Valuing the Lives and Health of Women

Universal Health Services Access Project: Integrating Policy and CBA
Creating an Accessible and Culturally Competent HIV Service Continuum for Women Living in the United States

National Women and AIDS Collective (NWAC)
December 2012 (Summarized 4.16.13)
About NWAC

• The National Women and AIDS Collective’s (NWAC) mission is to advocate and build the capacity of women-led and serving organizations and programs to work in partnership with women impacted by HIV/AIDS in order to improve their overall health and quality of life.
NWAC Goals

• **NWAC goals, in support of its mission:**
  1. Strive to reduce gender equities in an effort to achieve optimal health outcomes for women.
  2. **Improve the health and social well being of women through public policy, advocacy and service.**
  3. Develop the capacity and leadership of member organizations and women living with HIV to continue to deliver life-saving services and engage in policy work that enhances organizational integrity and community well being.
  4. Facilitate and participate in multi-disciplinary collaborations among organizations and leaders who are striving to address the social and health inequalities of women living in the US.
• **Engage in Public Policy and Advocacy**

NWAC advocates for changes in federal, state, and local HIV/AIDS policies that prioritizes the full acknowledgement and recognition of the socioeconomic, biomedical, and behavioral factors that lead to HIV vulnerability and acquisition among women.

– NWAC utilizes its policy position papers as advocacy tools to address gender specific social and health disparities in HIV/AIDS in the United States.
Issue Statement

• Women in the United States experience greater health disparities and do not benefit from unfettered access to HIV prevention, care, treatment and support.

• Due to the lack of gender responsive programming and gender responsive approaches, often times women do not enter into care, have difficulty entering in care, struggle to stay in care, are not fully engaged in care or fall out of care and therefore have greater adverse impacts as a result of not utilizing the full HIV service continuum offered in this country.

• Therefore, women experience poorer health outcomes and the erosion of one’s quality of life for themselves, their families, their significant others, and larger communities.
Gender Responsive HIV Service Continuum Strategic Framework

• GOAL

Develop and implement optimal standards of service delivery for:

– women who are vulnerable to HIV (disease prevention)
– women who do not know their HIV status (HIP and EIIHA)
– women who are HIV positive who are not in care (unmet need)
– women who are HIV positive and are in care (prevention with positives).
Gender Responsive Approach

- Develop a gender responsive HIV service continuum that incorporates the following:
  - Recognizes the social and behavioral differences between women and men
  - Promotes policies and practices that:
    - target women’s pathways to service by providing effective programs, interventions and activities that address the intersection of substance abuse, trauma, mental health, and economic marginality
    - consider women’s relationships, especially those with their children, partners, family members and their roles in the community when delivering services and interventions.
Anchoring the Approach
Guiding Principles

• Gender
  • Acknowledge that gender makes a difference

• Environment
  • Create an environment based on safety, respect and dignity

• Relationships
  • Develop policies, practices and programs that support relations and promote healthy connections to children, family, significant others and community
Guiding Principles Cont.

• **Services and Supervision**
  • Address the issues of substance abuse, trauma and mental health through comprehensive, integrated, culturally relevant and appropriate services and supervision

• **Economic and Social Status**
  • Improve women’s economic/social conditions by developing their capacity to be self-sufficient

• **Community Mobilization**
  • Establish a supportive environment within the community which encourages participatory citizenship
Health Service Continuum Strategic Framework

- Graphic Display of Analysis Model

Level One
- Focus Population

Level Two
- Health or Disease Condition

Level Three
- Vulnerabilities, Risk & Assets

Level Four
- Service Provision

Level Five
- Policy

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Women Vulnerable to HIV and Living with HIV

Disease Prevention

<table>
<thead>
<tr>
<th>SOCIAL DETERMINANTS</th>
<th>BEHAVIORAL HEALTH</th>
<th>SERVICE BARRIERS</th>
</tr>
</thead>
</table>

### Identification
- Partner Notification
- Outreach
- In-reach
- Service Integration
- Social Media & Marketing

### Testing
- Hospital ER
- Doctor’s Office
- ASO/CBO
- Correction Facilities
- Family Planning Centers
- Substance Abuse Treatment Centers
- Pharmacies
- Non-tradition
- Home

### Linkage to Services
- Self
- Family
- Linkage to Care Network
- Verification: Appointment & Service
- Peer models, e.g., Peer Navigators
- Interventions
- Supportive Services

### Service Provision
- Medical Care
- Treatment
- Biomedical
- Medical CM
- Housing
- Substance Abuse Treatment
- Mental Health
- Sexual/Reproductive Health
- Interventions
- Supportive Services

### Service Retention
- Provider Efforts
- Adherence Program
- Peer Navigators
- Housing
- Food
- Substance Abuse Treatment
- Mental Health
- Interventions
- Supportive Services

### Service Re-Entry
- Provider Efforts
- Lost to Follow-up Care
- Peer Navigators
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- Mental Health
- Interventions
- Supportive Services

---

Health Care Reform (aka Affordable Care Act)

Gardner Spectrum of Engagement

<table>
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<tr>
<th>NHAS</th>
<th>HIGH IMPACT PREVENTION</th>
<th>EIIHA &amp; UNMET NEED</th>
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</table>

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Health Service Continuum
Strategic Framework

- Graphic Display of Analysis Model

Level One
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Focus Population

WOMEN
Health Service Continuum Strategic Framework

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Women and HIV

• How HIV manifests itself in women
  • Delayed diagnosis
  • Delayed entry to care
    • Most women don’t access care until they become pregnant or experience symptoms
    • Late initiation of ART
  • Poorer treatment outcomes
    • Less access and utilize of ART
  • Progress to AIDS faster than men
  • Shorter survival times; excess mortality
    • Highest amongst African American and Latina women
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Vulnerability results from a range of factors outside the control of the individual that reduce the ability of individuals and communities to avoid HIV risk.

Risk is defined as the probability or likelihood that a person may through their own actions become infected with HIV.
Basis of Vulnerability & Risk

- **SOCIAL DETERMINANTS**
  Social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system.
  1. Biology and genetics.
  2. Individual behavior.
  3. Social environment.
  4. Physical environment.
  5. Health services.

- **STRUCTURAL FACTORS**
  HIV-related structural factors are defined as barriers to, or facilitators of, an individual's HIV prevention and care behaviors; they may relate to economic, social, policy, organizational or other aspects of the environment.

- **BEHAVIORAL HEALTH**
  Behavioral health encompasses the promotion of emotional health; the prevention of mental illnesses and substance use disorders; and treatments and services for substance abuse, mental illness, and/or mental disorders.
Intersectionality of Vulnerability and Risk

**Socioeconomic**
- Poverty
- Reliance on others for economic support
- Low health literacy
- Lack of insurance coverage

**Violence**
- Domestic violence
- Intimate partner violence
- Sexual assault
- Childhood abuse

**Behavioral**
- Substance abuse
- Mental health
- Trauma
Impact of Vulnerability and Risk

• The inter-sectionality of physical, behavioral, social and economic conditions faced by women often pre-determines:
  1. Their vulnerability & risk for HIV infection;
  2. The success of HIV prevention and care programs in addressing their vulnerability and needs; and
  3. Their ability to care for themselves and successfully live with this disease.
HIV Vulnerability Framework

Vulnerability Factors
- Genetics
- Race/Ethnicity
- Gender
- Sexual Orientation
- Human Needs (Maslow)
- Family History
- Personal Timeline
- Relationships
- Community (Norms & VL)
- Public Policies
- Violence
- Stigma
- Trauma (PTSD)

Risk
- Transmission
- Acquisition

Diagnosis
- HIV Negative
- HIV Positive

Recovery
- Disclosure
- Linkage to Care
- Treatment
- Services
- Assets
- Aspirations
Health Service Continuum Strategic Framework

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Barriers to Care

• Lack of services designed to support access and retention in care basic needs (transportation, food, childcare, housing, etc.)
• Lack of mental health
• Substance abuse
• Physical and/or sexual abuse
• Lack of insurance
• Inability to take time off work
• Being too sick care for self, family or go to work
Level Four Analysis: Service Provision
Prevention, Care, Treatment & Support

Identification:
- Partner Notification
- Outreach
- In-reach
- Service integration
- Social Media & Marketing

Testing:
- Hospital ER
- Doctor’s Office
- ASO/CBO
- Correction Facilities
- Family Planning Centers
- Substance Abuse Treatment Centers
- Pharmacies
- Non-tradition
- Home

Linkage to Services:
- Self
- Family
- ASO/CBO
- Linkage to Care Network
- Verification: Appointment & Service
- Peer models, e.g., peer navigators
- Interventions
- Supportive Services

Service Provision:
- Medical Care
- Dental Care
- Anti-Viral Treatment
- Medical CM
- Housing
- Substance Treatment
- Mental Health
- Sexual/Reproductive Health
- Interventions
- Supportive Services

Service Retention:
- Provider Efforts
- Adherence Programs
- Medical CM
- Peer Navigators
- Housing Plus
- Substance Treatment
- Mental Health
- Interventions
- Supportive Services

Service Re-Entry:
- Provider Efforts
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Health Service Continuum
Strategic Framework

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Considerations: Policy Initiatives

<table>
<thead>
<tr>
<th>NHAS</th>
<th>HIP</th>
<th>EIIHA &amp; UMN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core Indicators</td>
<td>Priorities</td>
<td>Components</td>
</tr>
<tr>
<td>HIV Positivity</td>
<td>Testing</td>
<td>Identifying</td>
</tr>
<tr>
<td>Late HIV Diagnosis</td>
<td>Linkage to Care</td>
<td>Testing</td>
</tr>
<tr>
<td>Linkage to Care</td>
<td>Condoms/Sterile Syringe</td>
<td>Counseling</td>
</tr>
<tr>
<td>Retention</td>
<td>Prevention with Positives</td>
<td>Referral to Care</td>
</tr>
<tr>
<td>Treatment (ART)</td>
<td>SA Treatment</td>
<td>Linkage to Care</td>
</tr>
<tr>
<td>Viral Load Suppression</td>
<td>Primary Prevention</td>
<td></td>
</tr>
<tr>
<td>Housing Status</td>
<td>STD Screening &amp; Treatment</td>
<td></td>
</tr>
</tbody>
</table>

HCR/ACA
Pre-Existing Conditions, Essential Health Benefits. Preventive Services – Women and Patient Navigators

Gardner Spectrum of Engagement
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<table>
<thead>
<tr>
<th>Demographic</th>
<th>Diagnosed</th>
<th>LTC</th>
<th>RTC</th>
<th>ART</th>
<th>VLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Positive Individuals</td>
<td>82%</td>
<td>66%</td>
<td>37%</td>
<td>33%</td>
<td>25%</td>
</tr>
<tr>
<td>African American</td>
<td>81%</td>
<td>62%</td>
<td>34%</td>
<td>29%</td>
<td>21%</td>
</tr>
<tr>
<td>Heterosexual Women</td>
<td>85%</td>
<td>70%</td>
<td>41%</td>
<td>36%</td>
<td>26%</td>
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HIV Service Continuum
Aligning Policies and Services

Women Vulnerable to HIV and Living with HIV

Health Care Reform (aka Affordable Care Act)

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Find
Diagnosed
LTC
Initial
Retained
ART
VLS
Find

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Level Four Analysis: Services

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100% Women
85% Tested [T = 5,400 (2009)]
70% Linked to Care
41% Retained in Care
36% ARV Treatment
26% Viral Suppression

- Est. Living
- Diagnosed
- LTC
  - Initial Visit
- Retained
  - 1 visit every 6/mo per year
  - ARVs
  - On Combination Therapy
  - VLS
  - HIV-1 RNA <400 copies/ml
Gender Responsive HIV Service Continuum Strategic Framework

• OUTCOMES
  – Increased knowledge of HIV status
  – Increased linkage to care
  – Improved adherence to medications
  – Consistent engagement in care
  – Improved follow-up leading to less missed visits

• IMPACT
  – Improvement in viral load suppression
  – Reduced HIV & STD transmission
  – Improved overall health outcomes (wellness)
  – Improved quality of life
How the Continuum can be Used

• As a strategic framework that can be used to assist organizations with:
  – Service design, planning, implementation (including collaborations) & monitoring and evaluation

• As a tool that can be used to assist organizations with
  – Assessing client service access & utilization
  – Assessing client progression through the continuum
  – Developing collaborations to address gaps
  – Mapping of public policies and funding
  – Conducting focused public policy and advocacy campaigns

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  2. Improve the health and social well being of women through public policy, advocacy and service.

  3. **Develop the capacity and leadership of member organizations and women living with HIV to continue to deliver life-saving services and engage in policy work that enhances organizational integrity and community well being.**

  4. Facilitate and participate in multi-disciplinary collaborations among organizations and leaders who are striving to address the social and health inequalities of women living in the US.
# My Personal Timeline

## Vulnerabilities & Risk Taking

<table>
<thead>
<tr>
<th>Age</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Childhood sexual abuse starts</td>
</tr>
<tr>
<td>16</td>
<td>Exposed to marijuana</td>
</tr>
<tr>
<td>18</td>
<td>Started binge drinking</td>
</tr>
<tr>
<td>19</td>
<td>First experience with partner violence</td>
</tr>
<tr>
<td>32</td>
<td>Diagnosed w/ HIV</td>
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## Recovery

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<thead>
<tr>
<th>Age</th>
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<tr>
<td>33</td>
<td>Started HIV primary care</td>
</tr>
<tr>
<td>36</td>
<td>Entered SAT &amp; family counseling</td>
</tr>
<tr>
<td>37</td>
<td>Started HIV anti-retroviral treatment</td>
</tr>
<tr>
<td>37</td>
<td>Volunteered at local ASO</td>
</tr>
<tr>
<td>39</td>
<td>Passed the NY Bar Exam</td>
</tr>
<tr>
<td>32</td>
<td>Co-founded CBO</td>
</tr>
<tr>
<td>48</td>
<td>Joined the staff of a national ASO</td>
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My HIV Vulnerability Framework

Vulnerability Factors
- Genetics
- Race
- Gender
- Sexual Orientation
- Human Needs (Maslow)
- Family History
- Personal Timeline
- Relationships
- Community (Norms & Characteristics)
- Stigma
- Trauma (PTSD)

Risk

Transmission
Acquisition

Diagnosis
HIV Negative
HIV Positive

Recovery
- Disclosure
- Linkage to Care
- Treatment
- Support Services
- Other Services
- Assets
- Aspirations

- Trauma
- Stigma
  - External
  - Internal
My HIV Service Profile

Women Vulnerable to HIV and Living with HIV

Disease Prevention, Containment & Reduction: HIV

Vulnerability & Risk: HIV-Related

Identification
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Informed and engaged patient
Linked, retained and (mostly) adherence to care & treatment
Reduced HIV-related health disparities
**My Health Outcomes**

- Early diagnosis of HIV
- Early entry to care
- Early initiation of treatment
- Suppressed viral load
- 24 known years of HIV survival
Next Steps

• Webinar Series
• Sisters-in-Service Network
• Membership
THANK YOU!
National Women and AIDS Collective

• Vanessa Johnson, JD
  National Coordinator
  NWAC
  c/o Center for Health and Gender Equity (CHANGE)
  1317 F Street, NW
  Suite 400
  Washington, DC 20002
  Tel: (301) 768-2852
  Fax: (202) 733-1303
  vjohnson84bj@gmail.com