

Directions in HIV Service Delivery & Care

A POLICY BRIEF

Number 1

Vulnerable Populations

**Office of Policy and Program Development
HIV/AIDS Bureau
Health Resources and Services Administration
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in HIV Service
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Vulnerable Populations

Caitlin Ryan, MSW, ACSW
Editor

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Introduction

When the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was initially authorized in 1990, lack of public infrastructure and capacity to provide services for affected persons, particularly low-income and uninsured/underinsured people with HIV/AIDS, posed profound challenges to communities throughout the country. Since that time, the CARE Act has established a critically needed planning process and infrastructure to develop and sustain essential health and social services for persons living with HIV/AIDS. These services have improved the lives of thousands of poor, uninsured/underinsured men, women, children, youth and families throughout the United States. And their effectiveness has been borne out by the reduction in HIV morbidity and mortality among the most impoverished communities.

Although substantial gains have been made, challenges remain in meeting the care and support needs of historically underserved populations, including minorities, women, families, substance users and people with mental illness. And these continuing disparities represent new challenges for the CARE Act in its second decade.

Guiding Principles

As the CARE Act entered a second reauthorization cycle last year, HRSA's HIV/AIDS Bureau (HAB) conducted a comprehensive assessment of disparities in access to services and care. This assessment was based on the policy framework established by HAB Associate Administrator, Dr. Joseph O'Neill, who identified four principles to guide the Bureau's mission. These include: 1) changes in demographics; 2) access to emerging therapies; 3) changes in health care financing; and 4) program accountability.

During a year-long review of the role and structure of CARE Act services, HAB explored various changes, issues and needs affecting HIV service delivery, using these principles as a lens by which to identify and assess current and future challenges in caring for uninsured and underinsured people with HIV/AIDS. HAB examined these issues in light of the following questions:

- ◆ How can HRSA strengthen CARE Act-funded programs to ensure that all persons with HIV/AIDS, regardless of race, co-morbidity, geographic location or income, have access to needed health and support services?
- ◆ How can HRSA ensure that CARE Act services meet current standards of quality HIV care?
- ◆ How can HRSA and CARE Act grantees help providers maintain fiscal and administrative viability within rapidly evolving health delivery and social welfare systems, while creating opportunities for new providers to care for affected and underserved populations?
- ◆ How can HRSA improve its ability and that of CARE Act grantees to monitor and evaluate services, becoming more accountable to Congress, State agencies and, most importantly, people with HIV/AIDS who depend on these services for their survival?

Program Review Activities and Policy Studies

Under the guidance of Dr. John Palenicek, Director of the Bureau's Office of Policy and Program Development (OPPD), staff engaged in extensive consultation with constituents, community members and people living with HIV/AIDS. This includes collaborating with HRSA's AIDS Advisory Committee to sponsor a series of public hearings to solicit broad feedback in preparation for reauthorization. During the past year, OPPD staff undertook a comprehensive evaluation of current program activities to understand the dynamic of HIV care within an evolving system of health care finance and delivery. And they initiated a series of targeted policy studies to more fully understand the factors that affect access to care and ability to remain in care for poor, low-income and traditionally underserved populations.

Topics selected for these studies include the following:

- ◆ The experience of vulnerable populations (e.g., minority women, children, and substance users) in accessing needed services and care;
- ◆ The changing nature of health care delivery and finance systems for HIV services and their relationship with CARE Act-funded programs; and
- ◆ The role and structure of Title I, II, III and IV programs within communities.

The goal of these studies is to expand on current knowledge and to generate findings that can inform future policy directions or suggest administrative or legislative changes for the reauthorized CARE Act. Results of these studies will be presented in a series of policy briefs—*Directions in HIV Service Delivery & Care*—to help grantees and CARE Act providers render more effective services to people with HIV/AIDS. Findings and recommendations will also help inform HRSA's administrative procedures, technical assistance and training activities, improve service delivery, and enhance inter-governmental relationships between Federal agencies and among Federal, State and local jurisdictions.

These studies are especially relevant for CARE Act providers because they focus on populations and issues that—although difficult to address—offer the greatest potential for significantly improving outcomes for the Nation's most underserved populations. HRSA grantees are encouraged to read these reports and to incorporate findings and recommendations into their ongoing planning and program activities. HRSA welcomes feedback from readers on the usefulness of these monographs for their work. Send comments to: jgrantling@hrsa.gov.

Women's Equity in AIDS Resources

Mindy Thompson Fullilove, M.D., Robert E. Fullilove, Ed.D.,
Jennifer Stevens, M.P.H., Lesley Green, M.P.H.

PURPOSE: To assess the ability of the Ryan White CARE Act to meet the needs of minority women living with HIV/AIDS. **METHODOLOGY:** Investigators conducted focus groups and interviews with 120 informants, including HIV-positive women of color, university clinic and social service providers, Planning Council members and HIV-affected minority women in five cities. Data collection focused on whether the processes used to prioritize and allocate HIV services funding can be improved to better meet the needs of minority women with HIV/AIDS. **FINDINGS:** Some women receive appropriate, culturally-sensitive care; however, many others are often unable to access ancillary services, such as case management, transportation, childcare, and treatment for mental health and substance abuse. Minority women are least likely to be politically engaged or to be effective advocates for their own needs: financially, politically, and socially, they are disadvantaged in competing for funds to create and maintain needed services. **RECOMMENDATIONS:** The authors include suggestions for improving planning and delivery of care to women of color affected by HIV/AIDS.

Impact of Ryan White CARE Act on Services Provided to Women, Children and Families

Barbara Aranda-Naranjo, Ph.D., R.N., Carmen Portillo, Ph.D., R.N., FAAN,
Helen Schietinger, M.A., R.N., Gary Norgan, Ph.D., R.N.

PURPOSE: To better understand the needs and health-seeking behaviors of women living with HIV and the services they and their families receive from CARE Act-funded agencies. **METHODOLOGY:** In-person interviews were conducted with 24 women with HIV/AIDS in California and Texas to identify essential health and daily-living needs for themselves and their families. **FINDINGS:** Because women with HIV are the primary caregivers in families that may also include children with HIV/AIDS, they are often unable to properly meet their own medical needs. Challenges include: fear of disclosing their HIV status to family members; desire to put the care of their children ahead of their own; external factors, such as poverty, immigration status and employment discrimination; and lack of HIV understanding and the importance of drug regimens. Coping with HIV/AIDS often results in a stronger sense of self that helps many women take charge of their lives beyond HIV infection. **RECOMMENDATIONS:** The authors provide suggestions for caring for women and families with HIV/AIDS and ensuring support for ancillary services and Title IV programs.

Investigation of the Adequacy of the Community Planning Process to Meet the HIV Care Needs of Active Substance Users

Ruth Finkelstein, Sc.D., Anna Greenberg, B.A., Christine Lubinski, M.A.

PURPOSE: To assess the adequacy of Title I community planning in serving the needs of active substance users with HIV infection and to develop recommendations to more effectively meet their needs. **METHODOLOGY:** Investigators reviewed extensive background materials from published and unpublished sources, and conducted interviews and focus groups with key people in each of six EMAs to determine the adequacy of Title I planning for active substance users with HIV/AIDS. **FINDINGS:** A majority of Planning Councils studied did not engage in a comprehensive needs assessment for active substance users, so they tended to fund little or no drug treatment. Some incorrectly interpreted "payer of last resort" to mean that they were restricted to funding non-reimbursable services and they interpreted HRSA guidance to mean they cannot use Title I funds for case finding. In addition, lack of technical rigor in gap analysis along with lack of data sharing between service systems was found to be a significant barrier to effective planning. **RECOMMENDATIONS:** The authors provide suggestions for enhancing services to active substance users with HIV in a variety of settings, including training and technical assistance to ensure effective planning for this population.

Women's Equity in AIDS Resources

Mindy Thompson Fullilove, Robert E. Fullilove, Jennifer Stevens, Lesley Green

Background

As the demographics of persons affected by AIDS have changed dramatically over the course of the epidemic in the United States, women and minority communities are shouldering a larger portion of the epidemic. Comparing AIDS cases reported in 1996 to cases reported cumulatively through 1987, AIDS dropped among whites from 60 to 43 percent, rose among African Americans from 25 to 38 percent, and increased among Hispanics from 14 to 18 percent. During the same period, AIDS cases in women rose from 8 to 21 percent.¹

It has been suggested that women of color with HIV/AIDS are at increased risk for HIV due to biological vulnerability,^{2,8} gender inequality,^{6,8,9,11} discrimination,¹² and poverty.⁶ AIDS can thus be understood as an environmental disease that takes advantage of the poverty, social disintegration, sexism, and stigma suffered by marginalized groups and individuals.^{11,13,15} Given the range of social and family-related problems these women experience, their needs can be assumed to go beyond those traditionally defined for medical care.

This study seeks to address information gaps in the comprehensive *HIV Cost and Services Utilization Study* (HCSUS),¹⁶ which examined variations in care utilization between 1996 and 1998, by conducting a qualitative study of the care-related needs and experiences of minority women with HIV. An important finding of the HCSUS study was that gender, race, and economic disadvantages were associated with "inferior patterns of care." As comprehensive as it was, however, the study lacked specifics on issues of care related to minority women.

Methodology

To assess the ability of the CARE Act to meet the needs of minority women with HIV/AIDS, investigators examined four key areas: 1) the impact of HIV infection on women of color in five cities; 2) their stated and unstated needs related to medical care; 3) the extent to which prioritization and allocation processes for funding Federal HIV-related services consider the impact of HIV on their medical and social needs; and 4) the potential for administrative or legislative changes in the CARE Act to more effectively direct resources to women of color.

Researchers designed the study to explore the interactions of a variety of people concerned with HIV/AIDS in five cities. They used a "snowball sampling" method to identify participants, asking a small number of participants to recommend others. The first round of names was culled from CARE Act funding applications. Persons contacted were asked to suggest others, including women with AIDS, who might have relevant insights. Focus groups and interviews were then conducted with HIV-positive women of color, university clinic and social service providers, HIV Health Services Planning Council members, and HIV-affected minority women. Researchers sought persons who would reflect differences in racial/ethnic status, class, gender, sexual orientation, education, and profession. Women in recovery, those with poor access, those identified as being "less compliant," and those who were relatively healthy were also included. The investigators sought to include key participants who differed in terms of their roles, interests, actions, and personal perspectives. They also examined key aspects of the problem in terms of the setting, size, scope, and geography.

Research was conducted in five cities selected for size, geographic diversity, ethnic diversity, history of ethnic settlement in the area, and variation in AIDS incidence. The cities and number of

Purpose of the Study:

To assess the ability of the Ryan White CARE Act to meet the needs of minority women living with HIV/AIDS.

Sites Selected

Los Angeles ♦ Miami
New York ♦ San Antonio ♦ St. Louis

interviews conducted in each site include: Los Angeles (12), Miami (17), New York (25), San Antonio (18) and St. Louis (7). Because some interviews were conducted in groups, the actual number of participants was 120. Most sessions were audiotaped and interviews lasted from 60 to 90 minutes.

Limitations

Investigators noted several limitations in conducting the study:

- ◆ The study was not designed to investigate the intricacies of policy formation and implementation;
- ◆ Although the study was intended to collect participants' perceptions of CARE Act processes, participants were not uniformly expert in care organization, financing, and administration; and
- ◆ The small sample size and limited geographic representation makes it difficult to generalize to the experiences of all women of color affected by HIV/AIDS.

The strengths of this study are its overall assessment of the situation and its attempts to balance individual accounts with objective information and case studies of each city.

Findings

In all five cities, the structural inequalities of American society were a significant factor in the local AIDS response. Race, ethnicity, gender, sexual orientation, and poverty contributed to every HIV-related interaction that researchers observed or participants described. However, amidst significant examples of inequitable distribution of HIV services, researchers found some locations where services approached the ideal of "woman-sensitive care," which they described as "islands of success in a disjointed system." They conclude that, rather than all women having some unmet needs, it is more likely that some women have some or many unmet needs, while others are receiving completely satisfactory quality care. What follows are common characteristics of programs that met minority women's needs, as well as those that did not.

◆ Characteristics of "Successful" Delivery Systems

In general, the most successful programs were designed with women's needs in mind (see table 1). Even if they do not have children, women are the primary caregivers for other family members. They need homes from which to organize family life and transportation to access services and manage daily needs. They need support to integrate HIV-related care into the complex round of daily chores, and assistance coping with drug addiction, mental illness, incarceration, and victimization. In addition to problems faced by all women, minority women also need help addressing discrimination, immigration, and other issues related to racial and ethnic inequality.

TABLE 1

Characteristics of Successful Programs for Minority Women with HIV/AIDS
<p>Successful programs:</p> <ul style="list-style-type: none"> ◆ Offer a continuum of care ◆ Provide co-located services ◆ Are easy to negotiate ◆ Provide a home-like decor ◆ Make women feel at home ◆ Create a sense of community ◆ Provide an atmosphere of acceptance and empowerment ◆ Welcome family and support network ◆ Are flexible and responsive to women's needs ◆ Have adequate staff to provide help and support, when needed

Finding ready access to a full range of services is an ongoing challenge for minority women with HIV. In general, medical care and medication are top funding priorities. Case management, transportation, childcare, substance abuse, and mental health services vie for the remaining dollars, creating gaps in care. Minority women face additional challenges in overcoming these obstacles since they are less likely to be socially, financially, and politically empowered than other women.

Successful programs made women feel at home, were easy to negotiate, and had enough staff that women could get help when needed. The settings were woman-centered in style and culture, and the decor was designed to be home-like, not institutional. More importantly, the settings welcomed a woman's family and support network. The importance of creating an accepting atmosphere cannot be overstated. Minority women with HIV often feel stigmatized, marginalized and vulnerable; rejection from the health care system can drive them away from treatment.

Proximity of services to one another was an important characteristic of effective service delivery for women; optimally, services were located in the same facility. This minimized transportation barriers, and permitted staff to nurture a sense of community that was invaluable for clients and providers alike. Given the generally high

levels of material deprivation and social isolation that minority women face, finding a supportive community in a treatment center was a powerful aid to healing. Perhaps most significant was the way this support helped empower clients both outside and inside the treatment setting. Flexibility of service delivery—such as the ability to offer a 2-hour mental health counseling session to a depressed, HIV-positive teenage client—was also important, as was recognizing the additional cultural, linguistic, and power issues faced by minority women.

◆ Characteristics of Delivery Systems that Failed to Meet These Women’s Needs

Two features were found to be especially problematic: 1) some good services were spotty in design and implementation, so not all women could access them; and 2) even services rated “best” by clients and staff were subject to inadequate funding and often received insufficient support.

Care System Gaps

An effective continuum of care depends on the availability of component services. In no city did investigators find adequate substance abuse or mental health services to assist minority women with AIDS. In fact, these were often treated as “optional” services. In one city, substance abuse treatment was so limited that women, desperate for treatment, were at times advised to commit a minor offense so that they could access treatment through the jail system. Similarly, access to childcare and transportation—essential to the care of minority women with AIDS but not considered a priority by the system as a whole—was subject to fluctuations in funding.

For women of color with HIV, drug addiction, homelessness, incarceration, family problems, and mental illness are common experiences. However, the “multi-problem client” poses a challenge to standard systems of care. Physicians with office hours are unable to manage the constant crises these women experience, nor are they prepared to deal with chronic social problems. Rather than standard office-based care, women with multiple problems require a supportive milieu that can respond to their level of functioning and offer a wide array of services.

Geographic Obstacles

Transportation remains an ongoing problem for minority women with HIV. CARE Act programs address transportation, but health planners have had only limited success making effective use of existing transportation systems. In one city where funds could be used for bus tickets, gas vouchers, and cab rides, cab vouchers could not be used for travel to mental health appointments—instead, they are restricted to primary care appointments and for people who are very ill. Geography was least problematic in New York, where recent changes in transportation funding have generated a monthly transport pass. This is a superb policy that frees poor people to travel as needed for care and other services.

More Responsiveness Needed

Theoretically, funding decisions should be guided by local surveillance, which would help Planning Councils identify existing and emerging needs, and allocate funds across the spectrum of need. An evaluation process would assess the effectiveness of programs and guide re-funding decisions. But this does not always happen: Competing demands by unmet needs create difficult situations. One service center that was highly rated by clients and staff lost a major portion of its funding and had to reduce services. Such stories are not uncommon, and reflect the struggles that characterize AIDS funding processes in these cities.

Politics, Power, and Stigma Complicate Decisions

In-fighting, competition and disagreements between racial and ethnic groups and between women and gay men complicate decision-making and place women at a disadvantage in

CARE-RELATED CHALLENGES FOR WOMEN

“You are a woman who is infected, and you have two kids. One is infected and one is not, but both are under the age of six. You have got to go to provider A for your primary care for your HIV. You might have to go to provider B for your outpatient substance abuse treatment that is on the west side of the county. Your infected child has to come here to the clinic for infected kids. But your affected kid needs to go to a different provider; maybe health department clinic, for his immunizations. One of those kids needs psychological services, and is being tested for developmental delay, a perfect example. The infected kid has a developmental delay secondary to the viral invasion of the central nervous system. You as a woman have to orchestrate all of your service providers and all of the service providers for your kids, and you’ve got to haul them around almost every day. Plus you’ve got to go to the store, plus you’ve got to get your meds, plus you’ve got to go to the welfare department, plus, plus, plus... It’s mind boggling.”

—A care provider

prioritizing their funding needs. Minority women, in general, lack political organization and skills, are under-represented on planning bodies and have vastly different needs than gay men who are well established in the AIDS program hierarchy. Given an orientation to home and family, a lack of political skill, and little sense of empowerment, minority women are at a profound disadvantage in the CARE Act planning process.

Impact of Personal Circumstances

The health delivery system lacks tolerance for clients who are not persistent, focused, knowledgeable, assertive, self-assured, or “traditional.” Because face-to-face encounters with providers are essential, socially skilled women are best able to articulate and address their needs, while women who lack these skills find navigating the health care system almost impossible. Even though women with dual diagnoses, such as mental illness or substance abuse, may need care most, they are often least able to obtain it. Family obligations also complicate care, because women are likely to place family members’ needs above their own.

Denial and Secrecy

Denial and secrecy characterize the experiences of minority women with HIV/AIDS. People who do not consider themselves at risk are unlikely to use barrier protection during sexual intercourse or to get tested regularly. Women are also likely to ignore their own health needs and symptoms for many reasons, secrecy among them. Few women feel free to inform their family and friends about their health status, fearing that they will be rejected. And denial about bisexuality is perceived to be an ongoing problem that is not openly addressed; this lack of honesty about sexual activities puts both women and men at risk.

Other circumstances that increase the likelihood that women of color will fall through the cracks include incarceration, drug use, immigration status, and inability to speak English. The Special Projects of National Significance (SPNS) Program was routinely acknowledged for successfully identifying and addressing difficult, unsolved problems. However, a lack of follow-up funding after the initial grant ends remains an unsolved problem that affects both clients and providers.

Recommendations

Although the problems of continued social divisions along lines of gender and race lie largely outside the provenance of the Ryan White CARE Act, it is essential that the CARE Act seriously address the influence of social structure on treatment access. Similarly, the lack of funding for substance abuse and mental health is a problem that must engage the entire health system, not simply the CARE Act.

I. Describe a standard of care for women with HIV/AIDS that recognizes the full continuum of care they require.

There is general agreement about this standard of care and what it includes, and exemplary programs are in place in sites throughout the country. Flexibility, attention to the needs of women and their families, and responsiveness to socially-challenged women are all key to effective programs. Articulating such a standard of care will help Planning Councils make funding decisions that protect the needs of minority women.

II. Ensure that local areas have the capacity to deliver the full range of care.

The absence of a full range of health services is a serious threat to the health of many women of color living with HIV/AIDS. Services must link across such systems as local communities, jails and prisons. Creating a system with full capacity requires extensive cooperation among HRSA and Federal, State and local partners.

III. Continue to support programs that address emerging treatment issues and find ways to ensure that they can continue to operate.

The SPNS Program plays an important role in addressing emerging problems. Successful SPNS projects should be maintained after the initial funding period has ended.

IV. Enhance the use of surveillance and evaluation in the local planning process.

Local planning has been successful, but it is important to ensure that decisions do not imperil the rights or health needs of minority groups. Data-driven decision processes offer sound protection.

V. Develop minority women's ability to participate in the planning process.

Minority women are represented in local planning efforts, but may lack the skills needed to participate effectively. Skills enhancement should be provided to facilitate active participation, including assistance with public speaking, interpreting the funding process, organizing interest groups, and developing effective coalitions.

VI. Include information on fighting AIDS-related stigma in all dissemination efforts.

Stigma remains a serious obstacle to accessing AIDS-related care. Efforts to overcome stigma should be included in CARE Act-funded outreach and information distribution efforts, including educational projects to openly discuss AIDS.

VII. Create a process for the discussion of male bisexuality.

Many participants agreed that the lives of both men and women are endangered by lack of open discussion about male bisexuality. Given the homophobia that exists in minority communities, it continues to be difficult for men to be honest about having sex with other men. Discussing these issues will improve HIV prevention and treatment.

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Impact of the Ryan White CARE Act on Services Provided to Women, Children, and Families

Barbara Aranda-Naranjo, Carmen Portillo, Helen Schietinger, Gary Norgan

Purpose of the Study:

To understand the needs and health-seeking experiences of women living with HIV infection and the impact of CARE Act programs in facilitating or inhibiting care for them and their families.

Background

Since the beginning of the epidemic, AIDS has disproportionately affected women of color. In the United States, African American and Hispanic women currently account for more than three-fourths of women with HIV

infection.¹ Increasingly, ethnic and racial minorities, women, and families are affected by HIV/AIDS. Because women are primary caregivers, however, their diagnosis with HIV disease precipitates a family crisis.²⁻¹⁰

Little research has been conducted on women's ability to balance HIV disease with attempts to maintain their health and obtain health care, to care for their children and families, struggle with overwhelming social challenges, and make crucial decisions about their present and future lives. Nevertheless, HIV infection in women is clearly a family issue, imposing social, psychological, and economic burdens on women who care for family members while they themselves are ill. When multiple family members are infected with HIV, these issues are compounded, and it is difficult to determine how long a woman will be able to care for her children and how disabled she will become before she eventually succumbs to AIDS. As her health begins to deteriorate, multiple needs arise and family members' lives become more complicated. Often social needs supersede medical needs. When women lack housing, food and transportation, they are often unable to meet their needs for medical care. Thus, their well-being and that of their children depends on their care-seeking ability and on the knowledge and sensitivity to the complex nature of their needs by health care providers, planners, and policymakers.

In a consensus-based system of HIV planning, several factors decrease the likelihood that women's needs (and those of their children and families) will be met: 1) women represent a smaller (albeit growing) proportion of HIV/AIDS cases, compared with men; 2) women are socialized not to assert themselves, particularly when interacting with men, in social, care-seeking and planning transactions; and 3) women's role as caregiver impacts on their ability to access and adhere to medical care. As the primary component in the CARE Act to address the needs of women, children, and families, Title IV plays a critical role in developing family-centered programs to reduce these barriers to care.

Methodology

Sites Selected

California:

Fresno ♦ Los Angeles ♦ San Diego

Texas:

Austin ♦ Corpus Christi ♦ Dallas
♦ Fort Worth

Researchers conducted an evaluation study that used exploratory, qualitative methods to examine: 1) how women with HIV/AIDS experience living with the disease; 2) how they meet their own and their families' needs; and 3) what services they identify as helping or hindering their care.

Seven sites were selected in California and Texas based on a distribution of CARE Act-funded programs (Titles I-IV) and on epidemiological data; sites include Fresno, Los Angeles, San Diego, Austin, Corpus Christi, Dallas, and Fort Worth. Two States were selected to minimize differences in Medicaid programs. Sites ranged from Los Angeles (the most urban, with 9.5 million people in 4,000 square miles) to Corpus Christi (the most rural, with 1.6 million people across 11,000 square miles),

although every site but Los Angeles served women in rural areas. The percentage of women with AIDS ranged from 6.6 percent of cumulative cases in Los Angeles to 20 percent of recent cases in Fort Worth.

The methodology had two primary components, including an examination of background data and telephone interviews with key informants. Investigators reviewed written sources to obtain information on service utilization, including CARE Act funding applications and documents from local health departments, other government agencies and community-based organizations, as needed. Three women living with HIV who received services from CARE Act-funded programs were selected from each site, representing different types of experiences (e.g., typical, unique and women with special circumstances, such as grandmothers caring for young children). Women received a range of services from Title I, II, III and IV programs.

A total of 24 women with HIV participated in individual interviews of 2-3 hours in English and Spanish, using an open-ended interview guide. Interviews were audiotaped and transcribed, and participants received a small stipend. Seventeen (71 percent) were women of color, most of whom were Latina. One in six speak English at home, and one-fourth had less than a high school education. Their average age was 35, and the majority of women were between the ages of 25-34. All had lived with HIV for an average of 5 years. Collectively, their families included 48 children (two of whom are HIV positive), 12 husbands or partners, and 25 other relatives. At the time of the interviews, three were pregnant. Twenty relied on Medicaid or public insurance, three had private insurance or a combination of private and public insurance, and two had no insurance at all. Seventeen were on combination therapy, three were on single protease inhibitors, and four were taking no HIV medication. Twenty-one received medical care from an HIV specialist, while two were treated by a general practitioner, and one did not receive care from a physician.

Limitations

Investigators noted several limitations in conducting the study:

- ◆ Although attempts were made to obtain uniform data to enable comparisons in all sites, in many cases, such data were either unavailable or were dissimilar;
- ◆ The small sample of 24 women in 6 cities (and 2 States) limits the investigator’s ability to observe a diverse population of women in different geographic areas; and
- ◆ This is an exploratory study and findings are not conclusive; additional research is needed to expand on this study and to further clarify women’s needs and experiences in CARE Act-funded programs.

Major Findings

Women in both States faced the challenge of HIV disease while simultaneously serving as their families’ primary caregivers. Amidst the complexity of their daily lives—which were at times marked by discrimination—the majority of women worked to reintroduce a sense of “normalcy” in their lives and the lives of their children. Women shared a sense of purpose with their families that they derived from learning to live with HIV. This spiritual energy helped them take charge of their lives beyond HIV infection.

◆ Women viewed their lives and identities in the context of their relationships to their children, other family members and friends.

Since they provide stability in their homes as primary caregivers, women in the study felt that it was very important to bring a sense of “normalcy” back into the lives of their children and other family members. Although they had their own health problems, they focused most of their energy on their children’s needs, in particular, helping them accept the reality of HIV in their lives. Women saw their children as primary motivators for living and for not wanting to die early. A woman from San Diego said: “I have to take care of myself so I can be around to see her (baby girl) grow and have a normal life, as normal as it can be.” A Dallas woman said: “I kind of set goals for myself. I was very ill last summer. I was in the hospital. I just wanted to be there for my little boy’s first day of kindergarten. The thought of him going to kindergarten with me not being there was devastating. But there I was, and there I was on the last day of kindergarten, too.”

TABLE 1

<p>Women’s Role as Caregiver Primary Aspects</p> <ul style="list-style-type: none"> ◆ Normalcy Women sought to bring stability back into their families’ lives ◆ Children Women spent most of their time getting help for their children and helping them accept the reality of HIV/AIDS as a part of family life Children were their primary reason for living ◆ Self-reliance Women relied on themselves and on their relationships with other women for support and strength
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That kind of goal-setting reflects a self-reliance that characterizes many of the woman interviewed. Women relied on themselves as the primary caregiver for their families and themselves. They also relied on their relationships with other women, including their mothers and friends, for strength and support.

◆ **Disclosing their HIV status is a profound, complicated decision for women, whether they choose to disclose to everyone in their life, to some people or to no one.**

Secrecy and disclosure were major issues for all the women interviewed. Women have difficulty disclosing their HIV status to family members for fear of rejection and out of concern

TABLE 2

Secrecy and Disclosure Primary Concerns
◆ Nuclear Family Women have a difficult time disclosing their HIV status for fear of rejection or burdening their family
◆ Extended Family Women were selective in who they told for fear of discrimination or loss of employment
◆ Community Women in rural areas are especially reluctant to disclose their HIV status

that they might burden their parents or children. Many have experienced discrimination within their families, in the workplace and in accessing medical care. Women were selective in who they told outside of their nuclear family. Women who live in rural areas are especially reluctant to disclose for fear of discrimination and loss of employment. An Austin woman who has not told her family said: "I don't want my family life to change. I love my family dearly and I would hate for them to mistreat me, or to have my nieces or nephews mistreat me because of what my illness is...I really don't think they suspect. I know that they know that I am ill. And they are concerned about me. But they have not gone to that extreme to [ask] say what's really wrong with me. I have decided that if they should ever ask, I will tell, but it's something that I'm not ready for."

A woman in Dallas experienced rejection from her extended family after she shared her status with them: "Yes, things changed. They started giving my husband and I separate dinner plates... Whenever I would lay the baby down in bed, and after I would pick him up, they would right away take the blankets and wash them."

A woman's HIV infection can also impact the lives of her children when word spreads through her community. From a woman in Fresno: "My kids have struggled with a lot of discrimination. Parents not letting the kids come over and spend the night. A lot of really ugly stuff. They've come out stronger now, but it was really hard for them when they were little." Some women have used their HIV status as a way of educating other women and families in their communities, however, women in the sample displayed a wide range of responses and concerns.

TABLE 3

Negotiating Healthcare Ongoing Concerns
◆ Basic Needs Women spend most of their time meeting basic needs, e.g., food, housing, transportation and child care
◆ Access to Care Women have to negotiate care for themselves and other family members, both HIV-infected and affected
◆ Immigration Status Some women (and their spouses) are illegal immigrants which poses a barrier to care
◆ Adherence Treatment adherence is complicated by lack of understanding of the medications and by placing their children's health needs first
◆ Provider Relationships Some women find it difficult to find providers they trust who have good communication skills

◆ **Maintaining access to healthcare for women with HIV who have children requires strong skills negotiating the healthcare delivery system and balancing issues of health and family.**

All of the women interviewed devoted a great deal of time and energy to meeting basic family needs, such as food, housing, transportation, employment, and childcare. Most had to negotiate medical care for themselves and their children, both those who were HIV infected and those who were otherwise affected. For some, providing care for their spouses or themselves was further complicated by illegal immigration status. Women reported having a hard time adhering to medication regimens, either because they did not understand how the medications would help, or because they were simply too occupied with the health needs of their children to properly care for themselves.

Arranging daycare for children—whether HIV infected or not—was a pronounced concern for all the women in the study. A Dallas mother was relieved to have found a respite center to care for her son: "For those first ...3 years where he had a safe place to go, I knew they loved him and nobody was scared of him. They were a godsend to us, they truly were." But more common is the experience of a frustrated woman in Fresno: "There's nothing out there for respite care unless you have a disability, and they don't consider AIDS a disability per se, like not being able to see or hear."

Women relied heavily on case managers, who became their “brokers” for all health-related concerns. At the same time, some women sought help from multiple providers, trying to find one who would spend time with them, explaining medical concerns, and showing that they cared.

◆ **Most women developed a stronger sense of the value of life in the course of accepting their HIV status.**

Many women developed a spiritual identity that was not part of their life before their diagnosis and deepened their appreciation for ordinary events. For many women, spirituality did not take the shape of formal religion, but rather a personal philosophy that gave meaning to their suffering and to all their life experiences.

Women described living with HIV as a journey that helped them develop a philosophy to deal with life and their families. A woman in Austin said, “I’ve learned to love life and . . . to do what makes me happy, what makes me feel good. I pray for all things in people that I can’t change. I spend lots of time with my family. I try to be involved with the things that are important to me, like my children’s education, other people living with the disease. And those things make me feel good. They warm my heart, they give me a sense of purpose. They make me realize why I live.”

Recommendations

The services women identified as being most critical for their children were transportation and day care. The most important service they identified for themselves was help in accessing health care for all members of the family. Women also reported that case managers were the most helpful provider in linking them to medical and psychosocial services.

I. Recognize the importance of case management in providing HIV-positive women with access to primary care.

One of the CARE Act’s major goals is to assure access to coordinated primary care for people with HIV/AIDS. All of the women interviewed describe the case manager as the person responsible for linking them to medical and psychosocial services. The case manager also became a trusted friend for many women who had been rejected by their families or communities.

II. Recognize all dependent family members (regardless of HIV status) as “affected” family members, and encourage providers to recognize childcare as an essential support need.

All of the women interviewed had to negotiate childcare before they could address their own health care needs. The definition of basic needs should include not only food, housing, transportation, and employment, but also childcare. HRSA’s policy of limiting childcare to affected children¹¹ is not in the best interests of parents who are living with HIV and is a barrier to adherence with appointment schedules and medication regimens. Childcare is especially important to parents who are current or former substance users and those who have been incarcerated; for them, obtaining appropriate childcare is critical to maintaining custody of their children.

III. Encourage Title I and II grantees to provide family-centered care for women with HIV in communities that lack Title IV programs.

Women with HIV need help caring for their families, including children who are not HIV infected; without it, they are unable to meet their own medical needs. For many women, the primary motivation for living is caring for their families. CARE Act programs must acknowledge the family as the unit of service, supporting parents with HIV/AIDS in meeting the family’s basic survival needs (e.g., housing, food) as well as their medical and social needs.

The presence of Title IV funding often determines whether services meet the needs of women and their families. Two program characteristics associated with Title IV funding that are especially important for women are: 1) the immediate availability of pediatric services at sites where perinatal services are provided; and 2) “co-location” of pediatric and adult HIV primary care.

IV. Require all CARE Act-funded programs to have a protocol to follow women (particularly those diagnosed during pregnancy) after they receive an HIV diagnosis.

Women need intense followup after they receive an HIV diagnosis. Many women who are their families' primary caregiver do not have time to address their own emotional needs before having to negotiate health care for their children and for themselves. All the women in this study experienced trauma when they learned that they were HIV infected; they reported becoming depressed, suicidal, paralyzed with emotion and, at times, unable to function at all. Many remained depressed until by their own self-reliance they were able to reinstate a sense of normalcy for their children and other family members.

V. Provide training and technical assistance for grantees to help women disclose their HIV-positive status to their families. Require grantees to provide mental health support for women to help incorporate their HIV status into family and social life.

All programs should have a protocol in place to provide intensive case management for women who need to disclose their illness to young children, teenagers, partners, or other family members. Such a protocol should include staff training. As primary care-givers, women may have special difficulty disclosing to family members who are uninformed about HIV, and may need support in preparing for potential rejection by family members they love and depend upon. In addition, clients need help in making decisions about disclosure to employers and in protecting themselves from possible discrimination in such areas as housing and employment.

VI. Provide training and technical assistance to grantees to help women with planning for long-term needs, including returning to work.

Even though many women with HIV/AIDS live in poverty or become impoverished as a result of HIV disease, they have many inner strengths. Many demonstrate great self-reliance in negotiating life, in general, and the health care system, in particular. Any health care assessment must recognize the strengths of women as individuals and as primary caregivers. With antiretroviral therapy extending the lives of people living with HIV, programs must begin to help them integrate back into society. Many participants in this study want to return to work; however, recent restrictions in public benefit programs have left gaps for women with HIV who have dependent children and who want to return to work or who need job training to enable them to enter the workforce.

VII. Require linkages between systems of care that serve women (e.g., prenatal and family planning clinics) and CARE Act programs to ensure that women's care-related needs are addressed.

To serve women with HIV effectively, the CARE Act mission must require all titles to establish strong linkages with other points of entry through which women access care (e.g. prenatal, family planning and substance abuse treatment programs and prison health services). Because these facilities serve as entry points for women's care, they represent valuable linkages for providing HIV-related services and care to women and families affected by HIV/AIDS. If linkages were established, CARE Act funds could support essential outreach and referral services for women in these programs.

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Investigation of the Adequacy of the Community Planning Process to Meet the HIV Care Needs of Active Substance Users

Ruth Finkelstein, Anna Greenberg, Christine Lubinski

Purpose of the Study:

To assess the adequacy of Title I community planning in serving the needs of active substance users with HIV infection and to develop recommendations to more effectively meet their needs using Title I funds.

Background

The HIV/AIDS epidemic has continued to have a dramatic and devastating impact on substance users. Nationally, injection drug use (IDU) and sex with IDUs accounted for over one-third of reported AIDS cases in 1998.¹ In areas hardest hit by the epidemic, IDU-related

transmission accounts for up to 60 percent of reported cases.² With no decrease in incidence in either HIV/AIDS or substance use, these twin epidemics continue to intersect and to disproportionately affect poor communities.^{1,3}

Substance users with HIV/AIDS have multiple care and service needs. They often suffer from other co-morbidities, particularly mental illness, requiring planners to assess various needs across traditionally separate service systems. Aside from the direct treatment of HIV, substance use, and other co-morbid conditions, they have needs similar to other disenfranchised populations, such as housing, entitlements, and employment readiness. Substance users with HIV also face many barriers to care, drug treatment, and related social services. These include lack of trust in the medical system, competing survival priorities, unstable housing, provider bias against drug use, legal barriers to entitlements, lack of insurance, lack of knowledge and ability to navigate the health care system, and fear of disclosure of drug use and HIV status.^{4,8} As a result, many tend to enter the health care system at a later stage of illness than other persons with HIV disease.^{9,10}

Although Medicaid remains the single largest public payer of HIV/AIDS medical services,¹¹ Title I services are intended to provide “emergency relief” to eligible metropolitan areas (EMAs), cities or counties hardest hit by the HIV/AIDS epidemic, by filling gaps in coverage, covering ineligible populations, and funding HIV-related support services. Title I grants are made to develop and improve the continuum of care for uninsured or underinsured people living with HIV and AIDS. In each EMA, service priorities for allocating Title I funds are set by a local HIV Health Services Planning Council. Each Planning Council must determine and prioritize components of appropriate care for specific target populations by considering available data and community input and

Sites Selected

Baltimore ♦ Boston ♦ Detroit
Jersey City ♦ Phoenix ♦ New York City

weighing a broad range of competing issues. Planning for substance users with HIV is complicated by multiple unmet needs and lack of consensus on the best way to access optimal HIV treatment.

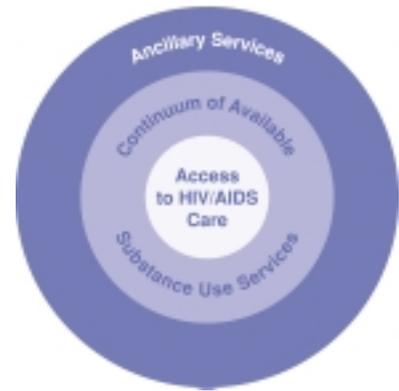
Methodology

The community planning process is a complex dynamic, combining the contributions, expertise, and relationship of local planners and grantees to address: 1) the changing epidemic, as it affects local communities; 2) appropriate standards of care and accessibility of a care continuum for different populations; 3) the adequacy of other funding streams in meeting the needs of people living with HIV/AIDS; and 4) the level of collaboration with other funding sources to effectively serve people living with HIV/AIDS. In undertaking this study, the investigators used a case study approach to reflect these complex and interrelated dynamics, selecting six EMAs to provide a basis of comparison. Their selection was based on variability in terms of: 1) the relationship between the substance abuse and HIV/AIDS epidemics; 2) the adequacy of other funding streams, especially Medicaid, to serve people living with HIV/AIDS; 3) the strength and size of the public substance abuse treatment system; 4) regional diversity; and

5) the length of time the EMA had been receiving Title I dollars. The EMAs included Baltimore, Boston, Detroit, Jersey City, Phoenix, and New York City.

Investigators conceptualized the HIV-related care needs of active users in three concentric circles, with the inner circle ensuring access to HIV/AIDS care, the middle circle representing the continuum of available substance use treatment services, and the outer circle comprised of ancillary services that enhance access to both HIV care and substance use treatment (see figure 1). Planning Councils use different strategies to meet the care needs of active substance users with HIV, depending on how they have defined their needs. One strategy might focus on providing ancillary services to address the barriers to available medical care and substance use treatment, while another might provide funds in different categories by co-locating case management, substance use treatment and medical care. And still another approach might focus on promoting recovery for active users before they receive HIV care.

FIGURE 1
HIV Care Needs of Active Substance Abusers



The data collection methodology had two primary components, including background data and in-person interviews. Before conducting interviews in each site, investigators gathered information on local epidemiology; contributions of various funding streams in meeting the needs of substance users with HIV; the impact of recent changes in welfare, Medicaid, and SSI for substance users within each State; and the planning and prioritization process for each EMA. They reviewed various published and unpublished sources, including primary documents such as the two most recent Title I applications. They also reviewed recent Title II applications; HRSA Annual Administrative Reports; State Medicaid reports, including the Kaiser Report and the National Conference on State Legislatures Report; Kaiser State Profiles on demographics, income, and health needs indicators; Urban Institute State Reports; Drug Abuse Warning Network Data on emergency room admissions; and current welfare laws related to active users. Based on these data, they prepared a preliminary assessment of decision making in each EMA to compare with information they would obtain from local planners.

The researchers then conducted a series of one-on-one interviews and focus groups with key people in each EMA who were directly and indirectly involved with and affected by the planning process. They interviewed 20-30 people in each site, including city/state planners and staff members in HIV/AIDS and substance abuse administrations; Planning Council members, staff and committee members; medical providers serving active users; AIDS service providers; substance abuse treatment providers; and consumers (who were and were not involved with planning). They developed eight interview protocols to reflect the perspectives of different categories of people who were involved with planning. In 1-3 hour semi-structured interviews conducted in each EMA, informants were asked to talk about how substance user's needs were prioritized and addressed in terms of HIV medical care, substance use services, and ancillary services that may enhance clients' ability to access and remain in care.

Limitations

Investigators noted several limitations in conducting the study:

- ◆ Defining the “needs” of active substance users with HIV differs according to planners' perspectives and experiences and there is no consensus on what constitutes optimal care for this population;
- ◆ The data needed to compare actual outcomes of different planning and service delivery strategies (in terms of numbers of clients served, within and across systems of care and their impact on health) do not exist or are unreliable; and
- ◆ The small sample of study sites limited the investigator's ability to observe a full range of patterns in planning for this population, nationally.

Despite these limitations, the extensive data review and case study approach enabled investigators to assess how different Planning Councils identified existing and emerging needs, as well as their process for educating voting members. The qualitative approach enabled investigators to assess people's perception of factors that inform their decision making, resulting in an understanding of the intricacies of planning within each EMA. This ultimately

allowed the investigators to independently assess whether active substance users' obvious needs were being addressed.

Major Findings

Active substance users with HIV have extensive service needs. The investigators conceptualized a continuum of care for active users that includes access to a range of primary care, specialty care, substance abuse treatment, and support needs (see table 1). Despite variability in the local epidemic, CARE Act funding, comprehensiveness of the service delivery system or composition of the Planning Council, each EMA faced similar barriers to meeting these needs.

- ◆ **A majority of Planning Councils studied (four of six) did not engage in a comprehensive needs assessment for active substance users, so they tended to focus on one or two needs, to the exclusion of others. Moreover, a majority (four of six) fund little or no drug treatment.**

Most EMAs focused on only one aspect of care. For example, New York City's Planning Council focused on developing a comprehensive system of harm reduction services, while co-locating social services with primary care, mental health and housing, but has not examined the needs of active users in traditional drug treatment. Detroit, on the other hand, focused on case management needs to the exclusion of all others.

Ambivalence About Funding Drug Treatment

TABLE 1

Continuum of Care for Active Substance Users with HIV/AIDS
<ul style="list-style-type: none">◆ Access to detox on demand◆ Access to a continuum of drug treatment modalities, appropriate for clients in various circumstances◆ Harm reduction and recovery readiness services that link clients with entitlements, basic survival services, and primary care◆ Primary care that supports clients' adherence and maintenance in care◆ Specialty care for HIV, hepatitis C, TB, and mental health needs◆ On-going, intensive social services and case management to support treatment adherence, and maintenance in primary and specialty care◆ Safe housing◆ Employment readiness assistance◆ Access-enhancing services, including transportation, childcare, and escort services

Most Planning Councils studied identified lack of available slots across drug treatment modalities as the single biggest unmet need of active substance users. This need was often expressed by failure to prioritize HIV status within the drug treatment system; lack of HIV knowledge among drug treatment providers; or lack of capacity in specific modalities, such as longer-term treatment, and methadone maintenance. A further complication for planners is that long delays in obtaining substance abuse treatment results in clients dropping out of care.

Planners offer a range of explanations for why drug treatment receives very little Title I funding (see table 2), but part of the problem may also be that prior to the last CARE Act reauthorization in 1996, substance abuse treatment was not specified as a covered service. Moreover, HRSA did little to educate or encourage Planning Councils to consider funding drug treatment.

- ◆ **At least two of six Planning Councils incorrectly interpreted "payer of last resort" to mean that they were restricted to funding non-reimbursable services, which greatly restricts their ability to identify gaps in drug services.**

Variability in interpreting Title I's role as payer of last resort has sometimes resulted in a decision not to fund drug treatment slots. This provision is intended to prevent Title I funds from being used to double bill for a particular visit or to replace an existing funding stream. However, Title I funds can be used to pay for visits that are not currently reimbursed,

modalities within a particular service that are not covered by an existing funding stream, clients who are not covered by other payers, or enhancements to target existing services for specific populations. Unlike substance abuse treatment where investigators noted that Planning Councils consistently failed to address unmet need, planners have opted to increase or develop additional services in some areas already covered by other funders, such as dental care or food banks.

- ◆ **The perception that only HIV-positive clients may be served greatly restricts the ability of Planning Councils to focus on case finding and the needs of those who are receiving care.**

This provision also serves as a barrier to meeting the needs of active users with HIV who have not yet accessed the health care system. Planners report that case finding is almost impossible

to fund since it crosses the boundary into prevention and may involve serving HIV-negative clients. As a result (with the exception of New York City), planners only focus on serving people who receive Title I services. Unfortunately, this means that many people who have difficulty accessing or staying in care will not benefit from Title I services, including those who access care through non-HIV specific services, such as mental health or drug treatment. At a systems level, this approach prevents Title I planners from focusing on the needs of people who are not in care.

TABLE 2

Reasons Why Planning Councils Don't Fund Drug Treatment

Drug treatment is:

- ◆ The responsibility of another funding source
- ◆ Subject to the “payer of last resort” rule so it is ineligible for Title I funds
- ◆ An expensive service, without a guaranteed outcome
- ◆ Like a bottomless pit: once you begin to fund these services, you will expend all available funds
- ◆ Included in other services, such as harm reduction

◆ **Lack of technical rigor in gap analysis, and lack of data sharing between service systems, is a significant barrier to effective planning.**

Planning Councils lack accurate data about services covered by other funding streams, such as Medicaid, which impairs their ability to accurately identify gaps in care. Although this data deficit is not limited to drug treatment services, it directly affects substance users since lack of accurate information precludes effective planning. For example, because drug treatment programs, due to confidentiality restrictions, do not collect or make use of information related to clients’ HIV status, planners are unable to conduct an accurate gap analysis. On a broader level, lack of a uniform data collection system across CARE Act Titles, and other service delivery systems, such as mental health, further impedes accurate planning for clients with multiple needs.

Recommendations

Although these recommendations are based on an examination of the specific needs of active substance users with HIV, they are relevant to improving the effectiveness of planning for other Title I populations.

I. Encourage and, in some cases, require co-location of HIV primary care in drug treatment and social service programs.

Title I planning must include strategies for reaching active substance users with HIV who are not fully accessing the HIV service delivery system. Linkages should be made with programs that serve uninsured and underinsured active substance users with high rates of seroprevalence. Title I funding should support co-located, low threshold primary care services, integrated into these settings to provide a full continuum of care for HIV-positive clients who are not served in HIV clinics.

Suggested Options:

1. Modify reauthorizing legislation to allow case finding and care of high-risk HIV-negative clients under Title I.
2. Allow grantees to fund case finding and co-located primary care in settings with high-risk negative clients, with rigorous justification.
3. Coordinate and integrate funding from the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA) to support local co-located services.
4. Create incentives to coordinate and integrate HRSA, CDC, and SAMHSA funding at State and local levels to implement co-located initiatives.

II. Require demonstrated, reciprocal linkages between HIV primary care, drug treatment, and ancillary services by all contractors serving substance users.

Providers serving substance users with HIV need strong linkages to primary care, drug treatment, and ancillary services to optimize the chance of meeting their needs. Grantees should be responsible for requiring these linkages and monitoring their effectiveness.

Suggested Options:

1. Modify the Title I application guidance to require demonstrated, reciprocal linkages of all contractors serving substance users.
2. Create incentives for localities to require demonstrated linkages in Title I contracts.

III. Require enhanced triage in emergency rooms and other points of entry for active substance users with HIV.

Emergency rooms that serve indigent patients provide an important point of contact with the health care system for many active substance users with HIV who seek acute care, detox, or basic primary care services. However, emergency rooms are often not equipped to triage clients to all appropriate services, including HIV-related care. Title I planning should include strategies to provide case management and referral, detox, drug treatment slots, and other social services to HIV-positive clients seeking care in emergency rooms.

Suggested Options:

1. Create enhanced triage demonstration projects in selected emergency room settings.
2. Modify the Title I Application Guidance to include enhanced triage as an evaluation criteria to respond to the changing epidemic.
3. Create incentives for localities to fund enhanced triage initiatives in emergency rooms.
4. Encourage localities to jointly use HRSA, CDC, and SAMHSA funds to enhance emergency room triage.

IV. Require grantees to guarantee that Planning Councils receive the cooperation of city agencies for more effective planning.

Lack of coordination with other city agencies and providers is often a barrier to effectively planning for active substance users and other populations with HIV. Planning Councils are often unable to obtain adequate data on services provided to target populations from other city agencies. Requiring grantees to ensure that Planning Councils receive cooperation from appropriate city agencies will enhance planning efforts.

Suggested Options:

1. Modify the Title I Application Guidance to require documentation of requests and responses to ensure cooperation.
2. Strengthen the legislatively required role of other city and State agencies on Planning Councils in the reauthorization process.

V. HRSA should require and provide training and technical assistance to ensure effective planning.

Many of the barriers to effective planning for active substance users with HIV are the same as those for all affected populations. Training and technical assistance (TA) on effective planning, provided to all Planning Councils, can help resolve several major planning needs. These activities should include: 1) clarifying Title I's role as the payer of last resort; 2) implementing a curriculum on full spectrum planning for the needs of substance users with HIV, including strategies for tailoring a range of services to meet their needs; 3) providing training and TA on effective gap analysis; and 4) providing assistance in developing and implementing innovative services, such as use of peer support to share effective planning strategies.

Suggested Options:

1. HRSA should significantly modify its major technical assistance contracts.
2. HRSA should require that all Planning Councils receive specific technical assistance in planning and gap analysis (either through the reauthorized legislation, in guidance, or as a condition of grant award for EMAs).

VI. HRSA should take the lead in developing better data systems for more coordinated planning.

Fragmentation of data systems across services within EMAs hinders planning efforts. HRSA can help facilitate informed planning across Titles by: 1) disseminating funding stream information from all Titles to CARE Act grantees (e.g., through the HIV/AIDS Bureau web site); and 2) helping Planning Councils resolve specific barriers, such as confidentiality of HIV status in drug treatment programs, either locally or in collaboration with SAMHSA.

Suggested Options:

1. Create incentives for localities to consolidate client-level data collection across Titles and, if possible, across payers.
2. Require client-level data collection with defined elements in reauthorized legislation.

3. Conduct demonstration projects within localities for consolidated client-level data collection, with a defined timetable for national implementation.
4. Expand the capability of HRSA's technical assistance contractor for developing integrated data systems.

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