

Delivering HIV Care in Rural Areas

Best Practice

Good HIV care is the same, no matter where you live. If done properly, it provides the same type of medications and, hopefully, the same quality of care. What differs for rural areas is how services get designed and delivered. Given such obstacles as an inadequate supply of clinical practitioners, particularly those trained in the treatment of HIV, high staff turnover, large geographic distances to cover, and stigma, a rural way of providing HIV care has emerged.

Interviews from across many rural sites suggest these programs are making a difference in the patient experience. They range from efforts in the rural South — the region with the highest number of rural HIV/AIDS cases — to western frontier states facing added challenges, ranging from enormous travel distances to delivery of services in Native American tribal areas with limited resources and multiple cultural complexities. Services are delivered by a spectrum of agencies and individuals — from state health departments to small community clinics. Given the heavy impact of HIV on minority and low income populations, federal resources such as the Ryan White Program and state funding provide crucial support for HIV specialty care.

“If your knowledge is mediocre, but your compassion is up there, you’re going to succeed.”

North Carolina rural doctor

Some of the techniques used by rural programs are outlined below and have been learned through trial-and-error, sharing of ideas, and constant change. They include things such as setting clinic hours of operation and even deciding where to locate clinics. “It’s not necessary to reinvent the wheel,” said a North Carolina rural doctor on the value of rural sites learning from each other.

HIV CARE DELIVERY TECHNIQUES

- Individuals Taking the Lead
- HIV Integrated Within General Health Care
- Consultations and Co-Management
- Traveling Clinics
- Centers of Expertise
- Pharmacy Services
- Getting Services: On-Site or Through Referral
- Case Management
- Peer Support
- Personal Touch
- Adjust Schedules



INDIVIDUALS TAKING THE LEAD

Rural areas often have limited health services, although a smattering of rural HIV programs operate around the nation through Ryan White and state funding. But some rural communities have something that nearly transcends money: a clinician who stepped up to the plate. He or she puts in extra hours, travels long distances to see a few clients throughout the state, and gets called on to help with tough cases. They are catalysts. These standout providers typically serve as a spark to broadening HIV care in the community by urging fellow clinicians to learn more about HIV treatment. As for the long car rides, providers feel the drives are worth it because they get to reach HIV patients

across broad regions and can also work with general practitioners and educate them so they can, in turn, take on more HIV work. "I always speak about the [clinician] heroes" as a way to urge

"People value the care we give them. Some give us the change in their pockets."

Georgia county health department provider

clinicians to get involved in delivery of HIV care, said the director of the National HIV/AIDS Clinicians' Consultation Service under the AIDS Education and Training Centers or AETCs, a Ryan White program.

Typical of this rare breed is a clinician in Ohio, who provides annual training for clinicians and local hospitals and even helps co-manage patients by focusing on HIV complexities that are less familiar to general providers. Regular doctors handle the non-HIV work for these clients. He explains his role this way:

"In most of our counties, the private physicians don't want to deal with HIV because it's so complex."

Georgia county health department provider

"Some clinicians elect to call me to say, 'can you do HIV patient care for me' or 'I'd like to manage certain segments, so can you help me along with this and see my patient, say, two-to-three times a year and review their medications, do a quality visit, and review labs.' And they manage their kidney stones, hypertension, whatever."

This clinician sees his HIV knowledge as a matter of sharing the wealth. "If I've taken to learn as much as I can about HIV management, I should share that." Leaders like this are likely to be found by word-of-mouth or via such resources as the AETC Resource Center at <http://www.aidsetc.org/> or by contacting a nearby Ryan White program at <http://careactarget.org/community.htm>. The National Alliance of State and Territorial AIDS Directors, NASTAD, also maintains a listing of various state health programs at http://nastad.org/About/res_state_directory.aspx, ranging from HIV care funded by Ryan White to other HIV-related concerns such as Hepatitis C, which is a leading cause of morbidity and mortality among persons living with HIV disease.

HIV INTEGRATED WITHIN GENERAL HEALTH CARE

HIV care is complex. Antiretroviral regimens are ever-changing and require careful monitoring. Additionally, people living with HIV often have other conditions such as Hepatitis C that require expert attention. Any one of these conditions

requires specialized treatment. When combined with HIV, providing appropriate care becomes even more challenging. Sustaining specialty HIV or infectious disease clinics in rural areas can be a luxury for many rural areas as they lack the money, the clinicians, and the patient volume to make it work.

In response, many rural areas have folded HIV within broader primary care services — to make do with what is available. As circumstances would have it, HIV care has been moving in the very same direction, evolving toward chronic disease management to address a host of morbidities besides HIV. That's because people with HIV are living longer and increasingly facing conditions such as liver disease and lifestyle factors — drinking and smoking most notably — which are often more likely to kill them than HIV. With such mainstreaming, providers must be cautioned that HIV remains a complex disease to address and demands specialized knowledge.

There are limitless examples of how HIV care is incorporated within general rural medical services. A Georgia county health department is illustrative. As part of their state's public health system, providers cover a 16-county region and address many health concerns that happen to be front-and-center concerns for many patients with HIV, such as diabetes, hypertension, STDs, and women's health. They added HIV to their care list some time ago because they are "the only game in town," according to their program director. The advantage is they can readily link clients to other health programs.

Providing other, non-HIV, services can also be an effective hook. Some clients with HIV are more focused on getting care for conditions such as hypertension, observes a North Carolina clinician. Addressing these needs first can help programs to eventually engage clients into care for their HIV disease.

Find out about HIV care guidelines at <http://aidsinfo.nih.gov>. See the AETC National Resource Center at <http://www.aidsetc.org> to learn about various guidelines and protocols for managing co-morbidities such as Hepatitis C and Tuberculosis as well as approaches to primary care and HIV.

CONSULTATIONS AND CO-MANAGEMENT

Because there are few HIV experts in rural areas, creative steps are taken to bring such expertise to isolated and low resource areas. Co-management is one of the terms used to describe a series of techniques whereby an HIV expert or clinic serves as a consultative colleague with a non-HIV practitioner. It might be interpreting lab results that look a bit iffy or guidance on dosing, drug interactions, or regimen changes.

Co-management is a common practice in medicine, observed an HIV clinician in Ohio. "When you look at sub-specialists, such as cardiologists, they have formal agreements. People agree to accept the patients and the payers." Why not the same for HIV care? Here are some of the many ways that rural areas do it.

■ **Calls to HIV Experts.** In many areas, phone consultations aren't formalized or outlined in agreements. They are simply a matter of a clinician calling a known colleague or consultation source in the community with a straightforward question, on an as-needed basis.

A national resource also exists to handle such calls. It's a federal program called the National Clinicians' Consultation Center, or NCCC at 800-933-3413. They are staffed by HIV experts at San Francisco General Hospital. Typical is a caller from a remote coastal town of 20,000, who uses the

TELEHEALTH

In some areas, technology is increasingly being used to overcome rural isolation and facilitate delivery of health care. This may involve a video conference where an HIV expert and a generalist go over an HIV patient's issues. The patient may even be in the room to take part in the discussion. Key resources include the Rural Assistance Center at <http://www.raconline.org/> (search for telehealth) or the HRSA's Telehealth resources at <http://www.hrsa.gov/telehealth/>.

NCCC because they "don't have access to the specialists or sub-specialists, and lots of our patients don't have the finances to put gas in their car to get to specialty clinics."

In some areas, pre-scheduled consultation call time is set-aside, like one rural site that schedules educational conference call sessions lead by an AETC representative. Providers can get CME's by participating. It's held monthly and a review is conducted of all new and returning patients. Consultations cover quality indicators and topics such as patient retention.

■ **Ongoing Case Consultations.**

Phone and in-person case reviews and frequent calls to check-in help enhance quality by providing that expert perspective, especially for complex HIV issues. Topics for discussion might include review of medications and drug contraindications to avoid. Illustrative is Panhandle Community Services Health Center, a small community health center in Gering, Nebraska with a small HIV caseload. Lacking an HIV specialist in the region, they secured expertise by setting up a contract with Denver Health and Hospitals, which runs a thousand-patient HIV clinic. On a quarterly basis, a Denver HIV clinician travels 200 miles via plane or car and spends two days at the Nebraska clinic seeing around 25 patients. Appointments are pre-scheduled, and the show-rate

is amazingly high, perhaps because patients know that this is their opportunity to sit and talk with an HIV expert. At the end of the two day rotation, a debriefing is held. In-between site visits, Panhandle clinicians can call with specific HIV questions. Panhandle is funded to deliver HIV care by Ryan White's Part C Early Intervention Services program.

■ **Sharing Protocols.** Another technique is to help non-HIV clinics know and follow guidelines on HIV care. There are many, from use of antiretroviral therapy to delivery of HIV primary care (see <http://aidsinfo.nih.gov> and <http://www.aidsetc.org>). In addition is helping clinics put procedures in place, such as standard intake forms and processes commonly used to ensure quality care. HIV-specific tools and techniques also exist, like flow sheets that outline what should be done in certain situations, such as monitoring immunologic test results and testing and caring for such chronic conditions as Hepatitis C. Handy places to find such forms include the National Quality Center at <http://nationalqualitycenter.org>, a Ryan White program under the Health Resources and Services Administration or HRSA. This service compiles quality management resources from across the nation and makes them available to programs.

■ **Chart Reviews.** This is a process of reviewing patient charts to help clinics identify gaps and areas for improvement — for HIV and other diseases. In Montana, an AETC representative offers to do chart reviews, but only after building relationships and trust with clinic personnel. After all, clinics are unlikely to open their records to unknown entities. Initial trust-building steps used by this AETC include sharing educational materials, telling clinics about available training, and stopping by the office to establish personal relationships. The offer to conduct a chart review on HIV care is always done with the following positive spin: this service can help you deliver better care and we'll do the review for you. Chart reviews might identify areas for improvement, which are then shared with clinics. Providers reportedly find such feedback helpful as it makes their jobs easier in focusing on specific ways to improve patient care.

TRAVELING CLINICS

Location, location, location. It's the realtor's repetitious mantra and is equally important for rural areas when thinking about where to site HIV services to make them convenient for clients. Location can even mean packing the van and bringing the clinic to clients in areas where there are no other services. That makes a lot of sense for areas with small numbers of HIV cases spread over great distances. Locating an HIV clinic in a single spot would be impractical in such cases. Georgia, Maine, West Virginia, and Nebraska are but a few areas where traveling clinics or satellite sites operate. Clients with HIV typically learn about traveling clinics from their regular doctors, through referrals from community agencies, and even via word-of-mouth from other patients. Appointments are then scheduled in advance, just like with a regular clinic. Here are typical features found in most:

- Services are done at set times, perhaps once monthly or more.
- Multiple staff load up the van and go on site — clinicians, nurses, nutritionists, and occasionally others like a dentist or substance abuse counselor.
- Temporary clinic sites are located in places that offer space at little to no cost, such as a doctor's office with extra space or a community center or even a church.
- Links are often made with local agencies that deliver services such as HIV education. They can help transport clients to traveling clinics and even use the traveling clinic site as a place to offer HIV counseling and testing.

Less structured than a traveling clinic, but perhaps more common, is the HIV clinician who gets in the car and devotes time to long drives to deliver HIV care in general care clinics. Many such clinicians are out there in rural America. One such doctor has been providing HIV care since 1992 in southeastern Ohio and even a few Kentucky and West Virginia counties. He services 11 counties in Ohio, comprising a patient load that has increased from fewer than 20 people to over 70 today. Recently, that increased by 20 more patients after an infectious disease doctor in a town two hours south left his position.

CENTERS OF EXPERTISE

In various regions around the nation, certain clinics have developed a reputation as the place to turn to for expertise on HIV care. Doctors may call for help with a client or might even just refer clients there. For their part, these clinics handle topics such as how to handle adverse drug reactions, review quality indicators of a non-HIV clinic, and tips on retaining patients in care.

In some cases, these centers set up formal agreements to serve as consultative centers. A North Carolina clinic is one example. They have a

"The patients are so wonderful. They give so much and make the work so interesting."

North Carolina rural doctor

formal agreement with the regional AETC, whereby rural providers from around the multi-state area can come on-site for a preceptorship. They provide a hands-on, one-to-two day learning experience in the HIV clinic to go over HIV care issues, A to Z. When not shadowing HIV clinicians, visiting providers spend time reviewing treatment protocols, case studies — whatever is needed to fit their individual needs.

Unsurprisingly, clinics that serve as expert centers usually have HIV funding to make their expanded work possible. Ryan White funds are the most common source, like an Idaho clinic that receives Ryan White Part C

PHARMACY SERVICES

Antiretroviral drugs have revolutionized HIV care, with Medicaid and the Ryan White Act providing significant funding given the heavy impact of HIV on low income individuals, along with the relatively new Medicare Part D prescription drug program. Beyond the drugs, pharmacists are crucial sources of information for many clients as they can reinforce clinician instructions about correct use of drug regimens, explain eligibility requirements for drug plans, and even refer clients to mail-order access for their medications. To learn more about accessing these programs, see NASTAD's listing by state of AIDS Drug Assistance Programs (ADAP) at, http://nastad.org/About/res_state_Directory.aspx.

(Title III) Early Intervention Services funding. They build HIV expertise in providers around the state to help cut down on patient travel time needed to get to the closest HIV expert. Their work to expand the pool of providers will get even more intense in light of a new national initiative to increase testing to help more people learn their HIV status and get care. Upwards of one-third of HIV-infected Americans don't even know they are infected. Programs such as this Idaho clinic will need to build rural provider capacity even more than before if increased testing results in more HIV-infected individuals learning their status and seeking a nearby source of care.

GETTING SERVICES: ON-SITE OR THROUGH REFERRAL

Clients in rural areas need access to services — in a local clinic or via referral to other agencies that can readily see them. How to structure access varies from program to program and depends on such factors as funding and the existence of other services in the community. Take the case of a North Carolina clinic, which decided that an on-site pharmacy was crucial to their work. “We started in the back of a church and understood if [patients] didn't have access to medications, the prescription slips would be in the parking lot.” An added benefit was easier monitoring of patient adherence. “I would see when their last refill was,” said their clinician.

Adding multiple services in one location, the one-stop model, may simply be impractical from a funding and management standpoint. From the client perspective, it can be too much of a time commitment in the clinic. “We wanted to do one-stop shopping but were over shopping,” said the clinician from this same North Carolina clinic. It was “too many people to meet” for clients. One fix they made was to shorten

their intake process and even conduct some assessments over the phone.

No matter how desirable, having multiple services under one roof is rarely affordable; that's why partnerships and referral networks are crucial. Providers who appreciate the value of referrals make a point of knowing where to send patients when they can't do the work in-house. However, steps are needed to make sure that referrals actually happen. It might mean a follow-up call to see if the patient kept the appointment. It may also entail taking some time to make the patient comfortable with going to a new provider. Such linkages can be easy to make in rural areas with limited numbers of providers. “We all know each other,” said a Montana provider, sharing a common refrain from many rural providers interviewed for these NRHA best practices summaries. A Nebraska provider observed that physicians in the state working on HIV respect each other and know they have to share the workload in order to see everyone. They see each other as collaborators. Said a Georgia program director: “The doctors are really great. We have a great relationship because we work closely with them...A lot of referring clinicians, such as gastrointestinal doctors [a crucial discipline in treating hepatitis], will pick up our clients for specialty care.”

CASE MANAGEMENT

Case management is hardly unique to rural areas. It is called the “glue that holds everything together” by a Nebraska rural provider. “They see the clients more than anyone else...they look at everything that's going on in that patient's life. Housing, food, disability checks, the fact that their mother-in-law is moving in on them or they've broken up and are depressed.” In rural areas, case managers tend to address an array of health and human service needs. They rarely focus just on HIV because there is simply no money to devote to such case management specialization.

MAKING REFERRALS, GETTING CARE

Below are some ways to locate an HIV or other health care agency.

Rural Health Programs

http://www.nrharural.org/opportunity/sub/rural_HIV.html

State HIV/AIDS Programs

(Ryan White/Other HIV/AIDS Prevention and Care)

http://www.nastad.org/About/res_state_Directory.aspx

Medicaid and Medicare

(Biggest payers of HIV/AIDS care)

<http://www.medicare.gov/>
<http://www.cms.hhs.gov/home/medicaid.asp>

Ryan White Program

(State and Local HIV/AIDS Care)

<http://careacttarget.org/>

Community Health Clinics

(Federally Funded Primary Care for Low Income Persons)

<http://ask.hrsa.gov/pc/>

Substance Abuse Treatment Locator

(Federally Funded Sites)

<http://dasis3.samhsa.gov/>

Mental Health Services Locator

(Federally Funded Sites)

<http://mentalhealth.samhsa.gov/databases/>

Patient Assistance Program/ Expanded Access Program

(Pharmaceutical Sponsored Access to Medications)

<http://www.atdn.org/access/pa.html>

Clinical Trials

<http://clinicaltrials.gov/>

(Federal Efforts, Often Provide Care for Participants)

A case manager can help arrange services and assist clients in getting to appointments — the referral work mentioned above. They often know when clients are not making their medical visits and do something about it, such as calling with reminders about upcoming appointments. The work can also involve determining if substance abuse and mental health issues are standing in the way of HIV care and referrals to needed services. There are many case management methodologies in use around the nation, such as a nurse case management approach used by an Ohio provider. The nurse handles non-medical needs as well as medical issues by acting as a physician extender. The case manager creates a “comfort level” with clients, says the clinician at this site. “Once you get that comfort level, people will come back. It’s more than caring about their CD4 or viral load level. Those support services really do bring people back. Wellness is more than just making sure your labs are okay.”

Another case management approach is used by a Nebraska agency. They have a social case manager and nurse case manager who work with all HIV clients at the clinic. The goal is to attend to both medical and social needs, under the thinking that you can’t serve client medical needs adequately if support needs are ignored. The two case managers therefore are in constant contact to share information about clients and their needs and to plan needed follow-up.

Regardless of the case management methodology, case managers can be overwhelmed with caseloads. The ideal number can be around 35-40 people but is often much higher. It is likely to go up over time, since antiretroviral therapy is working wonders and people are living longer and more productive lives, and are not necessarily falling off case manager workloads. In addition, new cases enter the system all the time. Learn more about various case management

methodologies at the TA Library of the TARGET Center at <http://careacttarget.org>.

PEER SUPPORT

Clinicians are typically busy and in short supply. Patients may be apprehensive about asking their doctors too many questions. In some cases, the result may be poor communication and sub-par care. Enter peer counselors, used by a number of rural programs around the country to give a bit of extra time, advice and help to clients.

The peer role is largely about enhancing the service experience for patients, with the hoped-for result being retention in care and better health outcomes. Said an Ohio clinician who found much value in having a peer on site: “Clients want to ask things like: ‘Will I get better? What will happen to me if I take this?’ These aren’t things that patients typically want to ask a doctor.” When a patient does share something with a peer that the doctor should hear, the peer will ask if it’s okay to share that information with the professional. It’s an important permission to get because it keeps the trust between peers and patients.

Peers can also reinforce what doctors say. “Often, people heard half of what I said,” this same Ohio doctor observed. Peers can reinforce and clarify what was communicated.

Here are some common features of peer programs:

■ **Training.** Peers need up front training and ongoing supervision. Training will cover topics such as medical record confidentiality (security, Health Insurance Portability and Accountability Act, (HIPAA) requirements), patient-provider communications, and understanding limits in what they focus on with patients (largely, non-medical topics). Peers may also need some pretty basic AIDS 101

training, according to a Nebraska provider, covering topics such as disease transmission and care, and even how to disclose their own HIV status to family and friends. Regardless of the training, most clinics keep to a standard of confidentiality and accountability, and thus typically require peers to go through the same training protocols that professional staff must follow.

■ **Variable Tasks.** Peers can take on different tasks and levels of responsibility. Some focus on patient intake (e.g., putting patients in rooms, collecting patient information, helping patients complete paperwork, and appointment scheduling). Some do specific administrative tasks such as reviewing medical records and cleaning them up. Some do counseling with infected persons and avoiding transmission to their partners. Others tackle more medically-related tasks, although these duties require much more training and caution. Examples include one-on-one patient education about drug regimens (especially with new patients to reinforce what doctors told them) and checking adherence through home visits. A peer in a Florida clinic actually became so proficient that he began preparing lab tests for shipment and doing patient intakes — so much so that patients needed to be reminded that he was a peer and not a provider and thus couldn’t dispense medical advice.

■ **Time and Pay.** Peers typically work part-time, paid or volunteer. A key benefit with this arrangement is their flexibility as they can spend more time with patients, one-on-one, which busy clinicians can’t do, given back-to-back patient appointment scheduling. Programs are often hard-pressed to finance even part time peers, but some have found funding through sources such as community grants and pharmaceutical companies.

■ Peers are Motivated People.

The best peers, unsurprisingly, are motivated and enthusiastic about helping people. Such people do exist and are cited by rural providers who benefited from their help. The trick is finding them, although they are usually right there — in the form of a current patient.

■ **Keeping it Simple.** HIV is complex and can overwhelm patients, especially those with limited backgrounds. Peers can help get messages across, said an Ohio clinician, “though I think I’m good at communicating, the peer has made suggestions, like: ‘Hey Ellis, why don’t you say it this way.’”

■ Understanding Client Culture.

Peers, in the truest sense of the word, come from the community of clients being served and can thus provide invaluable access. Such is the case with a volunteer who works with a Florida clinic. She’s a nun from Mexico who started out as an interpreter. She first got training to learn about interpretation techniques and setting limits, such as keeping confidences and not making judgments on information being conveyed. Over time, this peer became an outreach worker with migrant farmworkers, providing a valuable access point to this hard-to-reach client population. The Florida doctor she works with adds that she’s helped him understand the culture of his client population.

Ideas for peer education can be found at <http://careacttarget.org/> (see Sources of TA or the TA Library). National standards for cultural and linguistically appropriate services in health care are available at <http://www.omhrc.gov/clas>.

PERSONAL TOUCH

Touch the patient. On the knee or shoulder. A hug. Whatever is appropriate, according to a North Carolina clinician. “So many times, I’ve been told [by patients] this is the only place someone will touch me. Just think if you lived by yourself and your family is all afraid of you and wash your dishes separately but they won’t tell you.”

Physical contact is literally the personal touch. Honesty also counts. It means telling patients, directly, when things are going well or not. That’s but one part of building a personal relationship with a patient, says a Nebraska provider. “If you have a physician who is business-like, or you aren’t connected to the social worker or nurse, it can diminish returning to care.” And it doesn’t all have to be on the doctor’s shoulders, according to this same provider. “The more people engaged in that person’s life, the more likelihood the person will connect with someone.”

ADJUST SCHEDULES

Rural clinics are creative. Take the case of a North Carolina clinic that adjusted appointment scheduling to deal with the preponderance of mental health needs of their clients — up to 50% face depression, post-traumatic stress, or personality disorders of some type. “If I left these issues on the burner, there would be no such thing as adherence,” said their clinician. Unlikely to find mental health services for her clients, she instead gave them something else they needed — although also in short supply, more of her time. The problem was that she had few minutes to spare in the climate of a busy community clinic running like a mill with back-to-back appointments for patients with a host of chronic conditions. That’s why the clinic schedule was adjusted to see HIV clients with mental health issues toward the end of the clinic day. The reaction of clients: “I’d tell them, I’m scheduling you at the end of the day

and want to be able to focus on you, and they were happy with that.”

Such end-of-day scheduling of appointments may not always work when patients are faced with long driving distances and only a limited number of time slots to pick from. Take Nebraska, which reportedly has just a handful of primary care clinicians doing HIV care, with most located in the eastern part of the state in Lincoln and Omaha. In Wyoming, there are just two infectious disease practitioners, and both are in one city in the middle of the state. Said a Nebraska provider:

[A client who has to drive that far for HIV care probably] “doesn’t have a good car and the car they have isn’t a confidence builder. They may not make the appointment in time and it may have to be rescheduled. Or the client may have found someone to bring them in and the clinic may want the client to see multiple providers, but that can’t happen on the same day because the client’s friend might not appreciate sticking around all day.”

The client may have a job, possibly earning minimum wage with few if any benefits, which means getting time off from work and losing pay for missed hours. Nebraska HIV clinics have worked hard to overcome obstacles like these. What they did was coordinate the timing of appointments, factoring in what services they have. The strategy differs at their two main sites. In Omaha, same day scheduling works well as multiple providers are located within a medical center, providing ready access to back-to-back appointments on the same day. Such is not the case in Lincoln, however, as services are spread around town. One technique they use is to have patients get their primary care clinic visits in Lincoln. Patients then make the trek to Omaha for other services, which are available in the medical center facility and can be scheduled for the same day. It’s not perfect but it works.

CONCLUSION

In the context of limited funding, there is no single best model for providing rural HIV/AIDS care, as the countless ideas shared with NRHA suggest, although common approaches were identified. A New Mexico state health department provider summarized it this way: "A lot depends on the local infrastructure. In some locations, hospitals take the lead. In others, it's state or local health departments or other nonprofit organizations. Of particular value is partnering and coordination of services. This can range from clinician-to-clinician dialogue to agencies working together in handling referrals. Case managers play a major role in program coordination. They are the individuals who understand various programs and can navigate patients through sometimes overwhelming health care systems, particularly for newly-diagnosed patients."

Then there are the small steps, some with incalculable meaning, like the reassuring hand of a doctor on a patient's shoulder.

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