

The Impact of HIV Policies and Politics on Communities of Color

M. Keith Rawlings and Deborah Parham Hopson

Medicaid, Medicare, and the Ryan White HIV/AIDS Program are the three primary public payers of HIV/AIDS care in the U.S. today (see Fig. 1). Though far from flawless, they create access to services for scores of underserved minority people living with HIV/AIDS (PLWHA). These programs are key to scaling back the ominous and disproportionate presence of HIV/AIDS among underserved people of color.

In 2005,* this presence was visible in the demographics of PLWHA (see Fig. 2):

- Approximately half of the people who developed HIV/AIDS were blacks[†] and one-fifth were Hispanics.¹
- African American men were nearly eight times more likely to have AIDS than non-Hispanic white men, and Hispanic men were nearly three times more likely to have AIDS than non-Hispanic white men.²
- African American women were nearly 23 times more likely to have AIDS than non-Hispanic white women, and Hispanic women were five times more likely to have AIDS than non-Hispanic white women.³
- American Indian and Alaska Natives were more than twice likely to have AIDS than non-Hispanic whites.²

In addition to disproportionate rates of HIV/AIDS, health disparities and poor access to health care among minorities living with HIV are well documented in the literature.⁴ Public health programs must work with increasing effectiveness to mitigate those problems. This imperative is made more difficult by interrelated problems such as disproportionate rates of poverty; lack of health insurance; and a shortage

* At the time of publication, 2005 was the most recent year for which HIV/AIDS statistics were made available by the Centers for Disease Control and Prevention.

† “Black” is used by the U.S. Census Bureau.

M.K. Rawlings (✉)
Peabody Health Center, AIDS Arms, Inc., Dallas, TX, U.S.
E-mail: Krawlings@aidsarms.org

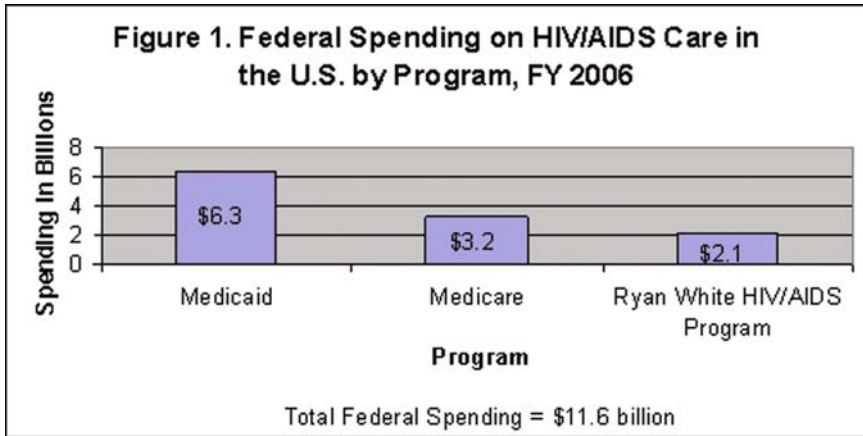


Fig. 1 Federal Spending on HIV/AIDS Care in the U.S. by Program, FY 2006 (Henry J. Kaiser Foundation - KFF)

Race/Ethnicity	Males	Females	Total
White, non-Hispanic	12.1	2.0	6.9
Black, non-Hispanic	95.1	45.5	68.7
Hispanic	36.0	11.2	24.0
Asian/Pacific Islander	7.2	1.6	4.3
American Indian/Alaska Native	14.3	4.4	9.3
Total	24.9	8.6	16.6

Fig. 2 AIDS Rate by Race/Ethnicity and Gender, 2005 (per 100,000 population) (CDC)

of indigenous, high-quality health care providers in many communities of color.⁵⁻¹⁰ Moreover, some communities of color are palpably wary about the “government” aspect of public health care programs and thus hesitate before engaging the health care system. Each of those barriers must be overcome for the promise of Medicaid, Medicare, and the Ryan White HIV/AIDS Program to be realized among PLWHA of color.

The roles of the nation’s public health programs are complementary and critical to addressing HIV/AIDS. The two largest programs in terms of public investment are Medicaid and Medicare, but they leave gaps in coverage in terms of both program eligibility and services covered. The mission of the comparatively small Ryan White HIV/AIDS Program is to fill those gaps, which it currently does for

approximately 531,000 PLWHA per year – between two and three times as many PLWHA as are covered by Medicaid.¹¹

Understanding the relationship among the large federal programs serving underserved PLWHA of color is necessary if our nation is to stem the tide of the HIV/AIDS epidemic among minorities. With that understanding, health disparities among minorities – including the disproportionate impact of HIV/AIDS – can be addressed.

Medicaid

Medicaid is the largest public health care program in the nation and is the largest payer of care for PLWHA by far.¹² At \$6.3 billion, Medicaid accounted for 51% of all federal HIV/AIDS spending in fiscal year 2006, with more than 200,000 PLWHA enrolled in the program.¹³ No other public or private insurance plan or assistance program covers such a comprehensive range of services (see Table 1).¹⁴

Medicaid is a federal–state (and territory) partnership. Each state and territory operates its own Medicaid program. The federal government matches state spending on Medicaid on an unlimited basis. States maintain significant discretion in designing and administering Medicaid programs, but federal law sets minimum eligibility requirements for mandatory populations, including the following:

- All pregnant women, regardless of age or family circumstances, if their incomes are at or below 133% of the federal poverty level (FPL)
- Children under age 6 with family incomes totaling less than 133% of the FPL (\$1,737 per month in 2004 for a family of three) and older children (ages 6–18)

Table 1 Medicaid Summary, 2004, The Henry J. Kaiser Family Foundation (KFF)

Who is eligible	What it covers	Administrator	Total served	PLWHA served
Low-income children and parents, people with disabilities, and seniors (age 65 and older)	Physician and hospital care; laboratory and diagnostic services; nursing home care; and at State option, a comprehensive array of acute care and long-term services (e.g., personal assistance with activities of daily living)	States, subject to oversight by the Centers for Medicare and Medicaid Services	58,420,500	>200,000

Source: The Henry J. Kaiser Family Foundation Total Medicaid enrollment, FY 2004. Available at: www.statehealthfacts.org/comparemaptable.jsp?ind=198&cat=4. Accessed December 14, 2007

with family incomes totaling less than 100% of FPL (\$1,306 per month in 2004 for a family of three)

- Some low-income parents of minors [parents' Medicaid eligibility standard is usually tied to the standard used in a State's Temporary Assistance to Needy Families (TANF) program instead of to the FPL and tends to be considerably lower than the 133% of the FPL used for pregnant women]
- Low-income people with disabilities and the elderly who qualify for the Supplemental Security Income (SSI) program or meet similar state-set income requirements (SSI guarantees benefits only up to 74% of the FPL; approximately 78% of Medicaid beneficiaries with disabilities qualify on the basis of their SSI eligibility); a person is defined as disabled under Social Security when he or she is unable to work because of a medical condition and his or her medical condition is expected to last at least 1 year or to result in death.¹⁵

The eligibility criteria help open doors to health care that might otherwise be closed for many minority PLWHA. States can go beyond these federal minimum eligibility standards to ensure even greater access to care. For example, many states choose to extend Medicaid to people with disabilities who have income up to 100% of FPL instead of up to the federal threshold of 74%.

Of the more than 200,000 PLWHA with Medicaid insurance in the U.S. today, most qualify on the basis of disability and eligibility for SSI benefits. A second major eligibility pathway for PLWHA is "optional coverage for the medically needy," offered by 36 states and the District of Columbia. This coverage permits people in a Medicaid eligibility category with income above the income standard to qualify if medical expenses subtracted from income leave a dollar amount below the state-established medically needy limit. In some cases, people must spend down to very low income levels to qualify as medically needy. In one study, the median medically needy income limit was 55% of the FPL.¹⁶

Medicaid: Reaching PLWHA of Color

Medicaid has provided access to services for tens of thousands of PLWHA of color. Several components of the program ensure its relevance to eligible PLWHA.

Guaranteed coverage. Unlike the Ryan White HIV/AIDS Program, Medicaid is an entitlement program with defined sets of benefits. All people who meet the program eligibility requirements have an enforceable right to enroll in Medicaid and to receive services on a timely basis. Eligible people cannot be denied Medicaid.

Mandatory services. Just as federal law requires that Medicaid cover specific populations, it also stipulates mandatory services that states must cover. Mandatory services include core services such as ambulatory and inpatient care, laboratory services, and nursing home care. States can also offer additional "optional services" to meet the needs of the Medicaid population. Optional services include prescription drug coverage (which is currently provided by all Medicaid programs), physical and occupational therapy, personal care, and rehabilitation services.

Obligatory coverage of children. Minorities account for the vast majority of AIDS cases diagnosed among people under 19 years of age in the U.S.^{17,18} For example, among reported AIDS diagnoses in 2005, only 17% of adolescents 13–19 years of age were black, yet they accounted for 69% of reported HIV/AIDS cases.¹⁹ In the same year, 86% of babies born with HIV/AIDS in 2005 belonged to minority groups.²⁰ All children who are U.S. citizens with family incomes below the poverty level are eligible for Medicaid. Medicaid's Early and Periodic, Screening, Diagnosis, and Treatment (EPSDT) benefit guarantees coverage for beneficiaries under age 21 for all mandatory and optional Medicaid services when medically necessary. People in this group cannot be denied a Medicaid-covered service because a state has chosen not to provide it to adults. Additionally, people in this group are not subject to coverage limits that may apply to adults.

Safeguards against discrimination and long waiting periods. Federal law extends several consumer protections to Medicaid beneficiaries. Services must be provided statewide; benefits must be comparable among different groups of Medicaid beneficiaries, and benefits must be adequate in amount, duration, and scope to reasonably achieve their purpose. Medicaid must also provide benefits with reasonable promptness. States cannot determine that a beneficiary needs a service and then impose a waiting period.

Beneficiaries cannot be denied service because of an inability to pay. States can impose cost sharing for Medicaid coverage for people with incomes below the FPL, though cost is typically less than \$3 per service unit. States with cost-sharing provisions must ensure that beneficiaries living below the FPL are not denied care because of an inability to pay. If coverage for a prescription drug is in doubt, pharmacists are required by law to dispense a temporary supply in emergency situations (i.e., where drugs are necessary to prevent death or serious harm to health) in which payment authorization is initially denied. Medicare, on the other hand, does not have such a requirement.²¹

Medicaid: Recognizing the Shortcomings

Although Medicaid creates access to care for eligible PLWHA, it is not without its flaws and can, in some circumstances, limit coverage to those in need. Such limitations create the need for other public interventions, such as the Ryan White HIV/AIDS Program and Medicare. They also illuminate why Medicaid works for some minority PLWHA but for not all.

Onerous application process. Applying for Medicaid can prove problematic. In some states, the application itself can be around 20 pages in length – not a trivial issue for minority PLWHA with low literacy and daily functioning levels.^{22,23} Applicants must provide detailed financial documentation to prove that their income and resources (e.g., savings) are below Medicaid limits. This requirement seems straightforward, but it poses difficulties for people who have never had a bank account or a steady job. In addition, a citizenship documentation requirement

established by the 2005 Deficit Reduction Act can create unintended difficulties for U.S. citizens who do not have a passport or a birth certificate to prove their citizenship.

Restrictive and inadequate definition of disability. Several features of Medicaid's disability requirement can penalize PLWHA. Most PLWHA become eligible for Medicaid because they have been determined "disabled" and meet SSI income standards. Currently, PLWHA who do not have an AIDS diagnosis cannot be determined disabled. Moreover, people deemed disabled must be unable to engage in any "substantial gainful activity" as a result of a medically determinable impairment that has lasted or is expected to last for a period of at least 12 months or to result in death.²⁷

Not all physical and mental impairments are considered to be markers of disability. For example, drug addiction and alcoholism are specifically excluded as primary disabling conditions, even if they prevent a person from working.²⁴ Because those conditions are linked with higher rates of HIV in communities of color, such restrictions may limit access to Medicaid insurance for minority PLWHA.

Low provider reimbursement rates. States have considerable latitude in establishing service reimbursement rates. States can make service provision to Medicaid-insured minority PLWHA unaffordable when reimbursement rates are inadequate for covering provider costs. Low reimbursement rates for HIV specialists and dental and mental health care providers have been persistent problems in some States.

Limited autonomy in choosing a care provider. Many Medicaid programs have moved or are moving to managed care arrangements for beneficiaries. Managed care typically requires beneficiaries to enroll with a specific primary care provider who, by contract with the Medicaid agency, accepts certain responsibilities for providing and authorizing needed medical care. Providers who are not in the managed care network or who are not referred by the primary care provider in a Primary Care Case Management (PCCM) system may not be able to be reimbursed for services provided to Medicaid beneficiaries.²⁵ Thus, Medicaid-managed care programs can limit the access of a person living with HIV/AIDS to his or her provider of choice.

The requirements are not aligned with the nature of HIV/AIDS in the age of highly active antiretroviral therapy or with the need for Medicaid coverage among PLWHA of color in whom HIV disease may not yet have progressed to AIDS. The requirements do not take into consideration that someone who is disabled today may not be disabled tomorrow, thanks to effective treatment tools like highly active antiretroviral therapy (HAART), and they penalize those who are capable of maintaining employment but who, nevertheless, struggle with the costs of treatment.

Because eligibility for Medicaid and Medicare on the basis of disability cannot be established without an AIDS diagnosis, many PLWHA are left without insurance. This lack of coverage works as a disincentive to stay in care and promotes the use of emergency rooms for ambulatory medical care. The result is more opportunistic infections, accelerated disease progression, and higher rates of comorbidity and mortality among the uninsured.

Policy makers are considering proposed legislation to permit states to extend Medicaid to a new optional population: predisabled people living with HIV.²⁶ At the

present time, only a small number of states cover predisabled people with HIV through waiver programs.

Medicare

Medicaid is largely a program serving groups of low-income people (i.e., poor children, parents, seniors, and people with disabilities), whereas Medicare is a health insurance program for workers who pay into Social Security and their spouses and dependents. People pay to the Medicare system throughout their work lives. They become eligible for Medicare coverage

- Once they reach age 65 or
- If they are under age 65, once they have been determined to have a disability and have satisfied the Medicare waiting period [no waiting period exists for people with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease]

Medicare currently covers 41 million people, approximately 35 million of whom are over 65 years of age.²⁷ At least one-third of Medicare beneficiaries of all ages have disabilities or a long-term illness such as HIV/AIDS that limits their independence.

Medicare is the nation's second largest source of financing for HIV/AIDS health care services; it accounts for approximately one-fourth of federal spending on HIV/AIDS care in the U.S.²⁸ An estimated 100,000 PLWHA currently receive Medicare benefits.²⁸ Most PLWHA who receive Medicare benefits are under age 65 and qualify as a result of their disability status.²⁹

Medicare helps pay for a broad array of services that are relevant to the care and treatment of HIV/AIDS (see Table 2). Medicare's coverage of long-term care is limited to postacute care through its skilled nursing facility benefit and home health care benefit.

Medicare: Benefits for PLWHA of Color

Wide choice of providers. The Medicare program generally offers higher reimbursement rates to providers than Medicaid does, which makes Medicare more attractive to providers. The result is greater choice for minority PLWHA who often live in underserved communities of color where medical care may be scarce.

Access to prescription drugs. The Medicare Prescription Drug, Improvement, and Modernization Act (Part D) of 2003 created a right for Medicare beneficiaries to purchase prescription drug coverage and established subsidies for low-income people. Part D gives prescription drug coverage to roughly 42 million Medicare beneficiaries, including an estimated 100,000 PLWHA who are receiving Medicare benefits.³⁰ Under the Part D program, Medicare beneficiaries choose coverage to purchase from a selection of competing private plans.³⁰

Table 2 Medicare Summary, 2005, The Henry J. Kaiser Family Foundations (KFF)

Who is eligible	What it covers	Administrator	Total served	PLWHA served
<ul style="list-style-type: none"> • People age 65 and older • Workers, spouses, and adult dependents under age 65 who have disabilities • People with end-stage renal disease (i.e., permanent kidney failure requiring dialysis or a transplant) 	<p>Broad array of routine, acute, and preventive care services, including:</p> <ul style="list-style-type: none"> • Physician services • Hospital services • Rehabilitation and home health services • Medical equipment essential to the health and independence of beneficiaries 	<p>Centers for Medicare and Medicaid Services</p>	<p>Total of 41 million are served:</p> <ul style="list-style-type: none"> • 35 million age 65 or older • 6 million under age 65 with physical or mental disabilities that will prevent work for at least a year or that are expected to result in death 	<p>100,000</p>

Source: The Henry J. Kaiser Family Foundation Navigating Medicare and Medicaid, 2005: resource guide for people with disabilities, their families, and their advocates. 2005; February. Available at www.kff.org. Accessed January 2, 2008

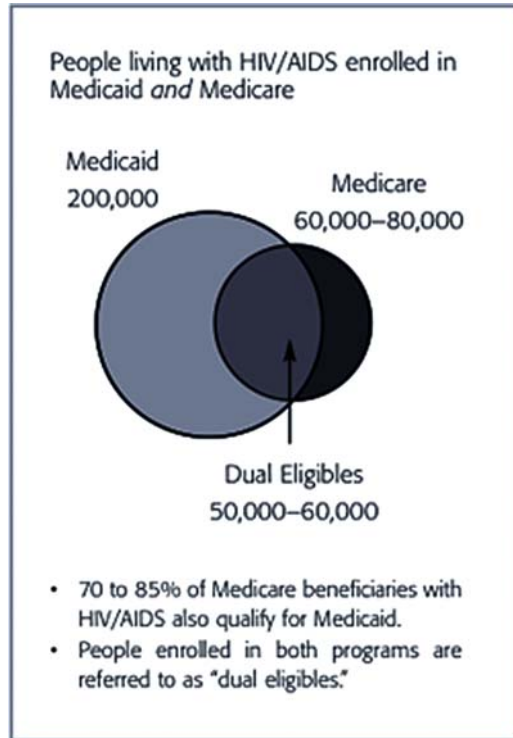


Fig. 3 People Living With HIV/AIDS Enrolled in Medicaid and Medicare (HRSA)

Because PLWHA are disproportionately poor compared with other Medicare beneficiaries, the majority of Medicare beneficiaries with HIV/AIDS are “dual eligibles” (i.e., eligible for both Medicare and Medicaid) who received comprehensive drug coverage through Medicaid prior to the establishment of the Medicare Part D program (see Fig. 3). Most of those beneficiaries have comparable drug coverage to Medicaid, but in some cases, plan variations and other benefit features have created new gaps in drug coverage.

Although the Part D program may have taken some fiscal pressure off Medicaid programs, high-cost sharing has created new pressures for AIDS drug assistance programs (ADAPs) that have stepped in to protect against gaps in coverage for Medicare beneficiaries with HIV/AIDS. This problem particularly affects low-income PLWHA whose incomes are too high to qualify for the low-income subsidy that provides assistance in paying the Part D premium and cost sharing (available to beneficiaries who qualify based on low incomes capped at 150% of the FPL).³¹

Medicare drug coverage may provide advantages over ADAP for PLWHA of color. Medicare covers many non-AIDS-related treatments that are not covered in many State ADAP formularies. Moreover, because Medicare is an entitlement, those who are enrolled in Part D are guaranteed coverage. State ADAPs can run out of

funds entirely, which forces them to create waiting lists for enrollment. Although ADAPs have generally been successful at avoiding total depletion of funds, they have been compelled to limit drug formularies.

Medicare: Problems for PLWHA of Color

Despite Medicare's role as an insurer for many Americans, Medicare policy can create significant eligibility and financial burdens for people of color. This burden arises from the time lapse between determination of a disability and start of Medicare coverage. Additionally, the cost-sharing structure for Medicare benefits is better suited to seniors with higher incomes than most nonelderly people who depend on income assistance from the Social Security Disability Insurance (SSDI) program.

Lengthy enrollment process. Once someone is determined by Social Security to have a disability, workers (or spouses and some adult dependents) apply for SSDI. SSDI provides income assistance to people with a permanent disability, and benefits begin 5 months after Social Security makes a disability determination. Once nonelderly people with disabilities start receiving SSDI, an additional 24-month waiting period exists before Medicare coverage begins.³² The result is a wait of at least 29 months before beneficiaries can receive benefits through Medicare – a significant gap in coverage. The lowest income people with disabilities can receive Medicaid, which begins right after a disability determination, but many low-income people are “too rich” for Medicaid coverage.

Level of benefits reflects income history rather than current need. SSDI benefits are directly related to the amount of Social Security paid in by the beneficiary, which, in turn, is directly related to income earned. In 2006, the median income for a white, non-Hispanic household was \$52,423 compared with \$31,969 for a black household and \$37,781 for a Hispanic household. People of color are often able to contribute less to Social Security and, thus, receive less SSDI when they need it.³³

Discourages employment and autonomy. For people under age 65, the Medicare program has historically discouraged or prevented people from working while receiving benefits. In an effort to allow more people to work while receiving Medicare, Congress added several work incentives to the Social Security Act. Now, beneficiaries can receive education, training, and rehabilitation to start a new line of work and keep some or all SSDI or SSI cash benefits, Medicaid coverage, and Medicare coverage while working.

Drug coverage is out of reach for many. Medicare beneficiaries are not guaranteed drug coverage, although the Modernization Act (Part D) has made such coverage available to more beneficiaries. Some beneficiaries, particularly those who are eligible for the Extra Help program, whose resources are less than \$11,710 (single) or \$23,410 (married) will have minimal costs; others may face significant out-of-pocket expenses. About 30,000 Medicare beneficiaries with HIV/AIDS are not dually eligible for Medicaid and Medicare. Many of those people are believed to face gaps in their prescription drug coverage, sometimes including barriers to

accessing antiretroviral therapy. People without drug coverage are more likely to have lower incomes than those who have coverage. Disturbingly, people most likely to need such coverage because of poor health – like PLWHA and people of color – are no more likely to have drug coverage than those with better health.³⁴ PLWHA who lack Medicare prescription drug coverage often use ADAPs as their primary source for HIV medications.²¹

The Henry J. Kaiser Family Foundation estimates that between 12 and 13% of the hundreds of thousands of PLWHA who are in care are dually enrolled in both Medicare and Medicaid.²⁹ This group consists of people with disabilities who qualify for Medicare and who, on the basis of their very low incomes, also qualify for Medicaid. Medicaid can supplement gaps left by Medicare coverage, although it cannot pay for prescription drugs that are covered by Medicare.

Ryan White HIV/AIDS Program

The Ryan White HIV/AIDS Program fills gaps in coverage left by Medicaid, Medicare, other insurance programs, and the person’s ability to pay. The program is the “payer of last resort” for underserved PLWHA; program funds may not be used to replace other funds.³⁵ The Ryan White HIV/AIDS Program reaches approximately 531,000 PLWHA and family members per year (see Table 3).

- Of those 75% are from communities of color (52% black, 23% Hispanic).³⁶
- 71% of HIV-positive clients and 81% of HIV-affected clients had incomes at or below the FPL in 2004.³⁶

Unlike the typical insurance program, the Ryan White HIV/AIDS Program does not distribute funds or insurance cards to HIV-positive consumers. Instead, funds are awarded to providers across the country (approximately 2,300 in 2007) that deliver services to underserved people for whom no other payer exists.

The Ryan White HIV/AIDS Program offers an even greater level of state and local autonomy than Medicaid. This autonomy allows jurisdictions to build

Table 3 Ryan White HIV/AIDS Program Summary, HRSA (HRSA)

Who is eligible	What it covers	Administrator	PLWHA served
Low-income, uninsured, and underinsured men, women, children, and youth with no other way to meet their needs for; medical care and support	Wide array of outpatient medical care services, medications, and essential support services that help bring people into care and keep them in care	Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB)	531,000

Source: HRSA. About the Ryan White HIV/AIDS Program. Available at: www.hab.hrsa.gov/aboutus.htm. Accessed December 13, 2007

programs that address the manifestations of the epidemic that are unique to their specific communities and that reflect the different cultures and populations served.

The Ryan White HIV/AIDS Program: Doing What Others Cannot

The Ryan White HIV/AIDS Program exists to fill the many gaps in service for PLWHA. Ryan White funding is always finite because it is a line-item appropriation rather than an entitlement; therefore, it is essential that all PLWHA who are eligible for Medicaid or Medicare obtain all possible benefits from those programs first.

Ryan White provides health services to both uninsured PLWHA as well as to the underinsured, that is, people who may have some coverage but whose coverage is inadequate for meeting essential needs.

Reaches beyond an AIDS diagnosis. Medicaid and Medicare generally restrict eligibility to PLWHA whose disease has progressed to AIDS; the Ryan White HIV/AIDS Program does not, thus it is the only major safety net for uninsured people living with HIV whose illness has not progressed to AIDS. This difference means that the demographic profile of Ryan White HIV/AIDS Program clients more closely mirrors recent infection patterns than does the demographic profile of Medicaid and Medicare beneficiaries with HIV/AIDS. Therefore, the Ryan White HIV/AIDS Program is particularly important to providing health care services to people of color.

A commitment to reflectiveness and cultural competency. The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) administers the Ryan White HIV/AIDS Program. HRSA has ensured that the composition of the program staff reflects the epidemic demographically in terms of age, gender, and race. This composition helps HRSA bring a sense of cultural understanding to policies and programs that address HIV/AIDS among minorities.

HIV/AIDS-funded grantees and providers are required to demonstrate cultural competency. They must also demonstrate that they know where the greatest need in their community lies and that they have a plan for reaching that part of the community. For many grantees, the greatest need lies in communities of color. The funding requirements ensure that organizations are better attuned to the needs of minority PLWHA and develop programs that reduce barriers to access and disparities in health outcomes.

Community and consumer involvement. Community involvement in the service planning and delivery process is a cornerstone of the Ryan White HIV/AIDS Program, particularly of the program's two largest initiatives: Part A, Grants for Eligible Metropolitan Areas and Part B, Grants for States and Territories. Community members ranging from activists to health care providers and from health departments to community-based organizations are actively involved in planning and delivering HIV/AIDS services. This component of the Ryan White HIV/AIDS Program helps to ensure that local Ryan White investment is made where it is most needed. By giving states and metropolitan regions a measure of autonomy, the Ryan White

HIV/AIDS Program develops relevant services for a wide range of settings in a variety of communities.

PLWHAs are also involved in the planning and delivery of services under the Ryan White HIV/AIDS Program. This involvement predates passage of the first Ryan White Comprehensive AIDS Resources Emergency Act (CARE Act) in 1990. Consumers were actively involved in lobbying for a program that reflected the real needs of PLWHA. Over the past 17 years, they have been involved in administering the program at every level.

The legislation did not leave consumer involvement to chance. For example, Part A requires each grantee to have a planning body, and PLWHA must compose at least 33% of that body. Other grant programs have urged, and in some cases required, the creation of consumer advisory boards. Consumers have also worked in a variety of professional capacities, from clinician to case manager, within HIV/AIDS service organizations. As a group, they reflect the local population of underserved communities. Consumer involvement helps align community plans and services with the daily reality confronted by local, underserved, minority PLWHA.

Clinical and technical training. The Ryan White HIV/AIDS Program supports grantees and providers through training. Initiatives such as the AIDS Education and Training Centers (AETCs), which includes a National Minority AETC, build capacity among minority health care professionals and organizations serving communities of color. Such services improve the ability of local organizations to serve minority PLWHA, as do capacity-building and planning grants targeted to underserved communities.

Funds are targeted to areas with greatest need. Several features of the Ryan White HIV/AIDS Program ensure that funds are awarded on the basis of current unmet need. Funds can be redirected as the epidemic evolves from year to year. Because of this flexibility, federal grants were awarded to organizations serving communities of color when the epidemic began spreading rapidly among minorities.

Particularly in the Part A and Part B programs, grantees also have the ability to redirect funds to serve areas where needs have emerged in their jurisdictions. Thus, in communities where need is most significant among white men who have sex with men, grantees may target funds to serve that population. Likewise, if need is greatest among minority heterosexual men, grantees may use funds to meet the needs of that population. If unmet need exists in several subpopulations, as is typically the case, flexibility within the Ryan White HIV/AIDS Program allows and, indeed, mandates that funds be used to meet the needs of all.

The Ryan White HIV/AIDS Program has targeted the needs of minorities from the federal level. Since 1998, the Minority AIDS Initiative (MAI) has provided specific resources to increase the availability of services and access to care for minority PLWHA. The MAI was codified into law by Congress in 2007 as part of the reauthorization of the Ryan White HIV/AIDS Program in the Ryan White HIV/AIDS Treatment Modernization Act. Throughout the history of the Ryan White HIV/AIDS Program, a number of special initiatives have also helped to improve access to care for minorities. Examples are the Part D African American Children's Initiative and the Special Projects of National Significance that address HIV/AIDS along the

U.S.–Mexico Border, among young MSM of color, and among American Indians and Alaska Natives.^{2,37}

Ryan White: The Other Side

The extraordinary success with which the Ryan White HIV/AIDS Program has adapted and grown to meet the needs of minorities raises an important question: Do Medicaid, Medicare, and the Ryan White HIV/AIDS Program collectively provide a sound safety net for all PLWHA of color? The answer, unfortunately, is no.

Ryan White funds are limited. Ryan White HIV/AIDS Program spending is a “discretionary” item in each fiscal year’s federal budget. Funding levels often do not – and have not in the past – equal the level of need among underserved PLWHA. Moreover, because Ryan White is not an entitlement, eligible people are not guaranteed access to Ryan White-funded services. When an organization’s Ryan White funds have been exhausted, few options exist besides providing uncompensated care.

Unintended impact on personal choice. Ryan White funds are awarded to organizations rather than to individuals. Given the limited nature of Ryan White funds, typically only a few organizations within a region receive funding. In some suburban, exurban, and rural areas, only one organization may be funded – or none at all. This limitation restricts access to care through logistical and transportation barriers as well as through barriers associated with cultural competency.

Technical requirements may favor heavily resourced organizations. The technical process surrounding application for a Ryan White HIV/AIDS Program grant can favor large, heavily resourced organizations. Grant writing and proposal preparation require a high level of technical knowledge, business acumen, and writing expertise, and award conditions carry significant administrative requirements related to issues such as quality management. Such demands can put small, cash-strapped organizations that serve minorities at a disadvantage when competing with larger entities for funds.

Needle Exchange

HIV and Injected Drug Use in Communities of Color

Since the beginning of the epidemic, injected drug use (IDU) has directly or indirectly accounted for one-third of the AIDS cases in this country.³⁸ In 2005, injected drugs use accounted for 14% of all new HIV infections.³⁹ Of the cumulative AIDS cases diagnosed through 2005 attributed to injected drug use, over 50% of the cases were black, non-Hispanic and 26% Hispanic compared with 20% white,

non-Hispanic individuals. These statistics confirm IDU as an ongoing significant factor in the spread of HIV in communities of color.

The high association of HIV transmission with injected drugs led activists and clinicians to seek interventions to reduce risk. One such intervention is needle exchange programs (NEPs). Formal needle exchange programs date back to the early 1980s in Amsterdam when the first program was formed in response to a concern for a Hepatitis C virus (HCV) outbreak among injected drug users. The first NEPs specifically directed toward the prevention of HIV began in Britain soon after and other European countries developed their own NEPs. After learning about the success of European needle exchange programs, similar programs, both legal and illegal, began to form around the U.S.

Most NEPs are based on the principles of harm reduction. The premise of harm reduction theory is to reduce negative consequences of individual behaviors by leading one to safer behavior that will ultimately lead to abstinence of such behavior.⁴⁰ Thus with IDU, the harm reduction philosophy behind NEPs provides not only direct benefits but also indirect benefits. Although the initial focus of NEPs is to exchange clean needles and/or syringes for used ones, the intention of many programs is to provide a linkage point for IDUs to access drug rehabilitation and treatment services. Several studies have shown that needle exchange programs significantly decrease the transmission of HIV.⁴¹

Ban on Federal Funding for Needle Exchange Programs

Despite the supporting evidence of NEPs as an effective prevention tool, the use of federal funding for needle exchange programs has been banned by Congress since 1988. The rationale for this ban is tied to the notion that governmental support of such programs would directly conflict the government's stance on the war on drugs. Some have suggested that injected drug use and crime would increase. Despite the evidence that needle exchange programs are effective in combating the spread of the virus, the federal ban on needle exchange continues to stand. Various medical organizations including the American Medical Association and World Health Organization along with civil rights groups such as the National Association for the Advancement of Colored People and the National Urban League have identified needle exchange as an effective prevention method for combating HIV.

Over 200 needle exchange programs exist in over 36 states, including the District of Columbia, but each program has its own distinct funding source. These differences in funding policies and regulations impact the effect these programs have against transmission of the infection.⁴² With the lack of a national policy on such programs and the continued federal ban on funding of NEPs, the virus will continue to spread not only among IDUs, but to their families and the broader community. Because of the fact that racial and ethnic minorities compose a large percentage of IDUs (or are indirectly affected by IDU) and access to care is low among this population, NEPs appear to provide a crucial linkage point to medical services. The

policy of banning funding for needle exchange programs needs to be reevaluated in the context of current demographic shifts in order to address the racial disparities in HIV transmission.

Implications of New CDC Testing Recommendations

Description of CDC Testing Recommendations

Currently, approximately 25% of the estimated 1,039,000–1,185,000 persons in the U.S. living with HIV are undiagnosed and 40% of those newly diagnosed develop AIDS within 1 year of diagnosis.⁴³ In response to these statistics, in 2003, the Center for Disease Control (CDC) launched the *Advancing HIV Prevention Initiative* to “reduce barriers to early diagnosis of HIV infection and increase access to quality medical care, treatment, and ongoing prevention services for HIV-positive persons and their partners.”⁴⁴ The findings from this initiative revealed that testing of high-risk individuals in acute care settings, such as emergency department, remained low.⁴⁵

Previous CDC guidelines have recommended routine HIV testing for inpatients and outpatients in acute-care hospital settings.⁴⁶ The 2001 guidelines were amended to add routine testing in health care settings with $\geq 1\%$ HIV prevalence and recommended targeted testing based on risk factors in health care settings with lower HIV prevalence rates, and routine testing for all persons seeking treatment for sexually transmitted diseases.⁴⁷

In September 2006, the CDC released its Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings to provide for health care settings to incorporate HIV testing into normal medical care.⁶ The four points of the recommendations are to advocate for voluntary “opt-out” screening in health care settings rather than “op-in” screening, no requirement for a separate written consent for HIV testing, annual retesting for high-risk individuals, and rescreening of pregnant women in their third trimester.⁶ Overall, the new testing policy has been received with much agreement and enthusiasm by the medical community especially with respect to increasing the testing capabilities. Despite the wide acceptance, some patient advocacy and social justice organizations have expressed concern over the informed consent process and lack of counseling involved with testing.⁴⁸

How the New Recommendations Affect Communities of Color

With the removal of barriers from previous recommendations, the new guidelines are designed to increase efforts to diagnose those with HIV and link infected patients

into care. Although the CDC's revised recommendations increase testing access to minorities that utilize the health care system, there still exists a marginalized and hard to reach population that does not utilize the healthcare system.⁴⁹ This marginalized population is largely composed of racial and ethnic minorities, substance users, and the poor where the epidemic is rapidly spreading.¹⁰ Grass roots organizations and community-based outreach programs that directly target this group are effective forces in reaching this group.

Provider Training and Access to Care

Healthcare disparities continue to exist within communities of color.⁵⁰ The disparities are more profound in HIV care. Many factors contribute to these disparities and lead to differences in the provision of care and treatment.

A significant portion of blacks and Hispanics present to care at a later stage than their white counterparts.⁵¹ Once these patients receive care, their receipt of antiretroviral therapy and other therapeutic drugs is less likely than other HIV patients, which reveals differences in quality of care.

As noted in the previous section on Medicaid and Medicare, health insurance status is a significant factor in the access to care for communities of color. Black and Hispanic HIV/AIDS infected patients are more likely to have Medicaid or be uninsured than white HIV/AIDS infected patients.⁵² Although insurance status is critical, the Institute of Medicine report indicated that regardless of insurance coverage, racial and ethnic minorities with HIV had worse access to care than whites.⁵³ This leads to the conclusion that access to adequate providers with HIV-related experience is a serious consideration in access to care for minority HIV patients.

Demographic data shows that the HIV epidemic is spreading rapidly in communities in the Southern part of the country where 55% of the black population and 33% of Hispanic population are located.^{54,55} Unfortunately, the majority of providers with HIV experience are not located in those geographic areas.⁵⁶ Not only is the geographic distribution of medical providers that care for HIV/AIDS patients not consistent with the distribution of new cases of HIV, but there are few medical personnel who reflect the same racial and ethnic background as the groups most affected by the epidemic. Racial concordance is cited as another critical indicator of improved access and quality to HIV care.¹²

Additionally, there is no clear agreement in the medical community of the types of providers and training suited to care for HIV-infected patients.⁵⁷ This lack of consensus creates an additional barrier to comprehensive care and has a deleterious impact on communities of color.

Discussion

Medicaid, Medicare, and the Ryan White HIV/AIDS Program play important roles in extending health care to minority PLWHA. Without those programs, many PLWHA who receive ambulatory care today would be forced out of outpatient care and back into emergency rooms. AIDS morbidity and mortality would increase, as would the suffering of PLWHA and their families.

Despite the benefits, the shortcomings of the three largest public payers of HIV/AIDS care must be addressed. The patchwork system of public health coverage in the U.S. currently leaves many PLWHA of color – and many Americans – uncovered.

Significant barriers to enrollment and care in these programs exist for PLWHA of color. Many people who meet Medicaid and Medicare enrollment requirements and who are eligible for Ryan White HIV/AIDS Program services are unaware that they are eligible for support. Moreover, navigating the technical attributes of the programs can be daunting, even for health care professionals, and can prove insurmountable for many eligible people.

Like most insurance programs in the U.S., whether public or private, Medicaid, Medicare, and the Ryan White HIV/AIDS Program lack adequate preventive care components. The Ryan White HIV/AIDS Program was developed for people already living with an HIV/AIDS diagnosis; however, Medicaid and Medicare were not. Many eligible PLWHA of color become enrolled in Medicaid and Medicare only after they have tested positive for HIV and are provided enrollment assistance by a Ryan White-supported case manager or entitlements counselor. Ultimately, the costs to people of color are paid in wholly unnecessary and preventable morbidity for a host of acute and chronic conditions.

Potentially hundreds of thousands of PLWHA in the U.S. are not in care, and Medicaid and Medicare do not generally cover the kinds of outreach programs that could help reach those people. The Ryan White HIV/AIDS Program does outreach to a diminishing extent given its increased focus on medical care and reduced spending on support services such as outreach. Current federal policy tasks the Centers for Disease Control and Prevention's HIV prevention programs with reaching PLWHA who are not in care.

The discussion of federal health policy that more adequately responds to the needs of PLWHA of color is taking place in the context of a national conversation about how to improve health care for all Americans. Given the technical and political issues at stake, it is not likely that this conversation will be brief or that the barriers to care for those not receiving it will be resolved in the near term. Thus, everyone concerned with serving PLWHA of color must understand how the principal programs in place today – Medicaid, Medicare, and the Ryan White HIV/AIDS Program – work independently and together to improve access to care for underserved people. Because only with this understanding can improve the health and lives of underserved people and to stem the tide of HIV/AIDS among communities of color.

A national policy addressing the access to care and training issue is critical to combating the spread of this infection and is sorely needed. There is a high probability that the new testing guidelines will identify more people who are HIV infected. However, like the current demographic of recently diagnosed individuals, they will be poor, minority, and live in the southern U.S. This population will greatly strain existing resources particularly in the public sector. National policies that address the geographic maldistribution of providers provide incentives for clinicians to enter (and remain) in HIV care, and standardized HIV training at the pre and postgraduate level is needed. Failure to do so will most assuredly lead to an exacerbation of the current disproportionate impact of HIV on communities of color.

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