



## 'Silence = Death:'

### What single-payer advocates can learn from AIDS activists

***"It's hard to capture just how profound the rejection was of people with AIDS and how necessary a militant movement response was." - Michael Lighty***

*Dispatcher: 911, what's your emergency?*

*Caller: America's healthcare system is broken and people are dying! (ambulance siren)*

Welcome to **Code WACK!**, where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar**.

(music)

This time on **Code WACK!** In honor of Pride month, we're examining LGBTQ activism in health care. How did the HIV/AIDS crisis devastate the community and what spurred many members toward militant activism? What can the Medicare for All movement learn from these activists? To find out, we spoke to **Michael Lighty**, president of the Healthy California Now Coalition and former constituency director for Bernie 2020.

**Welcome to Code WACK! Michael.**

**Lighty:** Well, thank you, Brenda. It's great to be back.

***Q: June is Pride Month and LGBTQ members have been on the front lines for decades when it comes to healthcare access and equality in both California and in the nation. AIDS killed more than 324,000 people in the U.S. between 1987 and 1998 alone. What can you share about the early days of the pandemic and its impact on the community?***

**Lighty:** The word that comes to mind is devastating. Certainly gay men of my age and older, in some cases, in many cases, lost everybody they know, literally, every friend they had died. And it wasn't that, oh, this group did something, you know, unique or different or lived differently from how others in the gay community lived during that time. It was basically they lived the way they lived, and many of them were exposed to HIV/AIDS at a time when they really didn't know what it was about and as a result, contracted a disease that was fatal, primarily because there wasn't an adequate education and public health response. And so it was defining for a whole era of gay men and lesbians, frankly, because many people with AIDS were taken care of by lesbians.

And it wasn't limited to gay men, certainly. There was a whole set of IV drug users who were exposed. There were people who were exposed who were partners of IV drug users, and ultimately, HIV/AIDS became a devastating disease in communities of color. And to this day, Black men who have sex with other men have a much higher prevalence of HIV than I think any other group. In Washington DC, it's estimated that one in two Black men who have sex with other men are HIV positive.

And of course, AIDS became an international disease and was devastating to parts of Africa. So, I think it's really an era-defining experience for gay men, but the impact of it is literally global. And it literally, of course, became a global pandemic and the psychological personal toll was profound. The social toll was immense and the loss...there are various Instagram sites that chronicle gay men who have died of AIDS but the cultural impact of artists, theater actors, other actors, musicians, fashion, kind of a lot of the creative communities, but not just that, I mean, the folks on Wall Street were hugely impacted, of course.

So just if you look at this cohort of gay men who died, the social impact on the life of this country is immeasurable.

***Q: Wow, truly devastating. And who else is most likely to contract HIV?***

**Lighty:** Essentially, if you want to know who is most likely to have HIV look to who has the least access to health care, who is socially disadvantaged in other ways. That wasn't true at the beginning of the pandemic, but it became true over time.

***Q: Wow, that's so interesting. What do you think can be done about that?***

**Lighty:** Look it, we could eradicate HIV/AIDS within, at one point, we were talking around 2013 working with different folks in the AIDS activist world within seven years, because through the use of prophylactic treatments known as PrEP and other means you could eliminate the transmission of HIV through treatment and then combine that with education. You could literally stop everywhere if there was sufficient... It was really purely a question of money. If you devoted enough money to dissemination of PrEP treatments – so you reduce the viral load in those already infected and prevent new infections – and educate folks, you could eliminate HIV transmission. So this is not an inevitable disease. It is now completely preventable. There's not a vaccine. There's not a cure, but you can prevent new transmissions. And once you prevent new transmissions, then obviously it can end.

***Q: Got it. And so PrEP, correct me if I'm wrong, but those are pills that you take orally so that your partner doesn't transmit it to you?***

**Lighty:** You don't transmit it and also you do not get it, essentially. So it works both ways. And you know, the drug companies, of course, are <laugh> making out like bandits. I mean, the price is as high as \$22,000 a year.

***Q: That's unbelievable. Imagine how many less infections we'd have if it was financially accessible to everyone.***

**Lighty:** Ultimately, it'd be zero.

***Q: Wow. I'm still thinking about the \$22,000 a year. Is that because it's a monopoly?***

**Lighty:** There are a couple of versions of this type of therapy, but yeah, why is there (this) price? Because that's how the pharmaceutical industry works, right? Of course the government could produce the drug cuz they could argue that, 'hey, you're not producing this in an affordable way. So we're going to invoke our authority, what's called compulsory licensure. You're abusing your patents, so we're going to produce it,' just like California's talking about doing it with insulin.

The federal government has that power to do nationally, this is a public health crisis. There is, you know, intense social need for this treatment. We're going to eradicate HIV/AIDS and we're going to produce this drug, and we're going to offer it to people for free if necessary. And that is completely doable. It's just a matter of politics, political will, and taking on the most powerful lobby in the country known as the pharmaceutical and healthcare industry.

***Q: So infuriating. So how did the federal government under former president Ronald Reagan react in the early years of the pandemic?***

**Lighty:** Just in the most inhumane and horrific way. You cited 324,000 deaths. Some people hold Ronald Reagan responsible for most of those because there was a period, quite frankly, until the mid-nineties, like 1996 – really from 1980/ 81 to 1996 – where if you contracted HIV AIDS, except in very rare cases, there were some people who had sufficient immunity and have been long-term survivors, but even they have significant health effects, you basically died because there was no treatment and they instituted these AZT treatments, but they were poison.

And so until what's called the drug cocktail emerged in around 95-96, there was no effective treatment and even that treatment didn't necessarily prevent death, but it really, in many cases, ultimately did. Imagine COVID coming on the scene and for all of his just unbelievable faults, President (Donald) Trump got on it and said, 'okay, we're going to develop a vaccine at warp speed.'

And they did. Imagine if that never happened. Imagine if that didn't happen for 15 years, how many people would die? Now, COVID is a lot more transmissible than HIV, but we knew how HIV was transmitted. Did the federal government fund even a public health education campaign to tell people? 'It's a gay cancer.' That's how it originally started, you know, gay related. GRID was the acronym.

***Right, GRID stands for Gay Related Immune Deficiency.***

**Lighty:** It was originally stigmatized as a gay disease. So if you had HIV, you were gay. And this is not, you know, the era of legal gay marriage. This is the era when people like me got fired for being gay... which happened to me as well. We, in fact, in the early nineties, my partner and I were denied a rental property in Oakland by a landlord who said, 'well, God, what if they get AIDS?'

***So terrible!***

**Lighty:** Now, she didn't say that to me. She said that to someone else that got back to us. That's the era in which we're talking about. And that's like 1994. So imagine what it was like in 1983! So, you know, for me personally, I was a gay man coming out just as HIV and AIDS became known, and there was a lot of misinformation. And so it was just, you know, you had to kind of either really be committed to safe sex, which was, you know, condom and quite a bit of other, you know, at that time, a lot of precautions had to be taken, and it wasn't that well understood. So absent a really clear public health education campaign, which cities like San Francisco and New York, and ultimately LA and other areas did undertake, but not with federal support, not with, you know, until really the Ryan White Act when essentially a

young straight hemophiliac got HIV, well, all of a sudden now, 'okay, let's fund education and treatment.' For our generation of gay men, it's pretty hard not to be cynical. Essentially it's a life defining experience.

***Q: Yeah, right. Thank you, Michael. So, in the face of the government's refusal to respond for many years, the community was galvanized into action. What can you tell us about AIDS activism and ACT UP?***

**Lighty:** Well, ACT UP was a profound movement, not unlike, you know, it obviously had historical precedence in the women's health movement in, certainly in even in the 20th century, right? The reproductive rights movement, the women's movement, the movement of midwives and so it wasn't like the first time that people, you know, tried to take control of the healthcare system in a sense and of their own health care. But it was at that moment quite significant, because of course, health care was evolving into an industry. And so these were in many cases, you know, relatively socioeconomically privileged gay men -- not by any means all of them -- but there was certainly a cohort of them, particularly on Wall Street, who were like outraged because all their friends were dying. All of our friends were dying. And they realized no one cared <laugh> and no one was doing anything.

***How horrible!***

**Lighty:** And, you know we have to remember that during this time Anthony Fauci was on the scene. So, you know, he had a mixed reputation at the time. And so that effort to basically demand, you know, in some ways it had a very focused demand, you know, drugs into bodies. They wanted a pharmaceutical solution, which eventually developed. But then there was all this other grassroots work from hospice care to public education, community based public education campaigns, distribution of condoms in clubs, and baths, I mean, essentially what it was, was both a militant movement against the government and the pharmaceutical industry primarily demanding treatment and access to care and places like San Francisco General (Hospital) in the front lines of compassionate HIV care and having a dedicated ward. I mean, you have to understand because there was such a lack of information disseminated, healthcare workers didn't know how it could be transmitted and so they would basically shun AIDS patients, and they would isolate them.

I mean, you talk about you know COVID, well COVID is almost like a kind of PTSD experience for gay men because it's so reflective and echoes so much how HIV and AIDS played out and was experienced, right? Because I mean, literally, I mean, families disowned. If you got HIV/AIDS, chances are your family disowned you. And

then after you died, they'd come in and, and take all your possessions away from your live-in partner.

***Oh my gosh! How tragic.***

**Lighty:** The horror stories are really unbelievable. And the AIDS Memorial Instagram feed is quite instructive in that. So you have to understand that in, that's the context for ACT UP. And it was a militant, you know, a series of die-ins and you know, ultimately there was, you know, demonstrations at the (U.S.) Health and Human Services Agency in Washington that I was at, and the FDA and it was very effective. It was this combination of really smart, graphic symbolism, like silence equals death and it was international. There was a huge ACT Up in Paris, right? It wasn't just the United States. And of course, out of that organization, like the Gay Men's Health Crisis in New York is well known. So it became, again, this kind of community based public health healthcare activist and advocacy movement that was both graphically creative, was sophisticated politically, was militant politically and you had artists involved.

Famously this one artist David Wojnarowicz designed a jacket that said, 'if I die of AIDS, forget burial, just drop my body on the steps of the FDA.' And so there was just this unbelievable militance that was born out of direct experience of horrifying deaths, discrimination, and just denial and neglect. It's hard to capture just how profound the rejection was of people with AIDS and how necessary a militant movement response was.

***Q: So do you mind talking about what other ways you were personally affected by the AIDS crisis?***

**Lighty:** It was just traumatic to come out as a gay man and basically be told, 'well, if you have sex, you can die.' I mean that's basically what the deal was. Safe sex, but for me, more like abstinence and, and monogamy seem to be <laugh> the way to go. In San Francisco it was a very different scene. I had friends who worked at hospice and lived really in part of the gay neighborhood. And you just couldn't, you know, you just couldn't escape it.

I mean, it was just literally everywhere. The AIDS quilt emerged at about that time. And, you know, there's a big fight over the public bathhouses where a lot of gay men went to have sex. It was just defining personally and culturally and socially and the emergence of lesbian organizations. Lesbian political power occurred in part because, you know, gay men were not really able to continue.

Like a lot of the political organizers that I knew, you know, from that period who had worked around (San Francisco Supervisor) Harvey Milk and, and Harry Britt, two gay supervisors after (former San Francisco Supervisor and police officer) Dan White murdered Harvey Milk, Harry Britt became a supervisor and a lot of the gay political organizers around them died of AIDS. So in San Francisco you could certainly live life as an openly gay man like you couldn't in other places certainly.

As I say that, I moved to LA and that's where I had a union job where they didn't, you know, where they found out that I was gay and then didn't renew my contract. Literally, this one officer came over to my house to see, 'oh, who's he living with?'

**Whoah.**

I mean, I lived in New York for a number of years after that and, you know, participated in ACT UP and so forth. So there was just a lot of political activism and the quilt, I saw the quilt in Washington DC that was incredibly profound.

And there was a national march for LGBT rights and so it was hard to capture in a way the intensity of the experience, the life and death feeling, and just, you know, the historical impact of all that, which we're still feeling, frankly.

There's not a gay man of my generation and certainly my husband who's a bit older whose life wasn't in large measure defined by the AIDS pandemic.

***Q: I'm so sorry, Michael, that you went through all of this. And it sounds like you knew a lot of people who died as well.***

**Lighty:** I did, but I probably knew fewer than many. I mean, if I had been five years older, it would've been literally everybody probably. And certainly, my husband, you know, was in the middle of the pandemic in New York when I was, you know, still in college. You hear on social media sometimes like on Reddit 'why aren't there any gay men in their, you know, sixties? It's like, well, yes. And it's like, 'well, they're all closet cases.' 'Well, no, actually many of them are dead.'

***Q: Wow. Millions of Americans face today, millions of Americans face financial ruin, delayed care, disability, and even death as a consequence of our healthcare system. Yet change has been a long time coming. What can the single-payer movement learn from HIV/AIDS activists?***

**Lighty:** Well, what we have to never forget is that militancy and creativity matter. So silence equals death was a very defining slogan of ACT UP. And that's the same thing. I mean, whether you're immune compromised as I am in dealing with COVID,

if you're quiet about it they're just going to let you, you know, potentially die because everyone else has moved on.

If we are silent about the need for comprehensive reproductive health services, we're not going to get them. And if we are silent about the, you know, rapacious and murderous behavior of insurance companies while they profit somewhere around \$31 billion last year with much of their revenues from public taxpayer sources, if we don't challenge that, it's going to continue. I think especially though specific treatments, and the public funding of those treatments and public dissemination of pharmaceutical treatments when it's publicly funded research that develops them is a fundamental principle that I think Act Up put out there but hasn't been realized. Right. We still need a democratic transformation of the pharmaceutical industry.

***Thank you, Michael Lighty. Stay tuned next time when we continue our discussion with Michael about single payer-advocacy and the LGBTQ community.***

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