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CREATING AN AGENDA FOR RESEARCH AND EVALUATION: HIV SERVICE DELIVERY, THE RYAN WHITE CARE ACT, AND BEYOND

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Introduction

Care for individuals with human immunodeficiency virus (HIV) increasingly is a focus of health and social service delivery systems across the country. Through the implementation of Federal programs and private sector initiatives, the pressing need for more focused health services research and evaluation related to HIV care has become more clear (1). Major Federal efforts, including the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, pediatric service demonstrations, and HIV training programs, have highlighted many service delivery and community-based planning issues.

An analysis of the first generation of HIV-related health services research, mostly supported by Federal dollars, reveals that it was dominated by cost-focused and cost-related studies. These and other issues basic to the formulation of an effective public health response to the epidemic certainly warrant continued, even expanded, research. However, the time has come to build on that knowledge and learn about other vital areas that affect quality of life for people with HIV disease, such as those related to patient outcomes from the patient's perspective. Given limited funding for all HIV-related efforts, the development of a research and evaluation agenda for HIV service delivery issues needs to be both strategic and timely.

To stimulate thinking about those choices, the Health Resources and Services Administration (HRSA), the Agency for Health Care Policy and Research (AHCPR), and the National Community AIDS Partnership (NCAP) convened a working meeting in Washington, D.C., on November 12 and 13, 1992 (2). Approximately 50 persons from throughout the nation participated, including experts in research and evaluation, policymakers, advocates, people with HIV, HIV service providers, and representatives of private and public funding organizations. This diverse group came together to discuss creation of a national agenda for research and evaluation on HIV service delivery issues and to initiate a plan of action to generate swiftly the knowledge needed to make informed and responsive policy decisions.

The meeting participants collectively identified and prioritized approximately 50 research questions and, from these, selected nine key study areas. Specific research and evaluation studies for examining these nine areas were then suggested by participants meeting in small groups. The point of departure for each small group's work was relevant existing research and evaluation activities in its study area(s). In general, the nine areas relate to issues of coordination and linkage among funding sources and services (particularly as they affect client outcomes), consideration of broadly applied service models (e.g., case management, clinical care, and support), questions focusing on service needs from the client's point of view, and processes of CARE Act consortia and planning councils.

This article discusses the interests and goals of the conveners, describes the meeting's process and outcomes, and presents the nine key study areas chosen by the group. Summaries of the small group discussions on CARE Act planning councils and consortia and on case management also are included. To frame the discussion and further

document the need for expanded efforts in HIV/AIDS health services research and evaluation, data on funding of HIV/AIDS services research available since the November 1992 meeting are summarized.

Meeting Goals

The three sponsoring organizations came together to consider what might be accomplished now to improve HIV service delivery through enhanced evaluation and research efforts. The meeting was based on the premise that such efforts, particularly in the context of a coordinated national agenda, can help to promote HIV service delivery systems that are cost-effective, responsive to the needs of the diverse populations affected by the epidemic, and reflective of the lessons learned so far. The goals of the meeting were to:

- Analyze already funded research and evaluation studies on HIV-related services.
- Examine existing gaps in evaluation and health services research.
- Determine priority research issues.
- Recommend ways of implementing HIV-related research projects that address the priority issues.
- Develop an action plan for initiating needed HIV-related research, disseminating the results, and integrating the findings into planning, policymaking, and practice.

This conference did not address HIV clinical research in the fields of medicine and basic science, but participants did address service delivery issues that integrally related to clinical management. Similarly, even though economic aspects of HIV-related services delivery were not the main focus of this meeting, important issues of cost, financing, and

cost-effectiveness were discussed at some length. In formulating a national research agenda, the economic and clinical issues that influence the delivery of HIV care clearly need to be considered.

History of HIV/AIDS Services Research

The purpose of the November 1992 meeting was to create an HIV/AIDS services research agenda that both acknowledged and complemented what already had been done in this area. Both Federal agencies and private foundations have supported HIV-related health services research and evaluation. That research formed the meeting's context.

Federal funding

In the first generation of Federally funded research in this area, prior to the enactment of the Ryan White CARE Act, the U.S. Department of Health and Human Services (DHHS) spent almost $43 million on HIV-related studies (3). Five DHHS agencies–the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA); AHCPR; the Health Care Financing Administration (HCFA); HRSA; and the National Center for Nursing Research (NCNR) – funded 106 extramural studies between January 1986 and December 1991. These research and evaluation studies can be described in terms of study purpose, methodology, and unit of analysis. Fifty-four of the 106 projects (51 percent) had as a primary, secondary, or tertiary interest examining the cost and financing aspects of delivering HIV-related care. In 30 of these studies, cost and financing issues were the primary focus. Quality of care tended to be of secondary or tertiary importance. Only 16 studies (15 percent) addressed access to care; of these, six had a primary interest in access to care.

Descriptive studies accounted for almost 40 percent of the funded projects and the total funds awarded. Theory building/hypothesis testing studies accounted for approximately one-quarter of the funded projects and the total funds awarded. Methods and data development projects and policy and evaluation studies each accounted for 17 percent of the funded projects. Only two of the 106 projects funded during the five-year period involved the dissemination of health services research findings.

Studies of individual attitudes and/or behaviors accounted for 80 percent of the funded projects and 91 percent of the total funds awarded. This included HIV-positive individuals as well as providers of care. One-quarter of the studies and nearly one-third of research expenditures focused primarily upon homosexual/bisexual men, only 10 percent on women and children. Studies with organizations or community or state systems as the unit of analysis accounted for only 11 percent of all funded projects and less than three percent of the total funds awarded.

Federal funding for HIV services research peaked in 1989 with the initiation of 36 extramural evaluation and research projects. By 1991, new Federal investments in health services research on HIV/AIDS had dwindled to 18 projects. Recently, however, the Health Resources and Services Administration, which administers the Ryan White CARE Act programs, has begun emphasizing the evaluation of these programs. In studies conducted either internally by staff or externally through contracts, HRSA is investigating the following issues: changes in the provision of services for active/recovering drug users with HIV in new Title I cities; identification and description of models of HIV-related service delivery systems in rural areas; factors that facilitate participation of people with HIV in community-

based care systems; the role of Title I funding in capacity building among community-based organizations serving Hispanic populations; the development and organization of Title II consortia; and how the needs of women with HIV are being addressed by the Title I planning process.

Private sector funding

According to Funders Concerned About AIDS (4), private, corporate, and community foundations granted approximately $250 million for HIV/AIDS service programs between 1981 and 1992. Most of these grants have not included rigorous evaluation requirements. The information required by funders generally has been restricted to routine program and financial reports. Given the high level of need and the relative scarcity of resources, many funders have been reluctant to support evaluation efforts. Some private funders, however, have had a strong interest in assessing the effectiveness of the programs they supported and in informing the field about lessons learned.

There have been four large-scale evaluations of service and prevention programs conducted for private foundations or funding consortia. The Robert Wood Johnson Foundation's evaluation of its AIDS Health Services Program (AHSP) is the most ambitious. The AHSP was intended to test the replicability of the San Francisco model of care, which emphasized community-based services and case management. The Foundation expended more than $17 million on the AHSP. The evaluation, initiated in 1986 and conducted by the Center for Gerontology and Health Care Research at Brown University, examined the implementation of a coordinated system of HIV care in 11 communities. It also assessed a variety of service use, cost, and client impact issues. Brown University researchers have

reviewed both HIV planning issues and the provision of services based on the experiences of the AHSP communities (5-10).

Another large-scale evaluation supported by private philanthropy is the ongoing assessment of The National Community AIDS Partnership (NCAP). NCAP provides resources to local communities for HIV/AIDS care, prevention, and public policy programs. The effort began in 1988 with partnerships in eight communities funded by the Ford Foundation and other national funders. Since that time, the program has grown to 32 communities. More then 400 community, corporate, and private foundations and businesses have provided more than $25 million to support nearly 1,200 projects to enhance or, in many cases, initiate local responses to the epidemic. NCAP funding has provided for direct services, prevention education, public policy activities, and technical assistance. The NCAP evaluation, conducted by Harder & Kibbe Research & Consulting, documents the process of creating national and local funding mechanisms and includes a longitudinal study of the impact of NCAP on 13 of the participating communities. Recently, the evaluation has expanded to examine selected grants for services to HIV-infected children, the coordination of HIV services, and public policy. NCAP has published the results of its evaluation in a series of special reports (11-13).

The Sierra Health Foundation's Northern California AIDS Initiative, which began in 1988 and ended in 1992, granted more than $3 million to HIV/AIDS programs in a mostly rural, 26-county region surrounding Sacramento. The Foundation's grants focused on: case management and community development; education to high-risk persons; AIDS education in county jails; regional planning; and other targeted services. The Foundation

funded an accompanying three year evaluation to track the implementation of the Initiative and document the effects of the grants. The Foundation was especially interested in assessing the effectiveness of its case management and community development grants. Several publications have resulted from this evaluation and more are in development [14-16].

Another, newer private philanthropic effort, smaller in scope than the other three, is the Kaiser Family Foundation's funding of the Western Consortium for Health Planning to evaluate the implementation of the Ryan White CARE Act. This project, funded in early 1993, will assess the impact of the CARE Act in Baltimore, Maryland and Oakland, California one year after these two cities received their first monies through Title I. It follows up a study, contracted by HRSA, to gather baseline data on the organization, distribution, adequacy, availability, and accessibility of community-based HIV services in these two cities.

Process and Methods of the November 1992 Meeting

The November 1992 working meeting to plan a national agenda for HIV-related services research and evaluation was organized collaboratively by the three sponsoring organizations – HRSA, AHCPR, and NCAP. Approximately 100 individuals were contacted to invite their participation in the meeting, to solicit the names of other persons to invite, and to provide suggestions for the meeting's content and format. Contacts represented a wide range of perspectives.

The meeting was conducted using a facilitated process that emphasized the specific research and evaluation needs of various constituencies involved in HIV service delivery

policymaking, administration, management, and advocacy. Meeting participants were asked to respond to a series of prepared questions designed to identify the information that is critically needed to make HIV service delivery-related policy decisions. This process resulted in the identification of 50 research and evaluation questions. Criteria for prioritizing the questions reported out by the subgroups included:

- How frequently have you heard or discussed the question?
- Do you believe answering the question will increase understanding of HIV service delivery issues or improve the effectiveness of CARE Act programs?
- Can the question be answered through research or program evaluation?
- How important is the question in terms of its significance for public policy and the knowledge gap it addresses?
- How timely is the question?
- Is the question a broad or specific one?
- What is your personal connection to or knowledge of the area the question addresses?

Each meeting participant then voted for priority questions to be examined in greater depth. Through this voting procedure, participants selected nine sets of priority questions, which covered what the group identified as the key issues.

The remainder of the meeting was devoted to small group discussion of specific mechanisms and methodologies for addressing these nine key study areas. These groups defined major study questions related to the issue, reviewed the data sources already available to answer these questions, identified gaps in data, developed a list of the primary audiences for study results, summarized the policy issues that the study (or studies) would help these audiences address, and recommended strategies to initiate study of the area.

In the final session of the meeting, each group presented a summary report to all participants, as well as to guests from government and the private sector invited to this session.

Outcome of the Meeting: An Agenda for Research and Evaluation

Nine key study areas were identified at the November, 1992 meeting as the priorities in a national agenda for research and evaluation:

Linkage, Integration and Coordination

- Do effective linkages exist among AIDS service organizations and between HIV service delivery providers and other community agencies? Do these linkages make a difference in funding, in the number and mix of people in care, in the comprehensiveness of care, in communication among providers, and in the coordination of care across the entire spectrum from primary prevention to tertiary treatment?
- What are the most effective methods of coordinating and integrating care for shared clients? What are the current methods? What barriers exist to coordination and integration of care? How does reimbursement policy affect coordination and integration of care?

Federal/Non-Federal Funding

- To what extent are the Federal programs (e.g., Medicaid, Medicare, Veterans Administration, CARE Act, and Social Security) and non-Federal programs (e.g., employer-based insurance, State and local health departments, private sector funding) meeting the needs of HIV-positive individuals?

Case Management

- What is "case management" in the context of HIV/AIDS? What are its goals? Is it working? For whom? What are the various models and how do they compare with those employed for individuals with other diseases?

Funding Streams

- What is the impact of fragmented funding streams on services, on access to care for HIV-positive persons, and on the health care delivery system as a whole?

Coordination of Funding Streams

- What have been the intended and unintended consequences of Federal policies and funding on coordination (or lack of coordination) at the client level? At the community level? What will the consequences be with any health care reform?

Client Service Needs

- What services do clients want and need at different stages of the disease spectrum and what services are available? What are the actual barriers to access to care? What are the perceived barriers? From the perspective of resources, how do supply and demand compare? What is the degree of unmet need?

Optimal Care (17)

- What constitutes optimal care for HIV-positive clients?

CARE Act Councils and Consortia (18)

- Is the CARE Act planning process working to meet needs at the client level? To what extent are CARE Act consortia achieving their goals? Does the presence of existing planning bodies help or hinder the development and functioning of CARE Act planning councils and consortia?

Impact on Clients of Services (19)

- What is the impact on both the individual and the service delivery system of various categories of services including housing assistance, case management, benefits counseling, counseling and testing, drug treatment, mental health services, and primary care?
- What benefits are clients receiving from the services in terms of quality of life, health status, and reduced barriers? To what extent are clients aware of existing services? How does information about services reach clients?

Small Group Discussions of Two Study Areas

The above summary of the key issues discussed in each of the small groups does not adequately describe the in depth discussion that actually took place. To provide some indication of these discussions, the work of two groups is given here in more detail.

CARE Act Councils and Consortia

The group which examined CARE Act Councils and Consortia began by agreeing that basic questions on the functioning and impact of the planning bodies' activities need investigation. Sufficient information is not available on the decision-making processes of the planning bodies, council and consortia resource allocation processes, mechanisms for

monitoring the use of delivered funds, how community needs assessments are conducted, and the influence of membership composition and decision-making processes on the distribution of funds. If information on the operational aspects of the councils and consortia were available, specific functions of these entities could be assessed. The results of such an assessment could be used to determine whether specific functions of these planning bodies could be improved by implementing standardized procedures.

The group also felt that more needed to be learned about the way in which CARE Act planning bodies are perceived within their communities, by public agencies, nonprofit service providers, persons with HIV, and members of the general public. Learning what these and other interested parties feel about the representation, fairness, and effectiveness of the CARE Act planning processes would help us to understand to what extent the planning entities have community credibility–and with whom. Policymakers also need information concerning the extent to which Title I and Title II planning bodies interact; if interaction is limited, specific mechanisms for improving collaboration must be found.

The group also concluded that the impact of CARE Act funds on the distribution of other funds for HIV-related services in a community is not well understood. Policymakers need a more concrete understanding of the ways in which CARE Act planning bodies interact with and affect other health and human services planning entities, especially those that oversee HIV prevention and education programs.

The group recognized that some studies (20) are already underway in this area and they hoped that the research community would build on activities being undertaken by HRSA, AHCPR, and the Kaiser Foundation to further investigate CARE Act planning bodies.

The group concluded that, ultimately, more information regarding the operation and effectiveness of CARE Act planning entities is needed to determine whether client-level needs are being met.

Case Management

The group which examined research and evaluation pertaining to case management began by acknowledging that little quantitative research has been done to determine the effectiveness of case management in the care of sick persons. A preliminary study on case management of persons with AIDS found that it may result in longer survival time between HIV diagnosis and death, and survival between first AIDS-related hospital admission and death (21). However, more research is needed to develop models of case management in the context of HIV positive and AIDS patients in order to understand the specific goals of case management for these individuals. The group felt that a key component of future research will be the determination of appropriate outcome measurements for the evaluation of case management.

Members of the group agreed that the development of case management typologies is needed for: (a) service components within case management; (b) models of case management under the CARE Act and other funding streams; (c) models for the organization and overseeing of case management; and (d) models for coordinating case management in one setting among different agencies. They recommended research models and methods, including the use of quasi-experimental designs, the development of qualitative studies, and the use of task analysis. The group felt strongly that service providers should be involved in the design of research, especially data collection strategies.

It was the group's belief that information is needed to develop an effective model for allocating resources between case management and other direct services, determining effective methods for setting caseload size in relation to severity of need, and determining the kinds of training, skills, and qualifications needed for case management. They suggested that reviews of existing models of service delivery and evaluation are necessary, such as the Sierra Health Foundation's National Symposium Report, the Bureau of Primary Health Care, Division of Special Populations Report, Health Care Financing Administration and Robert Wood Johnson Foundation-funded demonstrations on chronically ill frail elderly [23-28], and HMO experience (e.g., Kaiser Permanente). The group also suggested that data collected by HRSA from its CARE Act grantees could be augmented and made consistent to include number of clients served, number of encounters, number of initial assessments, number of psychosocial referrals, location of service visit, medical system capacity and experience with it, demographics, disease stage, and comorbidity. Initially, it might be possible to extract a brief summary on case management from the quarterly reports submitted by CARE Act grantees to HRSA.

The group asserted that it is essential that Federal programs, such as those authorized by the CARE Act, make use of set-asides for evaluation in order to learn whether services are being implemented and are effective. Simple data collection methodology should be integrated into a quarterly reporting system for the CARE Act. Systems that are now collecting useful data should be identified and explored for potential transferability. Finally, the group agreed that incentives for private-public partnerships should be created to study the methods and results of case management.

Follow-up Activities

The November 1992 meeting was the first step in a process designed to catalyze and focus interest in HIV/AIDS services research among both potential funders of and participants in such research. The agenda developed for research and evaluation has been disseminated widely through summaries in newsletters and at conference workshops, as well as through distribution of the full conference report. The conference findings were presented as a poster at the Berlin International AIDS Conference in June 1993. A number of the priority areas identified have been subsequently translated into research activities. For example, HRSA is funding the second phase of its study of consortia development and organization. The Kaiser Foundation is embarking upon a study of CARE Act Title I planning councils in Baltimore, Oakland, Los Angeles, Chicago, and Houston. AHCPR plans to issue two funding announcements that at least partially grew from the agenda developed at the meeting; the first is a Request for Proposals for the HIV Cost and Services Utilization Study (HCSUS), the second a program announcement for research projects on Health Care Services for Persons with HIV. Discussion is underway about creating a Public Health Service (PHS) workgroup to facilitate and coordinate implementation of the agenda across interested PHS agencies.

Conclusion

It is hoped that this article will stimulate further interest among private and public funders and the research community in fostering the implementation of this critically important agenda. The article describes the results of a meeting in which HIV-related research and evaluation issues were identifed for future study. These issues – which have

been overlooked or inadequately studied in the past – are broader and more encompassing than early research and evaluation efforts. Moreover, new priorities that have only emerged since the availability of categorical Federal funding for HIV/AIDS care, were identified and included within the proposed research and evaluation agenda. Focusing our research and evaluation efforts on those areas could have important outcomes: grounding the upcoming CARE Act re-authorization process in real data on the effectiveness and effects of the Act's programs; developing new knowledge to address stubborn service delivery problems; identifying and disseminating the best practices in service delivery; helping the HIV service delivery system adapt to a new environment that may include universal health care financing; generally contributing to the public health effort to respond effectively to an ever-expanding epidemic that still lacks effective treatment or a cure; and, most important, eventually bringing about better quality of life for people with HIV/AIDS in the United States.

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17. The group first developed this working definition of optimal care: "Optimal care is an aggregate of services that provides persons with HIV or persons vulnerable to infection with choices for their clinical management and support that respond to individual desired outcomes. Optimal care is delivered through systems that maximize access to these services. This concept does not assume that a single mix of services will be suitable for all individuals. Services will need to evolve as knowledge and experience increase."

18. The group determined that questions concerning the organization of planning councils and consortia should exclude measuring the impact of services on clients and the quality of services provided because of the difficulty of linking council and consortia organizations to client-level outcomes. The focus of councils and consortia studies should be on more direct and immediate factors such as group decision-making, inclusion of community organizations and individuals in the decision-making process, and impact of councils and consortia on the distribution of funds.

19. The group defined core services to include counseling and testing, case management, primary care, and drug treatment. Additional elements are housing, entitlements, mental health services, home health care, transportation, pharmaceuticals, etc. Client outcomes are health status, quality of life, knowledge, financial status; the group pointed out that system-level outcomes also need investigation.

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ABSTRACT

HRSA, AHCPR and NCAP convened a working meeting in November 1992, to discuss creation of a national agenda for research and evaluation on HIV service delivery systems that are cost-effective, responsive to the needs of the diverse populations affected by the epidemic, and reflective of the lessons learned so far. In this article, the interests and goals of the conveners are described; the meeting's process and outcomes are discussed and the nine key study areas that were identified and chosen by the meeting participants are presented. It is hoped that this article will stimulate further interest among private and public funders and among the research community in fostering the implementation of HIV service delivery-related research and evaluation studies. If this is accomplished, decision-makers will be better enabled to make informed and responsive policy decisions.