Community-Based Participatory Programming and Research for Black Gay and Bisexual Men

Lessons learned from the CRUSH and Project Silk research programs

April 22, 2016
Overview
1. Project Overview CRUSH
2. Community Based Participatory Research Principles (CBPR)
3. The Continuum: Community Based Participatory Practice (CBPP)
4. Project Overview: Project SILK
5. Outcomes and
6. Lessons Learned and Take Aways
His Health
Background
His Health

- **His Health** is a united community of advocates and healthcare providers passionately committed to raising the standard of care for black gay men.

- We believe that shifting the HIV epidemic among black gay men is a **shared responsibility** for patients, providers, and administrators operating at every level of our nation’s health care systems.
His Heath will launch in the summer of 2016

For Providers, Patients, Consumers

- Identify, evaluate, and highlight promising care models that advance HIV care linkage and retention among Black MSM
- Design CME units to accelerate delivery of high quality HIV care for Black MSM patients
- Disseminate technical assistance (TA) and CME training to provider and patient audiences
His Health

- We recognize how stigma, discrimination and medical mistrust act as tremendous barriers to good health for many black gay men.

- To restore **trust**, we must break down silos and foster better communication between black gay men and care practitioners.

- To **grow strong**, we must work **together**.
Our Vision

• His Health envisions a world where HIV – related health disparities among black gay men are meaningfully and vigorously addressed to no end.
Connecting Resources for Urban Sexual Health (The CRUSH Project): A Sexual Health Clinic for Young MSM in Oakland, California
Key Questions: Why a sexual health clinic for young MSM? What would the model be?

- MSM between 18-29 made up 81% of new cases between 2010-2012
- Affordable Care Act pushed younger people to become insured
- NO municipal/public supported STI clinic in Alameda County
California HIV/AIDS Research Program (CHRP): Epidemiological Interventions Initiative

- Funded April 2013, 4 years, 3 sites in CA: multi-million state wide investment
- Integration of PrEP into existing HIV care clinics

Goal of CRUSH:
- To integrate routine sexual health services for Y/MSM within the setting of an existing HIV primary care clinic

Establishing a Model Sexual Health Clinic
CRUSH: Specific Aims

1. Aim 1: Test & link >400 young MSM of color to sexual health services
2. Aim 2: Enhance & evaluate engagement & retention strategies for young HIV+ MSM of color
3. Aim 3: Engage & retain HIV- young MSM of color in sexual health preventive services, including PrEP
Key Questions

- Why a sexual health clinic for young MSM?
- What would the model be?
- If we build it, will they come?
- Who do we need to include in the process to make CRUSH happen?

*Invoking the need for critical community input, process, buy in and COMMITMENT*
“a collaborative process that equitably involves all partners in the research process & recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.”

Kellogg CHSP, 2001; Israel et al, 1998
CBPR Principles

• Recognizes community as a unit of identify
• Builds on partners’ strengths and assets
• Focuses on locally relevant problems & social determinants of health
• Co-learning, power sharing process
• Systems development & local capacity building
• Balances research and action
• Commits for the long haul to enable sustainability

Israel et al, 1998; 2005
Cultural Humility:

*A life long commitment to self evaluation and self critique* to redress power imbalances and *“develop and maintain respectful and dynamic partnerships with communities”*

Tervalon & Garcia, 1998
Community-engaged research: What’s the added value?

More effectively focuses research questions on issues that matter to the community.
Example: Meaningful Community Engagement of Y/MSM of color

- Establishing a robust Community Advisory Board
  - Developed outreach materials
  - Developed website
  - Community trust: clinic is a safe space zone for youth
  - CAB as Ambassadors who speak on behalf of the project
- Our patients/participants
Community Engagement for Sexual Health of Y/MSM of color

- Working with community partners
- Establishing a robust Community Advisory Board
  - Board and partners intertwined
  - Developed outreach materials
  - Developed website
- Our patients/participants
  www.CRUSH510.org
CRUSH: Community and Scientific Partners

Gladstone Institute of Virology and Immunology
Continuum from Research to Programming

CBPR to Community Based Participatory Programming:

“A process that, through defined structures of good participatory practice (a commitment to stakeholder engagement, peer staffing, dedication to relevant programming beyond the needs of funders, continuous assessments of participants’ satisfaction with programming, and willingness to act on information gathered from the community served), CBPP can be used to optimize recruitment, engagement, access, uptake, and outcomes by providing programming salient to the community served”

Friedman, 2016
Continuum of Community Engagement

From Participant…

Opinions actively solicited throughout the entire process of implementation through specific processes: CABs; Peer based staff, etc.

Partners in implementation, design

Leverages results & partnerships to promote social change

Context influences program design and/or research questions

Participation in dissemination of results

Level of Community Engagement

Traditional Programming

No influence on design

CBPR/CBPP

…to Partner

Adapted from Morello-Frosch, 2010
Program Intro: Silk
Backstory

• DOH asked us to conduct focus groups with youth around Pennsylvania on barriers to HIV/STI testing
• Pittsburgh group: Young Black gay and bi men, trans women
  • HBC affiliated
  • Ages 13-24
• “There’s nowhere for us to go”
• Other issues included distrust of local clinic; inaccessibility of hours open; perceived discrimination based on gay/bi/trans status; lack of appreciation for clinic ambience
• “How can we get something that is just for us?”
Grant focus areas

• Piloting **structural** and behavioral interventions for young gay and bisexual Black men and trans women

• Innovative HIV CTRS activities

• Enhanced linkage to care and retention in care

• What’s missing? Community goals…. 
Examples: CBPP approaches at Silk

- **CBPP principles** consistent with Principles of Good Participatory Practice (GPP) and asset-based youth development (YD)
  - Extensive formative research/community discussions
  - Stakeholder engagement and direction
  - Peer-based staffing, recruitment, programmatic input
- **Recreation-based** community public health space
  - Open 4 nights/week: every night has recreational programming recommended by YAB and frequent community members
  - Accessible location; mixed-use building (<stigma)
  - Structural response to need: “nowhere for us to go”
  - HIV & STI testing on- and off-site, peer and non-peer
  - Additional House-only hours on weekend evenings
- Strict adherence to **community-developed** safety protocols
Visual Logic Model
Project Silk: core components

• Recreation-based safe space, to be open at times convenient for target population members.
• Asset-based youth development structures for program planning, staffing, recruitment, and engagement.
• Demonstrated cultural competency in all staffing and volunteer roles.
• Strong agency buy-in and support.
• Co-located mental health and supportive services.
• Integrated HIV and STI testing and self-testing.
• Peer navigation to PrEP, HIV-related care, and social services.
• Patient-centered, Harm Reduction philosophy.
Myth busting CBPR/CBPP

• Addressing Resistance to engagement:
  • The community doesn’t really know what the real problems are

Counterpoint: actually it KNOWS exactly the problems and more than you do, and also has LOTS of ideas about solutions

• Example: Patients encouraged to give active feedback to providers, CAB interprets, providers respond
Myth busting CBPR/CBPP

• Hard to capture outcomes

But….we have outcomes!
Concrete Example: CRUSH

Enrollment

• First participant enrolled on 2-10-2014
• Last participant enrolled on 3-6-2016
• Total 381 participants

• Main source of participant recruitment:
  • the participants/clinic users themselves
  • Young women: fluidity of social networks of young people; women were GREAT recruiters of gay/bi men

“If you build what is needed, we’ll come”
Intake sources

- Other
- Online
- Personal
- Community Org
- Study Participant
- Community Provider
- Study/Clinic Staff

SHS only | PrEP | HIV+ | Total
Myths: Too Expensive

• Comparison of cost per new HIV diagnosis
  • Project Silk data (2014—2015)

<table>
<thead>
<tr>
<th>Year</th>
<th>Expenditure</th>
<th># HIV tests</th>
<th># new HIV dx</th>
<th>Expenditure per new dx</th>
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<td>$15,781.79</td>
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<tr>
<td>Total</td>
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<td>229</td>
<td>11</td>
<td>$17,169.54</td>
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</table>

• Category A data for testing in non-traditional settings in same county (2014—2015)

<table>
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Concrete Example: Project SILK
Myths: no outcomes

- Project Silk has the highest average seropositivity rate in the jurisdiction: ~5%
- Unplanned finding: high numbers of previously positive individuals disclosed to providers after receiving “ancillary” services at Silk; re-engaged
- Mean age across project: 19.9: Black gay, bisexual, and trans youth are not “hard to reach”
- Mean: 226 target population members/year in space: >30% of total estimated no. in county
The importance of social spheres

- Creating a welcoming space engenders social participation beyond just service-seeking
- This can lead to additional service-seeking
- Increases community investment
- Safe social spaces are a self-perpetuating mechanism for recruitment, access, uptake, and outcomes
- Space and services independent of serostatus
  - Directly confronts HIV-related segregation/stigma
Silk as an alternative social sphere

• Intake system to allow for clients to request services via mobile and Internet-connected devices
  • Direct response to destigmatizing service provision

• Youth Advisory Board meetings vet, establish and maintain structured, peer-led educational programming to promote wellness, increase life skills, healthy role modeling and provide appropriate recreation and socialization for youth

• Peer-based navigation and organic rapport-building from safer space creates low-threshold barriers to access
CBPR in Action at CRUSH

Youth Outreach Corps: Outreach team composed of community partners OW and program managers; linked directly to CAB

CRUSH Roadshow: short presentation of CRUSH to over 50 local partners and agencies in the Bay

CAB and RYSE created 2 short videos “Webisodes” on PrEP and Sexual Health
YOUR SOURCE FOR
SEXUAL HEALTH SERVICES
LIKE PREP, PEP, & STD TESTS

Get Truvada. Get tested. Get much more.

You’re in the right place for taking care of all your sexual health needs.

- PreP Helps reduce your chances of HIV transmission
- PreP Helps prevent HIV transmission after you’re exposed
- APIS Help keep you healthy if you’re HIV positive
- HIV Testing Detects the HIV virus as early as one week after exposure
- SSTI testing & treatment Screening & treatment for sexually transmitted infections

CLICK FOR SERVICES

CRUSH Project Presents...
CBP-inspired programs at Silk

- Beauty day
- Vogue 101
- Games night
- Mini-balls
- Healthy eating; yoga; stretching; meditation
- Interviewing for jobs: what to wear and say
- Sexual health discussion groups
- Trans mixers
- House leadership meetings
Social sphere considerations

• Utilization of safe space is not a bait and switch! You don’t need to uptake service
  • People will use the services if they are there
• Rules of respectful use must be established and enforceable
• Theoretically supported: strengths-based approach to remediating loneliness and alienation from minority strength structures
  • Increases in social support and social capital
  • “Best gay experience of my life”
Policy implications

• Federal and local funders beginning to require community-based participatory processes
  • NIH: GPP for clinical trials in developing world
  • HRSA: stakeholder engagement in HPGs
  • CDC: advisory boards for HIV-serving CBOs
  • SAMHSA: community needs assessments
• Example: Based on Project Silk’s successes, PA DOH is funding other programs adhering to core components
• Example: CHRP (CRUSH funder) requires CABs or all its research collaborative studies
Expect Pushback

- Resistance to community-based participatory research/programming can come from multiple sources
  - Funders
  - Collaborating agencies
  - Agency administration
  - Landlords/fellow tenants
  - Staff
Tackling Resistance

Using CBP/R approaches to deal with pushback

• Arrange gatherings with landlords, co-tenants
  • How we can help solve these security concerns?
• Engage funders and YAB in mutual dialogue
• Cross-training all staff: HIV testing, intake, consent, lab processing, referrals, etc.
• Strengthening intra-agency collaboration ultimately helps with clinic flow in working with youth clinical service delivery
CBPP/CBPR: things to remember

• Ask; listen; **act**; and then ask again (CBPP)
• Plan; do; study; **act** (CBPR)
• Be flexible to the needs of the community that you serve
  • (Within program’s constraints)
• Keep your sense of humor!
Takeaways

• Communities, funders, and public health practitioners often want different things

• CBPP/R can and should take these complexities and tensions into account when planning programming

• But ongoing CBPP/R work can also help translate the needs of communities to funders, and the needs of funders to communities

• In a dynamic and flexible process, this can help optimize programming so everybody gets what they want (including you)
CRUSH

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Project Silk
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- Youth Advisory Board
- National and Local Houses
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  - Revlon
  - Mizrahi
  - Blahnik
  - Infiniti
  - Elite
  - All the 007s!
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- Centers for Disease Control and Prevention, PS12-1201 C
- Community Human Services
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