

## **Penny Acrey**

### **Disability rights activist and Director of the Office for Students with Disabilities at UT Arlington**

*Interview conducted by  
Miles Shaffer  
in 2013 in Arlington, Texas  
Transcription by  
Nichole Sheridan*

Disability Studies Minor  
Special Collections and Archives  
University of Texas at Arlington  
Copyright © 2016 by University of Texas at Arlington Libraries

#### **Biography**

Penny Acrey is originally from Houston but now lives in Fort Worth. Since 2010, she has served as Director of the Office for Students with Disabilities at the University of Texas at Arlington. She earned a BSW in 2002 and MSW in 2004 from the UT Arlington School of Social Work; she is now an LMSW with a focus on disability, trauma, and mental health. Acrey served as Associate Director of UT Arlington's Office for Students in Disabilities from 2004 to early 2009. After spending eighteen months as Assistant Dean for Student Success in the School of Social Work, she returned to the Office for Students with Disabilities in 2010 as Director.

After Acrey's first child, Sarah, was born with Osteogenesis Imperfecta (OI), Acrey became active in the OI community, "came out" as a person with a disability, and started advocating for disability rights. She has fought to ensure that students at Southwest High School in Fort Worth—the high school that serves most students with physical disabilities—have equal access to choir, band, media technology, and other electives as well as the auditorium stage, among other campaigns. She assisted with the founding of UT Arlington's Disability Studies Minor and teaches "Gender and Disability" in the Minor. Acrey also serves on a number of advisory boards of regional agencies serving people with disabilities, including Helping Restore Ability and the IDD Needs Council of Tarrant County.

#### **Topics discussed**

- Childhood, family background, and experiences growing up with Osteogenesis Imperfecta
- Accessibility experiences in K-12 public school
- Accessibility in the 1970s, especially at college and with driving
- Life after school, parenting a child with a disability, and emerging awareness of disability rights

- Experiences in the medical world as a person with a disability and as a parent of a child with a disability
  - Evolving attitudes towards people with disabilities
  - Disability community, identity, and feeling normal
  - Finding the OI community and "coming out" as a disabled person
  - How the ADA has and hasn't changed attitudes about disability
  - Daughter's disability and emergence as a disability rights activist
  - Fighting for full access to electives at Southwest High School in Fort Worth
  - UT Arlington and accessibility
- 

### Shaffer

Today is November 5, 2013. The time is 9:40am. We are in the University Hall, Office for Students with Disabilities, room 102E conference room.

I'm interviewing Ms. Penny Acrey about her experiences with disability, and architectural access within the realms of education. My name is Miles Shaffer. I think that's it, for that.

None of this will be used for anything other than academic reasons and we're going to try to place this in the university archives with your permission if that's okay, which I think that would be a really great thing to do. Thank you for being here. If we could just get started we'll start out with if you don't mind, stating your full name.

### Acrey

I am Penny Glenn Acrey, and I'm director here in the Office for Students with Disabilities, and I am a person with a disability.

### Shaffer

<topic>Childhood, family background, and experiences growing up with Osteogenesis Imperfecta</topic>

If you don't mind could you just tell us about yourself? Little things like where you born, what type of disability you have, and your category or, what you like to call yourself, or I'm sorry, how you like to define your disability rather?

### Acrey

Okay cool.

Well I was born in 1958 in Houston, Texas. My disability is Osteogenesis Imperfecta. It's often called a brittle bone disease, and I think that's because the most common manifestations are lots of fractures. However, "OI" as it's called for short, is really a collagen disorder, and could be grouped in with a number of collagen disorders such as Marfan's [Marfan's syndrome], Ehlers-Danlos syndrome, and others. It is something that does run in families. With each pregnancy there is a fifty-fifty chance of passing the disease to the child.

My father had OI. My grandmother (his mother) had OI. We think possibly her mother may have had it, but we don't know a whole lot about her. My brother and I were the only two children from the marriage of my birth mother and birth father, and we both had OI. My brother passed away in 2009 from cardiac arrest. He had hypertension for years that he didn't

treat. He didn't take care of himself, and he literally got up one day, and just dropped dead. He was forty-nine. So, that was...

**Shaffer**

I'm sorry about that.

**Acrey**

Yes, thank you. That was quite the shock.

Actually, there are some cardiac risk factors that are known now to exist in people with most types of OI. There are at least six readily identified types of OI. Mine is most often categorized as type four, which really means nothing other than degree of affectation [degree affected]. It gives doctors a point of reference when they're describing people such as myself. We tend to be shorter in stature, we have fractures, some hearing loss is possible later in life, so that's something I try to keep track of. There can be some affection of [effects on] the teeth. My teeth, my dentist always says are perfectly normal, although I don't think they are. I think they're a little bit kind of opalescent. You can kind of see through them a little bit...the enamel is kind of thin.

There are people with some types of OI who have what's called Dentinogenesis Imperfecta. It's a real serious involvement of the teeth, and the teeth are usually brown and they crumble a lot...a lot of dental work. It's easy to fracture the teeth when you're eating. My teeth are pretty good. They're not great, but they're pretty good. I do have an awful lot of fillings in my mouth, mainly because my brother and I were raised by grandparents. We were very poor and by grandparents' standards, you didn't go to the dentist unless you had a toothache. I didn't go to see a dentist until I was fifteen years old, and by then I had a lot of cavities, a lot. We didn't know what floss was, taking care of our teeth was not a priority for my grandparents.

**Shaffer**

You were raised by you grandparents?

**Acrey**

Yes, my father had OI. He was thirty-two when he married my mother, and my mother was fourteen. I was born when my mother was fifteen, and then my brother was born when she was almost seventeen. You can imagine that kind of a mismatch, and my father had so many physical disabilities and things going on. That marriage did not last.

My brother and I were brought up by my paternal grandparents. My father lived with us off and on until he died when I was eleven. My father was born, just as a point of interest, in 1925. At that time no one had any clue what OI was, or how to treat it, or what to do. He just broke many, many bones, and consequently he wound up not getting an education. They didn't have home bound teachers back in those days. There was no state vocational rehabilitation commission to help people with disabilities, so if you weren't physically able to go to school back in his time, you just didn't get an education. I think he dropped out in about the sixth or seventh grade.

When my father was a teenager he went out with some buddies, and they were drinking. They wrapped a car around a telephone pole. Of course no seatbelts or anything like that, so my father reportedly broke almost every bone in his body including his skull, and they basically sent him home with my grandmother to die. They gave him pain medicine and all

that. Well he didn't die, but he did survive, and then was addicted to all the pain medication. My father lived the rest of his life addicted to prescription pain medicines, unable to work. I think for a time he was an elevator operator, and I think he actually at one point may have worked for Goodwill back in the back room fixing little appliances, things like that. He never really lived independently, or was able to make a living. Complications from his chronic drug use, a broken arm from a fall, and pneumonia are what killed him.

It's now known the number one killer of people with OI is respiratory issues. They used to think that people with OI died from pneumonia and complications because we're short-statured, and our lungs don't have room to expand, but they actually know now that there are some tissue changes in lung tissue in people who have OI.

I do have an asthma and allergy doctor that I go to try and keep track of that, I take that real seriously. Since I've gotten older I do get bronchitis more often. I'm just more sensitive to smoke and things like that.

**Shaffer**

I believe you might have stated it before could you tell me the date of your birth, if you don't mind?

**Acrey**

Yes, it's 05/28/58, and those are my lucky numbers too (laughs).

**Shaffer**

<topic>Accessibility experiences in K-12 public school</topic>

Very good. Could you, if you don't mind telling me about your experiences in school? Things that you remember from the earliest time? I guess as a progression?

**Acrey**

Okay well, getting around at home I primarily got around on crutches or crawling. I didn't do a whole lot of walking. When they took me out they would put me in a stroller when I was five or six because I was small anyway, and it was just the easiest way.

When I went to first grade...kindergarten wasn't something everybody did back in the day, and of course still is not required, kindergarten is optional. Many people don't know that now because everybody goes. I started first grade, and I remember going in a little walker for my safety so that I wouldn't fall, and it was a weird kind of little walker. It had a strap that kind of went between my legs and buckled so I could sit down anytime I wanted...but, to get into it either somebody had to lift me in and put me in from the top, or I would just unbuckle it and climb out from the bottom, which is what I usually did.

My elementary school.... I didn't ride a bus. I was dropped off, and dropped off on the bus loading dock, so it was level with the school. There was one area in second grade, there was a wing that went outside where I had to go down a pretty big step, but I was able to do that just by lifting the walker up and pulling it, and getting up by myself. I didn't need any help then.

I went to that school, I was the only child there that had a visible disability. This was back...gosh, it must have been 1964 or so. This was prior to IDEA [Individuals with Disabilities Education Act], so it was still legal and perfectly commonplace for students with any type of disability to be sent to a self-contained campus. They had the school for the disabled, and it could be anything...anything from brain injuries, cerebral palsy, blind, deaf, orthopedic, it didn't

matter. The kids in those schools were on all different kinds of levels as you might imagine. The quality of education they got was probably quite poor. I'm not exactly quite sure how I escaped going there other than my grandparents just enrolled me [in regular school], and took me to school, and since I wasn't causing any problems it was fine.

We hit our wall, our first wall when it was time to start fifth grade. The school year started off with me being in a classroom in the building, and then I guess as typical for school districts even now, numbers can fluctuate, especially at the beginning of the year, and they decided they were going to have to move classes out into some portable buildings. They decided they would move all the fifth graders out into portables. Well, I couldn't get up and down the portables, we tried it for a little while, but there were four or five pretty steep steps with no kind of handrail, and I just couldn't safely do it. It was a really scary difficult thing for me to do, to get in and out. My grandfather went, I remember this meeting with the principal, and he said, "Can't you just put one fifth grade class in the building, and maybe one fourth grade class out?" I remember the principal saying, "Well, we're not required to do that."

**Shaffer**

This is the '60s?

**Acrey**

Yeah, so this was kind of how it was. They weren't required to do that, and they didn't. Buses were another thing. I didn't ride the bus every day, but when we would go on a field trip at least once a year, I couldn't get on and off the bus. My grandfather would come along, and I would ride in his car with him. We would follow the school bus, and go wherever. Almost always the location we would go to, whether it was a museum, or concert—I mean one time we visited the telephone company back in the day when they [had] all kinds of wires and weird cool things to see..

**Shaffer**

Yeah, a switchboard operator?

**Acrey**

Yeah!

...there was all this fun stuff to see, but those places were not accessible. He wound up just carrying me because, again, I was small, and young enough that I wasn't too embarrassed about that at that time. That was how we got around. When it became evident they were not going to move the fifth grade classroom we were told that a new school was being built, and was just about to open, and that we were free to check that out, and they would okay a transfer.

I transferred then to a little school called Johnson Elementary, and it was at least twice as far from our house. It was all one level, so that's where I transferred to. That was kind of tough for me because when you're different, and you look different anyway, trying to make friends and fit in is always weird. Leaving the friends I had that had been with me since the first grade was really tough. That was kind of a depressing year for me I recall.

We had to get up earlier every morning to allow for the drive. After my fifth grade year was complete I had an orthopedic surgery on my leg to put a rod in my femur. I have rods in both my femurs to stabilize for fractures and all that. After the surgery, I was in the hospital for a

while, in a cast for about six weeks, and then I was using a wheelchair for about a year. I didn't get up on crutches again for a good year, year and a half. They decided it would just be better and easier to give me a homebound teacher.

Beginning in sixth grade I had a teacher come to my house twice a week, and stay with me for an hour and a half. She would bring books, the only library books I ever got were—she would go to the library and choose a few for me to read. That was great fun, because as a family we never went to a public library or anything, so I didn't have that. There was at least two years that my brother also was on homebound, so the teacher would come and be with me for a while and then be with him for a while. The rest of the time we just sat home and watched TV. We didn't go out a lot, and growing up with grandparents they don't like to go out and do a lot of things, and they weren't able to do a lot of things...didn't have any money to go anywhere anyway. Lots of TV, that was my life...TV and Barbies, those are my favorite things.

Seventh grade I also had a homebound teacher. You know sixth, seventh, eighth grade, those are those really horrible, awkward years where the hormones are kicking in, and you're starting to wonder what kind of life you are going to have, and all this horrible stuff. That was a real bad time.

My father died in '70. That was a real traumatic thing in our family. My grandmother just was in horrible grief for a couple of years. She was just crying and wailing every afternoon laying on her bed. He was her only child, and she had a lot of guilt about passing this disease onto this child who had such a miserable life and all this. Those couple of years when my grandmother was doing her grieving, her big grieving, my brother and I just laid low. We tried to stay out of the way, not cause trouble.

Eighth grade it was decided by my family doctor that he would not write the note [for homebound schooling]. He thought I needed to go to school, so middle school was, like, such a shock for me. The last time that I had seen peers they were fifth graders, and now I saw peers that had beards, and they were all nine times as big as me. It was quite the shock. I was very sheltered and protected as a child, and going in and being with eighth graders was really, really different. That was a tough year for me. I did go to school in a wheelchair because I could not walk as far, as the school was huge. They were very worried about me getting pushed down at class change, and slipping down on a wet floor, that kind of thing. The school was not terribly attentive to me. I always had to get a friend or somebody to carry my tray in the cafeteria or I would bring my lunch, because they didn't have any aides who would come and just grab my tray and take it to a table, no one took any kind of responsibility for doing that, it was totally on me.

Interestingly enough, just to jump forward when my own daughter was in middle school, we found out after the fact that some of that was going on at her school, and that there were days that she was skipping lunch because she was too embarrassed to ask. Things don't move as quickly as we would like to see them. The other really awful thing about the middle school was that it didn't have any accessible bathroom. There was no bathroom that a wheelchair could go into, no accessible stalls. The only way I could go to the bathroom was to go to the nurse's office, which meant I had to miss some of my class, and everybody knew where I went, and it was really embarrassing. Most of the time, honestly, I just didn't drink anything all day because I didn't want to have to go. It was just that bad.

**Shaffer**

That's not good.

**Acrey**

No! It wasn't good at all. It was terrible, but that's what I did rather than be embarrassed like that. Eighth grade...try and remember being thirteen. It's horrible. When you're thirteen you feel like everybody's staring at you, and that you're weird. When you really do look different, and they're staring at you, it's so much worse. It's a really hard time, really hard time.

**Shaffer**

Having to worry about things that are so...that you shouldn't have to think about.

**Acrey**

Like going to the bathroom, yeah. When we would have fire drills and things...if I was in a part of the school that didn't have the loading dock for the bus, they would actually recruit a couple big guys to grab my wheelchair, and carry me down the steps. That was very embarrassing, and sometimes my chair would come apart. The sides would pull out, and they'd freak out. My chair was really old and ratty, it was one my grandfather got somewhere and spray-painted. It was just awful. I can't even tell you how awful it was. (Laughs)

**Shaffer**

That's not good. Was there ever anything such as band, or any kind of art class, or anything extra that you wanted to participate that...?

**Acrey**

I did have an art class as an extra elective because I didn't have to do P.E. The sad thing though...I'm not quite sure how they structure things now, but back in the day when a kid went to P.E. that's where health was integrated into that. That's where you learned about reproduction, and the body, and all that good stuff. A lot of people with disabilities missed out on any of that, because it was included in, it was integrated in with P.E. I didn't get that.

**Shaffer**

Is that something that they did not encourage you to do, or did they discourage you from participating in P.E.?

**Acrey**

Oh yeah.

**Shaffer**

Did you want to?

**Acrey**

I didn't really want to, because I knew that there'd be too many things that I couldn't do. By then P.E. wasn't just recess where you went out on the grass and sat, which I did in elementary school because it was being outside.

**Shaffer**

Yeah!

**Acrey**

Once it got to that point they were actually structuring exercises. They were doing jumping jacks, and there was some kind of presidential fitness campaign or something that was going on that meant schools had to do more structured things for the older kids. I knew I couldn't do any of that. That was eighth grade. It was pretty horrible.

When eighth grade was over I went back on homebound. I was glad to do it because I felt kind of traumatized by the school. I had ninth grade at home, I had tenth grade at home, I had eleventh grade at home. After I completed my junior year we realized that in the state of Texas at that time you only had to have—I've forgotten now how many credits—but it was basically your basics in order to graduate. We realized I only needed senior English, and political science, and they would have to let me graduate.

I went to the high school using my wheelchair—again no access at all—the reason I didn't go to high school was because the high school was two-story, and the library...no...let's see.... The one school...one school that I had a choice to go to, the library and all the labs were upstairs, so I couldn't have possibly gone there. This other school, I went to summer school there and took English and political science using my wheelchair. Then they mailed me my diploma that August.

I didn't get a senior year, I did get to graduate early.... I had just turned seventeen.

**Shaffer**

<topic>Accessibility in the 1970s, especially at college and with driving</topic>  
So, you never got to experience prom or anything like that?

**Acrey**

Oh, none of that, no. No, I didn't even have any peers my age. It was different.

Now, my brother on the other hand, he wasn't as physically affected by the OI as I was. He did have some fractures, but he was able to somehow get over them quicker, and he didn't have as many surgeries. He did go to school, he rode a bike, and he had a senior year, and got into all the mischief boys get into in high school. He had a car, and all that. He had a little more freedom than I did.

**Shaffer**

Do you ever remember any times where specifically an architectural barrier, physical access, got in the way? I know we've discussed some things, but anything else that you can remember just from this time frame that really sticks out in your head?

**Acrey**

Well, any place you went there were no curb cuts. There were no accessible parking places. There was nothing, and if I could use my crutches or my walker when we went out I could at least get up bumps, but the times when I was in a chair—you know this—a bump this big



[holds hands six inches apart] could keep you out...unless you have got someone there to pop you up, so going anywhere...

I remember when the first mall in Houston opened, if you can imagine—I feel really old now...but the first mall in Houston opened, and I remember going to that. I couldn't go into the bathrooms unless you could get out of your chair and walk, you couldn't really use the bathroom there. A lot of doorways were narrow; there were some stores inside the mall that even up steps, so lots of that. I didn't know anything different...that was the world.

**Shaffer**

Do you remember the first handicap accessible parking?

**Acrey**

I kinda do remember that. It started coming out after I was in college, but I didn't have a permit. I didn't know how to get a permit. I remember early on using some of it, and it was lucky I never got a ticket. I think probably is as true now they don't enforce it very well. There's lots of people that do abuse those spaces, and they don't get tickets even now. That's a problem, but that was in the mid '70s that I remember really starting to see those. You think, "Wow, hmm."

After I graduated from high school and got my diploma in the mail in August of '75, I had applied to go to Stephen F. Austin in Nacogdoches. I don't know why, I can't recall who recommended that school, or why they thought that would be a good idea for me...but it really did not work out very well. I went off to school because it's what you do, and I didn't know what else I would do. Sit home and watch TV some more, and my home life was not a happy place, so that's not what I wanted to do.

At least I would say probably the one good thing I had going for me, that never seemed good to anyone else, was that I was very stubborn and very intent on what I wanted to do. I did go off to school. I went to Nacogdoches, got a car; my grandfather rigged it up so I could reach the pedals. There was no adaptive equipment you could buy, there seriously wasn't, there was nothing, so he rigged it up. The car was an old Mercury Montego, and it had a bench seat, and he took the bolts loose from the floor and moved it up then put a block under the back to lift the seat forward like that. Really, no normal-sized person could ride comfortably in the front with me because it was a bench seat.

I remember what was funny when I took my driving test, because I got the car before I got the license, and of course I couldn't take driver's ed. This is still true, you can't find a driver's ed program that has cars with adaptive equipment. I went through that with my daughter. You do the home teaching or you don't do it...there's still a lot of issues. When the state trooper got into the car with me he bumped his head and knocked his hat off, and I laughed at him. I did fail that test, it was bad (laughter). He didn't pass me. I had to go back.... Laughing at him probably was a mistake, but it was pretty funny.

When I got to Stephen F. Austin, I was in a residence hall that had no accessible entrance, so I was walking up steps on crutches, and there was no parking. Sometimes I would park far, far out and walk in on my crutches, carrying things. It was really all about survival of the fittest, and I was clearly not the fittest. I wound up dropping classes, I think I came away with two classes that I passed that I got credit for.

**Shaffer**

All due to not being able to make it on time?

## Acrey

Just mobility, and if it was pouring down, or if it snowed or iced I couldn't go out, I could not get out. The crutches...I can't carry an umbrella, couldn't run. It was just really miserable, and I didn't know what else to do so I kept trying. I didn't like that school very much. It was a big alcohol school. It was out in the middle of the woods, kind of a redneck atmosphere there. If that wasn't your deal, there wasn't a whole lot to do.

I wound up going back to Houston; I just went there the one semester. Went back to Houston, went to a community college, took a semester of classes there that were actually held in my old high school at night because the community college was being built at the time. I was back in high school at night, but at least it was an accessible building. Took classes there, then I took some classes that first summer session, after that. Then I went to UNT [University of North Texas in Denton].

I decided I had to try this again. UNT was much, much worse than Stephen F. in terms of accessibility. It's very, very hilly, a lot more snow and ice—just really a bad idea—bigger campus, even harder time getting around. I was there probably a year and a half. I dropped more classes than I completed. It was just a train wreck. There was no disability service office. I didn't have a permit to park even though there were some parking places. I didn't have a permit or know how to get one. It's hard to imagine somebody not knowing how to do that, but we didn't have the internet. Really, information just wasn't out there. I did have a DARS [Department of Assistive and Rehabilitation Services]—it was called Texas Rehabilitation Commission—counselor at the time, and they were paying for at least for my tuition. He was really bad. He was one of the worst DARS counselors. I didn't know this, but he was all I knew, but he was probably among the worst I have ever seen or heard speak.

## Shaffer

About what year was this?

## Acrey

<topic>Life after school, parenting a child with a disability, and emerging awareness of disability rights</topic>

That was 1976, fall of '76 and then spring of '77. I wound up getting a job, getting my apartment. It was a little efficiency apartment. It was all I could afford, but it was good enough for me. I met my future husband there. We got married in '78, and moved back to Houston. I decided to get a job and let him finish his degree first because he was closer to getting it than I was. I wasn't sure I could even do it, to tell you the truth, after having so many bad experiences. He went to U of H [University of Houston] and worked at UPS at night, and we managed. We lived in an apartment on the North side of Houston, and we were down there about three years.

I worked, let's see... I worked at a jewelry store at the mall for close to a year, and then I took a job at a small hospital. I worked there for several years until we moved back up here [the Dallas-Fort Worth area]. Then I worked for a clinic...didn't make a lot of money because I didn't have any education.

I got pregnant in 1985. I stopped working then, and I stayed home. My first child has the bone disorder that I have, so it was just decided I really needed to be home to take care of her. It was a scary thing trying to think about putting her with a babysitter who might break her bones just changing a diaper, or doing something simple. I was happy to stay home. I hadn't had a wonderful experience out in the world. I don't think I even really remember noticing when the ADA [Americans With Disabilities Act] passed to tell you the truth.

I had just had my second baby, and was real busy doing mommy track stuff, but when Sarah started school it must have been about '96...no...'92. Sarah started school in '92, which was two years after the ADA passed. We were very concerned about her safety going to school, and being in a classroom with kids running around. I got very involved in schools, and just slowly discovered things are kind of different.

The schools were still old, they weren't accessible, but they were coming in, and they were pouring ramps...pouring concrete, makeshift ramps. They actually asked me about her needs in the bathroom, and we went in and we looked. The stalls were okay for her, but the doors opened in, and I said, "If this door would open out, this would be accessible for her." They came in, and they switched the hinges, and I thought "Wow, these people are so nice."

I hadn't really put it all together about the ADA. I don't think they fully understood what they were supposed to do. I do know quite a few years after that, when she was in high school, and I was working with the district, they didn't have a master plan about transitioning all their facilities that the law required they have. There were a lot of things they didn't know how to do and weren't doing very well, but at least for her...because she had an involved parent, and I was on the PTA board and all that stuff, things got done for her.

It was real different, the buses had lifts now, and she could ride the bus and go on field trips. It was real different.

#### **Shaffer**

<topic>Experiences in the medical world as a person with a disability and as a parent of a child with a disability</topic>

How would you describe the attitudes as you were growing up, and you noticing the change? What changed in your opinion, or your experience?

#### **Acrey**

Well, access, awareness, sensitivity. A big thing that comes to my mind is all the medical trauma I went through as a child—breaking bones and being in hospitals. That was just the most horrible thing for me as a little kid. If I broke my leg they didn't put it in a cast and just send me home, they admitted me and put it in traction, and I stayed there for weeks. My grandparents could only visit until 8 pm, [then] visiting hours were over and they had to go. I had to be in the hospital in John Sealy in Galveston because we were on Medicaid. We didn't have money or insurance, so that was the orthopedic clinic I had to go to. If I did have a fracture, I got a forty-five mile very bumpy drive down I-45 going to the hospital.

I remember having femur fractures set with no anesthesia; it was just barbaric... horrible, horrible. I have memories of being a little kid in a big ward with a dozen other kids. They'd flip the lights out, and we'd all lay there and cry ourselves to sleep.

#### **Shaffer**

Really?

#### **Acrey**

Yeah!

When my daughter was born we got some of her care at Cook's [Cook Children's Hospital in Fort Worth]...we got some over at Scottish Rite. It was very different. It was a happy place

with lots of toys and bright colors and volunteers and popcorn. It was much less scary. My whole experience with the medical world as a young child was, it was just a chamber of horrors, it was horrible.

**Shaffer**

Just treating you as a subject with regards to say the medical model, and then a transition as disability civil rights progressed into a more, not solely social but...

**Acrey**

Yeah! A little more person-centered.

For example, when Sarah was in Cook's when she had a surgery on her leg, they've got these big comfy chairs that fold out into a bed. They expect parents to come and stay, because the child does better, and the parent of course wants to be there. It helps the nurses out if there's a parent in there. If the child needs something...it just benefits everybody.

I remember when I was a kid them telling my grandparents "You have to leave now, visiting hours are over." We didn't even have TV's in those wards, no TV. If you wanted a TV you could bring your own, or you could rent one for something like five dollars a day, which was a fortune back then. Imagine not having a TV, laying in a bed in a cast or in traction, and not even a TV. Pretty bad.

**Shaffer**

Yeah that doesn't sound good at all.

**Acrey**

No it wasn't good at all, nothing good about it.

**Shaffer**

<topic>Evolving attitudes towards people with disabilities</topic>

How did the teachers, how did they view you getting an education, and you growing up, and going to school? Did they encourage you, or did they ever help or assist you in any way?

**Acrey**

In grade school, I think that they did assist me, and they were sensitive to me. They watched out for me. I didn't really have any problems. I only had that one eighth-grade experience in middle school. It's very hard to form any kind of relationship with a teacher when you're only in there only fifty-sixty minutes, and you change classes. I didn't really get to know any teachers then. I really think the administrators there just put up with us because they had to.

I remember one very embarrassing time when I was in eighth grade, and I was using the wheelchair. Somebody came to my class and said the principal wanted to see me, and I was horrified because I didn't ever like to call attention to myself. I thought, "Why would the principal want to see me? I haven't done anything." The office aid that was sent to get me, pushed me in my wheelchair down to the principal's office. What he wanted was.... They were working with a crew to renovate the bathroom, he wanted to see if my chair could fit through the door.

That was a little embarrassing, but again I guess you could consider that was progressive because it was before the ADA and they didn't have any regs [regulations or standards] to go by. I think they were looking at doing something, but that's where all these retrofits come from is people's either good intentions, or feeling like they had to create some access but not doing it right. That was very embarrassing to get called to the principal's office to see.

I remember another incident after I was working in Houston, I was working in a hospital, and I worked in the business office. I did all the insurance billing for the ER. It was typing, answering phones, stuff like that. One day the administrator of the hospital—who's like the president of the university here—you never see them, you don't really get to interact with them. His secretary called and said, "Mr. Tobias would like to speak with you. Could you come to his office?" I was horrified again. Why would he want to talk to me? I went down to the administrator's office, and he said, "Oh I just thought I might see if you could give me some advice here." He said, "I've gotten this letter from these people from the..." What was it?.... They gave the initials.... What it turned out to be was the Coalition for Barrier-Free Living. They had just signed their name and then put the initials. He didn't know what that was.

He said it was someone who was a wheelchair user who had come to the hospital to visit a patient, and could not go to the bathroom off the lobby. They had written him this scathing letter about it. I felt singled out, because I wasn't even using a wheelchair then. I was using crutches, but he called me. It's kind of something we laugh about as people with disabilities, or anybody that looks different, or even if you're African-American, or you're Hispanic.

People assume that you know everyone else in that group. He said "Do you know this person? Do you know what they want?" I thought about it later, and I thought "How offensive to just assume because I have a disability, I'm going to know this person, and we're all gonna be friends and I can tell you about them."

**Shaffer**

They all, we all go to conventions together, and know each other.

**Acrey**

Exactly, exactly yeah! It happens all the time, it's pretty funny. It's as if they consult one of us about something, and expect us to be the spokesperson for all people with disabilities. I just basically told him I don't know anything about that. I'm not connected to that group I'm sorry, I don't have any information. I think he was disappointed, but I was able to tell him that I thought that stood for Coalition for Barrier-Free Living. But again, we didn't have the internet, you couldn't just look stuff up, it was really difficult to know about that. Who do you ask?

**Shaffer**

Did you ever have any types of experience with any sort of disability community?

**Acrey**

<topic>Disability community, identity, and feeling normal</topic>  
Yes, just a little bit.

Back in 1970, the OI Foundation [Osteogenesis Imperfecta Foundation] was begun by a parent of a child with OI who I think passed away at a young age. I think they had a pretty

severe type of OI. Anyway, she did an interview for *Redbook Magazine* or some very well-known magazine, and it became nationally known. Then the OI foundation was born, and then we started to see these chapters forming, and it stands to reason; the people who are the most involved in these kinds of organizations are parents. If you have a child that's got a diagnosis, and you've never heard of this... You don't know what this is, you don't know what the future will hold, what treatment options. You want to talk to other parents. You want to find out information.

A group of parents had come together in Houston. I guess we had connected through the hospital in some way because there's no other way that they would've found us. We got invited to this OI meeting, and it was down in a park under a big gazebo. We went and we met these people. We went to a couple of events. I think they gave us free circus tickets, and everybody wants to take the poor disabled children to the circus. We got to go to the circus, and that was kind of funny.

My brother and I were just on the edge of being a little too old to want to identify. I still see that a lot, young adults don't necessarily want to hang with other disabled people their age. They want to just be normal for a while. Just live their life and be normal, not always be the OI kid in the OI group in the special ed class.

I hear it here, my clients will come in, and they'll have a disability that really would have been good for them to come see us a year ago so we could help them out with some things, but developmentally young people just want to be like everyone else. It's very normal, it's not unique to people with disabilities. There's a real falling away from that, I think, as you approach adulthood. I wanted nothing to do with that, and they were all about the kids, and I thought "I'm not a little kid anymore. You had your chance, and I didn't get anything, so now I'm moving along and see what I can do."

<topic>Finding the OI community and "coming out" as a disabled person</topic>

When I had my daughter we connected with a group, again to see what kind of research had they got going on now. "Are there new treatments?" There are some things that we didn't know about, so it's beneficial to families...even the national conferences that I go to, I don't go every year. I've only have been to about five OI conferences, they have them every two years, but it's great. They have researchers there, there are doctors there, geneticists, they meet with families; give you all kinds of great information.

The coolest thing though about it, my very first conference was in San Antonio, it must have been in...around 1991 maybe. We went to this conference, took my two girls, and Sarah was using her walker and wearing her braces and all that, and I was never so shocked in all my life, Miles. When we got out of the car and went into this hotel, I looked around and I saw hundreds of people that looked like me. It was like that old *Twilight Zone* episode where they pick the guy that's deformed and doesn't look like the other Earthlings, and he volunteers to go off on to this mission to another planet. Then the other planets send their misfit to earth, and it just so happens that everyone on that other planet looks like them, and they fit right in.

That was the weirdest thing, I met all these people; people that were short, people who... there's actually a look to people with OI and I can spot it. When I see somebody who has OI I can tell they have OI. I've had people come up to me and actually say, "Hey, have you got OI?" We sort of do that little wink and handshake thing, because it's like we're in a little secret club. It's like, "Yeah! I got that too!" It's pretty cool.

I am connected to a group on Facebook now that's very, very active and talk about everything in the world, and that was... I call it my "coming out moment." People laugh at me and they say, "How can you come out? You've always been out; we've always known you were disabled." I said, "But I wasn't disabled up here [points to head]."

I didn't accept it. It was like the elephant in the room. I behaved normally, I sucked it up, I didn't complain about stairs, I did it. I just needed to fit in and be normal; it's what we all want to do.

After all that, when I met all these cool people, and I saw some young people that had so much self-confidence. If they had curvature in their bones and their legs, or scars from surgeries, they didn't care if they wore shorts. I thought, "Wow, I would've never done that, I would've never been brave enough to do that." These people were out there, and it was great.

I stayed up one night 'til like three in the morning in the bar with these people I had just met having the most personal conversations. "Well, did this happen to you, and did this happen to you? What about when you got married, and when you had your child did they say this to you?" We just had all these very personal conversations, and it was so empowering.

I remember after all of that just trying to mentally process it, and it sounds dumb to discuss now and think that way, but it really was a coming out. In every sense of the word, it was a coming out. I remember just feeling like I wanted to cry for days, and then after that I felt okay in my skin, and that was so freeing. It was cool, all of a sudden it was okay to say...

I remember one night we had a bible study at our church, and I said, "Oh, I left my Bible in the car." I said "Yeah, I can't really walk out there and get it. It's raining, it's too slippery it's not worth it." I would have never said that, I would have said, "Oh I don't need it. I already read it... I must have left it in at home. No big deal, I'll look on with you." I would've never said I couldn't do it, but it was okay now to say "I can't do that, sorry." Even though people probably always knew that was a problem for me. I guess maybe the messages I was sending them let them know that wasn't an okay thing to talk about, so they never did. That was very weird, but it was good, good weird.

**Shaffer**

<topic>How the ADA has and hasn't changed attitudes about disability</topic>  
Do you think in any way that physical barriers, and as the attitudes started to change, physical barriers started to become a break through that it was a parallel for what was happening in disability civil rights as we...attitudes and acceptance started to come about?

**Acrey**

I wish I could say that, but honestly I think most people comply with the law because it's the law. I don't think attitudes have changed that much. I think the reason that ADA has been opposed as much as it has is because no funding came with it. Building cities, entities were told, "You have to create access," but they didn't give them any money to do it. Fear, I think, has and still continues to keep people from hiring people with disabilities.

In a job interview, for example, if an employer is smart they're never going to ask you about the disability, but they are going to make some assumptions based on what they see and what they're thinking. "What am I going to have to do for him, would I have to put in an elevator, would I have to widen a door? What am I going to have to do?" In most cases any modification needed for a person with a disability is less than fifty dollars. That's the average.

**Shaffer**

It's a lot like.... I would say it's a lot like paying someone minimum wage, you're saying that I'm only paying you this because I have to.

**Acrey**

Yeah.

**Shaffer**

Otherwise I wouldn't.

**Acrey**

Exactly! That's why I think we have to have the laws. We have to have them because people will not do it out of the goodness of their heart. If they do, they will do it in such a way that you are kept in your place.

I signed up my daughter for a vacation bible school one summer at this Baptist church that was close to where I lived. They had all these rooms downstairs, and they were going to decorate them.... When I went and signed her up I had asked about the facilities, and I told them she was using a walker. Then we got something in the mail telling about it...the upcoming, where to go, what to bring, and all this. It turned out they put her classroom upstairs, so I called and I said, "I know this is upstairs...my daughter is disabled she can't do the stairs." "Oh, don't worry about that." I said "Would it be possible to switch her room with one of the ones upstairs?" They said, "No the teachers have already decorated the rooms, so no, we can't do that." I said, "Well, I'm just really worried. I don't think that is going to be safe." They said, "Oh! We got a lot of nice men over here, they'll be happy to carry her up and down." I thought—she was about ten by then— I thought "No." Not only would that be embarrassing for her, but do I trust you not to stumble carrying my child with brittle bones up and down some stairs?

When I argued with them the pastor who's a very well known pastor said something like, "Well..." I think I used the word "liability..." "I think it would be a real liability to be carrying her up and down stairs." And he just recoiled and said, "It sounds like if there is anything litigious considered, this is not the program for her." Basically, "You're not welcome here."

**Shaffer**

Wow!

**Acrey**

That was pretty bad. He's very well known too. I won't mention his name, that's okay.

That's another thing that really, really bothers me. Churches are exempt from ADA. They don't have to comply with ADA. Now, modern building standards, if they build a new facility it does have to comply with building codes; which ADA guidelines for Texas pretty much covers, but for programming and things like that there's nothing that says they have to do that.

I actually left a church at one point because they refused to do anything, and I had been, and talked to them, and I gave them regs in writing and offered to help consult because it is kind of what I do. Instead, they decided they would just give me all those papers back and not get back to me.

In this case, I spoke to a male veteran in the parking lot one night, who was a chair user, and asked him about the bathrooms. He said, "I've never been in there. Honestly, I just go before I get here." He said "I'll definitely say something about it." He went to a parish council meeting, and he brought it up. All of a sudden, because a man had suggested it, they were



doing something about it. They appointed a committee, and they actually sent a letter to my husband and invited him to be on the committee, not me. I was really, really offended as you might imagine. I shook the dust from my feet, and was done with that one, very offended.

I think disappointment is something I've dealt with a lot, really expecting better of some people in some places. When it comes down to money, that seems to be the driving force. It's not about doing the right thing. The really stupid thing to me about discriminating against people with disabilities; it's one thing if you're a racist and you think, "I don't like African Americans," or "I don't like Hispanics" or whatever, whatever. You can be pretty sure you're not going to wake up one morning and be African-American, Hispanic, female, or whatever group is that you feel like you're a little better than. But, being disabled, this is a group anybody can join. You can have a stroke, you can dive off a diving board, anything in the world could happen to you, and you're in the club. If you live long enough...if you're blessed with a nice long life, you will acquire some disabilities, and somebody you know will. It just makes no sense to me.

**Shaffer**

Was there anything you ever had to do, or your caretakers, your grandparents had to do to adapt your house, or anything like that you remember?

**Acrey**

No, not much because we had a ramp off our back porch going into the yard that my grandfather built, but going out the front door they pretty much always helped us, or we used our crutches. We did have the ramp out back. I think they probably would've done that if they'd had money. My family just had no money. None of that was possible...would've been nice.

**Shaffer**

<topic>Daughter's disability and emergence as a disability rights activist</topic>  
You're basically used to, or you were used to having to adapt to whatever situation? Not used to saying, "This needs to change?"

**Acrey**

Absolutely, yeah!

**Shaffer**

Until your daughter came along?

**Acrey**

Until my daughter came along.

I believe there's a reason for everything, I believe that there are things that we will never understand what those reasons were. We may not like the reasons, but she was kind of that impetus for me to start doing my homework. I think you've heard the story I've told in the class about her high school not having access to the whole back wing in the school where the band hall was...what I went through with the school district and all of that trying to get a

ramp put in because they really didn't want to do it. That was very, very hard. That was the incident that taught me about how to get things done.

Anybody that wants to effect change, there's three things I always say. First of all, do your homework, know what the law says, and know what your rights are. You don't want to be yelling something that you're never going to get. Know your rights, get your facts. Second, you want to find out proper channels. Don't go complain to wrong person who has no power to do anything. Go through proper channels; don't go over people's heads, because that just sets up an adversarial kind of atmosphere. Then the hardest one is to stay calm, and not let them see you sweat, or cry, or get mad. The minute you cry, or raise your voice they no longer hear what you're saying. They're focused on how you're saying it, and they're thinking, "Man she's crazy," or "Whew I don't want any part of that," or "She's probably going to try and sue us. Let's not talk to her anymore." You want to always be calm, respectful, and have your facts, and talk to the right people, and things will happen. I've seen it.

**Shaffer**

<topic>Fighting for full access to electives at Southwest High School in Fort Worth ISD</topic>

Could you maybe discuss a little bit about the incident with your daughter, and how you enacted that?

**Acrey**

Yeah, I'll try to give you the *Reader's Digest* version. Basically, when Sarah went to school the elementary school was a good school. We had a good experience there getting what she needed, although, for kindergarten they did start her off in a self-contained class with other children who had multiple types of disabilities. The reason they said they wanted to do that was for her safety. They were very worried about her getting pushed down, getting her bones broken, whatever. Little kids, they can be a little excitable and that kind of thing, so we went along with that.

By Christmas her teacher said "Sarah doesn't belong in this class. We are not moving at the same rate as the other classes," despite what I had been told in the ARD [Admission, Review, and Dismissal] meeting. Although they had the same curriculum and all that, she had kids in her class that were not even verbal, and so obviously they were not moving along as quickly. What we decided to do in that spring of kindergarten was to move her to a regular class, just do it through language arts. They gradually increased the time, and when they saw, "Oh, it seems like really there aren't any problems," so she was in mainstream. That was my first barrier with getting her in mainstream.

When we switched to the middle school we started to go to Wedgewood sixth grade school. We visited the school on open house night. I went and met with the counselor, and I said, "Sarah wants to do band, and I'm seeing that the ramp going out the back to the band hall goes down a hill and there's no railings on either side, and I'm worried about her falling off and getting hurt." That counselor said, "You know, Sarah might really be happier in choir." I said, "I don't think so."

**Shaffer**

What year was this?

**Acrey**

What year was that...? It must have been about '96 or '97 because she was starting middle school. Anyway, we wound up finding the applied learning middle school, which had a much better philosophy. It was a smaller kind of a Montessori-based teaching, a lot of projects, team teaching, kids moving along at their own pace. I went to that open house, talked to the principal. I said, "What is your philosophy in providing educational experiences to students with disabilities?" She just shrugged her shoulders and said, "Well, whatever they need we just try to give them." I said, "This is where we belong." Sarah went to the applied learning middle school, and had a good experience there.

Now, when it was time to go to high school, our home school is Southwest High School. It is also the school that Ft Worth ISD has, for many years, sent their kids in chairs, because it's all one level. It's not really one level, there's one whole wing of the school off the back that goes down nine steps. Nine steps is pretty steep. It just so happened that the band rooms were down there, the band hall, the choir room was down there...that wasn't even an option...the media tech program, which was their magnet program, all that was down that hall.

We went to the school, we looked and we saw it, and Sarah wasn't worried she said, "Oh mom I know you'll get it taken care of." I thought, "My kid is counting on me here. I've got to get this done." I thought, "There's no other access down this hall?"

This was at the end of the spring semester, preparing for fall. I went and I talked to the school, and they said, "There actually is access, they can go down this hall through the auditorium—which is locked, someone would have to unlock it—down the slope, the middle of the auditorium, around the stage into a supply room, then into a classroom, then out into the hall." That was one way.

#### **Shaffer**

Convenient.

#### **Acrey**

"Or, she could go to the front of the school and exit one of the few accessible entrances, or exits, walk all the way around the building, go through a parking lot where teenagers are driving—and she's short—and come up through the back door. Either way it's accessible." I said, "No, no, not accessible."

I didn't know what to do though, because I just didn't know what to do. They had given us a campus map that was to scale. It showed all the rooms, the layout, the hallways, all that...big school. With the help of a physical therapist who worked there, we got a tape measure, we measured how wide the hallway was, and then we could tell by knowing how many feet that hallway was, how many feet wide the rooms were. I looked at a room that was just adjacent to the stairs, and I said, "What is this room?" They said, "That's just a storeroom, and it's where the drill team keeps all their stuff, and all that." it was a pretty good-sized room. It also went along a main hall, and I knew how high the ceiling was, and I said, "Why couldn't we cut a door into this room off the main hall and put a ramp in here with a switchback?" I did find out that in order to ramp that, you've got to have a foot of run for every one inch of rise. We would've had a 55-foot ramp in the hallway, and that would've made the hallway inaccessible. It would've blocked doors, it wasn't going to happen.

I proposed doing the switchback ramp in this adjacent room. We met up at the school, I knew my school board member, he went with me one night, we met with some people from the superintendent's office, the principal, and an architect. We went into the room and the architect measured it, and he said "Well, we could do it. We could do that." I thought "How ironic is this that someone's mom who is not an architect or anything else figured out how you could do this?" What they had proposed as a solution was, putting a...lift on those stairs. Have

you ever seen those kind that are flat against the wall, and you turn it on and then they lay down, you roll onto it and then you go down? Number one, that lift could not be operated independently. Somebody has to operate it from the top, and then come down and get you off at the bottom. She couldn't do it by herself. The other worry was, it was a flat lift and she was standing in a walker. I said "I'm really scared about that I think that's made for wheelchairs that can lock." They said, "All we're required to do—this was downtown—is provide access, and that type of lift will provide access, so that's what we're going to do." I said, "You aren't even worried that she could fall off that and be killed." They said, "Ma'am we are required to provide access, this lift will provide that, and that's what we're going to do." I was really upset then, and I thought, "Oh my God, they don't even care if they kill her."

I went and I got a copy of the ADA. I had to call Washington, because no internet, remember? They sent me a big, thick copy in the mail. I went all through there, and I found this one little piece that talked about lifts. It said, "Care should be taken when selecting ramps for semi-ambulatory populations as lifts such as these are designed for wheelchairs that can be locked down." I highlighted that, copied it, sent it to them and said, "We've determined that this would be an undue danger to her, and not the type of lift she could use. Therefore, we're going to need some other type of access created." I was there on the day the cement trucks backed in and they poured that ramp. I just sat in the parking lot and cried. I was so happy I knew nobody would ever go through this again. Very cool.

In the auditorium they also had a stage with no access, and we had friends who had a daughter with CP [cerebral palsy] who went there before Sarah. In order for her to get up there and sing with the choir they had to lift her up onto the stage in front of everybody. When I brought that up, the principal denied it. She said, "Oh, no, we have access to the stage." I said, "No, I don't think you do because my friend had to be lifted up there." She said, "Well, if she got lifted up there, that was her choice." I said, "Why don't we go back and look at that?" The whole group of everybody with the architect, we went to the back, and it turned out they wanted to create a ramp back there, but they hit concrete underneath. There was some kind of support beam under the stage... What they did was put a self-contained lift with a little gate on it, but it was back behind the stage. You could get back there privately and come out on the stage, so they did that. We had a few hitches with that, because on picture day they were using the stage to take the pictures, and no one had a key to the lift and no one knew who had it. So, other little things...issues.

We had accessible entrances that would be locked. They had to study for the SAT or something one Saturday, and I called ahead and I said "I'm going to need that accessible door unlocked for Sarah." They said, "No problem, Mrs. Acrey. We'll have it done." We get up there, it's pouring down rain, we go up there in the rain, and the door is locked. Sarah has to go all the way around school to get in...in the rain! I was furious. I wrote more letters to that administration, and I said, "You don't train your people, you have an accessible door, and you lock it. That's not access!" It's still a struggle still, still, still.

**Shaffer**

Is there anything that you can recall that I might have missed, or that you can think of that you would like to add?

**Acrey**

<topic>UT Arlington and accessibility</topic>

I can't think of anything regarding childhood or my own school experiences or anything. Other than to maybe just say how rewarding it is to work at UTA where they are responsive. You look at all door openers and things we have around here. It's not perfect, they do break and have to be replaced, but if we tell them we need a door opener, they just come right out and do it. They put remote controls in people's personal vehicles to open the gates to get into the lots, and they just really go the extra mile. It's not a place where I have to fight people to

do the right thing. I don't think I could work some place like that. I think I'm too old for that now. (Laughs)

It takes a lot of mental energy to be able to have those battles. I think we all do what we can do, and then we got to pass the torch to someone else who's younger and got some energy and can do a little of that. It takes a lot of people. It can't just be one crazy lady, because they'll just... "Not her again." It's got to come from more than one person.

**Shaffer**

How important was, and is, education in your process of just being independent and accomplishing goals?

**Acrey**

It's everything. When you're ignorant, you're powerless. You don't know what your rights are, you don't know what you should have, and you don't know how to get it, so you just sit. Education is power; knowledge is power, so it's everything. Good Stuff!

**Shaffer**

I think that's it for now, I thank you. It was very good. I appreciate you taking the time to do this.

**Acrey**

I appreciate your interest, because it's important stuff, and there've been a lot of people that have gone before us that have fought those battles. A lot.