THE HENRY J. KAISER FAMILY FOUNDATION

HIV/AIDS

HIV/AIDS POLICY FACT SHEET

Waiting for AIDS Medications in the United States: An Analysis of ADAP Waiting Lists

December 2004

Introduction

Waiting lists are a reality of state[1] AIDS Drug Assistance Programs (ADAPs), which rely on specific federal appropriations, or capped funding, each year. Capped funding determines an ADAP's income eligibility criteria, the number of drugs on its formulary, and the number of people who can be served. Waiting lists have been in place in some states for several months, if not years, and there is significant fluctuation in the size of waiting lists within and across states over time. In recognition of ADAP funding shortfalls and the waiting lists that result, President Bush announced the availability of an additional $20 million in FY 2004, for medications in 10 states with ADAP waiting lists in place in June 2004.[2,3] The Initiative began distributing medications to eligible individuals in October 2004.

This fact sheet provides an overview of ADAP waiting lists based on analysis of data collected by the National ADAP Monitoring Project[4,5] between July 2002 and November 2004, which includes the implementation of the $20 million ADAP Initiative. States were surveyed on a regular basis over the period, for a total of 18 times, to assess the status of waiting lists and other cost containment measures.

Background[4]

ADAPs, part of the federal Ryan White CARE Act, provide HIV-related prescription drugs to people with HIV/AIDS who have limited or no prescription drug coverage. ADAPs reach approximately 30% of those estimated to be living with HIV/AIDS and receiving care in the U.S. each year. Administered and designed by the states, they operate in 57 jurisdictions including all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, three U.S. Pacific Territories and one Associated Jurisdiction.

ADAPs are discretionary grant-funded programs, with "capped" funding each year. Unlike entitlement programs, ADAPs receive a fixed amount of federal funding from Congress each year and funding does not necessarily correspond to the number of people who need services or the costs of those services. Although ADAPs may also receive some state and other funding, these are highly variable and limited. At the same time, demand for ADAP services has increased over time due to several factors: a growing number of people living with HIV/AIDS; rising costs of prescription drugs; and increasing complexity of HIV-related treatment regimens requiring multiple drugs. Changes in the larger fiscal environment may also affect demand for ADAPs; if other programs, particularly Medicaid, face tighter fiscal times, they may reduce program access, thereby increasing demand for ADAP services. As a result of these factors, access to ADAPs varies across the country.

Within these constraints, ADAPs have only a limited set of cost containment "tools" available for managing their programs, many of which may compromise access and result in unmet need. Waiting lists are perhaps the most visible example of unmet need. Those on ADAP waiting lists cannot get medications through ADAP, even though they meet all eligibility criteria. These individuals may go without medications at all, or they may be able to access a state- or manufacturer-operated pharmaceutical assistance program (PAP). However, only a handful of states operate PAPs for the non-elderly disabled[6] and pharmaceutical manufacturer PAPs generally require people to apply as often as every month, with separate applications to the manufacturer of each medication needed, creating an extremely difficult process to navigate, especially for someone on a multiple drug regimen. Some states may not have waiting lists in place, but may have other program restrictions or limitations. Other cost containment tools used by states, some of which can affect access, include:

- Lowering financial eligibility criteria;
- Limiting and/or reducing ADAP formularies;
- Instituting monthly or annual limits on per capita expenditures;
- Using drug purchasing strategies (discount programs, rebates, purchasing alliances and coalitions);
- Using ADAP dollars to pay for insurance coverage instead of medications directly;
- Seeking cost recovery through drug rebates and third party billing; and
- Using non-ADAP Ryan White CARE Act funds (Title II base) for ADAPs, often at the expense of other critical services.

To date, no state has eliminated current clients from its ADAP when faced with the need to implement a waiting list for new applicants. Nevertheless, states with waiting lists are faced with many challenges, such as:

- How to monitor those on waiting lists;
- How to help those on waiting lists access prescription drugs through other programs, if available;
- Whether criteria should be developed to bring people off waiting lists into services or whether new clients should be accommodated on a first come, first serve basis; and
- What kinds of future decisions could be made to reduce or eliminate the need for waiting lists, while least compromising access for all clients? For example, should a state add a newly approved medication to its formulary if that also would mean having to institute a waiting list?

Key Findings
ADAP Waiting List Trends: July 2002 – November 2004

- The number of people on ADAP waiting lists was 1,108 in 7 states in July 2002 and 813 in 9 states in November 2004.
- Waiting lists fluctuated significantly across states over the period:
  - The number of people on waiting lists ranged from a low of 537 to a high of 1629; the average was 862.
  - The number of states with waiting lists in any given survey period ranged from a low of 6 to a high of 11.
- Waiting lists also fluctuated significantly within states over the period:
  - The number of people on some state waiting lists often went up and down. For example, the size of the waiting list in Alabama was 250 in July 2002, 89 in August 2003, and 244 in November 2004;
  - Several states (AK, AR, IN, MT, NE, NC, SD) were able to eliminate their waiting lists at some point over the period only to reinstate them at a later date;
  - Fluctuation is hard to predict and is due to several factors such as changes in a state's fiscal environment, client demand, and costs of medications (including the introduction of new therapies).
- A total of 18 states had a waiting list in place at some point during the period (AL, AK, AR, CO, Guam, HI, ID, IN, IA, KY, MT, NE, NC, OR, SD, UT, WV, WY).
- Most states with waiting lists had them in place for more than one survey period
  - One state had a waiting list in all 18 survey periods (AL)
  - Seven other states had waiting lists in at least 10 of the survey periods (KY, MT, NE, NC, OR, SD, WV).
- The highest number of individuals on any one state's waiting list was 891 (NC); the lowest was 1 (AK and MT). North Carolina had the highest average number of people on its waiting list over the period (412), followed by Alabama (205). The lowest average was 2, in Wyoming.
- As of November 2004, 13 states had also instituted other cost containment measures (other than waiting lists) over the last year; 6 anticipate having to implement new or additional cost containment measures during the remainder of the fiscal year due to limited funds.
- The $20 Million ADAP Initiative has resulted in a reduction of the number of individuals on waiting lists:
  - A total of 591 individuals eligible to receive medications through the Initiative had been enrolled by November 2004 (representing 44% of those eligible[7]);
  - Five of the 10 eligible states had eliminated their waiting lists by November 2004, 3 due directly to the Initiative (ID, KY, MT) and 2 due to additional state appropriations (CO, SD);
  - In the remaining 5 eligible states, the number of individuals on waiting lists has been reduced, with 758 eligible individuals remaining to be served.
  - Four states instituted waiting lists after June 2004 and therefore are not eligible for the Initiative (AR, HI, NE, WY). Collectively, they had 55 individuals on their waiting lists as of November 2004, bringing the total number of individuals on waiting lists in that month up to 813 (758 eligible for the Initiative, 55 not eligible).

Please see accompanying Table and Figures 1-4

Conclusion

People with HIV/AIDS continue to be placed on ADAP waiting lists despite their need for medications and otherwise meeting ADAP eligibility criteria. There is significant variation in the number of people with HIV/AIDS on ADAP waiting lists within and across states over time, making it difficult for states to predict and manage need. The $20 Million ADAP Initiative has reduced the size of the waiting lists in eligible states in FY 2004. Waiting lists in non-eligible states will not be addressed by the Initiative. It is uncertain whether this approach will continue in FY 2005 and beyond; as currently configured, the Initiative addresses the waiting list problem in a subset of states at a fixed point in time in the current fiscal year. The challenge posed by ADAP waiting lists, and variability in access to ADAPs more generally, will be a key issue in the Reauthorization of the Ryan White CARE Act in FY 2005.

References

[1] The term "state" used in this fact sheet includes states, territories and associated jurisdictions.
[2] White House, "President Bush Discusses HIV/AIDS Initiatives in Philadelphia", June 23, 2004; White House, *Fact Sheet: Extending and Improving the Lives of Those Living with HIV/AIDS*, June 23, 2004.
[3] NASTAD, *Fact Sheet: President Bush's $20 Million ADAP Initiative*, December 2004.
[4] The National ADAP Monitoring Project: www.kff.org/hivaids/ADAP.cfm; see specifically, *Fact Sheet: AIDS Drug Assistance Programs*, May 2004.
[5] NASTAD, *The ADAP Watch*, December 2004.
[6] Kaiser Family Foundation, *Financing HIV Care: A Quilt with Many Holes*, 2004; also in, Institute of Medicine, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, Washington DC: National Academies Press, 2004.
[7] Of those eligible at time of implementation in November 2004.

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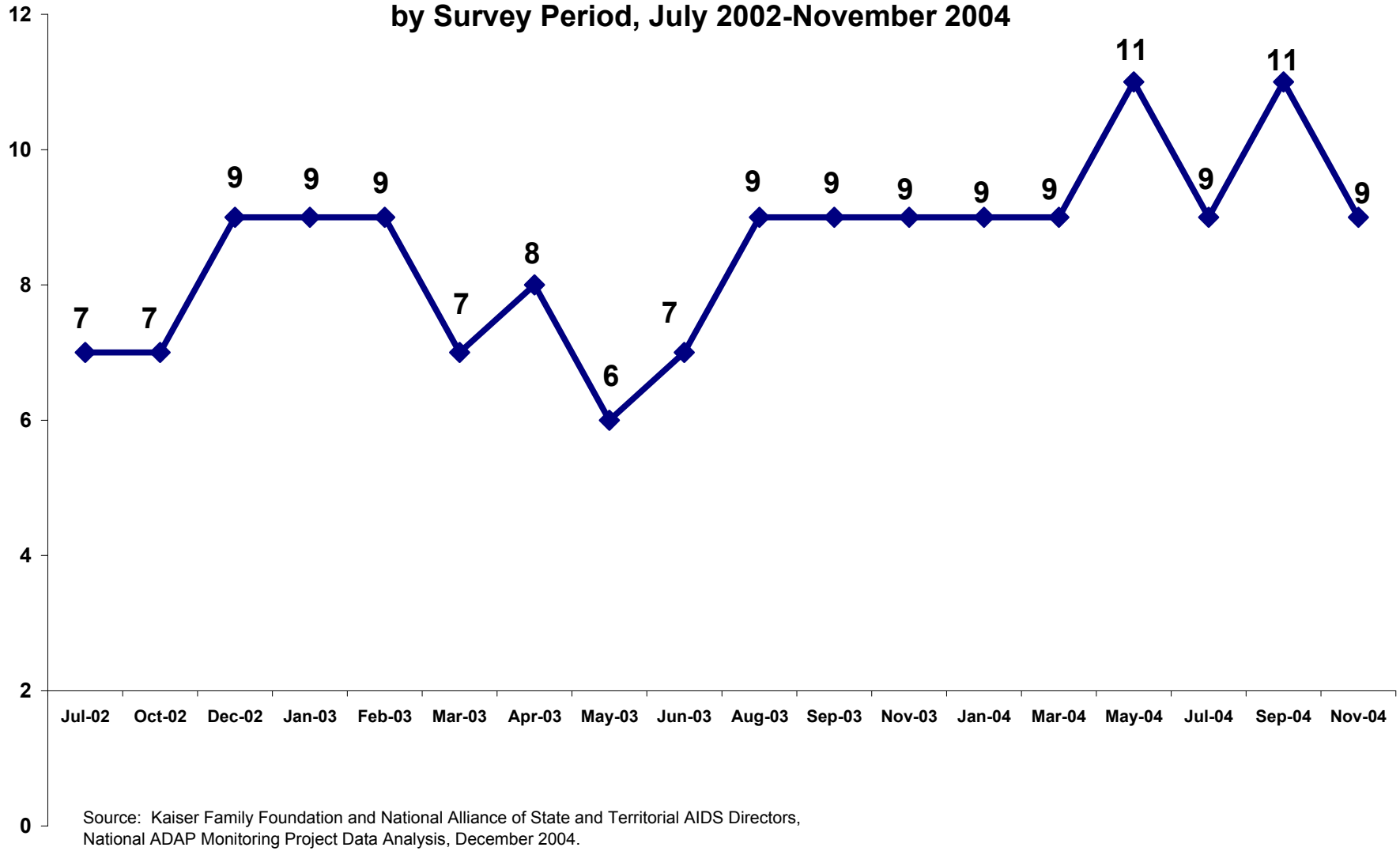
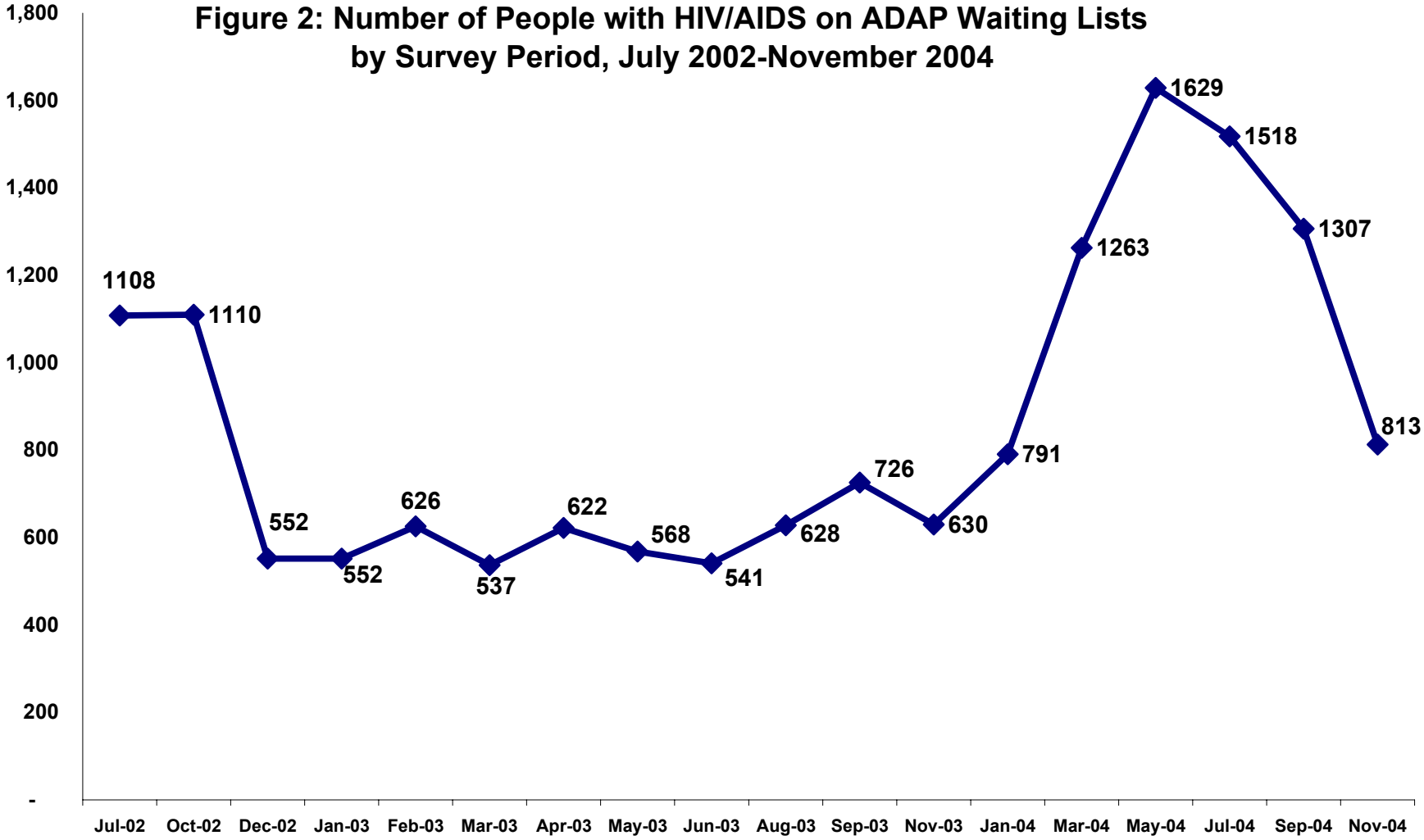
Figure 1: Number of States with ADAP Waiting Lists by Survey Period, July 2002-November 2004

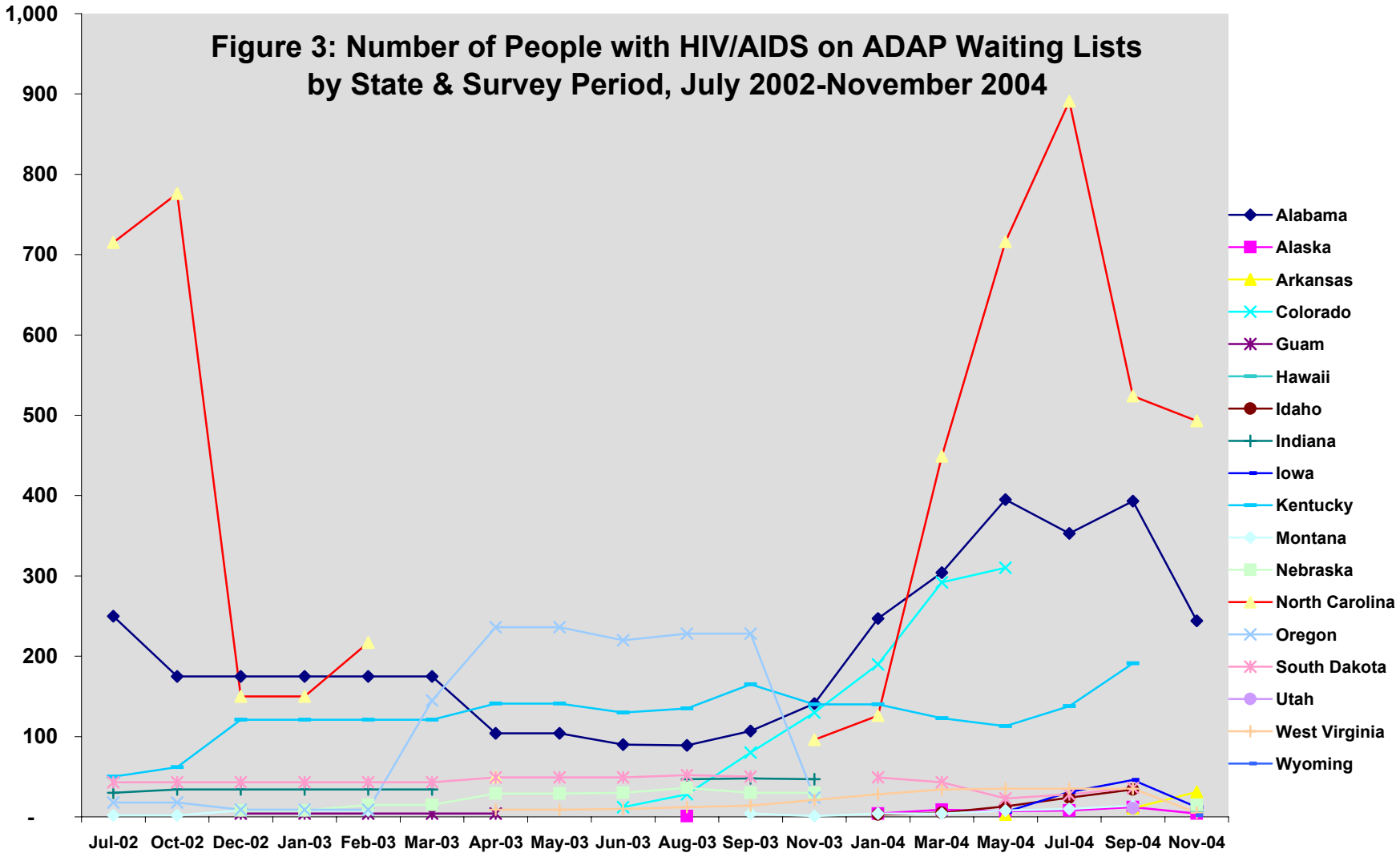


Source: Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Data Analysis, December 2004.

Figure 2: Number of People with HIV/AIDS on ADAP Waiting Lists by Survey Period, July 2002-November 2004

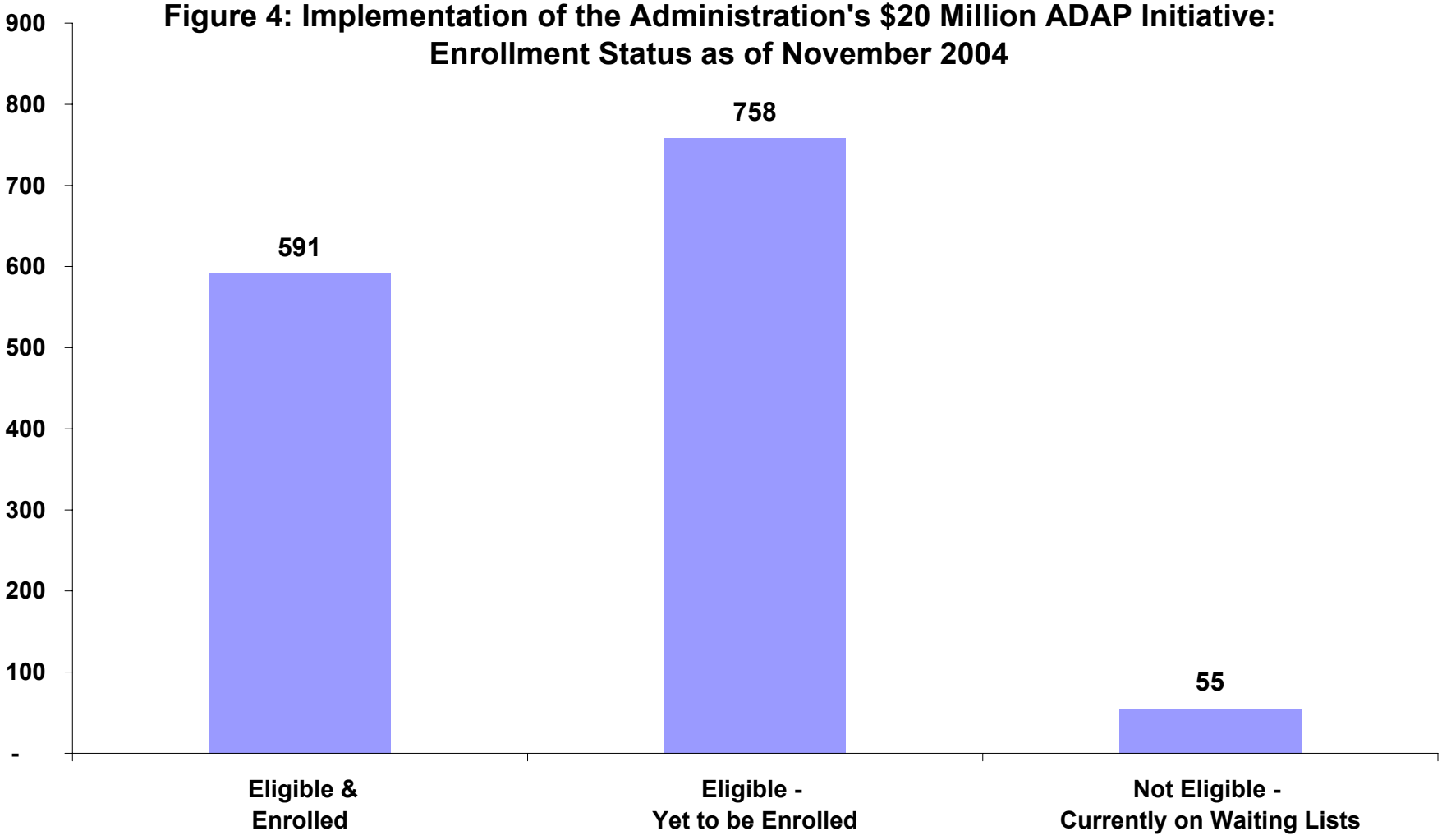


Source: Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Data Analysis, December 2004.



Source: Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Data Analysis, December 2004.

Figure 4: Implementation of the Administration's $20 Million ADAP Initiative: Enrollment Status as of November 2004



Source: Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Data Analysis, December 2004; NASTAD, *ADAP Watch* , December 2004.

Table 1: AIDS Drug Assistance Programs (ADAPs) - Waiting List Status, July 2002 - November 2004

State/Territory*	Jul-02	Oct-02	Dec-02	Jan-03	Feb-03	Mar-03	Apr-03	May-03	Jun-03	Aug-03	Sep-03	Nov-03	Jan-04	Mar-04	May-04	Jul-04	Sep-04	Nov-04	# of Periods w/Waiting Lists	Average # of People on Waiting List
Alabama	250	175	175	175	175	175	104	104	90	89	107	141	247	304	395	353	393	244	18	205
Alaska										1			4	9	7	8	12	4	7	6
American Samoa																				
Arizona																				
Arkansas															3		11	31	3	15
California																				
Colorado									12	28	80	130	190	292	310				7	149
Connecticut																				
Delaware																				
District of Columbia																				
Florida																				
Georgia																				
Guam			4	4	4	4	4												5	4
Hawaii																		7	1	7
Idaho													3	5	13	24	34		5	16
Illinois																				
Indiana	30	34	34	34	34	34				47	48	47							9	38
Iowa															6	31	46	12	4	24
Kansas																				
Kentucky	50	62	121	121	121	121	141	141	130	135	165	140	140	123	113	138	191		17	127
Louisiana																				
Maine																				
Marshall Islands																				
Maryland																				
Massachusetts																				
Michigan																				
Minnesota																				
Mississippi																				
Missouri																				
Montana	2	2	8	8	8						4	1	4	4	8	10	14		12	6
N. Mariana Islands																				
Nebraska			8	8	15	15	29	29	30	36	30	30						15	11	22
Nevada																				
New Hampshire																				
New Jersey																				
New Mexico																				
New York																				
North Carolina	715	776	150	150	217		50					96	126	449	716	891	524	493	13	412
North Dakota																				
Ohio																				
Oklahoma																				
Oregon	18	18	9	9	9	145	236	236	220	228	228	24							12	115
Palau																				
Pennsylvania																				
Puerto Rico																				
Rhode Island																				
South Carolina																				
South Dakota	43	43	43	43	43	43	49	49	49	52	50		49	43	23	28	36		16	43
Tennessee																				
Texas																				
US Virgin Islands																				
Utah																	11		1	11
Vermont																				
Virginia																				
Washington																				
West Virginia							9	9	10	12	14	21	28	34	35	35	35	5	12	21
Wisconsin																				
Wyoming																		2	1	2
Total # People on Waiting Lists	1108	1110	552	552	626	537	622	568	541	628	726	630	791	1263	1629	1518	1307	813		862
Total # of States with Waiting Lists	7	7	9	9	9	7	8	6	7	9	9	9	9	9	11	9	11	9	18	

Note*: States in bold eligible for $20 Million ADAP Initiative

Source: Kaiser Family Foundation and National Alliance of State and Territorial AIDS Directors, National ADAP Monitoring Project Data Analysis, December 2004.

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