



TRANSCRIPT

Key Conversations with Phi Beta Kappa

Exploring Disability as an Identity with Professor Rosemarie Garland-Thomson

Professor Rosemarie Garland-Thomson is a disability justice and cultural thought leader, bioethicist, educator, and humanities scholar. Garland-Thomson grew up with a congenital disability, an experience that highlighted the barriers that exist for people with disabilities. Inspired by the Civil Rights movement and hearing the narratives from Black authors for the first time, the disability pioneer explores the perspectives of disabled people in all aspects of society. In this insightful conversation, Garland-Thomson discusses the destructive idea of normal, the reality that most people will become disabled at one point in their lives, and the ways that barriers create social categories for people with disabilities.

Fred Lawrence: This podcast episode was generously funded by two anonymous donors. If you would like to support the podcast in similar ways, please contact Hadley Kelly at hkelly@pbk.org. Thanks for listening.

Hello and welcome to Key Conversations with Phi Beta Kappa. I'm Fred Lawrence, Secretary and CEO of the Phi Beta Kappa Society. Since 2018, we've welcomed leading thinkers, visionaries, and artists to our podcast. These individuals have shaped our collective understanding of some of today's most pressing and consequential matters, in addition to sharing stories with us about their scholarly and personal journeys. Many of our guests are Phi Beta Kappa Visiting Scholars who travel the country to our Phi Beta Kappa chapters where they spend two days on campus and present free public lectures. We invite you to attend. For more information about Visiting Scholars' lectures, please visit pbk.org.

Today I'm excited to welcome Professor Rosemarie Garland-Thomson. Professor Garland-Thomson is Professor Emerita of English and Bioethics at Emory University and Senior Advisor at the Hastings Center. She's a disability justice and cultural thought leader, bioethicist educator, and humanities scholar, and consults on many academic and bioethics projects. Her 2016 op-ed *Becoming Disabled* was the inaugural article in the ongoing weekly series in the *New York Times* about disability by people living with disabilities. Her academic and scholarly work has been foundational to the field of critical disability studies and the health humanities, bringing forward disability, culture, access, and justice to a broad range of institutions and communities. Welcome, Professor.

Garland-Thomson: Thank you, Fred. I'm delighted to be here.

Fred Lawrence: I mentioned your 2016 op-ed in the *New York Times* in the intro, and that's where I'd like to start. It was an opportunity to speak to a very broad audience. It was the inaugural article of their weekly series that featured people living with disabilities, and you opened your op-ed with the example of a friend who, in a well-meaning way, as you said, said to you, "I didn't know that you were disabled." Talk to us a little bit about that kind of conversation and why did you choose that as the way into this field for this op-ed.

Garland-Thomson: Thank you for the question. When I was first contacted by Peter Catapano, who is the editor at the *New York Times* who launched this series of opinion pieces, which are really personal essays that were in the *New York Times* starting in August of 2016, what Peter said to me is that he moved to a new location in New York and started riding the bus to work from his new home. What he said was that in riding the bus, he started seeing people with disabilities that he had never seen before because they were on the bus, and that that made him recognize a population, if you will, that he had never had the opportunity to encounter before.

He was very interested in that and decided to devise the series, and somehow he found me and asked me to contribute the inaugural piece. I said, "Of course, I would be thrilled to be able to do this." But I was very taken by what might be called his journey and the discovery of people with disabilities on the bus, because that has a great deal to do with the history of what we think of as disability and who we think of as people with disabilities in America.

Fred Lawrence: One of the things you have written, of course, is that all of us, certainly most of us, but I think, arguably, all of us, will move in and out of disability in our lifetime: illness, injury, just aging. How does that, if you will, expansion or maybe deconstruction of the notion of disability, affect the idea of disability rights and disability studies?

Garland-Thomson: There are theories of identity and identity categories that put forward the really important concept of what we sometimes call intersectionality. And of course, what

that means is that when you think about social systems, and this is a whole theory that sociology has given us, there are a variety of social systems. We call them gender or race or ethnicity or sexuality, and we are all members of these various social systems. We all have relationships with and positions within these social systems, and disability, or the ability system, which some people like to call it, is one of these social categories.

It's a little hard for many people to understand the disability system similarly to the way we can understand what we think of as the racial system or the gender system or the sexuality system because of what you mentioned, this kind of porousness of the category disabled and how people move in and out of it. So in this sense, it's both a porous social category and an unstable social category, and that makes it harder for us to recognize our membership in that category. So someone can identify as non-disabled and be identified as non-disabled for most of their lives, and they can break a leg or step in front of a car as they cross the street or they can live with a particular illness or their bodies can be, as we sometimes call, medicalized in some way and suddenly they're in a whole new category that they weren't in before. And that makes it very hard for us to figure out who we are when we're with one another in the social sphere. And that's what I think is quite confusing about what we think of as disability as an identity category.

But one of the things that I say very often is that you come into disability when you realize that there are barriers in the world. Sometimes those are attitudinal barriers and sometimes they are literally physical barriers that make you understand that you are a person with a disability and that you need to do something in order to accommodate those barriers, to remove those barriers from your life, and that you need to request in your workplace or you need to use, in some way, the designed and built environment in new ways. And that's what makes people understand the benefit of identifying as disabled.

Fred Lawrence: Donald Murray famously said that "all writing is autobiography". I wonder how much that's true for your body of work, particularly in the disability area. Take us back to your childhood and growing up. Is it a direct line from that to being a scholar or are there some zigs and zags along the way?

Garland-Thomson: Well, there are certainly some zigs and zags along the way. I grew up quite a while ago in what we now call the pre-ADA era, for sure. I have a congenital disability that affects my arms and hands, and so they look quite unusual. When I was going to school, and I was very lucky to be able to go to school because I could get in the door, people with congenital or early onset disabilities who needed to use wheelchairs or sometimes even crutches couldn't go to school at that time because the schools were literally built to be inaccessible, and the barriers were largely barriers around things like typing and machines. So I was able to use a pen and a pencil, and I was able to get around the barriers that existed for a while.

When I finished college and I went to my state university in Nevada, and when I got out of school, like most everyone else, I got a job as an English teacher for a long, long time. When I had the opportunity to go back to graduate school and I was living in the greater Boston area at the time, I had three small children, and it was the time of when the Women's Movement and the Black Civil Rights Movement had transformed education by integrating voices, works, perspectives that had been largely excluded in the past. It was a very exciting time, and I wanted to go back to graduate school and study English and I wanted to read these books that had been written by people whose voices, if you will, had not been much recognized. People like Frederick Douglass, people like Zora Neale Hurston.

What I recognized was the perspectives of disabled people, people with disabilities, the stories of disability, had largely not been recognized as such. They were there just like all of these stories of other people in marginalized groups, if you will, were there, but they had not been recognized. And so I wanted to go back to graduate school and I decided on Brandeis University

Fred Lawrence: Brandeis University in Waltham, Massachusetts, where I had the privilege to serve as the eighth president.

Garland-Thomson: Yes, Waltham, Massachusetts.

Fred Lawrence: And although you and I did not overlap, you were there in the, what, late '80s and early 1990s.

Garland-Thomson: That's exactly right.

Fred Lawrence: Why did you go to Brandeis and who did you study with there? Who was influential?

Garland-Thomson: I went to Brandeis because it had the best parking situation and the best commute situation for me because I had three small children. Brandeis was very welcoming. When I started taking classes and started working on what we think of as our academic project, I said to the people I was working with, "I want to study the representation of disability in literature, particularly American literature," which was the area that I was most interested in pursuing, "and to work with this in terms also of feminist theory."

The people I worked with at Brandeis said to me the wisest thing ever, and I've said this to many students I've worked with, and they said, "I don't know anything about this. I've never thought about disability as a social construction. I've never thought about the politics and representation of disability in literature, but I really know how to direct these kinds of projects, and so I welcome you to be the expert on your own topic and I will work with you to shape what you do." And that's a really important field-building perspective that I received so effectively at Brandeis where I became the director and the expert of my own field, but I was also put in touch with other resources.

So, after a few years at Brandeis, I discovered that a sociologist right across the way from the English department there was a man named Irving Kenneth Zola, who was the founder of disability studies in sociology, and he also, of course, was the founder of a journal that was mimeographed at this time called Disability Studies Quarterly, which is a very important journal for disability studies now. I met Irv Zola later and I attended the Society for Disability Studies conferences that were held every year for many years and was really able to participate quite fully in building the interdisciplinary enterprise that is what we think of now as critical disability studies. So in terms of field-building within institutions, Modern Language Association, and other professional organizations, I was able to do, really, a lot of that work starting at Brandeis and then in my other jobs at Howard University in Washington, DC and later at Emory University to bring perspectives and knowledge about disability into the academic world.

Fred Lawrence: There's one idea in particular I'd love for you to talk to us about a little bit, and that is the notion of normal, if you will. It largely does not occur till the mid 19th century, and obviously as with any of these ideas, there are reasons that it comes on the scene then, but it affects this whole idea of who's normal and who's not normal in a way that had not been part of the conversation, which ultimately gets us into eugenics and a number of other extremely complicated, problematic areas. Can you talk to us a little bit about your insight there?

Garland-Thomson: Normal has been called one of the most destructive ideological concepts of the 20th century by Ian Hacking, who is a philosopher who has done a great deal of important work in this area and also in many other areas. The ideological work of the word normal, of course, is to elevate a certain way of being in the world to a status that gives it privilege and gives it cultural and social capital, if you will. And along with that, people who are not able to, let's say, achieve normal or enact normal in their lives or act normal or look normal in their lives, must then navigate a life with, what might be called I like to talk about barriers, what might be called the barrier of normal. And so that can be a challenge that is met with creativity and resourcefulness.

That's the story I like to tell about disability, is that it's an opportunity to become more human, it's an opportunity to make a life that may not be expected, it's an opportunity to live kind of against the grain of what's expected, and especially it's an opportunity to relate to other people in a human and empathetic way because, as I've mentioned and as you've pointed out, disability is a category that we will all end up being in sometime over our lifetime. My point is that we are better off to welcome it and to figure out how to accommodate it, then we are to ignore it and to push it away from our lives.

Fred Lawrence: You began your teaching academic career at Howard University here in Washington, DC and then moved to Emory University, and after nearly two decades at Emory, you get a master's degree in bioethics in 2019. What led you to pursue, at that stage, additional formal graduate study?

Garland-Thomson: I began working as an English teacher right out of college, which means that I was always working with narratives, with stories, and these stories were stories that we think of as literature, film, things that we think of as, what I call, the narrative humanities, and as long as I was working in English departments or in the humanities, my audience was my academic peers and the students.

I realized at some point if I was going to really think about disability as an identity and in a life experience, that I needed to extend my audience toward medicine and science, and I decided the only way to do that that I could figure out was to start entering into the academic field that is related most closely to that, and that is bioethics or healthcare ethics or what we sometimes call health humanities. I was at Emory University and I thought this is a good way to learn about the field of healthcare ethics or bioethics, to credential myself by having a master's degree, but also to enter into conversations and to spaces and to communities and to institutions where I would have an audience of scientists and healthcare professionals, doctors in particular, and to establish a voice and to participate in that set of institutional and professional organizations and knowledge communities to reach doctors and scientists.

Fred Lawrence: You have been involved now, in one form or another, teaching students and issues related to disability rights, disability justice for the better part of three decades. I wonder what changes you see over that time, and I'm thinking both in terms of the Americans with Disabilities Act of 1990s, transformational, one of the major pieces of civil rights legislation in American history and the foundational piece with respect to disability rights certainly, and that's 1990s that affects this whole time. At the same time, we're currently living in such a hyperpolarized, hyper-partisanized time, so virtually no issue escapes the vortex of that kind of polarization. How have you seen student interests in these issues and the very way in which these issues teach change over time?

Garland-Thomson: The desegregation, I like to use that word, of all institutions in higher education and in professional fields such as law and medicine, has created, I think, opportunities for introducing disability as a concept to recognize.

What I've seen over and over again when I made visits through being a Phi Beta Kappa Visiting Scholar or guest teaching, talking to audiences, really, across the country and internationally, what I see is that there's an aha moment very often when people will say something like, "I never really thought about this before, but yeah, my grandmother," and then they tell me the story about that. Or, "Yeah, I have a sister with Down syndrome, and of course she's a valuable member of our family and we love her, but I never really thought about what you're saying." Or at some point, many people come and say, often quietly, "Look, I think I have a disability," or, "I am afraid, because if somebody finds out that I have this disability that is presenting where I have

run into barriers," this is how I like to talk about it, "I'm afraid that I'll lose my job, or I'm afraid I'll get a bad grade. I don't know what to do. Help me with this."

And then I can say what I say and that is, "Welcome. Let me help you. The first thing you have to do is go register at the Disability Services Office and you have to figure out what accommodations you need and then go ask for those accommodations. And this is scary, but this is what you need to do because you merit these accommodations so that you can do your work in the world."

Fred Lawrence: You alluded to having been a Phi Beta Kappa Visiting Scholar, and we're so grateful for your time and service as a Phi Beta Kappa Visiting Scholar, and you went to eight different schools, gave public lectures, visited with students, met with faculty. I wonder if you have some particular stories from your Visiting Scholar time that you'd like to share.

Garland-Thomson: Absolutely. People would come up after the lecture, people would arrange for a coffee and they would say, "I'm struggling. I need something that my school is not giving me. I am so happy to have had your lecture, because I've not been recognized enough by the teachers I work with, by my colleagues and friends, and I am validated by simply your presence as you, a person who identifies as disabled, but also by the fact that this prestigious lecture has been brought to our school, that this is being validated structurally by the Phi Beta Kappa visit and other activities around it."

Fred Lawrence: I know that some of our listeners have a great deal of experience, background, and knowledge in the disability rights area, and for some, this has really been an introduction, which you described as an aha moment. Could you give us a couple of book recommendations, both for those for whom it's an aha moment that this is a good way to get started and learn more about the field, as well as for those with some extensive background where you can make some suggestions as to how they can take their knowledge to an even higher level?

Garland-Thomson: People like my book, *Extraordinary Bodies*, which is a book that's been out there for a long time, there's a 20th anniversary edition of it, and so that's a classic, quite readable book. But a book that I think is quite wonderful that has recently come out is by an author who is a designer and architect, a woman whose name is Sarah Hendren, who's written a book called *What A Body Can Do*, which is about design and accessible design. That's an excellent book that is very readable.

Fred Lawrence: You have given a lot of us aha moments with op-eds and with your scholarly work, and I'm pleased to say through your service as a Phi Beta Kappa Visiting Scholar, thank you for all of that, and we look forward to more that will be coming from you in the days and years ahead. Thank you for joining us today on Key Conversations with Phi Beta Kappa.

Garland-Thomson: Thank you, Fred. It's been a pleasure.

Fred Lawrence: This podcast is produced by Phantom Center Media and Entertainment. Kojin Tashiro is lead producer and mixed this episode, Michelle Baker is the editor, and Hadley Kelly is the Phi Beta Kappa producer on the show. Our theme song is Back to Back by Yan Perchuk. To learn more about the work of the Phi Beta Kappa Society and our Visiting Scholar Program, please visit pbk.org. Thanks for listening. I'm Fred Lawrence, until next time.

CITATION:

Lawrence, Fred, host. "Exploring Disability as an Identity with Professor Rosemarie Garland-Thomson" *Key Conversations with Phi Beta Kappa*, The Phi Beta Kappa Society, November 6, 2023. www.pbk.org.

Produced by:

