Sexual and Reproductive Health, Rights, Justice, Pleasure, and HIV

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Introduction

Reproductive justice asks: "What needs to change so that all people can live our best and freest possible lives?"

Sexual and reproductive healthcare is often separate from HIV care for women living with HIV across the gender spectrum (range of ways to identify or express gender). This happens even though HIV is most often transmitted via sex, and diagnosed during the childbearing years, worldwide. Going to HIV and reproductive healthcare appointments is an important part of taking care of your whole body and your full wellbeing. However, doctors and medical concerns are not the only things that matter when it comes to sexual and reproductive health for people living with HIV. Many complex factors affect women's health and lives beyond living with HIV or being vulnerable to acquiring HIV.

For example, racism, sexism, poverty, and violence have an impact on the wellbeing of people who experience these injustices – including being able to access healthcare and enjoy full sexual and reproductive lives. Addressing these experiences through what is known as the *reproductive justice* framework can be a helpful way to hold all of these complex factors at the same time, identify ways to remove barriers to wellbeing, and ensure the best possible health outcomes for women living with HIV.

Where the core question guiding reproductive ***health*** might be:

"What care and services do people need?"

... and reproductive ***rights*** might ask something like:

"What laws or policies must be in place for people to have that care and those services?"

... reproductive ***justice*** asks:

"What needs to change so that all people can live our best and freest possible lives?"

These are all related because, for example, some barriers may be rooted in policies that can be changed through advocacy based on people's ***rights***; and some supports may come in the form of healthcare and services delivered by those working in reproductive ***health***. But reproductive ***justice*** seeks to look at and improve the full picture of people's lives by making sure that the power to make change is in the hands of the people who are most affected by those changes.

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What Is Reproductive Justice?

Overall, reproductive justice – as defined by SisterSong, a large US-based collective of organizations by and for women of color working toward reproductive justice – is the human right to:

- maintain personal *bodily autonomy* (control of what does and does not happen to your body)
- have children, or not have children (access to *fertility decision making*)
- live and parent the children we have in safe, sustainable communities (*social justice*)

Human rights are founded on the principle that every single human being has basic dignity. Human rights are not meant to be earned or granted by living in a certain country or being of a certain age or doing anything but being alive. Human rights are fundamental and ***should not*** be based on your citizenship or your *social identities* (groups you are part of that shape who you are). These rights should never be taken away no matter what the circumstances of your life. However, too often access to human rights is limited based on what country you live in, where you are a citizen, and other factors such as your race, gender or sexual orientation, whether you have been involved in sex work or been in prison, or other aspects of people's experience that many societies *marginalize* (discriminate against).

Human rights include, but are not limited to:

- the right to education
- the right to health and security
- the right to consensual marriage and family building
- freedom from discrimination
- the right to privacy

Reproductive justice is based on the United Nations Universal Declaration of Human Rights – a powerful document accepted by most countries in the world that explains the standard freedoms that all people worldwide should have. Governments are also responsible for protecting these rights. While there are human rights tools to hold nations accountable for these responsibilities, there are also countless examples worldwide of failures to meet them – particularly when it comes to people living with HIV or vulnerable to acquiring HIV, such as women across the gender spectrum, other members of LGBTQ communities, and Black and brown people.

Human rights are not meant to be earned or granted by living in a certain country or being of a certain age or doing anything but being alive.

Reproductive justice looks at human rights with a focus on the ways oppression (systems of unjust treatment) affects people's agency (ability to take action) over their own bodies and decision making about their families. This framework recognizes and responds to the fact that many aspects of society must change in order for people who experience oppression based on race, gender, and other aspects of identity to enjoy full human rights.

What Are Sexual and Reproductive Health and Rights?

It is important to understand the differences between reproductive justice and other related ways of thinking about people's sexual and reproductive lives. It is also important to note that when we talk about "sexual and reproductive lives," we're not limiting it to the time in which a person may or may not be able to become pregnant or have a baby, but including a person's whole lifespan.

Sexual and Reproductive Health

Sexual and reproductive **health** has to do with direct care, services, and education individuals need to take care of their bodies, have safe and satisfying sexual lives, and create, end, or prevent pregnancies based on their own decision-making. This also includes the physical, emotional, mental, and social

wellbeing corresponding to sexuality.

According to the World Health Organization (WHO), a massive agency which leads public health efforts worldwide, sexual health ought to include:

- comprehensive education and information
- gender-based violence prevention, support, and care
- HIV and sexually transmitted infection prevention and care
- sexual function and psychosexual counselling

Reproductive health includes:

- perinatal (before, during, and after childbirth) care
- contraception counseling and provision
- fertility care
- safe abortion care

Women living with HIV often face HIV-related stigma associated with their sexuality or desire to have children – even from providers, who may not offer women full access to their options in this area. Furthermore, reproductive healthcare providers often are not trained or educated about HIV and therefore may hold stigmatizing views that lead them to not provide regular HIV testing, talk about HIV prevention, or offer other HIV-relevant care to women who are not living with HIV. Providers may be limited not just by their HIV-related ignorance, but also by stigma based in racism, sexism, transphobia, homophobia, bias against sex work, poverty, or drug use – among other forms of stigma experienced by women living with or vulnerable to HIV.

When we talk about "sexual and reproductive lives," we're not limiting it to the time in which a person may or may not be able to become pregnant or have a baby.

Sexual and reproductive healthcare for women living with and vulnerable to HIV must take into account important aspects of a person's identity or experience. These include your race and ethnicity, whether you make enough money to live the life you want, how you identify or express your gender and sexuality, whether you are a parent or caregiver to elders or others, where you live, whether you have experienced violence and trauma, etc. – and how these experiences shape your life, access to healthcare overall, and engagement in sexual and reproductive healthcare in particular.

Sexual and Reproductive Rights

Sexual and reproductive **rights** seek to make sure people have the practical ability to access services and resources related to our sexual and reproductive lives. The focus of reproductive rights advocates is often on policy goals and legal protections. Abortion rights, and the movement to protect them, are a very visible example of reproductive rights – but these rights are not limited to this goal.

The WHO names the right to "enjoy sexual health," as well as to "fulfill and express [one's] sexuality" a part of sexual rights for all people. Reproductive rights ensure that people who can give birth can decide when, how, and whether or not they want to do so; and have access to sexual and reproductive health services to support those decisions, including contraception, abortion, fertility treatment, information, and education. Reproductive rights have been recognized by global agencies to be key to addressing concerns like widespread poverty and gender *inequity* (unfair conditions) worldwide.

Part of sexual and reproductive rights is freedom from discrimination, coercion (threats), and violence while exercising them. Laws and policies that create restrictions to accessing healthcare, or punish people for having sex or for breast/chestfeeding a child while living with HIV (HIV criminalization), violate the reproductive rights of people living with HIV. These policies are examples of *reproductive*

oppression (controlling people through their bodies, sexuality, and reproduction). Such policies often claim to be focused on public health and avoiding HIV transmission without considering the rights and bodily autonomy of people living with HIV. It is especially clear that these laws and policies are more about ignorance and control than public health when you consider that:

- advances in HIV treatment make it impossible for people whose HIV viral load is undetectable to transmit HIV to their partners through sex (known as Undetectable Equals Untransmittable, or U=U – discussed below)
- the chance of transmitting HIV to babies during birth or breast/chestfeeding can also be as low as under 1 percent when birthing parents living with HIV are on effective treatment

Sexual and reproductive healthcare for women living with and vulnerable to HIV must take into account important aspects of a person's identity or experience.

Sexual and Reproductive Health and Rights in HIV Care

Since the beginning of the HIV pandemic, HIV has been considered separate from other aspects of health and in particular from women's health. In the past, this served an important purpose: Setting this condition apart from others was the only way to attract much-needed attention and funds for HIV services, as most health movements were not willing to incorporate HIV into their agendas. While this strategy was successful in forming the systems of HIV care and treatment that we have today, those systems have *not* been successful in responding to and serving the needs of women across the gender spectrum. Furthermore, segregating HIV from other parts of healthcare is stigmatizing.

Making sexual and reproductive health services a normal part of HIV care and prevention – and vice versa – is known to be a key step in improving access to care and health outcomes for people living with HIV while reaching more people and reducing new HIV cases. However, some nations – including the US – are far behind in making these important connections in care.

Racism and Reproductive Justice

Efforts to recognize the impact of oppression on people's sexual and reproductive lives – and change the balance of power over those lives – have existed for a long time. But the term "reproductive justice" came about in 1994 following a gathering of Black women activists, largely based in the US South and connected with women's organizations in the global South. The gathering planted the seeds of a multiracial movement that puts people most likely to be pushed to society's margins at the center of its work. That original group included women living with HIV and working in the HIV field, who recognized the connection between experiences of living with HIV and women's sexual and reproductive lives.

Reproductive justice and HIV remain intertwined, in part because rates of HIV cases and related illnesses, as well as unjust criminalization and lack of access to care, are highest among people around the world who are already marginalized and stigmatized. This is not an accident -- it is the result of many generations of bias and unequal treatment in the medical system and beyond.

Historical Context

In the US, for example, advances in science and medicine have been built on abuse, exploitation, and experimentation on Black women since they were first forced into enslavement. One key example is Dr. J. Marion Sims, called the "father of gynecology," who developed gynecological surgery techniques by experimenting on enslaved women without their consent and without using anesthesia.

While learning about and acknowledging history is an important step, it is also important to recognize that ongoing unjust power dynamics (including white supremacy, patriarchy, and structural racism) continue to advance reproductive oppression.

Current Crises in Black Women's Health

Right up to the present day, studies show that providers believe that Black people do not feel pain to the degree that white people do. This is just one of countless indications that the racism and disregard for the bodies of people of color that helped build the medical system in the US still exists within it. For more information, see our fact sheet Black Women, Racism, and HIV in the US.

In recent years, many terrible stories have come to light showing disregard for Black women's pain and concerns during pregnancy, labor, and birth. A highly publicized example is Serena Williams, widely considered the most renowned athlete in the world. Williams nearly died giving birth to her first daughter in 2017, because medical professionals did not take her concerns seriously. She has used her global platform to show how her experience is not rare and is part of the crisis in the US of Black maternal and infant mortality: Black mothers are three to four times more likely to die, and their infants are more than twice as likely to die, than their white counterparts. Systemic factors like racism are what drive high HIV rates and devastating rates of illness, complications, and death for Black birthing parents and babies – not people's individual behavior, or individual provider biases. Therefore, to change these outcomes on a large scale, the unjust systems under which people live, access care, and even train as medical professionals must change as well.

Sex, Pleasure, Freedom, and HIV

All women living with HIV across the gender spectrum deserve to have full, satisfying sexual lives. The ability to have pleasurable, safe sexual experiences if you choose to has been declared to be a central part of health and wellbeing by many institutions around the world, including the WHO. Despite this, people's experiences of pleasure (or not) are rarely discussed in sexual and reproductive healthcare or in HIV prevention and care. There is also not enough research about sexual pleasure for women living with HIV, and not enough policies supporting pleasure. As discussed above, these key and connected aspects of people's care are too often considered separate, which has contributed to providers missing opportunities to reach and serve women. For example, many healthcare providers do not know about PrEP (pre-exposure prophylaxis) – or they only understand the benefits of PrEP as it concerns cisgender men rather than women across the gender spectrum, who have different factors that lead them to be vulnerable to HIV.

The few studies that do exist looking at the experiences of women living with HIV related to sex and pleasure have found that an HIV diagnosis does have an impact on women's sexual functioning, including their ability to experience pleasurable sex. A groundbreaking 2013 report authored by women living with HIV addressed the fact that women's pleasure was often blocked by anxiety about possibly transmitting HIV to their partners, as well as about condom use. It is worth noting that this report was published when the first PrEP drug, a promising prevention tool for HIV-negative partners of women living with HIV, was newly approved – and before U=U became widely recognized as scientific fact. As noted above, U=U recognizes (through many scientific studies) that people living with HIV and taking effective treatment cannot sexually transmit HIV to a partner who is not living with HIV. Knowledge about U=U can actually enhance sexual pleasure by easing anxiety about HIV transmission during sex, making condomless sex possible while still preventing HIV, and even opening up new partnership possibilities for those who may have limited their potential partner options due to HIV status.

All women living with HIV across the gender spectrum deserve to have full, satisfying sexual lives.

This points up reasons why providers must acknowledge and work to address their biases about sex more broadly, about people living with HIV, and about people living with HIV having sex. This could

lead to providing accurate, current, and sex-positive information related to HIV, including about U=U and PrEP. Sharing this information freely and widely would reduce stigma and promote the wellbeing of their clients. It is important that the *wellbeing* of women living with HIV – including their sexual health and pleasure and regardless of their viral load – be the central indicator of whether their HIV care and treatment have been successful.

What else needs to happen to increase sexual and reproductive justice and liberation for women living with HIV or vulnerable to acquiring HIV across the gender spectrum?

- Far more research into the area of sexual pleasure and satisfaction as well as relationships for women living with HIV – guided and led by diverse teams of women living with HIV, and taking into account the many complexities that shape women's lives, so that the results of the research will be as relevant to as many women as possible
- Greater attention to the sexual and reproductive health needs of women living with HIV who are Black, indigenous and other people of color, gender and/or sexually diverse, engaged in sex work, using drugs, and other intersectional identities
- Sexual health education that centers sexual pleasure – as promoted by The Pleasure Project
- Comprehensive and inclusive sex education in schools that provides up-to-date facts and affirmation about living with HIV and does not stigmatize HIV
- Infusion of affirming, inclusive sex positivity throughout all relevant aspects of society – including media, education, and healthcare

... and the list goes on.

Language Matters

How do you feel about terms like "HIV risk," "high-risk," "unsafe," and "risky" – as in "risky behaviors"?

"Risk" focuses on people's individual behavior as the main way to avoid HIV transmission when individual behavior is rarely the driver of a woman's likelihood of acquiring HIV.

We know that words matter when it comes to talking about sex, sexuality, health, and HIV. Words help shape our understanding of ourselves, our communities, and the world we live in. HIV advocates have known for years that the language of "risk" – which currently saturates public health and medical language around HIV – is stigmatizing and can shut the door on conversations about the ways HIV is relevant to people's lives.

Further, "risk" focuses on people's individual behavior as the main way to avoid HIV transmission when individual behavior is rarely the driver of a woman's likelihood of acquiring HIV. For example, while US Black women are ***not*** more likely than white women to engage in sexual behaviors that increase their chance of acquiring HIV, they are 14 times more likely to acquire HIV than white women. And yet providers rarely consider or talk to clients about how poverty, houselessness, the area where you live, having a current or past experience of intimate partner violence, being of a race or ethnicity historically disrespected and disregarded by health systems, and other factors all compound the likelihood that a woman will acquire HIV. For women who are not yet living with HIV, HIV prevention can be a set of tools to support their agency in controlling their sexual health in response to these oppressive circumstances – and it is important to be supported in finding the best tool for their own experience.

The language of risk, fear, and shame can be replaced with nonjudgmental language that acknowledges:

- Desire – how we engage in pleasure, and how to enjoy what we desire in the context of HIV
- Relevance – what are the ways HIV is relevant to our lives
- Reasons – what are my reasons for HIV prevention
- Strength – how remarkable it is that we and our people continue to survive – and what actions we want to see happen for us to thrive

These are just a few examples of how women living with HIV and other advocates are reframing risk and normalizing HIV, pleasure, and attention to structural drivers of HIV in order to better reach and connect with women.

*How do **you** want to see HIV talked about outside of the risk "box"?*

Take Action!

Many individuals and groups worldwide – The Well Project among them – are working to break barriers separating care models and movements; center pleasure and healing; and secure sexual and reproductive justice for women living with HIV and all people. Here are a few ways to join this effort:

Shift the research agenda. The Well Project's Women's Research Initiative on HIV/AIDS (WRI) took on looking at the intersection of HIV and women's sexual and reproductive health at their annual meeting in 2021. The resulting report contains a ton of wisdom and recommendations for research, policy, and service provision in this area. Read the report (PDF) and share it with providers and other stakeholders in your community to change narratives and practices in women's health.

Promote a culture of wellness. The Well Project's new and growing SHE/HER/THEY initiative supports normalizing HIV in sexual and reproductive health, and vice versa, toward a culture of wellness through a holistic lens. Learn more, sign up to receive updates and have affirming materials delivered anywhere in the US as they become available. Great for starting conversations in support groups, with family members, in schools, and more!

Keep uplifting U=U! This powerful information has reached far too few people. Get the facts, join the movement!

Follow our partners. Organizations that also happen to be partners of The Well Project – including Positive Women's Network - USA, SisterLove, SisterSong, and The Afiya Center – are also working directly at the intersections of reproductive justice, bodily autonomy, and HIV – learn more about their work as well, and ways to get involved.

Bottom Line

The highest possible quality of care for women of all HIV statuses across the gender spectrum takes a sexual and reproductive justice approach and ensures women's agency in controlling their own bodies and destinies. Healthcare and service providers must learn about this crucial framework and incorporate it into their practices if they are truly committed to women's health and wellbeing.

We must move beyond just identifying systemic factors like racism, gender inequity, houselessness, and poverty driving poor health outcomes among communities that experience these forms of oppression. Part of achieving sexual and reproductive justice is addressing those systems at their roots and working to eliminate them and all their manifestations so that women across the gender spectrum can have full power and resources to support decision making about our sexuality, reproductive desires, health, communities, economic futures, families, and all areas of our lives.

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- Reproductive Justice (SisterSong)
- UNSPOKEN: Sexuality, Romance, and Reproductive Freedom for Women Living with HI…
- Reproductive Health and Rights (The Center for HIV Law & Policy)
- Leading Women: Honoring 30 Years of SisterLove (POZ)
- Sexual & Reproductive Health, Rights, and Justice (Positive Women's Network-USA)
- Sexual Inactivity and Sexual Satisfaction Among Women Living with HIV in Canada…
- Meet The Advocates Who Are Reframing the Reproductive Rights Conversation to Ad…
- Sexual Health (World Health Organization)
- Sexual and Reproductive Rights (Amnesty International)
- Sexual & Reproductive Health (United Nations Population Fund)
- Bodily Autonomy: A Framework to Guide Our Future (Positive Women's Network-USA)
- Universal Declaration of Human Rights (United Nations)
- A New Vision for Advancing Our Movement for Reproductive Health, Reproductive R…
- Issue Brief: Black Maternal Health (PDF; Black Mamas Matter Alliance)
- How Serena Williams Saved Her Own Life (ELLE)
- Trans-Centered Reproductive Justice: Family Formation and Sustainable Living (P…
- Sexual and Reproductive Health and Rights and HIV (PDF, UNAIDS)
- Center for Reproductive Rights
- Reproductive Justice Advocacy Requires More Than Being "Pro-choice" (Black Yout…