The Road to Washington
Mobilizing Communities to create a supportive environment
to help eliminate vertical Transmission

GIPA Facilitator
Olive Edwards
Jamaican Network of Seropositives
(JN+)
Creating an enabling environment for more meaningful involvement of people with HIV within self support groups and HIV positive women’s networks
Presentation Content

• Background and concept of Jamaican Network of Seropositives Self Support Groups
• Partnerships and collaborations that supports the strengthening of PHIV involvement
• Jamaican Community of Positive Women
• Opportunities for more meaningful involvement in the PMTCT program
• Barriers to more meaningful involvement
Background and concept

• JN+ established 1996 and registered 1999 after its first assembly of 60 men and women living with HIV in 1998.

• Vision:... PLHIV recognized as full citizens

• Mission: to advocate for rights and concerns of PLHIV and their affected family

• Motto: “Supporting ourselves for survival”

• Constitution stated that JN+ is a network of support groups
Concept & Operations Systems

- The draft operations systems for self support groups 2007
- The concept is inclusive of health system services, social service partners and network of self support groups
- and their role in the health and wellbeing of people diagnosed HIV positive and their families.
Illustrated Diagram

**Diagnosis**
- voluntary counseling and testing, provider initiated testing, contact investigating, PMTCT,
- Refer for medical and mental health care, treatment and support services

**Treatment (Sites) and Care**
- **Treatment & Care Team**: doctor, nurse, social worker, psychologist, adherence counselor, nutritionist
- Treat, refer for peer support

**Peer support (JN+)**
- **Mobilize**: interview → membership → self support group → capacity building, coping skills, share information and experiences
- Refer for training, participation and representation in research and advocacy
- Refer to network of social support services (health, welfare, education, spiritual)
A Network of Self Support Groups (JN+ SSG)

• **Goal:** People living with HIV empowered to participate in the reduction of stigma and discrimination, new infections and achieve their full potential.
...Mending

• The HIV positive person decides to become a member of the JN+ self support group (SSG)
• The principle of GIPA (greater involvement of people with HIV) becomes a part of their existence.
• GIPA enables a HIV positive person to be more likely to participate in groups and gatherings
Redefining Life

- Elect to participate in self support groups
- Peer counseling & support coping skills HIV101
- Life skills advocacy training
- Leadership skills personal development
- Employment representation disclosure group facilitation
2004, 2006 needs assessments

• more men than women were registered members of JN+
• women were facilitating 10 of the 12 groups
• more than 75% of those who attended meetings were women.
Discussion with the group leaders

concluded that:

• the specific health and social need of women had to be targeted for attention

• the only compensation for their work was when they participated in sensitization interventions as living testimony

• Training in group facilitation, report writing and computer literacy was needed
An enabling environment for more meaningful involvement of PHIV

Requires:

✓ Partnerships (program planning, M&E)
✓ Collaborations (implement, sustain, 
✓ Networking (linking, sharing, gain, maintain 
✓ Resources (human, financial, space, 
   equipment, materials)
✓ Advocacy (human rights, laws, redress
Partnerships & Collaborations

The National HIV/STI Program/Enabling Environment and Human Rights Component

• Employment for PHIV
• Partner on National HIV related Discrimination Report and Redress System
• Stipends for Presenters, SSG field coordinators
• Training in HIV Sensitization Interventions
Partnerships & Collaborations

ITPC/Collaborative Fund/CTAG
Strengthening support groups for treatment preparedness
Women’s empowerment and life skills building

UNFPA
- Training Sexual Reproductive Health and Rights
- Condom Access (male, female condoms)
Jamaican Community of Positive Women (JCW+)

The JCW+ is an organization of HIV positive women created to

- Provide a space and forum for positive women to prepare and implement actions and activities aimed at self empowerment and participation in decisions that affect their lives
Participation in the GNP+/ICW consultation

ICW enabled JCW+ to participate in the consultation on IATT’s Strategic Framework for PMTC Components 1 & 2

Focus Group discussions was a creative way to get more responses from women who had little or no access to computer and internet to complete a survey.
Enabling our participation

• ICW’s advocacy enabled our first consultancy and leadership workshop
• UNAIDS Jamaica Office provided guidance for us to plan and implement the three day workshop for 20 women
Enabling our participation

• ICW and ATHENA enabled the inclusion of Caribbean women in the Universal Access consultation

Result: The JCW+ women were so proud to see their logo and expressions in print!

Now they are trying to access internet to complete Global Fund survey...smile
Strengthening HIV positive women networks

For more meaningful participation

• the woman must be seen as more than the recipient of PMTCT programs and projects

• The holistic approach to our treatment and care is essential to reaching our full potential

• Investing in positive women's organization will improve ability to participate at all levels of HIV response
What about our MEN!

The fathers of our children

The partner we don’t have... maybe even when we are pregnant
Our men, father of the babies

- Men’s Space: A space for HIV infected and affected men who are partners of the HIV Positive women
- To support improvement of sexual reproductive health and family planning among PLHIV
- To enhance treatment adherence support for HIV positive women
Barriers and challenges

Barriers to partnerships and collaborations

• Exclusion from crucial HIV planning and programming
• Unsustained initiatives,
• Lack of human and financial resources
• Lack of mentoring and psychological support
& Challenges

• PHIV personal needs
• Lack of respect and recognition for the work and participation of PLHIV
• Discriminating attitudes of health workers
• Discriminating behavior social service providers
• Internalize Stigma among PHIV
What would help

• A space and the professional help to debrief after an intervention
• Opportunities to take stock of our work and achievements
• Documenting our activities in a way that captures data useful for evaluation and programming ..and the human resource to assist