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**National Solution Could Help Address ADAP Funding Crunch:
The Design and Implementation of an Enrollment Database**

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Introduction

State AIDS Drug Assistance Programs (ADAPs), which receive their funding through Title II (Part B) of the Ryan White CARE Act (RWCA), have continually struggled with funding shortfalls that have forced these programs to meet increasing demands with fewer resources. ADAPs are a vital source of care for underinsured and uninsured people living with HIV/AIDS. These programs currently serve almost 142,000 people in the United States, however, the benefits a person receives varies significantly from State to State¹. The average cost of therapy per ADAP client per month is estimated to be \$1,099 for FY2008², though funding shortfalls have forced States to introduce formulary limitations and waiting lists, in some instances.

The increased demand on the ADAP system has been attributed to a number of issues, including continued innovation in the HIV/AIDS treatment arena, the addition of drugs to State formularies to treat the patient, and the prevalence of other payers including Medicaid and Medicare. In turn, State ADAPs face many challenges in their operation, including:

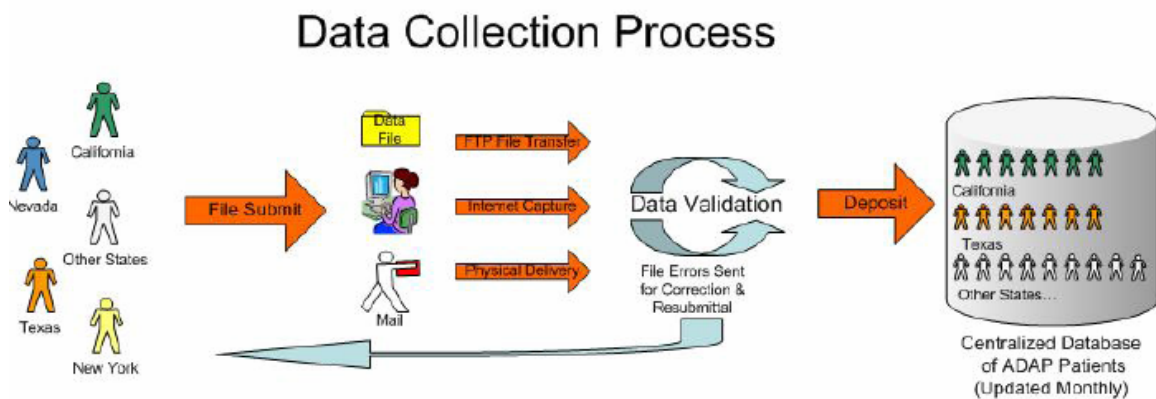
- **Overall quality management**, such as ensuring the ADAP is the payer of last resort and benefits abuse.
 - **Payer of last resort:** RWCA requires that ADAPs function as payer of last resort, however, current systems where a State operates on its own without collaboration with other outside parties (e.g., third-party private insurers, Medicaid, Medicare) makes this particularly difficult.
 - **Benefits abuse:** Benefits abuse occurs when a patient utilizes services in their home state and an adjacent state. This use of two State ADAPs can create funding issues and instances where another HIV/AIDS patient is denied access to the ADAP or placed on a waiting list.
- **Emergency preparedness** has become an important consideration for State ADAPs across the country. Natural disasters, such as Hurricane Katrina, have highlighted the importance of continuity of care for those living with HIV/AIDS and have forced States to consider how to deal with ensuring ADAP clients receive the treatment they need. In fact, estimates from Hurricane Katrina suggest that more than 21,000 were affected by the disaster and had to seek treatment elsewhere.

These challenges present an opportunity to improve overall ADAP quality management via a national database of State ADAP registration information designed to maximize limited RWCA funding, and ensure access to care in the case of an emergency. Our previous article, published April 11, 2007, examined the benefits of this proposed system and rationale for its implementation.

In this article, we will explore how a national enrollment system could be developed that allows each State to maintain its autonomy, security requirements and current enrollment practices, and its potential benefits for ADAPs from both a cost effectiveness and health outcomes perspective.

The Architecture of a National Enrollment Database

Given ongoing funding issues for RWCA and the current challenges faced by State ADAPs, the creation of a national enrollment database is a logical step in working towards a more efficient system. The proposed national enrollment database would operate as an Internet-based system, requiring States to upload specified data about their ADAP enrollees on a preset schedule that is agreed upon by the national enrollment database administrators and each State. Cross checks would be conducted by the national enrollment database administrator on a scheduled basis with alerts generated to State ADAP administrators. Below is a detailed description of each of the components of the database.



Data Collection Process

In order for the system to operate to its full capacity, a minimum number of fields about enrollees would be collected from each State ADAP program and stored on a central server. The stored data would be maintained in a fault tolerant, highly secure, weather resistant environment deployed across multiple locations

The suggested minimum fields of information to be collected would include:

- Demographics, such as name, social security number and date of birth, allowing for the national database administrator to run reports to check for benefits duplication and abuse in ADAPs
- Zip code of original diagnosis and enrollment and zip code at point of service, providing valuable information on where the enrollee is seeking services; the current system provides funding to the State of original

diagnosis but does not account for the mobility of the population, thus causing funding shortfalls for States where the HIV/AIDS patient moves

- Date of original enrollment in the ADAP program, as well as effective date and expiration date of coverage

Supplemental fields, such as viral load, CD4 counts, and prescription history could be included in the database, which would allow the national database administrator to generate a variety of valuable reports, including those examining disease progression or drug utilization. Disease progressions reports that take into account viral load or CD4 counts could help showcase the value of the ADAP by tying the program to improved health outcomes. Additionally, drug utilization reports would be very helpful in budgeting and forecasting for future fiscal years, at the State and national level.

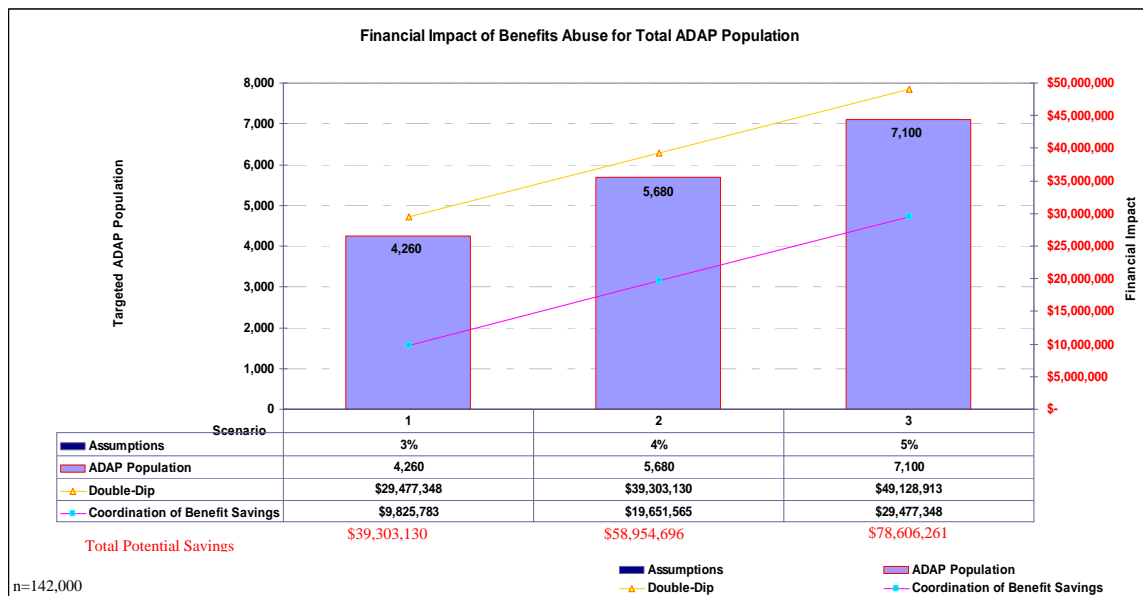
The data would be submitted by State ADAPs on a preset basis (monthly or quarterly). The national enrollment database would be completely flexible and allow for States, whether they keep electronic or manual records, to easily submit information. Electronic records could be uploaded via a secure FTP site, while a State running a manual system could fill out a spreadsheet with relevant information and submit the form via the same FTP site. In the long run, the system might allow States to reduce their administrative costs by streamlining their reporting processes and allowing for quicker budgeting, potentially freeing up additional funding for treating more patients.

Once the data is collected from each State, the national database would become an invaluable tool for States in a variety of situations. The database would allow States to respond in a quick and efficient manner during an emergency, such as a natural disaster, blackout or other unforeseen situation. By working with the administrators of the national database, States would have the ability to reprint prescription cards for use during the emergency time and provide ADAP administrators at a State level with eligibility information immediately. Hurricane Katrina in 2005 highlighted the importance of a national system when ADAP records in New Orleans were under several feet of water. Displaced citizen sought services in surrounding states, especially Texas; however, these States had little or no way to verify eligibility for these applicants.

The database would also provide States with a way to monitor the mobility of their population so that funding can be adjusted accordingly (e.g., Patient A was diagnosed in X State but has received services in X, Y, and Z states over the past 5 years). Importantly, the database would allow States to view a snapshot of how their patient population is doing. By evaluating the treatments administered and the outcomes, the database would provide a useful tool for measuring the effectiveness of the program and its overall cost effectiveness.

Data Verification Process

Once the information is uploaded to the secure database, the national database administrator would run preset data checks to screen for enrollees participating in more than one ADAP program, as well as ADAP patients using services despite having another payer who could provide care and treatment (e.g., Medicaid, private health insurance). These data checks could yield savings for State ADAPs and ensure that the enrollees being served are truly eligible for the services.



The chart above illustrates the potential savings of implementing these data checks. The line on the bottom of the chart shows projected savings (\$49.1 million per year) related to enrollees participating in more than one ADAP (Double Dip). The top line shows projected savings (\$29.5 million per year) tied to ADAP patients using services while having coverage from another payer (Coordination of Benefits). It is estimated that the total savings to ADAP by implementing both of these data screening capabilities is \$78.6 million.

System Alerts

Once the data checks are conducted, the national enrollment system would generate alerts that are sent to ADAP administrators via email or secure postal service mail depending on the State and its current system. The alerts would only state that the system noticed a duplication of service or other issue, and would request that the Administrator or responsible party log on to the secure website or call a toll-free number to learn more about the alert.

After confirming their identity, the administrator of the State ADAP or other pre-authorized ADAP employee, would receive additional identifiable details about the duplication. Accessing this information allows State ADAP Directors to quickly address the potential inefficiency and reallocate funds to help serve additional patients. Only the States affected by the particular issue would receive the alert. At the outset, the system would likely generate large quantities of alerts, however, over the subsequent months, the number of alerts would decrease as States check and confirm eligibility for the enrollees flagged by the system, and assign them to their proper ADAP or help them access their other benefits.

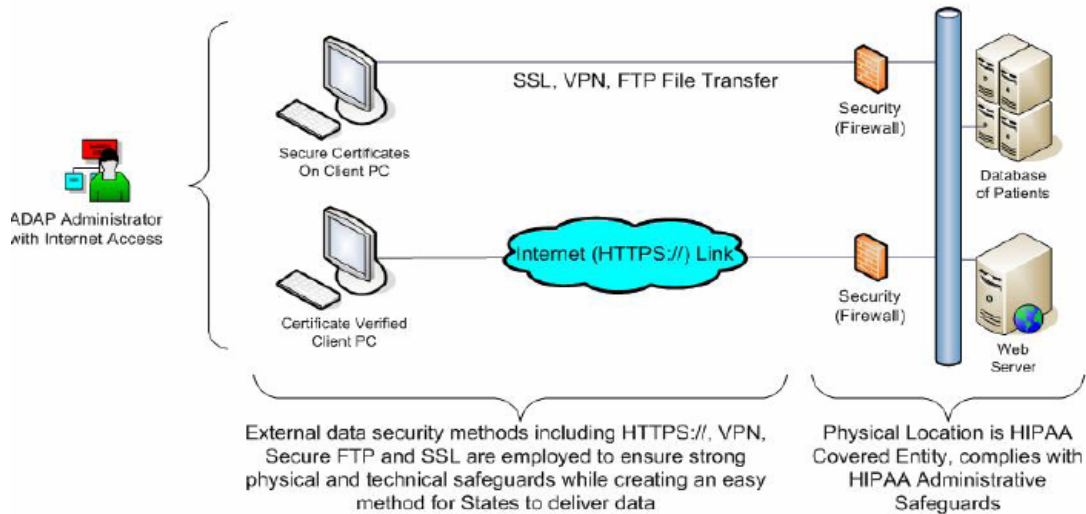
Security and Confidentiality

The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, was enacted on August 21, 1996. Sections 261 through 264 of HIPAA require the Secretary of Health and Human Services to publicize standards for the electronic exchange, privacy and security of health information. The security standards set forth by HIPAA are divided into three main categories:

- **Administrative safeguards** that require delineation of the security responsibility to an individual and implementation of specific security training requirements
- **Physical safeguards** that include the requirement to protect electronic systems and their data from threats, environmental hazards and unauthorized access. These safeguards include restricting access to electronic protected health information and ensuring there are offsite computer backups
- **Technical safeguards** that are the processes used to protect data and control access. Some of these safeguards include authentication to verify identity and encryption of data during storage and transmission³

Recognizing the increasing concerns about privacy and security in an electronic world, the national enrollment database system would comply with all federally mandated rules for maintaining and handling confidential data. All alert information would be accessed at a secure website and require users to complete an authentication process each time they access the site. The physical locations housing ADAP patient data information would be maintained and managed to meet all HIPAA compliance requirements

HIPAA Compliance & Data Security



Why the National Enrollment Database Makes Sense for ADAP

The national enrollment database holds the potential to enhance the quality management of State ADAPs by utilizing available information to eliminate errors and duplications. These enhancements will lead to a positive impact on the financial and administrative bottom-line for these programs.

Cost Savings: Current budget constraints on State ADAPs make every opportunity to improve eligibility screening and verification crucial. These improvements in data analysis could save money for State ADAPs and potentially allow States to serve additional HIV/AIDS patients who need ADAP services. By using reports generated by the national enrollment database, States could ensure they are serving the patients that are truly eligible for service and in turn, further expand their services to meet the growing needs of the ADAP population.

Disaster Recovery: The System allows for continuity of care in the case of an emergency, including the generation of replacement Benefits ID cards, and the recovery of files that might otherwise have been lost. Furthermore, States would have the ability to retrieve data stored on the database rather than recreating hard copy files or other documentation, representing potential administrative cost savings.

Ease of Implementation and Use: The System does not require States to overhaul or change their existing ADAP administration. Rather, the System is designed to work with the current method being used by each individual state.

Data Reporting: The ability to review data on a State-by-State and national level can provide State ADAPs with worthwhile tools to forecast and budget, while, real-time reports on drug utilization, ADAP enrollment and other

parameters could be made available publically quicker than the current system allows. Current federal data can sometimes be as much as two years old.

Conclusion

The proposed national enrollment database is a completely feasible solution that can maximize ADAP funding while allowing States to continue to administer their programs autonomously and with minimal changes. The national enrollment database can greatly benefit States by enhancing quality management. From a financial perspective, States can reduce their administrative costs, save money by eliminating benefits abuse and duplication, and access data that can help them more accurately forecast for future years. From an administrative perspective, the System allows for continuity of care in the case of an emergency, including the ability to replace benefits ID cards, and allows States to recover files that might otherwise have been lost. It is time to discuss the best way to move towards the proposed system to ensure quality care for all HIV/AIDS patients.

The ideas and opinions expressed in this paper are those of the Flowers Heritage Foundation alone.

About Flowers Heritage Foundation, Ramsell Holding Corp., and Public Health Service Bureau

Public Health Service Bureau (PHSB) is a subsidiary of Ramsell Holding Corporation. Flowers Heritage Foundation is the separate 501 c3 charitable and public policy voice of the Ramsell family of companies based in Oakland, California. PHSB is a highly efficient pharmacy benefits administrator and information management company that provides customized services for public health programs. Its proprietary software and healthcare expertise enables health care entities to make funds go further, thereby assuring that patients have access to life-sustaining medications they need to survive and thrive. As an important commitment of the Ramsell family of businesses to give back to the community they serve, Public Health Service Bureau gives a portion of its profits to the Flowers Heritage Foundation, a non-profit organization with programs that include funding medications for ADAP waitlisted patients, and AIDS awareness programs for High School students. For more information on Flowers Heritage Foundation, go to www.flowersheritagefoundation.org . For more information on PHSB, go to www.phsb.com

¹ The Henry J. Kaiser Family Foundation, *National ADAP Monitoring Project Annual Report: Summary and Detailed Findings*, April 2007.

² The National ADAP Working Group, *Annual Ryan White CARE Act – Title II ADAP Needs Projection – ADAP Program Year (1 April 2008-31 March 2009)*, March 1, 2007. Retrieved from <http://www.tiicann.org/FY%2008%20ADAP%20Need%20Summary.pdf>.

³ Department of Health and Human Services, *HIPAA Security Series, Volume 2, Paper 1, 11/2004 revised 3/2007*.