

# SURVIVOR EXPERIENCES

## Individual Profiles

- **Gertrude**, 39 years old, developmentally disabled living in a hotel in Baton Rouge
- **Mack**, 72 years old, single man living alone in a rented room in New Orleans
- **Dawn**, mid-50s, living with multiple health problems in a hotel in Baton Rouge
- **Linda**, late 40s, caring for her 12 year-old disabled grandson in Baton Rouge
- **Melissa**, 45 years old, single mother with two sons living in a trailer in New Orleans
- **Michelle**, 37 years old, living in a hotel room under construction in New Orleans
- **Sharonda**, pregnant mother living with family in a rented house in Baton Rouge
- **Lynn**, 61 years old, caring for her elderly mother suffering from Alzheimer's in New Orleans

## Individuals with HIV/AIDS

# GERTRUDE

**“I miss my children, my mom,  
... my sister,  
... my brother  
... I miss my people.”**

Gertrude, 39 years old, developmentally disabled woman living in a hotel in Baton Rouge, interviewed January 17, 2006

**“All my family and friends was down there.”** Gertrude is a 39 year-old African American woman who suffers from multiple chronic physical conditions as well as a mental disability. Prior to the Hurricane, she lived with her boyfriend in an apartment in Kenner, an area right outside New Orleans. She lived near her mother, who was caring for four of Gertrude’s six children; the other two children are older and were living on their own. Her mother has cared for Gertrude’s children since they were born given Gertrude’s disability.

Although she did not live in the same residence as her mother and children, Gertrude noted, “that was like every day that we seen each other.” As she described, “I just go catch a bus by her house to go see her. Or she come in her car to come see me.” Gertrude said, “I loved it in New Orleans;” being surrounded by family and friends made her happy.

Gertrude qualifies for Supplemental Security Income (SSI) due to her disability. She had been living independently, but her mother served as her guardian and was the recipient of her SSI checks. In addition to her disability, Gertrude suffers from diabetes, asthma, high blood pressure and high cholesterol. She was taking a total of four prescription drugs for her mental and physical conditions. Gertrude did not have a regular doctor in New Orleans but would go to clinics or the emergency room when she needed care. She also saw a psychiatrist who maintained her psychiatric medication.

Gertrude has been covered by Medicaid since she was a child through her disability. Although Medicaid kept her drug costs low, she still sometimes had difficulty affording them. As she described, “they tell me I have to pay \$1.50 or fifty cents, sometimes I didn’t have the money to buy. It would take two or three days until I get my welfare check or until I get my SSI check to get it.”

**“It was sad because that was the last time I seen my mama.”** Gertrude evacuated to Baton Rouge the day before the storm in a car with her boyfriend and her boyfriend’s mother. Her mother evacuated to Texas with Gertrude’s children. As Gertrude described, “it took me about two months to get in touch with them.” She said, “I was scared because I thought my mom and them wasn’t all right.”

Gertrude has not seen her mother and children since the storm, but she speaks with them on the phone. She noted, “I be calling every month. It’s long distance and that’s the only time I can talk to them, one time a month.” The separation from her family has been traumatic. She said, “I miss them. I miss my children, my mom, ... my sister, ... my brother ... I miss my people,” and noted, “every time I talk about them I always start crying ... I always cry.”

When Gertrude and her boyfriend first arrived in Baton Rouge, they stayed with her boyfriend’s family in a

house. The house was crowded and Gertrude said, "... they didn't have enough room, we had to sleep on the floor." She eventually left the house and moved into a hotel.

***"I been down here four months and I ain't been taking my medicine."*** Gertrude had very little with her when she left New Orleans. She said, "they had told us to hurry up and pack up our stuff and go ... I left my medicine and all that." Gertrude did not have any of her medications with her and has been unable to obtain any since the storm. As she described, "I went to the doctor and ... when they asked me the name of my medicine I didn't know ... So the doctor couldn't give me nothing." Another challenge Gertrude faces in obtaining care is transportation. She said, "... if I had a car I would have been went to the right doctor to get me medicine."

When Gertrude feels sick, she uses the diabetic testing machine of her boyfriend's grandmother. She said, "When I test it, it be like really low, but she give me peppermint food. I need the medicine because I started having a problem at the bottom of my leg." Gertrude is also going without her asthma inhaler and her high blood pressure medication, as well as medication for her mental disability. She said, "I'm not taking nothing for my nerves because I shake a lot, then I rock. I like to rock a lot and I'm kind of paranoid because sometimes I hear voices and stuff. That's what my medicine was for."

Gertrude is concerned about her health. She said, "I don't know what might ... happen to me if I don't take that medicine ... I don't want to lose none of my legs because that's what they say, that you go in a coma, and I don't want none of that to happen to me."

***"I didn't have no money to get nothing to eat."*** It seemed that Gertrude had not yet received any financial assistance from FEMA. She said, "We are still waiting for the money from FEMA. We about to get our trailer soon but we ain't got the money right now to turn on the lights and water." Gertrude has been struggling financially. She said one of her biggest challenges is "trying to get something to eat. They stopped serving food at the hotel. They stopped giving us emergency food stamps." She noted, "I didn't have no money to get nothing to eat so I use to have to borrow money from people at the hotel just to get something to eat until I get the money from FEMA."

***"I don't know how the future going to turn out."*** Gertrude remains very uncertain her future and the biggest issue on her mind is whether she will be able to see her mother and children again. She said, "I don't know how the future going to turn out, if I'm going to see them again. I hope I do. I miss them ... I don't remember their faces no more. It seem like a long time."

**“The doctor said I should have been out  
of my pressure pills long ago.  
I told her I stretched them.”**

Mack, 72 years old, single man living alone in a rented room in New Orleans,  
interviewed January 30, 2006

**“I lost everything.”** Mack is a soft-spoken, 72 year-old African American man with a slight build and an easy laugh. Mack’s dedication to his job and his church defined his pre-Katrina life. Before the levees were breached, he lived alone in a home he rented in Uptown New Orleans. His “very, very small family” includes two sisters, and neither lived near him in New Orleans. Not owning a car, he commuted through a maze of bus transfers each day to a suburban mall where he worked as a maintenance man seven days each week. When not at work, he could usually be found volunteering at his local church where he was a deacon.

**“Before Katrina I was getting a check up every couple months.”** Mack was in fairly good health before Katrina. Still working at 72 years old, his job required him to stay physically active. He explained, “Every job I’ve had has made me walk, walk, walk. I think that’s got something to do with it.” Despite his level of activity, Mack does have hypertension. He said, “One thing is I have high blood pressure. The doctor told me as long as I stay skinny like this I’m okay.” Mack’s only prescription medication is “pressure pills” to control swelling associated with his hypertension. In addition, Mack had major surgery several years ago at Tulane Hospital to remove blood clots in his legs, but he fully recovered.

Mack received his health care through the Charity Hospital system. Enrolled in both Medicare and

Medicaid, Mack could have received care from a wide variety of providers in the New Orleans area, but he chose a Charity clinic where he saw the same physician regularly and which he could reach easily by bus.

**“You’re a member of our family now.”** Mack’s long evacuation saga began at his home, where he rode out the storm itself. He fled his home in waist-deep water to seek shelter in a church with nothing more than a change of clothes, his wallet, some Ritz crackers, and his “pressure pills.” As a deacon, he was entrusted with a key, which he felt he may have used inappropriately to unlock the deserted church and wait out the flood on a higher level with no food and little drinkable water. After three days, a member of the congregation rescued him in a boat and said, “you’re a member of our family now.” With this church member’s family, Mack proceeded to an overpass out of the flood waters, where he was picked up by a preacher’s bus on its way to Little Rock, Arkansas. After some time, he headed to Fort Worth, Texas in a military SUV and from there to Baton Rouge where his sister lives. Finally, he returned to the New Orleans area to live alone in an apartment in Algiers.

Katrina destroyed Mack’s home and all his possessions, including a collection of maps and pictures assembled over a lifetime. “The pictures and maps ... I had hundreds. I lost all that. It was in that water. I lost everything.” Although he has no children of his own,

Mack was “like a father” to a young man in his neighborhood who was evacuated to Tennessee and has no plans to return. “Now he’s just gone. He’s in Tennessee. That’s what bothers me, people and friends.”

***“I might doze off, but the rest of the night I was up all night. I never told anybody about it.”*** Mack has not discussed the emotional trauma he has suffered since the storm with anyone and was hesitant to do so during the interview. He has had difficulty sleeping since the storm, and feels he is suffering from “stress.” Admitting his mental health has declined since Katrina, Mack said, “As far as mentally, I don’t think I’m 100 percent like I was before the storm.” However, he said he would be reluctant to see a mental health provider for treatment.

***“The doctor said I should have been out of pressure pills long ago. I told her I stretched them.”*** Though his health remained relatively good after Katrina, Mack lost the network of caregivers he routinely accessed in New Orleans. The Charity clinic where he used to get treatment was destroyed, and he has no way to contact his physician. At the time of the interview, he had only one brief visit with a physician while in a shelter in Arkansas, who advised him to find a new supply of hypertension medication but was not able to provide any. Mack had not found a new primary care physician, and had no idea where he would turn when he needed a new prescription or should he fall ill.

Mack was forced to “stretch” his medication by taking less than the recommended dosage. “By me knowing I’m not going to be able to get them, I just took one every now and then.” Although he left with his entire supply of medication when evacuating, he quickly found himself without an adequate supply. Once back in the New Orleans area, Mack struggled to find a pharmacy that was open and that would fill his prescription. In sorting through the wreckage of his

flooded home, he found a water-logged prescription that he was able to fill at a national chain. At the time of the interview in January, Mack had received a card at his current address for prescription drug coverage through the new Medicare Part D benefit. Previously, he could get a month’s supply for \$3 at Charity, but his copayment rose to \$10 when he filled his prescription after Katrina at the national chain.

***“It takes me an hour and a half to get to work, but it takes me three and a half hours to get home. Trust me, it affects you.”*** Mack was able to resume his job working in maintenance at a suburban mall by December. Prior to Katrina, he rode city buses an hour each way to reach the mall where he worked seven days a week. Now that he lives in Algiers on the opposite side of the Mississippi River, Mack must take a ferry and several additional buses that run far less frequently and reliably than before Katrina. Other jobs were available in the tight post-Katrina New Orleans labor market, but none were accessible because of inadequate public transportation. “I turned two good jobs down because of transportation,” Mack said.

***“It’s going to be a long time for New Orleans to come back.”*** Mack received some aid from FEMA but declined cash assistance because he believed it required granting FEMA access to his savings account. His distrust of FEMA prevented him from receiving financial assistance. He also preferred to find his own apartment—“They wanted me to get a trailer. I don’t want a trailer.” Mack’s independence and work ethic allowed him to reestablish a residence in the New Orleans area and return to his job despite his incredibly long commute. Mack is committed to returning to his old neighborhood and church if possible, though he recognized that the road to recovery will be a long one and that his life and city are likely changed forever: “I don’t think things will be done. Not in my lifetime ... It will never be back to what it was before.”

## DAWN

**“I have a medical card,  
but what good is it if I can’t use it.”**

Dawn, mid-50s, living with multiple health problems in a hotel in Baton Rouge, interviewed January 17, 2006

**“They were happy times.”** Dawn is an African American woman in her mid-fifties. Prior to the hurricane, she lived by herself in the Uptown area of New Orleans in a rental home. She has fond recollections of life before the storm, and said, “I remember sitting on the porch and seeing all my friends. I was very sociable. I know everybody and I had good friends in New Orleans.” Outside of her friends, Dawn was basically on her own. She has three grown children but was not living with them. Dawn felt like she was doing quite well for herself in New Orleans. She worked part-time on the line at a shrimp factory that she had worked at off and on for years and had no trouble getting around the city. As she said, “It was easy. Everything was within walking distance, and buses run every ten or fifteen minutes.”

While Dawn viewed much of her life before the storm positively, she was dealing with a number of health issues, including high blood pressure, high cholesterol, and bipolar disorder. She had a primary care doctor that she had seen for years. He had recently retired and she had begun seeing a new doctor. She was quite pleased with both and said, “They are both very good doctors.” She visited her doctors in a primary care clinic outside of Tulane Hospital. She said she was able to get preventive care including mammograms and other screenings and had no difficulty getting the five prescription drugs she was

taking. As she described, “All I had to do was call the doctor and leave a message at the desk and say that I was out of my medication, and they’d fill the prescriptions. I’d pick them up, or they’d send them to my house. It was very easy.”

Dawn has been on Medicaid since the early 1990s. She qualifies as disabled due to her bipolar disorder and began receiving Medicaid when she applied for Social Security. She said, “It’s been a blessing, yes, it’s been all right.” Because of her Medicaid coverage, Dawn did not have any trouble affording her health care in New Orleans. Dawn noted, “I have Medicaid, so they basically take care of the bulk.”

**“I had the clothes on my back period and that was it.”** When the hurricane hit, Dawn stayed in the city and waited it out at a neighbor’s house. After the storm, she hitchhiked out of the city directly to Baton Rouge. She had almost nothing with her except her identification, medical card, the medications she took during the day, and a few changes of clothes. Dawn went straight to a hotel in Baton Rouge where she has lived in since the storm. She has been alone since the storm and unable to connect with her family. She said, “I can’t find anyone. I haven’t talked to any of my kids or my grandchildren, and my son’s even here ... and I can’t find him.”

The hurricane has taken an emotional toll on Dawn. She feels abandoned and said, “We’ve been left without anything. I know the good Lord is here for us, but it’s like we’ve been left here and nobody cares and it hurts. It really hurts.” She reported having frequent crying spells and said, “... even though I have a problem anyway with depression and things, I’ve never cried as much.” She also described problems sleeping and eating, noting, “I’ll sleep for about 20 minutes and then wake up and stay up for some hours, but my sleeping is very, very bad. My eating has gone completely berserk. All the foods I liked before, I don’t like anymore.”

***“I have a medical card, but what good is it if I can’t use it.”*** Even though Dawn has continued to be covered by Medicaid since the storm, she has been unable to receive needed health care, and she is frustrated and concerned. The major challenge facing Dawn appeared to be finding a doctor that would see her and that she could reach. Her only mode of transportation in Baton Rouge is her bicycle, as taxis are too expensive. She said, “I’m the only health care I have. It’s either too late and it’s hard for me to go, even on a bicycle, because some days I don’t feel good.” Given these challenges, Dawn has relied on the emergency room for care. However, as she described, “My shortest wait was eight hours, unless I ride my bike to Our Lady of the Lake, which is a bit too far from the hotel.” Dawn has been unable to see any specialists and noted, “Specialists are what you call the impossible. It’s something you don’t get.”

***“... My level of depression and anxiety and things of that nature are a lot worse because I don’t have the medication.”*** Given her problems obtaining care, Dawn’s physical condition has deteriorated since the storm. Her biggest health problems stem from her

disconnection with her prescription drugs. Prior to the hurricane, she was taking five prescription drugs, including one for her depression. Since the hurricane, the only medication she has been able to obtain is her high blood pressure medication. As she described, “I rode my bicycle to Baton Rouge General and went to emergency and that’s the only one they would give me ... they give me sixty pills, and what I’m supposed to be doing is taking two a day and instead what I’ve been doing is taking one a day ... so the medication will stretch out over a longer period of time.” She also noted that her high blood pressure had become worse since the hurricane due to problems accessing healthy food while living in a hotel. She said, “I try to eat everything I’m supposed to, which I can’t do living in a hotel, it’s impossible ... it’s basically impossible to eat a good healthy meal.”

***“Now that I’m living in a hotel, they’ve cut me off of food stamps completely, except for twenty-nine dollars.”*** Dawn is looking forward to the future with some excitement because the church recently helped her find a house in Baton Rouge to which she will be moving. However, she has financial concerns, noting that much of her food stamp money has been eliminated because of the added money she received through FEMA assistance and that she is unable to work because she is separated from her medications. She is currently relying on her Social Security and FEMA assistance. However, she hoped to get herself settled and reconnected with care. She noted, “I’m just going to have to wait until I get my house straightened and until I’m completely moved in and when I can eat better. I’ll get myself to the Labor Board and start working a side job to pay for a doctor.” On returning to New Orleans, Dawn commented, “I would like to, but I don’t think I’ll ever go back.”

## LINDA

**“I’ve been trying to get my medicine for my diabetes and stuff and since my insurance has stopped, I don’t have anymore.”**

Linda, late 40s, caring for her 12 year-old disabled grandson in Baton Rouge, interviewed January 18, 2006

**“We were doing very good.”** Linda is an African American woman in her late forties. Although she is a widow with grown children, Linda did not live by herself before the hurricane. About a year before the hurricane, Linda started caring for her twelve year-old grandson, whose father was murdered. She also lived with one of her brothers in a rented apartment on the West Bank. With twelve brothers and sisters, Linda had lots of family close by for support. She said, “We were all living around the corner, down the street, across the street from each other.” Linda had a steady income from her job at Winn-Dixie, which allowed her to put a little money aside for savings. About life in New Orleans, Linda commented, “I liked it out there because I was working.”

Both Linda and her brother have diabetes. Linda has several other health conditions, including rheumatoid arthritis and depression and was getting treatment for them. Her grandson’s overall health is pretty good, but his vision is deteriorating because “he was born with one of his eyes not too good” and did not get proper treatment for it at a young age. Because of his vision problems, the grandson qualifies as disabled and receives checks from Social Security. When Linda and her grandson needed to see the doctor, they visited a clinic at the West Jefferson Medical Center. She commented, “I was able to see the doctor whenever I needed to.”

Linda was able to manage her conditions through the health coverage she received from Winn-Dixie. She did face out-of-pocket spending for her prescription drugs and doctors visits, remarking, “Although you have the health insurance, you still always have to pay a portion of it in order to get it.” When Linda took over custody of her grandson, his mother gave Linda a Medicaid card and said, “if you ever need to go to the doctor, just use that little gray card.” Linda was not told that she needed to reapply for Medicaid, and so her grandson’s Medicaid expired before the hurricane.

**“They were going around the neighborhood with bullhorns.”** Having been warned of the potential for flooding in her neighborhood by officials with bullhorns, a small group of Linda’s family waited out the hurricane in a high-rise condominium made available by her brother’s work. When news of the burst levees reached the group, Linda said “we need to go.” After stopping by Linda’s already flooding house to get a few items, they headed directly to Baton Rouge to seek shelter. Linda was able to bring a few things with her, including “my clothes and a couple of pill bottles, that’s about it, some money.” Linda, her grandson, and two others are now living in a small shelter behind a church. This is the second shelter they have lived in since the hurricane. They have no hot water or shower, so they boil water and use “big Tupperware-like tubs” to take a bath. Despite this, Linda thought their situation was better than in the previous shelter.

Since the hurricane, Linda has had difficulty sleeping because of anxiety. She explained, “Somewhere around three or four I will probably drift off, but then I am up at seven because I’ve got to get my grandson to school.” Much of Linda’s anxiety stems from her living situation and lack of a job. Her grandson has also had difficulty adapting to life after the hurricane. Linda observed, “It wasn’t until we got into the other shelter where he had a bed to sleep in that he really started calming down.” She wished her grandson could speak with a counselor. To help her grandson cope, Linda encourages him to write down his problems and feelings. She tries to stay positive in the face of all this, relying on her faith and family to persevere. She said, “I just go ahead and do the things that I need to do and read my Bible. That keeps me going.”

***“I’ve been trying to get my medicine for my diabetes and stuff and since my insurance has stopped, I don’t have anymore.”*** In addition to the emotional challenges arising after the storm, Linda has had a difficult time managing her illnesses. She lost her job at Winn-Dixie after the storm and consequently lost her health coverage, which she discovered when trying to refill her prescriptions. As a result, she has gone without all of her prescriptions since the storm. She noted, “Ever since my insurance stopped, I don’t have any more.” Linda is trying to control her diabetes through better eating habits and said, “You know you need your medicine, you know you need to take it, but then you don’t have it, so therefore you just try to I guess eat right.”

***“I haven’t been able to go to the doctor for it.”*** Linda has also had difficulty getting care for her and her grandson without health coverage. She traveled to the Baton Rouge General emergency room once when her grandson was very sick. She took him early

in the morning to avoid a long wait, and she reports, “They saw me right away.” Another time, when she tried to see a doctor to get her diabetes prescription renewed, she ran into difficulties. She said she was told “you need to get a letter from the shelter stating that you are an evacuee from New Orleans.” Linda plans on applying for Medicaid for herself and her grandson at the welfare office but is not sure of all the necessary steps.

Linda’s lack of access to health care has affected her health. She has had sinus problems that are left untreated and worsen every time she visits her home in New Orleans. She said, “Sinus is real, real bad, was really, really infected and I haven’t been able to go to the doctor for it.” Though she has not had any major complications with her diabetes, she noticed that “I do go to the bathroom more than I ever did, though, because they say that is one of the signs.”

***“My biggest challenge now is getting into a home where we will feel like this is our home.”*** Though Linda would like to one day return to New Orleans, she also sees this as an opportunity for a new start with her grandson. She said, “After his daddy was murdered, I was like you know I really want to go somewhere else and start a new beginning with him. I didn’t want him to be around all that crime.” Linda is focused on making sure her grandson is stable and getting the education he needs and thinks that having a more secure living environment is a key step. Linda also views getting her job back at Winn-Dixie as very important financially and for her health. “If I can start working, I can reestablish myself with the insurance ... if I can go back to Winn-Dixie and they will accept me there, I know that will really, really be a blessing for me right now.”

# MELISSA

**“It is so hard to find anybody...  
especially when you have  
so many medical problems.”**

Melissa, 45 years old, single mother with two sons living in a trailer in New Orleans, interviewed January 30, 2006

***“I had two cars, I had two jobs, and we were living comfortably.”*** Melissa is a 45 year-old white single mother with two sons, 12 year-old Michael and 8 year-old Patrick. Melissa lived in a double-wide trailer in St. Bernard Parish, which is part of the Greater New Orleans area, with her two sons prior to the hurricane. By working hard at two jobs, Melissa was generally able to make ends meet for her family. Her children were happy—“they had their friends, they had their schools, and they got to play in the evenings.”

Aside from “female problems,” Melissa was in pretty good health before the hurricane. Her two sons, however, were receiving treatment for serious chronic conditions. Both sons were born with monotonic dystrophy, a type of muscular dystrophy that can include seizures. As Melissa described, the younger son “has asthma, ADHD, monotonic dystrophy, seizures. He is deaf in the right ear.” The oldest son was also diagnosed at about the age of seven as a bipolar schizophrenic. The boys were taking a number of prescriptions to manage their conditions—seven for Michael and two for Patrick—and had frequent medical appointments. Melissa reports, “My son has always been seen by a psychiatrist, since he has been seven, because he is a schizophrenic bipolar.”

Though Melissa got health coverage through her job with the school board, from birth, both her sons have

qualified for Medicaid coverage based upon their health conditions. Even with all of the health care needs of her children, including monthly psychiatrist appointments for Michael, Melissa never had difficulty paying for their care. “The Medicaid paid for it,” she responded when asked about purchasing the boys’ numerous prescription drugs.

***“I expected to be back in four days.”*** Melissa and her family left their home having packed as much as they could fit into the family van. “I packed four sets of clothes for them, took all their medicines, took my medicines, pulled every picture off the wall, packed it up in a suitcase, loaded up the van and got the dog and the hamster.” Fortunately, Melissa also packed important documents like birth certificates and social security cards. The family traveled to Tupelo, MS, on Sunday of the storm and was able to find a hotel room. Though Melissa expected to be gone only four days, the family stayed at that hotel for over a month. The family received a small FEMA trailer, which is now located on their old property in St. Bernard Parish. Melissa has found a part-time job, but her health insurance through her old job at the school board was scheduled to expire in the summer.

***“My twelve year-old, it has affected him a great deal.”*** In the time since the hurricane, Melissa and her boys’ mental status has declined. Melissa reports, “I

find myself very depressed, more on edge now ... It is like my whole life has just come to a dead end." Melissa does not sleep well at night. However, the storm has been hardest on her older son, who suffers from bipolar schizophrenia. Melissa noted, "My twelve year-old has tried to kill himself due to the storm, being moved around, picked on."

The disconnection from care and from some of his psychiatric medications after the storm was a contributing factor to her older son's decline. Though Melissa took medications with them when they evacuated, Michael went without medicine for his schizophrenia for two weeks because, "at the time, there was no one out there to get it. They didn't have any refills, no doctors." Melissa noted, "... with a schizophrenic when they are out of medicine—even when they are on medicine, they still have episodes. They flicker like a light switch." Melissa was in the process of trying to reconnect Michael with his psychiatrist when the suicidal episode occurred. Michael met with his psychiatrist shortly after the episode and returned to his full regimen of medications.

***"It is so hard to find anybody ... especially when you have so many medical problems."*** Melissa and her family had a difficult time reconnecting with all their providers, including Michael's psychiatrist, after the hurricane. Melissa worked to find providers "through the phone book or word of mouth" to get her sons into treatment again. She tried calling Medicaid to get a list of providers but "could never get through.

Sometimes I would be on the phone four or five times a day, trying to call them." Melissa is still searching for a gynecologist for herself but has finally found providers for her children's medical needs.

***"You don't want to go anymore because of the traveling time."*** Melissa now faces new challenges getting to medical appointments because the providers are scattered across the region. "Before we had everything in a close knit community, it was like the dermatologist, pediatrician, dentist was all right there ... Now we have to travel ... which takes sometimes two hours ... you don't want to go anymore because of the traveling time."

Melissa and her sons have maintained their health coverage throughout the time since the hurricane, which has been helpful in accessing medical care. Melissa was able to replace a breathing machine lost in the storm that manages her younger son's asthma. When asked about out-of-pocket medical expenses she has paid since the storm, Melissa replied "just for my medicine, my copay, that is all, but not for my kids, no."

***"Try not to continue the disruption we already had."*** In the wake of so many changes for her family, Melissa is currently focused on maintaining as much consistency in her family's life as possible. She has been making sure the boys get to bed on time, eat well, and keep up with school. Melissa is currently working part-time and plans to apply for another job.

## MICHELLE

**“Mentally I am tired...  
I’m good one minute and the next minute  
I can plunge.”**

Michelle, 37 years old, living in a hotel room under construction in New Orleans, interviewed February 1, 2006

***“I cry a lot more than I ever cried in my whole life.”***

Michelle is a 37 year-old African American woman with an 11 year-old son, Matt. Michelle moved to New Orleans in 2001 from Chicago, where her mother still lives. A self-described “tomboy,” Michelle was a hard-working, uninsured restaurant cashier before the storm. Though Michelle’s health was pretty good before Katrina, she did have eczema and sinus problems that required medical attention. Michelle also needed glasses to correct her vision.

Despite her lack of health coverage, she had become a savvy health care consumer and was able to navigate the patchwork system of free and reduced-cost charity care that existed in New Orleans prior to Katrina. Michelle received free care regularly at Charity Hospital and could be treated at Charity’s weekly dermatology clinic for her eczema. She also obtained free medications from Charity and several other programs in town and was tied into a free vision screening and glasses program. “[Before Katrina] if you didn’t have insurance, yes you had to wait in a line ... but you get what you need.”

Michelle left New Orleans alone on the Friday before the storm struck and drove toward Texas. Her son was visiting his grandmother in Chicago and her boyfriend, a self-employed tow-truck operator, refused to leave New Orleans. She made it across the border but ran out of gas in the middle of the night after sitting in traffic

for much of the day. After walking five miles and hitchhiking to the nearest gas station, she got her car back on the road and finally arrived in Houston. Once there, however, she had difficulty finding resources for people who had voluntarily evacuated from New Orleans prior to Katrina’s arrival. Without money or a place to stay, she called the police department for help, and eventually found a shelter in a Houston suburb. With most forms of communication taken out by the storm, Michelle spent her first few weeks in Houston alone and worried about her boyfriend’s safety; her son remained safe with his grandmother in Chicago.

***“You could feel the difference in how people treated you.”***

After a month in the shelter, Michelle had reestablished contact with her boyfriend. He reported that their place had flooded, but he was living with neighbors and the towing business was booming. Michelle wanted to return to New Orleans, but, with no place to live, she instead moved to a FEMA-sponsored apartment in Houston and began to look for work. She went on numerous interviews but could not secure a job and felt discriminated against as a Katrina survivor. She sensed that people viewed her as stupid or lazy, and, despite help from several community groups and churches, she could not find a job in the area.

***“I’m displaced, but does that mean I have to accept wherever you want to put me?”***

After three months in Houston, Michelle was able to visit her son and mother

in Chicago, then returned to New Orleans to live with her boyfriend in January. Jobs appeared plentiful in New Orleans since so much of the workforce had left or been evacuated, and reports of signing bonuses and high hourly wages at fast food restaurants were attractive. Housing proved to be more problematic, however. The neighbors who took in her boyfriend did not have room for one more in their FEMA trailer, so he and Michelle set out to find a hotel where they could live and prepare to rebuild their lives. The only availability was in a FEMA-sponsored high-rise hotel that had been under construction with no hot water or working elevators. Michelle and her boyfriend were required to sign a waiver prior to checking in acknowledging the construction and potentially unsafe conditions. “It’s not safe and it’s very hazardous to my health. I got mold on the wall so I am breathing that in every day.”

***“I am so far behind in checks ups, I need a pap smear, I haven’t had one in about two years and I know that is not healthy.”*** In addition to the eczema, sinus and vision problems Michelle had before Katrina, she developed difficulty sleeping, an anxiety around water, and intestinal problems after the storm. Still lacking health coverage at the time of the interview, Michelle had been unable to see a doctor or fill a prescription since the storm. She was unable to find health care while living in Houston and had difficulty navigating the large and unfamiliar city. “I never knew Texas was so big,” she explained.

In New Orleans, the supply of free and lower-cost health services was dramatically reduced. Few clinics were open, and those that were had very limited slots for non-emergency visits. Despite her drive and knowledge of the health care system in New Orleans, every

resource Michelle knew of was unavailable at the time of the interview. As she said, “People are used to be able to go to Charity Hospital.” Even in the case of an emergency, Michelle feared the one emergency clinic that was open in the New Orleans Convention Center: “I don’t want to go in the Convention Center after all the stuff that went down ... I could imagine what’s down there!”

***“I learned from Katrina—budgeting is a whole new concept.”*** The affordability of health care was a critical issue for Michelle. She needed to get new eyeglasses, but she worried about paying for the eye exam. “You can go in there and give him \$20 dollars, you get your eyes examined and glasses. I just haven’t been there, because I really didn’t have it. They say, ‘it’s only \$20 dollars, it’s only \$15 dollars,’ when you are budgeting every cent. I learned from Katrina—budgeting is whole new concept.” Without access to affordable doctors and prescriptions, Michelle has been “trying to home-remedy” herself to manage her health issues.

***“It’s mental issues that is going to come after this ... this wasn’t just your average storm, I got washed out. My thing is who is preparing us for the aftermath?”*** Michelle expressed concern that there were no counseling resources available for the thousands like her who were suffering such great emotional trauma. Michelle was trying to piece her “washed out” life back together; although still unemployed at the time of our interview, Michelle had several job offers and was helping out with her boyfriend’s towing business in the interim. Michelle hoped to leave the unsafe living situation at the hotel for a new apartment soon, though rents had more than tripled since the storm. Michelle predicted that she would eventually leave the area, hopefully, to be reunited with her son Matt.

# SHARONDA

**“Every clinic I go to they say  
we don’t do prenatal care.”**

Sharonda, pregnant mother living with family in a rented house in Baton Rouge, interviewed January 19, 2006

**“It was nice and quiet.”** Prior to Hurricane Katrina, Sharonda lived in New Orleans East with her 3 year-old son Jeb. With just the two of them living in an apartment, Sharonda reflected, “It was nice and quiet. There was no crime or anything.” She worked as a housekeeper at a hotel on Canal Street, earning enough to support a simple life for herself and her son. Sharonda’s mother also lived nearby in New Orleans, and Sharonda felt like she was part of the community there. At the time of the interview, Sharonda was pregnant and due to deliver in late March.

In her job as a housekeeper, Sharonda exposed her hands to harsh chemicals. She reported, “I’ve had problems with my hands because of me doing housekeeping. I get a cyst in it ... the chemicals were strong.” In addition, Sharonda suffers from asthma and occasionally must see a doctor for it. Her son Jeb is generally in good health.

**“I didn’t have a primary doctor. I just went to the free emergency hospital.”** When Sharonda needed to see a doctor, she went to Charity Hospital. Though she sometimes faced wait times over five hours, Sharonda was usually able to get treatment quickly when her asthma flared up. “They’ll see me quick for my asthma,” she explained. Sharonda did not have any health coverage before the hurricane, so she only saw the doctor when she was sick. Knowing the potential for

long waits, she tried to visit the hospital when she did not have to work at the hotel, saying, “Normally when I go, I’ll be off.” Sharonda was not taking any prescription medications. Sharonda did not learn she was pregnant until after Katrina, so she was not receiving any prenatal care in New Orleans before the storm.

Sharonda’s son, on the other hand, had Medicaid coverage and received health care from a private pediatrician. Sharonda reports, “He went to a primary doctor. He didn’t deal with Charity at all.” Sharonda liked Jeb’s pediatrician and never had any trouble with Medicaid paying for services. Because he was starting school in the fall, Jeb was up to date with his check-ups and immunizations shortly before the hurricane. “He got checked up in August because he needed it to start school.”

**“I and my baby were walking in the water on Canal Street. We walked to the New Orleans Superdome.”**

After Katrina hit and the city flooded, Sharonda and her son took refuge at the Superdome, “walking in the water on Canal Street” to get there. Sharonda remembers her time there as “horrible, horrible. No bath, no food.” She stayed there about four days before heading to the Astrodome in Houston on a school bus. The Astrodome was an improvement. Sharonda summarized, “It was good. Air—fresh, clean air—food, water.” After staying at the Astrodome in Houston for

some time, Sharonda and Jeb returned to the Baton Rouge area, traveling between Baton Rouge and Houston regularly. At first, Sharonda stayed with relatives in a dorm room at Southern University and then she moved into a house with her mother, aunt and grandmother. Sharonda reported that their current house, which is down the street from a FEMA trailer park, is “real nice. It’s beautiful.” Sharonda is hoping to work but has not yet found a job.

The disruption in Sharonda’s life following the hurricane has affected her. “I’m not home. I can’t function right. I can’t find a job or babysitter.” Though she was offered counseling services in the Astrodome, Sharonda did not use any. Thankfully, Sharonda reported that her son Jeb is handling life after Katrina well, noting, “He’s fine. He doesn’t really know what’s going on.”

**“He was well taken care of.”** In September, while they were staying at the Astrodome, Jeb got sick. “He was dehydrated, he had diarrhea and vomiting.” Sharonda took her ailing son to an area in the Astrodome designated for medical care where “there were a bunch of doctors.” The doctors told her it was a virus, and Sharonda said her son “was well taken care of.” Since then, Jeb has “been having a runny nose, but that’s off and on.” Sharonda has given Jeb over-the-counter cold medicine to help him feel better.

**“We don’t do prenatal care.”** While Jeb had no trouble getting treated at the Astrodome, Sharonda has had a much more difficult time finding a doctor, especially one for prenatal care. “Every clinic I go to they say we don’t do prenatal care and all this,” she explained.

When she was in Houston, Sharonda was able to make an appointment at a clinic for early December, but when she arrived they postponed the appointment until February. She eventually left Houston for Baton Rouge, where she had recently visited a mobile clinic treating patients at the FEMA trailer park near her current home. The doctors there gave her prenatal vitamins but referred her to the hospital emergency room for further care.

Sharonda has tried to get medical appointments, but her lack of health coverage has been an issue. “I’ve been calling since November to see a doctor. They said they couldn’t see me because I haven’t had Medicaid. So I’ve been waiting for a Medicaid card.” When she was in Houston, Sharonda applied for Texas Medicaid at a food stamps office. When no word of her Medicaid coverage came, Sharonda tried getting in touch with the Medicaid office. She said, “I called. They don’t answer the phone.” During her recent visit to the mobile health clinic in Baton Rouge, where she is now living, a staff person helped Sharonda apply for Louisiana Medicaid. Jeb’s Medicaid coverage has been consistent since the hurricane, and Sharonda said he did not have trouble using it in Texas.

**“I believe in God. I think I’ll be okay.”** Sharonda has a positive outlook for the future, trusting through her faith that she will regain normalcy in her life. Sharonda reported that her next goals are to try to find a job, get Medicaid, and get her son into preschool. She plans to put her son in pre-school in the Baton Rouge area and settle there for awhile, eventually returning to New Orleans once it rebuilds.

## LYNN

**“... You know she comes first.**

**It has to be that way, but it is  
very, very, hard.”**

Lynn, 61 years old, caring for her elderly mother suffering from Alzheimer's in New Orleans, interviewed February 1, 2006

*“Something was going to have to give, we just didn't know what.”* Lynn is a 61 year-old white woman who lived in Metairie with her husband and was caring for her bed-bound, 81 year-old mother prior to the storm. Lynn was already facing very difficult times before the storm. Not only was she struggling with her own health problems, including severe diabetes, but she also was dealing with her mother's multiple conditions, including Alzheimer's, heart and lung problems, and diabetes.

Lynn lived in a house that she and her husband had owned for over 30 years. Her mother lived nearby in her own house. Lynn's mother had a primary care doctor that oversaw and coordinated her care. The family also had a private sitter that came five days a week, and Lynn and her brother rotated nights and weekends providing care. Although Lynn's mother is covered by Medicare and private supplemental insurance, neither the sitter services nor her prescription drugs were covered, and they were a significant expense. The sitter services cost about \$600 per week, and her mother's ten prescription drugs cost \$700 or more per month. These costs were being paid with her mother's savings and with income from a rental property owned by her mother, but they were becoming unaffordable.

Lynn was under significant stress caring for her mother, and it was taking a toll on her health. Prior to the storm, Lynn's doctor told her that she needed to slow down because of the impact on her diabetes. She went on sick leave from her job working with the school system, but she intended to return.

*“We couldn't get her in and out of the car to stop and even to go to the bathroom.”* Lynn and her husband evacuated prior to the storm in a car with her mother. To prepare for the evacuation, Lynn had all of her mother's prescriptions filled and packed all of her supplies, including her wheelchair, potty, walker, clothes, bed pans, and diapers. The evacuation was very challenging, since her mother cannot walk. Lynn noted, “Getting her in and out of the car alone was a horrible experience,” and “I had to take my mom and put her in my car lying down because she can't sit up. We were on the road for 12 hours.”

They initially evacuated to a hotel in Mississippi. However, the hotel suffered damage and they then traveled another 12 hours to a hotel in Alexandria, Louisiana. Throughout these difficult circumstances, Lynn was able to maintain her mother's medications, aided by assistance from drug stores. She said, “The drug stores were wonderful. I just brought the bottles to different places. In fact one druggist I went to ... gave it to me for cost.”

***“She ended up in the hospital from all the stress.”***

Lynn returned to the New Orleans area in late September with her husband and her mother. Her mother’s house suffered significant damage and needed to be gutted. Lynn’s house was damaged but livable, but she did not think it was safe for her mother because it needed to be cleaned out. Thus, initially, her mother stayed with her brother. However, he could not handle caring for her, and she moved over to Lynn’s after several days.

Lynn’s mother began experiencing heart problems from the stress of the situation, and she was taken to the hospital. She stayed in the hospital for two weeks and left with new orders for home health care and oxygen. Lynn noted, “That’s when they put her on oxygen. Now she’s going to have to stay on it.” Her mother returned home for two weeks and then returned to the hospital for another few weeks due to complications with her blood sugar. In addition to her physical problems since the storm, Lynn’s mother has had difficulty understanding what happened. Lynn noted, “Every day I’ve got to go over the same thing over and over and over again. She can’t comprehend even if we tell her, we show her pictures.”

Lynn said the care her mother received in the hospital was what could be expected given the circumstances and the shortage of staff. She described several instances when her mother sat needing changing or other assistance for hours. Her mother’s original primary care doctor oversaw the hospital visits, but, since then, Lynn has had difficulties with this doctor. It took him weeks to call back with results, and he generally was not responsive to Lynn. The home health service nurses caring for her mother eventually helped Lynn find a new doctor, who has helped

stabilize her mother’s medications and been much more responsive.

The new doctor also told Lynn about the new Medicare drug benefit. However, Lynn said, “I haven’t had time to do anything about it or find anything about it.” A friend offered to let Lynn use her computer and to help her figure out the best program for her mother. Lynn noted, “That’s the only way I can do it, because the drug stores ... are so busy ... they don’t have time to help you.” She does not want to ask her doctor for help because she does not want to burden him.

***“I’m going to miss my house.”*** The combination of the stress from the storm and caring for her mother has taken a major toll on Lynn’s own physical and emotional health. Prior to the storm, Lynn was suffering from depression and anxiety, and these problems have gotten worse. One of the main issues Lynn is struggling with is that she and her husband have decided to give up their house and move into her mother’s home since it is better suited for caring for her. Lynn is very sad and emotional about leaving her home, but says “I mean we have to do what we have to do ... We feel like it’s our responsibility.” Lynn’s physical condition has deteriorated so badly that her doctor advised her to go on disability. She said, “I can’t go back to work and my blood sugars are crazy.”

Even in the face of these challenges, Lynn has received very little in terms of assistance. She received food stamps and unemployment for a short period of time following the storm but did not seek further assistance. She said, “I just think there are more people that need it than us and I’d rather them get it. We can survive and we’ll make it.”





## 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.