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Judy Auerbach: Hearts and Minds of The Well Project

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20
YEARS
STRONG!
thewellproject

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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Strong Roots; Broad Fields

I am a born-and-raised San Franciscan. It's very much part of my identity. It was a great place to grow up as a kid: a lot of independence; a lot of public, free things you could do. I grew up in a very rich cultural moment in the '60s and '70s, when a lot was going on and San Francisco was a particularly great place to be.

> I had become a feminist sociologist when feminist scholarship was just emerging. … When I got into HIV work specifically, I always had an eye on women and girls.

Connected to my San Franciscan-ness is a family ethic, corresponding to the ethic of the city – which is very progressive, very inclusive, very open – and to my cultural community, which is Jewish. I am not a religious person. I have an aversion to organized religion like I have an aversion to anything that appears to me to be zealous or xenophobic. But my cultural connections to my Jewishness are very deep. It's an ethical system, a global, cultural community; and there's a very particular history for my people that includes oppression, annihilation, and otherness.

The ethics are pretty fundamental – from Hillel's admonition: "Do not do unto others that which you would not have others do unto you"; to *tikkun olam*, an ethic within Jewish faith around healing the world. An aphorism I subscribe to is from *Pirkei Avot*– a collection of sayings from the fathers (old rabbis). The one that always has stuck out to me essentially says that: "It's not incumbent on you to finish the work, but neither are you free to refrain from it."

I heard that as a kid and was like, *Yes! That's what I understand is what all this is supposed to be about.* I can't create world peace or racial justice on my own. But I can do my part, and I am not allowed to refrain from doing my part.

At the time when I grew up, San Francisco was a working-class town predominated by people of Catholic orientation or background. Our neighborhood was very much that. I had the very strong sense that I didn't fit in. I'm also the middle child of five kids. Coming from a large family that had very limited material and financial resources, surrounded by people who had more than we did in the neighborhood where we lived, also affected my way of looking at things, and who I identified with.

When I went to college, I took courses in every kind of liberal arts thing you could at the University of California, Berkeley. Then I took a sociology course and I said, *This is everything, under one discipline* – economics, anthropology, political science, history – plus it asks all the questions around how community and society are organized in such a way that confers benefits and disadvantages differentially to people based on things like power and wealth.

> I can't create world peace or racial justice on my own. But I can do my part, and I am not allowed to refrain from doing my part.

I had a policy fellowship that brought me to Washington, DC, two years after my PhD. I worked in Congress for Pat Schroeder, one of the first feminist Congresspersons with a national identity. I got to work on the Family Medical Leave Act and the early versions of the Women's Health Equity Act, which resulted in the creation of the Office of Research on Women's Health at the US National Institutes of Health (NIH).

I had become a feminist sociologist when feminist scholarship was just emerging. I brought that to my policy fellowship, trying to look for ways to advance feminism within the science policy agenda. When I got into HIV work specifically, I always had an eye on women and girls, and gender generally.

My personal passion for HIV is not just that I chanced upon this job. First, I saw the pandemic as sort of the genocide of my time. I was born only 11 years after the end of Second World War and the Holocaust. That was a pretty fresh historical experience for my tribe. We grew up with *Never again* and *You have to do whatever you can to make sure this doesn't happen to anybody else.* When HIV came around, it felt to me like, *This is happening to somebody else.* How could I not be involved and engaged? And then, my youngest brother died of AIDS in 1991. My second-youngest brother died of an injecting overdose two years later. He was a heroin user, and there's a lot of stigma about that. So I lost my two little brothers to HIV and associated things.

People always ask me, *Is that how you got into HIV, when Matt died of AIDS?* I was already in it, but it certainly has kept me in it to some extent. I do this work in honor of him, and also Bob – who didn't have HIV, but did have an addiction that killed him. That's part of my overall commitment to the field and everything associated with it: health inequalities, access to health, how people are treated and discriminated against.

A Model by and for Women in Research

Image

I spent 20-plus years in DC. I eventually ended up in the newly created Office of AIDS Research (OAR) at the NIH. I was hired to head the social and behavioral science program. There was a larger conversation about where are women in health research, particularly at the NIH – the lack of representation in clinical trials, the lack of focus on diseases and disorders that are unique to or more prevalent among women – and then specifically, where are women in the HIV research response? I worked with others in the OAR to create an area within our office on women and girls and HIV that I then headed.

The first year of the WRI (Women's Research Initiative on HIV/AIDS), 2003, was actually my last year at the OAR. I met Dawn Averitt, founder of The Well Project, around then. I remember the first conversation about the WRI, and the OAR co-sponsoring it, and having this think tank, which was the first version of it. To have an entity that could bring together the different sectors – which was how Dawn presented it, that she could bring industry, community, researchers, and clinicians together – was a dream.

I was hooked. I became a long-standing member of the WRI and an attendee and eventually part of its advisory group; and meanwhile also got very engaged with The Well Project and then became a board member.

I got to know a lot of people involved in HIV research and research advocacy from all different kinds of places – which isn't true of everybody, because most people tend to stay focused on their own discipline and sector.

I've been very active in the planning of the WRI and thinking about the themes. After I left the NIH, I went to amfAR, The Foundation for AIDS Research, to head their Washington office before moving back to San Francisco in 2006. In the course of all those Washington jobs, but particularly given that I had worked in this office that coordinates research across the NIH, across topics and disciplines, I got to know a lot of people involved in HIV research and research advocacy from all different kinds of places – which isn't true of everybody, because most people tend to stay focused on their own discipline and sector. I made it my business to work across scientific disciplines and sectors – everybody interested in the HIV response. So that has contributed to my role as someone who can easily identify the right people to invite to the WRI, for example.

I do a ton of what we like to euphemistically call "volunteer work." When you're involved in work that is more than work – it's a cause, a commitment, a passion – you get asked to do an awful lot of things without pay, because you care. I have to think about what I most want to dedicate my time and energy to. The Well Project and the WRI are top of my list, hands down. It's a combination of compelling features:

- *Focus on women of all persuasions*
- *Focus on the US* – though we also are international, very few organizations are paying attention to US women – and maintaining that focus
- *Focus on research.* I'm very science-based, evidence-based, evidence-informed, you ground things in knowledge. And you have to have all knowledge respected and made accessible to people, and a feminist lens helps do that.

The Well Project and the WRI have always been respectful of the range of scientific disciplines and have tried to bring them together in a way that often doesn't happen.

The WRI is about research – but the connection with the rest of The Well Project's activity is the embodiment of what I like. You have science and how science gets connected to activism, community building, programmatic developments, and hopefully positive outcomes for women themselves, individually and collectively.

As a social scientist, we are always at the margins of the biomedical conversation. We are constantly the butt of disparaging remarks: *It's all flaky, you can't change individuals' thinking and behavior, society is too complicated to try to change* – but mostly it's like, *It's not "real science."* What we do is systematic knowledge production, like everybody else who does science. The Well Project and the WRI have always been respectful of the range of scientific disciplines and have tried to bring them together in a way that often doesn't happen.

One of my other passions is around community-engaged research, which increasingly should be community-led research. The Well Project is honest and true about connecting researchers and community members who are not necessarily research trained to work together and advance knowledge and its application by connecting in ways that a lot of people talk about, but don't actually make happen. The WRI is a great model for making that happen. We facilitate connection by having those people around the table in a very intimate environment for a few days where that can become more possible.

Advocating for the involvement of communities of women in the research conversation, bringing women living with HIV and advocates to the table with researchers, and recognizing the subject matter expertise of women living with HIV to help frame the whole conversation about what should be researched in the first place, how we do the research, and what results we hope to get: That's a big contribution. The Well Project has been absolutely instrumental in doing that.

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

Judith Auerbach, PhD, is a longtime member of the Women's Research Initiative on HIV/AIDS advisory group and serves as vice chair of The Well Project's board of directors.

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