Securing the Future of Women-Centered Care

Findings from a Community-Based Participatory Research Project

National Women and Girls HIV/AIDS Awareness Day
March 10th, 2016 1pm EST
Naina Khanna
Executive Director

Arneta Rogers
Legal Fellow
WEBINAR GOALS

- Context
- Project Implementation: Community Based Participatory Research
- Key Findings from Ryan White Research Project
- Report Recommendations
CONTEXT
Obama Signs Health Care Overhaul Bill, With a Flourish

By SHERYL GAY STOLBERG and ROBERT PEAR  MARCH 23, 2010

Current Status of State Medicaid Expansion Decisions

NOTES: Data as of August 30, 2014. **WA, WA, HI, and NY have approved Section 1115 waivers for Medicaid expansion. In PA, coverage will begin in January 2015. **WA is implementing the Medicaid expansion, but the state plans to scale a waiver at a later date. **WA is pending a waiver to implement the Medicaid expansion. **WA is pending a Medicaid state plan and is enacting a Medicaid state plan and is enacting Section 1115 waiver to cover adults up to 138% FPL, in Medicaid, but has not signed the waiver.

SOURCES: Current status for each state is based on data from the Centers for Medicare and Medicaid Services, available here, and KCMJ analysis of current state activity on Medicaid expansion.

Services for Women Are Not Disposable! PWN-USA Responds to the President's Budget Proposal to Eliminate Ryan White Part D
Diagnoses of HIV Infection and Population among Adult and Adolescent Females, by Race/Ethnicity 2014—United States

Note: Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

*Hispanics/Latinos can be of any race.
Diagnoses of HIV Infection among Adult and Adolescent Females, by Transmission Category and Age at Diagnosis 2014—United States and 6 Dependent Areas

<table>
<thead>
<tr>
<th>Transmission category</th>
<th>13–19 N=365</th>
<th>20–24 N=901</th>
<th>25–34 N=2,233</th>
<th>35–44 N=2,078</th>
<th>≥45 N=2,895</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injection drug use</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Heterosexual contact&lt;sup&gt;a&lt;/sup&gt;</td>
<td>85.1</td>
<td>89.6</td>
<td>87.8</td>
<td>87.6</td>
<td>85.4</td>
</tr>
<tr>
<td>Other&lt;sup&gt;b&lt;/sup&gt;</td>
<td>5.9</td>
<td>0.6</td>
<td>0.4</td>
<td>0.1</td>
<td>0.2</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays and missing transmission category, but not for incomplete reporting.

<sup>a</sup> Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

<sup>b</sup> Includes blood transfusion, perinatal exposure, and risk factor not reported or not identified.
High prevalence of trauma among HIV-positive women in the US

Michael Carter
Published: 16 February 2012
IMPLEMENTATION
Research Team

- 7 teams of 2 women with HIV recruited and trained in CBPR principles & survey design = 14 researchers
  - Partnered with Dr. Sonja McKenzie at Santa Clara University
- 4 webinars conducted from April-May for training, development of research questions, survey design
- Reading materials provided
- Monthly team conference calls
- Supported by PWN-USA staff
- Researchers received an honorarium for their time
Research Team

Loren Jones
Berkeley, CA

Meta Smith
Baton Rouge, LA

Lepena Reid
Tampa, FL

Patricia Clark
Kalamazoo, Michigan

Heather Arculeo
San Diego, CA

Sharon Decuir
Baton Rouge, LA

Janet Kitchen
Tampa, FL

Evany Turk
Chicago, IL

Rachel Moats
San Diego, CA

Veronica Brisco
Columbia, SC

*Not Pictured:
Shurand Adams; Chicago, IL, Cynthia Sanchez, Bay Area, CA; Deidre Rick, Michigan
Loren Jones
Researcher
Berkeley, CA

Janet Kitchen
Researcher
Tampa, FL
Community-Based Participatory Research (CBPR)

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge and action for social change to improve community health.”

- WK Kellogg Community Health Scholars Program

For the People, By the People

CPBR is conducted by and for those most directly affected by the issue, condition, situation, or intervention being studied or evaluated.
• Recognizes **community as a unit of identity**
• Builds on **strengths and resources** within the community
• Facilitates **collaborative, equitable involvement**
• **Integrates knowledge and action** for mutual benefit of all partners
• Promotes co-learning & empowering process that attends to social inequities
• Cyclical and incremental
• Addresses health from positive & ecological perspectives
• Disseminates findings and knowledge gained to all partners

Evany Turk
Researcher, Chicago, IL

Lepena Reid
Researcher, Tampa, FL
Data Collection

- **180 Participants** recruited from points of entry in the health service delivery system including: AIDS service organizations (ASOs), local clinics, social service providers, community-based organizations (CBOs), support groups

- **Geographic areas covered**: Bay Area, CA; Baton Rouge, LA; Chicago, IL; Orangeburg, SC; San Diego, CA; Southern MI; Tampa, FL

- Survey administered on Survey Monkey, May-July 2015
  - As needed, researchers supported participants in responding to questions
  - Participants received $20 Walmart or Target gift card

- All medical data is *self-report* (no medical records)
Survey Administration

Sites
• Support Groups
• Clinics
• Hospitals
• CBO’s
• Housing agencies
• Special Events

Methods
• Groups
• Individual
• By phone
Barriers to Administration

- Travel
- Question framing
- Not enough computers
- Wifi access
Lessons Learned

• Women living with HIV care very much about their reproductive health & are willing to travel & take a survey for a small compensation

• Compensation for their time was appreciated but not needed for some & the reason that some participated because they needed it

• Being connected to the community makes it easier to recruit

• Better accuracy if you go over the questions one by one and encourage them to ask questions if they don’t understand

• Surveys are complicated to the brightest individuals so going over them with everyone gathers better data
FINDINGS
## Respondent Demographics

<table>
<thead>
<tr>
<th></th>
<th>Percentage of HIV epidemic in US</th>
<th>Percentage of Survey Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AA/Black</td>
<td>63%</td>
<td>67%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>18%</td>
<td>16%</td>
</tr>
<tr>
<td>Latina/Chicana</td>
<td>18%</td>
<td>9%</td>
</tr>
<tr>
<td>Multiracial/Biracial</td>
<td>unknown</td>
<td>4.9%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reproductive Age</td>
<td>45.8%</td>
<td>40.8%</td>
</tr>
<tr>
<td>45 and over</td>
<td>54.1%</td>
<td>* Mean age=46.7 yrs</td>
</tr>
<tr>
<td><strong>Sexual Orientation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td></td>
<td>78%</td>
</tr>
<tr>
<td>Lesbian/Gay</td>
<td>6.1%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Bisexual</td>
<td>4.9%</td>
<td>4.9%</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern (non Medicaid exp*)</td>
<td>48%</td>
<td>43%</td>
</tr>
<tr>
<td>Non-South (Medicaid expansion)</td>
<td>52%</td>
<td>57%</td>
</tr>
</tbody>
</table>
Respondent Characteristics
Income & Family Responsibilities

- ≤138% FPL: 89.7%
- ≤100% FPL: 73.8%
- < $10,000: 45%

Dependents in household:
- any age: 42.4%
- under 18 in household: 33%
- 2+ children under 18 in household: 11%
Respondent Characteristics: Housing

- Rent subsidized by Section 8, HOPWA* or other: 35.6%
- Rent (unsubsidized): 34.5%
- Homeowners: 6.7%
- Live primarily on streets: 1%
- Housed primarily in shelter: 4.2%
- Housing provided by another family member: 10%
- AIDS Housing: 8%

HOPWA: Housing Opportunities for Persons with HIV/AIDS
Respondent Characteristics:

Length of Time Since Diagnosis

- Mean time since diagnosis: **16 years**
- 20 years or longer: **36.3%**
- 10 years or longer: **76.7%**
- > 5 years: **11%**

<table>
<thead>
<tr>
<th>Condition</th>
<th>% respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>30%</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>21.6%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>17.2%</td>
</tr>
<tr>
<td>Chronic Lower Respiratory Disease</td>
<td>12.7%</td>
</tr>
<tr>
<td>Cervical Cancer</td>
<td>9%</td>
</tr>
<tr>
<td>Chronic Liver Disease</td>
<td>7%</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>6%</td>
</tr>
<tr>
<td>Another form of cancer</td>
<td>5%</td>
</tr>
</tbody>
</table>

* self-report
Respondent Characteristics:
Healthcare Coverage

*ADAP = AIDS Drug Assistance Program
99.4% had seen a medical provider for HIV care within the past year

86.4% reported taking medication daily to manage their HIV

79% reported having an undetectable viral load at the time of their last lab results

6% reported not taking HIV medication
QUALITY OF CARE
82.9% of women of reproductive age had received a pap smear within the past 3 years.

74.5% of women over reproductive age had received a pap smear within the past 3 years.

Only 40% of women of reproductive age (44 & under) had been asked if they needed birth control.

Just 39.4% of women of reproductive age (44 & under) had been asked if they wanted to get pregnant.

38.1% of participants had not been told that achieving viral suppression would dramatically reduce risk of transmission.
MENTAL HEALTH

- Many women are coping with mental health challenges:
  - 17% diagnosed with post-traumatic stress disorder (PTSD)
  - 64.9% diagnosed with depression.

- And would like support:
  - Nearly 2/3rds of respondents reported that they would like to see someone for counseling or therapy.
  - Of those, 41% were unable to access therapy as needed due to cost, lack of coverage, lack of available services or waitlists for services.
BARLIERs TO CARE
Transportation:

• **50%** of respondents who had missed a medical appointment cited lack of transportation as the reason.

• **24%** of respondents who missed filling a prescription for HIV medications in the past year cited lack of transportation as the reason.
Financial Insecurity:

- 15% of respondents who missed filling a prescription cited **copay cost** as the reason.

Childcare:

- 50% of participants who reported needing child care services on site at their medical provider did not receive those services.
SUMMARY POINTS

- Participants are severely low-income and have significant family responsibilities
- Women with HIV are also dealing with other health challenges
- Ryan White system is generally working
- Major barriers to care are cost of copays, transportation, and childcare
- Mental health services & support groups are needed
- Quality of sexual and reproductive healthcare is inconsistent, especially as women age with HIV
RECOMMENDATIONS
1. Mandate meaningful involvement of women living with HIV in integrated prevention & care planning processes

   • Representation and leadership in decision-making & advisory bodies
   • Support, train & build capacity of communities most impacted to participate
   • Utilize local PLHIV networks as a resource
2. **Implement interventions that improve the fundamental economic conditions of women’s lives**

- Integrate services designed to provide a pathway out of poverty for women living with HIV into HIV care settings
- Foster linkages, cross-training & collaboration with job readiness & training, vocational rehabilitation
- Institute computer and Internet literacy training
- Eliminate structural barriers to employment – such as hiring practices that discriminate against people with criminal records
3. **Improve the quality of HIV care provided, with a focus on expanding mental health services, upholding sexual & reproductive rights, and addressing comorbidities**
   
   - Expand high-quality SRH services through all parts of the Ryan White Program (not just Part D); ensure they are available to all people with HIV of all genders and ages.
   
   - Train providers on updated treatment as prevention science and delivery of affirming sexual & reproductive healthcare for PLHIV.
   
   - Implement trauma-informed primary care in settings serving WLHIV.
   
   - Expand availability of peer-led support groups and mental health services.
   
   - Address comorbidities; expand treatment literacy programs.
4. Invest in **supportive/facilitative services** and reduce **structural barriers to care**

*Improve medical transportation access.*

- Improve services for women of all ages with family responsibilities (childcare, transport that allows minors to travel)
- Lift ADAP monthly medication restriction
- Extend/diversify clinic and pharmacy hours
- Expand mobile phone-based telemedicine delivery

**Positive Women’s Network USA**

Sisterhood • Solidarity • Action

[www.pwn-usa.org](http://www.pwn-usa.org)
5. **Address stigma, including institutionalized stigma in the form of HIV criminalization**

- Eliminate laws criminalizing or otherwise targeting people on the basis of HIV status
- Implement interventions shown to reduce stigma, including internalized stigma
- Train providers, healthcare workers, and other service providers to deliver non-judgmental and affirming care and services
DISCUSSION
Join Positive Women’s Network - USA, Greater Than AIDS & The Well Project

**Thurs., March 10**
**3 PM EST**

for a Twitter Chat in honor of

**National Women and Girls HIV/AIDS Awareness Day**
March 10

- What is the connection between HIV and intimate partner violence?
- What do women living with HIV need to stay healthy?
- What resources are available to help women get the info & support they need?

#NWGHAAD
#PWNspeaks
@uspwn
@greaterthanAIDS
@thewellproject
Full report available at:

2 page summary available at:
https://pwnusa.files.wordpress.com/2016/02/rwp-teaser-v5.pdf
This project would not have been possible without our incredible research team
Shurand Adams * Veronica Briscoe * Patricia Clark * Sharon Decuir * Heather Garza * Loren Jones * Janet Kitchen * Pat Kelly * Rachel Moats * Lepena Reid * Deidre Rick * Cindi Sanchez * Meta Smith * Evany Turk

Others who contributed to this project
Bianca de la Piedra * Nerissa Irizarry * Vanessa Johnson * Dr. Sonja Mackenzie * Jennie Smith-Camejo

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Positive Women’s Network USA
THANK YOU

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