Building IT Capacity: Using Client-Level Data to Meet Consumer Needs

Data make a difference. Much more than just numbers, data provide a means for the Ryan White HIV/AIDS Program and its grantees to improve service delivery and, thus, improve the health of people living with HIV/AIDS (PLWHA). From identifying populations that fall out of care to charting a client's response to a new treatment regimen, data paint a picture of what Ryan White providers are doing well and what they can do better.

Data also help the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) ensure the most effective use of its funds in increasing access to treatment and care and addressing health disparities. With grantee data reports, which track client demographics, core medical and social services provided, and client outcomes, HAB can meet legislatively mandated reporting requirements and evaluate the impact and quality of services funded by the Ryan White HIV/AIDS Program. Data reports also let grantees monitor their own progress in delivering cost-effective care and show where improvements can be made in their own programs.

Making changes to better serve PLWHA depends on having the most accurate data possible. Access to client-level data ensures this accuracy. With client-level data, grantees and the Ryan White HIV/AIDS Program receive comprehensive information on each client and the care he or she has received. For years, annual Ryan White Program grantee reports have included aggregate data from providers, which led to duplicated counts when clients visited multiple providers. Unduplicated, client-level data, in contrast, allow grantees to track the true number of clients in care as well as the services received by each client, the quality of those services, and health outcomes, thereby giving the full scope of a client's health. With this data, grantees can better track progress on meeting performance measure guidelines, and HAB can ensure that it continues to reach the communities most in need of support.[1]

Congress made client-level data reporting a requirement for Ryan White HIV/AIDS Program grantees in the 2006 Ryan White HIV/AIDS Treatment Modernization Act, which reauthorized and made changes to the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. As of January 2009, Ryan White HIV/AIDS Program grantees began collecting client-level data as part of the requirements for the new Ryan White Services Report (RSR). The RSR will be submitted twice annually and replaces the Annual Summary Data Report (RDR), which collected data in the aggregate rather than by individual client. (For more information, see box, p. 4.)

Implementation and Security Challenges

Documenting client-level data requires electronic systems that are responsive to user needs. Such systems reduce the time providers must spend on a computer, giving them more time with the clients who need their care. By showing trends in client outcomes and clients' opinions on service delivery in "real time," the systems also support ongoing program evaluation and provide up-to-date evidence that can be used to advocate for program change, thereby helping to quickly and effectively improve services. Systems that give users some choice as to which data to track create greater provider buy-in and foster collaboration among area providers on how to improve service delivery locally or even statewide.

Developing the information technology (IT) capacity for client-level data collection, however, can be challenging. Many expensive and time-consuming tasks are involved, including staff training on system use, acquiring hardware for data storage, and simply maintaining and updating a system. Grantees also must tackle concerns about data security. Collecting and storing client-specific information often requires continuous security updates, firewalls, and client–provider consent forms.

U.S. Department of Health and Human Services

HRSA
Health Resources and Services Administration

Ryan White HIV/AIDS Program Parts A & B IT Capacity-Building Grantees

- Baltimore City Health Department
- Florida Department of Health
- Hawaii State Department of Health
- Hennepin County (MN) Department of Primary Care
- Hudson County (NJ) Department of Health and Human Services
- Multnomah County (OR) Health Department
- Nevada Department of Health and Human Services
- City of New Orleans
- Orange County (FL) Board of Commissioners
- Paterson (NJ) Division of Health
- Philadelphia Department of Health
- Puerto Rico Department of Health
- Rhode Island Department of Health
- Sonoma County (CA) Health Services Department
- Texas Department of State Health Services
- Utah Department of Health
- Wisconsin Department of Health and Family Services

SPNS Program Efforts

The Special Projects of National Significance (SPNS) Program launched the Capacity Building to Develop Standard Electronic Client Information Data Systems Initiative (IT Capacity-Building Initiative) to help Ryan White providers address the technical, implementation, and security challenges associated with building their electronic network systems for high-quality client-level data collection. Since September 2008, the initiative has helped 17 Part A and B grantees purchase electronic health information systems or additional resources for enhancing and maintaining existing systems, including software, hardware, and system technical assistance for the duration of the SPNS grant cycle.[2]

Grantees of the SPNS initiative can use any software system for client-level data reporting that is in compliance with the Health Insurance Portability and Accountability Act (HIPAA). Grantees are advised to learn more about various software programs by consulting with vendors or grantees already using them.[3] Systems used by the SPNS grantees are built from commercially available software, such as AIDS Regional Information and Evaluation System (ARIES), LabTracker, or larger electronic medical records (EMR) systems.

The Ryan White HIV/AIDS Program provides CAREWare data collection and reporting software at no cost; the software can quickly produce the RDR and RSR once providers enter data.[4] CAREWare can run as a stand-alone application on individual grantees' computers; over a local or wide area network of grantees; or on the Internet, where it allows a network of users to link in real time to a central database containing unduplicated records. This approach eliminates the need for providers and subgrantees to manually forward data to a central domain and for Part A and B grantees to spend time sifting through mounds of documents to find reporting errors.

Many Ryan White grantees and their providers are well prepared to collect client-level data and have been doing it for years, but others still have gaps to fill when it comes to readying their hardware and software systems for client-level data collection. The SPNS grantees featured in this bulletin are at various stages of IT capacity development, and they offer different strategies for increasing capacity—and, ultimately, delivering the best possible care to PLWHA.

Laying the Foundations

Grantees new to client-level data collection, like the Puerto Rico Department of Health, can increase their capacity quickly as long as they have a good, comprehensive plan for adopting a new electronic network system in place. The first step is to secure appropriate software and hardware. Cost and grantee technical capacity must be taken into consideration when choosing a system.

Many Ryan White grantees choose to use CAREWare, given that it is available free of charge and meets Ryan White HIV/AIDS Program data reporting requirements. Puerto Rico, a Ryan White Part B grantee, adopted CAREWare in October 2008 after having collected data manually from several of its 30 subgrantees. One-half of Puerto Rico's subgrantees were already using older versions of CAREWare software at the time. "We now have 75 percent of our subgrantees linked into the system. It's so simple to use, and we've had very few problems," says Luis Peréz, project manager.

Quality data reporting from the start depends on more than having good data collection and hardware systems. Grantees must address important system usage issues, such as existing IT and programmatic capacity, personnel who will use the system, and contingencies for financing system maintenance and technical assistance in the future.[5] Getting a high level of buy-in among key stakeholders and creating system "champions" among providers are helpful steps in any comprehensive capacity-building plan.[6] "We've shown providers how data will help them do everything from improve services to write proposals. But involving them from the beginning is the most important thing. They must help create

that comprehensive plan for data collection to feel as invested as possible,'' says Peréz.

Peréz and others at the Puerto Rico Department of Health strive to ensure that the providers they support through their Part B grant, especially those new to the system, are comfortable with using CAREWare and use it correctly from the beginning. "I go on site visits and do trainings one-on-one with providers. I always have my phone on me so they can call if they have problems and get help immediately, and I've also trained two other staff members at the health department office to help providers if they call with a question," says Peréz. Presentations available on the HRSA HAB Technical Assistance Resources, Guidance, Education and Training (TARGET) Center Web site (www.careacttarget.org/) advise conducting trainings via Web or conference calls and recommend doing "dry runs" with providers to work out kinks in the collection process and identify problem areas and solutions.[7]

Data should also be checked routinely from the beginning to ensure consistent accuracy and completeness. Puerto Rico formed a data quality assessment committee early in its SPNS grant cycle and has continually checked data by sending random samples to project supervisors on a monthly basis. The data are drawn from several categories, including those that Ryan White HIV/AIDS Program grantees are required to report to HRSA, such as client characteristics (e.g., gender) and health indicators (e.g., CD4 counts). "Less than 5 percent of that data has come out with errors, which sometimes happen when providers change the status of a patient from having AIDS to having HIV when their CD4 count rises above 200," says Peréz. The health department also emphasized accurate reporting during five training sessions and plans to keep holding those sessions regularly.

Although only in its early stages of reporting client-level data, Puerto Rico is already using data to improve service delivery and, thus, achieve the Ryan White HIV/AIDS Program's goal of delivering the best care possible to PLWHA. "We review the data monthly and then send performance measure reports to our quality committee, which is made up of providers and health department staff. These meetings aren't mandatory for providers, but we still get about a 90 percent provider turnout," says Peréz.

Meeting Present and Future Needs

Out-of-date systems and varying levels of IT capacity and experience among providers can complicate client-level data collection for grantees, blurring the "big picture" of service delivery in a county, community, or State. Part A and B grantees must ensure that they, as well as the providers they fund, are ready for client-level data reporting, both for the RSR and to meet county and city requirements.

The County of Hudson (NJ) Department of Health and Human Services, a Ryan White Part A grantee, found that many of its sub-

Client-Level Data: What to Keep in Mind When Building a System

- Choose hardware and software systems that meet provider needs and match available resources. Surveying providers and learning from other Ryan White grantees who have systems in place are two strategies that can help with selection of systems.

- Make sure the system meets HIPAA requirements and protects client privacy. These goals can be met by developing policies for data sharing and accessing user records and ensuring that only trained personnel enter HIV-medical related information into the system.

- Ensure that the system tracks all client data required in the Ryan White Services Report. A list of required data fields is available at www.careacttarget.org/library/rsr/datafields.pdf

- Provide hands-on training in system use. Offer technical support to providers, and do routine checks to get their feedback on the system and ensure that they are comfortable with its use.

- Perform routine data checks to ensure that reports are as accurate as possible.

grantees lacked both the necessary hardware to update to the newest version of CAREWare in 2007 and internal technical support. Hudson applied for a SPNS grant to bring its providers and its own system up to speed with CAREWare and to meet RSR and local reporting requirements.

Ensuring the security of client-specific data is an important step in configuring an electronic network system. Hudson secured data from its grantees by setting up a two-server configuration, in which one server receives the data and the other stores it. After setting up this configuration and upgrading the hardware at all local provider agencies, Hudson immediately worked to meet provider training needs, helping to reduce the demand for time-consuming onsite technical support. "We had a general session where we trained providers in a classroom at the New Jersey City University with computers running CAREWare, which showed them directly how to enter and track data," says Carol Wilson, director of the County of Hudson Department of Health and Human Services. The training also helped clarify data collection questions (e.g., Does "first encounter date" refer to date of testing or date of first medical appointment?"). A shared understanding of the meaning of data fields is critical for obtaining consistent and accurate data.

Trainings can be used to ensure system accessibility and continuity as well. For example, Hudson County offered useful tricks for remembering system passwords to reduce provider frustration and

Ryan White Services Report 101

The Ryan White Services Report (RSR) is a data collection and reporting system for reporting information on programs and clients served. The RSR contains three separate reports—the client, grantee, and provider reports—which together provide information on each client receiving Ryan White services as well as the total number and type of services provided by grantees and providers. A 2009 RSR submission timeline is available at http://hab.hrsa.gov/manage/cldtimeline.htm. Over time, the RSR will replace the Ryan White Data Report (RDR). Grantees must submit both the RDR and the RSR in 2009.

Some helpful tools for completing the RSR can be found at the sites listed below:

- Client-level data: Archived webcasts on strategies for preparing grantees of all Ryan White Program Parts for client-level data collection and RSR completion: www.careacttarget.org/rsr_archive.asp

- HRSA's Office of Health Information Technology: Health IT Adoption Toolbox: http://healthit.ahrq.gov/portal/server.pt?open=512&objID=1077&cached=true&mode=2&userID=7330. Grantee login is required and can be requested at healthit@hrsa.gov

- dataCHATT Training and Technical Assistance: www.datachatt.jsi.com/

time wasted as the result of system lockouts. Hudson also designated one of its training sessions as a "train the trainer" model to ensure continuity of internal capacity at local sites. Hudson has been developing a CAREWare User Manual to support local training efforts and to document how to produce the RSR as well as customized reports specific to its TGA.

Hudson County also uses its data to drive program changes. The county produces an annual medical outcomes report card, which details aggregate health data provided by its Ryan White Part A subgrantees. Hudson County staff compare this information to epidemiologic data from the Centers for Disease Control and Prevention (CDC). "If a certain population is underserved by a subgrantee we'll incorporate requirements into our contracts with them to better work to meet the needs of that population," says Wilson.

Building System Capabilities for Better Care

Enhancing network systems over time can improve data quality and service delivery—but only if those enhancements engage providers in the data collection process. The City of Paterson, New Jersey, a Part A grantee supporting care delivery through 18 subgrantees in Passaic and Bergen counties, sought a SPNS grant to further enhance the quality of data reported through its system. Paterson's Web-based integrated platform is called the Electronic Comprehensive Outcomes Measurement Program for Accountability and Success (eCOMPAS), or e2.

Paterson has created a high level of provider buy-in through its user-friendly, engaging system. The e2 system, for instance, automatically generates charts and graphs from real-time data, allowing providers to quickly pinpoint trends among clients and service utilization and identify areas for improvements in care delivery. Providers can build on service quality by presenting information from the graphs and data to other providers as part of a peer learning network, in which participants discuss reasons for particular trends and strategies for improving care. "With our system we are

showing providers that client-level data help tell stories about what's happening because it's based on evidence rather than anecdotes. That evidence tells its own stories of challenges and successes and is what helps inform policy and contributes to improved care delivery," says Jesse Thomas, e2 project director.

For example, one provider at a local hospital that receives Ryan White HIV/AIDS Program funds from Paterson observed from the charts that HIV-positive women of childbearing age were missing appointments. After presenting data to the hospital administration that revealed this trend, the hospital decided to offer an extra night's hospital stay to women falling into this demographic to help keep them in care.

To further improve consumer care, project directors make courtesy telephone calls to providers every 6 to 12 months. The calls are opportunities to collect feedback about additional client-level data that grantees want to track. "By reaching out to users proactively, instead of only when they need tech support, they open up about ideas that are useful on the frontlines. Those ideas produce real improvements when implemented, and we get sincere system buy-in when providers see that their ideas have materialized," says Thomas. Paterson also obtains consumer feedback on service delivery by sending out surveys on quality management measures. "The surveys are online, so key stakeholders get access to real-time data that let them know what clients around the county think about their services," says Thomas.

Paterson also recently improved data quality by making data "clickable." "If providers see a graph that looks 'off,' they can click on it and it will bring up a list of all their clients and associated data, like the number of times they've come in for appointments. This lets providers deal with mistakes immediately rather than having us come back to them and tell them there's a problem, which takes up so much time," says Catherine Correa, Paterson's Ryan White Grants Division director.

The e2 allows grantees to update data continuously, and if data need to be corrected, it can be done even in past reports. "This function allows us to adjust the data element within a past report without affecting any of the other data," says Thomas.

A New Era in Reporting, a New Era in Care

Strategies and lessons learned highlighted in this bulletin can help grantees channel client-level data into real program improvements. HRSA is also striving for accountability and the best possible consumer outcomes through the new RSR and its provider, grantee, and client components, which grantees were required to report starting in July 2009.

Although only grantees receiving Ryan White funds to provide ambulatory medical care or case management services (whether medical or nonmedical) must submit a client report during the first reporting year, which ends in December 2009, all grantees must submit all three components (provider, grantee, and client) in 2010. Completing the client report requires uploading an electronic file that contains a single health record for each client, and each record must have an encrypted "unique client identifier" (UCI) number. The UCI ensures the privacy and security of the client's health care information yet provides the benefit of linking reports belonging to the same client but received from multiple providers.[8]

HRSA and SPNS have a variety of tools for helping grantees meet—and exceed—RSR reporting requirements, including the RSR data dictionary, sample reports, and the XML file format schema as well as a special tool to assess grantee readiness to collect and report client-level data. HRSA/HAB has also hosted a series of Web conferences on the RSR and its implementation; videos of the conferences are available online. All of the materials are available through the TARGET Center Web site (http://www.careacttarget.org/rsr.asp). Grantees can also access dataCHATT (www.datachatt.jsi.com) for additional information on data reporting, including archived webcasts and frequently asked questions on important topics related to collecting data on the provision of Ryan White HIV/AIDS Program services (see box, p. 4).

The Office of Health Information and Technology at HRSA has developed a Health IT Adoption Toolbox (see box, p. 4) that has modules ranging from basic IT system development and collaborative opportunities to advanced modules on health IT standards and standards development organizations. The toolbox will soon include a module with a comprehensive set of useful online IT resources for HIV/AIDS care providers.

SPNS will launch another IT Capacity-Building Initiative beginning in September 2009 to help Ryan White Part C and D grantees prepare for data collection and reporting.

Conclusion

By further building IT capacity, grantees—and HRSA/HAB—are expanding the possibilities for enhanced service delivery beyond what was once imaginable. "You can look at service utilization patterns in a matter of minutes and determine how your resources are being allocated to meet the emerging needs of clients. You can enhance linkages by checking on how your referrals are working and how well people are making appointments and keeping them," says Jessica Xavier, public health analyst at SPNS and project officer for the IT Capacity-Building Initiative. With providers' dedication and client-level data, the Ryan White HIV/AIDS Program will continue to ensure accountability in service delivery and, most important, work to improve the lives of PLWHA everywhere.

Endnotes

1 Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Special Projects of National Significance Program (SPNS). *Capacity building to develop standard electronic client information systems: program guidance.* 2007a, p. 9. Available at: https://grants.hrsa.gov/webexternal/FundingOppDetails.asp?FundingCycleId=65C5A406-5AEF-4E99-AECE-283378290A97&ViewMode=EU&GoBack=&PrintMode=&OnlineAvailabilityFlag=True&pageNumber=1.

2 HRSA HAB SPNS, 2007a, p. 10.

3 HRSA HAB SPNS, 2007a, p. 10.

4 HRSA HAB SPNS, 2007a, p. 10.

5 HRSA HAB SPNS. Information technology: improving HIV/AIDS care. *What's going on @ SPNS.* July 2007b. Available at: /www.careacttarget.org/library/SPNSBulletin/spnsbulletin.jul07.pdf.

6 HRSA HAB SPNS, 2007b.

7 HRSA HAB SPNS. April 27, 2009. *Ryan White HIV/AIDS program services reporting system. Part B grantees: preparing your providers.* Available at: www.careacttarget.org/library/media/datacollection/RSRPartBReporting.pdf.

8 HRSA HAB SPNS. *UCI and you.* November 10, 2008. Available at: www.careacttarget.org/library/media/datacollection/UCIandYou.pdf.