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**ORAL HISTORY INTERVIEW WITH
LAWRENCE CARTER-LONG
DECEMBER 7, 2015
INTERVIEWER: JANE HARLAN-SIMMONS
VIDEOGRAPHER: PEGGY HOLTZ
RECORD ID: 035-DO**

**LCL: LAWRENCE CARTER-LONG
JHS: JANE HARLAN-SIMMONS**

[00:00:10]

JHS: And you can look at me rather than the camera.

LCL: Okay, got it.

JHS: All right, so if you can start just by telling us your name and where you're from.

LCL: Sure. My name is Lawrence Carter Long. I currently live in Washington, DC. Grew up in Indianapolis, Indiana, and was here 'till I was 10 years old. And then Terre Haute, Indiana, until I was 18.

JHS: I didn't realize you were from Indy too.

LCL: Yeah.

JHS: You're the Public Affairs Specialist for the National Council on Disability. Can you tell us a little bit about what that position entails?

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LCL: I'd be happy to. The National Council on Disability is an independent federal agency. And we recommend disability policy to the President, to Congress, and to other federal agencies. We don't have enforcement authority, we can't make them do the things that we recommend that they do, but we can certainly use the bully pulpit. Which is what we did with the Americans with Disabilities Act 25 years ago, in order to push certain pieces of legislation or certain policy positions forward in order to benefit Americans with disabilities.

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[00:01:12]

JHS: Okay, you're recognized as an expert in the area of media and disability. How do you see the portrayal of disability in the media as having an impact on the larger culture and its perceptions of disabled people?

LCL: We're at a very interesting time in our history and in our culture regarding the depictions of people with disabilities in the media. And this would include television, this would include movies, this would include audio and radio. We're seeing more and more efforts like the one that you are doing, where it's not someone else speaking on behalf of the person with the disability. You don't have the teachers or the preachers or the social workers sort of pushing the agenda, but more and more there are opportunities, whether it's via the Internet, YouTube, Facebook, for people to blog, to put their own stories out there. And so I think what's happening now is we're seeing a change in the types of stories that are being told. It used to be the disabled person on the outside of society. It was always monochrome in terms of them either being tragic or heroic. Anybody who's lived a little while knows that life is more complex than that. It's more complicated than that. There's a lot more color in the spectrum. But sadly, up until probably the last 10, 15 years, with very rare occasions, we didn't get a chance to see that. I think with more disabled people being creative behind-the-scenes, whether it's writing, producing, directing, acting, whatever those efforts might be in terms of telling those stories, the stories that we're hearing, the stories that are coming out now, and this is something relatively new in the last 5 years or so, really. I have seen that kind of catapult forward. We're seeing more complexity in those stories, more depth in those stories, more authenticity in those stories, and as a result, they've become less lazy and they've become more interesting, because the nuances are all there in ways that we really haven't seen before.

[00:03:08]

JHS: Great. What do you think is the driving force behind these changes that are happening in those portrayals?

LCL: There are numerous driving forces behind that happening I think right now at our point in time in the culture. Part of it is technology. You can't deny it, you know, 5, 6 years ago, there was no YouTube. You couldn't just take a video on your phone and put it up there for anybody to see. You can do that now. If you do it with some creativity, with some panache, with some sort of a little different spin, right, coming at from left field and from right field. You can get some traction. You can get some attention. People are no longer limited to the, let's say, television networks, you know, NBC, CBS, ABC, PBS.

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They can produce a web short, a web series, that's 10, 15 minute episodes on their own. Boom, it goes on there, they get a following, they can get funding to actually do the real thing, whether it's a short film or whether it's a feature length. So people now, the blockades have come down. The gatekeepers no longer have the same types of power. If you've got ways to put something creative together, because of things like Facebook, because of ways for people to connect and come together, that can push that material forward, give people an opportunity to see it. And more and more, we know that people are hungry for that. They're tired of the same old same old, tragic heroic stories. They want to see more complexity. They want to see themselves represented. And I think we've got more and more

opportunities not only to create it and produce it and put it out there, but we're seeing more and more people writing for themselves, directing for themselves, producing for themselves. They're not anymore relegated to say, you do this for me, trying to put forth that effort. No, they're taking it into I think they're taking the responsibility for themselves and creating it themselves. And that's making all the difference.

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JHS: These are real see changes and very positive. It seems like when groups have sort of pushed themselves forward more, there's always pushback. Are you finding that, are you seeing that as people with disabilities are more out there, are they facing some pushback that they wouldn't have gotten otherwise?

LCL: There's always going to be pushback. I think if you're pushing the envelope, it's part and parcel. It's part of that process. I don't think it's unexpected. And in some ways, I think it's necessary. You know, when we put together, Heidi Latsky put together the dance company, and when we had the Gimp Project, a lot of people that were nervous, hesitant to use that word. Why would you call yourselves gimp? You know, and we'd say, well, look at all the various definitions of that word. It's fighting spirit or vigor. It's trembling with ecstasy. It's, you know, the obvious one, one who limps or hobbles. It's interwoven fabric. There are multiple definitions of that word. If we're only limited, if we're only thinking about one of them, we're missing out on everything else. Part of the reason that we named that dance ensemble, that piece that we did, Gimp, was to bring together all of those different definitions. Now, if you have a limited way of thinking, if you're not used to challenging yourself, you might bristle at that phrase. But we found that once people became aware of all those other definitions, they would come on board, once your minds are open, right, once you see the work for itself. And I think the complexity of the work, the integrity of the work, people's minds are opened. And I think that's what art should do.

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JHS: In raising the issue of language, I know, is one of your many interests. Maybe you could talk to us a little bit about the issue of how people, disabled people, want to refer to themselves to the extent that you can generalize a group of people. Because, of course, you know, there's the whole people first language, movement, that we've had. And it seems like now there's some going beyond that in a new direction. So if you could just comment on that.

[00:07:09]

LCL: Sure. As a self-professed word nerd, and a proud one, I'm finding what's happening in the culture is reflected also on what's happening with language, and they push and they pull each other. They force the culture to move forward. They force the language to move forward. You know, there used to be an assumption, right, because disability was thought of in the old medical model, that it was something we needed to distance ourselves from. That it was something that we needed to put forth. And we were more than that medical condition, that we were people first. And I think what we found in the post ADA generation, that there's a new crop of people that are saying, wait a minute, I'm not ashamed of anything. I don't need to distance myself from anything. In fact, I am a disabled person first, right. And

that they have to put the community forward. They recognize that it's bigger than themselves, and that they're not at all shy about doing that. I think that's reflective of the evolution of language and reflective of the evolution of culture. And yes, there might be some tension there, but that tension always forces people to rethink, to redo, and to move things forward in a different direction.

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JHS: You're also an expert on cinema and disability. How do you see the betrayal of disability in film specifically as having an impact on the larger culture and its perceptions of disabled people, and in what ways has that portrayal changed over the years?

LCL: If you think about the ways that cinema informs our culture and our culture informs cinema, you can separate one from the other. When in 2012, we did a history of disability in film on Turner Classic Movies. Now, that reached 87 million people. And I had the daunting task of sitting down in an attempt to curate this, to watch 237 movies, to decide the 20 that we were going to show. And I knew that in order to be fair to the different communities within the larger disability community, to be fair to the rabid fan base within Turner Classic Movies, you had to have a broad selection. You had to reach a variety of different people a variety of different ways. And you had to give them some combination of films that they thought they knew, that they were familiar with, but maybe had never considered from a disability-centered perspective before. So you're re-looking at films like "An Affair to Remember," that are beloved. Or films like "Miracle Worker." Or films like "Best Years of Our Lives," through a brand-new lens, through a slightly different perspective. And then what we were also able to do, because of Turner's library, is go into the vaults and find films that were significant. They were doing things a little bit differently in the '40, a little bit differently in the '60, that hadn't been released on DVD. Maybe because they didn't have the A-name director, or they didn't have the A-list actor. And say, this was significant for that time, this is what they did, why aren't we doing it now. So you have film like "Sign of the Ram" that was done in 1948.

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They built this vehicle for an actress named Susan Peters. Susan Peters was an up-and-coming star. She had become injured and a wheelchair user as a result of a gunshot accident. And the studio loved her so much, they bought the rights to this book, "Sign of the Ram," where the protagonist, the matriarch of this family, was sort of hell on wheels, literally, a wheelchair user. Kind of a Joan Crawford character, right. And it was a revered performance. She chewed the set up on this thing. And, you know, because that film had never been released on DVD, it had been lost to history. And so part of the question, we could bring that out of the vault, we could put it on TCM. We could show it with audio description and with open captions. And we could say, if they can create a vehicle and produce a vehicle for a disabled actress in 1948, why aren't they doing more of that in 2012 or 2015 or any of the decades since. And so it was a fantastic opportunity to look back as a way to position ourselves and to say, how do we want to move forward. And I think we continue to do that. You know, cinema comes into somebody's living room in a way that a dance performance can't do. It comes into your living room in a way that a theater troupe can't do. They're going to wreck the house, right. But with Netflix, with things like YouTube, you can click the remote, there it is. And you can sit, you can think, you can reflect, and you can maybe go

back and watch another one. I think we've got the smorgasbord at our fingertips in ways that we never have before.

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JHS: And you provided kind of a lens through which people could look at those films. Dance performance is one of the ways you get involved in the arts. We'd like to hear about that. And you started to talk about it.

LCL: Sure. It was quite the surprise to me to find myself being involved in modern dance. You know, I'd grown up as a person with a disability. I'd never shied away from it, I'd never been ashamed of it. But when you're there in your high school, talking to your high school guidance counselor, and you're going down sort of the list of things that you might want to do as a career, which I did in the mid-'80s, modern dance was never an option for me, and it was never anything that I thought about that I could do. Never even considered. Sort of like being a linebacker, you know. It wouldn't even enter my consciousness because of my physicality and because of having cerebral palsy. It wasn't until years later, until I was in my 30s, and I was doing -- to connect it back to film for a second -- a film series in New York City called "Dis This." And the tag line was disability through a whole new lens. And we talked about it as no handkerchief necessary, no heroism required. And I had a reporter from the Hollywood Reporter say to me, well, what else do you show then, right. And it was kind of amusing and yet frustrating at the same time, to say, exactly.

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So if it's sappy, safe, or sentimental, we don't show it. If it's what you expect, we don't show it. So it might be independent. It might be foreign. You know, it might be edgy. A bit in your face. A raised fist, if you will. And my question to myself when we began that series was, will an audience show up. If we put this out there, we give people an opportunity to see something they may not have an opportunity to see otherwise, will they come? Or will I be the only one sitting here watching movies I already like, eating popcorn? And what we found was with the first screening, it was 25 people. In the second screening, it was 50 people. In the third screening, it was 75 people. In the fourth screening, it was 100 people. In the fifth screening, we couldn't get any more in the room. We go, we're on to something here. And it wasn't only screening the films, it was the discussions that we'd have afterwards. There was this organic coming together of community people that were hungry to see something beyond the tragic heroic depictions that they'd become accustomed to. And they were like, wow, I'd never seen a romance before.

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Wow, I had never seen an action movie before. Wow, I'd never see a documentary about a punk band with intellectual disabilities before. You know, and their minds were blown and they were eager and they were hungry for more. And in the midst of showing those films, the first year of showing those films, I screened a film called "The Cost of Living." It came out of a physical theater company in England called DV8. And one of the performers was a gentleman is a gentleman that has no legs. And the question that people and I wanted them to ask themselves, and actually the question I asked myself is, how do you dance without legs? Something that had never even occurred to me before. What they

depicted on film, gorgeous, beautiful, something unlike I'd ever seen before. And it planted that seed in my brain.

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And I thought, well, okay, you can't just be doing the same one, where else are they doing it? Maybe the Internet. I look around, Axis Dance Company out in the San Francisco Bay area, was having their week-long intensive. It was kind of a crash course, you know, choreography, different ways of movement, kind of getting into inhabiting the space within your skin, if you will. I'd never done it before, so I was very curious to say, well, what's going to happen if I go to a place like that and I am forced by design to communicate without opening my mouth? How does that happen? I'm very used to talking. I'm very used to writing. And so I just went out there kind of on a whim. You know, I applied, they accepted me, and I just went into it wide-open to say, where is this going to go. And it went places that I never could've imagined at that time. I met friends out there, people who are still colleagues. A woman by the name of Lisa Bufano, who has since passed away, but she was a bilateral amputee. Which means she has amputations on all 4 limbs, below the knees, no fingers on either hand. And gorgeous, gorgeous dancer, you know. And so Lisa and I become friends. Lisa gets a [inaudible] grant to come to New York City, which is where I lived. And she starts working with choreographer Heidi Latsky. Heidi Latsky hadn't worked with disabled performers before, but Lisa hired her.

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Heidi and Lisa start this collaboration. As a result of that, because I was tapped into the disability community, I was doing things like "Dis This." I was the program coordinator for the Disabilities Network of New York City. They'd asked me because my background in media and PR to help promote the show. So they each had solos in this show. I was happy to do that, right. So I'm getting the word out on web servers, making phone calls and pitches for media. And at the end of the show, they have the wonderful premier, very warm response by the audience, everybody was pumped. As we're leaving to go have a drink afterwards and to celebrate the success, Heidi, the choreographer, is sort of watching me move, right, and she says to me, I've been dancing for 30 years, I can't move like you. And I'd love to work with you. And because even though I'd done the Axis dance intensive and even though I'd screened the film "Cost of Living," and I'd been introduced to dance, I was still thinking she wanted me to do PR for her on some level.

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I said, I'd really love to but I'm super busy and I just did this as a favor. And she stopped me, and she said, no, no, as a dancer. And because I couldn't conceive of myself doing that or how I would do that, I said, well, I guess we have to. There was no other option. There was no way out at that point. I was like, if I couldn't conceive of it, yeah, I had to dive in, and I had to try. And it was a result of that collaboration that, you know, I got connected with the other dancers in her company. We brought other people into the company. It became a show. It started to be called Gimp. We started touring. And it became, you know, this whim sort of, this adventure that, you know, now has 3, 4, I think, different casts and has a life beyond the cast that originated it. Which I was glad to be a part of. And so part of the magic, I think, of something like dance now is we're seeing younger people with disabilities who don't have to wait

until they're in their mid-30s to start exploring the space inside their own bodies and the movement of their own bodies.

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And are starting to question, how do we dance in the bodies that we have? How do we dance in the bodies we've got? What does that look like? What does that feel like? How do we put that out there in front of audiences? What's the esthetic of disability dance, and how is that different from classical ballet and modern dance or any of the other types of dance that are out there? So it's a brave new world of where there's this collision of dance and disability that nobody ever could've anticipated. There was some room out there for a period of time, a wheelchair dance. But if you were an amputee, if you had cerebral palsy, if you, you know, many different things, nobody had really done it to that degree before. And I think we're still in the infancy stages. But I'm getting emails all the time, you know, I get people contacting me on social media all the time, saying, I saw the film clip from Gimp, you know, how can I do more, and what can I do in my community. And we see companies popping up in places like Atlanta, and out in Portland, Oregon, and across the world giving people the opportunity to inhabit that space within their skin that's unprecedented that we really haven't seen before.

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JHS: And since you're kind of talking about the arts, more generally with the arts, what trends do you see for disabled performers and other disabled people in the arts? I know this is a really general question. But, you know, writers, visual artists as well, do you see some overall trends in terms of the intersection of arts and disability?

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LCL: I can see for myself that, if I hadn't had the background in the arts, if I hadn't taken a theater class in high school, and I hadn't had that teacher encourage me to audition, that I probably wouldn't have taken -- I can almost guarantee that I wouldn't have gone the path and direction and the trajectory that I did. It was sort of being in a position to put myself out there on stage and having to bring the goods, deliver the goods. You know, you're up there in front of a few hundred people, you can't fudge it. You know, you can't BS your way through it. You've got to bring it, you've got to do it, you've got to commit to it, you've got to have the discipline. That's what we did with Gimp. The sad reality I think of our culture in some ways is that if you are a performer with a disability, you've got to be better than good to even get noted. The expectations for you are so low, that you basically have to blow the doors off and blow people's minds for them to go, whoa, I've never seen anything like before. And what I think is happening more and more within the arts community is people are -- whether arts' programs are being defunded in schools and those sort of things that were available to me in the mid-'80s, aren't available to many students now. But I think there are other arts' programs within communities. There are arts' programs that people are developing among themselves even to really, you know, in terms of some of the Internet work, to create something new, to create something different. I think that urge is primal. I think that urge is something that is always there. We've always had some sort of story inclination to tell stories and to make meaning and to make sense of the world around us. And that's been as true for people with disabilities as it has been for anybody else. I think probably what's happening now post the

Americans With Disabilities Act, is we're not resigned to second best anymore. We're not resolved to say, okay, we have to go in the back door, we have to get that the table scraps. But the people are just taking the bull by the horns and they're creating that work themselves. And I think that's new, and I think that's fresh, and I think that that's innovative, and it's something that I'm very excited to see across the board.

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JHS: Well, my last question, you kind of touched upon when you talked about that theater class. But what was it like for you growing up in Indianapolis and Terre Haute. I mean, this is the Indiana Disability History Project, so feel free to name names and places, you know, especially that class if you want to talk about exactly what school that was. But yeah, what was it like? Did you have some formative experiences like that that shaped your later involvement with media, film, and the arts?

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LCL: I can say without any hesitation that my work with my theater class there, I think I was a junior in high school, was absolutely foundational and absolutely formative. It forced me to expand in ways that I imagined were possible but didn't have the practical experience. And what happened with that class, and all the credit in the world goes to Jean Shutt, Terre Haute North Vigo High School, who saw something in me that I didn't see in myself. And I think largely I didn't see it in myself because I hadn't seen it reflected in the media around me. I hadn't seen it in television. I hadn't seen it in movies. So being an actor was nothing -- and I was always something of a ham. It was nothing that I thought that I could actually do. And so it was the teacher, it was the teacher who said, you need to audition, kid, you need to put yourself out there, you're good at this. And she didn't take any guff, you know. She didn't allow me any slack, didn't cut me any slack.

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And she pushed me to be as good as I could be. And she forced me to do things that I wouldn't have imagined possible. And when I went away to college, you know, it was Kay Butler at Southeastern Louisiana University, who took that and I think pushed it one step forward. So if I wasn't announcing to the degree that I needed to be for that role, she put marbles in my mouth and made me rehearse with everybody trying to enunciate with the marbles in my mouth. Embarrassed me to the point where I was never going to do that again, you know. It was that commitment to excellence. It was that dignity of risk that said, I should be allowed to fail just as well as anybody else. You know, crash and burn gloriously. And until you put it all out there and you have that opportunity to say, all right, time to put up or shut up, pal, you're never going to know what you're capable of. I knew that when I went out on stage, in a Jean Shutt production, that I had to bring it.

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I knew that when I went on stage with a Kay Butler production, I had to bring it. And, you know, when were I think maybe 6 weeks into rehearsals, where one of our key cast members in a show became ill, and she all of the sudden moved me from the role that I had where I had maybe a dozen lines, to one of the leads in the show. And she said, you can do this, right. And I got a tape recorder and I'm memorizing my lines and I'm pulling my hair out, but it's been largely because she had that belief that I could do it, that I discovered that I could. And I think it's that kind of commitment, right, that kind of willingness to sort of jump into the abyss that people with disabilities actually almost have an innate ability to foster and to embrace. Because we are forced to live in a world that wasn't built with us in mind. Where the architects didn't think about us.

And so we have, whether we know it or not, kind of the skill set to jerry rig things, right, to adapt and to maneuver, and to try to figure things out, because we have to just getting in the building. And but that's only going to go so far, unless you foster it, unless you give it -- unless you pour some water on it, plant some seeds, and let it sprout and let it grow. And I think if we did that not only in the arts, but if we did that in business, if we did that in entrepreneurship, and we did that in so many areas across the board, we continue to see how it benefits all members of society. You know, text messages were first put out there for people who are deaf. Now who among us doesn't text, right. Something for a segmented community folks thought that no one else would use it, now basically everyone uses it, right. My 65-year-old mother uses it. And I think it's having that kind of commitment to innovation, that when we include people with disabilities, everybody else benefits.

JHS: That's great. Yeah, that's fantastic. I've asked all the questions I wanted to. If there's anything else you want to add, I'm sure.

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LCL: No, I think I think I covered it.

[END OF INTERVIEW]