Long COVID Justice

A new organization addresses the needs of people living with HIV and long COVID.

January 9, 2023 By Sarah Hamilton

JD Davids has long played an important and visible role in the HIV response. He continues to do so today, working at the center of many intersecting issues, including chronic illness, social justice and—as the founder of Strategies for High Impact (S4HI) and its Network for Long COVID Justice—the impact of the COVID-19 pandemic.

S4HI recently announced a new $1.5 million investment from the Balvi Fund, a scientific investment and direct gifting fund supporting high-value COVID-related projects that will bring cutting-edge communications science to the advocacy efforts of people living with long COVID and other chronic conditions. S4HI is also a recipient of the first allocation of the Disability Frontlines Fund of the Third Wave Fund.

Funders Concerned About AIDS (FCAA) recently interviewed Davids to hear about his work and what people affected by both HIV and long COVID need most. Below is an edited excerpt.

Tell us about the work you're doing now and why it's so important to you.

I was concerned, even in the earliest days of the COVID pandemic, when it was described as something that wasn't much of a concern because it was only going to affect people who are already sick or disabled. No one in the media or the government was talking to people who were sick or disabled about what this may mean for us. So I pulled together a webinar in early March 2020 to ask people with chronic conditions, "What are your concerns? What are your questions?" Since then, I've stayed really centered in the emergence of COVID-19 as a chronic condition.

We've been able to connect the history and present day of HIV advocacy and service delivery with this new, emerging community of highly affected people in the COVID-19 pandemic. For example, we've been able to have long COVID research advocates meet with HIV treatment activists who have been working within and outside the Centers for Disease Control and Prevention and the National Institutes of Health for years. Together, we were able to talk about the strategies and structures of research advocacy. We've been able to talk about COVID and long COVID through an HIV community lens.

It's really stunning how much people have not been able to dial into the particular information that they and their communities need. We are trying to bridge that gap. We've heard so much

misinformation. We are trying to break through the noise to give people the information—and the humanity—they need.

Where have you seen progress? And where are the biggest challenges?

In the beginning of the pandemic, as operations shifted more to remote and virtual work, there was, in some ways, a flourishing of access. Case managers got iPads to rural folks so they could get online. Organizations helped pay for cell phone connections. I was working closely with The Reunion Project [an alliance of long-term survivors of HIV] when the pandemic started. We turned meetings into webinars, and people who had never been able to come in person were able to participate. Events like these are very concrete measures against isolation.

Today, there have obviously been changes in the capacity to treat COVID. And access to vaccination has reduced rates of severe disease and mortality. However, there are people who remain at high risk or are in community with people who are at high risk. Even the baseline of risk might be uncomfortably high if more was known about what it's really like to live with these kinds of complex chronic conditions and how much it affects your life.

What do community members need from funders?

In the emergence of the COVID-19 pandemic, people were moved to contribute billions of dollars in rapid relief, across all sectors of philanthropy, to do anything they could to make things work. But, as we know well in the HIV community, there is a difference between an ongoing versus an acute disaster. And we didn't see a recognition that the situation was likely to continue.

Even before the pandemic, there was never anywhere near adequate support for disability justice and disabled organizers. COVID-19 and long COVID raise the bar for understanding and being transparent about the complexities of funding. It's not going to work to have one-year program grants change everything when ableism is a structural condition that's baked into our society. There's a lot to do to be able to shift funding and power in a way that is untethered from ableist standards.

We need to be able to recognize how people of color and disabled, queer and trans people and immigrants have crafted worlds of survival and interdependence. How do we apply resources to what disabled people living with forced poverty and huge rates of marginalization and isolation have learned from one another by taking care of one another? How can we start recognizing and supporting that?

Look to the caregivers and program leaders in the communities. Provide capacity building, technical assistance and training support to mentor people so that they are able to be the leaders. They already are leaders, but help them with the skills that will allow them to teach others to lead too. We already know how to do this—it's been the most vibrant part of the HIV community response.

What lessons learned from the HIV response can be applied to long COVID?

Long COVID is not one thing. We need to emulate what we have across the spectrum for HIV—the Ryan White CARE Act, wraparound services and the understanding that it's not just about treatment but also access to housing and support, etc. In the case of complex chronic conditions, there's a need—just like there is with respect to HIV—for provider training.

There's a need for provider and service infrastructure as well as education about long COVID. We need to bring information, treatment, care and support to the millions of Americans who are dealing with it, many of whom were already chronically ill. How do we work within the care and service sectors that exist—for HIV, for diabetes, for elder care—to be able to bring rapid relief? How do we bring economic support for people who have lost their capacity to work? There's a lot that we could do right now.

I'm confident that we're going to have treatment for at least a big slice of people with long COVID. What we need to be doing now is treatment preparedness. With HIV, we had effective treatment available in the United States and other wealthy nations for years before activists around the world united to bring the price down through generics and extend access worldwide. We need to ensure COVID treatments are going to be available to people worldwide.

How can HIV-informed funding be applied to long COVID?

One key is to center the caring economy and caring work. The origin of the HIV community was people caring for one another and demanding that the government and funding entities also care.

What does it mean to center us in terms of our wisdom and our methods without requiring chronically ill and disabled people to be marginalized, impoverished and isolated? That means really supporting community-level solutions, not just paying for what it costs to provide them but leveraging these models so that we can bring things to scale in other places.

We've seen from the HIV response that we can have incredible breakthroughs and treatments and still lack access and experience enormous loss. We need to have systems in place to actually get treatment to people. No pure biomedical solution can do the work on its own.

There's a lot going into technological fixes that aren't going to reach many of those who are most affected. But we need the low-tech stuff. We need childcare, training, economic supports, housing. We need all of that. Let's not make all the same mistakes again. Let's get to what works.

Go to StrategiesforHighImpact.org to learn more about Davids and this work. Sarah Hamilton is operations director at FCAA.

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