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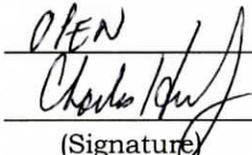
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An Interview with Charles Henley

Place of interview: Houston, Texas

Interviewer: Sarah Canby Jackson

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Approved:   
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Date: 8/20/14

TAPE 1 SIDE A

SARAH CANBY JACKSON: This is Sarah Canby Jackson interviewing Charles Henley for the Harris County Archives Oral History Program. The interview is taking place on August 20, 2014, in Houston, Texas. I'm interviewing Mr. Henley in order to obtain his recollections concerning the response of the Harris County government to the HIV/AIDS epidemic.

Would you please describe your family to me?

CHARLES HENLEY: I'm Charles Henley. While born in Alabama, I was raised in San Antonio. My family moved there when I was an infant. That would be my father, Charles Henley, Sr., my mother, Mary Eleanor Henley, and my sister, Lucy Henley. We lived on the north side of San Antonio, close to Fort Sam Houston. My father was a retired Army colonel that had served in the Pacific during World War II in the Corps of Engineers. He had had some service-related health issues so when he retired from the service after the war, he had been treated at Fort Sam Houston, I think that's why he settled in San Antonio. I certainly didn't have a vote in it at that point in my life. So we settled in the northeast side of San Antonio, which is relatively close to Fort Sam Houston if you are familiar with the city. He went to work to begin with when I was young with H. P. Zachary Construction Company as an engineer and later, probably when I was about ready to begin middle school, he left Zachary and went to work for the city of San Antonio as the Engineer for Public Works.

So, I grew up in San Antonio, went to elementary school and high school in the Northeast School District. My sister is seven years older than me so by the time I was about thirteen she had moved out and started a family with her husband that she had met while they were in high school. In my teenage years I was the only child at home. After graduation from high school I served in the Marine Corps. After that I came back to San Antonio, finished my first two years of college at San Antonio Junior College and then did my undergraduate work in sociology and got my bachelors at Trinity University.

JACKSON: Let me ask you a question, something that we haven't discussed before but I was wondering. In San Antonio during the 1950s and 1960s, what was your experience with segregation? And especially from the military background it was a little different.

HENLEY: Although my father was out of the military on or about the time I was born, so until I was a young adult, if I would go to the doctor or anything, we used the Army hospital facilities at Fort Sam, I don't know if that is true now for families that are no longer affiliated with the military. Interestingly enough, San Antonio's a very diverse city especially with their Hispanic population. But the way the city was configured, the high school that I went to, our graduating class was about 800 seniors in 1967. The best of my recollection, there was one Hispanic family that had a couple of their children in the high school. There were no African American families or children in our district where I went to high school. Northeast had a couple of high schools -- actually expanded to four in my senior year. So, it didn't have much impact one way or the other.

The neighborhoods had been developed we lived in a relatively new neighborhood at the time. That would have been 1955, 1956, when we moved into the house I grew up in once I started school. There just were not families from other

backgrounds. I think, as far as I knew, one of my friends who lived down the street, on the same street I did, was from a Jewish family and that was really it. It was very much a Protestant, Catholic, Anglo neighborhood. But San Antonio's underlying cultural gestalt, for lack of a better word is very much based on, San Antonio's a very old city compared to Houston especially, so I was very much immersed in that background, being around a city that had a high Latino population and so I always felt very comfortable with it. But as far as school mates and stuff, we were pretty apolitical I suppose.

JACKSON: For example, if you went downtown, were you exposed to legal segregation at that time? "Coloreds Only" drinking fountains like you would have been in Houston.

HENLEY: I didn't get to Houston until 1980 and we're going to talk about that as we move along. The only real thing I remember and it may have been more that it was sort of more of a legacy than it was still a fact when we would go downtown there is a great movie theater. San Antonio has a couple of these really old movie theaters. They had lots of balconies and alcoves and very elaborate, ornate. The Majestic Theater had the floor and it had three balconies. They got smaller as they went up and I remember that the top balcony was referred to as the colored balcony. Because my grandparents lived in Alabama in a very, very small town, you know when we would make a trip as I was a kid, a car trip, back to the home front in Alabama you would see remnants of that but in terms of my family, since my family had been in the military, but even the military was essentially segregated through the 1950s. Even though there were African Americans in the military they tended to be in their own companies or units, they weren't just dispersed, right?

JACKSON: It was officially integrated by Truman with the Korean War.

HENLEY: Right. I don't know immediately that African Americans would have been just randomly placed in different companies and things. As I got older and majored in Sociology and then later in life in my career, it was clear that even in the military into the 1960s and 1970s and beyond there were issues with ability to ascend in rank and that kind of thing. Most of my experience was hearing about it or learning about it, never in my face.

JACKSON: You never had to confront it.

HENLEY: Never had to confront it and interesting because you talk about the military, the Hispanic, Latino population was, my experience was they were very much a group of people who joined the military. And so, in terms of Hispanics and Latinos they were sort of on equal footing. As I talked about a few minutes ago, because of the way the city developed, there were large parts of the city that were primarily Latino and other parts of the city at that time primarily on the north side were Anglo. The east side was where the African American population of San Antonio was.

In terms of you look back and you wonder what people thought, when we were young, we would go out to the Eastside [Eastwood] Country Club which was just a night club which was clearly a night club when we were eighteen and nineteen and go to that night club which was for and about the African American community. They never gave us any hassle. In retrospect, it was a classic thing, not quite out of Animal House but we would just go to the club and we didn't really see it.

I know anecdotally and from reading and what was going on in some schools there would be a lot of racist stuff and the way people talked. The neighborhood I grew up in then was primarily middle class. There were fewer ranges of middle class back

then. Most people, almost every one of my friends lived in a household where the father worked and the mother stayed home. Most of the help was either African American or Spanish. The “N-word” was virtually never used. The term that I remember being used when I was growing up was “colored people.” I was aware it was there but it was not in my face and I wasn’t really confronted with it. I can’t say that I ever saw a drinking fountain that said, “Whites Only” and if think I might have it maybe that I saw it on television.

JACKSON: Saw a picture of it and it’s in your mind.

HENLEY: It was not that kind of segregation going on. Maybe San Antonio was very different from Houston because of the Hispanics who were there before the Anglos in San Antonio. In socio-economic ways, as the military came in and more and more Anglo families were in San Antonio there wasn’t a lot of discrimination or leveling out although my guess is that is influenced by my perception and there may well have been folks who thought they could be doing a little better. The traditions in San Antonio, the events that occur annually around Fiesta and parades, there was quite a social structure for Latinos. Within that culture there was clearly the wealthy and the upper class and the middle class and the working class. That sort of mirrored the Anglo population. My impression was they were always sort of on par with each other. There wasn’t a hierarchy among them, but each one had their own. The wealthy folks hung out with other wealthy folks. That’s been true for a long time.

JACKSON: Since time began.

HENLEY: In retrospect it was very insular and it was largely an economic situation and the neighborhoods, the suburbs, which now would be considered inside the Loop like in

Houston, because there is a Loop 410 in San Antonio and we lived inside that loop. My high school was just outside of it. That's where the new housing had been built and that's where families bought houses and raised their kids. In retrospect, all the kids looked like me. There wasn't a lot of multi-family development. Maybe that's something that exploded everywhere in the 1970s and 1980s. There weren't large apartment complexes or things like that.

TAPE 1, SIDE B

JACKSON: Why did you major in Sociology?

HENLEY: That seemed to be the kind of scholarly direction that I was good at. I just seemed to understand and be interested in relationships between groups and how you can look at things and make determinations. I was not good enough to do something like medicine because I had enough trouble in chemistry and I was not going to be able to pass organic chemistry. As we grew up most of my friends at least began college. Not all of them finished, certainly all of us finished, some less quickly than others, completed our degrees at different times. So I knew it wasn't going to be science or math, even though I was very interested in science, but that wasn't my strong suite. And psychology to me was a more popular degree for people that weren't good in math, but that sort of individual focus and then looking at it outward was much for me just the way I was wired, sociology, looking at the group and systems was just more natural. That's what interested me and it turned out to be a good match even though later I transitioned to

social work which is not sociology, but it's not a dissimilar subject area especially if you are a social worker that is more macro-focused, practice-focused person I am.

JACKSON: When did you graduate from Trinity?

HENLEY: I graduated from Trinity in 1974. So like many of my peers, I took about four years to do the first two years of college at San Antonio Junior College cause that's what community colleges were called back then. Getting through those Freshman English and all those cut classes whose intent was to cull the herd. In 1969 I enlisted in the Marine Corps and I had completed boot camp and was stationed in Memphis, Tennessee, which is an odd place for the Marine Corps, but I had been assigned to Marine Corps Aviation so I was learning and working on maintaining aircraft. After seven months both of my parents had serious health problems and I was eligible for a service related discharge because of my parents since I was the only kid at the time. My sister had married and moved away to Houston by coincidence really that I moved there later. So I was discharged. I'm a Vietnam Era veteran although I never served in country in Vietnam. So that was about a year of my life all together. Great experience but I never got a later urge in life to go re-enlist.

Then when I got back, at that point it was 1972 when I finished the first sixty hours of college. Then I went to Trinity University and that's where I really settled on sociology because in that first two years the courses you're taking are pretty generic, that maybe somewhat true these days too. You have to get through freshman and sophomore English and you have to get through Algebra, you know after three or four tried I did. Then you could drop classes, you didn't have to stick it out.

When I went to Trinity I did seventy-three hours in two years, so I basically went full time, fifteen hours a semester, plus two summers and graduated in the summer of 1974. Once it got over the tipping point with “get the education,” then that’s what I did.

JACKSON: After graduation you worked in child welfare. Could you please describe that job?

HENLEY: You know after I got my degree in sociology, graduated from Trinity, it was kind of like, “Okay, now you’ve got to get a job.” I actually supported myself going through Trinity by throwing newspapers. It was a great job. So for two years, every day, I had a route of about 1200 people. It was a great job, for going to school. I would just go pick up the newspapers about 2:00 a.m. and deliver them. That provided enough income to have an apartment and pay for my car and all that. Fortunately, my family paid my tuition which was much less than it is now. I don’t even thing just in proportion. Everything, gasoline was 35 cents a gallon then, but education costs have outstripped the increases in many other things. So, I was fortunate that my family could afford to pay my tuition and I lived on my own, not at home at that time. It was time to get a job where you had to go to work from eight to five.

I looked around at what I could do. Back then it was called Child Welfare, and now Protective Services. So I took a job in Uvalde which is about ninety miles west of San Antonio on Highway 90. There wasn’t anything available in San Antonio. I worked for the state and I was assigned to three counties: Uvalde, Edwards, and Real, it’s where Leakey is. It was a great job in one respect because I traveled all over the hill country in those three counties to follow up on what by today’s standards were relatively straight forward cases of kids being abused and neglected. Thankfully during my tenure there I didn’t really have cases where there were really horrible things. Mostly kids that were,

there will still always be the incest kinds of situations, but a lot of it was travel. So one day you would go visit a family that was 90 miles away.

I started doing the courtroom parts of the process where you would go to the district court which was in Uvalde for that area and time. You started to get that experience of being able to work with the judge, with the Texas Rangers, with the local authorities in terms of processing things through court. What I realized for example the first time I was called to give testimony, in a case where they are trying to get temporary or permanent custody, I wasn't challenged by that. I felt comfortable. Some people are not comfortable when they are called on the stand. So it was kind of like, "Ok, this is something I can do." I sort of saw how the bureaucracies worked and didn't work which probably helped form some of the way I approached things later when I was more responsible for how things worked or didn't work in a bureaucracy in that kind of a system. But it was still that systems thing. There's the quiet, there's the judicial system, the law enforcement system, being able to talk to the people whether it's the family, the relatives, the social services which you know there's not a lot of today and there certainly was certainly less back then. So I did that for a while. I was still young and Uvalde was not a particularly active place.

JACKSON: Is it now?

HENLEY: It probably is, because it's like San Antonio, sort of on the edge of the Hill Country so you go north from Uvalde and west you get into Leakey and Concan and all those great little roads and things, so that was great -- going around the Hill Country and checking on things. So after doing that for a couple of years, there was a position in San Antonio and I took that.

In San Antonio, the office for Child Welfare, which allowed me to move back and have more options in terms of my non-work life, being around my friends and things like that. Going back to San Antonio to do that though really put me more into what I would call the Child Welfare or Protective Services situations you would see in contemporary times.

JACKSON: In what way?

HENLEY: Really bad cases of children being severely neglected or abused.

JACKSON: And you didn't find that in rural areas?

HENLEY: No, not so much. People sort of took care of their own in the rural area. Even the few cases where there was probably some very inappropriate behavior going on between a father and daughter, a lot of people were very poor in that area where I had been working. In San Antonio, I really saw face to face the real hard choices and life situations that poverty produced and just the intensity of the issues. What I learned about myself then, in retrospect, this bore out as I transitioned into social work, even though I had a sociology background, doing child welfare, I was starting to do social work even though I was not a social worker. You are doing assessments of family situations, of individuals, you are helping people come up with a plan and especially if it's neglect or situations where people didn't have parenting skills. You are working with the system to get resources for them, case manage them through the legal system so you can resolve it or the situation was improved enough for the kids to come back home or stay at home. The connection to Child Welfare Services could discontinue as things resolve.

So, in San Antonio, there was a particular case I remember where we were sent out to a family that had a couple of kids and they lived in a trailer with no utilities. It was

a story very similar to this in the Houston area, up in the northern part of Harris County or it was in Montgomery County recently where they just lived in this old trailer with no utility services at all – no electricity, no water, no sewage. They were two individuals who were married who had very marginal skills, were probably special needs individuals would be more the term we would use now. It was a combination of a hoarder, neglect kind of thing and going into this trailer which was full of flies and spoiled food and human feces and actually pulling off a pot, a fly-ridden pile of dirty clothes and there was a baby down there. We didn't have cell phones and things like that. This was 1976 or 1977 at that point. I had someone with me. I tended to be very calm and able process the situation. My partner was someone who was probably more comfortable with like holding the baby than I was, but was not doing well in seeing all that. The parents were running around in the yard screaming, "They're taking my children." It was very difficult to talk to them, both their cognitive skills and the fact they were in a total panic. So I basically told her to go get the constables and contact our office to begin the protective custody order. So, I remained with the parents and managed to keep the situation from escalating further until reinforcements arrived.

#### TAPE 2 SIDE A

HENLEY: What I gained from that experience was that situationally I was able to be calm in the center of the storm and gather the facts, provide as much useful information to the people involved that they could process and accomplish what needed to be accomplished: which was to get the children out of there safely, to at least not exacerbate what was a

very out of control situation. I just remember thinking, my pulse rate didn't go up and I didn't have a deer in the headlights look. My partner, who was actually a more tenured person, did. So, later on and perhaps in working with the HIV epidemic at the beginning and later when assigned to a shelter of last resort for medically needy individuals during Hurricane Ike and things like that, I learned that I don't seem to be one of those people that comes in there and looks like I'm throwing things left and right but I actually can hold things pretty steady through the chaos and get to the other side and have gotten the information necessary and created the work plan that worked. That was something I must have filed away in my "this might be something I should do."

I learned doing Protective Services, using the terminology of today, that people didn't seem to have an issue telling me things. Very direct personal things about what was going on with them. It wasn't like I had gone and been trained in particular skills, because in sociology we did interviews and surveys where we would knock on doors and things like that, but that was largely script driven. But, you do at least get to talk to people you don't know about something they didn't know you were going to be talking to them about. I sort of picked up it didn't take a lot for me to get people [to talk]. Oftentimes I was "the man"; they weren't there by their choice. People seemed to talk to me. I can remember thinking, "Why are you telling me this?" But they did. So that's been something that's held true. I had listening skills even though I didn't know to call them that at the time because that's not the kind of training you do in sociology so much. That was something I was good at. I think it's held true. It's one of the challenges of large cities and counties and all across the state.

Child Protective Services work is pretty much a dead end in terms of you just work at it until you burn out. There's not a lot of advancement. I guess you can become the person who trains or supervises the burned out, the potential "burnees." I could tell this wasn't going to be something I was going to do forever. So I thought about to really do something a little bit farther along the scale of growing up, that I probably needed to think about going back to school. Once you start doing that, because masters degrees are very practical oriented, it's where you are going to learn something you are actually going to use and do [for a career]. So I thought about going to school and then I thought about what kind of work I would need to do. It was just time to relocate. A lot of people, and I'm sure it wasn't just true about San Antonio; Houston was a place you could go. My sister had moved here, but I really wasn't moving here to hang with my sibling. It's just that I knew people in Houston that I had met in San Antonio that had gone to school at Trinity and other places. In Texas you have to make a choice early on whether your potential bigger city you go to is either Houston or Dallas. I knew it wasn't going to be Dallas. It's about the same from San Antonio. You could relocate up the I-35 corridor to Dallas or I-10 to Houston, so I chose Houston. I loved Austin, but Austin to me, especially in the 1970s was just the place you went to listen to music and to have a good time. Since I lived on the north side of San Antonio, going to New Braunfels, San Marcos, and Austin, stuff you did on the spur of the moment kind of thing. So, I never really considered Austin as a destination. I think if I had said I wanted to keep working for the state and wanted to make a career, to go work for the state like the Health Department or Child Welfare Services at the state level, but that didn't appeal to me at all at the time.

So I came to Houston. At that point I was going to be paying for my education and everything on my own; I was thirty years old, so that was 1980. To get a job I looked around and I didn't want to come to Houston and go work in Child Welfare Services. I knew I had done my time with that particular type of work. So, in pursuing the want ads, the classifieds, and looking at things I could do where you needed a bachelor's degree but it didn't necessarily have to be a specific kind and I'd be good at, I was drawn to working in mental health facilities, psych hospitals. So I took a job in Alief General Hospital which had an adolescent wing. Pretty quickly I figured out that was a good niche for me. In particular working on the adolescent unit some of the skills I sort of figured out I had and skills I used later in subsequent career choices were really things that served me very well in working in the mental health system and in the in-patient psychiatric programs. In the early 1980s mental health services, especially when it came to children and adolescents, were very different than what is available now in large part because of how things were done in the 1980s, many families cannot get the kind of help they need. I started with Alief General Hospital which was Hospital Corporation of America owned and operated and they had turned a wing of the general hospital into a psych unit for adolescents. One wing became adolescents and the other became adult. But, I started and stuck with adolescents the whole time I was doing this type of work for about the next six years.

Back then the kids were admitted a lot of times just because their parents had insurance and these kids could be in the hospital for a year or more. And sometimes they were there because they had a lot of very serious Axis 1 type issues, mental health treatment terminology, in other words they had very serious psychiatric issues, but a lot

of the kids were also there because they ran around and they were having sex and doing things, this was still the early 1980s. The way the system worked, the kids could be put in the hospital for acting out. And, they could stay there for a long time. It was a way to start to see how things also worked, what drives things. Kids were in the hospital sometimes because their parents didn't want them sneaking out with older men, they didn't want them doing drugs, they couldn't manage them, and then they would stay there for a long time because that was a very lucrative opportunity for both the doctors and the system. While the care was obviously beneficial, it also kept the kids off the streets. But literally, million dollar policies were gone through. Ultimately that led in the late 1980s to a complete turn around and now families who have kids that are really in big trouble, very self-destructive with very risky behaviors, can't get the child admitted more than seventy-two hours and that's only if the child is literally saying, "I'm going to kill myself or you." Unfortunately, the bilking of the system led to a reaction where it swung so far the other way that really it's been a very negative outcome from that.

Doing that work, that's where I figured out I should consider Social Work School to be someone more than the person who worked on the floor with the adolescents and that was primarily my role, to help manage the unit and help the kids work their plans and get to their activities and talk to them. I had a good way of being able to help people do what they didn't want to do and to be able to listen, to be yelled at and still be the "never the less." "Yes I am the worst blankety blank blank blank that's ever been on earth but you still need to tidy up your room so you can earn your points and that way," this shows you how times have changed, "you can go outside into the courtyard and have a cigarette." These are teenagers but back then it was a permissible incentive to let the kids

go out and smoke a cigarette if they earned their points for the day. But, it still was a way to basically refocus someone in a situation not of their choosing and not something they wanted to be doing to be able to see how to be able to do what needed to be done in a way that they could at least accept. That ability to set limits and maintain a relationship, to parent without being the parent, and not getting the negative, stubborn reaction where the person can't do what's actually in their best interest, I sort of figured out that skill. It was something I just had. It wasn't like I decided to do this and had to learn it. I certainly used the training and schooling I had gotten the education to make it better and to learn what to call it, but that ability to do it seemed to be there. That served me well in the Ryan White Program later in life.

That's when I enrolled in the University of Houston Graduate School of Social Work, I think now it's called the Graduate College of Social Work or College of Social Work, and went part time which is not unusual in Masters Programs particularly in social work programs. In fact, the exception to the rule, maybe a little less so now, people had gone from undergraduate work and worked for some years in a field where they were doing social work like activities, then they would go back and get their Masters in Social Work. That was the pattern I took. So I never went to school full time. My mother died right before I moved to Houston and while I was in Social Work school in Houston my father died. So, there was a semester or two where I didn't take any hours. But then, like my undergraduate, when I finally got to a point I took one year and finished out the degree program and got my Social Work degree, Masters in 1986.

JACKSON: And that was the same year you started to work for Harris County.

TAPE 2, SIDE B

JACKSON: So, in 1986 you began work for Harris County.

HENLEY: For MHMRA of Harris County.

JACKSON: The full name is

HENLEY: The Mental Health and Mental Retardation Authority of Harris County. However I think it is as true today as it was then; you are not a Harris County employee. You do not have the same retirement plan. So I think this is the normal set up. MHMRAs are sort of county-state. . . .

JACKSON: one of those hybrids.

HENLEY: That may have changed, but I remember it was not the same retirement plan. And so in 1986, I looked around for opportunities. So as a social worker my choices were to keep doing what I had been doing but instead of being the mental health worker at the psych hospitals, I could transition into being a therapist. Maybe not right away into private practice but certainly the folks who actually facilitated the groups and individual sessions in the programs I had been working were licensed social workers or professional counselors. They were either LPCs or LCSWs I think the licensure was at the time. More than half of my fellow students in social work were people who were in social work to get the degree so they could get the license and then put up their shingle that said they were a therapist. Even though I had clinical jobs and I could do the more traditional formal therapy that was not the part of social work that really jazzed me. I liked the more macro practice that focused on the group and the systems. So I was not interested in really pursuing, going back to West Oaks Hospital where I was working up until I took

the job with MHMRA, and saying I would like to move over to the clinicians' side, because as a mental health worker, you're not a clinician.

So I looked around, and I saw this opportunity for doing adult mental health case management which appealed to me. Then when I learned about it and did the interview with a woman named Kate Sexton, I kind of said, "I think this might be something I would like to try." This program was working with the individuals who cycled back and forth between the state hospitals, the chronically mentally ill, the folks you see with the shopping carts living under the bridges or in the personal care homes, who usually had a mental illness to a degree that they were already determined to be disabled. So, you are talking about Axis 1 things, schizophrenia, some other disorders, which made them very hard to be in society.

But what had happened in the last ten to fifteen years before I took this job, people were being deinstitutionalized. So, the state hospitals were no longer caring for people for a lifetime. So they were basically pushing folks out of the hospitals, the mental health state hospitals which were residential treatment facilities, and back into the community where they almost always didn't do very well because there wasn't really enough community support. So this case management model which is tried and true and probably still largely done in a similar fashion, hopefully with some better meds than we had then, people would get them on their meds, get them out of the hospital, send them back to the big city whether they came from there or not, Houston being many things, a prime destination for people coming out of institutions whether it's the mental health system or the criminal justice system, and these folks were sort of one or the other or both at the same time. And you know, working with these folks where they are at in the

community, doing home visits. They didn't come in to see us in our office; we went out and worked with them.

The staffing model for this type of work was to use non-licensed lay case managers some of whom were like I had been a person with a bachelor's degree and maybe had done a little bit of mental health work like I had and in some cases some longer termed, longer tenured folks who had been grandfathered in when somebody had said, "We need to make sure all the case managers at least have a four year degree." So, there was a combination of bachelor's degree, non-bachelor's degree. Because I was a social worker I was both seeing some clients, some consumers that's when we started different terminology that the folks wanted to be known as, and supervising those lay folks.

I was working for a social worker, Kate Sexton, who was very invested in that model, and it was really, you work with people where they are at. Your job is to develop a relationship with them and get them to go to their appointments and stay on their medications. That is a theme that will stay true all the way through my tenure with Ryan White and the HIV/AIDS program. That was the key. The medications were / are very difficult to take in most cases especially with the bi-polar and manic depressive clients and a lot of times folks have a combination of diagnoses with undifferentiated schizophrenia and bi-polar. The medications could reduce their symptoms but in most cases it also made these individuals, and I believe they would say it just numbed them. It took away all the stuff that they liked. While it made them more complainant and less likely to offend society in anyway, it also they would just go off their meds after a while. Then they would deteriorate and they would get picked up by the police or somebody

would call and you would have to go and see if you could engage them. Without this case management program, what would happen is they would deteriorate and then they would run afoul of the criminal justice system. Not necessarily for committing a specific crime, but because someone would call and say, "This person is ranting and raving and threatening me," and so then the police would pick them up and take them to jail. The system would send them back to the hospital, they would get put their meds, and they'd stabilize and be sent back. The whole point of the case management program was to try and intervene in that community stage where they haven't gone off their meds yet. And to keep them on their meds by checking in with them, by visiting them and meeting them where they lived or where they wanted to get coffee or where they wanted to put their shopping cart, in their cardboard box. So you were getting used to working with people who didn't bathe, screamed at you. The kind of people most everybody else would walk to the other side of the street rather than walk by.

Once again I seemed to be able to deal with those folks. You had to be comfortable with them. If they needed to go to the clinic, you can say, "You need to go take the bus to get there," but in many cases that was like saying, "Go climb Mt. Everest." So, you put them in your car to take them. You had to be comfortable with people that were not necessarily who you wanted to be hanging out with. That seemed to be something I could do. I could help the folks I was supervising be able to do that, to cut through it. It was a classic thing. "I know the people in the wall are talking to you, but you still need to take a bath. You still need to go to the clinic every three weeks and get your shot, even if the people in the wall are talking to you." It's not like you are telling people, "No, that's not real." You're just saying, "Whatever it is, you still have to do this

other thing.” That sort of focus on adherence and taking people where they are at in their life and not imposing some sort of other framework that somebody thinks you need to adhere to was the basis of what we did and it was a very useful model later especially in the early stages of the in the AIDS epidemic when there wasn’t a lot of treatment options.

JACKSON: When you were dealing with basically people on the street, were you beginning to see AIDS patients at that time?

HENLEY: No.

JACKSON: I’m kind of surprised.

HENLEY: Well, I think I probably made some of those kinds of assumptions. Remember I was doing this from 1986 to 1991. By and large the people we worked with were so far off the reservation that they weren’t engaging in behaviors that put them at risk. There weren’t people having sex with them and by and large they weren’t injection drug users. Their mental health challenges were dissociative schizophrenia and bipolar disorders and so surprisingly not. Anecdotally from something I learned later, there are always sometimes assumptions that the homeless population must have a higher incidence. Sometimes that does not turn out to be true. Now if homelessness is tied to the fact you are an injection drug user, yes, and if it is tied to you are exchanging sex for money to survive, yes.

The other thing I was working with folks on the street but a lot of them were in these very poor, awful, personal care homes. So I really saw a lot of exploitation. You know you are really in a tough spot. One of the things that has always served me well in life and you are sort of born with this or not, I rarely see anything in black and white. So, this is a really bad situation. Almost invariably the consumers in these mental health

situations I've been talking about, they become very attached to these caregivers. Basically take their check that they get from Social Security, their SSI check, they take the whole check and they live there and they provide room and board and supposedly a bunch of other stuff and they're not licensed. They're still not licensed. It's a real cesspool of exploitation of people that still goes on. The consumers get very attached to them and these people take advantage of it. Sometimes it was well, "This is really an awful place and God forbid that my loved ones or myself would ever be faced with that choice," but it was not necessarily the least, worst option that person had to face. A lot of it was checking on folks, we had then and I don't know how much better it is, the MHMRA had very limited statutory authority to tell a place to do something better. You could try to convince the client to not live there, but you couldn't tell them they couldn't. You couldn't tell the people that you were going to close them down, because you couldn't. You just learned to deal with it as it was. Like I did in that one incidence in San Antonio, we had to be okay going into places you would not think you would want to go into and you had to be able to feel safe and be able to talk to caregivers, and I'm using that term to describe who they say they are.

#### TAPE 3, SIDE A

HENLEY: Perhaps now but certainly then MHMRA was very hamstrung for resources. Even then, we weren't dealing with people who had adjustment issues or they were going through a tough period because they had lost a loved one to cancer or a car wreck or violence. These were chronically mentally ill folks and the basic intervention was they

needed to get to one of MHMRA's clinics and get their medication. When they didn't then things went to hell in a handbasket very quickly. Once again, you had to interface with the court system. And, back then, it was Judge Scanlan. You just got to know the Judge very well because we would have thirty or forty of these folks on a case load, the people I supervised and me, and you know you got to know them. Judge Scanlan knew them. We'd take them into the courtroom because they would have been picked up and taken to the hospital. At the very end of my tenure they opened the psychiatric hospital over on McGregor. Before that, they were just at Jeff Davis and it was not a good situation. That facility got better, but they would be taken by the police, involuntary pick up, they would go talk to the Judge. I remember a particular individual who was actually very colorful but he would get off his medications and start talking about how Jackie Kennedy could launch the missiles and the Judge would let him talk for a little while and would just say, "Mr. Smith (not his name) you can go back to Rusk for a little while."

These folks would know that's where they were going to go. Sometimes they wanted to go back. The challenge was they couldn't stay. The movement to deinstitutionalize individuals, quite frankly, a lot of these individual's quality of life went from bad to worse when they were forced out of the hospital. If you've ever been to a state hospital, they have a big campus. They were all sort of conceived and built a long time ago, so they have that vibe to them. They would get there and they would be structured. They would take their meds, there would be a routine. They would go to the cafeteria, smoke cigarettes, they'd take their medications, they'd worked their program. They knew the people who worked there, who were long time employees. I took my team up to Rusk once so we could say, "Look, here's where the people we send to Rusk,

come.” So they could walk it with their own shoes. But then they would come back. Three months later you would get the notice that Mr. Smith was being discharged back and his first appointment was this date and this is where we are sending him. We would go deal with that.

The other thing, in some cases, in that position you also worked with family members who had washed their hands of their child, adult child at this time, of their children who had these mental health issues that made them somebody they didn't want other people to know was in their family. Again, in retrospect, it was a good precursor for what came next in my life. So you would work with these families who would call you and say, “Well, they're coming around and doing those old behaviors.” Or they were the opposite and just couldn't accept the fact, and in schizophrenia in particular it's a late onset illness. A lot of times these were bright, beautiful children and young adults. Then at about twenty it kicks in. You start hearing voices and doing the self-destructive behaviors and their hygiene habits change in ways the family didn't approve of. So, the families would stay real invested in making sure the case workers were supposedly doing all these things that should be done, and so then you had to learn to manage a family that either wanted perhaps to be involved in a way that wasn't productive or had washed their hands but you still needed to have them in the loop. Because sometimes the family could provide something that would at least enhance that person's quality of life. If you could afford to help this person have their own apartment, we could come by and visit them once a week. His case manager could come by once a week and check on him to make sure they hadn't just left the water on or the stove on or taken the doors or windows off or put up a lot of aluminum foil. That was just kind of the vibe of that job. Working in a

system with people who were outcast from society through largely things they had no control over. Some folks had probably exacerbated underlying conditions through massive drug use or something, too much LSD in their earlier years, but for the most part those kinds of mental health issues I think a lot of it is determined by your DNA, things like that. It's not like you can choose to not have an Axis 1 diagnosis. But, there's a lot of stigma, again something to deal with HIV, "If you would just get a job, take a bath, and get your act together, then this wouldn't happen." So you obviously from some sort of self-imposed lazy character defect you are choosing to be a homeless, schizophrenic person who yells at the bus on the street corner which is completely untrue. That's the prevailing attitude of the time and still is a challenge for people with mental health and other chronic illnesses that produce a situation for someone where people don't want them around.

My mentor who had hired me, Kate Sexton, she was very big in that model. I did that for the bulk of my career at MHMRA. But like a lot of things, that's something you can do for a while. MHMRA brought in a new executive director and as that always happens, they changed things just so they could say it was their things. An opportunity came up that was more of a traditional mental health therapist – therapy type of thing, so the last year or year and a half I worked at MHMRA, and I worked there five years in total, I became the Director of the Child and Adolescent Unit. For children in adolescent services, MHMRA at least at that time was still able to offer some more traditional family counseling type interventions. So you could do group therapy and family therapy and individual therapy for children and adolescents and that later part I supervised those folks. It was still outpatient, but it was definitely much more traditional social work

focused on family and individual mental health issues, not like my previous work with the chronically mentally ill.

So I've done that and I also in my personal life I enjoyed doing things outdoors, hiking, camping. I grew up in San Antonio and one of our favorite activities we would go up to New Braunfels and to Edge Falls and other places and go inner tubing. I like floating down a river. I got very interested in doing river trips and I had fallen in love with Idaho. My experience with Idaho was strictly in the summertime but it's a little bit of a less known thing that Idaho has some of the most beautiful wilderness in the country. You think of the Rocky Mountains, you think of Colorado, but Idaho has more mountain ranges and more natural forests and wilderness that's never been settled or apportioned in private hands. So I began going up there once a year to do river trips on the middle fork of the Salmon River and Selway River and I really loved it. It's a long way from Texas to Idaho. You would have to take off three weeks to do a one week river trip so I said, "You know, this chronically mentally ill focus and working with folks in the community with these chronic mental illnesses, they got those folks in Idaho too." Although Idaho is a state at that time that had fewer people living in it than southwest Houston did at the time. So the total state population was like 700,000 people. For that small cohort of individuals, there's nothing unique about Texas when it comes to having folks that have long standing chronic mental illness.

I actually began a process of looking for a job in Idaho to do what I had done with MHMRA for the bulk of my career. To go up there and it was called an ACT – Assertive Community Treatment – just somebody put a name to what we had been doing, being out there and doing that. I said, "Heck, in Idaho it will be more like my job in Uvalde. I'll

have to go a hundred miles up to this little town and meet some guy that stays holed up in a cave to make sure he takes his meds, puts down his long gun and maybe cuts his beard occasionally.” I did the interviews by phone and really pursued it with a passion because I wanted to do it. I had actually gotten to where they had offered the job and I had tentatively accepted it.

Coincidentally and serendipitously, at the same time my former mentor at MHMRA, Kate Sexton, about the time I had left to go up to do the Child and Adolescent, she had left MHMRA. She was someone that was more affiliated with the LGBT community. She had taken a job in what was then the very beginning of the Ryan White Program, which I didn’t know a lot about. I was not someone who had a family member or a loved one who had been personally affected by AIDS but I had become aware of the AIDS epidemic. We’re talking 1990 – 1991. We are starting to see the stories. The people especially in the late 1980s had really been on Ronald Reagan’s case about not responding to the epidemic. Then in 1988 George H. W. Bush became president. He’s the president who actually signed the Ryan White legislation that took effect in 1990. So I was aware of the epidemic and I was beginning to be aware even of its local impact, but still not directly. I mention that because overwhelmingly the individuals who were the first folks to pick up the shovel and pick up the axe and all to fight the AIDS epidemic were people that were actually directly affected by it. They were seeing their lovers and significant others and family members and close friends being diagnosed with AIDS and die very quickly. It was clearly an epidemic.

JACKSON: Before you continue, I just want to put some dates in here for people who aren’t that aware that AIDS itself wasn’t first documented until 1981 by the CDC. It wasn’t

called AIDS until September 1982 by the CDC. As you mentioned it was totally ignored by the Reagan White House. So what happened, non-governmental organizations had to take up the banner to deal with it, primarily in San Francisco and New York City to begin with where there were large populations that were being affected very rapidly.

One of the other things I think we will probably talk about later, but I would like you to discuss, especially in the 1980s, how panicked people were. The whole population panicked about AIDS. Rock Hudson died in 1985 who was really the first celebrity to die, a popular cultural hero. And, no one knew how it was transmitted.

HENLEY: I certainly remember in 1986 when I started at MHMRA, I finished with graduate school and it brought me out of the private psych hospitals where I had worked to support myself until I finished my degree, I began to become aware of the extent of the epidemic. You would see the stories from San Francisco and New York and I began to see but not personally experience that visceral anger that was starting to build up over the lack of response.

But in Houston it still wasn't something that got splashed across the headlines. It was not something the city leaders or the county leaders were saying, "We'd better get on this," although, as I learned, Houston was one of the epicenters. When the Ryan White Program was put into the place in 1990 was one of the original cities awarded funds along with New York and San Francisco, Houston was in the original group that the epidemic hit so hard. I think there were only eight so you had Washington, DC and Philadelphia, New York and San Francisco, Miami and Houston. It was big urban epicenters. I did know by the mid-1980s that the Montrose Area of Houston was the neighborhood, the gay neighborhood. It was a fun flamboyant neighborhood and that

certainly changed in the 1980s as the epidemic pretty much affected everyone there. And the Montrose Area had also fallen on harder times and that allowed people to move in and become that community. I don't think it was just some sort of coincidence that there was an opportunity for people to live in a neighborhood where they felt like they were with people they got along with and treated them with respect and part of a bigger village so to speak. I began to be aware of that, but it had not really gotten my attention. Because of the work I did, I certainly paid attention to the stories maybe differently than someone else would have. So the confluence came – it had gone from GRID [Gay-Related Immune Deficiency] then it became AIDS. They still really hadn't figured out how to test for the virus in the blood. Early on hemophiliacs who were exposed to blood transfusions comprised a relatively large percentage of the cases. So you already had a population of individuals with AIDS that had not been exposed through a life-style choice.

JACKSON: An article I read mentioned the 4-H Club: homosexuals, heroin addicts, hemophiliacs, and Haitians.

HENLEY: And Haitians I think because it had gotten into Haiti and it really hammered a population. Yes, the 4-H Club. I don't know if I had ever heard that but it certainly makes sense.

JACKSON: That was from a 1982 article.

HENLEY: I didn't live in that part of town; I lived more in southwest Houston. In fact, when I worked for MHMRA, I lived in Harris County but not in the city limits. I lived up north of 1960. So, I was kind of removed from it. With the population I worked with for MHMRA, it was really not on the radar either directly or as we learned afterwards, it

should have been. It just was not affecting those folks. They weren't getting blood transfusions. They weren't engaging in risky behaviors with other people who had been exposed.

As I began to say earlier, after Kate Sexton left MHMRA, she went to work for a then organization known as the Greater Houston AIDS Alliance. And the Greater Houston AIDS Alliance was an early attempt by the local authorities and others to form an umbrella organization that could bring a little order to all these very passionate but disconnected efforts to do something in response to the epidemic. So money was just beginning to become available from governmental funding sources. Even though the money was intended for agencies that provide services for people with HIV, most of the agencies, you're talking about the non-governmental to use a more contemporary term, AIDS service organizations were largely founded by people living with HIV and affected by HIV. Even the traditional social services providers with a few notable exceptions who should be credited, they didn't want to deal with HIV. So the local programs that helped people with food and shelter and housing, they didn't want the AIDS patients at their agency. They thought that was going to transmit the virus to them or their normal constituency. That awareness that people would think that HIV positive people are already out there in their waiting room, they did not want that. They didn't necessarily jump up and say, "Okay, here's the new thing." It was very grassroots driven. But those organizations were very ill-prepared to compete for the governmental money largely just because of the rules. Once money became available through the federal and state government, it went out through the normal business rules that grant funding is done. So, you had to be a non-profit, you had to at least be a real organization, not a collective of

friends that had started something that has a name. Because the response had been like people dealing with a fire, not planning to deal with the fires, so they were just fighting it by forming these coalitions and things. The thought was we form this umbrella organization that can create a plan and have a means to get the money and then farm it out to these more community-based organizations.

JACKSON: And this was in 1988, 1989?

HENLEY: The late 1980s, and so like a lot of things in life, the road to hell is paved with good intentions. The epidemic continued to just expand. However many people were affected last year, there was twice as many the next year. It was clear that it was just decimating an entire community among others. There was unbelievable stigma. Twelve Oaks and I think Park Plaza had started in-patient programs and I think the indigent were at Jeff Davis. Largely people quickly progressed to being so sick they had to be in the hospital and when they went into the hospital, they didn't come out and they died. Tangential to that in terms of how I started what I did and how I got involved, there had been families that pretty much ostracized their family members with HIV/AIDS, they weren't wanted by their church, by their friends, by their family. Businesses didn't want them to come in the door. It was tragically not difficult to identify someone who was living with AIDS because there was virtually no treatment that actually improved ones health status. There was a few that mitigated some of the symptoms for a brief period of time. There was a physical appearance that people began to associate with someone living with AIDS and they were just ostracized, stigmatized, forced out of what could have been normal ways you could have gotten assistance. The people with AIDS and their supporters began to form their own food pantry and their own housing program. Necessity is the mother of

invention. If nobody else wants you, you band together. And of course out of that in other cities and then it began in Houston, collective activism saying not only are we getting together so we can maybe as a small village do better than we can individually, to assert themselves against the system and demand more resources. So as those resources became available, the thought was we could defragment some of this by creating the AIDS Alliance. Like I said, good intentions.

Something I learned after going through this, when there is an emergency, a widespread emergency that creates enough political pressure that the government responds, the government really has one capability. It has one bullet which is money. It wasn't that there was a bunch of people up in Washington or in Austin who knew what to do. It wasn't that people with skills were being withheld. There weren't people with skills. What knowledge about how to help people was completely contained by the people who were affected by the disease and were doing it. So the government does what it can in an emergency whether it's Katrina or when there is a big disaster the government sends money. The state to begin with and then Washington began to send money. The Washington money was consolidated and put under the program called the Ryan White CARE Act. CARE stood for Comprehensive AIDS Resource Emergency Act. There's an emergency. The pressure finally caused the government to open its purse and send money. It sent no guidance, no instructions, it just sent money. That's also I learned, how it happens. The government can do one thing which is to give out money. The emergency and the political forces that actually got to the tipping point of forcing the government to respond with money, means that once that happened, the money has to get

out. The money showed up and everybody did the best they could even if in an absolute sense it was a poor effort.

The money came to Houston. People fight over money. There is never enough money. It was a set up for things to not go as well as they could. This bore out whether it was New York or San Francisco or elsewhere. The money came in. People fought over it. Everyone with the best intentions but there was very little infrastructure for it. Once it got here it needed to quickly get out to the community-based agencies and others that were at least making an effort to help. So, the money went out like in any sort of emergency, the people who stood up first or got hired first didn't necessarily in retrospect have the best capabilities to manage it and they were responding to the pressures of the day the best they could. So the AIDS Alliance was doomed from the beginning (a) because the epidemic was overwhelming, the amount of anger and loss was inconceivable and (b) because there was no structure that came with the money other than get it out to make things better. When you are on a sinking ship and it's on fire and there are no lifeboats, everybody has a different idea of what makes it better even if every one of the ideas ends up with the same outcome of a sunken ship and no survivors. In retrospect for a lot of reasons, there were challenges.

Kate Sexton had gone to work at this agency and she was basically coming in to start a case management program. Because even though what created the need for case management, the approach that had been used, the psycho-social type of case management that was used by MHMRA to meet people where they are at and help them.

## TAPE 3, SIDE B

That type of intervention was actually a relatively effective way to respond, which was, “We don’t have anything that will cure the disease, have very little that can even prolong someone’s life, but we can use what we’ve got,” -- try to help people get connected with support, try to see if we can rebuild some family or loved ones support, help the individuals who are living with AIDS, access the resources that are becoming available,” -- in other words, case management. We need to develop a mechanism to train the case managers to be able to do this job, because by and large they were lay case managers. This is just like who we used in HMRA. These were not social workers or other licensed individuals. Whether you were a social worker, a dentist, a housewife, or a bus driver, pretty much in the late 1980s or early 1990s you really didn’t want somebody with AIDS around. It sounds a little harsh now, but the dentist didn’t want somebody with HIV and AIDS sitting in their chair. The doctor didn’t want you in their office. The school didn’t want you in their school and that bears very true with Ryan White and now we got the legislation that was named in memory of him.

We took those skills, and Kate had done that, and working in that office with then director Sue Cooper who had been tabbed as the leader by the powers that be at the time. The county had some influence in that I suppose. She [Kate Sexton] said, “Charles when you worked for me you understood the model but you also had this ability to bring your obsessive compulsive personality to getting things organized and working with parties that were at odds with each other and focus on what needs to be done without getting side tracked by all the drama.” There was an ample amount of drama.

Time is factored by an earlier decision to seek work in Idaho, I heard about this job and met with Sue and talked to her about it and she said, "I'd like to hire you." I remember the conversation I had with myself. I'm a social worker and this is the plague of the century. While I could go to Idaho and there would be a lot of personal satisfaction in that and I could do what I do and it has value, it's like I'm a soldier and this is the war that's broken out. So I could go to Idaho and be a peace time soldier or I could man up and head to the front line. I just said, "This is what I need to do." It may have actually helped me through those first several years after I made that decision. I didn't come in because my partner had died or my brother had died or my best friend had died of AIDS. I was a little removed from that deeply personal sense of loss but I could certainly because if that innate skill had I been born with that I talked about earlier that I learned about myself in Child Welfare, I could relate to people and I could talk with them and they could share with me and I could hear what they really needed to say. I could then take that and run it through my processor and come out with, "There are some things we can do with what we have. We can MacGyver this with what we have into something that will be better than what it is now." That person with HIV will see that some of what they said has been validated. Some of what they needed has been built into this response. That proved to be a very useful skill because I was able to be a part of it but still have that 30,000 foot view of what we had to do today and what we could do today that would make it better tomorrow and what we could do tomorrow after many tomorrows would be a policy change or a strategic change that would result in even more benefits.

I remember I went to work in November in 1991, that's when I began that job so I left MHRMA

JACKSON: and you were hired to do what?

HENLEY: To be the project director for the state money at the time. The Greater Houston AIDS Alliance began with money that came from the state government, the Texas Department of Health. Then once the Ryan White Program was going to happen, there were actually some demonstration projects that got funded out of Health and Human Services, HHS is the part of the federal government that does health response and is where Ryan White is housed. So, they had sent some money to Houston to help start an interconnected system that was connected by computers to help with case management. It had been awarded to the Greater Houston AIDS Alliance and Kate Sexton was doing that, building the beginnings of the system we have now that's proven to be one of the best practices in the nation. I came in ostensibly to manage that money that came from the state, to do all the paperwork for it, to run the process that picked the agencies that got that money, to do the reporting, to get the contracts out. But I basically parachuted into a war zone with a very poorly run headquarters. While that was my job description, I also started doing everything else. There were probably eight employees. It wasn't like there was a big cadre of people.

My boss at the time was someone where her interests seemed to lie was in all the ups and downs and ins and outs of who was this and who was in favor and who was out of favor – really not about the business of this money. There were things you had to do even without the instructions there are still basic things. You have to document things. You have to keep things organized so somebody else can find it. You have to follow processes so that the money comes in you can show you did an independent process to pick the best provider to do that service not withstanding who their buddies are or whose

in favor or whose out. There's a lot of inherent danger of conflict of interest in the Ryan White Program, more so in the beginning but still now because the people who were affected by the disease were also the same people who ran the agencies, the same people that were on the planning bodies which became known as the Planning Council to decide what to do with the money.

Because the only people that knew anything about HIV/AIDS were the people that were affected by HIV/AIDS. If you wanted to bring in people to help make decisions or operationalize things, the only people who had any knowledge and were willing to be in the same room were the people that were already willing to be in the same room. The rest of society said, "No thank you." Because it was that emergency response in the middle of an epidemic, everybody was passionate and angry and thought that if you did it how they said it would be better than how he or she said. I just seemed to have the ability to hear that conversation, be a part of it, and come up with something at the end that everyone could at least agree enough and move forward on it. I was able to start building trust with providers and with the consumers and with the other stakeholders in the system at the time. My natural tendencies is to keep things organized and remember when stuff is due and if you do something in government work it needs to be documented, recorded, and kept in a way that it is useful for an archivist later, that just seemed to be a good match.

JACKSON: Just to emphasize this point, I want you to tell me how they kept records when you came in because this is the best example of what you are talking about.

HENLEY: When I came in, we were at Thomas Street Clinic [2015 Thomas Street, Houston, Texas 77009] which was and is the first and largest freestanding HIV/AIDS clinic in the

United States. It was started by the Harris County Hospital District and the county in the late 1980s in response to the epidemic. They had taken over the old abandoned Southern Pacific Hospital. It was a building that had been built in 190\_ something. It had been used for different things over the intervening century and then had been abandoned but still belonged to the county so when they needed a spot they said, "Let's use that."

Our offices were in that as was the clinic. It had not been rehabbed or anything at that point. We were on the top floor and I could tell when we went in there it was going to be a good fit for me, but remember the old saying, be careful what you wish for. There was no record keeping. Records were simply put into stacks. I always called it the sedimentary system. So if you looked at a stack and you could kind of think, that's the stack that might have gone to, once I got a feel for the illogic that was behind it, then the older record would be closer to the bottom of the pile and the newer thing at the top of the pile except when somebody looked for something in the pile and that jumbled it up. That was actually a mountain that was too high. I started the process of keeping things in order going forward. We never ended up having time going back and bring order to some of the pre-existing chaos. So contracts were being written and not kept in order. Things that belong with one contract were in a stack or stapled to something that was something else. The person I worked for, that was not her focus. She wanted to talk to people and be pulling the strings even though it was clear that she had very little credibility in the community as someone who ought to be pulling any strings.

JACKSON: And this was Sue Cooper.

HENLEY: This was Sue Cooper. Now Sue was a social worker and she hired me and we worked together for several years. So, I'm not going to beat on her. She got beat on by

enough people. But she did not really understand the role of the administrative agency within the context of the Ryan White Program and the AIDS response. Which was, we needed to be the part that brought the stakeholders together, helped along with the stakeholders create processes that generated enough trust that the processes were valid and had credibility, and be able to document things to the standards necessary for receiving millions of dollars of money.

The Greater Houston AIDS Alliance was a nonprofit. When the Ryan White money had first been awarded, the way the legislation was and is still written, by law the Harris County Judge is the grantee. The money must go to the chief elected official in the jurisdiction who has responsibility for the largest number of people with AIDS. The Houston area that the Ryan White money covers is six counties. It's Harris, Fort Bend, Waller, Montgomery, Liberty and Chambers counties. Not Galveston County and that seems to be true of a lot of things. Galveston County rarely seems to ever be pasted into any multi-county thing that includes Harris County. There are probably long, historical reasons for that. Obviously, 95 percent of the cases were in Harris County. In Texas health care is a county responsibility. That's why in the Houston area, it's the Harris County Hospital District. By law, the money went to the county judge and not the mayor of the city of Houston. In other states the grantee would have been the mayor. So, in New York it's the mayor's office, in San Francisco it's the mayor's office but in a Texas city that gets Ryan White Part A money it's the county judge. When the county got this money there was this AIDS Alliance and they said, "We don't know what to do and we are going to pass that money through to the AIDS Alliance." That pre-dated when I began, but not by much.

I began work in November 1991. The first week I was at work Magic Johnson announced he was HIV positive and retired from the NBA which was a big light bulb in the country and was a very memorable way for me to remember when I began. I remember going down into the room where there was a TV and somebody using the rabbit ears had tuned into one of the local TV channels and had seen the CBS or NBC breaking news that Magic Johnson had said he'd been diagnosed with the virus that causes AIDS. That was a marker in the national awareness of the epidemic. The money had come to the AIDS Alliance. The money was still the county's responsibility. But I don't know that the county knew it was basically going into a black hole. Not that there wasn't an effort to do things and some of the money went into services that helped people but it was unaccountable. I saw that right away as an issue. You cannot get this kind of money and say that the emergency is so great you don't have to take the time

JACKSON: What kind of money are we talking about with the first grants?

HENLEY: At that time I think it was probably four to five million dollars.

JACKSON: So, a significant amount of money not being accounted for.

HENLEY: It wasn't ten or twenty thousand dollars. Now some of the sub-awards, the awards that were being made by the AIDS Alliance, might have been twenty or fifty thousand because there were twenty-five or thirty contracts that were all in a big pile with no records. There was a lot of anger. So the way some of this coalesced that created the path that I went on, I came in it was clear that the Ryan White Program and the money that went along with it that had been passed through to the AIDS Alliance was poorly administered especially in terms of documentation and processes and policies and procedures that would allow you to do what you do on a consistent basis and allowed

there to be trust, there was no trust. There already was no trust because there had been such a lack of a national and local response to the epidemic. People were dying. More and more people were being infected and dying. Because of the nature of HIV and the lapse between when you are exposed by transmission to when you become symptomatic there was just this big backlog of people who were infected and really hadn't known about it and then got their first symptom maybe the sarcoma [Kaposi sarcoma] or the pneumonia [Pneumocystis pneumonia (PCP)] and from there maybe they had six months. So there was this visceral anger. People were literally dying. Thomas Street, our office was there, but also it was a clinic and it was the only clinic at the time. Literally, patients would come there and die in the waiting room. People would come there and have to be transported to Ben Taub on a daily basis. You were in the war. Once I began there, I wasn't back at headquarters where we got reports about the war front. We were in the front.

The nature of the Ryan White Program means we created a planning council. An innovative part of the Ryan White legislation that's still today largely not done with any other major disease that the government responds to. With HIV/AIDS, Ryan White money, there is a Planning Council whose members are appointed by the CEO, the county judge in Harris County's case, who makes the decisions about what services those funds are going to be used for. They don't pick which agency gets the funds but the county judge or our office when I ran the Ryan White Program cannot make those decisions and cannot change them. So if the Planning Council makes a poor decision that other individuals like the administrator of the program or Commissioners Court but specifically the judge says, "That's a bad decision," they cannot change it. The council

has total autonomy to decide what the people who are affected by HIV/AIDS need.

That's unique whether you are talking cancer or heart disease or other diseases where there is literally hundreds of millions of dollars of funding in national, federal resources – NIH, Food and Drug Administration, HHS, Centers for Disease Control. The only one where the people who are affected by the disease make the decisions is Ryan White.

Without trust that decision making process is even more difficult because the people who are affected are at the table banging. Not everybody agreed on what the best thing to do was. Because the council was comprised of both the people living with HIV and the people who worked for the agencies who got the money, that's required by the law, there's a lot of conflict of interest potential. But, you can work through it if there is trust and you develop methodologies that acknowledge that and then processes that address that so you can make the decision without the conflict of interest. You can award the funds to where they are most needed. You can monitor effectively.

Under Sue's reign there was no monitoring of services. Nobody was going out to see that anything was being done, but that was not unique to Houston. Money had shown up. If you're the HIV/AIDS community, and you know your local government just got five million dollars to help fight the epidemic, you're not going to be okay with that federal government then taking a year to decide on how to do it to make sure everything is in place. So, the county just passed the money through to the AIDS Alliance and said, "You're supposed to be doing that, you must be doing that, we hope you're doing that." But it clearly was not functional, this strife of people fighting over the money, fighting with each other. Sue's inability to develop trust and probably not seeing that was a key step in order to make the rest of it work led to this constant butting of heads. There was a

lot of pressure on the AIDS Alliance to the point where we had constables in our office because of the bomb threats.

I started November and by the spring it was clear this was not a tenable situation.

JACKSON: By the spring the county was talking about taking it over. They didn't do it officially until July.

HENLEY: Yes, they were talking about it because the people living with HIV and the activists understood that the money belonged to the county judge. This is a mistake that has been made multiple times in multiple cities by a chief elected official who really doesn't want to do this. This is not what they got elected for. They got elected to build bridges, build jails, usually build different things, that's traditionally what they do, budget for county departments that provide services for the citizens and infrastructure. So, they had passed it through but the legislation said the chief elected official gets this money; ultimately, that is where the buck stops. They started going to Commissioners Court. Harris County Commissioners Court is a uniquely, efficiently run operation. They used to meet more often than they do now, I think, but if you go to a Commissioners Court meeting, there's not a lot of torch carrying, pitchfork carrying, yelling and screaming. They go through a business like agenda and you have to listen carefully to even know something was approved. There is little discussion. So, it's unlike what you might see in the Houston area with the Houston City Council. This is still the early 1990s and there's still elected officials, regardless of which county official it was, they weren't doing photo ops with people with AIDS but they certainly weren't unsupportive, they just weren't making a large, public display of it.

The pressure started to build on then Judge Lindsay to fix it. Then the County Attorney explained in clear terms that even though this money had been passed through, it had been passed through to an organization that was insolvent and that if it can't be accounted for it's going to come out of the county's budget. That really gets the attention of Harris County or probably any other county officials when something is being poorly run and the county might have to pay money back. That's just as true now as it was then and probably for all time. So it became clear that if somebody came and said, "Show us what you did with this money, account for it. All this money has been spent or paid out. Show me the documentation." It wasn't there. I think a bit of heightened awareness occurred in a short span of time. It wasn't going to get better.

It was clear that the AIDS Alliance was not salvageable. There was just too much strife. It had its own board of thirty plus people since it was a nonprofit; it had a board, a board that the county had no ability to appoint members to or to manage the membership. The Planning Council had a membership of about thirty-five. When the original Planning Council was formed and Judge Lindsay appointed the members, a lot of the activists felt they had been ignored and not appointed. But they were all members of the AIDS Alliance. So the AIDS Alliance, essentially, somehow, and I wasn't there when this happened but I saw the outcome of it, they figured out a way or some decision was made that all the board members of the AIDS Alliance were also members of the Planning Council. They were obviously appointed by the Judge but then it had been done by saying maybe these people should be on and he really didn't understand the magnitude of it. The Planning Council was seventy people all of whom were extremely passionate and very angry and had their own particular interest or agency or issue. That was completely

dysfunctional. No group of seventy even in the best circumstances can make a good decision. The discussions began and then in the spring it became clear that it wasn't going to happen.

To go back to something you asked me to revisit, the records. The chaotic stacked to the ceiling records kept piling up because this kind of operation creates a lot of paper. There's a contract, there's bills, monthly bills, and the billing structure that had been originally created the methodology was the kind that created the absolute most paper and least accountability. Basically rooms stacked to the ceiling with paper. In early 1992 that old Southern Pacific building that was now Thomas Street was renovated. One day they were working on the roof and the workers didn't put the tarps over the roof when they left and overnight we had one of those torrential spring rainfalls and literally tens of thousands gallons of water flooded through the ceilings into the rooms where all those records were stacked to the ceiling. These records remember weren't just the Ryan White money, it was the state money. So, some of that money was from Austin.

#### TAPE 4, SIDE A

HENLEY: What happened was poorly organized records were inundated with water.

Disorganized became virtually unsalvageable. There had been a couple of years of the state money plus the first round of the Ryan White awards in 1991, and it was just a mess. There was no way you could really recreate anything. Plus, what was going on at this time was the divorce. The county with Judge Lindsay and in large respects, I remember we worked a lot with Ron Deere who was the Judge's Chief of Staff, were

beginning to discuss pulling the money back. I think then the County Attorney basically said the county is on the hook for this money because the money really belongs to the judge and not really the whole commissioners. That's a particular liability for the county judge because it puts that official at a disadvantage. The responsibility isn't shared across the other elected officials. The decision was made, we need to pull this back into the county because ultimately the county is the one accountable for the money and maybe there is business infrastructure which will be of assistance.

The decision was made to pull the money back and that decision was made in June and July of 1992. Then August 1992 the county made a decision, it was signed off, I think there was an item that went through court, but it was really the judge's call to pull the money back. I remember at the time, we all came in, all the AIDS Alliance employees and were told this was happening. Now we knew discussions were going on and I had already been going to meetings with Sue at Judge Lindsay's office with Ron Deere, mostly with Ron Deere (as is usual when you meet with to an elected official to meet with a chief of staff or an aide) but occasionally with the Judge. It was going to happen. So we were all given the option. The county couldn't disband the AIDS Alliance, it could simply say, "We are pulling our money out of there but you're a non-profit and you've got some money from the state." Arguably it was going to be a very difficult thing to keep going without what amounted to probably 60 or 70 percent of its total budget, but all of us were given the opportunity to become county employees. Across the board with one exception, everybody said, "We'll go with the county." It seemed like the best decision. I was actually lobbied by members of the community because I had begun to get the reputation that I was even-handed and I wasn't taking sides, but I was trying to

make things better. I'd been lobbied, "You stay and run the AIDS Alliance and the state money." I listened to them but I was not in doubt. The Ryan White Program was the program that was going to be the major player. Because of where I had worked with MHMRA, we needed to go into some place where there was some business infrastructure. All but one of us elected to go. The one person who elected to stay with the AIDS Alliance stayed for a week. I think this person knew they were going someplace else and just didn't see any point in becoming a county employee.

We became county employees overnight in one fell swoop. Which is I think a little unusual. We were able to transfer over. The last day of July we worked at the AIDS Alliance and the first day of August we were Harris County employees.

JACKSON: At that time you were under the Budget Office to begin with.

HENLEY: When we first came over, now I had already gotten to know who Dick Raycraft was because anytime you had a discussion in the county that involved money and budgets and things like that, Dick Raycraft, who was the Director of the Budget Office and I think it became Management Services later on, he was clearly the person who the commissioners and judge went to when it involved a decision. Usually the more controversial, the more likely it was going to get assigned to Dick Raycraft because he had a way of being able to figure out how to do it and had a lot of trust apparently with the court. They said we are pulling you back and you are going to be in the Budget Office because it's a grant.

It's referred to in the local HIV/AIDS lore as the "Midnight Raid." One afternoon and into the evening, a truck showed up with Paul Scott [Harris County Records Manager] and the county records management people and some trustees from the Harris County Jail. They loaded up all the records which weighed a lot more than they used to

after they got wet, into a big flatbed truck with guards around us because at least there was some perception there was danger, in retrospect there wasn't any that called for that level of law enforcement. All of that was loaded up and taken over to the Cotton Exchange Building [1310 Prairie, Houston, Texas 77002] where the county had recently begun putting in some of their offices. We were put up there in a suite that also had a couple of individuals, some folks who already worked in Dick Raycraft's office. We were assigned to a particular person there, I think Linda (?) and David Benson who later on worked for Commissioner Lee and is actually a council member. That happened in August. We were really a tough fit. Even then in the county we were on the same floor and I'm not picking on them, it's just an example, we were on whatever it was, the 17<sup>th</sup> floor or something in this office building. We had gone from being in the clinic where people with HIV/AIDS were treated to this upper floor in a building. So we went from the front lines back to the Pentagon in one night. And all that stuff was just kind of dumped out into the new office space.

Those people in the Cotton Exchange Building looked at us and we looked at them. We had plenty to do though because we were now trying to organize things and separate everybody's job so it was now just with Ryan White and clean up this enormous mess of massive contracts that had now been taken over by the county while they were in progress in a fully documented way. Even then, we were on the floor with another county office and we would see that these folks would wipe off the door handle before they would go into the restroom on that floor because we were the HIV/AIDS people. It wasn't a big deal to us because we already knew that stuff went on, but it was clear just like the rest of the community, and people who worked for the county were people who

lived in the community. It was like, “We’re not real comfortable with this. Who are these folks? What does it mean to me if they’re here?” Not in a business sense but in a personal sense. We were always a little bit like, “Why don’t y’all keep your distance.” The Budget Office, Dr. Raycraft’s office, was very much about running a business. Even though we were an administrator of a grant, we were way too touchy feely and involved. We were only this far (holding up thumb and forefinger) removed from the actual care people were getting. It was not a place that was going to be very easy for anyone to be able to visit us.

The Ryan White program really works best when it is plugged in and accessible to the community, so there was some inherent challenges. Not all that long after we went to the county and the Budget Office, the decision was made to reassign our office to the Health Department. In general across the country the most common county or city department where Ryan White Program is, is the health department. There’s some sort of obvious reasons why that would be. The county really had no other response, even in the health department about HIV/AIDS. The county has never been responsible for surveillance and epidemiology for HIV/AIDS in Houston. That has always belonged to the city of Houston which is not true for some other things. The county health department does do surveillance on other diseases, but not for AIDS.

So, we were moved in one night to the county and then on another date we were moved to the Health Department. We still stayed in those same offices for a while after that decision although we were quickly walled off from the people, our co-workers in the Budget Office. In fact in one day, a wall was built so there was no mistake that we had been transferred to the Health Department. Boom, boom, boom. The sheetrock went up

and the wall was there. We kind of just said, “Oh, well.” At this point there were a lot of things happening that we weren’t being asked about. It didn’t change what we had to do. If you work in the county all your whole life and you need a wall built or something it doesn’t necessarily happen the next day, but this one happened pretty quickly.

The Health Department felt like a better home. Dr. Tom Hyslop who was then Director of the Health Department, he knew about the epidemic, he knew about Ryan White, he had been a board member.

JACKSON: Wasn’t Thomas Street still a part of the Health Department or not?

HENLEY: No, Thomas Street was part of the Hospital District.

JACKSON: Okay, I keep getting those confused.

HENLEY: We were county employees, now in Harris County Public Health and Environmental Services.

The county then bought this building where we are talking today where our offices have been since we relocated from downtown. The county bought this building on the West Loop [2223 W. Loop South] and we were the very first Health Department people here. So, “Can we find someplace else for these people? We’re not sure what they are about, but we know they aren’t about what *we* do, so they would be better off in their own place.” Whatever. So we were actually the first people out here and then the Health Department which had been in Rice Village was moved over here and they filled in around us.

That was in 1994. Since then we’ve been in the Health Department and the Ryan White Program took off. Sue Cooper was still in charge. We really began, because we were now part of the county, I became much more involved in being the administrator of

the program. Sue still had the job and fancied herself as the person going out and pulling all the strings and trying to get this and that to happen. For the immediate future after we came to the Health Department, it was still Judge Lindsay. So, even though we had been physically moved there was still a lot of anger. One thing I need to revisit, when we were put downtown on the Midnight Raid and all the records were loaded up. ALL the records were loaded up. There was this challenge of trying to still run the program. When they brought all the records over, the activists, it was very public that this had been done and people were outraged. Some people were glad it happened. There was nobody that was ambivalent. You either thought it was long overdue and had to happen, or it was the worst thing that ever happened. It was something akin to exploitation and genocide.

The county recanted a little bit and said, “Well, we probably shouldn’t have taken all the records because some of them were actually about the state’s money,” which we had no oversight over. So they told us about three days later, when we were still sorting through the mess of it all being thrown in a truck and taken out of the truck. They told all of us to leave the office one morning, and they let the other side, the activists come in to go through the records and get what was theirs with nobody watching them. So whatever there had been which was already in poor shape and damaged by water and not well organized – I’m being generous, was then pillaged by another group that was mad that it had happened in the first place and I can’t believe that if I was in that situation I wouldn’t be trying to find something I though was incriminating evidence besides what really belonged to the other funding source. After that, that’s what we were left with – damaged, ransacked records that had been gone through by God-knows-who how many

times. So, pretty much everything was a loss. There was very little useful information from back then that would have been kept in an orderly way.

So then began a several-year process of going forward trying to build in policies and procedures that allowed things to be properly documented. From writing contracts that went through commissioners court and got signed off by the County Attorney that were set up in the county's accounting system and then building in for the first time going out and monitoring agencies and collecting data. Early on we talked about the case management system and that my mentor that led me to this job I ended up doing for so long. We got that case management system going and we kept improving it. We allowed agencies to be connected at least in terms of case management or else every agency would have thought a person that came in for services and services were very fragmented, usually the patient had to go to six agencies to get six things. It allowed them to at least say, "Well, okay, you have a case manager over at this agency so we don't need to assign one." It was the start of a decentralized system where multiple agencies could be connected in at least the most fundamental way about case management. Then it allowed us to start collecting data that was useful for planning and reporting purposes and accountability.

For the next four years, and then there was a change in who was the county judge, the anger and lingering mistrust of Sue Cooper continued. And Sue really never really stopped using the shovel to dig the hole deeper. She felt in her heart her role was there to save the patients and she knew how to do it. For better or worse, that was her approach. It was sort of damn the rules and, "If I know better than what the group thinks, then I need to make sure we do it the way I think." I had many discussions with her, even if she

is right her method is not going to result in the intended, hoped for outcome because people aren't going to trust it. They aren't going to buy into it because they don't feel they were a part of it. Even if you are right when you decide it is your way and no other way, if you don't build the trust and develop the process in a way that a third party can come in and see how you got there, you are really short changing what may have been a great way of doing something or a good approach to addressing a need of the community

That continued on and on. The change in judgeship allowed a fresh start for the Ryan White Program. Understandably, Judge Lindsay's office had been very invested in the program and whenever there's a battle, then the folks on one side circle the wagons. That side's ability to process the full spectrum of what the issues are and how you might resolve them regardless if somebody loses face is hampered. So Judge Eckels came in and it was brought to him, "Look, this Ryan White thing," and I'm sure when he was running for office, it hadn't been like, here is the thing you need to think about when you become county judge. Those are the things they tell you about the day after you are sworn in. He said, "You know what, we are going to make this better." He was engaged and active and brought on someone, Modelle Brudner, and said, "Let's learn about this." He listened to all sides and he talked to the people in Washington. Houston was not unique. This all sounds horrible but this was happening in New York and Chicago and in Washington, D. C. In fact, if anything, Houston got to the other side of that dark sea more quickly than many other cities did. It was just an inevitable outcome of the nature of the situation and the way the response naturally occurred. Judge Eckels became very engaged and I think they made a decision, his office with his aides and with his liaison that had been assigned to the council, they were going to have to make a change in the

leadership in order to at a minimum re-establish the opportunity for trust to be developed and to bring more accountability.

Ultimately I was fortunate enough to be given that opportunity to lead that change and then subsequently manage the program. I think that's because throughout I had been willing to say, "Look just because we did it, doesn't make it right." The county can be wrong and if we don't acknowledge it and fix it, we're just going to be trying to put sand bags around a pot hole that eventually is going to be exposed as something that needs to be fixed. I think the Judge was savvy enough to know this was not going to be something he wanted to have linger for months and years. And I think he also realized it made a difference to people in the community. If the program was run better, the people would do better. I always was impressed by Judge Eckels because he never sought to be recognized as someone who was back there acknowledging the needs of the community. We were fortunate because working in this job our counterparts in the city of Houston and that government that do the HIV prevention activities in Houston, I could tell very quickly that the county government was a much more business-like operation to work in. So when it came to getting contracts processed and purchase orders written and the funds being managed and getting assistance from the County Attorney, it was much better. And every one of those offices, I would be remiss if I didn't say this, starting with Mercedes Leal in the County Attorney's Office and Mary Lou Sotolongo in the Purchasing Office with Mike Post in the County Auditor's Office, Steven Gardner in the County Auditor's Office.

Back then, all those key people, they knew about Ryan White because they knew about this big problem. People would call the county or they would go to Commissioners

Court. Anybody goes to Commissioners Court, somebody in each of the county departments that are affected, knows about it real quick. So there were people in each one of these county departments that learned about Ryan White that I developed relationships with that understood the program. One thing about Ryan White, the county gets many, many hundreds of millions of dollars in one way or another through the federal government, it's inevitable. There are some things that are very consistent about federal grants, but the Ryan White Program has a number of unique differences that aren't common place. So each one of these key individuals in each one of those county departments, I apologize to those I didn't mention, they began to understand, "Yes, this is the way something would normally happen, but this is Ryan White."

In fact, one of the challenges going on these days and I suppose I am now part of the problem in that respect if for no other reason is, by and large these people who were there for a long time and knew what Ryan White was when it was in trouble and then helped make it to be a model program for the country, are beginning to transition out of local government. They're not there anymore. The person that replaced them, they got some of it because there was still enough DNA there to absorb some of it, but now they're gone. It seems from where I stood there's more reorganization going on; sometimes for reorganization's sake it might appear. There's been a loss of institutional memory. Institutional memory, even more so than what we are doing today, in how to make things work.

The last few years I was in my position before my retirement, I would spend a lot of time on the phone or in person telling somebody downtown why we need to be different because they would say, "This is not how we do things." We don't want

different things, just anything that's different from the regular is an extra piece of work, and it requires an exception. Those folks that are currently in the positions now do not know what it's like if it is not running well. They only know the Ryan White Program that runs well. They would say, "We are going to require this now." "Are you sure? Let me tell you why we don't do that." We've been able to hold our own, but I think and this is actually a microcosm of what is going on across the AIDS world in the United States, the whole cadre of folks that came on in the 1980s and early 1990s, it was their life's work. They are now transitioning out. So whether you are talking about case managers or doctors or administrators, there's a whole new group of people who never even saw the epidemic as it was and saw the people dying, emaciated, and that visceral anger when communities would be wiped out. Even though there are many more people living with HIV/AIDS now than there were then, thankfully now, many, many people with HIV can essentially live their normal life span. But still, that loss of institutional memory continues to be a challenge that goes forward.

When Judge Eckels replaced Judge Lindsay, he really set the stage for us to prosper. I can remember Judge Eckels was very disarming, very much not someone who made you aware he was a VIP and he was. In 1997 I took the position and began my tenure of leadership, one of the first things we did although it was 2000 when we did it, we said, "We've got this little data system that we have built to originally connect case management agencies." One of the challenges all along with the Ryan White Program in Houston and other places is you have many passionate voices at the table. Everybody very sincerely says, "What I am saying is the most important thing." So you are basically inundated with passionate pleas. The planning council are people that live in the

community and they are living with and affected by HIV and the providers that are on the council are dealing with it and also have their own interests. No agency comes to meetings trying to say, "Please take our money back." There was no data. Everybody had their largely anecdotal impression of what was going on and what would help.

Without data we would work with the council and say, "Look, we need to shift resources here," or somebody would come and say because in the late 1990s you saw was the epidemic then start to be managed in the original communities affected and really start to impact new emerging communities and that was primarily African American and Hispanic. A whole new set of individuals and families and people were being impacted by HIV and people from those communities like their predecessors before were coming and saying, "The county, the Planning Council, the Ryan White Program, was not responding to," the African American community or Hispanic community.

#### TAPE 4, SIDE B

HENLEY: It was very difficult to help the Planning Council which I said earlier has the sole authority to make decisions, to make decisions based on data versus emotions. People would come and say, "You aren't responding to the epidemic in the Hispanic community because you're not sending money to agencies that I believe if they had money then Hispanics would be getting services." But, there was no way to really document that. Then there were reporting requirements to Washington, the level of reporting in those days was unbelievably simplistic and virtually useless. It was aggregate. What I mean by that is every agency could say, "We served 200 people, 50 were African American, 50

were Hispanic, 50 were white and 50 were Native American.” But, there was no way to differentiate that. One agency said they served a thousand people and another agency served 500 people and another agency served 1200 people. All they did in Washington and all they did up until we made some changes here, you just added those numbers together. It was still only the same 1200 people; they just went to multiple agencies. It was useless data. But data even if it’s useless, people grab ahold of it and use it to support their positions.

We talked to the council and we said, “We need a better solution.” The council said, “We agree. Go make a better system.” They basically gave us a budget because to do that then, we couldn’t afford to do it out of the statutorily allowed amount of money the grantee can keep for administration which at that time was only five percent. In later years it became ten percent. We said, “We can do this.” We brought in all the stakeholders. Consumers, “We want this but we don’t want our information shared.” There was still a lot of fear that governments would take databases of people with HIV/AIDS and round them up. Certainly some elected officials, not so much in Houston but across the country, virtually threatened to do that, especially in the late 1980s and early 1990s. We said, “Ok, those are their concerns.” We talked to providers, “Well, we need something that complements what we already have or provides us something because we don’t have anything when it comes to automated information.” Other activists who said, “Well, we want this to be able to tell us this.” Because once you start to collect data, everybody thinks you ought to be collecting some piece of data that if it was known would help their cause or their program.

These can be notoriously complex projects. We were authorized by the council. We started using “sweep up” money. Every Ryan White grant year is an intact year that stands on its own. So, although if you don’t spend money one year there is a process after you’ve closed the books to ask Washington to bring it forward, unlike most federal grants, the Ryan White money doesn’t automatically roll forward. So we said, “Look, every year there is an amount of money that for one reason or another doesn’t get spent.” Because it is very difficult up front to budget the expense of this data system, “What we will do is use some administrative money to get things going and do some planning on it and then we’ll use “sweep up” money to pay for it.

So we took some guidance that was just coming out in draft form about the next level of what the Ryan White Program grantees would be required to report and took those data elements, we took all that stakeholder improvement, and we went out and came up with what we wanted and came up with a process to find a developer. We went outside the usual suspects and got a company that had never done anything except stuff like for oil and gas companies to build a database. We hired somebody that became our expert consultant to tell us when they were telling us something that wasn’t right. We built the Centralized Patient Care Data Management System or the unwieldy acronym of CPCDMS in essentially six months from when we sat down to first decide what it should be until it went into production. For a local government to build a complex data system that connects multiple entities in six months is pretty exceptional. And then to build one that actually worked, is another piece of exception because and this is probably true in other fields where there is homelessness or other social programs or health programs that are run through government bureaucracies. Nationally the Ryan White Program was

littered with failed attempts to build a client level data system. So we built ours because we took what people wanted and we didn't put in all the extra stuff that people said, "I wish it could do this." Everyone wishes it could do things. We respected the consumers' preference that it be de-identified. To this day, there has never been a name, an address, a telephone number or social security number in the system. Yet every one of the now current 11,000 plus Ryan White clients, who are currently active and getting one or more services each year, is uniquely identified. They can go to multiple agencies and they are unique in the data system from agency to agency.

JACKSON: Let me clarify. So, you must have some central list with the names and number.

HENLEY: No. There is no list anywhere. The methodology where we create a unique number based on limited elements from a person's name, date of birth, and gender. So, you take the first and third letter of the first name, the first and third letter of the last name, the six digits that create your date of birth and a one or a two for a gender code. That eleven character stream is then run through an algorithm that turns it into something even a little less identifiable. So the most that is ever in there is an eleven character stream that has four letters from your first and last name, date of birth, and a gender.

JACKSON: What happens if I forget my code?

HENLEY: You don't because you don't forget your name and your date of birth.

JACKSON: So I've been to one agency, I've gotten my unique number. I go to another agency and they say do you have your case management number. I say, yes but I can't remember it.

HENLEY: You are never expected to know even that eleven character code. Because all we do we say whenever you go to an agency, you have to fill out an intake and they ask you for

your proof of identify so they know who name is and we have a whole list, a driver's license.

JACKSON: So all that information is on there and people at the agency are able to

HENLEY: I'm just saying just give us the information we would normally collect. You know they would ask for Sarah Jackson if you are going to get services from ABC agency, they have to know you're Sarah Jackson.

JACKSON: Sure.

HENLEY: That allowed consumers to buy into this system. To this day, actually there is much less reluctance of consumers to share names now than there used to be. We've always maintained that. The state several years later, after about five years – we only took six months; they built a data system for the Ryan White Program for the state. The state has Ryan White Part B money for the whole state. And every area in Texas but Houston uses the state system which is called ARIES, their acronym makes a word. We use CPCDMS in Houston. Their system requires names and yet we sync to their system without names so if you go to the state HIV/AIDS data system that they manage all their Ryan White Program through, you could see the name of clients in every city in Texas other than Houston. We figured out they didn't need the name. They simply need to be able to create the code with this information. After several more years, the feds actually got to the point where they could collect it on client level. When it finally filters up to the federal level for reporting, it's being done on that same eleven character code and they tried all kinds of esoteric ways to create a code and they came back to that eleven character code. It's actually statistically sound enough that it doesn't create issues. There might be an occasion where somebody would actually have the same one and in

that case, we just let the second person know, “Look there’s already someone with your client code so when you go to the next agency, just tell them we’re going to add this extra piece of information.”

JACKSON: The agency where the client receives care, not only has the name, they have the date of birth.

HENLEY: Out of 100,000 people that could happen because each agency still knows who you are, you have a personal relationship with them. They see you when you come in. For us, even if statistically there was one duplicate, it would be insignificant in the reporting. But with that data system which also did something that’s phenomenal. There have been efforts in Harris County and more efforts and failures than anybody in office would probably want to admit, since 2000, Harris County, us, the Hospital District, the City of Houston, the VA system, numerous other health systems, the jail have all been connected by a real time data system that allows this information to go from one entity to the other and be shared. Yet, you will still see stories, “Big Initiative,” to see if the Hospital District can talk to the city or the county can talk to something. There was this little success story out there. We just never felt we should be thumping our chest. We were more worried somebody would come and mess with us, “What are you doing? We didn’t know you were doing that!” It’s been a terrific asset and that decision has then allowed us in our Planning Council to start making decisions and planning based on numbers.

So, when the activists, who are very understandably wanting to advocate for their community and their neighborhood, come and say, “Hispanics are not getting services,” we can say, “Well, this is what I can tell you. Hispanics make up 21 percent of the people with HIV in Harris County. And 30 percent of the people getting Ryan White

services are Hispanic. So actually, Hispanics are not only being served at a rate equivalent to their percentage of the overall affected population, they are over represented. Isn't that exactly what the Ryan White Program is for, is to reach out to the underserved community?" So as time went on the original impacted community, the gay, white community, is really a smaller subset of where Ryan White resources come because the epidemic essentially reeked it's havoc, the new treatment capabilities came along, and so a lot of long, prospering patients that are from that original group that were able to make it until the new meds came along. Now they are in many ways able to get along with things to almost a normal lifespan but we are now able to reach out to these new communities that are being more affected and being able to allow the council not to respond to that passionate plea in a disproportionate way. They still want to hear it, they still need to know if people don't think they are getting services, but sometimes it's just that they don't know that they are.

There is another way of reporting and surveillance where there is documentation where people live when they are diagnosed. There is not a lot of information about where they go afterwards. We can actually analyze where are the people who get Ryan White services living. We do have the zip code; that's as close as we get, that's the only piece of address we get. We can look at where the surveillance data shows people are living when they are getting diagnosed, when they are being tested. Then we can compare what the relationship is between where services are and where people are when they are diagnosed. It's not completely the sort of natural intuitive thing that everybody wants to have a service provider that's across the street. A lot of people do not want to go across the street, especially in our outlying counties. But even locally, you don't

necessarily want to go down to the health center that's in your neighborhood because if there is anyway it's known that you are there on the day when they see the AIDS patients, then other people in your community are going to see you there and you are going to have your confidentiality at risk. What we try to do is build a system that allows people to access care where they want and create other systems that allow them to get where they need to to access that care. Houston is so big. It's a huge geographic area. The size of Harris County, it's one of the largest counties in the country.

JACKSON: Do you want to talk about your transportation solutions?

HENLEY: Another solution the data system has helped us to leverage and operationalize. A couple of things have gone on. In 2000 the data system came online and its capabilities have improved over time and its usability. One of the key decisions we made with the data system early on, I think it's important to mention, is we realized that some agencies were going to have their own data systems. So we said, "We are either going to build a system we can provide to an agency that gets our money that they can actually use and enter data into our system in native format." In other words, Sarah can sit at the computer and enter information. Or, the agency can just export the information they already collect in their data system to ours so Sarah only has to enter it once. Another thing that plagued a lot of HIV systems that were built that we made a conscious effort not to do was double data entry. You have to enter it for the Hospital District and then you have to enter it for us. We said, "No. Enter it once, share it across the board." All of our agencies export the bulk of their data to CPCDMS, they just use their own. Now, most providers have their own electronic health records system. So why would we need them to re-enter something?

Using that data system and then the new treatments were coming along, so the model of care which had been largely palliative to begin with in the early epidemic like we talked about at Thomas Street, just helping people die with dignity and have more comfort as the disease progressed. Now we were really looking at actively engaging people and keeping them in treatment. Ryan White has really evolved to a pretty simple step that would have been obvious in the beginning but many things that are you don't see until later. We need to find everyone who is HIV positive, especially those people who don't know they are positive. Once you know your diagnosis, once you have been tested and given the result, we need to link you to care. Because, if you are in care, if you are adherent, maintain a reasonable quality of health with what would have been your normal lifespan. But you have to be in treatment. We want to link people to services and retain them in care. To retain them in care, the services have to be accessible. They have to be available and accessible means people have to be able to get to them. Ultimately, we want them to be retained in care and be in treatment to the extent that their viral load is suppressed. If their viral load is undetectable, it's very rare that they can even transmit the virus if they engage in a risky behavior. So, you can essentially keep people healthy, have them live longer, and stop new transmissions if you diagnose people, get them into care and keep them in care.

One of the huge challenges in Houston is getting people to the clinic. Ryan White probably funds nine clinic sites in multiple parts of the town and in other counties. But people have to get there and it's always been a challenge. Early on there was a van system done by the Red Cross but it was largely taking people from Montrose to Thomas Street which is located just north of downtown off Main Street, between the Heights and

downtown. Once the epidemic changed and affected other communities and Montrose became a very extensive place to live, we needed something else. We began to look at the bus system. We made it a requirement that all of our agencies that are located in Harris County have to be on the bus system, have to be on a bus route. Generally, those kind of agencies would be because they are going to be serving an indigent population, or relatively indigent. Then we started looking at the transportation options. We don't have subways and other things that people in Houston lament that we don't have but vigorously don't want. So, the bus system was the natural choice but how to make it manageable?

So, we went to METRO, the Houston area regional public transit provider, and at the time they had a disability pass. Now truthfully people with HIV/AIDS are not disabled except in some cases where the illness progresses so far they actually can be determined to be disabled for social security purposes. At that time under an older regime at METRO, they had come up with a pass they would let certain nonprofit and other entities buy that would help people that they served get around. We said, "This is a great solution for us." They said, "We agree. Your folks are eligible." So, early on Ryan White money had been used to buy bus passes. We had been taking that money like all other money and we would put it in a contract and let an agency do it. There was a little bit of the money we gave the agency going for bus passes and a bunch of the money being used to administer the program. A client then had another agency they had to deal with, right? They had to go to the transportation agency. Sometimes we didn't feel like that particular agency that would get the contract because most any agency that knows about it, that's the last thing they want to be is a transportation provider, it's a real

headache to run. So, we said, "Let's reinvent this. What's a better way to do this?" We listened to the consumers, other stakeholders who said, "The pass itself is a great deal. Fifty-two dollars a year, unlimited rides," if you are in a group they say is eligible. They said our group was. We said, "Ok. Instead of us funneling this out, our office, my office we will just buy the bus passes." We will go to METRO, METRO will be our vendor, we will buy the bus passes, we will develop capabilities in our data system that we built to track them, and we will then distribute the bus passes from our office to the agencies where clients go to the doctor and those agencies will actually give out the voucher that the client takes to the METRO Ride Store to get their disability pass.

We took all the overhead out of it. There is zero overhead. Every dollar that's spent on bus transportation goes to bus rides. Not a nickel goes to anything else. And, it made it much more straight forward because now if a client were to go to an agency and say, "I need a bus pass," they just look in the CPCDMS and say, "You have one. Maybe you should use that one because METRO doesn't want anyone to have more than one." It's an annual pass. That has been a great solution and it's very cost effective. You can do a thousand clients for \$250,000 per year or whatever it is because it's so effective.

Unfortunately, METRO a few years ago changed its business model. They eliminated those passes. METRO now uses for all its ride interactions whether you are a one-time person or a multiple times a week person, they use a system that is almost like a toll tag, it's a card. You put value on the card and swipe it. They said, "We are eliminating those passes." All sorts of agencies that had served developmentally disabled individuals, individuals with other physical challenges really were upset because this had been a really great thing and now you're having to buy this thing you had to put money

on versus \$52.00 and it doesn't matter how often you use it. Our Planning Council advocated to METRO, this is like David v. Goliath – our David is a very good David, a very passionate David – METRO said, “No, we are doing this. You can't drop money in the bus anymore. You have to swipe a card.” But METRO grandfathered in all the people who were currently on those kinds of bus passes. That's still true to this day. So that original cohort of about 2500 people, every one of those folks who can still benefit from a bus pass, can still get one. For the other folks that came since because we didn't grandfather the slots, we grandfathered the person so that number goes down each year a little bit, but anybody that came on afterwards never had a chance to get the pass that got grandfathered. Then we went to METRO and worked out a deal essentially using the same criteria, we now furnish clients with the Q Card that has \$50.00 worth of value on it. If you have that disability Q Card you get half price. So if the ride is \$1.00, it only charges the card \$.50. We just basically told folks, “Look, if you are using the card to go to the doctor, if you are accessing care just like the other people, we'll without question load that card twice a year.” So, basically they get \$50.00 for six months and then you can get another \$50.00 for the next six months. If you are somebody who has to go to the doctor a lot, we'll add more money to the card more often. What we didn't want to do is create two different classes of folks. The card allows you to also do other things. We are spending the fifty bucks so you go to the doctor. You could spend that on one cab ride, one time. This person could go to the doctor once a week for a year and it's still \$52.00 or now \$100.00. We're okay with that. If they person says, “On Sunday I'm going to see my Mom, I'm going to go to the movie,” we don't care just like we didn't care when the

person had the unlimited ride one. It empowers clients and solves our need. Because of the data system it allows us to make it accountable.

JACKSON: And with the data system you can see whether or not they are actually going to the doctor.

HENLEY: We know they are going to the doctor. So, the data system quickly became and has continued to be the basic business infrastructure. It doesn't just track where people go, it's the billing system. So every visit, every case management session, every dental visit, every prescription that we pay for, every single piece of information, related to that transaction is in the data system. Agencies have to put that information into the data system and that is used for their billing. So now there is direct accountability between every dollar that goes to an agency and which service it's used for, for which client, on which day. That streamlined data collection, billing, service analysis, and promoted planning so now you can actually trend out what services are being used. In the days of somebody advocating to continue a service because Ryan White has been more focused on medical the Council has had to make tough decisions to not fund emergency financial assistance in housing and other services like food pantry that clients are very attached to. People need to eat and they need a place to sleep but the services generally didn't produce an outcome you could measure. Between the people who went to the food pantry and the people who didn't, they had no difference in their CD4 counts, no difference in their stage of illness, no difference in their viral load. Of course, they needed it. We serve by and large, low to no income individuals, and so if you queried a group of individuals with those similar characteristics, they are going to have similar needs, some of whom will also say they need access to medical care and medications for

HIV but all of them need help with food and housing and transportation. We addressed transportation, we said, “Look. I know you like a cab ride but we can give you a bus card. And if you are in a situation where you can’t really ambulate,” which can happen not just because you have AIDS vs HIV, non-AIDS, but because you have a particular symptom that’s making it difficult to walk. Then, your doctor does a certification and you can be transported by the van-based transportation which is still funded by Ryan White.

#### TAPE 5, SIDE A

HENLEY: The data system has supported a lot of things as the Ryan White Program began to transition quite a bit after 2000. The treatment regimen had become more effective. There was actually a way to help folks stay healthy, to not progress to AIDS as quickly or at all. Other things that were going on then were really all leaning to this sort of direction the Ryan White Program’s been going since the 1990s which is much more focused on health care and access to health care and retention in health care and adherence to health care the Ryan White Program can offer.

As I look back at that, we were able to build a system in Houston through the Planning Council’s vision and coupled with our office and the Judge’s office being supportive, starting to build clinic systems. We talked about at the beginning there was Thomas Street Clinic, it was the only option. It continues to be an unbelievable place to go visit and provide care to the consumers, but we needed more options, particularly in the late 1990s and 2000s. As more individuals in the African American and Hispanic community began to be infected and need services, Thomas Street with all of its assets

and immeasurable value to the community, first of all it in itself has some limitations. They've had more than 5000 patients but that in itself represents fewer than half the people who get Ryan White services every year now and it was associated with a couple of things that made it a little more difficult to get people to want to go there. It was for understandable reasons seen somewhat as the place where someone who was gay would go, because that was the population it served, and it was also because of its history, some of the consumers who were newly diagnosed from these emerging communities in their head it looked like someplace where maybe the patients were too sick. That's not a very elegant way of saying it, but to walk into Thomas Street, if you had been out at a testing event in Southwest Houston or the Fifth Ward or in Channelview or wherever, and you weren't sick but you had learned through a testing event that you were positive and you get referred to Thomas Street, you are walking into a four story building that has a patient census of 100 percent HIV of over 5000 people. Some folks just weren't willing to engage in care there. It was just too big of a jump. It didn't look enough like where they would go to get help when they needed help.

For better or for worse, you can debate that in an academic sense but we needed some options. One is that is the only option. Even though the Ryan White Program invested in that clinic heavily and it's the single largest contract and has always been the single largest annual contract, it's not enough. So we needed other options and if something had happened to Thomas Street then there would have been nothing. I've always been a big fan of there is the way you do something and then there is the back-up plan, the redundancy.

So how do we build this capacity? So beginning in about 1999, late 1990s, we worked with the council to begin putting additional funding into the category of primary medical care which funds doctor's visits and lab tests. It was going to be dedicated to community-based organizations. We were able to carve it out so that those agencies that would begin to apply to build that capacity wouldn't be competing against Thomas Street nor would Thomas Street be competing against them. It was really done in a win-win way. So the money that goes out to the nonprofits for primary care, the nonprofits compete for. The money that goes to the public system which nobody else can compete for, which provides a great deal more in resources than even the large amount that we provide them, can also be sustainable. Starting with what was then Montrose Clinic, and this was through a competitive process, Montrose Clinic was an agency in the community that now has become Legacy Community Health Services that also saw the future with providing care to people with HIV is to provide medical care. So they had a fundamental mission expansion because they had not been a primary health care provider, they had been a sexually transmitted disease clinic, they had done outreach, they had done testing, they had done a lot of services, but they didn't have clinics where you would go to the doctor. They competed and they got funding through Ryan White and that began their tenure as a clinic that provided services to people with HIV.

And in the intervening next few years we also brought on two more agencies that competed for funds to do primary care. So ultimately we had Montrose Clinic which became Legacy Community Health Services, we had Houston Area Community Services, and St. Hope Foundation. In all three of those agencies and particularly HACS, the Houston Area Community Services, and St. Hope, they were AIDS Service

Organizations. In many ways Montrose Clinic was too but they actually began as a provider to the gay community around sexually transmitted diseases. With a little bit of an asterisk, they were an ASO. What I mean, their sole mission to begin with was serving folks with HIV/AIDS. That expansion meant we now had new clinics, newly formed primary care providers that looked much more like the people who were then being diagnosed. If you were someone who was asymptomatic, that had learned you had HIV and you weren't necessarily okay with going to Thomas Street, sort of going from being unaware you were HIV positive to walking in and being in a four story, thousands of patients solely HIV/AIDS. If you really hadn't wrapped yourself around being HIV positive, now we had these options which really turned out to facilitate enrolling new clients into the system. They now had options. They could go to Thomas Street, but they could go to HACS or St. Hope or Legacy and those clinics were able to tailor their services in a less formal setting to provide access.

By using the data system we could show how the clients going to these new clinic options were much more heavily weighted to the African American and Hispanic community, depending on which one. We were getting more of the newly diagnosed clients into care and Thomas Street has evolved a little. It's still a primary first stop for people who are diagnosed, but it's also become the center of the hub because Thomas Street offers a much broader range of in-house services. At Thomas Street if you need a referral to a renal specialist or dermatology or another specialty, "Go down the hall to that door." This is actually unique among Harris County Hospital District, Harris Health System, health centers. They have all the specialties in one building.

JACKSON: But who provides the doctors for Thomas Street?

HENLEY: Like any Hospital District facility, all their doctors come through affiliated medical services, AKA, they come from UT or Baylor.

JACKSON: Right, the medical schools.

HENLEY: That's no different for Thomas Street or any place else. That's the long standing arrangement in Harris County. That's something that comes with doing business with the Harris Health System and even they don't have any choice about that if you understand the intricacies of how Harris County works. That occasionally makes for some challenges, I know in the health care delivery system. But it also has this huge positive silver lining in that HIV/AIDS researchers are also affiliated with medical schools and universities. So that the doctors and other health care professionals that are a part of that system are also world class because they are also involved in making discoveries about new ways of treating HIV and new strategies that improve adherence. It has been a real winner. That allowed more clinical trials than probably would otherwise have been available to clients, to be readily available.

The other thing that we did in Ryan White in Houston with the growth of these other three clinic systems, and this is Ryan White Program nationwide, Ryan White pioneered the medical home model which is, when you have individuals who have complex, chronic disease that needs a lot of effective, integrated management to get the best health outcomes, it's really better that you have a health home. In other words, you don't have to go here and there and everywhere. In the late 1990s and 2000 working with our Planning Council we began to embed all the services that the client needed, especially the clinical services into a single program. So if you wanted to get Ryan White money to provide primary care, we required for your own good and particularly

for the patient's own good, that you provide case management, that you have medications, that you have the full range of what you are able to do, that you can refer out to all the specialties so the client didn't have to go to multiple places to get their health care. They still might have to go to a different agency to go to the dentist, you never find a dentist at the place you go to see your medical doctor. I'm guessing those two professions are fine with that. So we would build in those capabilities and we also said that case management needs to be there. Historically in case management and this was true of Houston, agencies grew up and began as a case management provider. So a client would have to go to AIDS Foundation for their case manager but they were seeing a doctor at Thomas Street. Well, that was very disconnected because the case manager can only really be effective if they are a part of the treatment team and if they have access to the medical information. When a case manager worked for a difference agency, they didn't look at the medical record. The doctor couldn't say, "Ask the case manager to come in. I just met with this client." Even though they didn't say anything to the case manager when they were talking to me, they said, "Their lease is out and they are going to be homeless." The client decides who they tell what they tell.

This medical home model which is an underlying concept in the Affordable Care Act is not the stuff the politicians fight about. It's actually this thing that says you need to consolidate services so that the consumer can access them all in a single point and their multiple needs can be addressed. So it's not fragmented and the information is shared among a treatment team so that if the nurse learns something that the doctor needs to know or the case manager needs to know, then that can be shared.

We built that medical model and one of things, if you really want to get out there and brag about Houston, all three of our AIDS Service Organizations [ASO] started as Ryan White funded primary care providers and evolved into Federally Qualified Health Centers. That's a huge step because now they are diversified in their funding. They are sustainable. So if Ryan White goes away or has some major change in how it provides funding, they have another mechanism to sustain their agency. The other thing it's done and this is another one of those side effects, first of all FQHCs are fundamental components of the Affordable Care Act because that's how services are going to be provided for all these heretofore uninsured people who now may have insurance. That doesn't mean there's a lot of capacity for doctors to see people just because they have insurance. By definition FQHCs have to be in a medically underserved area. If you go to a wealthy, affluent neighborhood where everybody is insured, it's unlikely the feds are going to put a FQHC there. Now in Houston because of the way Houston is constructed, you can go from block to block and that can change.

This was a huge breakthrough because one of the challenges in the generic way of looking at FQHCs is they didn't feel and don't feel they have the expertise to treat people with HIV and even though they can't say this, there is some feeling on the HIV side they really didn't want the HIV folks in their clinic. It made not just some of the other patients uncomfortable, it made the board and some of the providers uncomfortable. Just because you have a medical background doesn't mean you don't carry a stigma about HIV. By going from an ASO to a FQHC, means you bring that integrated client center holistic approach to a bigger population. You bring that expertise that's hard to send down to a FQHC that has not had experience with HIV. It's there but like everything,

there is a ying and a yang. The challenge, and Legacy being the oldest of the ones and the first one to do that and they went to Boston to the Fenway Center and saw how they had done it, what would it be to be a FQHC if you were an AIDS Service Organization and now you were a FQHC. You were now a clinic in a community that services everybody. What Legacy's challenge and this is particularly at their beautiful facility on California St. in Montrose that they moved into a few years ago, they are the clinic for that neighborhood. If you were taking care and had either no means to pay or were on Medicaid and here's Legacy's beautiful facility. So now the waiting room at Legacy isn't just the people with HIV and Legacy in particular among the FQHCs has the largest cohort of the initially affected group of HIV/AIDS clients that are still alive. You want to find a cohort of patients that looks most like 1988 or 1994 you would go to Legacy and Thomas Street because Legacy is in the Montrose. They've had challenges with some of the long time clients living with HIV/AIDS wondering why suddenly the women in there with little kids running around. Why are there children in the waiting room? What's this about? There's all the, "That's it! We're on the right track," but then there's the unintended or unanticipated challenges. But the fact that all of those providers are now FQHCs, they were poised to take advantage of the Affordable Care Act regardless of how it ultimately plays out in Texas, that has made those providers which the Ryan White system depends on but more than that the low income and historically underserved people in Houston depends on, that means they are viable in the evolving health care environment.

Ryan White has been an amazing program. Involving the patient in decisions being made, forcing drug companies to get drugs to clinical trials quicker, expanding the

number of people that are in clinical trials, getting drugs out of clinical trials and available to be prescribed outside of the trial more quickly. All of that came from AIDS activists. In the Affordable Care Act, that whole medical home when Thomas Street proudly presents itself, it's been designated a patient-centered medical home and some of our other providers have too, that's a designation that didn't exist fifteen years ago. We are doing what we figured out to do in Ryan White which is this medical home model.

That's Ryan White's contribution to the overall concept that community-based care where you really focused on the folks who need the most care will have those resources and folks who need less frequent care also have access. The concept is if you look at the people who go to the ER, there are some who come all the time. Instead of that person having to be put in an ambulance and transported to the ER because at home they are not ambulatory and they have a line and it gets infected or their IV every month it gets infected and every month there has to be a hospital visit. Ambulance is dispatched. Transport them to the hospital. Put them in the ER. Admit them. Stabilize. Send back. So, somebody said, especially if there is a cluster and it often happens with low income disabled people in a housing complex or something, "Why not put a clinic there? Then we can just keep the lines clean." Invariably a small percentage of patients account for a big percentage of expenditures. If you actually identified those patients and then proactively provide care for them in a way that they can access it, then you can reap huge cost savings across the whole system because you're not spending so much on so few and quality of life is much better for those patients. Ryan White has been a pioneer in that.

We've had to figure out how to get the resources to the people who needed it by putting things in their neighborhood, by creating transportation systems that get them there, and by combining the services so that person only has to go there and that's where their needs are met. Unlike civilians where we have to go to the Medical Center to see one specialist and out on the Southwest Freeway for another and there's no medical person coordinating all of that. That light bulb has started to go off. Even county employees now see Aetna Navigators and if you are having a couple of things you're getting prescriptions for, you're starting to get something to make sure you're not mixing them. It's like Ryan White 101. It's just being expanded. It's the uncontroversial parts to the Affordable Care Act.

Clearly the Affordable Care Act has pluses and minuses. It does create a mechanism that can potentially shift a lot of people who are uninsured to be insured. But that's only useful if there is a quality health care system that the people that now have insurance can be accessible to. If you don't do that, the fact that somebody has insurance

JACKSON: doesn't matter.

HENLEY: Even worse, it can make them ineligible to go where they used to go that only served people that don't have insurance. The Ryan White Program has been real good at designing those kinds of systems out of necessity, systems where the patients have a voice. That's one of the chronic complaints especially in the beginning, "We aren't listened to." We talked about the Reagan years and the activists chaining themselves to the gates of the FDA, drug companies, "Listen to us and we will tell you what we need." Some people started to listen. Some doctors got the message and now that will filter out. I recently scheduled something through insurance and I got a letter from the Memorial

system that said, “We are an accountable care organization.” That’s something a part of the Affordable Care Act, I knew what that is. It’s a designation. It means you get paid a little more and you are supposed to coordinate. Just this last week there was an announcement in the *Chronicle* that Medicare is now going to be paying doctors basically a coordination fee for patients with multiple chronic illness to case manage those patients in the system so that their multiple medical needs because of their different chronic conditions are managed.

JACKSON: I was married to a family physician for years, and this is no more than the model of family practice that modern American medicine has totally ruined and now they are acknowledging, “We need this back. We need the family physician to coordinate.”

HENLEY: His office was the medical home. Now with AIDS the fact that it became such a management issue, in so much high tech medicine if you don’t do that it’s all fragmented. By and large, especially as the epidemic is moving into different communities, people who are accessing the services didn’t grow up with access to medical care. There was no such thing as their family doctor. A lot of things in the change that you talked about that you experience in your personal perspective, the system didn’t make an accommodation for that. You needed to figure out how to use it, you needed to make your appointment when you needed to and all that. We can all get into that Protestant ethic, I’ve heard this more times than I can count when people know what I do. We talk about how we make calls to the clients to remind them about their appointments, pick them up and drive them to the appointments, we give them all these ways they can just drop in if they miss their appointment, and none of it is costing out of pocket for the client. And people will say, “If had a serious medical problem, I would go to the doctor, I don’t need all that.”

Whatever. From a public health outcome, an AIDS diagnosis is just one more challenge in their life. There is no infrastructure or history in their family of having access to routine care, you have to do that or else they're not in care, their viral load spirals upward. It's very easy for them to transmit the virus. By maybe by going what one person might think is a step too far, it's really to try to make it safer for everyone and help that person be healthier until they get to the point where they integrate and assimilate that ability to access care without that level of assistance. A tough thing for case managers, when and how do you build in independence and help folks become more able which is what we all want. You can't just say, "It's been two years." It might only take two weeks for one person and never for another. You still need them to be in care because the outcome in the community is better. We want to get to the point where we have fewer new infections rather than flat like it's been for ten or more years. We've got reduce the number of people who are transmitting the virus.

The best way to do that is to help people learn their status that's why the family doctors should be testing every one of their patients for HIV just like they check their cholesterol. One of the most widely ignored CDC mandates ever is to do routine HIV testing. You are drawing blood from people on a routine basis, why aren't you screening for HIV? Stigma. If I screen and you are HIV that must mean I think you are a drug using prostitute or something, right? It's been very difficult to get this CDC guideline of routine testing, that's not what doctors learned. And when they did learn about HIV, they knew you had to do all this pre-test counseling and post-test counseling, not why you need the test and about what the result means. Routine testing says we don't even do any pre-test counseling. In Houston we manage a very innovative program that's led the

nation where everybody going through the trauma centers in Houston is screened for HIV/AIDS.

JACKSON: Are they? What a good idea.

TAPE 5, SIDE B

JACKSON: Here's the last thing because we could talk forever about the implications of Ryan White on the AIDS Program. How do you feel about your contribution that you've made for the last twenty-three years working in this program?

HENLEY: It's obviously and clearly been the purpose of my life, something I am incredibly proud of. I think of myself, and when I told the Council I was retiring because I didn't do one of those things where I announce, "I'm going to retire in two years," I am more of a "rip the band aid off" kind of person, I said, "I'm a soldier. I came into this and I have done the best I can every day and I knew early on that I would not be able to do this so long that the epidemic would be gone." You got within six months when it was clear even today with all the advances, there's no cure. Even the baby they thought was cured has now shown there are some antibodies in the reservoir in the body. The HIV virus was clearly going to stay ahead of the science for a long time. Now the science about how to get care to people and the ability to treat people so their health outcomes and their ability to not transmit the virus has vastly improved. I told them I knew the battle would be longer than my assignment to the front line. There would be the next man up at least to do this. I've done my best and there've been lots of opportunities to do something you might look back and regret and thankfully I never took those options. Now, whether it

meant I had to battle with Sue Cooper, whether I've had to fight with the Health Department, whether I've had to explain to people why every other thing gets done this way but Ryan White's different. I've made the choice to draw the line in the sand and to fight the battle or to stop and listen to somebody even when I've heard what they are going to say five times from them and ten times from somebody else and to validate that. I did the best I could.

It's been very rewarding to get a lot of folks saying, "You really made a difference," particularly when that comes from consumers. Because of the way Ryan White works you are really in, it's not like we've been sort of hands off, at a distance, administrators of a program. We are day to day with it. The infrastructure we built, the data system, the monitoring systems, the quality management we didn't talk about. The office I managed for all these years, by the latter parts of my tenure, more people in our office worked, and there were thirteen positions all together, more folks in our office are dedicated to the quality of care people get than the monitoring of the service and the paying of the bills. That's a big turnaround. To begin with it was paying the bills, getting the contracts out which never became less important. It's one thing that I get the service out there and that somebody got the service and the provider got paid for the service and the money can be accounted for but that doesn't mean it did anybody any good. So, being able to actually demonstrate that the services produced improved health outcomes and improved patient adherence and satisfaction, and that the Planning Council trusts the administrator even when they do the things the client prefers you not, that they still said, "Okay but we know that y'all are doing the best you can and that you have our back." That's probably the most important long standing thing I get from it which is

even when we had to make decisions that one group or another felt we're the ones they wanted made, we established enough credibility that then they'd say, "Ok. We know we need to do it and we'll do it," and it got done.

The way the Planning Council, going back to something we talked about very early and this is a good way to close out and revisit it, the Council is the only one that can make the decisions about the where the Ryan White Program puts its resources. They have complete autonomy to make incredibly bad decisions. That goes with it. The legislation says only they decide that. The fact that they consistently in the last fifteen years made future looking, sound, difficult decisions to me is the greatest stamp that we've really been able to do what needed to be done. They made the decisions against what they felt in their gut and when the decision was up and some fifty people signed up to say, "If you do this I'll die," and that's not an exaggeration of what the passionate people would say. And the people making that decision are people like them, they're not just the bureaucrats, it's the Planning Council, the consumers, because the folks on the Council that work for agencies, they can't ever vote on those decisions because it involves money, the Council made those decisions even when you could tell it personally was very difficult. Then to face that, being told to your face that you're a cold-hearted bastard that's just trying to kill me, the fact that Houston has come to made good decision after good decision.

The Program is lined up for the future. If the future means not Ryan White and transitions to something else, or for whatever reason becomes less reliable as a funding source, the infrastructure that's in place now is sustainable under other mechanisms that are out there. They can't be changed unless you were to effect things to other people.

One of the things the Affordable Care Act has done and it's sort of subtle, most people I know we've had insurance through our employers for a long time, but there have been lots of people who can't get insurance because of pre-existing conditions. One of the things that was always true in HIV was our people were largely uninsured and they couldn't get insurance. Well, there's obviously a lot of political fighting to be done over the Affordable Care Act, but now people with HIV for understandably valid historical reasons distrust that the government will make decisions that might be harmful to them. If there was a decision made to get rid of the Affordable Care Act, and I can point out a lot of things that I would do differently, you couldn't get rid of the ability to insure people with HIV unless you got rid of the ability to insure people with cancer or diabetes or all these other conditions that insurance companies used to redline. This is not something that has really been integrated in the HIV community, anything that's rolled out this bad, that there's been this much political discussion about, clients weren't beating down the door to use Ryan White to get insurance, see Ryan White can pay for their insurance through the market place.

Now you are in a bigger lifeboat. You can't be the story of the ship that the Jews who fled Europe in. It came all the way over here and the US even said before World War II, "You can't stop here." Now the Ryan White consumers are in a bigger group of people that are going to be more difficult to take away. So, a lot of people probably say, just like they complained about government benefits, but don't touch my social security – and Amen to that as a retiree. People might want to change the Affordable Care Act or get rid of it, but I can't imagine at this point it's going to be feasible to pass something that would allow insurance companies now to go back and redline all these people. If

they change it or fix it or get rid of it, that's going to stay. There are too many people in that boat. That's what I tell folks about Ryan White. That's one of the reasons Ryan White started, they weren't allowed in the boat, their ship wasn't allowed to dock. Now you are just part of a passenger list of a bigger ship.

In some ways, especially the long time clients, they miss the fact that Ryan White is now being more main stream and medical care for people with HIV like the issue at Legacy and the new mix of clients in their waiting room. Now the long time clients wonder why there's families with babies in the waiting room, that's one side of it. The other side is of it is that's less special, it's less unique. You don't have as much of that tried insularity, but if you don't plan a way to at least ride with the wave, you'll get crushed. I think that has been my strategy all along and is something I've always done. I'm a lemonade maker. There've been plenty of lemons to squeeze in Ryan White. That's why I would tell the people in the Council, "Look, we got to squeeze the lemons. Let's make lemonade instead of just holding it above our eye socket and squeeze it."

JACKSON: That's a good image. Thank you very much, I appreciate this. Enjoy retirement.