Linking Ryan White HIV/AIDS Program Clients of Color to New Health Coverage Options:

OUTREACH AND ENROLLMENT CHALLENGES FACED BY GRANTEES AND PROVIDERS

This report was prepared by JSI Research & Training Institute, Inc. under Grant #UF2HA26520 from the Health Resources and Services Administration's HIV/AIDS Bureau. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the HIV/AIDS Bureau.

For more information or questions, contact the ACE TA Center at acetacenter@jsi.com.

ACE
AFFORDABLE CARE ENROLLMENT
TA CENTER

People Living with HIV & the Affordable Care Act

In the United States, HIV disproportionately affects people of color, those who are poor, and other populations who are underserved by the health care system, including men of all races/ethnicities who have sex with men (MSM); transgender individuals; and injection drug users (IDUs).

Today, more than 1.1 million Americans are living with HIV. More than 500,000 are black/African American and 220,000 are Latinos.[1] In 2010, 44% of new HIV infections were among black/African Americans (who make up 12% of the total U.S. population), and 21% were among Latinos (16% of the U.S. population).

The National HIV/AIDS Strategy outlines national efforts to reduce the number of new HIV infections and HIV-related health disparities, increase access to care, and improve outcomes for people living with HIV (PLWH).

The central goal of the Affordable Care Act (ACA) is to reduce the number of individuals who are uninsured and do not have continuous access to prevention, care, and treatment for chronic diseases, including HIV. According to recent analyses, millions will be newly insured and the number of people who are underinsured will drop significantly.

ACA implementation varies based on each state's current structure and focus, and its unique health care and insurance environment. For example, in June 2012, the Supreme Court ruled that states could choose whether or not to implement Medicaid expansion. As of this writing, nearly 60,000 low-income and uninsured PLWH live in states that do not plan to expand their Medicaid programs and who therefore are likely to remain uninsured.[2] In these same states, the mean percentage of uninsured people of color served by the Ryan White HIV/AIDS Program (RWHAP) is significantly higher than in states that are expanding Medicaid.[3]

Given that PLWH are poorer than the population at large, and that the RWHAP is a payer of last resort, efforts are underway to enroll RWHAP in newly available healthcare coverage options. Outreach and enrollment (O&E) are the first steps in an ongoing process to link, engage, and retain clients in care and treatment. Uninsured RWHAP clients of color may need assistance determining their eligibility for and enrolling in health care coverage through the health insurance marketplaces. Other substantial barriers to O&E include concerns about immigration status, affordability, and previous negative experiences with health insurance plans.

---

[1] CDC, HIV Surveillance Report, Vol.23; February 2013. CDC, Fact Sheet: New HIV Infections in the United States; December 2012. *US Census Bureau, 2010 Population estimates*. Available at: http://kff.org/hivaids/fact-sheet/black-americans-and-hiv-aids/

[2] Snider, J., Juday, T., & Romley , J. (2014). Nearly 60,000 uninsured and low-income people with HIV/AIDS live in states that are not expanding Medicaid. *Health Affairs*, 33(3), 386-393.

[3] U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). *2011 Ryan White HIV/AIDS Program Services Report*

Assessing Need

The Affordable Care Enrollment (ACE) Technical Assistance (TA) Center invited RWHAP grantees and funded providers to participate in a needs assessment (NA) to help define training and technical assistance (T/TA) services over the coming months and years. The purpose of the assessment was to learn about grantee and service provider experiences linking eligible clients to new health coverage options.

The 30-minute tool collected information on:

- background of respondent
- understanding of policy requirements
- providing support to RWHAP-funded providers
- outreach and enrollment support
- post-enrollment and re-enrollment support
- training and technical assistance

The data were analyzed to look at differences in state Medicaid expansion status, type of insurance marketplace in that state, RWHAP grantee type, enrollment capacity score, and post-enrollment capacity score.

There are a number of limitations:

- There is the potential for response bias since the questions were based on self-report.
- The response rate was low. JSI was able to estimate the percent of all RWHAP grantees and subgrantees that completed the assessment. The lowest response rate was among subgrantees, likely because not all grantees may have forwarded the NA to them (See Table 1).
- Some states were over-represented.
- The NA was in the field at the same time as the rollout of the ACA, a period marked by significant challenges with the federal marketplace website and with some state marketplace websites.

TABLE 1: ACE NA response rate calculated using 2013 ACE NA respondents and total RWHAP grantees (from the 2011 RWHAP State Profiles)

RWHAP FUNDING PART	# GRANTEES FROM 2011 RWHAP STATE PROFILES	# RESPONDENTS TO 2013 ACE NA	RESPONSE RATE
A	52	15	29%
B	54	25	46%
C	348	89	26%
D	91	31	34%
Subgrantees only	1,545	94	11%
Total	**2,026**	**231**	**11%**

Need Assessment Participants

There were 435 responses to the online ACE NA, of which 231 were included in the analysis.[4] A total of 265 individuals contributed to the responses, and 25 organizations had two or more individuals who contributed to an assessment. The map below (Figure 1) shows that the largest number of responses came from Florida, New York, Illinois, California, Pennsylvania, and Texas. States not represented in the analytic sample included Hawaii, Iowa, Oklahoma, South Dakota, and Wyoming. The U.S. territories of American Samoa, Guam, and Northern Mariana Islands were not represented either.

Of the 231 RWHAP-funded grantees and subgrantees who responded to the NA, half were from Medicaid expansion states (Figure 2). Fifty-four percent of respondents were from states using the federal marketplace, 33% were from states with their own marketplaces, and 12% were from states planning partnership marketplaces (Figure 3).

Most direct service providers (74%) reported providing O&E support to clients. Of those not providing O&E, more than two-thirds (69%) planned to start. Direct providers included Part C and D grantees as well as RWHAP subgrantees.

FIGURE 1. Respondents to online ACE NA by state

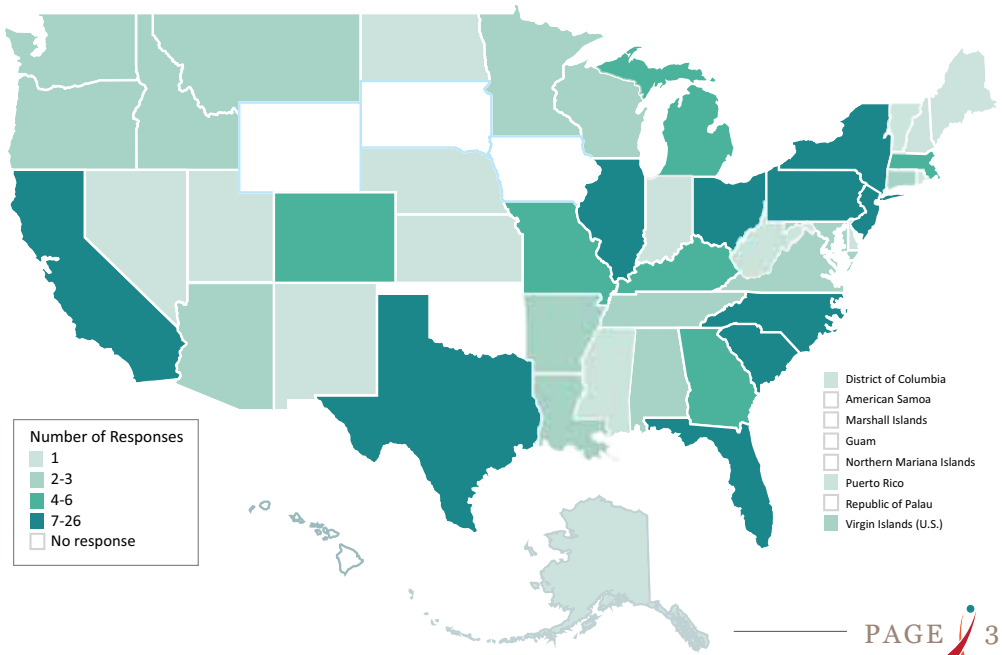


FIGURE 2. States' Medicaid expansion status (N=231)

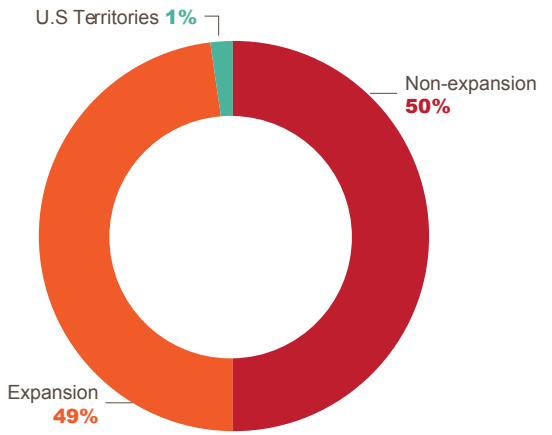
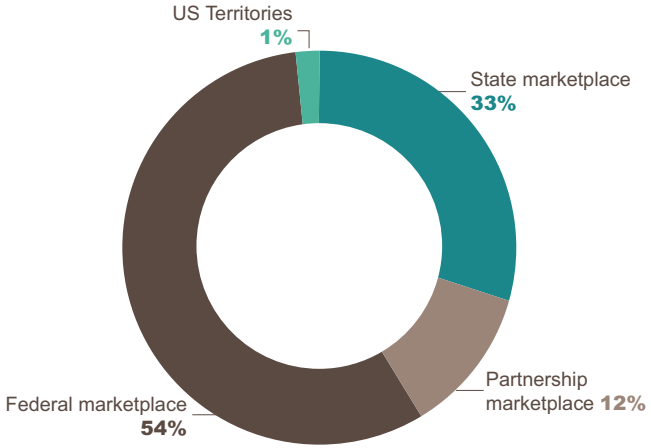


FIGURE 3. Type of state marketplace (N=231)



[4] Of the 435 responses, 220 were considered completed by the online survey software and 215 were considered partially complete. Of the 215 partially complete responses, 22 were complete but the 'submit' button was not hit. After duplicates were removed, the final analytic sample included 231 respondents.

Key Findings

FINDING #1

LIMITED KNOWLEDGE & EXPERIENCE

It is expected that RWHAP providers will play a role in O&E to RWHAP clients. Many direct service providers faced general O&E challenges related to lack of knowledge of new coverage options.

Among direct service agencies (n=97) that reported "low capacity" or "moderate capacity" in their organization's capacity to educate and enroll PLWH in new health coverage options, the **most challenging aspects of O&E were:**

- lack of staff to conduct activities (54%)
- lack of funding to support activities (39%)
- lack of knowledge of new health coverage options (39%)

Those who reported "high capacity" (n=76) were asked to identify challenges they had overcome to provide O&E assistance. The **top challenges they reported overcoming were:**

- a lack of knowledge of new health coverage options (53%)
- lack of staff to conduct activities (43%)
- lack of funding to support activities (37%)

Outreach activities may include education about the ACA, client eligibility and information about new health coverage options. Enrollment includes helping clients review health insurance choices, complete an application, and/or select a health plan. Post-enrollment and re-enrollment activities may include providing information on an appeals process, referrals to a client advocate, educating clients about new health coverage benefits, and helping clients report changes during the coverage year.

RWHAP Part A and B grantees also have a role in O&E activities by conducting T/TA activities for their funded providers. More than two-thirds (67%) said they provided T/TA to their subgrantees on delivery of O&E services. When asked to select the three most challenging aspects of O&E faced by their funded providers, Part A and B grantees (n=25) reported:

- lack of staff (60%)
- lack of financial resources (40%)
- lack of knowledge of new coverage options (40%)
- lack of coordination between their state Medicaid program and RWHAP (32%)
- existing O&E efforts did not respond to the specific needs of PLWH (20%)

These responses indicate that Part A and B grantees understand the challenges of their funded providers who are conducting O&E activities at the local level.

Part A and B grantees reported a higher capacity to train providers to help clients understand new health coverage program eligibility and options than to train providers to actually enroll clients in new health coverage options.

FINDING #2

BARRIERS TO ACCESSING CARE

RWHAP providers are working with clients of color who have historically faced barriers to accessing care and who may not be comfortable enrolling in new ACA coverage options.

All direct service provider agencies (n=145) who said they provided or planned to provide O&E services were asked about challenges they anticipated in providing these services to people of color living with HIV. Agencies reported that their challenges included:

- clients' lack of information/knowledge about their ACA options (73%)
- ineligibility due to immigration status (58%)
- fears related to clients' and/or family members' immigration status (46%)
- previous negative experiences with insurance, distrust/nervousness about enrollment (45%)
- language barriers (39%)

Clients are particularly concerned about plan affordability, as well as the possibility of needing to change providers.

Providers reported their clients were concerned about affordability related to co-pays, premiums, and other out-of-pocket costs. This is of particular concern in states that are not planning to expand Medicaid. According to one respondent:

"There are also concerns about enrolling RW clients in health plans and the possibility that some clients may choose to not access care and treatment due to the higher costs associated with doctor visits and labs." – Part C FQHC

Both O&E capacity and cultural competency are critical to enrolling and retaining RWHAP clients of color in ACA coverage options. Providers work with clients who have historically faced barriers to accessing care and who may not be comfortable enrolling in new ACA coverage options. Conversations about O&E are always influenced by clients' past experiences with the health care system.

Many RWHAP clients have developed long-standing relationships with their providers, many of whom work with large numbers of minority and/or LGBT clients and have gained credibility in their communities. These providers have proven themselves trustworthy to clients who have faced stigma or discrimination in prior health settings, while other providers may still require support to establish culturally competent care settings.

"The fact is that we have limited providers who only take certain insurances. So if the PLWH wants to keep the same clinical provider there are limited options. Our largest provider only takes [one insurance provider]. Many primary care doctors will not treat PLWH clients. Many providers do not have bilingual staff, especially for mental health services. Many mental health providers have no experience working with gay men of color."
– Part A HEALTH DEPARTMENT

FINDING #3

COMMUNICATION AND COORDINATION

RWHAP grantees and providers want more local guidance about policies and best practices. Gaps in coordination may have implications for how clients experience care.

All respondents were asked to complete questions about their familiarity with state and federal policies related to ACA implementation and associated challenges and T/TA needs. Table 2 shows respondents who indicated that they needed some level of support to implement these policies. There were significant differences in level of need by type of insurance marketplace and Medicaid expansion status for all policy topics except O&E services supported with RWHAP funds.

Respondents were also asked if they had specific questions about these policies, or any HRSA/HAB guidance or state policy related to O&E of PLWH clients into health coverage options.

One respondent noted: *"[I] need clarification on any specific distinctions in policy for [my state] as it related to coverage options for PLWH."*

– Part C FQHC – SUBGRANTEE CBO

TABLE 2: Need for support to implement policies overall and by type of marketplace and Medicaid expansion status

POLICY TOPIC	RESPONDENTS REPORTING SOME LEVEL OF NEED					
	Overall	Type of Marketplace			Medicaid Expansion	
	(N=231)	Federal (n=124)	Partnership (n=27)	State (n=74)	Yes (n=111)	No (n=114)
O&E services supported with RWHAP funds	40%	45%	37%	34%	37%	44%
Eligibility/enrollment rules and policies for federal ACA coverage options	46%	56%	33%	34%	32%	59%
Eligibility/enrollment rules for state Medicaid coverage	37%	43%	30%	27%	26%	45%
Relationship between state policies and ACA coverage options for PLWH	55%	62%	60%	42%	45%	65%

In particular, providers needed:

- additional guidance from their state or local health departments and state Medicaid about the ACA, their state AIDS Drug Assistance Program, and/or plan options
- basic training about how to determine which coverage option(s) are best for their PLWH clients
- help evaluating insurance companies' formularies and responding to situations where patients' current medications are not covered

Training and TA: Next Steps

Data from this NA are among the sources that will be used to define the long-term objectives of the ACE TA Center T/TA. These findings will complement knowledge gained from JSI's assessment of best practices and key informant interviews.

Based on the NA , the ACE TA Center plans to implement T/TA resources to address the following objectives:

- **Increase RWHAP grantee and service provider knowledge** of ACA coverage options and capacity to enroll clients in health insurance.
- **Increase RWHAP provider capacity** to build client confidence in the enrollment process.
- **Increase the capacity of health departments to give funded providers clear guidance** on ACA implementation, clarify RWHAP outreach and enrollment policy, and collaborate with state Medicaid programs.

Specific T/TA needs may vary depending on the local environment, including whether a state has chosen to expand Medicaid, the type of marketplace a state will be using, and state-specific decisions about how ACA information is communicated. NA data showed that direct service providers' capacity to educate and enroll PLWH in new health coverage options varied across insurance marketplace and Medicaid expansion groups (Table 3).

TABLE 3: Direct service providers' organizational capacity to educate and enroll PLWH in new health coverage options among those providing O&E support by type of marketplace and Medicaid expansion status

		DIRECT SERVICE PROVIDERS (n=141)	MEAN CAPACITY SCORE (Range 0 to 18)	P-VALUE
MARKETPLACE	Federal	75	12.0 (4.7)	Federal vs. state
	Partnership	20	12.6 (4.9)	
	State	46	14.1 (3.2)	0.03
MEDICAID	Expansion	72	13.5 (4.0)	0.03
	Non-expansion	69	12.0 (4.6)	

The ACE TA Center will emphasize a proactive model of culturally competent T/TA service delivery to support O&E, focusing some resources on the challenges faced by a larger number of grantees and ensuring that resources used for one-on-one and small group support can be directed to grantees and providers most in need of individualized attention.