



## INDIVIDUALS WITH HIV/AIDS

Included in the overall interviews was a subset of eight interviews with low-income survivors with HIV/AIDS and one provider who cares for people with HIV/AIDS. This subset of interviews was conducted to learn how these individuals, who often require complex medical care and consistent access to medications, fared in the aftermath of the storm. Most of these survivors take antiretroviral medications in addition to other medications for their physical and mental health. For antiretroviral medications to be effective, they must be taken in combination and on a fixed schedule. The interviews focused on these survivors' ability to stay connected with their health providers and obtain their antiretroviral medications and on the effects of any prolonged periods without care or medications. The interviews occurred in January-February 2006 in Baton Rouge, Houston, and New Orleans.

### Key Findings

**Before the storm, most of the survivors were part of an HIV-specific system of care that met the majority of their physical and mental health needs.**

Most of the survivors with HIV/AIDS in this study received their care through Charity Hospital's HIV Outpatient Program (i.e., HOP Clinic), one of the main sites of HIV care in New Orleans. Through the HOP Clinic, these individuals were able to access a

range of services from providers experienced in treating HIV/AIDS—everything from dental to mental health—regardless of their insurance status. Most survivors felt they received high-quality care through the HOP Clinic and had forged close ties with their providers. Services were low cost or free for those who lacked insurance and conveniently located in downtown New Orleans and accessible by public transportation. Most survivors used Ryan White funded services at the clinic and elsewhere in New Orleans, particularly the AIDS Drug Assistance Program (ADAP), and were able to obtain needed medications prior to Katrina. Many were also dual Medicaid and Medicare beneficiaries. This mix of coverage and assistance meant that most could obtain their medications, including their antiretroviral medications, at low or no cost and on a consistent basis prior to the storm.

*"I called HOP and was embraced from the day I walked in, and I still feel the same way today. They are a remarkable organization."*

John in New Orleans

**After Katrina, these survivors had difficulty connecting with health care resources due to the displacement and destruction caused by the storm.**

As with many survivors in the study, all of the survivors with HIV expected to be gone for just a few days

*“I knew that if I didn’t find out where I could go to get treatment for my medication that too many days off of it would kind of alter things so that was my biggest concern.”*

Trish in Houston

and so just took the bare essentials with them, including their medications and some cash. Some fled with family, such as Philip, who left with his wife Helen, and Peter, who evacuated with his partner and sister. Others, like Susan and John, left on their own. Some fared better than others, but all suffered anxious periods when they were unsure about whether they could refill their prescriptions and how they could reconnect with their providers. All knew the importance of monitoring their health and staying on their antiretroviral regimen, but doing so was difficult for a number of reasons:

- **Most of the interviewed survivors lost touch with their providers right after the storm, and some went months without contact with a medical professional.** Almost none had a way to contact their doctor after the storm. These survivors said they had deep connections with their regular doctors in New Orleans, and the separation from their doctors was hard on them. Only Trish in Houston had obtained her nurse practitioner’s pager number before the storm, which enabled Trish to call her for advice about where to find care in Houston. Some displaced providers and state staff from New Orleans took steps to help survivors reconnect with care. The HIV/AIDS provider interviewed for this study noted that she, along with other HOP Clinic providers, evacuated to Baton Rouge and then “planted” themselves in emergency rooms to wait for their patients to arrive. Similarly, the Louisiana state HIV/AIDS program staff worked closely with the HOP clinic, the LSU Health Care Services Division (HCSD), ADAP distribution sites throughout the state, and ADAP programs in other states to set up emergency services to assist survivors in getting refills of their medications and connecting to local HIV/AIDS resources.
- **These survivors faced many of the same challenges to obtaining needed care as other survivors.** They dealt with constant flux and motion in the days after the hurricane, the inability to reach health care providers or find operating providers,

the challenges of getting care in an unfamiliar community, transportation and information barriers, and anxiety and depression in the aftermath of the storm. They were on the move, disconnected from their providers and pharmacies, and just focused on surviving. Survivors with friends and family did better during this period because they had extra help and support, which eventually assisted them in getting the care and medications they needed. Those who were alone did much worse and faced more problems getting to doctors and refilling medications.

*“The buses are very slow. It takes you three hours to get to where you are going.”*

Zora in Baton Rouge

### **Five of the eight survivors experienced gaps in their care and medications, including their antiretroviral medications, soon after the storm.**

As a result of the challenges they faced in obtaining health care, five of the interviewed survivors went without needed care and medications, including their antiretroviral medications. This resulted in at least three individuals experiencing a lowered T-cell count when months later they finally connected to a provider (and could get their antiretroviral medications again) while the others said they experienced extreme fatigue and anxiety. The survivors noted several factors that led to their inability to obtain their antiretroviral drugs:

- **Lack of supply:** Most did not have enough supplies of their medications when they evacuated from New Orleans. All knew the importance of their medications—particularly their antiretroviral drugs—but did not expect to be away from home so long. Susan, who evacuated to a small town in Louisiana, tried to bring all of her medications, but the group home in which she lived—and which regulated her medications—would only give her a three-day supply. She ran out soon after the storm and could not refill her medications in the small town where she was staying. The local hospital did not have a supply of the antiretroviral medications she needed. She also said that she could not find an infectious disease doctor who specialized in HIV/AIDS.
- **On the move too much:** Others brought their entire supply of medications but ran out after days turned into weeks on the road. Philip’s wife Helen explained

that he ran out of his medications because the family had so many other worries during that time period that they just could not find the opportunity to refill his prescriptions. Daniel in New Orleans had a more unique experience—he was incarcerated right before the hurricane and, during the evacuation and subsequent move to another prison, he missed his medications.

- **Did not know where or how to get refills:** John in New Orleans has severe mental health needs. When he was evacuated from his group home, he was left to fend for himself for weeks until he finally reunited with his family in Houston. During this time, he ran out of his medications and did not know how to refill them. He had lost touch with his HIV/AIDS and mental health providers and had no one to call for assistance. Until he was reunited with his family a few weeks after the storm, John lived on the streets.

*“Needless to say, after the evacuation and stuff, I did not get proper medication for 35, 36 days. ... I was very weak.”*

Daniel in New Orleans

**Some survivors also went without treatment and medications for other serious mental and physical conditions.** These include bipolar disorder, schizophrenia, hypertension and epilepsy, which worsened in the weeks and months after the hurricane because they went untreated. The barriers survivors faced in obtaining HIV/AIDS drugs also prevented them from getting other medications and care they needed—they were on the road too much, they were disoriented and had no one to help, or they were in an unfamiliar city. Philip spaced out his supply of grand mal seizure medicine because he was afraid that he would run out before he was able to refill his prescription and suffered from seizures as a result. Zora, who was able to reconnect quickly to the health system in Baton Rouge thanks to the state HIV/AIDS program staff and ADAP, said that, while the ADAP formulary would cover her HIV/AIDS medications, it would not cover other medications she needed. Peter said he did not have his prescription bottles with him when he evacuated and so went four weeks without the medications he needed to control his bipolar disorder. He had two seizures during this period, bad nightmares, and found it hard

to cope. He was finally able to get medications once he arrived in Baton Rouge and connected with local organizations that help people with HIV/AIDS.

**Meeting pre-existing mental health needs, in particular, was problematic.** Susan, John, Philip, and Peter all had severe mental health needs prior to Hurricane Katrina and were not able to connect with their psychiatrists or get their medications for weeks after the storm. This left Susan and John especially vulnerable because both were alone during the evacuation and had to fend for themselves without their medications. John said he lived on the streets while Susan eventually moved in with strangers in Houston who, in her own words, “tried to institutionalize me.” Both were in unsafe situations, alone, and without help. In contrast, Philip had his wife for support, while Peter had his sister and partner caring for him, and this made a difference. While they both suffered seizures, anxiety problems, and other negative effects from being without medications and mental health care, they could rely on their loved ones. At the time of the interviews, six months after the storm, all were—or were about to be—reconnected with mental health providers and were able to get their mental health medications. However, they were shaken by their experiences and still felt unstable as a result of the missed care and medications.

**Six months after the storm, some were reluctant to return to New Orleans, and those who had returned found a health system with limited resources to meet their needs.** Some had heard the health system was still not up and running, and they did not want to disrupt their care again by going back to a system that could not adequately treat individuals with HIV/AIDS. Their top priority was getting healthy after the lapses in their care, and some felt they needed to stay in Baton Rouge or Houston until the health system was rebuilt in New Orleans. Those who had returned to New Orleans said clinics had moved locations, doctors had not returned, and some doctors’ offices were simply gone. The HOP clinic suffered damage that forced it to close after the storm. It reopened—in a smaller location with fewer providers and services offered—about six months after the hurricane. Survivors heard about open offices and clinics mostly through word of mouth rather than through formal communication. For example, Susan in New Orleans said that she heard the

HOP Clinic moved from its previous location but was unsure about the new address. The HIV/AIDS provider interviewed noted that the HOP clinic was having difficulty contacting former clients and advising them of the new location. The provider said that the clinic was much smaller than it used to be, with fewer providers and services available. She was worried about the large number of former clients who had not returned to the clinic and feared many were going untreated.

*“We’re moving [to Atlanta] ... I don’t want to say for good, but until they can get everything straight in New Orleans, that is where we will be staying.”*

Helen in New Orleans

## Conclusion: Survivors with HIV/AIDS

Mirroring many of the experiences of other survivors in this study, the eight Katrina survivors with HIV/AIDS faced challenges in getting the care and medications they needed after the storm. State staff and some providers took steps to help these survivors connect with care and resources after the storm. However, there did not appear to be any comprehensive emergency plans or arrangements in place prior to the storm to assure that individuals with HIV/AIDS would be able to receive care and their medications during and after the evacuation. As a result, a number were not able to connect to providers or the health system and missed important health services, mental health care, and medications, including their antiretroviral drugs. Due to these gaps in care and drugs, three of these survivors said their T-cell count declined. At least two endured unstable and unsafe situations in the weeks after Hurricane Katrina because, although they have severe mental health needs, they were left to fend for themselves. Indeed, unmet mental health needs made it that much harder for some of these individuals to negotiate new health systems and connect with their providers. Two had seizures, some had anxiety problems, and others said they were in a “daze” during this period.

Factors that made a difference in connecting survivors with HIV/AIDS to needed care and medications in the

days, weeks, and months after the storm include the following:

- **The emergency services provided by the state HIV/AIDS program staff and HOP Clinic.** As noted, HIV/AIDS program staff worked closely with the HOP Clinic, the LSU Health Care Services Division, ADAP distribution sites in Louisiana, and ADAP programs in other states, and displaced staff and providers undertook efforts to reach out to survivors to assist in connecting them with local resources and primary care and medications.
- **ADAP/Ryan White funded services.** The availability of Ryan White funded services, particularly ADAP, meant that poor individuals with HIV/AIDS who were uninsured could get their antiretroviral medications without worrying about cost.
- **Support from friends and family.** Those who evacuated with loved-ones were better off than those who were left alone, like Susan and John. This was especially true for those with mental health needs.

Overall, the interviews suggest that, as with other survivors, survivors with HIV/AIDS faced intense challenges in the period after the storm in reconnecting to the health system and getting vital medications. Many of these individuals had other conditions in addition to their HIV disease, particularly mental health needs, and going without care took a toll on them. Six months after the storm, many were still reeling. The situation was particularly challenging for these survivors because many had been used to receiving comprehensive and high quality HIV/AIDS and other care through the HOP Clinic in New Orleans. Despite their significant medical needs, most of these survivors slipped quickly outside the health care system due to their displacement and the loss of providers and clinics in New Orleans. Some were wary of returning to New Orleans because they believe the HIV/AIDS health system is too broken to provide the care they need. This suggests that continued rebuilding efforts are needed in New Orleans to assure that survivors with HIV/AIDS can return to a city with enough resources to provide care for HIV/AIDS as well as other physical or mental health needs.