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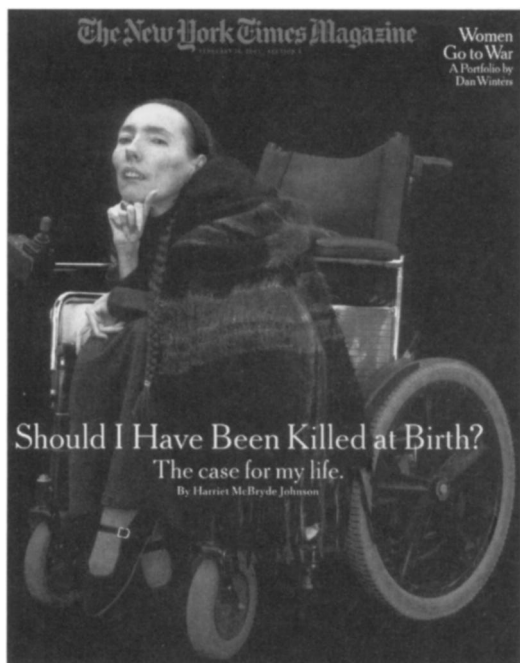
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and to represent disability as a tenable and valued way of being in the world.

Such resymbolization contributes to the project of social justice. Because our pre-

IN THE LAST TEN YEARS, DISABILITY STUDIES has become a major field of academic study. Many people are responsible for this happening—people with disabilities, family members and partners, activists and supporters. They have done the hard work to make the issue of disability visible and discussable. While a thriving field of disability studies had been developing since the 1960s (and earlier if we consider the work of considerable numbers of Deaf scholars, educators, and activists from the nineteenth century on), that work was mainly in the areas of the social sciences, applied health sciences, legal rights, and job

vailing representations constrict disability's complexities, they not only restrict the lives and govern the bodies of people we think of as disabled but also limit the imagination of those who think of themselves as non-disabled. Visual reimaginings such as these begin to fulfill the promise of an egalitarian order.

FIG. 4

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Disability: The Next Wave or Twilight of the Gods?

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discrimination. Disability studies in the humanities is a relatively recent phenomenon.

My aim today is not to rehearse the history of this phenomenon. I am sure many others will discuss the high points and touchstones. I would just add that disability studies seems to have arrived, and this conference is an important event in that arrival. Unlike, for example, the famous Johns Hopkins conference

The Languages of Criticism and the Sciences of Man, which launched structuralism in the United States in 1966, this conference is not an announcement of something new but the acknowledgment of something underway.

In thinking about this event, I reread my yellowed copy of the book about the Hopkins conference edited by Richard Macksey and Eugenio Donato. That book was ultimately published in 1970, four years after the symposium. That delay is telling—now we expect our publishers to move much more quickly, and the general pace of academic ideas and developments has accelerated accordingly. More telling is the fact that in the following year, the editors of the symposium noted in a preface, entitled “The Space Between—1971,” that “today we may question the very existence of structuralism as a meaningful concept” (ix). Indeed, it doesn’t take long for happening ideas to have happened. It is true that structuralism as such had its birth in France in the mid-1950s, so the arc of inception, publicity, circulation, controversy, internal disagreements, and eventually death lasted about twenty years.

I mention all this as a way of thinking through our own endeavor. Are we in the dawn, the midday, or the twilight of disability studies? Is there a post-disability studies waiting in the wings? Or, to think in other language, is there a second or even third wave of disability studies in the offing? Another question before us, to paraphrase *Variety*: does disability studies have wheels? Is it a subject that will continue to intrigue scholars and satisfy their needs and questions? Will its insights become obvious and therefore common sense—the desired goal of all research and inquiry, yet a goal whose achievement paradoxically spells subsequent demise? What are the cultural and social liminal requirements that might make disability studies unnecessary? That is, will disability studies melt away like the dictatorship of the proletariat?

I want to begin to deal with these questions by noting that despite the success of

disability studies, there are no senior disability scholars hired at any of the Ivy League schools as specialists in disability studies, nor are there any disability studies programs in such schools yet. (As something to try at home, search the Web site of Princeton University for the word *disability*. Aside from references to disability services, long-term disability insurance, and so on, you will find the only disability studies connection linked to Peter Singer, the philosopher who advocates euthanizing infants with severe disabilities.) The Big Ten does better, but my point is that unlike African American studies or other area studies, there are yet no major bidding wars, no *New York Times* headlines, for scholars who do disability studies. Disability studies, while having struck a chord with scholars and publishers and while exciting people with disabilities, does not yet have a larger social and cultural cachet. The controversy around the film *Million Dollar Baby* and the Terri Schiavo affair only emphasize how much more outreach needs to be done to promote a disability studies perspective.

What I’ve said is not entirely true. Another computer search, of *Amazon.com*, comes up with an amazing number of hits for disability-related books. Many of the people in this room are responsible for a major efflorescence of books on the subject. And many more books in related fields and disciplines show up.

Despite this good showing, I think we have to consider at this somewhat early point how we can avoid a twilight of disability studies. I have argued, and will continue to argue, that part of the problem is that disability studies in the United States has seen itself as linked intimately to identity studies in general. Taking its activist cue from the civil rights movement and the returning Vietnam veterans, the early phase of disability activism in the United States tended to think of disability as being like race, ethnicity, or gender. As Marx noted, historical movements borrow metaphors and influences from earlier suc-

cessful endeavors. Disability sought to locate itself among the politically and academically more triumphant identities. Indeed, much positive came out of those analogies. But in the last few years area studies have run into trouble. We are in a twilight of the gods of identity politics, and there is no Richard Wagner to make that crepuscular moment seem nostalgic and tragic.

If disability studies is to remain viable, it will have to incorporate into its collective vision the kind of complexities with which post-identity theory is grappling. In so doing, as I have proposed elsewhere, disability will have to scrutinize its own definitions. Is there a global reification around the concepts of disability and impairment? What do we do about the categories and moments that don't fit so well? What about the problem of definitions? If, using the social-constructionist model, we say that people have disabilities only when barriers are put in place, then are all people disabled if they face barriers? (In other words, if we buy the social-constructionist model, are we less than consistent if we don't also buy the British model that argues against an essentialist definition of disability?) If we go for a more somatized and rights-oriented definition—such as the one propounded in the Americans with Disabilities Act, which defines a disability as an impairment that limits at least one life activity or is perceived as doing so—then there is a troubling (or is it troubling?) expansion of the category of disability to include various and sundry characteristics. If we add chronic illness to this list, literally hundreds of conditions can be called disabilities. The courts and possibly the legislature have picked up on this critique, citing the ballooning number of people who are “disabled.” Then is our aim to protect the protected class or to expand the protected class to include everyone, as we do for civil or human rights?

This last question points out the problem of combining a social-constructionist model with a civil rights model. The constructionist

model argues for a subjective view of reality, while a rights model argues for something universal and inalienable. A Habermasian model could be used to link social constructionism and rights, but there would certainly be problems in that attempt. A discussion of this paradox will have to lead right into the lively area of antifoundationalist thinking characterized by writers like Richard Rorty and Stanley Fish. Such a discussion will compel disability studies, especially in what we might call the next wave, to interrogate its own presuppositions. Understandably, in the first wave we've tended to focus on unifying various categories and clarifying them through simplification. Now we need to entertain a kind of negative capability.

Deafness presents definitional problems as well. If Deaf people are seen not as a medical or somatized group but as a linguistic minority, as many Deaf wish to be considered, then is anyone who speaks American Sign Language (ASL) Deaf? If lack of hearing is the boundary, what about the hard of hearing? If some ineffable combination called Deaf World is the criterion, who decides which group inhabits that world? And how does the minority-language model of Deafness intersect with a somatized rights model of disability? Is an irreconcilable difference there? Why have so few disability scholars tried to learn sign language? Is disability more insular than we have been arguing if, by and large, it accepts the idea that ASL can be used to fulfill foreign language requirements at schools and universities but continues to isolate itself from ASL institutionally, so it remains a stunned tourist on a Perillo tour of Deaf World.

Then there is the vexed problem of medical and technological interventions. Is a Deaf person who has a cochlear implant still Deaf? Is a person with a disability that is alleviated by an invisible and functioning prosthetic or by some chemical or physical therapy disabled? What will happen if gene therapy, now ineffective, begins to work? Is a depressed

person on an effective Prozac regimen still depressed? Also, what will be the status of those without illnesses whose gene analysis indicates that they may develop a disease?

My point is that the next wave of disability studies will have to struggle not only with the injustices in the world against people with disabilities but also with the foundational categories set up by the first wave of disability scholars and activists. Initial definitions in political movements are generally sketched broadly to include as many groups as possible and to galvanize collective action and scholarship. But the next wave of scholars, in particular, find that they must investigate the opening categories. Tobin Siebers and Simi Linton have spoken strongly on the need to keep the issue of disability and persons with disabilities at the center of the discussion, and Siebers has critiqued a view of disability that emphasizes the instability of the category. But my position is that the instability of the category gives us a way of moving from identity politics to the next phase, which I have somewhat ineffectively called “dismodernism.”

Postidentity could be an opportunity rather than a problem for disability. That move would allow disability to become the ur-category of subjectivity and being. Indeed, the instabilities and destabilizations that threaten identity politics—the questioning of the validity of race, the notion of a gender continuum rather than a masculine-feminine divide, the emphasis on a new globality and cosmopolitanism—are in harmony with the kind of identity proposed by a second-wave disability studies.

In the process of destabilizing the twilight of identity politics, a number of issues will need new explanations. Younger scholars in disability studies have pointed these issues out to me. First and foremost, and somewhat paradoxically, is the issue of race. Disability studies has by and large been carried on by white people. We still await the disability studies book about the African American ex-

perience of disability. Yet it is clear that any such work will now have to acknowledge the postrace debate, and if it fails to do so, if it merely reinscribes an older idea of race as a distinct identity, it will be out of step with race studies in general. Another issue for those who would do work in race and disability is to locate the origin of racialized thinking and racialized subjects in the very discourse of disability as it developed institutionally during the nineteenth century.

Disability studies will have to be queered, as it recently has been by Robert McRuer and others. The queering of disability studies is an inevitable outcome of its second wave. This effort doesn't mean that feminist work is to be forgotten, but the rolling barriers and shifting definitions of masculine and feminine, the arbitrary and vague discourse of sexual orientation, and the creation of oppressive categories around that subject will have to be considered. The area of disability and sexuality needs much more attention, and some younger scholars are now beginning to publish in this field.

The area of cognitive and affective disabilities is only just beginning to see the light of day. In the same way that disability studies has been critiqued for its whiteness, it can also be critiqued for its bourgeois orientation and its elitism. New groups such as Mad Pride, Lunatics Liberation Front (walnet.org/llf), Mindfreedom (www.mindfreedom.org), Mad Nation (www.madnation.cc), and the Antipsychiatry Coalition (www.antipsychiatry.org) are starting to influence scholarship and research. The fact that academics are high-functioning people without, for the most part, serious cognitive disabilities has presented a kind of barrier to the construction of an autonomous subjecthood for people with cognitive disabilities. Furthermore, there is a pecking order for affective disorders, so that obsessive-compulsive disorder, depression, and anxiety disorders are more likely to be represented positively than schizophrenia (so-

called), other psychoses, and mental retardation. Upcoming conferences will be dealing more directly with how to link up academics with consumers of mental health services.

In other words, the history of disability studies is still intricately tied to a medical history. The distinction we have made between the medical model and the social model needs a careful reexamination. I would venture to call for a biocultural reassessment, as I've been describing it. By biocultural, I mean a critique that sees the full ramifications of the intersection of the human, the medical, the scientific, the technological, and the cultural.¹ Much of the analysis that has been done in the name of disability studies also falls into the realm of the biocultural, or I might say that disability studies has helped to launch the biocultural as a field. In the area of the medical-disability link, we are beginning to understand that the distinction between impairment and disability is not simple. This binary is putatively based on a medical diagnosis and then a cultural, social, political, and architectural barrier that turns the impairment into a disability. But the way in which medical categories are developed, particularly in the area of so-called mental illnesses, is unclear and problematic. Instead of trying to divorce medicine from disability, it might make more sense to see how the dyad of doctor and patient coevolved various diseases and conditions. This approach also addresses another problem—the lack of agency in some social-constructionist models, which postulate a dominant physician and a victim patient. I grant that this caricature has all too often been the case, but it has also been the desired template in disability studies. In fact, psychiatry and neurology developed in the nineteenth century far more through a complex interaction of physician actions, social expectations, patient desires and resistance, and progressivist programs than has been allowed. In this sense, the work of Foucault has been deeply misleading in its globalized view of power and its insistence on the hapless

and helpless role played by the patient in the activities of power. For example, in the nineteenth century hysteria evolved in a complex collaboration between patient and physician, who together developed a symptom pool and strategies for treatment. The important role of hypnosis, indeed, depends on such a collaboration. Of course, we want to be careful not to overestimate the influence of either the patient or the psychiatrist. Likewise, in conditions with a strong consumer component, like attention deficit disorder, depression, menopause, and erectile dysfunction, we might well see a combination of formation, identification, and treatment resembling Adorno's, Horkheimer's, Baudrillard's, or Debord's vision of consumption and resistance vis-à-vis the mass media.

I don't have enough time to go into all the areas of possible complexity and redefinition in disability studies, and I hope that the future will allow us to explore them more.

I want to end where I began, with the structuralist moment combined with a personal one. Eugenio Donato, one of the editors of the volume from the Hopkins conference, died rather young. I first met him at Edward Said's house, and Said did much to popularize structuralism in the United States, particularly with his articles that became the book *Beginnings*. I recently attended a memorial service for Said at Columbia University. During the service, a film by Ric Burns was shown, and I had the opportunity to see Said again, if only in film. He was my teacher, dissertation adviser, neighbor, colleague, and friend for thirty-five years. One thing he said in the film struck me as relevant to this discussion. He pointed out that the role of the intellectual was to fight the arbitrariness of power—whether the power served the interests of the oppressor or of the oppressed. A staunch critic of Israel, Said also severely criticized the Palestinian Authority.

I want to put this exhortation from beyond the grave into play here. What we must fear the

most in a developing and institutionalizing disability studies, as would be the case with any type of academic study, is its becoming orthodoxy. Disability studies has been—and, I hope, will continue to be—an open-ended investigation of the negotiations and dominations between power and the body, between rights and barriers, between the appearance of normalizing codes and the reality of the resistance of bodies and minds to those codes.

But one can see in certain aspects of disability studies a growing body of “truths.” These worry me because the line between truth and dogma is not entirely clear. When we unroll a set of assumptions—that people with disabilities should run disability studies; that selective abortion is a kind of genocide; that physician-assisted suicide is equivalent to murder; that cochlear implants are inevitably wrong; that the medical model, or the British use of “disability,” is inevitably incorrect—we begin to convert the fluidity of inquiry into the rigidity of stone tablets.

Of course, we must always be mindful that disability studies isn’t an inquiry in an isolation chamber but is and should be connected to the difficulties, political realities, and economic and social injustices experienced by people with disabilities. There is a necessary dialectic between the kinds of questions we ask and the kinds of solutions we

propose. The huge project of reclaiming lost texts and lost history remains. Through all this, and perhaps I speak the obvious, we have to be especially careful to make our intellectual endeavors aim for clarity and truth—not words I generally use—rather than expediency. After all, if we talk of strategy rather than inquiry, aren’t we saying in effect that the ends justify the means? Disability studies can open the book in new and intellectually demanding ways, but if it writes chapter and verse, it might better close the book, or else intellectuals will, as ever, find ways to challenge what had been the challenger. Rather than go that route, I hope that the next volume of disability studies will be as fresh, unusual, and abnormal as the first volume has been.

NOTE

¹ See the Web site *Project Biocultures* (www.biocultures.org) for further explorations of the “biocultural.”

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