



UNHEARD VOICES

Stories of LGBT History



David Barr and the Early Days of the HIV/AIDS Epidemic

Introduction to the Interview (Running Time 1:55)

David Barr was a young man when the first cases of AIDS were diagnosed. While many people he knew were getting sick and dying, Barr began working in the community to fight the epidemic. The work of Barr and his colleagues changed the response to AIDS in the U.S. and galvanized the lesbian, gay, bisexual and transgender (LGBT) community.

Questions to Discuss with Students Following the Interview

- What is a crisis? Why does Barr consider the spread of HIV/AIDS in the early 1980s a crisis? What made the LGBT community's response to AIDS an "historic response" to the crisis?
- Why do you think the initial response to HIV/AIDS by the U.S. government and medical community was so slow? Do you think anti-LGBT bias played a role? If so, how?
- While community organizations worked to stop the spread of the disease and treat those already infected, Barr says that the epidemic also "changed the way society looks at gay people." In what ways were people's ideas and beliefs about the LGBT community affected?
- Barr talks about how HIV/AIDS "politicized" and galvanized the LGBT community. What do you know about the LGBT movement before the HIV/AIDS crisis? In what ways do you think the response to HIV/AIDS advanced LGBT rights in the U.S.?
- Can you think of other communities that have faced health crises (for example, Sickle Cell Anemia in the African-American community, Tay-Sachs Disease in the Ashkenazi Jewish community, Breast Cancer in women)? How have they responded? Are there still disparities or discrimination in the current U.S. health system? Why or why not?

Suggested Activities and Assignments for Extended Learning

- In groups of 4–6, assign students to investigate the current state of HIV/AIDS in the U.S. today. Ask groups to research answers to the following questions: How many people are living with HIV/AIDS in the U.S. currently? Which populations are most at risk and why? How are young people impacted by HIV/AIDS? What is the current government response to HIV/AIDS? Then, ask each group to create an HIV/AIDS awareness campaign for their school, including slogans, posters, presentations, etc.
- Assign students to research the current data on HIV/AIDS cases worldwide. Have groups of 5–6 students each focus on one of the most heavily impacted regions (Sub-Saharan Africa, South and Southeast Asia, Central and South America, North America, Eastern Europe and Central Asia, Caribbean). Ask students to answer the following questions: How many people are living with HIV/AIDS in that region? What groups have the highest rates of infections? What myths do people in this region have about HIV/AIDS, who can get it, and how it's contracted? What are some solutions to

address the myths and the spread of HIV?

- Assign students to explore the history of the AIDS Memorial Quilt (www.aidsquilt.org). Assign each student to select one quilt panel from the searchable online database on which to focus. Ask students to answer the following questions: What clues about the person's life can be found on the quilt panel? What questions would you want to ask that person if you could? In groups or as a class, select 1-3 individuals from your local community who have died from AIDS and create a quilt in their memory.
- Assign students to research the governmental response to HIV/AIDS during the early to mid-1980s. Who were the prominent leaders in the White House and Congress, and what messages were they sending about AIDS to the American people? What were the counter-responses to these messages?
- While there was initially much focus on gay men as contractors of HIV/AIDS, other communities were also heavily impacted, including hemophiliacs and members of the Haitian community. Assign students to compare and contrast the experience of these three groups in the 1980s.
- In the early days of the HIV/AIDS epidemic, the medical community and government were slow to address the crisis, and it required the advocacy of the LGBT community and others to push them to respond faster and with greater seriousness. Ask students to consider if there are any health disparities today that affect certain groups of people more than others? Assign students to research current health disparities in the U.S. (people of color, residents of rural areas, women and children, the elderly, persons with disabilities) and what is being done to correct them, from medical, government and community perspectives.
- One method of raising awareness and fighting for LGBT rights was public protest. Assign students to create collages using slogans and signs from HIV/AIDS activists and groups during the 1980s and 1990s. Compare these signs and slogans to those from other social and civil rights movements in U.S. history. Have students create their own signs related to issues they care about.
- Get your students involved! Volunteer at your local AIDS Walk, meal service or other programs designed to raise money for treatment and research and meet the needs of those living with HIV/AIDS.



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Student Handout



David Barr

Living in New York in the early 1980s, David Barr witnessed his friends and loved ones getting sick and even dying from AIDS, a new disease that people knew little about. “I was there at the epicenter of the epidemic in the United States,” remembers Barr, “a member of the hardest hit community in the city. A lot of people were sick. People were dying constantly. We all felt like we were living in a war zone.”

The first officially diagnosed American AIDS deaths were in 1981. Many of those diagnosed with AIDS were gay men. Due to a lack of medical knowledge about the causes or transmission methods of the disease, it was initially assumed that gay men were the only carriers. Many people mistakenly feared they could contract AIDS through casual contact, shaking hands, sitting next to someone, a hug. For a while, airlines did not allow people with AIDS to fly, mortuaries refused to handle the bodies of people who died from AIDS and even health care professionals sometimes refused to care for patients with AIDS.

First termed “GRID” or gay-related immune deficiency, the disease was renamed AIDS (acquired immunodeficiency syndrome) in 1982 after it was found that other groups of people contracted AIDS, too. Discrimination against people infected with AIDS intensified as more and more people died. A 1983 *New York* magazine cover story on “AIDS Anxiety” reported that people with AIDS “have been fired from their jobs, driven from their homes, and deserted by their loved ones.”

Even though other groups of people were getting AIDS, many people still associated the disease with gay men. Combined with widespread homophobia, this misconception delayed the public response to the rapidly spreading human immunodeficiency virus (HIV), the virus that leads to AIDS.

By the end of 1983, AIDS cases diagnosed in the U.S. had risen to 3,064, killing 1,292 people. More than two thirds of these deaths occurred in New York City, where Barr lived. The city’s mayor, Ed Koch, held his first meeting with the LGBT community that year, but not much changed. Very little money and few resources were put towards dealing with AIDS.

Without much support from the government or traditional healthcare organizations, the LGBT community was left on its own to take care of its sick and dying. Barr recalls, “The response by the gay community to AIDS is an historic response of any American community in response to a crisis. It involved hundreds of thousands of people coming together, creating organizations, helping one another, really overcoming incredible adversity as individuals and as communities to address a problem.”

For example, Gay Men’s Health Crisis, which became the world’s first provider of HIV/AIDS prevention, care and advocacy, was founded by a group of friends who set up an AIDS hotline in one of their homes. Fresh out of law school, Barr joined the fight against HIV/AIDS in 1985 as a staff attorney at Lambda Legal Defense and Education Fund, where he worked on many of the first legal cases to battle discrimination against people with HIV/AIDS.

In 1987 Barr became a member of ACT UP/New York, a “diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.” ACT UP started a new, more political phase of AIDS activism. They staged protests in public spaces and presented political demands to federal agencies and pharmaceutical companies. ACT UP called for making medical treatment for HIV/AIDS more affordable and for speeding up the drug approval process. Still, by the end of the 1980s HIV/AIDS had killed 19,241 New Yorkers.

In the 1990s researchers and doctors were finding out more about AIDS and were developing better treatment options. The public started to realize that the AIDS crisis affected all Americans. Barr and many of his peers were now considered HIV/AIDS experts and started participating in public policy debates and medical research discussions. Barr continued his activist work from 1990 to 1997 as director of treatment education and advocacy at Gay Men’s Health Crisis. From 1997 to 2001, Barr organized the very first forums to develop research agendas and discuss the impact of HIV medicines and medical treatment on patients.

Since the beginning of the epidemic more than a half million people have died of AIDS in the U.S.—the equivalent of the entire population of Las Vegas—and more than 18,000 people with AIDS still die each year. Over a million people in the U.S. today are living with HIV/AIDS and one in five people living with HIV is unaware of her/his infection, posing a high risk of transmission to others.

Worldwide an estimated 40 million people are living with HIV/AIDS today and the epicenter of the crisis has long shifted from the U.S. to Africa. Barr is now a global HIV/AIDS educator and advocate who works with national and international organizations to help end the AIDS crisis around the world.

AIDS—and particularly the AIDS crisis in New York—is often described as one of the catalysts that spurred the modern day movement for LGBT rights in the U.S. “AIDS politicized the gay community. It created the organizations that became very powerful and politically savvy,” says Barr. And in the process, “it changed the way society looks at gay people.”