Delivering HIV Services to Vulnerable Populations: An Evaluation and Research Agenda

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SYNOPSIS

In May 2000, the HIV/AIDS Bureau of the Health Resources and Services Administration convened HIV experts from throughout the country to identify new and emerging areas of research needed to guide policy and programmatic decisions on HIV service delivery to vulnerable populations. This article describes the process used to develop an evaluation/research agenda, discusses key findings and recommendations of the conference, and proposes a set of principles to guide the design and conduct of future investigations. Conference participants identified nine major evaluation/research themes that span the continuum of HIV behavioral prevention services and treatment. They recommended focusing future research on questions relevant to populations experiencing rapid rates of increase in HIV infection (for example, women, people of color, and adolescents and young adults) and considering explanatory factors at multiple levels of analysis (individual, clinician, organization, service delivery system, and environment).

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In 1992, the Health Resources and Services Administration (HRSA), the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality), and the National Community AIDS Partnership (now the National AIDS Fund) cosponsored a national meeting on HIV-related health services evaluation and research.[1] Approximately 50 HIV experts discussed the first generation of studies on HIV service delivery and outlined an agenda for future evaluation and research. Since that time, HIV incidence rates have rapidly increased among historically underserved populations,[2] advances in antiretroviral therapy have intensified the need for early detection and treatment, and interstate variations in Medicaid and safety net programs have contributed to disparities in access to comprehensive HIV care.[3] These changes have created a critical need for an updated evaluation and research agenda that addresses the service needs of populations disproportionately affected by the HIV/AIDS epidemic, barriers to service access and utilization, the impact of multiple funding sources on service delivery, and the quality and outcomes of HIV/AIDS care.

To stimulate discussion about the evaluation and research questions that should be investigated, HRSA's HIV/AIDS Bureau held an invitational conference on New Directions in HIV Service Evaluation in Bethesda, Maryland, on May 5, 2000. The major aims of this conference were:

- "To review what is known about the accessibility, quality, and outcomes of services provided to groups that have been at high risk since the beginning of the epidemic (e.g., men who have sex with men and injection drug users) and populations that are experiencing rapid rates of increase in HIV infection (e.g., women, youth, African Americans, and Hispanics)";
- "To identify critical information gaps that should be addressed through future evaluation and research"; and
- "To generate new knowledge that could be used to improve HIV service delivery to vulnerable populations through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and other publicly funded programs."[4]

The 80 conference participants included health services researchers and evaluators, policy makers, CARE Act–funded service providers, administrative agents for CARE Act grants, and people living with HIV/AIDS. This article describes the process used to develop an evaluation/research agenda, discusses key findings and recommendations of the conference, and proposes a set of principles to guide the design and conduct of future investigations.

DEVELOPING THE AGENDA

A steering committee planned the content and format of the New Directions in HIV Service Evaluation Conference. Steering committee members included representatives of HRSA's HIV/AIDS Bureau, a HRSA consultant, representatives of the Henry J. Kaiser Family Foundation, a faculty member of the Harvard Medical School, and the Executive Director of the National Association of People with AIDS.

The conference focused on three dimensions of HIV service delivery to vulnerable populations: access, quality, and outcomes. Before the meeting, participants reviewed a background paper that summarized recent research on these topics.[5] Two panel sessions on "Access to Primary Medical Care" and "The Delivery and Impact of HIV Services" provided additional information on relevant empirical studies. Following each panel session, conferees met in facilitated work groups to discuss gaps in knowledge about HIV service delivery and priority areas for evaluation and research. (See Figure 1 for a list of work group topics.) Findings are based on in-depth analysis of conference transcripts, corroborated by the authors' observations as conference presenters (KMM, PDC, JK, JFO) or participants (MMM, SRY).

PROPOSED EVALUATION AND RESEARCH AGENDA

Conferees identified nine areas for future research on the accessibility, quality, and outcomes of HIV services (Figure 2). These research areas span the continuum of HIV behavioral prevention services and treatment and include multiple levels of analysis (individual, clinician, organization, HIV service delivery system, environment). In what follows, we present the major evaluation/research themes identified by conferees with examples of the types of studies that should be conducted in each area.

1. Why do people who know their HIV serostatus forgo or delay entry into care?

The Centers for Disease Control and Prevention (CDC) estimates that between 850,000 and 950,000 Americans are currently living with HIV infection.[6] Of the estimated 670,000 people who have been tested for HIV antibodies and know their serostatus, about one-third may not be receiving ongoing medical care.[6] Studies also have documented major differences in

the timeliness with which HIV-positive individuals seek care after receiving their test results.[7–9] To increase the proportion receiving care at an early stage of disease, conference participants recommended more focused studies of people who know their HIV serostatus but are not in treatment. Five sub-questions provide a framework for this research:

- *How should "not in care" be defined?* In addition to HIV-positive individuals who are not receiving any medical care, this population could include people who enter care and then drop out, people who access care on an irregular basis (e.g., for acute episodes of illness), and people who seek care for non-HIV-related conditions without revealing their HIV serostatus.
- *How can HIV-positive individuals who are not in care be identified?* What are the points of contact with health and social services for this sub-population? How can these service delivery sites be more effectively used to identify HIV-positive individuals and engage them in care?
- *How effective are the linkages between publicly funded HIV counseling and testing sites and HIV care providers?* What proportion of HIV-positive people tested at such sites are successfully linked to care? How does the average time interval between HIV diagnosis and entry into care vary among different subpopulations? How effective are partner notification programs in bringing HIV-positive individuals into care at an early stage of disease?
- *What are the major individual, clinician, organizational, service delivery system, and environmental barriers to service entry?* What efforts are HIV service providers making to identify and address these barriers? (See below for a discussion of multilevel barriers.)
- What kinds of outreach strategies and support services are most effective in bringing HIV-positive individuals into care at an early stage of disease?

2. What factors explain variations in service utilization patterns and continuity of care?

Efforts to make health and support services accessible to low-income and medically underserved individuals with HIV disease do not necessarily increase service use.[10] Surveys and medical record reviews of HIV-positive patients with different sociodemographic characteristics and payer types have documented significant variations in the number of primary care visits, emergency room visits, and hospitalizations and the receipt of combination antiretroviral therapies.[11–14] Both qualitative and quantitative studies are needed to explain why certain health services are being underused or misused and why patients drop out of care. Following are examples of questions that should be addressed:

- *What individual characteristics are associated with health service use and retention in care?* Although sociodemographic disparities in health service utilization have received much attention in the HIV/AIDS literature, the *reasons* for these disparities are not well understood. Future studies should explore possible differences in (*a*) awareness of available services, (*b*) understanding of when and how to use different components of the health care system, (*c*) life concerns and priorities, and (*d*) attitudes and perceptions (e.g., acceptance of HIV status, level of trust in medical care providers, attitudes toward antiretroviral treatment, readiness to adhere to a treatment regimen, concerns about confidentiality). Research should focus on populations that are experiencing rapid rates of increase in HIV infection (e.g., women, people of color, and young people); hard-to-reach populations (e.g., gay and bisexual men of color and homeless people); and populations with comorbidities, such as alcohol and drug abuse and severe mental illness.
- *What clinician characteristics are associated with health service use and retention in care?* When examining variations in health service utilization patterns, researchers tend to overlook the role of clinician factors and patient-clinician interactions. Future research should examine the effects of clinician characteristics, such as (*a*) HIV-specific training and experience, (*b*) communication skills, (*c*) interpersonal skills and ability to engage patients as partners, (*d*) sensitivity and responsiveness to individual and cultural differences, and (*e*) attitudes and perceptions (e.g., Do they view HIV as a chronic manageable disease or as a terminal illness? What are their attitudes toward people of color, substance abusers, and gay/bisexual men?). Researchers also should investigate whether racial/ethnic matching of clinicians with patients improves service use and continuity of care.
- *What organizational characteristics are associated with health service use and retention in care?* Relatively little research has been conducted on characteristics of service organizations that affect clients' use of health services. Some of the organizational characteristics meriting exploration include: (*a*) types of services offered, (*b*) experience providing HIV care, (*c*) number and specialty mix of staff, and (*d*) patient-staff ratios. Studies also should evaluate the impact of (*a*) geographic and physical accessibility (e.g., convenience of

geographic location and physical layout, co-location of health and support services), (*b*) financial accessibility, (*c*) logistical accessibility (e.g., eligibility criteria, days and hours of operation, waiting time for appointments, ability to accommodate walk-in patients, waiting time at the service delivery site), (*d*) cultural accessibility (e.g., availability of bilingual personnel, use of culturally and educationally appropriate educational materials), and (*e*) reputation in the community (e.g., perceived quality of care, extent to which people feel "comfortable" visiting the facility).

- *What characteristics of the HIV service delivery system are associated with health service use and retention in care?* There is a need for more research on system-level characteristics that affect health service utilization and continuity of care. At least five attributes of HIV service delivery systems should be considered: (*a*) *size* (the number of organizations providing health and support services), (*b*) *complexity* (the number and types of services offered; the number and specialty mix of health/social service professionals), (*c*) *centrality* (the extent to which HIV services are concentrated in a few core organizations), (*d*) *differentiation* (the extent to which each organization specializes in providing certain services), and (*e*) *coordination* (the extent to which organizations engage in joint planning and referrals, share client records, maintain regular contact, and work to eliminate conflicting policies and eligibility requirements).
- *What environmental factors are associated with health service use and retention in care?* Currently, little is known about the ways in which environmental factors influence health service utilization and continuity of care. Future research should examine the effects of (*a*) economic conditions (e.g., percentage of the population living in poverty, unemployment rate), (*b*) social attitudes and norms (e.g., degree of stigma associated with HIV/AIDS and HIV-related risk behaviors, level of community support for HIV services), and (*c*) government policies and regulations (e.g., variations in state and local funding for HIV-related services, state welfare policies, and Medicaid eligibility criteria and benefits).

3. How do multiple funding sources affect the accessibility, quality, and cost of HIV services?

Currently, health and support services for people with HIV/AIDS are funded by a "complex patchwork" of federal entitlement programs (i.e., Medicaid and Medicare), private health insurance plans, discretionary spending programs (e.g., CARE Act programs, Housing Assistance for People with AIDS), state and local appropriations, foundation and corporate grants, pharmacy assistance programs, and local fundraising efforts.[15] Medicaid and Medicare together account for almost two-thirds of federal spending for HIV/AIDS care.[16] Although CARE Act programs account for an additional 26% of federal spending, these expenditures are limited by annual congressional appropriations that do not necessarily reflect the number of people needing services or actual service costs.[15]

The multiple sources of coverage for HIV/AIDS care, variable levels of funding, and diverse ways in which financing programs are administered at state and local levels contribute to inequities in access to HIV services and the quality and cost of HIV/AIDS care. Some of the questions requiring further investigation are as follows:

- *How do multiple funding sources affect the development of an integrated continuum of behavioral prevention services, health services, and support services for people with HIV disease?* What problems do service providers experience when trying to manage multiple funding streams? How do these "administrative burdens" affect the number and types of providers that choose to participate in the HIV service delivery system?
- *What are the economic and social costs of maintaining separate and fragmented funding streams for HIV/AIDS care?* How can CARE Act grantees and planning groups identify and coordinate these funding streams to reduce disparities in health care access and quality?

4. How do variations in state Medicaid programs affect the accessibility, quality, and cost of HIV services?

Although states administer their Medicaid programs within broad federal guidelines, they have considerable latitude to determine eligibility criteria and benefit structures. Studies of state Medicaid policies affecting HIV/AIDS care have documented major differences in income and asset eligibility criteria, denial rates for people seeking HIV-related disability determination, coverage for prescription drugs and for health services, cost-sharing requirements, utilization controls, and capitation and reimbursement rates.[3,17,18] The impact of varying state Medicaid policies on beneficiaries' access to experienced HIV service providers and clinically appropriate HIV/AIDS care is an important area for future research.

Research is also needed on the different ways in

which states are implementing Medicaid managed care programs.[19–21] The Balanced Budget Act of 1997 authorizes states to enroll most Medicaid beneficiaries in managed care organizations, to limit beneficiaries' choice of managed care organizations, and to prohibit beneficiaries from disenrolling (other than for cause) for as long as 12 months.[22] As state Medicaid programs shift to managed care, two questions deserve careful investigation:

- *How does participation in Medicaid managed care affect access to experienced HIV service providers, HIV pharmaceuticals, and a continuum of health and health-related support services that includes substance abuse and mental health treatment?*
- *How do Medicaid managed care arrangements (e.g., capitation rates, terms and conditions of managed care contracts, and payment arrangements between managed care organizations and service providers) affect the amount and quality of care provided to people with HIV/AIDS?*

The Centers for Medicare & Medicaid Services have approved Section 1115 waiver proposals from Maine, Massachusetts, and the District of Columbia and is reviewing proposals from several other states to extend Medicaid coverage to low-income individuals with early-stage HIV disease who do not meet disability standards. Congress is also considering legislation that would give all states this option. As these demonstration projects are implemented, the following questions should be researched:

- *How do state demonstration projects that extend Medicaid coverage to people in early stages of HIV disease affect beneficiaries' use of medical services, access to combination antiretroviral therapies, and clinical outcomes?*
- *How are these demonstration projects meeting federal requirements for "budget neutrality"?* Are these projects negotiating drug price discounts? How does Medicaid expansion affect the scope of reimbursable services, utilization controls, and quality standards?

5. What criteria and measures should be used to evaluate the quality of HIV clinical care and health-related support services?

The CARE Act Amendments of 2000 require grantees to implement quality management programs that (*a*) help CARE Act–funded medical providers adhere to U.S. Public Health Service guidelines for HIV clinical care and (*b*) encourage ongoing improvements in the quality of health and health-related support services.[23] To accomplish these objectives, grantees will need guidance on the components of each service that should be evaluated and appropriate criteria for evaluating "quality." Additional questions requiring investigation are:

- *What minimum set of quality standards should be established for all components of the HIV service delivery system (including primary care, case management, substance abuse treatment, mental health counseling, health-related support services)?*
- *What measures should be used to evaluate adherence to these quality standards?* How can quality measurement be made "user friendly" so that service providers will collect the necessary data and use the findings to improve their programs?

6. How does the receipt of support services affect access to HIV primary care, adherence to treatment regimens, and clinical outcomes?

During fiscal year 2000, case management and other support services (e.g., transportation, housing assistance, nutritional counseling, emergency financial assistance) accounted for about 35% of aggregate Title I and discretionary Title II expenditures under the CARE Act.[24] Yet, only minimal research has been conducted on the impact and cost-effectiveness of these services. The studies that have been conducted suggest that the receipt of support services, such as case management, housing assistance, and transportation, significantly increases the likelihood of entering medical care and making regular medical visits,[25,26] and that close monitoring by case managers helps HIV-positive clients adhere to antiretroviral regimens.[27] Future studies should investigate the following questions:

- *What are appropriate outcome measures to use in evaluating support services?* The CARE Act Amendments of 2000 authorize funding for support services that "facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services for individuals and families with HIV disease"[23] (p. 7). How can accomplishment of these objectives be measured?
- *How do support services mediate the relationship between HIV primary care and clinical outcomes?* Do patients who receive both primary care and support services have better clinical outcomes than those who receive just primary care?
- *What clusters of health and support services work best for different HIV populations?* Do clients with different demographic or clinical characteristics require different mixes of health and support

services? How should health and support services be sequenced to retain patients in care and maximize health and social functioning?

7. What individual, clinician, and organizational factors are associated with better clinical outcomes?
Evaluations of the clinical impact of service delivery models and therapeutic regimens typically control for individual characteristics, such as gender, race/ethnicity, health insurance status, and comorbid conditions. To more fully explain intended and unintended variations in clinical outcomes, researchers need to consider the independent and interactive effects of multiple levels of influence:

- *Individual characteristics:* age, educational level, employment status, primary language, child care responsibilities, housing instability, disease severity, adherence to the treatment regimen.
- *Clinician characteristics:* HIV-specific training and experience, communication and interpersonal skills, sensitivity and responsiveness to individual and cultural differences.
- *Organizational characteristics:* clinic type (e.g., community-based, hospital-based, private physician practice), experience providing HIV care, patient-staff ratio, continuous quality improvement initiatives, provision of culturally competent care.

8. How can behavioral prevention services be effectively integrated with HIV primary care?
To date, HIV prevention programs have given relatively little attention to individuals who know their HIV serostatus but continue to engage in risky behaviors.[28] Behavioral prevention services offered in clinical care settings can help HIV-positive patients reduce their risks of transmitting the virus, becoming reinfected with new strains of HIV, and developing coinfections.[29] In addition to risk assessment and risk-reduction counseling, clinics may provide prevention case management, education on the symptoms and management of sexually transmitted diseases, partner notification and referral services, and/or interventions to improve adherence to treatment regimens. Because behavioral prevention services have tremendous potential to reduce the spread of HIV, an Institute of Medicine report makes the following recommendations:

> Prevention services for HIV-infected persons should be a standard of care in all clinical settings (e.g., primary care settings, sexually transmitted disease clinics, drug treatment facilities, and mental health centers). Health care providers should have adequate training, time, and resources to conduct effective HIV prevention counseling.[28] (p. 47)

To help accomplish these objectives, the following research questions must be addressed:

- *How, and to what extent, are behavioral prevention services being provided by HIV outpatient clinics, primary care clinics, drug treatment facilities, mental health centers, homeless shelters, and other community-based organizations?* What are the major facilitators and barriers to providing these services? How are these services being financed? What kinds of training and resources would enhance clinicians' ability to assess risk behaviors and counsel patients on risk reduction?
- *What outcome measures should be used to evaluate the effectiveness of behavioral prevention services?* How can clients be more integrally involved in evaluating the effectiveness of prevention messages and interventions?
- *What kinds of behavioral prevention services work best with different HIV populations and in different medical/social service settings?* Do clients with different characteristics (e.g., gender, race/ethnicity, comorbidities) or at different stages of disease require different prevention messages and/or interventions? How do outcomes vary when different types of health and social service professionals provide prevention messages and interventions?

9. What configurations of services and service providers work best with different HIV populations and in different environments?
The medical complexities of HIV disease and the growing incidence of co-existing chronic illnesses have raised new questions about the best ways to organize HIV service delivery systems and measure their performance.[30] Some of the questions requiring study are as follows:

- *What kinds of interdisciplinary teams are needed to effectively manage HIV infection and co-existing chronic illnesses (e.g., diabetes, hepatitis C, heart disease, renal and liver disease)?* What are appropriate roles for primary care physicians?
- *What patterns of service integration are associated with better clinical outcomes?* Do patients who receive support services in a clinical care setting (one-stop shopping model) have better clinical outcomes than those who are referred to other agencies for support services (parallel service model)? How can HIV primary care, mental health counseling, and substance abuse treatment be more

effectively integrated? How do gaps and barriers in service coordination affect clinical outcomes?

- *What performance measures should be used to evaluate the effectiveness of HIV service delivery systems?* What system characteristics are associated with high performance under different environmental conditions (e.g., high/low HIV prevalence, high/low resource availability, rural/urban location)?

GUIDING PRINCIPLES FOR EVALUATION AND RESEARCH STUDIES

Conference participants proposed five principles to guide future research on the accessibility, quality, and outcomes of HIV services:

1. Evaluation and research studies should focus on questions that are *relevant* to populations disproportionately affected by the HIV/AIDS epidemic (e.g., African Americans and Hispanics) and to populations experiencing rapid rates of increase in HIV infection (e.g., women, adolescents, and young adults).
2. When examining variations in service access, quality, and outcomes, researchers should consider explanatory factors at *multiple levels of analysis* (individual, clinician, organization, service delivery system, environment). To the extent possible, studies should examine multiple levels of influence simultaneously. For example, a longitudinal study at two urban medical centers investigated how characteristics of the patient, the physician-patient relationship, and the site of care were associated with patient-reported satisfaction with HIV primary care.[31]
3. The results of evaluation and research studies should be *timely*. Large-scale studies based on probability samples should be supplemented by smaller-scale "rapid assessment" studies to provide policy makers and the larger HIV/AIDS community with fast, actionable information.
4. The results of evaluation and research studies should be *useful* to policy makers and service providers. Researchers should take a more active role in disseminating information on effective models and interventions and helping service providers apply this knowledge in their programs and practices.
5. People living with HIV/AIDS and their service providers should be *active partners* in designing, conducting, and interpreting evaluation and research studies. By integrating community perspectives into the evaluation/research process, researchers can better ensure the relevance and applicability of study questions and results.[32]

DISCUSSION

This article summarizes new and emerging areas of research that are needed to guide policy and programmatic decisions on better ways of delivering health and support services to vulnerable populations with HIV disease. The CARE Act Amendments of 2000 require CARE Act grantees and planning groups to address many of these issues when allocating funds for HIV services and monitoring contractor performance.[23] Successful implementation of the evaluation/research agenda will require the active involvement of federal and state health agencies, private health foundations, associations of health professionals, health services researchers and evaluators, HIV service providers, and people living with HIV/AIDS.

While some research questions will require primary data collection, many can be answered by making more creative use of existing databases, such as the HIV-related databases maintained or supported by federal agencies.[33] Approaches that integrate qualitative and quantitative methodologies (such as the Rapid Assessment, Response, and Evaluation [RARE] approach being used to develop targeted strategies for curbing the rapid spread of HIV/AIDS among minority populations) may prove particularly beneficial.[34]

To move this research agenda forward, HRSA's HIV/AIDS Bureau has incorporated the major themes into a set of evaluation questions for CARE Act grantees and planning groups.[35] Bureau officials also are working with representatives of other federal health agencies and health professional associations to plan ways of supporting research in the nine thematic areas. In September 2000, the Bureau held a consultation with CARE Act grantees and health services researchers to discuss methods of identifying HIV-positive individuals who are not in care, determining why they are not in care, and assessing their unmet service needs.[36] The Bureau is also considering several new initiatives through the Special Projects of National Significance (SPNS) Program to study unmet needs and innovative outreach strategies.

The evaluation/research agenda described in this article offers a framework for a new decade of research on HIV service delivery to vulnerable populations. A major challenge will be to design and implement these studies in an environment characterized by rapidly changing HIV treatments and health care

financing schemes. As these changes occur, new knowledge gaps will emerge and evaluation/research priorities will need to be reassessed to ensure that the agenda remains relevant, timely, and useful for service planning and improvement.

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