



#IASONEVOICE
THEN AND NOW SERIES

Youth engagement in HIV Activism

This year marks the 18th International Youth Day (12 August), first observed by the United Nations General Assembly in recognition of young people as agents of change. In this Then and now series, six activists across generations share how living with HIV shaped their personal journeys toward activism. Three of them began their work in the earliest days of the epidemic, and they speak about the legacy of their advocacy. Three, new to HIV activism, share what drew them to the movement. Each person reflects on how to build and sustain the work of HIV activism. Here are their stories...

Erika Castellanos (42) is a transgender woman born in Belize. At very young age, she moved with her family to a small, conservative and extremely religious town, where she has very mixed memories of growing up. She remembers enjoying her childhood, but also faced stigma and discrimination. Erika was 18 years old when she became engaged in trans and HIV advocacy at the local, regional and now international level. She is the Director of Programmes at the Global Action for Trans Equality (GATE). This is Erika's story ...

I was eight years old when I told my parents that I didn't want to wear male clothing anymore. Coming from a very conservative family and from such a small town, it was a scandal back in those days. My parents sought advice from the local priest and others on what to do. They decided to put me on medical treatment to "cure" me. I was taken to clinics and given male testosterone, changing my body in ways I didn't want. High school years proved the most difficult and, at the age of 16, I immigrated to Mexico. My hope was to find a place where I could feel at peace and be accepted for who I am.

That journey continued when I was diagnosed with HIV in December 1995. At that time, it was difficult to make others understand that we were human beings and that we had a right to life. Antiretroviral therapy had just been discovered, but there were waiting lists for treatment and I remember going to funerals almost every day of the week. Families left their relatives in the hospices, never to be seen again.



Fear drove people to turn their backs on HIV and AIDS, hoping it (and we) would disappear. To get their attention, we needed to be loud and bold. So we took to the streets and demanded our rights, chained ourselves to one another, used coffins, and painted ourselves in red to represent the blood of the dead and dying. We were fighting for survival.

My own story is a series of moments of survival and perseverance. The first was defying the odds doctors gave me when they said that I had only six months to live. The next was accepting the gift of life and deciding to seek out community. That's when I found the first local network of persons living with HIV and began living openly with HIV. Soon, others followed, and together we felt that we no longer had to hide or fear what people thought about us.

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But self-acceptance does not guarantee that the road will always be easy, in life or in activism. Early on in my career, government and health officials, who claimed to value community perspectives, would ask me to step out of high-level conversations. The assumption was that as a young transgender woman who had not studied at university and who openly talked about doing sex work, I would be “bored” by technical discussions.

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This not-so-subtle elitism (and sexism) drove me to study for hours before each meeting or presentation, so that I could challenge the assumption that I couldn't understand. It was also one of the reasons why I eventually enrolled in university. Surviving migration, sex work and homelessness, all while being HIV positive and transgender, have made me strong and resilient in the work I do. And now, I serve as the Director of Programmes at GATE, where my experiences inform the breadth of my work doing people-centred advocacy.

Since then, I have had the opportunity to share my insights with young trans and HIV activists. I definitely recognize a gap between activism “then” and “now”, and I believe that it could be bridged through more open dialogue and mentorship between the generations. For so long, the old way of doing activism meant working in silos, fuelled by funding pressures that often exacerbates competitiveness among organizers. But the future and sustainability of our work lies in doing it together.

“WE ARE ONE COMMUNITY WITHIN MANY OTHERS AND THEREIN LIES OUR GREATEST STRENGTH TO ENDING THE HIV AND STIGMA.”

The next generation of activists is combining movements like sexual and reproductive health and rights, gender justice and communicable diseases, including HIV. This creates stronger networks to advocate for policy change, integrate healthcare services and share robust scientific knowledge. On a more intimate level though, it is especially important for seasoned activists like myself to provide guidance to young activists. We must tell our survivor stories from a place of compassion, not as a way to compare miseries and say how easy they have it. I am so thankful they have not been through the dark days of waitlists and endless funerals.