International Community of Women Living with HIV

**POSITION BRIEF 2017**

# *HIV PREVENTION THAT WORKS FOR WOMEN AND GIRLS*

This brief has been prepared through collaboration with the Global Network of Sex Work Projects (NSWP), The International Network of People who use drugs (INPUD) and the Global Network of People Living with HIV (GNP+) and acts as the beginning of a joint effort to highlight the specific preventions needs and rights of women and girls in all our diversities. Together, in solidarity we seek to present insights on HIV prevention that works for women and girls in order to contribute towards the achievement of Global HIV Prevention targets and improve the quality of lives for women living with HIV and our communities.

## Background

Globally women and girls in all our multiplicities continue to be vulnerable to HIV acquisition and remain disproportionately affected by HIV and AIDS in many regions particularly sub Saharan Africa. Current statistics show there were 1.8 million new infections among adults in 2016 of which 47% were among women while 58% of all new HIV infections among young persons (15–24) were among adolescent girls & young women and 2.1 million among children aged 0–14. There are 17.8 million women (aged 15+) living with HIV worldwide accounting for 51% of all adults living with HIV; 2.3 million adolescent girls & young women are living with HIV, accounting for 60% of all young people living with HIV.[1]

Even with the milestones realized on the effectiveness of ART not only for prolonging lives of people living with HIV but also as a HIV prevention intervention there is very still poor access and retention to ART. 54% of people aged 15+ and 43% of children 0–14 years are currently on Anti-Retroviral treatment[2] thereby directly affecting the success of treatment as prevention. The evidence is high particularly among women living with HIV in discordant relationships and within programmes to prevent 'vertical' transmission from pregnant women living with HIV to their infants (PMTCT) program interventions where challenges of retention and adherence remain high despite accelerated efforts to ensure prevention by achieving the 90.90.90 targets[3].

Despite significant advances in the HIV response, women around the world in all our diversity still face a daunting set of barriers to accessing the HIV prevention, treatment, care and support we need to live healthy and productive lives. We also face significant barriers to realizing our human rights including achieving our highest standard of health and respect for our sexual and reproductive rights. These barriers range from fear, stigma and violence[4] at the social and community level and lack of access to adequate and acceptable treatment, care and support; to violations of human rights. All of these barriers create vulnerability to HIV for many women. This vulnerability is exacerbated by HIV prevention programmes focused on individual behaviour rather than structural changes.

1 UNAIDS 2017 estimates

2 UNAIDS 2016, The GAP report

3 % of people know their HIV status, 90% of people who know their HIV status enrolled on antiretroviral treatment (ART) and 90% of those on ART virally suppressed. UNAIDS, 2015

4 http://www.stigmaindex.org

HIV prevention efforts for women are furthered hampered by the quite visible human rights violations that women already diagnosed with HIV often face. Human rights abuses faced by women living with HIV in healthcare settings include a lack of informed consent, stigma, discrimination and physical abuse at the hands of healthcare providers, refusals to provide services for example on provision of condoms, hostile attitudes towards women living with HIV who seek to have children, stigmatization, breaches of confidentiality, and involuntary and coerced testing for HIV. Forced or coercive sterilization has now been reported in over 30 countries worldwide.[5] These barriers negatively impact service uptake, treatment adherence, often result in lossto-follow-up and decrease good health outcomes for women living with HIV.[6] In addition, existing prevention programmes that provide social, academic, and social support services only to those girls who are not HIVpositive and excluding those living with HIV since infancy and those who acquired HIV in girlhood or adolescence trumpet the message that being female and having HIV means you no longer have a future or value in society. Women and girls may fear testing for HIV and avoid prevention, and even other health care services, to avoid testing positive and receiving these kinds of discriminatory treatment.

Differences of geography, religion, and politics notwithstanding, the global face of the HIV epidemic is largely female, yet women and girls continue to be marginalized within decision-making spaces and their input and expertise often tokenized and frequently dismissed. Women and girls who do sex work, women who use drugs, and transgender women face compounded violations of their human rights that, among other ill effects, limit or deny them access to HIV prevention and testing. Specific groups of women are disproportionately affected by HIV. An analysis of studies measuring the pooled prevalence of HIV in 50 countries estimated that, globally, female sex workers are approximately 14 times more likely to be infected than other women of reproductive age women who inject drugs are 28 times more likely to be living with HIV, and HIV prevalence is significantly higher amongst women who inject drugs[7] Lack of clear and disaggregated data on uptake and use of HIV prevention interventions by women particularly those from Key populations of prevention interventions like PrEP, PEP, use of condoms among others.

Additionally women need Prevention interventions that provide the dual ability to prevent HIV infections and prevention of other sexually and transmitted diseases while making it possible to enjoy their reproductive ability to get pregnant and have children.[8] HIV prevention for women must mean HIV prevention for ALL women, cisgender and transgender, women who use drugs, women who do sex work, heterosexual, bisexual, and lesbian, rural and urban women, and incarcerated women.

5 http://www.iamicw.org/resources/document-library/forced-and-coerced-sterilization-of-women-living-with-hiv

6 ICW and GNP+. Quality of family planning services and integration in the prevention of vertical transmission context: Perspectives and experiences of women living with HIV and service providers in Cameroon, Nigeria, and Zambia. Global Network of People Living with HIV. 2014 Aug. Available from: http://www.zero-hiv.org/wp-content/uploads/2014/10/ICW-GNP_FPVT-report_web-FINAL.pdf (accessed 4 September 2017).A focus on women: a key strategy to preventing HIV among children UNAIDS / JC2538E (English original, April 2016) Available at: http://www.unaids.org/sites/default/files/media_asset/JC2538_preventingHIVamongchildren_en_0.pdf (Accessed 4 September, 2017).

7 https://inpud.net/sites/default/files/Women%20Who%20Use%20Drugs%20and%20HIV%20Final%202015.pdf

8 UNAIDS 2016, The Prevention Gap report. 2 ICWEA, 2014; Are Women Organizations accessing funding for HIV and AIDS?

The existence of progressive HIV prevention strategies like PrEP as well as Treatment as Prevention (TaSP) that prove critical for reducing new infections among women and girls come within a backdrop a global threat to the availability of resources for HIV response which has resulted in reduced funding for HIV non biomedical programs that are critical for ensuring communities remain motivated to access and retain to HIV prevention interventions. Civil society, community and networks of people living with HIV are constantly grappling with the realities for doing more with less resources. In order to maximize on this situation it is imperative to invest in interventions that are responsive to the needs of women and girls in order to ensure effectiveness and sustainability of programs as well as creating a balance for innovative ways of ensuring that interventions that have been documented to work for women and girls for example drug policies, harm reduction services and sex work preventions strategies do not risk being sidelined.[9]

To this end, women and girls, in all our diversity, including transgender women, female sex workers, women who use drugs, and those living with HIV remain crucial stakeholders for successful HIV prevention interventions.

Women and girls who plan to or have children play an additional prevention role, through their influence on prevention of vertical transmission of HIV as well as ensuring that children born to mothers with HIV access immediate prevention interventions during pregnancy, birth and breastfeeding. Importantly, as caregivers of children and adolescents, they remain a direct link for their access to HIV prevention and treatment. Without women, we cannot effectively realise an end to new infections among children. Yet women who are sex workers or use drugs and women living with HIV too often are treated with disrespect and even violence when seeking sexual and reproductive health services. For example Women who use drugs face the very real risk of having their children taken into child custody services, as drug use is used as a criterion to remove children from their families. Women who use drugs may even be arrested.[10] [11] In Oder for women and girls living with HIV to remain committed to interventions that contribute towards prevention of new infection in children and their communities, they will need to be supported through implementation of progressive laws and policies that respect our rights including rights to sexual and reproductive health.

# Making HIV Prevention Work for Women and Girls

## Rights, Empowerment and Gender Equality

HIV prevention will only be effective in an enabling environment for which women and girls in all our diversities can be able to access HIV prevention interventions. Beyond the progress and effectiveness of biomedical interventions we know that there is no *Ending AIDS* without complementing structural interventions that support creation of an enabling environment in which women and girls can thrive and uptake HIV prevention intervention. Focus on addressing punitive and unfavourable laws that continue to criminalize HIV exposure, sex work, use of drugs, and non-conforming gender identity continue to be an impediment to up take and retention to HIV prevention services.

9 https://www.inpud.net/sites/default/files/INPUD%20PrEP%20-%20Community%20Voices.pdf

10 https://projects.propublica.org/graphics/maternity-drug-policies-by-state

11 http://www.inpud.net/Illicit_Drug_use_in_Pregnancy_An_Appropriate_Response-WHRIN_INWUD_2012.pdf

Stigma and discrimination has been evidenced as one of the leading reasons for women living with HIV dropping out of PMTCT care and non-adherence to ART that is useful for preventing vertical transmission.[12] [13] Programs for creating resilience among people living with HIV and their communities to address stigma and discrimination are key. Deliberate investment in the achievement of true gender equality that supports participation and engagement of all women and girls in design, planning, implementation and evaluation of programs that affect our lives is critical. The role of women's participation remains critical in order to realise the aspirations of an end to AIDS.

### Building Communities; Women at the Centre

At the heart of successful HIV prevention lies strong women's voices and participation. Despite decades-old evidence showing that most successful and effective responses to health challenges begin at the community level, many successful grassroots responses have yet to be scaled-up and strengthened to withstand internal and external pressures that continue to threaten our operations and impede their sustainability. The role of women's and girls' participation remains critical in order to realise the aspirations to achieve HIV prevention targets. Sustaining these efforts can only happen in an environment where community-led organizations including; networks of people living with HIV, women who use drugs, female sex workers, and lesbian and transgender women have the required capacity to design, implement and monitor health and HIV interventions including those that provide community awareness, peer support and increase demand, uptake and retention to HIV prevention and treatment services. Capacity to argue for need for investment in building up that capacity, or sustaining that capacity. Decision makers and stakeholders should make deliberate efforts to invest in capacity building of community- led HIV response from country to global levels to ensure meaningful involvement and sustain leadership for accountability efforts by women and girls living with HIV.

## Realizing The Dream

The global discourse and achievement of Global HIV targets can only be realized within a conducive environment in which women and girls, particularly women and girls living with HIV in all our diversity, are meaningfully involved and are at the centre of HIV prevention policy, program planning, development, implementation, monitoring and accountability processes. Preventing and reducing new infections 75% by 2020 is possible with deliberate involvement of directly impacted women. However these programmes must directly address structural drivers and gender norms that limit educational and career opportunities for women, legitimize violence against women, and criminalise women's autonomy. Women's engagement in the structure of the biomedical response can help to expand access to prevention and treatment commodities and services, improve uptake, increase retention thereby improving programme effectiveness and efficiency, reduce loss to follow-up and result in greater accountability within the HIV response for the longer term. The following are ways in which stakeholders can make HIV prevention work for women and girls:

- **Galvanized political commitments** – Towards investment in HIV prevention strategies for women and girls. Making clear country led investment cases for HIV prevention targeting women and girls having a direct impact on their overall sexual and reproductive health as well as maternal health outcomes.

12 Different factors associated with loss to follow up of infants born to HIV-infected or uninfected mothers – study of Cameroon; – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4358721/. (Accessed 26th September 2017)

13 Loss to Follow up within the PMTCT care cascade in a large ART Program in Nigeria;- https://www.ncbi.nlm.nih.gov/pubmed/25986371 (Accessed 26th September 2017)

- **Respect for rights** – Address structural gaps that continue to subject women to violations of our rights including sexual and reproductive health rights. Have clear indicators for measuring stigma among women living with HIV in all our diversities and develop programs for mitigating gaps identified including but not limited to replacing ineffective measures focused on criminalisation with rights affirming and evidence informed approaches.
- **Strengthen access** – Address access barriers including systemic gaps like stock outs of HIV prevention commodities and accessibility gaps from long distances to the health facility.
- **Consistent and correct messaging** – Provide correct messaging on HIV prevention consistently for women, girls, communities, health care workers and other stakeholders.
- **Fortify peer support** – For demand creation, uptake and utilization of HIV prevention and treatment services. This include retention to PMTCT services and adhering to ART for pregnant and breast feeding women living with HIV to reduce vertical transmission; and expanding HIV testing for women and girls post -partum and during post natal care.
- **Address structural drivers** – Instead of seeking magic bullet solutions to the crisis of HIV among women and girls, invest in the hard work and long struggle of identifying and addressing the root causes of gender inequality, entrenched gender power hierarchies – including informal and customary laws, regulations, and policies, and women's poverty.

**Women at the centre of HIV prevention efforts; nothing for us without us!**

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

INPUD International Network of People who Use Drugs

nswp Global Network of Sex Work Projects

ICW INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV

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