The Affordable Care Act: Impact on the Continuum of HIV Care in the US

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Note: For comparison with data for 1999 and later years, data for 1987–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.
Stable, healthy, serodiscordant couples, sexually active
CD4 count: 350 to 550 cells/mm$^3$

Primary Transmission Endpoint
Virologically-linked transmission events

Primary Clinical Endpoint
WHO stage 4 clinical events, pulmonary tuberculosis, severe bacterial infection and/or death

Immediate ART
CD4 350-550

Delayed ART
CD4 <250

Randomization

Cohen et al. IAS 2011
HPTN 052: HIV-1 Transmission

Total HIV-1 Transmission Events: 39

Immediate Arm: 4

Delayed Arm: 35

p < 0.0001

96% Reduction

Cohen et al. IAS 2011
Mean CVL and New HIV Cases, 2004-08

Mean CVL & Newly Diagnosed HIV cases $p=0.005$
Treatment = Prevention
CDC HIV Care Continuum (July, 2012)

- 82% Diagnosed
- 66% Linked to Care
- 37% Retained in Care
- 33% Prescribed ART
- 25% Virally Suppressed
The Care Challenge (2011)

<table>
<thead>
<tr>
<th>Stage of Engagement in HIV Care</th>
<th>Number of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-Infected</td>
<td>1,178,350</td>
</tr>
<tr>
<td>Need ART</td>
<td>751,760</td>
</tr>
<tr>
<td>Not Diagnosed</td>
<td>657,955</td>
</tr>
<tr>
<td>Not Linked to Care</td>
<td>453,048</td>
</tr>
<tr>
<td>Not Retained in Care</td>
<td>236,400</td>
</tr>
<tr>
<td>Not On ART</td>
<td>751,760</td>
</tr>
<tr>
<td>Not Undetectable</td>
<td>849,875</td>
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</tbody>
</table>
Our Goal

- HIV-Infected
- Diagnosed
- Linked to Care
- Retained in Care
- On ART
- Undetectable
CDC Treatment Cascade: Race

<table>
<thead>
<tr>
<th>Race</th>
<th>Diagnosed</th>
<th>Linked to care</th>
<th>Retained in care</th>
<th>Prescribed ART</th>
<th>Virally suppressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>81%</td>
<td>62%</td>
<td>34%</td>
<td>29%</td>
<td>21%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>80%</td>
<td>67%</td>
<td>37%</td>
<td>33%</td>
<td>26%</td>
</tr>
<tr>
<td>White</td>
<td>85%</td>
<td>71%</td>
<td>38%</td>
<td>35%</td>
<td>30%</td>
</tr>
</tbody>
</table>
LINKED TO HIV CARE - ATLANTA, GA

Proportion of adults/adolescents newly diagnosed with HIV from 2006-2010 with a reported CD4/viral load within 3 months of HIV diagnosis (%)
Impact of Social Determinants of Health on the Care Cascade

Every step is affected by

- Stigma and discrimination
- Racism, homophobia
- Poverty
- Risk of criminalization
- High incarceration rates and difficulty with transition
- Housing instability
- Employment instability
- Co-existing conditions: substance use, mental health disorders
How Could the ACA Impact the Continuum of HIV Care?
Increasing Diagnosis

- ACA will improve access to HIV testing in medical care settings
  - HIV screening, ages 15-65, and “others at increased risk” covered under Essential Health Benefits
  - USPSTF “A” recommendation supports coverage

- ACA decreases stigma by eliminating exclusion for pre-existing conditions and risk of being dropped or charged higher rates by insurer
Linkage and Retention

- Challenging to find a skilled HIV care provider: panels constantly changing; difficult to access or determine who is an HIV specialist
- ACA requires plans to include some – but not enough – designated Essential Community Providers (ECPs)
- Many RW clinics in public health departments do not have infrastructure for billing private insurance; ACA plans may disrupt continuity of care
- Co-pays and deductibles are daunting
- Depression, substance use disorders not well covered
- No coverage for transportation or child care
Antiretroviral Access and Adherence

- High levels of adherence are required to maintain optimal viral suppression
- Maximal viral suppression is required for
  - Optimal benefit for individual health
  - Optimal benefit for prevention of HIV transmission
- Continuous medication access is required
- Suboptimal adherence leads to viral resistance and virologic failure, affecting both current and future regimens
ACA Issues with ARV Access

- ARV usually on the highest tiers of ACA plans (sometimes different than non-ACA plans)
  - Tiers 4-5, and “specialty” = co-insurance rather than flat co-pays; cost-sharing may not apply to specialty drugs
  - Co-insurance can run 10-50% of total drug price

- May require prior approval thus slowing access

- Some plans cover only some ARV, but not all that are recommended by guidelines; some exclude single-tablet regimens that improve adherence
So, How’s It Going Out There, Georgia?

“Not pretty” is how ACA is going here, too many unknowns, high co-pay for HIV meds, etc. (RW Clinic Director)

- Patients have no concept of what "copay" or deductible or coinsurance means. It’s a steep learning curve. (RW Clinic Administrator)

- After the case manager explained what a deductible was, the patient said "Forget that, I can't afford it!" (RW Clinic Administrator)

- Patients are just refusing to sign up because they will have to leave the clinic. (RW Clinic Director)
What’s Up With That ACA, Y’all?

• We're on a Humana plan but BCBS won't accept us. (But patients have BCBS.) Our X-ray vendor doesn't take the ACA plans. (RW Clinic Director)

• We had a patient blow up at us today because we encouraged him to enroll and he said we cannot make him. (RW Clinic Manager)

• The ones who want insurance are the ones who had it before they lost their jobs. They understand it. The rest of our patients can’t afford it. (RW Clinic Manager)

• Many have had trouble getting meds covered, getting services covered, getting cards to verify that they are covered etc. It has been a bit of a nightmare. I don’t think I have talked to anyone where this has been smooth, but again my “n” is small. (RW Clinic Director)
Navigation Needed

- 50% have selected plans [in which] they can’t afford the copays on the medications...Most of these people did not use the services of a Navigator. We have a few trying to find out how they may be able to appeal their plan selections since they can’t get the medications due to copay costs. (RW Clinic Director)

- We couldn't become Certified Application Counselors because of the law in GA [HB 198] that requires a license costing about $300 per person. Now we can't even help our patients. We have to send them elsewhere to enroll. (RW Clinic Director)

- Very little education going to patients or patient navigation people. [Navigators] are not sophisticated about the issues with our [HIV] patients. (RW Clinic Director)
How About Those ARVs?

• A pharmacy that many of our patients use says that some HIV patients are walking away without their prescriptions. (RW Clinic Director)

• One man found a premium he could afford but researched the cost of Atripla® and found it would cost him $800/month. He called the clinic asking what to do and we really didn't know the answer. (RW Clinic Manager)

• Every one of our clients with ACA plans has trouble with their meds. (RW Clinic Director)
Really?!?

• Patient was on dolutegravir before changing to ACA BCBS and was running out of meds. BCBS required prior authorization. We spent an hour on the phone with [XYZ Pharmacy]. The pharmacist demanded an explanation of why he was on that drug. They said they would call back but they never did. He finally got his drugs a week late and it cost him $3000. (Nurse, private office)

• Co-insurance for medications is the number one determinant for not signing up for the ACA. Our clients cannot afford $300-500/month for meds as an insured person. (RW Clinic Administrator)
Key Recommendations

- Restricted provider networks are problematic: increase % of ECPs required and allow out-of-network providers when HIV specialty care is not available
- Improve quantity and quality of navigation efforts
- Provide intensive TA and infrastructure funding to clinics around insurance billing
- Need regulations to eliminate prior authorization and high copays/coinsurance for ARVs (discriminatory against people with HIV); assure all meds are covered (including single tablet regimens)
- Take action to eliminate obstructive state laws
Key Recommendations

- Provide transparency and clear tools for estimating out of pocket costs. Require transparency of insurers.

- Extend the open enrollment window for Ryan White patients due to structural challenges in transitioning to ACA.

- Begin immediate data collection and analysis is urgently needed to troubleshoot problems, maintain quality, estimate impact on care continuum.

- Be lenient about maintaining the RW safety net and easy ADAP access. People will be churning in and out of RW to maintain continuity of care and ARVs.
Key Recommendations

- HHS should review complaint appeals about ACA plans, especially in states that obstruct implementation

- Require all Ryan White programs to meet minimum standards and timelines for implementation of plans for premium, co-pay, co-insurance, and deductible assistance

- Require minimum standards for facilitating ACA implementation by all state health departments
Summary

- The ACA offers many benefits as well as significant challenges
  - Care provided by ACA plans must be equal to or better than that of Ryan White to be acceptable
  - Inconsistent access to medications could quickly erase significant progress in halting the epidemic

- We should take every opportunity to quickly give feedback to HHS, CMS, HRSA about real-world impact on people with HIV

- Where discrimination occurs, complaints should be made at the state and federal level and swift legal action initiated as appropriate

- We need data – and we need it NOW!