

# National ADAP Monitoring Project

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## Findings from the National Survey of AIDS Drug Assistance Programs

April 20, 2005

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and

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## *Current Survey*

- The 9<sup>h</sup> annual report released by the Project
- 52 of 57 ADAPs receiving federal ADAP earmark in FY 2004 responded
- Data from June 2004 and FY 2004 except where noted
  - Formularies as of September 2004
  - Waiting List and Cost Containment status as of March 2005

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## *ADAPs in Context*

- Critical safety net for prescription drugs
  - reaching about 30% of those with HIV/AIDS in care
  - still, 42%-59% of people with HIV not yet in care system
- Growing importance of ADAPs over time
  - shifting treatment environment
  - increasing number of people
  - increasing costs
- ADAP budget has risen but demand still outpaces funding in some states (not entitlement)
- Significant variation in program access/services across the country
- As payer of last resort, other system changes act as “levers” that can increase or decrease demand for ADAPs (e.g., Medicaid, Medicare)

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## *ADAP Clients, June 2004*

- ADAPs provided medications to 94,577 clients
  - 10 ADAPs accounted for 72% of clients served
  - Clients ranged from 13 in 1 state to more than 18,000 in another
- Trends:
  - 10% increase in clients served over last year
  - 38 ADAPs had increases in clients, 13 had decreases
  - Among the 41 ADAPs reporting data since 1996, clients served increased by 217%; slower rates over time
- Client eligibility
  - HIV positive; income eligibility ranges from 125% FPL in 1 state to 500% or more in 5 states
  - 3 ADAPs use additional clinical criteria

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## *Client Demographics, June 2004*

- Mostly people of color
  - African Americans 34%, Hispanics 26%, others are <2%, whites 36%
- Mostly male (79% were male, 21% female)
- Primarily younger adults (57% between 25 and 44)
- Very low-income (80% of clients fell at or below 200% FPL; 51% at or below 100% FPL)
- Most without insurance coverage (15% private insurance; 9% Medicare; 7% Medicaid; <1% duals\*)
- Indications of advanced HIV disease (50% of clients had CD4 count of 350 or below at enrollment)

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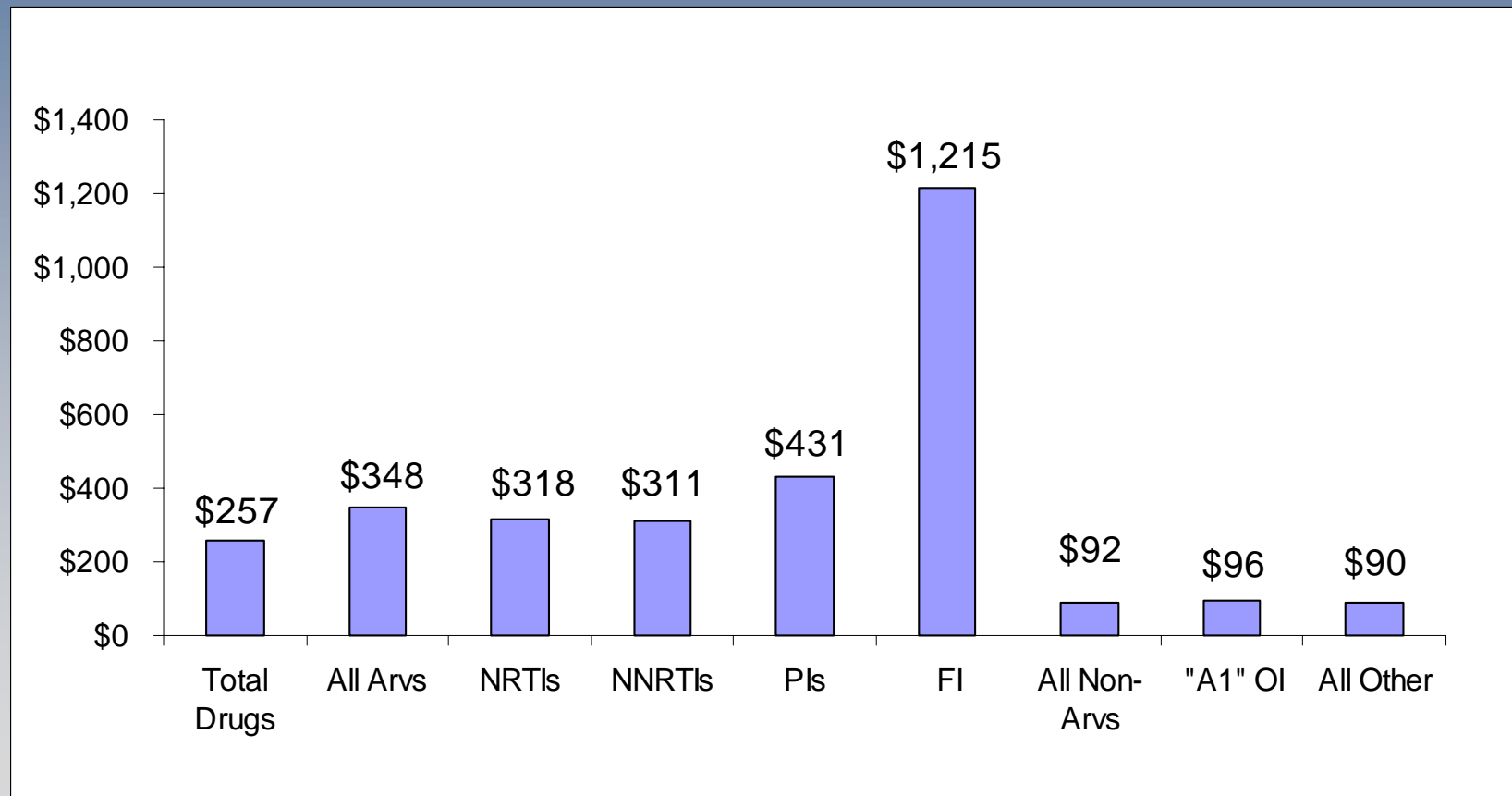
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## *ADAP Drug Expenditures, June 2004*

- ADAP drug expenditures totaled \$96.9 million
  - Annualized at \$1.163 billion, or 98% of total budget
  - 10 ADAPs accounted for 77% of drug spending
  - Ranged from \$14,410 in one state to \$21.2 million in another
- Trends
  - 25% increase in drug spending over last year, largest increase in recent years
  - 43ADAPs had increases, 8 had decreases
  - Among the 41 ADAPs reporting data since 1996, drug expenditures increased by 591%; slower rates over time, with exception of most recent period
- ARVs account for most spending and scripts; most expensive per prescription

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## *ARVs Most Expensive: Expenditures per Prescription, June 2004*



Note: American Samoa, Guam, Maine, the Marshall Islands, N. Mariana Islands, and U.S. Virgin Islands are not included..

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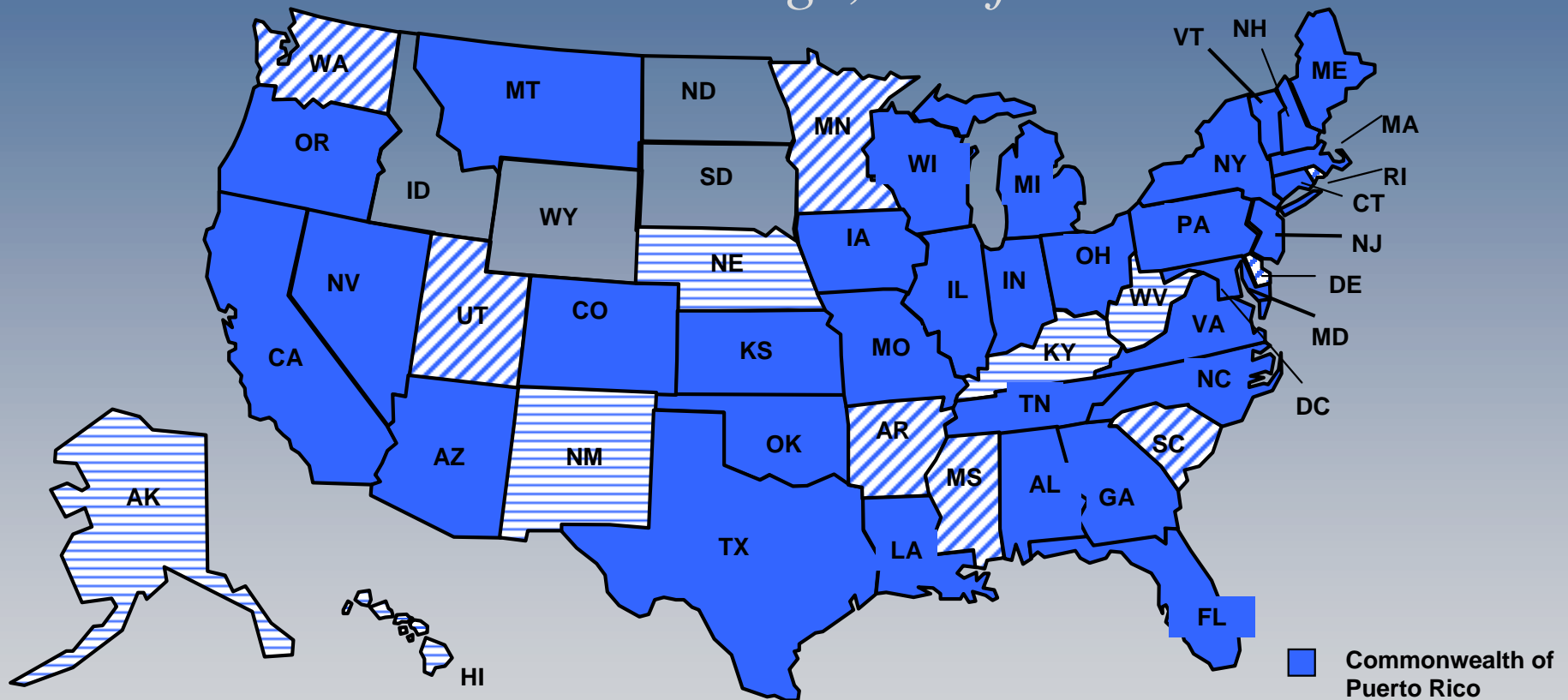
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## *ADAP Formularies, as of September 2004*

- Range from 25 drugs in 1 state to nearly 500 in another; open formularies in 3 states
- ARV coverage generally high
  - 35 ADAPs cover all FDA-approved ARVs; 17 ADAPs do not
  - 1 ADAP does not provide any protease inhibitors
  - 42 cover Fuzeon, 10 do not
- Coverage of medications for OIs and other conditions highly variable
  - 37 ADAPs cover 10 or more of the 16 drugs highly recommended (“A1”) by USPHS/IDSA for the prevention of opportunistic infections (OIs), including 4 that cover all 16
  - 15 cover fewer than 10 of “A1” medications
  - 1 ADAP does not cover any medications other than ARVs
  - 20 ADAPs cover hepatitis C treatments
  - 24 ADAPs cover hepatitis A and B vaccines

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## *ARV Coverage, as of 9/04*

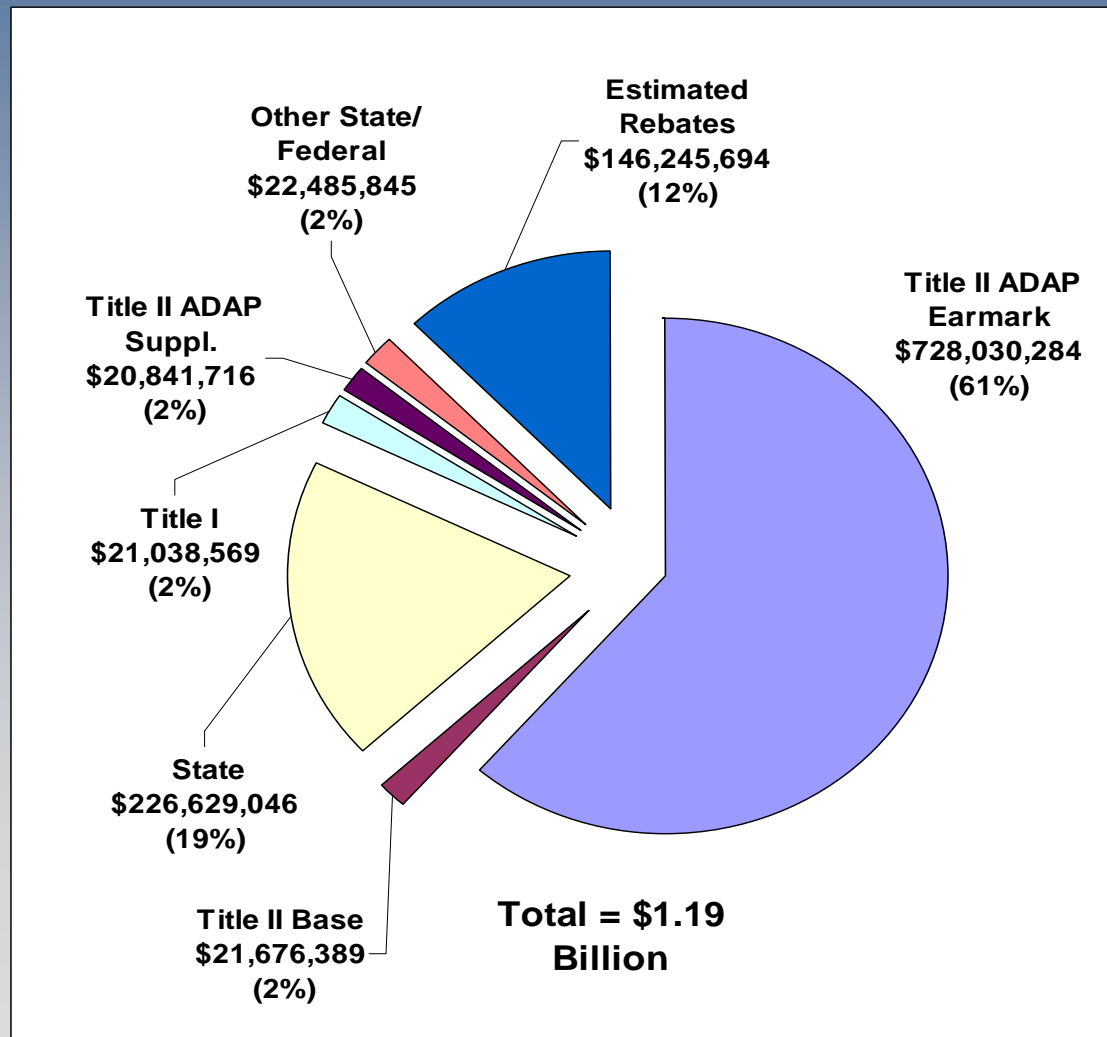


Note: Data not reported by 5 ADAPs: American Samoa, Guam, the N.Mariana Islands, Marshall Islands, and U.S. Virgin Islands



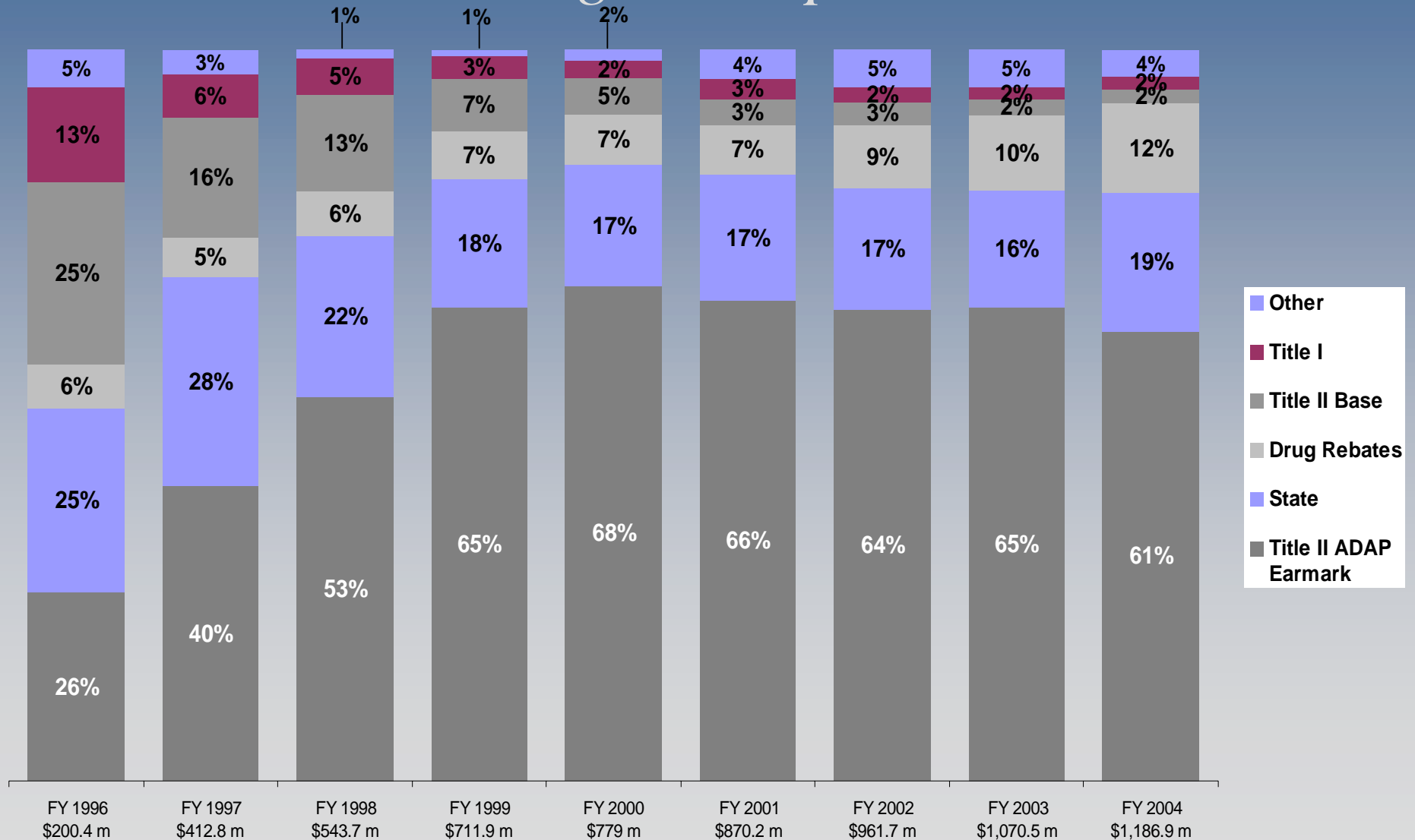
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## *National ADAP Budget by Source, FY 2004*



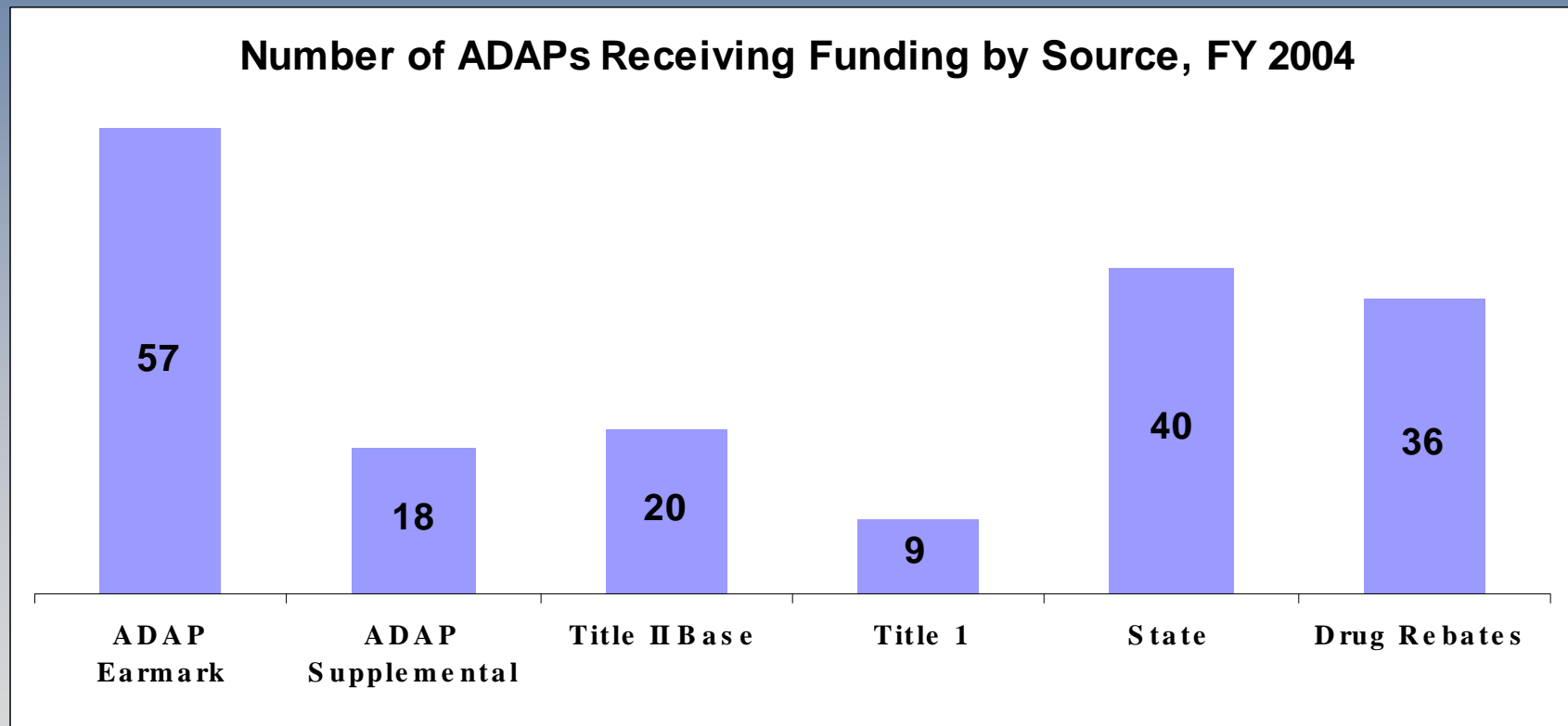
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## *National ADAP Budget Composition Over Time*



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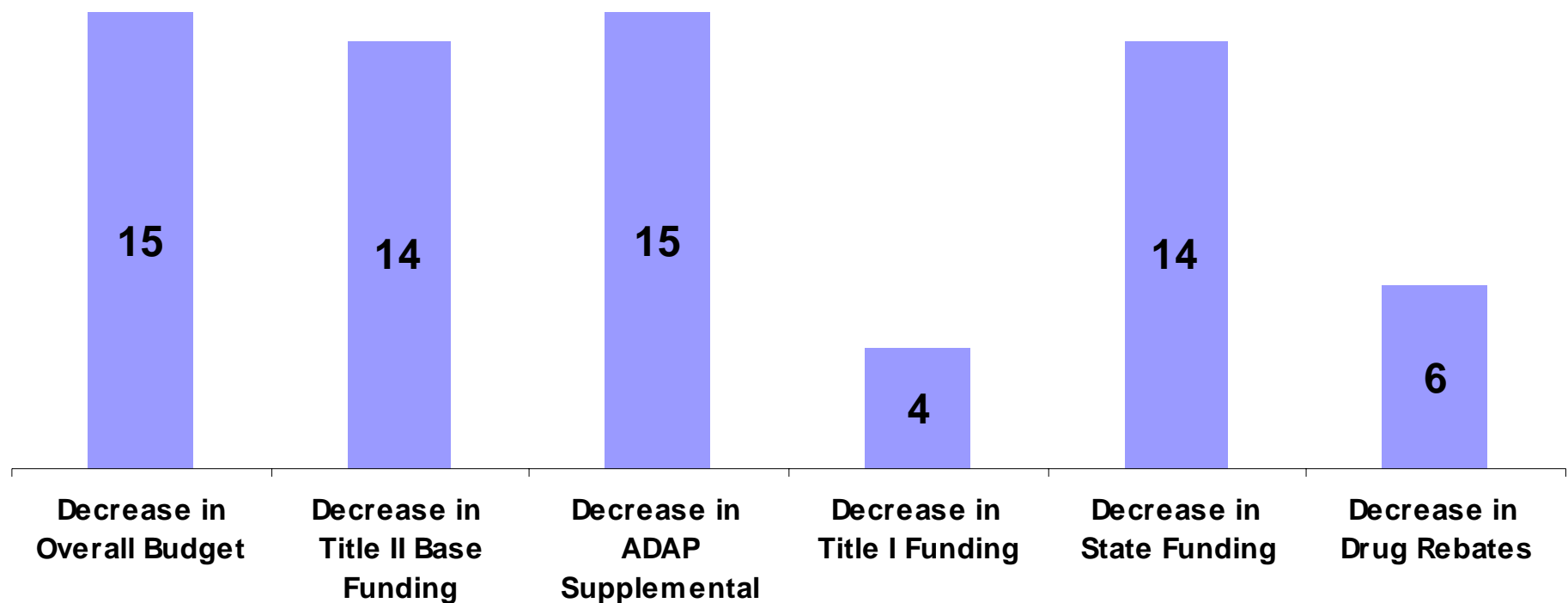
*Other than Earmark, Sources of Funding Highly Variable and Not Available to all ADAPs*



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*Several ADAPs Faced Budget Cuts Overall or For Particular Funding Sources*

**Number of ADAPs with Decreases in Overall Budget and by Funding Source, FY 2003-2004**



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## *Waiting List Trends*

- Surveys bi-monthly since July 2002
- Number of people on waiting lists ranged from a low of 537 (in 7 states) to a high of 1,629 (in 11 states)
- Average of 837 individuals on waiting lists
- 18 ADAPs have had a waiting list at some point during the survey period; 7 ADAPs had waiting lists in 10 or more periods
- Highest number of individuals on any waiting list was 891 (North Carolina); lowest was 1 (Alaska, Idaho, and Montana)

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## *President's \$20 Million ADAP Initiative*

- \$20 million, one-time initiative providing drug therapies to individuals on waiting lists in 10 states (as of June 21, 2004)
  - 1,738 treatment slots
  - only those on waiting lists in these states on June 21, 2004 eligible
- Currently serving more than 1,250 individuals through a mail-order distribution system – administered outside of ADAP
  - Eligible individuals in 2 states not yet processed to receive medications
- Initiative due to expire September 29, 2005
- ADAPs are expected to begin transitioning individuals from the program as it expires – no continuation funding has been provided to date

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## *Resource Constraints Lead to Cost Containment Measures that May Limit Client Access*

- 21 ADAPs have 1 or more cost containment measures in place
- 11 ADAPs have waiting lists (not only reflection of unmet need)
- Other cost containment strategies
  - Capped enrollment
  - Reduced formularies
  - Limiting access to certain medications
  - Cost-sharing
  - Expenditure limits (monthly or annual)
  - More restrictive eligibility requirements (medical, financial)

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*Waiting Lists, as of March 2005 (627 Individuals)*



- States with waiting lists in place as of March 2005 (107 individuals - 7 states).
  - States with individuals eligible for the President's \$20 million ADAP Initiative who are not yet receiving medications (401 individuals – 2 states), as of March 2005
  - States with waiting lists in place as of March 2005 that also have individuals eligible for the President's Initiative not yet receiving medications (104 individuals not eligible for the initiative and 15 individuals eligible but not yet receiving medications - 2 states)
- Commonwealth of Puerto Rico

Note: Data not reported by 5 ADAPs: American Samoa, Guam, the N.Mariana Islands, Marshall Islands, and U.S. Virgin Islands.



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## *Drug Purchasing & Insurance Strategies*

- 51 of 52 states reporting data participate in 340B program
- 27 are “direct purchase”; 25 use pharmacy networks
- ADAP Crisis Task Force negotiations to address drug prices for all ADAPs– estimated savings of \$90 million in 2004
- 26 ADAPs use earmark funding to purchase/maintain insurance coverage (cost-effective)
  - 7,277 clients served in June 2004
  - \$37.8 million in estimated expenditures for FY 2004
- 20 ADAPs use earmark funding to pay for insurance cost-sharing and deductibles

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## *Looking Forward...*

- Continued importance/role of ADAPs as safety net
- Reauthorization of Ryan White CARE Act (September 30, 2005)
  - Focus on ADAPs
  - How to address variability in access to ADAPs
  - Other CARE Act changes could affect ADAPs
- Challenges:
  - Growing population in need of care
  - Funding constraints in some states
  - Transitioning clients from the President's \$20 million ADAP Initiative (September 2005)
  - Implementation of the Medicare Part D Prescription Drug Benefit of MMA (January 2006)
  - Federal and state proposals to limit Medicaid spending