

# **VOICES OF THE STORM:**

Health Experiences of Low-Income Katrina Survivors



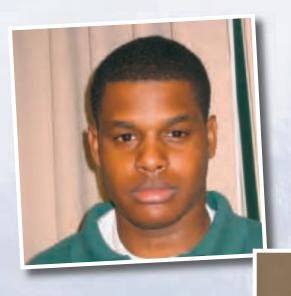




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# Health Experiences of Low-Income Katrina Survivors

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#### **AUTHORS' NOTE**

Some of the names of survivors have been changed to respect privacy preferences.

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#### **FOREWORD**

When Hurricane Katrina breached the levees of New Orleans and ravaged the Gulf Coast, it visited destruction on a part of our country already afflicted by deep poverty and poor health conditions. The storm rendered a major American city uninhabitable and displaced hundreds of thousands of residents, many of whose homes, communities, schools, and hospitals were washed away. The Kaiser Family Foundation responded quickly in the weeks and months following the storm, beginning with a joint survey with the Washington Post and Harvard University, which provided an important profile of Katrina survivors living in Houston shelters. This was followed with briefings, policy briefs, fact sheets, and a new section on kff.org, all focused on documenting the health impact of Hurricane Katrina.

This report is the Foundation's next effort to continue to document Katrina's impact on the people of New Orleans and their health care. It is based on interviews conducted roughly six months after the storm with over forty survivors from New Orleans, including individuals displaced to Baton Rouge and Houston as well as individuals who had returned to the New Orleans area. It provides a vivid and compelling look at the challenges survivors have faced obtaining health care while they attempt to rebuild their lives. This work is complemented by a video available on kff.org, Voices of the Storm: Health Care after Katrina, that documents several survivors' first-hand accounts of their health experiences in the months after the storm and provides insights from local leaders about the challenges of rebuilding the health system. These projects would not have been possible without the contributions of many individuals and organizations in Louisiana, and we thank them for their help. I am especially grateful to the survivors and providers who courageously and candidly shared their very personal and often troubling experiences to support this work.

In addition to these projects, the Foundation will continue to support planning and rebuilding efforts in Louisiana by providing ongoing analysis. The Foundation will also continue to follow and document the experiences of survivors and plans to obtain a more in-depth picture of the health and well-being of survivors through survey work in the fall of 2006—one year after the storm. It is my hope that these efforts will contribute a unique understanding of the impact Katrina has had on the health and well-being of survivors and on the health systems on which they rely to help inform continued responses to this disaster and the nation's ability to address future health care needs.

Drew E. Altman, Ph.D.

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President, Henry J. Kaiser Family Foundation







#### **EXECUTIVE SUMMARY**

Hurricane Katrina caused massive destruction to the Gulf Coast and had particularly devastating effects in New Orleans, where much of the city's infrastructure, including its health care system, was destroyed. Many of the hospitals and clinics in the city were closed, and thousands of physicians were displaced. The extensive Charity Hospital system, which was the primary source of care for poor and uninsured residents, was largely destroyed, and some parts of it may never be rebuilt. Individuals who have returned to the city face the challenge of obtaining health care in a changed community with a crippled health care system. Those displaced to other areas also must navigate an unfamiliar community and health system.

This report provides key findings from interviews with low-income Katrina survivors about their health care experiences after the storm to provide insight into how they fared and to highlight ways to improve the response to this and future disasters. The report focuses on low-income survivors with health care needs from the New Orleans area. These were some of the most vulnerable individuals both before and after the storm and, in addition to their personal losses, they lost much of their community and health care system. The report also includes several in-depth individual profiles of survivors' health care experiences and highlights some specific experiences of individuals with HIV/AIDS. The report is based on in-person interviews conducted with over forty survivors and seven providers serving

survivors, which took place in January–February 2006 (5–6 months after the storm) in New Orleans, Baton Rouge, and Houston. Follow-up interviews were conducted in June 2006 (by phone or in-person) with eight survivors.

#### **Key Findings**

Almost all survivors were suffering emotional and mental trauma. Many said they were anxious, depressed, and having difficulty sleeping and eating. Parents and grandparents said children were crying more easily, acting out in school, and/or becoming more withdrawn. Elderly survivors were particularly traumatized by the loss of connections with family and friends. Few survivors reported receiving formal counseling. Some said they would like to talk to someone but did not know where to turn for assistance. Many said they relied on faith and family for support.

"I still have trouble sleeping and eating. I don't really get an appetite too much anymore. I wake up at three o'clock every morning, sometimes just daydreaming and looking at the walls, just trying to get familiar with my surroundings most of the time."

Tiffany in Houston



Many survivors went without needed health care and medications in the weeks and months following the storm. Most said they experienced gaps in their care, and, six months after the storm, many were still unable to connect with a primary care physician, mental health provider, or specialist. Many were unable to access prescription drugs in the weeks and months after the storm, and some with chronic physical and mental conditions went without critically needed care and medications. A number said their physical or mental health declined as a result. Some of the most vulnerable individuals seemed to be the least connected with assistance, since they were the least able to advocate for themselves and seek help.

"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."

Gertrude in Baton Rouge

The loss of health care facilities and providers in New Orleans made it difficult for survivors to connect with care. Individuals in New Orleans struggled to find operating providers and clinics. Many of the hospitals, clinics, and provider offices upon which they had relied were no longer open or no longer physically existed. Accessing mental health services, particularly inpatient care, was extremely challenging due to lack of providers and psychiatric beds. The loss of health care resources in New Orleans increased demands on physicians and facilities that remained in operation. Individuals and providers reported that the health system in Baton Rouge was overstretched due to the influx of survivors—individuals faced long wait times at emergency rooms and had difficulty locating providers willing to see them, particularly specialists.

"I have a young man in our emergency room that is suicidal and needs medication and a psychiatric bed. We don't have one."

Psychiatric Nurse in New Orleans

Survivors also had difficulty connecting with providers because they lacked transportation and information. A number of survivors said they did not have a car, which made it difficult to get to provider offices or hospitals. Those in New Orleans had very limited public transportation options, and the few providers in the area were widely dispersed. Those in

Houston and Baton Rouge found it difficult to access public transportation, and survivors found Houston particularly difficult to navigate due to its large size. Further, many survivors said they lacked information about what health resources were available. They said there was no formal communication system and that they largely relied on word-of-mouth to obtain information.

"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."

Dawn in Baton Rouge

Uninsured individuals faced some of the biggest problems obtaining care and medications. While some were able to access free care and medications immediately after the hurricane, getting care became increasingly difficult as free emergency resources dwindled. Further, the number of uninsured grew as people lost their jobs and employer-sponsored coverage. With limited finances and uncertain futures, many uninsured survivors said they could not afford doctor visits or medications and were instead trying to self-manage their health. Also, with the loss of many sources of care in New Orleans, including Charity Hospital, many did not know where to turn for care. Those in Baton Rouge and Houston said there were fewer resources for free or lower-cost care in these cities or that they did not know what resources were available.

"If you call the doctor's office and say 'I need to be seen, but I don't have the \$75 to pay for your office visit,' then they're not going to see you. Sorry. If you don't have money you can't come in."

Becca in New Orleans

Survivors with Medicaid fared better, but some experienced problems using their coverage and others were unable to enroll. Having insurance appeared to make a big difference in obtaining needed care. A number of those with Medicaid said they were able to get medications, physician visits, and other care for themselves and their children. Some who evacuated to Texas found Texas providers willing to accept their Louisiana Medicaid, but others said that doctors and hospitals in Texas would not accept Louisiana Medicaid. Some survivors who attempted to

move from Louisiana Medicaid to Texas Medicaid, as well as newly uninsured survivors who sought Louisiana or Texas Medicaid, were unable to enroll because they were not eligible or did not receive a response to their application. Some had been waiting months for a response and were unable to get through when they called to check on the status of their application.

"I had a problem because it was Louisiana Medicaid. I had to apply for it here. A lot of people ... wouldn't even take Louisiana Medicaid."

Brenda in Houston

Many survivors were still trying to meet their basic needs, making it difficult to focus on their health care needs. Six months after the hurricane, most survivors were living day-to-day, unable to make long-term plans. A few described their living situations as "inhuman" and complained of mold, no hot water, too many people in too-small spaces, and unsafe situations. A number said they went hungry immediately after the storm, and a few said they were still not getting enough to eat. Money was running short for many, and a large number were waiting for resolution with their insurance company or FEMA over their lost homes and belongings. Unstable living situations also made it difficult to seek employment. Most survivors tried to remain focused on making a new beginning and reestablishing themselves, but it was difficult for them to do so in the face of these major challenges.

Nearly a year after the storm, the situation for some survivors had improved while others continued to face significant challenges. Follow-up interviews were conducted with a subset of survivors in June, nearly one year after Katrina. For a few, their housing or employment situation improved, and some were able to connect with providers for needed care, although these connections were tenuous. For others, life remained at least as challenging as in January or became even more difficult. Those who were uninsured continued to describe major problems connecting with care due to long waits, limited health care resources, and unaffordable costs. In addition, unsettled housing situations continued to cause stress and anxiety, as some were still living in temporary arrangements, such as a hotel, shelter, or trailer. While some maintained a positive outlook for the future, the cumulative effects of a year filled with uncertainty, loss, tough decisions, and separation from family were causing others to lose hope.

#### **Lessons Learned**

The experiences of these 44 survivors highlight the immediate and longer-term struggles low-income Katrina survivors from New Orleans faced getting needed care and medications. Several key lessons can be drawn:

Continued efforts are needed to connect people with critically needed care and medications. In the wake of the destruction of much of the health care system in New Orleans, the health care response left significant gaps in care. Many survivors did not receive needed care or drugs for days, weeks, and months, which led to the deterioration of both physical and mental health conditions. In addition, almost all survivors suffered new emotional and mental trauma from the storm, but very few received formal counseling. While emergency resources that were in place immediately after the storm helped some, it became increasingly difficult for people to access care as resources dwindled over time. Close to a year after the storm, some survivors still faced major challenges. As such, continued, long-term efforts are needed to address the health needs of survivors and connect them with care.

Response efforts must include a special focus on the most vulnerable individuals. Some of the most vulnerable survivors, including elderly individuals, a person with developmental disabilities, and children, were not connected with care or assistance. These individuals were the least able to advocate for themselves and seek assistance, and, in some cases, they had lost connections with important social, family, and/or provider supports. These findings highlight the need for continued outreach efforts to these individuals. They also illustrate the importance of developing a system prior to a disaster to monitor what happens to the most vulnerable individuals in a community and providing targeted outreach efforts to these individuals following a disaster.



Providing broader access to health coverage after the storm could have eased some of the access problems faced by survivors. Uninsured survivors experienced particularly acute problems obtaining care because they could not afford care, they had difficulty finding sources of care due to the loss of the Charity Hospital system and many other providers and health facilities, and the providers and facilities that remained in operation were overwhelmed. Survivors with Medicaid fared better. However, some in Houston had problems using their Louisiana Medicaid, and some survivors were unable to enroll in Louisiana or Texas Medicaid because they were not eligible or did not receive a response to their application. The federal government allowed states to make temporary Medicaid coverage available to limited groups of survivors. However, many survivors were ineligible for the coverage because it was limited to existing Medicaid income eliqibility levels and categorical groups, which do not extend to adults without dependent children. Further, to access the temporary coverage, eligible survivors from Louisiana who were displaced out-ofstate had to go through the Medicaid enrollment process in the state in which they were residing. A response that would have provided coverage to a broader set of survivors and transferred more easily across state lines may have eased some of the access problems reported by survivors.

Recovery will require long-term rebuilding efforts and short term assistance. Those who returned to New Orleans struggled to obtain health care in a crippled health system. It was difficult for them to find care due to the loss of many sources of care, including much of the Charity Hospital system. Those displaced to Baton Rouge faced an overburdened health system, and those displaced to Houston had to navigate a large and unfamiliar community and health system. Beyond these problems, some survivors had difficulty focusing on their health needs because they were struggling to meet their basic needs, such as housing and food. Further, many lacked transportation to get to providers or information about the limited health resources that were available. These findings show that response efforts must address a broad-ranging set of access barriers and illustrate the importance of integrating information on health care resources with information on housing, jobs, child care, food, and transportation. The findings also show that recovery will not only require short-term assistance but longterm rebuilding of the health system and efforts to provide primary, specialty, and emergency care while the system rebuilds.



## **VOICES OF THE STORM:**

Health Experiences of Low-Income Katrina Survivors

#### Introduction

Individuals and families impacted by Hurricane Katrina continue to face enormous challenges, and their ability to access needed health care is an ongoing problem and important piece of the story to tell. This report provides key findings from interviews with Katrina survivors about their health experiences in the months after the storm to provide insight into how they fared and to highlight ways to improve the response to this and future disasters. The report focuses on low-income survivors with health care needs from the New Orleans area. These were some of the most vulnerable individuals both before and after the storm and, in addition to their personal losses, they lost much of their community and health care system. The report includes several in-depth individual profiles of survivors' health care experiences (see pg. 19) and highlights some specific experiences of individuals with HIV/AIDS (see pg. 37).

Hurricane Katrina brought massive destruction to the Gulf Coast and had particularly devastating impacts in New Orleans, where flooding destroyed lives, homes, and the city's infrastructure, including much of its health care system. The impact on the people in Louisiana was stark. Over 1,500 lives lost, hundreds of thousands of people displaced, over 200,000 homes damaged or destroyed and jobs lost, and thousands of businesses destroyed (Table 1).

# Table 1 Katrina's Impact on People in Louisiana

More than...

1,500 Lives lost

780,000 People displaced

200,000 Housing units damaged or destroyed

220,000 Jobs lost

18,700 Businesses destroyed

Source: Louisiana Recovery Authority 2006 *Quarterly Report: February-May,* June 2006. Figures include impact of Hurricane Rita.

The impact on the health care system in New Orleans was also devastating. Many of the city's hospitals and clinics were destroyed or closed after the storm, and thousands of physicians and health workers were displaced (Table 2). Months later, many health care facilities remained closed and few physicians had returned. Much of the Charity Hospital system, which was the primary provider for the city's large poor and uninsured population, was destroyed. The closure of hospitals and facilities and loss of physicians and other health personnel shifted inordinate demands to those in other areas, such as Baton Rouge, and those that remained in operation or struggled to reopen within New Orleans.



# Table 2 New Orleans Health System Before and After Katrina

	Before	Six Months After
Staffed inpatient beds	2,269	453
Safety-net clinics	90	19
Physicians	2,664	1,200
Emergency Medical Services units	15-17	7
Nursing home providers	51	29
Nursing home beds	4,954	2,735

Note: Data are for Orleans Parish, except for nursing home data, which is for the New Orleans region.

Sources: Louisiana Department of Health and Hospitals, *Hurricane Recovery Plans*, April 2006 report and March 2, 2006 presentation; PriceWaterhouse Coopers report for LRA Support Foundation, April 2006.

#### **Methods**

In January-February 2006, about five to six months after the storm, over forty structured interviews were conducted with Katrina survivors who had resided in the New Orleans area prior to the storm. They took place in New Orleans and in Baton Rouge and Houston, two cities that received large numbers of survivors displaced from New Orleans. The interviews focused on low-income uninsured individuals and Medicaid enrollees with health care needs, as well as a subset of individuals with HIV/AIDS (see Appendix A for key demographic and health characteristics of all respondents). Seven health care providers serving survivors were also interviewed, including a pediatrician, a psychologist, a psychiatric emergency room nurse, an HIV/AIDS specialist, and several primary care providers. In June 2006, follow-up interviews were conducted (by phone or in-person) with eight survivors to determine how their situations had or had not changed since the initial interviews.

#### **Key Findings**

#### **Emotional Trauma**

# Almost all survivors were suffering emotional and mental trauma from the hurricane.

Their stress took various forms and some were doing better than others, but many survivors were experiencing anxiety, depression, and problems sleeping and eating. Annie in Baton Rouge said she had insomnia since the hurricane and that "I go days without sleep ... It's just terrible." Bob, who had returned to New Orleans, said he was "using medicine to cope ... and put me to sleep." Maureen, also in New Orleans, said, "I go to bed at night really not knowing if I will get up in the morning. I get upset very easy when I talk about [the hurricane]." Maureen described, "I wake up nights, literally hearing strong winds, things hitting windows, it is just something that is there, and I think it stays with you for a long, long time." A psychiatric nurse also described the mental trauma people are going through, noting that, "people have lost a fundamental sense of security."

"I still have trouble sleeping and eating. I don't really get an appetite too much anymore. I wake up at three o'clock every morning ... just trying to get familiar with my surroundings most of the time."

Tiffany in Houston

Parents and grandparents said that children were feeling the effects too—they were crying more easily, were acting out in school, or had become withdrawn. Maureen said the granddaughter she is raising had become "very withdrawn, she doesn't want to leave



[my side]. She cherishes everything that she has right now." Tiffany in Houston said her son, "tosses and turns so much throughout the night," and "if I leave him for more than a couple of hours he just has a fit." Crystal in New Orleans said, "My three year-old is more active than he was before the hurricane came. He's very, very antsy. I need something to calm him down." A pediatric psychologist said she had seen an increase in post-traumatic stress disorder and behavior problems among children survivors.

# The loss of connection with family and friends was particularly traumatic for survivors.

Many survivors had strong and large networks of family and friends that provided support and a sense of community in New Orleans. A number lost contact with family and friends in the weeks and months following the storm and did not know whether they were safe. Some still had not reconnected with family members at the time of the interviews. For many, especially the elderly survivors, the loss of a sense of community was difficult to bear. As Leonard, a 65 year-old survivor described, "It is definitely a step backwards ... We were settled and set-in ... . We had paid our dues and I had been teaching for 32 years ... and I was born and raised in New Orleans ... I am expecting to go back, but this drastic change took a lot out of me and took a lot out of my wife." Similarly, Hattie, an over-65 survivor, said, "You have struggled in order to try to get things and live peaceful as you get older, and then something like this happened ... it really is heartbreaking." Younger survivors were also troubled by the loss of connections. Raynelle in Baton Rouge noted, "my biggest challenge that I face since the hurricane is like missing all of my friends, ... my praying partners, my friends who gave me encouragement."

# Some survivors wanted to talk with someone about their feelings but did not know where to turn.

Jeff in New Orleans thought that he might benefit from talking with a mental health professional but had no idea how to find such a person. Annie in Baton Rouge said, "I really want to find somebody just to kind of like just talk to right now." Elizabeth in New Orleans noted, "I got to find me a mental health unit there or a psychiatrist ... I mean, I've got to go because I just get real depressed." Lachelle in New

Orleans said, "My 11 year-old needs mental health counseling. I don't know where to put him."

"Sometimes I think maybe I could talk to someone to see if I am functioning the way I should be, because I just spent a lot of days in a hotel doing absolutely nothing. So I am very concerned about that."

Pearl in Baton Rouge

# The faith community played an important role in providing emotional and social support.

Many survivors said their faith helped them through the hard times after the hurricane and remained an important source of strength six months later. As Linda noted, "I just go ahead and do the things that I need to do and read my Bible. That keeps me going." May in Houston joined a church, which provided her some one-on-one counseling. She said, "I've been blessed to have all of that provided to me through the church." The church also played a critical role in connecting survivors with social supports, food, clothing, and even housing. Becca in New Orleans said that Catholic Charities offered "all kinds of brochures, crisis hotlines, and stuff like that." Tiffany in Baton Rouge received food and clothes through a local church. Some survivors said they participated in lunch and dinner programs at their local churches.

"I mean I guess that's what's helped me get through it ... God."

Elizabeth in New Orleans

#### **Gaps in Care**

# Many survivors experienced serious and persistent gaps in care.

Almost all survivors said they lost touch with their health and mental health providers because of the storm. Many still had not connected with a provider or obtained needed care at the time of the interview. This caused serious problems for those with chronic physical and mental conditions. Many felt their health had worsened as result of going without care. Survivors with diabetes and high blood pressure explained that they tried to manage their health conditions on their own but that it was hard to do when living in shelters,





hotel rooms, or FEMA trailers. Some with diabetes and high blood pressure reported problems with "sugar levels" and "pressure." One survivor complained of new tingling in her legs and worried it was her diabetes. Some survivors were just beginning to connect with a provider six months after the storm, but many were still outside the health system. Most of the "unconnected" were uninsured.

Some of the most vulnerable survivors were disconnected from their providers and family and friends. They were the least able to advocate for themselves and seek assistance, and it did not appear that anyone was reaching out to them to provide help. Gertrude, who has had developmental disabilities since birth, had been separated from her mother (her legal guardian) since the hurricane and was living with her boyfriend in Baton Rouge. Without her mother or a health provider watching over her, Gertrude was not getting medical care or medications for her diabetes, high blood pressure, and asthma. She went to the emergency room to get refills but was declined because she could not recall the names of her medications nor did she have her old prescription bottles.

"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."

Gertrude in Baton Rouge

#### Many could not get their prescription medications.

Almost all survivors said they took at least some of their medications with them when they evacuated, but many ran out within days and weeks. There were some emergency resources in place, such as waived copays and pharmacies providing free refills for empty pill bottles, which helped some survivors. Additionally, the federal government took steps to centralize and make available electronic records from large chain pharmacies and other health care providers to assist in providing medications and care to survivors. This was helpful to some survivors who had records in the system. As Raynelle in Baton Rouge noted, "all you had to do was call ... and they would refill your medication without prescription, as long as it was in the computer." However, others said they were unaware of these resources or did not have empty bottles with them to get refills. A few taking pain medications found providers reluctant to refill them without a prescription. Some of the mobile units and other makeshift clinics created after the hurricane lacked enough supplies to fill prescriptions. Some survivors also moved around so much there was no time to fill prescriptions, while others assumed they needed to talk to a doctor before filling a prescription but were unable to connect with a doctor.

"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."

Dawn in Baton Rouge

Consequently, many survivors did without their medication or tried stretching them out or sharing with others. Dawn in Baton Rouge described, "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." As a result, her blood pressure problems have worsened. Similarly, Becca in New Orleans said, "I know you're supposed to take it every day, but I feel like as long as I take it every two days there's enough in my system to where I can feel it." Two individuals said they had seizures because they could not get their anti-seizure medications. Three survivors with HIV/AIDS said their T-cell counts went down because they ran out of their antiretroviral medications. One explained that the local hospital in the small town where she was staying did not have the antiretroviral medications she needed.

Six months after the storm, problems obtaining prescription drugs continued for survivors, particularly the uninsured. Free emergency refill services were no longer available and cost had become a major barrier. For example, Janetta in Houston was not able to fill an \$85 prescription to treat an allergic reaction until a stranger stepped forward and paid for it. Lynn in New Orleans paid \$200 for a prescription a few days before she was interviewed, and she said she could not afford to pay that amount much longer. Tina in New Orleans said she was not able to refill a prescription because she could not afford the \$120 for the drugs or the \$65 for a doctor visit to get the prescription.

# People with pre-existing mental health problems experienced major problems due to gaps in care and drugs.

Some survivors with mental health conditions that existed prior to Katrina explained that the combination of going without medications and not seeing their mental health providers—as well as the stress and uncertainty in the hurricane's aftermath—have worsened their conditions. These included individuals with bipolar disorder, depression, schizophrenia, and anxiety issues. A psychiatric nurse in an emergency room described, "What I have seen, are people in desperate shape, who have had mental issues before but seem to have deteriorated because of lack of medication."

"What I have seen are people in desperate shape, who have had mental issues before but seem to have deteriorated because of lack of medication."

Psychiatric nurse in New Orleans

Bob in New Orleans, who suffered from depression and bipolar disorder prior to the storm, went six months without treatment. He was able to get his medications during this period but said he was taking a larger dose of his anti-depressants than he was supposed to and was also taking sleeping medications regularly. Elizabeth in New Orleans went two weeks without her medications for her bipolar disorder. The result was that she felt like she was "going crazy" and "teetering" every time she tried to walk. Peter in Baton Rouge went four weeks without his anxiety medicine and had two seizures before he could get a refill from an emergency room. Melissa in New Orleans lost touch with her older son's psychiatrist during the evacuation, and, as a

result, her son went two weeks without medications for his schizophrenia. This led to severe behavior problems with her son and self-inflicted injuries.

"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 in Baton Rouge

#### **Barriers to Care**

The loss of providers and health care facilities in New Orleans left few sources of care for survivors and increased demands on providers and facilities that remained in operation.

In New Orleans, many of the hospitals, clinics, and provider offices were no longer open or no longer physically existed, including much of the Charity Hospital system. Further, thousands of physicians were displaced from the area. While some clinics and offices had reopened in new locations-such as the HIV Outpatient program (HOP) clinic-many survivors did not have this information. As such, they did not know where to turn for care. A provider who worked at the HOP clinic said they had a hard time getting the word out that they had reopened. One pediatrician who had returned to New Orleans explained that not only his office and equipment were lost but all of his medical records. He was sharing office space in the suburbs of New Orleans but had lost touch with most of his clients, and his practice had shrunk to a small fraction of what it had been. He was unsure if he would remain in New Orleans and said that many of his peers would not return.

A primary care provider reported that mental health needs were still tremendous months after the storm and there was a lack of providers as well as hospital beds to treat individuals with severe mental health needs. A psychiatric nurse in an emergency room also noted that, "all of the psychiatric hospitals literally were closed, and most have not reopened." She described how the lack of beds has led to severe psychiatric cases being held in the emergency room for days, noting, "I have a young man now in our emergency room that is suicidal and needs medication and a psychiatric bed. We don't have one."



"I have a young man in our emergency room that is suicidal and needs medication and a psychiatric bed. We don't have one."

#### Psychiatric Nurse in New Orleans

The loss of resources in New Orleans increased demands on physicians and facilities that remained in operation. In Baton Rouge, the health system was overstretched due to the influx of survivors. A number of survivors described very long waits in emergency rooms. For example, Chantrice in Baton Rouge said, "We went to the emergency room and sit there about four or five hours." One primary care provider explained that Baton Rouge "has not been able to absorb" the survivors—that it lacks the health care infrastructure needed to care for so many. Another provider commented that Baton Rouge received many of the sickest and neediest of residents from New Orleans.

"We called around some private places to see whether or not they would take people and what the situation was. Some of them wouldn't take people, even if they had Medicaid."

#### Nurse in Baton Rouge

It was not only difficult to locate operating providers and facilities, but it was also difficult to find doctors willing to see low-income Katrina survivors. A provider at a mobile health clinic in Baton Rouge described, "We called around some private places to see whether or not they would take people and what the situation was. Some of them wouldn't even take people, even if

they had Medicaid." Finding specialists, including obstetricians, cardiologists, and cancer specialists was particularly difficult. Dawn in Baton Rouge noted, "Specialists are what you call the impossible. It's something you don't get." The mobile health clinic provider further explained, "Pregnant women, that's a category in itself. We've had tremendous issues in terms of trying to get women who are pregnant into care. People have not wanted to take them." Sharonda, a pregnant woman in Baton Rouge also noted, "Every clinic I go to, they say we don't do prenatal care."

# Many survivors had difficulty obtaining care due to a lack of information and/or transportation.

Across the locations, most survivors felt they lacked information about what resources were available. They were unsure of where to turn for answers and felt very much on their own. While information and other assistance were available in the weeks and months after the hurricane, there seemed to be no formal communication system, and survivors obtained information haphazardly. They reported that the information they found in shelters, hotel lobbies, churches, FEMA trailer parks, emergency rooms and health clinics was not organized, user-friendly, or immediately helpful. Word of mouth seemed to be the main way survivors obtained information. Many said they formed close bonds with fellow survivors and that there was extensive sharing of information. Those who stayed in shelters seemed to get information and assistance more easily. May in Houston and Camille in Baton



Rouge said they did not go to shelters and had to do more searching on their own. To get information and assistance, it seemed survivors needed to ask a lot of questions, call phone numbers or seek out information online, and sustain efforts in the face of frustration and long waits. Those who were not able to take these steps appeared to have more difficulty connecting with information and help.

Further, survivors said getting to and from doctor appointments, pharmacies, health clinics, and emergency rooms was difficult, because many did not have cars. In New Orleans, public transportation was no longer reliable or as extensive, and the remaining doctor offices and clinics in the area were widely dispersed. As Melissa in New Orleans described, "Before we had everything in a close knit community, it was like the dermatologist, pediatrician, and dentist was all right there ... now we have to travel ... which sometimes takes sometimes two hours ... you don't want to go anymore because of traveling time." Survivors explained that the communities and health systems in Houston and Baton Rouge are spread out and that the cities lack extensive public transportation. Transportation in Houston seemed a particular challenge, since the city is much larger than New Orleans. It was very difficult for survivors to get around without a car, and some survivors said it was hard to find their way around even after months of being in the city. Tiffany in Houston said, "Everything is so far ... I mean I have transportation but it's trying to find your way around."

"You don't want to go anymore because of traveling time."

Melissa in Houston

# Uninsured survivors fared some of the biggest problems obtaining care and medications.

Initial emergency health services set up after the hurricane provided free care and medications to some survivors. For example, some shelters had medical professionals on-site and many of the large drug stores provided free refills for survivors who had pill bottles. However, as emergency services dwindled, it became increasingly difficult for survivors to obtain needed care or prescription drugs, particularly uninsured survivors. Further, the number of uninsured grew as people



lost jobs. Some interviewed survivors had already lost their jobs and employer-sponsored health insurance. As Tiffany in Houston noted, "The day I stopped working was the day my insurance was cancelled." A number of others said they expected to lose their jobs and health coverage in the near future.

"If you call the doctor's office and say 'I need to be seen, but I don't have the \$75 to pay for your office visit,' then they're not going to see you. Sorry. If you don't have money you can't come in."

Becca in New Orleans

Whether long-term uninsured or newly uninsured, those without coverage had major difficulty obtaining care in the months following the storm. According to survivors, having health insurance mattered a lot post-Katrina. For those without coverage, cost was a big barrier to care. A number of the uninsured said they could not afford a doctor visit, an emergency room bill, or prescription drugs. Tiffany in Houston described her experience seeking care from an emergency room, noting, "They told me because we were from Louisiana ... and if you didn't have any insurance you had to pay up front." Linda in Baton Rouge lost her job and consequently lost her health coverage. She said, "I've been trying to get my medicine for my diabetes and stuff, and since my insurance has stopped, I don't have anymore. You know you need your medicine, you know you need to take it, but then you don't have it." Jarvis in Baton Rouge was suffering from a "mental disturbance" since the hurricane but could not afford an office visit to a mental health provider. Pearl in Baton Rouge chipped her front tooth



during the evacuation but could not find a dentist she could afford.

Some of the uninsured survivors had obtained health services and were facing large medical bills they could not afford. For example, Tiffany in Houston, who was waiting to learn if she qualified for Medicaid, had incurred over \$400 in medical bills since the hurricane; Gwen in Houston had a \$200 charge for using the emergency room that she could not pay; and Patti in New Orleans was paying off emergency room bills of \$430 for herself and \$240 for her grandchildren.

The difficulties faced by uninsured survivors who returned to New Orleans were magnified by the loss of providers, clinics, and hospitals, including much of the Charity Hospital system, which was a primary source of care for low-income uninsured individuals. Some survivors said they did not know where to turn for affordable care, and some survivors and providers said it was only possible to get basic care as opposed to the broader services, including specialty care, that had been provided through Charity. Uninsured survivors in Baton Rouge and Houston faced similar challenges because they were unfamiliar with the resources for free or low-cost care in these cities.

"I know that if you went to Charity and there was something wrong with you that you weren't leaving until Charity found out what was wrong with you." May in Houston

# Survivors with Medicaid fared better, but some experienced problems using their coverage.

Medicaid coverage worked well for some survivors; they were able to get medications, physician visits, and other care for themselves and their children. For example, Annie in Baton Rouge said her Medicaid enabled her to get prescriptions filled with little cost and to visit a doctor to discuss her back problems. She said, "Medicaid helped out a lot with that after the hurricane ... it just worked out with the situation."

However, some survivors who were displaced to Houston experienced problems. Some found providers willing to accept their coverage, and a few were able to successfully enroll in Texas Medicaid. However, others were told that their Louisiana Medicaid did not work in Texas and that they needed to apply for Texas Medicaid. Brenda in Houston said when she tried to see a doctor, "I had a problem because it was Louisiana Medicaid. I had to apply for it here. A lot of people ... wouldn't even take Louisiana Medicaid." This also happened to Maria in Baton Rouge, a pregnant mother who was deaf and had evacuated to Houston with her husband and young son. While there, she learned her Louisiana Medicaid was not valid and that she needed to apply for Texas Medicaid. Gwen in Houston said her children's Louisiana Medicaid was not accepted by a Houston provider and she had to pay out of pocket for the care.

"I had a problem because it was Louisiana Medicaid. I had to apply for it here. A lot of people ... wouldn't even take Louisiana Medicaid."

Brenda in Houston

# Some survivors applied for Medicaid but were not enrolled.

Some survivors who tried to transition from Louisiana Medicaid to Texas Medicaid as well as newly uninsured survivors who sought Louisiana or Texas Medicaid were unable to enroll—they were either not eligible or did not receive a response to their application. Gwen in Houston applied for Texas Medicaid after she was told her Louisiana Medicaid would not be accepted, but she had not yet received a response. When she called to get an update on the status of her application, "the line is always busy." Patrice, also in Houston, said, "I went to apply for Medicaid but they gave me an appointment letter, so I have to wait maybe two, three weeks just to get an appointment." Becca in New Orleans applied for Medicaid a couple of months prior to the interview but said, "I sure haven't heard anything back from them." Raynelle in Baton Rouge said, "I applied for that and they told me I couldn't get it because I didn't have anybody that was sick. I said, well, I'm sick I need help right now for a couple of months."

## Some enrolled in Medicare Part D in the period after the storm.

Survivors enrolled in Medicare had the extra challenge of making decisions about Medicare Part D during this period. Part D is the new drug benefit offered by Medicare. Beneficiaries had to choose a prescription drug plan by May 15, 2006 to avoid a late enrollment penalty. In June 2006, the deadline was extended to December 31, 2006 for people affected by Katrina. For the most part, survivors who were Medicare beneficiaries seemed confused about the enrollment process and many had not received any information about the plans being offered, likely due to their displacement and/or disruption of the mail service in the New Orleans area. Maureen in New Orleans said, "The only thing I know is I think that Medicare is supposed to have a supplement prescription deal, and I haven't heard anything else about it. Before the hurricane and all, they had said they were going to send forms to fill out for you to choose—I never did get them."

Some had been enrolled in a prescription drug plan and had already used their plan at the time of the interview. While one beneficiary had not encountered any problems using his plan or noticed any differences, Hattie in Baton Rouge and Elizabeth in New Orleans both said their prescription drug costs had risen since being enrolled in Part D. Elizabeth also described difficulty making a decision about her drug plan due to out-of-pocket costs in the plans. She said, "it's the prescription plan I'm having problems with ... on the back of the pamphlet there are all of the different companies that I can pick from ... but I only get \$622 a month and I can't afford to pay a deductible of \$250."

#### **Living and Financial Situations**

# The health challenges survivors faced were complicated by unstable living situations.

At the time of the interviews, many survivors were still living in hotel rooms, with relatives, or in FEMA trailers. Few were in apartments or homes of their own, and most were tiring of temporary housing. Many had moved multiple times, which made it hard to establish a routine. Pearl in Baton Rouge was in her eighth hotel room since the hurricane. Some survivors said they were crammed into too-small hotel rooms, trailers, and apartments. Chantrice in Baton Rouge had ten people living in her temporary two-bedroom apartment. Others said their living conditions were not "fit for humans." For example, one survivor said his hotel room had no running water while a few were living in apartments still under construction. Two survivors said they had mold in their hotel rooms.

Also, a few said they felt unsafe in their temporary housing and unfamiliar communities. Two revealed they had been victims of assault at their hotels.

"... You get frustrated when you come here and see that you don't have a place to live. The hotel where we stay doesn't have hot water. You just can't get used to living in a hotel eating canned food and sandwiches. We need a hot meal."

Crystal in New Orleans

Making matters worse, a number of survivors felt they were getting the "run around" from FEMA about getting a trailer. Some were promised trailers that had not arrived. Others complained of the rules and administrative hassles they had to deal with in order to get a trailer. With the deadline for their hotel rooms looming, some were worried they would become homeless. Affordable apartments and housing were hard to find. Some said that landlords had raised rents even on run-down properties because there was such high demand.

#### Finances were a top concern.

Before Hurricane Katrina most of the survivors said they were getting by financially; most were working hard and had a strong network of family and friends that helped in times of need. However, few seemed to have savings that could get them through tough times. Since the hurricane, many families were dispersed. Many survivors lost what they had—their homes and possessions—and had little financial resources left six months after the storm. They said they were in "limbo" until they had resolution with FEMA or their insurance companies to settle their claims.

Most received initial financial payments and vouchers from FEMA that they used to pay for their immediate expenses like food, clothes, and rent. But this financial assistance was ending at the time of the interviews. Many survivors were laid off by their former employers and had no new job leads. Since they were still unsure about their living situation and their resolution with FEMA and insurance, they said it was hard to pursue a new job, although, for a number, getting a job was a top priority. Linda in Baton Rouge said, "If I can start working, I can reestablish myself with the insurance ... that will really be a blessing for me right





now." Annie in Baton Rouge said, "... I really want to work because it's the only thing I've ever known." Mothers of young children were especially frustrated about finding work because they were not finding many child care options, particularly in Baton Rouge.

"If I can start working, I can reestablish myself with the insurance ... that will really be a blessing for me right now."

Linda in Baton Rouge

# Some survivors went hungry, and those living in hotels and shelters found it difficult to get healthy meals.

Some went hungry immediately after the hurricane, running out of cash and unable to afford food. A few survivors were still going hungry months after the storm because of finances. Those with food stamps said the assistance has been helpful. Many also appreciated the emergency food stamps provided after the hurricane but wished that program lasted longer.

"I didn't have no money to get nothing to eat, so I use to have to borrow money from people at the hotel to get something to eat until I get the money from FEMA."

Gertrude in Baton Rouge

Many others were facing problems preparing healthy food. Those living in hotels said they could not cook hot food in their rooms and had to rely on fast food and canned food for every meal. Survivors in shelters experienced similar problems. This was problematic for those with diabetes, cholesterol issues, and high blood pressure, who need controlled diets to maintain their health. A number of survivors said they gained weight since the hurricane because of poor diet.

#### **Future Outlooks of Survivors**

Some were trying to be positive as they looked ahead, but most did not have a clear plan of action.

Some survivors were trying to put the hurricane behind them and be optimistic about the future. Brenda in Houston, for example, said, "I really feel that it's going to get better." Similarly, Annie in Baton Rouge said, "I'm trying so hard to find positivity in everything that I do and I go through." Many were focused on making a new start and reestablishing themselves, but, at the same time, most appeared lost and confused. They were waiting for information, help, or some direction before making decisions about the future. Some were surprised and frustrated by their inability to make decisions. Lachelle in New Orleans described, "I don't even know what's going on from one day to next. I can't really make any plans until I know what the government's going to do."

"I don't even know what's going on from one day to next. I can't really make any plans until I know what the government's going to do."

Lachelle in New Orleans

Even while they wait, many were aware that time was running out to make decisions about the future. They would be kicked out of their hotel room or other living arrangement, they would run out of money, their health would decline further, or something else would happen to force a change. Resolution of their insurance and FEMA claims seemed critical for some to plan for the next phase of their life. These factors will determine where they go to live, where they enroll their kids in school, what job they pursue, and if they will have resources.

## Many were not planning on returning to New Orleans.

Many survivors who had left felt the city was too damaged to return. "There is nothing there now. Nothing. It looks like a war-torn country," explained Chantrice from Baton Rouge. Camille in Baton Rouge said, "Based on what we're hearing, it's going to take another five years to get it back to where it was." Some were worried about the air and water quality in New Orleans. Gwen from Houston said, "Every time I go down there I'm getting sick. I'm feeling that it's toxic. So for me to go live down there, it's just like me trying to kill myself." Others felt that life in New Orleans after the hurricane would be hard for someone with a chronic illness—finding new doctors, getting around town, and getting their medications would be more difficult. Some with chronic health conditions said they were not planning to return to New Orleans until they know the health system is up and running. That was the case with Derek, who has HIV and was living in Baton Rouge. Even those interested in returning to New Orleans felt that work would be difficult to find and explained that rents had skyrocketed since the hurricane. With no job or place to live, they were likely to settle elsewhere.

#### Nearly a year after the storm, the situation for some survivors had improved while others continued to face major challenges.

Follow-up interviews were conducted with a subset of survivors in June, nearly one year after Katrina. For a few, their housing or employment situation improved. For example, one finally received a FEMA trailer, which enabled him to stay on his property in New Orleans while he worked on repairing his house. Another had returned to her home in New Orleans and had finished repairs to much of the house. A third reported that her work was picking up, which was a help to her finances. Some were able to connect with providers for needed care, although these connections were tenuous. For example, Linda in Baton Rouge finally received notice



that she had been enrolled in Medicaid, and she was able to visit a physician and get the medications for her diabetes that she had gone without for months. However, she will need to renew her Medicaid enrollment in August, and she is concerned about what will happen if she loses the coverage.

For others, life remained at least as challenging as in January or became even more difficult. Those who were uninsured continued to describe major problems connecting with care due to long waits, limited health care resources, and unaffordable costs. Patti in New Orleans put off seeking care for a fever and illness because she was concerned about the cost of care and did not know of any affordable places to go. Her situation worsened, and she eventually had to seek emergency care, which resulted in surgery. She is now extremely concerned about how she will pay the hospital costs. In addition, unsettled housing situations continued to cause stress and anxiety. Some were still living in temporary arrangements, such as a hotel, shelter, or trailer. While some maintained a positive outlook for the future, the cumulative effects of a year filled with uncertainty, loss, tough decisions, and separation from family were causing others to lose hope.





#### **Lessons Learned**

These interviews reveal a troubling picture of how Hurricane Katrina survivors fared in terms of obtaining needed health care through the months following the storm. They highlight the immediate and longer-term struggles survivors faced getting critically needed services and drugs in the wake of the destruction of much of the health system in New Orleans. They also illustrate the dangerous repercussions of not getting care for both their physical and mental health. Several key lessons can be drawn from these findings that may inform continuing efforts to provide health care to survivors as well as responses to future disasters.

Continued efforts are needed to connect people with critically needed care and medications. In the wake of the destruction of much of the health care system in New Orleans, the health care response left significant gaps in care. Many survivors did not receive needed care or drugs for days, weeks, and months, which led to the deterioration of both physical and mental health conditions. In addition, almost all survivors suffered new emotional and mental trauma from the storm, but very few received formal counseling. While emergency resources that were in place immediately after the storm helped some, it became increasingly difficult for people to access care as resources dwindled over time. Close to a year after the storm, some survivors still face major challenges. As such, continued, long-term efforts are needed to address the health needs of survivors and connect them with care.

Response efforts must include a special focus on the most vulnerable individuals. Some of the most vulnerable survivors, including elderly individuals, a person with developmental disabilities, and children, were not connected with care or assistance. These individuals were the least able to advocate for themselves and seek assistance, and, in some cases, they had lost connections with important social, family, and/or provider supports. These findings highlight the need for continued outreach efforts to these individuals. They also illustrate the importance of developing a system prior to a disaster to monitor what happens to the most vulnerable individuals in a community and providing targeted outreach efforts to these individuals following a disaster.

Providing broader access to health coverage after the storm could have eased some of the access problems faced by survivors. Uninsured survivors experienced particularly acute problems obtaining care because they could not afford care, they had difficulty finding sources of care due to the loss of the Charity Hospital system and many other providers and health facilities, and the providers and facilities that remained in operation were overwhelmed. Survivors with Medicaid fared better. However, some in Houston had problems using their Louisiana Medicaid, and some survivors were unable to enroll in Louisiana or Texas Medicaid because they were not eligible or did not receive a response to their application. The federal government allowed states to make temporary Medicaid coverage available to limited groups of survivors. However, many survivors were ineligible for the coverage because it was limited to existing Medicaid income eligibility levels and categorical groups, which do not extend to adults without dependent children. Further, to access the temporary coverage, eligible survivors from Louisiana who were displaced out-of-state had to go through the Medicaid enrollment process in the state in which they were residing. A response that would have provided coverage to a broader set of survivors and transferred more easily across state lines may have eased some of the access problems reported by survivors.

Recovery will require long-term rebuilding efforts and short-term assistance. Those who returned to New Orleans struggled to obtain health care in a crippled health system. It was difficult for them to find care due to the loss of many sources of care, including much of the Charity Hospital system. Those displaced to Baton Rouge faced an overburdened health system, and those displaced to Houston had to navigate a large and unfamiliar community and health system. Beyond these problems, some survivors had difficulty focusing on their health needs because they were struggling to meet their basic needs, such as

housing and food. Further, many lacked transportation to get to providers or information about the limited health resources that were available. These findings show that response efforts must address a broad-ranging set of access barriers and illustrate the importance of integrating information on health care resources with information on housing, jobs, child care, food, and transportation. The findings also show that recovery will not only require short-term assistance but long-term rebuilding of the health system and efforts to provide primary, specialty, and emergency care while the system rebuilds.







#### **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**



#### SURVIVOR EXPERIENCES

# GERTRUDE

"I miss my children, my mom, ... my sister,

... my brother

... I miss my people."

Gertrude, 39 years old, developmentally disabled women 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 quess 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 parttime 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 hardworking, 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 hitch-hiking 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 homeremedy" 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 house-keeper 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 checkups 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.

## Appendix A: Demographic and Health Characteristics of Respondents

Total Respondents	44				
Sex					
Female Male	70% 30				
Race					
African American Hispanic White Don't Know/ Refuse	66% 2 27 5				
Age Range					
18-34 35-54 55-64 65+ Don't Know/ Refuse	32% 41 9 9				
City in which Interview was Conducted					
Baton Rouge Houston New Orleans	48% 16 36				
Insurance Status					
Medicaid Uninsured Medicare Private	32% 52 11 5				
Ongoing Health Conditions	(Multiple responses)				
Asthma Diabetes High Blood Pressure HIV/AIDS Mental Health Problems None	16% 11 18 18 20 20				
Caretakers					
Caring for Children Caring for Adult Caring for Both	59% 2 2				







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