

An Invisible Barrier to Integrating HIV Primary Care with Harm Reduction Services: Philosophical Clashes Between the Harm Reduction and Medical Models

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SYNOPSIS

Overall AIDS mortality in the United States has declined in recent years, but declines have not been consistent across all populations. Due to an array of barriers to care, minorities and poor people who are active substance users have not benefited as others have from advances in the treatment of HIV disease. One way to address this problem is to integrate HIV primary care into harm reduction programs that already effectively serve this population. Such collaborations, however, are difficult to initiate and sustain. Philosophical differences between the medical model and the harm reduction model, which often remain invisible to the parties involved, underlie these difficulties. This article addresses the issue by describing a partnership in the Bronx, NY, between CitiWide Harm Reduction Inc. (CitiWideHR) and the Montefiore Medical Center. It focuses specifically on the sources of philosophical differences between models, and briefly assesses the potential for successful collaborations of this sort.

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In recent years, overall AIDS mortality in the U.S. has declined, but declines have not been consistent across all populations. In particular, AIDS mortality rates among minorities and injection drug users (IDUs) have decreased more slowly than those of whites and groups not identified as drug users.¹ Minorities and IDUs, particularly those who are unstably housed, are less likely to receive treatment with highly active antiretroviral therapy (HAART)² and less likely to access HIV primary care.^{3,4}

In addition to unstable housing, many barriers to medical care have been identified for this population, including competing survival needs (i.e., food and shelter), active substance use, lack of health insurance, health care costs, long wait times, lack of transportation, lack of information, discrimination, and disrespectful clinic staff.⁵⁻⁷ These findings were corroborated by a study of drug users in New York City.⁸ This study found that people who use drugs in New York City are unlikely to seek health care until they are in dire circumstances, and don't remain in primary care largely because of negative experiences they have had with the medical establishment. Many study participants felt they were discriminated against by medical personnel, from clinic or hospital administrative staff members to the physicians treating them. The following quotes reveal attitudes toward medical professionals common among poor people who use drugs in New York City:

- "I have to be in so much pain or something that's threatening before I go to a doctor. It just isn't worth it, the way you're made to feel."⁸
- "This [doctor] tells me, 'You have to stop using drugs!' That, I agreed with. But I said, 'I'm an addict, I've been using drugs for years. It's something that I have to stop gradually. I can't just stop like that. I understand it's bad for me, but I cannot stop like that. If you could help me out with that and still help me with my HIV, that would be great.' But it was told to me, 'No, I just have to stop.'"⁸
- "You know, I think that [physicians] get very removed from the personal aspect of it and they look [down] upon you just because you're a drug addict, and it's like health care professionals a lot of times their attitude is 'You did this to yourself.'"⁸

These quotes illustrate how poor people who are active substance users feel misunderstood by medical professionals and have had negative experiences getting care, making it difficult for them to attempt to secure or remain in health care, even when they need

it. White and middle-class people may experience these relationships differently. Middle-class white women, for example, seem able to create workable relationships with health care providers because of their ability to pay for services or utilize private insurance and because they have cultural support for addressing substance use as an illness, rather than a personal failing that defines their identity.⁹

One way to address this issue and increase access to care for more poor people who use drugs is to create partnerships between community-based harm reduction organizations that have good reputations among drug users in the communities they serve and medical providers who are willing to work with them. Collaborations of this sort, however, are difficult to initiate and sustain given that medical and harm reduction organizations operate according to different philosophies and approaches to care delivery for this population. A national study of the coordination of HIV care, substance abuse treatment, and mental health services by the Policy Resource Group noted that differences in program philosophy or treatment paradigm posed a significant barrier to care coordination,¹⁰ but explorations of these differences have not been articulated in the literature.

This article addresses the issue by describing the partnership in the Bronx, NY, between CitiWide Harm Reduction Inc. (CitiWideHR) and the Montefiore Medical Center, focusing specifically on the sources of philosophical differences between models, and the potential for successful collaboration between service providers in both the medical model and the harm reduction model.

THE CONTEXT AND THE COLLABORATION

CitiWideHR was founded in 1994 by Brian Weil, an AIDS activist, and La Resurreccion United Methodist Church to provide harm reduction outreach and syringe exchange to residents of Single Room Occupancy (SRO) hotels in New York City. Private owners of these hotels contract with the city's HIV/AIDS Services Administration (HASA) to provide emergency housing (shelter) to homeless people living with HIV/AIDS (PLWHAs).

Because these hotels are commercial facilities, no social services are available on-site. The SRO hotel environment is characterized by poverty, violence, and high rates of substance use, and sites are often the focal point of drug-dealing, loan-sharking, and sex work operations.¹¹⁻¹³ These operations target PLWHAs placed at the sites for emergency shelter.¹¹ To serve the people living in these hotels, CitiWideHR has grown

over the years from a syringe exchange outreach program into a multi-service harm reduction organization providing expanded outreach services, case management, support groups, housing placement, psychiatric counseling and care, holistic health treatment, prevention and harm reduction education, and job readiness training at a drop-in center in the South Bronx.

In the course of providing these services, CitiWideHR staff members have discovered that while people living in the SRO hotels are often very sick, they often do not receive regular health care because of barriers they experience due to the stigma of being active drug users and homeless. To promote supportive access to medical care, CitiWideHR explored relationship development with a variety of hospital- and community-based medical providers in the Bronx and Upper Manhattan. However, in addition to the challenges of negotiating relationship terms and medical staff integration with CitiWideHR's programming, it was difficult to find medical providers willing to tolerate the difficulties of working collaboratively with a harm reduction organization to create and sustain a good relationship. Because having the right people involved plays a key role in establishing effective organizational relationships, it was important to locate individuals willing to collaborate on an even playing field for this project.

Finally, CitiWideHR began laying the foundation for a pilot medical collaboration through a sub-contract with Montefiore Medical Center's Residency Program in Social Internal Medicine, funded by a government contract for harm reduction outreach to SRO hotels held by CitiWideHR. This project was designed to integrate physicians into the agency's evening outreach team; to contact and engage agency participants for health-related needs, including education, wound care, triage and evaluation, and medication prescriptions; and to facilitate entry into the medical system. The project reduces the threshold for access to HIV care by providing home-based (SRO hotel-based) access to a friendly health care provider, and promotes bilateral trust and relationship development between participants and providers in participants' homes, respecting and affirming participants' strengths rather than judging and mandating behaviors. Within this harm reduction framework, participants are offered immediate access to local clinic-based care with these same outreach physicians, building on relationships established in the SRO hotel for access to and engagement and retention in HIV primary care.

CitiWideHR assists with clinic appointments by managing appointment scheduling and providing daytime supported transportation to and from the local

clinic. At the clinic, CitiWideHR staff members help participants complete paperwork, enabling quicker entry into the clinic system. Once in the Montefiore system, CitiWideHR participants have access to specialty care, with coordination of these appointments for transportation, escort, and advocacy provided by CitiWideHR, as necessary.

Because CitiWideHR has built an excellent reputation among the SRO hotel resident population, its association with Montefiore physicians has led to immediate physician credibility with participants. Participating in outreach activities has allowed these medical providers to engage SRO residents in their own living environment, rather than in a clinic, allowing providers insight into participants' life contexts and the multiple issues they confront. In turn, participants have the opportunity to get to know the medical provider, to test the waters for engaging in care. In effect, participants use this opportunity to screen physician attitude and approach.

Within this development of the participant-provider relationship, CitiWideHR plays the role of facilitator and ombudsperson. Although the relationship between providers is collaborative, participants understand clearly the separation between provider roles, and are able to lodge concerns and relate issues or barriers encountered in care to the harm reduction agency for resolution, rather than simply "dropping out of care" with the medical provider. In addition, consistent daily outreach activities at the SRO hotels provide ongoing opportunities for re-engagement and retention in care among participants (e.g., a missed appointment does not prevent another being made), and relationship-building is supported by consistent physician presence during outreach and ongoing available appointment slots at the clinic.

In April 2001, Montefiore and CitiWideHR expanded the collaborative effort by creating the ROOM-based MEDical Outreach (ROME) program. ROME integrates CitiWideHR's SRO hotel-based presence through outreach with Montefiore medical personnel to provide comprehensive on-site HIV primary care in a harm reduction framework. Examples of services provided by ROME providers include blood tests, physical exams, gynecologic exams, and prescriptions—all within the SRO hotel rooms. ROME enhances existing CitiWideHR outreach- and center-based services by offering home-based care and service coordination to participants at SRO hotels who are unable to utilize other available options—and more standard or traditional options—for care (i.e., clinics). Often, participants utilizing the ROME program are experiencing the debilitating effects of HIV infection and/

or are involved in intense substance use or relationship issues that prevent them from straying far from the SRO hotel environment.

The collaboration continues today, with both parties working toward a comprehensive medical program of outreach, clinic- and home-based care, and center-based education. Recently, the collaboration was funded for an outcome evaluation by the Health Resources and Services Administration (HRSA) as a Special Project of National Significance (Grant No. 1H97Ha00247-01). With the addition of a researcher to the collaboration, it has become possible to study and articulate the challenges faced in this continuing collaboration.

Highlighting the collaboration's major achievements and articulating its timeline of development tends to depict the relationship between CitiWideHR and Montefiore Medical Center as progressive and worry-free. In fact, the collaboration has not been, and is still not, easy. To identify the primary sources of differences and difficulties, we reviewed e-mails, memos, and other communications related to the collaboration and reflected on key situations that resulted in conflict. Table 1 summarizes the collaboration's major achievements and indicates where difficulties arose.

COLLABORATION AND ITS DISCONTENTS

Problems began immediately with the establishment of the contractual agreement in 1999. With the involvement of grant money came the need for financial accountability, highlighting the challenge of meeting the expectations of both parties involved. Difficulties included mutual distrust, miscommunications regarding financial accountability, challenges to physician authority, systemic problems related to clinic appointment limitations and long waiting times, and the inflexibility of a variety of institutional requirements.

One way to understand the complexity of these interactions is to illustrate how the parties involved operate from different, conflicting—and often invisible—philosophical frameworks. Most of the difficulties encountered during the collaboration result from basic structural and philosophical contrasts between the medical and harm reduction models. The medical model maintains broad institutional legitimacy in our society, prescribing limits and hierarchies in its relationships, roles, and approaches to work. This lies in direct contrast to the fluidity and responsiveness inherent in the harm reduction model. Finding its strength in a willingness to evolve and change with the community it serves, the harm reduction model resists parameters or limiting definitions. These values are fundamentally at odds with prevailing approaches to the organization, management, and delivery of medical services.

The following sketches outline eight domains that help describe the contrasts between the medical and harm reduction models (Table 2). These domains include: structural philosophy, institutional legitimacy, theoretical framework for understanding drug use, system design, provider perspective on approach to care, provider role, user role, and locus of control.

The philosophical clashes we describe are more complex than the sketches may suggest. They span scientific, medical, public health, social, psychological, and political domains and cannot be fully articulated for this article. Our purpose is to illustrate one way of beginning to understand the difficulties of collaboration across such divides and to provide a conceptual framework that may be useful to others experiencing similar difficulties.

Structural philosophy

Harm reduction is grounded in a structural philosophy that embraces individuals as experts. Their contri-

Table 1. Timeline of program development and collaboration

Year	Development
1994	CitiWideHR initiated as syringe exchange outreach program.
1996	Montefiore physicians begin voluntary participation with CitiWideHR outreach team at SRO hotels.
1999	Formal sub-contract established for consistent Montefiore physician and resident participation with CitiWideHR outreach team, related data gathering, and designated clinic sessions for CitiWideHR participants.
2000	Concerns arise regarding financial accountability, consistency, and approach. Experience of the philosophical clash between the models is heightened.
2001	ROom-based Medicine, Education and Outreach (ROME) program initiated.
2002	Collaborative outcome evaluation of outreach for engagement into HIV primary care initiated. Philosophical clash articulated.

Table 2. Philosophical clashes between the harm reduction and medical models

	<i>Harm reduction model</i>	<i>Medical model</i>
Structural philosophy	Inclusive, community decisions, process	Hierarchical chain of command
Institutional legitimacy	New, always becoming, in process; controversial	Established early 20th century; acceptance in mainstream society
Theoretical framework for understanding drug use	Drug, set, setting	Pharmacology/disease model
System design	Low threshold for accessing care	Prescribed procedures for getting care; higher threshold
Provider perspective on approach to care	Actively questioning assumptions, avoiding judgmental stance (fluid)	Expert knowledge (discrete)
Provider role	Provide information, collaborative decision-making	Prescribe treatment; seek "compliance" and "adherence"
User role	Understand options, make choices, small changes, reduce harms	Accept and comply with treatment
Locus of control	User-centered	Physician-centered

butions are acknowledged, drawn upon, and respected as valuable perspectives and sources of expertise informing the work.¹⁴ Harm reduction providers encourage participant input in order to build more effective, "whole" organizations, wherein shared roles and processes are emphasized through ongoing development and improvement measures. Knowledge development occurs at the grass-roots level.

The structural philosophy framing the medical model relies on the authority of expertise and formal, specialized knowledge. Doctors possess the most formal educational knowledge and are ultimately responsible for the decision-making authority in the medical care and treatment of the patient. Physician authority is thought of as *the* legitimate medical experience, expertise, and knowledge.

Institutional legitimacy

It follows then, that the medical model also commands institutional legitimacy in society, by virtue of its authoritative position in the delivery of care and in implicit messages conveyed through its structural philosophy. The rise of medicine as a profession in the early 20th century coincided with the rise of other trades invested with faith in the scientific method, embraced as the most appropriate means to inform cultural norms.^{15,16} Institutionally, our society relies on the existence of the medical model as a basic source of knowledge and support for the population. It is indispensable.

Harm reduction has emerged as a response to the spread of infectious disease in the population.¹⁷ This approach to care delivery acknowledges and suspends

judgment on the ways people have sex and use drugs, ways that are associated with risk for disease transmission. Instead, harm reduction promotes safety in these behaviors; its tenets do not require prescribed changes in behavior, such as mandating abstinence or imposing penalties for use.¹⁸ Such an orientation runs contrary to the official stance our country maintains and enforces domestically and, increasingly, abroad regarding the use of illegal substances. For this reason, harm reduction has not yet achieved institutional legitimacy in the United States, though it has a strong scientific basis^{17,18} and has become part of national policy in countries where governments have made a commitment to public health as well as to the health of individuals.¹⁷

Theoretical framework for understanding drug use

In a harm reduction approach to understanding drug use and providing services to people who use drugs, the prevailing theoretical framework is "drug, set, and setting."¹⁹ Briefly, this theory states that the outcomes of drug use are dependent upon (1) drug (the pharmacological effects of the chemical on human beings), (2) set (the psychological mind-set of the person using the drug), and (3) setting (the social circumstances of use—both the immediate setting and the broader social/cultural/political setting). People who use drugs can learn how to employ this framework to understand their own drug use, the benefits they get from use, and the harm it may cause them, as well as to find strategies for changing the ways they use in the direction of less harm.¹⁸

The theoretical orientation to drug use in the medical

model generally coincides with that of mainstream drug treatment institutions. Physicians do not receive much training in substance use issues and usually adhere to conventional or anecdotal views of substance use and users.²⁰ Active drug use is more commonly referred to as “substance abuse” and is a standardized psychiatric diagnosis.²¹ It is perceived as a problem that lies outside the realm of primary medical care, and is therefore not addressed by, or considered to be the responsibility of, the primary care provider, though attitudes toward this appear to be changing.²² People with “substance abuse problems” are most often referred to drug treatment professionals; in the medical setting, this entails a referral to a social worker to arrange drug treatment. Treatment usually requires abstinence from all non-prescribed intoxicating substances, or may require compliance with a pharmacological maintenance or replacement therapy.

System design

The harm reduction model seeks to bring care to users “where they are.”²² This approach is integral to its success; by reducing/lowering the threshold for care, the user is more likely to seek and receive care. It is a practical approach that makes access a priority and maximizes access by molding itself to users’ needs. Therefore, organizations and their staff members are oriented toward users and their self-defined needs.

In comparison, the medical model requires users to orient themselves toward the provider. The medical model reflects a hierarchical approach in its design; primacy is placed on the accuracy and order of care delivery, and this emphasis is reflected throughout the system. The higher threshold of the medical model requires that the user fit the system, and presumes the system will operate optimally when this is the case. In order to receive care, users must remain on the receiving end of the relationship.

Provider perspective on approach to care

The medical model perceives and approaches care through the lens of the credentialed, expert knowledge of the medical provider. This discrete information set provides the basis for identifying and addressing care needs. This information is presumed to be the best available to serve as the basis for the delivery of care. Non-medical issues affecting or impacting health are not acknowledged—health is viewed simply as the absence of disease.

By contrast, the harm reduction model approaches the delivery of care from a fluid and holistic perspective, seeking to adapt and change to fit the immediate and ongoing needs of users. Implicit in the design of

the harm reduction model is an effort to actively question provider assumptions, and to avoid adoption of an authoritative and judgmental stance in care delivery. The harm reduction model perceives this fluidity as its strength, assuring quality care delivery. Emphasis is on health promotion, resulting from a broadened approach to health that includes non-medical issues.

Provider role

In the medical model, the provider’s role is to prescribe treatment and care. In essence, the provider seeks to impose parameters and regimens on the user by telling the user what to do. As the medical expert, the provider seeks compliance with and adherence to the medical model from the user, and requires that the user adopt prescribed behaviors and actions to fit the model.

Harm reduction providers view their roles as information resources, educators, advocates, and guides for services and care. The model’s fluidity supports providers in listening to and collaborating with users for goal-setting, decision-making, and action planning—with the goal being simply engagement and retention in care in order to reduce the harms associated with drug use and related life issues.

User role

It follows then, that the user in the medical model should accept and comply with provider-prescribed treatment and care. This will assure quality results and achievement of the primary goal: engagement and retention in care, leading to improved medical outcomes. The user’s only role is to fit the model prescribed by the medical establishment.

In the harm reduction model, as the provider aims to inform and guide the user, the user is expected to understand the available options, move toward self-defined incremental positive change, manage choices, and learn to reduce identified harms. By fulfilling these expectations, users aim for quality care and improvement in both medical and non-medical outcomes.

Locus of control

The medical model is physician-centered. Physicians prescribe treatment plans based upon the discrete information set for which they are credentialed experts. Ultimately, the medical model relies on the physician as the locus of control in the delivery of care.

The harm reduction model relies on the actions and decisions of the user for optimal care delivery; thus, it is user-centered. The provider acknowledges the changing needs of the user by ensuring that tailored, appropriate care is delivered within the param-

eters defined by the user. The primary goal of engagement and retention in care is achieved by ensuring that care for the user is user-defined and controlled.

CONCLUSIONS

Framed in different terms and with differing perspectives on drug use, ways to address drug use, and the role of users and providers in care, the two models emphasize opposing models of care delivery and related decision-making authority. However, it may be possible for the medical model to alter its system with the needs of substance users in mind.²³ Given that both models seek to engage and retain the user in care as a primary goal, the medical model may adapt systems and theoretical underpinnings to embrace the user "as is," and to lower the threshold for access to care. Individual providers may find ways to incorporate user-centered practices in their delivery of care and to advocate changes to medical systems that broaden their reach and scope for the user. An early investigation of the impact of our collaboration indicates that including physicians on harm reduction outreach teams is associated with a greater proportion of SRO residents who (1) have a regular health care provider, (2) utilize HIV-related medications, and (3) perceive an improved quality of care.²⁴

We are able to articulate these philosophical clashes between our medical and harm reduction organizations because our difficulties have evolved over time during our ongoing relationship. Although we believe this framework gives other medical and harm reduction collaborators a template to work from, we recognize that not all aspects of this framework may be applicable to all partnerships. It may be possible that our ability to sustain a successful relationship is due to the specific individuals involved and their willingness to learn and adapt, or to the necessity of the financial relationship. Likely our ability to sustain the collaboration is multifactorial, including our ability to identify and work through these specific philosophical differences.

Our collaboration continues, despite ongoing challenges. Negotiations are made possible when the sources of difficulty are better understood, when both parties engage in good faith and are willing to tolerate the inevitable conflict of models, and when all involved are willing to make the changes necessary to continue to work together to provide quality health care to this marginalized population.

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