



Oral History and Folklife Research, Inc.

An Interview With Christian Powers

Interview Conducted By
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Westbrook, Maine
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Transcript by
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MG: This is an oral history interview with Christian Powers. Today is August, 7th, 2014. The interview is taking place at 30 White Birch Lane in Westbrook, Maine. I'm Molly Graham. Can I call you Chris or Christian? What do you prefer?

CP: Chris, is fine.

MG: Chris, just to begin, can you tell me when and where you were born?

CP: I was born April 24th, '75 in Augusta.

MG: What was growing up like for you?

CP: Moved around a lot. My parents divorced when I was three and my mother remarried when I was ten – actually, nine. It was sort of odd for me because – in the sense that I had an older brother, but I knew something was different for me at an early age of a kid. I didn't know what, what was exactly – I spent a lot of time at Boston General and Boston Medical getting tested for – I would say – just seemed like just about everything. I was sensitive to certain things. It made it interesting growing up because – I mean, the smallest things could be challenging for me. I knew I was socially awkward at a young age; I just didn't know how socially awkward I was. It was different because, unfortunately, we moved around a lot growing up. The most I ever spent at one school was maybe a year and a half. Two years, I think is the longest I ever spent at one school and that was like three different states. Between Maine, Illinois, and Missouri, we moved around a lot.

MG: How come you were moving around so much?

CP: Let's see. One was obviously my parents got divorced. Most of the time, it was just economics. It wasn't military family. It was just economics and when my mother and my stepfather got married, we moved out to Illinois because my mother was going to school. Then it was getting close to work, getting close to stepdad's work, couldn't afford to live where we were living, and just variety of reasons we ended up moving and ultimately came back to Maine when grandparents were getting old. It was OK, time to come, move back to Maine, and I don't think I ever really stopped moving, unfortunately. [laughter] It's sort of been my downfall in life, is I've never stopped moving.

MG: How would your mother describe you as a child?

CP: I was definitely one of those odd children, in the odd sense that I was very quiet. As far as going out and hanging out with friends, it was not something I particularly did. I was drawn to academics, probably at an early age. Hey, school is not a really terrible big deal, but the problem for me with schooling was that I was in the special ed. Rooms. I knew I didn't do all my classes with regular kids. Obviously, I had various health issues. I had hearing issues. I had sensitivity to things. I don't think I had a year of – actually, I think, in my entire schooling, I think I had one year where I actually went to school every day. I had trouble staying healthy as a kid. I really did. I had trouble – it was not

uncommon for me to push that button of how many days, the maximum you could miss for school because it seemed like if there was a cold or something around, I caught it. When she was raising two kids, and then, ultimately, when my mother got married, we had two stepbrothers. It was four boys in the house – made it a handful.

MG: You said small things were a challenge for you. What were some examples of that?

CP: Dressing. Even up until high school, I couldn't literally – and sadly, I still do it, unfortunately, is I would walk out and my mother would have to make sure that my clothes were right, because it didn't click to me. I could say some – I had a unique challenge, even today, but it's not as bad as today, where I would stay something and not realize what I was saying was offending somebody. It was rather strange, not knowing that you were saying something – might not be taken the way that you thought it was taken. As far as writing goes for me, I knew what I wanted to put down on paper, but I had trouble getting it down, so – my thoughts weren't always getting down on paper, and that was a challenge for me, going in through schooling. Obviously, I knew right away math was going to be a huge, huge problem for me because I just struggled in math my whole life.

MG: Did you have any favorite subjects?

CP: I'm a history buff. I really am. My bookshelves are covered with history books. Yes, I think my parents found out early on in age that – because my mother, when I was a kid, took me to Springfield, Illinois. That's when I fell in love with the Civil War. Since then, it's become an obsession along with a hobby. Yes. My parents found out early on that history and politics were my thing.

MG: What about the Civil War fascinates you?

CP: I don't know. There's just something about it that has intrigued me since I was a kid. I can't put my finger on it, but I would say eighty to a hundred-plus books later, flags – I've had guns. I've even been briefly a Civil War reenactor. It's definitely been something that I would say dominates a good portion of my life. Even today, I'm always buying the newest books and the videos and stuff like that. I'd do Civil War reenacting, but it's too expensive of a hobby to do.

MG: How would you say you were different from your brothers?

CP: Well, my brother, obviously, was almost four years older than me. Between the two of us, he was more outgoing than I was. He had ADHD. That made it even more unique. If he had a bad day, I usually sometimes got the brunt of it. But I was probably different because he was taller too. He didn't have the height/weight issues that I did. I think we were almost opposite worlds in some ways because of the fact that he knew my parents were divorced and he handled it, I think, because I didn't have any idea. I really didn't. Still, it was one of those – if he did it, I wanted to do it. If he did baseball, okay, I want to try little league, too. I didn't follow into football, but it was one of those challenges.

My mother had an ADHD kid and the other kid she knew had other issues, just weren't diagnosed quite what they were.

MG: Were you ever misdiagnosed?

CP: Probably a few times, I think I probably was. I don't know if – I mean, I can look through the reports from the schools today and scratch my head and wondering just how far off they really were. Nobody knew of Asperger's in the '70s and '80s. That word wasn't even talked about. They knew I had a learning disability. That was early on. They got that. They knew something socially wasn't quite right there, but I don't know if they knew truly what was going on, because the services really weren't there back then. When I was a kid, they weren't available. They stuck kids like me in the LD [Learning disability] room and said, "That's it. That's where you're at."

MG: For the record, LD is learning disability.

CP: Yes.

MG: How do you think growing up would have been different if you had gotten the Asperger's diagnosis early on?

CP: I think it might have made my life – I think if I had had a diagnosis then and the way the schools handled them a little bit better today, I think it might have been able to handle – tackle a lot of the problems, social issues, a lot of the minor issues head on and been able to get me the medications because I was – I mean, I was on a variety of different medications, but I don't think I was ever on the medications like I am today. I think it certainly would have made college a lot more different for me. I think certainly, it would have made high school different for me because the services would have been there for a post life after high school and a post life after academics. That's been the biggest struggle for me. It's been a struggle at times. Definitely if the services had been there as they are today, I think – I can't say what differences it would have made, but certainly, there definitely would have been some differences.

MG: Giving something you're confused about or unsure about a name, that kind of clarification does a lot of work.

CP: I was diagnosed in 2006 and really, I've spent the last seven years being able to look back on a lot of those things and making sense of them and trying not to label them because the last thing I want to do is label anything. At the same time, it has made life certainly interesting in the aspects that, I've been able to look back and point out things that I knew. Thanks to my mother, who was a social worker, I've been able to point out things and say, "Oh, yes. That's why that happened the way it happened. And that's why that did the way it did."

MG: Do you have an example?

CP: Well, definitely, like I said, I laugh at the fact that now when I do say something and not realizing it – I went to see one of my doctors not long ago, and he saw me fidgeting. I said, “Go to an autism conference, you will see more people fidgeting.” I think that’s what hit me the first time I went to my first autism conference in Massachusetts. Literally, I’m just sort of looking out, trying to gauge and study everybody. Everybody’s fidgeting their hands. They can’t stop moving. I’m like, “Yes. This is my crowd. This is my crowd of people. I know exactly that.” I will say being on the [Maine Developmental] Disabilities Council has been a real eye opener because that has allowed me to see things and be presented things and be able to travel and see different things. I think the Council has been a huge part of my life since 2006.

MG: Before we get there, I want to know how else growing up was different for you?

CP: Well, obviously, moving was tough for me, because as socially awkward [as] it was for me, I think it was even more challenging because every new school I went to, I had to learn the new teachers. I had to learn – they had to re-diagnose me. They had to go through all the paperwork again. It made it tough at times, getting to make new friends. For me, a hard part was losing those friends, because for me, I never knew how long I was going to be. We always hoped that that was going to be the last move, but we never knew. It made it challenging trying to keep friends and make friends. I literally do envy people when they say they went to school for most of their life. I’m like, “You have no idea how lucky you are in that, because I would have given anything for that.” I had that finally when I went to college, but even then – thankfully, I went to the same college for four years.

MG: Where did you go to school?

CP: University of Maine in Machias. I got my bachelor’s there and then I went and got my master’s out in Webster University out in St. Louis.

MG: Did you have any allies growing up, people you felt were close to you or you could relate with?

CP: Probably just people – if the word nerd came into it, I guess those are the people I associated with. I associated with kids who were like me. I didn’t know if they had autism, but I got to make friends in those rooms. I hung out with the kids that people picked on, essentially, because we were the ones who liked the academics, we were the ones who weren’t great at athletics. Those were the kids that I hung out with. I could make friends once I got there, obviously, in the social class standard. That wasn’t a problem for me, but obviously, I didn’t hang out too much after school.

MG: Were you aware of the disability rights movement and the Americans with Disabilities Act?

CP: The first time I heard about that act, I think was when I was in college.

MG: When was that?

CP: I think it was like in '95, '96 that I heard about it. I had no clue about it before then. I really didn't. I knew more about the Brady Bill and I knew more about probably other political acts going on, rather than the disability movement. At that time growing up, I really had no idea what the disability movement probably was until really after I got out of college and I started hearing about it. I would say almost it was not until 2006. Then I really got more – I started becoming [knowledgeable] of it.

MG: Yes. I was wondering if you thought it would have anything to do with you until 2006.

CP: I really didn't. I had no idea what the – I knew of the ADA act because I took some political sciences classes in college. I was a Poly-Sci minor. I heard about it. I knew. I'm sure I probably even had to write about it. If it affected me, I had no idea.

MG: What was happening in 2006 that led to your diagnosis?

CP: Well, my mother, being the social worker that she was had started reading up on Asperger's. The more she read up on it, and the more she read up on – she read this book. I came home one day, and she said, "Read this and check off all these things." [She] said, "I think you've got Asperger's." I was reluctant to get tested because I didn't want to get labeled. I figured, okay, I had enough of that labeling stuff going through schooling and all this. But I said, you've struggled with employment since and all these things socially, they matched up, almost to a T. I was resistant just because I said, I didn't want to get labeled. I didn't want to feel anymore awkward than I probably was, but it took losing – for me, I think ultimately, it took losing a job that I considered to probably be my dream job. That said, okay, I got to get [diagnosed]. I got to find out what's going on here. I just lost the job of a lifetime. I had this job in Boston working for a law firm – great pay, great office, and I missed every social communication cue that you could possibly imagine. I missed it. As a result, I lost the job. I was devastated. The next day, we went and we started getting tested. It was a persistent mother – ultimately, it was a social worker that finally said, OK, let's find out what's going on here.

MG: How's your life changed since 2006?

CP: Well, it's still been a bumpy road. It's definitely a struggle at all times. But it's definitely made me more open to now knowing what's going on out there, what things do affect me and what social changes and what employment changes, and why I struggled, where I continue to struggle – there's a reason behind it. It's definitely made – well, there's both been good and bad times.

MG: What have been some good times?

CP: Obviously, being involved with the Council has been one of the enormous huge – I’ve been now involved in the Masons. I’m an officer in the Masons and the Knights of Columbus. It’s gotten me to where I want to be able to show what I can do. I was married for a brief time and that was good, but it ended the way it did. Obviously, that was definitely one of the better moments in my life as well, even though it didn’t turn quite the way it did, but still, it’s been getting – I had steady employment. [I’m] hoping to rekindle that. It has definitely – it’s definitely highs and lows, but it’s been one of those that I’m able to look back at things a lot easier than I used to, but still it’s still – the challenges are coming more as you get older, that I have to live with.

MG: Like what?

CP: I’ve never been good with finances, so bills are a struggle for me. I always get tensed up around the beginning of the month and obviously payday. I get really tensed up about those. Like, “Oh, great. Did I pay on time?” I’ve struggled with finances, which has led to depression and anxiety terribly. It’s one of those, like, “Oh, great. What have I done wrong?” Everything from having a car reposed to having written bad checks, but it’s been definitely a challenge, both good and bad.

MG: What things sort of de-tense you?

CP: Volunteering seems to relax me. Being able to go for walks, just being able to get in my car and travel seems to relax me and even work, to some extent, does relax me. Well, now. It never used to. It didn’t used to, but now it does seem to relax me a little bit more.

MG: Tell me a little about getting involved on the Maine Developmental Disabilities Council, how that happened?

CP: That actually started out with a program they no longer have. They had a leadership program and my mother saw it and said, “You should apply for it.” I did. It was a two program, which the Council – I wish we could get it started back up again. We just haven’t been able to get any interest for it, unfortunately. But I went to this program and I got to see it, and I got to see what advocacy was about and be a part of it and stepped away after that for two years. About a couple years – about two years after it ended, one of my good friends, who was on the head of the Council said, hey would you be interested in joining the Council? I said, “Sure. I’d love to. I’ve been on it since 2010.

MG: What’s the mission of the Maine Developmental Disabilities Council?

CP: It’s to better advocate for people. It’s to get the word out on issues. We work with the Disability Rights Center. We work with advocacy program, housing. We’ve been pushing for the Employment First. We were able to push the R word out of the Maine State Legislature. Like I said, Employment First was one of the things we’re working and still continue to work on, which is a challenge in itself. So, the Council has a wide-

reaching appeal. We're constantly still working on that obviously. We're under new leadership we've had for now two years.

MG: Are there any special stories that stand out from your time on the Council?

CP: Probably just recently. A bunch of us went down to Washington, DC for three days, for an Employment First Conference. We got to obviously go and we got to sit down with our legislative body from Maine and we also got to hear various things. These are always interesting to go to whenever you get to go to them. This one was, I think, especially neat because it was in Washington. To sit down in front of congressman and a senator and say, "Hey, things aren't great at home. This is what's affecting us." I think the highlight was one of my friends – we sat down with Congressman Michaud, in fact, and said, "In this room you have three people with two master's degree and a bachelor's degree, but you wouldn't know it looking at us." He was sort of [taken] back by that. His reaction was great. We actually ended up doing that to all three other members of Maine's delegation and each time – their reaction, just seeing that and understanding hey, we just want what everybody else in this room has. I hope they got something out of it as much as we did, because we were there to get the word out to them and remind them. From what we've gotten back – (inaudible) we were hoping they heard us. Obviously, come November, we'll find out if they did.

MG: How is advocating for a developmental or mental disability different from fighting for ramps and physical access?

CP: They go hand in hand. I don't see any difference because the ADA, that's all included under the act. I have two good friends who are in wheelchairs and without those ramps, they wouldn't be able to do it. My grandfather's ninety-one. He just moved in with my parents and they've had to build a ramp so that he can get in. I understand. It's disability rights in general, not just whether or not you have autism or not. That makes a huge difference.

MG: This might sound like a silly question. What would be the equivalent of wheelchair access and ramps, access to public transportation and buildings for the autistic community?

CP: Well, obviously, it opens up opportunities. I can't go [to] a place anymore without me looking and seeing, is there access? Why is it not there? Why is not available there? I've gone to a number of – I would say transportation still lacks. I think Maine is far behind it. I think Maine is very poor when it comes to its transportation issues. That's something that gets brought up constantly at conferences, is if you don't live in one of Maine's, say, three or four major cities, the transportation isn't there. Now they've cut – essentially, the bus services have been – the smaller bus services have been essentially cut. It makes it even more difficult. Greyhound's not exactly ADA. Concord Trailways is not exactly – as good as a bus service as it is, I have friends who can't take that Concord Trailways. They can't take Greyhound because their wheelchairs aren't going to make it on those buses. That part is definitely still very obvious.

MG: What about services for people who have learning disabilities?

CP: They're there. I haven't gotten to go into the schools as much as probably would like, but obviously, computers have been a huge lifeline. I would say the laptop program has been a world, because it's opened up the autism community and the non-speaking communities that are able to have these tools now available to them. So, as technology's getting better available, it's helping people more, but it's still obviously – one of the things we're working, especially with the Council, is early diagnosis. We're pushing that it gets done before the age of two, so that parents have the time to get these services in place. Obviously, the one thing that I would still love to see that's not happening as much is once that child leaves high school, we can't stop – their disability doesn't go away. It's there for life. There needs to be better services and plan for adults, that there are available for children – needs to be on the same level, which it's not. I think once you turn adults, it's almost, "Okay. We're done."

MG: Can you talk about some of the connections or relationships you've made since 2006 or since getting involved?

CP: Obviously, the connections are with lifelong friends that I'll have for the rest of my life. Wherever I go, they're either a phone call away or email away or it's definitely opened up to having some people that I know definitely are true friends. It's even made it different where people see you differently. In my case, it's one of those, they see me in two different ways until I say it one way, until I tell them, because I don't exactly look like somebody with autism, but (inaudible) you say, "Oh, okay." It's always different when you explain that to them. But the friendships are definitely there. It's one of the great things about the Council, is that we're a very close-knit group.

MG: What things do you hope the Council tackles next?

CP: We're still working on the early diagnosis. I think the adult transition is something that I would love to see more worked on, because it's not talked enough about with adults – is what happens when that child becomes an adult and is on their own, if they have the opportunity to be on their own. If they're on their own, okay, can we make sure that the services are there, that I'm going to make them – so that if they aren't able to drive, can they get to work? Do they have the ability to work? Do they have the ability to have at least a close enough productive life with them? If they can, then great. Definitely I would love to see the adult services worked on, as well as, I think, the early diagnosis for children because that's certainly important that we get those services done in place, so that we can make – we can start at the beginning and make things easier. I don't know if those things will happen based on the current political climate that we're in, unfortunately. I'm fearful come November if our current governor is kept in place. If that happens, I don't believe – I respect the governor for who he is, but he has been the worst. He has a hatred for the autism community like I've never seen before. It's really unfortunate.

MG: You're talking about [Governor Paul] LePage?

CP: He has taken on DHS [Department of Human Services] and systematically – we have members from DHS that are on our Council. It seems like almost every meeting there's a new person in there. It's been hard to keep that continuity in there. As much as we argue and we advocate, at the end of the day, I hope whoever is in office, whether it's him, whether it's Michaud or Cutler, understands that not everyone has the financial means to do what they're able to do. To keep cutting our services and keep cutting the medications is making it more and more difficult each and every day. The political climate, I would say, in Maine, definitely has to improve.

MG: This is maybe another silly question, but what would say people who are not on the spectrum take for granted?

CP: Again, going where they need to go, not having to worry about sometimes about their mediations or their services that they need. Somebody normal doesn't worry about – okay, if the social security doesn't come through, am I able to survive? Can I get to the doctor's? Am I able to get a job? Do I have to worry about being discriminated for employment simply because I'm a normal person, not because, well, I have a disability now. I have to worry – that's additional discrimination that can be used against me. Having been down that road, I know it's not a pleasant feeling. Honestly, the way it is today, there's not much difference anymore, I think, between what's – I don't think there is a normal anymore. I really don't. I don't think there is a normal. I wouldn't know a normal person, I think, if I saw one, personally, because I just don't. Everybody seems to be in the same boat now.

MG: I saw that you were involved in the Autistic Self Advocacy Network. Can you talk a little about what that is?

CP: I have to remember when that was actually. SUFU? It's not SUFU, because I haven't been involved. I think that was part of the employment conference that I was part of. Again, that's connected with the Council. That's interconnected with the Council and what we do with them.

MG: What have you learned about Asperger's Syndrome since being diagnosed?

CP: That are a lot more of us than people think there is. You know what? Seven years later, I can't explain it. [laughter] I always get asked by people, "So what exactly is it?" I say, "Well, unless you have it, you really can't explain it." [laughter] I said, "Unfortunately, the best way I can explain to people is our minds don't quite work we would like them to work ninety-five percent of the time." It's one of those we do things by patterns, we do things by the way we do them, because it's the only way that makes sense for us. If they seem awkward to others, they seem perfectly normal to us. When the poster child is Einstein that tells you a lot.

MG: That's interesting you say that because I think there's a lot of misconceptions around Asperger's and autism.

CP: Yes, it is. That's been the one – I will say Congress and every legislature at least once says, "Okay, we're going to knock that word right out of the autism spectrum."

MG: What word is that?

CP: Asperger's. It's been on the cutting board a number of times in the last couple of years, that it's going to get – it wouldn't surprise me in the least, it probably does get cut out, but – I shouldn't say thankfully, but the numbers keep going down. The numbers keep going up for the autism spectrum. I think that's going to keep it in there, just because more and more kids are getting diagnosed every day and more adults. I think as a result of that, it's going to say, where as before it wasn't. It was teetering on being eliminated all together.

MG: Can you explain to someone who might listen to this interview, what the difference is?

CP: The best way I can describe [it] myself, would be that what others take for granted, I don't. I can't go out anywhere without planning what I'm going to do. I go to work, I have it planned out what I'm going to do. I leave in the morning. I plan out things. I have to have things a certain way. Most people go out on a Friday night to a club or a bar and take that for advantage. That's not something I can really do. That's a challenge for me just to do that, to be able to go out in a social climate like that, that I'm not comfortable with and to be able to interact with people going up to them and not feeling even more awkward than it already is. Definitely, it's a social and mental challenge. My wedding, I joked with people. For my wedding alone, I probably took more pills at my wedding than I probably wanted to just because I was – married, for a normal person is already enough anxiousness. Getting married for somebody with autism is like totally – I would love to do it again, but I'll have to make sure I have more. I think I'll have to make sure that I have better pills or something. That was probably one of those – I don't think I breathed for most of the day. It was a socially awkward challenge. Even to go to my brother's wedding last year, I had have to have plan – and I was the best man. So, it was okay, I had to have things planned in my mind. Like, okay, this, this. I had to keep things organized. At his wedding, I had a few extra pills in my pockets just in case that anxiety started kicking in. I had to back away. A couple times during the reception, I had to go outside, take a breather, because I'm like, "Okay. I can feel it coming on. Anxiety's kicking in. I got to step away here, because if I don't, I won't be good for myself." The average person can go to a carnival and go to a fair and not feel socially awkward and not feel anxiety. I can go into someplace – if I can control my environment around me, I'm okay, but if not, those events would be considered absolutely terrifying.

MG: What happens when your plan changes?

CP: Well, that's when you – a planner like me, I have contingency. I'm always having plan B, plan C in my head. But when they do change, it's a matter of just relax. Try to relax the body, relax the mind, say "okay," and adapt the best way you can adapt to it, but not to get overwhelmed by the moment. That, even today, is a challenge for me. If it happens suddenly, okay, I have to mentally get my body to relax, because I've already taken a pill for the day, so I can't take anymore. It's okay, what do I got to do to get the – every person's different in the autism spectrum of how they control their anxiety or they control the change in movement. Everyone has their own different little things. For me, like I said, it's a matter of getting my mind to refocus upon the situation. Sometimes, that can take a shorter bit of time. Sometimes, it can take a little longer, but not to show it. That's the other thing. You try not to show it, that what you're going through is – somebody might think you're just nervous. No, it's not nervousness. It's anxiety. It's a different type of nervousness. That's what you have to explain to people. I'm not nervous about the situation. It's my mind is not liking the change, so I have to get my body so it's not looking like it's having a terrifying experience.

MG: Can you describe that that anxiety feels like?

CP: It can feel almost like a sense – you're being trapped. It can almost feel like you're breathing into a bag. You can feel like you're enclosed in. You can really feel like you're enclosed in. You feel like you're trapped, you can't move, and you're losing control. I will say, the Asperger's thing is having that control. That's a huge thing in the Asperger's community, is having that self control, of your body and your mind. If you can't – you lose control of those, that's when the anxiety starts kicking in. If you lose either one of them, or if you lose them both, then that's even more of a challenge. It's hard to describe what it feels like, except it's inner terror within a person. Sometimes, even as an adult, I've had it where I've sat in a chair and I've not moved for a couple hours, just because I couldn't. I wanted to, but mentally, my mind was just – it had [taken] over control of my body and that was it. I wasn't moving.

MG: Before, you were talking about your wedding day and the anxiety you felt then. I was curious how you met your wife.

CP: We had actually dated in college and then broke up. When I moved back to Maine after living out in (inaudible) for a number of years, I found out she was available. I just started talking to her again. We rekindled, but ultimately, we found out we had differences. We probably should have lived together before we got married, but we didn't because we were Catholic. I will say my autism played a part in the marriage not lasting, because I had some trust issues. I had some mental issues that were plaguing me that were difficult to overcome. I think, ultimately, after three years, I think we both just realized it just wasn't going to work out. When she announced that it was going to be over, it hit like a rock, but at the same, it was almost a relief, because I was glad it was over. But, we've reconnected. Who knows what we're – if we were ever to give it a second shot.

MG: I'm wondering what negotiating autism is like in a relationship.

CP: Well, in this case, like I said, I married someone who didn't have autism. My wife did have a condition called radio club hand, which is a short hand. Her hand was deformed. She had disability. It was one of those – yes, I couldn't use my disability because she had one. But it was one of those – I think neither one really knew each other's disability that well. She certainly never used hers against herself. I tried not to use mine. I would say that was one of the things I loved about her. She was always making sure I tried not using mine. But, at times, I couldn't – it was needed and I couldn't be helped. But it definitely – one of the biggest challenges that I would miss on a lot of the social cues that probably somebody who was not – didn't have autism in a marriage would pick up on. I wasn't always picking up on the things that she was saying to me or not saying to me. I wasn't picking up on them. As a result, that lead to problems, because I wasn't getting the signals that I probably should have been getting. They just weren't registering. It definitely made it a challenge. It made it difficult when those things – as a result of that. I definitely know that was one of the reasons that ultimately it didn't last because of that. Marrying somebody without autism – which, I still would love to. I definitely want to get remarried, but to me, it doesn't – as long as somebody knows ahead of time, that “Hey, I'm bringing autism to the table. You can either take it or not.” [laughter]

MG: What things would help in a relationship? Would saying exactly what you meant help?

CP: Not [necessarily]. That would be nice, obviously, but at the same time, I'm not looking for someone to go out of their way, to have to. Unfortunately, it's one of those you have to learn to pick up on them better. That's something that I deal with, not just in marriage, but I still deal with in life, not picking up on the signals and the signs. I struggled with employment because of that reason, because I'm not always picking up on what is being said to me.

MG: What were the signs you were missing at the law firm in Boston?

CP: I think one of those things that I was not picking up there was – I think was their expectations of what exactly – I was, almost to the point of, waiting for them to take the lead. It was the opposite. They wanted me to take the lead more. It was sort of odd because as soon as I left, the position itself was eliminated, that I was there for. It probably wasn't the best, because I was living in a hotel for pretty much the whole month. I was going home on the weekends and then coming back down to Boston. I don't think I picked up on some of their comments that they was sending back as feedback. I wasn't always quite picking up on that. I think if it had been allowed to progress, I think it might have been better, but unfortunately, the law firm I guess, didn't have that luxury or for whatever reason they didn't have it.

MG: You said this was a dream job. What were you doing?

CP: I was a library assistant at a Fortune 100 law firm. It had offices throughout the country. Had a \$38,000 a year pay, a view of downtown Boston. Like I said, you couldn't get any better as where this place was and to go down to interview and then barely, two or three days later, "You want the job?" "Yes, absolutely. No problem." I was in love with the position. It was a position I felt like if given the time – unfortunately, where a lot times – and I've noticed this with different friends, people [with] autism need a little more time to adjust and adapt to their work environment. It can't happen just right away as much as we would like to. If it doesn't, that's where we struggle. I think if this had been allowed to, I probably would have done well, but I can also see where it would have failed, too, because I don't know if – finding a place to live was becoming a challenge for me. Obviously, I don't know how well I would have done in the Boston area living-wise. I've always been more of a small city type of person.

MG: You just were saying it would have taken you some more time to get accustomed to the environment. Does that have to do with your feeling that you want to understand your surroundings?

CP: Well, yes, surroundings. Getting a feel of what it was going to be like there, what the every day process was going to be like, getting better conditioned mentally to understanding what the cues, what they were saying to me based on their tone of voice or not what they were saying to me through emails. Because where I struggled a lot with them was I wasn't getting the gist from the emails. Unfortunately, emails don't talk. I wish they did, but I wasn't picking up on the mental cues in the emails that they were sending me either. But again, that would take time. That takes a little time to get adjusted to those.

MG: Earlier, were you talking about the possibility of removing the term Asperger's syndrome and just referring to it as autism spectrum?

CP: Well, actually, no. Congress and Maine, a number of state legislatures have talked [about] eliminating Asperger's out of the autism spectrum altogether.

MG: Making it separate?

CP: Either separate, but by doing so, it would almost eliminate any help federal-wise for services, essentially, that's what's come down – at times, Asperger's been on the chopping block for DHS. It's been on the chopping block a few times for federal government because it's not always viewed as autism, but it is. It's clearly defined as autism. But it's the challenge of – for years, its been keeping it in there, so that it doesn't get eliminated. Because if it gets eliminated, so goes the services that come with it, and the help that comes with it.

MG: Is that one of the things that the Maine Developmental Disabilities Council is –?

CP: We've worked on it, because through early intervention and obviously, I don't see it being eliminated anymore. I don't know how it can be eliminated anymore based on

every time the news comes on, it's more and more being heard. I think four or five years ago, you wouldn't have heard it on the news, now you hear it on the news. It seems like more and more every day. The one in sixty-eight number that just came out, which I pointed out to Congress. Said, "Hey, (inaudible) numbers went down, not up." So, I think because of that, I don't see it getting any more of it, but still, the challenge is making sure that the services don't get cut with it, because those services can still be cut.

MG: For those who don't know a lot about Asperger's or autism, can you describe the connection and what they each mean or how they're different?

CP: I don't really know if there's any much difference, because autism can be a variety of different disabilities, but at the end of the day, it's a mind or body. You're either on the high end or the low end of the spectrum in the autism – I know friends who have Asperger's who are on the high end. I'm considered the low end, because I'm not in a wheelchair. I don't have many of the physical challenges that many of my friends have. I do take medications. I do take asthma medication. I do have hearing issues. So, I do have some of the mental – some of the physical traits, but not quite as many as they do. To me, they go hand in hand. I have a friend who has cerebral palsy. He's in a wheelchair, but we're both – at the end of the day, we're still – we may have different names, but at the end of the day, they are still in the autism community. They're still a disability. They're still a developmental disability.

MG: Earlier you talked about what you hoped to achieve in the future, but what are some more realistic predications for the future and how things are going to change?

CP: For?

MG: For the disability rights movement and for autism advocacy?

CP: Well, when I can go to a conference in Washington, DC, and see almost nine hundred people in attendance from nearly every state represented, when you can see that the changes are being made when not long – when we were down there, we had mentioned to Congress that they were considering a bill called Combating for Autism. We said, the spectrum disorders – we say, "Can you please, for the – take the word combat off it. We don't like the word combat. I don't care what you guys have to change it to do, but take the word combat [out]. I'm not a disease. You don't have to kill me." Thankfully, this past couple weeks ago, that legislation, I think it's pretty much stalled now, but the word combat was taken off. We're getting out more and more. We're getting our voices heard more and more. The councils are all figuring out, hey, if we team together, rather than do it – if one state has a good idea, okay, let's share that with the other states and see if it'll work. Maine's program for getting kids diagnosed at an early age has caught on to a number of other states. The Employment First has now caught on – it seems like more and more states are now dealing with – all of the sudden, the disability community's hey, we want equal opportunity, we want equal footing. You're seeing more of it. The political climate is changing enough where the autism community has basically come out and said, "Hey, you got to hear us." I would love to

see an autism march on Washington. I told a friend one day, I said, “That would be the one – every group throughout history has had a march on Washington. We’ve got to have ours. Let’s have our walk on Washington.” I would love to see that.

MG: Are there any state models or programs that you point to that would be great for us to have?

CP: I know the State of Washington itself has had a few good little models that we’ve seen. Some of the progressive states have – Pennsylvania’s had a couple good ones in recent years. I know Georgia’s come out with a few good as far as food. They had a really good one where – as far as food markets were concerned and growing food and that was doing well. So, every state – seems like every time a state comes out with a new idea, word gets out about it. It’s helping because now, you can email, you post it, and I think the social media’s definitely helped that go a long way. When you go to a conference you can leave – people are passing out website and email addresses, so that you can stay in contact with them. If they know something, they can pass it along a lot easier than it used to be. If a state legislature’s not doing something they should be doing, all of sudden, okay, states, they can gather support for them in ways they never thought possible.

MG: What have been some setbacks in the disability rights movement?

CP: Well, unfortunately, for Maine, I definitely would say the last four years as governor have been setbacks for us because when DHS is constantly being changed, it’s constantly being rewritten. Portland alone is thinking about moving its office over to South Portland, its DHS office, which currently is on marginal way. Now, they want to move it down by Scarborough. Well, that doesn’t help the people because the transportation is not there as easy for people to get to that office. They would have to take a bus and where it’s currently at ideally, is a perfect location for a lot of people, not just Portland, but surrounding communities. But to move it where the governor is suggesting he wants to move it, would be disastrous for a lot of people, because they don’t have a way to get over there to Scarborough as easy as they would like to. Unfortunately, it hasn’t helped in Washington that Congress doesn’t want to work with each other. That has ramifications for everybody, including the disability community that – just caught on the news two nights ago that kids were – they’re now using Tasers on kids in group homes. I’m just like, “Wait a second. Why are Tasers being used? So the kid doesn’t hurt himself? No. He don’t need to use Tasers.” I was floored by watching this news. It almost seems like when you think there’s change being done, there seems like there’s a way someone’s wanting to take two steps back. It definitely makes it for awkwardness.

MG: You mentioned earlier, Einstein as someone –

CP: I’ve seen him on a number of posters. I don’t know – a group called (inaudible) has his – out there. It seems like a number of autism conferences I’ve gone to, I’ve seen his picture. I didn’t pick up onto it until I read and said, “Oh, yes.” It’s sort of a kick now, people trying to go through history and find out people that might have been diagnosed it,

who had the signs of it. Everybody points to him as having all the signs. I'm like, Oh, why not? That's a plus for us. We created the bomb. Why not? That's a plus for us."

MG: Does that help, when certain people can point out the special skills?

CP: Well, I don't get offended when some of the celebrities come out now. Some people think, "Well, they're just saying for publicity purposes, when celebrities come out and say, 'Hey, we've been diagnosed or I have it or my children has it.'" I think in a lot of ways that's a plus because it gives a face to it. Susan Boyle coming out and saying she had it gives a face to it. These athletes, professional athletes coming out, saying their children have it, gives a face to it. With that face can come funding. All of a sudden, doors might get opened a lot more easier because they have that influence that some people, ordinary people might not be able to open up. As long as that person's coming out for the good reasons, to say it, and not just trying to say it. Because I've heard a couple celebrities come out and say (inaudible) I can tell the reasons weren't sincere. As long as everything's sincere and they're going to do something about it. If they're in a position to do something about it, do it, then I'm all for them coming out and saying, "Yes, I have it."

MG: Yes, I'm thinking particularly of the work of Temple Grandin.

CP: Yes, and I've met her. I think she's been one of the better poster [children] literally for coming out and doing – because people know her, not just in the autism community. It does help when you see those things, when people have a face with it. We've even made it to *South Park*. So, we've been laughed on by *South Park*. I told my mother when I saw that about a year ago, I said, "Asperger's has arrived; we just got slammed by *South Park*."

MG: What happened on *South Park*?

CP: They had a character that was – I can't remember totally about it, but I said, "Hey, guess what? We've arrived. *South Park* has made fun of it. So, we're in a good position if *South Park*'s made fun of it."

MG: I'm curious about what you think when you see depictions of people with autism on television or in movies.

CP: My ex-wife was great about this. She would love to see people with disabilities being portrayed by actually people with disabilities. Growing up as a kid, now looking back, I think *LA Law* had a character. She pointed out the one character in *Facts of Life* that had autism, but it would be great if they were done by the people that are actually – it would be nice to see a movie about Franklin Roosevelt and actually showing him in the wheelchair. I'm glad they've finally come out and made that monument that has him in a wheelchair finally, because hey, he had it. It's hard to watch sometimes. It really is. For me, it's hard to watch because I think it was in the movie *Tropical Rain* [*Tropic Thunder*] that was – it got a lot of slack and I have to admit I'm not a big fan of the movie just

because it got a lot of – it made fun of people and the character in – it got a lot of flack from the autism community and I saw why, but at the same time, I even laughed in the movie, too. When *Rain Man* is considered – I would think *Rain Main* is probably as close as it's come in the last couple of years.

MG: What's been a personal source of pride for you?

CP: I think just being involved in the community. I'm never one that's satisfied. I'm a perfectionist. So, I'm not one of those people that – I don't really look on too much of my own laurels as much as I look onto everybody else's. I'm not one of those that – everyone says, "You should be proud of this, this, this and this." I'm like, "Yeah." It's me. I don't really look on – I don't look on those things too much.

MG: Even though you weren't aware of the ADA until a few years after it passed, can you point to any differences it's made in your life?

CP: Obviously, I don't think I would be – yes, employment opportunities would be available as they are for me today. Obviously, housing certainly wouldn't have been available for me. I've got housing I'm in because I have a disability. Otherwise, I might be still waiting on the housing list. It's opened up housing opportunities. It's certainly allowed me to get the necessary medications that I need to be able to get through my life. I think a result of that law – which it still needs to be worked on. It's not even been passed by every state. The fact that I can live my life, for the most part, fully, is something I wouldn't have probably been able to do without that law. But, it's a work in progress, though, twenty years later. It definitely still needs to be worked on.

MG: I think you touched on a lot of what still needs to happen.

CP: Yes, because not every place is in compliance. Twenty years later, you can still go around almost any town and see where it's not in [compliance]. You can see businesses that aren't compliant with it. You live in Maine. Unlike some states, transportation's still not there. So, if you live in one of the Maine smaller communities – I have a friend that has a friend that lives in Windham. He has to have somebody who will take him to work because there's no bus service for him to get to work. That's a difficult thing for him because there's no bus service for him or it doesn't run on a schedule that – he has to work, he has to have his schedule work around his friend, which makes it awkward.

MG: What would you want someone who might listen to this interview to know about your experience?

CP: Probably that it's a learning progress. It's a work in progress. It's constant learning. It's not being totally set on what's happening. So, I think as a result of that, I don't think I've – for me, it's still wanting to be in a place where I want to be and I know I'm not there.

MG: What would you want them to know about the ADA?

CP: That it's a work in progress like any [legislation]. Like the Constitution, like any federal legislation, it's a work in progress. About the only way that progress is going to be done is if people don't sit down and look at it and do nothing. It's getting out and making your voices heard by any means necessary.

MG: How would your life be different if you hadn't gotten that diagnosis in 2006?

CP: Probably a lot more difficult, because obviously, like I said, I've gotten the health services that I've been able to need. I've gotten the medication. I think my anxiety would have gotten a lot worse. I don't believe I would have gotten married. I don't know if I would be more – I don't know if I'd be actively socially in organizations that I am today. I think I would have continued to struggle with employment. I think I would literally would have continued to struggle with employment, with life, in general. Literally, would have been a struggle. I think it would have been harder than it already is for me.

MG: You talked earlier about how you have a plan and then some contingency plans. I was curious what your plan for the rest of today is.

CP: Well, let's see. I got to go from here. I have to head into Portland, pick up a charger, mail a few things and then coming home.

MG: It's pretty simple today.

CP: Today's pretty simple. Tomorrow's work. So, tomorrow, Saturday and Sunday are work.

MG: What do you do at the Hotel and Tavern.

CP: Front desk. Unfortunately, I can't make beds. I'm not great at beds. Sadly, this is an industry I've been part of for almost fourteen years.

MG: Why do you say "sadly?"

CP: I say sadly because it's an industry that I fell into, because I was going to school. Not to be able to do what I went to school for all those years, and I'm in debt until probably hundred and fifty is discouraging. It's not what I went to school for. Certainly, to be limited by – when you go to work, knowing you're limited by the amount of hours you can work, and you have to be mindful of how much you're getting paid. It makes it tough. You try not to think about those things that when the schedule comes out, you have to think about those things. When you get paid, you have to think about those things. I would say right now, I'm working at a place that is enjoyable. After working at a lot of low-scale hotels, I'm finally working in an upscale hotel. It's a different, better, clientele for me to deal with. But I love the interaction with people, and I love the interaction with the guest and everything. Thankfully I'm with a staff. I'm with people

that do understand what I have. I think that's sort of helped in having employers that know what they're getting in store with me. Obviously, who knows? I wouldn't mind running my own bed and breakfast someday. So, that's something that's always been in the back of my head.

MG: When, in getting to know someone, do you explain you have Asperger's?

CP: It sort of depends on the environment. Really, it all depends for me on the environment. I don't come out and say it unless it's important to somebody. If they don't know I have it then I don't bother saying it. It sort of depends on the environment and time where I'm at.

MG: Well, Chris, I've gotten to the end of my questions, but I really want to make sure that there's nothing I'm missing or if there's other stories you want to tell me.

CP: I'm good.

MG: Well, what I might do is listen back to this and if I come up with any follow up questions, I'll reschedule. Otherwise, I'll send you a copy of this CD.

CP: Great.

MG: Thank you for spending the time me. It has been a real treat to get to talk to you.

CP: No problem.

MG: Thank you so much.

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Reviewed by Molly Graham 2/7/2016