

## Moving Away from the “Medical Model”: The Development and Revision of the World Health Organization’s Classification of Disability

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**SUMMARY:** Recently, there has been a prominent call in the history of medicine for greater engagement with disability perspectives. In this article, I suggest that critiques of the so-called medical model have been an important vehicle by which alternative narratives of disability entered the clinical arena. Historians of medicine have rarely engaged with the medical model beyond descriptive accounts of it. I argue that to more adequately address disability perspectives, historians of medicine must better historicize the medical model concept and critique, which has been drawn upon by physicians, activists, and others to advance particular perspectives on disability. My present contribution describes two distinct formulations of critique that originated in differing interest groups and characterized the medical model alternatively as insufficient and oppressive. I examine the World Health Organization’s efforts to incorporate these distinctive medical model critiques during the development and revision of its *International Classification of Impairments, Disabilities, and Handicaps*.

**KEYWORDS:** medical model, World Health Organization, disability, classification

In a 1967 lecture, Mount Sinai psychiatrist M. Ralph Kaufman addressed recent criticism directed at his field, noting, “A group of individuals, for the most part professionals from the behavioral and social sciences, have been attacking what they call the ‘medical model’ of mental illness.”<sup>1</sup> Kaufman argued that the criticism “demonstrates a fundamental misconception of the role of medicine and the physician in any society at any time; it also restricts the medical model to a very narrow conceptual frame of reference.”<sup>2</sup> He dismissed critics of the medical model for rejecting the important contributions of biology and psychosomatic medicine and suggested that their alternative “social model,” as he called it, “represents but one facet of the medical model.”<sup>3</sup>

Kaufman’s direct engagement with psychiatry’s detractors is notable in part because medical professionals rarely took ownership of, or actively defended, the so-called medical model. Indeed, the “medical model” concept and critique came into being during the 1950s as a pejorative construction, and most physicians saw no reason to redeem the term. A few, however, did lament the criticism, including George Engel, an internist and psychoanalytic psychiatrist at the University of Rochester, who in 1970 suggested that critiques of the medical model had become “fashionable.”<sup>4</sup> Like Kaufman, Engel argued that its detractors were misrepresenting the medical model, for instance by associating it with nineteenth-century germ theory.<sup>5</sup> But Engel himself was also a vocal critic of the medical model. In the 1970s, Engel critiqued what he characterized as the medical profession’s insufficient attention to the psychosocial aspects of disease. While Engel dismissed the medical model criticism of previous decades, he also saw a need for reform.

In this article, I examine two distinct formulations of the “medical model” critique that were specifically applied to the understanding and management of disability by medical

professionals. Each of these two critiques differed in its underlying presumptions and aims as well as its primary promoters. The first medical model critique that I highlight was formulated in the 1970s by epidemiologists, rehabilitation specialists, and other clinicians—including Engel—in North America and Europe. This critical perspective particularly targeted the so-called medical model’s *insufficient* engagement with the impacts of chronic illness and disability on individuals’ social roles and status. Proponents of this formulation of the medical model critique called for a greater awareness among physicians of the psychosocial aspects of disease and disability to supplement medicine’s primary focus on underlying biological causes.<sup>6</sup> A second form of medical model critique rose to prominence in the 1980s, this time led by disability self-advocates and scholars in the United States and United Kingdom, who argued that the medical model’s assumptions and approaches were *oppressive* to people with disabilities. Proponents of this formulation of the medical model critique argued that disability should be addressed as a social and political issue, rather than as an individual health problem with a biological cause.<sup>7</sup>

Recently, there has been a prominent call in the history of medicine for a greater engagement with disability perspectives, to supplement the field’s dominant focus on disease.<sup>8</sup> In this article, I suggest that medical model critiques have been an important vehicle by which alternative, and less disease-oriented, narratives of disability have entered the clinical arena. Historians of medicine have primarily described their view of what the medical model is, rather than focusing on how physicians, sociologists, disability advocates, and other historical actors have used the “medical model” as a rhetorical concept to advance certain perspectives. Here, I examine the medical model not as a long-standing and consciously applied approach to medical practice but rather as a discursively constructed critique with multiple meanings. I argue that to

more adequately engage with disability perspectives, historians of medicine need to better historicize the “medical model” concept and critique, and in doing so recognize that late twentieth-century invocations of this construction were not singular in their assumptions or aims. My present contribution to this effort examines the World Health Organization’s efforts to address two distinct critiques—one characterizing the medical model as *insufficient* and the other describing it as *oppressive*—during the formulation and subsequent revision of its *International Classification of Impairments, Disabilities, and Handicaps*, in the 1970s and 1990s, respectively. I demonstrate that these medical model critiques were constructed in distinct social and professional contexts, which made their perspectives difficult to reconcile and integrate.

## Disability and Disease in the History of Medicine

Disability perspectives have had relatively little influence in the history of medicine field. As Beth Linker has described, when they do address disability, historians of medicine have frequently done so by associating it with disease or some other clinical category.<sup>9</sup> Some historians of medicine and other scholars have argued for the value of distinguishing between physicians’ conceptions and perspectives of medically defined diseases and individuals’ experiences with illness.<sup>10</sup> Along these lines, Robert Aronowitz has described the stigmatization that can result when a physician refuses to legitimate an individual’s illness experience as a medical disease.<sup>11</sup> Alternatively, as I describe in this article, many disability self-advocates have strongly opposed direct linkages between their disability experiences and a medically defined disease. Balancing these disease and illness-oriented views of disability is an important concern for historians of medicine, as they work to further engage with disability perspectives.

The historical study of disease and disability requires an examination of various viewpoints on the social and biological nature of these conditions. As Charles Rosenberg has put it, while disease is a biological event, “in some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it.”<sup>12</sup> From this perspective, a central aspect in the transition of a disease from purely biological to social and cultural is the point at which we identify and name it. Taxonomy and classification have thus been key to framing disease and mediating relationships between individuals and social institutions.<sup>13</sup> We might assume that a similar transition from biological to social, by way of diagnosis and classification, also applies to disability. While historians of medicine often view disease as having a biological antecedent, whether to approach disability similarly remains an open question—especially as historians work to assess the medical understanding and classifications of disability.

Historians of disability, responding to the relative exclusion of disability perspectives in academic history, have adopted a more activist approach than most historians of medicine.<sup>14</sup> As Beth Linker has described, disability historians often openly espouse opposition to, or seek to offer an alternative viewpoint from, the “medical model” of disability.<sup>15</sup> Engagement with the medical model concept and critique has been much more limited among historians of medicine. The term has been used in reference to somatic explanations of mental illness, the medicalization of childbirth, nursing practice, and the dominance of germ theory in public health.<sup>16</sup> However, historians of medicine have rarely examined the medical model in its use as an actor’s category among clinicians, scholars, and self-advocates. Jacalyn Duffin characterized the medical model view of disease as “individual, bad, and discontinuous.”<sup>17</sup> Importantly, Duffin also highlighted opposing perspectives, which alternatively viewed diseases as affecting entire populations, as

always present, or as being tolerable—and even good—rather than uniformly negative. She pointed out that these alternatives to the medical model have appealed to some people with disabilities, who choose to reject disease labels and negative characterizations. Thus, while physicians, working within the so-called medical model, learned about diseases to prevent them, disability activists sought to demedicalize conditions to avoid social stigma.<sup>18</sup>

In its various presentations within the history of medicine literature, the medical model has often been made to appear uniform, ahistorical, and uncontested within medicine. We are left with the impression that the medical model is, and perhaps always has been, central to Western medical training and practice. However, confronted with attacks on the medical model by sociologists, disability activists, and their own clinical colleagues, physicians rarely spoke up in its defense. Some scholars have argued that the medical model is little more than a caricature. As sociologists Mike Kelly and David Field suggested, “On close examination, it is actually very hard to find this medical model in medical practice.”<sup>19</sup> Along similar lines, Tom Shakespeare and other prominent disability scholars noted that “opponents of the ‘medical model’ have created a straw man that stands for medicalization, prejudice, and the devaluing of disabled people. It is difficult to find any authors who espouse such a ‘medical model.’”<sup>20</sup> These scholars have raised important questions about the existence and essential role of the so-called medical model in medicine and other clinical professions. In this article, I propose that instead of referring to the medical model as a straightforward set of beliefs and practices, historians of medicine should recognize and historicize it as a discursive construction used to advance multiple distinct critiques of the understanding and management of disability by medical professionals.

## Early Critiques of the Medical Model

Thomas Szasz, a Hungarian American psychiatrist and psychoanalyst, introduced the first published references to the “medical model” in 1956, when he coined the term—not to comment on disability, but rather to criticize his own field’s construction of mental illness. Fundamental to Szasz’s view was the belief that mental illness had no biological basis. Szasz’s medical model critique was an indictment of what he saw as psychiatry’s inappropriate efforts to enhance its status in medicine by establishing the physiochemical basis of mental illness, and promoting pharmaceutical treatments. As he put it, “Clearly in this function the medical model has served psychiatry well.”<sup>21</sup> Szasz was troubled by psychiatry’s investment in what he called “the myth of mental illness,” a phrase that became the title of his first book, in 1961.<sup>22</sup>

The initial criticism of Szasz was soon followed by the work of American sociologist Erving Goffman, who had conducted ethnographic field work at a residential institution for mental illness in Washington, D.C. Based on his observations, in 1961 Goffman published *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. In this collection of essays, which included one titled “The Medical Model and Mental Hospitalization,” Goffman was critical of what he considered to be the inappropriate hierarchical power that psychiatrists wielded over their patients in asylums as well as the coercive nature of admission and treatment within these “total institutions” for mental illness.<sup>23</sup> Many sociologists continued Goffman’s criticism of the medical model of mental illness during the coming decades, including Irving Kenneth Zola and Peter Conrad, who lamented what they considered to be the inappropriate medicalization of behavioral deviance, such as in cases of addiction and homosexuality.<sup>24</sup>

During the 1970s, University of Rochester psychiatrist George Engel also began critiquing the medical model, but specifically distinguished his perspective from that of Szasz. Writing in the *American Journal of Psychiatry*, *Science*, and the *New England Journal of Medicine*, Engel characterized the medical model as *insufficient*, as currently practiced by his fellow psychiatrists and physicians more broadly. Breaking with Szasz, Engel did not reject the biological existence of mental illness or suggest that the medical model represented an inappropriate means for consolidating power in medicine. Rather, Engel argued that psychiatrists and other physicians were failing in their primary responsibility to adequately care for the sick because they gave insufficient attention to the psychosocial aspects of medicine. Describing his own conception of the medical model, he noted “the distinctive feature of the M.D. is that his ultimate concern is with the health or illness of each individual. It is this which constitutes the basis for the medical model, not some preoccupation with the body as a machine to the exclusion of psychological or social considerations, as some would have us believe.”<sup>25</sup> In Engel’s view, though many critics had mischaracterized the medical model, it was still *insufficient* as practiced.

In 1977, Engel presented his ideas for “a new medical model” in *Science*. He argued, “The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness.”<sup>26</sup> Engel viewed the molecular turn of the 1970s critically, seeing it as indicative of the growing reductive orientation of medicine, which he also, and interchangeably, referred to as the “biomedical model.” As Theodore Brown later described, Engel’s recommended alternative to the medical model was the “biopsychosocial

model,” in which physicians “weigh the relative contributions of social and psychological as well as biological factors implicated in the patient’s dysphoria and dysfunction.”<sup>27</sup> The biopsychosocial model maintained a dominant role for the physician, but also acknowledged the significance of the patient’s psychosocial context. As I describe, Engel’s medical model as *insufficient* critique, while not specific to disability, was developed at the same time as the World Health Organization’s first classification of disability and would later influence its revision.

### The World Health Organization in the 1970s

The World Health Organization’s (WHO) classification scheme for disability was developed during a transitional period in the agency’s history. Founded in 1946, WHO was one of the original United Nations (UN) agencies, along with the Food and Agriculture Organization, the Children’s Fund (UNICEF), and the Educational, Scientific, and Cultural Organization (UNESCO). The directive of WHO, as one among many new UN assemblies, was narrowly focused on health, while other agencies were charged with broader social, economic, and cultural issues. Randall Packard has suggested that this division of labor at the UN limited opportunities for broad-based approaches to improving health.<sup>28</sup> WHO did establish a broad definition of health in its constitution, stating, “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>29</sup> However, many of WHO’s signature initiatives focused on specific diseases, including small pox and malaria eradication, which, as Packard put it, “were based on the view that well-administered control programs, using powerful medical technologies, could eliminate diseases without transforming social and economic conditions.”<sup>30</sup>

In 1973, WHO elected Danish physician Halfdan Mahler as its third director-general.

Mahler sought to reorient the focus of WHO away from top-down hospital programs and toward primary health services and local community engagement.<sup>31</sup> Mahler's efforts culminated with the 1978 International Conference on Primary Health Care, held in the Soviet Union at Alma-Ata, in present-day Kazakhstan. The resulting Alma-Ata Declaration stated that "attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector."<sup>32</sup> Conference participants highlighted the vast disparities in health and wealth between "developed and developing countries" and called for a much greater investment in primary health care to address these inequities. As Mahler later noted, "the 1970s was a warm decade for social justice. That's why after Alma-Ata in 1978, everything seemed possible." In his view however, the hopefulness was short lived, and Alma-Ata was overshadowed in the 1980s by the turn toward neoliberal approaches to health, overseen by the World Bank and International Monetary Fund.<sup>33</sup>

Decades later, commentators retroactively framed the Alma-Ata Declaration as a corrective to the "medical model" perspectives that they believed dominated at WHO. In 1994, medical geographers Jonathan D. Mayer and Melinda S. Meade noted that, in highlighting social and economic factors as essential, the declaration had "far transcended the traditional medical model."<sup>34</sup> Marking the thirtieth anniversary of Alma-Ata, the current WHO director-general Margaret Chan argued that "the Declaration broadened the medical model to include social and economic factors, and acknowledged that activities in many sectors, including civil society organisations, shaped the prospects for improved health. . . . It was a radical attack on the medical establishment."<sup>35</sup> The same year, public health expert Stephen Gillam lamented that "the

social and political goals of Alma Ata provoked early ideological opposition and were never fully embraced . . . a medical model of primary care dominated by professional vested interests resisted the expansion of community health workers with less training.”<sup>36</sup> While the Alma-Ata Declaration did not mention the “medical model,” many observers later interpreted it as a critique of the *insufficient* nature of the medical model approaches informing WHO initiatives.

In line with the Alma-Ata vision, during the 1970s WHO developed a disability prevention and rehabilitation program as part of its primary health care initiative. This included programs to prevent forms of disability caused by disease, malnutrition, and accidents as well as the development of a WHO training manual to instruct families and local communities on how to better care for, integrate, and support persons with disabilities. As Mahler noted in a 1981 editorial, which described WHO contributions to the UN’s International Year of Disabled Persons, “Most of the essential rehabilitation tasks in developing countries are quite simple and do not require professional skills.”<sup>37</sup> WHO recognized that expensive biomedical approaches to addressing the high prevalence of disability would not be feasible in poorer member nations. Instead, the organization promoted much less costly community alternatives to medically controlled residential institutional services for people with disabilities.

New perspectives were also adopted during the 1970s in WHO’s disease classification schemes. In 1979, WHO introduced the ninth revision of the *International Classification of Diseases* (ICD), which was expanded to facilitate medical record indexing and coding, alongside its long-standing statistical account of medical conditions.<sup>38</sup> This revision of ICD was the only one during Mahler’s tenure, and his impact on WHO classification was notable. In addition to changes in ICD, WHO also approved a supplementary classification scheme, the *International*

*Classification of Impairments, Disabilities, and Handicaps* (ICIDH), published in 1980.<sup>39</sup>

WHO's interest in developing a classification system for disability and other consequences of disease was a novel endeavor for the organization, but one that followed quite naturally from their expanding commitment under Mahler's leadership to recognizing the social and economic causes and impacts of disease as well as preventing and ameliorating disability through community based primary health care. ICIDH was also a direct outcome of the medical model as *insufficient* critique, which was promoted by a few influential WHO expert advisers in the 1970s.

### The WHO Classification of Impairments, Disabilities, and Handicaps

During the 1970s, British physician Phillip H. N. Wood led the development of a classification scheme for impairment and its consequences. Wood was not the first to attempt a large-scale effort to classify disability. A decade earlier, American sociologist Saad Z. Nagi, in a report for the U.S. Social Security Administration and Department of Health, Education, and Welfare, had developed a new approach to conceptualizing disability, which included social and environmental factors. Nagi's disability framework was influential in the United States for decades thereafter and was adopted for use in 1991 by the National Academies Institute of Medicine.<sup>40</sup> Efforts to assess and classify disability were also under development in the United Kingdom during the 1960s and 1970s, by Amelia I. Harris of the British Office of Population Censuses and Surveys and the physician and rehabilitation specialist Margaret Agerholm. In a

1975 article on her approach, Agerholm noted the sense of urgency for developing a disability classification among organizations including WHO, which hired Wood as an expert consultant.<sup>41</sup>

The Ninth ICD Revision Conference approved Wood's disability classification scheme for eventual publication in 1975.<sup>42</sup> Over the next several years, Elizabeth Badley, a British epidemiologist, assisted Wood in making revisions to his system. Badley later commented that the embrace of Wood's work was "extraordinary . . . given the strongly biomedical focus of WHO at that time."<sup>43</sup> As a rheumatologist who specialized in arthritis, Wood had long been interested in the individual and social consequences of disease as well as the often-overlooked nature of rehabilitation as both a medical and social process.<sup>44</sup> In addition to Badley, the British sociologist Michael Bury collaborated with Wood on the conceptual formulation of ICIDH. As Bury later recounted, the authors' goal was to "challenge the medical model and assumptions about disablement."<sup>45</sup> During the lead-up to the publication of ICIDH, Bury and Wood noted, "The power of the medical model is self-evident, whereas the inability to account adequately for the particularities of the disease experience is an obvious drawback."<sup>46</sup> This included the severe economic disadvantage of people with disabilities.<sup>47</sup> Wood and Bury described ICIDH as a response to the *insufficiency* of the medical model in addressing disability.

ICIDH had a three-part scheme, which attempted to extend the focus of ICD—on diseases and their manifestation—into the social realm. The first classification was impairment, which ICIDH described as an abnormality in bodily structure or function, in some cases caused by disease. Impairments led to disabilities, which in ICIDH were characterized by individual limitations in the performance of specific activities. Disabilities sometimes brought about handicaps. In ICIDH, handicaps were described as "the disadvantages experienced by the

individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaption to the individual's surroundings.”<sup>48</sup> ICIDH listed impairments in intellectual capability and language, sensory perception, organ systems, and skeletal structure. Forms of disability included behavioral, communication, and mobility disabilities as well as personal care and situational disabilities, which involved a lack of tolerance for particular environments. Six categories of handicap were also classified: orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency handicaps. The authors held that these six categories of handicap impacted “survival roles,” which were “broadly transcultural.”<sup>49</sup> Notably, all three authors were white professionals who worked in Britain. The ICIDH manual does not acknowledge any outside, international, or culturally diverse input or assessment.

Handicap was the most novel and complex—and later the most severely criticized—aspect of the new classification. In recognition of this, the ICIDH introduction noted, in bold,

**Handicap is more problematical. The structure of the Handicap classification is radically different from all other ICD-related classifications. The items are not classified according to individuals or their attributes but rather according to the circumstances in which people with disabilities are likely to find themselves, circumstances that can be expected to place such individuals at a disadvantage in relation to their peers when view from the norms of society.**<sup>50</sup>

This concept was well outside the realm of ICD, which focused on bodily manifestations of disease in individuals. As Badley put it, the handicap classification in ICIDH “extended the medical model of disease into the psychosocial and society arenas.”<sup>51</sup> Indeed, the ICIDH authors adopted a medical model as *insufficient* critique that closely aligned with Engel’s perspective.

In 1980 Wood and Badley published *People with Disabilities*, which highlighted the value of ICIDH for improving interprofessional communication about people with disabilities and collecting useful information concerning the social challenges that they faced. In his summary of the volume, physician and rehabilitation specialist Carl Granger highlighted the similarities between ICIDH and Engel's contemporaneous medical model critiques: “<ext>Engel has expressed, ‘The dominant model of disease today is biomedical.’ . . . The introduction of the [People with Disabilities] monograph highlights well some of the obstacles to gaining information on the social role performance of persons with disability pointing out that we are not accustomed to considering how one’s personal expectations and social norms influence the day-to-day manifestations of disability.”<sup>52</sup> While they worked independently, Wood and Engel were proponents of a common form of medical model critique. In a 1978 article, Bury and Wood aligned themselves with Engel, and contrasted their view with that of Szasz, whose “myth” perspective on mental illness they likened to “glossing over of the biomedical origins of disablement.”<sup>53</sup> In doing so, Bury and Wood stated their belief in the biological causes of disablement. As I describe in the sections ahead, this presumption of a bodily antecedent to disabilities and handicaps, which was present in ICIDH, became the target of a second, distinct form of medical model critique in the 1980s.

## The Rise of Disability Self-Advocacy

During the 1950s and early 1960s, parents and clinicians were the primary leaders of disability advocacy movements, as they took up activism on behalf of their children and patients. During the civil rights era, however, people with disabilities increasingly began to advocate for

themselves.<sup>54</sup> In the United States, the early self-advocacy movement was led in part by scholars who had researched disability within their professional fields during the 1970s and then took on self-advocacy roles in the 1980s. Among the most prominent American voices were the sociologist Irving Kenneth Zola and the political scientist Harlan Hahn, both of whom had physical disabilities resulting from childhood polio. In Britain, Victor Finkelstein and Michael Oliver were similarly academics with physical disabilities who turned to political activism. Notably, it was educated white men who had stable forms of physical disability—rather than intellectual impairment, chronic illness, or a degenerative condition—who were the primary early voices in disability self-advocacy. The introduction of feminist perspectives and inclusion of people with a wider variety of disabilities took place in the self-advocacy community in the 1990s.<sup>55</sup>

Irving Kenneth Zola began attacking the medical model in the sociological literature during the early 1970s by characterizing medicine as “an institution of social control.”<sup>56</sup> With his 1982 book *Missing Pieces: A Chronicle of Living with a Disability*, Zola joined the still fledgling disability self-advocacy movement in the United States. In *Missing Pieces*, Zola described his increasing interaction with disability self-advocates during the late 1970s and his transition to identifying as a person with a physical handicap, through his recognition of the common struggles and oppression that he shared with other persons with disabilities.<sup>57</sup> During the early 1980s, Zola founded *Disability Studies and Chronic Disease Quarterly* (renamed *Disability Studies Quarterly* in 1985), which became one of the most significant journals in disability studies and helped to establish the medical model as *oppressive critique* in the 1980s.

Harlan Hahn similarly shifted during the 1980s from being an academic with a physical disability to a disability self-advocate. Drawing on his background as a political scientist, Hahn was an early advocate of a minority group perspective on disability, which viewed persons with disabilities as being discriminated against in society and thus in need of legal protections. Hahn critiqued the medical model, which, as he put it, “requires patients to surrender their autonomy to professional direction and devote all of their efforts to the ultimate objective of complete recovery.”<sup>58</sup> His alternative sociopolitical view held that “disability stems from the failure of a structured social environment to adjust to the needs and aspirations of aspirations of disabled citizens rather than from the inability of a disabled individual to adapt to the demands of society.” Hahn contrasted his perspective from earlier medical model critiques, which he associated with a “functional-limitations paradigm” of disability and rehabilitation.<sup>59</sup> Most notably, he rejected the presumption espoused in ICIDH that bodily limitations led to disability.

In Britain, an important milestone in the establishment of the disability self-advocacy movement was the 1976 publication of *Fundamental Principles of Disability* by the Union of Physically Impaired Against Segregation (UPIAS). This document argued that “it is society that disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation.”<sup>60</sup> One of the cofounders of UPIAS was psychologist Victor Finkelstein, who had a leading role in the British self-advocacy movement. Finkelstein, a white South African, was paralyzed in his mid-twenties in a pole-vaulting accident and later imprisoned for his anti-apartheid activities. He immigrated to the United Kingdom in 1968 and soon became involved, along with Paul Hunt, in the new disability self-activism movement. In 1972, Hunt called attention to the oppression of people

with disabilities in a letter published in the *Guardian* newspaper. His letter facilitated contact with like-minded people and led to the formation of UPIAS. Hunt was an outlier among early disability self-advocates in that he had a degenerative condition, muscular dystrophy, and was not an educated professional. Notably for this time, Hunt actively included female voices in his publications.<sup>61</sup>

Another prominent British self-advocate and disability scholar during the 1980s was Michael Oliver. In 1983 Oliver introduced the “social model” of disability, which he presented as a critique of what he called the “individual model” of service professionals, within which, he noted, “medicalization” was one component.<sup>62</sup> The social model located the causes of disability in societal barriers rather than in individual bodies. In his landmark book *The Politics of Disablement* (1990), Oliver characterized disability as “culturally produced and socially constructed.”<sup>63</sup> He further argued that medical approaches to understanding, classifying, and researching disability had “oppressive consequences” for people with disabilities, in large part because they were expected to be “passive recipients,” rather than participants in the process.<sup>64</sup>

Oliver’s critique of the “individual/medical model” of disability was widely influential and controversial among disability specialists, including those who espoused the distinct medical model as *insufficient* and *oppressive* critiques. Some proponents of these differing perspectives had developed tense relations by the 1990s.<sup>65</sup> A conference titled Accounting for Illness and Disability, held at the University of Leeds in 1995, showcased distinct critiques of the medical model’s implications for disability and put them into conversation. The following year, these interactions were published in *Exploring the Divide: Illness and Disability*. This edited volume included a back-and-forth between Michael Bury, an ICIDH coauthor, and Oliver, one of its

most vocal opponents.<sup>66</sup> While Bury defended the enhanced sociomedical perspective promoted by ICIDH as overcoming the *insufficient* medical model, Oliver argued that the WHO classification scheme actually continued the long-standing objectification of people with disabilities and the medical model's *oppressive* effects. In the sections ahead, I explore disability self-advocates' criticism of ICIDH, which led to the revision of this classification in the 1990s.

## Medical Model Critiques of ICIDH

The development of ICIDH was strongly influenced by the medical model as *insufficient* critique, which rose to prominence in the 1970s among clinicians and epidemiologists. However, the 1980 publication of ICIDH coincided with the formulation of a new form of medical model critique, espoused by disability self-advocates. In *The Politics of Disablement*, Oliver directly took on ICIDH, arguing that the classification focused on the effects of individual differences, not on social inequality. He wrote that, in ICIDH, "the social dimensions of disability and handicap arise as a direct consequence of individual impairments. This view of disability can and does have oppressive consequences for disabled people." Oliver argued that ICIDH was based on a unidirectional model, in which all disabilities and handicaps had a bodily antecedent in "personal inadequacies or functional limitations."<sup>67</sup> This, he noted, reinforced the dominant narrative of disability as a personal tragedy rather than an oppressive and imposed social status.

Finkelstein had similarly critiqued ICIDH five years earlier in a WHO conference speech, suggesting that "this classification scheme in its present form reinforces medical and administrative approaches towards us [people with disabilities]."<sup>68</sup> ICIDH, Finkelstein argued, was based on a "medical model" perspective and did not seriously engage with the perspectives

and needs of people with disabilities. Rather, it was rooted in a hierarchical approach of service providers defining the “problems” of people with disabilities and fixing them.<sup>69</sup> According to Finkelstein, this contributed to “the medicalisation of disability as a ‘complex collection of conditions’ (ie. problems) to be managed in the well-established manner by ‘people with abilities’ rather than as unique lifestyles that require unprecedented, original and creative support systems.”<sup>70</sup> As Oliver and Finkelstein saw it, the continued dominant role of able-bodied experts in defining and treating the “problems” of disability, through the creation and application of the ICIDH classification scheme, was a major source of oppression for people with disabilities.<sup>71</sup>

During the 1990s, many other disability self-advocates criticized ICIDH as an embodiment of, rather than an alternative to, the medical model. In 1996, Hahn lamented the unidirectional sequence presented in ICIDH from disease and impairment to disability and handicap and noted its similarity to the linear sequence in WHO’s ICD, from etiology to pathology to disease manifestation. Hahn argued that this aided “the theoretical purpose of ensuring that information gathered by the ICIDH remains anchored in a medical model, thereby excluding evidence engendered by competing paradigms.”<sup>72</sup> He further critiqued ICIDH’s intrinsic bodily focus and its lack of potential for extrinsic environmental change. He suggested that the concepts of disability and handicap presented in ICIDH “provide a means of analyzing the functional performance of individuals *within* the existing environment instead of a method of evaluating the effects of the environment on them.”<sup>73</sup> In his view, ICIDH failed to offer a framework for analyzing disability as a result of social and environmental forces.

British disability self-advocate Liz Crow similarly criticized the ICIDH classification scheme, noting, “Within this framework, which is often called the medical model of disability, a

person's functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure.”<sup>74</sup> Taking this critique a step further, American political scientist and disability scholar David Pfeiffer argued about ICIDH that “its conceptual basis is the medical model which leads to the medicalization of disability. From this point it is a short step to eugenics and a class-based evaluation of people with disabilities using the concept of ‘normal.’”<sup>75</sup> Pfeiffer went on to suggest that all WHO projects were inevitably medically oriented and declared that “disability is not a health question. It is a political one. By making disability a health question or by associating it with health problems, the WHO contributes to the oppression of persons with disabilities.”<sup>76</sup> As these views demonstrated, ICIDH faced severe criticism from disability scholars and self-advocates, who maintained a fundamental mistrust for WHO and its ambitions. Crow and Pfeiffer both responded to ICIDH with a medical model as *oppressive* critique, which criticized the classification’s underlying assumptions and conceptions of disability and health.

The coauthors of ICIDH were understandably troubled by the accusations made against their classification scheme, especially because their goal had been to provide an alternative to the medical model of disability. As Bury noted, “It has therefore been ironic, over the years, to see the ICIDH characterised by some as a ‘medical model,’ when the intention and the effect of the ICIDH was quite the opposite. The desire to challenge discrimination and disadvantage were at the heart of the ICIDH.”<sup>77</sup> In the decades after its publication, Wood and Bury defended the structure and aims of ICIDH and pushed back on criticism that it further stigmatized people with disabilities.<sup>78</sup> Wood and Bury countered medical model as *oppressive* perspectives, including Oliver’s social model, by arguing that ignoring biological aspects of disability was too reductive.

In doing so, they adopted a position that was similar to M. Ralph Kaufman's defense of the medical model, which I began this article describing. Like Kaufman's 1967 criticism of what he called the "social model" perspective of Thomas Szasz and other early medical model critics, the ICIDH coauthors dismissed the ideological motivations and constructivist views of medical model as *oppressive* critics, who held that disability was a political, not a health, issue.<sup>79</sup> Wood and Bury argued that the "oversocialised" view of disability scholars and self-advocates would ultimately impede professional assessment and societal support for people with disabilities.<sup>80</sup>

By the early 1990s, WHO officials recognized that their efforts to provide a corrective to the psychosocial and environmental insufficiencies of the medical model in ICIDH had proven unsuccessful in a new era of criticism by disability self-advocates. WHO soon developed a revision plan, which intended to also incorporate the medical model as *oppressive* perspective. While proponents of the medical model as *insufficient* critique continued to support the basic structure and presumptions of ICIDH, Bury acknowledged in 2000 that the term "handicap" was offensive to many people, and needed to be replaced.<sup>81</sup> This increased awareness and engagement with the perspectives of people with disabilities helped to shape ICIDH's revision.

## Revising ICIDH

In 1993, WHO reprinted ICIDH with a new foreword that highlighted the need for revision. In particular, the foreword called for greater engagement with "the role of the social and physical environment in the handicap process."<sup>82</sup> As the (unnamed) foreword authors acknowledged, however, these external factors were "strongly culture-bound" and thus difficult to classify in a universal manner. The foreword expressed hope that more specific national-level classification

terminology would be developed. Indeed, efforts to revise ICIDH, which was written in the globalized medicine style of ICD and other WHO documents, conflicted with a recognition that disability was a culturally specific concept and identity. Challenges included differences in the interpretation and offensiveness of terms like “disablement” and “handicap” across languages and nations. WHO sought to address these issues by establishing revision groups in North America and Europe as well as by including people with disabilities in their process.<sup>83</sup> Notably, while WHO acknowledged participants from over sixty nations, its Collaborative Centers for ICIDH revision were limited to North America, Europe, Japan, and Australia.<sup>84</sup>

Among the contributors to ICIDH revision was Patrick Fougeyrollas, an anthropologist who had a physical disability. Fougeyrollas was a member of the Quebec Committee on ICIDH, which was founded in 1987 to help revise the ICIDH section on handicap. In a 1995 article, Fougeyrollas noted that in ICIDH “handicap was still considered or understood in a medical perspective as an individual characteristic.” Outlining the Quebec group’s proposal for revision, he argued, “Handicap should always be considered the situational result of an interactive process between two series of causes of determining factors: the characteristics of a person’s impairments and disabilities resulting from disease and trauma; and the environmental characteristics creating sociocultural or physical obstacles in a given situation.”<sup>85</sup> The Quebec Committee recommended adding a nomenclature of environmental factors, both social and ecological, to ICIDH. Doing so, they noted, would force a broadening of the expertise required to revise ICIDH, to also include urban planners, anthropologists, engineers, and others.<sup>86</sup>

Participants in the revision process were indeed more diverse than the three original developers of ICIDH. Among the leading contributors were Canadian philosopher Jerome E.

Bickenbach and Turkish psychiatrist T. B. Ustun, director of the WHO Assessment and Classification Unit in Switzerland. Reflecting the desire to broaden ICIDH's focus, in 1999 Bickenbach and Ustun noted, "ICIDH-2 embodies what is now termed the 'biopsychosocial' model, a synthesis of medical and social approaches to disablement."<sup>87</sup> This view, popularized by George Engel in the 1970s, acknowledged and integrated the biological, environmental, and social components of health and medicine.<sup>88</sup> Bickenbach, Ustun, and their revision collaborators were also influenced by Irving Kenneth Zola's universalist model of disability, introduced in the late 1980s. In contrast to Harlan Hahn's minority group model, Zola framed disability as a fluid and contextual concept and status that was likely to affect almost everyone at some point in their lives.<sup>89</sup> Bickenbach and Ustun argued that ICIDH-2 adopted Zola's universalist perspective in that "functioning and disablement are understood as co-equal aspects of health, rather than polar opposites. . . . Disablement as captured by the ICIDH-2 is an intrinsic feature of the human condition, not a difference that essentially marks one subpopulation off from another."<sup>90</sup>

WHO published its final revision of ICIDH in 2001 under a new title, the *International Classification of Functioning, Disability, and Health* (ICF). During the late stages of revision—following the advice of disability self-advocates—the term "handicap" was removed and the three-part structure of ICIDH was replaced with two new classification lists.<sup>91</sup> The first, Body Functions and Structures, included the former impairment and disability components. The second, Activities and Participation, replaced and expanded the handicap classification. Further distinguishing their revision from ICIDH, the authors explained, "ICF has moved away from being a 'consequences of disease' classification (1980 version) to become a 'components of health' classification. 'Components of health' identifies the constituents of health, whereas

consequences focuses on the impacts of disease or other health conditions that may follow as a result.”<sup>92</sup> ICF was thus framed as a classification that applied to all individuals, rather than exclusively to people experiencing disability resulting from a biomedical event. Importantly however, as the authors made clear, ICF remained a health classification that was intended to complement WHO’s more disease-oriented ICD.<sup>93</sup> In this regard, ICF continued to raise the ire of most medical model as *oppressive* critics.

## Responses to ICF

Participants in the ICIDH revision process included several disability scholars and activists. Among them was British self-advocate Rachel Hurst, who was invited to represent Disabled Peoples’ International as part of the WHO revision process. Hurst later commented, “Disabled people were involved in the official revision process when it started in the early 1990s, but their participation was rather *ad hoc*. . . . However, later on in the process there was a commitment from WHO that disabled people should not only be heard, but also be listened to.”<sup>94</sup> In the late 1990s, Hurst was named chair of a Centers for Disease Control and Prevention (CDC) task force organized to identify environmental factors for classification in the ICIDH revision. After its publication, Hurst spoke of ICF with cautious optimism, characterizing it as “inevitably a compromise. . . . The ICF, with all its faults, can now be used as an international example of how the environmental impacts are the key to understanding the nature of disability and how solutions must come through social change.”<sup>95</sup> Shifting from her original medical model as *oppressive* critique, published in 2000, which argued that ICIDH was a “barrier to disabled people’s rights,” Hurst supported what she called ICF’s “interactive model,” noting in 2003 that ICF “defines

disability as the outcome of the interaction between impairment and functioning and the environment.”<sup>96</sup> Hurst was pleased that disability was no longer framed as a consequence of disease and that bodily impairment and social environments were addressed independently.

Colin Barnes, a British disability scholar, self-advocate, and prominent proponent of the medical model as *oppressive* critique, was less positive. While Hurst suggested that the ICIDH revision was satisfactory but flawed, Barnes believed that the WHO classification continued to disempower and objectify people with disabilities. In 2003, he published a critical review of the ICIDH revision process and the conceptual framework that informed it. Barnes wrote, “The outcome: ICIDH-2, despite the discourse to the contrary, is an inter-relational approach that is not that far removed from its predecessor, . . . Within this framework, disability remains a *health* rather than a *political* concern.”<sup>97</sup> He suggested that ICIDH-2’s adoption of the biopsychosocial model was an attack on the social constructivist approach of disability self-advocates and an attempt to neutralize and depoliticize disability. The primary goal of this framing, Barnes argued, was making disability more amenable to scientific research. He instead highlighted the value of research conducted by disability scholars and self-advocates, the perspectives of which, he believed, were being dismissed and ignored by the leading participants in ICIDH revision.

Criticism of ICF was not limited to disability self-advocates. In 2004, British sociologist Rob Imrie argued that ICF’s theoretical basis, rooted in universalism and the biopsychosocial model, was insufficiently developed. Imrie expressed concern that the authors’ efforts to adopt a middle-ground approach between medical and social models of disability ultimately allowed the biological view of disability to dominate. He wrote, “The biological body, for the ICF, is ‘a fact,’ and impairment, at the level of body functions and structures, is seen as a ‘pre-social,’ biological,

bodily difference.”<sup>98</sup> In line with Imrie’s critique, medical model as *oppressive* critics strongly rejected ICF’s framing of disability as originating with an objective bodily abnormality. The end result of this biopsychosocial approach, as Vic Finkelstein argued in his critique of the ICIDH revision process, was to make the social model simply become part of the medical model rather than to engage with the social model’s unique perspective on disability. In effect, ICF had accomplished just what Kaufman had argued for when he defended the medical model in 1967.<sup>99</sup>

British occupational therapists Anne McIntyre and Stephanie Tempest were similarly concerned about the continuing influence of medical model perspectives in ICF. In 2007 they offered a clinically informed assessment of the revised classification, which suggested that ICF might prove to represent “two steps forward and one step back.”<sup>100</sup> McIntyre and Tempest were responding to the development, since 2004, of disease-specific short lists of ICF categories, known as “core sets,” which were meant to ease clinicians’ uptake of the otherwise extensive classification manual (containing about fifteen hundred categories). As they put it, “It was determined that core sets should be devised for medical management of specific diseases as many physicians still see disability as the consequence of a disease process or health condition. However, it could be considered that core sets that are classified according to specific diseases (for example stroke), are entrenched within a medical model once again.”<sup>101</sup> While core sets made ICF more user-friendly, McIntyre and Tempest noted that their development, based on the input of clinical experts and not disability advocates, might actually counteract efforts to move ICF away from the medical model. Indeed, the authors expressed concern that core sets could turn disability self-advocates against ICF. Notably, for McIntyre and Tempest the medical model as *insufficient* critique still informed their specific perspectives on ICF. Their aims in criticizing

ICF core sets were not constructivist or political but focused on the insufficiency of overemphasizing etiology.

Responses to ICF were mixed. Many disability scholars and advocates viewed ICF as being cut from the same cloth as ICIDH. ICF, they argued, remained a classification of health, which characterized individuals with impairments as abnormal. The adoption of less offensive terms and removal of language directly linking disability to disease did not satisfy most medical model as *oppressive* critics.<sup>102</sup> Nonetheless, some disability advocates, including those who were directly involved and invested in the revision process, viewed ICF as an accomplishment for disability rights, which was, as Hurst put it, “many, many miles away from the ICIDH.”<sup>103</sup>

Ultimately, ICF remained rooted in a medical model as *insufficient* critique, just like the original ICIDH. While ICF’s perspective had moved past ICIDH’s “consequences of disease” framing, the authors of ICF chose only to acknowledge but did not take up the constructivist and political aims of medical model as *oppressive* critics. Instead, they adopted what they saw as a middle-ground approach, rooted in the biopsychosocial model, which many disability advocates viewed as little more than an expanded medical model. It is notable that even some medical model as *insufficient* critics expressed concerns about the creation ICF core sets. Indeed, the creation of core sets for specific health conditions suggests that even though WHO adopted a more complex view of disability in ICF, in practice it retained a disorder-oriented classification.

## Conclusions

In a 2013 positioning article, “On the Borderland of Medical and Disability History: A Survey of the Fields,” Beth Linker noted that disability scholars have often avoided associating disability

with disease and physicians, “for fear of perpetuating the medical model.” In this article, I have proposed that historians of medicine should do more to historicize the medical model concept and critique, by examining its various meanings and rhetorical uses—so as to avoid perpetuating the widely referenced presumption of a single medical model that informs all of Western medicine. In doing so, I have suggested that it is important to approach the medical model as a critical construction. While historians of medicine may debate whether the so-called medical model describes certain characteristics that are essential to Western medicine, we must not forget that physicians have almost never defended, or sought to own, the medical model.

This article has described two distinct formulations of critique that characterized the medical model as either *insufficient* or *oppressive*. The existence of more than one type of medical model critique led to multiple suggested approaches for reform. Proponents of the medical model as *insufficient* critique called for enhancing the psychosocial dimensions of clinical practice without fundamentally questioning the view of disability as a health problem and an appropriate target of medical intervention and support. On the other hand, advocates of the medical model as *oppressive* critique argued that disability should not be directly linked to a bodily antecedent and must be approached as a political issue, not as an individual health problem. These differing perspectives prevented the formulation of a universally accepted resolution to the medical model critique. As I describe, while WHO advisers engaged with medical model as *oppressive* criticism during the ICIDH revision process, ICF ultimately retained a medical model as *insufficient* perspective of disability as a health problem. Thus, ICF did not achieve the outcomes that most medical model as *oppressive* critics desired. Indeed, as

the history of the WHO disability classification shows, it was possible to simultaneously be a critic of the medical model and be accused of perpetuating it through an alternative approach.

Historians of medicine have only recently begun to examine the medical model critique as it was adopted and applied by disability scholars and advocates and have not yet examined criticism of the medical model from within the medical community.<sup>104</sup> Addressing the medical model as a singular and unchanging concept, as historians of medicine have largely done, could lead to a misinterpretation of my case study in this article. For instance, the adoption of medical model criticism by medical professionals and organizations might appear to suggest a new openness to constructivist viewpoints. However, as my analysis of the multiple formulations of the medical model critique shows, this was not the case. Rather, medical model as *insufficient* critics within the WHO believed, unlike proponents of the medical model as *oppressive* critique, that disability had a real biological antecedent. As historians of medicine continue to increase their engagement with disability perspectives, it is important to be aware of which versions of the medical model critique were promoted, taken up, or rejected by the medical community.

Historians of medicine should also carefully consider which formulations of the medical model critique they may be implicitly supporting, dismissing, or reifying in their accounts and analysis.

This article has primarily focused on applications of the medical model critique to disability. While adopted most prominently in this area, criticism of the medical model was not unique to this area. As I have described, early medical model critiques were applied to the medicalization of deviant behavior. Also, in his formulation of the medical model as *insufficient* critique, George Engel addressed the medical field broadly, including the relevance of his criticism to care for acute conditions.<sup>105</sup> Similarly, the focus of the medical model as *oppressive*

critique has not been limited to disability but has also been applied to sexuality, gender, race, and addiction.<sup>106</sup> Going forward, historians of medicine should explore other strains of the medical model critique as they have been applied to disability and other historically disadvantaged groups. In doing so, scholars may identify additional forms of critique and new insights on how the medical model concept was used by various historical actors—including physicians, scholars, and self-advocates—to promote new narratives and perspectives on disability and other forms of social disadvantage.

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<sup>1</sup> M. Ralph Kaufman, “Psychiatry: Why ‘Medical’ or ‘Social’ Model?,” *Arch. General Psychiatry* 17, no. 3 (1967): 347–60, quotation on 347.

<sup>2</sup> *Ibid.*, 351.

<sup>3</sup> *Ibid.*, 358.

<sup>4</sup> George L. Engel, “Sudden Death and the ‘Medical Model’ in Psychiatry,” *Can. Psychiatric Assoc. J.* 15, no. 6 (1970): 527–38, quotation on 535.

<sup>5</sup> George L. Engel, “Is Psychiatry Failing in Its Responsibilities to Medicine,” *Amer. J. Psychiatry* 128, no. 12 (1972): 1561–64, quotation on 1561.

<sup>6</sup> Thomas P. Anderson, “An Alternative Frame of Reference for Rehabilitation: The Helping Process versus the Medical Model,” *Arch. Phys. Med. Rehabil.* 56, no. 3 (1975): 101–4; Philip H. N. Wood and Elizabeth M. Badley, “An Epidemiological Appraisal of Disablement,” in *Recent Advances in Community Medicine*, ed. Albert E. Bennett (Edinburgh: Churchill Livingstone, 1978), 149–73; Michael R. Bury and Philip H. N. Wood, “Sociological Perspectives in Research on Disablement,” *Internat. Rehabil. Med.* 1, no. 1 (1978): 24–32.

<sup>7</sup> Irving Kenneth Zola, *Missing Pieces: A Chronicle of Living with a Disability* (Philadelphia: Temple University Press, 1982); Simon Brisenden, “Independent Living and the Medical Model of Disability,” *Disability, Handicap & Soc.* 1, no. 2 (1986): 173–78; Harlan Hahn, “Toward a Politics of Disability: Definitions, Disciplines, and Policies,” *Soc. Sci. J.* 22, no. 4 (1985): 87–105; Michael J. Oliver, *The Politics of Disablement* (London: Macmillan, 1990).

<sup>8</sup> Beth Linker, “On the Borderland of Medical and Disability History: A Survey of the Fields,” *Bull. Hist. Med.* 87, no. 4 (2013): 499–535; Beth Linker and Nancy J. Hirschmann, eds., *Civil Disabilities: Citizenship, Membership, and Belonging* (Philadelphia: University of Pennsylvania Press, 2015).

<sup>9</sup> Linker, “On the Borderland” (n. 8), 501–2.

<sup>10</sup> Roy Porter, “The Patient’s View: Doing Medical History from Below,” *Theory Soc.* 14, no. 2 (1985): 175–98; Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988); Jacalyn Duffin, *Lovers and Livers: Disease Concepts in History* (Toronto: University of Toronto Press, 2005), 5.

<sup>11</sup> Robert A. Aronowitz, *Making Sense of Illness: Science, Society, and Disease* (Cambridge: Cambridge University Press, 1998), 75–78. Also see Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996), 117–38.

<sup>12</sup> Charles E. Rosenberg, “Framing Disease: Illness, Society and History,” in *Framing Disease: Studies in Cultural History*, ed. Charles E. Rosenberg and Janet Golden (New Brunswick, N.J.: Rutgers University Press, 1992), xiii–xvi, quotation on xiii.

<sup>13</sup> Ibid., xxi. Scholars have described the development and significance of multiple medical classification schemes, which embody various underlying presumptions and goals. Diseases in

the *International Classification of Diseases* (ICD) are organized into families based on common etiology, organ system affected, and other traits. Despite efforts to provide a neutral nomenclature, Susan Leigh Star and Geoffrey Bowker have highlighted the political, ethical, and moral presumptions that underlie ICD. Classifications, they note, have real-world consequences, tying people to specific beliefs and narratives. As Allan Young has described in the case of the *Diagnostic and Statistical Manual* in psychiatry, classification systems also play an important role in facilitating communication among diverse perspectives. At the same time however, as Annemarie Jutel has put it, “Every classification engages some social perspectives and shuts down others, but once a classification is established it reproduces itself in an intuitive way that silences debate.” Thus, it is important for interest groups to be involved early in development; otherwise their views may be permanently excluded. Geoffrey C. Bowker and Susan Leigh Star, *Sorting Things Out: Classification and Its Consequences* (Cambridge, Mass.: MIT Press, 1999), 319; Allan Young, *The Harmony of Illusions: Inventing Post-traumatic Stress Disorder* (Princeton, N.J.: Princeton University Press, 1995), 102; Annemarie Jutel, “Classification, Disease, and Diagnosis,” *Perspect. Biol. Med.* 54, no. 2 (2011): 189–205, quotation on 202.

<sup>14</sup> For instance, see Paul K Longmore and Lauri Umansky, eds., *The New Disability History: American Perspectives* (New York: New York University Press, 2001); Catherine J. Kudlick, “Disability History: Why We Need Another ‘Other,’” *Amer. Hist. Rev.* 108, no. 3 (2003): 763–93; Susan Burch, ed., *Encyclopedia of American Disability History* (New York: Facts on File, 2009); Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon, 2012).

<sup>15</sup> Linker, “On the Borderland” (n. 8), 518–19.

<sup>16</sup> Roy Porter, *The Cambridge Illustrated History of Medicine* (Cambridge: Cambridge

University Press, 1996), 113; Robert E. Bivins and John V. Pickstone, eds., *Medicine, Madness and Social History* (New York: Palgrave Macmillan, 2007), 46; Eugene Declercq, “Childbirth History Is Everyone’s History,” *J. Hist. Med. & Allied Sci.* 73, no. 1 (2017): 1–6; Patricia D’Antonio and Julie Fairman, “Organizing Practice: Nursing, the Medical Model, and Two Case Studies in Historical Time,” *Can. Bull. Med. Hist.* 21, no. 2 (2004): 411–29. Historians have also used the construction “biomedical model”; see Allan M. Brandt and Martha Gardner, “Antagonism and Accommodation: Interpreting the Relationship between Public Health and Medicine in the United States during the 20th Century,” *Amer. J. Pub. Health* 90, no. 5 (2000): 707–15, esp. 711.

<sup>17</sup> Duffin, *Lovers and Livers* (n. 10), 27.

<sup>18</sup> Ibid., 34.

<sup>19</sup> Mike Kelly and David Field, “Comments on the Rejection of the Bio-medical Model in Sociological Discourse,” *Med. Sociol. News* 19, no. 2 (1994): 34–37, quotation on 35.

<sup>20</sup> Tom Shakespeare, Jerome E. Bickenbach, David Pfeiffer, and Nicholas Watson, “Models,” in *Encyclopedia of Disability*, Vol. 1, ed. Gary L. Albrecht (Thousand Oaks, Calif.: Sage, 2006), 1101–8, quotation on 1103.

<sup>21</sup> Thomas S. Szasz, “Some Observations on the Relationship between Psychiatry and the Law,” *AMA Arch. Neurol. Psychiatry* 75, no. 3 (1956): 297–315, quotation on 303.

<sup>22</sup> For more on Szasz’s opposition to biological psychiatry and support of psychoanalytic theory, see Edward Shorter, *A History of Psychiatry: From the Age of the Asylum to the Era of Prozac* (New York: Wiley, 1997); Richard E. Vatz and Lee S. Weinberg, eds., *Thomas Szasz: Primary Values and Major Contentions* (Buffalo, N.Y.: Prometheus Books, 1983).

<sup>23</sup> Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Garden City, N.Y.: Anchor Books, 1961). The “model” in medical model does not appear to have a singular conceptual origin or consistent meaning. The term’s first users, Szasz and Goffman, were each interested in the nature of professional service models, leading to their specific adoption of the term “medical model.” In 1956, Szasz coauthored an article with physician Marc H. Hollender titled “The Basic Models of the Doctor-Patient Relationship,” in which they described a continuum of approaches to medical care, ranging from complete paternalism to mutual partnership. Goffman, citing Szasz, wrote of the medical model as a variant on other professional service models, which offered expertise to solve problems in a particular physical location, such as in a workshop, mechanic’s garage, or hospital. Later critics of the medical model, such as clinical psychologist Wolf Wolfensberger and disability scholar Michael Oliver, spoke of the medical model, and other alternative “models” for understanding and managing disability, as being similar to Kuhnian paradigms, which were rooted—at times consciously and sometimes unconsciously—in specific values and ideologies. A common function among these uses of “model” in medical model was for describing patterns of professional behavior, understanding, and management of patients or clients. Thomas S. Szasz and Marc H. Hollender, “A Contribution to the Philosophy of Medicine: The Basic Models of the Doctor Patient Relationship,” *AMA Arch. Intern. Med.* 97 (1956): 585–92; Thomas S. Kuhn, *The Structure of Scientific Revolutions* (Chicago: University of Chicago Press, 1962); Wolf Wolfensberger, *The Principles of Normalization in Human Services* (Toronto: National Institute on Mental Retardation, 1972), 7–8; Michael Oliver, *Social Work with Disabled People* (London: Macmillan, 1983), 22–23. See also Shakespeare et al., “Models” (n. 20).

<sup>24</sup> Peter Conrad and Joseph W. Schneider, *Deviance and Medicalization: From Badness to Sickness* (Philadelphia: Temple University Press, 1980); Irving Kenneth Zola, “Medicine as an Institution of Social Control,” *Sociol. Rev.* 20, no. 4 (1972): 487–504; Irving Kenneth Zola, “In the Name of Health and Illness: On Some Socio-political Consequences of Medical Influence,” *Soc. Sci. Med.* 9, no. 2 (1975): 83–87. Zola coined the term “medicalization” during the late 1960s and began using it in his writing in the early 1970s. See Irving Kenneth Zola, *Socio-medical Inquiries: Recollections, Reflections, and Reconsiderations* (Philadelphia: Temple University Press, 1983).

<sup>25</sup> Engel, “Is Psychiatry Failing?” (n. 5), 1563.

<sup>26</sup> George L. Engel, “The Need for a New Medical Model: A Challenge for Biomedicine,” *Sci.* 196, no. 4286 (1977): 129–36, quotation on 129–30.

<sup>27</sup> Ibid., 133; Theodore M. Brown, “George Engel and Rochester’s Biopsychosocial Tradition: Historical and Developmental Perspectives,” in *The Biopsychosocial Approach: Past, Present, and Future*, ed. Richard M. Frankel, Timothy E. Quill, and Susan H. McDaniel (Rochester: University of Rochester Press, 2003), 199–219.

<sup>28</sup> Randall M. Packard, *A History of Global Health: Interventions into the Lives of Other Peoples* (Baltimore: Johns Hopkins University Press, 2016), 124.

<sup>29</sup> World Health Organization, “Constitution of the World Health Organization” (1946), 1.

<sup>30</sup> Packard, *History of Global Health* (n. 28), 134.

<sup>31</sup> Ibid., 233–34; Theodore M. Brown, Elizabeth Fee, and Victoria Stepanova, “Halfdan Mahler: Architect and Defender of the World Health Organization ‘Health for All by 2000’ Declaration of 1978,” *Amer. J. Pub. Health* 106, no. 1 (2016): 38–39; Socrates Litsios, “The Christian

Medical Commission and the Development of the World Health Organization's Primary Health Care Approach," *Amer. J. Pub. Health* 94, no. 11 (2004): 1884–93; "Primary Health Care Comes Full Circle: An Interview with Halfdan Mahler," *Bull. World Health Organization* 86, no. 10 (2008): 747–48.

<sup>32</sup> World Health Organization, *Alma-Ata Declaration* (Geneva: World Health Organization, 1978).

<sup>33</sup> "Primary Health Care Comes Full Circle" (n. 31), 748.

<sup>34</sup> Jonathan D. Mayer and Melinda S. Meade, "A Reformed Medical Geography Reconsidered," *Professional Geog.* 46, no. 1 (1994): 103–6, quotation on 105.

<sup>35</sup> Margaret Chan, "Return to Alma-Ata," *Lancet* 372, no. 9642 (2008): 865–66, quotation on 865.

<sup>36</sup> Stephen Gillam, "Is the Declaration of Alma Ata Still Relevant to Primary Health Care?," *Brit. Med. J.* 336, no. 7643 (2008): 536–38, quotation on 536.

<sup>37</sup> Halfdan Mahler, *The Work of WHO, 1978–1979: Biennial Report of the Director-General to the World Health Assembly and to the United Nations* (Geneva: World Health Organization, 1980), 47; Halfdan Mahler, "The International Year of Disabled Persons and the World Health Organization," *International Rehabilitation Medicine* 3, no. 1 (1981): 1–2, quotation on 2. The UN later expanded the International Year of Disabled Persons to span an entire decade.

<sup>38</sup> Jutel, "Classification, Disease, and Diagnosis" (n. 13), 196.

<sup>39</sup> Philip H. N. Wood, the primary author of ICIDH, highlighted the influence of Mahler's socially oriented vision in 1978. Wood and Badley, "Epidemiological Appraisal" (n. 6), 169.

<sup>40</sup> Saad Z. Nagi, “A Study in the Evaluation of Disability and Rehabilitation Potential: Concepts, Methods, and Procedures,” *Amer. J. Pub. Health* 54, no. 9 (1964): 1568–79; Andrew M. Pope and Edward N. Brandt Jr., eds., *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* (Washington, D.C.: National Academy Press, 1997), 64.

<sup>41</sup> Amelia I. Harris, *Handicapped and Impaired in Great Britain* (London: HMSO, 1971); Margaret Agerholm, “Handicaps and the Handicapped: A Nomenclature and Classification of Intrinsic Handicaps,” *Roy. Soc. Health J.* 95, no. 1 (1975): 3–8.

<sup>42</sup> Philip H. N. Wood, “Classification of Impairments and Handicaps,” Document WHO/ICD9/REV-CONF/75.15 (Geneva: World Health Organization, 1975); Halfdan Mahler, *The Work of WHO, 1975: Annual Report of the Director-General to the World Health Assembly and to the United Nations* (Geneva: World Health Organization, 1976), 161.

<sup>43</sup> Elizabeth M. Badley, “Obituary: Philip H. N. Wood,” *Rheumatol.* 48, no. 4 (2009): 456–57, quotation on 456.

<sup>44</sup> Bury and Wood, “Sociological Perspectives” (n. 6).

<sup>45</sup> Michael Bury, “A Comment on the ICIDH2,” *Disability Soc.* 15, no. 7 (2000): 1073–77, quotation on 1074.

<sup>46</sup> Bury and Wood, “Sociological Perspectives” (n. 6), 26.

<sup>47</sup> Bury, “Comment on the ICIDH2” (n. 45), 1074.

<sup>48</sup> World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Related to the Consequences of Disease* (Geneva: World Health Organization, 1980), 14.

<sup>49</sup> Ibid., 38–39. The coauthors noted that the survival roles were developed in part to correspond to Abraham Maslow’s hierarchy of needs. Thus, handicaps reflected social disadvantages for an individual in achieving both lower-order and higher-level desires.

<sup>50</sup> Ibid., 14.

<sup>51</sup> Badley, “Obituary” (n. 43), 456.

<sup>52</sup> Carl Granger, “Executive Summary and Commentary,” in *People with Disabilities: Toward Acquiring Information Which Reflects More Sensitively Their Problems and Needs*, ed. Philip H. N. Wood and Elizabeth M. Badley (New York: World Rehabilitation Fund, 1980), ii–iii.

<sup>53</sup> Bury and Wood, “Sociological Perspectives” (n. 6), 25.

<sup>54</sup> Katherine Castles, “‘Nice Average Americans’: Postwar Parents’ Groups and the Defense of the Normal Family,” in *Mental Retardation in America: A Historical Reader*, ed. Steven Noll and James W. Trent, Jr. (New York: New York University Press, 2004), 351–70; Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* (Philadelphia: Temple University Press, 2009); Linker and Hirschmann, *Civil Disabilities* (n. 8). On early student self-activism, including the “Rolling Quads” at the University of California, Berkeley in the late 1960s and early 1970s, see Fred Pelka, *What We Have Done: An Oral History of the Disability Rights Movement* (Amherst: University of Massachusetts Press, 2012), 197–226.

<sup>55</sup> Jenny Morris, “Personal and Political: A Feminist Perspective on Researching Physical Disability,” *Disability Handicap Soc.* 7, no. 2 (1992): 157–66; Wendell, *Rejected Body* (n. 11); Colin Barnes and Geof Mercer, eds., *Exploring the Divide: Illness and Disability* (Leeds: Disability Press, 1996), 6–7.

<sup>56</sup> Zola, “Medicine as an Institution” (n. 24); Zola, “In the Name of Health” (n. 24).

<sup>57</sup> Zola, *Missing Pieces* (n. 7); Gareth Williams, “Representing Disability: Some Questions of Phenomenology and Politics,” in Barnes and Mercer, *Exploring the Divide* (n. 55), 194–212.

<sup>58</sup> Hahn, “Toward a Politics” (n. 7), 88.

<sup>59</sup> Ibid., 93.

<sup>60</sup> Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability* (London: UPIAS, 1976), 4.

<sup>61</sup> Vic Finkelstein, “A Personal Journey into Disability Politics” (presentation, Leeds University Centre for Disability Studies, 2001), <http://www.independentliving.org/docs3/finkelstein01a.pdf>; Mike Oliver, “Vic Finkelstein Obituary,” *Guardian*, December 22, 2011. Also see Paul Hunt, *Stigma: The Experience of Disability* (London: Chapman, 1966).

<sup>62</sup> Oliver, *Social Work with Disabled People* (n. 23), 15–32.

<sup>63</sup> Oliver, *Politics of Disablement* (n. 7), 22.

<sup>64</sup> Ibid., 8.

<sup>65</sup> Oliver, *Social Work with Disabled People* (n. 23), 55. Oliver later rejected use of the term “medical model” and suggested that he viewed medicalization as one component of the individual model. However, up to and including his 1990 book *The Politics of Disablement*, Oliver did refer directly to the “medical model.” See Michael Oliver, “The Individual and Social Models of Disability” (paper, Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals, 1990), <http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf>.

<sup>66</sup> Barnes and Mercer, *Exploring the Divide* (n. 55). Notably, the divide referenced in the title was not between conceptions of disability and illness but rather between the long-standing perspectives of medical sociologists and a newer group of disability scholars and self-advocates.

<sup>67</sup> Oliver, *Politics of Disablement* (n. 7), 6–7.

<sup>68</sup> Ibid., 6.

<sup>69</sup> Vic Finkelstein, “The Biodynamics of Disablement? Disability and Rehabilitation Systems Research” (paper, Proceedings of the Workshop on Research Informed Rehabilitation Planning in Southern Africa, 1999), 5, <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-Biodynamics.pdf>.

<sup>70</sup> Ibid., 7.

<sup>71</sup> Oliver, *Politics of Disablement* (n. 7), 6.

<sup>72</sup> Harlan Hahn, “‘The H Factor’ in the ICIDH: What’s Left of the Original Concept?” (unpublished manuscript, Harlan Hahn Collection, California State University, Dominguez Hills Archives and Special Collections), 17–18.

<sup>73</sup> Ibid., 17–18.

<sup>74</sup> Liz Crow, “Including All of Our Lives: Renewing the Social Model of Disability,” in Barnes and Mercer, *Exploring the Divide* (n. 55), 55–73, quotation on 57. Crow was one of a growing number of feminist disability self-advocates who espoused the medical model as *oppressive* critique, but also argued for a renewed engagement with the real-world challenges that people experience because of their impairments. While many disability theorists resisted such an acknowledgment because they feared it would undercut constructivist arguments, acceptance of a hybrid perspective increased during the 2000s. See also Jenny Morris, *Pride Against Prejudice*:

*Transforming Attitudes to Disability* (Philadelphia: New Society, 1991); Sally French, “Disability, Impairment or Something in Between?,” in *Disabling Barriers—Enabling Environments*, ed. John Swain, Vic Finkelstein, Sally French, and Mike Oliver (Thousand Oaks, Calif.: Sage, 1993), 17–25; Susan Wendell, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” *Hypatia* 16, no. 4 (2001): 17–33; Tom Shakespeare, “The Social Model of Disability,” in *The Disability Studies Reader*, 4th ed., ed. Lennard J. Davis (New York: Routledge, 2013), 214–21.

<sup>75</sup> David Pfeiffer, “The ICIDH and the Need for Its Revision,” *Disability Soc.* 13, no. 4 (1998): 503–23, quotation on 503.

<sup>76</sup> Ibid., 519

<sup>77</sup> Bury, “Comment on the ICIDH2” (n. 45), 1074–75.

<sup>78</sup> Ibid.; Philip H. N. Wood and Elizabeth M. Badley, “Contribution of Epidemiology to Health Care Planning for People with Disabilities,” in *Functional Assessment in Rehabilitation Medicine*, ed. Carl V. Granger and Glen E. Gresham (Baltimore: Williams and Wilkins, 1984), 26–45; Philip H. N. Wood, “Such Sweet Sorrow,” *Internat. Rehabil. Med.* 8, no. 3 (1986): 97; Philip H. N. Wood, “Maladies Imaginaires: Some Common Misconceptions about the ICIDH,” *Internat. Disability Stud.* 9, no. 3 (1987): 125–28; Michael Bury, “Defining and Researching Disability: Challenges and Responses,” in Barnes and Mercer, *Exploring the Divide* (n. 55), 17–38.

<sup>79</sup> Kaufman, “Psychiatry” (n. 1), 358.

<sup>80</sup> Wood and Badley, “Contribution of Epidemiology” (n. 78), 30; Wood, “Such Sweet Sorrow” (n. 78); Bury, “Defining and Researching Disability” (n. 78), 30, 35; Bury, “Comment on the ICIDH2” (n. 45), 1077.

<sup>81</sup> Bury, “Comment on the ICIDH2” (n. 45), 1075.

<sup>82</sup> World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Related to the Consequences of Disease, Reprinted with Foreword* (Geneva: World Health Organization, 1993), 5.

<sup>83</sup> Ibid., 1–6.

<sup>84</sup> World Health Organization, *International Classification of Functioning, Disability, and Health* (Geneva: World Health Organization, 2001), 254.

<sup>85</sup> Patrick Fougeyrollas, “Documenting Environmental Factors for Preventing the Handicap Creation Process: Quebec Contributions Relating to ICIDH and Social Participation of People with Functional Disabilities,” *Disability Rehabil.* 7, nos. 3–4 (1995): 145–53, quotation on 147.

<sup>86</sup> Ibid., 151.

<sup>87</sup> Jerome E. Bickenbach, Somnath Chatterji, Elizabeth M. Badley, and T. Bedirhan-Üstün, “Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps,” *Soc. Sci. Med.* 48, no. 9 (1999): 1173–87, quotation on 1183.

<sup>88</sup> Engel, “Need for a New” (n. 26); George L. Engel, “The Clinical Application of the Biopsychosocial Model,” *Amer. J. Psychiatry* 137, no. 5 (1980): 535–44.

<sup>89</sup> Bickenbach et al., “Models of Disablement” (n. 87), 1181–82.

<sup>90</sup> Ibid., 1184.

<sup>91</sup> Hahn, “‘H Factor’” (n. 72); Bury, “Comment on the ICIDH2” (n. 45).

<sup>92</sup> World Health Organization, *International Classification of Functioning* (n. 84), 4.

<sup>93</sup> Ibid., 4; Bickenbach et al., “Models of Disablement” (n. 87).

<sup>94</sup> Rachel Hurst, “The International Disability Rights Movement and the ICF,” *Disability Rehabil.* 25, nos. 11–12 (2003): 572–76, quotation on 574.

<sup>95</sup> Ibid., 575.

<sup>96</sup> Ibid., 574; Rachel Hurst, “To Revise or Not to Revise?,” *Disability Soc.* 15, no. 7 (2000): 1083–87, quotation on 1084.

<sup>97</sup> Colin Barnes, “Extended Review,” *Disability Soc.* 18, no. 6 (2003): 827–33, quotation on 827–28. Notably, Barnes focused on the ICIDH-2 draft rather than the final ICF, even though ICF was published more than two years before the publication of his review. Unlike ICF, the ICIDH-2 draft retained the three-part impairment, disability, handicap scheme, of which disability self-advocates were highly critical.

<sup>98</sup> Rob Imrie, “Demystifying Disability: A Review of the International Classification of Functioning, Disability and Health,” *Sociol. Health & Illness* 26, no. 3 (2004): 287–305, quotation on 294.

<sup>99</sup> Kaufman, “Psychiatry” (n. 1); Finkelstein, “Biodynamics of Disablement?” (n. 69), 4–5.

<sup>100</sup> Anne McIntyre and Stephanie Tempest, “Two Steps Forward, One Step Back? A Commentary on the Disease-Specific Core Sets of the International Classification of Functioning, Disability and Health (ICF),” *Disability & Rehabil.* 29, no. 18 (2007): 1475–79, quotation on 1475.

<sup>101</sup> Ibid., 1476.

<sup>102</sup> Finkelstein, “Biodynamics of Disablement?” (n. 69); Barnes, “Extended Review” (n. 97);

David Pfeiffer, “The Devils Are in the Details: The ICIDH2 and the Disability Movement,”

*Disability & Soc.* 15, no. 7 (2000): 1079–82; Karen Whalley Hammell, “Deviating from the

Norm: A Sceptical Interrogation of the Classificatory Practices of the ICF,” *Brit. J. Occup.*

*Therapy* 67, no. 9 (2003): 408–11.

<sup>103</sup> Hurst, “International Disability Rights Movement” (n. 94), 574–75.

<sup>104</sup> Linker, “On the Borderland” (n. 8); Linker and Hirschmann, *Civil Disabilities* (n. 8).

<sup>105</sup> Zola, “In the Name of Health” (n. 24), 83; Engel, “Sudden Death” (n. 4).

<sup>106</sup> Rita Rhodes and Ann Johnson, “A Feminist Approach to Treating Alcohol and Drug-Addicted African-American Women,” *Women Therapy* 20, no. 3 (1997): 23–37; Leonore Tiefer, “Beyond the Medical Model of Women’s Sexual Problems: A Campaign to Resist the Promotion of Female Sexual Dysfunction,” *Sex. Relationship Therapy* 17, no. 2 (2002): 127–35; Franklin H. Romeo, “Beyond a Medical Model: Advocating for a New Conception of Gender Identity in the Law,” *Columbia Hum. Rights Law Rev.* 36 (2004): 713–53.