EXPANDING CARE FOR PEOPLE LIVING WITH HIV

A stepwise approach for health care organizations seeking
to add HIV care or to increase services for PLWH

This guide will help you:

- **Build your case for change**
- **Clarify your vision**
- **Review your strengths & weaknesses**
- **And get started!**

This guide incorporates the experiences of 6 different HIV service organizations who received HRSA SPNS funding to transform our practice. Each section has an overview of the issues, case studies from our experience, and a tool to help you take the next step forward. We share lessons learned and provide additional resources. Best of luck!

Sincerely, your peers who have been there

ACCESS Community Health Network, Family Health Centers of San Diego, Florida Department of Health Osceola County, MetroHealth, San Ysidro Health, University of Pittsburgh Medical Center

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U90HA27388 for the SPNS Workforce Initiative Evaluation and Technical Assistance Center. This information or content and conclusions are those of the authors and should not be construed as the official position or policy or, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

Step 1. Building the case for change

There are many compelling reasons for an organization to increase its capacity to provide HIV care and each organization will have a different motivation for embarking on this journey. We have found expanding the HIV workforce to be a rewarding but also complex and involved project. In order to be successful, you must be clear about your reasons for expanding HIV capacity and the HIV workforce. The first step in this guide is building your case for change and effectively communicating it to your key stakeholders.

6 reasons to expand your clinic's HIV care capacity

1. Improve patient care. HIV is now a treatable chronic medical condition and as long as a person living with HIV has access to antiviral medications and appropriate medical care, they have a very good chance of living a healthy, fulfilling life. Ensure you can meet your patients' needs by expanding capacity for HIV care.

2. Mitigate shortage of HIV providers. Due to medications, PLWH are living longer and improved screening means more people are being diagnosed. Despite a growing number of diagnosed PLWH, the number of HIV specialists is decreasing as the first generation of HIV providers begin to retire. We don't know who will replace them.

3. Combat the HIV epidemic. One of the exciting parts of HIV care is that effective medical care not only improves the lives of PLWH but also decreases the chance that they will pass the virus to other people. In HIV care, treatment is prevention. With effective treatment there is an opportunity to stop the cycle of infection and end the epidemic.

4. Recruit providers. Many organizations struggle to recruit and retain providers. Being able to provide HIV care may be a draw for some providers and help with both recruitment and retention. Some providers may have a special interest in HIV care or they might like the professional reward of developing expertise at the cutting edge of care.

5. Enrich your clinic model. HIV care is one of the best and most developed implementations of the Chronic Care Model. There are many, many lessons to be learned from the successes of the HIV care system whether funded by the Ryan White Care Act or through other health care systems. The comprehensive, whole person, coordinated care at the center of the HIV model can serve as a model for other chronic diseases.

6. Help the clinic bottom line. Certain aspects of HIV care such as the 340B pharmacy program, can be a significant source of revenue to the clinic. Ryan White Care Act grants, private foundations, and donors also support HIV-related programming.

Building Our Case in San Diego

Family Health Centers of San Diego is a Federally Qualified Health Center and a Ryan White Part C-funded provider of HIV medical care and support services. We provide HIV care to over 1,200 patients per year. Prior to starting the transformation process, we provided HIV medical care at three of our primary care clinics with 1.7 full-time equivalents HIV certified physicians. The largest of the sites also offered comprehensive wraparound services to PLWH. As one of our HIV specialist medical providers retired and we realized that HIV patients only utilized our largest HIV medical care clinic. W**e recognized that there was a gap in HIV medical care and wraparound services across our health center**. For this reason, we decided to expand the capacity of our primary health care workforce to provide HIV medical care. Our next step was to find funding and we secured a HRSA SPNS grant. Our main activities would be training medical providers to become HIV specialists alongside their current practice and training support staff to provide HIV care and services in a sensitive manner. Next we sought buy-in from already employed medical providers by offering them HIV specialty training courtesy of our physician champion. Though initial buy-in was slow, it soon picked up.

Our first hurdle. As our plan depended on providers volunteering to become trained in HIV care, we realized that rather than choosing the clinic site to expand care to, we instead needed to expand care at the clinic site(s) where the newly trained provider wanted to practice. Luckily we could be flexible in which clinics we would initiate HIV training.

Today, we have our second round of providers being trained.

"Many of the patients I see now either were not receiving routine care or had to travel longer distances to get the services they needed. Thanks to the training I received we are now able to provide care locally and engage patients who otherwise had limited access to HIV services and treatment."

Melanie Snow, DNP, FNP
Provider Trainee at
Family Health Centers of San Diego

Tool: Building Your Case

Take a few minutes and answer the following questions. Consider interviewing some of your colleagues to see if they have additional thoughts in response to these questions. If you feel that a question is not relevant to your setting, feel free to skip it. When you are finished, consolidate your answers into a brief 3 minute "elevator speech" that you can use to talk with potential partners and stakeholders about your project.

1. How will patients be better served by increasing HIV capacity? Is there a specific patient story you can tell?

2. Can your organization play a role in developing the next generation of HIV providers? How are you uniquely qualified to address the workforce shortage?

3. What role does your organization want to play in ending the AIDS epidemic? What impact will this have for your community?

4. What is the business case for increasing HIV capacity for your organization?

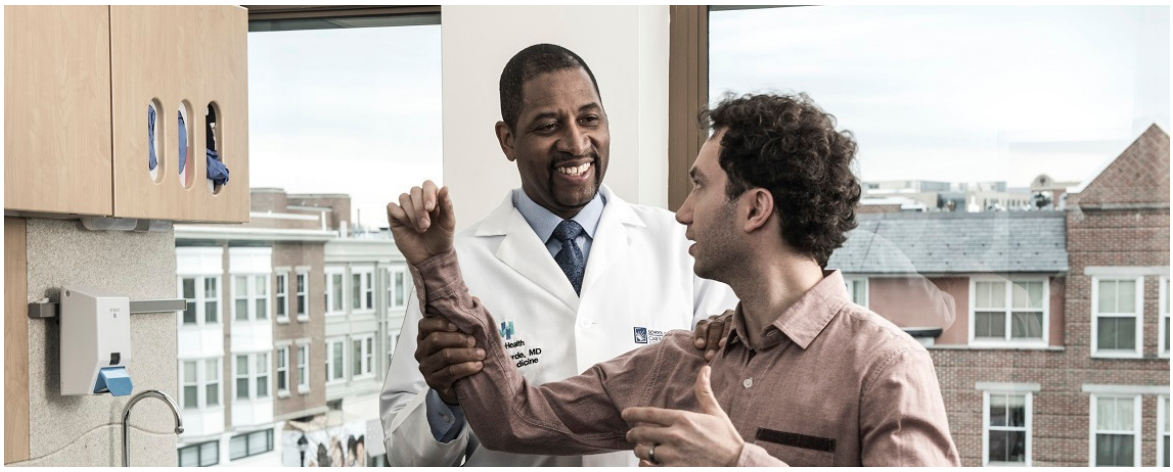
5. How will increasing capacity for HIV care help with recruitment and retention of providers?

6. How will adding capacity for HIV care enrich the other chronic disease programs in your organization?

7. Any other reasons you think your organization should increase HIV capacity?

Step 2. Clarifying your vision for HIV care expansion

After exploring the story of why your organization and community will benefit from expanding the HIV care capacity, the next step in the change process is building a model of what HIV care can look like in your setting. In order to build this model, you need a clear picture of the strengths and the challenges of the current care system. You need to identify the current gaps in care. It's important to remind that there are many different models for HIV care expansion. The following tool is meant to help you figure out what will work in your setting.



Envisioning Mental Health Expansion in Cleveland

As the primary provider of indigent care in Greater Cleveland, we at MetroHealth were looking to **provide more holistic care**. Long standing team based care offered a platform to integrate behavioral health. Prior to the transformation, mental health symptoms, especially depressive symptoms were often addressed with a referral for counseling (that the patient would not attend) or a prescription for medication without measuring its response. Our vision was to implement a collaborative care model for depression that includes measurement based care, care coordinators and expert case consultation with a team psychiatrist.

"Untreated depression was preventing our patients from fully engaging in their HIV care- we needed to do better!"

Ann Avery, MD, HIV Provider
MetroHealth

Tool: Visioning Check List

Please work through this list of questions and spend time finding the answers for your organization. If a question isn't relevant to you, skip it. If it is something you want to do, identify your next step to getting it done before moving on to other points in the list

- [ ] Do you know who has a hard time accessing HIV care in your community?
- [ ] Have you identified the reasons people can't access care?
- [ ] Have you conducted focus groups or done interviews with patients to identify their barriers to care?
- [ ] If you already serve PLWH, have you reviewed your retention and viral load suppression data to identify areas for improvement?
- [ ] Does you community have HIV Care Continuum data? (footnote)
- [ ] Have you described unique ways your organization can address the barriers you have identified?
- [ ] Have you written a short description of your vision for HIV care that will address the barriers you identified?
- [ ] Have you gotten feed back on your model? From colleagues? From patients?
- [ ] Can you describe how this model will address barriers in the care continuum?

Step 3. Reviewing your strengths & resources

Expanding HIV services is possible through avoiding duplication and leveraging existing networks and services in the community. However, HIV clinics frequently exist in isolation so strong connections to the non-HIV world may not be in place. These bridges need to be built before any expansion of care project can go forward. They will also need to be maintained in order for your project to be sustainable. This is a process that takes time.

Building Bridges in San Ysidro

At San Ysidro Health Center, we have a long-standing Ryan White funded HIV program providing comprehensive HIV services, located within a large federally-qualified health center. Our health center houses many programs to support our patients and community, such as general health education, diabetes prevention and management, cooking classes, behavioral health, etc. Despite these resources, the HIV clinic has existed in a “bubble," rarely accessing (or even being aware of) these services for our patients. The HIV bubble historically has been a way to consolidate HIV specialty care, ensure high-quality medical care in a culturally competent setting, and protect the patients from stigma they faced in other clinics. But as PLWH are aging and living with other chronic diseases, we began to see the price we paid for the “bubble”. **Our patients were missing out on the services available to HIV-negative patients with other similar comorbidities.** They deserved more. But how to get it?

We were not familiar with the non-HIV departments and they were not familiar with our patients. We began by identifying our initial goals: increased access to women’s health, behavioral health and health education departments. We set up meetings with leadership within those departments to get initial buy-in, and then began a series of ‘**HIV 101’ lunches with each department** to introduce them to our program and get to know each other. We identified the barriers they may face in seeing our patients and learned how best to refer patients. These personal relationships have made it easier to send patients to receive services in these non-HIV departments.

One of our goals was to **increase access for our HIV-positive patients to the services in our health center’s excellent behavioral health department**. We started with informal bridge building and then they invited us to do an “HIV 101” lunch. It turned out many of the behavioral health providers had interest in HIV and wanted the opportunity to interact with our patients. But there were billing barriers between the two departments. Our team worked with theirs to create a workflow to handle the billing issues. We began referring more patients to their services. We also invited their providers to attend our HIV interdisciplinary meetings and currently have 2 behavioral health providers consistently attend.

Developing a 'Hub and Spoke' Model in Pittsburgh

University of Pittsburgh Medical Center (UPMC) partnered with the UPMC Latterman Family Health Center (LFHC) in McKeesport, PA to build HIV care capacity in a medically underserved, economically depressed smaller community 15 miles away. UPMC is a Ryan White-funded medical home that provides comprehensive HIV care to ~1700 individuals in an academic medical center. LFHC provides primary care to ~4,000 patients annually, and is a major training site for the University of Pittsburgh-affiliated McKeesport Family Medicine Residency Program. In McKeesport, routine HIV testing was not common practice. Patients were either sporadically engaging in HIV primary care in Pittsburgh, or receiving primary care at LFHC, and not receiving HIV specialty care despite referrals to UPMC. **We identified a need to improve the HIV continuum of care in that area.** We set out to increase HIV screening, expand HIV education and improve HIV cultural competency of staff and providers, increase provider capacity to deliver competent HIV care, and train residents for future work with PLWH in underserved communities. As the project launched, **we faced the reality of multiple challenges**. **A surprising challenge** was patients' perceptions of HIV-related stigma and discrimination in their community. Some UPMC patients declined to transfer their care to LFHC due to this. Another hurdle that emerged was that some patients were unwilling to seek care closer to home if it meant switching physicians.

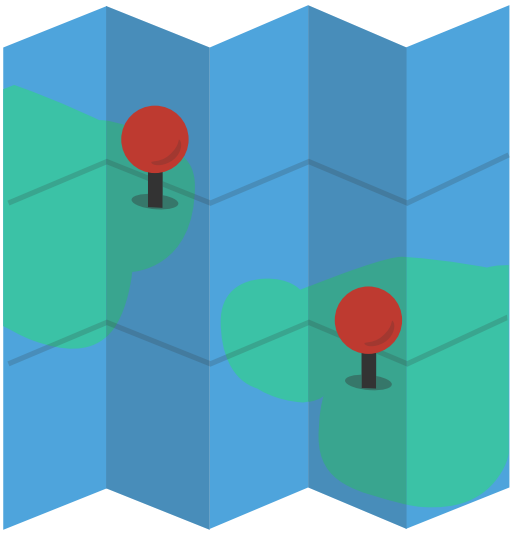
We expanded LFHC community outreach efforts to key community stakeholders to promote routine HIV testing, sought state funding to support HIV testing for uninsured individuals, and strengthened ties to organizations serving at-risk individuals. We began a campaign to promote the availability of HIV care at LFHC through printed, electronic, and social media and enlisted an articulate Peer Advocate.
Progress came with a learning curve. In addition to the perception of HIV-related stigma by patients, some LFHC staff, faculty, and residents expressed reluctance to provide HIV care, considering it to be a specialty need requiring referral. We experienced higher than expected turnover among staff and faculty, necessitating repetitive training. Care for uninsured individuals seeking care at LFHC required retooling of billing operations. Transitions of care from UPMC to LFHC required very warm hand-offs. Patients wanted to know if they would continue to receive multidisciplinary care as they did at UPMC. The number of PLWH in care at LFHC increases incrementally each month.

"The SPNS Project to me is more than just a model that links patients to care. The funding provided by this project has allowed the members of the McKeesport community to collaborate with local service organizations by working together to help break down the barriers to healthcare. I am proud of the work that we have done to build bridges in the community so that all PLWH have access to quality healthcare."

Neal Holmes, UPMC, Peer Advocate

Tool: Workflow Mapping[1]

Clinics transforming their practice commonly use workflow mapping as a way to visualize what they do now and make deliberate choices about how to improve that process. Are your referrals falling through the cracks? Are your clients wasting time sitting in the waiting room? Workflow mapping is one way to find to look at specific process in detail. It is a great activity to involve multiple staff members in.



SIX SIMPLE STEPS

Step 1. Pick a process to map and pick a lead person

Step 2. Determine the beginning and end points in the process

Step 3. Identify each step in the process

Step 4.Put the steps in order (on paper, with stickies, or on computer -- word, powerpoint, Vizio)

Step 5.Review and edit first draft

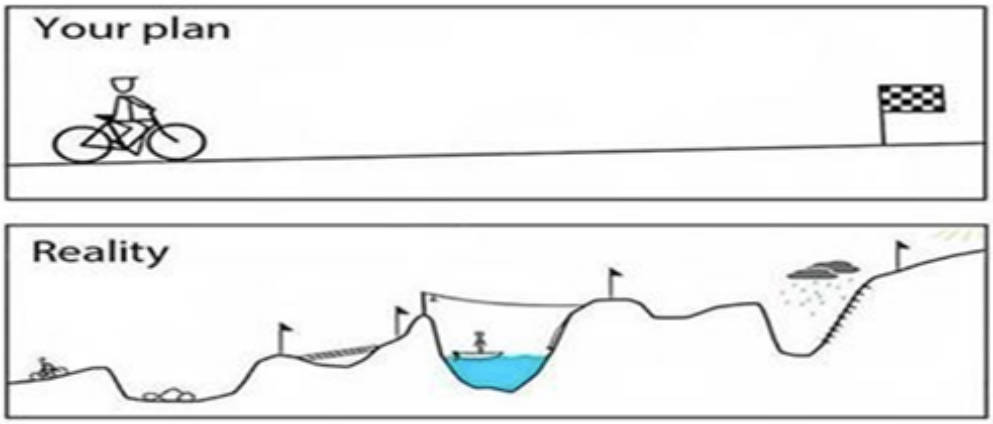
Step 6.Review flowchart with the team for input and to ensure the flow chart is accurate

Quick tips while using this tool maintain an *open and constructive* environment, *focus on the system* or process, not the people, map out the process you *currently* have (not the one you wish you had) and remember that this is a tool for *continuous* improvement.

[1]Adopted from the UCSF Center for Excellence in Primary Care. The 10 Building Blocks of Primary Care Overview of Workflow Mapping 2014.

Step 4. Getting started

Once you have gone through Steps 1-3, you are ready to begin implementing the change in your healthcare setting. Expect the process to be slower than you anticipate, expect buy-in from stakeholders to be more elusive than you would hope, and don't be afraid to deviate from your original plan. Flexibility is key! We found over and over again that creative solutions and new ways of thinking reinvigorated our efforts. Along the way we experienced surprises, unanticipated facilitators, and expressions of gratitude. This work is important and will touch many lives. We wish you luck!



Iterations of Change in Florida

The Florida Dept. of Health in Osceola County's initial assessment showed the **need for the expansion of HIV primary care**. Before implementing a project, we conducted multiple interviews of the Federal Qualified Health Center (FQHC) providers and staff to gauge their experience, comfort, and knowledge of working with PLWH. Two main concerns with implementing a project of such magnitude emerged. Initially it revealed that the organizational culture and practices could not fully support the depth of the project without changes. Clinician and staff surveys revealed resistance and stigma strained transformation efforts. Providers anxiety focused on HIV care and medication interactions. Furthermore, surveys identified staff held judgmental views and underlying fears about PWLH. Additionally, some clinicians and staff perceived that the HIV services "spoiled the patients" with easy scheduling, ability to contact providers, same day lab testing and other conveniences, care aspects much less available in primary care. To resolve these issues, education and training were catered specifically to the needs of clinicians and staff. All FQHC staff was also cycled through the HIV clinic to increase knowledge via first-hand experience with PLWH and clinic operations. System changes were made and revised as the project unfolded to adapt to the need.

"Changes to systems are always difficult and need commitment, understanding and buy-in from all leadership and stakeholders. True, deep rooted support from the whole team can make the transition easier, but realistically, you have to create that buy-in and sustain a clear vision of the outcome."

David Bradley MBA, MHA, Project Manager
Florida Department of Health Osceola County

Tool: Provider/Staff Surveys

At the Florida Dept. of Health Osceola County, surveys with providers, clinical staff, and front line staff were performed every six months, with a 90 day follow up help to monitor the evolution. The surveys provide vital information on the present and developing needs of the care team. Using this tool, they identified the need for specific training tailored to certain clinic roles. In addition, addressing the need for on-going and updated training due to staff turnover is important. Surveys support organizational efforts to provide and sustain quality care for patients during and after the clinic transformation.

Tool: PDSA Cycles

This Plan-Do-Study-Act (PDSA) tool is commonly used in quality improvement projects that take place in healthcare settings. The tool is used to test a change or changes. If testing multiple solutions to a problem, complete the PDSA for each solution and compare results. Many in-depth PDSA tutorials can be found online but the basic principles are below and provide enough direction for most users. Consider using a PDSA cycle as a way to spark conversation among frontline staff, providers, and administration about an issue you're trying to tackle in the clinic. Many clinics have found it helpful to structure meetings around this tool in order to track their iterations of change and get input from a range of participants on facilitators and barriers to that change.

Lessons Learned

Over the course of 4 years, we learned a lot. We faced unexpected challenges that we hope you can prepare for. We also discovered helpful tips and tricks that we wish to share with you. Every project is unique but here are our generalizable lessons learned.

People

Buy In. Garnering support and acceptance by providers and staff will likely take longer than anticipated. Start early and check in often!

Champions. For each type of staff (nurse, case manager, patient services representative, physician, etc.) consider identifying and training a champion.

HIV Expertise. An HIV-trained physician or primary care provider is a prerequisite for providing HIV services at any site.

Often overlooked partners. When defining your partners, don't forget about IT, HR, or your physicians!

Activities

Spread the news. Everyone at the clinic needs to know about the project, including patients.

Reciprocate. Building bridge with other departments by arranging a visit to ask about THEIR goals. Invite them to participate in your team meetings.

Continuous networking. Set up mechanisms for ongoing interaction (i.e. standing meetings, frequent feedback, regular re-assessment).

Training pledges. If training up providers, consider incorporating a commitment to remain with the practice for a certain period of time.

Culture

Flexibility. Some things will look good on paper but won't work out in practice. Adapt!

Middle Leadership Support. Engage this level of management, such as staff supervisors and both clinic director and associate director.

Capacity building. Anticipate the need for staff job training, cycling, and education. Schedule in advance and consider including food!