



the**well**project

Lifetime Survivors of HIV

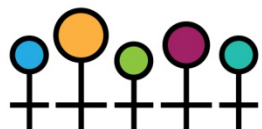
Last updated: January 5, 2024

Together, we can change the course of the HIV epidemic...one woman at a time.

#onewomanatatime

www.thewellproject.org

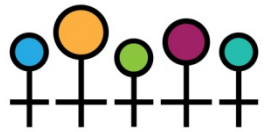
#thewellproject



thewellproject

Female Lifetime Survivors of HIV

- Lifetime survivors: acquired HIV as babies
- HIV testing, treatment advances, blood product screening
 - Fewer transmissions to babies now
 - People who have acquired HIV early in life are aging
 - US 2021: 13,000 lifetime survivors of HIV, mostly over age 13
- Lifetime survivors of HIV often not seen as a distinct group



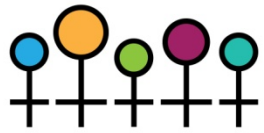
the**well**project

Treatment Experience and Challenges

"[T]here are plenty of long-term survivors that can relate because we have the same chronic illness, but it's nothing compared to sharing the life experience of being born HIV-positive with others that were also born HIV-positive. Managing HIV as children and into adulthood is an experience and a bond that is difficult to describe."

~ HIVictorious, "My First USCHA Experience" (from *A Girl Like Me*)

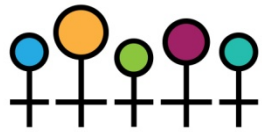




the**well**project

Some Language to Know

- Dandelions
- Early acquired HIV
- Lifetime survivors of HIV
- Long-term HIV survivors
- Perinatal HIV transmission
- Perinatal acquisition, perinatally acquired
- Vertical HIV acquisition
- Vertical HIV transmission

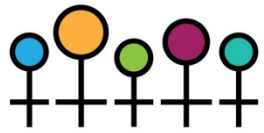


thewellproject

Terms to Avoid

These terms are considered stigmatizing but are still used:

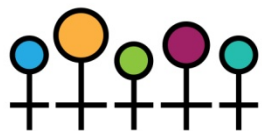
- Mother-to-child transmission of HIV (MTCT)
 - Use vertical HIV transmission instead
- Perinatal infection, perinatally infected
 - Use perinatal acquisition, perinatally acquired instead



thewellproject

The Dandelions Movement

- Started in 2023 at Washington, DC gathering led by women of color with early acquired HIV
 - Spoken-word piece “Dandelions” by Mary Bowman
- Visit Dandelions Movement website to connect with that community
 - <https://www.thedandelions.org/>
- Watch special episode of A Girl Like Me LIVE on Lifetime Survivors of HIV
 - https://www.youtube.com/watch?v=VsplK2_pgs4



the**well**project

Individual and Social Challenges

- Disclosure
- Limited Support Systems
- Mental Health
- Substance Use and Sexual Risk
- Violence
- Intersectional Experiences of Oppression



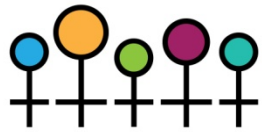
the**well**project

Disclosure

"Disclosure has been one of the scariest things to navigate in my experience. You don't know how people will react—what they'll say, or if they'll freak out."

~ Porchia Dees, "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care (from *A Girl Like Me*)

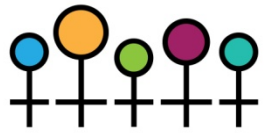




thewellproject

Finding out HIV status

- Parents/guardians may not tell young people that they are living with HIV
 - Teen may have internalized HIV stigma before knowing their own HIV status
 - Teen may find out on their own
- Knowing status is important for managing one's care
- Timing of disclosure to child may depend on:
 - Caregiver's concern for child's mental health
 - Caregiver's own internalized stigma
 - Surrounding social rejection of people living with HIV



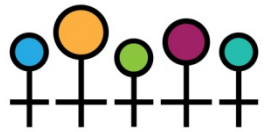
thewellproject

Dating and Sex



“Growing up positive added its own layers of difficulty to the [dating] equation. I used to describe myself as poison ivy. I let the negative viewpoints of society and the stigma that I felt whenever people indirectly insulted me by joking about HIV alter the way I perceived myself.”

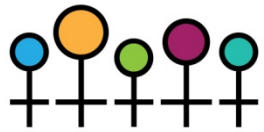
~ Lynnea, “My Cup of Tea” (from *A Girl Like Me*)



thewellproject

Limited Support Systems

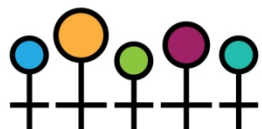
- Caregivers:
 - Primary caregiver may have died
 - Caregiver may have their own health struggle
- Young people:
 - May try to feel in control by stopping to take HIV medications
- HIV care institutions need to be “medical homes”:
 - Medicines & tests
 - Social support & emotional care
 - Strategies for coping with stress



thewellproject

Mental Health

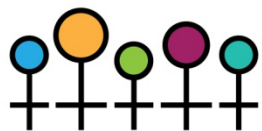
- Young women especially vulnerable to mental health concerns
- HIV and related stigma impacts mental health
- Move from adolescent to adult care stressful
- Survivor guilt over parents or friends with HIV who have died



thewellproject

Substance Use and Sexual Risk

- Substance use experiments like other teens
 - Effect on health of long-term survivors is greater
- Sexual risk taking
 - Fewer partners than other teens
 - But: condomless sex -> STI and transmission risks
- Need to educate young people:
 - U=U
 - Effect of substance use on viral suppression

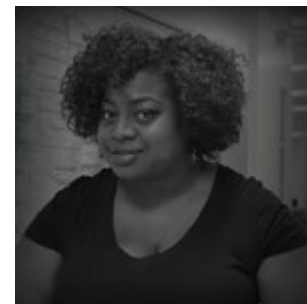


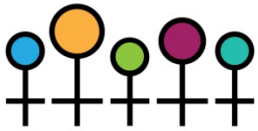
thewellproject

Violence

“I think it's important to talk about sexual violence in intimate partner relationships as a barrier to being in a relationship while being positive. Being born with HIV can impact how you feel about yourself, but also what you might believe you deserve.”

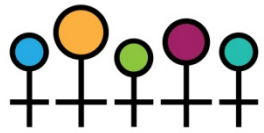
~ Kim Canady, Member of The Well Project's Community Advisory Board





thewellproject

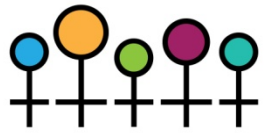
- Important: if you are feeling threatened right now:
 - National Domestic Violence hotline
800-799-SAFE (1-800-799-7233)
 - Text START to 88788
 - Call 911 if that is a safe option
- Search for a safe space:
 - Domestic Shelters



thewellproject

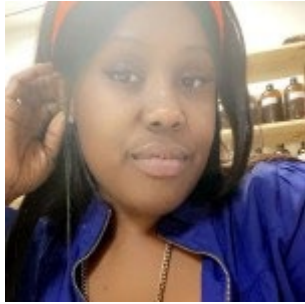
Intersectional Experiences of Oppression

- Structural factors affecting lives and health outcomes:
 - Systemic racism
 - Sexism
 - Classism
 - Transphobia
 - Ableism



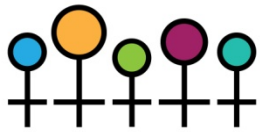
thewellproject

Women Surviving and Thriving Over a Lifetime with HIV



"... Sometimes I even forget I have HIV! I have so many other things to do, I'm not really thinking about it – besides at night when I pop my pill – but otherwise, HIV is not my life. I refuse! I have too much else to think about and do. And I am loving the mom life!"

~ Raven Lopez, public speaker and longtime advocate



thewellproject

Learn More!

- To learn more:
 - [Lifetime Survivors of HIV](#)
 - [Medical Concerns for Women Lifetime Survivors of HIV](#)
 - [Mujeres con VIH adquirido a edad temprana](#)
- For more fact sheets and to connect to our community of women living with HIV:
 - www.thewellproject.org
 - www.facebook.com/thewellproject
 - www.twitter.com/thewellproject
 - www.instagram.com/thewellprojecthiv
 - www.youtube.com/thewellprojecthiv