About NASHP

The National Academy for State Health Policy is a nonpartisan forum of policymakers throughout state governments, learning, leading, and implementing innovative solutions to health policy challenges.

To accomplish our mission we:

- Convene state leaders to solve problems and share solutions
- Conduct policy analyses and research
- Disseminate information on state policies and programs
- Provide technical assistance to states

At NASHP, we provide a unique forum for productive interchange across branches and agencies of government involved in the delivery of health care and development of health care policy.

Learning Objectives

- Share opportunities to promote partnerships between Medicaid and Ryan White HIV/AIDS Program (RWHAP);

- Explore HIV data sources, development of data sharing agreements, and use of data analyses to inform policy and programmatic improvements;

- Highlight examples of states who are innovatively using data to improve health outcomes for people living with HIV.

HIV Health Improvement Affinity Group

- The National Academy for State Health Policy (NASHP), in partnership with the Health Resources and Services Administration, the Centers for Medicare and Medicaid Services, and the Centers for Disease Control and Prevention, convened the HIV Health Improvement Affinity Group in October 2016.

- The Affinity Group provided cross-agency teams from 19 states with 12 months of technical assistance focused on sharing and then using data to inform policy and programmatic improvements to increase rates of sustained virologic suppression.

Participating States

Sharing Robust Data is Key

- Sharing data between state health department HIV and Medicaid programs is integral to providing comprehensive and high-quality care to people living with HIV (PLWH).
  - Two different agencies with pivotal roles;
  - Two different data systems;
  - Dealing with complex chronic conditions where coordination and continuity of care are essential.
- When successful, sharing data across state agencies can provide a more complete picture of the proportion of PLWH who are engaged at each stage of the HIV Care Continuum.
- States can more accurately assess how available clinical care and support services, address the needs of PLWH, and identify what policy or program changes could have the greatest impact.

HIV Data Landscape

Data System	Description
State Health Department HIV Surveillance Data *Collected by the state health department.*	States collect surveillance data to monitor and analyze patterns in newly identified HIV diagnoses, HIV prevalence, clinical outcomes (e.g., CD4 and viral load), and morbidity and mortality rates. State health departments receive surveillance data from a variety of sources, including laboratories, health care providers, and viral statistic registries.
Ryan White HIV/AIDS Program Service Report (RSR) , *Collected by Ryan White HIV/AIDS Program (RWAHP) within state health departments.*	The RSR compiles individual client level data (a client report) annually for individuals who receive one or more RWHAP- funded services, as well as grantee and service provider information. Client reports generate a unique identifier for each RWHAP client based on name, date of birth, and other protected health information (PHI).
ADAP Data Report (ADR) *Collected by Ryan White HIV/AIDS Programs within state health departments.*	The ADR reports all ADAP-funded medication and insurance services that ADAP clients receive during the reporting period.
Medicaid Management Information System (MMIS) , *Collected by the state Medicaid agency.*	Each state operates a MMIS to process claims and collect data and information for Medicaid beneficiaries, such as demographic, eligibility, and utilization data.

Data Sharing Can be Complicated

Sharing data across state agencies or departments can be complex due to:

- Federal and state laws that regulate certain types of information, including protected health information (PHI);
  - HIPAA
  - 42 CFR Part 2
  - State statutes or regulations that address confidentiality of PHI, and often specifically the disclosure of HIV-related information
- A lack of consensus across state agencies of what data can or should be shared, frequency of data sharing;
- Different data systems and issues with data matching;
- Inadequate state information technology (IT) infrastructure; and
- Limited state resources.

Accurate Data Are the Building Blocks

HIV CARE CONTINUUM:

The series of steps a person with HIV takes from initial diagnosis through their successful treatment with HIV medication

- DIAGNOSED WITH HIV
- LINKED TO CARE
- ENGAGED OR RETAINED IN CARE
- PRESCRIBED ANTIRETROVIRAL THERAPY
- ACHIEVED VIRAL SUPPRESSION

Source: https://hab.hrsa.gov/about-ryan-white-hivaids-program/hiv-care-continuum

Data Use Agreements (DUAs)

- Govern the sharing of limited data sets by covered entities, such as health plans, health care clearinghouses, or health care providers who electronically transmit any health information.

- Medicaid and state health departments are generally considered to be covered entities that perform qualifying functions, such as providing health insurance and/or providing services.

- DUAs establish how the limited data set may be used, and how it is protected.

- Sharing HIV-related data across Medicaid and state health departments may require modifying or amending an existing DUA, or developing a new DUA between Medicaid and the state health department HIV programs.

Key Considerations for DUAs

- **Clearly articulate the questions that need to be answered.**
Clearly defining the policy or program issue that needs to be addressed can be a helpful first step in the development of a DUA.

- **Be strategic when drafting or expanding DUAs.**
When expanding or drafting a DUA, it can be helpful to consider not only what data is currently desired, but what data may need to be shared in the future.

- **Clearly define and understand the legal parameters of what data can be shared and how it can be used.**
Due to the interplay of state and federal rules around data sharing, states found developing or amending DUAs is not necessarily a one-size-fits-all process.

- **Establish and maintain partnerships across agencies.**
The more data that states have available to them, the more accurate a picture of exactly where gaps in health care exist for PLWH.

State Snapshot

Georgia: Used existing DUA that enabled the sharing of desired data elements.

- Shared data between Department of Community Health, which houses Medicaid, and the Department of Public Health, which houses HIV Epidemiology and the HIV Program.

- This interagency agreement had originally been put in place to improve public surveillance efforts.

California: CA Health and Human Services Agency has an overarching DUA in place for data exchange between departments.

- Includes the Department of Health Care Services (Medicaid) and the Department of Public Health (Office of AIDS).

- The departments developed a business use case that specifically outlines the parameters of sharing HIV-related data.

The state reports that the overarching DUA has streamlined the process of sharing data for specific projects.

Analyzing/Using Data to Inform Policy

With a more complete data picture, states can make informed policy decisions about how and where to target existing services and to focus additional resources to achieve better outcomes and experiences for PLWH. This can include identifying:

- PLWH who were not identified by either Medicaid or HIV surveillance and RWHAP;
- PLWH who are/not linked to or engaged in regular care;
- PLWH who are/not filling their prescriptions for ARTs;
- IPLWH who are/not are not virally suppressed;
- Geographic areas with resident PLWH with high service needs; and
- Disparities among underserved populations and racial and ethnic minorities.

Key Considerations: Using Data Effectively

- **Understand a state's IT infrastructure and capacity**.
  A strong IT infrastructure is central to a state's ability to share and analyze comprehensive data sets across state agencies.

- **Identify the population**.
  DUAs can allow Medicaid agencies to share claims from its entire population, or they can limit data sharing to claims from individuals who are likely to be PLWH.

- **Anticipate data-matching challenges**.
  Data matching compares variables between data sources, such as health department HIV surveillance and Medicaid claims data.

- **Communicate data in ways that are accessible to stakeholders**.
  To truly improve outcomes and inform policymaking, data must be presented in a way that clearly and concisely displays the results of the analysis to appropriate stakeholders. Tailored

State Snapshots

## Affinity Group Washington State Action Plan

Objectives

- Identify and analyze data for persons living with HIV (PLWH) who are Medicaid clients and NOT virally suppressed

- Increase number of Medicaid PLWH clients receiving optimal medical care or case management services

Outcomes

- Collaborative data analysis

- Increase number of Medicaid HIV Positive clients with viral suppression
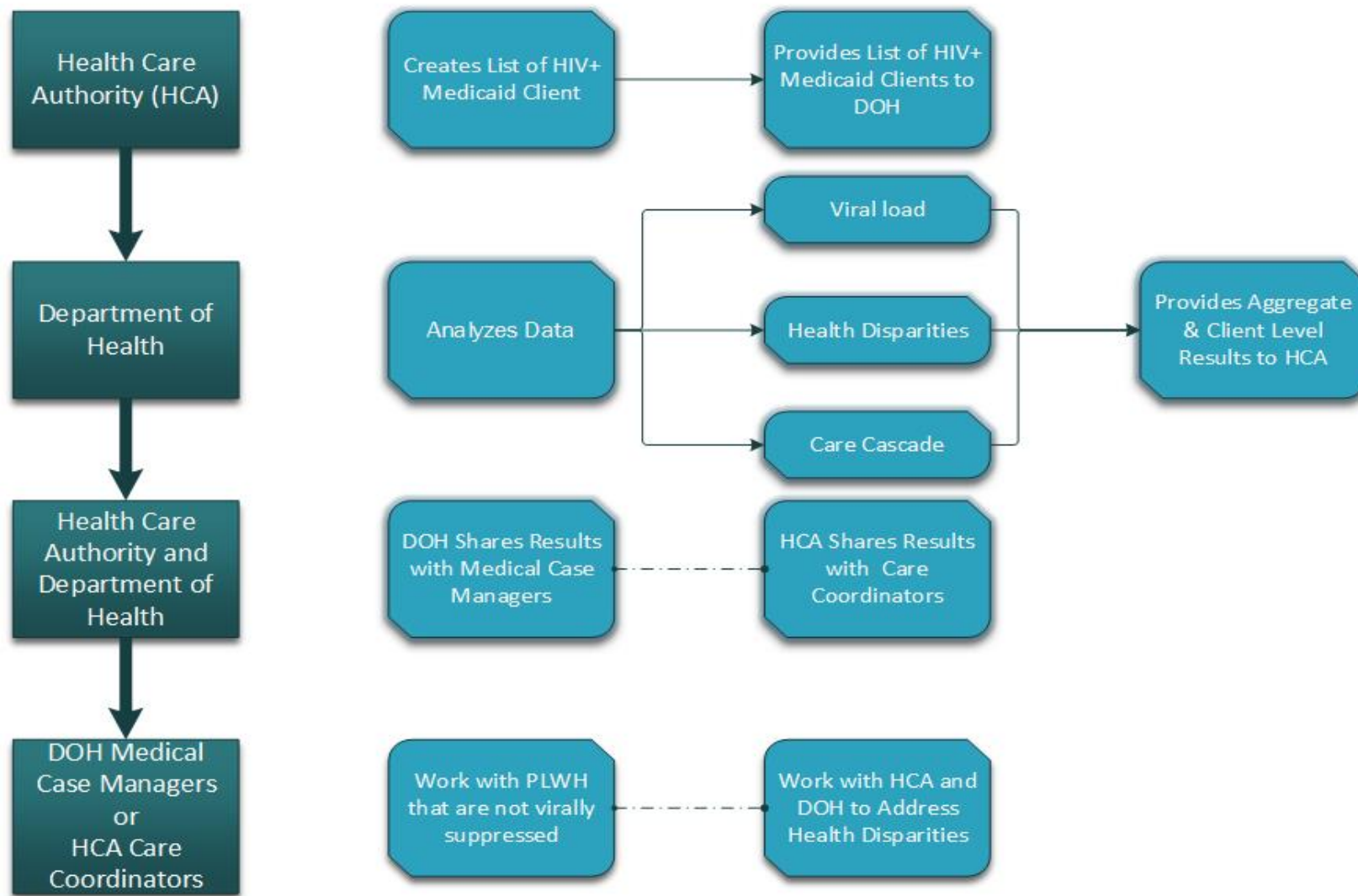
Conclusion

- Strong cross-agency collaboration and partnership is critical to providing comprehensive, high-quality care to PLWH in effort to increase rates of virologic suppression.
- Sharing and analyzing multiple data sets can help state officials make more informed policy and programmatic decisions, and target limited resources to where they can have the greatest impact on outcomes for PLWH.
  - Improving care
  - Targeting limited resources and reducing duplication of services.
- Promising practices and lessons learned:
  - Develop and formalize collaborative relationships with other state agencies;
  - Understand what data is available to help inform policy decisions;
  - Work closely with legal counsel to develop DUAs that can meet long-term data needs;
  - Be ready to troubleshoot issues that may arise when analyzing the data; and
  - Once compiled, present data effectively for key audiences.

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