What is the future of the Ryan White program?

Does it have a future?
Overview of the Ryan White Program

- **Ryan White HIV/AIDS Treatment Extension Act**
  - Provides medical care and supportive services to persons living with HIV/AIDS
  - Designed to fill in gaps in services
  - Funded at $2.392 billion
  - Provides services to approximately 529,000 persons living with HIV/AIDS
    - Most are below poverty line and are racial/ethnic minorities
    - ADAP serves about 175,000 clients
Parts of Ryan White

- **Part A** provides emergency assistance to Eligible Metropolitan Areas and Transitional Grant Areas that are most severely affected by the HIV/AIDS epidemic.
- **Part B** provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 5 U.S. Pacific Territories or Associated Jurisdictions.
- **Part C** provides comprehensive primary health care in an outpatient setting for people living with HIV disease.
- **Part D** provides family-centered care involving outpatient or ambulatory care for women, infants, children, and youth with HIV/AIDS.
- **Part F** provides funds for a variety of programs:
  - Special Projects of National Significance
  - AIDS Education Training Centers
  - Dental Program
  - The Minority AIDS Initiative
Key Dates in History

- The legislation was first enacted in 1990 as the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act.
  - First appropriated at $220.5 million
- Current program’s authorization period ends on September 30, 2013
How Has the Program Changed Over Time?

- The Ryan White legislation has been adjusted with each reauthorization to accommodate new and emerging needs, such as:
  - Increased emphasis on funding of core medical services
  - Changes in funding formulas (transition from AIDS to living HIV cases)
  - Separation of Part A into EMAs and TGAs
  - Expansion of role of Part D and Dental Program
What’s Different This Time? - Politics

- Congress and Washington atmosphere
  - Rise of “Tea Party” elements in Republican party has reduced or eliminated bipartisanship even on most non-partisan of issues
  - High level of brinkmanship and unwillingness to compromise
  - Speaker Boehner does not entirely control his party – debt negotiations prime example
  - US Senate Democrats lead by Harry Reid, but they do not have critical 60 votes to block filibuster attempts
    - Democrats 53  Republicans 47
  - Outcome of November election will critically shape next session of Congress and White House
  - Attacks on all things healthcare related
What Else is Different? - Science

- **HPTN 052** is the name of a clinical trial which examined the extent to which antiretroviral therapy (ART) can, when taken by people who have HIV, decrease their infectivity and thereby reduce the chance that they will pass HIV on to their sexual partners.

- Initiation of ART by HIV-infected individuals substantially protected their HIV-uninfected sexual partners from acquiring HIV infection, with a 96 percent reduction in risk of HIV transmission.

- **Result:** Treatment is Prevention
PLWHAs Connection to Treatment

Engagement in HIV care:
- Estimated HIV-infected: 133,417 (100%)
- HIV-diagnosed: 110,736 (83% of infected)
- Ever linked to HIV care: 95,340 (71% of infected)
- Retained in care in 2010: 71,168 (86% of diagnosed)
- Retained in care in 2010: 71,168 (53% of infected)
- Presumed ever started on ART: 64,094 (75% of linked to care)
- Presumed ever started on ART: 64,094 (90% of retained in care)
- Suppressed viral load (<=400 copies/mL): 52,015 (39% of infected)
PLWHAs Insurance Status

56% of PLWHA in the NY EMA are Medicaid recipients

59,915 PLWHA in the NY EMA received Medicaid services in 2010

Total cost of services provided = $2.3 billion
Health Care Reform – Current Situation

**Right Now** -- Insurance carriers cannot refuse to cover children with HIV/AIDS

**Right Now** -- Insurance carriers cannot withdraw coverage of adults/children with HIV/AIDS who become ill

**Right Now** -- No monetary cap on essential health benefits for PLWHA over the course of the lifespan

**Right Now** -- ADAP counts toward true Out of Pocket spending limit for medications for Medicare recipients
Health Care Reform - Coming

2014 -- PLWHA who earn less than 138% of the FPL will be covered by Medicaid

2014 -- Insurance carriers cannot refuse to provide insurance to PLWHA and cannot establish cost caps

2014 -- PLWHA lacking access to insurance can purchase private coverage through Insurance Exchanges

2014 -- Low- or middle-income PLWHA will be able to obtain tax credits for the cost of insurance
An estimated 50,000 to 70,000 New York residents will become newly eligible for Medicaid as a result of Medicaid Expansion.

In addition, an estimated 110,000 to 440,000 individuals may become enrolled in Medicaid or Insurance Exchanges.
What does health reform mean?

- Starting in 2014, most PLWHAs will have access to health insurance either through Medicaid or insurance exchanges.
  - Medicaid discrimination against persons with HIV but not AIDS ends.
  - Huge movement of PLWHAs into some level of insurance coverage.
- Coverage for HIV care in many cases will be dramatically improved.
So…

- With major expansion of health coverage, why do we need Ryan White?
  - Unpredictability of health care reform – gaps in coverage unclear
  - Non-native born residents
  - Access to supportive services: housing, case management, food/nutrition, legal services, etc.
  - Preserving Ryan White system of care
What are our Options?

- Full reauthorization
- Simple extension of program
- No activity
Benefits of Reauthorization

- Eliminate 75/25 core/non-core medical services requirement – no guarantee would happen
- Ensure continued viability of program / ensure stability in HIV infrastructure
- Update programs to accommodate change in treatments and epidemic
- Better position Ryan White programs for implementation of health care reform

- Expansion of program to other populations (Hepatitis C) – is this a benefit?
Disadvantages to Reauthorization

- Fractured partisan Congress with unpredictable legislative process
  - What would be the outcome?
- Collapsing or elimination of Parts of program a possibility
- Elimination of local control and Planning Councils possible
- Divisions within HIV community over structural changes
- Raise liabilities in some populations we serve
Member in House and Senate must sponsor/introduce legislation

Goes through Congressional Committee process
- House: Energy and Commerce Committee
  - Chair: Fred Upton (R-MI)
- Senate: Health, Education, Labor and Pensions Commission
  - Chair: Tom Harkin (D-IA)

Vote on floor of both chambers

Conference Committee process
- Revote in both chambers

Signed by President into law
If no reauthorization...

- Program can continue beyond its authorized period without reauthorization
  - Congress can continue to fund program without reauthorization
  - Many programs are never reauthorized (HOPWA) and still continue
  - No changes made: core/non-core medical services requirement continues
  - Hold harmless provisions will disappear
Going Forward….

- Many in HIV community are leery of full reauthorization
  - Unpredictability of Congressional leadership
  - Lack of agreement among national HIV partners can cause complications
  - Elections in November will change prospective on how to proceed in 2013
For information

Matthew Lesieur

Director of Public Policy
VillageCare

Vice President for Public Policy
The National Association of People with AIDS

(212) 337-5601
MatthewL@villagecare.org
mlesieur@napwa.org