

## DISABILITY, HEALTH, LAW, AND BIOETHICS

Historically and across societies, people with disabilities have been stigmatized and excluded from social opportunities on a variety of culturally specific grounds. In this collection, the authors explore the impact that the philosophical framing of disability can have on public policy questions, in the clinic, in the courtroom, and elsewhere. They examine the implications of this understanding for legal and policy approaches to disability, strategies for allocating and accessing health care, the implementation of the Americans with Disabilities Act, health care rights, and other legal tools designed to address discrimination. This volume should be read by anyone seeking a balanced view of disability and understanding the connection between the framing of disability and policies that have a real world impact on individuals.

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# Disability, Health, Law, and Bioethics

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## Dedication

*Anita Silvers, one of the coeditors of this volume, died on March 14, 2019.  
This brief memorial is written by three of her friends and collaborators,  
Teresa Blankmeyer Burke, Leslie Francis, and Mary Varney Rorty.*

Anita Silvers shaped the fields of philosophy and disability substantively, institutionally, and ethically. Her own life was shaped by a severe case of polio, which she contracted as a nine-year-old at scout camp. She received her B.A. in philosophy from Sarah Lawrence College in 1962, her Ph.D. from Johns Hopkins University in 1967, and studied at London University in 1965. When she finished her Ph.D., Silvers was advised by her mentors that, because of her visible disabilities, it would be prudent to apply for positions in philosophy where in-person interviews were not standard. So, she accepted an offer to join the faculty at San Francisco State University, where she built a highly distinguished career as professor for over fifty years and department chair for several terms. She did this even though, for many years, she had to arrive at her office very early in the morning to keep students and colleagues from seeing the effort it took her to reach her inaccessible office and classrooms on the upper floor of a building without an elevator.

Among her many books and articles were seminal works in aesthetics, bioethics, justice, and philosophy and disability. Silvers' early philosophical writing was in aesthetics. At the time, the field was locked into the analytic tradition, attending to questions such as whether there are necessary or sufficient conditions for an object to count as a work of art. Silvers demonstrated, to the contrary, that this analytic program failed crucially to engage with the world of art as actually practiced. She coauthored *Puzzles About Art*,<sup>1</sup> a volume that gave generations of students the materials with which to challenge fundamental assumptions about art and its making. Silvers also deployed her world-centered approach to aesthetics to literature and critical thinking more generally, writing about the role of art in education and philosophy in schools.

<sup>1</sup> Margaret P. Battin et al., *Puzzles About Art: An Aesthetics Casebook* (1989).

From her pathbreaking work in aesthetics and throughout her career, Silvers was recognized for the breadth of her contributions to the humanities. In 1978, she was named California Distinguished Humanist by the California Council for the Humanities. In 1980, President Jimmy Carter appointed her to the National Council for the Humanities, the governing board of the National Endowment for the Humanities. Silvers received the inaugural California Faculty Association Human Rights Award in 1989. In 2009, she became the only recipient from a non-research-intensive university to be awarded the Quinn Prize for Contributions to Philosophy by the American Philosophical Association (APA). She was the 2013 winner (with Eva Kittay) of the Lebowitz Prize for Philosophical Achievement and Contribution by Phi Beta Kappa and the APA. Silvers also received the Wang Family Excellence Award for extraordinary achievements in the California State University system in 2017.

By the early 1990s, Silvers turned her acute philosophical eye to bioethics and disability. Drawing on her insights about art, she criticized the role played by judgments about “the normal” in assessments of the capacities of persons as agents, or judgments about the effective deployment of healthcare. In *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*,<sup>2</sup> Silvers and her coauthors argued that equality for people with disabilities, like equality for others, means seeing them as competent contributors to cooperative social practices rather than as persons in need of welfare. This understanding of equality, Silvers contended, provides the theoretical foundation for disability rights as civil rights. Such civil rights are not special privileges; they are accommodations for difference that enable persons with disabilities to work, engage socially, or function successfully in multiple aspects of life, just as others with different bodies or minds are able to do. Such accommodations must open doors in ways that provide meaningful access for people to function, rather than becoming mere empty promises. With Leslie Francis, Silvers edited a volume celebrating the first ten years of the civil rights accomplishments of the Americans with Disabilities Act<sup>3</sup> and authored many articles on disability civil rights in healthcare, reproduction, employment, and public accommodations. Silvers also edited field-defining volumes on justice in healthcare such as *Medicine and Social Justice: Essays on the Distribution of Health Care*,<sup>4</sup> *The Blackwell Guide to Medical Ethics*,<sup>5</sup> and *Medicine and Social Justice: Essays on the Distribution of Health Care*.<sup>6</sup>

<sup>2</sup> Anita Silvers et al., *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (1999).

<sup>3</sup> Leslie Francis & Anita Silvers (eds.), *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (2000).

<sup>4</sup> Rosemond Rhodes et al. (eds.), *Medicine and Social Justice: Essays on the Distribution of Health Care* (2002).

<sup>5</sup> Rosemond Rhodes et al. (eds.), *The Blackwell Guide to Medical Ethics* (2007).

<sup>6</sup> Rhodes et al. (eds.), *Medicine and Social Justice*.

In her extensive bioethics scholarship, Silvers was especially concerned to address disability discrimination in healthcare. Drawing on her own experiences as a partial quadriplegic, she sought tirelessly to point out how thinking about disability goes wrong in healthcare by locating problems in bodily differences rather than features of the world, such as the design of warning systems that fail to communicate successfully with people with sensory disabilities. She argued for critical distinctions between disability discrimination and the imposition of misplaced paternalistic judgments or values held by others, such as the determination that life should be preserved at all costs. To illustrate, in her recent testimony before the National Academy of Medicine in their workshop on physician-assisted death, she powerfully argued against the requirement that persons seeking physician-assisted death must administer the doses to themselves. Such misplaced protectionism, she contended, deprioritized the choices those people made and risked subjecting them to greater harm. She sought to implement these insights in her long years of service on the ethics committee at San Francisco General Hospital, in the many classes on bioethics that she taught at San Francisco State, and in all of the mentoring she did for others.

Silvers's work on disability justice was grounded in her experience as a disabled person and her activism on behalf of people with disabilities. The conclusion from her essay "Formal Justice" says it best:

Listening to the voices of people with disabilities in their own words quoted throughout this essay, we cannot help but have observed that, foremost, they desire a public sphere that embraces their presence. For them, equality means taking their places as competent contributors to well-ordered cooperative social and cultural transactions. For them, justice must offer, first, the visibility of full participatory citizenship, not a spotlight that targets them as needing more than others do.<sup>7</sup>

From her time as a graduate student at Johns Hopkins to her explosive laughter that could be heard down the halls of so many meetings, Anita Silvers buoyed us all. She was mentor, colleague, advocate, contributor, teacher, roommate, and friend. She will be greatly missed.

<sup>7</sup> Silvers et al., *Disability, Difference, Discrimination*, 145.

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## Introduction

*Carmel Shachar, I. Glenn Cohen, and Michael Ashley Stein*

Historically and across societies, people with disabilities have been stigmatized and excluded from social opportunities on a variety of grounds. These justifications include assertions that people with disabilities are biologically defective, less than capable, costly to treat and employ, suffering, or fundamentally inappropriate for social inclusion. Rethinking the idea of disability so as to detach being disabled from inescapable disadvantage has been considered a key to the twenty-first century reconstruction of how disablement is best understood.

Such “destigmatizing,” however, has prompted hot contestation about disability. Bioethicists in the “destigmatizing” camp have lined up to present non-normative accounts, ranging from modest to audacious, that characterize disablement as “mere difference” or in other neutral terms.<sup>1</sup> The arguments for their approach range from applications of standards for epistemic justice to insights provided by evolutionary biology. Conversely, other bioethicists vehemently reject such non-normative or “mere difference” accounts, arguing instead for a “bad difference” stance. “Bad difference” proponents contend that it is correct to weigh disability negatively.<sup>2</sup>

The “mere difference” versus “bad difference” debate goes beyond the halls of academia. The choice of disability framework can have serious implications for legal and policy treatment of disability, and shape strategies for allocating and accessing healthcare. For example, the framing of disability impacts the implementation of the Americans with Disabilities Act (ADA) and other legal tools designed to address discrimination. The characterization of disability also has healthcare allocation and accessibility ramifications, such as the treatment of preexisting conditions preclusions in health insurance. For example, proponents of disability as “bad difference” warn that destigmatizing disability could be dangerous because social support for medical programs that prevent or cure disability is predicated on solidarity hinging on a disability being a condition that it is rational to avoid. Construing disability as

<sup>1</sup> Elizabeth Barnes, *The Minority Body* (2016), 4.

<sup>2</sup> See Guy Kahane and Julian Savulescu, *Disability and Mere Difference*, 126 *Ethics* 774 (2016).

normatively neutral thus could undermine the premises for resource support, access priorities, and cultural mores on which the practice of medicine depends.

The purpose of this volume is not to construct a framework of disability that will ultimately resolve the question of “mere difference” versus “bad difference.” Rather, we seek to explore how the characterization of disability can have strong impacts on our medical, legal, and social structures. Many of the contributors to this volume lean towards the “mere difference” camp. Their work points to areas where utilizing this framework can result in less problematic, “fairer” policy solutions, such as revisiting immigration law to remove stigmatizing assumptions about the connections between disability and economic dependence in Part IV, or revising rules around organ transplantation to let disabled individuals participate more fully in both donating and receiving organs in Part III. Other contributors to this volume – inspired by, if not completely allegiant to, the “bad difference” view – tease out when negative ramifications of disability result from social structures and when they are based in biological realities, such as in the exploration of chronic pain in Part III. The contrasts in the frameworks used by the various authors force readers to consider their own conception of disability and the policy ramifications of that choice.

The volume begins, though, with Tom Shakespeare setting the stage for the explorations to come in the connections between disability framing and policy. Shakespeare identifies several important themes that appear throughout the volume.

First, Shakespeare raises the importance of honoring and acknowledging the diversity of disability. Part of the challenge of framing disability, whether the “mere difference” or another framework is more appropriate, is that disability can encompass a wide range of conditions. While individuals with blindness and individuals with mental health concerns can both be considered disabled, their impairments have relatively little in common. In some cases, it may be the specific condition that determines where the “mere difference” framework or a different conception of disability is best applied. The diversity of disability can also have important policy implications. It is easy to say that physicians’ offices must be made more accessible to all patients, no matter the type or level of disability, as explored in Part III by Adam Cureton. But consider the work of Rebecca Dresser in Part II and Matthew Smith, Tara Allison, and Michael Ashley Stein in Part IV, each of whom discuss issues around consent and capacity, an under-addressed component of accessibility. The complication that people with dementia were once considered “fully competent” while many with intellectual disabilities are never considered fully competent despite functional capability creates a distinction in the central questions raised in the two chapters. How do we honor the wishes of the past “competent” self without negating the wishes of the current impaired self in the case of dementia patients, while on the other hand better respecting the human rights of people who have always been defined as limited by their impairments to engage in sexual (and other) activities? The work of Marie-Eve Lemoine and Vardit Ravitsky in Part II around disclosure of information to couples whose fetuses test

positive for Down syndrome further reinforces the diversity of the disability experience. Lemoine and Ravitsky explore concepts of determination, consent, and capacity similar to Dresser, Smith, Allison, and Stein, but in the context of decisions that will prevent the existence of the individual with a disability entirely.

Another theme that runs throughout the book, identified by Shakespeare, is the need for additional information about the realities of disabilities. In some ways, this theme picks up on work covered in the Petrie-Flom Center's previous volumes, including *Big Data, Health Law, and Bioethics*<sup>3</sup> and *Transparency in Health and Health Care in the United States*,<sup>4</sup> which explore the importance of data in directing and improving healthcare. Without empirical information about the lives of people with disabilities, it is too easy for scholars and decisionmakers to adopt framings of disability that do not reflect reality, leading to bad public policy. Indeed, Part VI is dedicated to better quantifying the experiences of those with disabilities and translating this quantification into actionable policy recommendations, such as in the work of Govind Persad and Nir Eyal. But the importance of better data is a seam woven throughout the book, for example, in Lemoine and Ravitsky's Part II contribution on providing information on Down syndrome to expectant parents as to make better informed decisions about terminating fetuses with that condition. Even in chapters not explicitly about information, the value of data shines through. For example, in Part V Wendy Salkin develops and examines the idea that judges can adequately represent the interests of the severely intellectually disabled as their representatives. To provide this judicial representation, however, these judges would clearly need significant information about the experiences of those with intellectual disabilities. Throughout the volume readers should be asking themselves questions regarding the importance of data such as, "what information about a particular disability is missing from the policy discourse?", "how can this information be better conveyed to decisionmakers?", and "would information about the lived experiences of people with disabilities cause me to shift the framing of disability I would adopt?"

Shakespeare then turns to the flipside of rights – the obligations or duties that are imposed when individuals are accorded rights. In a volume that seeks to place disability framing and philosophy within legal and health policy, the reader will constantly encounter questions as to what the obligations are of our legal and healthcare systems to people with disabilities. Several authors provide an overview of those rights and obligations, especially as it applies in areas of law, such as Daniel Goldberg in Part I and Craig Konnoth in Part V. Other contributors look at similar questions, but applied to the medical field, such as Ani Satz in Part I, as well as Omar Sultan Haque and Michael Ashley Stein in Part III.

<sup>3</sup> I. Glenn Cohen et al. (eds.), *Big Data, Health Law, and Bioethics* (2018).

<sup>4</sup> I. Glenn Cohen et al. (eds.), *Transparency in Health and Health Care in the United States* (2019).

The book is divided into six parts. Part I, introduced by I. Glenn Cohen, is intended to provide an orientation to the reader of some of the theories and framings that will be used throughout the volume. In particular, the three chapters in Part I demonstrate to the reader the harms that certain framings of disability can pose. When disability is defined as a problematic deviation from “normal,” it can give rise to disability stigma. Additionally, it can warp systems into creating problematic policies that only serve to harm and undermine people with disabilities, rather than to empower them. Part I, therefore, can be read as a warning against assuming there is a true “normal” for human beings, or that species-typical functioning should be the goal for all individuals.

Elizabeth Barnes, in Chapter 1, “Disability, Health, and Normal Function,” pushes back on one of the all too commonly accepted theories of “normal” health. Her piece takes apart the idea that there is a “biological norm of species-typical functioning” and takes umbrage with the assertion that disability or illness can be considered a deviation from this “normal.” Barnes cuts to the heart of the argument she critiques when she argues that one cannot hinge disability on a reduced ability to survive and reproduce, because many disabilities do not impact either of those abilities. Instead, she notes that it is possible to function well as an individual with a disability even if one does not achieve species-typical function. This pushback on the framing of disability as not “normal” sets an important tone for the rest of the volume, reminding the reader that disability and an inability to function do not go hand in hand.

Ani B. Satz, in Chapter 2, “Healthcare as Eugenics,” seeks to understand and then critique the connection between disability as a negative deviation from “normal” and the healthcare system. In some respects, Satz’s chapter is the applied version of Barnes’s – both critique a similar framing of disability, one from a philosophical perspective and the other through tracing its impact in our medical system. Satz asserts that the American healthcare system currently prioritizes normalizing individuals by preventing, ameliorating, or eliminating disability because medical providers are trained to view disability as a problematic deviation from normal species functioning. As a result, the healthcare system ignores other, equally or more effective atypical methods of functioning that could be used by people with disabilities. Satz labels this as a form of “negative eugenics,” arguing that this approach devalues people with disabilities and ensures that they receive suboptimal healthcare.

Daniel Goldberg closes Part I with Chapter 3, “Epistemic Injustice, Disability Stigma and Public Health Law.” While Satz focuses on the healthcare system, Goldberg explains the harmful connection between disability stigma and public health law and policy. Goldberg uses the concept of “epistemic injustice,” or the harms that come when one’s capacity as a knower is undermined, to articulate how the negative framing of disability harms people with disabilities in the public health context. He demonstrates that disability stigma contributes to both testimonial and



hermeneutic injustice when it comes to public health, leading to policies that discount and devalue the lived experiences of those with disabilities.

Part II of this volume, “Disability in the Beginning and the End of Life,” also introduced by I. Glenn Cohen, considers the impact that disability can play on decisions relating to the beginning and end of life. Each chapter wrestles with situations in which nondisabled actors make decisions on the lives, value, and autonomy of the disabled. The first chapter of this section explores when the state substitutes its judgment in lieu of allowing pregnant women to determine their reproductive choices, on the basis that pregnancy somehow diminishes their decision-making capabilities to the point of disabling them. The second chapter of this section explores the challenges of expectant parents using prenatal testing to determine whether to continue with pregnancy, even if that pregnancy leads to a child with a disability. The last chapter focuses on the difficulties between weighing the preferences of an individual at different points of their struggle with dementia and whether to honor the wishes of the previously competent patient or to respect the value of the life of the current patient living with late-stage dementia. In each case, the importance of framing disability correctly, and the impact that framing choices have on public policy, is front and center.

In the opening chapter of this part, “Abortion, the Disabilities of Pregnancy, and the Dignity of Risk,” Mary Anne Case argues that abortion jurisprudence and bioethics frame pregnant women as disabled. Drawing from examples in both American and German case law, including *Gonzales v. Carhart*, she contends that judges such as US Supreme Court Justice Kennedy often assume that women are not capable of being rational decisionmakers because their faculties have been disabled by pregnancy. In some cases, this assumption supports access to abortion; for example, in Germany women pregnant with a fetus with diagnosed disabilities are presumed to be under sufficient mental strain to justify legal late term abortions. In other cases, this paternalistic assumption that pregnant women are overwhelmed to the point of disability by their condition can be used to undermine access to abortion, such as when Justice Kennedy argues that the risk of women coming to regret their abortions justifies preemptively limiting their access to this procedure. Case, in her work, reminds the reader that pregnant women should be given the dignity of risk – the ability to make choices even if they may later regret those choices – rather than being assumed to be diminished mentally or emotionally by their pregnancies. She does so by drawing upon the work of disability scholars and advocates to emphasize the importance of allowing individuals the dignity of risk, regardless of abilities, to allow for true independence.

Marie-Eve Lemoine and Vardit Ravitsky, in Chapter 5, “The Down Syndrome Information Act and ‘Mere Difference’: Redefining the Scope of Prenatal Testing Conversations?”, explore the ethical considerations in counseling pregnant women who consider testing their fetuses for Down syndrome. Lemoine and Ravitsky explore the different frameworks used to justify prenatal testing for Down syndrome,

arguing that there has been a shift away from public health justifications to a desire to promote informed choice among pregnant women. In order to properly facilitate that choice, they note, advocates have pushed for regulations requiring that health professionals offering these tests provide complete information on Down syndrome, including its positive aspects. The authors locate motivations for these laws in the framing of disability – in this case, Down syndrome – as “mere difference.” While Lemoine and Ravitsky are ultimately supportive of the concern to avoid unnecessarily negative depictions of Down syndrome, they also argue that the “failure of our societies to provide social and physical environments that maximize everyone’s well-being and social participation” ought to be an important factor in prenatal testing conversations.

Rebecca Dresser, in Chapter 6, “Dementia, Disability, and Advance Directives: Defensible Standards for Dementia Care,” brings us from the beginning of life to the end of it. Dresser attempts to untangle the challenges around supporting patient decision-making in the context of dementia care. She notes that many patients seek to use advance medical directives to prevent extended life with dementia, to the point of authorizing the withholding of ordinary food and water in late-stage dementia. These advance directives present a major tension in promoting respect for autonomy and self-determination: can competent individuals, i.e., the “current” patient, dictate care for and even discriminate against their later disabled selves, i.e., the “future” patient? Dresser argues that allowing advance directives that promote harm against the future self should be seen as discrimination that reinforces negative judgments of the value of disabled people. In a way, Dresser’s piece can be read as a companion to Lemoine and Ravitsky’s contribution, because both chapters explore to what extent nondisabled actors should be allowed to make decisions about the lives of disabled individuals, even to the point of choosing nonexistence of these individuals.

Part III, “Disability in the Clinical Setting,” introduced by Carmel Shachar, addresses the framing of disability in the medical system, most specifically in the delivery of clinical care. The contributions in this section note again and again the challenges that people with disability face in achieving access to care. These barriers to care are often motivated by “ableism,” as discussed by Omar Sultan Haque and Michael Ashley Stein, and are expressed in the very structures of our medical system, as documented by Adam Cureton. While revising the framing of disability to that of “mere difference” can often lead to improved public policy, chapters by Emily Largent, Caroline Huang, and David Wasserman caution us not to treat all disability as alike and to consider when we should use a different framing to result in the best clinical outcomes and treatments.

Adam Cureton, in Chapter 7, “Expressing Respect for People with Disabilities in Medical Practice,” examines the physical environments of the healthcare system that confront patients with disabilities. This includes not only the structure of waiting and examination rooms, but also the staff of the healthcare system – including physicians,

nurses, etc. – who often act carelessly or even harmfully when interacting with people with disabilities, as well as the policies of these environments. Cureton emphasizes the importance of respect as “one of the most important attitudes that we should strive to cultivate because of its connections with the *dignity* that all humans equally share.” The failure of the medical environment to express respect for its users with disabilities is unjust, and communicates that the rights of disabled people are unimportant and that disabled people are “less than” other patients or even objects.

Emily Largent, in Chapter 8, “Disabled Bodies and Good Organs,” also explores the negative framing of disability woven into the medical system by considering transplantation policies as applied to disabled donors and recipients. She acknowledges that disabled individuals often face additional hurdles in accessing scarce organs but, disturbingly, are often seen as a good source of organs. Largent then suggests that using the “mere difference” framework would allow for better access for disabled organ recipients while treating disabled potential organ donors similarly to other potential organ donors. Incorporating the “mere difference” framework, therefore, will lead to an overall more equitable transplantation system by incorporating such public policy changes as revising the dead donor rule and adding better procedures to ensure that individuals being evaluated for organ recipient lists are given reasonable accommodations as required by anti-discrimination laws.

Omar Sultan Haque and Michael Ashley Stein, in Chapter 9, “Humanizing Clinical Care for Patients with Disabilities,” consider the prejudices against people with disabilities present in the medical system, describe the impact that this “ableism” has on the experiences that patients with disabilities face when pursuing medical care, including impacting clinical outcomes, and suggest interventions that would improve the framing of disability used by many clinicians. Haque and Stein, similar to Cureton, trace the indignities and prejudices present in the clinical system, noting that they result in unequal access to care and undermine the clinician-patient relationship itself. Fortunately, they argue, this pervasive ableism can be combated through improved educational and clinical interventions, such as including a section in the medical records where clinicians can document biases that may arise for their patients with disabilities and encouraging clinicians to provide this information in the presentation of patients on clinical rounds. These are important tools for shifting the framing of disability in the minds of clinicians from an ablest mentality to that of “mere difference.”

Caroline Huang and David Wasserman close Part III with their contribution, “Chronic Pain As a Challenge for Disability Theory and Policy,” by exploring the challenges of applying the “mere difference” framework to chronic pain. They note that chronic pain has much in common with more familiar disabilities in that it substantially limits functions and elicits stigmatizing social responses. Chronic pain, however, is challenging in that it can vary in duration and persistence, and often can be difficult to validate with outward signs. Also distinguishing chronic pain, they argue, is the fact that it is intrinsically bad – it confers no benefits and makes life

worse for people who live with it. Therefore, they argue, the “mere difference” framing is helpful but not always the right lens to use to understand this condition. The most significant outcome, they note, of the difference between chronic pain and other conditions that lead to disability is that, while there should be a right to pain relief, this right comes with significant responsibilities on the rights-holder. At heart, Huang and Wasserman maintain, “the case of [chronic pain] makes it clear that disability theory, practice, and policy cannot be one-size-fits-all.” This is an interesting contrast to many of the other contributions, especially in Part I, that act as strong proponents for the “mere difference” frameworks.

Part IV, “Equality, Expertise, and Access,” introduced by Michael Ashley Stein, considers the connection between rights and access. Access, in the case of these three chapters, varies from the clinic to the bedroom but reflects the assertion that there is no equality without some sort of meaningful access to social participation and experiences. The authors of these contributions consider whether our current rights regime is sufficient to overcome barriers to access and, all too often, find that this is sadly not the case. In one chapter, the reader is asked to consider whether better access to a certain type of information will actually improve the disability rights regime – an interesting flip on the relationship we explore in this part.

Leslie Francis and Anita Silvers open this section with Chapter 11, “Making ‘Meaningful Access’ Meaningful: Equitable Healthcare for Divisive Times.”<sup>5</sup> Francis and Silvers explore meaningful access as a cornerstone of addressing harms imposed by disability discrimination. They are concerned with the distinctions between pursuing accommodations and modifications to achieve meaningful access, arguing that accommodations, which are personalized or individualized, are often mistaken for more global modifications by courts reviewing claims of disability discrimination. The risk inherent in this misidentification is that modifications are more likely to be rejected as unfair privileges, unreasonably expensive interventions, or fundamentally altering the service or benefit in question. Francis and Silvers suggest the differences between accommodations and modifications are particularly salient in the healthcare context. Unfortunately, especially when it comes to Medicaid coverage decisions, courts are particularly prone to make these confusion-based errors. Francis and Silvers note that, while modifications are appropriate in some contexts, it is important to clarify the types of solutions being requested to best promote meaningful access in healthcare.

Jasmine Harris continues to explore issues of access in Chapter 12, “The Privacy Problem in Disability Antidiscrimination Law.” In this contribution, the reader is asked to consider the importance of access to information and its counterpart,

<sup>5</sup> This volume began its journey as a collective effort with Anita Silvers, and was completed after her passing. She was a dear friend, colleague, and mentor for over twenty years. I benefitted immeasurably from Anita’s wisdom as one of the rare academics with visibly discernable disabilities writing within the disability field. And I was blessed to have been touched by her joyful personality and indomitable spirit. *Michael Ashley Stein.*

privacy, in the context of disability. Harris challenges the predominant privacy approach to disability status, that government institutions, employers, and private actors have treated disability identity as a private fact that must be given heightened privacy status. She argues that we should privilege disclosure of disability identity as supporting the core values of disability antidiscrimination law: integration, acceptance, and destigmatization. By assuming that disability identity carries a sufficient stigma to justify the current privacy approach, Harris worries that we are not advancing the goal of disability rights law, which is for people with disabilities to live in the world with full access. One of the innovations of Harris's contribution is her suggestion that rights seem to follow access, rather than rights conferring access. Without access to disability status information, it is more difficult to implement a rights regime that will result in the achievement of the goals of disability antidiscrimination.

Matthew S. Smith, Tara Allison, and Michael Ashley Stein close Part IV with Chapter 13, "Sexual Agency as a Rights-Based Imperative for Persons with Intellectual Disabilities." They consider the role of rights in ensuring access to sexual intimacy for people with intellectual disabilities. These individuals have often been denied the ability to express their sexuality by guardians, caregivers, and service providers. Smith, Allison, and Stein consider the constitutional and civil rights protections available to Americans with intellectual disabilities and find that they fail to protect against these paternalistic incursions on autonomy. By contrast, they argue, individuals with intellectual disabilities may find more protection for their sexual expression in both international rights-based constructs that compel positive state action to protect these rights, and an "architecture of intimacy" conceptual framework that likewise compels state action. Pursuing this internationally inspired, positivist human rights approach will not only fulfill the human rights imperative to ensure full community inclusion for persons with intellectual disabilities, which includes sexual intimacy, but also bring the reality of these individuals closer to the American ideals of freedom and liberty.

Carmel Shachar introduces Part V, "Disability, Intersectionality, and Social Movements," which focuses on the interplay between the framing of disability and the rights that people with disabilities can be expected to enjoy. Part V opens with an exploration of an area of law, immigration, that remains weighed heavily against individuals with disabilities because it relies on negative framing of disability, including that disability is a "bad difference" or a public health concern. The reader is then asked to consider how various framings of disability have shaped the field of disability rights, both in terms of bestowing resources and rights, and curtailing them. Last, this section explores situations in which the "mere difference" framing of disability is not an easy fit, when we consider how to appropriately champion the rights of the intellectually disabled from the bench. This asks the reader to consider alternative tools, such as representation, as well as the obligations of other actors to promote the interests of those with disabilities.

Medha D. Makhoul opens this part with Chapter 14, “Destigmatizing Disability in the Law of Immigration Admissions,” by tracing the treatment of disability within American immigration law. She notes that immigration law has been directly shaped by the framing of disability. At the turn of the century, disability was perceived as a strong negative, with implications for future generations, and people with disabilities were considered economic burdens. This framing led to regulations that treated disability as a presumptive disbarment to immigration. Makhoul argues that the “bad difference” framing of disability is still persuasive in immigration regulations because the relevant exclusions portray applicants with disabilities as being useless, marginal, and a burden on society. In order to reshape immigration law to hew closer to the “mere difference” framing of disability, Makhoul proposes that we must consider disability as a form of human variation and acknowledge the value of supporting the immigration of people with disabilities.

Craig Konnoth continues the exploration of the connection between the framing of disability and rights in Chapter 15, “The Normative Bases of Medical Civil Rights,” which explores the origins of disability rights in the prevailing paradigms of the day. Konnoth argues that disability rights are “best explained by how society conceives of the onset and causes of disability.” In the first wave of disability rights regulation, policymakers were informed by a model of disability as bad luck and therefore motivated to offer resources for people with disabilities. The second era’s dominant disability paradigm was, by contrast, disability as deriving not only from a lack of resources, but also from a lack of social regard and respect, similar to the disability as “mere difference” framing discussed throughout this volume. This yielded regulations that sought to alleviate social harms rather than provide welfare resources, such as the Rehabilitation Act and the ADA. Konnoth reminds us that these approaches to disability regulation have not fully displaced prior understandings based in individual fault, as a result of which rights and resources afforded to people with disabilities are limited. This chapter serves to remind the reader that the passage of time is not always synonymous with forward progress and that better framing and treatment of disability as time moves on should not be taken for granted.

Wendy Salkin, in Chapter 16, “Judicial Representation: Speaking for Others from the Bench,” considers the rights of individuals and groups to be represented in key proceedings, even when they cannot participate directly themselves. Salkin focuses her arguments on the example of judicial representation of people with severe intellectual disabilities by judges who are not intellectually disabled. Using *Cleburne v. Cleburne Living Center*<sup>6</sup> as an example, with a special focus on Justice Marshall’s partial dissent in the case, Salkin concludes that judicial representation may be appropriate in certain circumstances. Certainly, Salkin acknowledges that there are concerns as to whether members of the judiciary could adequately represent a group of which they are not a part, but in situations in which it is not

<sup>6</sup> 473 U.S. 432 (1985).

possible for a member of that group to serve as a judge, there is a special responsibility for the judiciary to represent their interests. While this chapter does not directly discuss the “mere difference” model of disability, it raises interesting questions about appropriate responses when the challenges facing people with certain disabilities are not wholly derived from social constructs.

Part VI, “Quantifying Disability,” with an introduction by William P. Alford, explores the challenges of trying to measure disability, especially in the context of the “mere difference” framing. These chapters ask the reader to consider how we can measure whether certain interventions are feasible, how to reflect the realities of living with a disability in healthcare resource allocation and prioritization, and how to update regulations to avoid “quantifying disability discrimination” through the use of new technologies. Throughout each of these chapters is an important thread for the reader: the choice of how we frame disability reflects how we attempt to measure it and how we incorporate those measurements into our public policies.

Nathaniel Z. Counts, C. Taylor Poor, Julie Erickson, Thomas Hart, and Kelly A. Davis, in Chapter 17, “Can We Universally Accommodate Mental Health and Should We? A Systematic Review of the Evidence and Ethical Analysis,” conduct a systematic review of articles published in medical journals to identify evidence for potential universal accommodations in mental health. Counts et al. argue that the ADA reflects, in part, the social model of disability through its emphasis on universal accommodations for physical disabilities. By contrast, they note, the ADA did not provide for universal accommodations in mental health, instead emphasizing individual accommodations as the potential solution for individuals with mental health challenges. This is problematic because universal accommodations “more fully realize the ethical objectives of the social model than individualized accommodations.” From a review of the relevant literature, the authors identify a small number of articles documenting the application of universal accommodations in response to mental health needs, suggesting that mental health conditions do not uniquely require individualized approaches for accommodations. While the authors acknowledge a need for further research into the applicability of universal accommodations in this area, they suggest that the social model of disability and the need to provide equity in treatment across physical and mental health conditions are compelling reasons for adopting the universal accommodations approach.

Mason Marks, in Chapter 18, “Algorithmic Disability Discrimination,” considers the threat of disability discrimination in the application of artificial intelligence (AI) technology. Mason notes that, with the rise of AI-based tools, disability-related information that would have previously been confined to the individuals in question, their doctors, family members, and other confidants, may be collected and analyzed by corporations based on purchase histories, social media posts, and internet habits. Alarming, current data privacy regulations do not appear to protect

people with disabilities against such data mining, nor does disability antidiscrimination law as it currently stands sufficiently protect against AI-generated conclusions that may devalue people with disabilities. In order to prevent AI from contributing to the social construction of disability, as argued by the “mere difference” framing of disability, Mason contends that we must amend existing regulations to limit the mining of disability-related data and otherwise strengthen our data protection laws. This chapter is particularly interesting in the context of the rest of the volume because it traces the rise of a modern socially constructed burden on people with disabilities, strengthening the argument that disability arises, at least in part, from social choices and framing.

Govind Persad picks up some of the challenges of trying to account for the “mere difference” framing of disability in healthcare resource prioritization and resource allocation in Chapter 19, “The Pathways Approach to Priority-Setting: Considering Quality of Life While Being Fair to Individuals with Disabilities.” Persad maintains that the use of quality-adjusted life-years (QALYs) to set healthcare priorities devalues people with disabilities. Instead, we should consider the pathways, as Persad terms it, via which disabilities impose disadvantages. For pathways that are the result of the laws of nature, resource scarcity, or permissible trade-offs, policymakers should be allowed to take disability into account when setting priorities. For other pathways, similar to the social constructs and discrimination reflected in the disability as a “mere difference” model, disability should not be considered when allocating resources, at least not to deny individuals access. Persad argues that this pathways approach allows us to avoid acting “as if we were in a perfect world where disabilities imposed no disadvantages, nor . . . as if all the disadvantages that disabilities impose can be reduced to a single number and used to set priorities without regard to social justice.”

Lastly, Nir Eyal, in Chapter 20, “Measuring Health-State Utility via Cured Patients,” tries to reconcile the discrepancy between the assessments of quality of life articulated by patients with disabilities who have adapted to the reality of their conditions and the quality of life assessments of the more general public or that of health professionals. Eyal proposes that we heavily weight the assessments of longtime patients but keep in mind “the sound reasons that sometimes exist to disfavor these assessments,” in part because all humans are fallible, and in part because some of the assessment by longtime patients may be colored by their adaptive responses. Eyal works to demonstrate how comparing the quality of life assessments of former patients who had experienced the relevant health state but then were “cured” could yield a new measure that would allow us to calibrate current patients’ assessments.

The characterization of disability as “mere difference,” by emphasizing the role that social structures play in the challenges faced by individuals with disability, can have important policy and ethical implications. The authors of this volume present a nuanced view of the framing of disability, exploring ways in which the choice of



framing can have an impact on our medical and legal public policies and on the lives of those with disabilities. While this volume does not resolve the debate between whether and to what extent disability is socially constructed or is rooted in inherent biological challenges, it does articulate the importance of understanding which framework is being utilized when we make decisions around resource allocation, the rights of the individuals, the obligations of society to those individuals, and the interaction of professionals – including physicians and judges – with those with disabilities.

## Preface

*Tom Shakespeare*

It may be paradoxical to approach a book which concerns so many problems with such joy but, nevertheless, I greet this volume of law and ethics as applied to diverse disability dilemmas with gratitude. The scholars here assembled have done the rest of us a huge service in thinking so effectively through a whole series of difficult issues. Not least our late friend and colleague Anita Silvers, for whose forensic thought and generous hospitality I will always retain the highest regard, admiration, and fondness. Her death is a great loss for our field, as was that of Adrienne Asch a few years back. To their memory we owe our continued dedication to work seriously and in a friendly manner on these important questions.

In this preface, I claim the luxury of referring to a few cross-cutting questions that occur to me as significant, raising them here impertinently but offering no wise solutions, merely the urging that we expand and deepen our engagement with disability law and ethics so as to address these and other issues that are always arising and challenging us. I wonder, for example, about what ethical and legal questions the US opiate epidemic raises. It's easy to spot gaps, but nevertheless timely for us to attend to current difficulties, drawing appropriately on our past insights. Nor am I exempting myself from oversight when it comes to the most pressing human tragedies.

The first question is that of the diversity of disability. I have long thought that some of the failure of mainstream, usually consequentialist, bioethicists and disability rights advocates and thinkers to engage with each other is due to a divergent conceptualization of disability itself. The bioethicists who view with alarm lives that appear to be full of suffering, dependency, and even futility are equating disability with its more serious and troubling cases, such as Tay-Sachs, motor neuron disease, or profound autism. The advocates and thinkers who respond by claiming disability as mere difference or pointing to the role of environments and barriers as comprising the true character of disability may sometimes be equating it with its less biologically determined variants, including deafness, paraplegia, restricted growth, or Asperger's syndrome. Rather than speaking of "disability" dilemmas, then we

should surely speak of “disabilities dilemmas,” to which there are a range of responses that need careful nuance and detailing to capture the complexities and specificities. To be sure, there are cross-cutting issues to which we should attend: prejudicial cultural representations, the need for reasonable adjustments, and so forth. Not only illness and impairment, but also responses to illness and impairment are more variable than either advocates or mainstream ethicists and lawyers might suppose, and our accounts should capture that.

The second question that occurs to me in reading this volume is about the very many empirical questions that are not yet settled. Here, the blame surely lies at the feet of the social science community of which I am a member, as well as our clinical and biomedical colleagues. For example, I am troubled that we do not fully understand the quality of life of an average person with Down syndrome and their family members. There are accounts from that community, and there is quality of life literature, but there is not a natural history of the condition that is accepted by all sides, which makes it very difficult to give prospective parents helpful guidance, as the chapter by Lemoine and Ravitsky indicates. And what is true for trisomy 21 is also true for many other conditions, not least because healthcare is improving, treatments and technologies are becoming available, life expectancy is advancing, and so old data and recommendations appear pessimistic. A related challenge is raised by Huang and Wasserman’s chapter on chronic pain. It’s all very well that we have an organic basis for the neuropathic pain that people like myself suffer as a consequence of spinal cord injury, but very troubling that many conditions such as fibromyalgia, chronic fatigue syndrome, and other Medically Unexplained Symptoms continue to be so ontologically and epistemologically uncertain. Not for the first time I resort to that ubiquitous phrase: more research needed by the scientists and social scientists. As an aside, I found Barnes’ contribution here especially delightful, in elegantly dismantling the assumptions of the Boorsean normal function view of disability, and thus demonstrating that more thinking is also needed by philosophers and lawyers.

My third question is about naming the duty-bearers, to use a term of art from the human rights field. A treaty such as the Convention on the Rights of Persons with Disabilities is expansive in its vision of promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promoting respect for their inherent dignity, to quote from Article 1. Yet, whose job is that? It does not just happen because a state ratifies the Convention; over the last decade, progress has been slow, uneven, and even retrograde in the case of my own country. The Convention is pioneering in combining negative freedoms with positive freedoms. Fully implementing the Convention obviously requires much more than simply respecting civil and political rights. But who ensures that persons with disability have access, for example, to family life, as Smith, Allison, and Stein discuss in this volume? When it comes to disability, something positive is required to ensure access to many of these human rights, and

most states have so far been deficient. Moreover, duty-bearers cannot simply be policymakers. Health and social care professionals play an important role, but the rest of us cannot ignore our own responsibilities, not least parents and family members. And even after we have settled these important legal questions of state and professional action, there remains our own need for ethics guidance and support with troubling dilemmas. I have never forgotten how Rayna Rapp once wrote of amniocentesis that it “makes every woman (to which I would add ‘and man’) into a bioethicist.” Now that we are opening up possibilities of medical decision-making and increasingly turning to lay people and patients to exercise choices, how much wise guidance and support are we able to give to people contemplating prenatal screening, treatment decisions, end-of-life decisions, or decisions to participate or not in clinical trials? In an era when genetic knowledge shows how each of us is vulnerable to disease or disability, these questions increasingly concern us all.

My final question (for now) is about another aspect of diversity, building on that last thought. Readers outside the United States may be frustrated that this is a volume that is often very located in the particular North American legal and rights traditions. But notwithstanding that grounding, there is also the question of the many cultural differences within the United States (and certainly beyond it). I am thinking that the legal subjects with which this book is concerned may be from secular, Christian, Muslim, Jewish, Hindu, New Age, or other ethical traditions, or none. Given that religion is part of life for some people, and an influence on their thinking for many others, we might need an account of how thoughts about embryos, healthcare, suffering, and dying often impinge, implicitly if not explicitly, on religion. My own current work is concerned with disability and development and I am struck, reading the literature, by how little we know about how people in East Africa, or South Asia, or Latin America, formulate questions of reproduction, parenting, or end of life. There are many relevant cultural differences which stop me in my tracks and reveal how my own assumptions are cloaking realities as experienced by my research participants.

I hope it can be seen as a tribute to this collection that a reader is prompted to raise questions like these. It’s certainly not a criticism. There is much work to do, for lawyers and philosophers and social scientists of all kinds. I am thankful to the editors and contributors of this volume for challenging our assumptions, troubling our knowledge, and pointing out the gaps that remain. I am so abidingly glad that disabled and nondisabled scholars are coming to our aid and moving forward our thinking. I hope we can continue to have these conversations in the elegant and convivial way that Anita made her trademark.

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