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Linda Scruggs: Hearts and Minds of The Well Project

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Image



Hearts and Minds of The Well Project is a storytelling project that shines a spotlight on some of the extraordinary individuals who have been instrumental over the past 20 years in making The Well Project the organization it is today. The series features portraits of women living with HIV, members of

our community advisory board and board of directors, staff members, partners, and other allies of The Well Project. In honor of our 20th anniversary year, we released 12 new stories between November 2022 and November 2023 to highlight the diversity of our community. Read all the stories in the Hearts and Minds of The Well Project series

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Content warning This piece discusses sexual assault, including childhood sexual abuse (resources available at the bottom of this page)

Becoming a Leader by Being Who You Are

I have spent over 30 years in the HIV community. The community identifies me as a leader. I identify myself as a servant.

I am the youngest of four girls by my mom and the youngest of nine through a blended family by my father. I grew up in a middle-class military experience, with two of my three sisters and my parents. My dad is retired Navy intelligence, so we moved from time to time. My mother worked for the military department store as the warehouse supervisor, which is where I got my love of fashion. I was born in New Bern, North Carolina, and still consider it our family home.

As a child, I was often lonely and unsure of how I fit into my family. I felt my sisters all had something more valued than me. My oldest is the prettiest girl in the world, and she could dance and sing. My second sister, who lived with our aunt, is an artist; she could draw and sculpt pieces that left you mesmerized. My sister who's just older than me, my best friend in the world today, is the scholar of the family. She'd *look* at a book and make an "A." I didn't know how to be in that shadow, with those "D"s on my report card. I wish I had known how to verbalize the type of struggles I was having.

I took those struggles into middle school where I began experimenting with my first drug, which was tobacco (Kool cigarettes); then marijuana. It was also in middle school that I came to grips with my experience of incest. From a very early age, around 4 or 5, I have memories of one of my uncles touching me, up until I was about 14 years old. Before we were a blended family, my mom would often send us girls to North Carolina to one of her sister's houses for the summer; that's where the molester was. She didn't know and we didn't tell her, because we were told not to tell.

I remember never wanting to go but not having the option not to go. At the time my aunt was very sick with cancer, and my mother was struggling with three daughters. I remember my uncle saying things like, *You're gonna wake your aunt up; you know she's sick.* Predators use those things to trap young girls. I realized, through an experience in middle school health class, that what my uncle had been doing was wrong.

I experienced rape for the first time at 16 through a casual friend's father; then at 18, at gunpoint, walking home from night school. Again, I did not know who to tell.

In my mind, they were going to use my body, so I figured, how do I benefit from what they were going to do anyway? Because I didn't see myself as smart. I didn't see myself as valued.

I began to look at men very differently, which created a spiral of me experimenting with other drugs. One of the benefits of middle-class experience is I knew how to dress up, how to be cute, how to move in different spaces. I had access to men who liked that. I spent my late teens and early 20s with older men who had money, who had resources. Many of them were in drug or other financial spaces, and they fueled my energy as well as my drug habit, at that time of cocaine, very nicely. In my mind, they were going to use my body, so I figured, how do I benefit from what they were going to do anyway? Because I didn't see myself as smart. I didn't see myself as valued.

In my mid-20s, I decided I was tired of that. Then I met HIV. I was 25. I had been in recovery for about 18 months. I had moved to Baltimore with this guy who was the total opposite of any guy I had ever been with; he provided a life different from what I had been doing for the last decade. I was pregnant and had decided to have a baby, and I got an HIV diagnosis. I married him because everybody said, He's a good guy; he'll help settle you down. Even after my HIV diagnosis, he said, OK, but just don't tell anybody – forcing me into another secret. But I had had a lot of secrets up until this point. HIV was the secret I couldn't keep. I didn't have room for it.

We're still great friends; we both married again, raised a fabulous son together, and created another beautiful blended family. He just wasn't a great guy for me. I left because he gave me an ultimatum that, If you tell, you can't be here.

Walking out that day opened up a whole new world. I'd never been on my own. I hadn't worked in two years. I talked to the manager at a rental building about apartments, and she was the first person I disclosed my HIV status to. I didn't want to go home, because my mother was saying, *Stay with him and make it work. That's what Black women are supposed to do. You have to be strong. Make it work. You've already failed everything else in your life. Make this marriage work.*

On September 19, 1992, without any money, my 16-month-old son and I moved into a high-rise apartment on the seventh floor – not a studio, a one-bedroom apartment. I lived there rent-free for four months. The rental manager shared with me the loss of her brother a few years earlier to AIDS. The loss of her brother with HIV gave her compassion for me, and offered me a place of refuge. Early on in my HIV diagnosis, the universe made a way for me.

The HIV community says, *Don't be judgmental. Don't have a bias.* We all come with bias. But the key of it is that humanity trumps all the cards we hold.

That holiday season, I went to the Johns Hopkins pediatric HIV Christmas party. My son Isaiah had just gotten his HIV-negative diagnosis. I had been working with a nurse there on getting one of the little girls with HIV, Brianna, into school. That's how my work in HIV started: as a result of helping three 5-year-old kids who were dying, all of whom have died now, and advocating for them in the school system – not knowing I was advocating. I just didn't understand why they couldn't go to school.

The nurse said, *Linda, please come to the holiday party*. I didn't know that, at the holiday party, she was going to introduce me to this woman in the adult clinic who was running a research study for women who had babies. I got hired as a women's health advocate literally on the spot.

Image



As I entered into this new space at Hopkins, I found voice. I have spent over 30 years in the HIV community. The community identifies me as a leader. I identify myself as a servant. When I first got hired at Hopkins, in Baltimore, IV (intravenous) drug use was the drug. I'd never been an IV drug user. These women had tracks and scars. They were *physical* with the burden they lived. I remember asking God, *How do I help? What can I do here?* I remember hearing the voice of God, saying, *Just be who you are*.

I put one of my very first clients out of the office, because she was high and nodding. An hour later I go into the waiting room and she's still there, waiting on me – and I hadn't been willing to wait on her. Her name is Sheila; she gave me permission to share. She was the person that God used to teach me 70 percent of what I needed to know in HIV. And that was just humanity. That everybody has a story. Everybody's story is unique.

The HIV community says, *Don't be judgmental. Don't have a bias.* We all come with bias. But the key of it is that humanity trumps all the cards we hold. Sheila taught me that.

Staying at the Table and Shaping the WRI

I met <u>Dawn Averitt</u> for the first time at a conference in about 1998. She was coming in the door of a hotel and I was going out, and we had a five-minute exchange. I went to work with AIDS Alliance for Children, Youth, and Families in 2002; at their meeting, I saw Dawn again. She said, *Hey, I've been trying to connect with you; we keep missing each other.* She invited me to the Women's Research Initiative on HIV/AIDS (WRI) meeting in 2003. I didn't know what the WRI was. I hadn't done any research work outside of Hopkins for a couple of years, but it was in Arizona and I wanted to go.

The WRI first opened me up to the fact that there's a lot that other folks know about women, that women don't know about themselves – and they needed to know.

Chuck Wira was the first person I met at the WRI. He is a big old white guy and has this big grin. He's a gynecologist, and he did this whole presentation on the gynecological tract and HIV. I was overwhelmed. I kept wanting to run away. I had entered another realm of HIV that I had never imagined. I remember thinking, *How do I keep getting into these places? Why am I in this meeting with all these white people?* What Chuck was saying in his presentation – women living with HIV don't know this. The WRI first opened me up to the fact that there's a lot that other folks know about women, that women don't know about themselves – and they needed to know.

I spent the next year having almost every presenter from the WRI come on conference calls (we didn't have webinars back then) for meetings and trainings with my women's groups, talking about not just the research, but the women's health stuff.

I found out about The Well Project through the WRI – that the meeting was part of a bigger program and organization. I didn't realize what I'd attended was the first WRI meeting until a decade later.

Getting to the Heart of The Well Project

In 2008, I decided to go back to school. A lot of the ladies I was mentoring were going back to school,

getting college degrees, and I didn't have that. I remember thinking, *How are you "leading" and everybody's overtaking you?* So I signed up for Lincoln University in Pennsylvania and did a dual degree – I got my bachelor's certificate and my master's degree in three years. People say that's incredible, but it was such a stupid thing to do! I almost lost my mind. I was working a full-time job, traveling, the executive director (ED) of my organization left and I was interim ED and had never been an interim ED, I got sick with pneumonia – all at the same time. But what I did at that time was I stepped down off all the boards of directors and the planning council I'd sat on.

My role is to ensure that women's voices have value as well as volume.

When I got the call from Richard Averitt, co-founder and board member at The Well Project, I had just determined I needed to get back in the game and help somewhere. I had sat on a lot of local, national, and global boards. I had been participating in the WRI and knew about The Well Project. Richard asked me if I would join their board. I said, Yeah, I'll do this. It was a perfect decision for me at that time. I had just started Ribbon; when you start an organization, you're buried in it. It was refreshing to put myself back in the seat of service.

One of the unique things I love about the board is that it's intergenerational, interprofessional, and community space. I think my role is to ensure that women's voices have value as well as volume. But the heart of The Well Project is always beating. That is the staff of women who are at so many different intersections of HIV – living with HIV, impacted by HIV, or have committed a portion of their life to the HIV community. Those intersections of how staff show up make our job easy on the board.

We have women on staff who had not been employed in HIV; who have built their skills and capacity; who have become leaders, where other women across the country are looking at their trajectory. When I think about the community advisory board, women having elevated voices and elevated access to information and knowledge: This is different. This is modeling what we want to see in other organizations.

This narrative has been edited and condensed for clarity from a longer conversation.

Linda Scruggs is the chair of The Well Project's board of directors and a member of the Women's Research Initiative on HIV/AIDS (WRI) advisory group. She has been involved with the WRI since its first meeting in 2003. She is the founding co-director of Ribbon, a partner organization of The Well Project.

Read all the stories in the Hearts and Minds of The Well Project series

If you or someone you know would like resources or support in relation to the themes above, please see:

- Resources on the Intersection of Women, HIV and Violence
- Trauma and HIV
- Violence Against Women and HIV



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