THE HENRY J. KAISER FAMILY FOUNDATION

The ACA and People with HIV: Observations from Focus Groups in Five States

Lindsey Dawson

Kaiser Family Foundation

lindseyd@kff.org

http://kff.org/hivaids

May 4, 2016

Background

- Focus groups conducted in 2014 & 2016: HIV positive participants from five states discussed impact of ACA era coverage opportunities
- New report based on 2016 findings

Focus Group Site Details

State	City	Marketplace Type	Medicaid Expansion	State Share of Domestic HIV Epidemic
California	Los Angeles	State	Yes	13%
Florida	Miami	Federal	No	11%
Georgia	Atlanta	Federal	No	5%
New York	New York City	State	Yes	14%
Texas	Dallas	Federal	No	8%
Total				*50%**

Source: CDC Atlas. Persons living with Diagnosed HIV, 2013.

**Note: State percentages detailed above do not add to 50% due to rounding.*

Key Findings: Knowledge of the ACA and Insurance Coverage

- Some participants seemed to have a better basic understanding of ACA coverage opportunities compared to the 2014 groups
  - Penalty
  - Medicaid Expansion

- But for most, lack of insurance literacy persists, making informed purchasing and plan comparisons difficult; not always clear on eligibility

"I'm still not quite sure if I understand when they talk about out-of-pocket, what does that mean actually…?"

– New York Marketplace Enrollee

***

Example From the Field

Uninsured GA man is paying $2,000-$3,000 out-of-pocket each month for non-HIV medications; would likely have lower costs with Marketplace coverage even without a subsidy

THE HENRY J. KAISER FAMILY FOUNDATION

Key Findings: Knowledge of the ACA and Insurance Coverage II

- Yet understanding that access to care for those with HIV varied across the country
  - Those in FL, GA, and TX pointed to greater access in CA and NY
  - Those in NY and CA say they were fortunate to have the access they do

"If you are HIV positive, New York is the state for you."

– *New York Medicaid Enrollee*

***

Example From the Field

A New York Medicaid enrollee had just moved to the state from Georgia, specifically to gain health coverage. In Georgia he qualified for a Marketplace subsidy but at $208/month it was unaffordable to him.

THE HENRY J. KAISER FAMILY FOUNDATION

Key Findings: Enrollment & Plan Selection

- Variety of reasons for enrolling, cited coverage mandate and desire to avoid a penalty more than in 2014
- Case managers play important role in helping with enrollment, as enrollees remain confused by the process, feel overwhelmed
- Plan selection often based on costs, provider networks, case manager recommendation, but sometimes other factors (e.g. ratings)
- Many who remain uninsured looked into getting ACA era care but were told they did not qualify or felt it was too expensive
  - Many looked only once; the remaining uninsured may need a significant push

"The first time I tried it, and I did, they denied me for Obamacare. I never tried again so…"

– Miami uninsured

THE HENRY J. KAISER FAMILY FOUNDATION

Key Findings: Enrollment & Plan Selection II

- Only a few participants changed coverage over the course of open enrollment periods once insured:
  - A CA man with a platinum Marketplace plan switched to a gold plan for lower premiums; was met with higher out-of-pocket costs and now puts off follow-up care
  - A NY participant learned he could not stay with his Medicaid plan, presumably the plan was coming off the market; selected a new plan with help of clinic
  - A NY man churned from Medicaid coverage to Marketplace coverage (with subsidies and ADAP premium assistance) to NY's Essential Plan
    - Has managed fairly well but was without coverage for one month

THE HENRY J. KAISER FAMILY FOUNDATION

Experiences with Coverage: NY and CA

- Like in 2014, those with Medicaid and the Marketplaces coverage generally very grateful, report feeling more secure
- Both Medicaid and Marketplace enrollees worry about maintaining coverage
  - Marketplace enrollees worry about out-of-pocket costs
  - Medicaid enrollees worry about staying on top of recertification
- Some participants report that if they were not insured they would be in worse health; some say they would die and do not consider Ryan White as an option
- Only a few saw changes in HIV care with coverage, have not seen major problems
- Many who gained coverage feel their health is easier to manage

THE HENRY J. KAISER FAMILY FOUNDATION

Experiences of the Uninsured: FL, GA, & TX

- Little has changed since 2014 : All are meeting HIV needs through Ryan White, but suffer from significant health problems going unaddressed

- Many don't know about their state's Medicaid expansion decision; when explained, they are dismayed, not surprised. They would enroll, if they could

- Health insurance matters but finances are the bigger concern:

  Most are unemployed, budgets exceed incomes, some homeless/ living with family, some struggle with transportation needs, food security, child support, and debt (including devastating medical bills, bank and school loans)

- Living without insurance is scary and frustrating

"It's like night and day as far as having health insurance ...knowing that if something happens you don't have to worry...You're gonna be taken care of. But now the reverse is [as an uninsured person] you can't get sick...or anything like that because you got to wonder, how is this gonna be covered? How is it gonna affect HIV?"
–Dallas uninsured

THE HENRY J. KAISER FAMILY FOUNDATION

The Role of the Ryan White Program

- Ryan White plays or has played an important role in the lives of all participants
- Uninsured deeply value Ryan White, say they would be dead without it
- Main challenge with Ryan White is recertification which participants say is burdensome
- Most with coverage are unsure about the role Ryan White plays in their care despite using support services (e.g. case management) likely Ryan White funded
  - Contrasts to 2014 groups where individuals were transitioning to insurance
- Some uninsured worry about how gaining coverage would affect access to Ryan White

Providers and Pharmacies

- Most have positive views of their providers
  - Describing personal relationships with their providers, saying their doctors know everything about their lives
- All say access to HIV specialists is important: they are up-to-date on changing science; new medications coming to market
- Maintaining access to providers is important during coverage changes; losing these connections is a fear of those who have not gained coverage
- Respondents expressed a wide variety of pharmacy preferences:
  - HIV specialty pharmacies vs. mainstream pharmacies
  - Location based on efficiency/ personal service
  - 24 hour availability
  - Mail-order pharmacy vs. brick and mortar

Key Takeaway Points

- ACA is changing the insurance landscape for many with HIV but not evenly across the population:
  - Those in non-expansion states have limited access
  - Access to/knowledge of ADAP support for engagement with private coverage varies
  - Enrollment in affordable coverage highly individualized
  - Others remain uninsured (e.g. undocumented, those with complicated circumstances)

- Ryan White continues to play a crucial role in the lives of many: those who have gained coverage and especially those who remain uninsured

- Ongoing needs:
  - To continue to improve insurance and coverage literacy
  - To continue to collect data and take pulse on the ground, informs future policy

THE HENRY J. KAISER FAMILY FOUNDATION

Implementation of the Affordable Care Act and the Ryan White HIV/AIDS Program

Laura Cheever, MD, ScM
Associate Administrator, HIV/AIDS Bureau

RWHAP Clients, by Health Care Coverage, 2014

- Medicaid: 33.4
- No coverage: 25.4
- Medicare: 10.0
- Medicare and Medicaid: 7.7
- Multiple coverages: 7.6
- Private Employer: 6.3
- Private Individual: 5.3
- Other plan: 4.0
- Veteran's Administration/TriCare: 0.3
- Indian Health Services: 0.0

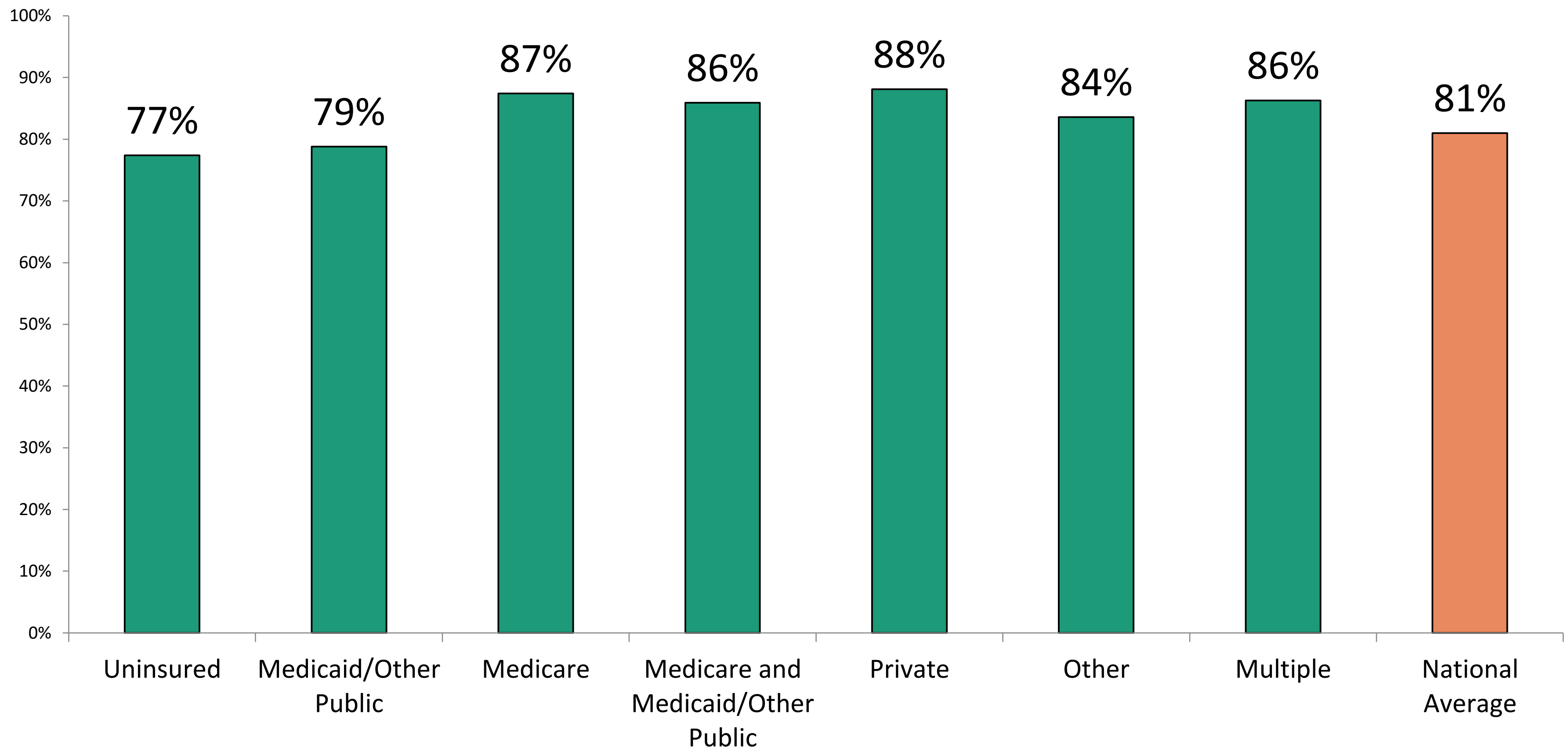
RWHAP Clients, by Federal Poverty Level and Health Care Coverage, 2014

	All clients	≤100% FPL	101–138% FPL	139–250% FPL	251–400% FPL	>400% FPL
Multiple coverages						
No Coverage	25.4	26.1	22.2	25.3	19.6	29.2
Other Plan						
Medicare and Medicaid	7.7	8.3	12.0	5.7	4.3	2.6
Medicaid	33.4	42.9	24.0	14.4	14.9	13.2
Medicare	10.0	7.5	18.7	14.7	8.1	5.6
Private individual						
Private employer						
Bracket (Medicare and Medicaid + Medicaid + Medicare)	51.2%	58.7%	54.7%			

Y-axis: 0%, 10%, 20%, 30%, 40%, 50%, 60%, 70%, 80%, 90%, 100%

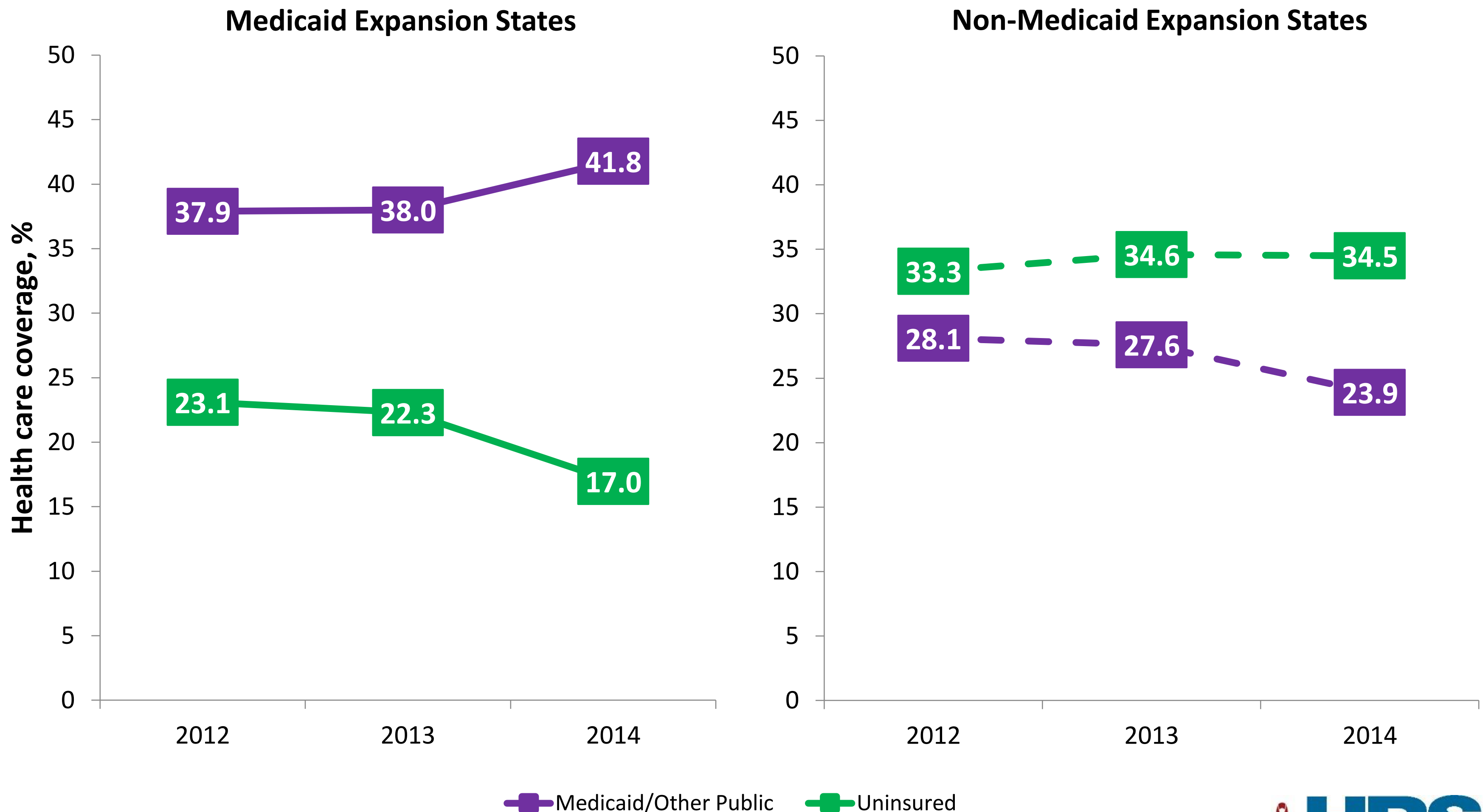
Legend: Multiple coverages; No Coverage; Other Plan; Indian Health Services; Veterans Administration; Medicare and Medicaid; Medicaid; Medicare; Private individual; Private employer

Viral Suppression among RWHAP Clients by Source of Health Care Coverage, 2014



HRSA
Ryan White & Global HIV/AIDS Programs

Health Care Coverage, by Medicaid Expansion Status, 2012–2014



HRSA
Ryan White & Global HIV/AIDS Programs