

NHGRI Presentation
“Irreducible Subjects” Symposium
Rosemarie Garland-Thomson
October 6, 2022

Part One: How I Became Disabled

I like to say that **I became disabled at school**. This is true, but not in the way most people would expect. No tumbling off the playground equipment or medical event during class. I became disabled through what I call the primal scene of disabled social life. Growing up as I did in a pre-Americans with Disabilities Act era, I encountered this scene intensely in elementary and secondary school.

Most everyone with a disability will recognize the scene. Someone asks with either their words or their eyes that relentless question, **“What's wrong with you?”** As a schoolchild and young adult with no access to disability consciousness or community, my awkward answer was some version of **“I was born this way.”**

Because I was born with six fingers altogether and one quite short arm, I learned to get through the world with the body I had from the beginning. **Such a misfit between body and world can be an occasion for resourcefulness.** Because all of us will experience disability sometime in our lives, it is a great advantage to start early, as many disabled people know. Not that it felt that way growing up. Although I certainly recognized that the world was built for what I call the fully fingered, not for my body, I never experienced a sense of losing capacity and adapted quite readily, engaging with the world in my preferred way and developing practical workarounds for the life demands my body did not meet.

My well-intentioned family had no disability experience or consciousness when I was growing up. Many people with congenital disabilities are born into nondisabled families who are completely unprepared for us. The provincial medical system of my childhood offered no sure cause for my unusual shape. Throughout my life, phrases from the poetic to the pathological have described my unusual body: “freak of nature,” “funny looking kid,” “thyroid deficiency,” “birth anomaly,” “sporadic limb deficiency.” The most generic and wince-worthy for me was: **“birth defect.”** From charity telethons to alcohol consumption admonitions, FDA warnings, and

grim environmental hazards-- the anchoring threat is always "BIRTH DEFECTS." "I was born this way," was my weak claim to disability identity and self-respect preservation as a person bereft of any community, affirmative language, and positive identity narratives.

I quietly hated all of it and developed a range of **dignity maintenance strategies** on my own. I had no other way of understanding my body and its place in the social world until I went to graduate school where I became disabled at school in another way. Until I learned about disability studies, culture, and community when I was a graduate student in the English department at Brandeis University the late 1980s, I had no idea—no consciousness, feminist, disabled, political or otherwise—of what it meant to be disabled, that there was a history, culture, and politics of disability. Until then, I had been **in the disability closet**.

But since other people with disabilities have entered the worlds where I live and work, I have found community and developed a sturdy disability identity. **I learned to be disabled**, even though I've had the same body throughout my whole life. Now, I'm likely to begin one of these awkward encounters with, "**I have a disability**," and to complete it with, "**And I need these accommodations**." This is a claim to inclusion and right to access resources.

My story here of becoming disabled in school offers two lessons: First, to be liberated into a disability consciousness that restores our dignity, we need to **be legible to others as people with disabilities with rights and obligations** equal to nondisabled citizens; and, second, we have **equal claims to moral personhood**. The social process of identifying as disabled and being identified as disabled is a dynamic enterprise we must navigate consciously and perpetually. Even though the physical form of my arms and hands is quite unusual and noticeable, I must claim disability identity to place myself in community and to request reasonable accommodations.

Even though I have had a lifetime of practice living in this familiar stable body, I must perpetually renew my relationship with the expectations of my social and technological environment. I need new accommodations frequently. In the workplace, my disability has

become very salient, not in appearance but in function, because the mounting demand for digital manipulation of computers in our jobs has made me increasingly disabled. Every day digital demands increase, even though the form and fundamental function of my body has not changed from when I was a child. **The workplace environment disables me daily.** The account I must now give of myself in this context is not “I was born this way” but rather I require new and creative disability accommodations to do my job. Because the concept of equal access is legally mandated under civil rights legislation, becoming disabled this way includes rather than excludes me from the workplace, which is my access route to economic resources.

Part Two: How I Became a Bioethicist

Becoming disabled through the social situations and by the designed and built environments has offered me an opportunity to take up the enterprise called bioethics or healthcare ethics. **Working with disability culture, knowledge, and communities expanded the scope of my work from being an English teacher to becoming a disability bioethicist.**

Even though I knew the medical approach to disability always hovered around cultural understandings of disability, I had to gird myself to face the title wave of pathology that came my way when I started speaking with and to people in healthcare and medicine. As a **bioethicist with a disability, I am an unusual hybrid of patient and expert.** In professional healthcare settings, I am often taken to be a patient. My diagnostic category and treatment history has become much more salient in bioethics than it was in the humanities and cultural studies. Being on both sides of the medical gaze has nonetheless been a productive perspective, as it has for many of my colleagues who work in bioethics and also identify as disabled.

My task as a bioethicist is to **bring social, cultural, and political perspectives about disability and living with disabilities into conversations and considerations about medical treatment and technology development that eventually shape biomedical policy and practice.** As an academic healthcare ethicist or bioethicist, I write articles, give presentations, and speak with colleagues like many of you in our audience today about bioethical topics that affect people

with disabilities. In the broadest sense, my job is to remind everyone that **disability is everywhere once we know how to look for it.**

Our modern culture tells us that disability is an exception when in fact it is the rule of the human life. Disabilities and living with our disabilities are fundamental to what the philosopher Hannah Arendt calls “the human condition.” The CDC says one in four Americans has a disability, totaling 61 million Americans with disabilities. According to the United Nations Convention on the Rights of People with Disabilities, about 10% of people worldwide live with disabilities. Indeed, people with disabilities are the largest minority group in the U.S. and a growing constituency as American demography shifts and new disability categories such as neurodiversity, psychiatric disabilities, disabilities of aging, and learning disabilities emerge and grow. The prevalence--indeed universality--of disability is a surprise to almost everyone, including many people who have disabled family members or who qualify themselves as disabled.

Indeed, **all of us will become disabled if we live long enough.** The human lifecycle and our encounters with the environment as we move through life transform our bodies and minds in ways medicine and society call disabilities. The human variations we think of as illness and disability come to all of us over a lifetime, shaping our bodies, lives, families, and communities quite literally. Because we live in-- because we *are*-- beings made of flesh, blood, and bone, we are vulnerable over our lives to encounters with the world around us that will shape and reshape our bodies as we move through life and world in the process we think of as development or as a lived life. Some of us begin life with disabilities we acquire in the womb or in our emergence from it into the world. Our individual genetic shaping gives some of us our distinctive disabilities, manifest or forthcoming, even as embryos. As we move through life, our encounters with what human communities make imprint our bodies with what we call disabilities. Our human interactions with tools, machines, vehicles, buildings, activities, sports, wars, food, and perhaps most harshly our cars, guns, and computers make our lives and work possible, but they disable us as well as we use them. Disabilities inhere in human development. Everyone becomes late life deafened and at least partially blinded. The demands on our joints

and skin of life building take us to disability eventually. Viruses, bacteria, and the very substance of our cells bring the disabilities medical science considers diseases, some of which will end our lives. The diversity of our minds in a world that values a particular mode of cognition contour our lives, work, and relationships. We might say that disability is a record written on the body of flesh encountering world.

Perhaps most significant for our sense of who we are is that becoming disabled shapes our own sense of self and how we are understood by others. Moving into disability shifts us from membership in the comfortable category of the ordinary and normal into an unfamiliar terrain of existence that can be profoundly unsettling. Disability is in our bodyminds and activated through the way we necessarily undertake our lives.

Nonetheless, when disability comes our way, we are much better prepared now than I ever could be grown up before the **Americans with Disabilities Act of 1990 and 2009** and the laws that led up to it. Everything changed for people with disabilities starting in the 1960s as a broad disability rights movement encouraged legislation and policy that gradually desegregated the institutions and spaces that had kept disabled people out and barred them from exercising the privileges and obligations of full citizenship. Education, transportation, public space, and the workspace steadily transformed so that people with disabilities came out of hospitals, asylums, private homes, and special schools into a rebuilt and reorganized world.

This integration of people with disabilities has been slowest to come perhaps to the world of medical science and healthcare practice, which is often committed to eliminating disability from the world more than accommodating disability. Along with many other colleagues who work in healthcare and healthcare ethics, my work aims to **bring the perspectives of disability culture, integration, and ethics into awareness and practice in healthcare**. Practitioners of disability bioethics bring forward new perspectives and knowledge about such topics as genetic editing, development and use of genetic testing, life ending practices such as euthanasia and abortion, diagnosis and prognosis narratives, equity and access in healthcare, and most recently disability cultural competence, an enterprise that may serve not only disabled people but all of us.

As a bioethicist, I have made the **case for disability as a resource to be conserved** rather than a liability to be protected. Conserving rather than eliminating disability could offer the human community often unbidden opportunities for unexpected resourcefulness or flourishing that disability can present. Accepting the people with disabilities who enter our lives as unexpected and often unwelcome gifts may be an ancillary benefit of disability conservation. The primary benefit would be valuing the inevitable growing into disability inherent in the human condition.

To support the ethical aim of conserving disability, my colleague Lisa I. Iezzoni and I, along with others, have put forward a call for a more developed curriculum and healthcare education on disability cultural competence. Dr. Iezzoni is a Professor of Medicine, Harvard Medical School Health Policy Research Center and the lead author of two studies suggesting that doctors and healthcare workers need to know more about how their patients live with disabilities, what accommodations we might need, and how to provide for those accommodations, to include accessible technologies for disabled people.

Disability cultural competence is a structural knowledge enterprise designed to implement justice and autonomy in healthcare practice. It aims to provide a practical toolkit that identifies and develops supports for people living with disabilities as they are. The fact that all people will acquire or experience disability over a lifetime means that disability cultural competence is an essential life skill for all healthcare workers, active patients, and potential patients-- which means everyone who participates in the healthcare system.

Everyone needs to know how to be disabled. Learning to be disabled requires more than receiving medical treatment and rehabilitation. Becoming disabled requires adjusting to new functioning, appearance, and social status. It requires learning how to flourish and live effectively as a person with disabilities, not just living as a disabled person trying to become nondisabled. In other words, disability cultural competence is a skill set everyone will need to navigate life and to implement the promises and obligations of egalitarian democratic societies. Becoming disabled is what we need to move from isolation to community, from ignorance to knowledge about who we are, from shame to pride, and from exclusion to access.