

THE
OH
PROJECT | Oral Histories
of HIV / AIDS
in Houston,
Harris County,
and Southeast Texas

To collect, preserve and make available the experiences
of people impacted by the HIV/AIDS epidemic in
Houston, Harris County, and Southeast Texas

Oral History # 049

An Interview With
Danielle Sampey

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AN INTERVIEW WITH DANIELLE SAMPEY

LYNN SCHWARTZENBURG: This is Lynn Schwartzburg interviewing Danielle Sampey for The oH Project. The interview is taking place February 4, 2019, in Houston, Texas. I am interviewing Ms. Sampey to document her recollections concerning the response to HIV/AIDS in Houston.

Welcome.

DANIELLE SAMPEY: Thank you. It's my pleasure.

LYNN SCHWARTZENBURG: Tell me, when and where were you born?

DANIELLE SAMPEY: I was born in 1966 in Ochsner Hospital, New Orleans.

LYNN SCHWARTZENBURG: Tell me about your family.

DANIELLE SAMPEY: I have my mom and my dad. They still live in Louisiana. My sister and my brother are here in Texas with me.

LYNN SCHWARTZENBURG: What did your father do?

DANIELLE SAMPEY: My dad was in oil, so we moved a lot.

LYNN SCHWARTZENBURG: Where did you live as a child?

DANIELLE SAMPEY: Gosh, we lived in many places in Louisiana. I won't make you look all of them up, but Houma, Chalmette and New Orleans and Gretna, Marrero. Then we came to Houston, and then we moved to Corpus Christi, and then to Katy, and then to Bellville, and then I went to A&M.

LYNN SCHWARTZENBURG: How often would you-all move?

DANIELLE SAMPEY: Oh, gosh, really very, very frequently. It was only when I was a senior in high school that I had actually gone through a school. My dad told me,

actually my junior high year, that we were moving to Bellville, and I said I want to graduate from Taylor, so I actually drove back and forth from Bellville early in the morning to go to Taylor High School, and then drive back in the evening after I went to work.

SCHWARTZENBURG: What was it like to be in a new school so frequently? How did you cope with that?

SAMPEY: I don't think I coped very well with it. You just did what you had to do.

Relationships and friendships, that became something that really didn't exist for me because you were there one minute, and then you were gone. You know how hard it is to make friends. It takes a minute, and by the time that minute happened, we were moving, so I didn't really have a lot of lasting friendships.

SCHWARTZENBURG: You said during high school, you had a job. What was your job?

SAMPEY: My first job was in veterinary medicine. I was just cleaning kennels, but the clinic was across the street from Taylor. Still is. My dad wanted me to quit playing football with the kids in the street, so he told me I had to get a job. Then I found out I was 15, so I couldn't get a job, so I was so happy to go tell him, "Dad, I'm only 15. I can't have a job."

He said, "Volunteer."

SCHWARTZENBURG: "Oh."

SAMPEY: So I had to start volunteering and working for free at that clinic, which was a lot of fun. It was great fun.

SCHWARTZENBURG: How long of a drive was it for you?

SAMPEY: The drive from Bellville was a little bit more than an hour.

SCHWARTZENBURG: Significant.

SAMPEY: Yeah. In the beginning it was scary because I'm driving my mother's car, and it's dark, and I'm very young. I'm 16 years old. I had my sister and my brother, because they wanted to finish their years. In the dark. Sometimes it's foggy, or it's cold, or it's rainy.

SCHWARTZENBURG: You were the oldest?

SAMPEY: Yeah, driving there and then driving home.

SCHWARTZENBURG: Then what did they do after school if you were volunteering?

SAMPEY: They would hang out with their friends.

SCHWARTZENBURG: Oh, they got to play?

SAMPEY: Yeah, they got to play. That's exactly it. They were very happy about it.

Then I'd go pick them up, and we'd drive back. Saturday, I would go in to work, and I'd drive back to Bellville.

SCHWARTZENBURG: This was back in the day when there was actually homework to do. Kids don't have homework now.

SAMPEY: Yeah.

SCHWARTZENBURG: How did you manage that?

SAMPEY: Then, school was easier, to me. Right before it was due, you're walking into the class, you sit out in the hall real quick, and turn it in. That's when school was easier, to me.

SCHWARTZENBURG: Did you have time for any extracurriculars, or was it just work?

SAMPEY: No, nothing.

SCHWARTZENBURG: Did you want to work at a vet clinic?

SAMPEY: I did. I wanted to be a vet. It was just one of those things where I was

passionate about animals. I just loved them and anything to help them. It was easy to love them.

SCHWARTZENBURG: Did you have pets?

SAMPEY: I did. Gosh, when I was a little kid, my dad had a dog named Grits, and then we had Pepe, and then Dad didn't want any more dogs, but I did, and I begged and I begged and I begged. For my 10th birthday, my mom said if I saved my money, I could buy a dog, so I did. I bought a poodle, a puppy.

I asked my dad, "What's a good name?" because he was French, and I was loving my French heritage. I said, "What's a good name for a French poodle?"

He said, "Ralph."

I thought he was serious. His name was Ralph.

SCHWARTZENBURG: "*Mais*, that's not French."

SAMPEY: I said, "He's got a French name."

"Yeah? What's his name, yeah?"

"Ralph."

SCHWARTZENBURG: You achieved the goal of graduating from Taylor, not having to change schools.

SAMPEY: Thank God, yeah.

SCHWARTZENBURG: Do you go to A&M?

SAMPEY: Yeah.

SCHWARTZENBURG: Tell me what that was like. You were pre-vet, so what kind of studies were those?

SAMPEY: It was biomedical science, which is pre-med, pre-vet for A&M. A&M was overwhelming. It was an amazing campus. I was kind of going through some

hard times with my family at that time, so I felt isolated. It was very eye-opening and inspiring on one side of the spectrum, and then on the other side, it was probably one of the saddest times of my life. It was hard.

SCHWARTZENBURG: Being estranged from your family?

SAMPEY: Yeah, just having a hard time with all of that. When I was in high school, I'm taking AP [advanced placement] classes and breezing through, placing out. I didn't have to take a lot of math when I went to college, or English or histories. But then I get to A&M, and you're on this huge campus, and I feel so isolated and alone, and class became a struggle for me.

SCHWARTZENBURG: What about a social network?

SAMPEY: No. I was working full-time and going to school. Once I got above the general studies and into the true classes, my grades went up significantly. It was radiology and pharmacology, anatomy and physiology. That's when I started shining again, but before that, I just felt I'm sitting in a class of 100 people. I went to every single class. I never missed. I was always there, but I was up sitting at the very top, feeling very much isolated. It was a struggle.

SCHWARTZENBURG: That's hard.

SAMPEY: Yeah, it really was. It was.

SCHWARTZENBURG: What happened by the time you graduated? What did you want to do?

SAMPEY: Because my grades in the beginning were such a struggle, I didn't have the GPA [grade point average] immediately to go to vet school. I knew I was going to have to do some postgraduate studies and raise my grades up. I went to talk to my counselor about it. He said, "Vet school? Don't go to vet school. Become a

model.”

I was like, “Oh, my God. Oh, my God.”

SCHWARTZENBURG: That’s not good advice.

SAMPEY: No, and very defeating, because it took me over five years, five and a half years, because I had to work to pay to get through school. You put all that energy and effort in, and to hear that. “Oh, God, now what?”

SCHWARTZENBURG: And so now what?

SAMPEY: I moved to Houston because I knew I could get a job in the medical center with my degree. I knew I was going to be taking some classes. That first job I took was as a research assistant at UT [University of Texas] Health in studying malignant hyperthermia, which was kind of neat because I got to help with surgeries on the dogs. In fact, they had me doing the muscle harvest for the dogs. You start off with a litter of puppies, and as they grew up, we would take little muscle biopsies from them. I also got to participate or watch humans have their muscles harvested, and I did the studies on that. That was really, really cool.

Dr. Red Duke would walk by my office every day, and he was such a cool guy. What a cool man. He’s hyperintelligent, so genuine, and would always say hi to everybody. He was pretty much a highlight of the day.

As the Labs grew up, there came a time that the research scientists said we had to euthanize them all, and not all of them were positive for the malignant hyperthermia. I watched them as a puppy grow up to be adults, and I had to be the one that euthanized them, and I couldn’t. I did what I had to do, but knowing that we were going to get another litter of puppies and start all over again. I tried to get homes for a lot of the puppies because the techs that worked downstairs in

the shelter part of the hospital, they loved the dogs. They were phenomenal.

They were Labs, just good dogs. Dogs are good anyhow, but no, no.

SCHWARTZENBURG: They wouldn't allow it?

SAMPEY: Huh-uh. You have to destroy the animal when you're done. It just made me sick.

SCHWARTZENBURG: How long were you there?

SAMPEY: A little bit more than a year. I don't like being flippant. If I'm making a commitment to something, I want to stay with it, but I couldn't. I just couldn't. Pigs, porcine get malignant hyperthermia, and they're closer to human than you realize, and so we were working with the pigs, and even just euthanizing the pigs, it's hard, so I had to leave there. That's why I started working in veterinary medicine again.

SCHWARTZENBURG: Where did you do that?

SAMPEY: At Bissonnet Southampton. It was a really nice clinic and very progressive, and a lot of responsibility was delegated to the technicians, so I got to do cystocentesis. I got to do a lot of stuff. The radiology. I did all of the clinical pathology. That was one of my favorite parts of it. Looking at cellular tissue samples, and I'm looking for any evidence of cancers. I loved it. I loved, loved, loved that. Disease, it's like an investigation, and that just really excited me, that part of it. The hard part of it was the euthanasia. That always still existed, and it was always something that was difficult for me. It never got easier. Each next euthanasia was a little bit harder than the last.

SCHWARTZENBURG: Even though this time it was because of a dog's health and it wasn't research, but even so, that was still hard?

SAMPEY: Absolutely, yeah. Most of the time, it was definitely about health.

Sometimes people didn't have the funds, and they had to make hard decisions, and that was hard to participate in because you'd see people struggling emotionally. You knew if I had the money, I would have paid every single one of them. I'd be like, "Okay. I'll pay for his surgery." If I could have, I would have. That was hard. I started taking my master's studies. I started taking classes postgraduate at University of Houston–Clear Lake.

SCHWARTZENBURG: Were you living in town?

SAMPEY: I was living at 45 and Scarsdale, driving back and forth. Over here for the clinic, and then over to Clear Lake for school. And taking some really cool classes like apoptosis, which is programmed cell death, or the molecular biology of HIV. Just really, really cool. Cell signaling. I mean, these classes were fun and phenomenal, and I had several professors there that were cutting edge. They would get the information like that week and then share with us, so really, really cool, and that's when my grades went back to what they were in high school. I didn't feel so isolated. I was in a better place in my life, and it was easy. It was easy.

SCHWARTZENBURG: You're a science geek.

SAMPEY: I love it, yeah.

SCHWARTZENBURG: You mentioned HIV. Around what time frame was that, and what was happening with HIV, as far as you knew?

SAMPEY: I had just a little bit of experience with friends who had friends who were positive and struggling. The reason I got really connected with HIV is, I knew that I had to supplement my application that I was going to put out for med

school, and you have to show volunteerism. Someone suggested to me Omega House, and I had no idea what it was. I knew it was a hospice. I was like, “I’d love to go help people.”

I went to this hospice, and Sandy Stacy had just recently taken a position there. It was the early 1990s. She was the night nurse on Tuesday nights. She was the coolest thing I ever met. I worked on Tuesday evenings there with her and Jim. He was another volunteer. It opened my mind and fed my heart, and I knew that I had to do something.

SCHWARTZENBURG: Tell me more about what Omega House was like and who was there and how many patients, clients.

SAMPEY: Residents, yeah. It was always full. The transition was quick. That was hard, because people would come in, and some, by the time you’re done setting them all up and just getting to know them for a minute, they were gone. Gerrie Mergola was there, Margo was there, and Claudia was there. That was all in the upper leadership. Gerrie was the volunteer coordinator. She still does that. She’s pretty awesome. That’s an awesome lady. Ed was another nurse that worked alongside Sandy. That’s who I remember working there.

Every once in a while, I’ll see a volunteer out and about that I haven’t seen in 20 years, and I’m like, “Yay!” When you share common experiences like that, golly. “Remember this person?” “Remember that person?” You meet so many residents there, and they make such lasting marks in your heart. I saw so much. HIV doesn’t just affect that person, but everybody around them. All their family, their friends. In the 1990s, the early 1990s like that, there was still such a stigma. Oh, it was hard.

The one that really got me was, there was a resident there, he was so kind, what a good man, and he was very, very ill, and he was having one of the other volunteers help him Christmas shop for his family because he wanted to buy everybody presents. He knew this was his last Christmas, and he wanted to give something meaningful. Every Tuesday, I'd show up and there would be more presents wrapped and stacked because he was just getting ready for Christmas. Wrapped and stacked, and it was just filling up his whole room. I was like, "Oh, my gosh, look at all this stuff."

Well, fast forward to Christmastime. His family doesn't show up. An in-law, I think it was like his brother-in-law, shows up for a moment, and he had a Hefty bag with a bunch of gifts inside, and he said, "Could you give this to him?"

I'm like, "Is somebody coming to visit him?"

Nobody came to see him. I know people had fears then, but he didn't have a single visitor, and I had to bring his presents to him. He was anticipating something and somebody, and he was ready and trying to look his best for it.

I bring this Hefty bag full of presents to him, and I could see him just cave inside. He's sitting in his bed, and he's trying to pull all the gifts out of the bag, and one by one, he opens a gift up, and he reads the card. "Oh, could you write this down? This is from so-and-so." "Look at this sweater. It's so lovely. Will you write that down, because I want to send them a thank you note." One by one, I would watch him open up a gift. "Oh, how lovely."

SCHWARTZENBURG: So dignified.

SAMPEY: Oh, my God. He didn't last much longer after that, and he took a piece of my heart with him. I mean, you saw things like that a lot, where people were afraid

for whatever reason. I don't know what it was, but that they didn't come visit.

One resident, I remember her very, very well. Her husband had HIV, and these are people that for whatever reason, they don't fit what you would normally expect when you see HIV. They weren't gay. They just didn't fit the model. She was older. When he was dying, nobody got to know what he was dying of. They just said that he had cancer. Then when he passed, she became ill. Then the family finds out what's going on. She ends up at the Omega House, and she didn't want anybody to talk to her, she didn't want any food, and she didn't want anything else. She just wanted —

SCHWARTZENBURG: To die.

SAMPEY: Uh-huh. I mean, moments like that forever change you.

SCHWARTZENBURG: Absolutely.

SAMPEY: They do. They forever change you.

SCHWARTZENBURG: How did you cope?

SAMPEY: I prayed a whole lot. I did. I prayed a whole lot. Sandy Stacy really taught me to love people through your fears. Probably within the first month of me volunteering there, she's calling me and asking me to come in and help her with one of the residents. He's super thin, and he's got a diaper full of diarrhea. Not to be graphic, but copious amounts of diarrhea. He's lying in it, and she's like, "Can you help me change him?"

I'm sweating so bad out of nerves, I can't even put my gloves on. They're sticking to my hands, and I'm so nervous. Every time we're shifting him, he's like, "Don't!" and he's kind of locked in a position anyhow.

She holds him and cradles him. He's covered in sweat. He's super thin.

She's holding him and cradling him and loving him as I'm trying to pull that chuck out with the diaper, and she's just busy. I'm trying to hurry up because I can hear him moaning a little bit. She's just lovingly wiping him and holding him like a baby, and then I'm hurrying up with the chuck, and unrolling and putting the diaper back in. "We're ready. Okay. Okay, now."

She's like, "Not yet," because I see now he's holding her. Oh, my God, just a moment like that. Oh, powerful, powerful.

SCHWARTZENBURG: Like watching Mother Teresa.

SAMPEY: Oh, she's phenomenal, phenomenal. TDC [Texas Department of Corrections] had some kind of — I don't know how it was, but when we would get inmates at Omega House, people who were about to die. There was one guy that we knew some history on him, and he wasn't a good guy. He had some tough, tough history, but he was super young, and he could act out sometimes and get agitated. One time she was helping him, and he — maybe he was a little autistic too. I'm not sure. He couldn't communicate exactly right. She was trying to help him, and it was painful for him. He was like, "Aah!"

She's like, "I'm trying to help you. You can cry all you want. You can cuss me all you want. Don't swing at me, or I'm going to stop."

He's like, "Okay."

She finishes what she's doing, and she gets on the couch next to him because he was moved to the couch, and he lay down and he put his head in her lap, and she just stroked his head as he fell asleep. I mean, what a woman. What a woman. He just acted out towards her aggressively, and we knew he had a little bit of a history. She just loved him until he went to sleep.

SCHWARTZENBURG: No fear. All love.

SAMPEY: That's all she was. There were moments that I'm like, "Oh, Sandy, I'm not sure about" —

She'd be like, "Danielle, if you're not comfortable, you don't do it, but don't be afraid."

She helped me work all through that. Because honestly, in the beginning, you're like, "How does all of this work?" "What am I supposed to do?" "What don't I do?" because you want to be cautious and everything. But then I got to the point that I'm like I'm not being cautious about the HIV; I'm being cautious because it's people and there's sweat. I have germophobia, but I learned to get over sweat and cooties and stuff like that. You don't get over it. You learn to love them more than you hate that, so if you see them struggling and they need a hug, then you do it. It's easier to do that than to go home and say, "Why didn't I hug him? Why didn't I hug him?" because that was probably the last time I'd see him. That definitely changed my life. Sandy.

SCHWARTZENBURG: To live without regret.

SAMPEY: Yeah.

SCHWARTZENBURG: To love when and where you can.

SAMPEY: You have to. Nobody promises you tomorrow, and you don't want to see people hurting. It's amazing what an eye contact — always find out somebody's name, and then talk to them by their name, and be kind. Touch.

SCHWARTZENBURG: That's a very powerful experience.

SAMPEY: It was. Probably one of the biggest life-changing moments for me, and to see the number of people suffering and dying.

SCHWARTZENBURG: Is that what started you on a path of working with people with HIV?

SAMPEY: No. It was probably God just planting a seed for me. I'm sure that was. What I was planning wasn't that. I was like, I'm just going to use this. Like I said, I was thinking UTMB [University of Texas Medical Branch], go to school there. I had been accepted into autopsy as employment at UTMB, and so I was working there and having different kinds of experiences. That was like the ultimate stage of disease, the end of it, right? I thought I could do autopsy.

SCHWARTZENBURG: Human autopsy?

SAMPEY: Human autopsy. Because one, that's so intriguing, right? What happens, and can I figure it out? What is it really like? Two, I wouldn't have to deal with pain anymore because the person no longer feels pain.

I took that job, and I thought that was fantastic. Then I didn't realize that I actually had to go talk to the family and tell them, "I'm going to be taking your loved one," because this was at the hospital, so that person just passed. "I'm going to be taking your loved one down, and we're going to be doing an autopsy, and I need you to sign this."

Oh, my God. Oh, my God, dealing with that pain, trying to keep yourself together. I could only do that for a little bit more than a year also. I loved the figuring out what happened, but then when you had the true backstory of it, like I met this 12-year-old boy's grandmother, his mom's in jail, he just had an asthma attack in the care of his grandmother, and now he's on my autopsy table, and I have to go tell her that I'm doing an autopsy on her grandson.

Taking a two-year-old little girl out of her mom's hands because the mom

had kept her home because she had a cold, and had her checked by the doctor. The doctor gave her a prescription. “Go get the prescription filled and put her down. Give her her medicine and do your chores, and go check on her,” and she died because the pharmacy gave the wrong prescription.

So human suffering, it is unbearable, I’d say almost unbearable, but it is unbearable. So I said, “I can’t work in autopsy any longer.” This was too much.

SCHWARTZENBURG: Scratch that off the list.

SAMPEY: That was.

SCHWARTZENBURG: It sounded good. It wasn’t enough.

SAMPEY: “I’m out of here.” That summer, I had taken several courses, and one of them was for certification at Baylor Sports Medical Institute for fitness training, to be a certified trainer, and I did that just for my own benefit to learn how to exercise. Nobody could ever tell me what to do the right way. I loved that, and I was really enjoying that certification process, and someone told me that a clinic was looking for new trainers, and it was for HIV-positive people.

I said, “I am going to apply for this.”

That night, I heard about it. The next day, I was doing an interview. It was awesome. I hadn’t worked as a trainer either yet. I mean, I had some ideas and all, but I was just certified. I did do an externship, so I wasn’t green. I followed a bunch of trainers and worked for Q for a while. So here I go and I do this interview at Kinetic, and they hired me on the spot. That was phenomenal, phenomenal, getting to use what I love about disease and working with the people that I grew to love so dearly and seeing how exercise actually made them stronger. It was the opposite of what we knew.

At that time in the 1990s, they were telling people who were positive, “Don’t move. Don’t burn any extra energy because it will accelerate the wasting, and you’re just quickening the process of everything.” It was actually the opposite. We saw the exact opposite. We saw people who couldn't walk anymore because they were so thin and they had wasted so much, and with a modified exercise program, something very specific to the condition, we saw the opposite. We saw people gaining muscle mass. Teaching nutrition to them and doing their right exercise program, people started thriving. You’d see even their skin color would look better. You’d see less sores. It was phenomenal.



Danielle Sampey and Rachelle Welch
Trainers at Kinetic Clinic, 1999.

I called Rachelle. She and I had worked together at a veterinary hospital, and I called her, and I said, “I found the place, and I want you here working with me,” because she’s a very passionate person.

She’s like, “But I’m not certified.”

I said, “You need to get certified. Go now. Go learn. I’m going to make sure we hire you.”

She did, and that was probably one of the best things I did for them and for me.

SCHWARTZENBURG: What was the clinic like? Was it a gym, or how was it set up?

SAMPEY: It was a small clinic. Maybe it was 1,500 square feet. It was off of Stella

Link. Ed Kinser was the brilliant man behind creating it. He had experience with exercise, he was a great bodybuilder, and he had friends who were positive. I'm sure he just knew and saw the benefits of it. I know he was friends with Nelson Vergel, and Ed just had the insight to create a program.

SCHWARTZENBURG: How was it funded?

SAMPEY: It was a clinic, so it was through insurance. Medicare paid very well for it. It was physical therapy, doctor-prescribed physical therapy, which was just basically progressive resistance training. It was a hoot. It was a great time. We saw about 50 patients a day.

SCHWARTZENBURG: How long would they stay with the program?

SAMPEY: It was 12 weeks. You needed a minimum of that time before you really see the true benefit of it. Some people stayed longer.

SCHWARTZENBURG: Then they would continue the program on their own?

SAMPEY: There was a maintenance program on Tuesdays and Thursdays and Saturdays that would be private pay, and it offered that. It was very discounted, almost free. He was good about taking care of the people. His end game was running a good business. He made a decent living for all of us, and then he was doing great things with it. I started out as a trainer there and quickly became the director. He moved me up to the director.

SCHWARTZENBURG: How did that change what you did? What was that like?

SAMPEY: I got to do the programming and manage the patients. I did intake and then reevaluations and then write the program and just be present to their needs. I did the nutrition for them and helped the physicians with their reevaluations. I loved it. I got to see people when they first began, and I got to see them when they were

done with their program, going home.

SCHWARTZENBURG: It had to be very satisfying.

SAMPEY: It was hugely satisfying because this was a time that you'd be checking the obituaries every week, and you'd see someone you knew. You'd check them every day, and you'd see someone every week that you knew or that was your friend's friend. Every week, you'd see somebody. And the number of funerals, the number of funerals. It wasn't that people didn't die who were coming to Kinetic too, because we did have people still die, and that was hard too.

SCHWARTZENBURG: Was there ever a waiting list and people you just couldn't get to, or do you feel like everybody that needed you had the opportunity?

SAMPEY: This is just to my knowledge, because Ed would know that answer better than me. We always had somebody coming in. I don't know if there was a waiting list. We stayed busy. I hope that we were serving everybody that needed us. Body Positive came around about the same, not much longer after Nelson and Ed and a group of people talked about making it an affordable opportunity for people who can't, and that's Body Positive. That was a great organization to be a nonprofit, and they did.

SCHWARTZENBURG: For people without insurance or that couldn't afford it.

SAMPEY: I think they did it through insurance. You had to quantify. Maybe it was the degree of wasting and things like that. I don't know exactly how they did all their billing, but they offered another opportunity. I remember at that time thinking we could probably have satellite clinics everywhere just to make sure that everybody knew that that opportunity existed, because I don't think everybody knew that that was a possibility and that that would help.

SCHWARTZENBURG: Do you think that there was resistance to “Oh, that’s not going to work,” or physicians saying, “No, they’re wrong”?

SAMPEY: Oh, yeah, absolutely. Oh, absolutely. I remember things like when crix belly came around, cardiologists putting clients who were so thin, barely have any muscle, I could see their bones in their arms and their legs, but they had this distended abdomen from the lipodystrophy, by their cardiologist being put on a no-carb diet. In order for your muscle to exist, you have to have a fuel, and that fuel comes from your carbohydrates. They were trying to treat lipodystrophy, which is not a normal fat, by starving it. Instead, their arms would be thinner, if that could even be possible. Their face, thinner, but their abdomen would look bigger.

There was a lot of misunderstanding about how to address the lipodystrophy and muscle mass, because you could be wasted, you could be very, very thin — muscle mass, we’re talking about wasting — and still have a body weight that’s higher than before your diagnosis because you either have fluid or you have lipodystrophy, and that’s not a functional fat. That’s not serving you. I can remember people telling me how their doctor said, “You call this wasting?” and patting their belly.

SCHWARTZENBURG: Oh, no.

SAMPEY: When we’re doing a body composition analysis of them and they had barely any muscle and their phase angle was telling me how sick they are, they’re so sick.

SCHWARTZENBURG: What is phase angle?

SAMPEY: Phase angle is something with the BIA [bioelectrical impedance analysis]

that we do, and it kind of gives you an idea of cellular health. They use it in some clinical settings to quantify co-morbidities, like the lower your phase angle, the more likely you are to have another issue that can contribute towards a morbidity.

SCHWARTZENBURG: Some other metabolic issue?

SAMPEY: Exactly, or another disease process, yeah. There was a lot of misunderstanding about what's actually happening to the body as it's wasting.

SCHWARTZENBURG: Was there much research literature about cachexia we're talking about with the muscle wasting?

SAMPEY: Not at that time, no. In fact, the NIH [National Institutes of Health] was really limiting cachexia to cancer. I don't even know if they considered wasting cachexia at that time. Maybe a sarcopenia, a smaller muscle, but it was actually wasting of that muscle mass. Definitely the exercise program showed us something totally different.

SCHWARTZENBURG: That's very visionary at the time to go on your own and "Let's try this," and see results.

SAMPEY: Oh, yes, it was fantastic.

SCHWARTZENBURG: And being able to convince some physicians, at least, to refer to you.

SAMPEY: Yes, that's exactly right. Ed had that good relationship and that good rapport, and all you had to do was send one of the patients back to their physician, and you're like, "There you go. There you go. Now what? Oh, you want to send more to us. Oh, yeah." He did very well. He did. It was brilliant on his part. I wish that place could have gone on forever.

SCHWARTZENBURG: What happened?

SAMPEY: Between insurance changing how long they would support and just changing within the clinic itself, it closed, unfortunately. I think almost all of the Medicare patients had to go off and couldn't participate anymore for the funding, and the private insurance kind of followed suit. That was hard to see that place close. Nobody wanted to see that.

SCHWARTZENBURG: Where do the people go?

SAMPEY: Exactly, exactly.

SCHWARTZENBURG: What do they do with their muscle wasting?

SAMPEY: Yes, it was early summer when it closed. I'm getting confused with my dates. Is it 2001, Allison happened? That was a tropical storm? A lot of the patients had become tremendous friends, intimate friends. Personal training, if you've ever personally trained with someone, there's some intimacy. If you're willing to struggle and sweat that hard for somebody, you'd better like them.

One of the patients, a dear friend, Reggie, called me, and he knew that I was doing some private training. After that, everything was going on. I was going to go to med school, and I was supplementing my income with private training, and I was working out of this nicer, upscale gym run by a friend of mine, Healthspan, and Reggie somehow got ahold of me, and he said, "I need your help. I can't walk anymore."

Reggie had an eight-year-old daughter and a wife that he would drive to work. He was the husband and the dad and the caretaker, and he couldn't walk anymore, so how is he going to drive his wife to work? How is he going to take care of his eight-year-old daughter that was his baby girl?

I said, "Reggie, I'm not a doctor. I can't help you."

He said, "I know you're training. I want you to train me."

I said, "All right."

He said, "I can't pay you."

I said, "I know. I know. Can you make your way over here somehow?"

He said, "I'll get there."

I said, "Okay."

So I went and I talked to Robert, the owner of Healthspan. I said, "Robert, I have someone who wants me to train him." And he knew I worked at Kinetic in the past. He was a fan of that. I said, "I can't charge him anything, because he can't pay me."

He said, "You owe me 25 percent of everything you charge."

SCHWARTZENBURG: "That's a deal."

SAMPEY: "He can't pay me." It took me a minute to catch on.

He said, "Danielle, I need to make it clear: I expect a check from you at the beginning of every month, on the 1st, 25 percent

I was like, "Okay."

He said, "I want that check."

I was like, "I hope I'm understanding what you're saying."

Sure enough, at the beginning of the month, I gave him a check for zero, right? I'd put it in an envelope, and I'd hand it to his office manager. He was a stickler, because if you were 10 minutes late, he's calling you. "Where's the check?" His name was Edward.

"Oh, Edward is on the phone. He wants the check."

"I can get that check of zero to you."

So Reggie started working out of this really nice clinic and starts out in a wheelchair, and a couple of weeks later he's on a walker, and then by the end of the month he's walking with a cane. It was phenomenal. He just needed some good strength training, something that was very appropriate for his needs.

I said, "Reggie, don't tell anybody," and Reggie told everybody, everybody. I don't know how he got everybody's number, but he did. He called everybody from Kinetic, or as many as he could.

Rachelle knew I was training him, and Boyd knew I was training him. They would have work with me at Kinetic, and I was like, "Rachelle?"

She said, "Let me help."

I said, "I'm not making any money over it."

She said, "I don't care."

Boyd said, "I'll help."

The next thing you know, we had like 11 people that we were training. We just knew we had to do something.

By September, I was filing for the articles of incorporation, because I knew it had to be some kind of business that would be a charity. I didn't know how to do a 501(c)(3), and probably if I did, I would have never done it. That's the God's honest truth. I would have been, "No." I just knew I needed it.

I went to the Houston's, got that website out of the small biz, you know, how to set it up, and they gave me little perks. I saw a dba [doing business as] and articles of incorporation. "Oh, okay. I'll do all of this."

Then a 501(c)(3) for a charity? We didn't even have a building. The name came when we did the articles of incorporation. I didn't know what to put down. I

hadn't even done the dba. That was all filed at the same time. I remember sitting at my desk, trying to figure out, "What do you call it?" I didn't even think it through. It was like one of those moments where God's just in your ear. "Lazarus House," and everybody said, "Lazarus House? Why Lazarus House?"

I'm like, "Hmm," and it's just been through experience that I realized both Lazarus in the Bible were appropriate. One, Jesus's friend Lazarus that he used to show it's not time to die. "I want you to be happy, and I want everybody around you to be happy. Lazarus, come out."

Then the other one, Lazarus was the poor man that the rich man stepped over on the steps of his house. The rich man had a lot of money, but he just stepped over this man who was suffering and didn't give to him. If he would have helped him just a little bit, not only would Lazarus have lived and felt better, but that rich man would have felt better by himself, too. He would have done something that made his life good. That's just one of those things that we just kind of live. Seventeen years into Lazarus House, it's all making sense. It all makes sense. That's how we came to be.

SCHWARTZENBURG: Where did you get your funding?

SAMPEY: Friends, in the beginning. "Thank you, friends." We opened the doors without our 501(c)(3), so any kind of donations that came in weren't tax deductible. There was a lot of grace. Everybody donated their time. My dad was looking for an investment property. At the same time, I was trying to find a storefront, and I had just a little bit of money that I had saved. I was buying fitness equipment, and it was at an auction. University of Houston, all their equipment flooded from Allison, and I was buying all their used, old stuff at these

auctions. It was taking what little money I had, so I couldn't invest in buying a building. I didn't have that much money. When my dad said, "I hear you're looking around in Houston. Find me an investment," I said, "I keep driving by this one building in midtown."

The reason we were looking in midtown is, this was really Third Ward, and it was the least expensive at that time. I said, "I'm looking at this one house."

He said, "A hundred thousand."

I said, "How about two?"

He said, "All right."

I said, "I'll lease it from you."

He said, "Okay. Even better."

Then for the first two years, he called me slow pay. It was hard. It was hard.

SCHWARTZENBURG: At least it's not no pay.

SAMPEY: It was definitely slow pay. It was hard. We had to install an air conditioner.

This is my lighthouse, but it was worth every moment of it.

SCHWARTZENBURG: How many clients did you really start with?

SAMPEY: Eighteen. It wasn't bad. People were waiting for us to open up. All the trainers gave back one way or the other. They either gave me their paycheck back, or they would give me donations. They were phenomenal. Boyd and Rachelle and Ralais and Darwin are all people who worked for me at Kinetic, and they all helped there.

Phenomenal. I couldn't have done it without them. Changing this building and making it into what it is was Rod,

Rod Ryan, and he was a friend of mine, a patient from Kinetic, who loved me and I loved him. He did all this labor for me converting this house into what it is today. It's been hard the whole way through. Let's just be honest. But the first two years, I just didn't know what I was doing. I still don't know what I'm doing, but now I know God's hand.

I remember I had to live here because I couldn't afford to live anywhere. I couldn't pay rent, so I was living up here. I remember one Sunday morning, I was going downstairs to make me a cup of coffee, and I sat down on the stairs and just wept. There was no door down there. I was just sitting on the stairs, and I was weeping because I was like, "What have I done? What have I got myself into? And I can't."



L to R. Cary Sallee, Staff; Rachelle Welch, Staff; Boyd Edwards, Board Member; Danielle Sampey, Executive Director; Elizabeth Smith, Board Member.
Lazarus House, June 15, 2005.

In the middle of my weeping, I heard someone hammering. It's 7:00 o'clock on Sunday morning. I'm like, "Oh, no. Oh, no." I'm trying to get myself together and making sure I'm presentable, and I'm walking around, and I see Rod's truck in the front. I'm like, "Oh, God, he's here?" I'm frustrated that he's here, and I'm going around to the back bathroom, and he had just finished tiling it, and it was so beautiful, and he did it for me because I didn't want cheap. I wanted it to be nice. I wanted to give the best to the people, and it was beautiful.

He had a mask on because he was cleaning up all the grout mess and everything, and I startled him. I was like, "Rod," and then I realized because I'm giving him a grumpy "Rod!" and he's startled, and he's like, "Yay," and it was gorgeous.

I was like, "Well, that's how. That's how," because I was saying, "How am I going to do this?"

[END OF AUDIO PART 1]

SCHWARTZENBURG: You weren't alone.

SAMPEY: No, not at all. Rod stayed and worked until God took him home with lymphoma. He was phenomenal. Rod was my "You can't quit, you can't quit."

SCHWARTZENBURG: "I'm not quitting. You can't."

SAMPEY: That's exactly right. With his lymphoma, he showed up. He had the HIV-associated lymphoma in his stomach, and he would still come here. I'd find him lying down on his back, in a sweat, and I'd be like, "Rod, go home, honey."

I mean, he'd say, "Nope. It's passing. It's passing. It's gone. Okay. Let's go. Let's finish."

That made me really check myself. "I'm tired. I want to do something

different. What about me?” Boy, did I have to learn a lot about me. I didn’t like the me. Lazarus House, the whole time, has taught me that. You think you’re having a bad day? You think you have your right to have the little *boude* or *vay ya*, and then somebody comes in who’s got it harder than you and has a smile on their face and they’re happier than you. “I better check myself.”

SCHWARTZENBURG: They’re happy because they’re here, and they’re here in this place, and they’re seeing you and their friends, the other trainers.

SAMPEY: That’s exactly right. I think walking through the fire, people have a decision to make. You do. Everybody should make that decision before we get to the fire of, “What am I going to do with this day that God gave me?” It’s my choice. Nobody can make me this or that. It’s always my choice. Every morning, when I open the door, I have to remind myself, “Make the right choice.” If you don’t do it for yourself, do it for the people around you. Then it becomes for you.

SCHWARTZENBURG: Then you get the reward.

SAMPEY: Oh, yeah.

SCHWARTZENBURG: Let’s talk about fundraising, grant writing, the community in Houston.

SAMPEY: The community carried Lazarus House in the beginning and still contributes significantly to us. It really was. It was the community that said either they’re participating and benefiting from Lazarus House or they know someone who is or they just know that we need to keep options available.

Hollyfield was our first grant, and that really made me feel like we can do this. Black Tie, I remember going to all the Black Ties and thinking, “One day, Lazarus House.”

Sure enough,
Black Tie chose
Lazarus House, and I
was like, “Yay!” That
was a huge moment
for us.

Getting the
checks, getting bigger
and bigger and
allowing us to work

with more and more people. We always worked within our means, but we want
to do more. There’s a need, and if we have the means, we’ll do it, we’ll do more.
We operated off of a shoestring budget that was pretty much community
supported, one way or the other.

[BRIEF INTERRUPTION]

SCHWARTZENBURG: How long has Lazarus House been open?

SAMPEY: For the true opening, it’s 2002, so that’s 17 years, which I can’t believe it’s
17 years.

SCHWARTZENBURG: How is it the same? How is it different? What has been the
evolution?

SAMPEY: In the beginning, our clientele was almost 100 percent HIV-positive people,
and we were addressing lipodystrophy a lot and the diarrhea phenomenon that
came on in the early 2000s. Now we’re seeing longtime survivors, and there are
different concomitant diagnoses we see, right? So you have to know how —



Back: Dora Ramos, Carlos Reyes, Rachele Welch, Steven Christenberry
Front: Carlos Cordova, Melissa Serra, Danielle Sampey
Houston Black Tie Dinner, 2004.

SCHWARTZENBURG: Right. People are living longer, and now maybe they have heart disease or diabetes.

SAMPEY: Yes, Exactly.

SCHWARTZENBURG: It's not just HIV that they're struggling with.

SAMPEY: No, it's not. But when you get a diagnosis of having some kind of coronary issue, HIV still has its hand in it one way or the other, and so you always have to make sure that if you're addressing somebody, you have to look at that person completely and make sure what you're doing is appropriate for both sides, and how much is HIV influencing the other diagnosis?

SCHWARTZENBURG: Are you still getting prescriptions from physicians, or is the treatment program just kind of all yours at Lazarus House?

SAMPEY: Because we're not clinical in nature, we don't work through prescriptions. We do work with the physician. We get a release when we want them to qualify their patient and say that, "Yes, my patient does have this illness," and then we want them to give us some suggestions. Tell us about their medications they're taking and if there are any requests or limitations. Then we kind of take their patient from there.

SCHWARTZENBURG: In conjunction with them?

SAMPEY: Yes.

SCHWARTZENBURG: So this is a very different model than Kinetic was?

SAMPEY: It is, correct, yeah. Ed's was clinical, completely clinical, and this isn't clinical, so we're not doing treatment.

SCHWARTZENBURG: Right, but you're taking all of those disease processes into consideration.

SAMPEY: Right. For each client, we give them a disease-specific exercise program. It has to meet their needs. If it's leg day and everybody is doing legs, we try to have something similar because people like to feel like they're having the same kind of suffering together, right? They enjoy that. But if you hang out, you'll see that each one has been a little tweaked and modified to meet their needs.

Some people who may have cancer and they're going through treatment will do one set of exercises, very lightweight, or two sets. It depends. They're actively in a catabolic state, their cachexia is going on right there, and we don't want to contribute to it, so we modify. Their progressive resistance isn't very progressive, and it's just minimal resistance, but a little goes a long way, where someone who's positive, a longtime survivor, we're going to be challenging them a little bit more and saying three sets, heavier weights.

SCHWARTZENBURG: Describe to me what that's like. You have how many clients at a time here in the house that's set up with different workout stations? Is everyone doing one set at a time, or each individually working with a trainer? How does it work?

SAMPEY: The way Lazarus House works is, everybody has a scheduled appointment time, and it's pretty much your appointment time throughout your program. Say you're the 7:00 a.m. Depending on your needs, if you're high needs, if you're in a wheelchair and you're not very stable, or you just need more attention for your process, then you will work out by yourself with your trainer. It will be just you and your trainer, one on one.

Otherwise, if we can, we pair you with someone who's going to be a good match for you. That also creates a bond and a friendship, and people like to suffer

together and be against their trainer. Then it's two of our clients against one trainer. In an hour, you'll have three trainers on the floor, and each will have one or two clients each. The house rotates in a direction, so



Training Day at Lazarus House
Ralais Harper, trainer, with clients, 2005.

everybody is doing their own hour, or you're coming at 7:20, or you're coming at 7:40, and the house is rotating, and everybody is kind of doing — “Oh, I just did those exercises. Girl, you're going to hate that.” That's not your workout partner, but that is your friend, because you know you'll see them in that hour.

You see the open concept of the house. There's a lot of community and a lot of poking fun and just good humor and also a lot of friendships and people go have lunch after this.

Lazarus House is where you could come in. You don't have to make any excuses or explanations. You are who you are. If you share your diagnosis, because it's up to you to share your diagnosis — we don't disclose anybody's status for anything — but if you share your diagnosis, and then you find out through other people sharing they have a same diagnosis, then you're sharing doctor information and experiences. “Have you had that diarrhea?” “Did you try the BRAT [bananas, rice, applesauce, and toast] diet? Girl, that rice.”

There are moments that they get to share their health issues, and nobody

will ever understand what it feels like to have HIV unless they have HIV. No matter how much they love you, you don't know. Nobody knows what it feels like to have cancer unless you have cancer. Your friends and your family and your doctor all love you and they're all there for you, but they don't know. If you have people around you that do and you see them working hard and you want to be like that, you want to participate in that, and they get you. Some days you're going to have the day that isn't that day, and they'll be like, "Got it." It's like on *Cheers*, walking in, right? And everybody knows your name, and you're you, and you don't have to make any excuses.

My client who comes in in a wheelchair and one leg, he doesn't have everybody making you feel you're anything less than. You're exactly like everybody else around you. That's something that has proven the success for Lazarus House, because everybody knows they should exercise, but nobody wants to exercise, even when you're healthy, right? It's like, "Sweat? Why do I want to sweat?" Right?

SCHWARTZENBURG: It hurts.

SAMPEY: Yeah, exactly. If you're doing it right, it's hard. When is it going to get easy? Never, if we're doing it right. Then add a diagnosis to it. It's hard to come in and exercise, especially with a diagnosis. What's going to get people coming in here? Why do they come in? Because it's successful? No. I think that contributes to them coming back, and the feel-good aspect of it, because you do feel physically and mentally better when you exercise, but the thing in the beginning is the community support of your peers, your true peers who know exactly what it feels like.

SCHWARTZENBURG: Right, you will never get that at 24 Hour Fitness.

SAMPEY: No. That was something that I saw at Kinetic. I saw how the program was so successful when it works, but it was the community aspect that kept people coming back. We work really hard. As we expand Lazarus House and as we grow, a big part of our expansion is going to be something called a treehouse where it's a community gathering. It's a multipurpose room, but on regular days, it's going to be modular furniture on casters that can move back and forth. Go up there, sit down with your friends, drink coffee, watch a movie, play video games, just chew the fat, because a lot of people don't want to leave here when they're done with their workout, and they hang out. We have to flip the lights on and off. "It's time to go home, kids." It's a good thing. It's a good place. If you're going to hang out anywhere, hang out at a healthy place. Then we want to create more access for them. If you want to go eat lunch together, have that place to hang.

SCHWARTZENBURG: How long do people stay as a client?

SAMPEY: The minimum, because the program at Kinetic showed it, it's got to be at least 12 weeks, so we ask for that commitment. Since there's not a cure and you always have the need, as long as we can, we provide your service. A lot of people do their program, they get to a healthier, happier place, and they say, "Can I do my workout on my own?" So we do their workouts, write them down, and then we give their workouts, "Go do it. Go to 24 Hour. Have a great time. Come back and let me do your measurements, make sure. In six weeks, let's make sure you're doing right. When you're ready to come back here, then come back here if you need a refresher or whatever it is."

We teach them the life skills of what they should be doing and what they

shouldn't do, because that's also a big fear. "How do I do this exercise, and am I going to hurt myself? Am I going to end up like I was when I first came here?"

We try to teach people so that they can go on and do their workouts. We've had people here for years because if there's no cure, there's that need.

SCHWARTZENBURG: With the camaraderie, why would you want to go?

SAMPEY: That's right. Why would you? Why would you?

SCHWARTZENBURG: It must be hard if you lose someone. It must be hard for you also, but especially the clients.

SAMPEY: Yeah, it's devastating. It's devastating. It's like losing a family member. It still happens. It doesn't happen as often, but it still happens. It's not unusual that we ride together to the service. Then the house has its own bit of a memorial because the front door is where everything is, and in those hard times, people find out and learn, and then they share moments together, because it's like losing a family member.

For World AIDS Day, we always put everybody's name on the door. To see that list grow, everybody is like, "Oh, Rod. Oh, man."

I love Rod. When I was looking at the pictures, trying to find the picture from the past, that was really hard going through that album because almost every page, because that's from the 1990s, and I'm like, "Oh, my God, my friends." It's like "All My Ex's Are in Texas." All my friends are in heaven, a lot of good people.

SCHWARTZENBURG: Summing up, what experiences in your life would you say prepared you for your role during the HIV/AIDS crisis and for your role here at Lazarus House? Why were you the right person at the right time?

SAMPEY: I'll answer that last one first. I don't know that I was the right person at the right time.

SCHWARTZENBURG: We'll take a vote.



Danielle Sampey, 2018.

SAMPEY: Yeah. When I was young, I didn't want to see a mosquito hawk hurt. Remember the mosquito hawks?

SCHWARTZENBURG: Yes.

SAMPEY: In Louisiana, that's a big deal. They're everywhere. To me, that was like a butterfly, and they're so beautiful. I remember finding one that wasn't doing well and was wounded, and I'm trying to give it some water and vitamin C. I couldn't be six years old, and my mom was like, "*Sha*, that thing is going to go to heaven."

I said, "Well, I want to take care of it until it goes to heaven." I put it in a matchbox, and then in the morning when I opened it up, that thing flew away. I don't know what happened with it, now. Who knows? But in that moment, I was like, "Okay."

SCHWARTZENBURG: "I made a difference."

SAMPEY: I didn't feel like it was me. I felt like if someone would just stop for a second and give somebody a cup of water. Then having that passion for disease and medicine, and then learning the value of people. Each person, so valuable. I think that God gave me compassion. And I didn't know this; that compassion means — you know what "passion" means?

SCHWARTZENBURG: Tell me.

SAMPEY: Suffering. I didn't know that, not until not that long ago. "Passion" means suffering, and "com" is with, and that you suffer with, right? And I feel that. I feel that, other people's pain. It's palpable. I think we all do. I think we all feel it, but you've got to allow yourself to. Not that I want to feel other people's pain, but I also feel their joy.

If I can give you a cup of water and it gives you a little joy, then that didn't extend myself, right? It's the least I could have done, because now you gave me joy. I think that's what really led me, and Sandy Stacy, you know, teaching me to love people no matter who they are in all of their brokenness.

I'm not even talking about HIV. I'm just talking about people, because there are a lot of people that they're just *tête dur*, hard head, you know. "I'm not helping that person. He called me a" — and she taught me to love them through that.

My parents providing a means, whether they did it intentionally or unintentionally, it happened, and I'm grateful.

Then every single person around me, I've had tremendous support. I always say Lazarus House succeeded despite me because I think I could completely have undone it, but the people that God put around me, whether it's Rachelle and Boyd and Ralais, who were there from the get-go, and Rod, and every other volunteer. I'm just saying the ones that I saw every single day, that I couldn't have done it or I wouldn't have done it without them.

Then being able to go home and tell Melissa about it, and getting that support from her, because a number of times I was like, "I don't know how," and she said, "You don't have to know how. God always finds a way."

She was right. Every single time I'm like, "That's it. We don't have enough money. It's not going to happen," she said, "You say this every year."

She kept me —

SCHWARTZENBURG: Grounded.

SAMPEY: Uh-huh, completely. My sister, who tells me, "Don't forget to enjoy the good part of it, because when Fiesta has a big, huge party but the toilets are overflowing," oh, my God, and my volunteer says like — she had the margarita in her belly, and she said, "Don't worry, but I've got some news." I could see she's a little — with her margarita. She says, "I've got some bad news. The toilets are overflowing."

I was like, "Oh, mother of God."

She's like, "Don't worry. I have a guy peeing in the shower instead."

I was like, "Oh, my God. Everybody out." I go call my sister. "I don't know what to do."

She said, "Are they having a good time? Just tell them the bathrooms are out of order, and don't miss out on the good time."

And then my brother, who was there supporting me every minute of the way, telling me he's proud of me. He's usually the first one to make a donation when I do my little — yeah, it's been God's grace.

SCHWARTZENBURG: Thank you so much.

SAMPEY: It's my pleasure, my pleasure.

[END OF AUDIO PART 2]

[INTERVIEW CONCLUDED]

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