of an individual's global "mental impairment" and the probability that he or she could be classified as a "case" with a mental disorder.

In the early 1970's, a growing fund of knowledge about the biological foundations of mental illness rekindled interest in a more medical approach to psychiatric epidemiology. The adoptive studies by Kety and Rosenthal, Heston, and Mednick et al. provided strong evidence of a genetic basis for schizophrenia. Similarly, psycho-pharmacological studies underscored the role of neurochemical factors in the etiology of psychopathology, particularly affective disorders. These currents, combined with increasing rapprochement and interdependence between the medical and mental health research and service communities, stimulated reexamination of existing psychiatric nosologies and diagnostic approaches, and a concurrent exploration of ways to identify discrete psychiatric disorders through community surveys of untreated populations. Efforts were undertaken to improve the cross-cultural comparability of diagnostic data on mental disorders through two large-scale international research projects: the United States-United Kingdom Diagnostic Project, and the World Health Organization's International Pilot Study of Schizophrenia. Further, through a combination of intramural and extramural studies, the CES of NIMH encouraged the development and application of instruments to measure the prevalence of specific mental disorders. Systematic development of such instruments has paved the way for more widespread application, such as the surveys now being undertaken within the Epidemiological Catchment Area studies (see below).

b. Current Organization and Research Foci (FY 77: $5.6 M)

Responsibility for epidemiology research at NIMH rests primarily with the Center for Epidemiological Studies of the Division of Biometry and Epidemiology. However, many epidemiological and epidemiology-related activities also occur outside the Center, both within other Branches of the Division of Biometry and Epidemiology (DBE) (e.g., the Survey and Reports Branch and the Applied Biometrics Research Branch), and within other NIMH Divisions (e.g., Division of Extramural Research Programs, Division of Special Mental Health Programs, and the Intramural Division of Clinical and Behavioral Research). Indeed, given this organizational structure, only

about half of the total NIMH epidemiology research awards are granted by the Center (see Figure 2).

The Center for Epidemiological Studies sponsors a limited intramural program of research, a program of grant support for investigator-initiated research, and a program of grant support for training programs in epidemiology. Research program areas include the development and refinement of epidemiologic methods, development and testing of epidemiologic hypotheses (particularly regarding incidence and prevalence of mental illness), and experimental epidemiology.

The major emphasis of overall NIMH grant, contract, and in-house epidemiological research (FY 77) is on risk factors of mental illness (commanding 37 percent of total epidemiology funds). Other significant areas include methodological studies (15 percent of funding), and studies of the natural history of mental illness (14 percent).

When current NIMH epidemiology research activities are analyzed by the age of subject groups, it is obvious that two key target groups have been understudied: the young and the old. Studies addressed particularly to these populations are very sparse, reflecting in part fuzziness in the field (especially clinical and diagnostic) regarding mental illness in pediatric and geriatric populations.

A significant research initiative, begun in FY 78, is the development of the ECA program to study the incidence and prevalence of mental disorders over time in well-defined populations, and to relate these to service utilization patterns in the same communities. The long-range plan is to develop 5-10 ECA's throughout the Nation at the rate of one or more per year, each of which will be maintained for at least five years to permit longitudinal studies. Each ECA will provide the geographic setting, manpower resources and technical capability to permit: (a) surveys and follow-up of randomly selected individuals in households, and measurement of incidence and prevalence of specific mental disorders; (b) data from special institutions (e.g., prisons, homes for the aged, colleges and universities, etc.) comparable to (a); (c) data on persons coming under care in the organized mental health specialty settings and from psychiatrists in private practice; (d) data on psychiatric disorders in other non-psychiatric medical settings (e.g., medical in- and outpatient facilities); (e) special studies of high-risk groups (e.g., the unemployed, separated and divorced, retired, crime and accident victims, etc.).

If the proposed Epidemiologic Catchment Area Program progresses as planned over the next three years, ECA programs will begin with surveys of prevalence but will collect additional data for risk factor studies, and longitudinal data for incidence studies. In addition, methodology work for classification will increase.

2. NIDA

a. Historical Background

The present epidemiology program of NIDA began as the NIMH Center for the Studies of Narcotic and Drug Abuse, established in 1967 (the same year as the NIMH Center for Epidemiologic Studies). Despite virtually no up-to-date epidemiology data on drug abuse, there was a clamor for quick answers to many questions, such as: How much drug use is going on, and among whom? Why are more drugs being used today? and How much damage is being done?

The earliest studies of the Narcotic and Drug Abuse Center were focused on the groups most visible in the late 60's--students and hippies--and on drugs then most alien to the society--cannabis and the hallucinogens. The bulk of the research was funded through Public Health Service grants. Many studies were solicited by staff from investigators known for the quality of their work in allied fields.

In 1972, funds were made available in the White House Special Action Office for Drug Abuse Prevention (SAODAP) for large solicited grants for sample surveys of the general population and of special populations thought to be of greater risk. Two landmark studies were O'Donnell's survey of young men at the age of greatest risk at the peak of drug "epidemic," and Robins' study of returned Vietnam veterans. SAODAP also approved plans by NIMH to continue the series of nationwide surveys begun by the National Commission on Marihuana and Drug Abuse in 1972. The nationwide survey of 1977 (George Washington University and Response Analysis, Inc.) is the third by NIMH/NIDA and the fifth in the total series.

It was recognized early that specific thrusts should be made to improve the quality and coverage of the program, especially regarding: (a) longitudinal studies, to permit determination of changes and to understand cause and effects; (b) subcultural studies, to cast light on the intensity of use in certain groups (e.g., blacks and Chicanos) and on possible

cultural variation; and (c) studies on basic phenomena such as socialization, personality, group processes, youth culture, family, and the like. In FY 75, a year after the establishment of NIDA, a research center (now a program project) was funded at Columbia University's School of Public Health to provide staff time and resources to bring a number of these efforts to early maturity. Two of their longitudinal studies of adolescents have yielded important findings. These studies and several others conducted with students were the bulwark of the epidemiology program for several years.

Deliberate efforts have been made to improve research methods for utilization by the research community, with anticipation of later dividends for the public and service programs. For example, a task force organized to develop more consistent drug use measurements has published a monograph reviewing experience to date and recommending methodological options. A follow-up publication (in press) proposed specific items to enhance cross-study comparability. Another effort was a validity study of the National survey instruments, completed before the first NIDA survey. Other improvements in progress are innovations in the National survey to improve coverage of heroin use, and studies to learn how various indicators are interrelated.

With the creation of NIDA in 1974, the intramural projects in the Forecasting Branch of the Division of Resources Development were begun. DAWN (see page 52) was the larger project; others were various explorations of indicator data. These were added to fill the need for more up-to-date reports than grants and research contracts could provide, and to supply trend data on phenomena predictive of future increases, decreases, or qualitative changes in incidence, prevalence, and adverse consequences of use.

b. Current Organization and Research Foci (FY 77: $3.9 M)

The epidemiology projects of NIDA are carried on in four units of the Institute. The Psychosocial Branch of the Division of Research accounts for the largest number of projects and the heaviest funding. Other projects are located in the Forecasting Branch of the Division of Resource Development, in the Division of Scientific and Program Information, and in the Office of Medical and Professional Affairs.

The Institute's grant, contract, and in-house studies are largely clustered in three categories: surveys of prevalence

(quantity and frequency of drug use/abuse); studies of risk factors predicting drug abuse; and natural history studies. Surveys of prevalence command the largest share of funding. These clusters, and the fact that there are only three, reflect the nature of drug abuse, but also current research gaps. The notable absence of studies of syndromes is testament to the fact that drug addiction or dependence is a concept still subject to debate and disagreement about its referents, and therefore is not often measured in surveys. Studies of these states or conditions tend to be limited to cases or clients in treatment (and therefore studied more within the health services research rubric). Current NIDA epidemiology research activities, while strongly oriented toward adolescents and young adults, have not been particularly addressed to the youngest and oldest ends of the age spectrum.

3. NIAAA

a. Historical Background

The epidemiology program of NIAAA was formally initiated in 1977 with the establishment of the Epidemiology and Special Studies Branch within the Division of Extramural Research. Prior to that time, research which might be considered within the Workgroup's definition was conducted by the Extramural Grant Program and by contracts in the Office of Program Development and Analysis (OPDA). (A brief description of this work is provided in the NIMH Research Task Force Report[8/], which covers the period from October 1966, with the establishment of the National Center for the Prevention and Control of Alcoholism (NCPCA), to the establishment of the National Institute of Alcohol Abuse and Alcoholism (NIAAA) in May 1971.)

Research grants during this period examined the distribution of alcohol consumption at National and regional levels, by age, sex, ethnicity, religion, and social class. Several grants addressed issues of etiology and natural history of alcoholism. These studies included comparisons of alcoholic patients in the United States and France, determination of the effects of frustration on drinking, and assessment of social-personality factors which lead to careers of alcohol problems or heavy drinking. A longitudinal/cross-sectional study of teenagers focused on the development of delinquency, aggression, and the use of drugs as they related to the socialization process, personality factors, and social relationships.

b. Current Organization and Research Foci (FY 77: $2.8 M)

Since the inception of the National Institute on Alcohol Abuse and Alcoholism (NIAAA) in 1971, epidemiological research has received continued support through research grants in the Division of Extramural Research (which funds the bulk of studies), contracts in the Office of Program Development and Analysis (OPDA), and, more recently, in the Epidemiology and Special Studies Branch of the Division of Extramural Research (recently transferred to the Intramural Research Program).

The major clusters of NIAAA epidemiology research are in the areas of definition, identification and classification (seven studies; studies of risk factors (seven studies); the natural history of alcohol use and abuse (four studies); and surveys of prevalence (four studies).

Current research grants cover a wide area of interest, including specific attention to the Fetal Alcohol Syndrome (three projects); and studies of natural history and maturation (two projects). Research on children is sparse; however, fetal alcohol syndrome studies have been particularly productive. Patterns of alcohol use and abuse by the elderly have received some attention, but should have more.

Seven National surveys conducted under contract since 1971 have provided information on the distribution of drinking practices of American adults aged 18 and over by age, sex, social class, residence, ethnicity, and religion. Information on adult drinking practices was complemented by a National survey of junior and senior high school students in 1974. Current extramural contracts extend these studies with analyses of drinking trends and a follow-up of the 1974 National survey of adolescents. This latter study provides a longitudinal follow-up of students studied in 1974 together with a new cross-sectional design for 1978. It was jointly sponsored by NIAAA and NIDA to include information on alcohol and other drugs.

Several current studies in the Epidemiology and Special Studies Branch are examining the role of alcohol as a risk factor in cancer and cardiovascular disease.

A new National survey of adult drinking patterns is being designed for implementation in 1978. It will provide estimates of the relative prevalence among various population subgroups, and studies of special issues related to women.

Several contracts address hypotheses of alcohol use and abuse as interactions between individuals and broader social forces. These include the distribution of alcohol availability, opportunities to consume alcohol, and the normative structure of alcohol use among certain population groups.

B. Problems and Issues

Epidemiology research at ADAMHA, although actively supported by all three Institutes, has not been organized to yield some of the basic incidence and prevalence data required for many policy and planning activities.

Ideally, it should be possible to describe or estimate with some accuracy:

1. The number of persons who have specific alcohol, drug, or mental health disorders and problems at a given point in time (point prevalence), and over a period of time such as a year (period prevalence). It should also be possible to describe the rate at which new cases develop (incidence). Drug, alcohol, and mental health incidence and prevalence data should lend themselves to aggregation to provide an unduplicated count of individuals with ADM problems/disorders, expressed as a percent of the total National population, and as a number of affected individuals.

2. The degree of overlap among these populations, that is, the number of individuals with concurrent ADM problems (e.g., alcohol + drug, alcohol + mental health, mental health + drug, and alcohol + mental health + drug).

3. The distribution of specific disorders and problems within the broad framework of alcohol, drug, and mental health categories (e.g., the number of people with depressive disorders, Korsakoff's syndrome, heroin addiction, or combinations of disorders).

The best data currently available from the three Institutes do not satisfy these criteria. NIMH has survey-based estimates on the period prevalence, annual prevalence, and annual incidence of "mental disorders" (as defined in the ICDA,* which includes in its classification scheme drug and alcohol addiction). The NIMH figures indicate that at least 10 percent of the U.S. population (or 21 million persons) have "mental disorders" at any given point in a year, with a 15 percent rate per year (almost 32 million). The annual incidence rate is estimated at 5 percent per year. However, these data present several problems.

* International Classification of Diseases, Adapted

First, specific alcohol, drug, and mental disorders cannot be disaggregated, and the alcohol and drug disorders included represent only the more severe end of the substance abuse spectrum. Further, National data are not yet available on the distribution of specific mental disorders. The available data only yield National rates of global "mental disorders," and do not permit identification of, say, the rate of depression or schizophrenia in the population at large.

NIAAA, based on its community surveys, has estimated that 7 percent of adults, or approximately 10 million, are "problem drinkers" (including alcoholics), with an additional 3.3 million "problem drinkers" among youth in the 14-17 year age range (19 percent). However, it is not possible to distinguish the types and levels of problem drinking within these populations, nor is it known how many also have drug and/or mental health problems.

NIDA provides estimates of the prevalence of drug use rather than drug addiction per se. Its household survey data have yielded use rates of marijuana/hashish vs. stronger drugs (cocaine, hallucinogens, heroin and other opiates) by population age groups. However, many drug categories of use overlap, and cannot be added to yield a total figure. It is possible, for example, to identify the 18-21 year olds as having the highest use rate of any age group for marijuana/hashish and for stronger drugs; however, it is not clear within any population group how many would be identified as having problems and/or disorders. The categories "drug abuser" or "drug addict" are not used in analyzing these surveys. NIDA, like NIMH and NIAAA, has not attempted to document overlapping ADM problems.

The sources of these differences among Institutes, and the aggregation problems they present, are many. However, two major issues can be identified: lack of accord among the Institutes and their respective constituencies concerning an appropriate classification system and way to conceptualize ADM problems and disorders consistently, and lack of coordinated effort to identify populations with overlapping problems and disorders.

On the conceptual-classification issue, it is obvious that NIAAA and NIDA resemble one another in approach more than they do NIMH. At NIMH, epidemiology research work has proceeded on the assumption that an essentially medically oriented classification system (e.g., ICDA or RDC) could yield a satisfactory description of the population with "mental disorders." Recent efforts have concentrated on developing refined ways to describe discrete disorders through household surveys without requiring trained clinicians as interviewers. At the same time, NIMH has supported development and testing of a new mental health classification scheme (DSM-III) which incorporates social and behavioral as well as symptomatic data in the assignment of individuals to diagnostic categories.

NIDA and NIAAA have been reluctant to adopt any of these classification systems for the conduct and analysis of community surveys, on the assumption that they are essentially premature. Since it is not yet clear what constitutes an alcohol or drug "problem" or "disorder" as distinguished from presumably "normal" alcohol or drug use (or even, in the eyes of some, that such instances of socially defined deviant behavior should be regarded as true medical "disorders"), their efforts have concentrated on describing community patterns of drug and alcohol use and related behavior, without identifying individuals as having disorders. Studies and conceptualizations in the substance abuse field have suggested that it may be necessary to define behavioral pathology by its social consequences, an approach not now incorporated in current mental health classification approaches.

Given the basic conceptual differences that underlie epidemiology research at NIDA and NIAAA vs. NIMH, it seems ill-advised to attempt to develop aggregated data on ADM disorders without developing a classification system capable of incorporating the perspectives of the various Institutes and their respective research communities. Initial exploration by the Workgroup members indicated that a multiaxial classification system was at least conceivable, using as major descriptors an individual's clearly defined disorders or syndomes; symptoms; drug and alcohol intake; and social function patterns. Obviously, however, considerable collaborative study is required to see if such a multiaxial scheme is feasible, and to examine how it might link to existing and developing National and international classification schemes. Another aspect for study concerns the statistical ramifications and complexities posed by such a system.

The development of a common conceptual-classification framework should facilitate several other types of coordinated studies across Institutes. First, it should permit the Institutes to mount cooperative studies addressed to the degree of overlap among their respective clientele--a necessary step in the creation of a comprehensive picture of the scope of ADM problems in the population at large.

Second, it should facilitate a common perspective in the conduct of prevalence surveys, and heighten awareness that surveys by one Institute can, if properly designed, yield data of interest to the others. For example, the NIMH Epidemiology Catchment Area project could be used to identify individuals with drug and alcohol problems, as well as those with mental health problems. Similarly, National surveys by NIDA and NIAAA on patterns of drug and alcohol use could incorporate some questions on mental health. (In the same vein and spirit, health services research studies by one Institute could yield data of interest to the others, e.g., studies by NIMH of CMHC users could document drug and

alcohol problems among their presumably "pure" mental health clientele), while NIAAA and NIDA studies of participants in their special programs could include data on mental health problems and service use by their clientele).

In the development of a multiaxial classification scheme for ADM problems and disorders, special attention should be given to the classification issues regarding children and the elderly. Both populations pose special diagnostic problems which must be resolved if satisfactory prevalence and incidence data are to be developed. Both populations are considered to be seriously underserved and in need of intense programmatic effort; however, unless their ADM problems can be better identified, and their magnitude documented, we risk inappropriate service development and delivery.

The Workgroup members naturally devoted considerable attention to issues related to development of comparable incidence and prevalence data across Institutes since it was this problem, in part, that precipitated the Workgroup's formation. However, the study of the entire range of epidemiology research at ADAMHA revealed other research- and policy-related issues in epidemiology that demand immediate attention.

Growing awareness of the limitations of a remedial health care system, combined with increased sensitivity to public health approaches to health care, have stimulated interest in preventive programming. The strong preventive orientation of the President's Commission on Mental Health has given particular emphasis to prevention within the ADM field. Epidemiology has an important role to play in providing a scientific underpinning for preventive programs. Through long-term and cross-sectional studies of the risk factors associated with ADM problems and disorders epidemiology studies can help to target populations at risk for whom preventive interventions might be particularly effective. Further, experimental epidemiology studies can be mounted in which well-targeted manipulable risk factors are systematically altered. All three Institutes have mounted some risk factor studies; however, efforts to date have not been sufficiently intensive or extensive and have not been designed to study interactions among ADM problems and disorders themselves. Nor has sufficient attention been given to the reciprocal interactions between health problems and ADM problems. In view of the increasing pressure to mount preventive programs, it is essential that adequate epidemiological risk factor studies be conducted to assure that interventions will be appropriately targeted.

Another issue deserving immediate attention is the development of closer lines of contact betwen epidemiology research and clinical genetic studies. As interest grows concerning the genetic origins of ADM

disorders and problems, genetic researchers are moving toward large-population studies requiring the methodologies of epidemiologic research. ADAMHA should be in the forefront in encouraging information exchange between these fields, both within its own Institutes and in the studies it supports. Epidemiology research has tended in the past to be oriented particularly toward the social sciences, a trend which may be accelerated through its association with the growing field of health services research. However, care must be taken to assure that close ties also exist between epidemiology research and the basic and clinical sciences.

C. Recommendations

1. Each Institute should accelerate activities on the definition and multiaxial classification of ADM disorders and related problems. Their goals should be the establishment of reliable, reproducible criteria for determining the presence of specific disorders and problems in clinical settings and population surveys. Criteria are necessary for a multiaxial classification of the following:

   (1) ADM disorders or syndromes

   (2) Quantity/frequency of related symptoms and behavior

   (3) Social functioning and adverse consequences of ADM disorders or problems

   a. A conference composed of ADAMHA representatives and consultants should be established under the ADAMHA Health Care Research Advisory Committee* to evaluate existing multiaxial classifications of ADM disorders and related problems. In addition to facilitating further development of the DSM-III criteria for ADM disorders, criteria must be developed which differentiate between alcohol and drug substance use, heavy use, problem use, abuse, dependency, disorders/syndromes, addiction, and the more general categories such as alcoholism.

   b. Separate conferences should be convened to address the unique difficulties in case identification and classification of ADM disorders among children and the elderly.

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* See Recommendation No. 2, page 70.

2. Epidemiological surveys of defined population groups should be undertaken by each Institute to assess the incidence and prevalence of specific ADM disorders or problems using case identification interviews which incorporate the latest state-of-the-art definition and classification criteria and diagnostic case detecting techniques. These surveys should utilize a multiaxial framework, as discussed in the first recommendation. Such surveys are necessary to assess the scope of the problem or true prevalence of these conditions in the total population, as well as in special population groups of children, the aged, and racial minorities. The feasibility of coordinated joint epidemiology surveys among the three Institutes should be studied.

3. Cooperative, cross-Institute longitudinal epidemiological studies should be initiated to obtain data on the scope and overlap of defined ADM disorders and problems. The NIMH Epidemiological Catchment Area (ECA) project may serve as a useful model for obtaining these data from the total population groups, including non-institutionalized and institutionalized persons from a defined area.

4. Studies which assess risk factors associated with ADM disorders must be undertaken to establish a scientific basis for prevention activities.

   a. Sociodemographic, genetic, and environmental exposure correlates of ADM disorders and problems must be obtained from cross-sectional and longitudinal surveys which determine the prevalence and incidence of these conditions. Four types of risk factor analyses are required, including: (a) correlates as risk factors for ADM disorders and problems (e.g., being female as a risk factor for depression); (b) one type of ADM disorder or problem as a risk factor for other ADM disorders or problems (e.g., depression as a risk factor for alcoholism); (c) ADM disorders and problems as risk factors for other health disorders (e.g., alcohol use as a risk factor for the fetal alcohol syndrome); (d) other health disorders and their treatment as risk factors for ADM disorders and problems (e.g., chronic physical illnesses as risk factors for depression and drug and alcohol abuse).

   b. Long-term experimental epidemiology studies must be undertaken in which risk factors are manipulated over time (e.g., by the implementation of preventive service programs) to determine their relative contribution to the incidence of ADM disorders and problems. The multi-risk factor intervention trial (MRFIT) studies of the Heart Institute may serve as one model.

5. Classifications used in epidemiological studies should be compatible with those derived from clinical, psychopathological, genetic, neurobiological and sociological research to permit linkage between conditions recognized in clinical practice and those identified in epidemiological surveys.

IV. ADAMHA HEALTH SYSTEMS RESEARCH

A. Current Organization and Research Foci

1. NIMH (FY 77: $3.2 M)

Health systems research at NIMH spans all of the major areas of study outlined on pp.19-20, with special emphasis on assessment of the supply and utilization of services. Although responsibility for such studies is divided among many NIMH organizational components, the Office of Program Development and Analysis (OPDA), the Division of Biometry and Epidemiology (DBE), the Division of Manpower and Training Programs (DMTP), and the Division of Mental Health Service Programs (DMHSP) are the major sponsoring units overall.

In the area of manpower studies, collection of manpower data about whole mental health professions or disciplines has been usually sponsored by the DMTP, e.g., contracts with the American Psychiatric Association (APA) and similar organizations to conduct surveys of their professions. Within the DMTP, a small program analysis section has been responsible for generating data analyses on NIMH grantees and the grant program. The Experimental and Special Studies (ESS) grant program has recently been redirected to incorporate manpower research grants covering such topics as maldistribution, substitutability of different types of manpower, and related topics. In addition, the DMHSP Mental Health Services Development Branch is sponsoring a study of the private practice mental health services of psychologists, while the OPDA has contracted to pretest a nationwide survey of State manpower planning capacity.

With regard to needs assessment data, the NIMH has focused primarily on the development of the Mental Health Demographic Profile System (MHDPS), an in-house program cooperatively developed and maintained by DBE and DMHSP. It is designed to produce indirect measurements of needs for mental health services in a community. While the Applied Biometrics Research Branch of DBE addresses problems in the area of needs assessment, provides the service function,and coordinates all Institute activities related to the MHDPS, much of the analysis of the existing MHDPS data files has been conducted by the Population Research Section of the Mental Health Study Center (MHSC). Support from other NIMH organizational units for needs assessment studies has been modest and sporadic. Occasionally, the Mental Health Services Development Branch of the DMHSP funds grants in this area; contracts through either the 1 percent funding or the 2 percent technical assistance funding also address needs assessment issues. Current NIMH needs assessment research includes a near-completed feasibility study to develop criterion standards for mental health services, funded by the OPDA.

In the financing area, the OPDA has shown considerable interest and has sponsored several research contracts. The DBE, in addition to its in-house data collection program, has obtained some modest information on funding and expenditures, as well as on unit cost. Further, DBE staff have been involved heavily with the substantive and technical development of contracts sponsored by OPDA and DMHSP in the area of cost and outcome studies. The DMHSP, through its Mental Health Services Development Branch, has sponsored some grants in this area. The Mental Health Care and Services Financing Branch of DMHSP has devoted itself primarily to program issues regarding funding of mental health services, but has not become deeply involved in the development of research projects. The special interest centers of NIMH have sponsored some studies related to cost. For example, the Center for Studies of Schizophrenia has developed estimates of the cost of schizophrenia to the Nation (as has the Division of Extramural Research Programs (DERP) with regard to depression).

Current insurance-related studies include: a comparative analysis of utilization patterns with patterns for other health services in a large insurance program (sponsored by OPDA); a study of insurance and length of treatment in psychiatry; and a study of the short-term mental health benefit on family utilization of general medical services in a prepaid group practice medical program; and a study of cost and delivery patterns in a CMHC under a Health Maintenance Organization (HMO) grant (DMHSP/MHSDB).

Regarding the general area of supply and utilization of mental health resources, the data collection program of the DBE (see pp. 49-50) has been the major initiative of NIMH in producing facility and patient data on mental health resources. However, this largely in-house program has had only modest contract monies available and no grant monies. Within the DBE, the Survey and Reports Branch is primarily concerned with the data on mental health specialty sector, while the Applied Biometrics Research Branch conducts studies on the utilization of mental health services within the general health sector, such as general practitioners' offices, HMO's, and other organized health settings. Several studies related to the development of methods and criteria for assessing the quality of mental health care are being carried out under OPDA/PAEB sponsorship.

Occasional grants and contracts on particular topics include those of the Center for Minority Group Mental Health Programs of DMHSP relating to the utilization of services by minority groups, as well as those of the Mental Health Services Development Branch of DMHSP.

2. NIDA (FY 77: $1.3 M)

Health systems research at NIDA is conducted primarily through contracts sponsored by the Office of Program Development and Analysis (OPDA). Other NIDA units with health systems research-related contracts include the Division of Community Assistance (DCA), the Division of Resource Development (DRD), and the Division of Research (DR). In one instance, OPDA and the Services Research Branch of the Division of Resource Development are planning joint sponsorship of a contract on drug abusers in community mental health centers (CMHC's).

Most NIDA health systems research contracts are addressed to financial aspects of drug abuse and treatment, e.g., development of units of cost, assessment of social costs of drug abuse and methods of estimation, and studies of cost effectiveness of NIDA-supported services, as well as explorations of new financing mechanisms for drug treatment, such as studies of the feasibility of developing a Blue Cross drug abuse benefit package, or analysis of eligibility of drug abusers for SSI (planned).

Two studies are addressed to needs assessment and its methodology: a review of methods for estimating the number of narcotic addicts in New York City, and an analysis of inner-city heroin prevalence rate variation in the heroin problem index.

A major longitudinal investigation is TOPS (Treatment Outcome Prospective Study), a prospective study designed to examine critically the natural history of clients entering federally funded drug treatment programs. The study includes demographic, process, outcome, and community impact variables.

The planned contract study on drug users in CMHC's should provide data on utilization patterns and interactions beween the mental health and drug abuse treatment systems.

3. NIAAA (FY 77: $2.5 M)

NIAAA health systems research, almost entirely contract-based, is primarily sponsored by the Office of Program Development and Analysis (OPDA). Other sponsoring units include the Division of Special Treatment and Rehabilitation Programs (DSTRP), the Division of Research (DR), and the Division of Resource Development (DRD), Training Branch.

The main emphasis of NIAAA health systems research is on client outcome and treatment effectiveness through special studies and the

ongoing information system (NAPIS - see page 53) which is being refined. Other studies stress financial aspects of alcohol abuse and treatment, e.g., studies of cost and cost benefits of alcohol treatment, economic cost of alcohol abuse, and the relation of alcoholism treatment to earnings; studies of potential private health insurance and alternate funding sources for alcohol treatment programs (including a proposed feasibility demonstration of a prototypical Blue Cross alcoholism benefit package); and a study of the impact of 80 percent funding level in NIAAA treatment projects.

A grant-funded study of alcoholism treatment within four prepaid practice HMO's is addressed to the delivery of services and measures of their impact and effectiveness. Other studies related to assessing program impact include a four-year follow-up study of alcoholism treatment center clients, and a follow-up of Texas State Hospital alcoholism clients.

One study relating to needs assessment and service utilization is the Teenage Drinking Survey, designed to determine the extent of youth involvement in existing treatment, prevention, and training programs funded wholly or partly by NIAAA, and to obtain the perceptions of grantees of the need for additional services.

In the manpower area, the Institute's Training Branch sponsors a contract to develop an alcoholism manpower prediction system.

B. Problems and Issues

Health services research is a growing, multidisciplinary field which is gaining considerable Federal support, recognition, and visibility as "a critical component of health policy decisionmaking." The National Center for Health Services Research (NCHSR) has been a focal point for health services research, but its activities have emphasized the general health care system, with relatively little attention to the specialty ADM sector of the U.S. health service system. In view of the historical separation of the ADM sector from the general health services system (reflected both in the organization of service delivery and in the organization of Federal agencies concerned with supporting and studying the health care system), it is unlikely that Federal agencies other than ADAMHA will devote intensive resources to ADM service system research.

Given the need to develop a comprehensive understanding of the total health care system as a foundation for rational health policy development, ADAMHA has a special responsibility to develop a systematic understanding of the ADM service system, to guide its own efforts at improving the system, and to contribute to broader National health care policy development. Seen from this perspective, the current health services research activities of ADAMHA are in need of review and revision.

Although the Workgroup has focused particularly on only one aspect of health services research at ADAMHA--namely, health systems research--many of its findings can be generalized to ADAMHA health services research in toto. Our major findings concerning ADAMHA health services research in general are followed by discussion of particular issues related to health systems research.

Health services research at ADAMHA is highly decentralized, with many organizational units having responsibility for the conduct and sponsorship of research (see Figure 2). Such decentralization could work well if a) decentralized units were following a central plan that articulated overall research goals and identified areas of responsibility; and b) mechanisms existed to coordinate information-seeking and data integration across Institutes and units. However, no such mechanisms now exist. As the Agency is now structured, there is minimal systematic coordination and planning of health services research in toto across and within Institutes, and no overall guiding policy or research plan.

The net effect of the current arrangement of health services research at ADAMHA has resulted in:

a. Relatively low visibility for health services research as a research field, a factor that impedes adequate funding of an area in need of development.

b. Lack of adequate development of research personnel to conduct health services research studies, resulting, in some instances, in lower research quality than is desirable.

c. Inefficient use of scarce resources. There are many knowledgeable and talented individuals at ADAMHA whose skills can and should contribute to the systematic development of health services research policy and programs. However, their relative isolation from one another hampers the exchange of ideas, and contributes to the frequent ad hoc support of research without adequate pooling of talent in its overall guidance. The resulting research lacks coherence, and, on occasion, is duplicative or not readily pooled with related findings.

d. Lack of systematic knowledge development. As outlined on pp. 18-22, health services research has many components which should be closely linked in the development of a knowledge base about the service system, evaluation of its ongoing functions, and the design and implementation of needed changes. For example, techniques developed through clinical research should be systematically carried through to carefully evaluated trials in clinical settings, and, where appropriate,

implemented on a larger scale, possibly becoming integrated into and studied in the National ADM service system when they prove successful. Given the current organization of health services research at ADAMHA, such systematic R&D is difficult to achieve. Similarly, the National data developed through health systems research should be reviewed for clues to structural and functional problems subject to small-scale experimental study and interventions, a process that occurs less frequently than it should.

Greater cooperation and linkage is needed among the three Institutes to make best use of their respective resources in the development of a common body of knowledge. The three Institutes share an interest in a service system that has many overlaps in clientele, facilities, manpower resources, treatment approaches, funding resources, and researchers. They also share some common knowledge gaps and problems. At present they tend to conduct health services research with relatively little attention to these commonalities, and no necessity to see how their respective research endeavors contribute to the development of a common pool of knowledge about the ADM service system.

The creation of mechanisms to encourage ADAMHA-wide health services research planning and coordination would yield many benefits: (a) The identification of knowledge gaps that can be filled through a cooperative plan of study, e.g., a systematic plan for developing improved measures of costs and outcomes; (b) The more system-wide description of ADM services and their interconnections, possibly suggesting new models of ADM service delivery; (c) The agreement to use common terms, definitions, research strategies, etc., to aid in the collection and pooling of data; (d) The design of a strategy to link ADM health services activities to those of other Federal agencies concerned with the larger health system; (e) The development of closer links between health services research at ADAMHA and other related research and service endeavors, e.g., epidemiology research and preventive programming.

Within the health <u>systems</u> research area specifically, several problems, issues, and key research areas have been noted. Although the entire area of health services research is underdeveloped at ADAMHA, the health systems area is particularly in need of immediate attention and additional support in view of its central importance to health policy decisionmaking. Major work and an infusion of funding are needed in each of the five areas outlined earlier in this report: cost and financing of ADM disorders

and their care; the assessment of need for ADM services; the measurement of the supply and distribution of resources; the supply and distribution of manpower; and studies relating to this system as a whole. However, priority is given in our recommendations to certain areas due to the immediacy of the need or because essential developmental work must be done to assure future payoff:

1. Basic studies are essential to the development of alcohol, drug, and mental health benefits under National health insurance. Such studies should include the use of ADM services by insured versus uninsured populations; the effects of introducing mental health coverage on demand for services and their price; substitution of services within the ADM area; relationships of different providers and the effects of one versus the other; the effects of coverage on the supply and price of services; and the impact of differential utilization of various service settings. Studies of areas such as these are critical to effective participation and debate on the shape of National health insurance and should be given immediate priority.

2. The primary care health sector is the major health care contact for 60 percent of the persons with a mental disorder during a year. Yet we know relatively little about the characteristics of persons receiving care for ADM disorders within this health care sector; the effectiveness of the treatment they receive; the relative cost and efficiency of such treatment compared to the specialty ADM service sector; the relative efficiency of different primary care settings and treatments; the adequacy of the training of primary care providers for identifying and treating ADM disorders among their patients; and a host of other critical questions regarding the type, quality, and cost of care provided in the settings. The magnitude of the number of persons seen in these settings, as well as the critical importance of this area in shaping the development of ADM benefits under National health insurance make it essential that priority be given to this area in health systems research.

3. Considerable amounts of data have been accumulated on the number and types of persons using different specialty ADM service settings. Relatively little, however, has been learned about the comparative effectiveness of these settings, or their efficiency and efficacy in producing different levels of outcome among common groups of patients. It is essential, therefore, from the point of view of resource allocation, system development, and other factors, to investigate this area as soon as possible.

4. While direct survey techniques are on the immediate horizon for developing estimates of the number of persons in the community with ADM disorders of specific types, such surveys probably will never be available for general use due to their cost. Indirect methods of measuring the needs for ADM services are critical to meet local planning requirements. ADAMHA efforts in this area have been substantial but unbalanced in their emphasis on the demographic indirect method. With the passage of the Health Planning Act and the increased pressure from the Health Services Agencies for effective planning tools in mental health, it is critical that ADAMHA develop substantial resources to further development of needs assessment methodology.

5. Manpower studies are critical to the continuing debate on the Federal and ADAMHA role in supporting training and manpower development for ADM services. There are many pressing areas requiring detailed research regardless of whether the ADAMHA role is one of support for basic training, or as a monitor of the system as a whole providing needed support to areas not covered by other resources. Such research areas include: studies of long-term effects of the anticipated decrease of foreign medical graduates; research on the contribution of primary care providers to ADM services; studies of the competencies required to perform different ADM tasks and functions, and the relationship between credentials and competencies; and studies to determine the types of financial incentives and alternate delivery systems that would encourage ADM professionals to locate in shortage areas and redress their geographic maldistribution.

C. Recommendations

1. Each Institute should increase the resources devoted to the study of the cost and financing of care, with immediate priority given to studies assessing the utilization and cost of ADM services under current health insurance and projected National Health Insurance plans.

   a. Methodology of measuring both the direct and indirect costs of ADM disorders should be refined and substantive studies in these areas pursued.

   b. The methodology of cost/outcome, cost/benefit and cost/effectiveness studies as applied in the ADM area should be reviewed; alternative models, such as the human capital model, should be explored, and substantive studies in these areas pursued.

c. The methodology of cost finding and accounting procedures, the determination of units of service (e.g., inpatient days, outpatient visits) in different settings, and the feasibility of developing standard service units in ADM settings should be reviewed.

2. Studies are essential which link direct measures of need from epidemiological surveys with research findings on services utilization, and with indirect indicators of need for ADM services such as the community sociodemographic profiles used in area health services planning.

a. Initiate studies on methodological aspects of needs assessment such as: (a) the interrelationship of different techniques; (b) their relative effectiveness in identifying the level and types of needs in a community; (c) their relative efficiency, reliability, validity, and cost effectiveness; (d) the potential of synthetic estimation techniques in needs assessment; (e) the validation of indirect measures of need by comparison with direct surveys, possibly through the ECA program of NIMH.

b. Explore the feasibility of transferring the basic maintenance and development of the NIMH-Mental Health Demographic Profile System (MHDPS) to the National Center for Health Statistics; expand the funding base to include all user agencies within the Public Health Service; and explore the utility of this system for NIDA and NIAAA.

3. Studies should be initiated on the current and optimal division of responsibility between the general medical and the specialty ADM services sector for the care of patients/clients with ADM disorders.

a. Intensify comparative study of the provision of care for persons with ADM disorders in general health settings vs. ADM settings, investigating such aspects as: (1) type of treatment received; (2) effectiveness and cost of treatment.

4. The relative efficacy, effectiveness, and efficiency of alternative ADM treatment settings (e.g., CMHC's, private office practice, HMO's) should be studied, with priority given to studies in which outcome measures are applied to cohorts of patients.

a. Initiate methodological studies on the measurement of cost and outcome in ADM settings.

b. Conduct an analytical review of the literature in these areas, summarizing the work that has been done in the ADM areas as well as that done in the general health areas that is transferable to ADM settings.

c. Investigate the feasibility of developing criteria and standards for the amount and types of ADM services necessary (e.g., number of acute psychiatric beds needed per 1,000 population).

5. Factors which facilitate or deter the receipt of treatment by people with ADM disorders or problems should be specifically evaluated at all levels of health services research.

6. Manpower studies must be supported which relate data on the supply, distribution, and utilization of ADM service personnel to information on ADM service needs, staffing mix, staffing standards, organization, financing, and practice incentives.

V. ADAMHA HEALTH STATISTICS/DATA SYSTEMS

A. History, Current Organization and Data Systems

1. NIMH

a. Historical Background

The National Reporting Program (NRP) of the NIMH, the oldest of the three data systems, was established initially to provide statistics on the hospitalized mentally ill. In 1947, when the National Mental Health Act was enacted, the Census Bureau's annual census of mental hospital patients (begun in 1840) was transferred to the Division of Mental Hygiene of the Public Health Service, and it remained with the new NIMH when it was established in 1949. In 1951, the Institute took the initiative in establishing a National Reporting Program to produce reliable and comparable data on first admission rates, resident patient rates, movement of patients through hospitals, and length of stay by age, sex, and diagnosis. This was done in cooperation with 11 States and the Veterans Administration. A few years later, as more and more outpatient clinics were established with funds granted to the States under the Act, data collection was expanded to outpatient services as well. Subsequently, data collection on general hospital psychiatric services was added to the roster; following passage of the Community Mental Health Centers Act in 1963, CMHC's were also surveyed, as were other mental health treatment settings, such as day treatment centers, and residential treatment centers for emotionally disturbed children.

The Institute's Reporting Program has always been oriented more toward research than management, since only relatively late in its history was the Institute responsible for monitoring programs receiving Federal (NIMH) funding (e.g., CMHC's). The voluntary reporting system used by NIMH has long been based on regular and continued consultation with State and local agencies, a practice endorsed strongly by the President's Commission on Mental Health, which has recommended:

> That the practice of involving State and local agencies in the design of information systems currently employed by NIMH be utilized in the design of the consolidated ADAMHA information system.

b. Current Organization and Systems (FY 77: $0.5 M)

NIMH monitors the mental health service system through nationwide surveys of mental health facilities conducted by inhouse staff of the Survey and Reports Branch (SRB) of the Division of Biometry and Epidemiology (DBE). Two basic types of surveys are part of the current National Reporting Program (NRP): (a) complete enumeration surveys covering all organized mental health facilities on an annual or biennial basis (e.g., psychiatric hospitals, general hospital psychiatric units, CMHC's, outpatient psychiatric services, and halfway houses); and (b) sample surveys of admissions to or discharges from selected typs of mental health services (e.g., public and private psychiatric hospital inpatient services, general hospital psychiatric inpatient units, and outpatient psychiatric services). The annual and biennial enumeration surveys focus primarily on characteristics of facilities, such as caseload, staffing, expenditures, and services provided. The sample surveys are more client oriented, focusing on demographic and socioeconomic characteristics, diagnosis, prior psychiatric care, referral source, type of treatment, referral on discharge, length of stay, and source of payment. (The CMHC annual surveys also provide client data, on an aggregate basis.) The NIMH provides technical assistance to States to encourage uniformity in reporting, but does not fund or require uniform recordkeeping by them. Given the relative size of the client population receiving psychiatric services, it has chosen, in the interests of economy and efficiency, to obtain individual client data on a sample survey basis (with the exception of CMHC's), rather than seek complete enumeration of clients.

The DBE is currently developing a Mental Health Statistics Improvement Program (MHSIP) which represents a major initiative to revise its basic program data collection activities, decentralize them to the State level, and bring them into closer accord with those of other Institutes and Federal data-collection efforts. The MHSIP is being coordinated with the program of the National Center for Health Statistics (NCHS); a memorandum of agreement has recently been signed regarding the relationship of the two programs (see Appendix B). This decentralization, expected to be operational in 1984, will have at least three major implications: (1) reducing duplication between Federal and State levels in data collection, lessening the reporting burden on mental health facilities, and permitting better coordination both at the State and Federal levels;

(2) providing for the input of a modest amount of resources at the State level which will result in a major increase in the amount and quality of data available on mental health resources, their utilization and cost; (3) freeing existing DBE staff to concentrate more on the analysis of data relating to policy and program issues. Completed work includes the development of uniform data sets for mental health manpower, facilities, and patient/client data.

2. NIDA

a. Historical Background

The data systems of NIDA, like their parent Institute, are relatively new. They are generally more client- and management-oriented than those of NIMH, since many stem from the need to monitor a rapidly proliferating array of drug treatment programs, particularly those receiving Federal funding.

The Institute's primary source of client data, the CODAP system (Client Oriented Data Acquisition Process) was implemented in 1973. NIDA's major source of treatment facility data, NDATUS (National Drug Abuse Treatment Utilization Survey) was first conducted under the Institute's sponsorship in 1974, although an earlier form of this annual National survey had been conducted by the White House Special Action Office for Drug Abuse Prevention in 1973. The DAWN (Drug Abuse Warning Network) system started under Joint NIDA-DEA sponsorship in 1973, although the initial project DAWN originated somewhat earlier.

In addition to the Institute's roster of data systems, a related activity is currently underway: FMIS (Financial Management Information System) developed in 1974, designed to aid States in the collection of financial data on treatment programs.

Since 1974 NIDA has made a long-term commitment to cooperative efforts with States in data collection and utilization through such mechanisms as IDARP (Integrated Drug Abuse Reporting Process).

b. Current Organization and Systems (FY 77: $2.3 M)

The data systems of NIDA are operated largely on contract, although there is, especially in the case of CODAP, extensive in-house involvement as well in managing these systems and

using their products for a variety of applications. Most of the major systems (CODAP and NDATUS--as well as FMIS) are administered by the Division of Scientific and Program Information (DSPI). DAWN is administered within NIDA by the Division of Resource Development, Forecasting Branch.

CODAP (Client-Oriented Data Process)

The CODAP system obtains client-oriented data on federally funded drug treatment programs (regardless of sponsorship of the larger facility, e.g., freestanding, VA, Bureau of Prisons, State mental hospital). Some 1700 local clinics and programs fill out daily data collection forms which are assembled monthly and transmitted to their responsible Single State Agency (SSA), which in turn sends them to NIDA on a monthly basis. Three basic forms are the core of the system: (a) an admission report for each client admitted for treatment; (b) a similar discharge report for each discharged client (which together describe a complete treatment episode); and (c) a monthly client flow summary. The admission and discharge reports contain basic client-related data such as type and pattern of drug abuse at the time of admission and discharge, basic demographic characteristics, and prescribed treatment regimen. The monthly client flow summary contains clinic activity data such as the number of clients in treatment on the last day of the month, and indicates how these clients are distributed across various treatment modalities and environments. This reporting system is mandatory.

NDATUS (National Drug Abuse Treatment Utilization Survey)

NDATUS is NIDA's primary source of data on the total universe of drug treatment facilities. The NDATUS questionnaire is mailed annually to all known treatment units, with collection and control of the system shared by the States and NIDA. Information is collected on the number of actual treatment slots, census of clients in treatment, utilization rates for specified treatment modalities, and funding sources. Clinic staffing data are also collected.

FMIS (Financial Management Information System)

FMIS is a model management information system used by some States to obtain financial information from drug treatment facilities. While not a National data system, its broad adoption is expected to enhance financial data reporting through NDATUS.

DAWN (Drug Abuse Warning Network)

This data system, administered jointly by NIDA and the Drug Enforcement Administration of the Department of Justice, monitors drug abuse episodes that have resulted in a "crisis." It is based on reports by emergency rooms, crisis centers, or medical examiners regarding drug-related admissions or deaths. The current DAWN system monitors a representative sample of emergency departments, county medical examiners and coroners, and crisis intervention centers in 24 relatively large core cities and their adjacent areas. The data are used to determine primary drug usage patterns and trends of drug use among various populations in several geographic locations.

3. NIAAA

a. Historical Background

Like the data systems of NIDA, those of NIAAA are relatively recent. They also reflect a strong orientation toward clients and management, although the influence of researchers concerned with societal etiology in alcoholism is evident in a stress on sociodemographic data items.

NAPIS (National Alcoholism Program Information System) was established in 1972 to monitor Institute-funded alcohol treatment programs. SAPIS (State Alcoholism Profile Information System) was begun in 1976 to provide an overview on the scope and types of alcoholism programs available throughout the Nation.

More recent data systems-related NIAAA activities include: (a) the Council on State and Territorial Alcoholism Authorities Project (designed to aid States in developing data systems compatible with the NAPIS system); (b) current work to develop a means for routine collection and presentation of data on alcoholism programs of all Federal agencies; (c) current efforts to determine NIAAA and State information needs, in cooperation with State Alcoholism Authorities, as a prelude to developing a modular information system to cover all major needs; (d) development of common client-oriented data elements with NIDA; and (e) inclusion of NIAAA needs in the NIDA NDATUS system.

b. Current Organization and Systems (FY 77: $.9 M)

Major responsibility for the development and administration of NIAAA's data systems resides within the Office of Program

Development and Analysis (OPDA). Its Program Analysis and Evaluation Branch (PAEB) administers the two major data systems (SAPIS and NAPIS), and is responsible for current contracts to design State alcohol information systems and develop an integrated State alcohol management/evaluation information system.

NAPIS (National Alcoholism Program Information System)

The NAPIS system serves as the data base concerning Institute-sponsored treatment programs. This client-based system provides demographic and drinking behavior data, as well as data on treatment services provided and program resources. It covers fully about 500 NIAAA-funded alcoholism treatment projects. It is based upon monthly reports on individual clients, relying upon a followup interview with clients as a key to outcome. This system covers three major areas: client data, treatment data, and resource information.

SAPIS (State Alcoholism Profile Information System)

The SAPIS system collects selected information from the States on an annual basis at the end of their fiscal years, augmented with data from the State plans, also submitted annually. It includes program data on prevention, treatment, training, and research activities. There is a considerable emphasis upon sources of funding and obligated funds by program area, as well as some information on State-funded service facilities (although private facilities are not covered in all States). The system, still undergoing revision, includes as well National data on arrests, alcohol consumption, mortality, etc. (by State) to make the programmatic information more useful to the States and NIAAA.

Development of State Alcohol Information Systems

The Alcohol and Drug Problems Association (ADPA) as an NIAAA grantee developed State alcohol information systems (an extension of the former NIAAA grant to the Council of State and Territorial Alcoholism Authorities, CSTAA). A total of 25 States have contracted with the ADPA for system development efforts, to develop client treatment information systems compatible with NAPIS. Several States are submitting computer tapes of NIAAA grantee client information to the Institute monthly.

Integrated State Alcohol Management/Evaluation

Touche Ross, on contract to NIAAA, has developed a preliminary State alcohol information system model, oriented toward use by

the State Alcoholism Authorities, and intended to assist the SSA's to develop new, or enhance existing State information systems. Information requirements of the SSA's and NIAAA were identified and a modular conceptual model designed.

Interagency Data Effort

NIAAA has contracted with MACRO Corporation, as a result of Interagency Committee recommendations, to develop a means for routine collection and presentation of data on alcoholism programs of all Federal agencies. The soon-to-be-completed project has collected data from all Federal agencies participating in alcohol abuse and alcoholism activities. It describes resources expended (manpower and funding) on all Federal Employees Alcohol Abuse and Alcoholism Prevention, Treatment and Rehabilitation Programs, and provides a detailed descriptive inventory (by agency) of specific programs and projects operating during fiscal years 76, 77, and planned for FY 78.

B. Problems and Issues

NIMH, NIDA, and NIAAA all collect recurrent data on major quantitative aspects of the National ADM service system and its clientele, based on reports by service facilities. The three data systems were developed independently, differing in focus, emphasis, and data-collection techniques in accord with the unique needs, roles, resources, charges, and histories of the Institutes. The uncoordinated categorical development of these Federal data systems has its parallel at State and local levels, where many types of alcohol, drug, and mental health reporting programs and data systems have evolved to meet particular information, management, and research needs.

Major differences among the data systems of the three Institutes currently impede the development of an integrated ADAMHA data system. First, there are differences in the size of the client populations to which the data systems are addressed. For example, within the specialty ADM sector only, specialty mental health facilities serve approximately seven million people a year, while alcohol and drug programs each serve approximately one million people yearly. With regard to the budget of the different data systems programs, NIDA has been more generously funded, historically, than NIAAA or NIMH.

The oldest of these systems, that of NIMH, arose as a basic research effort with the beginning of the Institute in 1948. The data collection programs of the other two Institutes, on the other hand, developed much

more recently, primarily in response to the need to monitor newly funded Federal programs in the area of alcohol and drug abuse, with a special emphasis on those receiving NIDA and NIAAA funding. The programs of NIDA and NIAAA have recently expanded their focus to incorporate data collection on the entire alcohol and drug abuse delivery system, while NIMH has intensified its data collection to include more management-oriented data on CMHC's. While the programs have become somewhat more similar in the multitude of their purposes, basic differences still permeate the systems.

NIDA service programs address clients whose drug use or abuse is usually illegal. Thus, the Institute must cooperate with regulatory and legal agencies, as well as the usual health and human service agencies. This results in special data needs and inter-governmental cooperation not common to the two other Institutes. Further, NIDA and NIAAA have a specific legislative mandate and a compulsory data collection system for their federally supported programs. NIMH has operated a voluntary program under the general mandate of the Public Health Service Act and only recently has obtained a specific legislative mandate to collect data on CMHC's in detail.

All three Institutes have developed independent of the health sector, with little linkage to the National Center for Health Statistics and other parts of the Public Health Service. Such categorical development, while initially essential to garner necessary support for these programs and to produce the detailed data needed by the ADAMHA programs, now appears unduly parochial. Thus, there has been a recent attempt to integrate some ADAMHA data programs with those of the PHS.

All three programs suffer in varying degrees from major areas of data gaps. For example, each data system has considerably more data available on the ADAMHA-sponsored programs than on non-ADAMHA supported programs. The data systems are notably sparse in information on patients/clients served in the non-ADAMHA programs, particularly those in the private sector. None of the three systems provides any systematic information on the ADM services provided in the general health sector.

While all three systems have dealt extensively with the State authorities in the development of their programs, there have been varying experiences with funding of State-level data systems. NIMH has been actively pursuing the development of a Federal-State-local cooperative system, but has not received budgetary support for this activity. Both NIDA and NIAAA have received budgetary support in the past for the development of State alcohol and drug abuse systems, and they have had varying degrees of success with such programs.

Although the three data systems serve their respective Institutes and constituencies relatively well, growing dissatisfaction has been expressed, at both local and Federal levels, with shortcomings in the current organization of data collection on the ADM service system.

From an ADAMHA perspective, viewing the data systems as a means of yielding National data on the scope of ADM services, there are several problems:

1. Data from the three systems cannot be readily aggregated to yield unduplicated counts of clients, facilities, and manpower, and do not permit ready identification of service costs.

2. The data systems are too narrow in scope to yield comprehensive description of the total ADM specialty service sector, let alone a description of ADM services within the general health or social service sectors.

3. The data systems are not organized well to link readily to other Federal health statistical systems, and do not take full advantage of data resources of other Federal agencies.

4. The data systems are not organized consistently to make most efficient use of ongoing State data collection activities and resources, and to enhance Federal-State-local cooperation.

From the State and local perspective, other objections have been voiced:

1. Lack of coordination of data collection by the three Institutes results occasionally in duplicated data requests to States and/or facilities with funding by two or more Institutes.

2. Undue effort in recordkeeping is required to satisfy related but inconsistent data requests by the three Institutes.

3. The types and forms of data requested by ADAMHA may not necessarily be consistent with local forms and systems of accounting, reporting, etc., resulting in an added burden to already overburdened local reporting systems.

The high visibility of many of these problems prompted the President's Commission on Mental Health to recommend that:

> The Administrator of the Alcohol, Drug Abuse and Mental Health Administration take the necessary steps to consolidate the information and data-gathering requirements of the National Institute of Mental Health, the National Institute on Drug Abuse, and the National Institute on Alcohol Abuse and Alcoholism into a single reporting system.

As noted earlier, the Commission also recommended:

> . . . that the practice of involving State and local agencies in the design of information systems currently employed by NIMH be utilized in the design of the consolidated ADAMHA information system.

Prior to the Commission's report and the formation of this Workgroup, preliminary efforts were already underway to explore the development of minimal data sets for ADAMHA, through a three-Institute working group. Members of the ADAMHA Workgroup on Epidemiology, Health Services Research and Statistics (Data Systems), some of whom had participated in this effort, continued in the spirit of the President's Commission's recommendations to explore ways to achieve greater uniformity and rationality in data collection across Institutes, while respecting the essential role of the States as active participants and partners in the data collection process.

Underlying the Workgroup's recommendations has been the assumption that ADAMHA data collection could be streamlined to reduce duplication and increase uniformity, while retaining three separate but better coordinated data systems. It was recognized that while some data collected by the Institutes could be viewed as part of a common and uniform ADAMHA data base, the individual data systems also served special functions for each Institute which could not and should not be removed from individual Institute responsibility--e.g., monitoring service programs receiving Institute funding.

The central thrust of the recommendations contained here for ADAMHA data systems is to increase the comprehensiveness and policy relevance of data available on ADM services without increasing the response burden on service providers. This strategy is pursued by means of three major activities as follows:

1. To maximize the use of existing mechanisms wherever possible. For example, the primary focus within the PHS for collecting general-purpose baseline health statistics data is the National Center for Health Statistics (NCHS). A wide array of National

surveys are conducted by this agency. It is much more efficient for ADAMHA to work with NCHS to develop data on persons receiving services in the health sector for ADM problems than it would be to develop competing and independent ADAMHA systems.

2. To increase where feasible the compatibility and commonality of the ADAMHA data systems. Toward this end, recommendations are made for increasing the comparability of the client data systems within ADAMHA. This will enable States and local facilities to develop integrated ADM information systems, and will permit more relevant policy analysis of ADAMHA programs.

   Similar recommendations are presented with regard to manpower data. The different systems developed by NCHS and the Bureau of Health Manpower (BHM) should in the long term meet ADM needs for basic data in this area.

3. The long-term strategy for decreasing respondent burden and increasing the comprehensiveness and policy relevance of ADAMHA data systems must be the decentralization of these basic ADAMHA data systems to the State level through a Federal/State/local cooperative system. This decentralization will:

   (1) provide a mechanism for appropriate Federal cost sharing;

   (2) strengthen and enhance availability of data produced at the State and local level, thereby increasing the comprehensiveness of the data available for analysis at the ADAMHA level;

   (3) reduce the burden on the respondent by reducing the number of times a given piece of information is collected; and

   (4) free limited ADAMHA staff from data collection duties and enable more staff time to be devoted to policy analysis.

While these recommendations are presented as discrete, they are, in fact, highly interrelated. For example, a major difficulty with the existing ADAMHA data systems is their incapacity to produce small-area data for analysis, either by ADAMHA or by health systems agencies. Such data are essential, for example, in the determination of health scarcity areas and other problem and policy issues. The development of a Federal/State/local cooperative system will greatly enhance the availability of small-area data, as well as reducing the respondent burden.

C. Recommendations

1. Closer integration of the ADAMHA data systems should be achieved by: (a) developing a common set of client data items for use across all three Institutes; (b) exploring the feasibility of developing a single alcohol and drug abuse client system for use by NIDA and NIAAA; (c) exploring the feasibility of developing a common facility/unit inventory for use in all ADM service settings by all three Institutes.

   a. Separate technical subcommittees to the ADAMHA Health Care Research Advisory Committee* should be established to develop, with State and local participation, by June, 1979, a common set of client data items; to develop and conduct a pilot study of an alcohol and drug abuse system by June, 1980, and to develop and pilot test a common ADAMHA facility/unit inventory by June, 1980.

   b. Baseline data on ADM manpower employed in facilities should be collected through the Facility/Unit Inventory. ADAMHA should work with the National Center for Health Statistics and the Bureau of Health Manpower to incorporate ADM manpower categories in the Cooperative Health Statistics System (CHSS) manpower component. This will provide baseline data on the entire membership of various professional groups. ADAMHA's in-house capacity to conduct special studies in the manpower area, as well as to monitor ADAMHA training programs, should be enhanced.

   c. All currently required financial reporting mechanisms of the three Institutes for ADAMHA-supported service facilities should be reviewed; the feasibility of developing an ADAMHA Financial Reporting System to collect standard categories of sources of income and expenditure data for the three Institutes should be investigated; expenditure and income data for non-ADAMHA supported units should be collected in the ADAMHA Facility/Unit Inventory

2. The conversion of the routine basic data systems of ADAMHA to a Federal-State-local model, in conjunction with the Cooperative Health Statistics System, should be accelerated in order to: (a) provide the necessary participation of all three parties in the development of common data systems; (b) provide a mechanism for Federal cost sharing in the operation of these systems; and (c) provide the necessary technical assistance and training to upgrade these data systems at all levels. The cooperative model should build on the prior experience of all three Institutes, e.g., NIDA's

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* See Recommendation No. 2, page 70.

IDARP, NIAAA's SAPIS and Integrated State Alcohol Management/ Evaluation model, and NIMH's MHSIP.

a. The development of legislative authority and budget support for the NIMH Mental Health Statistics Improvement Program (MHSIP) should be accelerated. As common data sets and reporting mechanisms develop, these should be integrated with efforts of NIDA and NIAAA, with the long-range objective of developing an ADM Statistics Improvement Program.

3. The comprehensiveness and policy relevance of the ADAMHA data systems should be enhanced, with particular attention given immediately to: (a) filling current data gaps (e.g., obtaining data on patients served in CMHC's, and on patients/clients served in non-ADAMHA sponsored service programs); (b) enhancing the in-house capacity to analyze existing data.

a. The NIMH should initiate a patient data system for CMHC's on a sample basis, incorporating the ADAMHA common client data items, which can provide cost/outcome data on cohorts of patients treated in CMHC's.

b. NIDA and NIAAA should develop mechanisms for obtaining patient/client data on non-ADAMHA alcohol and drug abuse service programs. The feasibility of different alternatives, such as (1) using National samples, or (2) adding to NIMH or the National Center for Health Statistics samples (with cost sharing for increased sample size, etc.) should be investigated.

c. All three Institutes should develop or improve methods of monitoring services provided by the private ADM specialty sector as well as by the general health sector. For the latter, maximum use should be made of existing surveys conducted by NCHS, where feasible.

4. The capacity of each Institute to analyze existing data should be increased by: (a) providing positions for relevant professional disciplines and an organizational structure which allows such positions to be devoted to policy analysis; (b) devoting increased contract money to policy analysis studies which cannot be conducted efficiently by inhouse staff due to relatively long time frames, or special analytic skill requirements.

VI. RESEARCH TRAINING AND TECHNICAL ASSISTANCE

Improving the state of research-based knowledge concerning the ADM service system and its clientele requires a community of able researchers from many disciplines with special expertise in alcohol, drug, and mental health problems and issues. Operating effective data systems requires, as well, the informed participation of services, management, and statistical personnel throughout the Nation who contribute to and use such health statistics data systems. Current research training and technical assistance programs of the three Institutes designed to strengthen these essential human resources are described below.*

A. Research Training in Epidemiology and Health Services Research

Epidemiology Research Training

NIMH

The Center for Epidemiologic Studies (CES) of the NIMH Division of Biometry and Epidemiology sponsors a comprehensive training program in psychiatric epidemiology which includes an institutional program with eight sites currently funded. The budget for this program includes $808,000 for institutional training support and $36,500 for fellowship training support. The program is designed to increase the number of epidemiologists specializing in mental disorders, and to provide training in the principles of epidemiology for mental health professionals. The CES also sponsors continuing education and in-service training to increase awareness of psychiatric epidemiology by professionals working in the field. In addition to the CES program, there is a single training program in psychiatric epidemiology at Johns Hopkins supported with $123,000 by the NIMH Division of Manpower and Training Programs. It is anticipated that this grant will be transferred to the CES in the coming year.

NIDA and NIAAA

To our knowledge, there are no training activities in epidemiology sponsored directly by NIDA or NIAAA. Both Institutes have experienced difficulty in stimulating interest in epidemiology

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* This section represents an introduction to the complex area of health care research training and technical assistance. Based on the identification of several general problems and issues, a set of broad recommendations has been proposed. No specific programs or budgets have been suggested.

training in alcoholism and drug abuse. However, there is a pioneering plan for a cooperative effort between NIAAA and the CES of NIMH. NIAAA has transferred nearly $35,000 to NIMH to introduce alcoholism studies into a training program in psychiatric epidemiology at the University of Pittsburgh.

Health Services Research Training

NIMH

Within NIMH, the Division of Manpower and Training Programs (DMTP) and the Division of Biometry and Epidemiology (DBE) sponsor the majority of the health services research training programs. The DMTP supports 73 trainees in 12 programs, with $1.1 million through its Social Sciences Section, 29 trainees in five multidisciplinary programs with $0.5 million through its Special Programs Section, and 32 trainees in six programs with $0.2 million through its Psychology Education Branch. In addition, epidemiology training programs, sponsored through the CES, include some important areas of health services research: needs assessment and aspects of operations research. The majority of the DMTP health services research training programs emphasize the health behavior research component of health services research. Some include elements of training in health program research and a few are devoted to health systems research. The Division of Special Mental Health Programs (DSMHP) is also becoming involved in research training in the evaluation of programs for populations with special mental health needs: e.g., delinquents and urban populations. Currently, training sponsored by this division emphasizes qualitatively oriented research in health behavior and the description of the dynamics of social problems.

NIAAA

NIAAA has recently embarked on several research training programs related to health services research. Although none of them is involved in health systems research, five research training programs, budgeted at approximately $306,000, prepare trainees to evaluate alcoholism programs and to investigate the prevention of alcohol abuse.

NIDA

NIDA is not engaged currently in specific health services research training activity. However, under its Research Fellowship Training Program, some NIDA-sponsored trainees are involved in aspects of health behavior and clinical research. None of the research training activities sponsored by NIDA is in the area of health program research or health systems research.

B. Technical Assistance in Data Systems

Each of the three Institutes provides technical assistance to users and potential users of statistical and management information systems, however, their emphases differ. At NIAAA, technical assistance primarily involves instruction in the use of the data systems designed by the Institutes for reporting on local and State programs. In the case of the NIMH, technical assistance involves upgrading State and local data systems which are already in place. NIDA's technical assistance effort is geared to "the enhancement, improvement and utilization of information for intelligent decisions at State and local programs."

NIMH

At NIMH, the Statistical Program Development Branch (SPDB) of the DBE provides technical assistance to State and local programs to help them upgrade their statistical and management information systems capabilities. In addition, it offers two levels of training: continuing education or in-service training, and academic or degree-level training. In the first, short-term courses are conducted in cooperation with the NIMH Staff College and the National Center for Health Statistics Applied Statistics Training Institute. In the academic training area, the SPDB stimulates training grant applications to the DMTP in the areas of biostatistics and management information system. The Branch also sponsors an annual National Conference on Mental Health Statistics to inform State mental health statisticians about new development in mental health programs, statistical methods, utilization, and forthcoming data collection efforts.

NIAAA

Through annual training meetings and continuing contact through the year, NIAAA provides technical assistance to federally funded alcoholism programs in the use of NAPIS. Recently, NIAAA helped the State of South Carolina to apply NAPIS to meet Federal reporting requirements, as well as the State's own data needs. This data system has become a model which may be shared by other State programs. Computer assistance from the NIAAA data system contractor may be used by any State or local program. The NIAAA also offers a conference to State agencies in the use of SAPIS.

NIDA

In addition to teaching local drug abuse programs and States about the use of CODAP and NDATUS, NIDA provides technical assistance to States to enable them to establish their own data systems, drawing on other sources and providing information beyond Federal needs.

NIDA also provides assistance in the development and application of mathematical and statistical techniques, better retrieval mechanisms, and methods for developing special studies. Technical assistance is also provided for data system planning and data processing.

C. Problems and Issues

Research Training in Epidemiology and Health Services Research

Growing demands for systematic information on the health care system create increased demands for research manpower. However, as noted by many observers,[9/,10/] the current research manpower supply in both epidemiology and health services research is limited. Shortages of researchers trained in biostatistics, epidemiology, and health services research-related skills have been documented repeatedly in the general health care research field, and have been observed as well within the ADM area. Research manpower growth in these fields is unlikely to keep pace with future information needs unless adequate attention is given to research manpower development, particularly in the ADM area. Although ADAMHA currently provides some research training support, it appears to be insufficient to assure adequate numbers of well-trained ADM-oriented researchers for these growing fields. When research personnel resources are limited, research quality tends to suffer. Greater attention is needed to gauging research manpower supplies and needs in ADM epidemiology and health services research, and to amplifying ADAMHA's role in assuring an appropriate balance.

There has been a lack of emphasis and focus on training programs for persons in the area of health services research relevant to the ADM service system. Researchers entering this field come from a variety of backgrounds such as medicine, sociology, nursing, political science, economics, and other areas. Additional graduate training in the techniques and methods of health services research, and a specialized course of study highly related to biostatistics and epidemiology training programs, are required to provide an adequate pool of researchers in the field and to make progress in the areas outlined above. The number of health economists, for example, working in the ADM areas is extremely limited. An aggressive, visible, and vigorous training program in this area is essential to the development of the field.

Research manpower development in epidemiology and health services research must be closely linked to research program development to assure that training sites have adequate research support and that research training content provides knowledge and skills appropriate to

ongoing research problems and issues. Given the highly interdisciplinary nature of both epidemiology and health services research, and their overlapping and complementary interests and contributions to health care research, research training programs that foster cross-disciplinary training should be encouraged.

Technical Assistance

The development of reliable and useful health statistics data systems depends on the cooperation of many individuals and organizations throughout the country, not only to supply data, but to provide feedback to facilitate efficient and appropriate data selection and collection. The three ADAMHA Institutes have each conducted individual technical assistance programs appropriate to the unique characteristics of their health statistics data collection programs. However, as the Institutes move toward more uniform data collection, their technical assistance programs must be more closely coordinated to facilitate efficient development of a Federal-State-local cooperative program. Stronger linkages are also needed with other technical assistance programs such as the National Center for Health Statistics Applied Statistics Training Institute.

D. Recommendations

1. The supply of researchers competent to conduct epidemiology and health services studies relevant to ADM problems and services must be increased through an expansion of current ADAMHA research training programs.

2. Research training in epidemiology and health services research must be more closely linked at ADAMHA to research program activities and emphases in these areas.

3. Technical assistance and short-term training programs of the three Institutes regarding their data systems should be reviewed for overlap, relevance to the field, enhancement of ADM course content, and the potential for cost sharing--among the three Institutes and with the Applied Statistics Institute program of the National Center for Health Statistics.

VII. ADMINISTRATION

A. Problems and Issues

In the preceding sections we have outlined a number of recommendations designed to strengthen our knowledge base about the ADM service system. Under the guidance of an inter-Institute committee, aided by special task forces, many of these recommendations could be implemented within the next two years. Doing so, we believe, would significantly reduce many of the immediate problems articulated in our original charge.

However, it would be shortsighted to view our charge narrowly as simply the solution of immediate problems. If we consider the Workgroup's task in its larger historical, social, and political context, many other problems and issues emerge for consideration that may require more enduring administrative mechanisms to assure long-term coordination and coherence in ADAMHA's epidemiology and health services research efforts.

The call for a review of ADAMHA's resources for broad description and evaluation of the ADM service system is timely. It coincides with comparable efforts by many other Federal health-related agencies to assess their knowledge bases regarding the health care system, and to shape their data collection to facilitate comparability and National aggregation. Such efforts are required to lay the groundwork for a more rational and efficient method of describing the total service system.

Efforts to study the general health service system have been quite intense, facilitated by such agencies as NCHS and NCHSR. However, to avoid duplication, their purview has not included the ADM service system, either in the collection of general-purpose statistical health data, or in the sponsorship of health services research studies. Given the historical separation of the ADM service system and its Federal counterpart, ADAMHA, from the general health care sector, this situation is not surprising, nor is it likely to change appreciably in coming years.

At a time when far-reaching policy decisions are being made about the health care system, many of which are likely to have profound effects on the ADM service system (whether or not such effects are anticipated or intended), ADAMHA clearly should be an active participant in the National policy development and planning process, and should contribute to it essential information on the ADM service system and its relation to the broader service systems. ADAMHA can be an important Federal resource for focused, systematic study and data collection on the ADM service system. Indeed, if it is not, it is hard to see what other

agency or organization would assume this role. A well-thought-through ADAMHA program of research and data collection, designed, in concert with similar efforts of NCHS, NCHSR, and the Health Care Financing Administration (HCFA) can contribute immeasurably to the development of a comprehensive picture of how Americans do and should receive health care, how the ADM service segment does and should fit in with the whole, and how its own components best fit together in the interest of better patient care and health. However, developing such a program requires new ways of looking at ADAMHA and its research and data collection activities, and perhaps new ways of going about them.

The need for timely, policy-relevant data on the ADM service system is too great to permit the luxury of haphazard knowledge development and ad hoc research sponsorship. We need to organize and target our efforts more rationally to use ADAMHA resources as efficiently as possible. Doing so requires attention to three levels of ADAMHA's epidemiology and health systems research activities:

Interagency coordination- Assuring synchrony and consistency between ADAMHA's service system research and data collection and comparable activities of: (a) other relevant Federal agencies (e.g., NCHS, NCHSR, HCFA, NIH), and (b) State data collection efforts - to reduce duplication, enhance data aggregation, and explore cooperative studies.

Inter-Institute coordination - Assuring consistency, synchrony and cooperation across ADAMHA Institutes in the conduct of epidemiologic research, and health systems research (including data systems), and greater ADAMHA-wide coordination of epidemiologic and health services research efforts. Coordinative efforts should encourage the ultimate fit between ADAMHA-wide data and other National data.

Intra-Institute coordination - Developing better lines of communication, coordination and planning among relevant elements of each Institute:

a) Across divisions conducting epidemiology research
b) Across divisions conducting health systems research
c) Across divisions responsible for data systems
d) Among all of the above
e) Among divisions responsible for health systems research and those conducting other types of health services research.

An ADAMHA advisory committee with Institute-ADAMHA representation could lay the groundwork for many of these functions by:

a) Temporarily serving as a coordinative body vis-a-vis other Federal agencies and the States in the development of more consistent data systems;

b) Providing a means for achieving greater inter-Institute coordination and outlining major research goals, directions, and priorities to be pursued in future studies;

c) Through its Institute representatives in epidemiology, health systems research and data systems, encouraging greater intra-Institute coordination of these activities.

However, we believe that these functions should eventually be built into the structure of ADAMHA and its Institutes on a more long-term basis.

Ultimately, we envision the establishment of a permanent ADAMHA advisory body and/or coordinator concerned with the ongoing guidance and coordination of all ADAMHA health care research, with clearly identified counterparts in each Institute. Several transitional steps are required to reach this goal, however.

First, since the present Workgroup concerned itself with only a limited aspect of health services research, a comparable body should be established to study the rest of health services research - the level of effort, its structural characteristics, and the functional relations among its major components--behavioral research, clinical research, and program research (including program evaluation)--and their relation to health systems research. Particular attention should be given to the conduct of evaluative studies at all levels, and the pattern of responsibility for them. A health services research task force could be organized to meet with members of the present workgroup to develop an overall plan for better integration and rational organization of all health services research at ADAMHA.

Second, clearer lines of organization and responsibility are needed within each Institute for the conduct and coordination of epidemiology and health services research. Given the structural and functional differences among the three Institutes, it may be difficult to achieve parallel types of organization in all; however, the following principles should be considered as each Institute seeks an appropriate organizational framework:

1. Each Institute should have within it an administrative unit with recognized knowledge of and delegated responsibility for overseeing the conduct of epidemiology research, health systems research, and data systems.

2. To the extent feasible, functionally related activities pertaining to the collection and analysis of information on the ADM health services system and its actual and potential clientele should be tightly linked organizationally. Where it is feasible, it is desirable that this take the form of integration at the level of a research division.

   While this level of integration would accelerate the development of applied research for an understanding of the health services system, it should not hinder the continued development of more basic epidemiologic, demographic, or other research which has a more distant application to the services system.

B. Recommendations

1. An Advisory Coordinating Committee on Health Care Research should be established within each Institute, with membership and chair appointed by each Institute Director to include representation from the areas of health services research, epidemiology research, data systems, and policy development and analysis. Functions of the three parallel coordinating committees should include:

   a) Facilitating coordination of activities within these designated areas at each Institute;

   b) Charting potential research directions and priorities for health care research at each Institute;

   c) Exploring possible directions for stronger intra-Institute organization of related functional activities, including their potential integration at the divisional level.

   d) Suggesting, coordinating, and implementing ADAMHA-wide policies and programs regarding health care research through linkage to the ADAMHA Advisory Commiteee on Health Care Research (see below).

2. An ADAMHA Health Care Research Advisory Committee should be established by the Administrator of ADAMHA, with representation drawn from the three Institute Advisory Coordinating Committees on Health Care Research. Its responsibilities, coordinated by the ADAMHA Director of Program Planning and Coordination, should include:

   a) Guiding implementation of major recommendations of the ADAMHA Workgroup on Epidemiology, Health Services Research, and Statistics (Data Systems).

      Subcommittees of the ADAMHA Health Care Research Advisory Committee, augmented as necessary by special task forces, should be established to facilitate maximal coordination of high priority activities such as cooperative epidemiologic studies, health systems studies, and ADM data systems revisions across Institutes.

   b) Providing a framework for developing long-term coordination of health care research activities and policies across Institutes, including supervision of the ADAMHA Task Force on Health Services Research (see Recommendation No. 3).

   c) Serving as a vehicle for coordination of ADAMHA health care research activities and related policies with those of other Federal and State agencies:

      (1) Working with the United States National Committee on Vital and Health Statistics Technical Consultant Panel on Mental Health Statistics to coordinate development of uniform ADM reporting categories for use by all Federal health agencies, including ADAMHA, the National Center for Health Statistics, and the Health Care Financing Administration.

      (2) Expanding the NIMH-NCHS Memorandum of Understanding and the Interbureau Data Committee to include NIDA and NIAAA representation, and mutually exploring with NCHS: (a) the feasibility of developing and including items on mental health, drug, and alcohol use in NCHS National surveys; and (b) the possibility of ADAMHA Institutes' obtaining client data from private practitioners through NCHS surveys.

3. An ADAMHA Task Force on Health Services Research should be established by the Administrator of ADAMHA to study the entire health services research field at ADAMHA, and to recommend better ways to integrate and coordinate health services research activities within ADAMHA. Its deliberations should focus on aspects of health services research not addressed in detail by the present Workgroup, e.g., clinical research, behavioral research, and program research, with particular attention to the role and organization of evaluation studies. Its final recommendations should be developed with consultation from members of the present Workgroup.

4. An urgent goal of intra- and inter-Institute deliberations concerning health care research should be to develop within each Institute a critical mass of epidemiologists, sociologists, demographers, health economists, statisticians, and research clinicians with budgetary and other staff resources for implementing a balanced and comprehensive health systems research program. Such a program should be placed in an organizational context, such as a research division, where the maximum coordination of related research activities can take place.

VIII. BUDGET

A. ADAMHA Expenditures: Epidemiology, Health Systems Research and Health Statistics/Data Systems: FY 77

In FY 77, ADAMHA devoted $23 million,* or 3 percent of the total Agency budget to epidemiology, health systems research, and health statistics/data systems. As shown in Table 1, epidemiology commanded the largest share ($12.3 million), followed by health systems research ($7.0 million), and health statistics ($3.7 million). Better than half of the total funds for the three areas ($12.1 million, or 53 percent) were devoted to investigator-initiated grants, with the remainder allocated to contracts ($9.7 million) and in-house costs for data systems ($1.2 million).

NIMH received the largest share of funding overall for the three areas ($9.3 million), followed by NIDA ($7.5 million), and NIAAA ($6.2 million). However, as a percent of its total Institute budget for FY 77, the NIMH share was smallest (2 percent), followed by NIDA (3 percent), and NIAAA (4 percent). (See Figure 1, page 4.) The same general pattern is evident when the Institute commitments to epidemiology and health systems research are compared to their total research budgets. NIMH received the most funds for epidemiology research ($5.6 million, NIMH; $3.9 million, NIDA; and $2.8 million, NIAAA); however the combined funding of epidemiology and health services research for NIMH represented only 8 percent of the total NIMH research budget, while the percentages for the other two Institutes were appreciably higher: 15 percent for NIDA and 36 percent for NIAAA.

In the area of data systems, generally funded from program support rather than from research budgets, NIDA allocated significantly more ($2.3 million) than NIDA ($.09 million) or NIMH ($.05 million). These amounts represent, respectively, 14.6 percent, 10.6 percent, and 2.1 percent of the NIDA, NIAAA, and NIMH program support budgets.

B. Proposed ADAMHA Budget:** Epidemiology, Health Systems Research and Health Statistics/Data Systems: FY 80-82

The FY 77 budget for epidemiology, health systems research and health statistics/data systems represents the essential core of activities in the three areas. However, our study of current ADAMHA programs has revealed the need for more intensive and focused development in all three fields. The following budget (see Tables 2 and 3) outlines additional funds, beyond the base budget, required to implement the Workgroup's substantive recommendations.

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* Excluding staffing, except for data systems

** Excluding training

Table 1. ADAMHA Costs*: Epidemiology, Health Systems Research and Health Statistics (grants, contracts, and data systems inhouse costs), FY 1977

	NIMH	NIDA	NIAAA	ADAMHA Total
Grand Total----------	$9.3	$7.5	$6.2	$23.0
Grants----------	6.5	3.6	2.0	12.1
Contract ----------	2.4	3.2	4.2	9.8
Inhouse ----------	0.4	0.7	0.0**	1.1
Epidemiology				
Total----------	5.6	3.9	2.8	12.3
Grants----------	5.4	3.6	1.5	10.3
Contracts----------	0.2	0.3	1.3	1.8
Health Systems Research				
Total----------	3.2	1.3	2.5	7.0
Grants ----------	1.1	-***	0.5	1.6
Contracts----------	2.1	1.3	2.0	5.4
Health Statistics/Data Systems				
Total----------	0.5	2.3	0.9	3.7
Inhouse----------	0.4	0.7	0.0**	1.1
Contracts----------	0.1	1.6	0.9	2.6

* In millions of dollars
** Greater than zero, but less than $50,000
*** No funds reported

The budgets represented in Tables 2 and 3 have been developed from individual estimates of the amount of money required by each Institute in each of the three areas. In most cases, however, additional staff will be required to administer expanded programs, as follows: Two new positions will be required for each Institute for each of the three areas. In addition, two positions are required at the ADAMHA level. Hence, if current staff cannot be reallocated, a total of 20 new positions is recommended.

This budget is specific for each recommendation only in the area of health statistics/data systems. Funds allocated to the remaining health systems research and epidemiology areas will require oversight by each Institute's Coordinating Committee on Health Care Research to ensure that the funds are actually expended in the priority areas recommended by this Workgroup. The budgets for health services research and epidemiology, shown for FY 1980, represent continuing annual costs to increase the investments of these areas. Within each Institute, the individual amounts devoted to the priority areas as recommended in this report would be under the overall direction of its Coordinating Committee on Health Care Research.

The budget for data systems is shown for FY 1980-82. Due to the phasing aspects of these recommendations, major changes in the budget are required over this time period. Two different parts are shown for data systems as follows: (1) Joint systems, representing the development of joint ADAMHA data systems funded by three-Institute cost sharing, and (2) individual Institute programs specific to the data collection program of each Institute.

Table 2
FY 1980 Research Grants/Contracts
Additional Budget Requirements (in 000's)

	Total	Health Systems Research	Data Sytems	Epidemiology
Total.....	22,040	9,660	5,800	6,580
NIAAA.....	4,160	1,660	500	2,000
NIDA.....	3,580	2,000	500	1,080
NIMH.....	10,000	6,000	500	3,500
ADAMHA (Joint data systems).	4,300	-	4,300	-

Table 3. Data Systems Budget (in 000's)

	FY 1980	FY 1981	FY 1982
Data Systems Total	5,800	7,100	6,500
Joint Systems	4,300	5,600	5,000
1a-Develop common set of client data items 1/	-	-	-
1b-Alcohol and drug abuse client system 2/	200	500	2/
1c-Common Facility Unit Inventory 2/	300	400	200 2/
2 -Development of Federal/ State/local systems 3/	3,000	4,000	4,000
2a-Technical assistance to States related to above	500	500	500
3a-NIMH-CMHC patient data systems	300	300	300
Individual Institute Programs Total	1,500	1,500	1,500
3b,c-Client data for non-ADAMHA alcohol and drug abuse systems & increased coverage of private sector	500	500	500
4b-Increased contract monies for policy analysis	1,000	1,000	1,000

1/ No budget necessary-developed with inhouse resources.

2/ Costs shown for FY 1980-81 are developmental. It is expected that costs for FY 1982 and beyond would be partially covered by conversion of existing expenditures for NAPIS/SAPIS, CODAP/NDATUS to support of these new joint ADAMHA systems. The $200,000 shown represents the additional NIMH cost for the facilities/unit system for which no existing funds can be converted.

3/ Costs for recommendations 1b and 1c must run parallel to and duplicate the developmental and operating costs of a Federal/State/local system for a three-year phase-in period. In 1983 and beyond, it is expected that the systems developed under 1b, 1c, and 3a would be taken over by the Federal/ State/local system and the annual operating costs could be reduced accordingly.

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APPENDICES

APPENDIX A

MEMORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION
OFFICE OF THE ADMINISTRATOR

TO : Institute Directors, NIMH, NIAAA, NIDA

DATE: FEB 27 1978

FROM : Administrator, ADAMHA

SUBJECT: Charge to the ADAMHA Workgroup on Epidemiology and Health Services Research Data

I. Background

The preliminary report of the President's Commission on Mental Health and additional ADAMHA analyses have pointed to serious gaps in our knowledge about both the prevalence of specific alcohol, drug and mental health (ADM) disorders and the number of persons with such disorders who are actually receiving treatment services. These deficiencies in our epidemiological and health services research data bases will increasingly impede the further development of our research, manpower and services programs.

As a result of these concerns, this Workgroup has been established to undertake a comprehensive review of our epidemiological research and health services research programs. The general goals of the Workgroup in these two areas are as follows: (1) to review current and planned ADAMHA sponsored epidemiological research with a special emphasis on studies designed to obtain national incidence and annual period prevalence data for specific ADM disorders and associated problems; (2) to review current and planned programs for describing and analyzing ADM services provided to the U.S. population. Special emphasis should be accorded to obtaining information on the number of persons served in one year (annual treated prevalence), organization of services, type of services, intensity of services per person, and cost of services; (3) to recommend research activities that would fill major gaps in the current information base on the epidemiology of ADM disorders; (4) to recommend methods of improving and coordinating current ADAMHA data collection and other health services research programs.

Institute Directors, NIMH, NIAAA, NIDA

In order to clarify some of the major problem areas which have occasioned this Workgroup effort, the following examples of our concerns are included:

1. The use of different definitions of ADM disorders, and associated problems has resulted in major scientific case identification problems for determining the prevalence of specific disorders. A lack of information on the number and distribution of specific ADM disorders makes it impossible to undertake field investigations which can identify risk factors associated with these disorders. In addition, the lack of uniform diagnostic criteria will impede the implementation of clinical trials which require homogeneous diagnostic groups to study the effect of alternative treatments for these conditions.

2. The policy implications of different definitions are illustrated by our inability to determine the overlap between the estimated prevalence of 10 million persons with alcoholism and alcohol problems, the 2.5 million with drug addiction or drug abuse problems, and the 30 million persons with mental disorders. Policy planning for manpower development and services to meet these needs are hampered by the inability to specify the scope of ADM disorders in greater detail.

3. The lack of uniform time intervals in studies determining the period prevalence of ADM disorders has resulted in an inability to compare rates between different studies.

4. The inability to aggregate comparable ADM service facility, patient and cost data across the three Institutes has hampered policy and budget analyses.

5. The duplication in State and local ADM facility reporting requirements has led to increased demands from these agencies that ADAMHA achieve a greater coordination and comparability in the data gathering activities of the three Institutes.

6. The uneven development of data in critical areas such as cost effectiveness of ADAMHA programs points up the lack of comparable data in other Institutes. The lack of coordination between Institutes may result in duplication of effort in research methodology development.

For a variety of historical, legal and programmatic reasons, the ADAMHA Institutes have developed somewhat independent health services research data systems and epidemiological research programs. While significant efforts have been made in the past to coordinate the various data gathering and research activities of ADAMHA, the aforementioned problems

continue to exist. It is recognized that the amelioration of all of these problems will not occur immediately but that both short range and long term plans are required to achieve our objectives.

II. Detailed Charge

It is anticipated that the Workgroup will be divided into two subgroups with one focused on epidemiological research and the other on the health services research area. The following activities are organized under the respective subgroup areas of responsibility.

A. Epidemiology research

1. Review currently used definitions and classifications of ADM disorders and associated problems. Particular attention should be given to the classification of disorders for children and the aged population subgroups.

2. Review and categorize current and proposed in-house and contract funded epidemiological research in each Institute.

3. Review and categorize grant supported epidemiological research in each Institute. Efforts should be made to determine the extent of epidemiological activities in all intramural and extramural divisions of the Institutes for both contract and grant supported research.

4. Compare the epidemiological programs of the three Institutes in order to identify gaps in available information and research programs.

5. Make Fiscal Year '79 research recommendations for the three Institutes in the area of epidemiological research.

B. Health services research

1. Review current and planned health services research data collection activities of the three Institutes, including those concerned with the following areas: (a) the characteristics of facilities and services provided for persons with ADM disorders. Particular attention should be paid to the provision of ADM services within the general medical as well as the specialty ADM delivery system; (b) the number and characteristics of patients served in the various facilities for ADM disorders; (c) manpower requirements for ADM services--this activity should be in concert with the

findings of Dr. Waldrop's ADAMHA Manpower Task Force;
(d) expenditures for and the financing of ADM services;
(e) cost benefit data on ADM services.

2. The data systems of the three Institutes should be compared to identify duplication and information gaps. Recommendations should be made on how systems might be strengthened, how comparability might be increased, and how gaps in information might be filled both on a short-term and long-term basis.

3. Recommendations should be made on the appropriate liaison relationships between the ADAMHA Institutes and other PHS agencies, including both the National Center for Health Services Research and the National Center for Health Statistics regarding data acquisition and analysis activities. Additional attention should be given to the relationship with the Health Care Financing Administration (HCFA).

4. Recommendations should be made for Fiscal Year '79 research and data acquisition activities for the three Institutes in the health services research area.

The final report should contain a summary of current and proposed epidemiological research activities which is presented in categories for cross-Institute comparison (e.g., definition and classification of ADM disorders, national or local incidence and prevalence surveys, genetic studies, etc.). Recommendations for additional research and necessary staff and budget resources should be included. The final report should also contain a summary of the health services research activities appropriately categorized for cross-Institute comparison. Recommendations should be presented for increasing data comparability and organizational coordination, for defining relationships with other data systems in PHS and HCFA, and for estimated resources required to accomplish the recommendations. It is expected that the final report will be completed by May 31, 1978.

Since many methodological problems and other issues may need resolution prior to the implementation of the Workgroup's recommendations, immediate interim and long term steps necessary to carry out these recommendations should be specified. The final product should be a concrete plan with a specific list of recommendations which take cognizance of available resources and the prospects for major increases of funds and staff for these areas. This detailed plan will provide the material for the Forward Plan and statistical plan requirements, as well as needed justification for budget requests in these areas.

Institute Directors, NIMH, NIAAA, NIDA

III. Workgroup Structure

The Workgroup shall consist of a chairman appointed by the ADAMHA Administrator and six additional members nominated by the Institute Directors with the approval of the ADAMHA Administrator. Each Institute Director shall nominate one member to the Epidemiology Subgroup and one to the Health Services Research Subgroup.

The Chairman shall be responsible for calling all meetings of the Workgroup, monitoring the activities of each Subgroup, coordinating the visits and activities of the consultants, and supervising the writing of the final report. Each Workgroup member will serve as the Institute Director's representative with responsibility for coordinating a comprehensive review of all Institute activities relating to the respective Subgroup charges. Hence, it will be the responsibility of the Institute Directors to assure that appropriate staff, resources, and cooperation necessary for the accomplishment of these objectives are available.

Consultants

A total of six outside consultants will be utilized to review the activities of the three Institutes. Each Institute Director will nominate two consultants, subject to approval of the ADAMHA Director, with one assigned to each of the Subgroups. These consultants should be familiar with the state-of-the-art of alcohol, drug and mental health epidemiological or health services research and will serve in two groups of three each in parallel to the respective Subgroups.

The consultants will be responsible for jointly reviewing all ADAMHA programs covered by the Subgroup charges in order to identify strengths and weaknesses in the programs of each Institute and in the overall ADAMHA effort in these areas. In addition, it will be expected that the consultants will be responsible for a joint or separate written report(s) containing their impressions of and recommendations for the ADAMHA activities in these areas.

It is anticipated that the consultants will attend three single day meetings, with intervals of approximately four weeks between each meeting. The first meeting at the end of March will be to receive summaries of all of the activities of each Institute in the health services research and epidemiology research areas. The second meeting at the end of April will be to review the progress of the Subgroups in comparing and making recommendations for coordination of activities across the three Institutes. The final meeting at the end of May will be to review the final Workgroup report and to make their independent recommendations to the ADAMHA Administrator.

Institute Directors, NIMH, NIAAA, NIDA

The total per diem, travel and honoraria support for the six consultants, attending three single day meetings, at an average of approximately $400 per day, would amount to $7200 for the consultant services. These funds will be made available from the discretionary funds of the ADAMHA Administrator or the respective Institute Directors, as deemed appropriate.

IV. Membership

The following members have been nominated by the Institute Directors and approved by the ADAMHA Administrator:

Chairman: Dr. Darrel A. Regier, Acting Director, Division of Biometry and Epidemiology, NIMH

Epidemiology Research Subgroup:

1. Mr. Ben Z. Locke, Chief, Center for Epidemiologic Studies, Division of Biometry and Epidemiology, NIMH

2. Dr. Thomas C. Harford, Acting Chief, Epidemiological and Special Studies Branch, Division of Extramural Research, NIAAA

3. Dr. Louise G. Richards, Chief, Psychosocial Branch, Division of Research, NIDA

Health Services Research Subgroup:

1. Mr. Carl A. Taube, Acting Deputy Director, Division of Biometry and Epidemiology, NIMH

2. Mr. Donald G. Patterson, Chief, Program Analysis and Evaluation Branch, Office of Program Development and Analysis, NIAAA

3. Dr. William H. Spillane, Director, Division of Scientific and Program Information, NIDA

V. Conclusion

It is anticipated that the Workgroup will build on the substantial previous cross-Institute efforts and will coordinate its activities with those of other currently functioning ADAMHA workgroups. The Workgroup should begin functioning immediately, as outlined above.

Gerald L. Klerman, M.D.

APPENDIX B

Memorandum of Understanding
National Institute of Mental Health, ADAMHA
and the National Center for Health Statistics

Purpose

The purpose of this memorandum is to formalize agreements between the National Institute of Mental Health (NIMH) and the National Center for Health Statistics (NCHS) with regard to the responsibilities of the two agencies for (1) meeting the needs for mental health statistics at the National, State, and local levels, and (2) the support activities provided to State and local agencies participating with the Federal government in mental health statistics programs designed to meet these needs. Other areas of coordination and cooperation between the two agencies are not covered in this memorandum of understanding.

Background

NIMH and NCHS each operate their statistical programs to meet the following two distinct objectives in pursuing cooperative arrangements with State-local areas.

1. To collect or otherwise obtain data for National health program planning, monitoring and evaluation; and for serving the needs of others; such as Congress, the health industry, the public, and researchers for National data purposes (for programmatic and general purpose uses).

2. To assist State-local areas in a variety of ways to expand and improve capability to meet the needs for data and statistical services at those levels. These ways would include

    a. technical assistance
    b. training
    c. data use demonstrations
    d. standard setting
    e. funding and personnel support

Historically NIMH and NCHS have operated their statistical programs with relative independence; NIMH in areas of mental health and NCHS in other health areas. Informal working arrangements have held any duplication of data collection to a minimum in past years.

Increasingly more formal working arrangements have been required (1) as the CMSS program was developed and expanded support for State-local comprehensive data systems, (2) as the needs for improved and more comprehensive data in the mental health area become more apparent, and (3) as data needs expanded for planning, evaluation, and cost-containment at the State and local levels.

Objectives and Principles

NIMH and NCHS, in recognition of the need for close cooperation, agree on the following stated objectives and principles.

1. To plan and conduct their separate and shared data activities in such a manner that will enhance the capability of State-local area statistical endeavors to reduce duplication and cooperate in more comprehensive shared data systems.

2. To use the United States National Committee on Vital and Health Statistics as the advisory group to assist in defining minimum data sets which represent those data elements needed at all levels but with special emphasis on those needed at the National level. This refers only to data to be collected regularly through inventories and abstracting systems that are essentially complete and comprehensive. It does not refer to content of ad hoc or infrequent sample surveys designed for specific purposes.

3. To agree on systems for obtaining data for National purposes which move toward single time data collection and processing at the State and local levels for shared purposes at those levels and at the National level.

State of Agreement

The National Center for Health Statistics (NCHS) and the National Institute of Mental Health (NIMH) agree that:

1. The NIMH has responsibility for Federal mental health programs and operates its statistical programs to meet that responsibility. Therefore, the NIMH, working with National, State, and local agencies, has the responsibility for defining and meeting National mental health data needs and representing State and local levels, nationally, with regard to their data needs.

2. The NIMH agrees to work in cooperation with the Cooperative Health Statistics System (CHSS) to meet mental health data needs common to the National, State, and local needs. The current CHSS components and basic minimum data sets meet some, but not all, of the needs of NIMH and mental health agencies for basic minimum data. Therefore, NCHS and NIMH will jointly pursue the development, implementation, and funding of modifications to the existing CHSS components and minimum data sets establishing, where necessary, specific mental health statistics components or subcomponents to meet the basic mental health data needs.

3. Mental health data requirements of NIMH, beyond those met by the revised CHSS minimum data sets will be met by the NIMH statistical reporting system. These activities will be developed, implemented, and funded by NIMH. The data collection activities of NIMH are to be consistent with comparable CHSS data sets and definitions.

4. NCHS will include an NIMH staff member in the CHSS project management team and provide for review by NIMH of any other CHSS contract which involves data collection in the mental health area.

5. NIMH and NCHS agree that a Technical Consultant Panel (TCP), to recommend the structure and content of mental health statistics components or subcomponents, should be established by the U.S. National Committee on Vital and Health Statistics. This TCP would be jointly funded by NIMH-NCHS, and both would make recommendations concerning the composition of the TCP and have review authority on selection of members.

6. There will be established a NIMH-NCHS Interbureau Data Committee to develop joint plans and help maintain the closest possible cooperation and coordination in accomplishing the functions described above; exchange information; and review positions on common issues. This Committee will be jointly chaired by the Director of NCHS and the Director of the Division of Biometry and Epidemiology, NIMH. Additional members shall be appointed by each agency. Other participants may also be invited on particular issues. This Committee will meet usually monthly to discuss and resolve operation problems. The NCHS and the NIMH will share the duties of executive secretary and staff support for the Committee.

7. The NIMH and NCHS will agree on a long-term plan of operation and function relative to Federal-State-local issues of mutual concern. This will include at least the following:

a. Data collection in States with CHSS facilities and manpower contracts.

b. Allocation of resources in terms of staff and funds.

c. Technical assistance on substantive issues.

d. Training in statistics, data systems, etc. for various audiences.

e. Development of minimum data sets for mental health.

f. Development of demonstrations of shared data systems.

This agreement shall remain in effect from date of mutual signatures until amended by mutual consent or until terminated by either party upon 30 days written notice.

Bertram S. Brown Nov 29, 1977
Director, National Institute of Mental Health Date

Dorothy P. Rice Dec. 12, 1977
Director, National Center for Health Statistics Date

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