



Collecting and Using Practice-Based Evidence:

A Community-Based Participatory Research (CPBR) Approach



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Housing Works: A Brief Overview

- Founded in 1990 – spun off of ACT-UP – now the US’s largest minority controlled provider of housing & supportive services for homeless people living with HIV/AIDS.
- Four Adult Day Healthcare Centers, including four complete medical clinics.
- Community-based (COBRA) case management programs in all five boroughs of NYC; the largest in NY State.
- The Harm Reduction Place
- Advocacy offices in NYC, Albany, Washington & Mississippi
- Job Training Program
- Social Enterprise: 11 Thrift Stores; Used Book Cafe; The Works Catering; Gotham Property Management
- 145 units of housing



Housing at Housing Works

- Women's Housing Program
- Transgender Housing Program
- Staten Island Housing Program
- Stand-Up Harlem House
- Jefferson Ave (in development)
- Keith D. Cylar House
- East New York House





Evolution of Software Acquisition

- Search for case management/data collection software began in 2001.
- Began demo-ing software in '02; chose vendor in '03.
- Had a series of meetings – sought to find common ground among stakeholders.
- Process must balance: reporting requirements; research/evaluation needs; & day-to-day service delivery by program users.



Evolution of Software Acquisition

- At the same time, implemented a program for medical CM (2 systems).
- Process of CM software implementation broke down, in part, because folks could not agree on centralized forms.
- Discovered that original CM vendor was difficult to work with. Even though they sold us on their adaptability, once we paid they were very resistant to customization.



Evolution of Software Acquisition

- After investment of five years and about \$100,000, decided to drop original vendor.
- After completely rolling out above-mentioned medical CM program, discovered significant functionality issues; eventually dropped it also.
- New vendors now for both social services CM and medical CM.
- In the process of launching both.

WTHP Research Project

- During same time period, Housing Works launched a research collaboration with the University of Pennsylvania.
- **Project:** Process evaluation of a community-based participatory research project (CBPR) examining the effectiveness of a transitional housing program for female prisoners living with HIV/AIDS (FPLHA).
- **Partners:** Research team from the University of Pennsylvania; staff & residents of Housing Works' Women's Transitional Housing Program.
- **Participants:** Participation in the study was completely voluntary. Residents of the WTHP were recruited by research & program staff.



Community-Based Participatory Research: Elements

- The establishment of a **strong collaborative relationship** between academic researchers and their partners.
- The effective use of **research outcomes**.
- Challenges to implementing CBPRs that are rooted in **issues of feasibility and sustainability**.

Community-Based Participatory Research: Advantages

- Critical of traditional research which prioritizes the perspective of the researcher over the subject.
 - subject as a partner in the research process, rather than simply the object of the study.
- “Community Based”
 - Designed to elicit community participation.
 - Greater involvement of communities in research-related decisions.

Community-Based Participatory Research: Advantages

- Scholars note that CBPR:
 - Produces more meaningful engagement with the **informed consent process** with subjects.
 - Ensures stricter **adherence to ethical guidelines** and accountability.
 - Higher rates of **retention and access to subjects**
 - Use of measures that are more commensurate with the lived experiences of subjects.
 - Use of outcomes to forward community interests.



Process: Establishing the Relationship

- Common interests brought the PI, U Penn team and Housing Works together.
 - Ginny Shubert, a Housing Works co-founder, now works as a consultant to develop a policy-oriented research agenda.
 - PI is trained as a social worker and has a history of engagement in empowerment-based advocacy research.
- PI presented at a NAHC conference in 2007 and was approached by HW at that time to discuss possible collaborations on advocacy-based research projects.
- All share a strong advocacy orientation.
 - Housing Works has long been a leader of advocating for homeless people living with HIV/AIDS.
- HW sought to embark on a regimen of applied research aimed at: **1) generating empirical evidence that housing was an effective intervention for HIV prevention and treatment, and 2) establishing a research culture that supported the collection of data and scientific evaluation of programs.**



Process: WTHP

- As mentioned above, the WTHP houses single women that have recently been released from jail or prison and that are living with HIV/AIDS.
- Subjects in the WTHP were compared to matched subjects receiving case management services, but not housing.
- WTHP staff was very savvy in dealing with the challenge of attrition.
- One WTHP staff, who counts herself as part of the community that HW serves, shook her head in disbelief at the inadequate measures proposed by the U Penn team and stated: *“You sure need to learn a lot about following up with us folks. You gotta ask people about their friends, their mothers, their friends’ mothers and their mothers’ friends. You gotta get every follow-up detail from them. We use a form to get all of this info – y’all had better start using it, honey!”*



Process: Instruments

- The final battery of instruments, taking about 20 minutes to complete, included brief instruments that assessed mental health, substance use, sexual risk and homelessness history.
- The instruments were incorporated into routine assessments.
- This rooted case management is the best principles of evidence-based practice.
- The U Penn team held a series of workshops where WTHP case managers were trained in the use and the interpretation of the instruments.
- The project required the buy-in of staff members.



Process: Implementation → Advocacy

- Periodic meetings were held with CMs to discuss their thoughts about the instruments, which led to modification of the instruments.
- There has been a high level of buy-in by WTHP CMs.
- One staff member led a discussion of implementing evidence-based practice at a NAHC conference in New York City.
- WTHP staff members have become key consultants in a HW agency-wide initiative to extend the WTHP model to other HW programs through the implementation of standardized assessment measures and tools.



Process: U Penn

- The U Penn team underlined their orientation to advocacy and social change, to the empowerment of staff and clients through a collaborative partnership, and to capacity-building through training in evidence-based practice.
- The U Penn team had to balance the scientific requirements of utilizing validated instruments with the practical consideration of instruments that needed to be brief and easy to use.



Challenges

- A CBPR approach seeking to democratize decision making processes can **destabilize established organizational hierarchies**.
- **Case Example:** The PD of the WTHP was reluctant to provide full support to the project.
 - Seemingly threatened by the shared decision-making, she asked the U Penn team to route communication exclusively through her.
 - PI was consulted and asked to meet with HW senior management, the WTHP staff and the U Penn team to emphasize the importance of the shared decision-making process, as well as state support for the research project.
 - This allowed the team to circumnavigate the PD's resistance; she eventually left and her replacement, who has previous research experience, has emerged as an enthusiastic supporter of the project.



Challenges

- Another challenge that emerged was the reluctance of CMs to ask questions regarding sexual risk and sexual violence history.
- Initially reluctant, but eventually felt comfortable with asking them after learning the rationale behind the questions.

Conclusions/Discussions

- The project established the feasibility of using standardized instruments as tools of assessment and data collection.
- Currently being incorporated into a new computer-based assessment system (Salesforce) as the standardized tools for all of HW's programs.

Conclusions/Discussions

- The relationship forged between the U Penn team and the WTHP staff was critical.
- The research team demonstrated a genuine orientation to advocacy.
- Staff and clients were consistently treated with the utmost respect by the U Penn team.
- The WTHP has a broad-based representation of the community on its staff, which lends itself to true advocacy for FPLHA.



Housing IS Health Care

- Research shows a direct relationship between housing status and risk behaviors among extremely low income HIV+ persons with multiple behavioral issues.
- Homeless or unstably housed persons were 2 to 6 times more likely to use hard drugs, share needles or exchange sex than stably housed persons with the same personal and service use characteristics.
- Homeless youth were 4 to 5 times more likely to engage in high-risk drug use than youth in housing with some adult supervision and over twice as likely to engage in high-risk sex.
- Homeless women were 2 to 4 times as likely to have multiple sex partners as housed indigent women - in part due to the effects of physical violence.
- Harm reduction and other behavioral prevention interventions are much less effective for participants who lack stable housing.



The International Declaration On Poverty, Housing Instability, and HIV/AIDS

Article 25, the Universal Declaration of Human Rights

- **Whereas** adequate and secure housing has long been recognized as a basic human right,
- **Whereas** growing empirical evidence shows that the socioeconomic circumstances of individuals and groups are equal or even more important to health status than medical care and personal health behaviors,
- **Whereas** in the case of HIV/AIDS, the link between poverty and disparities in HIV risk and health outcomes is well established, and new research findings demonstrate the direct relationship between inadequate housing and greater risk of HIV infection, poor health outcomes and early death,
- **Whereas** poor living conditions, including overcrowding and in extreme cases, homelessness, undermine safety, privacy and efforts to promote self-respect, human dignity and the attendant responsible sexual behavior,
- **Whereas** the lack of stable housing directly impacts the ability of people living in poverty to reduce HIV risk behaviors and homeless and unstably housed persons are two to six times more likely to use hard drugs, share needles or exchange sex than similar persons with stable housing,
- **Whereas**, in spite of the evidence indicating that adequate housing has a direct positive effect on HIV prevention, treatment and health outcomes, the lack of adequate housing resources has been largely ignored in conferences and policy discussions at the international level, and
- **Whereas** the United Nations, in both its 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration on HIV/AIDS, embraced the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010.



The International Declaration On Poverty, Housing Instability, and HIV/AIDS

- ***Therefore, we hereby demand that policy makers address the lack of adequate housing as a barrier to effective HIV prevention, treatment and care; and we further demand that all governments fund and develop housing as a response to the AIDS pandemic.***



So Do Something Useful!

Go to

[http://nationalaidshousing.org/2008/07/
endorseconference/](http://nationalaidshousing.org/2008/07/endorseconference/)

to endorse the *International Declaration on Poverty, Housing Instability and HIV/AIDS* which was developed by a global coalition at the 2008 International AIDS Conference in Mexico City

Join the International AIDS Housing
Roundtable Listserv at:

<http://groups.yahoo.com/group/iahr/join>

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