Introduction

he pieces gathered here include both works of scholarship and instances of political advocacy. Many meld the two. The last is largely autobiographical. At the same time, the entire collection represents something more than the understanding of an individual. It reflects a broader transformation in social consciousness and societal practices: the disability rights revolution. Written or delivered over a period of twenty years, these articles and speeches are themselves, on one level, documents of that revolution. Though prepared for a variety of audiences and for particular purposes, they are grounded in an overarching perspective about disability that constitutes the foundation of both disability rights activism and disability studies research. They attempt to explain contemporary advocacy and current academic studies as responses to a historical pattern of systemic prejudice and institutionalized discrimination against people with disabilities. In a sense, all of these pieces taken together describe the historical and contemporary background, the cultural and political context, that explains why I burned my book. Hence the title of the collection.

Underlying both activism and academic work is a basic reconceptualization of "disability." The new mode of analysis challenges the medical paradigm that has generally shaped modern social practices. The medical model assumes that pathological physiological conditions are the primary obstacle to disabled people's social integration. Defining disability as limitations in social and vocational functioning, it makes disability the exclusive and inevitable consequence of physiological impairments. It renders disability as a series of physiological, psychological, and functional pathologies originating within the bodies of individuals.

The new conceptualization of disability grew out of the efforts of activists to address the problems and obstacles faced by people with disabilities. Those advocates have recognized that for most people with most kinds of disabilities most of the time the greatest limitations are not somatic but social: prejudice and discrimination, inaccessibility and lack of accommodations. They explain the difficulties of people with disabilities in social and vocational functioning not as the exclusive and inevitable consequences of bodily impairments, but as products of the interaction between the social and built environment as presently arranged and individuals who look or function in nonstandard ways. In particular, they ascribe disabled people's typically disadvantaged status to deep-seated, pervasive cultural devaluation and systemic institutionalized discrimination. They regard people with disabilities as sharing a common social experience and therefore needing to engage in collective political action. Activists in the United States formulated the new approach as the minority group model of disability, while their counterparts in the United Kingdom fashioned what they call the social model. Both paradigms shift the focus from individuals and pathologies to institutions and ideologies.

This transformative analysis of the social sources and character of disability has generated new public policies and social practices. For example, it forged innovative concepts in American civil-rights theory, such as equal access and reasonable accommodations, community-based living and independent living, mainstreaming and education in the least restrictive environment. In the process, the activists, individually and collectively, have been redefining the social identities of people with disabilities. They have also been forming disability communities and subcultures. In all of this, they have been recasting what disability actually is. Many of the pieces collected here either exemplify or seek to explain those objectives.

Disability studies emerged in the 1980s as the academic counterpart to disability rights advocacy. It aims to do the work of research and critical analysis necessary to any effort at social reconstruction. It critically analyzes the ideas about disability that have shaped societal organization and public policies, cultural values and architectural design, individual behavior and interpersonal encounters, professional training and delivery of services. It also explores disability experiences and identities, communities and cultures, from the perspectives of people with disabilities themselves. In addition and just as important, this field raises

profound questions about basic values and arrangements in every sphere of society.

The study of disability was, of course, already present throughout academic research and teaching. For instance, a quick survey at San Francisco State University, where I teach, found 257 courses that addressed disability-related topics. They instructed students in nine bachelor's degree programs, twenty-two master's programs, thirteen minors, ten certificate programs, and six credential programs. A search for comparable curricula at neighboring Stanford University counted courses in every school and many disciplines: business, education, engineering, ethics, feminist studies, human biology, law, linguistics, medicine, philosophy, policy studies, population studies, religious studies.

The frequency of disability as a subject of study will no doubt surprise most people. It takes only a moment's reflection to recognize that disability appears frequently in teaching and research because it is a common feature of human existence. It is a major category of modern social organization and policy formulation. In its socioeconomic, ethical, and policy significance, it is comparable to class, gender, and race or ethnicity. The problem, then, is not that the academy neglects disability, but rather the ways in which this subject is addressed. The danger is not that we will ignore disability, but that we will reach intellectual, sociocultural, ethical, political, and policy conclusions about disabled people without examining the ignorance, fear, and prejudice that deeply influence our thinking.

In 1995, the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education noted the failure of research "to assess the comprehensive phenomenon of disability and its complex interaction with all aspects of society, particularly from the perspective of individuals with disabilities." That deficiency characterizes academic research not only in the applied fields, but also in the social sciences and humanities. Beyond the academy, that defect impairs professional practice in a wide array of disability-related fields, including education, medicine, policy making, psychology, social work, and vocational rehabilitation.

The problem with academic consideration of disability stems from the paradigms that shape research and teaching. The medical model remains the typical perspective not only in medicine, rehabilitation, special education, and other applied fields, but in the social sciences and humanities as well. As a result, traditional academic study represents disability

as a defect located in individuals that requires corrective treatments. This approach not only medicalizes disability, it thereby individualizes and privatizes what is in fundamental ways a social and political problem. Academic research and teaching still typically operate from old modes of analysis that do not adequately explain, let alone remedy, the social and economic disadvantages endured by people with disabilities. Current academic discourse fails to examine disability as a "comprehensive phenomenon" that interacts "with all aspects of society" in complex ways.

Disability studies seeks to remedy these deficiencies. It is a multidisciplinary project that analyzes the intricate interaction of social, cultural, political, and economic variables. The disability studies scholars Simi Linton and Lennard Davis sum up the approach. "Disability Studies," writes Linton, "challenges the idea that the social and economic status and assigned roles of people with disabilities are inevitable outcomes of their condition, an idea similar to the argument that women's roles and status are biologically determined." Instead, explain Davis and Linton, "Disability studies centers the study of disability on its social construction, the processes that have accorded particular meaning to disability and that have determined the treatment and positioning of people with disabilities in society."

As with disability rights legislation and activism, disability studies has arisen because of the deficiencies of traditional paradigms and the policies and practices derived from them in addressing the current changing circumstances and problems confronted by persons with disabilities. Because the reigning models frame disability as a defect in the individual that requires curative or rehabilitative treatment or other "special" remedial services, they usually overlook the impact of developments such as improved accessibility, disability rights activism and legislation, changing disability demographics, and the emergence of minority group identity across disability types. Nor have approaches based on medical models responded effectively to a range of controversial ethical and policy dilemmas. For example, the shriveling of public-sector resources has necessitated discussion about "entitlements" and "accommodations." How much can society afford? What do disabled people have a right to expect? Likewise, the crisis in the health care and health-financing systems has generated policy and ethical debates about who has a right to how much medical treatment. Innovations in medicine continue to prompt legal cases regarding both the right to treatment and the socalled right to die, not just for terminally ill persons, but for others who have disabilities. The medical model of disability cannot address these sorts of issues because they involve, not diagnoses of pathologies, but analyses of values. In contrast, disability studies takes as its domain the examination of cultural values regarding "disability" and their relationship to social arrangements, public policy, and professional practice.

It is necessary to distinguish in detail the differences between disability studies and other modes of studying disability in order to clear up a conflation and confusion that is currently befogging the field. Some researchers in rehabilitation and special education continue to use the medical model but have appropriated the term "disability studies" to legitimize their work and secure funding for it. But for more than twenty years, the basic theoretical texts in "disability studies" have laid out a mode of intellectual analysis based on a minority group or sociopolitical paradigm. This theoretical approach has been developed in part to critique disability research based on various versions of the medical pathology paradigm, including putatively progressive ones. To confound disability studies with these other ways of studying disability is erroneous and obfuscating. We must insist on accuracy and precision in academic labeling.

Disability studies, like disability rights, has encountered strong opposition. Some critics condemn it for pushing parochial ideologies and political agendas, for lacking intellectual credibility, and for contributing to the "balkanization" of learning. A senior fellow at the conservative Pacific Research Institute in San Francisco used that term and leveled all of those charges in commenting on a National Endowment for the Humanities Summer Institute for College Teachers I codirected in 2000 with the leading disability studies scholar Rosemarie Garland-Thomson. "Although he [the Pacific Research Institute critic] does not know much about the emerging field of disability studies," related a San Francisco Chronicle reporter, "he said he imagines it will be similar to the movement for ethnic or gay and lesbian studies. 'All these specialty studies end up being promotional studies for particular ideologies. . . . You don't really have a broad-based inquiry into the area; you tend to have an indoctrination into the area. It is not about open-minded philosophical inquiry. It is about people's special agendas." One wonders how "open-minded" a "fellow" is who would dismiss an entire field he admits he doesn't know much about.

More important, reactions such as this indicate vast ignorance not merely about the historical and contemporary experience of people with disabilities, but also regarding the social significance of issues related to disability. By any measure, everything directly or indirectly connected with disability is being transformed. The vastness and complexity of the changes underway make necessary a thorough rethinking of public laws and policies, of social, professional, and institutional values and practices regarding persons with disabilities. The emergence of disability studies has profound implications for research, policy making, professional practice, and general academic inquiry.⁵ The essays in this collection seek to demonstrate the importance of disability issues in virtually every sphere of society and the consequent necessity of serious scholarly inquiry into them. That is the "agenda" of disability studies.

Further, the charge that disability studies is narrow rather than "broad based" fails to recognize the implications of this emerging field for all areas of scholarship and thought, for values and practices in every sphere of society, for every dimension of human experience. It offers a new angle of vision regarding not only concepts of equality and community, minority status and justice, but also individualism and independence, fitness for citizenship and the "health" of the body politic, as well as gender, appearance, and sexuality. In short, the issues raised by disability studies reach into every discipline, into all spheres of intellectual inquiry.

A growing number of academicians outside the applied fields traditionally assumed to be the proper academic home for the study of disability recognize the far-ranging social and intellectual significance of disability studies. For example, writing in the *Chronicle of Higher Education*, the literary scholar Michael Berubé urged his colleagues in the liberal arts to incorporate the study of disability into their work. "The cultural representation of people with disabilities," he said, not only "affects our understanding of what it means to be human; in more practical terms, it affects public policy, the allocation of social resources, and the meaning of 'civil rights.'" In other words, disability studies has both philosophical and political implications, and academic inquiry ought to explore the linkage between the two.

Finally, the accusation that disability studies merely promotes a particular ideology, that it indoctrinates rather than engaging in "openminded philosophical inquiry," is, to put it charitably, naive about the processes and products of academic scholarship and intellectual inquiry. All analyses, all arguments, are consciously or unconsciously shaped by moral values, philosophical presuppositions, sociocultural norms, and political premises. Some forms of knowledge are privileged and others marginalized. Every philosophical position has implicit political con-

tent. In every inquiry, specific interests are at stake; they are represented in every explanation. The intellectual and political debates in American society during the past four decades should have taught all of us by now that public discourse and intellectual analysis are enriched when we examine and critique the premises and interests underlying each particular position. In addition, the controversies of the last two generations should have alerted us to the value of critical perspectives developed from the margins of society.

That is why the pieces that follow give particular attention to issues of voice and authority. What sociocultural mechanisms and social actors have the power to define the social identities and roles permitted to or required of people with disabilities? Who is competent to decide what the real problems and needs of disabled people are? Who gets to frame disability-related agendas for public policies and professional programs or for social and political change? What have been the framers' motives and purposes?

These issues of authority and agency have become more complicated, more controversial, and more important because of the frequent discrepancy between disabled and nondisabled understandings of disability issues. People with disabilities and people without disabilities often perceive "disability" in very different ways. Indeed, many times their assumptions and perceptions radically conflict. As a result, their expectations and prescriptions of "what needs to be done" clash too. This disparity in understanding and disjuncture of agendas has intensified since the advent of mass disability rights movements, but it is not a recent historical development. It seems to have been a feature of the historical experience of disability throughout, at least, the modern era. The pieces gathered here recount those historical oppositions and call attention to their current prevalence.

In addition, much of the time, in the present as in the past, nondisabled perspectives have dominated, while disabled views have typically been regarded as illegitimate. Nondisabled voices have automatically assumed authority to declare what "disability" is and what disabled people need. Disabled people have often been considered unqualified to speak for themselves, to interpret their own experience. They have frequently been rendered voiceless.

The essays and speeches that follow depict these disparities of power. They examine the material interests at stake. They also report, and at times represent, the historical and current attempts of people with disabilities, singly as well as collectively, to claim our voices. The struggle of disabled people seems always to have been a struggle for both self-determination and self-definition.

This collection also reflects my own commitment and effort to labor simultaneously as an academic and an activist, a historian and an advocate. These pieces move back and forth between analysis and activism, sometimes within the same essay or speech. I make no pretense of a spurious objectivity, no false pose of a stance outside and therefore independent of the welter of human concerns and contentions. I trust that not only my commitments but also my controlling assumptions stand forth plainly in the pieces that follow.

Yet scholar-activists betray the causes we espouse if we seek merely to legitimate dissenting dogmas and validate alternative mythologies by festooning them with footnotes. It has seemed to me that I could most usefully contribute to advancing social justice for people with disabilities by producing and facilitating rigorous disability studies scholarship, by applying it to current disability issues, and by critiquing disability rights advocacy and ideology from within. I have hoped that constant connection with disabled people would keep my work grounded in their lived experience of disability, in their daily confrontation with prejudice and discrimination. At the same time, I have wanted disability studies research to deepen and strengthen the analytical component of disability rights advocacy.

Disability studies scholars in every discipline, disability rights activists in every campaign, confront the selfsame skepticism. All must combat deeply embedded cultural assumptions about disability and disabled people. Both scholarship and advocacy must struggle against the entrenched power of the medical model to shape thinking about "disability." That model has naturalized what are, to a large extent, social constructions. It has presented historical artifacts as facts of nature. It has made cultural representations and ideological formulations seem merely a description of the personal and social consequences of physiological realities. In the case of disability, biology becomes the exclusive determinant of destiny. This medical discourse effectively removes from social, political, or historical analysis most of what people actually experience as disability. By portraying people with disabilities in certain limited ways, as, for instance, patients or clients, it renders invisible the true character of their social experience and of the social status "disabled."

The power of the medicalized perspective also masks or distorts the presence of disabled people in contemporary society, as well as in the his-

torical record. As a result, when disability issues are addressed, when disability experiences are described, they are framed from the perspective of nondisabled people. Accounts of disability are told as the story of what nondisabled people have done for or to people with various kinds of disabilities. It is a story of treatments or derelictions, benefactions or neglect. As a result, disabled people are hidden or depicted as passive and inert. The essays collected here report how people with disabilities, past as well as present, have actively sought to shape their individual lives and collective destinies.

The contemporary disability rights campaigns are, of course, embedded in historical processes. Present concerns always prompt questions about the past: how did we, as individuals and communities, come to be who and what we are? As one would expect, many disabled activists have been asking about experiences of disability in earlier times. How did societies in previous eras regard and treat people with disabilities? What values underlay cultural constructions of disabled people's identities? What factors shaped their social careers? How did people with various disabilities view themselves? In what ways did disabled people embrace or resist reigning definitions of their identities? How did they attempt to influence or alter sociocultural beliefs and societal practices in order to manage their social identities and social careers? Were there communities and cultures of disability in the past? What are the connections between those many pasts and our present?

Some historians talk about constructing "usable pasts." I take that to mean the fashioning of historical explanations that can aid us in understanding our own present so that we can build a future that will be different, which is to say, more just than it would otherwise probably become. The explicit effort to forge a usable past is commonly and unsurprisingly an agenda of scholars who write the histories of currently marginalized groups. They hope to mold historical tools outsiders can use to shape contemporary change.

Critics often accuse this sort of historical scholarship of the fallacy of present-mindedness: the imposition on the past of present-day concerns and values, the distortion of earlier historical experiences by interpreting them, not on their own terms, but simply as precursors of ours. That danger is real, but it is a pitfall of all historiographical enterprises, not just those that are politically engaged on behalf of outsider groups. Moreover, we often fail to notice or acknowledge two basic realities in the reconstruction of history. Like the fellow at the Pacific Research Institute, we not only ignore that all historical writing is influenced by

philosophical and political values; we also often disregard that virtually all interpretations of the past are put to use for present-day purposes. Some historiography is employed to effect societal change; much is marshaled to uphold elements of the status quo. The mid-1990s controversy over the National Standards for History illustrates that vital interests are at stake in the interpretation, teaching, and uses of history.8 Likewise, proponents of explicating the U.S. Constitution according to the framers' alleged "original intent" obviously mean to make historical accounts serve a contemporary political agenda. Most pertinent to the subject of this book, opponents and supporters of the Americans with Disabilities Act, arguing before the U.S. Supreme Court in Garrett v. University of Alabama (2001), disputed whether or not Congress had compiled evidence of a historic pattern of state government discrimination against disabled persons sufficient to justify imposing the ADA on the states. The lead attorney for the State of Alabama asserted that the ADA "exaggerated" the extent of that discrimination. The Court accepted his argument. In that aspect of their ruling, the justices were embracing a particular interpretation of history.

Chronicles of the past that sustain presently reigning arrangements often go unquestioned because they are seen, not as interpretations, but simply as the way things were. The great English historian J. H. Plumb observed: "The personal ownership of the past has always been a vital strand in the ideology of all ruling classes." Dissenting historical viewpoints, like dissenting political activism, have to establish their credibility against a presumption of partisanship. Outsiders must verify their claims to ownership of the past, must prove their qualification to explain their own history.

Many of the essays collected here are part of a search for a "usable past" for the disability rights movement. Even the pieces that address contemporary issues usually seek to locate those concerns in a larger and longer-term historical context. That historical agenda parallels the broader agenda of disability studies to forge the analytical tools necessary to the task of building a society that guarantees equal access, which is to say equal opportunity, to people with disabilities. The reconstruction of a usable past can contribute to the building of an accessible future.

Rereading these articles and speeches calls my attention not only to the issues I have tried to address, but also to those I have neglected. Unfortunately, occasional and fugitive pieces such as these do not permit the expansive systematic analysis a subject as complex as disability demands. In addition, many of the essays were composed during the first phase of disability studies. They were designed to help introduce and establish new ways of thinking about disability. They thus evidence, not only my own limitations of analysis, but, I think, the theoretical limitations of that stage of the disability studies and disability rights movements. In the present moment, the social and minority group models, as much as the medical model, stand in need of critique. The pieces that follow do not offer the critical examination of disability definitions and paradigms, disability rights ideology and campaigns, disability studies theories and methods we now need.

At the same time, some themes that do appear here deserve much fuller examination. The deeper I delve into disability history, the more I am persuaded that issues of gender are central to the historical and contemporary experience of disability. Gender, it is clear, has been a key factor in social constructions, social prescriptions, policy definitions, cultural representations, and political advocacy regarding disability. In practical terms, in terms of lived lives, ideologies of gender combining with ideologies of disability have shaped the daily experiences of every woman and man with every sort of disability. They have lived at the intersection of gender and disability. Although some of my work has touched on issues of gender, that theme demands much more attention.

The articles that follow tend often to focus on people with physical disabilities because that is the experience I understand best and can explicate with most assurance. It is risky to extrapolate from one type of disability experience to all disability experiences. "Disability" is not a monolithic category. Disability experiences are not homogeneous. We need careful studies of disability-specific histories and contemporary experiences as the foundation for rigorous analysis of disability as a common category.

This collection only briefly refers to a disability-based critique of dominant culture. I have long believed that disability experiences can supply the tools for a profound analysis of modern cultures in general and American culture in particular. The very features of disability that have caused those cultures to devalue people with disabilities so fiercely can provide disabled people a degree of cultural—and moral—independence, the clarifying distance of outsidership. From the perceptual advantage of that position, disabled intellectuals could formulate a distinctive critical inspection of contemporary societies, disabled people

could fashion a distinctive set of values rooted in disability experience that could serve as an alternative to dominant values. A few of the pieces gathered here touch on this potential for analysis. Although I have elsewhere attempted a somewhat lengthier cultural critique from a disability perspective, we need more thorough analyses. ¹⁰

Some of the disability- and gender-related terminology used in these essays will seem archaic. That language, now outdated, reflects either the historical era I was examining, or the historical moment in which I myself was writing.

I hope that these preliminary efforts can help to stimulate more sophisticated work. Perhaps their explanations can serve as part of the provisional framework that should and will give way to more thorough empirical research and shrewder and deeper analysis. Much work remains for us to do, work that critiques and improves on itself.

During my two decades of reading and research, of talking and thinking and writing, countless numbers of people have deepened my understanding and encouraged my work. In an introductory endnote to each essay, I have expressed my thanks to the individuals who particularly contributed to the production of that piece. Cathy Kudlick, Carol Sue Richardson, Sue Schweik, Lauri Umansky, and two anonymous readers gave me helpful and generous feedback on the entire collection. Over the years, I have also learned and received encouragement from academic colleagues and community activists, in particular Rosemarie Garland-Thomson, Mary Johnson, Richard Scotch, Sandy Sufian, Anthony Tusler, Cheryl Marie Wade, and the late Barbara Waxman and Irv Zola. None of this work would have been possible without the logistical support of a battalion of transcriptionists, research assistants, and personal aides. I especially want to thank Diane Banks, Barbara Berglund, Judith Engle, Laura Meek, Diane Reichwein, Christine Stapp, Abby Stoner, Alan Waldman, and Brooke Wirtschafter. The article on the League of the Physically Handicapped would never have been written without the partnership of David Goldberger. Robert Dawidoff proposed that I do this book. I hope it justifies his encouragement and faith.

Returning to these essays has prompted me to think about the influences that have helped to shape my thinking about disability. Although many experiences and people have furthered and helped me to refine my views, several individuals have had a particularly profound influence.

Harlan Hahn and William Roth introduced me to the minority group model of disability analysis. In the early 1980s, their writings contributed to the intellectual foundation of disability rights and what would become disability studies. Their theoretical explorations combined social science scholarship with policy analysis and advocacy. Their expositions of a minority paradigm of disability supplied me with the groundwork on which to build my own ideas.¹¹

If these and other academic colleagues handed me scholarly tools of analysis, a great many community activists offered me models of advocacy that generated its own populist political and cultural analysis. In particular, Doug Martin, for decades a leading national advocate of policy reform, taught me many of the most important things I know about disability policy and disability politics.

Over the years, time and time again, men and women in the disability community have instructed me. In their savviness and tenacity at surviving in a society that so often oppresses them, in their wise and complex understanding of the disability experience—an understanding often richer and more profound than that of academicians in either traditional rehabilitation research or transformative disability studies—in their dedication to securing freedom and dignity for their disabled brothers and sisters, they have taught me and (to use a word that often makes disabled people bristle, but that in this case is the only appropriate word) inspired me. The fact is that every movement for justice needs its heroes. Some heroes become famous for doing great deeds. Others never get their names in the history books. The latter form of heroism consists simply in this: in the face of society's contempt, they just live their lives. Two women, Mary Helen Fisk and Emma Saenz Eivers, represent for me the heroism of a great many disabled people. They instructed me in how to live my life as a disabled person as I watched how they lived theirs.

There is strength and pride and wisdom and clear-eyed good sense in the disability community at its best. Larry Voss epitomizes those qualities. He is for me a model of disabled manhood.

Carol Gill has influenced my thinking about disability more than any other individual. Her comprehensive, rigorous, subtle, honest, and profound grasp of the experience of disability in all its sociological and psychological, cultural and political, physical and medical elements has not only instructed me, but stimulated me to work harder at thinking about these issues.

In the end, as I reread my own work, one central theme, one main point, stands out. More than anything else, in various ways, yet over and over, I seem to have been saying: "Disability" is not what most of us commonly think it is. People with disabilities are not who or what we have been taught to assume they are. The experience of disability is not what we have been told. Much of the reigning social thought about disability is distorted. Most of the conventional wisdom about disabled people is wrong. The disabled poet Cheryl Marie Wade made the same point succinctly when she wrote: "I emphatically demonstrate / It ain't what it seems." 12

The danger is that dominant ideologies of disability will pinion our perceptions, shackling efforts to think in new ways about disability and disabled people, and about "normality" too. Describing this sort of constricted mindset, e. e. cummings wrote: "he does not have to think because he knows / . . . because he knows, he cannot understand." All of us, disabled and nondisabled alike, will never truly understand disability experiences and identities unless we examine what we think we know. We all have a lot of relearning to do.

Notes

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- 8. Gary B. Nash et al., *National Standards for History*, Basic Edition (Los Angeles, 1996); Gary B. Nash, Charlotte Crabtree, and Ross E. Dunn, *History on Trial: Culture Wars and the Teaching of the Past* (New York, 1997).
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