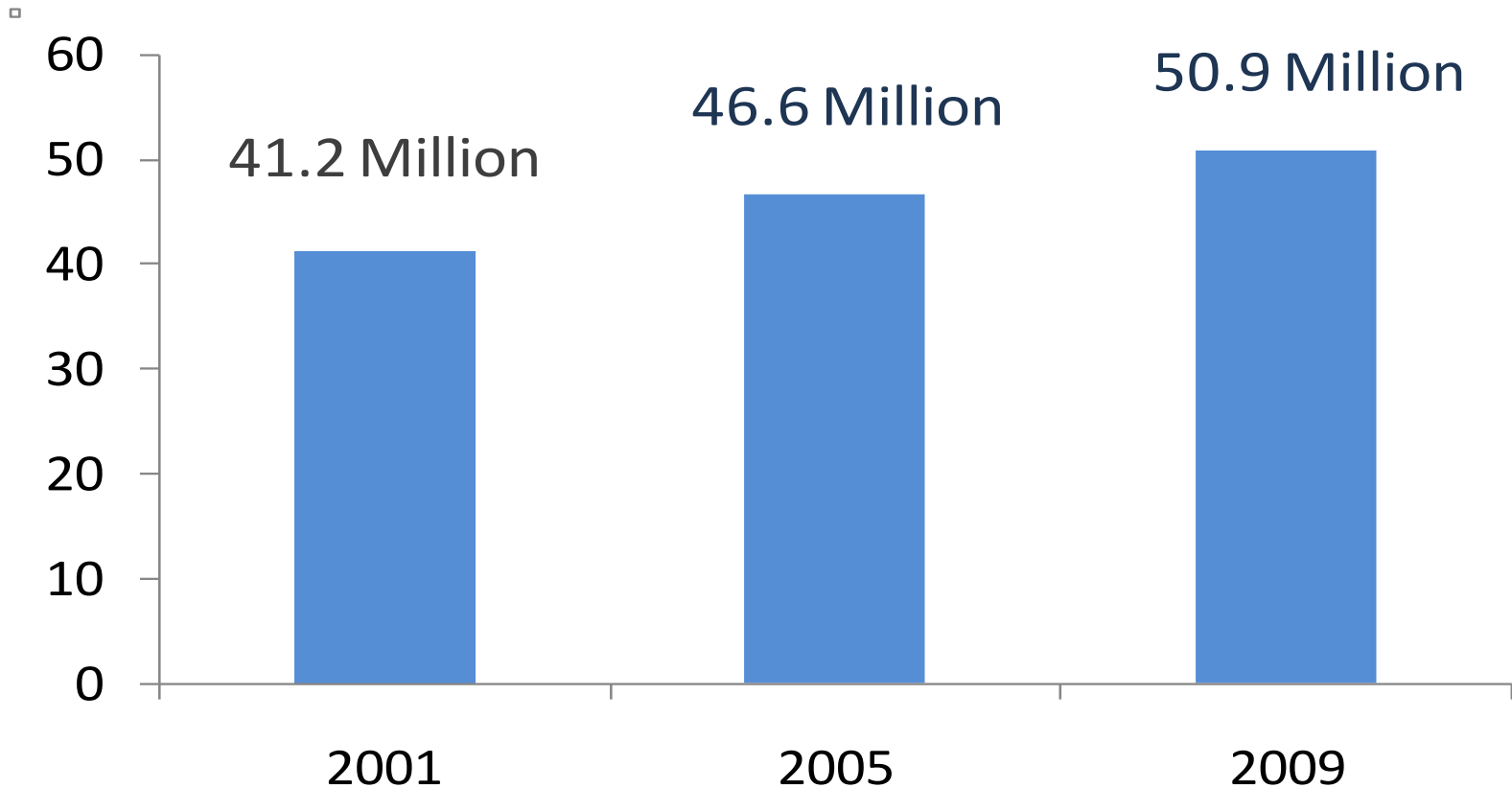


# Health Care Reform Update: Initiatives to Address the Care and Treatment Needs of People Living with HIV

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November 2012*

# Number of Uninsured Americans



Sources: Center on Budget Policies and Priorities, *The Number of Uninsured Americans is at an All-Time High* (2006), Kaiser Family Foundation, *The Uninsured: A Primer* (2010).

## Where We Are:

Status Quo = Access to HIV Care Crisis

Medicaid/ Medicare are lifelines to care, but disability standard means they are very limited

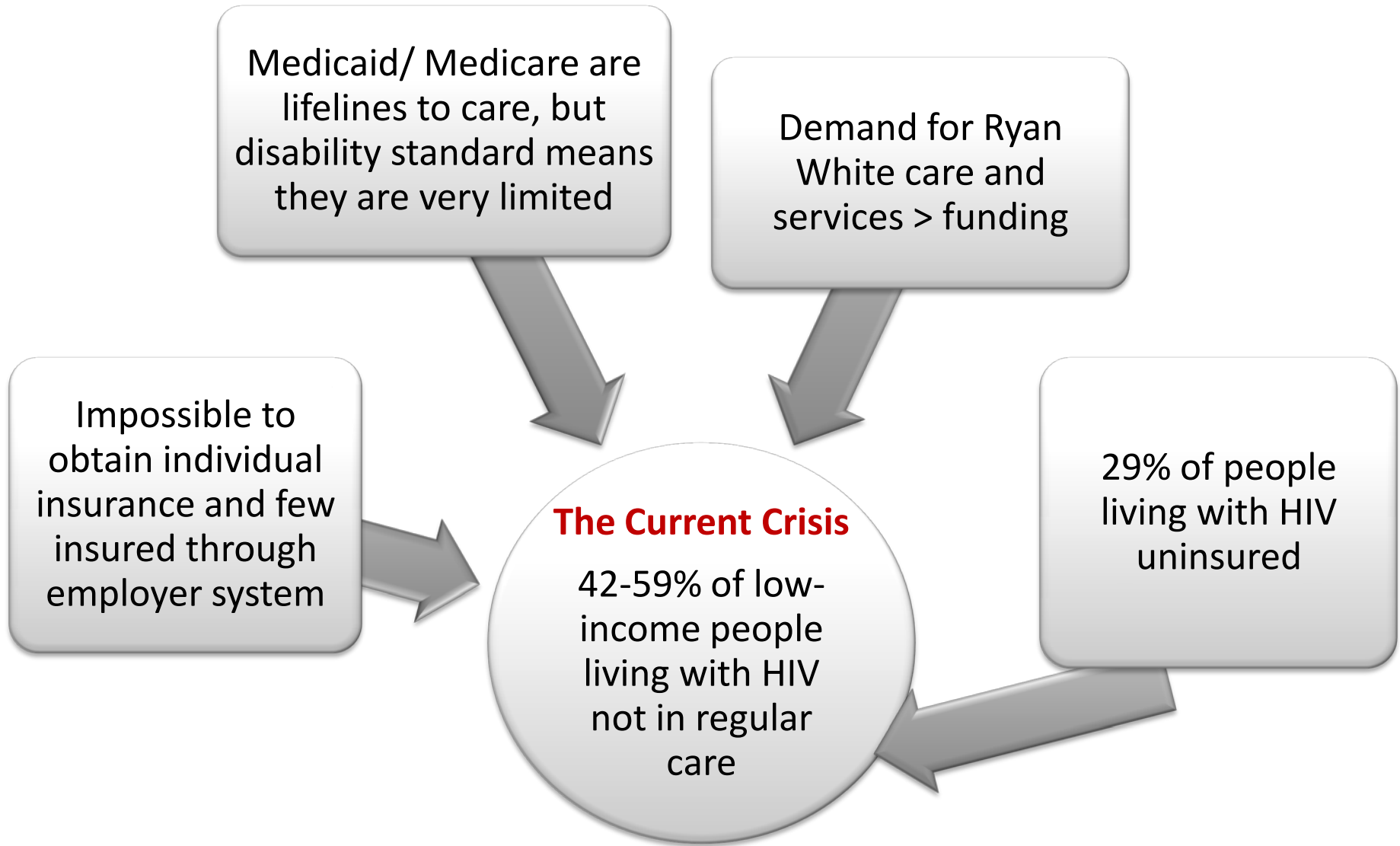
Demand for Ryan White care and services > funding

Impossible to obtain individual insurance and few insured through employer system

29% of people living with HIV uninsured

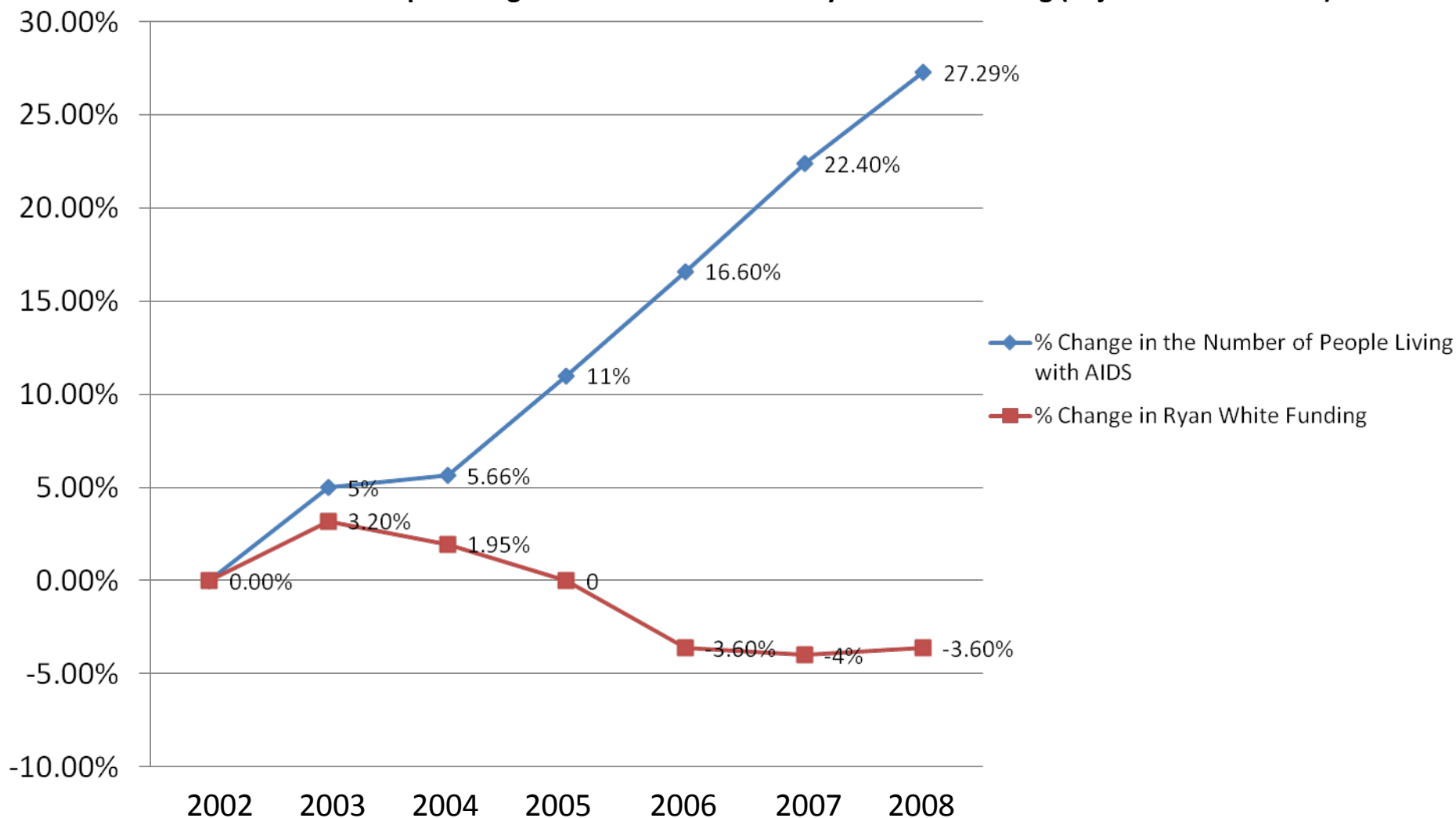
### **The Current Crisis**

42-59% of low-income people living with HIV not in regular care



# Ryan White Program Not Keeping Pace with Increased Need

Number of People Living with AIDS in the US vs. Ryan White Funding (adjusted for inflation)

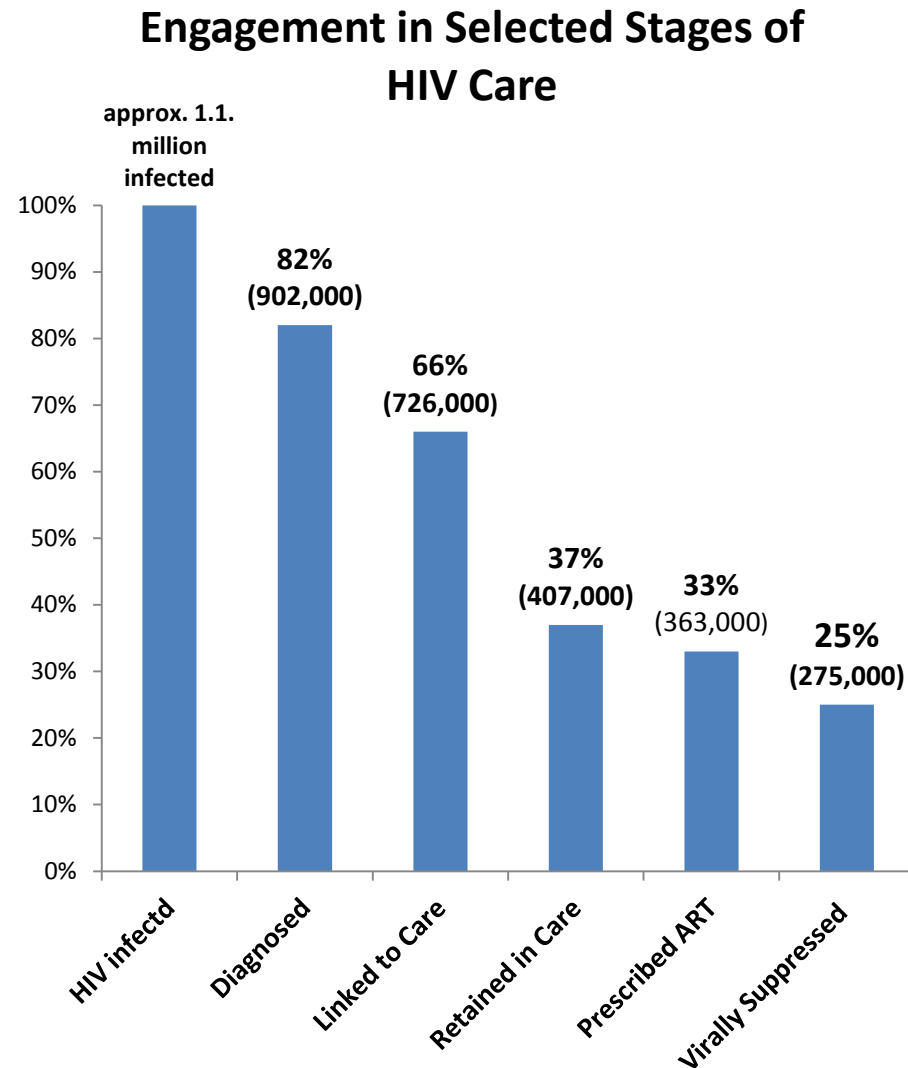


Sources: "Estimated Number of Persons Living with AIDS," Centers for Disease Control and Prevention, <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/table12.htm>; Ryan White Appropriations History, Health Resources and Services Administration, <ftp://ftp.hrsa.gov/hab/fundinghis06.xls>. Inflation calculated using <http://www.usinflationcalculator.com>; [www.cdc.gov/hiv/surveillance/resources/reports/2009report/pdf/table16a.pdf](http://www.cdc.gov/hiv/surveillance/resources/reports/2009report/pdf/table16a.pdf); "Funding, FY2007-FY2010 Appropriations by Program, [hab.hrsa.gov/reports/funding.html](http://hab.hrsa.gov/reports/funding.html)

# ACA Implementation Must Address Engagement and Retention in Quality Health Care

## National HIV/AIDS Strategy calls for:

- Increasing HIV screening and improve linkages to care
- Increasing retention in care rates
- Closing the gap between those who need antiretrovirals (ARVs) and those who are on ARVs
- Providing needed care and support services to increase treatment adherence and number of persons with undetectable viral load rates



# Where We Are Going:

## Successful Health Reform Implementation Could End the HIV epidemic in the U.S.

*Comprehensive Health Care Through Medicaid Expansion and Exchanges  
Will Dramatically Increase Viral Suppression*

### Medicaid

Expands eligibility ([guidance](#)); provides essential health benefits (EHB) ([regulation](#)); improves reimbursement for PCPs ([regulation](#)); includes health home ([guidance](#)); provides free preventive services ([guidance](#))

### Exchanges

Provides subsidies up to 400% FPL ([regulation](#)); eliminates premiums based on health/gender; provides EHB ([regulation](#)); supports outreach, patient navigation and enrollment ([regulation and guidance](#))

# Massachusetts as a Case Study of Successful Health Reform Implementation



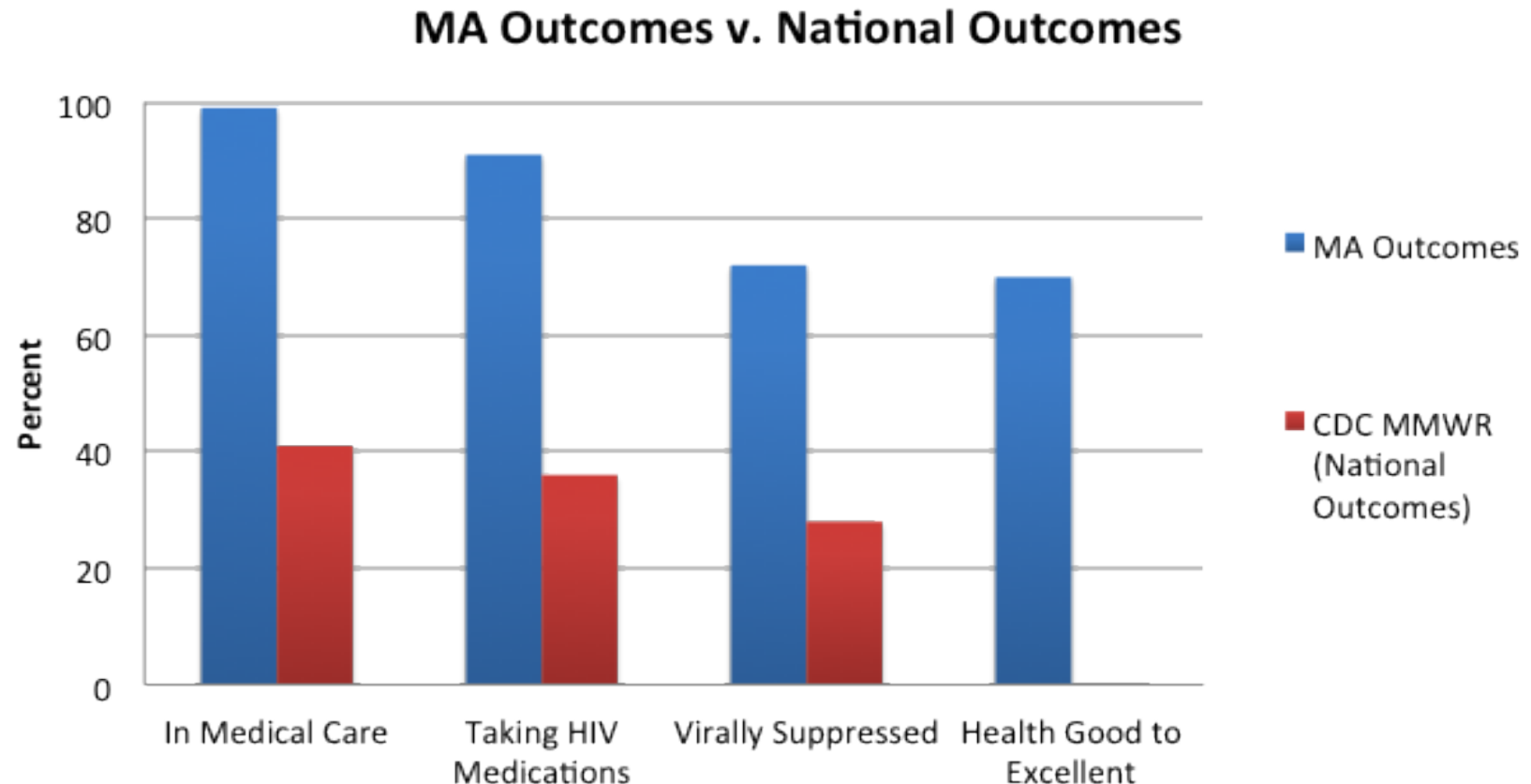
# Massachusetts: A Post Health Care Reform State in a Pre-Reform Country

- Expanded Medicaid coverage to pre-disabled people living with HIV with an income up to 200% FPL (2001)
- Enacted private health insurance reform with a heavily subsidized insurance plan for those with income up to 300% FPL (2006)
- Protected a strong Medicaid program for “already” & “newly” eligibles
- Re-tooled Ryan White Program
  - ADAP funding largely spent on insurance not Rx (2006)
  - Ryan White Program 75/25 rule waived to allow for increased support of essential support services (2007)
  - Maintaining unrestricted formulary and 500% FPL eligibility (2006 - present)

***The MA case study provides insight into how health reforms and Ryan White Program work together to meet NHAS Goals***



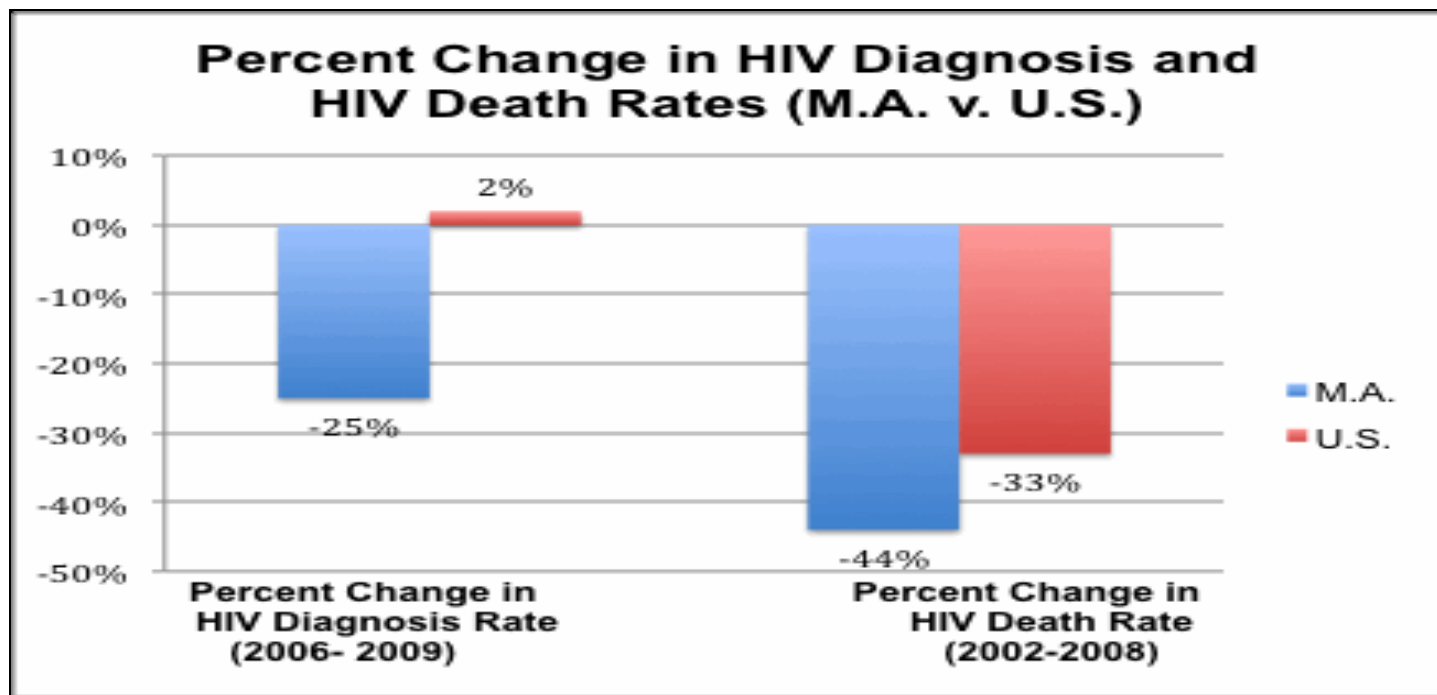
# Massachusetts' Successful Reform Implementation Improves Health Outcomes and Meets NHAS Goals



Source: *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study Final Report*, December 2011, JSI Research and Training, Inc. Note: MA Outcomes N = 1,004

Source: Cohen, Stacy M., et. al., *Vital Signs: HIV Prevention Through Care and Treatment — United States*, CDC MMWR, 60(47);1618-1623 (December 2, 2011); Note: National Outcomes HIV-infected, N = 1,178,350; HIV-diagnosed, n=941,950

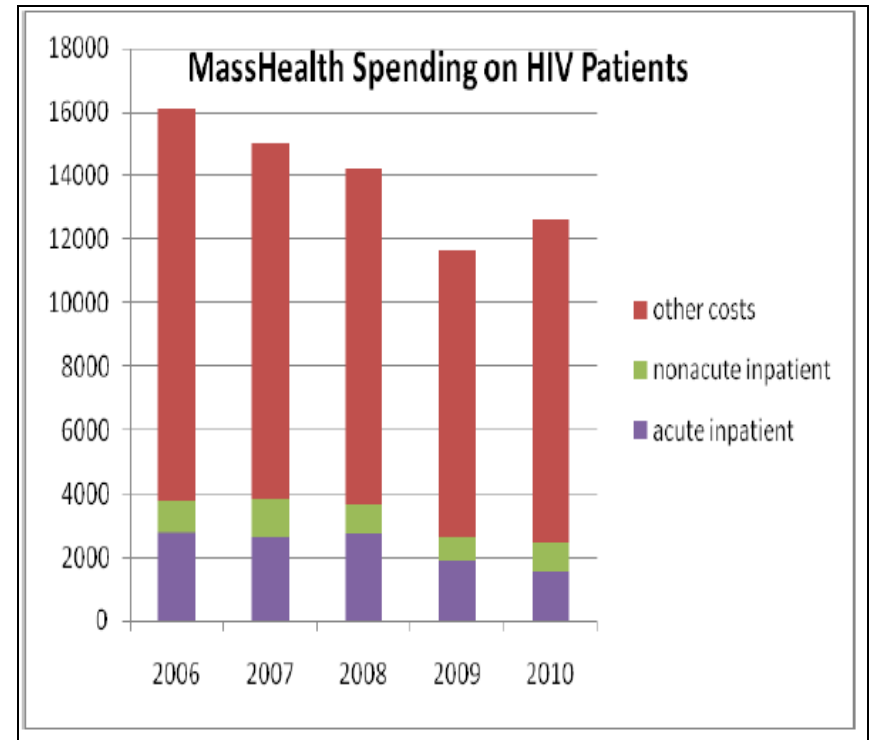
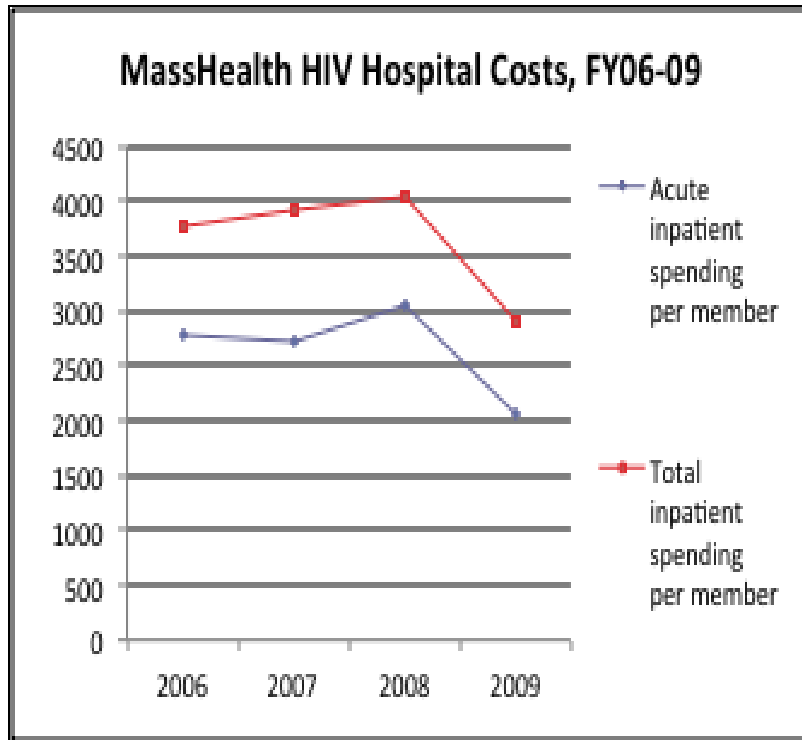
# MA Reform Demonstrates Successful Implementation Reduces New Infections and AIDS Mortality



- Between 2006 & 2009, Massachusetts new HIV diagnoses rates fell by 25% compared to a 2% national increase
- **Current MA new HIV diagnoses rates have fallen by 46%**
- Between 2002 & 2008, Massachusetts AIDS mortality rates decreased by 44% compared to 33% nationally

Sources: MA Dept of Public Health, *Regional HIV/AIDS Epidemiologic Profile of Mass: 2011, Table 3*; CDC, *Diagnoses of HIV infection and AIDS in the United States and Dependent Areas, 2010, HIV Surveillance Report, Vol. 22, Table 1A*; CDC, *Diagnoses of HIV infection and AIDS in the United States and Dependent Areas, 2008, HIV Surveillance Report, Vol. 20, Table 1A*.

# MA Reform Demonstrates Successful Health Reform Implementation Reduces Costs



- Massachusetts cost per Medicaid beneficiary living with HIV has decreased, particularly the amount spent on inpatient hospital care
- Massachusetts DPH estimates reforms reduced HIV health care expenditures by ~\$1.5 billion in past 10 years

# A Post-Reform State Needs the Ryan White Program (RWP) to Meet National HIV/AIDS Strategy (NHAS) Goals

YEAR	Full Pay	Co-Pay	Premiums	Total Cost	Enrolled
FY05	\$ 9,756,201	\$ 1,839,807	\$ 6,112,132	\$ 17,708,142	4738
FY11	\$ 4,467,727	\$ 3,175,917	\$ 10,990,818	\$ 18,634,462	7009

***The RWP is essential to reducing gaps in care and affordability  
to meet retention in care and viral suppression goals***

- ADAP reduces barriers to HIV medications
  - Individuals with income of \$16,000 (149% FPL) cannot afford ~\$3,000
  - Families with income of \$33,000 (150% FPL) cannot afford ~\$6,000
- RWP provides essential care - dental, vision and behavioral health...
- RWP provides essential services - case management, transportation, food and nutrition...

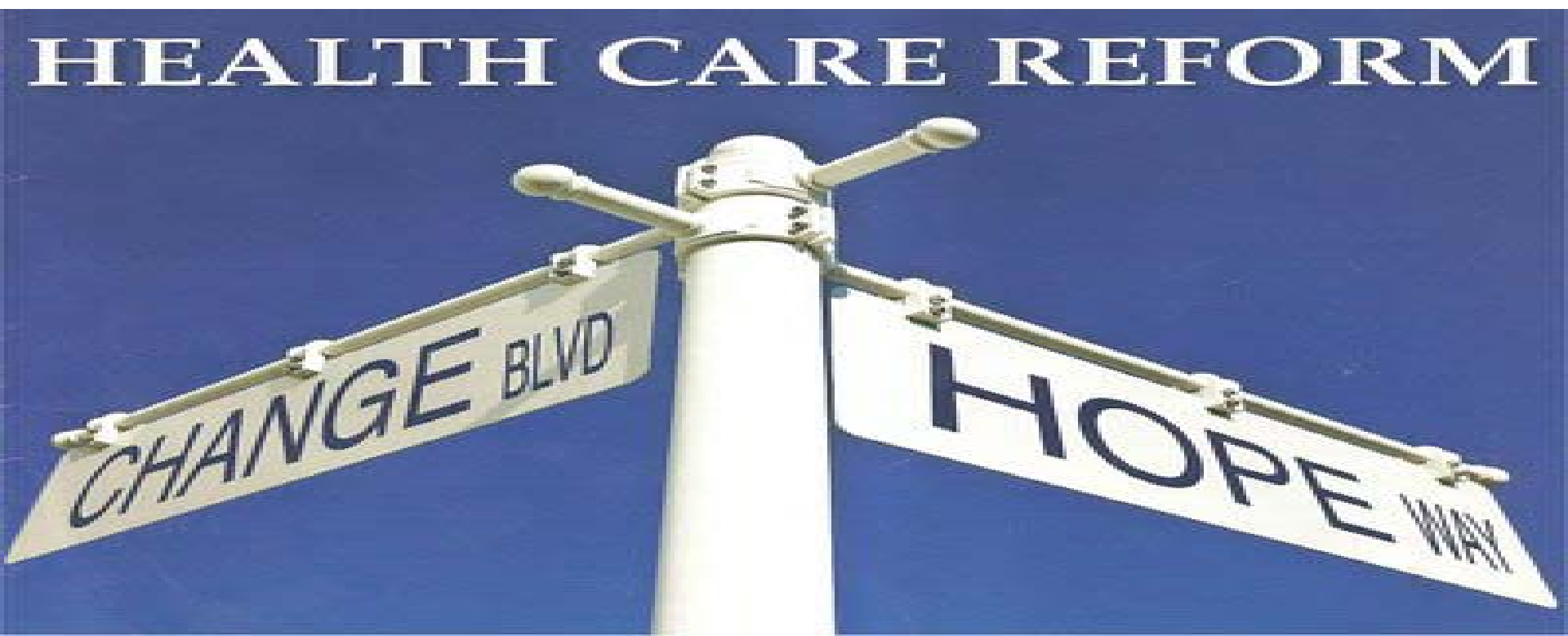
## California's Ineffective Implementation Undermines NHAS Goals

Lack of Proper Planning and Oversight Results in Disruptions in Care (Moving Us in the Wrong Direction)

***Both federal and state officials largely failed to account for people living with HIV who became newly eligible through reform***

- Failed to ensure that the health benefits package met HIV standard of care
- Failed to integrate HIV providers and models of care delivery
- Failed to consider Ryan White Program coordination and “payer of last resort” provisions

# Key Advocacy Priorities for Successful Affordable Care Act Implementation



## Action Needed to Ensure Success:

### Step 1. Federal and State Regulations to Promote Retention in Care and HIV Standard of Care

***Success will depend upon strong federal regulations & state regulations to the extent the federal government falls short***

- Comprehensive Essential Health Benefits (EHB) for Medicaid and Exchanges
- Limits on / Regulation of Utilization Management
- Outreach, navigation and enrollment systems that promote access and linkage to care and successfully integrate people living with HIV and other chronic health conditions, their providers and models of care into health reforms
- Anti-discrimination protections and enforceable appeals processes

# ACA Statute Requires Strong Regulation of Medicaid Expansion and Exchanges

**ACA's Essential  
Health Benefits  
Mandates**

**+**

**§ 1937  
Benchmark  
Mandates**  
(applies to Medicaid)

**+**

**ACA Non-  
Discrimination  
Mandates**

**=**

**Regulations that Ensure Medicaid and Exchanges  
Successfully Provide HIV Standard of Care**

## **Access to care, treatment, and services that reflect national standards:**

- Outreach & patient navigation services successfully integrating people with HIV
- Sufficient provider networks and access to specialists
- Access to necessary medications
- Case management, care coordination, treatment adherence, & counseling
- Comprehensive mental health & substance abuse services
- Preventive & wellness services



## Action Needed to Ensure Success:

# Step 2: Federal and State Point People on HIV Health Care Reform

*Success requires high level officials at HHS/CMS and in states coordinating health reform implementation with consumers and providers*

### Guidance to states:

- Expansion of Medicaid, Health Home, Prevention services
- Medicaid, Exchanges, and RWP coordination
- Inclusion of AIDS service providers as navigators for outreach, enrollment, and retention efforts

### Technical Assistance:

- Workforce development
- Integration of people living with HIV and their providers

### Oversight:

- Streamlined HIV measures and reporting requirements (to monitor & manage the epidemic)

# Medicaid Expansion Update: Texas Case Study --Many Reasons to Opt In

*SCOTUS decisions turns the Medicaid expansion  
into a state-by-state advocacy issue*

**Chronic Disease:** Free preventive services prevent high-cost care

**Infectious Disease:** 26,000 HIV+ uninsured Texans eligible for Medicaid

**Hospital Solvency:** DSH payments reduced for hospitals

**Federal Funding:** 100% for 2014-2016 and gradually reduced to 90%

**Net Savings:** First 5 years Texas realizes \$554 million in net savings

*Will Texas want its residents' federal tax dollars  
supporting access to care in NY, CA and MA?*

## Action Needed to Ensure Success:

### Step 3: The Medicaid & Ryan White Program Challenge: Advocacy Needed for Ongoing & Sufficient Funding

#### Medicaid

- Currently an entitlement program (if you're eligible, you're in)
- Block granting or capping federal spending will shift costs to already cash-strapped states
- **States will likely cut services and eligibility to the most vulnerable without strong federal/state protection of Medicaid**

#### Ryan White Program

- Premature to discuss cost-offsets or destabilization
- **Post 2014, we need to re-tool the Ryan White Program and preserve its ability to fill gaps in essential care and services and gaps in affordability**

# Maximizing the Potential For an AIDS-Free Generation



## We Must Work with the Existing AIDS Infrastructure to Successfully Transition to a Post Reform Environment

- **Advocate** for policies and programs that support people living with HIV and the role of HIV providers in meeting essential care, treatment, and service needs
- **Integrate** with larger providers that have diverse portfolios of services and funding
- **Grow** to expand capacity/mission and decrease reliance on Ryan White Program that will likely not be able to provide sufficient ongoing support
- **Go** forward as is, but understand that overtime you may not be able to exist as a free-standing disease-specific organization without diversified services and funding

# We Must Lead Federal & State Advocacy

Maximizing the potential that the care, treatment and service needs of millions of Americans living with HIV and other chronic health conditions are met requires:

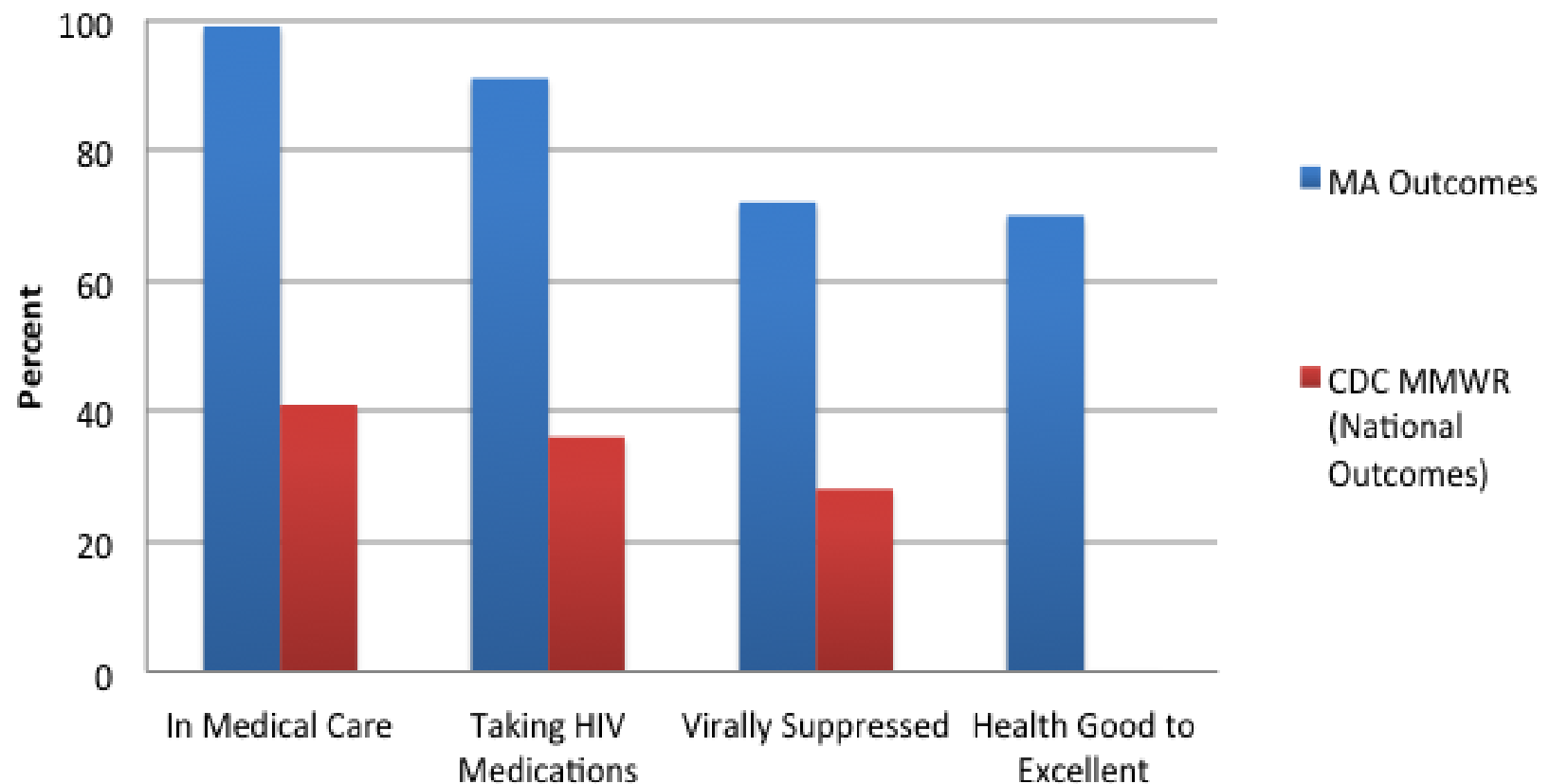
- Monitoring, analyzing, and providing comment on health reform implementing regulations and policies
- Developing and disseminating education and advocacy materials about health reform implementation, Ryan White reauthorization, Medicaid, and other federal and state issues affecting HIV care for community-based advocates nationwide
- Advocating directly with federal and state officials on issues affecting HIV care, treatment, and services, in collaboration with other national organizations

# We Must Engage State-Based Advocates in Federal & State Level Advocacy Development

- ACA “boot camps” - focused, detailed trainings on specific and ongoing ACA implementation opportunities and other care, treatment and service issues
  - ACA’s Medicaid expansion, essential health benefits, patient navigation and outreach, and integration of people living with HIV and their providers into new health system models
  - Medicaid defense
  - Ongoing support and re-tooling of the Ryan White Program
- State-specific education and advocacy materials demonstrating individual health, public health and fiscal importance of health reforms
- “Rapid response” resource for states to provide targeted technical assistance and advice about specific implementation challenges
- Financial and advisory support to state-based policy advocacy coordinators,.

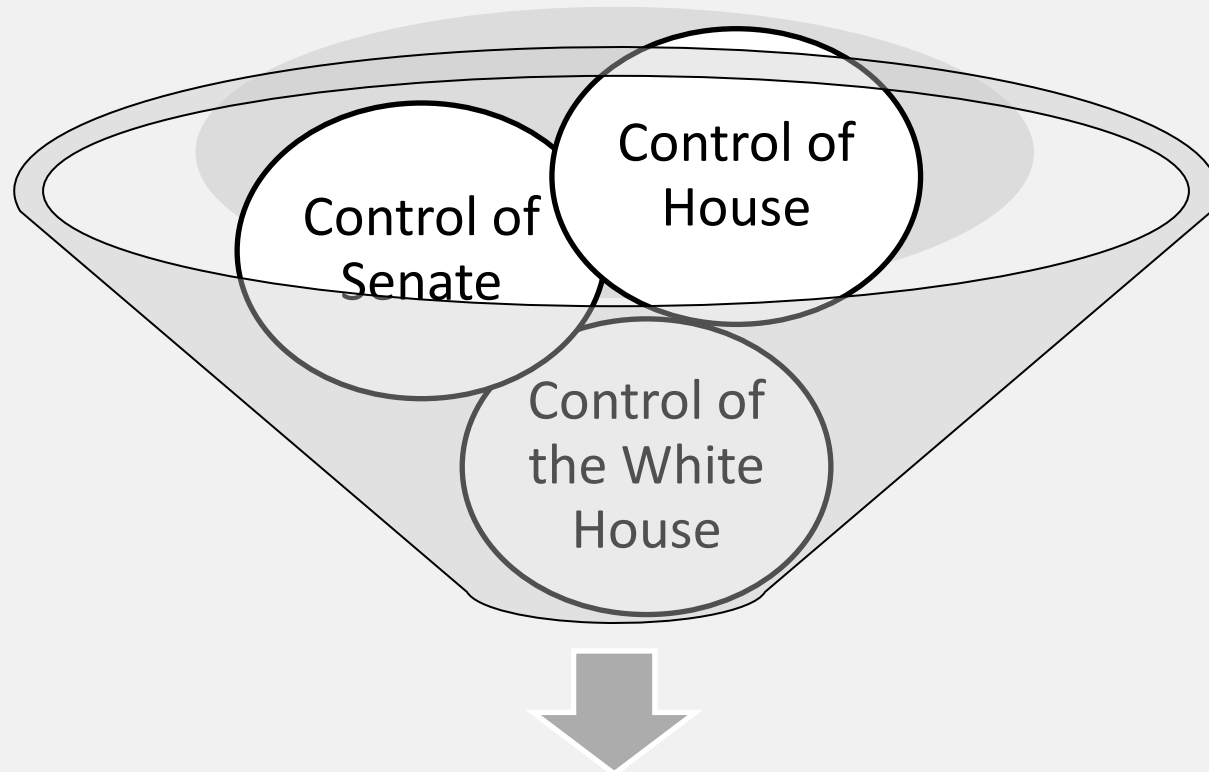
# Metrics of Success

## MA Outcomes v. National Outcomes





# 2012 Elections = Watershed for Health Reform... but everything was not won or lost



Will the ACA be fully implemented?

Will deficit reduction be achieved responsibly?

Will our health care safety nets (Medicaid, Medicare,  
Ryan White Program) be preserved?