



What's Going on @ SPNS



AN UPDATE FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTH RESOURCES AND SERVICES ADMINISTRATION, HIV/AIDS BUREAU, SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

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■ Sustainability Results in Better Care for More People

“It is programs like this that help me get through life.”¹

—Patient Enrolled in a SPNS Initiative

For more than 20 years, grant funding from the Special Projects of National Significance (SPNS) Program, part of the Health Resources and Services Administration’s (HRSA’s) HIV/AIDS Bureau (HAB), has been expanding the reach of the Ryan White HIV/AIDS Program. Through participation in various SPNS initiatives, grantees have been able to test many innovative models of care.

That success, however, is only part of the story. It is important that SPNS demonstration projects improve the care of and the capacity for treating people living with HIV (PLWH) during the grant period. It is equally important that grantees continue using what they have learned and leveraging the partnerships they have established to create longer-term safety nets. After all, when a program ceases to exist, the health and well-being of the PLWH who have come to rely on that care is at risk.

In fact, over the years sustainability has become a hallmark of successful SPNS initiatives. In 2005, HRSA funded a study evaluating the long-term impact of SPNS models two to nine years after completion. Of the 108 SPNS projects included in the study:²

- 92% continued to provide services beyond the life of their grant.
- 95% used their status as a SPNS grantee to secure additional funding.
- 76% had collaborated with other Ryan White HIV/AIDS Program Parts during or after their SPNS grant cycle.

This commitment to sustainability continues to be a focus of SPNS initiatives. An Evaluation and Technical Assistance Center (ETAC) is typically selected to provide participating sites with implementation and sustainability technical assistance by offering on-site strategic guidance. In addition, the ETAC conducts multisite evaluations, which are particularly valuable because they provide evidence-based documentation of results. That proof of efficacy assists grantees in obtaining ongoing funding and helps facilitate the replication of effective interventions by other providers.

For more information about this SPNS dissemination project and to download training materials, visit www.careacttarget.org/ihip.



SPNS further supports replication through its Integrating HIV Innovative Practices (IHIP) Project. IHIP transforms lessons learned from the most successful demonstration projects into extremely practical training resources. Depending on the subject matter, IHIP materials can include training manuals, curricula, related webinars, monographs, and pocket guides. In fact, IHIP training materials for several initiatives discussed in this bulletin — on linkages in jail settings, oral health care, and hard-to-reach populations — currently reside on the IHIP landing page on the TARGET Center website. See the IHIP box at left for the Web address.

What Does Success Look Like?

SPNS is designed to respond to the emerging needs of HIV-positive patients by testing new care models to improve the lives of PLWH within their communities. Helping other providers replicate those successful models within their programs is the key to broadening that impact and to reducing health disparities for some of the most vulnerable populations in our society. In this way, SPNS is a vital part of meeting the objectives of both the National HIV/AIDS Strategy and the federal HIV Care Continuum Initiative.

SPNS grantees featured in this edition of *What's Going on @ SPNS* have documented success in expanding access to care for PLWH during their funding cycles and beyond. The lessons learned over the funding period and the best practices that have come out of their SPNS demonstration projects have become embedded in their work.

Tips for Building Sustainability

The most important step grantees can take to foster sustainability is to think about and begin planning for it from the beginning. Waiting until year three or four of a five-year grant is too late. Here are additional tips, as gleaned from numerous grantees, including those featured in this bulletin:

- *Location.* Co-locating with or within other organizations to share costs is one route many projects have taken.
- *Alternate funding.* Successful grantees have explored funding from other Ryan White HIV/AIDS Program Parts and/or private foundations. Many also have sought continued funding from Medicaid or private pay reimbursement, or by instituting sliding fee scales for patient payment.
- *Staff continuity.* Innovative grantees have sustained program staff through community partnerships (such as with teaching institutions) or through engaging volunteers.
- *Cross-training.* Whenever possible, grantees have leveraged program training by including additional staff, whether or not they are funded by the current initiative.
- *Consumer involvement.* Involving consumers in program design and evaluation helps ensure that the services offered continue to meet changing needs.
- *Documented success.* Grantees confirm that spending time and effort on data collection to prove project efficacy is a valuable part of the process. That's because programs that deliver evidence-based outcomes are more likely to secure funds and external buy-in.
- *Ongoing outreach.* Continuing to promote services within a community creates an ongoing pipeline of referrals.

Linkages to Care in Jail Settings

NEW YORK CITY

The New York City Department of Health and Mental Hygiene/Rikers Island Transitional Consortium (DOHMH) was 1 of 10 demonstration sites funded under the five-year SPNS Enhancing Linkages to HIV Primary Care and Services in Jail Settings Initiative (EnhanceLink Initiative). Like the other sites in this SPNS cohort, the New York City team implemented and evaluated innovative methods for linking PLWH who are scheduled to be released from local jails soon (or were recently released) and actively linking them to HIV care and services.

Although the team had already piloted a model of care in the jail setting before becoming a part of the SPNS EnhanceLink Initiative, the timing of the grant was integral to creating a successful, long-term program. “There were already partners at the table with us who also were working with the targeted jail population without having a tested model,” says Alison Jordan, executive director of Correctional Health Services/Transitional Health Care Coordination for New York City’s DOHMH, “but the grant allowed everyone to be more intentional and strategic.”

According to Jordan, the grantee team started the project with some clear questions. “We wanted to test how we could enhance what we were already doing and if what we did could be a model for others.” They also wanted to learn more about how to make it a sustainable effort.

The team assessed what services they were already collectively providing and brought in new partners to fill identified gaps in care. They also did their homework by looking at other similar jail-based projects around the country, such as one in South Carolina that instituted jail-based HIV testing. “This was something we had not tackled at Rikers before,” Jordan says.

Testing turned out to be a game changer. “By adding jail-based testing to the model in our SPNS grant, our team was able to show a difference in reducing the number of new infections,” she explains. In addition, they were able to link more PLWH into primary care, improve overall treatment adherence, and enhance viral suppression. Through careful evaluation and documentation, Rikers now has a sustainable, in-facility HIV testing program.

Reaching Beyond Jail Walls

One of the successes that came out of the DOHMH project was the ability to build strong linkages of support for incarcerated PLWH after they are released into the community. For example, Jordan says a significant number of inmates come from the Bronx, and return there once they are released. During the SPNS grant, the Rikers team worked with the Bronx Health and Housing Consortium to address the needs of returning PLWH who struggle with unstable housing. The collaboration helped to secure additional funding to continue the work of providing services and resources to homeless PLWH in the Bronx.

Creating Connections to the Courts

Another significant success of the DOHMH project was the establishment of an effective court advocacy program within the jail for PLWH. “In the very beginning, we hoped to get up to 200 people in the court advocacy program as a part of the discharge planning for eligible inmates. Last year, we had close to 500,” Jordan says. To sustain the effort, the Rikers team recently hired a person to continue to coordinate the court advocacy component. “Now, because of the strategic evaluation and success of our program, we get calls from courts all around the country.”

Tips for Success

Jordan offers these tips to other existing and new grantees that are working in the jail/prison population:

- Build a staff that is committed and has genuine care for the jail population.
- Bring in nonjudgmental people who understand the inherent disparities involved.
- Add team members who understand the “culture of corrections” and know how to navigate the system.
- Make sure staffers understand how to address all the barriers a soon-to-be-released PLWH may encounter.

RHODE ISLAND

Another EnhanceLink Initiative grantee — The Miriam Hospital in Providence, RI — worked with the Rhode Island Department of Corrections (RIDOC) to provide community-based linkages to care and case management support for short-term jail detainees both within the jail setting and after release. Timothy Flanigan, M.D., an infectious disease specialist with The Miriam Hospital and Brown University’s Alpert Medical School, helped implement this project. He says that much of the work focused on improving mutual trust and building relationships with the patients.

Creating Sustainable Partnerships

Ongoing relationships with other community-based organizations are a critical part of creating sustainable programs. Consider these “rules” for lasting partnerships:

1. *Do your homework.* Identify gaps in services to make sure you reach out to appropriate organizations.
2. *Embrace transparency.* To avoid “turf wars,” clearly define roles and responsibilities up front.
3. *Follow through on MOUs.* A good memorandum of understanding is just the beginning; stay in touch with monthly meetings.
4. *Give it time.* Relationship building takes time; account for this in your timeline and rollout of your program.

“Because of the work to connect PLWH to resources, services, and care within the community, we have seen a decrease in recidivism.”

—Timothy Flanigan, M.D.

“This work with [incarcerated] PLWH isn’t easy and it requires a thick skin,” says Dr. Flanigan. “They may be released into communities that offer them few or no positive relationships.” And PLWH frequently suffer from post-traumatic stress disorder, substance abuse disorder, homelessness, and other issues that often take priority over self-care for HIV.^{3,4,5}

Echoing Jordan’s tips for working with jail populations, Flanigan emphasizes the importance of building a committed staff that is willing to advocate for individual patients after they are released. Dr. Flanigan says it takes a special kind of person who is passionate about the work and the individuals they serve: “They need to understand the many levels of chaos that exist in this person’s life.”

Dr. Flanigan says that type of dedication and collaboration between the staff and the internal and external partners, on behalf of the patients, has paid off. “We used to have between 110 and 140 PLWH return to jail each year. Now we have between 20 and 40 returnees,” he explains. “We attribute those numbers to our ability to link them to care once they leave the facility.”

Meeting the Unmet Need for Oral Health Care

The SPNS Innovations in Oral Health Care Initiative was a five-year demonstration project at 15 sites across the country. Each of the sites in the Initiative was charged with creating comprehensive oral health care services models that would address the unmet needs of underserved PLWH.

Jane Fox, project director for the Initiative’s Evaluation Center for HIV and Oral Health (ECHO), explains that oral health care often falls to the bottom of the list for PLWH because they have so many medical care appointments and other aspects of the illness to manage that they perceive as more important. PLWH also face enormous systemic barriers, including limited financial resources and a shortage of dentists who are familiar with, or willing to treat, HIV-related oral health care needs.⁶ Oral health care, however, is a critical component to total health for PLWH; addressing oral health needs can improve PLWH’s nutritional intake and improve antiretroviral therapy (ART) absorption — a critical step to improving medication efficacy and thus lowering HIV viral load.⁷

The SPNS Oral Health Initiative demonstrated excellent patient oral health and medical care outcomes, including serving 2,500 PLWH who had been out of oral health care for one year or more, enabling 14,500 patient visits, and performing 26,000 dental procedures.⁸

“It definitely helped me,” remarks one patient at Harbor Health Services Inc., a grantee in Massachusetts, about the care he received.⁹ “I had an infection for probably one-and-a-half years. So when [the dentist] did my top teeth, my T-cells jumped nearly 100 points,” he adds. “I feel a lot better.”

Harbor Health was 1 of 5 grantees that used SPNS funding to open satellite clinics, thus expanding oral health access in their service areas. Grantees chose different approaches to launching their satellite clinics, including leasing treatment space from a local hospital and repurposing an existing office. In general, however, these satellite clinics enabled the SPNS grantees to enroll large numbers of new patients, and all were sustained beyond the life of the grant.

“We have since expanded hours and rolled it out to the general patient population,” says Walter Phinney, project manager for the Harbor Health demonstration project. “Serving a broader patient population, while continuing to serve PLWH, enabled us to sustain operation of the clinic [beyond the original SPNS funding].”

Opening the clinic also allowed Harbor Health to measure the effect of case management and outreach workers to engage PLWH

in oral health care. “We worked to remove the barriers — such as transportation, patient education, and assistance with navigating the clinic systems — that kept PLWH from coming in for dental care,” says David Reidy, lead investigator for the Harbor Health demonstration project. While Harbor Health was not able to continue the dental HIV case management effort, according to Phinney, they do maintain a medical HIV case manager that serves all PLWH in all service lines, including dental. “This position is funded through our Department of Public Health,” Phinney explains.

Collaboration and Commitment

Collaboration between grantee sites was also essential to the overall success of the Oral Health Initiative both during and after, according to Fox. “Many of the project agencies have continued to work together on issues such as securing funding and leveraging resources beyond the initial life of the SPNS initiative,” she says.

The many successes that came out of the Oral Health Initiative also have created an opportunity for grantees to share best practices within the field. While there were 15 sites that participated directly in the SPNS initiative, there are literally hundreds around the country that must wrestle with access to oral health for the PLWH in their communities, as oral health is often cited by PLWH as one of the top unmet needs.¹⁰ “Getting the story out has been instrumental in the sustainability of the work,” Fox says.

SPNS Supports Sustainable Technology

Over the past decade, the Special Projects of National Significance (SPNS) Program has funded many sustainable health information technology (HIT) systems. These projects have demonstrated tangible and replicable results — both in building the capacity of Ryan White HIV/AIDS Program grantees to measure and report data and in sharing that information within regional health data exchanges. Consider these examples:

- The 2008 *Capacity Building to Develop Standard Electronic Client Information Data Systems Initiative*. As a result of this funding, many grantees were able to purchase a software program called Electronic Comprehensive Outcomes Measurement Program for Accountability and Success, known generally as eCOMPAS, and customize it for HIV data reporting. Many more providers than just the original grantees, however, have benefited. “At least 250 providers across the country currently are either implementing or have implemented the

software for HIV data reporting,” says Jesse Thomas, a developer with RDE Systems, the creator of the software.

- The 2007 *Electronic Networks of Care Initiative*. This initiative funded the enhancement of existing health information exchanges (HIEs) for people living with HIV (PLWH) in underserved communities. One of the most successful projects in this initiative was the Louisiana Public Health Information Exchange (LaPHIE), which linked HIV surveillance data to patient-level data. The project has been so successful in linking PLWH to care that the federal HIV Care Continuum Working Group specifically cited LaPHIE as an example of a HIT initiative that successfully supports the goals of the HIV Care Continuum Initiative.¹¹ What’s more, the Georgia Department of Public Health is in the process of replicating LaPHIE’s work by creating its own public health information exchange.

Tips for Cross-Site Collaboration Success:

Fox offers these tips for success and sustainability as learned in the SPNS Oral Health Initiative:

- Be committed to thinking outside of the box. Think creatively about needs, gaps in services, and partnerships.
- Find creative solutions. Fox cites a program in Pennsylvania that started accepting private pay oral health patients to offset the cost of services for clients who did not have the ability to pay.
- Have an internal champion within your oral health program who is passionate about the outcomes and has the time commitment to keep the project moving.
- Retention in oral health care is one of the measures of success. So often we think about “if we build it, they will come.” In addition, think about how your program will meet patient needs, so they will stay.
- Understand the importance of community-based agencies. They need to know the costs and benefits of referring to your program.
- Continue to tell the story of why the project matters and, in the case of oral health services as a part of the HIV Care Continuum, what it can do for health outcomes.

Helping Vulnerable Young MSM of Color

Yet another example of sustainability is the continuation of a SPNS demonstration project to improve retention in care for HIV-positive African American and Hispanic/Latino young men who have sex with men (MSM) of color. In recent years, this population has been facing an increasing HIV burden.¹² So much so that in 2004, SPNS launched an initiative called Outreach, Care, and Prevention to Engage HIV Seropositive Young Men Who Have Sex with Men of Color in HIV Care. As part of this initiative, the University of North Carolina, Chapel Hill, developed an innovative outreach campaign called STYLE (Strength Through Livin’ Empowered). Although the SPNS project ended in 2010, STYLE is ongoing because it has received extended funding through the Centers for Disease Control and Prevention. Visit www.cdc.gov/hiv/pdf/prs_compendium_style_ei.pdf for more information.

Note that this project and others targeting hard-to-reach populations are included in IHIP training materials. In fact, a recorded webinar featuring in-depth information about STYLE is available at <https://careacttarget.org/library/engaging-hard-reach-populations-outreach>.

Creating Lasting Impact

SPNS grantees understand that helping PLWH engage and stay engaged in care is not a one-shot proposition. While advances in the treatment of HIV and increased access to care provided by the Affordable Care Act offer a lot of hope to many PLWH, the need for ongoing services remains vitally important. SPNS projects continue to advance that agenda precisely because they test better ways of providing and expanding access to care through sustainable and replicable models.

For More Information

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