What Works?

In a blog post titled "Why Science Shows Us the Best Way to Beat HIV Stigma," long-term survivor Bob Leahy talks about what HIV looks like in 2019 versus 1989. Below is an edited excerpt.

May 20, 2019 By Bob Leahy

Ask a group of people living with HIV whether HIV stigma is better or worse than in the old days and mostly you will hear "the same" or even "worse." Attempts to move the needle have been fruitless—or that's the perception.

Whether that perception mirrors reality is moot. The evidence is skimpy. Thirty years in, we have tools to measure stigma, but data is sparse. We desperately need a battle plan, plus good measurement tools and sustained data collection.

So what works? I've often argued that the personal testimonies of people living with HIV are hugely important. They may not change societal views at anything but a snail's pace, but they can and do change minds one at a time.

Stigma is so pervasive, however, that I'd wager far more people work hard to hide their status than to share it with others. Relying on more people living with HIV to come out—because the challenges to doing so can be extreme—clearly isn't enough.

I'm not arguing that we should dissuade people from coming out and telling their stories. I'm also not arguing we shouldn't continue to mount broadly based social media campaigns to attack HIV stigma. Instead, we need to be more effective.

Using a values-based approach is something we have seldom really tried. Essentially, this means we shouldn't blame people for their illness. I like ethics that work.

But with HIV, there is a more important factor to contend with. It's the fear of transmission, a fear that service providers have inadvertently amplified for decades.

That HIV is no longer what it was gives us an opportunity to present a different narrative. True, it involves normalizing HIV in a way that some have resisted, but the public has to know what HIV looks like in 2019, not 1989. There is, of course, a huge difference.

The new face of HIV, although sadly not yet universal, is a healthy face. It's a face on a body that lives as long as the next person. It's a face that need not be feared. Why? If we are on successful

treatment, we do not transmit the virus to our sexual partners.

These are facts we can prove. This information not only changes our lives but also has the potential to alter our place in society. We are no longer a threat. Voices that share this new reality are our most powerful weapon yet.

In other words, we have entered an era of science-based messaging. The “I Can’t Pass On HIV” campaign from the Terrence Higgins Trust was an early example. The ubiquitous Undetectable Equals Untransmittable (U=U) message from Prevention Access Campaign is another. The uptake and influence of both messages have been massive, as described in the March 2019 issue of POZ.

Importantly, these campaigns address the fear of HIV transmission that has clearly driven stigma. They also speak to the health and well-being of people living with HIV. It’s a winning combination, and in 2019, it represents the best path forward to end stigma.

More importantly, instead of throwing anything anti-stigma against the wall and hoping that it sticks, we now have a tool with a much higher chance of success. The U=U message is incredibly powerful. It’s based on science, of course, but science that is simplified. It will take time to convince a hesitant populace that we no longer need be feared.

We must at the same time be sensitive to the fact that—because of treatment access issues or adherence issues or choice—we aren’t all undetectable. It’s no surprise that not all of us are undetectable. The most marginalized face the largest challenges. They need support, not further stigmatization.

That being said, the opportunity to change the face of HIV is out there like never before. Ending HIV stigma is no longer a distant dream. It’s attainable.

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