

**Introduction: Disability, the
Missing Term in the Race,
Class, Gender Triad**

We are prisoners of a grammar invented at an early stage of human evolution, and it seems that, since we can think only by using language, our reason too is conditioned by the most primitive notions of reality.

Friedrich Nietzsche, *The Will To Power*

I

The term 'disability,' as it is commonly and professionally used, is an absolute category without a level or threshold. One is either disabled or not. One cannot be a little disabled any more than one can be a little pregnant.

One must view with suspicion any term of such Procrustean dimensions. A concept with such a univalent stranglehold on meaning must contain within it a dark side of power, control, and fear. The aim of this book is to look into this dark side, to rend the veil from the apparently obvious object: the disabled person.⁷

For most temporarily abled people,⁸ the issue of disability is a simple one. A person with a visible physical impairment (someone with an injured, nonstandard or nonfunctioning body or body part) or with a sensory or mental impairment (someone who has trouble hearing, seeing, or processing information) is considered disabled. The average, well-meaning 'normal' observer feels sorry for that disabled person, feels awkward about relating to the person,

believes that the government or charity should provide special services, and gives thanks for not being disabled (as in ‘I cried that I had no shoes until I met a man who had no feet’).

What does not occur to many people is that disability is not a minor issue that relates to a relatively small number of unfortunate people; it is part of a historically constructed discourse, an ideology of thinking about the body under certain historical circumstances. Disability is not an object – a woman with a cane – but a social process that intimately involves everyone who has a body and lives in the world of the senses. Just as the conceptualization of race, class, and gender shapes the lives of those who are not black, poor, or female, so the concept of disability regulates the bodies of those who are ‘normal.’ In fact, the very concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability, or rather, the concept of disability is a function of a concept of normalcy. Normalcy and disability are part of the same system.

It has been the rule that the subject of disability, until quite recently, has been written about by professionals who work with, medically treat, or study the disabled. In that discourse, people with disabilities have been an object of study, and the resulting information produced has constituted a discourse as controlling as any described by Michel Foucault. It has only been in recent years that people with disabilities have found a political voice and power and have been able to write about this experience. The previous discourse, heavily medicalized and oriented toward care and treatment, served its institutional purposes well. But it failed to understand dialectically its own position in the economy of power and control, and it failed to historicize its own assumptions and agency.

So the first task at hand is to understand and theorize the discourse of disability, to see that the object of disability studies is not the person using the wheelchair or the Deaf person but the set of social, historical, economic, and cultural processes that regulate and control the way we think about and think through the body. In addition, the presumption that disability is simply a biological

fact, a universal plight of humanity throughout the ages, needs to be challenged. This study aims to show that disability, as we know the concept, is really a socially driven relation to the body that became relatively organized in the eighteenth and nineteenth centuries. This relation is propelled by economic and social factors and can be seen as part of a more general project to control and regulate the body. This analysis fits in with other aspects of the regulation of the body that we have come to call crime, sexuality, gender, disease, subalternity, and so on. Preindustrial societies tended to treat people with impairments as part of the social fabric, although admittedly not kindly, while postindustrial societies, instituting ‘kindness,’ ended up segregating and ostracizing such individuals through the discursivity of disability.

The category of ‘disability,’ while politically useful, particularly in the advantages and legal protection provided by legislation such as the Americans with Disabilities Act, is not without problems. Many Deaf people, for example, do not see themselves in the category of disabled, preferring to call themselves a linguistic minority. Indeed, the term ‘physical minorities’ gives more of a political sense to physical difference than the more abstract category ‘disabled.’ In the task of rethinking and theorizing disability, one of the first steps is to understand the relationship between a physical impairment and the political, social, even spatial environment that places that impairment in a matrix of meanings and significations.

To do this, one must begin to rethink disability so that one may consider the world-view presented by that disabled moment. I use the concept of the ‘moment’ in its philosophical context to allow us to think of blindness or deafness, say, as modalities not disabilities. I also want to separate the attribute from a time frame – so that blindness is not placed in a time continuity (a ‘chronotope,’ to use the literary critic Mikhail Bakhtin’s term). When one speaks of disability, one always associates it with a story, places it in a narrative. A person became deaf, became blind, was born blind, became quadriplegic. The disability immediately becomes part of a chronotope, a time-sequenced narrative, embedded in a story. But by narrativizing an impairment, one tends to sentimentalize it

and link it to the bourgeois sensibility of individualism and the drama of an individual story, as we have seen in so many films treating the subject of disability. So deafness, a physical fact, becomes deafness, a story, with a hero or a victim, a love story, a set of attributes (lively, hard-working, hot-headed). By using the concept of the disabled moment, I want to defamiliarize disability, denarrativize it, and in a sense debourgeoise it. Of course, I do not intend permanently to divorce disability from people, but such a move might be necessary as an initial tactic.

As an example of the act of defamiliarization I am discussing, consider that everyone who reads this book is deaf. Even if you are not Deaf, you are deaf while you are reading. You are in a deafened modality or moment. All readers are deaf because they are defined by a process that does not require hearing or speaking (vocalizing). The sign language they are participating in is one that uses marks of ink on paper (or electrical/chemical markings on computer screens). Reading is a silent process, and although anyone can vocalize what he or she reads, the vocalization is a second-order activity. In fact, to be alive and thinking in the twentieth century implies that you have performed a lot of non-oral/aural activity of this sort. Your ideas, your thoughts, your beliefs, even your emotional, erotic life have been shaped by this nonverbal, nonauditory mode of sign language. This is a moment of disability.

I am making this point to illustrate how audist our biases are when it comes to thinking about deafness and hearing. It will be one of the aims of this book to lay bare the routine assumptions made about the 'clear' polarities of deafness and hearing, of disabled and abled. That binarism, like so many others – straight/gay, male/female, black/white, rich/poor – is part of an ideology of containment and a politics of power and fear. While many progressive intellectuals have stepped forward to decry racism, sexism, and class bias, it has not occurred to most of them that the very foundations on which their information systems are built, their very practices of reading and writing, seeing, thinking, and moving are themselves laden with assumptions about hearing, deafness,

blindness, normalcy, paraplegia, and ability and disability in general. Indeed, our language is peppered with words and phrases like 'lame,' 'blind,' 'deaf and dumb,' 'deaf, dumb, and blind,' 'idiotic,' and so on that carry with them moral and ethical implications.⁹

For many years it has become a mark of commonplace courtesy and intellectual rigor to note occasions when racism, sexism, or class bias creep into discourse. The intellectual left, indeed, has been accused of being too rigorous in its insistence on calling people 'African-American,' 'Ms,' 'othered' and so on. Yet there is a strange and really unaccountable silence when the issue of disability is raised (or, more to the point, never raised); the silence is stranger, too, since so much of left criticism has devoted itself to the issue of the body, of the social construction of sexuality and gender. Alternative bodies people this discourse: gay, lesbian, hermaphrodite, criminal, medical, and so on. But lurking behind these images of transgression and deviance is a much more transgressive and deviant figure: the disabled body.¹⁰

The disabled body is a nightmare for the fashionable discourse of theory because that discourse has been limited by the very predilection of the dominant, ableist culture. The body is seen as a site of *jouissance*, a native ground of pleasure, the scene of an excess that defies reason, that takes dominant culture and its rigid, power-laden vision of the body to task. The body of the left is an unruly body: a bad child thumbing its nose at the parent's bourgeois decorum; a rebellious daughter transgressing against the phallocentric patriarch. The nightmare of that body is one that is deformed, maimed, mutilated, broken, diseased. Observations of chimpanzees reveal that they fly in terror from a decapitated chimp; dogs, by contrast, will just sniff at the remains of a fellow dog. That image of the screaming chimpanzee facing the mutilated corpse is the image of the critic of *jouissance* contemplating the paraplegic, the disfigured, the mutilated, the deaf, the blind. Rather than face this ragged image, the critic turns to the fluids of sexuality, the gloss of lubrication, the glossary of the body as text, the heteroglossia of the intertext, the glossolalia of the schizophrenic. But almost never the body of the differently abled.

Recently, an editor at a prominent university press denied this assertion of culpability by claiming in all good faith that academics really were not exposed to many disabled people. This silence was a sin of omission rather than commission, he maintained, since how many deaf people did one run into? But this editor was simply participating in an ableist discourse – setting the limits of the argument with common sense. In some universities where diversity requirements have been instituted, there has been a struggle over including disability – which seems to some people of color to be a side current that would simply muddy the waters about the central issue of racism.

To the dominant culture, even to what can still be considered the counter-culture, by their own definitions, only a small fraction of the population appears to be disabled; these people with disabilities would be equally distributed across race, gender, and class lines. This notion must, however, be seen as ideology, not as knowledge. In the realm of the body, ableist culture still reigns supreme. However, by most calculations, about one in ten people are disabled. About the same percentage have some hearing loss, if you include late-deafened adults. But the editor maintained that such people, hard-of-hearing grandparents or cousins with bad knees or eyes, could be excluded since they were not 'really' disabled. And advocates of diversity requirements do not recognize that cohort as constituting a legitimate minority.

Did these people realize that when they encountered the work of Rosa Luxemburg (who limped), Antonio Gramsci (a crippled, dwarfed hunchback), John Milton (blind), Alexander Pope (dwarfed hunchback), George Gordon Byron (club foot), José Luis Borges, James Joyce, and James Thurber (all blind), Harriet Martineau (deaf), Toulouse-Lautrec (spinal deformity), Frida Kahlo (osteomyelitis), Virginia Woolf (lupus), they were meeting people with disabilities? Do filmgoers realize when they watch the films of John Ford, Raoul Walsh, André de Toth, Nicholas Ray, Tay Garnett and William Wyler that these directors were all physically impaired (Norden 1994, 4)? Why is it when one looks up these figures in dictionaries of biography or encyclopedias that

their physical disabilities are usually not mentioned – unless the disability is seen as related to creativity, as in the case of the blind bard Milton or the deaf Beethoven? There is an ableist notion at work here that anyone who creates a canonical work must be physically able. Likewise, why do we not know that Helen Keller was a socialist, a member of the Wobblies, the International Workers of the World, and an advocate of free love? We assume that our 'official' mascots of disability are nothing else but their disability.

The problem, of course, is that the manner in which this society defines disability in fact creates the category. Able-bodied (or temporarily able-bodied) people safely wall off the severely disabled so that they cannot be seen as part of a continuum of physical differences, just as white culture isolates blackness as a skin color so as not to account for degrees of melanin production. How many people with hearing aids consider themselves deaf; how many people with knee braces consider themselves impaired?¹¹

The fact is that impairment of the human body is a relatively common phenomenon. It has been estimated that there are some 500 million severely impaired people in the world, approximately one in ten among the world's population (Shirley, 1983). That statistic is repeated at the national level: in 1991 the Institute of Medicine estimated a total of 35 million disabled in the USA, one in seven people. Other federal data go as high as 43 million. But these data do not include those with AIDS or those who are HIV-positive. (Shapiro 1993, 7). A United States census estimates that 13,110,000 people aged from sixteen to sixty-four have work-related disabilities, putting 8.5 percent of all working-age females and 9.3 percent of all working-age men in this category (US Bureau of Census 1982). When we consider that about one in ten Americans lives below the poverty line, or that one in eight women will develop breast cancer, we can see that disability is by no means uncommon.

In the process of disabling people with disabilities, ableist society creates the absolute category of disability. 'Normal' people tend to think of 'the disabled' as the deaf, the blind, the orthopedically

impaired, the mentally retarded. But the fact is that disability includes, according to the Rehabilitation Act of 1973, those who are regarded as having a limitation or interference with daily life activities such as hearing, speaking, seeing, walking, moving, thinking, breathing, and learning. Under this definition, one now has to include people with invisible impairments such as arthritis, diabetes, epilepsy, muscular dystrophy, cystic fibrosis, multiple sclerosis, heart and respiratory problems, cancer, developmental disabilities, dyslexia, AIDS, and so on (Fine and Asch 1988, 9). When we start conceiving of disability as a descriptive term and not as an absolute category, then we can begin to think in theoretical and political ways about this category.

Another issue to recall is that disabilities are acquired. Only 15 percent of people with disabilities are born with their impairments. Disabilities are acquired by living in the world, but also by working in factories, driving insufficiently safe cars, living in toxic environments or high-crime areas. Poor people comprise a disproportionate number of the disabled – this is borne out by comparisons both within the United States and between First and Third World countries – frequently born with low weight, succumbing to diseases that vaccines and medicines would prevent, working and living in dangerous conditions, and living with poor public hygiene. In Uganda, for example, the major causes of disabling impairments are malnutrition, communicable diseases, low quality of prenatal care, and accidents including crime-related incidents (Mallory 1993, 87). In addition, people aged over sixty-five make up one-third of those with disabilities (Shapiro 1993, 6). The longer we live, the more likely we are to be disabled. Furthermore, medical advances have kept people alive who otherwise would have died from their disabilities. This increase in the numbers of the disabled is particularly notable in the case of premature babies, those with spinal cord injuries, and older people with debilitating conditions. In sum, there are more disabled people in the USA than there are, say, African-Americans. The odds are pretty good that many ‘normal’ people reading these words will become disabled within twenty or thirty

years, and many readers with disabilities will become people with multiple disabilities.

Why we think of disability as a totalizing category is complex. ‘The label of disability carries with it such a powerful imputation of inability to perform any adult social function that there is no other descriptor needed by the public’ (Gliedman and Roth 1980, cited in Fine and Asch 1988, 12). The point is that successful disabled people – the Julius Caesars, the Itzak Perlmans, the Sarah Bernhardts – have their disability erased by their success. And as for the more famous people with remembered disabilities – John Milton, Ludwig van Beethoven, Franklin Delano Roosevelt, or even Stevie Wonder – we tend to see them as people who overcame their disabilities or used them in ways we conventionally associate with the genius of creativity.

It is interesting that the historical record rarely reveals disability among figures in government, perhaps because a physical impairment was not judged important to one’s ability to perform the duties of public office in the preindustrial world. It comes as a surprise, therefore, to read the following description of King James I of England by a contemporary: ‘His legs were very weak, having had, as was thought, some foul play in his youth, or rather before he was born, that he was not able to stand at seven years of age – that weakness made him ever leaning on other men’s shoulders’ (Youngs et al. 1988, 133). Similarly, though rarely referred to in contemporary records, we know that Peter Stuyvesant, first governor of New Amsterdam, had only one leg, that Gouverneur Morris, who helped draft the Constitution and was later a senator from New York, wore a ‘rough stick’ to replace the leg he lost in a 1780 carriage accident. Stephen Hopkins, one of the signers of the Declaration of Independence, had cerebral palsy, which he referred to when he took the pen to sign the document saying, ‘My hand trembles but my heart does not’ (Shapiro 1993, 59). The fact that we do not know this history of disability, that the record has never taken note of these impairments, shows us, perhaps, that such differences were not, by definition, memorable. Or if they were memorable were not seen as impairing function.

'The crucial point is that the disabled person, as conceived by the nondisabled world, has no abilities or social functions [and] . . . those who do perform successfully are no longer viewed as disabled' (Fine and Asch 1988, 12). This erasure occurs because stereotyping requires that a person be categorized in terms of one exclusive trait. Disabled people are thought of primarily in terms of their disability, just as sexual preference, gender, or ethnicity becomes the defining factor in perceiving another person.

There is a tremendous conceptual gap between being impaired and being disabled. As soon as we use the term 'disabled' we add a political element: suddenly there is a disabler and a disabled. Claire Liachowitz makes the point forcefully:

much of the inability to function that characterizes physically impaired people is an outcome of political and social decisions rather than medical limitations . . . an increasing number of sociological and psychological theorists regard disability as a complex of constraints that the able-bodied population imposes on the behavior of physically impaired people. (Liachowitz 1988, xi, xiii)

This conceptualization involves the idea that in an ableist society, the 'normal' people have constructed the world physically and cognitively to reward those with like abilities and handicap those with unlike abilities. For example, television had the capacity to caption broadcasts for a long time, but by not making such technology available, networks made it difficult if not impossible for deaf viewers to follow programs. Now that all televisions in America will have a decoder chip built into them, deaf viewers can have the opportunity to watch and understand any television show. Similarly, people in wheelchairs would have no problem with access to buildings or transportation if architecture and design considered accommodating them. Only in 1994 did Avis, at the prodding of the Attorney General, agree to install more hand controls for paraplegics in its cars (*New York Times*, 2 September 1994, A:20). Operas, plays, and television broadcasts have begun, on a very limited basis, to provide visual interpreters

for blind people. Again, if exhibitions supposedly open to the 'public' were to accommodate the 10 percent of the population with disabilities by having interpretative facilities for the blind, the deaf, people in wheelchairs, and so on, then such people would be able to attend as if 'normal'.¹²

In fashioning some kind of theoretical approach to disability, one must consider the fact that the disabled body is not a discrete object but rather a set of social relations. In fact, the body generally, as I will discuss in Chapter 6, has been conceptualized as a simple object when it is in fact a complex focus for competing power structures. For example, if I ask you to think about the nude in art, chances are good that you will visualize a specific kind of body. Chances are remarkably good that the body will be female, white, and not visibly impaired. Few readers would imagine an Asian woman or a woman of color, even fewer a nude using a wheelchair. The reasons for such visualized assumptions are complex, involving further assumptions about beauty, about idealization, about sexuality, about gender, and so on. Intricately placed in that web of assumptions is a power move, I would call it, to fix the body as entire, intact, whole.

This process of visualization needs to be considered when one theorizes disability. Disability presents itself to 'normal' people through two main modalities – function and appearance. In the functional modality, disability is conceived of as inability to do something – walk, talk, hear, see, manipulate, and so on. This aspect of disability is of course part of a continuum of the many things that people can or cannot do. For example, I cannot do mathematical functions very well therefore I am somewhat learning-impaired. Few would consider that limitation a disability. But if I cannot walk very well with a prosthetic limb or a club foot, then I am disabled. The construction of disability is based on a deconstruction of a continuum. The functional modality has to do with standards of movement, sight, hearing and so on that have been established in a quantitative way. If my vision is less than 20/20 with glasses then I am legally blind, but if my vision is problematic but correctable, then I am not. These standards are part of a quantification of the

human body begun in the nineteenth century which will be discussed in Chapter 2. And these standards are perhaps not unrelated to the standardized movements of the body demanded in factory work. So the functional side seems at least to have a practical, technical, class-related side to it as well.

The question of appearance is the second major modality by which disability is constructed. The person with disabilities is visualized, brought into a field of vision, and seen as a disabled person. Here Erving Goffman's notion of 'stigma' comes into play 'since it is through our sense of sight that the stigma of others most frequently becomes evident' (Goffman 1963, 48). The body of the disabled person is seen as marked by the disability. The missing limb, blind gaze, use of sign language, wheelchair or prosthesis is seen by the 'normal' observer. Disability is a specular moment.¹³ The power of the gaze to control, limit, and patrol the disabled person is brought to the fore. Accompanying the gaze are a welter of powerful emotional responses. These responses can include horror, fear, pity, compassion, and avoidance.

Several points are to be made here. The first is that attention must be paid to the violence of the response – in a way more than to the object of the response. As Freud realized, disgust or repulsion masks a secret attraction to the object; so too must one analyze the negative feelings associated with disability. The common response of 'normal' people is to say that the disabled object produces strong feelings ranging from disgust to pity in the observer. But that approach seems to be more an ideological justification than a political explanation. Rather, it would seem more appropriate to say that the disabled object is produced or constructed by the strong feelings of repulsion. A person with an impairment is turned into a disabled person by the Medusa-like gaze of the observer; paradoxically, the observer becomes disabled by his or her reaction to the disabled person. The social context becomes disabled, as one sociologist detailed the stages of this process: '... the familiar signs of discomfort and stickiness [of the 'normal' toward people with disabilities]; the guarded references, the common everyday words suddenly made taboo, the fixed stare

elsewhere, the artificial levity, the compulsive loquaciousness, the awkward solemnity' (cited in Goffman 1963, 19).

What is repulsion after all but the personal, internalized version of the desire to repel, repress, extroject, annihilate the object? Repulsion is the learned response on an individual level that is carried out on a societal level in actions such as incarceration, institutionalization, segregation, discrimination, marginalization, and so on. Thus, the 'normal,' 'natural' response to a person with disabilities is in reality a socially conditioned, politically generated response. This aspect of repulsion, its constructed side, is obvious to anyone who has grown up with family members who have disabilities or to anyone who lives with a person with disabilities. In temporarily abled people brought up in disabled families the imperative to cast out, to repulse has never been established. The person with a disability is just that – a person with some kind of limitation or difference. One student told me that her mother had no fingers on one hand. As a child she had never considered this particularly strange, and she was always surprised when strangers stared at her mother's hand. To her it was a loving, caressing hand that she might joke about, kiss, or hold. The point is not that she was habituated to what others might consider a horror, but that she had not received the instruction to cast the hand away.

This brings me to another major point. Disability exists in the realm of the senses. The disabled body is embodied through the senses. So there is a kind of reciprocal relationship between the senses and disability. A person may be impaired by the lack of a sense – sight, hearing, taste, or even touch, although touch is almost never completely gone. Yet paradoxically, it is through the senses that disability is perceived. One understands this more clearly when one thinks of cyberspace. In the space of e-mail, for example, some disabilities disappear: the Deaf, for example, or people using wheelchairs or with other physical limitations, are not disabled. In 'talking' with Deaf colleagues on e-mail, particularly those whom I have never 'seen,' I often 'forget' that my interlocutor is deaf. Recently, in planning to attend a session at the Modern Language

Association on disability, I received and sent a welter of messages on e-mail to a number of people involved. I had no way of knowing which of these people was disabled, or in which way. When speaking on the telephone with a person who uses a wheelchair, I have no way of knowing if that person is unable to walk. The sense of sight, what James Joyce called 'the ineluctable modality of the visible,' is really not that ineluctable. Many disabilities are constructed through the sense of sight and can be deconstructed in virtually real locations that do not rely on sight. Or, to take another example, the Deaf are perceived as such because one hears a different speech inflection or sees sign language. Without those sensory clues, the Deaf are embedded in the sensory grid of the 'normal' person. To a passerby on the street, the Deaf person is indistinguishable from anyone else until he or she begins to engage in communication.

The point is that the body is not only – or even primarily – a physical object. It is in fact a way of organizing through the realm of the senses the variations and modalities of physical existence as they are embodied into being through a larger social/political matrix. As Robert F. Murphy points out (1987, 133), disability 'is not just a departure from the moral code, but a distortion of conventional classification and knowing.'

Another major point is that most constructions of disability assume that the person with disabilities is in some sense damaged while the observer is undamaged. Furthermore, there is an assumption that society at large is intact, normal, setting a norm, undamaged. But the notion of an undamaged observer who is part of an undamaged society is certainly one that needs to be questioned. The social critic Theodor Adorno subtitled his work *Minima Moralia as Reflections from a Damaged Life*. While Adorno was not disabled in any traditional sense, he saw his life as damaged because he saw society as profoundly damaged and damaging. 'Our perspective of life passed into an ideology which conceals the fact that there is life no longer' (Adorno 1984, 15). From a materialist perspective it is difficult to construct a model that does not include the notion that contemporary life

is disabled, dysfunctional, dystopic. Adorno wrote: 'The libidinal achievements demanded of an individual behaving as healthy in body and mind, are such as can be performed only at the cost of the profoundest mutilation . . .' (*ibid.*, 58). The attempt to make a simple relation between subject and object in which a disabled subject is linked to an able object is dialectical anathema. The process of perception is bound up in a toing and froing of interaction that makes the paradigm of the observer–observed patently simplistic.

So in thinking of disability, we have to consider the disability of thinking. Thought and modes of thought will necessarily contain within them their own disincentives to theorize disability. The problems of the ideology of language, the predisposition of philosophy and thought to contain within them reified elements of Enlightenment doctrines – doctrines that postulate the benefits of wholeness, of the ideal, of the totality of systems – will make it nearly impossible to wrest that language into the service of a new way of seeing (feeling, touching, signing). In theorizing disability, then, we must develop a different way of conceptualizing the visual field, of thinking about seeing, of perceiving thinking. In that sense, we will seek to correct the simple relation between subject and object, between subjected beings and bodies and their objectification by a world that sees them, and by seeing opposes them.

II

To make the point about the repression of disability more dramatic, I would like to focus on one of the foundational ableist myths of our culture: that the norm for humans is to speak and hear, to engage in communication through speaking and hearing. In challenging this supposition, I will rely on some of the arguments put forth by Jeffrey Kittay and Wlad Godzich in *The Emergence of Prose*. In the same sense that the norm of gender was seen as masculine, and the norm of race was seen as white, and the norm of class was seen as bourgeois, the norm of signifying practice is

seen as prose. As Kittay and Godzich point out, the impression we have is that people spoke in prose first and then in verse, while the opposite may have been true. But still we believe that the universal, undiacritical method of communication is prose. Their point is that the method that a culture chooses as its main signifying practice tells us much about that culture.

Which kinds of messages are transmitted through which kinds of signifying practices? What are the differences among signifying practices, and why is one kind of message rather than another relegated to one signifying practice rather than another? . . . Is it to be communicated between physical, bodily presences or via inert signs? (Kittay and Godzich 1987, 4)

From the point of view of this chapter, the facile equation made between speaking/hearing and writing – all seen as linked signifying practices – is actually a much more complex set of arrangements. If we look carefully, we can see that the aural/oral method of communicating, itself seen as totally natural, like all signifying practices, is not natural but based on sets of assumptions about the body, about reality, and of course about power. For example, Kittay and Godzich point out that the recording of verse, the writing down of the performance of the bard, is not a simple act of transcription; nor can we say that writing has taken over from performance. They maintain that in the Middle Ages, such written texts were meant not as texts *per se* but as scripts for performance, that is, ‘the text to be read is a virtuality to be actualized in performance’ (*ibid.*, 15). As texts became more common, a switch occurred to a consciousness of textuality that was no longer to be performed. It is at that moment that prose arose.

Prose for them ‘withholds itself from view. . . . It thus can claim a foundational role and functions as the ground of reference, a sort of degree-zero of language for all further formal elaboration. . . . Prose is meant to have no place; prose does not happen. Prose is what assigns place’ (*ibid.*, 197). In the same way that prose appears to be a neutral, surrounding medium that invisibly embodies

thought, so too speech appears as the anterior wall onto which prose throws its grappling hook. ‘But speech is not the end of the regress; speech is body-generated language; under and around speech, as in performance, is the individual *soma*’ (*ibid.*, 198). Prose points in a diexis to speech as the anterior logical ground for originary myths of signifying practice.

Kittay and Godzich alert us to beware of naturalistic explanations for signifying systems. In this world of signification, common sense makes bad sense. If we follow the commonsense explanation, humans begin in prehistory with gestures and then move to words. Rousseau puts the argument best. In his essay on the origins of language, he notes that ‘speech distinguishes man among the animals’ and that speech ‘owes its form to natural causes alone’ (1966, 5). He attributes speech to ‘instinct’ rather than rationality, and notes that while gesture and speech are both natural, ‘the first is easier and depends less upon conventions’ (*ibid.*, 6). Rousseau moves from gesture to speech to writing as a natural progression, although he allows gesture to coexist with speech. ‘It seems then that need dictated the first gestures, while the passions stimulated the first words’ (*ibid.*, 11).

What is wrong with this model? Or, more appropriately, what kind of assumptions are linked to this naturalized way of thinking about signifying practices? First, the model presumes crude gestures arose first leading to that articulated language – the aural/oral form of communication – seen as natural, common, and universal. But may we not construct another originary myth? What if a highly articulated and developed sign language like American Sign Language predicated speech? Why do we always assume that crude gestures preceded speech or, as with prose, that speech preceded writing? A sign language, as is currently spoken by the Deaf throughout the world, could well have been the first signifying practice. In fact, it is impossible to ascertain whether humans spoke or signed first; or, as with the native Americans, whether they spoke and signed concurrently.

I realize I am making an extreme argument, but I am doing so to question the simplicity with which we assume that speech and

prose are natural. Even Rousseau acknowledged that sign language could be highly elaborated and not composed merely of crude gestures:

The mutes of great nobles understand each other, and understand everything that is said to them by means of signs, just as well as one can understand anything said in discourse. M. Pereyra and those like him who not only consider that mutes speak, but claim to understand what they are saying, had to learn another language, as complicated as our own, in order to understand them. (*ibid.*, 9)

In fact, there is some evidence that sign language may well have preceded speech. Only about 250,000 years ago do we see the appearance of a human larynx similar to the one we have today. In terms of human evolution, this a very late development. If the facility for language appeared earlier, if the brain developed before the vocal chords, as it appears, then it is at least possible that sign language was the norm. The fact that the movements of the hands when people use sign language are controlled not by the motor part of the brain, which controls fine movements of the hand, but rather by the language areas in the brain called Broca's Region, indicates a somatic connection between language and signing. Researchers have recently shown us that sign language will evolve in deaf children whether or not there is a signing adult teaching them. Furthermore, research indicates that the sign language improves as the children speak with each other, even if the parent's sign language does not improve (*New York Times*, 1 September 1992, B:6). In other words, in individuals with a brain that processes language, a fully articulated sign language will develop whether or not there is a vocal capacity. Hence, a fully articulated and grammatical sign language could have been our first language, as it becomes every day when deaf children begin in the world babbling in sign.

Another point needs to be made here. In setting up the common-sense notion that language occurs in two forms and only two forms – speech or writing – we are engaging in a tautology based on an

equation of language as such and reason. Steven Pinker points out that there is no inherent connection between the particular language a culture uses and language *per se*. Nor is it correct to link that language to reason or thought. In fact, as he points out, thought and grammar are human instincts, not particularly dependent on language (Pinker 1994, 85). In other words, we can think and form concepts without language, using what he calls 'mentalese.' If what we have is a grammar that is built into our brains, or had been discovered at some time in human history, the particular kind of language that emerges – spoken, signed, or whatever – does not really matter. So the idea that sign language is the radical other of speech is actually quite incorrect (*ibid.*, 57). Speech is no better or worse than sign, and Pinker points out that writing and speech are by no means as clear forms of communication as we might think. Even the 'obviousness' or 'naturalness' of speech is called into question. For example, Pinker notes that 'all speech is an illusion' (*ibid.*, 159) in which we do not so much listen to a speaker as try to fit that speech into preconstructed categories, so that 'we simply hallucinate word boundaries when we reach the edge of a stretch of sound that matches some entry in our mental dictionary' (*ibid.*, 159–60). In other words, the limpid clarity of speech is itself an illusion that conceals the extent to which the receiver of speech is continually improvising to make the act of talking make sense. Likewise writing is called into question as the best possible way to record or transfer language. Pinker points out that while language is an instinct, 'written language was not' (*ibid.*, 189). He notes that most societies have lacked written language, that alphabetic writing was only invented once in history by a particular culture and then borrowed by other cultures. 'Illiteracy . . . is the rule in much of the world, and dyslexia . . . [is] found in five to ten percent of the population' (*ibid.*). By conceptualizing *language* as writing and speech, or by fetishizing the aural/oral incarnation of language, we are performing in effect an act of repression against language, in the largest sense of the term.

Rather than seeing speech as a naturally occurring and inherently superior method of communicating, it might be intellectually

more rigorous and less ableist to see that sign language may have been actively repressed in some cultures in favor of a hegemony of the aural/oral signifying practices and eventually in the direction of the hegemony of prose. For when sign language is repressed as a signifying practice, what is repressed is a connection with the body. The body of course will signify, and indeed linguistic studies routinely tell us that a great part, perhaps the majority, of communication is accomplished through body language.

As a signifying practice, what advantages are there to sign language? First, it is linked to the performative. As Kittay and Godzich suggest about verse, sign language does not have difficulty in pointing, in indicating. Prose must tortuously defy its own constraints to indicate who is speaking, who is acting, where things are. Verse and sign language quite simply are more closely associated with a certain kind of truth of being. The signifying process associated with bard or *jongleur*, associated with verse, participates in a world whose communications are more immanent. Sign language, like verse, is a language in which 'the deixis is *implicit*' (Kittay and Godzich 1987, 21). In other words, the language indicates directly by embodying, literally, the narrative.

The myth that needs to be debunked is that speech is somehow closer to writing than is sign language. The 'natural' progression gesture—speech—writing is in fact wrong. Sign language is far closer to writing than is speech. Speech is an oral production linked to the mouth. Sign language can be seen as a form of writing done in space rather than on paper. Typing, for example, is closer to signing than it is to speech. This analogy allows me to argue, in Chapter 3, that the Deaf person becomes actualized as a cultural icon in the eighteenth century when European society began, on a mass scale, to read.

An illustration of our bias toward speech and writing, as well as toward seeing and hearing, can be found in a fascinating short story 'The Persistence of Vision' by John Varley. He envisions a Utopian society called Keller in which all the people are blind and deaf. The narrator intrudes into this society and is befriended by a young woman who is the daughter of blind-deaf parents although

she, like all the offspring, can see and hear, since the adults were blind and deaf as a result of a rubella epidemic, not genetic factors. The narrator's words come to us through the medium of writing, but he discovers that the society communicates through 'bodytalk,' a variant of finger spelling. The narrator's written version cannot represent the hand gestures:

'That's (—) and (—)', she said, the parentheses indicating a series of hand motions against my palm. I never learned a sound word as a name for any of them . . . and I can't reproduce the bodytalk names they had. (Varley 1978, 284)

Varley has to face the dilemma of how to represent signing in a medium that authorizes the scriptable. His narrator has to conceptualize a world in which the priority of speech and prose is made irrelevant.

But in this society there is another level of communication called 'Touch,' a deeper kind of communication achieved through physical contact of naked bodies. Blindness when combined with deafness necessitates touch. Touch, as Varley makes clear, is very underutilized in an aural/oral/visual world. The line between the sexual and the nonsexual, between heterosexuality and homosexuality is erased, since all body contact is a form of talk, and everyone talks with everyone. The language Touch is itself a metalanguage, a language beyond language.

It was a language of inventing languages. Everyone spoke their own dialect because everyone spoke with a different instrument: a different body and set of life experiences. It was modified by everything. *It would not stand still.* (*ibid.*, 307, emphasis in original)

It is precisely in the place of deafness and blindness, so long considered to be a locus of inarticulateness, of confusion, that Varley sees the ultimate in communicative clarity. Yet the aural/oral/seeing narrator realizes he will never be able to be part of the society. 'Unless I was willing to put out my eyes and ears,

I would always be on the outside. I would be the blind and deaf one' (*ibid.*, 312). So he leaves, only to return later and receive the gift of blindness and deafness in some real and metaphorical way at the same time.

While the short story contains some of the stereotypical hallmarks of literature about the disabled, it also manages to make some interesting points. In following the clichés of such fiction, the author gives special intuitive or compensatory powers to the blind-deaf. They are empathetic and erotic, in tune with nature and ethically upright. The story is framed by a love connection between an outsider and one of the members of the society (although in this case Pink is both of and not of the society – she is bicultural, if you like). But the main point is a strong one: that our construction of the normal world is based on a radical repression of disability, and that given certain power structures, a society of people with disabilities can and does easily survive and render 'normal' people outsiders. The aim of the rest of this book is to show how and why this is so.

Constructing Normalcy

If such a thing as a psycho-analysis of today's prototypical culture were possible . . . such an investigation would needs show the sickness proper to the time to consist precisely in normality.

Theodor Adorno, *Minima Moralia*

We live in a world of norms. Each of us endeavors to be normal or else deliberately tries to avoid that state. We consider what the average person does, thinks, earns, or consumes. We rank our intelligence, our cholesterol level, our weight, height, sex drive, bodily dimensions along some conceptual line from subnormal to above-average. We consume a minimum daily balance of vitamins and nutrients based on what an average human should consume. Our children are ranked in school and tested to determine where they fit into a normal curve of learning, of intelligence. Doctors measure and weigh them to see if they are above or below average on the height and weight curves. There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated.

To understand the disabled body, one must return to the concept of the norm, the normal body. So much of writing about disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of color. But as with recent scholarship on race, which has turned its attention to whiteness, I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because

Visualizing the Disabled Body: The Classical Nude and the Fragmented Torso

A human being who is first of all an invalid is *all* body, therein lies his inhumanity and his debasement. In most cases he is little better than a carcass —.

Thomas Mann, *The Magic Mountain*

... the female is as it were a deformed male.

Aristotle, *Generation of Animals*

When I begin to wish I were crippled — even though I am perfectly healthy — or rather that I would have been better off crippled, that is the first step towards *butoh*.

Tatsumi Hijikata, co-founder of the Japanese performance art/dance form *butoh*.

She has no arms or hands, although the stump of her upper right arm extends just to her breast. Her left foot has been severed, and her face is badly scarred, with her nose torn at the tip, and her lower lip gouged out. Fortunately, her facial mutilations have been treated and are barely visible, except for minor scarring visible only up close. The big toe of her right foot has been cut off, and her torso is covered with scars, including a particularly large one between her shoulder blades, one that covers her shoulder, and one covering the tip of her breast where her left nipple was torn out.

Yet she is considered one of the most beautiful female figures in the world. When the romantic poet Heinrich Heine saw her he called her 'Notre-Dame de la Beauté.'

He was referring to the Venus de Milo.

Consider too Pam Herbert, a quadriplegic with muscular dystrophy, writing her memoir by pressing her tongue on a computer keyboard, who describes herself at twenty-eight years old:

I weigh about 130 pounds; I'm about four feet tall. It's pretty hard to get an accurate measurement on me because both of my knees are permanently bent and my spine is curved, so 4' is an estimate. I wear size two tennis shoes and strong glasses; my hair is dishwater blonde and shoulder length. (Browne et al., eds, 1985, 147)

In this memoir, she describes her wedding night:

We got to the room and Mark laid me down on the bed because I was so tired from sitting all day. Anyway, I hadn't gone to the bathroom all day so Mark had to catheterize me. I had been having trouble going to the bathroom for many years, so it was nothing new to Mark, he had done it lots of times before.

It was time for the biggest moment of my life, making love. Of course, I was a little nervous and scared. Mark was very gentle with me. He started undressing me and kissing me. We tried making love in the normal fashion with Mark on top and me on the bottom. Well, that position didn't work at all, so then we tried laying on our sides coming in from behind. That was a little better. Anyway, we went to sleep that night a little discouraged because we didn't have a very good lovemaking session. You would have thought that it would be great, but sometimes things don't always go the way we want them to. We didn't get the hang of making love for about two months. It hurt for a long time. (*ibid.*, 155)

I take the liberty of bringing these two women's bodies together. Both have disabilities. The statue is considered the ideal of Western beauty and eroticism, although it is armless and disfigured. The living woman might be considered by many 'normal' people to be physically repulsive, and certainly without erotic allure. The question I wish to ask is why does the impairment of the Venus

de Milo in no way prevent 'normal' people from considering her beauty, while Pam Herbert's disability becomes the focal point for horror and pity?

In asking this question, I am really raising a complex issue. On a social level, the question has to do with how people with disabilities are seen and why, by and large, they are de-eroticized. If, as I mentioned earlier, disability is a cultural phenomenon rooted in the senses, one needs to inquire how a disability occupies a field of vision, of touch, of hearing; and how that disruption or distress in the sensory field translates into psycho-dynamic representations. This is more a question about the nature of the subject than about the qualities of the object, more about the observer than the observed. The 'problem' of the disabled has been put at the feet of people with disabilities for too long.

Normalcy, rather than being a degree zero of existence, is more accurately a location of bio-power, as Foucault would use the term. The 'normal' person (clinging to that title) has a network of traditional ableist assumptions and social supports that empowers the gaze and interaction. The person with disabilities, until fairly recently, had only his or her own individual force or will. Classically, the encounter has been, and remains, an uneven one. Anne Finger describes it in strikingly visual terms by relating an imagined meeting between Rosa Luxemburg and Antonio Gramsci, each of whom was a person with disabilities, although Rosa is given the temporary power of the abled gaze:

We can measure Rosa's startled reaction as she glimpses him the misshapen dwarf limping towards her in a second-hand black suit so worn that the cuffs are frayed and the fabric is turning green with age, her eye immediately drawn to this disruption in the visual field; the unconscious flinch; the realization that she is staring at him, and the too-rapid turning away of the head. And then, the moment after, the consciousness that the quick aversion of the gaze was as much of an insult as the stare, so she turns her head back but tries to make her focus general, not a sharp gape. Comrade Rosa, would you have felt a slight flicker of embarrassment? shame? revulsion? dread? of a feeling that can have no name?

In this encounter what is suppressed, at least in this moment, is the fact that Rosa Luxemburg herself is physically impaired (she walked with a limp for her whole life). The emphasis then shifts from the cultural norm to the deviation; Luxemburg, now the gazing subject, places herself in the empowered position of the norm, even if that position is not warranted.

Disability, in this and other encounters, is a disruption in the visual, auditory, or perceptual field as it relates to the power of the gaze. As such, the disruption, the rebellion of the visual, must be regulated, rationalized, contained. Why the modern binary – normal/abnormal – must be maintained is a complex question. But we can begin by accounting for the desire to split bodies into two immutable categories: whole and incomplete, abled and disabled, normal and abnormal, functional and dysfunctional.

In the most general sense, cultures perform an act of splitting (*Spaltung*, to use Freud's term). These violent cleavages of consciousness are as primitive as our thought processes can be. The young infant splits the good parent from the bad parent – although the parent is the same entity. When the child is satisfied by the parent, the parent is the good parent; when the child is not satisfied, the parent is bad. As a child grows out of the earliest phases of infancy, she learns to combine those split images into a single parent who is sometimes good and sometimes not. The residue of *Spaltung* remains in our inner life, personal and collective, to produce monsters and evil stepmothers as well as noble princes and fairy godmothers.

In this same primitive vein, culture tends to split bodies into good and bad parts. Some cultural norms are considered good and others bad. Everyone is familiar with the 'bad' body: too short or tall, too fat or thin, not masculine or feminine enough, not enough or too much hair on the head or other parts of the body, penis or breasts too small or (excepting the penis) too big. Furthermore, each individual assigns good and bad labels to body parts – good: hair, face, lips, eyes, hands; bad: sexual organs, excretory organs, underarms.

The psychological explanation may provide a reason why it is

imperative for society at large to engage in *Spaltung*. The divisions whole/incomplete, able/disabled neatly cover up the frightening writing on the wall that reminds the hallucinated whole being that its wholeness is in fact a hallucination, a developmental fiction. *Spaltung* creates the absolute categories of abled and disabled, with concomitant defenses against the repressed fragmented body.

But a psychological explanation alone is finally insufficient. Historical specificity makes us understand that disability is a social process with an origin. So, why certain disabilities are labeled negatively while others have a less negative connotation is a question tied to complex social forces (some of which I have tried to lay out in earlier chapters). It is fair to say, in general, that disabilities would be most dysfunctional in postindustrial countries, where the ability to perambulate or manipulate is so concretely tied to productivity, which in itself is tied to production. The body of the average worker, as we have seen, becomes the new measure of man and woman. Michael Oliver, citing Ryan and Thomas (1980), notes:

With the rise of the factory . . . [during industrialization] many more disabled people were excluded from the production process for 'The speed of factory work, the enforced discipline, the time-keeping and production norms – all these were a highly unfavourable change from the slower, more self-determined and flexible methods of work into which many handicapped people had been integrated.' (1990, 27)

Both industrial production and the concomitant standardization of the human body have had a profound impact on how we split up bodies.

We tend to group impairments into the categories either of 'disabling' (bad) or just 'limiting' (good). For example, wearing a hearing aid is seen as much more disabling than wearing glasses, although both serve to amplify a deficient sense. But loss of hearing is associated with aging in a way that nearsightedness is not. Breast removal is seen as an impairment of femininity and sexuality, whereas the removal of a foreskin is not seen as a diminution of

mascinity. The coding of body parts and the importance attached to their selective function or dysfunction is part of a much larger system of signs and meanings in society, and is constructed as such.

'Splitting' may help us to understand one way in which disability is seen as part of a system in which value is attributed to body parts. The disabling of the body part or function is then part of a removal of value. The gradations of value are socially determined, but what is striking is the way that rather than being incremental or graduated, the assignment of the term 'disabled,' and the consequent devaluation are total. That is, the concept of disabled seems to be an absolute rather than a gradient one. One is either disabled or not. Value is tied to the ability to earn money. If one's body is productive, it is not disabled. People with disabilities continue to earn less than 'normal' people and, even after the passage of the Americans with Disabilities Act, 69 percent of Americans with disabilities were unemployed (*New York Times*, 27 October 1994, A:22). Women and men with disabilities are seen as less attractive, less able to marry and be involved in domestic production.

The ideology of the assigning of value to the body goes back to preindustrial times. Myths of beauty and ugliness have laid the foundations for normalcy. In particular, the Venus myth is one that is dialectically linked to another. This embodiment of beauty and desire is tied to the story of the embodiment of ugliness and repulsion. So the appropriate mythological character to compare the armless Venus with is Medusa.⁷⁰ Medusa was once a beautiful sea goddess who, because she had sexual intercourse with Poseidon at one of Athene's temples, was turned by Athene into a winged monster with glaring eyes, huge teeth, protruding tongue, brazen claws, and writhing snakes for hair. Her hideous appearance has the power to turn people into stone, and Athene eventually completes her revenge by having Perseus kill Medusa. He finds Medusa by stealing the one eye and one tooth shared by the Graiae until they agree to help him. Perseus then kills Medusa by decapitating her while looking into his brightly polished shield, which neutralizes the power of her appearance; he then puts her

head into a magic wallet that shields onlookers from its effects. When Athene receives the booty, she uses Medusa's head and skin to fashion her own shield.

In the Venus tradition, Medusa is a poignant double. She is the necessary counter in the dialectic of beauty and ugliness, desire and repulsion, wholeness and fragmentation. Medusa is the disabled woman to Venus's perfect body. The story is a kind of allegory of a 'normal' person's intersection with the disabled body. This intersection is marked by the power of the visual. The 'normal' person sees the disabled person and is turned to stone, in some sense, by the visual interaction. In this moment, the normal person suddenly feels self-conscious, rigid, unable to look but equally drawn to look. The visual field becomes problematic, dangerous, treacherous. The disability becomes a power derived from its otherness, its monstrosity, in the eyes of the 'normal' person. The disability must be decapitated and then contained in a variety of magic wallets. Rationality, for which Athene stands, is one of the devices for containing, controlling, and reforming the disabled body so that it no longer has the power to terrorize. And the issue of mutilation comes up as well because the disabled body is always the reminder of the whole body about to come apart at the seams. It provides a vision of, a caution about, the body as a construct held together willfully, always threatening to become its individual parts – cells, organs, limbs, perceptions – like the fragmented, shared eye and tooth that Perseus ransoms back to the Graiae.

In order to understand better how normalcy is bred into ways of viewing the body, it might be productive to think about the body as it appears in art, photography, and the other visual media. There has been a powerful tradition in Western art of representing the body in a way that serves to solidify, rather early on in history, a preferred mode of envisioning the body. This tradition, identified by Kenneth Clark, has been most clearly articulated in the 'nude.' The nude, as Clark makes clear, is not a literal depiction of the human body but rather a set of conventions about the body: 'the nude is not the subject of art, but a form of art' (1956, 5). Or, as he says, the nude is 'the body re-formed' (*ibid.*, 3). If that is the

case, then the nude is really part of the development of a set of idealized conventions about the way the body is supposed to look.

While some nudes may be male, when people talk about 'the nude' they most often mean the female nude. Lynda Nead, in a feminist correction of Clark, points out that 'more than any other subject, the female nude connotes "Art"' (1992, 1). And in that tradition, the Venus becomes the vortex for thinking about the female body. The Venus is, rather than a subject, a masculine way of fashioning the female body, or of remaking it into a conceptual whole.

I emphasize the word 'whole,' because the irony of the Venus tradition is that virtually no Venuses have been preserved intact from antiquity. Indeed, one of the reasons for the popularity of the Venus de Milo was that from the time it was discovered in 1820 until 1893 when Furtwangler's scholarship revealed otherwise, the statue was, according to Clark, 'believed to be an original of the fifth century and the only free-standing figure of a woman that had come down from the great period with the advantage of a head' (1964, 89).

The mutilation of the statues is made more ironic by the fact that their headless and armless state is usually overlooked by art historians – barely referred to at all by Clark, for example, in the entirety of his book. The art historian does not see the absence and so fills the absence with a presence. This compensation leads us to understand that in the discourse of the nude, one is dealing not simply with art history but with the reception of disability, the way that the 'normal' observer compensates or defends against the presence of difference. This is a 'way of seeing' not often discussed in art criticism. Of course, one can consider that art historians are really just making the best of a bad situation, but it is possible to make a number of further observations.

First of all, the headlessness and armlessness of Venuses link them, structurally, with the Medusa tradition. Many of these Venuses have in effect been decapitated. There seems to be a reciprocal relationship between the decapitations of Medusa in myth and of Venus in reality. It seems that the Venus is really only made possible in

coordination with the Medusa – that Aphrodite can romp because Medusa can kill. So it is a fitting dialectic that Medusa's beheading is contained within every broken Venus. The speechlessness of the art historian about the mutilation of his objects of beauty and desire is the effect of his metaphoric transformation to stone. This lapsus in speech is really an avoidance, a wish to avoid the castrating, terrifying vision of Medusa – the disabled, the monster, who is also the disabler. In a larger sense, as Nead suggests (1992, 17–18), all visions of the female nude, particularly in the Venus tradition, are attempts by male artists and critics to gird themselves against the irrationality and chaos of the body – particularly the female body:

It begins to speak of a deep-seated fear and disgust of the female body and of femininity within patriarchal culture and of a construction of masculinity around the related fear of the contamination and dissolution of the male ego.

In thinking about disability, one can extend this argument and say that the fear of the unwhole body, of the altered body, is kept at bay by depictions of whole, systematized bodies – the nudes of Western art. The unwhole body is the unholy body. Or as Kaja Silverman points out (1990, 14) about images of the body in film, society creates a 'protective shield' that insulates it against the possibility of mutilation, fragmentation, castration.

Indeed, the systematization of the body by artist and critic suggests a linearity, a regularity, a completeness that belie the fragmentary, explosive way the body is constitutively experienced. Clark exemplifies this systematic approach in discussing the Esquiline Venus of the fifth century, the first embodiment of these conventions.

But she is solidly desirable, compact, proportionate; and, in fact, her proportions have been calculated on a simple mathematical scale. The unit of measurement is her head. She is seven heads tall; there is the length of one head between her breasts, one from breast to navel, and one from the navel to the division of the legs... fundamentally

this is the architecture of the body that will control the observations of classically minded artists till the end of the nineteenth century. (Clark 1964, 75)

The amnesia of art historians to the subject of mutilation and decapitation (the Esquiline Venus has no head) is not accidental. The most we get from Clark in his entire book is one wistful mention of a Greco-Roman depiction of the three graces as 'a relief in the Louvre, headless, alas' (*ibid.*, 91). The 'alas' speaks volumes. This amnesia, this looking away from incompleteness, an averting of the attention, a sigh, is the tip of a defensive mechanism that allows the art historian still to see the statue as an object of desire. So the critic's aim is to restore the damage, bring back the limbs, through an act of imagination.⁷¹ This phenomenon is not unlike the experience of 'phantom limb,' the paradoxical effect that amputees experience of sensing their missing limb. In the case of the art historian, the statue is seen as complete with phantom limbs and head. The art historian does not see the lack, the presence of an impairment, but rather mentally reforms the outline of the Venus so that the historian can return the damaged woman in stone to a pristine origin of wholeness. His is an act of reformation of the visual field, a sanitizing of the disruption in perception.

This is the same act of imagination, or one might say control, that bans from the nude the representation of normal biological processes. For example, there are no pregnant Venuses, there are no paintings of Venuses who are menstruating, micturating, defecating – lactating and lacrimating being the only recognized activities of idealized women. There are no old Venuses (with the exception of a Diana by Rembrandt). One might think of a pregnant Venus as a temporarily disabled woman, and as such banned from the reconstruction of the body we call 'the nude.' Clark distinguishes between prehistoric fertility goddesses, like the Willendorf Venus, images of fertility and pregnancy, and the differently ideal Grecian versions which are never pregnant. As Nead notes (1992, 19), 'Clark alludes to this image of the female body [the Willendorf Venus] as undisciplined, out of control; it is excluded from the

proper concerns of art in favour of the smooth, uninterrupted line of the Cycladic [Greek] figure.' As artists and art historians shun the fluids and changes in shape that are incompatible with the process of forming the 'regular' body, the evidentiary record of mutilated Venuses must be repressed by a similar process.

A cautionary word must be said on the decapitated and armless Venuses. While it is true that male statues equally are truncated, the incompleteness of the female statues suggests another obvious point that has been repressed for so long – violence. Did all these statues lose their arms and heads by sheer accident, were the structurally fragile head and limbs more likely to deteriorate than the torso, were there random acts of vandalism, or was a particular kind of symbolic brutality committed on these stone women? Did vandals, warriors, and adolescent males amuse themselves by committing focused acts of violence, of sexual bravado and mockery on these embodiments of desire? An armless woman is a symbol of sexual allure without the ability to resist, a headless nude captures a certain kind of male fantasy of submission without the complication of the individuality and the authority granted by a face, even an idealized one. We do not know and will probably never know what happened to these statues, although the destruction of the Parthenon figures has been documented as done by occupying soldiers. The point is that the violence against the body, the acts of hacking, mutilation and so on, have to be put in the context we have been discussing. An act of violence against a female statue is constitutively different from that against a male statue – and these are acts that can be placed in a range of terrorist acts against women during war. Such acts create disabled people, and so, in a sense, these Venuses are the disabled women of art. To forget that is again to commit acts of omission of a rather damning nature.

Of course, a statue is not a person. But as representations of women, the Venus statues carry a powerful cultural signification. The reaction to such statues, both by critics and other viewers, tells much about the way in which we consider the body both as a whole and as incomplete. One point to note is that the art historian, like Clark, tends to perform a complex double act.

On the one hand, the critic sees the incomplete statue as whole, imagines the phantom limbs in order to defend against incompleteness, castration, the chaotic or 'grotesque body,' as Peter Stallybrass and Allon White (1987) have, using Bakhtinian terminology, called it. On the other hand (if indeed our standard is *two hands*), the critic and the artist are constantly faced with the fragmentary nature of the body, analyzing parts, facing the gaze of the missing part that must be argued into existence.

The model for the fragmentary nature of the nude is best illustrated by the famous story of Zeuxis, as told by Pliny. When Zeuxis painted his version of Aphrodite, he constructed her from the parts of five beautiful young women of his town of Kroton. His vision of the wholeness of Aphrodite was really an assemblage of unrelated parts. Likewise, the critic in regarding the whole nude must always be speaking of parts: 'their torsos have grown so long that the distance from the breasts to the division of the legs is three units instead of two, the pelvis is wide, the thighs are absurdly short' (Clark 1964, 91). The whole can only be known by the sum of its parts – even when those parts are missing. John Barrell has detailed the reactions of eighteenth-century men to the *Venus dei Medici*, and noted how they tended to examine every detail of the statue. Edward Wright, for example, tells observers to 'strictly examine every part' and a typical account read thus:

One might very well insist on the beauty of the breasts. . . . They are small, distinct, and delicate to the highest degree; with an idea of softness. . . . And yet with all that softness, they have a firmness too. . . . From her breasts, her shape begins to diminish gradually down to her waist; . . . Her legs are neat and slender; the small of them is finely rounded; and her feet are little, white, and pretty. (Barrell 1989, 127)

Another carp'd:

The head is something too little for the Body, especially for the Hips and Thighs; the Fingers excessively long and taper, and no match for the Knuckles, except for the little Finger of the Right-Hand. (*ibid.*)

These analyses perform a juggling act between the fragmentation of the body and its reunification into an hallucinated erotic whole.⁷² In imagining the broken statues, the critic must mentally replace the arms and the head, then criticize any other restoration, as does Clark in attacking the reconstruction of the Venus of Arles: 'the sculptor Girardon . . . not only added the arms and changed the angle of the head, but smoothed down the whole body, since the King was offended by the sight of ribs and muscles' (Clark 1964, 87). The point here is that the attempt of the critic to keep the body in some systematic whole is really based on a repression of the fragmentary nature of the body.

One might also want to recall that for the Greeks these statues, while certainly works of art, were also to be venerated, since they were representations of deities. For the Greeks, Aphrodite was not a myth; she was a goddess whose domain was desire. It somehow seems appropriate that the ritualistic or reverential attitude toward these statues, pointed out by Walter Benjamin (1969, 223–4), indeed their very appearance in stone (which Page Dubois sees as a cultic representation of the bones of the female spirits), has been reproduced in the attitude of that most secular of worshippers, the art critic. For the Venus has a double function: she is both a physical and a spiritual incarnation of desire. In that double sense, the critic must emphasize her spiritual existence by going beyond her physical incarnation in fallible stone, and her mutilations, to the essential body, the body of Desire, the body of the Other.

We can put this paradox in Lacanian terms. For Lacan, the most primitive, the earliest experience of the body is actually of the fragmented body (*corps morcelé*).⁷³ The infant experiences his or her body as separate parts or pieces, as 'turbulent movements' (Lacan 1977, 2). For the infant, rather than a whole, the body is an assemblage of arms, legs, surfaces. These representations/images of fragmented body parts Lacan calls *imagos* because they are 'constituted for the "instincts" themselves' (ibid., 11).

Among these *imagos* are some that represent the elective vectors of aggressive intentions, which they provide with an efficacy that might

be called magical. These are the images of castration, mutilation, dismemberment, dislocation, evisceration, devouring, bursting open of the body, in short, the *imagos* that I have grouped together under the apparently structural term of *imagos of the fragmented body*. (ibid., 11)

The process that builds a self involves the enforced unifying of these fragments through the hallucination of a whole body, 'a Gestalt, that is to say, in an exteriority' (ibid., 2), as Lacan has pointed out. The process 'extends from a fragmented body-image to a form of its totality . . . and, lastly, to the assumption of the armour of an alienating identity' (ibid., 4). When the child points to an image in the mirror – at that stage Lacan calls 'the mirror phase' – the child recognizes (actually misrecognizes) that unified image as his or her self. That identification is really the donning of an identity, an 'armor' against the chaotic or fragmentary body.

In this sense, the disabled body is a direct *imago* of the repressed fragmented body. The disabled body causes a kind of hallucination of the mirror phase gone wrong. The subject looks at the disabled body and has a moment of cognitive dissonance, or should we say a moment of cognitive resonance with the earlier state of fragmentation. Rather than seeing the whole body in the mirror, the subject sees the repressed fragmented body; rather than seeing the object of desire, as controlled by the Other, the subject sees the true self of the fragmented body. For Lacan, because the child first saw its body as a 'collection of discrete part-objects, adults can never perceive their bodies in a complete fashion in later life' (Ragland-Sullivan 1987, 21). This repressed truth of self-perception revolves around a prohibited central, specular moment – of seeing the disabled body – in which the 'normal' person views the Medusa image, in which the Venus-nude cannot be sustained as a viable armor. In Lacanian terms, the *moi* is threatened with a breaking-up, literally, of its structure, is threatened with a reminder of its incompleteness. In a specular, face-to-face moment, the ego is involved in what J. B. Pontalis calls 'death work,' which involves the 'fundamental process of unbinding [of the ego], of fragmentation, of breaking up, of separation, of bursting' (cited in Ragland-Sullivan

1987, 70). Thus the specular moment between the armored, unified self and its repressed double – the fragmented body – is characterized by a kind of death-work, repetition compulsion in which the unified self continuously sees itself undone – castrated, mutilated, perforated, made partial. In this context, it is worth noting that the Venus tradition involves castration at its very origin. Aphrodite is said to have been born from the foam of Uranus's genitals which Cronus threw into the sea after castrating his father (Graves 1955, 49). The dynamic is clear. Male mutilation is mitigated by the creation of the desirable female body. The disabled body is corrected by the wholeness of the constructed body of the nude. But, as has been noted, the emphasis on wholeness never entirely erases the foundation of the Venus tradition in the idea of mutilation, fragmented bodies, decapitation, amputation.

If we follow these terms, the disabled Venus serves as an unwanted reminder that the 'real' body, the 'normal body,' the observer's body, is in fact always already a 'fragmented body.' The linking together of all the disparate bodily sensations and locations is an act of will, a hallucination that always threatens to fall apart. The mutilated Venus and the disabled person, particularly the disabled person who is missing limbs or body parts, will become in fantasy visual echoes of the primal fragmented body – a signifier of castration and lack of wholeness. Missing senses, blindness, deafness, aphasia, in that sense, will point to missing bodily parts or functions. The art historian in essence dons or retains the armor of identity, needs the armor as does Perseus who must see Medusa through the polished shield. The art historian's defense is that mirror-like shield that conjures wholeness through a misrecognition linking the parts into a whole.

What this analysis tells us is that the 'disabled body' belongs to no one, just as the normal body, or even the 'phallus' belongs to no one. Even a person who is missing a limb, or is physically 'different,' still has to put on, assume, the disabled body and identify with it.⁷⁴ The disabled body, far from being the body of some small group of 'victims,' is an entity from the earliest of childhood instincts, a body that is common to all humans, as Lacan would have

it. The 'normal' body is actually the body we develop later. It is in effect a Gestalt – and therefore in the realm of what Lacan calls the Imaginary. The realm of the 'Real' in Lacanian terms is where the fragmented body is found because it is the body that precedes the ruse of identity and wholeness. Artists often paint this vision, and it often appears in dreams 'in the form of disjointed limbs, or of those organs represented in exosocy . . . the very same that the visionary Hieronymus Bosch has fixed for all time' (Lacan 1977, 4).

In understanding this point, we can perhaps see how the issue of disability transcends the rather narrow category to which it has been confined. Just as, I claim, we readers are all deaf, participating in a deafened moment, likewise, we all – first and foremost – have fragmented bodies. It is in tracing our tactical and self-constructing (deluding) journeys away from that originary self that we come to conceive and construct that phantom goddess of wholeness, normalcy, and unity – the nude.

One might even add that the element of repulsion and fear associated with fragmentation and disability may in fact come from the very act of repressing the primal fragmentariness of the body. As Freud wrote, 'the uncanny is in reality nothing new or foreign, but something familiar and old-established in the mind that has been estranged only [in] the process of repression' (Freud 1963b, 47). The feelings of repulsion associated with the uncanny, *das Unheimlich*, the unfamiliar, are not unlike the emotions of the 'normal' when they are visualizing the disabled. The key to the idea of the uncanny is in its relation to the normal. *Heimlich* is a word associated with the home, with familiarity – and with the comfortable predictability of the home. The disabled body is seen as *unheimlich* because it is the familiar gone wrong. Disability is seen as something that does not belong at home, not to be associated with the home. Freud notes that the terror or repulsion of the uncanny is ambivalent, is found precisely in its relation to and yet deviance from the familiar. That the uncanny can be related to disability is made clear when Freud cites specifically 'dismembered limbs, a severed head, a hand cut off at the wrist' as *unheimlich* (*ibid.*, 49). What is uncanny about

dismemberment seems to be the familiarity of the body part that is then made *unheimlich* by its severing. As Freud wrote, 'the *unheimlich* is what was once *heimisch*, homelike, familiar; the prefix "un" is the token of repression' (*ibid.*, 51).

But in this equation I think Freud is actually missing the earlier repression of the inherently fragmentary nature of the original body *imago*. The homeliness of the body, its familiarity as whole, complete, contained, is based on a dynamic act of repression. Freud is assuming that the whole body is an *a priori* given, as he had done with the concept of the ego. But as Lacan has shown more than adequately, the ego is a multifaceted structure to be understood in its philosophical complexity. Likewise the ground of the body, its materiality given by Freud, needs a re-analysis. The route of disability studies allows for this revisioning. In this process, the *heimisch* body becomes the *unheimlich* body, and the fragment, the disabled parts, can be seen as the originary, familiar body made unfamiliar by repression. Dominant culture has an investment in seeing the disabled, therefore, as uncanny, as something found outside the home, unfamiliar, while in fact where is the disabled body found if not at home?

I have been concentrating on the physical body, but it is worth considering for a moment the issue of madness. While mental illness is by definition not related to the intactness of the body, nevertheless, it shows up as a disruption in the visual field. We 'see' that someone is insane by her physical behavior, communication, and so on. Yet the fear is that the mind is fragmenting, breaking up, falling apart, losing itself – all terms we associate with becoming mad. With the considerable information we have about the biological roots of mental illness, we begin to see the disease again as a breaking up of 'normal' body chemistry: amino acid production gone awry, depleted levels of certain polypeptide chains or hormones. Language production can become fragmentary, broken, in schizophrenic speech production. David Rothman points out that in eighteenth- and nineteenth-century America, insanity was seen as being caused by the fragmented nature of 'modern' life – particularly the pressures brought to bear on people

by a society in which economic boundaries were disappearing. This fragmenting of society produced a fragmentation of the individual person. So the asylums that sprung up during this period recommended a cure that involved a removal from the urban, alienated, fragmented environment to rural hospitals in which order and precision could be restored. 'A precise schedule and regular work became the two characteristics of the best private and public institutions. . . . The structure of the mental hospital would counteract the debilitating influences of the community' (Rothman 1971, 144). As Rothman notes, 'Precision, certainty, regularity, order' were the words that were seen as embodying the essence of cure (*ibid.*, 145). The mind would be restored to 'wholeness' by restoring the body through manual labor. However, needless to add, one had to have a whole body to have a whole mind. The general metaphor here continues to be a notion of wholeness, order, clean boundaries, as opposed to fragmentations, disordered bodies, messy boundaries.

If people with disabilities are considered anything, they are or have been considered creatures of disorder – monsters, monstrous. Leslie Fielder has taken some pains to show this in his book *Freaks*. If we look at Mary Shelley's *Frankenstein*, we find some of the themes we have been discussing emerge in novelistic form. First, we might want to note that we have no name for the creation of Dr Frankenstein other than 'monster.' (This linguistic lapsus is usually made up for in popular culture by referring to the creature itself as 'Frankenstein,' a terminology that confuses the creator with the created.) In reading the novel, or speaking about it, we can only call the creature 'the monster.' This linguistic limitation is worth noting because it encourages the reader to consider the creature a monster rather than a person with disabilities.

We do not often think of the monster in Mary Shelley's work as disabled, but what else is he? The characteristic of his disability is a difference in appearance. He is more than anything a disruption in the visual field. There is nothing else different about him – he can see, hear, talk, think, ambulate, and so on. It is worth noting

that in popular culture, largely through the early film versions of the novel, the monster is inarticulate, somewhat mentally slow, and walks with a kind of physical impairment.⁷⁵ In addition, the film versions add Ygor, the hunchbacked criminal who echoes the monster's disability in his own. Even in the recent film version by Kenneth Branagh, the creature walks with a limp and speaks with an impediment. One cannot dismiss this filtering of the creature through the lens of multiple disability. In order for the audience to fear and loathe the creature, he must be made to transcend the pathos of a single disability. Of course, it would be unseemly for a village to chase and torment a paraplegic or a person with acromegaly. Disabled people are to be pitied and ostracized; monsters are to be destroyed; audiences must not confuse the two.

In the novel, it is clear that Dr Frankenstein cannot abide his creation for only one reason – its hideous appearance. Indeed, the creature's only positive human contact is with the blind old man De Lacey, who cannot see the unsightly features. When De Lacey's family catches a glimpse of the creature, the women faint or run, and the men beat and pursue him. His body is a zone of repulsion; the reaction he evokes is fear and loathing. The question one wants to ask is why does a physical difference produce such a profound response?

The answer, I believe, is twofold. First, what is really hideous about the creature is not so much his physiognomy as what that appearance suggests. The *corps morcelé* makes its appearance immediately in the construction of the monster. Ironically, Dr Frankenstein adapts Zeuxis's notion of taking ideal parts from individuals to create the ideal whole body. As he says, 'I collected bones from charnel houses. . . . The dissecting room and the slaughter-house furnished many of my materials' (Shelley 1990, 54–5). From these fragments, seen as loathsome and disgusting, Frankenstein assembles what he wishes to create – a perfect human. It is instructive in this regard to distinguish the Boris Karloff incarnation of the creature – with the bolt through his neck – or Branagh's grotesquely sewn creature, from the image that Mary Shelley would have us imagine. Dr Frankenstein tells us:

His limbs were in proportion, and I had selected his features as beautiful. Beautiful! – Great God! His yellow skin scarcely covered the work of muscles and arteries beneath; his hair was of a lustrous black and flowing; his teeth of a pearly whiteness; but these luxuriances only formed a more horrid contrast with his watery eyes, that seemed almost of the same colour as the dun white sockets in which they were set, his shrivelled complexion and straight black lips. (*ibid.*, 57)

What then constitutes the horror? If we add up the details, what we see is a well-proportioned man with long black hair, pearly white teeth, whose skin is somewhat deformed – resulting in jaundice and perhaps a tightness or thinness of the skin, a lack of circulation perhaps causing shriveling, watery eyes and darkened lips. This hardly seems to constitute horror rather than, say, pathos.⁷⁶

What is found to be truly horrifying about Frankenstein's creature is its composite quality, which is too evocative of the fragmented body. Frankenstein's reaction to this living *corps morcelé* is repulsion: 'the beauty of the dream vanished, and breathless horror and disgust filled my heart' (*ibid.*, 57). Frankenstein attempted to create a unified nude, an object of beauty and harmony – a Venus, in effect. He ended up with a Medusa whose existence reveals the inhering and enduring nature of the archaic fragmented body, endlessly repressed but endlessly reappearing.

Why does the appearance of the monster produce so powerful an affect? Routinely, one might view a deformed person, even a multiply deformed one, without desiring to kill that person. Here we see a man whose skin is strange or unnatural being transposed into the category 'monster.' The element of skin reminds us that the monster as a disturbance in the visual field is linked to the tactile field. The disruption in the skin's surface immediately translates into a threat of touching, of being touched. The idea of touch always initiates a dialectic of attraction and repulsion, of fear, hatred, or erotic attraction. Indeed, from a psychoanalytic viewpoint there is not much difference between these choices. So, inevitably, the disabled body becomes a site of the erotic, as instantly it is perceived

in either the Venus or the Medusa scenarios.⁷⁷ In Shelley's novel, after the creation, Dr Frankenstein has rather a peculiar response – he goes to sleep and has a dream about his fiancée:

I thought I saw Elizabeth, in the bloom of health, walking in the streets of Ingolstadt. Delighted and surprised, I embraced her, but as I imprinted the first kiss on her lips, they became livid with the hue of death; her features appeared to change, and I thought that I held the corpse of my dead mother in my arms; a shroud enveloped her form, and I saw the grave-worms crawling in the folds of the flannel. (*ibid.*, 58)

The rather incredible set of associations made by Dr Frankenstein would take pages to explore thoroughly, but what we might want to note here is that the immediate flight from the Medusa image of the monster's fragmented body leads immediately to the Venus body of Elizabeth, seen as frankly erotic. However, upon the first sexual contact the Venus myth immediately deconstructs, and Elizabeth's body initially changes to a corpse, then to the decomposing corpse of Frankenstein's dead mother. The visual leads to the tactile, which then contaminates the normal body. And all these moments lead back to the decomposing, fragmenting body. Later in the novel, when the creature demands a spouse, Frankenstein again creates the fragmented, now female, body. But at the last minute 'trembling with passion, [I] tore to pieces the thing on which I was engaged' (*ibid.*, 168).⁷⁸ Frankenstein's explicit reason for failing to give the monster a mate is fear that a race of deformed creatures would populate the earth and threaten the human race.⁷⁹ Thus the risk of the erotic touch, of the frankly erotic agenda for the creature, is seen as a contaminating danger to 'normal' people. So, the fragmented body is hacked up, exploded, into the fragments that make it up.

The work of Didier Anzieu, a psychoanalyst, might help to amplify how touch and skin contribute to the concept of the disabled body. Frankenstein's creation is driven out largely because of the nature of his skin, his covering, made hideous by its color,

texture, and incompleteness. Anzieu postulates that skin is in effect an *imago* of the ego. As such, when the infant hallucinates the whole body, he or she actually uses the concept and the reality of skin as a metaphor for wholeness, completeness, total enveloping of a unitary self. The skin is in effect a 'narcissistic envelope' (Anzieu 1989, 39). As Anzieu notes:

the boundaries of the body image (or the image of the body's boundaries) are acquired in the course of the child's detaching itself from its mother and they are to some degree analogous to the Ego boundaries which Federn has shown as being de-cathected in the process of depersonalization. (*ibid.*, 32)

For Anzier, the skin is the metaphor and the reality of the intact ego. Any perforation or alteration of the skin's entirety signals the deconstruction of the concept of unity, of envelopment.

In my view, the skin that has been torn from the body, if it is preserved whole, represents the protective envelope, the shield, which one must take from the other in phantasy either simply to have it for oneself or to duplicate and reinforce one's own skin. (*ibid.*, 50)

The disabled body presents in both visual and tactile terms the rupture of the skin-ego, whether that disruption is lack of limbs or dysfunction of sensory organs. Indeed, seeing is related to touching, as Freud has noted,⁸⁰ as is hearing – each of which connects an observer to an object that may be out of range of touch. Anzier tries to account for a prohibition on touching in Western culture, citing biblical injunctions, Christ's *noli me tangere*, incest and masturbation prohibitions, and even Freud's renunciation of touching as a therapeutic technique. The point to be made is that touching involves the contact of one's ego, literally in this case, with the ego of the object. In the case of the perceptual realms involved in the disability transaction between subject and object, the specular moment leads to the tactile moment. Thus, touching represents an opening up of the ego, a kind of risk that the envelope may fail

to contain the subject because of the moment of contact. 'The prohibition on touching separates the region of the familiar, a protected and protective region, from that of the strange, which is troubling and dangerous' (*ibid.*, 146). Our touch is familiar, but the touch of the Other is *unheimlich*; so the disabled touch is seen as both contagious and erotic.

That this touch is eroticized and connected with the Oedipal moment is significant.

The most primitive form of the tactile prohibition seems to run: do not stay clinging to the body of your parents . . . [but] the Oedipal prohibition reverses the elements of the prohibition on touching: what is familiar, in the first sense of familial, becomes dangerous . . . (*ibid.*, 146–7)

Around the Oedipal moment swirl the images of castration, mutilation, and a general prohibition against 'generalized contact, i.e. on the embracing, conjoining and confusing of bodies' (*ibid.*, 147). Touch represents a fragmenting of the body, a threat of mutilation, and a fear of losing one's boundaries, one's bodily integrity. In this sense, touching the creature, touching the disabled body, is both an erotic lure and a self-destroying gesture.

We can return, again, to the Venus, neatly enclosed in its marmoreal skin and thus representing an unperforated body, despite the mutilations that have disfigured it. Most of the visual arts eschew disability and disabled images, except perhaps for the romanticized images around madness. The work of Mary Duffy, a contemporary artist without arms, provides one notable exception to this reluctance to think of Venuses without arms as the equivalent of Medusa. In the first plate of a photographic series entitled *Cutting the Ties that Bind*, we see a standing figure draped entirely in white cloth against a dark background so that the figure beneath the drapery is not visible. In the second plate, the drapery is partially removed so that it covers mainly the thighs and legs revealing us a female body, the artist's, without arms. The figure is clearly meant to reproduce the Venus de Milo in the flesh. The third picture in

the series shows the figure stepping away from the drapery with a triumphant smile. The work serves to show how the female disabled body can be reappropriated by the artist herself. Duffy writes:

By confronting people with my naked body, with its softness, its roundness and its threat I wanted to take control, redress the balance in which media representations of disabled women [are] usually tragic, always pathetic. I wanted to hold up a mirror to all those people who had stripped me bare previously . . . the general public with naked stares, and more especially the medical profession. (*cited in Nead 1992*, 78)

The Medusa gaze is rerouted so that it comes not from the object of horror, the monstrous woman, but from the gaze of the normal observer. It is the 'normal' gaze that is seen as naked, as dangerous. And unlike Perseus slaying Medusa by holding up a mirror, it is now the 'object of horror' who holds the mirror up to the 'normal' observer.

This reappropriation of the normal gaze was further carried out by the photographer Jo Spence. Recognizing the inherent and unstated pose of normalcy imposed by the camera and by the photographic session, Spence revised her photography to be capable of representing the nude model as a person with disabilities. Her work, detailed in many shows and in her book *Putting Myself in the Picture: A Political, Personal, and Photographic Auto-biography* (1986), partly focuses on her mastectomy. Spence links this operative and post-operative process to an understanding and participating gaze that seeks to touch, not recoil from, bodily changes. In addition to the simple fact of the partial mastectomy, Spence includes in her work photographs and texts that question assumptions about age and beauty. Her body is middle-aged, irregular, and defies the canons of ideal feminine beauty. Her work is involved with 'explaining my experience as a patient and the contradictions between ways in which the medical profession controls women's bodies and the "imaginary bodies" we inhabit as women' (Spence 1986, 156).

The visual arts have done a magnificent job of centralizing normalcy and of marginalizing different bodies. As we have seen, initially the impulse came from a move to idealize the body and make up the perfect body out of perfect sub-units. Then with the rise of hegemonic normalcy, the impulse veered from ideal to normalizing representations. Either of these paradigms pushes the ordinary body, the abnormal body, out of the picture. Photographer David Hevey has written about the paucity of images of the disabled in photographic anthologies. He concludes that 'disabled people are represented but almost exclusively as symbols of "otherness" placed within equations which take their non-integration as a natural by-product of their impairment' (Hevey 1992, 54). When he looked for any images of disabled people, he found either medical photographs in which the 'patients' appear 'passive and stiff and "done to", the images bear a bizarre resemblance to colonial pictures where "the blacks" stand frozen and curious, while "whitey" lounges confident and sure' (*ibid.*, 53), or images like those of Diane Arbus that show the disabled as 'grotesque.' Ungrotesque, routine pictures of disabled people in advertising, 'art' photography, films and so on are hard to find. With the same regularity that bodies of color were kept out of the mainstream (and even the avant-garde) media in the years before the civil rights movement, so too are disabled bodies disqualified from representing universality.

One of the ways that visual images of the disabled have been appropriated into the modernist and postmodernist aesthetic is through the concept of the 'grotesque.' The word was used by Bakhtin to describe the aesthetic of the Middle Ages, which reveled in presenting the body in its nonidealized form. The grotesque, for Bakhtin, was associated with the common people, with a culture that periodically turned the established order upside down through the carnival and the carnivalesque. Gigantic features, scatological references, inverse political power were all hallmarks of the grotesque – an aesthetic that ultimately was displaced by humanistic notions of order, regularity, and of course power during the Renaissance.

While the term 'grotesque' has had a history of being associated with this counterhegemonic notion of people's aesthetics and the inherent power of the masses, what the term has failed to liberate is the notion of actual bodies as grotesque. There is a thin line between the grotesque and the disabled. Hevey examines, for example, how critics have received Diane Arbus's photographs of the disabled. Susan Sontag writes that Arbus's 'work shows people who are pathetic, pitiable, as well as repulsive, but it does not arouse any compassionate feelings.' Later she adds, 'Do they see themselves, the viewer wonders, like *that*? Do they know how grotesque they are?' (Hevey 1992, 57). The grotesque, in this sense, is seen as a concept without the redeeming sense of class rebellion in Bakhtin's formulation. Here it is simply the ugly, what makes us wince, look away, feel pity – more allied with its dictionary definition of 'hideous,' 'monstrous,' 'deformed,' 'gnarled.' Though artists and writers may use the grotesque, they rarely write about that state from the subject position of the disabled. The grotesque, as with disability in general, is used as a metaphor for otherness, solitude, tragedy, bitterness, alterity. The grotesque is defined in this sense as a disturbance in the normal visual field, not as a set of characteristics through which a fully constituted subject views the world. One problem with terms like 'disability' and 'the grotesque' is that they disempower the object of observation. The body is seen through a set of cultural default settings arrived at by the wholesale adoption of ableist cultural values.

In no area is this set of cultural values related to the visual more compelling than in film. Film is a medium whose main goal, one might say, is the construction and reconstruction of the body. The abnormal body plays a major role in the defining of the normal body, and so one might assume that film would be concerned with the issue of disability. Martin F. Norden has recently published the most complete account to date of disability in the film industry, *The Cinema of Isolation: A History of Physical Disability in the Movies* (1994). The remarkable thing about this book is the staggering number of films that have been made about the issue of disability.

When I first began to consider the issue of how the disabled body is depicted in film, I came up with my own list of twenty or so films, and I thought that I would mention the occasional way in which the disabled were included in a film industry that mainly focused on the normal body. In other words, I thought I was dealing with a parallel situation to, say, the depiction in cinema of African-Americans – a marginalized group who rarely appeared in Hollywood films until recently⁸¹ and, if they did, played mainly minor characters or supernumerary roles.

But the facts about the depiction of disability are quite the opposite of what I had thought. The film industry has been obsessed with the depiction of the disabled body from the earliest silent films. The blind, the deaf, the physically disabled were singled out from the very beginning of cinema. Norden finds movies about disability from as early as 1898, and the earliest one-reeler silent films of the period 1902–1909 include such representative titles as *Deaf Mute Girl Reciting 'Star Spangled Banner'* (1902), *Deaf Mutes' Ball* (1907), *The Invalid's Adventure* (1907), *The Legless Runner* (1907), *The One-legged Man* (1908), *The Hunchback Brings Luck* (1908), *The Little Cripple* (1908), *A Blind Woman's Story* (1908), *The Blind Boy* (1908), *The Cripple's Marriage* (1909), *The Electrified Humpback* (1909), to name only a few. Later multi-reeler silent films routinely told the stories of the disabled. D. W. Griffith made a few disability-related films, culminating his efforts in the famous *Orphans of the Storm* (1921) in which two hapless sisters (Lilian and Dorothy Gish), one of whom is blind, try to survive on the streets of Paris. But the noteworthy fact about this film is not merely its disability-related content but that Griffith's version was the fifth filmic remake of the 1874 French play *Les Deux Orphelines*. With film only in its infancy, this particular disability story had been told afresh approximately once every four years from 1900 through 1921.

Norden's book lists about six hundred disability-related films in its index, a far cry from my twenty or so. And if one stops and thinks about the subject, one realizes that films concerning people with disabilities are almost always playing at any given time. For example, at the moment I write this sentence on 5 January 1995,

I can go see movies about the deaf Beethoven in *Immortal Beloved*, the linguistically deprived girl in Jodie Foster's *Nell*, the emotionally impaired monarch in *The Madness of King George*, and of course the lovable, mentally challenged *Forrest Gump*. In recent years films like *My Left Foot*, *Lorenzo's Oil*, *Rainman*, *Children of a Lesser God*, *Elephant Man*, *Mask*, *Awakenings*, *Stanley and Iris*, to name only a few better-known films, have become major hits. In addition to films centrally about disabled people, there are hundreds of films in which characters, mainly evil, are depicted as using wheelchairs, missing limbs or eyes, walking with a limp, stuttering, and so on.

The point that Norden's book made clear to me is that the cinematic experience, far from including disabilities in an ancillary way, is powerfully arranged around the management and deployment of disabled and 'normal' bodies. Disabled stories, stories of people's bodies or minds going wrong, make compelling tales. But more than that, as with any obsession, there has to be an underlying reason why films are drawn obsessively to the topic of disability. In order to understand why film makers routinely incorporate disabled bodies into films, it might be relevant to ask what else routinely appears in films. The answer is more than obvious: sex and violence. While it is fashionable for liberals to decry the violent content of films, and conservatives to decry the sexual, it might be more accurate for them to think of films as vehicles for the delivery of images of the body in extreme circumstances. The inherent voyeuristic nature of film makes it a commodity that works by visualizing for viewers the body in attitudes that it is otherwise difficult to see. Few people in quotidian life see couples making love on a regular basis, but that is a routine experience to filmgoers. Likewise, most middle-class citizens rarely see dead, mutilated, bleeding bodies, but the average viewer has no shortage of such images.

So films, one could say, are a streamlined delivery system that produces dramatically these bodily images in exchange for a sum of money (as the Coca-Cola industry can be said to be a system for delivering caffeine and sugar, or as cigarettes are really time-release delivery systems for nicotine administration). As novels

were seen to be mechanisms for the cultural production of normativity, so films have to be seen in the same regard, with the addition that the phantasm of the body is particularly subject to these normativizing activities.

Films enforce the normal body, but through a rather strange process. The normal body, invented in the nineteenth century as a departure from the ideal body, has shifted over to a new concept: the normal ideal. This normal ideal body is the one we see on the screen. It is the commodified body of the eroticized male or female star. This body is not actually the norm, but it is the fantasized, hypostatized body of commodified desire. In order to generate this body and proliferate its images, films have constantly to police and to regulate the variety of bodily differences. These bodies are the modern equivalents of the nude Venuses, and to keep them viable, to think on and obsess about them, the Medusa body has constantly to be shown, reshown, placed, categorized, itemized, and anatomized. In short, we cannot have Sharon Stone without Linda Hunt; we cannot have Tom Cruise without Ron Kovic; we cannot have the fantasy of the erotic *femme fatale*'s body without having the sickened, disabled, deformed person's story testifying to the universal power of the human spirit to overcome adversity. As Norden points out, when films about disabled people are made, more often than not the disabled characters get cured by the end of the film (1994, 59). The tension between the whole and the fragmented body, between the erotic, complete body and the uncanny, incomplete body, must be constantly deployed and resolved through films.

The film *Boxing Helena* provides some interesting ways of seeing these tensions worked through. In the film, the surgeon Nick (Julian Sands) amputates the legs of Helena (Sherilyn Fenn), the bitchy, sexualized woman with whom he is obsessed but who rejects his advances. He performs the amputation initially to save her life after a car accident, but then goes on to amputate her arms as a way of keeping her and containing her – of rendering her helpless so he can take care of her.

A replica of the Venus de Milo decorates Nick's family mansion

and is used as a double symbol. In one sense, it is an illustration of the beauty of the dismembered Helena. But it also represents idealized female beauty (in its wholeness) and is associated with Nick's mother whose blatant sexuality was used to humiliate her son when he was young. The film maker wants us to see the dismemberment of Helena partly as an act of revenge against the castrating mother, whose legacy shows up in Nick's premature ejaculation syndrome (which in that sense renders him disabled). The mother, who has died, later returns to Nick's gaze, seen from the back as the naked and armless Venus, and the statue itself at one time falls on Nick and in another moment explodes from within, thus illustrating the repressed reality of the fragmented body.

The salient point is that when Helena is amputated, that is, becomes the Venus, she becomes merely idealized. Whereas before her dismemberment she is a rapacious fantasy of female sexuality unencumbered by the traditional female values of caring, nurturing or sweetness, after her dismemberment, she loses her sexuality. In a typical ableist moment, she says after her amputation, 'How can I ever look at myself and think of myself as worthwhile?' Her worth in this case is her sexuality, which is lost. Her disability is actually created and owned by Nick.

In another instance of bourgeois, ableist celebration of the discursivity of sexuality, both she and Nick regain their sexual function (thus becoming undisabled) through eros. He buries his head in her lap, which of course despite all the mutilation leads us to realize that everything that is conventionally part of female sexuality is still intact – and in a moment of his fantasy she comes alive sexually, a trope which is equated with her suddenly having arms and legs. She caresses his head, walks, and whispers the answer to Freud's question 'What do women want?' telling him how women want to be made love to. Her whispered erotic litany begins to release the bad dream of disability. But it is only he, as the owner of her body, who can fully accomplish this release, and so she begs him: 'I want to feel like a woman. Give me back what you've taken away.' The supplement that has been missing is

returned like the Lacanian phallus by Nick in a very Lacanian moment. As Helena watches through a semi-opened door, Nick makes love to another woman (who in the credits is called 'fantasy woman'), and we see he is no longer sexually dysfunctional. Helena's self is reconstituted through a triangularization of desire in which her mirror imago of the whole body is re-created by viewing the desire of the Other. The other woman represents her wholeness, and the entire issue of functionality is blurred into sexual ability.⁸²

As trendy as the director Jennifer Lynch is trying to be, she cannot separate herself from traditional views of people with disabilities. Never does the surgeon have to catheterize Helena or change her tampon; more tellingly, Helena is never allowed to be both naked and disabled – as her body was so openly revealed before her amputations. Her double-amputated body is partly held up as an object of beauty, but not of sexuality – and therefore it can never be seen naked as she had been revealed to the camera's gaze before the operations. Unlike Mary Duffy or Jo Spence, Lynch cannot allow herself to show us the naked, disabled body. This would be too great a primal-scene moment, in which the true nakedness of disability, its connection with the nakedness of the unwhole fragmented body, would be unavoidable and unable to be repressed.

The film ends with the revelation that the entire narrative has all been Nick's dream. Helena was hit by a car, but in actuality she was taken to hospital, and at the end of the film she remains physically intact. Disability is just a bad dream, as she herself had cried out when she first discovered she had had her legs amputated. She is cured.

The film returns to the whole, untarnished body because that is always seen as the norm. In general, when the body is mentioned in literature or depicted in drama and film, it is always already thought of as whole, entire, complete, and ideal. In literature, central characters of novels are imaged as normal unless specific instruction is given to alter that norm; where a disability is present, the literary work will focus on the disability as a problem. Rare indeed is a novel, play, or film that introduces a disabled character

whose disability is not the central focus of the work.⁸³ More often, the disability becomes part of a theme in which a 'normal' person becomes romantically involved with a person with a disability and proves that the disability is no obstacle to being attractive. At its most egregious, this theme is taken up in works such as W. Somerset Maugham's *Of Human Bondage*, in which the character's sexual life is cleared of problems only when the disability is removed. With an only slightly more educated view, films like *My Left Foot* confirm the character's inner worth when he attracts a wife at the end of the film. And Jennifer Lynch's *Boxing Helena* is simply part of this parade.

Throughout this chapter, I have tried to show that the concept of disability is a crucial part of the very way we conceive of and live in our bodies. In art, photography, film, and other media in which the body is represented, the 'normal' body always exists in a dialectical play with the disabled body. Indeed, our representations of the body are really investigations of and defenses against the notion that the body is anything but a seamless whole, a complete, unfragmented entity. In addition to the terms of race, class, gender, sexual preference and so on – all of which are factors in the social construction of the body – the concept of disability adds a background of somatic concerns. But disability is more than a background. It is in some sense the basis on which the 'normal' body is constituted: disability defines the negative space the body must not occupy, it is the Manichean binary in contention with normality. But this dialectic is one that is enforced by a set of social conditions and is not natural in any sense. Only when disability is made visible as a compulsory term in a hegemonic process, only when the binary is exposed and the continuum acknowledged, only when the body is seen apart from its existence as an object of production or consumption – only then will normalcy cease being a term of enforcement in a somatic judicial system.

Conclusion:

Uneasy Positions: Disability and Multiculturalism

I have been trying to make the argument that the concept of disability has been relegated to a sideshow, a freak show at that, far away from the academic midway of progressive ideas and concerns. While the main attractions of race, class, and gender continue to grab the attention of professors and students, as well as of the general public, the concept of disability is safely hidden on the sidelines away from much scrutiny. I have been directing the spotlight not so much on disability, which is the end result of a series of complex cultural, social, and political processes and obfuscations, as on the notion of normalcy that makes the idea of disability (as well as the ideas of race, class, and gender) possible.

Further, I have been trying to show how deeply tied to the normalized body are the assumptions we make about art, language, literature, and culture in general. In recent years, hundreds of texts have claimed to be rethinking the body; but the body they have been rethinking – female, black, queer – has rarely been rethought as disabled. Normalcy continues its hegemony even in progressive areas such as cultural studies – perhaps even more so in cultural studies since there the power and ability of ‘transgressive’ bodies tend to be romanticized for complex reasons. Disabled bodies are not permitted to participate in the erotics of power, in the power of the erotic, in economies of transgression. There has been virtually no liberatory rhetoric – outside of the disability rights movement – tied to prostheses, wheelchairs, colostomy bags, canes, or leg braces.

CONCLUSION

Of course, multiculturalism and the multicultural curriculum are by no means unproblematic spheres of activity. The general solution to problems raised around multiculturalism has been to include as many different groups as will fit into any curriculum, anthology, political party, or group. Although there are certainly differences of politics and aims among these multicultures, there is a general political, ideological, and social consensus that may be described, to the horror or glee of conservatives, as progressive.

So how, once the profoundly destructive marginalization of people with disabilities is recognized, may a new attention to the disabled body be included in the already crowded theater of multiculturalism? What can be done to accomplish this inclusion? Measures can be taken analogous to the familiar steps taken before with other groups: highlighting narratives, lyrics, and representations of disability in literature courses, teaching the politics of disability in courses that deal with social and political issues, making conscious efforts to include people with disabilities in media, and so on. Important as well would be the attempt to teach disability across the curriculum so that this subject does not remain ghettoized in special courses. This aspect of inclusion involves a reshaping of symbolic cultural productions and ideology.

In addition, legal measures can deal with issues of discrimination. In fact, in the United States, the centerpiece legislation concerning disability has already been passed. The Americans with Disabilities Act (ADA) of 1990 is a powerful piece of legislation that bans discrimination based on disability in the workplace and in public spaces. Its effect is that access has to be provided, accommodations have to be made, for people with disabilities. In a sense, the legal battle has been won (it is ironic that the law received strong support from conservatives as well as from liberals, partly because it was promoted by Senator Robert Dole, himself a person with disabilities). But remedies are not really so easily achieved. The ADA is only as effective as its enforcement. But there is no federal agency to enforce the provisions of this law. The situation remains today that the weight of the law can only be brought to bear through a lawsuit or the fear of a lawsuit. But lawsuits are costly

and time-consuming, and to bring them is beyond the means of most people with disabilities.⁸⁴ The somewhat predictable result is, according to the *New York Times* (23 October 1994), that after four years in effect, the ADA has 'not significantly increased' the number of people with disabilities entering the work force' (A:22). The *New York Times* cites a survey finding that only 31 percent of people with disabilities aged from sixteen to sixty-four were working part time or full time, down slightly from 33 percent in 1986 when the law was not in effect. In other words, discrimination against people with disabilities remains in full force.

The same is largely true in relation to the curriculum. The conventional attempts to demarginalize disability, to include disability in multicultural endeavors, might seem like logical steps to take in the direction of progressive political aims. But the reality is a bit different. It has been the experience of a number of disability activists that when attempts are made to include disability in university diversity requirements, for example, there may be considerable opposition. What is interesting is that the opposition often comes not from conservatives but from people of color, feminists, Marxists, or those in queer studies. Simi Linton, Susan Mello, and John O'Neill point out (1995) that 'the critics [of including disability studies in diversity requirements] are those who are the strongest proponents of diversifying the curriculum. What is even more disturbing is that the criticisms previously heard from proponents of the traditional canon are now being used against the inclusion of disability in curriculum transformation efforts.' Linton et al. cite specific comments made in this regard:

'scholarship on disability will "water down" the diversity requirement; its purpose is to increase self-esteem, or capitulate to interest group pressure; it's not valid or rigorous scholarship; it's parochial, and will further atomize the curriculum.' (*Radical Teacher* 47, 1995, 10)

Although we may envision an idealistic inclusion of people with disabilities into the multicultural family, in fact this family has some major dysfunctional aspects. What we discover when the

subject of inclusion comes up is not simply the uneasy tension that arises. For example, in discussions about diversity requirements at my university, a faculty member of color recently said that disability did not have to be listed specifically along with race, class, gender, and so on because the category of disability was inherently included in a proposed document under the heading of 'other asymmetries of power.' In other words, disability is seen, even by those who are themselves the object of discrimination, as marginal, othered, and not really a valid category of oppression.

This point was made more clearly recently when the New York City Board of Education voted in February 1995 to exclude disability and sexual preference from its multicultural curriculum. The board, representing many of New York's minorities and ethnicities, did not think that people with disabilities or gays and lesbians represented the board's vision of a multicultural society.⁸⁵ And, as this book was being written, New York State's 1995 budget slashed subsidies to people with disabilities from its list of entitlements as well as reducing funding for special education. Republican proposals for fiscal reform include measures that would cut Supplemental Security Income to a quarter of a million children with disabilities (*Nation*, 27 March 1995, 406).

What is being missed in these multicultural discussions is the way that race and gender connect with disability. The point is not that disability is a subcategory of discrimination involving relatively few people. With between 35 and 43 million Americans defined as having disabilities (Shapiro 1993), one is talking about a substantial percentage of the population. Rather than being marginal, the issues around disability are central to the construction of normalcy: disability is tied to a process that defines us all. Furthermore, disability is not, as is commonly thought, equally distributed throughout the population. People in the lower classes tend to be born with more disabilities and to acquire more disabilities than middle- and upper-class people, and people of color tend to make up a disproportionate part of the poor. Women make up a disproportionate share of those who develop disabilities in mid-life (Fine and Asch 1988, 245). Moreover, Third World countries

tend to have many more people with disabilities than do developed countries. Three-quarters of all disabled people now live in developing countries, and that proportion is expected to increase to four-fifths by the year 2000 (Nkinyangi and Mbundo 1982). The social oppression experienced by many Third World women ensures that they have the most difficult lot of all. As N. Begum, a woman of color with disabilities, puts it (1990, 6): 'women with disabilities are perennial outsiders; their oppression and exclusion [render] them one of the most powerless groups in society.'

The point is that disability is not an area that can be simply included into the issues of race, class, and gender – it is already there in complex and invisible ways. There is no race, class, or gender without hierarchical and operative theories of what is normal and what is abnormal. So, simply trying to include disabilities into a multicultural curriculum may be an action, if it is indeed taken, that fails to see how an ableist view of society may be so ingrained that it permeates the already established categories of race, class, and gender.⁸⁶

A disableist view of the cultural terrain may produce rather different readings of positions and events. While the race-class-gender grouping tends to coalesce around what might be termed 'progressive issues,' the disableist position may require realignments and rethinkings of some ideological 'truths.'

For example, and very tellingly, the position of people with disabilities on the issue of abortion and fetal screening is not seamlessly in accord with a liberal/progressive agenda. The idea of using amniocentesis to screen for birth defects and then aborting 'defective' fetuses is not a simple issue if one views it from a disabilities rights perspective. While most feminists would insist on a woman's right to abort a fetus that might be born deformed, mentally impaired, with Down syndrome, or some other defect, very few would agree with practices like those routinely performed in India in which parents screen for and then abort female fetuses. Indeed the general attitude of the American populace toward abortions when birth defects are detected is worth noting. In one

study, while only 40 percent of people believed it was acceptable to have an abortion if no more children were wanted, a full 70 percent felt abortion should be allowed if a birth defect was detected (Fine and Asch 1988, 304). Even the language involved in this choice – 'birth defect' or physical 'deformity' – must alert us that we are very much in a world of opinion, of ideology, rather than a cool, scientific world of fact. One person's defect is another person's strength. The indiscriminate grouping together of traits – whether Down syndrome, deafness, or limblessness – creates a general category that belies the difference of various 'defects.' If one does not speak of high-functioning or low-functioning people with mental impairments, one again loses the notion of a disabilities continuum. All too often, differences are automatically labeled 'defects' or 'deformities.'

The fact is that many people with disabilities, say for example with Down syndrome, do not wish they were never born. And not all parents of Down syndrome children wish they had never had their child. The area of prenatal screening becomes greyer if the genetic traits for deafness or blindness are detected *in utero*. Is it ethical to abort a fetus if the child will be born unable to hear or see? If some people would find such an abortion abhorrent, why would they approve of one involving leglessness, spina bifida, or Down syndrome?

This argument can be taken further: What if children of color were born randomly to women? And what if there was a test to determine whether a child would be white or of color? Would it be ethical to abort a child of color? Few would answer 'yes,' but many more would argue for the termination of pregnancies in which the child to be born might be born deaf, blind, genetically impaired, or physically or mentally disabled.

There is another side to this coin. With the growth of political consciousness among the Deaf, the possibility has been raised by genetically Deaf parents that it might be better to abort hearing fetuses. The rationale, absolutely the same one used by 'normal' parents who do not want to have 'deformed' children, is that a Deaf child would thrive best in a Deaf family, that a hearing

child would have trouble communicating with the parents, and that the family dynamic would be upset.

In addition, the gene for a kind of dwarfism has recently been isolated and the prenatal test for this gene has been made available to parents. The immediately obvious question is, should a 'normal' parent have an abortion if their child is to be born a dwarf? But other questions are posed. Parents who are themselves dwarfs have decided to use the test to make sure that their children will be dwarfs. The argument is that such parents often live in specially constructed dwellings built on a small scale which would be uncomfortable to 'normal'-sized people, and that remodeling could create a financial burden for the family. Furthermore, the oddity of a physically short family having to deal with, discipline, carry, and care for a rather large child might be disturbing to all concerned.

The position of progressive people with disabilities is that abortion is a woman's right and should not be tampered with. But at the same time complex ethical problems surround the use of prenatal screening to rule out the birth of a child with disabilities. As Fine and Asch put it (1988, 302):

Every woman has a right to make this decision in whatever way she needs, but the more information she has, the better her decision can be. Genetic counselors, physicians, and all others involved with assisting women during amniocentesis should gain and provide far more and very different information about life with disabilities than is customarily available.

This position straddles a difficult divide. While progressive people with disabilities do not wish to side with right-to-lifers, they may nevertheless recognize that the use of abortions for eugenic purposes is problematic. Of course, though most progressives would not like to admit it, eugenics is still practiced, only now it is done at the prenatal stage rather than at a later date. It is also worth noting that the most stringent aspects of eugenics usually came down to encouraging 'superior' parents to mate or discouraging those who

carried problematic traits from mating. What modern genetic testing has done is to move the discouragement or proscription of marriage (or of fertility) from the legislature to the genetic counselor's office. Nevertheless, the options remain the same: the limiting of fertility by birth control or sterilization. In effect, the offensive project of the Nazis to eliminate defectives is now practiced through the agency of modern medicine.

I want to make clear that I am not saying, nor are most progressive people with disabilities, that women should not have the right to abort fetuses identified as 'defective.' This choice is, as always, based on the individual woman's conscience, needs, and abilities. The problem is that since the general population is mostly 'ableist,' the choices made concerning abortion will necessarily be influenced in an ableist direction, by the prejudice that sees disabled people as living miserable lives, as objects of pity, as creatures whose birth it would have been a kindness to have prevented. This prejudice could, however, be overcome through the kind of changes in society at large that might foster an understanding of people with disabilities as whole, fully developed humans whose impairments place them within a continuum of ability of which everyone is part. The changes I am advocating involve not just goodwill or understanding, but definite government support so that the special problems of children and families with disabilities can be addressed. Moreover, as I argued earlier, disabilities appear or are highlighted in environments that produce disability. If our society were one in which difference could be more easily handled, impairments might not be seen as so 'devastating' as they are today.

Another area of uneasy positioning centers on euthanasia. The traditional liberal/progressive position is that we should have a law in place that permits euthanasia so that, for example, terminally ill people in comas should not have to suffer. Usually what is recommended is that people in comas should be detached from support systems and allowed to die naturally. In other cases, it is said, people who are severely impaired or dying should have the right to a physician-assisted suicide. This position is challenged by some people with disabilities. They feel that simply because a person is

in a coma, his or her life should not be terminated. Many people with disabilities, who themselves have experienced the unkind hand of institutional medicine, doubt the ethical right or even judgment of doctors and families to decide who should die. They identify with the otherness of the coma patient, and see the attempt to detach support systems as part of a similar system that might in fact like to cut financial support from disabled children or to rid the world of anyone who has a serious disability. They link such actions to those in which mentally impaired people were sterilized or unwillingly made the subjects of medical experiments. Furthermore, the detaching of support systems may itself cause pain through suffocation and starvation. (One might want to recall that it was official medical policy until fairly recently to cause babies born with severe spina bifida or other birth defects to die by withholding infant formula from them in the first days of life.) Thus many people with disabilities believe that decisions about life and death should not be made by 'normal' people. Rather, a person with disabilities should act as guardian for the patient facing court-decided euthanasia.

In the case of people requesting their own death, as have the patients of, most notably, Dr Jack Kevorkian, some of them may be reacting to the natural depression that comes from the loss of mobility, limbs, sight, hearing, and other bodily functions. But this depression, and the feeling that the quality of life is low, is partially the product of an ableist society that places a great premium on being 'normal'. If such people had access to the kind of support systems that disabilities activists draw upon, they might not feel the need to kill themselves, to carry out society's death warrant against difference.

Obviously, the argument about the relation between disability and euthanasia is a great deal more complicated than the position I am quickly sketching here. And let me emphasize, I am not saying that euthanasia is a bad thing, but rather that until we understand the social and political implications of disability, we cannot always make rational decisions about the right to die. The point of laying out these arguments is not to condemn abortion or euthanasia, but

to show the nature of the uneasy positions that arise when one takes into account a disabilities perspective. I also want to make the point that the simple inclusion of disabilities studies into a multi-cultural curriculum or the inclusion of a disabilities perspective into political agendas amounts to more than adding some demands to a list.

The difficulties abound. Take this example. At the 1995 Modern Language Association convention a group of Deaf scholars, who attended specifically to be part of a panel on 'deafness and textuality' as well as to attend an organizational meeting of disability studies scholars, found that the interpreters secured to translate were unable to understand academic discourse. These interpreters had been used routinely to assist deaf people appearing in court trials, and at social service hearings, weddings and funerals. Faced with discussions about discursivity, clitoral readings, and cyborgs, they literally threw up their hands in frustration. The Deaf scholars were thus unable to follow the presentations. If PhD-level interpreters, such as are found at Gallaudet University, had been available, this situation would not have occurred. But the larger point is that very few professional organizations are prepared to accommodate members with impairments. Few teachers in universities think about providing visual or aural supports for blind or deaf students. The environment is not open to the possibility of disability, or, put another way, far too often the environment creates the possibility for disability. Fairly sophisticated means exist to facilitate communication between hearing and deaf people, including real-time captioning, sign language interpretation, and pre-recorded speeches; there is also the very simple means of the distribution of papers in advance. The fact that most of these possibilities are not made available on a regular basis tells much about the priorities of academics and their organizations.

Another area of uneasy positioning is found in the judicial system. This system is set up with the expectation that the people processed through it will be in the possession of some linguistic ability – whether that be Spanish, American Sign Language, or

Korean. But when this 'normal' expectation is thwarted, the judicial system grinds to a halt. Throughout the USA hundreds of people, most of whom are poor and members of minorities, are languishing in jails and mental hospitals, their rights to a speedy trial, due process, and justice abandoned. These people have two things in common – they are deaf and they cannot sign or speak.

The assumption has been made throughout this book that the Deaf constitute a linguistic minority. But that argument can only be true if the deaf person has learned sign language. But some deaf people have never learned to sign. Take the following case:

José Flores, aged twenty-nine, has been in jail in Passaic County, New Jersey, since June 1992 awaiting trial on charges of kidnapping, burglary, and sexual assault of minors. Flores, profoundly deaf, has not received a speedy trial because he cannot read, write, or use sign language. Raised in a remote rural area of Puerto Rico, Flores had neither access to appropriate education or a Deaf community, both necessities to foster language in deaf children. Like the Wild Child of Aveyron, Kaspar Hauser, or Genie (in Russ Rymer's book of the same name), such people deprived of language until after puberty, find it very difficult to acquire language as adults. Because Flores could not communicate, his lawyer claimed that his client could not aid in his own defense and therefore should not stand trial. Although Flores has been evaluated by experts who are confident that he cannot understand concepts like 'guilt,' 'innocence,' 'trial,' and 'jury,' the prosecutors' attitude was that he would have to stand trial.

In New Jersey, as in most states, the only grounds for waiving a trial is 'mental incompetence,' that is, either insanity or mental impairment. This catch-22 results in the ridiculous consequence that if Flores were found to be incompetent, he would have to be confined in a mental hospital until he somehow miraculously learned American Sign Language on his own. On the other hand, if he were found competent to be tried, he would sit in the defendant's chair and watch a meaningless blur of activity, that to him would signify nothing.

The specter of the mental hospital is a very real threat to

inmates without sign language. Junius Wilson serves as a *memento mori* of what can happen when deaf people with limited language skills are treated as mentally incompetent. Wilson, at the age of ninety-three, was 'discovered' in 1993 in Cherry Valley mental hospital in North Carolina, where he had been 'lost' since 1925. In that year he had been arrested for attempted rape, but because he was deemed mentally incompetent to stand trial he was remanded to a state mental hospital, where he was eventually castrated as a sex offender, although he had never been tried. John Wasson, a social worker, discovered Wilson and made arrangements for his release. Four other similarly warehoused deaf people were 'found' in the North Carolina system as a result of a lawsuit brought by Wasson.

It is probably a safe estimate to say that there must be hundreds of such people scattered throughout the mental institutions of the United States; others are trapped within the penal system. No state, so far as I can discern, has a penal code that includes the concept of linguistic incompetence. So each case must be dealt with under the mental incompetence statute on an *ad hoc* basis, with each official cobbling together some solution. In addition, there currently exist no facilities in the United States established to teach deaf inmates sign language, even though the Americans with Disabilities Act specifies that disabled people must be provided with communication assistance to stand trial.

The fact that people without formal language end up in the prison system really should come as no surprise. After all, law is really a highly elaborated form of language. The broader question then is how are people without language making it to adulthood without education? Most of the cases of this kind concern poor rural or inner-city people who either never had access to or who were allowed to drop out of an educational system. These silent inmates are the products of an amazing failure of the educational and social service systems. It is appalling that people like José Flores could grow up in a world where no one taught them language. But it is even more appalling that these men should end up being punished for a situation they hardly brought about.

I pointed out these incongruities in an article, 'Prisoners of Silence,' in the *Nation* two years ago, and since that time no action has been taken to address this problem. The uneasy position is not so quickly made easy because the judicial system cannot allow for the idea that it may not be possible to try a whole category of people fairly, and because the Deaf community has largely shied away from its nonlinguistic brothers and sisters, since they represent an otherness to the notion of Deaf people as a linguistic minority.

Perhaps it is fitting to end with a meditation on this man, José Flores, in jail. He is incarcerated for being a person with a disability. He cannot hear, yet he is not Deaf. He is a Latino, a poor person, one of the most marginalized people in the world. His very existence, his lack of language, leads him to arrest. He is arrested for not being normal, for not having a language. Yet he was never taught to sign, a skill that would have turned his disability into merely an impairment. His lack of normality makes it impossible for him to be processed through the judicial system. Had he just been either poor and Latino, he would have fit the known categories and been tried and, given prevailing attitudes, convicted. But José Flores's impairment means that he is disabled, so profoundly disabled that he can never be released from jail, never be tried. Like part of a jigsaw puzzle that has been lost, he fits into no system. He is guilty of disability, and under a system that demands normality he will remain in limbo. In a recent discussion with his attorney, I found out that he will probably be committed to prison under a civil action as a danger to himself and others and placed in jail until such time as he is no longer a danger. Given the fact that he will never be taught sign language, that means he will be in jail for the rest of his life.

Flores is only one person in a world ruled by the norm. The hegemony of normalcy is, like other hegemonic practices, so effective because of its invisibility. Normalcy is the degree zero of modern existence. Only when the veil is torn from the bland face of the average, only when the hidden political and social injuries are revealed behind the mask of benevolence, only when the

hazardous environment designed to be the comfort zone of the normal is shown with all its pitfalls and traps that create disability – only then will we begin to face and feel each other in all the rich variety and difference of our bodies, our minds, and our outlooks.