

## Helen Beterbaugh

### Administer of Music and Episcopal Priest

*Interview conducted by Chase Martinez in 2018*

Disability Studies Minor

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#### Biography

Helen Beterbaugh served as an Administer of Music and as a priest for the Episcopal Church. Born in New Jersey in 1943, Beterbaugh obtained a progressive disability at a young age. She caught an unknown form of polio and did not receive proper medical care. This caused her spine to fracture. She eventually received a power chair and continued her involvement with Episcopal churches across the United States.

#### Topics Discussed

- Early years
- Marriage
- College education
- Becoming an Episcopal priest
- Developing a physical disability
- Dealing with ableism

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#### Martinez

This is Chase Martinez interviewing Helen Beterbaugh for The Texas Disability Oral History Project. Today is April 24<sup>th</sup>, 2018 and I am at The Estes. I'm here to talk to Beterbaugh about her life and her career. Thank you for participating in the university's oral history program.

#### Beterbaugh

Happy to do it!

#### Martinez

<topic>Early years</topic>

So give me a little background about what is your occupation.

**Beterbaugh**

I've had two lives basically. I started out as an...work in a Square Master, the Administer of Music in churches in New Jersey, Pennsylvania, Maryland, Arkansas, Nebraska, Texas. And when I was 46 years after being divorced, after 22 years of being married to my co-minister of music, co-organist, co-choir director. I went to Seminary, got my second Master's degree and a Doctorate. And I've taught in colleges along the way. I've been a journalist along the way. I published a lot of articles along the way. But basically been a church musician and then an Episcopal priest.

**Martinez**

Where were you born?

**Beterbaugh**

New Jersey. Grew up in North Carolina.

**Martinez**

Tell me a little bit what was that like growing up.

**Beterbaugh**

In North Carolina, I was not disabled as a child, so I had a normal experience. I would say the only issue was that there is a group of us whose dad has been transferred to do research down in Western Electric, North Carolina, all of whom who are "Yankees". And there was, in those days, still a lot of them North-South stuff. And that figured in sometimes. But lots of friends and had a good experience.

**Martinez**

What year were you born?

**Beterbaugh**

'43. I'm 75.

**Martinez**

So give me some little details about you said North and South. Did you experience that quite a bit as far as the number of jobs?

**Beterbaugh**

Yeah, people made real judgements that they knew when they were born. And anytime there was any issue, it was always, "She's a Yankee." So what do you expect? Which was really interesting. There was a community of us who were all "kids of Yankees", but we are all growing up in the South. So I think my parents learned a lot living in the South. I don't know if that got over a lot of their bigotry, but my mom had a lot of friends. So did my dad. And they made a fairly good adjustment, I would say. I was an only child. So much to my dismay and unhappiness at that part. But I also remember sitting in a train station waiting for my grandparents to come from New York for I guess it was Christmas and I was thirsty. And I went over to the sign that said, "Whites Only" over the water fountain said, "Out of Service" or "Out of Order" or whatever it was. And I moved to go over to the "Colored Only" water fountain. And my mother hollered no not to do that.

"Well why?"

"Well because it's dirty."

And of course I look back on that and think, "They were good enough to suckle the white children at times to wet nurse them. They cooked their meals, they cleaned the houses, they did everything. But yet, the water fountain was dirty."

It made me crazy. I knew instinctively that was so very wrong. And the fact that there were White benches and Colored benches and White schools and Colored schools. And I remember the "Colored people" got the first swimming pool from the city. And my father cracked about that and said incisively, "I couldn't understand why we didn't get a pool first."

And all of that...I just was born knowing that was wrong. I was very fortunate that I just had a very strong sense of justice and injustice. And to this day, I'm ashamed of having ever sat in a train station, even though I was five or six years old looking at that kind of thing. And I look back on it now and how wrong it was.

**Martinez**

Did it in anyway kind of influence you as you got older?

**Beterbaugh**

Oh definitely.

**Martinez**

How so?

**Beterbaugh**

Well for example, and in fact I haven't even thought about this in years, but I got thinking about it the other

day. And I thought, "I wonder what they saw that I didn't know."

But there were going to be a boy and a girl pairing, which I didn't know, selected from my high school, which happens to be the high school...I say with some shame and embarrassment...that Chris Christy went to and way years after me. But his parents actually moved to that town and borrowed money to build a house, buy a house there, so that their kids could go to that high school. It was an extraordinary high school! And I was in the first class all the way through when it was built.

But they were going to choose a boy and a girl to attend the National Conference of Christians and Jews Summer Camp conference. It was called camp/conference. And all of a sudden, my name was announced. And it was an extraordinary experience, I mean we were just as honest and candid. We talked about prejudices and who felt what worse and what names hurt more than other names. And we were in big camp cabins, rustic as it could be. We had to go down the road to use the outhouses and that kind of thing. So it was very rustic, but we had incredible lectures and presentations and workshops. And all for a week. And as I say, I wondered at the time a little bit, but I was so excited about going. I didn't think much about, "I wonder what led the faculty to choose me to go, of all the girls in the school."

So they saw something. And when I graduated from seminary, they...The Temple Emmanuel...the big temple down in Dallas on Hillcrest right at NW Highway, whose Rabbi was the President of the American Council of Rabbis...I think they call it. And then left there to become the president of their Seminary in a Rabbinical School. And then they gave me the award for social ethics when I graduated from Seminary.

And again, I was startled when I...That, when they did nominate several people I guess. And we got forms to fill out in what our involvement had been. And I had been, despite two jobs and two kids and sometimes three jobs in the commute, I had 400 hours of work across the board in a variety of issues during my four years in Seminary. I was frankly shocked.

**Martinez**

<topic>Marriage</topic>

You mentioned you have two kids. When did you get married?

**Beterbaugh**

1965.

**Martinez**

How did you meet your husband?

**Beterbaugh**

College.

**Martinez**

<topic>College education</topic>

Where did you go to college?

### **Beterbaugh**

Westminster Choir College in Princeton, New Jersey. I went to Ohio Westland in Delaware, Ohio my freshman year. Loved it! But it was not the meat and potatoes curriculum that I wanted. And so I transferred to the Choir College. And one of the real blessings of that school was that we gave concerts regularly every year with Eugene Ormandy, the Philadelphia Orchestra. That was the big name conductor and then Leonard Bernstein in the New York Philharmonic, the other big name conductor. Very different styles. It happened to be, was principle cello Bernstein. And we recorded with both orchestras. So those experiences were just phenomenal rehearsing and singing under people like that. Bernstein's wife did one concert series with us. She was an actress and she came to Princeton. We were going to narrate the piece that we were doing. And we were narrator and choir and orchestra. And I remember just being awestruck. She had this incredible fur coat that she just had swung casually over her shoulders, like it had come from...I started to say TGNY. That was the...that would have been the equivalent of Walmart or Target or something in those days. Just an elegant, elegant woman who died way too young. She was Chilean or Argentinian or Brazil...It think...Well anyhow, she was South American. Gorgeous woman! Very...the showstopper kind of beauty. An elegant, elegant woman.

### **Martinez**

What got you into music?

### **Beterbaugh**

Oh...born that way. I still, in fact I said to my son-in-law several years ago. I said, "We need to put together some kind of a MP3 or something or other...we still haven't done it...set of recordings of the music that best expressed my soul. So when I'm old and non-composmatic, somebody can push the button and I can hear the things that are so wonderful to me."

Plus, there was a very good concert series at Elon College in the Town of Elon College. But at the college, in North Carolina. And my mother would take me to the concerts when I was a little girl. Very little. And so I heard metropolitan opera stars Jerome Hines, Blanche Stewart. Big names in those days. Jerome Hines in particular, gorgeous Hollywood-looking bass. And many, many artists in that...Fell in love with that. And then I heard the great Virgil Fox, who was *the* virtuoso organist. Heard him...I guess I was probably ten or eleven. He was an obnoxious jerk, but he could play the organ. Just unbelievable! I can remember playing his recordings. Just wonderful.

And then I started playing the piano at about six. And then started organ my last year in high school or junior year. And I had my first organist job my last semester in high school.

### **Martinez**

What would you say...what led you to the path of Seminary?

**Beterbaugh**

I've preached for several ordinations of friends and for people who come to me for spiritual direction. I remember staying in one, something about the fact that you have to convince the committee and the bishop that your calling is from God. At the same time, you have to pass psychiatric test. Everybody laughed of course. Because some people will say, "Well if you think you are hearing God's voice, you nuts. You're certifiable and on the other side."

I just knew that I was supposed to do it. But I believed incorrectly it turned out. But I believed my first responsibility was to...they had been adopted. My husband was sterile as it turned out. And we wanted children, which was how we found out that there was a problem. And so we adopted two girls and it was through the Volunteers of America. He was the...the founder was the brother of the man who started The Salvation Army. And they actually worked together and had some kind of administrative falling out on how organizations were going to be run. And the one left to start the Volunteers of America and the other continued with The Salvation Army. And it was very much a Christian organization, very faith-based without being very overt and obnoxious about it. And we actually had a little service where we made vows as we got each of the girls two years a part. And I felt very strongly that I made vows before God. And that vague, I had a Master's degree. I went to John Hopkin's Peabody Conservatory and at Hopkin's, I got my first Master's and that I had had my chance. And that I owed them their chance in their education. And then when they were through, then I'd go to Seminary. The real reason was that I was not married to my husband, which was twenty-two years. And when we were divorced, there it was, "Bingo! There was your time. Go!"

I had a lot of trouble because of disability and being female, but ultimately, I got through obviously.

**Martinez**

Hold on one sec. Let me take this thing off. Give me one second...of noise. You come out perfectly, but I am just afraid to leave.

**Beterbaugh**

I am so sorry!

**Martinez**

No, no, no.

**Beterbaugh**

You never hear this much noise in here. I just apologize.

**Martinez**

[inaudible]

**Beterbaugh**

Is there some way we can prop it...if you want to look at your phone and do it. Do you want me to hold it for you?

**Martinez**

I got it. Alright.

**Beterbaugh**

Okay.

**Martinez**

How did you end up in Texas?

**Beterbaugh**

We were in Lincoln, Nebraska working for...I don't know if you know the name...Elmer Gantry. There was a very, very, very famous book and a movie called *Elmer Gantry*. He was an evangelist, alcoholic womanizer. The whole bit. Well, we worked for Elmer Gantry in the form of a man who had studied with C.S. Lewis. And he's an Oxford-Cambridge in England. He was a brilliant, brilliant man who had absolutely no moral conscious whatsoever. And ultimately, he had been sent away to dry out a couple of times and he was getting on him. And so, he in-turn made a big fuss with the music department and fired us.

And we went into a search process again. And my now ex was called to be Minister of Music at this dream church in Beaumont. And it was the first time we had ever been called to a church where we weren't called as a team. That one happened to...he was their first, full-time Minister of Music. And they had patched together the Junior Choir Director, the Youth Choir Director, the Adult Choir Director and the organist's salaries to get a full-time person. And so I went to work at Lamar University and took an Episcopal Church in arms. And it turns out I was the first person in the 132 year history of that church to come forth from enation. But when I had the interview with the director for the organist position. One of the first things I said to him was, "You need to know that I am called to the priesthood. We all have to deal with that at some point."

He just said, "Fine."

And then he said, "When the itch gets so bad you can't scratch it, then let me know."

And I went to him one day and I said, "I feel like I've got hives. We need to talk."

And the rest is history as they say. But it was torture in the meantime. It was awful.

## **Martinez**

So what led you to persevere?

## **Beterbaugh**

<topic>Becoming an Episcopal priest</topic>

Because I was absolutely, positively, definitely, no way going to go to a Seminary outside the Episcopal tradition because I had been an Episcopalian since 1974. And had never been able to work in full-time in an Episcopal church. So I wanted to be just brazen in that Epoch, which is very different from Protestant. And so I was just adamant. I was going to an Episcopal Seminary and there's one in Austin. And my GRE scores and everything. There was no question. I was then was long-sense a member of MENSA, which I did when I was told that my disability was permanent and would progress. And I had to...I think I had this thing to prove that something worked. I had a tote bag...I still have a tote bag that says, "I may not be totally perfect, but parts of me are excellent."

And so I was adamant that he thought that an Episcopal Seminary would be too easy for me and I would get bored. That was his estimation. And so ultimately, the Bishop of my Diocese was also the supervisor, director, whatever...of the Seminary in Austin, which is the only one in Texas. The only one in this part of the country. The next closes one was in Suwanee, Tennessee up in the mountains. And after I had my interview with the person on ministry, which my director was in the room with me the whole time and said, "Oh, this was just perfect!"

The only thing you need to be a bishop is a publisher and a golf cart and you've got the golf cart! And so it was just great and I said, "No it wasn't. Oh yes it was. No it wasn't."

And ultimately, I said, "They never asked me about my sexuality."

And I said, "That says to me that they didn't see me as a whole human being."

And sexuality was an enormous issue in the Episcopal Church at that point. No longer. But in some places like Dallas, it still is.

## **Martinez**

Why?

## **Beterbaugh**

Oh, because there is a homophobic bishop. And the bishop who ordained me was homophobic. So much so that I really struggled with letting him be the one to lay hands on me. We ultimately went out for lunch and people laugh about that experience. But anyhow, that's another whole story. But when this all came to the point that the commission called him in because they passed me after my interviews, then I would be at him. I was done except for him, to get his blessing. And they were scared to do that because of his attitude. His philosophy. His, "I need to put it on the records."



His name was Maurice Benitez. Short man. Hispanic descent, I'm not sure Mexican or what. But beautiful wife, nice kids. But very prejudiced about disabilities. And apparently, I learned later about lawsuits. And he'd thought there'd be lawsuits he ordained a woman in a wheelchair. Why would there be lawsuits? I have no idea. And the other bishop who told me that had no idea either, but that was his bent.

And so they called him in and told him about me. And they said, and this came from clergy. He actually turned thumbs down Nero with the lions and the Christians, and said, "Where would I send that? Who would want that?"

And my struggle began, I just simply got a letter saying "No...I had a lot of gifts and that I should continue to..."

I was doing Christian network in the Church and I had been a Minister of Music all those years. I was preaching actually in...No, I hadn't moved to Dallas yet. That's wrong. But obviously I had talent in music in blah, blah, blah and I should continue offering my services to God and the Church that way. And my question was constantly, "What book is he reading that's so different from the book I'm reading? How can we come up with totally different interpretations of the very same book? Meaning The Bible of course."

And then the Seminary pulled a fast one where they scheduled my interviews and my campus visits and all that. The dean scheduled it and the dean was gone with the board meeting that day! Imagine that. And so they hastily put together faculty committee. One of whom happened to be the brother of our infamous bishop who I adore, Jack Spong. John Shelby Spong. You may have heard of him. Considered a heretic by some. Very much a progressive, very much a biblical scholar of the First Order. But when I was turned down there, by that point I knew that Texas Rehabilitation would pay part of my Seminary expenses. And so I had to stay in Texas. It was TCU or SMU. And I went to...my interview at TCU was first and I had gotten permission for course overload and registered for my classes and done everything. Almost went back to Beaumont because someone was watching my kids and thought, "No, I'm just going ahead and go to SMU."

I sent students there for the Sacred Music program. I'd stay there in the dorm for American Gilded Organist National Convention back in '72. SO I thought I knew SMU went and...The woman whose class I attended is a dear, dear, dear friend and has been for many years. The most whole-brained lecture I've ever heard...that I have ever heard to that point. Very much all of the scholarly notetaking quickly was on funerals of all things! Historical background, writing Greek on the board, the whole thing. And then turned to the hard part and talked about her own experience when her son was born and his heart was plumped backwards. He's got a child of his own. He's a great guy. Became like a little brother to me. He always called me Helen Basketball.

"Mom! Helen Basketball is on the phone."

But I was just blown away by lecture. And then went to worship. And Zan Holmes...do you know that name? He was...he's still alive. He was pastor of Saint Mood Community United Methodist Church down at kind of the north end of South Dallas. African-American, phenomenal preacher. And the one who when Dallas was looking like there was going to be race riots, probably seven, eight years ago. It's been a while. It was Zan who calmed everything down. He's been a leader in the black community for years. Just a great man. He preached that day. And it was black worship.

**Martinez**

Is he still alive?

**Beterbaugh**

Yes. I think he's retired now. He's younger than I am. I'm pretty sure, but...or the same age. But it sounds crazy, but people who know both well understand there's some kind of place in the Ether where good, black worship and the music of good, black worship and High-Church Angolan absolutely meet and dovetail. And I thought I died and gone to Heaven. And worship at Bright frankly was dull. It was just dull. And to find the contrast and Margery's class on top of it, there was just no choice.

And I knew, in the meantime, my director back home said the same thing: I told you so!

And I did. I wrote him some time in the first semester and said, "I'd hate to admit it, but you were so right. This was the palace I'm going to be."

And it was an absolutely glorious experience. So I'm not an SMUer. I'm a Perkin's School of Theology-er. And so I taught a course there on disability and church after I got my Doctorate.

**Martinez**

<topic>Developing a physical disability</topic>

When did you become sick?

**Beterbaugh**

Become disabled? I'm not sick.

**Martinez**

Oh, I am so sorry.

**Beterbaugh**

And I have a big thing about that because I have a friend who would, who has always called my van, "The Sick Mobile" because he knows it gets under my skin. He's the brother I never had and will always kid with me about being sick. But there's a big difference between illness, even if it's a progressive illness, that's the cause of it. There's a big difference between that and being sick. To me sick, that whole identity leads you to the path of victimization. And I think that's probably more disabling than a physical disability. To give into that whole victim ephas because you surrender any push, any drive, any compensation and any of anything and you wait for everybody to take care of you. And to me, you might as well just curl up and die. For me personally, it is emotionally, spiritually, physically, psychologically every way possible...and intellectually...absolutely destructive. That whole victim mentality.

So anyhow, lecture on sick and disabled...

**Martinez**  
[inaudible]

**Beterbaugh**

No, it's okay. Please don't. And I hope you don't mind my babbling on about it.

**Martinez**

No, this is an area of people have heard many times.

**Beterbaugh**

I actually had a case of polio in one of those four, violent summer epidemics in North Carolina. And supposedly, it was what they called an Immunization Case where they couldn't identify which of the three kinds it was. And so the doctor said, "When they get a vaccine developed, you'd still have to give her the vaccine 'cause we don't which kind it is."

And supposedly, that was all over with. Then my first semester at the choir college, we were in a series of concerts with the New York Philharmonic. We came back, there was a violent ice storm that turned the old Route 1, which was the highway that would still there, but it was honestly I-95 now. But Maine to Florida was Route 1 and we took buses on Route 1 from Princeton into New York City. And it was just iced over and immediately. Very, very bad though. Lots of accidents. We ended up all...each bus went, no matter how far they tried to go to the left lane, the wrong lane on the bridge into Princeton. We all skidded and we all ended up having to jump out windows and walk back to school. The first students who got back who had cars started coming to the bridge and they'd pick up people and take them back in shuttles. And it was a campus of, it still is, 300 - 350 students. So it was a family and everybody was up. And this was about three o'clock in the morning, but the time everybody got back to school. The concerts weren't over until about 10:00 AM.

So next morning, they said the night before, our little gang, "Who can go get breakfast for us?"

And on Sunday morning, because everyone had churches who was...been there long enough, they used to put out Danish pastries and muffins. And they didn't do a...cook breakfast on Sundays. Everybody just grabbed it and ate in the car. And I said, "Well I'm pretty good at waking up when I want to without having to set an alarm and wake everybody up. So why don't I'll make the commitment that I'll go get breakfast?"

And I did and I got back with the pastries, realizing it was really dangerous. And then when everybody woke up, there were no drink machines in the girls' dorm. Only the boys had a drink machine in their dorm, which was new and there was one in the commons where the chapel was above and the commons where we ate was below. And I waited for somebody else to volunteer. There were six of us and nobody did. I said, "Well, I made it once. I guess I can make it again."

And I didn't make it. I did. I got up with a broken back and I made myself get over to the drink machine, I got what everybody wanted, I came back and I opened the door to the dorm and I hollered. And I said, "I can't get in because there were a couple of steps. And I just can't get in."

So, they took me to Princeton Hospital and a student took the x-rays. I remember that vividly 'cause she wasn't there by any chance that I know how to set the x-ray machine for spinal x-rays. And I said, "Good Lord, no!"

And he said, "You come over to my place and I can set the organ for the **Fornkay Minor Cora.**"

For example, "And you wouldn't have a clue as to what that was all about to set my buttons any more than I know how to set your buttons."

And they had their big Christmas parties the night before. And half of the staff was hungover frankly. And the other ones were a mixture. Couldn't get out of their driveways because Princeton has quite hilly driveways in a lot of neighborhoods. And they just didn't dare try to get out.

So it was the B and C staff. And I had a resident, I assume...I'm pretty good with dialects. I don't know what country he was from. I don't remember. But I remember they had a terrible time understanding it. And of course, they did x-rays. And I talked with someone on the phone. Name was Dr. Balfour. I remember that because Balfour is the name that used to make class rings for high schools. B-A-L-F-O-U-R. I don't remember his first name. But anyhow, he identified himself as Chief of Staff at the hospital, which I later learned he was, and said, well he looked at the x-rays. They were fine. I should take aspirin for the pain. Just beyond ludacris. Don't get constipated, wear a girdle and take hot baths. I hadn't been in a bath tub since, until I had a walk in bath tub about seven or eight years ago in the house in Providence. No way in the world could I get in and out of a bath tub. But anyhow, those were his four directions.

And then the dean of women, her husband had taken me. And we got in the elevator, this man got on and said, "Are you the young lady with whom I spoke?"

"Yes."

And he repeated the same four things. I have no idea how I remembered all these years because I was so aghast that that's what he said. A few days later was Christmas holiday and I got to see our physician who was an osteopath who...God bless him. I would have not had this much mobile if I did had it wasn't for him. But he immediately said, "It's broken."

"No it's not."

"Yes it is!"

"No it's not."

"Helen, I have never, ever seen this much damage done."

'Cause he put his hands on it. Nobody would touch a body with a spine injury. He had his hands on it. He said, "I've never seen this much damage without a fracture."

And I just can't bate because everything in here is just absolutely wrecked. And I said, "Look, you put me on a table, metal. They went behind a screen or whatever and said, "Don't breathe. Breathe."

And I heard *click* and they pulled the plate out. And I said, "Well isn't that an x-ray?"

“Yeah, you’re right.”

Well I went back to school after Christmas. And I finally called home the end of February. And I said, “I’m in serious trouble. Either I have a major physical problem or I have a major emotional problem.”

But I said, “I’m about to lose my mind because of the pain.”

And I couldn’t walk. I was shuffling. It was unbelievable. And I kept telling myself, “It’s not broken. Get over it. It’s not broken. Get over it.”

It was just mind over matter stuff and it just kept getting worse. So she called him and she said she “wants new x-rays before I see her. But get her home this weekend.”

I took the train up and saw a radiologist that Friday night. And that was written up in the journal of the American Medical Association because ultimately, it was the first time a radiologist ever testified against another doctor in the state of New Jersey. I guess nationally because they wouldn’t have published in the JAMA if it hadn’t have been of national interest. If it had been New Jersey, they wouldn’t have bothered.

But there was daylight between segments of the bone. And at that point, it should have been all healed. So it was a…my doctor. Dr. C. Norton Tillerson, East Orange, New Jersey. And he said, “I really outta put you in the hospital. We outta keep you flat.”

But he said, “They know if I did that. I’d have to make reservations to put you inside a mental hospital when it was over because you’re too much of a go-getter and you will go nuts if you’re pulled out of college and have to do this.”

Which, I wouldn’t have gone nuts, but I would have been a might unhappy kid. So when you’re that age, you think you have to do…accomplish it right then and get done with school or your life is going to pass you by. Because by 30, you’ve pretty much had it. And then at 40, you may have well give up. But, so I don’t know where we were. That all ended, developed later. But this came on and I got worse and worse and worse and worse and went various places. Various kinds of doctors: neurologists, orthopedic surgeons. Went to Duke where I had my tonsils out. They saved my dad’s life when he had parenitis back in the fifties. Early…about 1950. 1951, with an experimental drug that turned out to be one of the myosin drugs. The very beginning of the orthromyoson and artithromyoson, which were the first thing after penicillin. And they saved his life with what was then an experimental drug. So our family has always thought the world of Duke. I went there to see a neurologist. And couldn’t figure it out. Couldn’t figure it out. Had all kinds of spinal tests, neurological tests, anything.

And they, my doctors kept telling me they thought there was the physical, tangible thing with the spine, but that there was a disease process going on. And they couldn’t put their finger on the disease process. Ultimately in ’77, I had a spinal fusion. And when he got in there, he kept telling me I had fallen. And I kept telling him, “No, I hadn’t. I’d been in a standing body cast all the way down.”

And where he intended to fuse was not even attached to anything. It was just bloating. And everything around it was ripped and bloody and everything. So he was sure I had to have fallen or got hit with a baseball bat or something. No, no, no. So the fusion was doubled. But then I got worse instead of better. And my own experience of it was that going through that horrendous surgery put more of a burden, more of a strain of what was left of motor neurons from the polio epidemic. And they tested for this, that and the other. ALS, AMS,

everything. Just one test after another. Never could come up with it, but we're just sure.

Well in the meantime, I was getting a magazine that's gone through a couple of iterations. It's now called *Spinal Network*, I think. But it was solely focused on motor disability. And every once in a while, there would be an article on post-polio. I would read the thing cover to cover. And I learned about disability issues while reading that, other than my own experience. And when I would read an article about post-polio, I would be like, "I've never told anyone that."

But that's exactly what I experienced. And then finally, right before I was ordained deacon, so it would have been in '96, there was a whole issue devoted to post-polio. And I'd read an article that would say that, that, that and that. But it wouldn't this, this and this, so I can't be. And then I would read the next article and then this would be there. And then in the next article, that would be there. And then they listed in an article all the criteria, all of the symptoms. I've had every one but one.

So I went to my doctor...The kind of health plan they had that day. You had to go to your doctor and get a recommendation, referral to a specialist. You couldn't have just go to a specialist. And I did and her comment was, "I thought the first time I saw you that you were post-polio."

And I said, "Well why didn't you tell me? Well you've been to the Mayo clinic. You've been to Duke. What did I know?"

Typical female thing. And she sent me to John Harney, a neurologist in Richardson. And said, "If it were stroke or something, you could see anybody in that practice. For this, you see only him. If you can't get in, I'll schedule an appointment."

And I went to see him and told him my story. And I said, "I know this is going to make you crazy 'cause doctors hate for people to come up with things from magazines."

And I said, "I read this in a...I'm convinced that's what it is from a magazine." But I said, "It's not Read Book or some journal I read at the beauty parlor. It's a magazine focused on...a journal focused on disability issues."

And he got up and he came over and he poked a couple of places. And he said, "It's absolute textbook post-polio."

And he said, "I'll tell you something else...if, for anyone whose had it I'd say five years or more...and the same thing with MS. Five years or more...there's no way you can experience that and also not have fibromyalgia. This just has to be."

Those were the days when fibromyalgia was over lemons' heads. And I have to giggle now because if you drive around the Metroplex, you'll see many places that so-and-so said for fibromyalgia treatment. Of course, they do nothing but. But in those days, it was a...it is mostly women. Way more percentage of women than men. And so it's in your head. But I got that in your head for years. So much so, on the first article of disability I've ever published was about was the treatment of women by the medical community. And what pushed me to it was reading Gilda Radner's story.

**Martinez**

SNL?

## Beterbaugh

SNL. Yeah. And what was it? Something Banana? It was one of her characters. She was wonderful! Just wonderful. But they labeled her a hysteric. And she kept saying, "There's something wrong. There's something wrong."

"No, no, no, no. No, no, no, no."

And she died of ovarian cancer. By the time they finally went in and did something, it was too late. And that just pushed me over the edge. I thought, "This was just so wrong."

But I wrote the article and it was published in an Episcopal women's journal. The first thing on disability I've ever wrote. And you can imagine I've got a lot about that kind of thing. And I don't know about all surgeons, but I know it's a very wide practice by neurosurgeons and orthopedic surgeons that if somebody who comes in a hospital with a major spinal issue, they do them an MPI to be sure that it's not psychosomatic before they proceed with any physical treatment. And so the psychiatrist came in and said, "Do this test."

But I don't know if you've ever seen one, but they are endless. And they're also several times when they ask the same question, but with slightly different wording later, which annoyed me. You think I'm lying there and that I'm going to change my answer here. And I made some comment to him when he came in after I'd taken it and said, "Boy, I was...there were places where that was really annoying."

And the look on his face was, "Oh boy, I've got a live one here."

And he came in the next day or two days later and walked up and he said, "Will I rack you with pain if I sit on your bed?"

And the answer was yes. But I didn't tell him. I said, "No, not at all."

And he said, "The first thing they teach you in Med School is never, ever, ever sit on a patient's bed."

But he said, "I feel the need to do that because I'm sure...given the time we live in, given your case that you have been abused over and over and over and that you have been told that it's been all in your head," he said, "That could not be farther from the truth." He said, "You're so normal, it's ridiculous."

I remember every word of that because I so needed to hear it. And one of the things he said was, "If they had ever looked at your blood pressure..."

Because there were times that they had tortured me in hideous procedures. He said, "Your blood pressure never fluxuated."

And he said, "If you are a person who is psychosomatic, the two can't coexist. One cancels out the other. So he said, "I need to apologize to you on behalf of the medical community for what you've been put through."

And then later, there was some discussion of whether or not I should go to a pain clinic. Fairly new and quite the thing. And my...the supervising doctor, not my family doctor. But the supervising doctor. You want to think about it. And I happened to run into him.

“How are you doing?”

And we chatted a little bit. And I said, “What do you think about this?”

He said, “Absolutely not...I see you at concerts and I see you around town...You’ve done for yourself everything they would do. Don’t waste your time and money on it or it will just make you crazy.”

Well then I read some of the materials. It was something like, “The group could get together and decide that the group could clean up the kitchenette in their little area.”

Well that would have given me hives I’m sure. I had just planned a European tour for a high school choir. My youth choir. And the idea of having this big experience and deciding that you could actually do something and wash dishes...pressed every button I had. So I knew he was right. I don’t belong there.

### **Martinez**

So the medical field aside. How was the public treating you during this time?

### **Beterbaugh**

The church that we were serving in Lincoln was absolutely extraordinary. I’ve never seen people take care of a family the way they did, including things that thought of that I wasn’t just ready to process. Two of my adult male choir members, both the wives of phenologists and the one used to come every, single day. And the two of them visit together, told me we know how you feel about keeping your house clean and organized and everything. You’re not going to be able to do that.

And I was thinking to myself, “What do you mean not going to be able to do that. Just because I am in a standing body cast and I can’t bend?”

And you see, I was just going home. If you are taking nourishment and you are breathing air, then you are going to do what you are supposed to do. It never occurred to me that I wasn’t going to be able to clean, but they were so right. Anyhow, we’ve gotten students from community college. And they all come every week and clean your house for you. And I was just speechless. I literally just speechless and I realized that night I guess that I hadn’t said anything. And I called them both the next morning and I said, “I need to apologize. I think I didn’t say anything.”

“No you didn’t.”

I said, “I couldn’t even get the thought in my head, not even to point in the kindness and thoughtfulness, which was extreme.”

And I did that for two and a half, three years when I didn’t miraculously get better ‘cause the fusion was supposed to make everything all better. There were people, very definitely, who went to the sick thing. The gal who was doing both pastoral calling and who was not clergy had been secretary of the senior pastor for like 45 years. And she came to see me in the hospital. And she said, “Oh honey [a very maternal woman in her eighties at that point]. Oh honey, I know what kind of a person you are and I know you haven’t done something as an



adult to deserve this. So what did you do when you were young?"

And she put her ear down almost to my lips because that it was going to be so horrible that I wouldn't want to say it out loud. I would have to whisper it. And I said, and in a number of times in speeches, I just wished that I had the good sense to spit in her ear. But I didn't and I just think I kind of [babble]. What do you say to something like that?

I had another woman ultimately gave the harpsicord in memory of her husband who died while we were there who said to me, "Oh I know you so well."

Which she did. She was in the Single Choir and my Adult Male Choir. And, "I know you haven't done anything to deserve this, so you have carp longed a sin for the rest of your life."

And this was the church of the very highly intelligent people, most of whom at least had Master's degrees. Professional people. Almost exclusively it was 2,000 members, the second-largest Presbyterian Church in the state. Lincoln was a town where the legislature, it's the only unit counsel in the country. It's just legislators period. There is no Senate and House. It's just one unit counsel. One body. One chamber. And it's number two to Hartford, Connecticut in insurance. And the combined minority in those days, which was mostly Asian and Native American because of all the tribes from the Dakotas and Nebraska was under 2%, which I did not like. But the University of Nebraska, Nebraska Westland (I taught there), Union College (which is where they got the girls to do the cleaning. I taught there). And just a very heavily, academic town. To find that that was a pervasive mindset that somehow you had earned the disability and that what you were getting was penance or punishment or you hadn't earned it so now that you can go on and say that you've done the penance before you did the crime, I just couldn't get my head around that. I was also a time when one of the associate pastors was very focused on healing ministry. And the word, the concept phrase was, "God wants you to be perfect. God wants you to be whole. And if you are not, then you are blocking God's healing power."

And so they always wanted to do some kind of healing ritual privately. Two things, major things, in that for me. One was if God was omnipotent and God is the Creator, Redeemer, Sustainer, blah, blah, blah, how in the world can I, a flawed human, possibly block God? Who's got more power here? To me, that was just was so ridiculous. The other thing was that it felt very manipulative to me. God works through doctors and nurses and surgical procedures and medications and on and on and on...scientific research. Why does it have to be do this thing where people can get in a group and implore God for your healing, or demand it in some cases. And if you do "get better", then they've done it. That seemed to be incredibly manipulative and really bordering on heresy. And I would never...in an Episcopal church, I would go to the alter rail for "healing" for the body, mind and soul. I wouldn't ever say, "Right now, I demand to be fixed."

Plush which, I make an enormous distinction. And I think people who don't miss the boat incredibly between healing and cure. I think there's one thing to be cured, which is to be rid of whatever the illness or disability or whatever is and to be "normal", whatever "normal" is. Healing, to me, is more spiritual, psychological matter, an emotional matter and a faith matter. And you can be healed and still have the physical condition. Still have the problem or the illness or whatever. And I don't think the existence...I'm going to go a step further. I think in many cases, the existence of a disability actually leads to more profound healing that people without would experience. Because you've been through the long, dark night of the soul more than once. And to me, that healing and that wholeness is so vastly superior to getting fixed. Not that I wouldn't love to be fixed.

But I've heard that same kind of thing expressed many times over by people who say, which is to say I hope that I had the chance and the choice to say, "I'll get fixed."

But to do that, I would have to give up everything I've learned and all the growth I had through the experience of disability and the pain. And I hope that I would have the courage to say, "No thank you. I can't give this up. This is too important to me. I cherish it too much."

I've learned too much. I've grown too much. I can't give it up in order to get this. This becomes, once you have made the accommodations, once you got a van and a wheelchair and a place where you can get in and out of that kind of thing, I think in a lot of ways it becomes just the way you live without being a big deal. Other people may make a big deal of it, but you don't have to do that. You don't have to take it one because it's their hang up. So long answer.

**Martinez**

Did you have something to do?

**Beterbaugh**

I'm okay.

**Martinez**

Okay. I was just checking.

**Beterbaugh**

I'm going to take a new DVD, Paddington 2 the Bear, to my grandson who is sick. I stopped to pick that up on the way. I could give him a little treat. He's got bronchitis and laryngitis right now and a fever. And that sick little boy, I thought that would make his day. So I'm going to run that to him, but I can do that at any time.

**Martinez**

Well I think we could probably finish probably right now. But I want to leave you with one last question. How would you describe the attitude toward people with disabilities today compared to what they were when you first became disabled?

**Beterbaugh**

I didn't become sick. I became disabled.

**Martinez**

I didn't say sick.

**Beterbaugh**

Oh, I thought that you did. I'm sorry.

**Martinez**

I said disabled.

**Beterbaugh**

Oh, I'm sorry.

**Martinez**

No, no.

**Beterbaugh**

I'm sorry. I just heard this...

**Martinez**

I don't speak loud.

**Beterbaugh**

<topic>Dealing with ableism</topic>

No, it's all this interruption around here. It's funny because I was going to say I got one thing I don't want to forget. When I was the first Episcopal priest who uses a wheelchair to be called Director of a Parish, Senior Head Priest, Head Pastor...And they told me later that they had a harder time with the fact that I was a woman than they did with my disability. And it happened to be that the matriarch of that parish was a very poor, very devout African-American woman who I adored. And she was the one, she had very, very anti-women clergy and met me and talked to me and decided if God had called me, then she didn't have any business getting in the way and it would be just fine. And that kind of ended that because she was the spiritual voice of that congregation. She's dead now. She was in her nineties then. So that was that one experience.

It's really been an interesting thing to appear and observe. I like to sit in an airport and watch people. I'm a great people watcher. Always have been. There are people who I think feel that it's somehow catching and don't want to get near, and very clearly...There are other people who immediately want to do the caretaker, really imprison you almost. It's caring and compassion overall, but it's to an extreme. It's more harmful than it is helpful, even though you know it's well-intentioned. There are a lot of people, incredibly so, to this day, who associate mobility issues with lack of intelligence. And that if your brain worked, then your brain would tell your legs to move. And to the point where my girls were small, we'd go out for dinner as a family. And they, neither

one of them can't read. We'd get menus and my husband would get a menu. I wouldn't. This happened time after time in city after city. So it wasn't one place that happened to be that way. I would always write a letter to the manager and say, "Train your people better."

And the girls would happen to be in an IHOP sort of place where they have pictures in the menu, they point to, "Mommy can I have that?"

And there were times when I ordered for the girls, rather than my husband ordering for the girls. But then the waiter or waitress would look at the girls or my husband and say, "What does she want?"

And I got...after the first time, was just speechless...I would say, "She wants her own menu. She wants to make her own choices, do her own order and she wants to talk to the manager about sensitivity training for the wait staff."

That to me was stunning because the assumption was I couldn't read, I guess. And/or make a decision, have the mental process to say that I can come to a decision and/or communicate successfully what I wanted to eat. And that happened so many times. I laugh about it now, but at the time it was just unbelievable.

I've also...it's been interesting that you were in a mixer or a wedding reception or a convention at a mixer... cocktail hour, happy hour or whatever...and somebody wanted to come through with a tray or bring a projector through or anything, they would ask you, "Would you mind moving? We are gonna bring this thing through."

With somebody in a wheelchair, they'd try to push the wheelchair. Without, they will come up behind you and start pushing or trying to. Of course, with a chair like this, they can't push it because it's locked once you take your finger off the joystick. And I'd hear, "Ugh!"

Someone trying really hard to push it. That said to me, "Talk about objectifying!"

This is truly, "I'm going to move this thing out of the way here so that we can get it through."

Would never think of coming around and facing me or even tapping me on the shoulder, and say, "I'm sorry. We need to have space for whatever, Would you mind moving a little bit?"

They would just come up and start pushing. Lots of assumptions about, "You must be angry."

Lots of assumptions that you must own a lot of money because I assume that you've had a lawsuit of some sort and either you sued the person who hit your car or drunk driver, or whoever it was, or it was a birthing and you sued the hospital...your parents sued the OB/GYN or whatever. But lots of assumptions about entitlement and money. And *you people* get all the good parking places. *You people* most of the time can't find a place to park because the other *you people* are doing this thing where they park and they say, "Well I'm just going to be a minute."

Well honey, it's in that minute that turns into ten or twenty or thirty. And people will get very enraged if you track them down in a beauty parlor and someone would say, "I'm sorry. Could you move your car? I need to park."

And get very angry. It's your fault that they illegally parked in a space. That kind of thing that really startles me. There was a blessed few people. I remember the first gal who headed the gifted program in the schools in Lincoln. And she was an alto in the choir. And I had a luncheon for my daughter's godmother, a dear friend of

mine. And he mother, who was a principal in Arkansas and invited choir women and other friends to come to a luncheon. And I had the fusion a couple of months before. And she said to me, "How are *you*? I know the other stuff. How are *you*?"

And wow, I realized she was separating me from the disability as if we were not the same unit. She was clear that my life and identify were not wrapped up solely in the identity of being disabled. And I'll never forget. I can see where we were. Everything from that moment, she was the first person to ever recognize that to my face. Everything was always about the disability. The church obviously, in the form of the bishop, thought it meant "damaged goods." So I think there's a wide range. I've always been extraordinarily careful that if somebody offered, a stranger, offered to do something for me that I knew I could do, should do to keep myself going. I would be effusive in my thanks. I'll say, "Well, you're just an angel. I can do this. Thank you."

Because so many people, I learned this quickly, gets mad if someone offers to help. And I've had many, many people say to me, "I was afraid to offer to open the door. I was afraid to offer this or that for fear you get mad."

And I figured that the experience they had, the experiences they had made them turn away from helping other people. So I'm going to try to make up for it, even if I may not need that help in the moment, I probably will at some point. And I want them to feel free to do it for the next person and not treat the next person because I got uppity about getting help. I also make a big point, "If I can pick something up for somebody they dropped or hold the door open when I get it open or elbow it just so I can get my chair to block it, I'll hold the door for somebody else."

It's not just something I have to be done for, but that I can do something for somebody else. Because I think then maybe that's going to get somebody thinking that, "Oh, well."

I think it's always an educational process. I've noticed an enormous difference living with a disability...By then, I was no longer in crutches. I was using a wheelchair pre-ADA and post-ADA. And I think a lot of the people who have been highlighted in television, commercials, which have changed dramatically over the last year. And I've documented them where people with disabilities are shown doing normal things, like a blind woman doing the laundry for the family or a man with one arm changing a lightbulb in the ceiling. Those kinds of things where, "Oh gee!"

It opened the door. The gal that Hough...Julianne Hough I think, who was on *Dancing with the Stars* who had two prosthetics. It turns out that she did a great deal of research for prosthetics manufacturers. What did she need to do, whatever kind of dancing she was going to do? And she evaluated all kinds of things. And they developed new things based on her experiences. So that turned out to be not just somebody demonstrating a little bit of skill and grace that she did, but research that was going to be passed onto other people. But I think the educational processes continue and I think the fighting injustice. And I think most people are not aware we're moving from a Medical Model to a Social Model. I think most people are totally unaware of that. They're still stuck in the...everything having to do with the medical part of it, rather than, "You're a part of society." And just like anybody else, part of society.

I also had the experience many times where people coming up to me in the Church and saying, "I don't want to do it. I'm not the one saying your pain is worse than mine. Please understand."

I said, "Pain is pain, honey."

But I want you to know that I see myself as more disabled by \_\_\_\_ (Fill in the blank) than you are by using a

wheelchair. And most of the time, it's somebody who's afraid to speak who feels like they don't have a voice because self-esteem is so low. And they feel that that is hampered, limited, handicapped. The quality of their life way more than they see wheelchair, handicapped or disabling mind. That's been really interesting.

**Martinez**

One question. How many degrees do you have?

**Beterbaugh**

Four Bachelor's, two Master's and a Doctorate. One at Princeton, one at Baltimore...Hopkins and the last two at SMU.

**Martinez**

I think that's it. Thank you very much.

**Beterbaugh**

You're very welcome. My pleasure.