



Oral History and Folklife Research, Inc.

AN INTERVIEW WITH
JEREMY LIBBY

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MG: I like to start at the beginning. You told me where you were born, but when. You might have to say it again for the record.

JL: I was born May 17, 1979 in Dover-Foxcroft, Maine, but I grew up in Pittsfield, Maine.

MG: How old does that make you today?

JL: Thirty-five.

MG: What was growing up in Pittsfield like?

JL: Pittsfield was nice. It's an unusual community in that everything is really very well centered around the downtown. I lived downtown, so I was able to work to elementary school and then junior high and then high school was all within walking distance. We had nice parks. We had a movie theater, which is unusual for a small town in Maine. So, it was actually pretty pleasant to grow up there.

MG: What was Pittsfield's downtown like?

JL: Sure. Life in Pittsfield was pretty slow. Very small town. Everybody knew each other. We had a little police department. We had a nine o'clock curfew that every teenager tried their best to avoid. It was a pretty close-knit community. As I said, everything in town was centered around the downtown, so you didn't have to go far for anything you wanted.

MG: Tell me about your family?

JL: My family is kind of unusual. I never met my dad until I was thirteen. My mom has been married twice. We moved to Pittsfield when she met the man who became her second husband and lived there. I have a fairly – I have a number of siblings, but not many siblings that I grew up with for a long time. I have two stepsisters, a stepbrother, and five half sisters and all spread through different households.

MG: A motley crew.

JL: Yes.

MG: For the first chunk of your life, were you mostly an only child?

JL: No, I had my half-sister (Cheyenne?) was born when I was three or four years old. I grew up with her until she moved in with her dad when she was like fourteen.

MG: What else did you do growing up? What was your neighborhood like? What did you do for fun?

JL: I was a little bit – I did get in a little trouble when I was a kid. I was, I think, one of those kids that adults – I don't know how to say it diplomatically. I was a bit of a troublemaker when I was a kid. I lived through some of the consequences of being a troublemaker, but for the most part, I think I was pretty normal. I liked to play soccer. I did the little things you do as a teenager to escape when you're in a small town. I listened to a lot of music. I was as involved as a teenager can be in the high school art scene and that kind of thing.

MG: What did you expect for yourself growing up? What did you want to do?

JL: Growing up in Pittsfield, I very much wanted to get out. I wanted to experience the world. When I was a freshman in high school, I was fortunate enough to be able to take a trip to Russia that the school sponsored for a week. That really opened my eyes to a lot of possibilities. Being fourteen and finally seeing a part of the world that I never thought I'd get to experience. So, my intent was to finish high school and go on to an art school or design school. I had my eyes set on a design school in Rhode Island in, I think, Providence at the time. That's what I wanted to do.

MG: What was the rest of high school like?

JL: High school was challenging for me. I suffered my spinal cord injury when I was fifteen years old, during the summer. It was August 3, 1994. It was crowd surfing at a rock concert and fell and broke my neck. So, I missed my entire sophomore year of high school. I was in rehab – physical rehab for six months of it. Then, after I returned home, I continued rehabilitation at home. The initial year of my injury, for most of it, I couldn't even sit up straight. It was a long rehabilitation process to get myself where I was stable enough to even go out into the community, let alone think about school and following up on those kinds of very practical things. I was very fortunate. The high school actually sent a tutor to the rehab and then, to my home. That allowed me to keep up a little bit in school. When I finally returned to school my junior year, I was able to take some classes as independent study. They gave me the textbook, I took a test every three weeks or so, and I was able to pass some of my classes that way and keep up with my peers. My junior and senior year were very busy for me.

MG: I'm curious how life changed after that, but maybe in unexpected ways.

JL: After high school or after my injury?

MG: After your injury.

JL: At first, I found myself very isolated after my injury. Our home, as most homes in Maine, was not very accessible. A group from the Salvation Army actually built my ramp and donated their time and effort to do so, which was wonderful of them. I actually slept in our dining room after I returned home because we had a very narrow three-story home, and the bedrooms were on the second and third floor. The dining room was basically, the one place I could get to. So, the two years that I was home after my injury,

I slept in the dining room, had very little privacy. Didn't get out much into the community, though I started to a little bit after my health was stabilized enough that I could go out on my own. A lot of my friends in high school were a year or two older than me. So, they were going off to college at just about the same time I was returning to school. So, when I actually did return to school, I found myself a lot more socially isolated than I had been before. In addition to that, I was dealing with my own issues, the things that – one of the emotional things you deal with after a really devastating injury, is a lot of grief. Especially being a teenager, up until the point I was injured, I had an idea of what I wanted to become, an idea of what I wanted to do with my life. At the time, I felt like the injury robbed me of all of that possibility. It was very hard to come to terms with that, come to terms with a new identity and a new set of possibilities that I didn't like and I wasn't particularly comfortable with. Also, it was difficult to start thinking that I had to make a new life with some significant constraints that are caused by my spinal cord injury and decide for myself, how am I going to make this work. How am I going to build a happy life out of this new circumstance?

MG: I can't imagine having to make those decisions and negotiations at fifteen, sixteen years old. How do you think it would have been different if you were more fully formed as a human, later in life?

JL: I think everyone who – and most people will go through this eventually as they age, but often not until much later in life, but anyone who suffers an illness or an injury that drastically changes your physical ability, there's – we wrap so much of our sense of our identity up in what we do and what we do relies a lot on what we're able to do physically, whether it's drive a car or you perhaps do a manual labor job, like you're a welder or something like that. We wrap a lot of our identity up in that. Part of the grieving process is grieving for a loss of identity. I think when you're older, your sense of self and who you are, is wrapped up much more tightly in what you do. I think it's actually – it might have been more difficult to shift gears and accept that I needed to become something else maybe. At least, become something different than what I thought I could become.

MG: Part of this project has to do with the ADA. Was that something that you were aware of then?

JL: Sadly, not even remotely. I didn't even really have a good sense of what a spinal cord injury was when I experienced my injury.

MG: What were you being told from doctors, experts, and adults?

JL: After my injury, it was a barrage of things I could no longer do. You can't walk. You can't move your hands. That means you can't go back and play soccer. My whole world, at least for the first year of my injury, was coming to terms with things I can't do and maybe will never do again. That was difficult. I started to have to discover things that I could do and things that actually were within reach for me, and to not dwell on the things that I couldn't do any longer.

MG: Can you talk about some of those things that you discovered you still could do and enjoyed doing?

JL: Sure. It took a while, but I discovered that despite my hand impairment that I could still draw, that I could still create art. That was really nice for me. The discovery, unfortunately came much later than I would have liked. One of the things I gave up after my injury was the desire to pursue art school and design school, and I started to pursue other things. But coming back to that, was kind of a revelation for me, to discover that I could actually still create very good art despite having a significant hand impairment.

MG: Talk about that process. How did your art change? What were you doing differently?

JL: One of the things that changed significantly for me was I like to create very precise art before my injury, art that resulted from having a lot of control over my medium. After my injury, with the hand impairment, with muscle spasticity, I had very little control over the medium. I found that at first, I loathed it. I thought, gosh, I'm never going to create something I'm happy with this way. There's no tool that will grant me the type of control that I want over the medium. But over time, I found myself creating things that I actually liked, and that an element of the art I was creating that I enjoyed actually emerged from not having fine control over the pen, over the pencil, over the paint brush, and that that was creating something that was really quite nice and that I actually, over time, learned to really enjoy.

MG: What other things helped during this time period or were sort of comforting?

JL: I stayed in touch with friends who were incredibly supportive. My family was always quite supportive. They never put any limitations on me. They never said, "You better quit everything now. You're not going to be able to do anything." They were always very encouraging, very supportive. They went out of their way to make sure that what I did – as I was finishing high school, I decided to go to college. They went out of their way to make that happen for me, just through practical support – making sure I was able to get an adapted vehicle, helping me with care-giving tasks until I was able to get some help on campus, all of those sorts of things. They really went a long way to make sure I was able to do those things, by providing practical support and by providing some of the emotional support and encouragement that I really needed at the time.

MG: I'm wondering if you made any other connections at the time with people who had experienced similar things that you could connect with.

JL: Yes, when I went to college, I finally started to meet some other people with spinal cord injuries. I also found an online support group, that's actually hosted by Rutgers University. It's Carecure.org. The forum is set up for people who have experienced spinal cord injuries, and are learning to cope with the fallout of those injuries. I found a really wonderful support system there. I was able to learn a lot from people on that

forum, who'd been through what I was going through and who offered advice and strategies for dealing a lot of the same problems I was dealing with.

MG: A lot of my work as an oral historian has been with veterans and people who have experienced combat and PTSD. There's something different about the friendships formed between veterans than civilians and veterans. So, I'm wondering if there's something different about the friendships you're forming with people who have had similar injuries.

JL: I think there is something a little different. We share an experience that not a lot of other people share. We know what it feels like, in my case, to lie on the ground unable to breath and think, I'm dying, and then, to rebound from that, to start to get healthy again and start to rebuild a life with some new and very significant physical limitations. So, when I meet someone else with a spinal cord injury or someone who's experienced something similar and we become friends, I think we are able to relate to an experience that we really can't talk about with other people, unless they've had – unless they've experienced something really devastating like that, that they just don't have the vocabulary to discuss with us.

MG: I think that's some of what we're trying to accomplish with this. My approach to doing interviews is to achieve "felt life." It's a term borrowed from Henry James and the idea is to be as close as possible to understanding the experience of another human – what life felt like. You talked about rebounding. I'm wondering how that process went. What changed? Were things coming back to you that weren't there right away?

JL: It was a very long process for me. I think it was really a ten year process from 1994 to 2004 when I graduated from school, that I really – it was that entire period that I was finding – I was slowly figuring out who I was and what I could do and what I wanted to do with my life. Throughout that process, pushing the boundaries of what I thought was possible and some of the perceptions of what was possible that were given to me by doctor, initially, who just gave me that long list of things that I wouldn't be able to do and discovering that there were actually lots of things on that list that I could do with just a little modification to my environment, maybe with a little help from someone else. As I started to overcome those obstacles and move past those boundaries, I found myself enjoying a little bit more freedom here and there. That, over time, snowballed and it became a lot more freedom and a lot more ability and a lot more doors that were opening up for me. But that was a long process.

MG: Can you give me an example of something you crossed off your list?

JL: I think becoming employed was a big one. We have this unfortunate expectation as a culture that when you experience a significant injury that you kind of sign out from society. At fifteen, I hadn't even signed in yet. I still hadn't figured out what I was going to do at all. So, to have your entire future just feel like it was burned to the ground by an injury and then try to find a way to just live with that – no one, I think, especially no fifteen year old wants to just sit home all day and do nothing. You have dreams for your

future. You have aspirations. Actually, achieving some of those was fantastic for me and rejuvenating and extremely positive experiences. Really learning that I actually had something of value that I could still contribute to the world, that was more motivating probably than anything else. Part of that was just getting – my first job was as a teaching assistant at the university in the peace studies department. It was a small thing, a small job on a stipend, but being able to do that and being able to contribute to other people's learning and having something that I could share that was of value to people was wonderful.

MG: Where did you go to school?

JL: The University of Maine in Orono.

MG: Talk to me about those four years, that experience, and what started changing for you. Did what you wanted to do become more solidified?

JL: Sure. I think initially – well, I actually attended University of Maine in Orono for six years. I earned my bachelor's degree and then my master's degree in English. My first four years were challenging in the sense that I think I was probably a terrible student. I was the quiet miserable guy in the back who didn't talk to anyone. I was repeatedly cited for poor classroom interaction. I never answered questions, didn't engage much in classes. It was only until I started to gain a little confidence and feel a little more capable in terms of just my intellectual ability, my ability to handle the coursework and interact with my peers that I actually started to really grow and participate more in classes, and actually enjoy what I was doing.

MG: Did you have to overcome any hurdles in that? I think that some of the people I've interviewed say that people confuse a physical disability with a mental one sometimes and that's been frustrating.

JL: Yes. That was definitely a challenge. I don't think I helped myself much by remaining quiet and remaining on the fringe and not engaging. I think I missed opportunities to change the way people saw me. By being quiet I just sort of adopted whatever their preconceived perceptions were. I have run into instances where they see a guy in a wheelchair so maybe folks will speak a little louder or make comments that reveal that they have some misconceptions about more than my physical ability. The solution to those problems is always just engaging someone in a conversation.

MG: When did you start to become aware of the disability rights movement?

JL: It was a long time before I really – I was in college before I really engaged another person with a spinal cord injury or a disability of any type. So, I'd say it was a good four or five years after my injury before I really knew about the disability rights movement, thought about it at all and then began to learn about it.

MG: Talk to me about that. When did you start learning about it? What did you learn?

JL: I think, again, it was a gradual process. Then, as I came into my own, as I moved into the community, after school as I began to work in the nonprofit field, I started to learn a lot about what's gone on historically, in the legislature, on the national level and in communities to try and make, not only, I think, building accessibility a priority, but really to open up our environment to people with disabilities, with a recognition that just because someone has a physical impairment, that doesn't mean they do not have something of value to add to society. I think that I was learning about the disability movement at about the same time I was trying to force my way into the world and show that I had something to contribute.

MG: What was that work in the non-profit sector you just mentioned?

JL: That's actually what I continue to do now with Alpha One.

MG: That was when, that you started?

JL: I started with Alpha One in 2009. It was after I finished school. I continued to work as a teaching assistant for a few years. I was involved with hospice of Eastern Maine for a few years, just volunteering with them. Then, I found myself – I was actively looking for a full time job and had an opportunity at Alpha One. That's worked out for me.

MG: What has been your work here?

JL: I started here as an independent living specialist, doing things I really never foresaw myself doing – managing a loan program, helping people apply for grants, but these are all related to assistive technology needs, so financing for things like adapted vehicles and hearing aids, helping people who have new injuries. I get things they need to return home – critical things, like wheelchair ramps and bathroom modifications to make their bathrooms accessible, so they can be more independent. Meeting and talking to people who have new injuries or who have experienced illnesses that have left them with physical limitations of some type. So, the world of not only disability, but of assistive technology and beyond that, work that's gone into making grants and loans for assistive technology possible, really opened up to me after I started doing that work.

MG: I'm wondering if you can tell me about an instance where you changed access and it led to an opportunity or just changed the way someone's day to day life functions.

JL: Sure. That kind of task is something we do here every day. So, it's hard to cite one. I think an early example was meeting an eighteen-year-old girl who was paralyzed in a car accident and just helping her return home was a big one. I met her probably a month after her injury and worked with her directly for a while to get her a ramp on her home and get her back there. I remember the first time I met her, she just wept through most of our meeting because she thought her life was over. She thought there's nothing left for me in the world. I was able to talk to her, not just about some of the practical issues we were going to address with getting a wheelchair ramp on her home, but also the fact that

there's still a lot of possibility for her, that outside of what she's lost, there's still a lot in the world that she can do. We continue to work on that. I still know her. I still interact with her. One of many people we work with that eventually does return home. After you return home, you have a private space where you can deal with the grief of your injury. After you've dealt with the grief of your injury, at least to a degree, you can start to venture into the world again and start to pursue some of those activities that you thought you'd lost – pursue friendships, pursue whatever it is in the world that makes you happy. It's a long process, but I think that's – I see people go through that every day here.

MG: How is the rest of your life unfolding, outside of advocacy and work?

JL: Good. I've been very, very fortunate, I think. I've been able to build an accessible home. I got married last year, which was amazing. I never thought that would happen for lots of reasons that have nothing to do with my spinal cord injury. I didn't see it happening. So, that was great. I think overall, despite my injury, I'm probably at a happier place in my life than I've ever been. I feel very fulfilled and content with my work. My private life is full. It's really quite nice.

MG: How did you meet your wife?

JL: My wife, when I met her, she was working for the National MS Society, as a – actually, I'm not sure what she was doing for them, exactly, but we met at a meeting and then, after the meeting, she stalked me on Facebook a little bit. We started chatting back and forth on Facebook. A few months went by and we decided to have a date and it just kind of evolved from there.

MG: What do you think your life would have been like if you didn't have your injury?

JL: That's a big what-if for me. I have to say it's a question I've asked myself a lot. It gets harder to answer as the years go by. I think I would have had a very quick answer to that question when I was seventeen, but as years have passed and I've grown in a different direction, it's harder for me to imagine what I would have been as an adult, had I not been injured. I can only assume that I would have been hopefully successful in the path I had planned for myself, but I can't say that for sure anymore. It's a very – it feels very distant for me now.

MG: Is there any part of you that's still a troublemaker?

JL: Certainly, but I've learned to mitigate that a bit.

MG: I want to talk more about the Americans with Disabilities Act. Maybe your definition of it, how far it's gone and then we can talk about maybe where it needs to go.

JL: Sure. My definition of the Americans with Disabilities Act.

MG: Or just if you had to tell someone about it that didn't know what it was. Because I think it's an overlooked and misunderstood law.

JL: I agree, actually. So, might be easier for me to talk about my experience of it.

MG: Perfect.

JL: When I think back now on the Americans with Disabilities Act, when it initially passed in the early 90s, I think about a lot of the people who worked very hard to champion that law, people who lived in very isolated circumstances, who lived in a society that thought they had no value. In fact, so little value that why bother making my store wheelchair accessible, no one's going to use it? Or why bother making government facilities accessible? Why bother making college campuses accessible? These people belong in asylums or at home or wherever. I think it was a society that did not value the potential contributions of everyone. Part of the Americans with Disabilities Act that I appreciate is that I think it changed perceptions and it forced a change in perceptions that said, everyone, despite their physical ability has potential to contribute something good to society. I think I've benefited greatly from that change. Not just in practical ways. Not just being able to get into an accessible restaurant or something like that, but I think we live in a society that perceives disability differently because of the Americans with Disabilities Act, because people are able to leave their homes and participate in the world, and shatter a lot of the misconceptions that we have harbored as a society about what it means to have a disability. The way I think about my disability now is shaped by it. I don't think about my spinal cord injury as a yoke around my neck or as a long list of things I can't do. It's just a different way of living. My body's a little different. I have to do a few extra things day to day that are different than what most people deal with, but at the same time, I'm able to accomplish everything I want to accomplish. I'm able to pursue activities I enjoy. I'm able to participate in life in a really robust way. The Americans with Disabilities Act makes that possible. Without all of the small changes that go into universal design process, I wouldn't be able to go to work. I wouldn't be able to ask for a reasonable accommodation from my employer when I need it. All the things that make my daily life possible, find their roots in the Americans with Disabilities Act.

MG: It seems like you've been lucky in terms of employment, sort of finding the right fits for you, but I'm wondering – I've heard about lots of cases of discrimination, especially in employment and I'm wondering if you had any experiences like that.

JL: Definitely. The type of discrimination I experienced surprised me when it happened. It was after college and I was applying for teaching positions in the community. The type of discrimination I experienced was very – it was not overt. It was a matter of I would go in for an interview, and just instantly I could see the shift in the interviewer's gaze that they immediately signed out of that interview. They went through the process and said, thanks, have a nice day, we'll give you a call, but I could tell in the beginning that there was a shift in body language. There was a shift in demeanor that said, "You don't have a chance." That was really surprising to me. It's a hard thing to describe, discrimination of

that type, but it was there and over and over again, I would go in for interviews and experience that same thing. It was tough to deal with because there's no – I still don't know how to address something like that because it's easy to deny, I guess. But at the same time, it's incredibly evident when it occurs.

MG: Yes, I know those cases are tricky to try because it's hard to prove that they're discriminating.

JL: Right.

MG: I'm wondering if, when you go about your day, you can kind of point out areas of success or we need to – “that store needs to be accessible or this needs to be available.” I'm wondering where you see those things.

JL: You still run into accessibility issues in many places. It can be a little thing, like public restrooms for some reason. I find that the door weights are almost always set to be too heavy. It's not something an able-bodied person will know because most people lean into a door when they open it. But for me, I've lost count of the number of public restrooms I've gotten stuck in because the door was too heavy. It's ridiculous, but it's a minor issue that can really throw a wrench in your day when you're waiting for a half an hour for someone to come in and pass, so you can get out the door just because someone tightened the door a little too much. Especially in Maine, in some of the older communities, there's a lot of reluctance to make sidewalks more accessible and make stores more accessible. There's a lot of mistake in perceptions about what actually needs to be done to make something accessible. So, you run into a lot of places where there's just one step into the store and people say, “Well, what's the problem? It's just one step,” but that's still one step that is impossible for me to navigate on my own. When that happens, they might as well have a sign in the window that says people using wheelchairs not allowed because that's what I see every time I see a step into a store or another facility.

MG: How is doing this kind of work different in Maine? Are there some cities that are models for accessibility that we should try to emulate more?

JL: Sure. In Maine, I think it's challenging for a number of reasons. Municipalities don't have a lot of money to make these changes or to support them. There are funds through the mPower Loan Program and others that allow businesses to make some of these changes, if they're willing to seek financing for them. A lot of the stores – or a lot of the environments you deal with, they're not large conglomerates. Your Walmarts and your Targets and your McDonalds, they always meet universal access codes. But your mom and pop type locations, if they haven't dealt with someone who has a disability, if no one's approached them about the problems in their facility, they might not even be aware of them because in most communities in Maine, it seems code enforcement doesn't do a very good job monitoring access issues. They generally don't do a good job responding to complaints. I found that the best route for addressing an access problem in

Maine when it's a small business is to just talk to the small business owner and point out the problem. Very often they'll do what they need to do to make it work.

MG: How much further do we have to go or what things would you like to see happen down the road?

JL: I would really like to see a continued cultural shift away from seeing disability as something – I'm trying to think of a way to phrase it. We still see, as a society I think, disability in a negative light. We still see it as a list of things you can't. I would like to see that shift from seeing disability as a lack of potential and a lack of ability and simply view it as – the same way you might experience other differences and just acknowledge that someone with a disability has to do things differently, but it by no means removes potential or removes their capacity to contribute and be capable.

MG: How does becoming someone with a disability different than maybe being born with a disability?

JL: It's hard for me to talk about how it's different, since I wasn't born with a disability, but I have talked to people who are. I think, for me, one of the biggest challenges was having an idea of who I was and what I was going to become and having that really suddenly and violently stripped away, and having to come to terms with that and learn to grow into something else. I think often – and people who are born with the disability – I guess one example I have is I was talking a young woman with cerebral palsy. We were talking about our different experiences with regard to the way we live with our disabilities, the way they occurred. She said, "You are so lucky because at least at one time in your life you got to climb a mountain, you got to know what it felt like to have a body you could fully control." She said, "I will never have that experience. I will go my whole life without that experience." For her, she needs to – I think her sense of alienation is greater than mine. Her sense of alienation from able-bodied people, from able-bodied society is greater than mine. That's what I took away from that conversation. The work she has to do to integrate herself, I think, is even more challenging than the work I've had to do after my injury. Not just integrate herself in a physical way, but in helping other people appreciate what she has to contribute.

MG: I know you've done some work around changing the laws concerning crowd surfing.

JL: A little bit. Not too much. I think a lot of that happened as a result of my injury. It became, at least for a brief period, a national discussion. I feel like I've noticed in recent years. I think that is fading a bit. I see young people embracing that culture again. I worry about that, of course, but I haven't been involved in any legislative advocacy or anything like that.

MG: What would you change?

JL: With regard to concert protocols and safety and that kind of thing, I think vendors really need to do a better job of one, understanding that when you host an event, and you have seating or whatever it is for that event, that you have some responsibility for the people who are attending, and also, I think, there's a certain amount of irresponsibility in the way events are marketed to kids who are very impressionable, marketed in general. There's a certain element of marketing that is trying to sell this culture that goes along with – or things like, crowd-surfing and moshing and those activities follow and that they market those, they sell them, they sell them as a feature of their event and then when someone gets hurt, they try to wipe their hands of it and say we had nothing to do with it, despite that fact that they used that – that they elevated that culture and that they used it to lure people into that venue and profit from it, profit a lot from it.

MG: Has your relationship with music or concerts changed since?

JL: Somewhat. It was difficult for me after my injury to be in a crowd. It took me a long time to – I forced myself into crowds over and over and over again to get past that. I felt like it was the only way I could deal with the anxiety that resulted. Now, I think I enjoy concerts as well as anyone else. My only frustration with concerts is that often the accessible seating puts me in a place where people are standing in front of me. So, it's harder to appreciate the performance.

MG: Looking back on your life and your work, what stands out to you?

JL: In terms of?

MG: Special memories, sources of pride, achievements.

JL: Sure. I think for me, finishing school was a big one. It was really nice to actually accomplish that and feel like I did so through the merit of my own effort. Although, I have to say, professors I had in college were incredibly forgiving in a lot of ways, incredibly helpful. I owe many of them a great deal of – just a great debt for their compassion and their understanding and their willingness to work with me through stuff that they really didn't have to work with me through, but they did, and that was really wonderful of them. I certainly wouldn't have made it without them. I think moving out on my own was a big one. One of the things I yearned for before my injury – I just yearned to be independent. I couldn't think of anything I wanted more as a fourteen, fifteen year old, than to be out on my own, doing my own thing and dictating the path of my life. After my injury, I thought that would never happen. I thought I would be permanently dependent on the whims of caregivers, on places that were accessible or accepting in some way. I found that getting out on my own and just being able to dictate the course of my own day was revolutionary. It was a taste of the independence that I do still crave. There's still a degree of physical limitation that frustrates me. I can't go out for a run. There's still limitations on what I can do on a daily basis. I'm less frustrated with them now than I used to be, but as I have grown and broken down some of those barriers, I've become content with what I can do.

MG: Can you describe your home?

JL: Sure, a little bit. So, when we designed and built our home, one of our goals was to make a fully accessible home that the average person wouldn't even know was an accessible home, to show that you can have access without making it clinical. We accomplished that. I don't have a ramp anywhere in my home. I don't have a single staircase. The floor plan is very open and spacious, which in itself, makes for great accessibility because when you're moving around with a wheelchair, most of what you need is space – space to get through doorways and around furniture and that sort of thing. So, I have just a little bit of extra space everywhere and it makes a huge difference. People, when they visit my home, they comment on how open it feels and how comfortable and welcoming it is. They don't even notice the accessibility features, that the countertop is an inch lower than your normal countertop and that kind of thing.

MG: What am I missing? What haven't we talked about?

JL: I don't know. I guess, one of the things I'd like to say is I feel like the reason I've been able to have some quality of life despite my spinal cord injury is because people who didn't enjoy that quality of life thirty years ago fought really hard to put laws in place to make sure that the next generation could have a better experience. I feel that I owe a debt to them, I owe a debt to the doctors that saved my life, to live a responsible and productive life and take advantage of the opportunities that their effort – even though, they'll never meet me, we'll never know each other, but their efforts twenty years ago and thirty years ago are the reason I get to enjoy my life and that I have the opportunity to work hard and to pursue interests. Every day I think I need to honor their effort by living a good life and by pursuing the things that make me happy and make the world a little better. Also, too, when I'm able, work as an advocate, work in the community to change people's perceptions and their awareness so that the generation that follows me can enjoy even greater freedom and greater opportunities than I experience.

MG: Why do you think it took until 1990?

JL: I don't know. I imagine a lot of it was cultural. I think there were a lot of aspects of disability that weren't even survivable until the 1950s and 60s. Then, you have a generation of people who are experiencing life in a way that not many human beings survived to experience until medical technology caught up. So, you have a generation of folks who are growing up with disability, who are saying, "Hey, I want to participate in society," and society is saying, "No," and that's not right. I'm going to fight for the opportunity to participate. I think it took probably a solid two decades of that fight, particularly following the Vietnam War where a lot of people were coming back with disabilities to change the cultural perception and get people behind legal changes that needed to happen for access to be available to people with disabilities. It's a decades-long process to change perceptions and to change laws. It's unfortunate that it took until 1990, but I have to say I'm enormously appreciative that it did happen.

MG: How do you think modern technology's going to change access and the disability rights movement going forward?

JL: I think assistive technology has incredible potential to restore independence and freedom to people who have mobility impairments of different types and vision impairments and hearing impairments and a whole range of things we currently associate with disability. I think, in time, technology has the potential to erase the concept of disability because we'll be able to utilize technology to overcome all of the limitations that a physical disability and maybe even intellectual disabilities and other types might presently burden people with.

MG: There's one more question I want to ask and I'm not quite sure how to word it. I'm surprised by the lack of awareness [of] the ADA and the disability rights movement when it's something that by chance or by time, most people will face.

JL: So am I, actually. I don't know if it just comes down to human habit of avoiding an awareness of our mortality and our frailty because you really only think about disability – or at least in my experience, I never thought about it until I was experiencing it directly. I think a lot of people, unless they have a friend or family member who's gone through something or unless they're going through it themselves, they may not give a second thought to why access laws are important because, for them, it hasn't been an obstacle. If it hasn't been an obstacle, then it really hasn't been on the radar for their day-to-day activities.

MG: Well, I think I've asked all the questions I came here with. I've taken up an hour of your time. But I really want to make sure that there's nothing else that we didn't talk about. I can always give this a listen and see if there are follow up questions and come back.

JL: Yes, that'd be fine. I can't think of anything else I'd want to add.

MG: Well, if I go out the door today and you think, "Oh, I wanted to talk about this, too," jot it down and we'll gather it for next time. Thank you so much for taking the time and just telling me more about your story. I appreciate it.

JL: Well, thank you. I appreciate it.

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Reviewed by Molly Graham 9/24/2015