



Fighting Stigma and Denial

Best Practice

Over a quarter century into the epidemic and AIDS still carries much of the same baggage it always has. People who don't have HIV don't think much about it or don't think kindly if they do. Misperceptions persist about how HIV is transmitted, despite decades of public education efforts. Some providers would rather not deliver care to HIV-infected persons. People living with HIV often fear that their status will be disclosed, like in Montana, where a 2005 assessment of clients reported stigma as their number one concern. Such fear leads people to keep quiet about their status. They may become extraordinarily isolated as a result of having no social network to help them manage life with HIV. Collectively, these obstacles can make getting and staying in care a lot harder.

But life is not static in rural communities. Much has been done in small doses with large impact. Individual clinicians tackle cases and educate their colleagues. Agencies make adjustments so clients feel less intimidated when coming in for care. And individuals speak out and publicly say they are infected. Here is some of what has been done in rural areas around the nation to fight stigma and denial.

VISIONARIES LEAD

Clinicians typically do not want to be identified as the AIDS doctor in town. It's that simple. But some don't mind and, in fact, take on the role for an entire region. What motivates some clinicians and agencies to take the lead in delivering HIV care? "More often than not, they are of the community and want to see themselves as helping and contributing," said a Texas provider. It can also happen because patients simply start showing up as they have nowhere else to turn.

To point out specific visionaries, by name, would do a disservice to those not mentioned. Suffice to say that they travel across large regions to treat HIV patients and, just as important, work with other doctors to help break down stigma within the health care system. These clinicians, and the clinics they work in, serve as a training source to bring other clinicians up-to-speed on HIV care. This work might involve convening formal trainings, often through the AIDS Education and Training Centers under the Ryan White program, or by work with clinicians to

"Stigma is a big issue in rural areas because everyone thinks no one has it. Ask someone in New York City and they know someone with HIV."

Montana Provider



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"We're small counties and everybody knows everybody."

Georgia health department provider

observe and learn in the clinic setting.

Said a Texas provider: "We used to have a physician consultant in our bureau who would go to different

places around the state and work with doctors. It's helpful to have a doctor talk to a doctor about different issues." Such people are all too rare and hard to replace. Take this same Texas provider, who said: "Bob, unfortunately, is now an emergency room manager in Baghdad. He was one of a kind. He went down to the valley and to east Texas. He would travel and talk to the doctors there. The position is still vacant. It's hard to replace a one-of-a-kind."

HIV INTEGRATED WITH OTHER CARE

A big stigma breaker for HIV care is to deliver it as part of other primary health care, which is often necessitated by a lack of funds to craft HIV-specific services. It also makes sense in areas where there may be too few HIV cases to sustain a full-time HIV clinic. Clinics along the Texas/Mexico border typically operate that way, so clients don't fear being seen going for HIV care. They could very well be there for their diabetes instead. Georgia's local and regional health departments are also illustrative. They operate what are called Wellness Centers and offer a range of services, from diabetes management to health screening. The term "wellness," however, can have its drawbacks as they get the occasional phone call asking if they have a pool.

While an advantage of mainstreaming HIV care is reduced stigma, a requirement is for mainstream providers to be prepared to deliver quality HIV care. This might entail ensuring that a general practitioner can consult with HIV experts when needed, like infectious disease clinicians located nearby. It also may mean bringing special HIV provider training to the area.

CLINIC ADJUSTMENTS

Just as clinicians don't want to be known as the "AIDS doctor," clients don't want to be known as "AIDS patients." In rural settings, that's a much bigger concern as it's harder to remain anonymous in a small community. Clients go to great lengths to remain so. "One client's mom thinks we're a dialysis center," reported one provider. Others report clients who travel to neighboring counties for care, even though HIV services are close by. That is why many clinics do things to ease client concerns.

- **Remove HIV Clinic Identifiers.** Rural clinics that do HIV care make a point of avoiding any identifying terms like AIDS or HIV in their

clinic names or external operations. That includes clinics that specialize in HIV care, like a site that calls itself a Positive Clinic. Beyond the name, this clinic is also embedded in a larger clinical practice with multiple medical specialties; a client could be there for any of many different medical reasons. And, HIV clients are treated no differently than other patients. Taking such steps is essential. An Ohio practitioner reported that some clients are even resistant to going to the local infectious diseases clinic, the typical specialty area for clinicians doing HIV work, because others will conclude that "it doesn't mean you have strep; it means you have HIV."

- **Back Doors and Waiting Rooms.** "All of our centers have a back door. We still have people who park down the street and come to our building." This observation came from a Georgia program that makes a point of allowing patients with qualms to, literally, come in or out of their rear entry for services. In a Montana community health center, they promise clients that they won't have to sit in the waiting room,

MENTAL HEALTH STIGMA: BAD CASE OF THE NERVES

A North Carolina clinic hired a therapist to bring mental health services to HIV patients. Clients were not interested. "They would see me and cry for 15 minutes. They wouldn't see her," said the clinician, observing that clients often underplay the significance of mental health issues by calling them "a bad case of the nerves." The solution? "Now, we have a therapist who comes in the room with me. I'll do introductions and summarize my client's challenges with grief and despair. 'This is my good friend Bonny and she's an expert in this, Johnny.' In this context, they are more likely to engage with that therapist." Added the clinician: "Do I have data to show that patients are doing better with mental health services? No, but I know they feel better."

“Because of the stigma, they didn’t want to go to their family docs because down here, everyone knows your business.”

Georgia health department provider

which is typically full of patients. Such arrangements require special measures, however. After all, as anybody who has ever gone to a doctor knows, they call them waiting rooms for good reason.

- **P.O. Box Addresses.** When mailing notices to clients, many clinics use a post office box return address. That way, the envelope has no identifying information that a friend or relative might feel compelled to trace. That’s a real concern for individuals who have not revealed their HIV status to those closest to them, although programs typically urge clients to think about sharing their HIV status so that they might benefit from support and to also minimize the stress of always hiding that information.
- **Locations.** Where to put a clinic matters if you want people to show up. In West Virginia, in deciding among three potential communities to place a new satellite clinic, a needs assessment of clients was undertaken. Results suggested that clients would be resistant to attending a clinic if located in what providers saw as a more convenient spot — one that was literally “too close to home.” The program ended up not locating services there.

CONFIDENTIALITY — MAINTAINED

Remaining a face in the crowd is next to impossible when there is no crowd. People with HIV who live in rural areas face that all the time as they keep their HIV status private in the face of potential rejection by family, employers, and insurers. Health departments have a long and respected history of protecting confidentiality of health information, and rural providers have measures in place, just like all providers, to guard patient confidentiality. The standard in health care is guided by federal medical privacy rules, called HIPAA, Health Insurance Portability and Accountability Act (see <http://www.hhs.gov/ocr/hipaa>), along with state requirements for confidentiality and security of patient medical records.

Some agencies have adopted additional measures. One example used by some agencies is a rights and responsibilities statement, signed each year by patients, stating an agreement to maintain confidentiality about the other patients they see at the clinic. A Georgia health department facility goes so far as to require the same of repairmen coming into the clinic. “What goes on here stays in here,” said the Georgia program director about their policy.

Part of maintaining confidentiality is practicing common sense. A Maine agency that works with migrant workers teaches their health camp aides to speak with clients in private. It requires diligence in this agency as clients often live in crowded housing.

PEER SUPPORT

Patient support programs can do much to build client camaraderie about their HIV status and help diminish their anxiety, which is often driven by a sense of isolation. Reduced anxiety may translate into better emotional and even physical health. Program examples include discussion groups as well as drop-in rooms or social centers with hot meals and a laundry room. Discussion groups might be held on topics like HIV medications. However, support programs like these can be of limited value to patients who must travel long distances because they don’t have the luxury of sticking around for the sessions. They have to hit the road to get back home.

CONFRONTING STIGMA HEAD ON

Are the above steps tantamount to giving into AIDS stigma in that they give wide berth to its existence, so to speak? It hardly matters if they help patients. However, some efforts avoid the question altogether by tackling stigma head-on. Here are some examples.

Tackling Provider Denial.

Educating providers about the extent of HIV in a community is among the first and most obvious steps to confronting provider resistance to dealing with HIV. Said a Kansas trainer: “That’s why we’re doing the education program we’re doing, to get the word out there that although the parameters have changed, it [HIV] is still very much an epidemic and what they can do in response.” An Idaho trainer uses statistics to educate clinicians during training sessions to raise their awareness about the extent of HIV cases in their area.” We

present the data [on AIDS cases] and then cite data on those walking around with HIV who do not know they are infected.”

In some areas, informal networking among clinicians can spur attention to HIV, as has reportedly happened along the 1,200 mile Texas/Mexico border. This included establishing partnerships between rural border and urban clinics to break down resistance to doing HIV care and recruiting new clinicians.

Patient Education. One-on-one counseling with clients about their HIV status can cover many areas that focus on stigma. Providers can talk to clients about the need to be honest with family and friends about HIV — that it is an illness and not a value issue.

Several communities try to help clients feel more open about their HIV status through media and the arts. In North Carolina, clients were given cameras to capture images reflective of their experiences, be it living with HIV or simply living. In Montana, an effort on the drawing boards is to have local artists build “art boxes” and put patient photos inside — faces, hands, or even representative objects. Included would be something written about living with HIV. All would be revealed to patrons as they unlock the boxes, an apt analogy for understanding life with HIV.

A non-rural clinic’s work to break down patient stigma also merits mention. Birmingham, Alabama’s St. George’s Clinic also uses photos to fight stigma. Called Positively Living, they retained a volunteer professional photographer, Carolyn Sherer, who took high quality black and white shots of clients for a Ryan White program. Her photos are

displayed in the clinic waiting room as a way to help break down stigma by literally showing new clients that others are living with HIV — and doing so openly. To learn more, call Ann Atkinson of the St. George’s Clinic at 205-930-3662, to find out how your program can undertake a similar anti-stigma initiative.

Community Education.

Perceptions persist that HIV has little impact in rural areas. For some, AIDS continues to be inextricably linked to gay men and drug use and thus, only a concern for others. In rural areas, community outreach events are used to help break down such thinking, and appear in many forms. Local newspapers are always looking for stories and are receptive to running articles on uniquely local events, clinic activities, and individuals living with HIV/AIDS. These story lines can go a long way toward getting the attention of people in the community.

Community education forums and health fairs can draw a crowd as well as press attention, particularly if notable public officials attend and speak. World AIDS Day events are also often held and usually involve public officials; business, health, and faith leaders; and clients. There are a host of other AIDS awareness days as well, such as National Black HIV/AIDS Awareness and Information Day, which help focus community attention (see <http://www.omhrc.gov/hivaidsobservances/index.html> for a complete listing).

HIV/AIDS STIGMA RESOURCES

HIV/AIDS Awareness Days

World AIDS Day, National HIV Testing Day, Others
<http://www.omhrc.gov/hivaidsobservances/index.html>

Stigma Resource Center

Articles, Fact Sheets, Anti-Stigma Publications
<http://www.nmac.org/nmac2/stigma/resources/main.html>

Understanding and Challenging HIV Stigma: Toolkit for Action

Work Book Format Explains Root Sources of Stigma and Ideas for Combating
<http://www.aed.org/ToolsandPublications/upload/StigmaToolkit.pdf>

Evolution of an Epidemic: 25 Years of HIV/AIDS Media Campaigns

History of Public Service Efforts and Listing of Current Anti-Stigma Campaigns
<http://www.kff.org/entpartnerships/upload/7515.pdf>

Medical Privacy — National Standards to Protect the Privacy of Personal Health Information

<http://www.hhs.gov/ocr/hipaa/>



CONCLUSION

HIV/AIDS discrimination has clearly lessened over time. A child with HIV disease can go to school without much notice. Legal protections have helped address employment and insurance-related AIDS discrimination. But disease stigma still remains a major obstacle to educating people about HIV/AIDS, particularly in rural areas where geographic distance and demographics make HIV less apparent as a community problem. It is this same stigma that causes many individuals to avoid HIV testing

PROTECTIONS AGAINST HIV-RELATED DISCRIMINATION

For information on the rights of persons living with HIV/AIDS — from discrimination in care to privacy of health information — see the HHS Office for Civil Rights at <http://www.hhs.gov/ocr/hiv aids>

to learn their status and, if infected, to seek care for their disease. Rural and other communities continue to struggle with ways to work around AIDS discrimination, to confront it, and face it down. Many techniques to end this discrimination are being used successfully in rural areas — from clinic techniques to help patients feel

more comfortable coming for care, to media and other events that raise awareness and promote increased HIV testing. And, ultimately, individuals living with the disease stand up and speak out — an act of courage as meaningful today as what others did decades ago in helping America understand AIDS.

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