



The International Federation of
Gynaecology and Obstetrics
(FIGO)
7th October 2015

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GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV

Transgender Law Center
Making Authentic Lives Possible



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Background: WHO survey

- Values and Preferences Survey to update SRH & HR **guidelines**
- Led by a **Global Reference Group** of 14 women living with HIV
- User-led, **participatory**, community-based research
- 7 **languages** & 5 more through Focus Group Discussions
- Used positive, future-oriented “**appreciative inquiry**”
- ✧ 945 women living with HIV from 94 countries
- ✧ Aged 15-72, women with HIV in all their **diversities**
- **Largest** global survey of women living with HIV



Process

"... I found the experience to be cathartic, much to my surprise. Surveys don't generally have that effect. It was meaningful to answer questions that truly reflected my experiences both as a girl and young woman before HIV and since my diagnosis."



Outputs

- **“Building a safe house on firm ground”** report
- Four peer-review journal articles in pipeline:
 - Two on methodology
 - One on gender-based violence experienced by women living with HIV
 - One on mental health issues experienced by women living with HIV
- Survey report translated into Spanish for Latin America
- Use of questionnaire for further research in Ukraine
- Feeding into current WHO guidelines update process



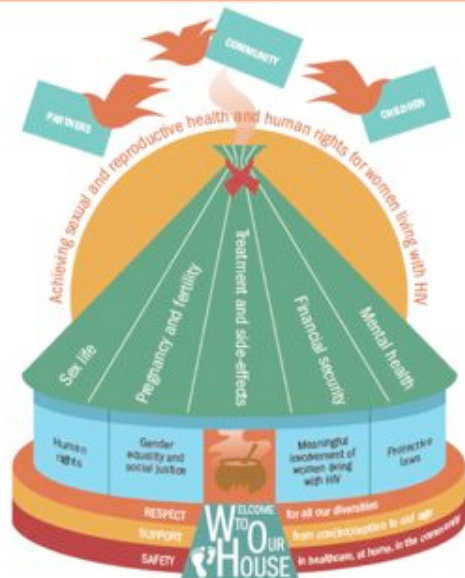
Results:

Welcome
to Our
House

[http://
tinyurl.com/
mzn3on5](http://tinyurl.com/mzn3on5)

Building a safe house on firm ground

KEY FINDINGS FROM A GLOBAL VALUES AND PREFERENCES SURVEY
REGARDING THE SEXUAL AND REPRODUCTIVE HEALTH AND
HUMAN RIGHTS OF WOMEN LIVING WITH HIV





POSITIVE SEXUALITY
AS A YOUNG WOMAN GROWING UP WITH HIV

L'Orangells Thomas Negrón
 Positive Youth Network from
 Latin America & Hispanic Caribbean

ICW
 ATHENA
 Salomandra Trust

World Health Organization
 GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV
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DATA

Challenges and barriers to a healthy sex life included:

1. Fear of onward transmission, pregnancy & STIs, & the impact & consequences of disclosure, inc. violence



DATA

Challenges and barriers to a healthy sex life included:

2. Lack of access to female condoms and difficulty in negotiating use of the male condom, resulting in anxiety & reduced pleasure for the woman &/or her partner.

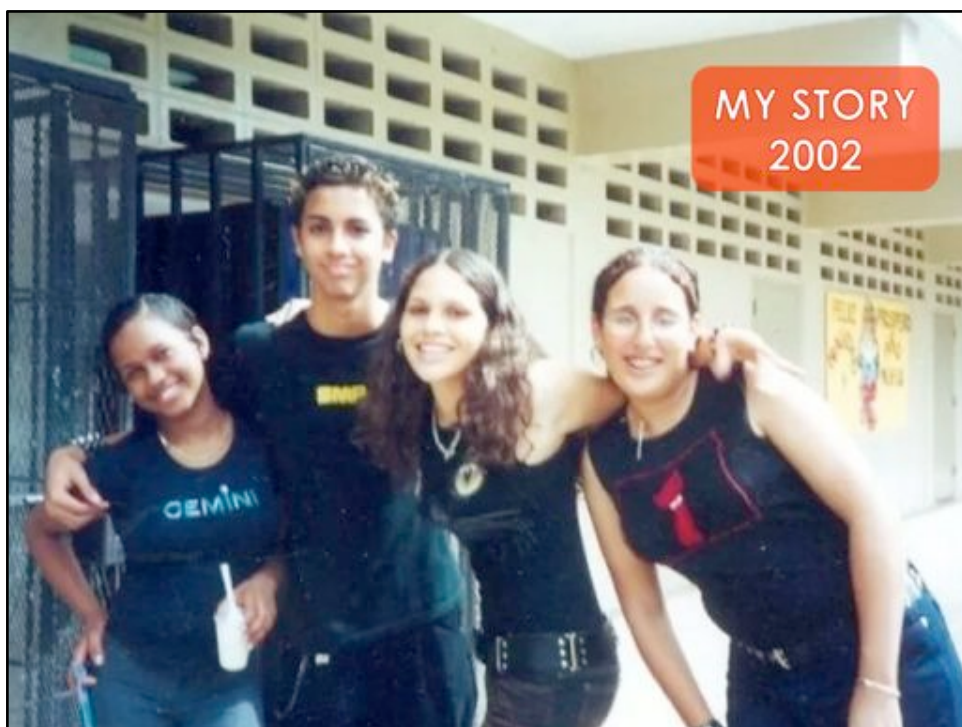


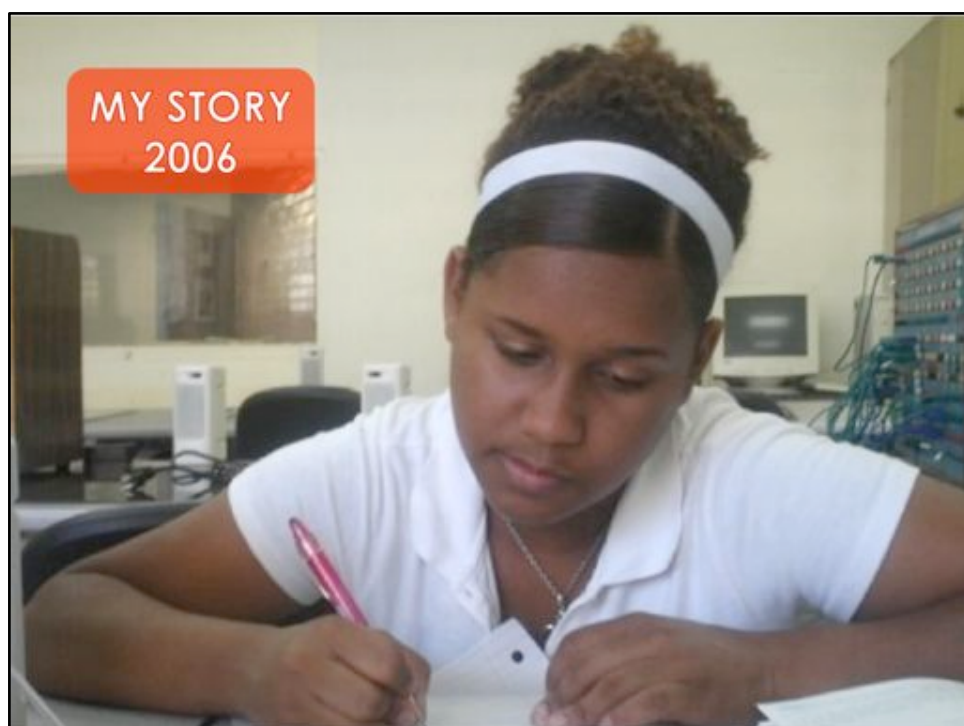
DATA

Challenges and barriers to a healthy sex life included:

3. Broader societal stigma & discrimination, e.g. service providers, leading to misinformation or the belief that women living with HIV shouldn't have sex. This results in self-stigma, low self-esteem & feeling 'dirty' or 'guilty'









THREE THINGS YOU CAN DO

Provide opportunities in health centres to talk positively about sex, including safe spaces with doctors, other health staff & peer mentors.



THREE THINGS YOU CAN DO

Ensure easy access
to male and female
condoms, lubricant
and other
commodities.

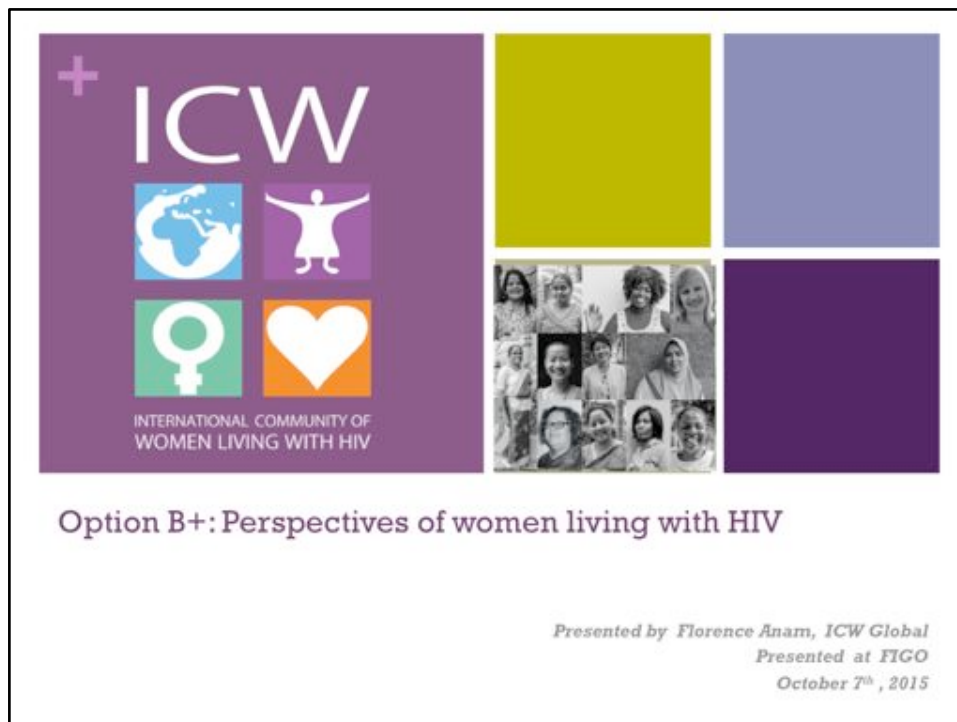




THREE THINGS YOU CAN DO

Promote gender sensitive, lesbian, gay, bisexual & trans (LGBT) -affirming sexual health literacy programmes for young people, inc. children in foster care





ICW is the only global grassroots network run by and for women living with HIV, we operate in 120 countries and through 10 regional networks and the chapter on Young women and Girls.

Option B+:

a prevention of vertical transmission approach for expectant mothers living with HIV in which women are offered treatment for life regardless of CD4 count.



ICW sits on the WHO Core Advisory Group working on Guidelines Review.

New WHO Early Release Recommendation:

ART should be initiated in all pregnant & breast feeding women living with HIV regardless of WHO clinical stage and at any CD4 cell count & continued lifelong.



(strong recommendation, moderate-quality evidence)

+

Option B + < Concerns of Women Living with HIV:

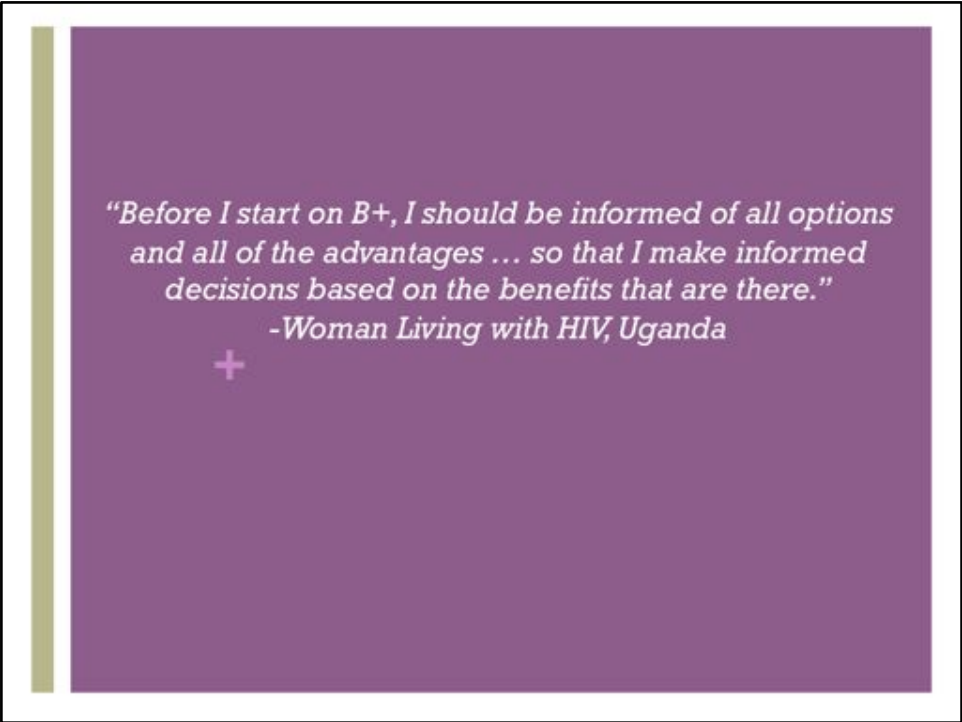
- **Barriers to service uptake and retention:**
 - **Human Rights Violations:**
 - Lack of autonomous decision-making;
 - Coercive testing & treatment initiation;
 - Lack of informed consent, sufficient time to evaluate options treatment;
 - Stigma, discrimination, negative health care workers attitude.
 - **Persistent Structural Barriers:**
 - Stock-outs
 - Distance
 - Drug Resistance & Availability of treatment lines
 - **Community Stigma, Treatment Side-effects:**
 - Side-effects- body image
 - Disclosure & vulnerabilities to violence

iCW in partnership with Option B + has developed a series of qualitative research studies which have explored different aspects of PMTCT including Family Planning, Early Infant Diagnosis and Option B +.

Option B+ intensifies many of the pre-existing challenges of HIV prevention and treatment programs. As women seek comprehensive services to prevent vertical transmission, they can experience various human rights violations, including lack of informed consent, involuntary or coercive HIV-testing, limited treatment options, termination of pregnancy or coerced sterilization, and pressure to start treatment.

- **Pressure on pregnant and breastfeeding women to be tested for HIV and initiate early and lifelong treatment.**
- **The reality and drivers of loss-to-follow-up has been a challenge for many countries implementing Option B+.**
- **stock outs, consistency, affordability for access to treatment.**
- **The decision to start treatment must be self directed**

Some Option B + adopters are utilizing rapid start treatment initiation but without adequate time to consider a preparation – women living with HIV in different countries have (Malawi, Uganda etc.) expressed concerns about treatment readiness.



*"Before I start on B+, I should be informed of all options
and all of the advantages ... so that I make informed
decisions based on the benefits that are there."*

-Woman Living with HIV, Uganda



+ Option B +/- Lifelong Treatment:

- Low retention and ART adherence:
- 60% of new HIV infections may now be occurring during the breastfeeding period due to poor systems of follow-up.
- 2014 Data shows that in Global Plan Countries six week transmission rate is 5% but climbs to 14% at the end of the breastfeeding period.
- Source: ADVANCE DRAFT COPY - 2015 Progress Report on the Global Plan towards the elimination of new HIV infections among children and keeping their mothers alive.

Option b + has been rolled out

+ What can FIGO members do?:



- Create an enabling environment:
 - Train all staff & healthcare workers,
 - creating stigma and abuse free setting
 - gender equality
 - informed consent & autonomous decision-making
- Ensure your program takes a rights-based approach to testing and treatment;
- Create mechanisms to address stigma, discrimination and human rights violations;
- Engage with & learn from women living with HIV to shape programs and responsive services;
- Promote and support peer-led/grassroots networks as facilitators of uptake and retention;
- Address structural barriers (distance, stock outs)

peer and community support strategies can promote treatment readiness, uptake, adherence, lifelong retention in care, reduce stigma and discrimination, and mitigate potential violence stemming from HIV disclosure. Ensuring available and accessible quality care, offering food support, and improving linkages to care could increase service uptake and retention.

+

“We should end this epidemic, but we can only do this if we put women living with HIV at the centre.”

*Teresia Njoki Otieno,
Former- ICW Global Chair at UN 2014.*



+

NOTHING FOR US WITHOUT US!

For more information visit:
www.iamicw.org





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Results from survey respondents

- **89%** reported experiencing at least one type of violence
 - From an **intimate partner**: 59%
 - From **family or neighbours**: 45%
 - In the **community**: 52%
 - In the **health care setting**: 53%
 - From **police / military / prison or detention**: 17%
 - **Fear of violence**: 68%
- High IPV levels before and after diagnosis. Higher levels of violence experienced **post**-diagnosis in **health settings** & in the **community**
- Experiences of violence in the health care setting often **worse** for women with *other* socially disadvantaged identities



So how can you be a supportive mother if you experience these levels of violence, especially from healthcare settings? For the next generation of young women growing up, with or without HIV

It is especially important to have good love, care and support from your mother, to be able to feel happy, healthy and SAFE.

“Violence against women with HIV”

“any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.”

Hale and Vazquez 2011



Hale and Vazquez definition – see also Galtung J 1969 and Farmer P et al 2006 regarding structural violence, which includes psychological violence

My Story

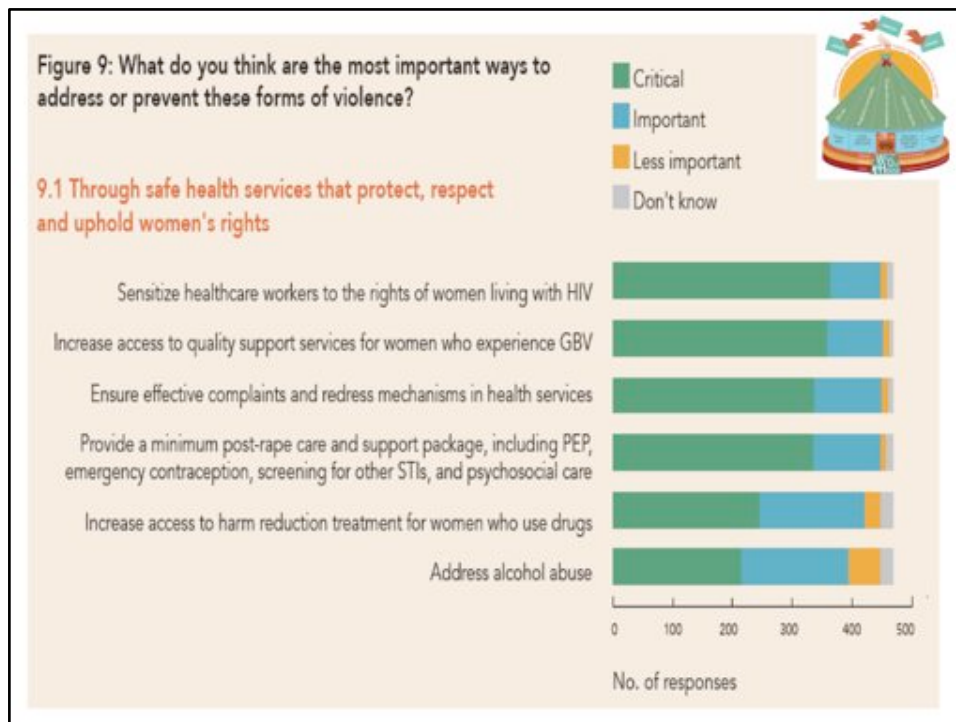
- Diagnosed 1992 while pregnant and otherwise healthy
- Extremely caring health staff and partner
- Still devastated – suicidal ideation
- Peer support saved my life – and still very important
- Huge psycho-social consequences
- Impact on ability to support other children
- GBV from other family members on disclosure
- Good support of health staff supported me
- Happy, Healthy Safe Women..... happy, healthy, *safe* children.....



<http://salamandertrust.net/motherhood/motherhood.swf>

<http://tinyurl.com/mzn3on5>

Gerhardt S “Why Love Matters” 2015 Routledge.



<http://tinyurl.com/mzn3on5>

Three Things You Can Do

1) Community-based participatory research

2) Trainee obstetricians and gynaecologists can be taught from the outset to put themselves in others' shoes. There's no such thing as a challenging patient, only a patient with challenging issues.

3) Psycho-social and economic determinants of health are as important for good clinicians to understand the health of those in their care as the physiological anatomy of the body.

4) A win-win situation



1) Community-based participatory research is a powerful approach to meaningful engagement of those most affected by an issue to shape, invest in and uphold effective policies and programmes.

2) Trainee obstetricians and gynaecologists can be taught from the outset to put themselves in others' shoes. There's no such thing as a challenging patient, only a patient with challenging issues.

3) Psycho-social and economic determinants of health are as important for good clinicians to understand the health of those in their care as the physiological anatomy of the body.

4) This is a win-win situation for clinicians, policy-makers and women living with HIV alike, creating outcomes that make everyone feel satisfied.

JAGOSH et al in BMC Public Health 2015;

Gerhardt S "Why Love Matters" 2015 Routledge;

<http://tinyurl.com/mzn3on5>

Community Participatory Involvement: A Sustainable Model in Global Public Health

Linda M. Whiteford and Cecilia Vindrola-Padros 2015

<http://www.lcoastpress.com/book.php?id=587>



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Cecilia Chung
GNP+,
Transgender Law Center



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My Story



My name is Cecilia Chung. And we will begin my presentation with a little about myself. I came out to my mother in late 1991, and by close to the end of 1992, I decided to live as my true self.

By 1993, my family turned their backs on me, I lost my job, had no home to go to, and by the summer of the same year. I tested positive for the HIV antibodies. For the following two years, I was trapped in a nightmare. I was sexually assaulted multiple times but was afraid to go to the police because I was doing sex work. I began self-medicating.

I thought that was how my life would end until I was assaulted by two men on an August night in 1995. They stabbed me, chased after me and dragged me to the ground and started kicking me.

Luckily, someone called the police. They were arrested and I was rushed to the hospital. My mom came to see me and that was the beginning of our reconciliation.

I am on ARV, have my family back in my life but still cannot shake off all that happened to me. I am still having the same dreams that I was trapped in a burning house with no escape.

My boyfriend often hears me crying and screaming in my sleep. And to me, it manifests into depression and a sense of hopelessness.

Data

- Symptoms of Depression: 80%
- Symptoms of Anxiety/PTSD: 75%
- High rates of HIV and Mental Health Co-Morbidity correlate with GBV and structural violence

"During night you dream things which at times if you wake up- you fear even to go out or you think maybe you can die."

Tanzania



And I am not alone.

Over 80% of respondents reported depression, & feelings of shame & rejection
Over 75% reported experiencing insomnia & difficulty sleeping, self-blame, very low self-esteem, loneliness, body image anxieties, or anxiety, fear & panic attacks (either before, as a direct result of, or after diagnosis)

Respondents' extremely high figures of HIV & mental health co-morbidity, which exceed previously quoted figures, may be provoked by, or have their roots in, a wide range of factors, including GBV (esp. sexual violence, stigma [either HIV-related or related to gender identity and sexual orientation] often worsened by punitive legal and policy environments), poverty or financial stress, & homelessness.

Three Things You Can Do

- **Eliminate barriers to mental health treatment and counselling, including peer counselling**
- **Stop the Stigma**
- **Meaningfully involve Women Living with HIV**



Women living with HIV need affordable, accessible, continuous, holistic & integrated psychological support & counselling in HIV care (beyond accepting diagnosis), relationship & sex counselling, & support with disclosure.

Promote respect from healthcare services for people living with HIV, co-morbidities, & mental health conditions

Support our resilience. Providers must understand that women living with HIV have endured traumas, discriminations and rejections. Some of us may be broken but we are never defeated. We want providers who partner with us and who do not talk down to us. By involving networks of women & people living with HIV in policy and service design, providers are creating an empowering environment where women living with HIV can truly heal and thrive.



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WHO Constitution

"health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity and that enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. Enjoyment of this right is vital to all other aspects of a person's life and is crucial to the realization of many other rights."



Health and Human Rights 101

Analysis and Action:

- 1) The impact of human rights violations on health**
- 2) The impact of health policies and programs on human rights**
- 3) The inter-relationship between the enjoyment and realization of rights, and the conditions that promote health**



Putting human rights in practice

- **Attention to vulnerable groups**
- **Human dignity**
- **Accountability**
- **Participation**



Putting the most affected at the center

- Opportunity to think differently
- Opportunity to partner toward realizing health and dignity for all
- Opportunity to demonstrate “kindness, honesty, confidence, and compassion”





Thank you



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Thank you to:

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WHO: Manjulaa Narasimhan



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