ACA Implementation for People with HIV: Current Challenges & Opportunities for Tomorrow

Carl Schmid
Deputy Executive Director
The AIDS Institute
Washington, DC
October 2, 2014
Seminar Overview

- Key Issues
- TAI/NHeLP discrimination complaint
  - Carl Schmid, The AIDS Institute
- National patient advocates response
  - Lisa Stand, The AIDS Institute
- State Perspectives
  - California: Anne Donnelly, Project Inform
  - Florida: Michael Ruppal, The AIDS Institute
- Medical Provider Perspective
  - Andrea Weddle, HIV Medicine Association
- HIV Testing Coverage - Lisa Stand
- Looking Ahead to 2015 - Lisa Stand

The AIDS Institute
Key Issues

• Enrollment
• Medicaid Expansion
• Plan Benefits
• Patient Out of Pocket Costs
• Coordination with Ryan White Program
• Public Opinion & Congressional Action
• Discrimination Complaint
Slow Start; Strong Finish

• Over 8 million enrolled in the marketplace
  – 1.4 million from CA
  – 28% age 18-35
• Almost 5 million in Medicaid & CHIP
• Over 3 million under age 26 on parents’ plan
• 5 million gain coverage outside marketplace
• Caveats
  – How many paid premiums? (7.3 million)
  – How many were previously uninsured?
  – How many enrolled since open enrollment?
Health Coverage Growing

- 12 million will gain coverage in 2014 due to ACA (CBO estimate)
- 4 percent of Americans are newly insured in 2014 — about half of them through the exchanges (Gallup Survey)
- RAND study found that much of the growth in coverage due to employer sponsored insurance
- CDC National Health Interview Survey: Rate of uninsured dropped from 20.4% in 2013 to 18.4% in 2014 (ages 18-64)
Uninsurance Rate Among Adults: 2008-2014

Sources: National Health Interview Survey; Gallup/Healthways.
The Affordable Care Act is Working
More Americans are covered
26% fewer uninsured in just one year.
HealthCare.gov
ACA's Initial Reception

How states fared in the first year’s effort to enroll individuals in private coverage through the Affordable Care Act. Percentages reflect by how much enrollment in each state by April 2014 exceeded or fell short of targets held by the Obama administration. Some states say their own targets differed.

Source: Department of Health and Human Services - The Wall Street Journal
# ACA Enrollment by State

<table>
<thead>
<tr>
<th></th>
<th>State</th>
<th>Selected a QHP</th>
<th>Found Eligible for Medicaid/CHIP</th>
<th>TOTAL</th>
</tr>
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<tr>
<td>1</td>
<td>CA</td>
<td>1,405,102</td>
<td>1,700,000</td>
<td>3,105,102</td>
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<td>FL*</td>
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<td>NY</td>
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<td>TX*</td>
<td>733,757</td>
<td>141,494</td>
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<td>6</td>
<td>IL</td>
<td>217,492</td>
<td>181,070</td>
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<td>7</td>
<td>KY</td>
<td>82,747</td>
<td>357,990</td>
<td>440,737</td>
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<td>8</td>
<td>NC*</td>
<td>357,684</td>
<td>73,898</td>
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<td>9</td>
<td>GA*</td>
<td>316,543</td>
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<tr>
<td>10</td>
<td>PA*</td>
<td>318,077</td>
<td>42,335</td>
<td>360,412</td>
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</tbody>
</table>

Source: HHS May 1, 2014
*State did not expand Medicaid for 2014
Current Status of State Medicaid Expansion Decisions

Notes: Data are as of August 28, 2014. *AR, IA, MI, and PA have approved Section 1115 waivers for Medicaid expansion. In PA, coverage will begin in January 2015. NH is implementing the Medicaid expansion, but the state plans to seek a waiver at a later date. IN has a pending waiver to implement the Medicaid expansion. WI amended its Medicaid state plan and existing Section 1115 waiver to cover adults up to 100% FPL in Medicaid, but did not adopt the expansion.
Sources: Current status for each state is based on data from the Centers for Medicare and Medicaid Services, available here, and KCMU analysis of current state activity on Medicaid expansion.
Recent Medicaid Expansion

Pennsylvania: August 2014 – Waiver approved
New Hampshire: June 2014 – SPA approved
Iowa: December 2013 – Waiver approved
Michigan: December 2013 – Waiver approved
Arkansas: Sept. 2013 – Waiver approved

Enrollment for People with HIV

• Slow start; strong finish
• Depends on State
  – Medicaid Expansion
  – State Ability/Willingness
• NASTAD Enrollment Reports (ADAP clients)
  – Medicaid: 12,004
  – Marketplace: 13,129
• Medicaid enrollment year long
• Special enrollment qualifications
Examined Number of people with HIV who will gain coverage

Of the 407,000 age 19-64 currently in care:

- 70,000 are uninsured who could gain new coverage
- With 26 states expanding Medicaid
  - 26,560 gain Medicaid
  - 25,190 receive subsidized marketplace coverage
  - 17,980 unsubsidized marketplace coverage
- If all states expanded Medicaid
  - 46,910 gain Medicaid
ADAP purchasing QHPs (premiums, Rx co-pays, or deductibles)

ADAP not purchasing QHPs (most are planning)

ADAP piloting QHP purchase
Ryan White Premium & Co-pays

- Ryan White has historically paid insurance premiums & co-pays
  - $397 million in FY13 (NASTAD)
- Blue Cross/Blue Shield in LA & ND refused to accept
  - Cited HHS statements that discourages plans to accept outside payments
- All LA plans then decided not to accept Ryan White payments
- Lambda Legal filed suit
- CMS issued interim final rule requiring plans to accept Ryan White Payments
  - Still discourages use of commercial payments
  - Issue of Rx co-pays by companies unresolved

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Plan Benefits

- Not all ARVs on plan formularies
  - Due to Essential Health Benefits design
    - Based on number of drugs in state benchmark
    - Combination drugs/single tablet regimens
      - US Pharmacopeia 5.0 does not recognize combination drugs
      - Draft version 6.0 does
    - Using current EHB process for first 2 years
  - Appeals process
    - Strengthened by CMS for 2015
Plan Benefits

• Formularies not transparent
• No requirement to cover new drugs
• Drugs removed from plans
• Utilization Management Techniques
  • Prior Authorization
  • Quantity Limits
Utilization Management

Utilization Management of HIV/AIDS Medicines

- Exchange Plans: 26% UM, 74% No UM
- Employer Plans: 8% UM, 92% No UM
- Benchmark Plans: 5% UM, 95% No UM
Co-Pays, Co-Insurance

- High co-pays, use of co-insurance
  - 50% co-insurance common
    - Plans supposed to mirror employer sponsored plans
    - HIV/AIDS Rx subject to coinsurance in about 55% of plans, with an average coinsurance of 35% (Avalere)
  - No transparency; beneficiary does not know cost
    - $1,000/drug
    - Out of pocket limits, but costs front loaded in year
    - Ryan White can help
  - Patients can fall out of treatment
  - Place HIV Rx on highest tiers
    - Is this discrimination?

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EXCHANGES IMPOSE HIGH OUT-OF-POCKET COSTS ON HIV/AIDS PATIENTS

- NNRTIs
- NRTIs
- Protease Inhibitors
- HIV - Other

Percent of Plans:
0% 8% 16% 24% 32% 40%

- Coinsurance of 40% or Higher for all RX classes
- Coinsurance of 30% or Higher for all RX classes

COINSURANCE FOR HIV/AIDS


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Deductibles

- High Deductibles
- Separate Rx Deductibles
- Milliman Study (May 2014):
  - 88% of employer based plans have combined medical and Rx deductible
  - 46% Silver plans have combined deductible
Relative Increase in Out of Pocket Costs for Typical Silver Plan with Combined Deductible Compared to Employer Coverage

- Hospital: 122%
- Professional & Other: 118%
- Prescription Drugs: 230%
- Total: 138%

Access to Care & Pharmacies

- High Deductibles
- Adequacy of Physician networks
  - Are Ryan White providers included in plan networks?
  - Ryan White Grantees are essential community providers
- Difficult to find providers on websites
  - Need Increased transparency
- Pharmacy networks
  - Mail order requirements

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Expanded Medicaid Benefits

- Alternative Benefit Plan
  - Based on Benchmark Options
  - State Plan Amendment
- To date, of the 27 Medicaid expansion states (including D.C.) (NHfLP, Aug. 2014)
  - 19 have aligned with current Medicaid
  - 5 have not
  - 3 still pending
Monitor Implementation

- Coordination with Ryan White Program
  - Is coverage completion happening?
- Are patients falling out of care & treatment?
- Is the medical care adequate and culturally competent?
- Is the appeals process working?
- Report problems
http://www.hivhealthreform.org/speakup/
Public Opinion

• Real Clear Poll Averages (Sept. 2-15)
  • Favor Health Reform: 41%
  • Oppose Health Reform: 51.4%
Congressional Opposition

- Highly Partisan
- Republicans attack every vulnerability
- Democrats defend law
- Administration focus on positive elements
  - Ultimately admitted web malfunctions
- Countless votes to repeal
- Focus now on changes
  - Little to no chance of passage, but November election
  - Individual mandate; medical devise tax, IPAB
- New HHS Secretary

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Florida QHP Discrimination Complaint

- Reviewed all 36 Silver QHPs offered in the Marketplace
  - 10 Issuers

- Rx Analysis
  - Covered drugs, cost-sharing and coverage limitations
Findings

- Most plans have a range of tiering and nominal cost-sharing for HIV drugs
- Four issuers placed every drug, including generics, on highest tier and had very large patient co-insurance (e.g. 40% or 50%)
## Examples of Good Florida Plans

<table>
<thead>
<tr>
<th>QHP Issuer</th>
<th>Benefit Design</th>
<th>Cost-Sharing</th>
</tr>
</thead>
</table>
| **Ambetter** | • Most HIV drugs on Tier 1 or 2  
• 2 HIV drugs on Tier 4 | • Tier 1 copays range $10-$25 (after deductible in some plans)  
• Tier 2 copays range $50-$75 (after deductible in some plans)  
• Tier 4 coinsurance ranges 20-30%, with one plan instead using $250 copay (after deductible) |
| **Blue Cross** | • Most HIV drugs on Tier 1 or 2  
• Only 1 drug on Tier 3 without a generic or other alternate form on lower tier | • Tier 1 copays range $10-$25 (after deductible in some plans)  
• Tier 2 copays range $40-$70 (after deductible in some plans)  
• Tier 3 copays range $70-$100 |
| **Molina** | • Most HIV drugs on Tiers 1 and 2  
• 1 drug on Tier 3  
• 2 drugs on Tier 4 | • Tier 1 copay $20  
• Tier 2 copay $55  
• Tiers 3 and 4 require 30% coinsurance |

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### Examples of Bad Florida Plans

<table>
<thead>
<tr>
<th>QHP Issuer</th>
<th>Benefit Design</th>
<th>Co-Insurance and Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td>CoventryOne</td>
<td>• Tier 5 – All HIV Drugs, Including Generics</td>
<td>• 40% after $1,000 Rx deductible</td>
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<td></td>
<td></td>
<td>• Most Require Prior Authorization</td>
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<td></td>
<td>• Quantity Limits (e.g., no 90-day supply)</td>
</tr>
<tr>
<td>Cigna</td>
<td>• Tier 5 – All HIV Drugs, Including Generics</td>
<td>• 40-50% after deductible ranging $0 - $2,750</td>
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<tr>
<td></td>
<td></td>
<td>• 30-day supply limits</td>
</tr>
<tr>
<td>Humana</td>
<td>• Tier 5- All HIV Drugs, Including Generics</td>
<td>• 40-50% after $1,500 deductible</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 30-day supply limits</td>
</tr>
<tr>
<td>Preferred Medical</td>
<td>• Specialty Tier- All HIV Drugs, Including Generics</td>
<td>• 40% co-insurance</td>
</tr>
</tbody>
</table>

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Sec. 1557 of the ACA

“an individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.)...or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance...”
The Rehabilitation Act

- The Rehabilitation Act prohibits programs and services which receive federal funds from discriminating against persons with disabilities.

- Regulations implementing the law state programs subject to the Rehabilitation Act may not “provide benefits or services in a manner that limits or has the effect of limiting the participation of qualified persons with disabilities”

- HIV and AIDS are disabilities
Enforcing Non-Discrimination Provisions

• We believe these plans violate the ACA non-discrimination provisions

• In reaction, we have:
  • Raised with Administration & Congress
  • Raised publicly through the Media

• CMS response:
  • Take case to state insurance commissions
  • As part of letter to issuers indicated it will conduct outlier tests for 2015 plans

• No regulations or guidance issued to implement Sec. 1557

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Discrimination Complaint

• The AIDS Institute filed complaint with HHS Office for Civil Rights on May 29, 2014 against 4 plans

• With National Health Law Program (NHeLP)
  • NHeLP “protects and advances the health rights of low-income and underserved individuals.”

• Asking OCR to investigate and take corrective action
  • Against Florida plans & others throughout country
Health care advocates said on Thursday that four insurers offering plans in the new federal marketplace discriminated against people with H.I.V. or AIDS by requiring them to pay high out-of-pocket costs for drugs to treat H.I.V., including generic medications.

Two groups, the AIDS Institute and the National Health Law Program, filed a complaint on Thursday with the Department of Health and Human Services’ Office for Civil Rights, saying the insurers had violated a provision in the new health care law that prohibits discriminating against consumers because of their medical conditions. They said the insurers had subjected people infected with H.I.V. to restrictions on medications that most patients take daily to keep the virus in check.

Four Florida insurance companies offering Affordable Care Act policies are discriminating against people with HIV or AIDS, according to two health-rights organizations that plan to file a formal complaint with the federal government Thursday.

The complaint by the AIDS Institute and the National Health Law Program — nonprofits advocating for the health rights of the poor and those living with chronic diseases — cites CoventryOne, Cigna, Humana and Preferred Medical for creating prescription-drug policies that the groups say discourage people with HIV/AIDS from enrolling in their Florida healthcare marketplace plans.

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Response from Insurers

- HIV drugs are covered as required by law
  - NYT: “Cigna said the company’s H.I.V. drug coverage was in line with accepted medical practice...offers an array of plans in the federal marketplaces, including some that offer more comprehensive coverage.”

- HIV patients protected by out-of-pocket cap
  - Healthline: “Once the out-of-pocket maximum is reached for the year, the plan pays 100 percent of the cost for any drug therapy, including HIV drugs,’ the insurer said.

- Charge high cost-sharing to other patient populations too
  - Tampa Bay Times: “Humana also noted that drugs for other conditions, such as rheumatoid arthritis and multiple sclerosis, are also on highest payment tier.”

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Patient Community Response

• “WOW!!! Finally Someone is doing something about the heck I have been going through. I read your complaint today on the Miami Herald, and reading it I swear you copied my notes from when I researched and individual policy.”

• Lawyer in Florida told AP of 30+ clients unable to afford HIV medications and wanting to disenroll from Humana, Coventry and others
  • “They go to the pharmacy and find their drug is not covered and they can’t afford them. There’s no way.”
Patient Community Response

• Several phone calls and emails from Humana enrollees in Georgia. For example, enrollee charged $1,200 per month in cost-sharing and can’t afford it.

• “My Humana Silver plan insurance the cost was $882.97 a month which I cannot afford.”
  --HIV negative partner of a HIV positive person who wants to take Truvada as PreP in Florida

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EVIDENCE MOUNTING OF DISCRIMINATION AGAINST PEOPLE WITH HIV BY SOME INSURANCE PLANS

Study Demonstrates Some Plans Put Every HIV Drug on Highest Tier, Stick Beneficiaries with Costs

Washington, DC – A study released this week conducted by Avalere Health offers growing evidence that certain plans offered through the marketplace are discriminating against people with HIV/AIDS and other health conditions by placing every drug in certain classes, including generics, on the highest tier and charging beneficiaries exorbitant amounts in cost-sharing.

In an analysis of 123 plans from all states, Avalere found that of the four classes of HIV drugs, between 27% and 39% of the plans placed every HIV drug, including generics, on the highest tiers, where patients are charged 30% or more in co-insurance. Of those plans, most are charging patients more than 40% co-insurance. [See graphic.]

“We want the Affordable Care Act (ACA) to work, and we want it to work for people living with HIV/AIDS and others with chronic health conditions,” said Carl Schmid, Deputy Executive, The AIDS Institute. “But shifting the cost of medications to the patients is not only blatant discrimination but can lead to poorer health outcomes, since beneficiaries will not be able to afford and access their life-saving medications.”
Next Steps

- The AIDS Institute & HIV advocates in other states interested in filing more complaints
- Other disease groups also interested
- Await decision from Office of Civil Rights
- Issuers submitting 2015 plans now
  - Hope CMS adequately reviews them
  - Community must review plans
- CMS also developing Sec. 1557 Regulations
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THANK YOU

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