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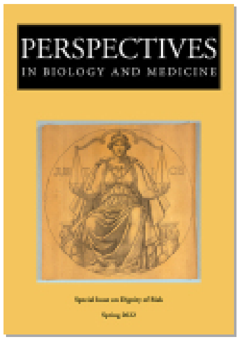

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WHAT DU BOIS AND I KNOW ABOUT DIGNITY OF RISK

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ABSTRACT This article uses multiple interwoven personal narratives to explicate the relationships among several concepts crucial to bioethics brought into focus by Robert Perske's 1972 article on "The Dignity of Risk," including *dignity, risk, paradox, disability, autonomy, uncertainty, diagnosis,* and *prognosis.* The use of personal narrative as a form of evidence and a knowledge-making method allows for the exploration of the meaning-making work of language and story and the introduction of humanities and social science concepts such as *stigma management* and *dignity maintenance* into Perske's concept of the dignity of risk. The personal narratives the article draws include Mark, a character in Perske's article; W. E. B. Du Bois; Frantz Fanon; and myself. Finally, the article calls for humility in medical science's predictive narratives for all patients, but particularly for people with disabilities.

Robert Perske's 1972 article on "The Dignity of Risk" begins with a "paradox" at the heart of bioethical considerations, policies, practices, and attitudes about people with disabilities. A 21st-century bioethicist now winces encountering language long legally and ethically outdated, such as "mentally retarded" and the unquestioned use of "normal." Nonetheless, Perske draws us into his reframing of risk management by offering what we might now call qualitative data, or what I prefer to call narrative evidence, to bring a good deal of flesh to this now strange academic article that appeared in a journal entitled *Mental*

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Retardation, a term that Rosa's Law—which passed in 2010 under the Obama administration and went into effect in 2017—literally outlawed.

Perske offers us the paradox of Mark, a "teenage mentally retarded son" in the family of the noted academic S. I. Hayakawa (Perske 1972, 24). In the judgment of medical science and the world it shapes, Hayakawa observes, Mark's life is "tragic." In the judgment of the Mark's family and the boy himself, however, Mark has a happy life. This paradox matters, Perske's article suggests, because the larger social system and medical science structure the terms of Mark's life based on what Hayakawa suggests is a tragic view of a life lived with a disability.

This tragic view of a life lived with what Rosa's Law now bids us call "intellectual disability" shapes the world open to Mark and thus his life chances. Perske's article lays out how a very specific narrative and the practices it prompts depletes Mark's agency in life choices and self-determination . Perske frames this paradox as a barrier on the path to an open future that liberal societies promise their citizens. Access to this path is the route as well to human dignity. Although in 1972 Perske did not have full access to the language and logic of civil and human rights that agreements such as the Americans with Disabilities Act of 1990 (ADA) and the UN Convention on the Rights of People with Disabilities of 2007 (UNCRPD) have given modern liberal nation states, his article is a rudimentary version about exactly what these broad pieces of civil and human rights legislation confer upon people with disabilities. The "risk" that Perske claims to be an enactment of human "dignity," is the exercise of autonomy, one of the four pillars of bioethical principlism (Beauchamp and Childress 2019).

Most anyone who has lived a life with a disability for long becomes conscious of how what I call here "Mark's paradox" structures life chances by complicating—as paradoxes do—our subjective relationship with identity formation and our lifework of carrying out dignity maintenance. Maintaining patient dignity is a crucial concept in health-care ethics that has been implicitly theorized in sociology under the infelicitous, if not frankly stigmatizing, term *stigma management*, a concept associated with the sociological enterprise known broadly as social interactionism. This attention to the social context of disability was launched in the 1960s by sociologist Erving Goffman, who employed narrative methods and structural analysis to explicate how people both advance and receive one another in everyday, face-to-face social interactions. Goffman (1959) explicated the social rituals people use to perform their social status through self-presentation strategies and impression management techniques that navigated the received hierarchical system of prestige in any given social order. In his 1963 book, *Stigma: Notes on the Management of Spoiled Identity*, Goffman ruthlessly analyzes received social hierarchies built on the uneven distribution of physical and cultural capital, employing the narrative style characteristic of some 1960s sociology to explicate how social relations mark individuals in what we would now consider minority categories as social deviants. According to Goffman, a social stigma adheres to those people societies consider "ritually polluted" on the basis of "having signs of physical disorder" or other devalued physical characteristics that signal a fall from grace or social depravity (Goffman 1963, 1). Calling up the image of literal branding with a red-hot iron characteristic of corporal punishment practices, Goffman describes how social orders impose the stamp of stigma to a wide range of "deeply discrediting" physical and behavioral attributes and the people who bear them. Inflicting stigma as a form of social branding, according to Goffman, ranges from people bearing what he calls the "tribal stigma of race, nation, and religion" to "blemishes of individual character" to "abominations of the body" (Goffman 1963, 1, 3, 4). These unsettling categorical descriptions would translate in today's post–civil and human rights society into the full range of racial and ethnic minorities, BIPOC folks, queer people, the poor, people with psychiatric and social disabilities, incarcerated people, underprivileged people, institutionalized people, the neurodiverse, and people with physical, mental, and sensory disabilities, and perhaps everyone over about 50 years old.

I first read *Stigma* in the late 1980s, and it was so toxic and true for me that I later wrote, in a short article on the 50th anniversary of its publication, that reading it was like seeing roadkill: a scene you are horrified by, but you can't take your eyes off because it's true (Garland-Thomson 2014). After wrestling with the grisly truths Goffman shoved forward about what the world thinks of people with disabilities like mine, I came to recognize that the lifework of people like me and Mark—indeed, of everyone with a disability, particularly those of us living with what Goffman distressingly calls "abominations of the body"—is dignity maintenance. My own work, *Staring: How We Look* (2009), which analyzes visual exchanges in social interactions, might be considered a companion piece to Goffman's *Stigma,* in that it focuses on the agency of people stigmatized on the basis of "abominations of the body" that we now understand as significant disabilities in order to bring forward dignity maintenance strategies people living under that category develop and employ in everyday life.

Now in the 21st century, the language of "retardation" and "abominations" has been purged from our medical scientific, bioethical, and political vocabularies—and more or less from our social interchanges. Insults such as "retard," "cripple," and certainly "feebleminded" have gone the way of "homo" and many ethnic slurs but are not yet as forbidden as the so-called N-word, although "retard" and "lame" have some current power to insult and provoke even as they are seldom understood as disability slurs. In writing about stigma in 1963, Goffman seemingly unselfconsciously used phrases such as "crippled girl," which is always a jolt for me, and a reminder that the academic vocabulary of 1960 lies on the other side of the mid-20th-century civil rights movement, and certainly of the disability rights movement that turned patients into citizens. And so too, of course, does Perske's explication of "the dignity of risk" with its 1970s language of "mental retardation."

Perhaps the most famous primers on dignity maintenance now in the American canon of literature are the race jeremiads from Black intellectuals of the 19th-century abolitionist and early 20th-century Black emergence into public discourse on race in America. One could read Frederick Douglass's autobiography, his so-called slave narrative, as—among many other things—a dignity maintenance apologia. So too with Harvard-educated sociologist W. E. B Du Bois's 1903 manifesto and lament, *The Souls of Black Folk*. Du Bois narrates in *The Souls of Black Folk* a story from his early, apparently racially integrated, childhood classroom that resonates with many of us who occupy the paradoxical social places of what Goffman (1963) calls "the discredited and the discreditable" (41). Du Bois relates his own childhood primal scene of racial identity formation, or what in social interactionist language might be the violent linguistic imprinting of Goffman's term "tribal stigma" upon a schoolboy. The schoolchild Du Bois is a racial innocent until one day one of his classmates refuses a card from him, delivering to him the epiphany of his racial stigma. Although Du Bois does not directly invoke dignity or its maintenance in the lifework as a sociologist, intellectual, and leader of Black liberation, his response to this *indignity*—the narcissistic wound, if you will—of the contempt and pity he judges the White majority's affect to be in relation to an encounter with a Black man is most certainly the social process Goffman describes as the social branding of a tribal stigma. And Du Bois's response of both "longing to" and attaining "self-conscious manhood" through his scholarly work and community leadership is surely his version of dignity maintenance (38).

Du Bois's scene of dignity stolen from a schoolboy and the eloquent lesson that he gives us helps clarify Mark's paradox and what Perske calls "the dignity of risk." Reflecting from the wisdom of adulthood and the developing academic field of sociology, Du Bois lays out how the wound—the stigma—inflicted upon the innocent boy marks the previously unmarked subject with race. He draws a psychosocial and ethical meaning from this identity-hailing experience that has now become a concept of "double consciousness," a condition that is widely recognized and applied to other psychosocial states and cultural experiences within emerging critical theories across many academic disciplines. "It is a peculiar sensation, this double-consciousness," or what Du Bois calls this "two-ness," coming from the "sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity" (38).

Du Bois does not interpret this hailing into a discrediting racial stigmatized identity as part of what we now call structural racism, but rather as a metaphorical branding with a red-hot iron, the kind of fleshly social marking earlier European cultures inflicted to quite literally brand criminals with a scar that at once punished the transgression and identified the transgressor for life. Du Bois transfers the emotional force of this schoolhouse disciplining into the adult experience of racism as a "sensation" of "looking at one's self" as his racist oppressor sees him and measures him—sizes him up—by contrasting him to an image of a white man, the member of the unmarked category, or what Goffman (1963) would call one of the "normals" (7). Psychologists would say that Du Bois has internalized the perspective of the dominant group, understood as "a world that looks on in amused contempt and pity." The insult of this toxic combination of contempt, pity, and amusement to what psychologists would call his self-esteem and what philosophers and theologians would call his human dignity is massive and mobilizing. He is aggrieved to the point of bitterness at what he learned at school and found everywhere else in 1903—at the indignity that a Black man was not of equal value to a White man in the eyes of others. Du Bois's indignation results from the theft of dignity to which racism subjects the racialized subject.

The hailing into a Goffmanian stigmatized identity that Du Bois outlines in his auto-ethnography anticipates the identity formation narrative of philosopher Simone de Beauvoir, who famously pronounced in *The Second Sex* that "One is not born, but rather becomes a woman" (Beauvoir 1949, 283). Over hundreds of pages, Beauvoir shows us the constriction of agency and thus dignity that the patriarchy's assignment of women to immanence and men to transcendence has wrought upon all humans subjected to the social processes of becoming a "woman," what we would now call a gendered social subject. Contemporaneously with Beauvoir's *The Second Sex* and a half-century after Du Bois exhaustively explicated the imprint of racial stigma came the similarly lashing indignation from Martiniquais psychiatrist Frantz Fanon in *Black Skin, White Masks* (1952). Fanon's analysis of Western racial identity-hailing practices and what we would now call the social construction of race and structural racism—a version of what we would now call critical race theory—follows the intellectual tradition of suggesting the centrality of dignity maintenance to the development of subjectivity and knowledge-making.

From the wound to Du Bois's dignity comes a strategy of dignity maintenance as a knowledge-making practice that psychologists would call intellectualizing, a way to generate abstract understandings about the relationships among ontology, epistemology, and phenomenology. I offer here an aspect of my own identity-hailing experience to consider what Perske's article on the dignity of risk prompted me to recognize. The narrative of Mark's paradox in Perske's article suggested to me that dignity maintenance is related to the social form of what medical science calls "risk management."

I have what I now understand to be a rare genetic condition called *syndactyly*. Until I undertook a clinical observation practicum in the genetics department of my university medical center, I did not "have" a rare genetic condition, but rather I had a configuration of congenital upper body deformities that I have come to call in lay terms "unusual hands and arms," or sometimes just an asymmetrical body shape. Upon meeting me, the geneticists I encountered in my practicum offered me one of their expanded categories of genetic diseases as an updated diagnosis of the body I had inhabited from birth into mature adulthood. Over my lifetime, I have had a series of evolving narratives, varying and shifting accounts of myself, about the shape of my body. These narratives range from social to diagnostic to political. Each places me into related but distinct psychosocial identity categories that have structured in different ways the dignity maintenance practices I have developed. Another way of saying this is that over my lifetime, several different identities have hailed me, similarly to how racial identities hailed Du Bois and Fanon. Each identity category drew me into its psychosocial orbit, requiring me to develop new repertoires of dignity maintenance and risk management strategies.

All along the way, Mark's paradox, or what Du Bois calls double consciousness, structured the shape of my life and my sense of who I was in community, interpersonal relations, and work. As my world expanded from family, local schools, and intimate communities, I became progressively more estranged from the comfortable native understanding of my embodiment characteristic of childhood. Like Du Bois, the further I got out into the larger world of the anonymous encounters adulthood brings, the more aware I became of how strange and rare was my bodily form to others and the more varied were the reactions to it from my fellow humans. The social skills I developed to assess and manage people's reactions to my physiological rarity are dignity maintenance skills particular to the psycho-emotional needs of my life and world. My dignity maintenance skill set ranges from knowing how and when to be nice, authoritative, distant, friendly, aloof, assertive, generous, or cantankerous—a final affect that did not fit well with my fundamental sorority sister persona. Like Perske's so-called "retarded" people, I had been accorded the opportunity to risk entering into a world that was potentially materially and relationally hostile to me, a social and a built environment that was not expecting somebody rare like me. Like Du Bois, the schoolboy—and perhaps Perske's kids— the risk to our senses of self-esteem and self-determination, to our dignity in the purest sense, was in the end an expensive benefit. The cost of this self-alienation for me, and perhaps for Du Bois and for Perske's kids, was less than the benefits. Still, the wound to one's dignity takes decades or perhaps a lifetime to heal with at least wisdom if not meaningful work. The narrative evidence left by Perske's reports and what those of us who have developed and reported suggests that Perske's subjects have flourished through the dignity of risk. Certainly, I have flourished, no more depleted or uplifted than the nondisabled people I've known over a lifetime.

My own agency or what bioethicists call autonomy was the engine of my dignity maintenance and risk management, just as it was for Mark and the "mentally retarded" for whom Perske so ardently advocates. What I have had that Perske's subjects did not is the advantage of a sense of an open future that the political identity *disabled* gave me, starting about in the mid-1990s. In other words, I began life as a tentative but plucky Goffmanian crippled girl; I then transitioned into a young disabled person in a world alive with the ideas of civil and human rights; from there I became a person with a disability requesting reasonable accommodations in a professional workplace; and most recently I moved into the medical scientific work of bioethicists, where I find myself to be at once a professional authority and a patient with a rare genetic condition. Each of these social positions are also narratives about what Perske calls the dignity of risk, and what Du Bois calls coming into the double consciousness—of recognizing the gap between the familiar self and the unfamiliar self, the unsettling collection of "abominations of the body" that apparently some of our fellow humans take us to be.

I conclude here with perhaps the most unwieldy and disquieting aspect of maintaining dignity through and despite risk. A commonality of the human experience is that we know what happened yesterday but have no secure knowledge about what is going to happen tomorrow. This phenomenon is the limitation of human embodiment, time, and knowledge—what philosophers at times call *finitude* and what economists and genetic counselors call *uncertainty*. Another way of describing this inherent human situation is to say that the withdrawal of the divine hand from the modern world has cursed us with the responsibility for determining tomorrow's consequences in today's actions. We think of this moral obligation to self and others variously as self-government, freedom of choice, or patient autonomy. More recently, we call this *risk management*.

Medical science calculates risk through statistics, which are quantitative narratives of the past. These calculations undergird the modern project of controlling future outcomes by present actions. Established medical narratives such as diagnosis, prognosis, and more recently selective testing and predictive health all traffic in the assumption that what happened in the past will happen again in the future. Moreover, we might draw from this epistemological epiphany a useful humility in our aspiration of interpreting the relationship between the past and the future as we make decisions and take action that we trust will control future outcomes. One medical scientific understanding of risk is the quantitative equation of how likely one is to end up in a very rare situation. Being born with a rare genetic condition is the most revelatory existential knowledge for understanding how to forge dignity from risk, as Mark and I know very well, and as Perske explained to bioethicists and health-care workers in 1972.

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