HIV/AIDS in Rural America: Prevalence and Service Availability





At the Heart of Health Policy

HIV/AIDS in Rural America: Prevalence and Service Availability

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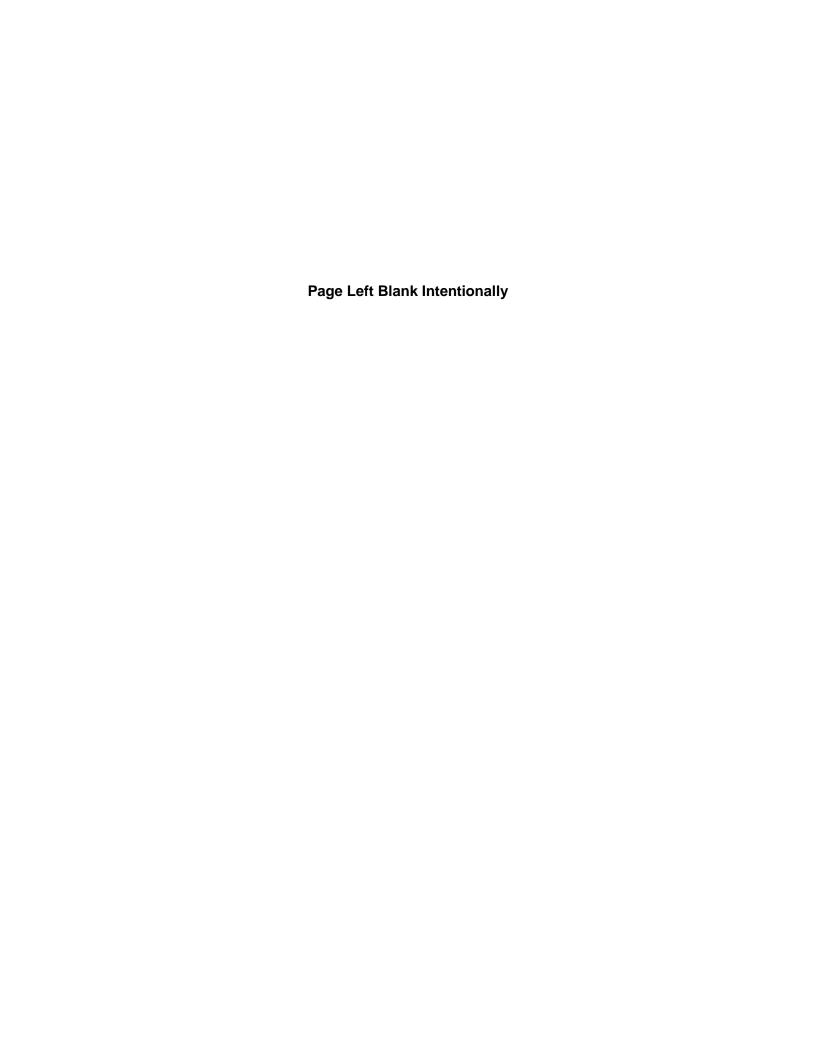
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Executive Summary

With the availability of effective anti-retroviral therapies, Human Immunodeficiency Virus (HIV) disease has become a chronic disease. For the estimated 1.2 million Americans living with HIV/AIDS, adherence to regular medical care, in addition to medications, is crucial to HIV management and overall health maintenance. Many persons living with HIV/AIDS (PLWHA) face challenges in accessing needed health care. Lack of providers who accept and treat PLWHA is one important contributor to inconsistent utilization of health care services among PLWHA. Ryan White medical providers are the safety-net providers who offer primary care and referral services to PLWHA irrespective of their insurance status or ability to pay.

The report that follows addresses rural PLWHA, a population that has received little attention. First, the report examines the prevalence of HIV/AIDS in rural counties across 28 states in 2008. Only 28 states published county-level data and could be included in the analysis of rural HIV/AIDS prevalence, thus, prevalence data is not fully representative of all of rural America. Information was available for states in each major Census region (six of nine Northeastern states, 10 of 16 Southern states, eight of 12 Midwestern states, and five of 13 Western states). Second, the report examines the rural versus urban distribution of Ryan White providers, using information from the Health Resources and Services Administration's HIV/AIDS Bureau website. Ryan White providers, who provide care for uninsured and financially vulnerable individuals, serve nearly half of all PLWHA. While many individuals receive care from other sources, its national scope and large service population make the Ryan White Program a good proxy for the availability of services for PLWHA in rural counties. All 50 states are included in the analysis of Ryan White service availability. Overall, the report represents an initial attempt to portray the distribution of patients and services across the rural-urban continuum.

Key findings:

HIV/AIDS Prevalence (28 states)

- The proportion of the population affected by HIV/AIDS is greatest in the South. In 2008, the overall prevalence of PLWHA was 247.8 per 100,000 among the 28 states that provided county-level data, with the South having the highest rate (307.2 per 100,000).
- Prevalence rates for HIV/AIDS in the 28 studied states were higher among urban counties than rural counties (274.6 per 100,000 in urban counties versus 91.0 across rural counties).
- Among rural counties studied, HIV/AIDS prevalence declined with rurality. The micropolitan rate was 98.2/100,000, while small adjacent counties had a rate of 90.2/100,000 and remote rural counties, 61.6/100,000. The Northeast was an exception. In the Northeast the rate in small adjacent rural counties (86.4/100,000) was higher than in micropolitan rural counties (71.4/100,000) or remote rural counties (48.2/100,000).
- New York ranked first for overall prevalence of PLWHA (609.6 per 100,000) while South Carolina ranked first for *rural* prevalence of PLWHA (320.0 per 100,000) among

the 28 states that provided county-level information. In South Carolina, rural PLWHA prevalence was greater than the overall state prevalence (320.0 versus 317.0 per 100,000 residents).

Ryan White Medical Providers (all 50 states)

- A higher proportion of rural counties (95%) lacked a Ryan White medical provider compared to urban counties (69%).
- Among rural counties, the proportion of counties lacking a medical provider increased as the level of rurality increased, from micropolitan rural (91% lacking a Ryan White Provider) to remote rural (98%).

PLWHA Living in Counties Lacking a Ryan White Medical Provider (28 states)

- Approximately one in seven PLWHA (14%) in 28 studied states lived in counties that did not have a Ryan White medical provider.
- The proportion of rural PLWHA who lived in a county without a Ryan White provider (74.8%) was markedly higher than the proportion of urban PLWHA living without a provider (11.0%).
- Across Census regions, the Midwest had the highest proportion of rural PLWHA living in counties without a Ryan White provider (97.4%) followed by the Northeast (80.6%), South (68.4%), and West (66.1%)

Policy Implications

- Medicaid expansions and health insurance exchanges outlined by the Patient Protection and Affordable Care Act may increase the number of health care options for low-income individuals who currently rely on Ryan White funding for medication and HIV/AIDS care.
- Practitioners with training and experience caring for PLWHA are essential for HIV/AIDS
 care. Low population density and, in general, lower prevalence rates make it difficult to
 devise economically viable service delivery programs for rural communities. Additional
 research is needed to identify techniques, such as distance education or telemedicine
 consultation, that can enhance the availability of quality medical care to rural PLWHA.

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Introduction

More than three decades since it was first identified, the Human Immunodeficiency Virus (HIV) remains a major public health challenge in the United States (US). Because HIV can be largely asymptomatic, particularly in the initial stages, laboratory tests are required to diagnose the infection. Untreated, the HIV virus decreases the number of CD4 lymphocyte cells, which are essential to combating infection. When the CD4 cell count drops below 200 cells per milliliter, or the HIV positive person experiences one or more of a group of specific disorders associated with a reduced immune system, he or she is defined as having Acquired Immune Deficiency Syndrome (AIDS). The level of illness and thus the need for care is more acute among persons who have progressed to AIDS.

Because of the severity of HIV disease and its communicable nature, the Centers for Disease Control and Prevention (CDC), through the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, conducts national surveillance of HIV infection. All states currently track HIV/AIDS prevalence. The CDC monitors the number of individuals who are HIV positive and the number of persons who have progressed to AIDS separately. Due to the stigma associated with HIV disease and confidentiality concerns, information about HIV prevalence, when publicly reported, is usually shown as a county or state level value, with little data pertaining to individual characteristics. Individual states vary in their public reporting of HIV/AIDS prevalence, with some separating the two stages of the disease, while others only report overall infection levels.

Changing trends in HIV/AIDS epidemic in the United States

According to the CDC, approximately 1.2 million persons are currently living with HIV in the US. ² Despite efforts to curb the epidemic, the HIV incidence rate has remained relatively stable for more than a decade, with approximately 50,000 new cases occurring annually between 2006-2009 (range: 48,100-56,000). ^{3,4,5} Established clinical care guidelines/practices and availability of Highly Active Antiretroviral Therapies (HAART) have achieved significant reductions in morbidity and mortality for PLWHA. ^{6,7} Age-adjusted HIV/AIDS-related death rates have decreased by more than 75 percent since 1995, largely due to advances in clinical care. ⁸ This reduction in HIV/AIDS associated mortality, coupled with a stable HIV incidence rate over the years, has resulted in increased prevalence of HIV disease in the US. ³ Based on data from 40 states with confidential name-based HIV infection reporting, at the end of 2008, the prevalence rate of HIV infection (including AIDS) was 276.5 per 100,000 population. ⁹ During the same period, the estimated number of persons living with AIDS increased steadily to 479,868 with a prevalence rate of 157.7 per 100,000 at the end of 2008. ⁹ Changing trends in the epidemic also indicate disproportionate impact of HIV on racial and ethnic minorities, women, persons living in the South, and rural residents. ⁹⁻¹⁴

With the transformation of HIV into a chronic disease, more focus is now placed on assessing health status and quality of life among PLWHA. Adherence not only to the HIV medications, but also to regular medical care is critical in maintaining overall health and quality of life. ¹⁵ Evidence suggests that after initial diagnosis of HIV, many PLWHA delay initiating HIV care and a significant proportion fails to remain in care. ^{16, 17} Various factors ranging from personal to community to policy levels influence health care utilization patterns among

PLWHA.¹⁸ Such barriers can not only prevent PLWHA from initiating care, but also result in episodic or fragmented utilization among those who have obtained care.^{19, 20} Lack of financial resources and lack of medical providers who accept uninsured/underinsured patients are among the barriers to accessing care among PLWHA. Rural PLWHA are also vulnerable to barriers associated with rural residence, such as lack of transportation and shortage of healthcare providers.

Ryan White Program

Nearly half of PLWHA, about 500,000 individuals, receive HIV care through the Ryan White HIV/AIDS Program. The Ryan White Program, administered by the US Department of Health and Human Services (USDHHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), provides HIV-related services to PLWHA who do not have healthcare coverage or sufficient financial resources to manage the disease. It is the largest federal program focusing exclusively on HIV/AIDS care. Because of its national scope and large service population, the Ryan White Program is a good proxy for the availability of services for PLWHA in rural counties.

The Ryan White CARE (Comprehensive AIDS Resources Emergency) Act was first enacted in 1990 and has been amended and reauthorized in 1996, 2000, 2006, and 2009, with the current program funded at more than \$2 billion. Under the Ryan White program, federal funds are awarded to local, city, or state agencies to deliver HIV care to eligible individuals, under different funding categories. The majority of funds are offered for supporting primary medical care and essential support services (parts A, B, C, & D) while a smaller portion funds technical assistance, clinical training, and research on innovative models of care (part F). Of note, a proportion of Ryan White funding is specifically directed at US metropolitan areas. All Part A funding goes to metropolitan areas; this amounted to \$679 million, or 30% of total funding in fiscal year 2010. Additional details regarding Ryan White funding are provided in the Technical Notes.

The Need for a Rural Perspective

While HIV/AIDS issues have been an important health services research topic for many years, less is known about the geographic dimensions of prevalence of the disease and access to services for the underserved in rural areas. To address this gap, our report consolidates publicly available information regarding the prevalence of HIV/AIDS and availability of HIV care across the spectrum of rurality. Information is drawn from two sources: state health department web sites that provide county-level information about PLWHA (18 – 28 states, depending on topic), and, for Ryan White provider locations, the website for the HIV/AIDS Bureau, Health Resources and Services Administration (all 50 states). Because we do not have information for all 50 states, and do not have information about the actual proportion of PLWHA in each area who must rely on Ryan White services, we cannot provide a full analysis of the match between need and service availability. However, we provide information addressing three key questions, to help promote reflection and analysis about HIV care in the rural US:

- 1. What is the prevalence of HIV in the US by county across rurality?
- 2. What is the distribution of Ryan White medical providers by county across rurality?
- 3. What is the match between prevalence of HIV/AIDS and availability of Ryan White medical providers, by county across rurality?

About This Report

Urban/Rural residence was defined at the county level using Urban Influence Codes (UICs). Counties were categorized as "urban" (UIC 1 or 2), "micropolitan" rural (UIC 3, 5, or 8), "small rural adjacent to a metro area" (UIC 4, 6, or 7), and "remote rural" (UIC 9, 10, 11, or 12) "Rural" in the aggregate was defined as UIC 3 through 12 ("All rural").

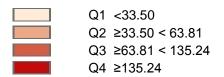
Data analysis of the match between the population in need and provider availability was restricted to 28 states that provided county-level information on persons living with HIV disease in 2008 in their publicly available surveillance reports. When HIV prevalence information was collated for this report, 2008 was the most published recent data. Other analyses are based on all 50 states. For detailed information on the methods including definitions of variables, data management, and data analysis, please refer to the Technical Notes.

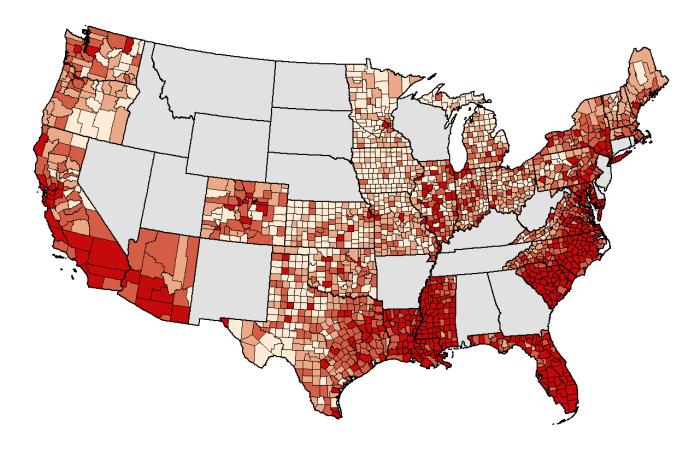
Prevalence of HIV/AIDS

Data availability

In total, 28 states provided county-level information on PLWHA for 2008 on public websites. Information was available for states in each major Census region (six of nine Northeastern states, 10 of 16 Southern states, eight of 12 Midwestern states, and five of 13 Western states). Eighteen (18) states provided county-level information on persons at different stages of infection: living with HIV, living with AIDS, and a total for both groups. Ten (10) states provided aggregate information for all persons with any level of HIV progression. Kentucky provided 2008 county-level information only for PLWA. (Figure 1, below; see also Technical Notes).

Figure 1: Prevalence of PLWHA per 100,000 residents, by county, 28 states, 2008 (Note: states shaded in grey did not publish county level information for PLWHA in 2008.)





Among the 28 states that provided 2008 county-level data on PLWHA, the overall prevalence of PLWHA was 247.8 per 100,000, with the South having the highest rate (307.2) followed by the Northeast (295.8), West (227.8), and Midwest (145.6; See Table 1, next page). As shown in Figure 1, below, prevalence for PLWHA declines with level of rurality. The single exception is the Northeast region, where small adjacent rural counties had higher prevalence of PLWA and PLWHA.

At the national level, HIV/AIDS prevalence rates for rural counties were about one third those of urban counties (e.g., rates of 91.0 for rural and 274.6 for urban, Table 1). The urban/rural disparity is markedly lower in the South, where rural prevalence for HIV/AIDS is 42% of the urban rate. Across other regions, the rural rate ranges from 23% (Northeast) of the urban rate to 29% (West). County-level HIV/AIDS prevalence was shown in Figure 1.

Figure 2. Prevalence rates for HIV/AIDS, 28 states, 2008, by region and level of rurality of county residence.

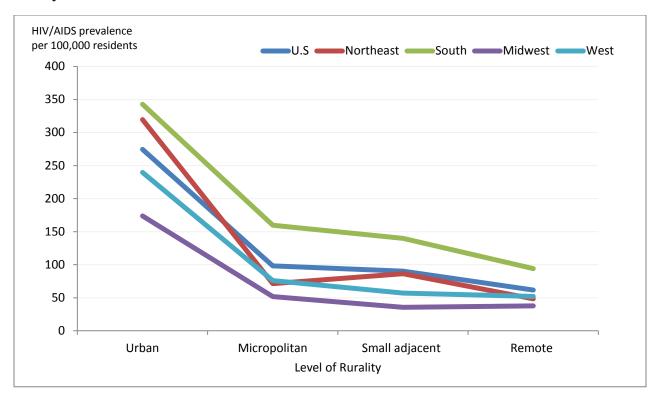


Table 1. Mean county-level prevalence* of HIV, AIDS, and HIV/AIDS, in rate per 100,000 persons, 28 states, by Census region and level of rurality, 2008

			All Rural	Micro- politan Rural	Small, Adjacent Rural	Remote Rural	
	All US	Urban	Counties	Counties	counties	Counties	
		Perso	ons Living wit	h HIV (18 state	es)		
U.S	78.0	86.6	28.6	30.4	29.6	20.0	
Northeast	122.0	132.2	27.2	28.0	27.4	18.8	
South	62.8	66.8	44.2	47.2	46.0	28.4	
Midwest	54.6	66.0	14.0	15.6	11.6	11.8	
West	84.2	88.8	22.8	23.4	20.2	23.2	
		Perso	ns Living with	n AIDS (19 stat	tes)		
U.S	100.4	112.0	32.6	34.6	33.8	23.0	
Northeast	170.8	185.2	36.2	37.2	39.6	14.6	
South	64.0	67.6	47.0	48.2	50.4	35.6	
Midwest	54.0	65.2	14.8	17.0	11.2	12.0	
West	135.8	143.2	35.6	39.2	29.4	27.2	
	Persons Living with HIV or AIDS (28 states)						
U.S	247.8	274.6	91.0	98.2	90.2	61.6	
Northeast	295.8	319.6	73.0	71.4	86.4	48.2	
South	307.2	342.8	145.0	159.6	139.8	94.0	
Midwest	145.6	173.8	45.4	51.6	35.4	37.6	
West	227.8	239.6	68.8	75.8	57.0	52.0	

Prevalence rates are based on the data reported in the State Surveillance Reports of the states that provided county-level information on PLWH (18 states), PLWA (19 states), and PLWHA (28 states). Because of different reporting frameworks, rates for HIV and AIDS do no sum to the combined rate.

Ranking 28 States by Rural and Overall HIV/AIDS Prevalence Rates

There were marked differences across the 28 states studied in the prevalence of HIV/AIDS in rural counties (Figure 3). The prevalence rates for HIV/AIDS in rural counties in South Carolina and Mississippi, the top two states in *rural* HIV/AIDS prevalence among the 28 states studied, were more than ten times higher than the prevalence of HIV/AIDS in rural Iowa. When only rural counties were considered, the top five states in HIV/AIDS prevalence, among the 28 examined, were all located in the South (Figure 3, below; details in Appendix). In 2008, six Southern states ranked among the top ten states in HIV/AIDS prevalence rates across rural and urban populations combined (Table 2, next page).

Figure 3. Prevalence of HIV/AIDS (cases per 100,000 residents), rural counties and statewide, 28 states, 2008.

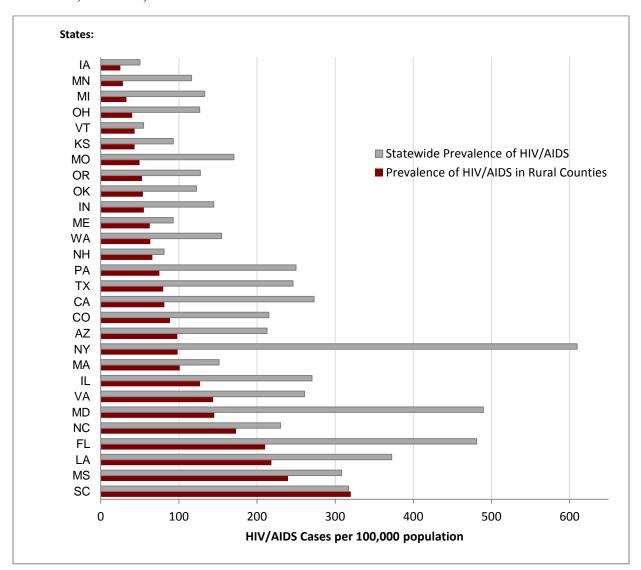


Table 2. Overall prevalence rates of HIV, AIDS, and HIV/AIDs, per 100,000 persons, and rankings by States, 28 States, 2008

(Note: 18 states provided separate prevalence estimates on health department web sites for HIV and for HIV that had progressed to AIDS. When available, this information is shown below. For the 10 states that reported only combined HIV/AIDS information, the HIV and AIDS cells are shaded and labeled "NR." Kentucky provided information only for AIDS prevalence; other cells are shaded and labeled "NR.")

State	Prevalence, HIV	Rank, HIV	Prevalence, AIDS	Rank, AIDS	Prevalence, HIV/AIDS	Rank, HIV/AIDS
New York	233.4	1	376.2	1	609.6	1
Maryland	217.6	2	272.0	2	489.6	2
Florida	NR	NR	NR	NR	481.0	3
Louisiana	173.0	3	199.4	3	372.4	4
South Carolina	154.4	4	165.4	5	317.0	5
Mississippi	NR	NR	NR	NR	308.2	6
California	92.4	12	180.6	4	273.0	7
Illinois	134.8	7	135.6	7	270.4	8
Virginia	144.6	5	116.4	8	260.8	9
Pennsylvania	106.4	11	143.8	6	250.0	10
Texas	NR	NR	NR	NR	246.0	11
North Carolina	143.4	6	96.2	10	230.0	12
Colorado	123.4	8	91.8	11	215.2	13
Arizona	110.8	10	102.0	9	212.8	14
Missouri	NR	NR	NR	NR	170.4	15
Washington	66.4	14	88.4	12	154.6	16
Massachusetts	120.4	9	31.0	19	151.4	17
Indiana	NR	NR	NR	NR	144.6	18
Michigan	61.6	17	71.4	13	133.0	19
Oregon	NR	NR	NR	NR	127.4	20
Ohio	66.8	13	59.8	16	126.6	21
Oklahoma	62.2	16	61.2	15	122.6	22
Minnesota	63.8	15	52.4	17	116.2	23
Kansas	NR	NR	NR	NR	92.8	24
Maine	NR	NR	NR	NR	92.6	25
New Hampshire	36.2	18	45	18	81.0	26
Vermont	NR	NR	NR	NR	54.8	27
Iowa	NR	NR	NR	NR	50.4	28
Kentucky	NR	NR	63.3	14	NR	NR

Availability of Ryan White Providers, 50 States

Information regarding the availability of Ryan White providers was available for the whole US (not limited to the 28 states that publish county-level HIV/AIDS data). The Ryan White program is not a complete picture of HIV care, as it serves just less than half of all PLWHA. However, as the principal federal program directed at ensuring access to care for PLWHA, it is an important part of overall care for this disease.

Across the entire US, the number of Ryan White medical providers in each state ranged from a single provider state-wide (Delaware and Utah) to as many as 155 (California), with 23 states having fewer than 10 providers (Table A-4, Appendix). Overall, 31% of urban counties had a Ryan White provider, but availability ranged from 47%, among urban counties in the Northeast, to 14% among urban counties in the Midwest (Figure 4, below). Availability of services at the county level varied across Census region and across rurality (Figure 5, next page).

Rural Ryan White provider availability was markedly lower in rural than urban counties. Of the 12 Midwestern states, only five (5) contained a Ryan White provider located in a rural county. The county-level availability of Ryan White providers across the US is mapped in Figure 5 (next page).

Figure 4. Percent of counties with a Ryan White Provider, by region and level of rurality, 2008.

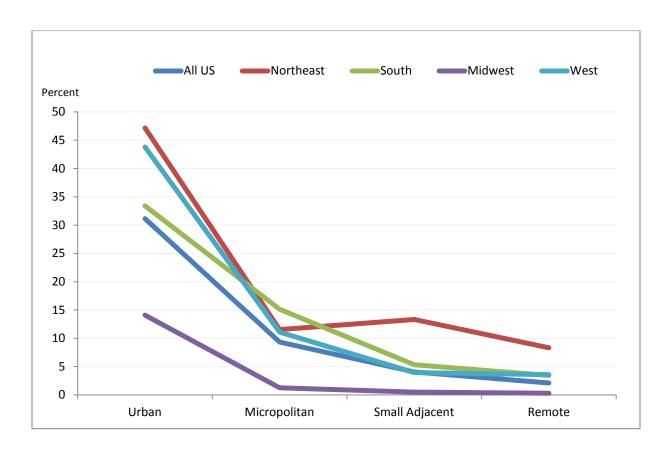


Figure 5. Counties with Ryan White Provider availability, by rural/urban status, 2008

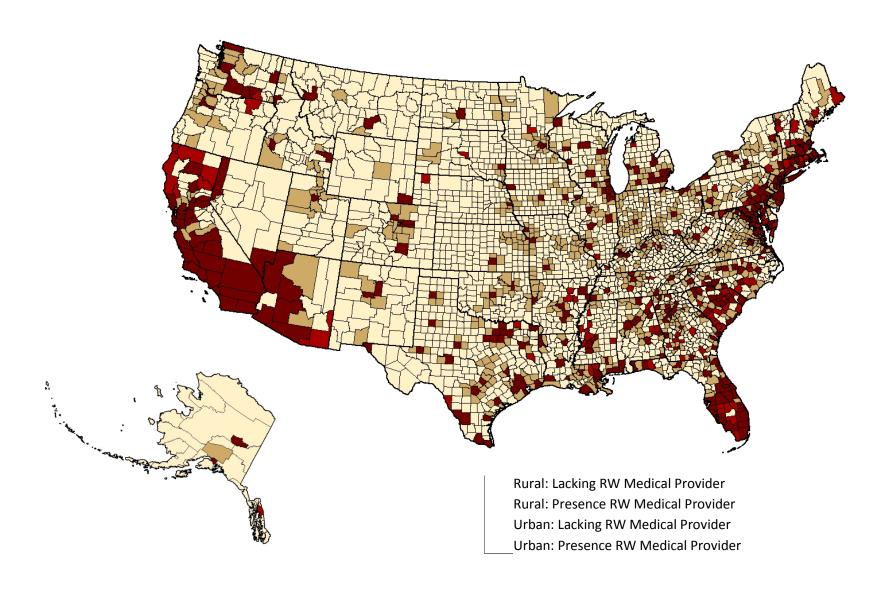


Table 3. Counties that lack a Ryan White Provider, by region and level of rurality, 50 states, 2008

	Total		Counties Lacking a Ryan White Medical Provider										
Region	Counties	All Cou	inties	Urk	oan	Ru	ral	Mic	cro	Sm	all	Rem	ote
		n	%	n	%	n	%	n	%	n	%	n	%
All US	3,133	2,691	85.9	745	68.8	1,946	94.9	612	90.7	637	95.9	697	97.9
By region:													
Northeast	217	148	68.2	65	52.8	83	88.3	46	88.5	26	86.7	11	91.7
South	1,418	1,166	82.2	363	66.6	803	92.0	241	84.9	338	94.7	224	96.6
Midwest	1,053	1,008	95.7	244	85.9	764	99.3	237	99.3	200	99.5	327	99.7
West	445	369	82.9	73	56.2	296	94.0	88	88.9	73	96.1	135	96.4

Proportion of PLWHA Living in Counties without a Ryan White Provider, 28 States

For the 28 states publishing county-level data, it was possible to calculate the number and proportion of PLWHA who live in counties without a Ryan White provider. Across the states studied, only 14% of all PLWHA, an estimated 26,341 persons, lived in a county without a provider. However, as shown in Figure 6, below, and Table 6 on the following page, there were marked disparities across both region and rural/urban county location. In the Midwest, 97% of all rural PLWHA (6,173 persons), and 100% of PLWHA living in remote rural counties (909 persons), do not have a Ryan White provider in their county. The South, while falling in the midrange for proportion of counties lacking a Ryan White provider, had the highest number of PLWHA living in those counties, at 15,134.

Figure 6. Proportion of PLWHA living in a county with no Ryan White provider, by region and level of rurality, 28 states, 2008.

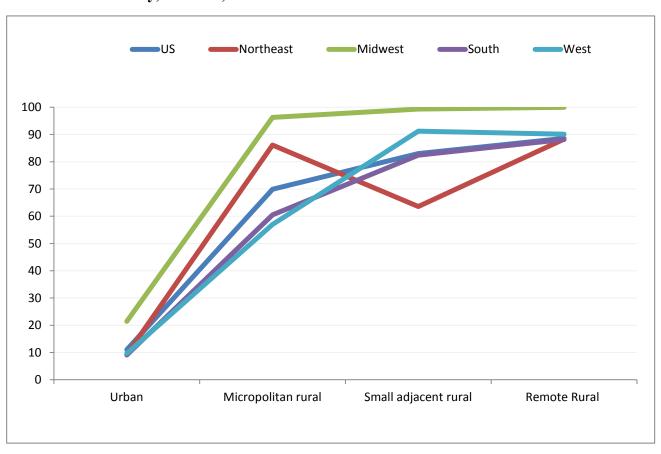


Table 4. Number of PLWHA and percent of PLWHA living in a county without a Ryan White provider, by region and level of rurality, 28 states, 2008

Region	То	tal	All u	rban	All r	ural	Micropol	itan rural	Small a	I	Remot	e rural
1109.011	N	n %	N	n %	N	n %	N	n %	N	n %	N	n %
U.S	94,616	14.4	68,275	11.0	26,341	74.8	16,272	69.7	7,064	83.0	3,005	88.6
Northeast	17,894	11.0	14,767	9.3	3,127	80.6	2,362	86.1	614	63.6	151	88.3
South	37,002	14.1	21,868	9.1	15,134	68.4	8,597	60.5	4,873	82.4	1,664	83.2
Midwest	24,582	26.7	18,409	21.4	6,173	97.4	4,112	96.3	1,152	99.3	909	100.0
West	15,138	10.8	13,231	9.7	1,907	66.1	1,201	57.0	425	91.2	281	90.1

N=Total number of PLWHA in 2008

n=Proportion of PLWHA living in counties without Ryan White medical provider

Summary and Conclusions

The overall prevalence of PLWHA in 2008 among the states that provided county-level information (28 states) was 247.8 per 100,000 persons. Among the Census regions, the South topped the list with a prevalence rate of 307.2, followed by the Northeast with the rate of 295.8 per 100,000. The prevalence rate of PLWHA was much higher in urban counties (274.6) than in rural counties (91.0), with the South having the highest prevalence within both urban (342.8) and rural counties (145.0). Although New York ranked number one for overall state prevalence, South Carolina ranked at the top of the 28 studied states for *rural* prevalence of PLWHA among the states.

In studied states, the distribution of Ryan White providers aligns with overall number of PLWHA: urban counties have higher prevalence and are more likely to contain a provider. However, this has implications for rural PLWHA. Nearly 94% of rural counties lack a Ryan White provider, versus 69% of urban counties. The proportion of rural counties lacking a Ryan White medical provider increased with increasing level of rurality, with 89% of micropolitan rural counties and 97.6 % of remote rural counties lacking this service. Thus, three-fourths (75%) of rural PLWHA lived in counties lacking a Ryan White medical provider, compared to only 11% of urban PLWHA. Among all Census regions, Midwest had the highest proportion of urban and rural PLWHA living in counties lacking a Ryan White provider (21.4% and 97.4%, respectively). Across 28 states in the four Census regions, the absolute number of PLWHA was highest in the South, where an estimated 21,868 urban and 15,134 rural PLWHA live in a county that does not have a Ryan White provider.

Although prevalence rates in rural counties were lower than those in urban counties, rural PLWHA still experienced a disproportionate lack of Ryan White medical providers. Approximately 75% of rural PLWHA within 28 studied states, if they are uninsured or underinsured, may have challenges locating a Ryan White provider and may have to travel longer distances to access such a provider. The structure of funding through the Ryan White program, which explicitly targets urban areas (Part A), reflects higher prevalence rates in urban counties. Ascertaining how best to ensure service availability where the number of patients is low is an ongoing problem for policy-makers and rural health care providers.

Implications of the Patient Protection and Accountable Care Act for HIV/AIDS services

The United States currently invests more than \$19 billion a year in federal funds for domestic HIV/AIDS research, prevention, testing, care and treatment. The Ryan White Program is the largest HIV/AIDS-specific source of funding for care, but Medicare and Medicaid are the two largest sources of funds for HIV/AIDS services, primarily care and treatment. The client base and roles of the Ryan White Program may change

Technical Note:

Data for this report were extracted from the state surveillance reports publically available on each state's health department website. Webbased, county-level information on PLWHA in 2008 was available from only 28 states. Even smaller number of states provided separate county-level numbers for PLWH (18 states) and PLWA (19 states). Therefore, results displayed in this report should be interpreted with caution and should not be compared with the CDC's surveillance report.

significantly as various components of the Patient Protection and Affordable Care Act (ACA) are implemented – although the precise nature of these changes is not yet known.

Ryan White financially supports care for PLWHA with limited incomes who are unable to obtain Medicaid, Medicare, private insurance, or other third-party coverage. In 2014, states will be able to undertake Medicaid expansions for residents up to 133% of the federal poverty level with federal matching funds and will be able to implement health insurance exchanges to help individuals purchase health care coverage. These measures may increase the number of health care options for low-income individuals who currently rely on Ryan White funding for medication and HIV/AIDS care. However, subsequent to the Supreme Court ruling in *National Federation of Independent Business v. Sebelius* (567 U. S. _____ (2012) states are not required to undertake Medicaid expansion, and only twelve (12) states had committed to this expansion as of November 8, 2012. ²³ Unlike Medicaid expansion, health insurance exchanges are anticipated to be available in all states, facilitated by the federal government if needed. However, the exact manner in which these exchanges will operate and their actual effectiveness at linking persons to coverage has not yet been examined. The situation of low-income PLWHA will need continued study.

Continued research is also needed to ensure that rural residents, and all PLWHA, are able to access high quality services for their disease as coverage expansions are implemented. HIV/AIDS is a complex medical condition; practitioners with training and experience caring for PLWHA are essential. If Ryan White provider availability is a valid proxy for the availability of knowledgeable practitioners, three-fourths of PLWHA living in rural America lack trained providers who can supervise their care. Addressing rural PLWHA is not simple: low population density and, in general, lower prevalence rates make it difficult to devise economically viable service delivery programs in rural communities. Additional research is needed to identify techniques, such as distance education or telemedicine consultation that can enhance the availability of quality medical care to rural PLWHA.

Technical Notes

Ryan White Funding

When assessing the distribution of Ryan White providers, it is helpful to understand the funding structure of the program. The urban/rural distribution of providers is responsive both to prevalence and to funding constraints.

- Part A (\$679 million in Fiscal Year 2010, 30% of total): This part provides funds to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) that are most severely affected by HIV/AIDS. Areas with populations of at least 50,000 are considered as EMAs or TGAs if they report at least 2,000 AIDS cases or 1,000 to 1,999 AIDS cases in the most recent 5 years respectively. The boundaries of EMAs and TGAs are based on the US Census designation of Metropolitan Statistical Areas. Part A funds can be used for offering core medical services (at least 75% of funds) as well as supportive services (not more than 25% of funds) to PLWHA. The core medical services include outpatient and ambulatory medical care, AIDS drug assistance program, AIDS pharmaceutical assistance, oral health, early intervention services, health insurance premium and cost sharing assistance for low-income individuals, medical nutrition therapy, hospice services, home and community-based health services, mental health services, substance abuse outpatient care, home health care, and medical case management services. Support services include outreach, medical transportation, linguistic services, respite care for caregivers of people with HIV/AIDS, referrals for health care and other support services, case management, and substance abuse residential services.
- Part B (\$1.2 billion in Fiscal Year 2010, 55% of total): This part provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the US Virgin Islands, and 5 US Pacific Territories or Associated Jurisdictions. These grants include a base grant, the AIDS Drug Assistance Program (ADAP) award, ADAP Supplemental Drug Treatment Program funds, and supplemental grants to States with "emerging communities" (500 and 999 cumulative AIDS cases over the most recent 5 years). Although Congress designates a portion of the Part B appropriation for ADAP, individual states make Part B spending decisions. The funds can be used to provide HIV medications, to purchase health insurance for eligible clients, and for services that enhance access to, adherence to, and monitoring of drug treatments
- Part C (\$207 million in Fiscal Year 2010, 9% of total): This part provides funding directly to providers for comprehensive primary health care in an outpatient setting. Part C includes three types of grants: Early Intervention Services (EIS), Planning Grants, and Capacity Development Grants. For the EIS, not more than 10% of the funding can be allocated to administrative costs and of the remaining at least 75% should be allocated to core medical services. Planning and capacity development grants do not fund any service delivery or patient care and are intended for a short period, usually one year.
- Part D (\$78 million in Fiscal Year 2010, 3% of total): This part provides funding for family-centered outpatient or ambulatory HIV care for women, infants, children and youth.
- Part F (\$48 million in Fiscal Year 2010, 2% of total): This part provides funding for a variety
 of programs including the Special Projects of National Significance (SPNS) which sponsors
 innovative models of care, the AIDS Education and Training Centers Program which
 supports a network of regional and national centers for conducting targeted, multidisciplinary

education and training programs for health care providers serving PLWHA, the Dental Programs which provide additional funding for oral health, and the Minority AIDS Initiative which provides funding for examining and addressing racial/ethnic disparities in HIV/AIDS.

<u>Data</u>

The data were drawn from three sources including individual state HIV/AIDS surveillance reports available on each state health department's website, Area Resource File, and HRSA's HIV/AIDS Bureau (HAB) website.

Publicly available, state HIV/AIDS surveillance reports were used to extract data related to prevalence of persons living with HIV disease (PLWH, PLWA, and PLWHA) in 2008. While extracting the data from state surveillance reports, we faced many challenges due to inconsistencies in reporting of the data. We examined the HIV/AIDS surveillance reports of all 50 states in order to develop our database. Not all states reported county level numbers of persons living with HIV disease. Some states reported only aggregate numbers for the entire state; some provided regional numbers, while others provided county-level numbers. Among the states that reported the county-level numbers, some states reported numbers of PLWH, PLWA, and PLWHA while others reported only PLWHA or PLWA. There were inconsistencies in years of the reports too. Some states had surveillance reports for each year while some had every other year and some had occasional reports. Some states provided information of PLWHA as cumulative for more than one year. Out of 50 state surveillance reports, we could find 28 states that provided information on PLWHA in 2008, 18 states that provided information on PLWH and 19 states that provided information on PLWA. The data were then entered manually in a data base using Epidata software.²⁴ Most of the states did not report the number of PLWHA if the count was less than 5 in a county. Some states did not report the number of PLWHA in each county if the value was very small. These missing data were replaced by one for the analysis. This occurred for 42 of the 99 counties in Iowa, which suppressed values less than four (4); and 24 of 77 counties in Oklahoma, which suppressed values less than three (3). These missing data were replaced by one for the analysis.

County-related information was drawn from the 2008 Area Resource File (ARF). Among more than 6,000 variables related to each of the nation's counties, the variables of interests were the census regions, fips codes (state and county), and population (state and county). Rural and urban counties were defined by Urban Influence Codes (UIC) which divide the 3,141 counties, county equivalents, and the independent cities in the U.S. into 12 groups based on population and commuting data from the 2000 Census in the case of metropolitan counties and adjacency to metro area in the case of nonmetropolitan counties. Metro-nonmetro definition is based on the official metro status announced by the Office of Management and Budget on June 1, 2003. UICs of 1 and 2 were classified as "urban" while all other UICs were classified as rural. Rural counties were further classified into three groups: "micropolitan rural" (UICs 3, 5, and 8) "small adjacent rural" (UICs 4, 6, and 7) and "remote rural" (UICs 9, 10, 11, and 12) [Table A-1].

Table A- 1. Classification of counties based on the 2003 Urban Influence Codes (UIC)

Rural Grouping	UIC	Definitions
Urban	1	Large metro area of more than 1 million residents
	2	Small metro area of less than 1 million residents
Micropolitan Rural	3	Micropolitan area (urban cluster of 10,000 population or more) adjacent to large metro area
	5	Micropolitan area adjacent to small metro area
	8	Micropolitan area not adjacent to a metro area
Small adjacent rural	4	Noncore adjacent to large metro area
	6	Noncore adjacent to small metro area and contains a town of at least 2,500 residents
	7	Noncore adjacent to small metro area and no town of at least 2,500 residents
Remote rural	9	Noncore adjacent to micro area and contains a town of at least 2,500 residents
	10	Noncore adjacent to micro area and no town of at least 2,500 residents
	11	Noncore not adjacent to metro or micro area and contains a town of at least 2,500 resident
	12	Noncore not adjacent to metro or micro area and no a town of at least 2,500 residents

Information related to Ryan White medical providers was extracted from a search tool available on HAB's website. This online search tool allows a person to view the information of each Ryan White medical provider in two ways; by name and address of the provider, if known or by state or county, if the name or address of the provider is not known. Using a drag down box, when one selects a state, a list of counties in that particular state is displayed in the next drag-down box. Once the selection is made, it displays the results in text as well as map. The data related to availability and number of Ryan White providers in each county for which we had the information on HIV/AIDS prevalence (28 states) were manually entered in a separate data base using Microsoft Excel. For the quality check, 25% of the data entered manually were double checked for accuracy before proceeding with the analysis.

<u>Analysis</u>

Descriptive analysis was conducted using SAS.²⁵ The data files related to prevalence, providers, and ARF were imported in SAS and then merged together in SAS using FIPS codes, keeping only the variables of interest from the ARF.

Prevalence was measured using the following formula.

Table A- 2. Number of persons with HIV (18 states), AIDS (19 states), and HIV/AIDS (28 states), by Census region and level of rurality, 2008

					Small	Remote
		Urban	Rural Total	Micropolitan	Rural	Rural
HIV*						
U.S	206,616	195,512	11,104	7,214	2,796	1,094
Northeast	67,041	65,595	1,446	1,073	306	67
South	53,382	46,634	6,748	4,200	1,944	604
Midwest	34,547	32,592	1,955	1,290	381	284
West	51,646	50,691	955	651	165	139
AIDS						
U.S	265,797	253,138	12,659	8,219	3,181	1,259
Northeast	93,832	91,911	1,921	1,426	443	52
South	54,383	47,204	7,179	4,294	2,129	756
Midwest	34,262	32,195	2,067	1,411	368	288
West	83,320	81,828	1,492	1,088	241	163
HIV/AIDS						
U.S	655,592	620,355	35,237	23,340	8,506	3,391
Northeast	162,424	158,545	3,879	2,743	965	171
South	261,199	239,064	22,135	14,221	5,915	1,999
Midwest	92,205	85,868	6,337	4,268	1,160	909
West	139,764	136,878	2,886	2,108	466	312

^{*} Does not include AIDS

Table A- 3. Background information for Figure 3, ranking of 28 States by Rural Prevalence Rate (per 100,000) of HIV/AIDS, 2008

State	Prevalence of HIV/AIDS in Rural Counties	Rank
South Carolina	320.0	1
Mississippi	239.6	2
Louisiana	218.4	3
Florida	210.4	4
North Carolina	173.2	5
Maryland	145.4	6
Virginia	143.8	7
Illinois	127.0	8
Massachusetts	101.0	9
New York	98.4	10
Arizona	98.0	11
Colorado	88.6	12
California	81.4	13
Texas	80.0	14
Pennsylvania	75.0	15
New Hampshire	66.0	16
Washington	63.4	17
Maine	62.8	18
Indiana	55.2	19
Oklahoma	54.0	20
Oregon	52.8	21
Missouri	49.8	22
Kansas	43.4	23
Vermont	43.4	24
Ohio	40.2	25
Michigan	33.0	26
Minnesota	28.4	27
Iowa	25.2	28

Table A- 4. Availability of Ryan White (RW) medical providers, by State*

State	# RW Providers	State	# RW Providers
Alabama	17	Montana	2
Alaska	5	Nebraska	2
Arizona	13	Nevada	5
Arkansas	16	New Hampshire	4
California	155	New Jersey	50
Colorado	14	New Mexico	2
Connecticut	46	New York	139
Delaware	1	North Carolina	40
Florida	96	North Dakota	2
Georgia	32	Ohio	12
Hawaii	5	Oklahoma	2
Idaho	3	Oregon	6
Illinois	102	Pennsylvania	59
Indiana	2	Rhode Island	4
Iowa	5	South Carolina	48
Kansas	3	South Dakota	2
Kentucky	7	Tennessee	22
Louisiana	18	Texas	66
Maine	3	Utah	1
Maryland	62	Vermont	18
Massachusetts	35	Virginia	51
Michigan	34	Washington	13
Minnesota	4	West Virginia	4
Mississippi	20	Wisconsin	13
Missouri	21	Wyoming	2

^{*} RW medical provider data retrieved on 3/1/2011 from

http://findhivcare.hrsa.gov/Search_HAB.aspx?byCounty=1

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Appendix

Links to HIV/AIDS surveillance by states that provided county level information

State	Website
AZ	http://www.azdhs.gov/phs/hvstdhpc/
CA	http://www.cdph.ca.gov/data/statistics/Pages/OAHIVAIDSStatistics.aspx
СО	http://www.cdphe.state.co.us/dc/HIVandSTD/surveillance.html
FL	http://www.doh.state.fl.us/Disease_ctrl/aids/index.html
IA	http://www.idph.state.ia.us/adper/hiv_aids.asp
IL	http://www.idph.state.il.us/aids/default.htm
IN	http://www.in.gov/isdh/23266.htm
KS	http://www.kdheks.gov/hiv/surveillance.html
KY	http://chfs.ky.gov/dph/epi/HIVAIDS/surveillance.htm
LA	http://www.dhh.louisiana.gov/offices/?ID=264
MA	http://www.mass.gov/?pageID=eohhs2terminal&&L=5&L0=Home&L1=Government&L2=D epartments+and+Divisions&L3=Department+of+Public+Health&L4=Programs+and+Servi ces+A+-+J&sid=Eeohhs2&b=terminalcontent&f=dph_aids_g_aids_landing&csid=Eeohhs2
MD	http://dhmh.state.md.us/AIDS/HIV_index.html
ME	http://www.maine.gov/dhhs/boh/ddc/hiv-std/
MI	http://www.michigan.gov/mdch/0,1607,7-132-2940_2955_2982_46000,00.html
MN	http://www.health.state.mn.us/divs/idepc/diseases/hiv/hivstatistics.html
MO	http://www.dhss.mo.gov/HIV_STD_AIDS/Data.html
MS	http://msdh.ms.gov/msdhsite/_static/14,0,150.html
NC	http://www.epi.state.nc.us/epi/hiv/
NH	http://www.dhhs.state.nh.us
NY	http://www.health.state.ny.us/diseases/aids/statistics/index.htm
ОН	http://www.odh.ohio.gov/healthStats/disease/hivann/hcty1.aspx
ОК	http://www.ok.gov/health/Disease,_Prevention,_Preparedness/HIV_STD_Service/HIV_STD_Statistics/index.html
OR	http://www.oregon.gov/DHS/ph/hiv/data/EpiProfile.shtml
PA	http://www.portal.state.pa.us/portal/server.pt/community/hivaids/14241/hiv_aids_annual_summaryother_reports/557343
SC	http://www.scdhec.gov/health/disease/sts/index.htm
TX	http://www.dshs.state.tx.us/hivstd/default.shtm
VA	http://www.vdh.state.va.us/Epidemiology/DiseasePrevention/Programs/HIV-AIDS/index.htm
VT	http://healthvermont.gov/prevent/aids/epi-profiles.aspx
WA	http://www.doh.wa.gov/cfh/HIV_AIDS/Prev_Edu/Statistics.htm

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