

# Who Decides Your Fate, When You Can't?

Mark Spencer, *The Legal Intelligencer*

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After years of advocating relentlessly for the Latino community and people with HIV, it was Samuel Morales who needed help at the most dire of times.

Morales, 57, suffered an aneurism in December 2015 while alone at home. He was found unresponsive a few days later.

Unfortunately, while fighting for the rights and well-being of others, Morales never obtained the legal documents he needed to make sure his wishes would be followed. He had no living will or medical power of attorney, documents that could have stipulated how he wanted to be cared for.

Who would make health care decisions on his behalf? What kinds of artificial life support and other end-of-life care did he want—or not want? Those questions have at times led to painful and protracted legal battles among loved ones.

His close friend Jose Benitez, executive director of Prevention Point Philadelphia, was among the people who came to his aid.

"There was a scramble to figure out how to take care of him during a part of his life when he wasn't able to make decisions for himself," Benitez said.

When Morales died on Jan. 17, having never regained consciousness, another set of questions had to be settled. What should be done with his assets? How should his remains be handled? Another friend, Ronda Goldfein, executive director of the AIDS Law Project of Pennsylvania, worked with Morales' family and Benitez to help settle his affairs.

The experience prompted Goldfein and Benitez to start a new program to help others avoid the same situation. Seeing it as a way to honor Morales' community activism, his family agreed to have the program named for him. The two organizations created a clinic, run by AIDS Law Project lawyers at Prevention Point's Kensington offices, to provide planning documents to the recovering drug addicts Prevention Point serves.

Throughout its 28-year history, the AIDS Law Project, a nonprofit, public-interest law firm, has been committed to educating its clients about the importance of wills, living wills, medical power of attorney and other planning documents, such as standby guardianship.

And it always has been dedicated to providing those documents free of charge, in whatever setting is best for the clients.

During the early years of the epidemic, documents were sometimes prepared at the last minute in a client's home or hospital room. As AIDS has become a manageable disease, documents are more often prepared in the AIDS Law Project's Center City office or at special events, such as the clinics it holds in collaboration with the LGBT Elder Initiative.

In 2015, the AIDS Law Project handled 689 legal issues concerning planning documents, about 12 percent of the total number of legal issues that year.

The importance of living wills was dramatically illustrated in the case of Terri Schiavo, which continues to have health care implications today. Schiavo, a young woman originally from the Philadelphia area, suffered massive brain damage after a heart attack in 1990. She eventually was placed on artificial life support. Legal battles between her husband, who wanted the life support discontinued, and her parents, who wanted it maintained, ensued.

More than a dozen appeals in state court, multiple suits in federal court and the involvement of state and national-elected officials kept her alive on artificial life support for 15 years after her initial medical crisis.

Ultimately, her feeding and hydration tubes were removed by court order in March 2005. She died later that month.

The case prompted many states to change their laws in a way that was not necessarily in the best interests of the LGBT community.

Pennsylvania and other states allowed specifically identified people to decide—even over the objections of a partner—the course of treatment for an incapacitated person who had no legal documents. The new Pennsylvania law created a hierarchy of people health care providers could consult, beginning with a spouse and proceeding to adult child, parent, adult sibling, adult grandchild and, finally, a close friend.

"Before marriage equality, that law put LGBT families at risk of their wishes not being followed," Goldfein said. "Even after marriage equality, people didn't necessarily run out and get married to secure their rights."

Goldfein and Benitez now want to educate Prevention Point's clients on the need for planning documents and provide a means to obtain them.

The AIDS Law Project and Prevention Point have a long history together.

In November 2015, they resurrected a program that started in 2003 but was suspended because of budget constraints.

AIDS Law Project staff members hold twice-weekly office hours at Prevention Point, where clients can get free legal

help with an array of issues, including HIV criminalization, HIV confidentiality, health insurance, immigration, landlord-tenant matters, obtaining legal identification and resolving outstanding warrants.

That program provided the foundation for the planning documents clinic, and the first one was held June 2.

"We felt it was unlikely many of them would seek out civil legal services or have the money to pay for it," Goldfein said.

Benitez said many of the recovering drug addicts Prevention Point serves have a long list of issues they need to address, such as paying bills, finding a place to live and attempting to reconnect with family.

"Often their personal lives are in disarray," Benitez said. "We want to make sure people have a say in what happens to them."

At the first clinic, Jacob M. Eden, staff attorney at the AIDS Law Project, met with eight people and completed six living wills, six medical power of attorney documents, three wills and one directive as to disposition of remains.

Benitez said there is a need for more education to get people to participate.

"Culturally, planning like this is not readily acceptable," he said. "It's almost like tempting fate."

Still, Benitez said those who went to the clinic had a positive response and expressed relief at getting their affairs in order.

"Once people got educated about the process, it became empowering," he said. •

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