

GREENSBORO POLIO HOSPITAL ORAL HISTORY PROJECT

INTERVIEWEE: Morgan Burroughs

INTERVIEWER: Natalie Branson

DATE: October 28, 2018

NB: This is Natalie Branson, today is October 28th, 2018 and I am interviewing Morgan Burroughs for the first time. The interview is taking place in Morgan's home in Asheville, North Carolina. The interview is part of an oral history project for Dr. Parson's course "Museum and Historic Site Interpretation: Principles and Practice." The project seeks to capture the stories of disabled individuals to gain a better understanding of disability history. Okay, so first I wanted to talk to you about your life growing up. So, where did you grow up?

MB: I grew up in New Orleans, Louisiana.

NB: [Laughs] Okay, and what's your family like?

MB: My family is weird [Laughs]... and awesome, and crazy, and we have a bond that's unbreakable because we have been through so much together with my past life. We're just really, really close and we get mad at each other but we always make up.

NB: And you and your mom are close?

MB: My mom, my brothers, my foster brothers, and my dad.

NB: So what was your schooling like?

MB: Um, it was good, but I- I went through home school in New Orleans for first grade, second grade, and half of third grade because I was dying and I couldn't go to school. But then, I got my medicine in 2003 and then I started going to public school.

NB: Okay. So you were homeschooled and you went to public school.

MB: Yeah after 2003.

NB: Okay, so did you have any favorite topics... or teachers?

MB: I liked math, and English, and there was one teacher I had that helped me learn how to read. I didn't know how to read because before no one knew how to teach me how to read.

NB: So what was your favorite part about your childhood?

MB: Oh, I don't know. I think when- My favorite part would be when we would go to my family's house and just hang out with each other and, like, eat food and have family time.

NB: Yeah. Family time?

MB: Yeah.

NB: Give me a snapshot, if you can remember, of your average day when you were growing up. What did you do, what were you interested in?

MB: My average day. Messing with my brothers, playing with my brothers. And then they would have friends come over and I'd play with them and with my brothers. And I would watch TV and, when I was dying, I was more so in bed, just trying to live. But then with the medicine, I came back to life. I went to school, I made friends.

NB: Okay, so I don't want to make the interview about your disability, but more so about your experience navigating the world as a person with different abilities. But, so that everyone who is going to watch this in the future, or listen to this in the future... [Laughs as Morgan makes a funny face]. But so that we can have a baseline, can you tell me about your disability? What caused it, when did it begin, etc.

MB: Well it began when I was born. I have a rare genetic disorder called Pompe Disease. It takes two parents, a mom and dad, that both have the same defective gene for even the chance to have it. You can either be a victim or a carrier. So, Pompe basically, without having to go into a whole long story, Pompe Disease is when your body makes too much glycogen, a glucose, that breaks down your muscle and tissue. My body doesn't break down glycogen, so this sugar goes into my muscles and breaks down the muscle and the tissue and over time your body becomes weak.

NB: So when were you diagnosed?

MB: I was diagnosed at 21 months-

NB: Okay-

MB: So two-ish.

NB: So how has Pompe disease complicated your experience as a person with disabilities?

MB: Well, when you're different- when you're seen as different- people are not as friendly towards you; they see you as a 'different' person, even though you're not really different. Like, I don't see myself as someone who has a disability. I am who I am and I was made as who I was supposed to be. It made me extra sensitive to the world around me, I view things very differently than most people. And I love my friends but it's always hard for people with disabilities because they don't have time for them. Like, the whole world is always moving and going and all that mumbo jumbo, they're- they're nice like "oh hey,

how are you!” and then they move on. People are dismissive or slow, they take their time, they aren’t moving fast. So like we don’t- we’re excluded from most things.

NB: So you were saying that you’re- you don’t see yourself as a person that has disabilities because you’ve been the way that you are for your whole life.

MB: Right, I was born how I was meant to be, the way I am now. No one is perfect, I believe that everything happens for a reason. You were supposed to walk and I was supposed to be in a wheelchair and I have a purpose in helping other people see differently.

NB: Yeah, and that’s something that I want to talk about.

MB: In a little bit.

NB: [Laughs] Yeah, in a little bit. So do you think that- you said that you kind of experienced the world differently because- and you have to navigate the world in a different way than people who aren’t in a wheelchair.

MB: I’m on the outside, looking in.

NB: So do you think that being in a wheelchair affected your childhood or the experiences that you had?

MB: Yeah. Yes.

NB: How do you think?

MB: I think my family, like my cousins- and I have a lot of cousins- they treat me differently. They don’t see me like a normal person. They don’t see that I can go out with them to parties or be a normal person- they think it’s too hard or that I can’t do anything but stay home and watch TV. People would go out like, “hey, let’s go do this!” And they don’t ask, “hey Morgan do you want to come with us?” They just leave. They don’t think about how that would affect me.

NB: That’s so sad.

MB: [Shrugs] It’s my life.

NB: But that’s just how it is?

MB: Yeah. It doesn’t bother me, I know people don’t mean anything by it- they just forget. When people do things like this they don’t stop and think, like, “how would this make Morgan feel?” They’re not thinking that.

NB: Do you think that experiences like that- since you were such a young child when it’s happening- do you think that those experiences made you... wanna rebel a little bit?

MB: [Laughs] Yeah. Sometimes, like, I’m not a bad person- [Laughs] What? Stop!

NB: [Laughs] Sorry, I know that you're not a bad person, you don't have to say that.

MB: I know sometimes that my mom says something and I'm like, "I don't care, I can do anything I want to do."

NB: So can we move on to high school?

MB: Sure!

NB: What was high school like for you?

MB: Freshman year was really hard on me 'cause I was in such a dark place. I had depression and was in therapy. I saw all the people around me changing into new people and becoming and making friends and taking classes for driver's ed so they could drive and I couldn't do that. And I was very mad about that. So, like, freshman year wasn't good for me. Sophomore year was... okay and then junior year was better. Senior year was... senior year I was happy, it was almost over, I made friends, joined some clubs.

NB: So did you start applying for college senior year?

MB: Yeah, senior year I applied to maybe like five different places. They have a question on the application, they ask "Do you have a disability, do you not have disabilities," and I always wanted to say "No," I don't have a disability. I asked my mom and said "Well what do I put on this application, I don't have a disability." "Morgan, you do have a disability." I would say "No I don't, I'm just... in a wheelchair, there's nothing wrong with me." She'd say "Morgan, they have to know that you're in a wheelchair." So. That was hard.

NB: Wow. That's hard.

MB: Yeah.

NB: Did you always plan on going to college?

MB: Yeah, I wanted to prove to myself and to other people that I can make something of myself, that I'm not someone who can't do anything, who doesn't know anything.

NB: So it was another rebellion?

MB: [Laughs] Pretty much.

NB: You said that you applied to five colleges?

MB: Yes.

NB: So what made you choose UNC Asheville?

MB: I think the closeness and the accessibility and it's very, like, small. There's 25 people in one classroom and in a big classroom you don't know anyone. There everyone knows who you are, you feel safe.

NB: So you liked how small things were?

MB: Yeah, you felt like they cared about you and your questions.

NB: What was it like for you to start freshman year, did you feel the same feelings you felt freshman year of high school?

MB: No, I was excited, I was happy, I was lost but... I'm always lost. It felt like, "Okay, I'm in charge now, but what do I do now?"

NB: I think that's how everyone feels.

MB: [Laughs] Right?

NB: So before you started college you were already living where we are now?

MB: Yeah.

NB: Okay, so did you ever live on campus?

MB: I did for two years. Mainly I'd sleep there when they didn't have enough nurses to sleep in my room with me. And then also during the winter months like if I had to lay down and rest. I'd go in my room, turn on my humidifier, do my homework if I had any. The winter is really hard on me. So when I was really sick I would have a safe haven to go to.

NB: Okay...

MB: [Whispers] Did you get that?

NB: Kind of.

MB: Basically I needed somewhere to go to when it was the winter so I wouldn't get really sick.

NB: Okay, so you just needed a place to be in the winter because of-

MB: -my medical stuff.

NB: Yeah. Okay. So, do you think that being in a wheelchair, cause I don't wanna say you have a disability-

MB: It's okay, I don't care. It's fine.

NB: But do you think that that changed your college experience?

MB: Yeah. Because it excludes you from most things like... they think you don't want to do the same things that they want to do. That we're different. Did you get that?

NB: Yeah. So, it was kind of like they just assumed that you don't want to do the same things as them?

MB: Yeah. Right. They don't realize that I have- that we have the same hopes, and desires, and dreams, and everything.

NB: You said that you hated having to check the box saying that you have a disability. Did you ever have any problems with accessibility on campus?

MB: Yes. All the time.

NB: What kinds of problems did you have most frequently?

MB: So you know those buttons that you press to open the doors? Those never work, they never work. Like, I am a political science major and the Zaiger buttons never work. My nurse would get really mad and keep pushing the buttons but she'd have to open the door because it never worked.

NB: Was it mainly an issue in that one building you were mainly in, or did it happen in a lot of the buildings?

MB: I think a lot of them probably worked, but when you go to one building so many times its more annoying.

NB: Since it was the primary building you were in.

MB: Yeah!

NB: Did you ever try to report-

MB: All the time. And then they would fix it and it would work for one week and then it was broken again. And then the parking, for like, wheelchair people? Everyone parks in wheelchair-accessible parking. So there's no parking for people like me.

NB: Yeah and it doesn't help that it's so- there's hills and steps and- yeah. So did you ever think that because of the issues you've had with accessibility, did you ever have to alter your plans or change your schedule because-

MB: Yeah. Yeah I had to. I remember two years ago I had a problem with transportation so I had to drop one of my classes and that put me a semester back, that's why I didn't graduate with you and Sarah.

NB: And it was because you didn't have a way to get there and it was the only time the class was offered? Wow.

MB: Right?!

NB: So how did that affect you- like, having to deal with those kinds of issues that you know that people who aren't in a wheelchair don't have to deal with?

MB: It would annoy me but... I'm so used to that situation that it doesn't really affect me. Because in life... You can't control anything in life. You just have to live it the best way you can and just- You have to do it.

NB: What advice can you give to a person who has disabilities- or someone who has a wheelchair, someone who's in a position that's similar to yours- who just started their first year of college. What advice would you have for them?

MB: Don't give up. Keep pushing on. And then when you have problems don't go to the person you have a problem with. Go to a person higher up in the system. Like I've had problems with professors and I've had to go to the chair of the department and say, "hey, this professor is treating me really crappily. Everyone else is doing wonderful in there and I'm failing. That's not fair."

NB: So you think that the best thing to do is to not take people's-

MB: Crap? Yeah, and to not take things personally. Like if they treat you differently, and they're awkward around you, don't take it personal. It just means that they haven't met someone like you and they don't know how to handle someone like you. And then don't be afraid to accept them as a normal person 'cause when they feel normal, they're more willing to accept you.

NB: So we met when we rushed the same sorority in 2015. We were both in Alpha Xi Delta. What made you want to join a sorority?

MB: I wanted to be a part of something bigger than myself. And I wanted to make friends, I wanted to make connections for the rest of my life. [Unintelligible.]

NB: Wait, repeat the last part?

MB: That didn't turn out the way I hoped.

NB: You didn't think that joining the sorority turned out the way you thought it would?

MB: No.

NB: What happened?

MB: People have their own cliques... Like, popular... Like different things. I have friends in the sorority, but not like friends like a lot of people have.

NB: Because everyone kind of separates-

MB: Separates, yeah.

[At this point Morgan requested that we take a break.]

NB: So now I wanna take some time to talk about some of the more difficult topics that surround people with disabilities, and especially people with Pompe Disease. I want to clarify first that these questions were approved by Morgan before the interview. Is that correct?

MB: Yes.

NB: Okay, so what was the hardest part- or the hardest parts- of growing up in a wheelchair?

MB: Um, I couldn't use what other people could use- like reading books. I had to stay behind on most things, like [unintelligible from 27:56-28:10] ... And I couldn't go because... I'm in a wheelchair. I couldn't do that. Like, running I couldn't do, or fishing, because they don't have any ways for me to do it. Or I couldn't just get up and say, "Okay I'm ready!" I had to do my own tour, make sure there's a ramp, and stuff like that.

NB: So it's kind of like... things just take longer.

MB: Yeah, it's like- it's like you have to have the patience for it. It's not just like, "Okay I'm ready!" You have to pack up the van, the ventilator, the... everything. I can't just up and go, put my shoes on and take off. It's step by step- and then you can leave.

NB: Do you think that you've developed the patience for it? Or-

MB: Yeah, yeah. Yeah. For me it's like I'm impatient, while I'm patient.

NB: Okay, so I don't want to go off on a tangent or anything. But I do want to give some context before my next question. So I vividly remember having a conversation shortly after we joined the sorority- a conversation that you were excluded from- specifically about you. And what to say, or not to say, to you or about you, regarding your disability. We were told that you were aware of the conversation and it was at that point that we were told about your diagnosis... and your prognosis. So, you shook your head when I said that you were told about it-

MB: I was never told... about that.

NB: So you didn't have any...

MB: I didn't know about it. And it made me mad- it makes me mad that Briar would do that. No one needs to know what I have, and if anyone is wondering they can ask me. Like, when you go on a website (to look up Pompe Disease) it doesn't... it's not always accurate. And if people want to make judgements before-

NB: You'd rather have told them yourself-

MB: Myself, yeah. And besides, I'm the one who has it. Not Briar. Briar didn't even know my whole situation.

NB: So she didn't ask you?

MB: No. She knew something was wrong- like all of our sisters did- but I never told, like, how long I was supposed to live, or what it is, or how it affected me.

NB: Can we talk about those things?

MB: Sure.

NB: So what was your prognosis that you were given?

[At this point, our interview was interrupted as the State Representative for Buncombe County, Brian Turner, came in to say hello to Morgan. Transcript resumes at 33:03 after he leaves.]

NB: Who was that?

MB: He's a congressman for, like, the district-

NB: A congressman?

MB: You know how people like, from a district like Buncombe County, Madison County... He comes around sometimes and, like, reelection is coming up.

NB: So it's like a campaigning thing?

MB: Pretty much.

NB: So you've met him before?

MB: Oh yeah, my brothers helped him with his campaign when he was first running.

NB: Oh cool, interesting!

MB: Yeah. He's- he's very sweet. [Morgan makes a funny face]

NB: [Laughs] Okay. So. We'll start back with... What was the prognosis that you were given and when were you given that?

MB: Well for the first prognosis I was given... I wasn't supposed to see my first birthday.

NB: Your first birthday?

MB: [Nods] I wasn't supposed to live. But then I lived past that and then they were like, "Oh you're only going to live until you're two." And then three. And then four. And then five. And now here we are and I'm almost 23.

NB: And now you're-

MB: 22. Almost 23.

NB: So you were-

MB: [Imitating the doctors] "Nevermind! Sorry!"

NB: So they were just wrong.

MB: [Laughs] Pretty much.

NB: So at this point are they still going with this process? Like, "Oh you're not going to live past 23," or... "We don't know what's happening here."

MB: No. I have medicine. Like, when I was diagnosed we didn't have any treatment.

NB: Oh, okay.

MB: So in 2003 I got my treatment for Pompe, which removes the bad stuff from my body and it slows down the progression of it. So I can live... well into my 90s, if I wanted to.

NB: Well into your 90s?

MB: Yeah! So they don't really have, like, a life expectancy anymore. It's like- you get diagnosed, you start treatment as soon as possible, and you're life is normal- well, as normal as it can be.

NB: So because you were able to start treatment when you were five-

MB: Well, 2003. So I was... seven, I think? 2003... so I was seven or eight. Right? Yeah? It doesn't matter. 2003, whatever.

NB: [Laughs] So because you started treatment in 2003, when you were... so young, it helped you? So prior to 2003-

MB: I was dying. Like, I was in my bed, fighting for my life. I went into the hospital many, many, many, many times. I think the longest time was maybe... four months in the hospital? And it was because I had pneumonia and I couldn't breathe. That was when they put me on the ventilator. I had had pneumonia, like, three times before that but this was more. It was more. I couldn't breathe.

NB: So how long have you been on the ventilator?

MB: I was... four.

NB: Since you were four?

MB: Yeah. So, a long time. I don't know life without my ventilator.

NB: So what would you say to a child who was diagnosed with Pompe Disease and they were young, and they were in the same position that you were... Except, maybe not. Since they could start the treatment sooner than you could. What would you say to them?

MB: Um, don't be afraid of... a random plastic tube in your neck. Think of it as something liveable because then it changes things... it helps you live your life longer than without it. Think of it as a friend... that helps you live. I have a name for my ventilator. Like, I named it.

NB: Wait, repeat that.

MB: I have a name for my ventilator.

NB: You named it? What is it?

MB: Yeah. Fred.

NB: [Laughs] Fred?

MB: Yeah! It helps me.

NB: How did you come up with that name?

MB: I don't know... It just came to me one day, like, "oh! I can name it Fred!"

NB: I mean it's been with you for most of your life so-

MB: Why not?

NB: So do you think that its difficult to talk to others about your prognosis- even though its not as scary as it was, I guess, before you started your treatment?

MB: Not really because it is what it is. And I'm not ashamed of it. I mean, yeah, I was supposed to die before I was one but... obviously I'm here, so. Why not talk about it?

NB: So how often have you really talked about Pomp-

MB: Pom-pay!

NB: [Laughs] Pom-pay Disease- before having this conversation with me? Like, how often have you talked in depth with someone about it?

MB: Um, when I was a freshman in high school I didn't want to talk about it at all because it was embarrassing. I was ashamed of it, and I didn't understand why I was picked to have Pompe. But now that I'm older, I'm more willing to say "Hey! I have this and I'm proud of it!" Because I'm better because of it. So, like, I'm not going to go out of my way to talk about it. But if somebody asks me about it I'm fine with it.

NB: Okay so if you- You talked about your activism and your, I guess, participation in the Pompe community.

MB: Yes!

NB: So what is the Pompe community?

MB: The Pompe community is people all around the world who have Pompe and they decide to come together and talk about the kind of symptoms they have, and like, “Do you have this? Or do you have that?”

NB: So before- I know that you went to a meet up. So were you-

MB: With people with Pompe.

NB: Yeah. And what was your experience with the Pompe community before that? Had you ever met anyone-

MB: I had never met anyone before that. I mean I may have but I don't remember.

NB: Is there anything else that you want to add about that? Or talk about?

MB: No, just that... Just that when you meet people that are the same as you, you feel more normal, I guess? But people diagnosed now are better off and more... healthy I guess, because they were able to start the treatment right away. They don't progress as much, they're making friends, they can walk, they're not in a wheelchair. So even though you feel normal... you feel different, because they didn't have the same prognosis as you.

NB: So have you met... Whenever you went to the meet up did you meet anyone else who had the same experience as you? Or who had experienced the same progression as you? Or started treatment around the same time as you?

MB: No. No, I was one of seven people who was diagnosed around my age. Two of them are no longer alive. So now there's five of us, and no one else is like us... They're more normal, I guess. They can walk- they have problems, like us, but not as bad as us who were diagnosed before treatment.

NB: So you're in undergrad now.

MB: [Smiles] Yeah.

NB: And you're about to graduate.

MB: I am.

NB: So, two questions. The first is: what are you getting your degree in?

MB: Political science.

NB: And what are you wanting to do after you graduate?

MB: I want to take some time off and just... figure out my life. I need to figure out if I can go off to law school, or if I need to go do law school online. And if not law school, my hope is to be in a master's program but to advocate for the rights of disabilities. I want to change policies, because the ones that we have now are not very helpful.

NB: So you want to work in advocacy-

MB: For disabilities.

NB: I guess as a final thought question, is there anything else that you'd like listeners, the people hearing this or watching this in the future- is there anything that you would like them to know? Or people in the future- young people to know?

MB: [Laughs] Repeat that?

NB: Is there anything that you would want people in the future to know about you? Or about Pompe Disease?

MB: Live your best life, because there are no certainties. And don't let life bring you down.

NB: I think that's good advice.

MB: Yeah? [Laughs]

NB: Yeah... Well, I want to say thank you so much for letting me come to your house and interview you today.