Good Counsel

After 30 years of advocacy, AIDS Law Project of Pennsylvania continues to offer free legal services to people living with HIV nationwide.

April 15, 2018 By Casey Halter

AIDS Law Project of Pennsylvania first opened its doors in Philadelphia in 1988. It's mission? To provide free legal services to people living with and affected by HIV/AIDS.

Back then, in the early days of the epidemic, no laws protected people living with the virus from discrimination. Things have gotten a lot better since then, but today –– as the organization marks its 30-year anniversary –– its advocacy-minded lawyers are still relentlessly fighting for the rights and futures of their clients.

Ronda Goldfein is the executive director of AIDS Law Project of Pennsylvania and has been representing clients living with HIV since she first started volunteering at the organization in 1992. Below, she overviews what it's been like fighting for the rights of the community over the years and why it's important to keep advocating.

Tell us about AIDS Law Project of Pennsylvania.

Ronda GoldfeinCourtesy of AIDS Law Project of Pennsylvania

We are, I believe, the nation’s only independent, public interest law firm providing free legal services to people living with HIV.

What I mean by independent is that this is all we do. We have a discrete focus of our legal services, and we’re not affiliated with a law school, a med school, a social service organization, a Bar association. We are a freestanding law firm that has only one population of clients.

Sometimes, I feel like we’re either ahead of the curve or dinosaurs because there are lots of other folks who are doing fine HIV-related legal services, but they all have other affiliations.

What types of legal services do you provide?

We provide representation on all types of things that are HIV specific. [For instance,] we provide legal assistance on things that are health-care-related, like “How do you get health care?” or “How do you get Medicaid or Medicare? How do you get private insurance?” We then answer questions like “Once I have it, how do I use it?” and “How do I get these services covered?”

We also provide assistance on things that are income-related. For example, “If I’m sick and I can’t work, what are my options?” or “How do I get Social Security benefits? How do I get long-term disability benefits? Are there other income replacement options for me?”

We also have a complete housing program. When we started our housing program, we envisioned that there would be a lot of discrimination in housing, and we see that for sure, but more so, we see people had trouble paying their bills.

It’s expensive to be sick. It’s expensive to have to step out of your life for a while and not work. So we have a housing program that focuses on those issues: rent, mortgage, utilities, helping people stay in and secure affordable housing, those kinds of things.

Relatedly, we also have a consumer debt program for people who are unable to work and maybe have incurred a lot of debt. We answer questions like “What do they do now? How do they manage their debt? How do they prioritize it? Is it debt that they’re never going to be able to pay off, or is it a debt that they can have a payment plan for?”

Within our 30 years, we’ve seen a major change in the lives of our clients. In the beginning, we were helping people make plans for their last days. It was a lot of questions like “Please help me get this medication, please help me get my social security benefits, please help me write my will.”

Now, we’re planning for people’s futures. Now, we’re helping people keep their jobs and go to school and make long-term plans — which is something that we just never thought that we’d see.

What are some of the legal rights that people living with HIV should be aware of?

The fundamental idea is that when a person tests positive for HIV, you are the same person. You haven’t lost any of your legal rights. You haven’t lost your right to be treated fairly, to be treated equally, to have the privacy of your medical information. None of that has changed.

So we do a lot of work on discrimination. Anybody who’s been treated unfairly, who’s been denied a job, been denied a health care service or been denied a place to live, simply because they have HIV. We pursue those cases aggressively.

Do you feel like HIV discrimination is getting better?

I want to say yes. And yet, it’s not completely true. Because every day we hear a different story. We get maybe three or four calls a week that somebody has been treated differently simply because they have HIV. You name an industry, you name an experience, we have heard that

somebody has been discriminated against. So there's still plenty of work to be done.

That's part of why we try to be so vocal about the work that we do. Because we have a staff of 12, we can't touch every bad employer in Pennsylvania or across the country. But we try to make enough noise when we pursue one of these cases that somebody else will stop to think about their behavior.

The idea is that if you make enough noise, then people are like, "Oh my God, I don't want to be that person that's in the newspaper next getting yelled at by this cranky lawyer."

What are some examples of such cases?

Several years back, we sued the Milton Hershey School, a private boarding school in Hershey, Pennsylvania. The school refused to admit a 13-year-old honor student because he has HIV. The school just had terrible statements they were coming out with, like "We think this boy will be a risk to all of the other 1,800 students."

Really? One kid? So we pursued that complaint with the assistance of the Department of Justice and got the school to change its position, in addition to awarding our client $700,000.

That case enabled us to have a major conversation around "What does it mean for HIV-positive kids to plan their futures? What does it mean for these kids to go to college, and what does it mean for people with HIV to be in congregate living?"

The story got crazy coverage everywhere. It was a really strong David and Goliath type of story — this public interest law firm in Philadelphia, where all of our furniture is mismatched, challenging the Hershey School, which at that time had billions of dollars in its endowment.

It was the second-wealthiest school in the world and people were like, "You can't challenge them," and we were like, "Why not?"

Another case involves Aetna. We were recently involved with a case where Aetna sent out 12,000 letters to people living with HIV and those on pre-exposure prophylaxis, where because of the construction of the letter and the envelope, their status was potentially made known to their friends, their family, mail carriers — a whole range of people.

I want to acknowledge that we ended up being in this odd position around confidentiality. On the one hand, HIV is a virus and there's no shame in having a virus. On the other hand, we need to protect people's privacy. It's like we're giving people a mixed message, but we're giving them that message because until we really do away with stigma, we have to protect that.

If you are in possession of people's sensitive information, be thoughtful about it, about how it's shared and how it's transferred. Don't gossip about people's status. Think about what the disclosure of a person's status does to that person. Not everyone has the opportunity to live

openly and freely. So that's the other part of why we do this work.

Do you have any advice for people who want to help your organization?

We have such a small operation and what we do is so specialized that we don't have the capacity for volunteers. But we are celebrating our 30-year anniversary and having a series of events that we post about regularly on our website and on our Facebook page.

So for people who are in the Philadelphia area, or really anyone who's interested, they should come to those. In October, we're having a huge salacious cocktail party with details to come. Also, we ask people to financially support us. I don't mean to be crass about it, but that's kind of the assistance that we need.

Why is it important to keep providing these legal services?

I think illness is random. Who's to say you're not the person who, on one day, needs help? I think that if we're going to get a handle on the epidemic, we have to address stigma, we have to address the things that fuel the epidemic. We're not going to completely medicate our way out of the AIDS epidemic.

The medications have absolutely changed the landscape in a dramatic, completely unexpected way, but I also feel like we need to have a lot more heart around the way we're treating people living with HIV.

I think it's all about some level of equality and fairness and empathy. It's a little trite, but we're all God's creatures and we could all use a little love.

For more information about AIDS Law Project of Pennsylvania's upcoming events and 30-year anniversary fundraisers, check out the organization's Facebook page. To read more about the cases AIDS Law Project is working on to protect the rights of people living with HIV, click here.

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