Gay Men's Health Crisis
New York City Department of Health & Mental Hygiene
New York State AIDS Institute
New York AIDS Coalition
Harlem United Community AIDS Center, Inc. &
Housing Works

present a

Community Meeting on Ryan White CARE Act Reauthorization

MEETING HANDOUTS

Thursday, September 21, 2006
2:00 PM–4:15 PM
GMHC Room 405 (119 West 24th Street)

TABLE OF CONTENTS

Part I

1. Meeting Agenda
2. Presentation: *Proposed Bill for the Reauthorization of the Ryan White CARE Act – An Overview of Current Policy Proposals*
3. Presentation: *Ryan White HIV/AIDS Treatment Modernization Act: Impact on New York*
4. Presentation: *Ryan White CARE Act Reauthorization 2006 – Policy & Funding Implications for the NY EMA*

Part II

5. Memo from the HIV/AIDS Bureau of the Health Resources and Services Administration: Impact of Adding HIV (Non-AIDS) Cases to the Formula Funding Allocation – INFORMATION
6. New York State House Delegation Letter (dated September 20, 2006)
7. New York State Senate Delegation Letter (dated September 20, 2006)
8. New York City Mayor Michael R. Bloomberg Letter (dated September 18, 2006)

Part III

9. New York City Department of Health and Mental Hygiene Commissioner Thomas R. Frieden, M.D., M.P.H. Letter (dated September 14, 2006)
10. New York State Department of Health Commissioner Antonia C. Novelllo, M.D., M.P.H., Dr.P.H. Letter (dated August 28, 2006)
11. Testimony presented at the Ryan White CARE Act Stakeholder Meeting held Monday, September 11, 2006 in Washington, D.C. from Guthrie S. Birkhead, M.D., M.P.H., Director of the New York State Department of Health AIDS Institute

Part IV

12. New York AIDS Coalition Letter (dated September 13, 2006)
13. Communities Advocating Emergency AIDS Relief (CAEAR) Coalition Letter (dated September 19, 2006)
14. AIDS Action Letter (dated September 18, 2006)
15. Greater New York Hospital Association Letters (September 19, 2006)
16. Community Proposal on Reauthorization: *Recommendations to the Bipartisan Bicameral Committee on The House Version of the Reauthorization of the CARE Act*

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MEETING AGENDA

2:00–2:15 PM Welcome, Introductions, and Meeting Overview
Darryl Ng, Gay Men's Health Crisis

2:15–2:45 PM Overview of Current Legislative Proposals
Robert Cordero, Housing Works
Matthew Lesieur, New York AIDS Coalition

2:45–3:05 PM Impact of Current Proposal on New York State
Humberto Cruz, New York State AIDS Institute

3:05–3:25 PM Impact of Current Proposal on New York City
Grace Moon, New York City Department of Health & Mental Hygiene

3:25–3:40 PM Impact of Current Proposal on RWCA-funded HIV/AIDS Providers
Patrick McGovern, Harlem United Community AIDS Center, Inc.

3:40–4:15 PM Ongoing Advocacy Efforts, Community Participation, and Next Steps
Panel Discussion
Moderator: Darryl Ng

Proposed Bill for the Reauthorization of the Ryan White CARE Act

An Overview of Current Policy Proposals

Why Reauthorize?

- When Congress passed first Ryan White CARE Act in 1990, it was never intended to be permanent
- Legislation has built-in sunset provision; law automatically expires after 5 years
  - Reauthorization gives Congress the opportunity to review law and ask (1) should it continue? (2) should it be changed to meet new needs/challenges?
  - Epidemic and treatments very different in 1990 than today
- Congress needs to reauthorize for Ryan White Act to continue

President's Principles

- July 27, 2005 HHS Secretary Leavitt Releases "Ryan White CARE Act Reauthorization Principles
- Clues to President's thinking were laid out in speech at Philadelphia church on June 23, 2004.
  - Broad approach laid out in Philadelphia speech:
    - Focus on access to life extending care (medical care)
    - Greater focus on areas of "severe need"
    - More flexibility for federal government to redistribute resources

The Proposed Bill

The Ryan White HIV/AIDS Treatment Modernization Act of 2006

S. 2823
Introduced May 17, 2006

Where are We?

- Bipartisan, bicameral negotiations have been conducted in secret behind closed doors
- Bill first released to public May 9, 2006
- "Feedback sessions" held to allow public to comment on bill
- Senate HELP Committee reviewed bill and passed out of committee 19-1
- House Energy & Commerce Committee passed bill out of committee 38-10
- Bill now moves to floor votes in Senate and House

Title I – Locality Funding

	Eligibility	Distribution (Supplemental targets "demonstrated need")	Hold Harmless	Planning Council
Tier 1	2000+ new AIDS cases last 5 years Or 3000 living AIDS	2/3 Formula, 1/3 Supplemental	Until 2009, 95% of previous year	Mandatory
Tier 2	1000-1999 new AIDS cases last 5 years Or 1,500 living AIDS	2/3 Formula, 1/3 Supplemental	None	Voluntary (except grand fathered EMAs mandatory until 2009)

Title I – All Tiers

- New York EMA tier 1
- Dutchess County and Nassau-Suffolk tier 2
  - Dutchess County EMA will disappear in three years
- Eligibility for funding is based on # of AIDS cases reported in the last 5 years but distribution of funds is based on living HIV & AIDS
- HIV Case Counts
  - Name-based states will use their reported number of persons living with HIV/AIDS confirmed by CDC
  - Code-based states will use their self-report number of persons living with HIV/AIDS, but then have cases reduced by 5% to allow for duplication errors
  - Code based states have cap on increase of 5%
  - CDC confidential study shows duplication error rate may be high as 28% in code-based states

Title I – All Tiers (*cont.*)

- New requirement to submit carryover applications to the Secretary of HHS
- Cap on administrative costs at 10% and would include Planning Council activities
- Boundaries of metropolitan areas would not change
- Woman, Infants, Children and Youth (WICY) requirements tied to number of HIV cases, not AIDS
- Tier 1 & 2 Supplemental grants change from "severe need" to "demonstrated need" = unmet need for services, increasing need for services due to related rates of increase in HIV, health care costs, limited access to health care, impact of co-morbidities
  - Will not qualify for supplemental funding if unobligated balance at end of fiscal year exceeds 2% of grant

Title II Base Allocation

- Title II: Funding for 50 states and territories
- Allocation of funds to change:
  - Change 80-20 to 75-20-5
    - **Old**
      - 0.80 * all AIDS cases in state
      - 0.20 * all of the AIDS cases outside Title I EMAs
    - **New**
      - 0.75 * all HIV & AIDS cases in State
      - 0.20 * all HIV & AIDS cases outside Tier 1 & Tier 2 EMAs
      - 0.05 * all HIV & AIDS cases for States not receiving any Tier 1 or Tier 2 funds

Title II Base (cont'd)

- Move towards client level data & severity of need index (SONI)
- In FY10, if Secretary decides SONI is ready, 75-20-5 is eliminated and SONI is implemented
  - Require HRSA to provide annual reports on client level data and SONI development
  - Implementation of SONI subject to Congressional Review Act
- New supplemental grant pool would be 1/3 of any additional funds over FY06 levels (not currently a part of the CARE Act – entirely new program)
  - Supplemental grants based on "demonstrated need"
  - Secretary may waive match for severe need supplemental if State provided all of its match for the rest of Title II
  - Will not qualify if unobligated balance at end of fiscal year exceeds 2% of grant

Title II (Con't)

- HIV Case Counts:
  - Name-based states will use their reported number of persons living with HIV/AIDS confirmed by CDC
  - Code-based states will use their self-report number of persons living with HIV/AIDS, but then have cases reduced by 5% to allow for duplication errors
  - Code-based states have cap on increase of 5%
  - CDC confidential study shows duplication error rate may be high as 28% in code-based states
- Hold harmless only until FY 2009. Set at 95% of previous year's grant
- HIV CARE Consortia's considered part of 25% allowed for supportive services

Title II – Emerging Communities

- Emerging Communities in May Senate bill had moved them to Title I Tier 3 – been placed back in Title II
- Eligibility based on 500-999 new AIDS cases in last 5 years
- Albany, Rochester and Buffalo potentially "Emerging Communities"

Title II ADAP

- ADAP = AIDS Drug Assistance Program
- Each state has unique ADAP program, with different formularies, and qualifications to participate
  - NY ADAP formulary: 480 drugs
  - W. Virginia 33 drugs & Alabama 38 drugs
- Required minimum drug list based on
  1. Classes of drugs
  2. PHS Guidelines for Anti-Retrovirals only – does not include medications for opportunistic infections or side effects
- All drug rebates must now be applied to ADAP program

Comparison of ADAP Programs (FY'05)

	New York	California	Alabama
Drugs	480	153	38
Financial Eligbility	460% FPL	400% FPL	250% FPL
Clients Served	12,686	18,275	915
Title II ADAP	$ 129,645,186	$ 90,028,301	$ 8,474,550
ADAP Supplemental	$ -	$ -	$ 804,633
Title II Base	$ 1,400,000	$ 11,377,873	$ 1,026,240
Title I	$ 10,955,614	$ -	$ -
State Funds	$ 37,350,000	$ 84,961,250	$ 2,999,632
Other State/Federal	$ 3,366,043	$ -	$ -
Drug Rebates	$ 55,200,000	$ 77,923,750	$ -

Title II – New State Mandates

- States will specify a lead agency to:
  - Receive all notices for grant awards
  - Develop statewide coordinated statement of need (SCSN)
  - Receive audits from all grantees within State
  - Outline key outcome measures
  - Other duties determined by the Secretary

Title II – Prevention "Incentive Grants"

- $30 million in CDC funds redirected to Ryan White to encourage states to enact the following:
  - Voluntary opt-out testing of pregnant women
  - Universal testing of newborns
  - Voluntary opt-out testing at STD clinics
  - Voluntary opt-out testing at substance abuse treatment centers

Title III – EIS

- Title III: Directly funded CBOs, clinics and hospitals that provide primary medical care
- Only RW funds need to follow RW counseling & testing guidelines
- Hep B/Hep C
  - Information about impact, infectivity, and treatment required in pre- & post-test counseling
  - Preference for awarding grants to include preference for examining Hep B/Hep C co-infection

Title III – EIS (*cont.*)

- Specify grantees serve underserved populations
- Require grantees to submit documentation of process used to obtain community input into design and implementation of Title III grant activities
- Indian Health Service facilities eligible as direct grantees

Title IV - WICY

- Title IV: Directly funded organizations that provide medical care and supportive services to women, infants, children and youth
- Clarify that focus of Title IV is family-centered care, not research
- Define family-centered care and youth (ages 13-24)
- Cap on administrative costs at 10% (currently no admin. cap on Title IV)
- Indian Health Service facilities eligible as direct grantees

All Titles

- 75% of funds must be spent on "core medical services"
  - Outpatient and ambulatory health services
  - AIDS drug assistance program treatments
  - AIDS pharmaceutical assistance
  - Oral health
  - Early intervention services
  - Health insurance premiums & cost sharing
  - Home health care
  - Hospice care
  - Home and community-based health services
  - Mental health services
  - Substance abuse outpatient care
  - Medical case management & treatment adherence
  - Medical nutritional therapy

All Titles (cont'd)

- Secretary may grant a waiver of the 75% requirement if grantee can demonstrate that there is no ADAP waiting list and everyone with HIV has access to core medical services
  - 25% of persons living with HIV have not been diagnosed and are unaware of their status
- Supportive services must now demonstrate that they improve clinical medical outcomes
  - Examples legislation cites are: respite care, outreach services, medical transportation, linguistic services, and referral for health care

All Titles (*cont.*)

- Every other year, grantees required to submit audits to their State (States would submit to HHS)
- Titles I-IV grantees required to include in grant application:
  - Coordination with the State and other grantees in State
  - How expenditures will improve overall outcomes
- Native American clarification
  - Native Americans may not be denied service (payer of last resort provisions)
  - Representation on planning councils as appropriate

Part E (Cont'd)

- Ryan White ban on certain activities:
  - "None of the funds appropriated under this title shall be used to fund AIDS programs, or to develop materials, designed to promote or encourage, directly, intravenous drug use or sexual activity, whether homosexual or heterosexual."
- White House/HHS approval of literature?
- Impact on harm reduction programs?

Part F

- SPNS
  - Recraft program to focus on:
    1. Development of health information technology systems to support client level data (as it relates to the SONI)
    2. Responding to emerging needs of populations served by RW
- AETCs
  - Training can include issues related to Hep B/C
- Minority AIDS Initiative
  - Competitive grants (used to be formula based)
- Dental Care
  - Maintain current connection between dental/dental hygienist schools and community-based dentists as part of the community-based dental projects

Appropriations

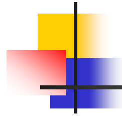
Appropriations for FY 2007-2011 are set in the legislation as follows:

	2007	2008	2009	2010	2011
Title I	$ 604,000,000	$ 626,300,000	$ 649,500,000	$ 673,600,000	$ 698,500,000
Title II	$ 1,195,500,000	$ 1,239,500,000	$ 1,285,200,000	$ 1,332,600,000	$ 1,381,700,000
Title III	*	*	*	*	*
Title IV	$ 71,800,000	$ 71,800,000	$ 71,800,000	$ 71,800,000	$ 71,800,000
SPNS	$ 25,000,000	$ 25,000,000	$ 25,000,000	$ 25,000,000	$ 25,000,000
AETCs	$ 34,700,000	$ 34,700,000	$ 34,700,000	$ 34,700,000	$ 34,700,000
Dental	$ 13,000,000	$ 13,000,000	$ 13,000,000	$ 13,000,000	$ 13,000,000
MAI	$ 131,200,000	$ 135,100,000	$ 139,100,000	$ 143,200,000	$ 147,500,000

* The legislation did not include appropriations levels for Title III

Humberto Cruz
Executive Deputy Director, AIDS Institute
New York State Department of Health

September 21, 2006



What have we done?

- New York delegation has done letters to committee leaders describing concerns with the Ryan White bill and the process. Most recently, New York's senators did a joint letter with senators from two other states (California and New Jersey), and all of New York's representatives in the House signed a letter opposing the bill.
- Governor has sent two letters to committee leaders; one was co-signed by four other governors: Florida, Maryland, New Jersey, Texas.
- Health Commissioner has sent letters to committee leaders and HHS.
- NYS AIDS Advisory Council sent a letter to committee leaders with comments and recommendations.
- Ryan White networks have sent letters and made calls to congressional representatives; some have held media events; some have done editorials.

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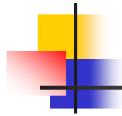

What have we done?

- The AIDS Institute has:
  - Worked closely with New York City and the other Title I EMAs in the analysis of proposals and development of strategies and recommendations.
  - Testified at stakeholder meetings held by Senate and House committees.
  - Submitted written testimony on several occasions.
  - Testified at House subcommittee hearing.
  - Conducted hill visits and delegation briefings on ten occasions.
  - Submitted questions for congressional hearings with the Administration.
  - Worked with the CSTE on comments on proposed formulas.
  - Submitted proposed language and amendments to Senate and House committee members.
  - Co-signed a letter with 17 other states challenging the proposed formula and other key provisions.
  - Circulated a sign-on letter to committee leaders that was ultimately signed by hundreds of individuals, providers, and organizations.

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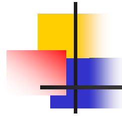
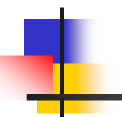
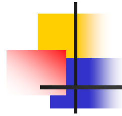


What have we done?

- The AIDS Institute has:
  - Maintained ongoing communication with committee representatives.
  - Worked with NASTAD on principles and recommendations.
  - Convened high-prevalence states to facilitate joint responses.
  - Maintained ongoing communication and coordination with key states.
  - Communicated with Ryan White networks and provided fact sheets and talking points.



II. Key Provisions that will affect New York State.



Revised Formula

- Establishes a separate system for reporting of HIV cases by states with code-based HIV surveillance.
- Since CDC will not validate data from code-based states, these states will report their HIV data directly to HRSA for inclusion in allocation formulas, thus bypassing rigorous CDC validation requirements that name-based states must meet.
- Establishes precedent:
  - Sets a double standard for HIV reporting.
  - Uses data that have not been validated in allocation formulas.

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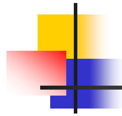

Revised Formula

- Proposes a duplication penalty for code-based states of five percent.
- Duplication penalty has no basis in science or evidence.
- CDC has determined that duplication ranges from one percent to 28 percent.
- Mandating a duplication penalty of five percent for all is unfair.
- Allocation formulas will not be based on accurate counts of persons living with HIV disease.
- Formula is arbitrary and unevenly applied.

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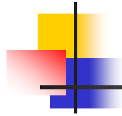

Revised Formula

- Impact:
  - New York State's proportion of cases will be reduced, resulting in reduced funding.
    - Cases in code-based states are likely to be inflated.
    - GAO data indicate flaws in case counts (e.g., the data indicate there are more cases in the city of Boston than there are in the state of Massachusetts).
    - As a name-based state with immature HIV data, New York's HIV reporting is not complete.

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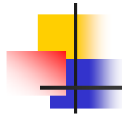

Hold Harmless

- Hold harmless provision limits losses for only three years.
- Hold harmless provision allows for five percent reduction in year one, an additional five percent in year two, and an additional five percent in year three.
- Hold harmless is eliminated in year four.
- Impact:
  - New York State will lose $8.7 million in year one, $17 million year two, $25 million in year three, and more than $28 million in year four, for a four-year loss of almost $79 million.

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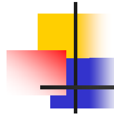

Severity of Need Index (SONI)

- Title II formula grants will be awarded using a SONI beginning in year five.
- The structure and impact of such an index have not been determined.
- It has been proposed that the SONI consider generosity of state Medicaid programs and other available resources for HIV/AIDS. As such, there is potential for such an index to penalize states, like New York, that devote resources to HIV/AIDS services, reward states that have not, and serve as a disincentive for states to allocate resources to meet the needs of their residents with HIV/AIDS.
- It is premature to mandate a yet-to-be tested severity of need index in law.
- Impact:
  - The impact of the SONI on New York's resources is likely to be grave. Losses cannot be estimated.

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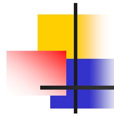

Impact of Title I Eligibility on States

- States are called upon to cover EMAs that become ineligible.
- If an EMA becomes ineligible, the funding is transferred to the national Title II base – not to the state in which the EMA is located.
- As a result, states will receive a small portion of the funding that had been directed to the EMA.
- Impact:
  - Example: If Dutchess County becomes ineligible under Title I, the State will see only about 12 percent of the funding that had been supporting services in the EMA.

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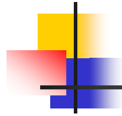

Data and Impact

- We question the accuracy of the GAO data.
- We question the assurance that there is "plenty of money" to make states and cities whole.
- Important to recognize that the true impact of this bill will not be known until it is implemented.

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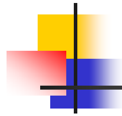

Overall Impact on New York

- There will be cuts in services throughout the State.
- Persons living with HIV and AIDS will be harmed.

14

III. Process and Politics

Broken Promises

- "Bi-bi's": staff of Senators Enzi and Kennedy, and representatives Barton and Dingle. Known as the "four corners."
- The "bi-bi's" made a firm commitment to governors – to make states and cities that lose whole.
- New York worked with the "bi-bi's" on language requiring priority grants to make states and EMAs whole.
- Bi-bi's backed away from their commitment and instead gave the Secretary discretion as to whether to give us priority money and how much.

16

Painful Process

- New York has been under attack.
- Claims that have been made:
  - New York does not spend its money anyway, so we can afford to take a huge reduction.
  - There are no cases in New York State outside of New York City (note: without the City's cases, New York State would be seventh in the nation).
  - New York State doesn't spend its money well. We don't serve anyone with this money.
  - New York is overfunded. The reduction will have no impact.
  - New York has not done a good job of directing resources to affected communities.
  - New York isn't doing any testing.
- Every time such a claim is made, the State has to defend the fact that we have an epidemic and justify our work to address it.

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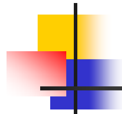


Painful Politics

- Senator Clinton has been assailed for trying to protect New York.
- Senator Frist's Buffalo News editorial:
  - Attempted to pit Buffalo against NYC and NYS.
  - Full of inaccuracies.

18

IV. What’s next?

Will it be reauthorized?

- Bi-bi’s and HHS secretary’s office are pushing hard for reauthorization.
- There is some support for reauthorization among jurisdictions: some jurisdictions win under this bill; and threats have been made about what will happen to us if the law is not reauthorized (i.e., money won’t flow the way it has been flowing).
- The bill was approved by the committee on the Senate side, by a vote of 19 to 1 (Senator Clinton was the one).
- The bill was approved by the committee on the House side yesterday, by a vote of 38 to 10 (New York’s representatives on the committee all opposed).
- Now to the House floor, then back to the Senate.
- Several senators oppose the bill.
- It only takes one senator to put a hold on it.
- Bottom line: Don’t know.

20

What if it’s not reauthorized?

- HRSA has issued a “what if” paper.
- Funds will shift:
  - HIV cases are used in formula.
  - Name-based states get credit for AIDS and HIV cases.
  - HIV cases in code-based states are excluded.
  - Code-based states get credit for AIDS only.
- Name-based jurisdictions, like New York, are likely to see gains.
- EMAs won’t lose more than 15 percent of formula award. Title I supplemental funds are used for hold harmless.
- States are held harmless. All ADAP supplemental funds will be used for hold harmless.
- HRSA estimates that an additional $40 million will be needed to support hold harmless provisions in Title II.

21

What can you do?

22

Ryan White CARE Act Reauthorization 2006

Policy & Funding Implications for the NY EMA
September 21, 2006

Title I Distribution of Grants

- **Current**
  - 50% Formula
  - 50% Supplemental
- **Proposed**
  - 66 ⅔% Formula
  - 33 ⅓% Supplemental
  - FY 2007 Tier 1 Funding (authorized to appropriate): $458.3M
    - Formula = $305.5M
    - Supplemental = $152.8M

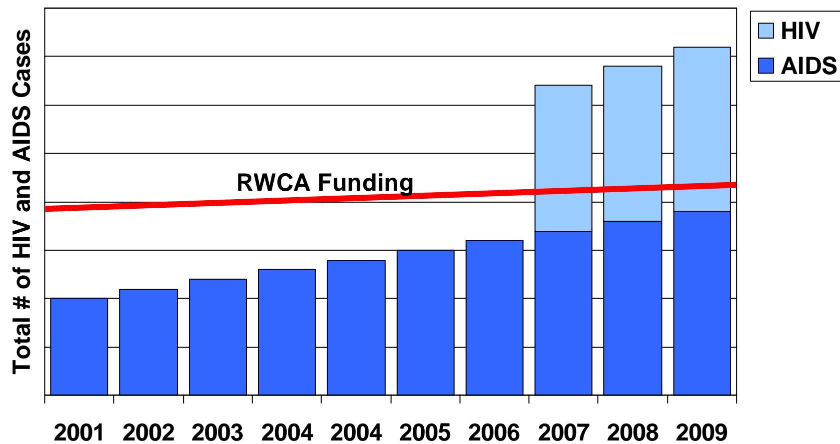
Title I Tier 1 Formula - $305.5 million

- **Current:** Starting in FY 07,10-year Weighted HIV/AIDS Case Band
- **Proposed:** Living HIV/AIDS cases reported and confirmed by the CDC
- **Exemption:** (“Code-based areas”)
  - EMA or State is exempt from requirements if the State submits a transition plan for reporting name-based data to CDC or a statutory change to name-based reporting by 10/1/06 and starts reporting name-based data by 4/1/08

Title I Tier 1 Formula (cont.)

- **Name-based areas:** living HIV/AIDS cases reported and confirmed by the CDC
- **Code-based areas:** living AIDS cases reported and confirmed by the CDC + estimated living HIV cases
  - Modify the number of HIV cases reported by an “adjustment rate” of 5% (“penalty rate”)
  - Code-based area cannot receive more than 105% of their previous year’s award.
- Funding for FY 11 will be based on all name-based living HIV/AIDS cases
- ***Impact: More HIV/AIDS cases counted yet total level of funding remains unchanged.***

RWCA Funding vs. HIV/AIDS Cases



Title I Tier 1 Hold Harmless

- **Current:** 1st yr–2%; 2nd yr–3%;
- 3rd yr–3%; 4th yr–3%; 5th yr–4%
- **Proposed:** FY 07–FY 09, EMAs cannot receive less than 95% of the formula amount of the previous fiscal year. No hold harmless after 2009
- Tier II EMAs - No Hold Harmless
- ***Impact: After FY 09, Tier I EMAs would not be held harmless and could see huge reductions in formula funding that would destabilize HIV care infrastructures***

Maximum Annual Loss		
Year	Current	Proposed
1	2%	5%
2	3%	5%
3	3%	5%
4	3%	100%
5	3%	100%

Title I Tier 1 Supplemental - $152.8 M

- **Priorities in funding**
  - Allocate funds for the hold harmless provisions
  - Allocate funds to EMAs with reduce funding to address reduction in services
  - Demonstrated Need (competitive)
- ***Impact***
  - ***Total pool of supplemental funds reduced due to the change from 50/50 to 66⅔ / 33⅓ so less supplemental funds available for EMAs***
  - ***With the new priorities in distributing supplemental funds, even less supplemental funding available to be distributed to EMAs based on demonstrated need***

Title I Tier 1 Supplemental - $152.8 M

2006	2007
Formula	Formula
Supplemental: HH	Supplemental: HH
	Supplemental: Formula loss
Supplemental: Competitive	Supplemental: Competitive

Title I Minority AIDS Initiative (MAI)

- Distribution of funds
  - **Current:** Formula Distribution
  - **Proposed:**
    - Competitive, supplemental grants to improve HIV-related health outcomes to reduce existing racial and ethnic health disparities
    - Competitive, supplemental grants to support education and outreach services to increase the number of eligible racial and ethnic minorities who have access to treatment
    - Planning grants
    - Delivery of comprehensive services for HIV disease for women, infants, children and youth
- ***Impact: NY EMA will need to compete; may lead to fluctuation in funding year to year***

ESTIMATED NY EMA FY 07 Funding

Formula (F)	*FY 06 $59M* $65.6M (GAO analysis)
Supplemental (S)	*FY 06 $49M* $26.8M
MAI (M)	*FY 06 $11M* $10.1M
Est. FY 07 Award (F+S+M)	$102.6M
Actual FY 06 Award	*$120.4M*
PROJECTED LOSS = -$17.8M	

Title I Core Services

- 75% to Core Medical Services
  - Outpatient/ambulatory healthcare; ADAP/ Medications; Oral health; EIS; Health insurance premiums/cost sharing; Home healthcare; Medical nutrition therapy; Hospice services; Home/ community-based healthcare; Mental health; Substance abuse outpatient care; and, Medical CM (including treatment adherence)
- Waiver available if: (1) no waiting lists for ADAP; and (2) core medical services available to all PLWH

Title I Carryover

- **Proposed:**
  - EMA must apply for a waiver to carryover funds
  - Must spend all carryover funds within one year
  - Unspent carryover will be returned to the Secretary
  - An unobligated balance will be returned to the Secretary to be distributed to other EMAs
  - An unobligated balance will be reduced from next fiscal year grant award
- ***Impact: The NY EMA must continue to spend Title I funds expeditiously***

What if there is no reauthorization?

ESTIMATED NY EMA FY 07 Funding

(based on UCSF' analysis)

Formula (F)	*FY 06 $59M* $65.6M
Supplemental (S)	*FY 06 $49M* $43.5M
MAI (M)	*FY 06 $11.9M* $11.9M
Est. FY 07 Award (F+S+M)	$121.0M
Actual FY 06 Award	*$120.4M*
PROJECTED GAIN= $651K	

Questions