

CHAPTER 1

Nothing About Us Without Us

I first heard the expression “Nothing About Us Without Us” in South Africa in 1993. Michael Masutha and William Rowland, two leaders of Disabled People South Africa, separately invoked the slogan, which they had heard used by someone from Eastern Europe at an international disability rights conference. The slogan’s power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice.

“Nothing About Us Without Us” resonates with the philosophy and history of the disability rights movement (DRM), a movement that has embarked on a belated mission parallel to other liberation movements. As Ed Roberts, one of the leading figures of the international DRM, has said, “If we have learned one thing from the civil rights movement in the U.S., it’s that when others speak for you, you lose” (Driedger 1989:28). In this sense, “Our Bodies, Ourselves” and “Power to the People” can be recognized as precedents for “Nothing About Us Without Us.” The DRM’s demand for control is the essential theme that runs through all its work, regardless of political-economic or cultural differences. Control has universal appeal for DRM activists because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalization. This dependency, saturated with paternalism, begins with the onset of disability and continues until death. The condition of dependency is presently typical for hundreds of millions of people throughout the world.

Only in the past twenty-five years has this condition begun to change. Although little noticed and affecting only a small percentage of people

with disabilities, this transformation is profound. For the first time in recorded human history politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. This is a militant, revelational claim aptly capsulized in “Nothing About Us Without Us.”

The Dialectics of Disability Oppression and Empowerment

Very little has been written on disability oppression and even less on the resistance to it. Furthermore, while there is a growing body of literature on disability in Europe and the United States, little information is available about disability in other parts of the world. What we know about disability—a significant part of the human condition—and hence about the human condition itself is thus fundamentally incomplete. I have undertaken such a discourse on disability. It is part descriptive, part conversational, part theoretical, and wholly argumentative. My thesis synthesizes theories and opinions about oppression and exploitation, power and ideology, resistance and empowerment. In the end, this book is as much a polemic, filtered by many voices and personal experiences, as anything else.

Chapters 2 through 6 explore the outrageous conditions in which hundreds of millions of people with disabilities live the world over—a reality that, unfortunately, cannot be contested. Beginning with chapter 7 I describe how some people with disabilities have organized to resist these conditions. Some might think any attempt to establish a comprehensive theory of disability oppression is preposterous, given the thousands of cultures and the political-economic disparities across the globe. These differences present many problems, but they are not, I believe, irreconcilable. One of the most important findings from interviews with more than fifty disability rights activists in ten countries is the similarity of lived disability experiences across cultures and political-economic zones. It is also clear that in the most disparate places the disability rights movement approaches and resists the particularities of the disability experience in very similar ways. Within this resistance lies the potential, however speculative and problematic, for the elimination of (disability) oppression. Simply put, this book is about the dialectics of

the disability experience: oppression and its opposites, resistance and empowerment.

My mission is threefold. First, I wish to familiarize readers with an epistemological break with previous thinking about disability—a break that has affected millions of people with and without disabilities and that will even more widely influence people in the decades to come. Second, I intend to suggest ways of thinking about relationships and conditions of oppression and resistance that have rarely been applied to disability. In doing so, I attempt to answer, among other questions, why so many people acquiesce to oppression and why some people not only individually resist these conditions but also actively organize to change them. Third, I want to provide a political, economic, and cultural context to better *understand and support* an emerging international disability rights consciousness and movement. The point is not that every person with a disability experiences the same kind of oppression and identically resists it but rather that people with disabilities are oppressed and resist this oppression individually and collectively in ways that are generalizable.

My motivation is simple. I have seen and felt how people with disabilities are treated. In the most obvious and the subtlest ways, these conditions cry out for attention and are, in themselves, a fundamental critique of the existing world order. This book is not a plea for pity. We have had enough of that. It is also not an expression of hope for a helping hand. Hope is useful only when it is not illusory, and help is useful only when it leads to empowerment. *Nothing About Us Without Us* both advocates an epistemological break with old thinking about disability and demands an end to the cycles of dependency into which hundreds of millions of people with disabilities are forced.

Methodology and Other Considerations

This book is founded principally on the everyday life of people with disabilities. It derives first and foremost from my own particular experiences as a person with a disability and as an activist in the disability rights movement in the United States. Second, it comes out of others' experiences described in conversations, discussions, and interviews or excerpted from the existing literature. The "evidence" that follows is on one level self-reflection. We might call this method of

observation “human sensuous practice” or “lessons from life.” I would argue that these experiences so closely coincide that they can be synthesized into a general, albeit partial, description of everyday life for people with disabilities.

Most of these lessons from life come from the Third World. To consider disability oppression as a generalized phenomenon, attention must be directed to those parts of the world where 80 percent of all people (with disabilities) live. To do this, I have used the analysis and personal stories of disability rights activists from these regions, along with those of activists and political theorists from other parts of the world. The political-economic and sociocultural dimensions of disability oppression, as well as peoples’ resistance and organization, are framed by these narratives.

Concerns and Limitations

It should be emphasized from the outset that this book rests on what Eric Hobsbawm called “curiously uneven foundations” in the preface to his book *The Age of Extremes*. Although I believe the everyday lives of people with different disabilities in different cultures have many common qualities and characteristics, I also know there are serious limitations my general exposition has to acknowledge. Many important geopolitical and cultural areas of the world are not covered in this study, among them, most prominently, northern Asia (Japan, Korea, the People’s Republic of China [PRC]) and the Middle East. My understanding of Europe, especially eastern and southern Europe, is also limited. Some aspects of Chinese culture are picked up in interviews with the Chinese DRM leaders in Hong Kong (and in secondary sources), but the reach of the PRC’s political, economic, and social influences is not shown. Cultures of the Middle East are not accounted for, although Moslem views and attitudes toward disability are partially covered in examining Indonesia and consulting secondary sources. I cannot say if Indonesian practices resemble those of the Arab Middle East.

In addition, many types of disabilities are not sufficiently represented. The absence of people with mental and cognitive disabilities is especially notable because these disabilities combine to make up the largest disability “category.” Although I have incorporated some material from U.S. sources, it is sketchy. Still, I received almost universal confirmation from disability rights activists that people with mental illness are the most

discriminated against and the most isolated in their respective countries. This is a significant finding.

Also meriting fuller representation are people who are deaf. Their isolation, especially in the Third World, parallels that of individuals with mental disabilities. The scarcity of sign language interpreters exacerbates this condition and also compounds the difficulty of identifying and interviewing even those who are politically active.

Finally, I have set the topic of AIDS aside to narrow the scope of this project. To be sure, in many countries and regions—indeed throughout Africa, Brazil, and possibly Thailand as well—one can reasonably argue that AIDS is the most important disability issue. There is no doubt that the ideological and social experiences of people with AIDS closely parallel those of people with other disabilities, especially disabilities closely linked with “illness”—cancer, mental illness, diabetes, and so on. Susan Sontag’s two brilliant expositions on the “feelings” embodied in and the imagery associated with various disabilities, *Illness as Metaphor* and *AIDS and Its Metaphors*, are applicable. General economic and specific sociocultural similarities do, however, unify the experience of disability. We realize this almost intuitively. Besides the ubiquitous conditions of poverty and degradation that surround it, we know that when a person becomes disabled, she or he immediately becomes “less”—what Wilhelm Reich refers to as “bio-energetic shrinking.” This is the phenomenon Sontag explores in *Illness as Metaphor* and is the thought most associated with disability per se. A person goes to a physician to get a routine physical exam. After the procedure, the physician, noticeably different in demeanor, announces that the “patient” has cancer. The person immediately feels sick (sometimes referred to as a sinking feeling) and shrinks. *They become less*, although there is nothing different from moments before, when the person felt healthy and full. The psychosocial manifestation of this phenomenon unifies all disabilities, from cancer and AIDS to spinal cord injury and amputation to deafness and blindness.

Terminology, Definitions, and Statistics

Now we come to questions of terminology and definition. The first term requiring definition is “disability.” For my purposes, disability is based on social and functional criteria. This means, first, that

disability is not a medical category but a social one. Disability is socially constructed. For example, if a particular culture treats a person as having a disability, the person has one. Second, the category "disability" includes people with socially defined functional limitations. For instance, deaf people are considered disabled although many deaf individuals insist they do not have a disability. People do not get to choose whether they have disabilities. Most political activists would define disability as a condition imposed on individuals by society. This definition is mirrored in the Americans with Disabilities Act of 1990: "The term 'disability' means with respect to an individual (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (b) a record of such an impairment; (c) being regarded as having such an impairment."

Estimates of the numbers of disabled persons based on this definition (broadly considered) have been available for twenty years and have not changed much. Writing in *Rehabilitation International* in 1981, John H. Noble, Jr., stated, "In 1975 people throughout the world suffering [*sic*] all types and degrees of disability numbered an estimated 490 million (12.3 percent of the world population); by the year 2000, their number will reach an estimated 846 million (13 percent). Whereas in 1975 more than three-quarters of this population lived in developing countries, by the year 2000 more than four-fifths of all disabled people will live in these countries." Ten years later, the U.S. General Accounting Office quoted the United Nations as estimating that 80 percent of the world's 500 million persons with disabilities live in the "developing countries" (the UN's term). In the 1995 UNESCO report, "Overcoming Obstacles to the Integration of Disabled People," England's Disability Awareness in Action breaks this number out further: 300 million people with disabilities live in Asia (70 million children); 50 million in Africa; and 34 million in Latin America.

The second term needing clarification is "oppression." Oppression occurs when individuals are *systematically* subjected to political, economic, cultural, or social degradation because they belong to a social group. Oppression of people results from structures of domination and subordination and, correspondingly, ideologies of superiority and inferiority. In *Justice and the Politics of Difference*, Iris Young presents five "faces" of oppression: exploitation, oppression that takes place in the process of labor; marginalization, the inability or unwillingness of the economic system to incorporate a group of people in its political, economic, and cultural life; powerlessness, a group's lack of power or au-

thority; cultural imperialism, the demeaning of a group by the dominant culture's values; and violence, random or organized attacks on a group (1990:48–65). These categories, if interpreted correctly, are helpful in defining oppression.

Most important, oppression, like all social processes, must be understood as experienced in and conditioned by real life. Political, economic, and cultural contexts determine the similarities and differences in the experience of people with disabilities.

Two other terms that require definition or at least an explanation are “underdeveloped countries” and “Third World.” These terms are intertwined, and many people do not much like them. Analogous terms or phrases include “transitional societies,” “developing countries,” “undeveloped countries,” “the periphery,” and “newly industrialized countries.” All of these mean different things to different people. I prefer “underdeveloped” because it implies the process colonies went through as colonizers expropriated and exploited the cheap labor and resources available there. These countries and regions were *underdeveloped*. In my use, “underdevelopment” denotes the expropriation and despoliation of huge chunks of what has come to be known as the Third World. Some prefer the term “maldevelopment.” Both locate the root causes of the political-economic circumstances of these regions in colonialism and imperialism without casting aspersions on the region's people, although both recognize the collusion of indigenous elites. This is my intent as well. Many prefer to use the term “developing countries.” The problem, of course, is that most, if not all, are not developing. They are, and have long been, stagnating in crisis. It is important to remember that “underdevelopment” is a political-economic condition and does not imply anything about history and culture. Economically poor countries have exceptionally rich cultures and histories.

And finally, I use the terms “Third World” and “periphery” to position Latin America, Africa, and Asia and parts of the Middle East in relation to the first (the United States) and second worlds (Japan and Europe) in the context of political economy. In the past, some people divided the first and second worlds between the capitalist and socialist worlds, but that division is now unnecessary. Significant political-economic divisions do, however, separate the United States from the rest of the world because of its military superiority. Some people have suggested the term “Fourth World” for those nations whose national economies generate less than \$1,000 per capita. This is splitting hairs. All nations of the Third World are poor whether they are at the low or

high end of the economic range (most often cited as \$200 to \$4,000 per capita). I use the terms “Third World” and “periphery” interchangeably because both imply an economic center and an economic periphery.

On Theory

Finally, a comment on theoretical work itself. However well formulated, I believe that any theory of oppression and responses to it can only provide a partial explanation. There are, of course, theoretical breakthroughs. And it is my hope to contribute a few bricks to the construction of a comprehensive theory. It cannot be otherwise. Disability oppression, like all kinds of oppression, is complex and multi-leveled. Disability oppression is itself most often a partial experience of oppression. People with disabilities experience other crucial kinds of oppression based on class, race, and gender. These are undoubtedly profound influences on the particularities of the lived experiences of people with disabilities, regardless of place. A literature has begun in some of these areas, as I try to note in passing. Acknowledging these severe limitations, I have pressed on. For it seems to me that while we can debate the extent, if any, to which rich white men with disabilities are oppressed, the more critical questions involve how the hundreds of millions of poor people with disabilities are surviving and what it will take for them to have lives of dignity and independence.

The Lived Experiences of Disability and the Transformation of Consciousness

As noted earlier, a remarkable and unprecedented paradigm shift has recently occurred which represents a historic break with the traditional perception of disability as a sick, abnormal, and pathetic condition. This shift poses a fundamental challenge to the ideological oppression of people with disabilities. For it sees disability as normal, not inferior, and demands self-determination over the resources people with disabilities need. This new perspective unfolds out of a changing world in which a relatively few political activists with disabilities are challenging the old ways of thinking about and treating disability. The sto-

ries of these people provide compelling evidence for the basis and direction of this paradigm shift. Because the lived experiences of people with disabilities are critical to my success in explaining this paradigm shift and in developing a broad thesis of oppression and resistance, I will present throughout this book short excerpts from the extensive interviews I conducted over the course of a decade. The excerpts below condense crucial influences in the life of two activists, Joshua Malinga, former chairperson of Disabled Peoples' International and the general secretary of the Southern Africa Federation of the Disabled, and Rosangela Berman Bieler, president of South America's first center for independent living in Rio de Janeiro and a leading activist in Brazil's disability rights movement since 1980. They are included here to indicate the nature of the interviews themselves and to begin the juxtaposition of lived oppression versus the transformation of consciousness into active resistance.

Jim Charlton (J.C.): "I am interested in the relation between disability oppression and the political consciousness of disability rights activists. Specifically, I am interested in your personal history and why it is that you have become a political activist."

Joshua Malinga: "I was born in 1944 about 100 kilometers from Bulawayo. As you know, we in Zimbabwe have two homes, in our village and also in the city where we must go to find work. My father was a village chief and had six wives and thirty-eight children. I was the only one to get polio. . . . From early on, all my brothers and sisters went off to school and I had to stay home to scare away the animals from our house and do errands. . . . Everything I am now, it's all because of accidents of fortune. In 1956, the first accident of fortune occurred. One of my brothers broke his arm and found himself in the hospital. There, my brother met this man, Jauros Jiri, who was developing a social service network which now is a very big charity agency of twenty-five to thirty institutions. After this discussion, my brother told Jauros Jiri about me, so Jauros Jiri organized for me to come to the institution. Although my parents didn't want me to go, there was obviously nothing at home for me. I was very young (13) but had never been to school, so all this was very new. Jauros Jiri began to train me in leathercraft and I had some classes for reading and math. Their only idea for me was to be a cobbler. In 1959, there was another accident of fortune for me. In that year, Jauros Jiri received money from the government to bring in a trained teacher. This teacher noticed that education was easy for me, and he encouraged me to go to school. Although the people at the institution didn't want me to go because this teacher within the institution was the one encouraging me, it was hard for them to stop me. . . . Even from day one,

I had an inborn attitude not to accept the attitudes at the institution. These ideas were very bad. For example, disabled people were told when to eat, when to sleep, that they couldn't make love, it was banned. . . . Especially in the period 1965–1967, I had a growing consciousness about disability.

By the mid-1970s I and a few others wanted to reject all these ideas and start our own organization. By 1965, I began organizing disabled people because I knew things were not right. First, we called ourselves Inmates Representative Council and then Trainees Representatives Council. Later, we became Council for the Welfare of the Disabled and then National Council for the Welfare of the Disabled. . . . In fact, I was the first Jauros Jiri person to go through primary and secondary school. Then I went to technical college and was probably the first black to go to technical college in Bulawayo. . . . When I left college I could not get a job except at the Jauros Jiri institution. My jobs escalated there from accountant to bookkeeper to administrator of the biggest Jauros Jiri project. When I left in 1980, I was the CEO of Jauros Jiri. . . . At that time, another accident of fortune occurred.

The year 1980 was an important one because at this time Zimbabwe became independent. At this time a fellow from the international development foundation OXFAM visited the Jauros Jiri institution to see about funding their programs. In the meeting, I could tell he didn't want to fund a charity. I think he was mostly interested in development, not services. So anyway, during the meeting I slipped him a note asking could he meet me after the meeting and he said okay. So when I met him, I told him that I detected he had some reservations about the Jauros Jiri institution, and I told him about a disability group I was involved with, that we were starting to organize but had no funds. That we had to take paper and other materials where we could and that we needed an office and secretary and some other things. I told him OXFAM should fund us because we were interested in civil rights and changing the world. He said okay again. Then I said that I knew about this upcoming international conference in Canada and could he find funds for me to go. This did happen, and I went to Winnipeg to attend the Rehabilitation International [RI] Conference. . . .

As you know, 1981 was the International Year of Disabled Persons, a year dedicated to full participation of disabled persons. But RI didn't really practice this. At the conference, there were 5,000 delegates but only 200 disabled persons. So the disabled delegates got together and demanded that the executive committee be 50 percent people with disabilities. This was overwhelmingly rejected, so there was a split and the 200 disabled persons and some others formed Disabled Peoples' International, of which I have held various posts. I am the current chairperson until 1994. When I returned I was a changed person. When I left I was very passive, but when I returned I was very radical. Immediately when I returned from Winnipeg in 1981 we changed our name from National Council for the Welfare of the Disabled to the National Council of Disabled Persons Zimbabwe. At that time, we began to recognize that disability was about human rights, about social

change, about organizing ourselves. We did not want to emphasize welfare but organization.”

Rosangela Berman Bieler: “I was in a car accident in 1976 when I was 19 years old. I was at the university studying journalism. As a quadriplegic, I was involved in rehabilitation for over a year. I became aware of disability rights because I had very good peer counselors who helped me avoid feeling pity for myself and to feel part of a group. We went to bars and movies together. In those years, it was very unusual to see someone using a wheelchair in the streets of Rio, but five or six people together using wheelchairs was shocking, it was a revolution. The peer counseling was very, very important to me. . . . Before my accident, I was a very active teenager. I played the guitar, went to bars, came home early in the morning, had lots of friends. My accident was a big change for me initially until I met those friends I was talking about. The university was very inaccessible so my family helped build ramps into the buildings. . . . I had my own consciousness about disability, but it was also part of the larger political movement of the country. . . . I started organizing at the rehabilitation center because I wanted to travel, do sports, and other social things. In 1979, we had our first meeting to discuss building a national organization and talk about what we would do for 1980. In those years, we had slightly more freedom to organize so we had to take advantage of it. There were many things going on at this time, especially among students. For example, I was involved in political activities as a representative of an art school in the student movement in 1982. All of my political consciousness was through the student movement. Each member of the student movement had to develop his or her own area. Mine was disability. In 1982 we had our first elections in the country. I was active in the Workers Party [PT] as a representative of students and painters. We were very organized and militant.”

J.C.: “How do attitudes and myths about disability get expressed in your country? I’m interested in how the political and cultural aspects of everyday life are connected. What are the prevailing attitudes today toward disability? Have you seen changes in attitudes over time? And are there differences between rural and urban areas?”

Joshua Malinga: “Now in Africa we have very backward ideas about disability. This is especially connected to witchcraft in the rural areas and to life as an oppressed people historically. . . . To be disabled in Zimbabwe, people think you are not a full human being. Our activities are not considered normal, you aren’t expected to play an adult role. We have a long way to go, although small changes can be seen. We began to target attitudes in 1981 because attitudes were key. To this end, we knew that we had to mobilize and organize people with disabilities. . . . Negative attitudes brought about charities, not movements, and when you talk about changing attitudes you don’t limit yourself to legislation; it can be an instrument but only that.”

Rosângela Berman Bieler: “The main characteristics of Brazilian culture are that it is paternalistic and it has a history of Portuguese colonialism. Brazil has incredible contrasts which have to be taken into account when analyzing the question of how paternalism works. For example, the south of Brazil was colonized by the Germans. It’s like another country. Paternalism influences the way people think about disability. The church has an important role in promoting it as well as the military dictatorship. Much of our situation in Brazil, the social problems, the poverty, and the apathy, is because of the military dictatorship. The dictatorship had a powerful role in the ideas of my generation and that of my father. This shows up in the lack of political leadership in Brazil. Very few people wanted to become involved in politics for about fifteen years. People were scared, and this limited the number of people with political experience. Also, many of the really good political leaders were killed or went into exile. . . . However, the problems of paternalism existed before the dictatorship. In spite of European colonization, we have more identification with the Americans than with the Europeans. So our backward attitudes are much more tied to the Latin American stereotypes. Paternalism has also affected us in the sense that disabled people do not have a habit of self-organization. . . . I would say that Rio is very liberated and open-minded. This made it easier for me as a teenager and as a young adult dealing with my disability. Everyone talks about sex and sexuality. I think it is easier for us who have disabilities in Brazil to be able to discuss and figure these kinds of things out. In fact, I think more women with disabilities are marrying in Brazil than in other countries I have visited.”

J.C.: “What kinds of organizations are there of people with disabilities, what kinds of political philosophies and tactics do they have, and what has been your personal experience with them?”

Rosângela Berman Bieler: “We began organizing at the rehab center. We put out newsletters such as *Camino* [trend, path] and *Clandestino* [clandestine]. The latter was a play on words because we called our disability group The Clan. The political meetings in those years were fantastic for me because I was involved from the beginning. I was in leadership at national and international levels. We also worked on a newsletter, *Etapa*, for our national organization. This was an information newsletter mostly. We had 12,000 people on our subscription list. We got money from advertisers. Everybody worked for free. . . . During this time, many people with disabilities who were active had a real catharsis. We developed a politics and a form of organization that had never existed in Brazil before. By 1983, there was a strong national organization. In the beginning, I was very radical. That has changed somewhat. I was radical in the sense that I did not want to cooperate with any institution that dealt with disability. I also believed only people with disabilities should vote at assemblies and meetings. Now I believe leadership should be disabled, but there is a role for the able-bodied.

We need a broader unity. . . . Now I represent Rehabilitation International for Latin America. Its history was to speak for the disabled. Really RI speaks for professionals, but they must adapt to the new conditions they are trying to influence. They have even elected a paraplegic as president who also represents New Zealand. An irony for me in this regard is that the person who preceded me as vice president for Latin America in RI was the same doctor who kicked me and my friends out of the rehabilitation center for organizing. . . . I have changed my attitudes about the movement in many regards recently. That is why I started the CIL [center for independent living] in Rio. I gave twelve years of my life to the national movement. Personal competition among disability leaders was very discouraging. I know this happened in many countries. I just became disgusted with the in-fighting. *Etapá* was very important for many people. For the first time, that newsletter brought information about disability to the rural areas. We worked on *Etapá* for eight years. . . . I feel fortunate that through my disability work I was able to visit many countries and get to know many disability rights activists. I went to Maryland where I visited CILs. I had never heard of independent living before my trip to Maryland. When other people decided to stop working on *Etapá*, I could no longer work in that movement so I, along with a few other people, formed the Rio CIL.”

J.C.: “Can you talk about what’s going on in the region? Where is disability rights strongest?”

Joshua Malinga: “When I came back from Winnipeg I was assigned to organize the region of Africa. We Zimbabweans have impacted the organizations of disabled people throughout southern Africa. I believe in South Africa they have as strong a movement as we have in Zimbabwe. Probably because of the struggle against apartheid the disabled community is more politicized, so it has progressed well. The newest is in Angola. It was the hardest to organize because of the destabilization there by South Africa and the American government. Of course, 90 percent of our problems in the region are directly related to the role of the United States. In Mozambique, an organization was formed three years ago which is very organized, although it was difficult as well, similar to Angola. I think the ruling party played a role. We always emphasize the independent role of disabled organizations and our movement from the government. This is the problem we are presently experiencing in Namibia, as in Mozambique, where most of the disabled people we are working with are ex-combatants who are very close to or in the ruling party. So our task is to break that relationship up. We do this because we must be independent so we can criticize anyone, even the government. The reason we stress the separate role of our organizations is that we must advocate for ourselves, always. We should not rely on political parties to liberate ourselves. Our progress in all the countries is uneven. . . . We have many barriers, but the most important is the level of

development in the region. But we have no proof about social systems. All governments treat disabled people badly. They all see us as a burden. All governments, whether socialist or capitalist, have separated us from the rest of society. By the end of the day, people are judged by their own activity. Until we are businessmen, politicians, community leaders, people at all levels of society, we will be marginalized and segregated.”

The sea change we are witnessing in the disabled community is embodied in and epitomized by disability rights activists like Joshua Malinga and Rosangela Berman Bieler. Whereas people with disabilities have always struggled to survive, many are now struggling to change their world as well. The replacement of the false consciousness of self-pity and helplessness with the raised consciousness of dignity, anger, and empowerment has meaningfully affected the way in which many people with disabilities relate personally and politically to society. The personal histories of each of the people I interviewed, in different ways and for different reasons, show raised consciousness as the real appreciation of one’s self, one’s own image, values, and interests, and not the manufactured images and projected values and interests of the dominant culture. In later chapters, I further track the development from raised consciousness to empowered consciousness, a kind of consciousness that involves a commitment on the part of the individual to act on his or her raised consciousness. There are many people with disabilities who have raised consciousness, but there are few who are politically active, who are committed to empowering others. These people are organizers, agitators, and educators who make up the disability rights movement.

Nothing About Us Without Us: The Politics and Organization of Empowerment

The disability rights movement is not unlike other new and important social movements demanding self-representation and control over the resources needed to live a decent life. Two years after hearing the slogan “Nothing About Us Without Us” in South Africa, I noticed on the front page of the Mexico City daily *La Jornada* a picture of thousands of landless peasants marching under the banner “Nunca Mas Sin Nosotros” (Never Again Without Us) (March 19, 1995). At that moment I began using *Nothing About Us Without Us* as my working title.

People with disabilities have formed a wide array of organizations to respond to political and personal needs. Each organization has its own motivation and agenda, lines of communication and leadership, and expectations and scope. These range from small political action and self-help groups, social clubs, and income-generating initiatives to large national and regional federations or coalitions of disability-related groups. These organizations, given their specific circumstances and histories, have developed strategies and patterns of organization that in a very short time have advanced the overall progress of their communities. They have promoted an increased identification with others who have disabilities and an interest in what many have come to call “disability culture.” The slogan “Nothing About Us Without Us” captures the essence of these developments for a number of reasons. First, to understand anything about people with disabilities or the disability rights movement, one must recognize their individual and collective necessities. “Nothing About Us Without Us” forces people to think about the broad implications of “nothing” in various political-economic and cultural contexts. Second, a growing number of people with disabilities have developed a consciousness that transforms the notion and concept of disability from a medical condition to a political and social condition. “Nothing About Us Without Us” requires people with disabilities to recognize their need to control and take responsibility for their own lives. It also forces political-economic and cultural systems to incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in making decisions that affect their lives. Third, while the number of people affected by this epistemological breakthrough is relatively small, a movement has emerged. The disability rights movement has developed its own ideology and politics. It is a liberation movement that is confronting the realpolitik of the world at large. The demand “Nothing About Us Without Us” is a demand for self-determination and a necessary precedent to liberation. Fourth, the philosophy and organization that the international DRM embraces includes independence and integration, empowerment and human rights, and self-help and self-determination. The demand “Nothing About Us Without Us” affirms the essence of these principles. Finally, the DRM is one of many emerging movements in which new attitudes and worldviews are being created. Through its struggle comes a vision that requires a fundamental reordering of priorities and resources. “Nothing About Us Without Us” suggests such a sea change in the way disability oppression is conceived and resisted.