Building Ryan White HIV/AIDS Program Recipient Capacity to Engage People Living with HIV in Health Care Access

2017 Needs Assessment Results

From January 12 to March 7, 2017, JSI invited Ryan White HIV/AIDS Program (RWHAP) recipients and subrecipients to share their successes and challenges in (1) providing health literate services and helping clients better obtain, process, and understand health information, and (2) helping their clients get enrolled in health coverage.

Total needs assessment responses by state*

(N=103)

*3 responses from Puerto Rico, 1 response from Hawaii (not shown).

Most respondents (54%) were RWHAP subrecipients. The remainder were directly funded recipients through Part A (4%), Part B (10%), Part C (28%), Part D (3%) or Part F (1%).

Most Part C recipients were hospital-based clinics or FQHCs/CHCs (78%).

Organization type

(N=103)

- State, county, municipal, city or other health department or administrative entity: 26%
- Community-based organization: 24%
- Federally Qualified Health Center/Community health center: 20%
- Hospital-based clinic (including university-based clinic): 19%
- Other private, non-profit service provider: 10%

HEALTH LITERACY

Respondents were asked to rate their organizations’ health literacy capacity, and to share challenges they have faced in becoming more health literate. They were also asked what technical assistance or training on health literacy would be most helpful to them.

HEALTH LITERACY FINDING #1

- Self-rated health literacy capacity is high among direct service providers.*
- However, many respondents (48%) said they had not heard of the Ten IOM attributes.
- Health departments provide limited training on health literacy.

* For each of the individual Institute of Medicine (IOM) Ten Attributes of a Health Literate Healthcare Organization

“Clients aren’t familiar with medical terms or how their bodies work [...] Clients have health conditions that require complicated self-care.”

— Subrecipient, Benefits/enrollment staff
HEALTH LITERACY

HEALTH LITERACY FINDING #2

• Self-identified health literacy challenges (e.g., limited funding, staff time constraints, need for general training) are consistent with early needs assessment findings in other topic areas (e.g., health coverage).
• Over time, these perceived constraints may be reduced by incorporating best practices into work approaches, rather than adding separate tasks.

Most challenging aspects of health literacy*

<table>
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<tr>
<th>Issue</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Lack of funding for health literacy activities</td>
<td>76%</td>
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<tr>
<td>Lack of time to address barriers to health literacy during client visits</td>
<td>61%</td>
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<tr>
<td>Not aware of training resources</td>
<td>49%</td>
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<tr>
<td>Lack of ongoing patient assessment to determine if they understand important materials</td>
<td>43%</td>
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<tr>
<td>Lack of health literacy, easy to understand, culturally competent patient materials</td>
<td>43%</td>
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<tr>
<td>Staff lack training in health literacy</td>
<td>37%</td>
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<tr>
<td>Lack of multilingual staff</td>
<td>26%</td>
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<tr>
<td>Translation services are not available</td>
<td>14%</td>
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<tr>
<td>Staff do not see health literacy as a barrier to care</td>
<td>13%</td>
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</table>

*Respondents function primarily as direct service providers.

HEALTH LITERACY RECOMMENDATION

1. There is an opportunity to address some key T/TA needs for health literacy, particularly sharing evidence-based methods. These methods are shared through the In It Together curriculum and resources. HRSA and its partners may also wish to prioritize some of these identified areas of need for additional health literacy-focused T/TA initiatives.

HEALTH LITERACY RECOMMENDATION

2. The process of becoming a more health literate organization requires initial investment (e.g., reviewing materials and environment, training staff). Following this initial investment, health literacy should not increase work load; rather, it should improve organizational effectiveness.
• Training and technical assistance is needed to help providers shift their understanding of what it takes to become a more health literate organization, and what they can achieve.

“This organization is just now starting to incorporate plain language into the written forms, largely due to the efforts of myself and the Patient Advocate. Our Legal Department usually insists on complicated language in most documents.”
— Part F Dental, Case management coordinator or client services coordinator

“Most of our patients are Hispanic and can’t read or understand English. Most of the educational information (brochures, flyers, and navigations websites) are in English.”
— Part D, Quality assurance staff

HEALTH LITERACY FINDING #3
Cultural competency is an important element of health literacy capacity. The needs assessment identified key differences between respondents in awareness of best practices such as the National Standards for Culturally and Linguistically Appropriate Services (70-80% of medical providers, compared to 30% of health departments, were familiar and able to implement), and the importance of routine cultural competency training.
HEALTH COVERAGE

Respondents were asked to rate their organization's capacity to implement various aspects of health coverage and to discuss related challenges. They were also asked about their technical assistance and training needs.

HEALTH COVERAGE FINDING #1

- Increases in health coverage enrollment and renewals capacity scores from 2013 to 2017 remain significant at p<0.05.
- There is variation in capacity depending on the type of organization.
  - Rates of enrollment assister certification vary by type of organization.
  - Some organizations use external partners. These partners are capable in many ways, but have only moderate capacity in key areas for RWHAP clients (e.g., determining whether a plan covers HIV medications and includes preferred HIV providers).
  - Almost all respondents have a health department or partner organization assessing plans for PLWH.

Top 5 enrollment challenges

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<thead>
<tr>
<th>Challenge</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Trouble helping clients submit all of the required documents for enrollment</td>
<td>37%</td>
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<tr>
<td>Challenges with state and federal (e.g., healthcare.gov) enrollment websites</td>
<td>35%</td>
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<tr>
<td>Lack of information about tax credits and tax filing</td>
<td>35%</td>
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<tr>
<td>Communication challenges at the state level</td>
<td>34%</td>
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<tr>
<td>Lack of funding to help clients get enrolled, use coverage and stay covered</td>
<td>32%</td>
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</tbody>
</table>

*Among respondents that function primarily as direct service providers.

Top 5 T/TA needs for enrollment

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<tr>
<th>Need</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Developing procedures for when clients do not meet eligibility requirements, choose not to enroll, or refuse to be screened</td>
<td>29%</td>
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<tr>
<td>Determining client eligibility for Medicaid and health insurance plans</td>
<td>29%</td>
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<tr>
<td>Affordability of HIV drugs under health insurance plans</td>
<td>28%</td>
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<tr>
<td>Developing a plan for your HIV program to engage and educate clients</td>
<td>26%</td>
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<tr>
<td>Keeping track of enrollment activities, outcomes, and challenges for quality improvement purposes</td>
<td>25%</td>
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“*We are a non-Medicaid expansion state, very cumbersome enrollment process for our clients, only four insurers to choose from, list shorter than last year. One insurer is not taken at our large hospital with most HIV clients. HIV drugs listed on fourth tier and very expensive on another insurer. Many clients still on learning curve for how to use health insurance.*”

— Part A, Program director or manager

HEALTH COVERAGE FINDING #2

Health coverage challenges and T/TA needs in 2017 are similar to 2015.

HEALTH COVERAGE FINDING #3

T/TA is still needed to support PLWH of color/key populations.
- The top T/TA need (selected by 75% of respondents) was “how to address client mistrust of the health care system” followed by “population-specific enrollment materials” (49%) and “cultural competency training” (47%).
- Top populations for tailored enrollment materials by respondents have changed. In 2017 the top populations are transgender (82%), men who have sex with men (82%), and Black or African American (72%).
HEALTH COVERAGE

T/TA needs for PLWH of color (n=79)

- How to address client mistrust of the health care system: 75%
- Population-specific enrollment materials and/or strategies: 49%
- Staff training in cultural competency: 47%
- Resources available in languages other than English: 39%
- Staff training in linguistic competency: 28%
- Other: 5%

How would you describe the impact of the changing health care landscape on RWHAP clients served by your HIV program?

Summary of key qualitative themes:
- Expanded access to coverage for clients, including access to specialty providers and non-HIV related care
- Allows PLWHA/pre-existing conditions to enroll in care
- Improved quality of life and overall health of clients
- RWHAP programs are more financially stable
- Plans are unaffordable and/or don’t provide all necessary care

HEALTH COVERAGE FINDING #4

The evolving health care landscape from 2013 to 2016 was largely a positive experience, but some systemic challenges remain.

- Level of awareness about Essential Community Providers (and level of certification) vary by type of respondent.
- Insurance status by Medicaid “expansion” status shows coverage disparities.
- Many respondents report no training on health coverage from city/county, state Medicaid agency or health insurance marketplace.
- Enrollment website challenges persist.
- There is some improvement in familiarity with health coverage options for PLWH (otherwise policy-related T/TA needs remain).

HEALTH COVERAGE RECOMMENDATION

1. Despite retained capacity, there remains a demonstrated need for training and education of individuals and organizations to support health coverage enrollment for RWHAP consumers.
   - T/TA needs remain across all the stages of enrollment (e.g., engagement, enrollment, retention in coverage).
   - As the health coverage environment continues to evolve, there is a continued need to build recipient capacity to understand and implement related policies.

2. Particular T/TA and support are needed to help recipients and subrecipients address the specific needs of PLWH of color and other key populations. These include addressing client mistrust of the health care system, and sharing resources that are relevant and appropriate to populations served by RWHAP recipients and subrecipients, most notably transgender individuals and men who have sex with men (MSM).

3. The RWHAP can continue to provide critical support through coverage completion services such as medical case management, transportation, housing, and food; coverage for medications and HIV medical care when clients have coverage gaps; and through support for premiums and out-of-pocket costs.
   - Together, these resources can help keep people maintained in care and improve rates of viral suppression.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U69HA30143: Building Ryan White HIV/AIDS Program Recipient Capacity to Engage People Living with HIV in Health Care Access. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.