

Introduction

Disability and suffering have been paired throughout history and remain inseparable companions to this day (Stiker 1999). Suffering always defines a disabled person as a type: one who suffers an affliction, who suffers punishment for some wrongdoing; one who is forced to bear the weight of divine intervention, who is barred from the center of society and relegated to its margins. Contemporary culture, particularly Western culture since the Industrial Revolution, represents disability as something that should be prevented or cured and sees disability as a tragedy that befalls some people. No one aspires to be that type, a disabled person.

Being a person who is not welcome, who is feared, pitied, and looked upon as a type no one would aspire to be is often difficult to bear, as I was reminded on a recent trip to Toronto. Toronto is a cosmopolitan city with a highly diverse population. But this modern and admired feature contributed to the disturbing character of my experience.

My partner, Tanya Titchkosky, and I moved from Toronto several years ago. Since then we have been living in Antigonish, Nova Scotia, and teaching sociology at Saint Francis Xavier University. Antigonish is a small town and we began to miss the big city and our friends there. Our respective and collaborative research projects also made it

necessary to visit Toronto. It was time to go to the big city for a couple of weeks.

Everything went smoothly for the first while. Our friends Kate and Mark picked us up from the airport and drove us to the University of Toronto residence where we had arranged to stay during our visit. But the room proved to be inappropriate for our needs. It was on the top floor of an old and very beautiful three-story building. In keeping with the architecture, the first three flights of stairs were very wide and of a smooth stone construction with banisters that did not run the entire length of the stairs. Beyond these three flights was a very narrow, very long and somewhat rickety flight of wooden stairs that spilled out into the corridor that led to our room. This last flight of stairs was also equipped with a banister but only on the right ascending side and only partway up.

Tanya and her dog, Cassis, followed me and my guide dog, Smokie, as we entered the building and, key in hand, made our way to the stairs. Smokie, responding to my request, found the stairs and stopped to let me know where they were. I located the first stair, gripped the heavy suitcase in my right hand and, flexing the fingers of my left around Smokie's harness, said, "Forward, Smoke."

Despite some slipping and sliding that Smokie experienced on the smooth stone of the first three flights of stairs and my having to careen the suitcase up the last flight of wooden stairs, we reached our room. It was very small with barely enough room for the four of us to turn around. It was also quite hot and stuffy and the one tiny window did not promise much relief. After giving Smokie and Cassis some much needed water, Tanya and I sat on the edge of the bed and wondered how we were going to manage for the next two weeks. Still, we were back in Toronto and happy to be there, and so we decided to think about our situation later and for now take Smokie and Cassis into the courtyard, where they could run around a little and relieve themselves after their long plane ride and trip from the airport.

We left our room and, once more, I asked Smokie to find the stairs. He did so and let me know by stopping. I said, "Forward," and as Smokie began to guide me down the stairs, I reached out with my right hand to find the banister. Nothing but a wall met my reach. Without a

banister, I had to pull back on Smokie's harness to counter his pull down the stairs so that we would not proceed too rapidly. Then, the last three flights of stairs. Again, Smokie found them and stopped. Again, no banister. After two or three steps, however, my hand inadvertently hit one. Grasping it, I lessened my pull on Smokie's harness and allowed him to guide me down the stairs at his customary quick pace. Suddenly, no banister but the stairs continued. Smokie and I took the last three or four stairs at a pace a little quicker than safety dictated. Nevertheless, we adjusted and made our way more slowly down the remaining stairs and out into the courtyard. Tanya and I unharnessed our dogs and let them roam the grassy and treed area of the courtyard.

We were happy for Smokie and Cassis and we both laughed as Tanya described the excitement and thoroughness with which our dogs investigated their new environment. Even though Tanya had trained Cassis to do guide dog work and she would be working Cassis in harness for our stay in Toronto, Tanya is not blind. She acquired Cassis about six months after I arrived home with Smokie from the guide dog training school. Driven by interest and curiosity and perhaps even empathy, Tanya began training Cassis to guide while she was still a puppy. Because of Tanya's training and, I suspect, Smokie's example, by the time Cassis was a year old, she was a very competent guide dog.

We were now back in Toronto, where Smokie and I had spent our first five years together and where Cassis and Tanya had learned to feign both guide dog work and blindness. Their feigning a guide dog team has allowed Tanya, Cassis, Smokie, and me to enter public establishments that bar all pets except working dogs. And it has had the added, serendipitous benefit of enhancing our research in Disability Studies. Even though research was not part of the motivation for training Cassis to do guide dog work, both the training and the subsequent work have given Tanya and me an entrée into the rich and fertile realm of social interaction that occurs in the meeting of blind and sighted persons in public places.

With the dogs' peeing and sniffing over with, we harnessed them up and set out for our room. This time, despite the lack of suitcases, the trip up the stairs was not much easier. We still had to contend with the

slippery stone stairs, the narrow wooden ones, and, of course, those ineffectual banisters.

And the room was hotter than before. Smokie and Cassis dealt with the heat by drinking more water and finding comfortable places to lie down on the floor. Tanya and I resumed our seats on the bed, since it was the only place to sit, and became more serious about the situation. We soon agreed that we could not manage several trips a day up and down these stairs over the next two weeks. We made our decision. Tanya grabbed the telephone book and I the telephone and she began reading telephone numbers of downtown Toronto hotels to me. It took about two hours, but eventually we found a spacious, air-conditioned suite of rooms in a downtown apartment hotel with a wonderful adjacent park for Smokie and Cassis. Our two weeks' stay in Toronto was both comfortable and productive.

The incident that jolted me into remembering the type I am came during the two-hour marathon on the telephone. We had difficulty finding a hotel because we needed one downtown for a specific two weeks. Most of the hotels we called had vacancies only for part of the time, others did not have any convenient relief areas for the dogs, and still others were far beyond our budget. After about an hour, when Tanya and I were beginning to feel desperate, I found a hotel with two-week vacancies. "Great," I said into the telephone. "Let me tell you our situation. I'm a blind person with . . ." Before I could finish, the person on the other end of the telephone line said, emphatically, "We don't rent rooms to blind people." I was in Toronto. This was my home for several years. I was in a big cosmopolitan city with a rich cultural and ethnic diversity. It was 1999. All these thoughts flashed through my mind as I digested the words that had just spilled from the telephone. The only word I could speak in response was, "Pardon?" Again I heard, "We don't rent rooms to blind people." And I said that that is against the law and that I was going to call the police. The person said, "Go ahead" and hung up. In disbelief, I slowly returned the receiver to its cradle and turned to Tanya who, by this time, was asking what was wrong. I told her and we both sat quietly for a few moments. Finally, Tanya broke the silence. "Shit! I'm sorry," she said.

Who Am I?

“Who am I?” is a question, according to Hannah Arendt (1958), that we ask and answer every time we speak and every time we act. Our identities are couched in speech and action and we speak and act with and from them. In a social world, others use our identity to define us and we use it to define ourselves. These identities are “ready-made” for us to step into as we immerse ourselves in the social world (Taylor 1989, 25–35).

In this book I interrogate the process of identity formation and the social and political significance of our stepping into our identities. While our identities are ready-made and we do step into them, as Taylor suggests, they are nonetheless *made* and are not natural. The ready-made aspect of identity results in our seeing ourselves and being seen by others as types. The types that define us can be sources of enjoyment or suffering.

There are many conventionally recognizable types that encompass the concept of social identity. They fall into categories of race, gender, ethnicity, profession, and so on. Now another type has been added to this list—disabled. Disability has existed as long as human life has existed but only recently has figured in human identity. It has generally been conceived of as something that happens to a person and thus as not a natural part of the human condition. Depending upon the culture in which it occurs (Ingstad and Whyte 1995), disability has been conceived of as being brought on by disease, accident, or flawed genes or curses and other supernatural phenomena, or it is retribution for wrongdoing often going back generations. Disability is natural only insofar as it is seen as the accident of nature or the intention of the supernatural. Still, it was understood as an “attachment,” as something extra that, for whatever reason, happened to a person.

Traditionally, disability has been understood as a phenomenon that has a tremendous effect (usually a negative one) on a person’s life but is not related to identity, to whom a person *essentially is*. Thus, disability is interpreted as happenstance and disabled persons are viewed, and view themselves, as persons *with* disabilities or as persons *first*. In

fact, the sociological concept of “master-status” is often invoked to characterize the negativity of seeing disability as an essential aspect of one’s identity.

Recent developments in the disability movement and in Disability Studies, however, have offered an alternative, if not competing, dimension to what has remained to this day the dominant perspective. Disability can now be understood from the perspective of politics. It is more than merely a private happenstance that must be suffered in the realm of privacy; it is also a public matter that must be suffered in and through the polis. Disability is not an exclusively individual issue; it is a collective one.

Nevertheless, those of us who are disabled find ourselves in the midst of many different ideas about disability. Regardless of how disability is conceived, we live our lives in these conceptions. Since every collective has ways of understanding and representing it, disability is lived in the midst of these collective representations and, therefore, bears a social and political character.

The idea that disability is a collective issue, however, is not easy to grasp. It seems to run counter to the traditional Western social and political philosophies, influenced by the Enlightenment, that place a tremendous importance on the individual. Combine this emphasis with belief in the superiority of reason and mind over the passions and vicissitudes of the body, also a legacy of the Enlightenment, and we can begin to understand why disability has long been conceived of as only an individual issue.

In keeping with this traditional concept of disability as an individual issue, society sees its responsibility to disability in the provision of preventive, curative, and rehabilitative measures. Disability must be prevented; failing this, it must be cured; if it can be neither prevented nor cured, society must see that the person is rehabilitated, the “final solution.” These responses are in keeping with the biomedical version of what it means to be human. This version, which emphasizes adjustment and adaptation, plays a dominant role in the contemporary understanding of disability. Unfortunate as it is, disability is something that *happens* to some of us and it is up to us to take advantage of what

society gives us in the form of medical and rehabilitation programs—and adjust.

The reasonableness and simplicity of this traditional perspective makes it quite attractive. Seeing disability as originating anywhere else than in accident and biology raises other questions about why, and these questions, because they are metaphysical, are often thought of as better left alone. It is better to leave questions of identity alone, too, to avoid having to address the question, “Who am I now that I am disabled?” The biomedical model provides an easy and attractive answer to this question: “You are who you always were. You haven’t changed. You remain an individual, a person *with* a disability.” Identity firmly in hand in the form of “person-first” ideology, a disabled person can now make his or her way through the social and physical world with its labyrinth of obstacles, such as hotels that refuse to rent rooms and negative attitudes that translate into sympathetic pats on the back. Ironically, this sort of “making” reproduces and reinforces the dominant ideology that one is a person first.

I understood my experience as a blind person in this way for many years. In fact, this understanding has not entirely left me and, despite my efforts to shove it aside, it makes an appearance from time to time. I try to keep in mind Friedrich Nietzsche’s observation (1967, 493) that “what does not destroy us makes us stronger.” I began experiencing sight loss in late childhood and I did have some sense that it might just kill me.

I lay there on my bed crying a little, but only a little, which surprised me because I was quite worried. I couldn’t see the blackboard for the last couple of days now. But today, was really tough. A line-drive was hit right to me and I saw it and then I didn’t see it! It hit me right on the cheek. That had never happened before. I couldn’t believe it—I saw it then I didn’t see it. Laying there I didn’t know what was wrong. Remember, I was only nine years old.

I could hear my mother and my grandmother talking in the kitchen. They were speaking their first language but I could understand them. My grandmother said she was getting old and that she couldn’t hear well any more nor could she see well. She said that soon she would die. My body froze in fright. I thought, I really thought, that I was dying. What else could it be? It seems silly now, but I spent the next few days testing my hearing to make sure that it was holding up. (Michalko 1998, 36)

That sight loss represented premature aging and death was beyond question for me at this point. That it would make me stronger, however, was certainly doubtful. I just wanted this fuzzy and unclear world to go away. Playing baseball, reading blackboards and books, just playing—that is what I wanted. I did not want a life without these things and, what is more, I could not even imagine such a life. But more than anything, I did not want to die, not yet anyway.

Over the next two or three years, I was examined by several ophthalmologists. But even after the first of these examinations, the verdict was in: I was blind. This struck me as odd at the time. After all, I could see. Perhaps line drives were disappearing, but I could see. The ophthalmologist explained this oddity to my parents, who then tried to explain it to me. My macula had developed pigmentation, probably genetically based, causing my visual acuity to decline and the sharpness of the images my eyes saw to deteriorate. It was like a broken fine-tuning switch on a television, my parents explained. Because I could not recognize the “big E” on an eye chart, I was “legally blind.” All of the ophthalmologists I saw at that time said that I would retain this “10 percent vision” for most of my life and that I might lose all of my sight but not until well into adulthood.

So I was not dying after all. I could still play some sports, especially those involving a ball bigger than a baseball, such as football. Reading would have to be done holding the book a little closer to my eyes and sitting a little closer to the blackboard. Losing all of my sight would not come until late adulthood and, from my point of view at age eleven or twelve, that was forever and knowing that I might lose my eyesight at that time seemed as abstract to me as knowing that I would die. So blindness continued to hold the same meaning for me as death did. I would eventually go blind and I would eventually die, same thing.

About a year after the line drive disappeared, we had moved to a large city because, my parents reasoned, we would surely find more sophisticated medical and educational services. But even “big city” ophthalmology could not loosen the grip that legal blindness had on me, and educational services had little to offer me. Mainstreaming had not

yet caught on as an educational theory for disabled students, and the alternatives were stark in their opposition—it was either “blind school” several hundreds of miles away from home or regular school in my neighborhood.

Legal as my blindness was, neither my parents nor I thought of me as blind. After all, 10 percent was pretty good sight in the “country of the blind” (Wells 1911). Thus, the choice was plain from the beginning—I would attend regular school. The Department of Education had some large-print books, as well as some recordings of books, and occasionally a “special” teacher would visit me to help me out. With this minimal assistance and with the help of my parents, I finished the rest of my elementary education and completed junior high school.

High school was a turning point for me. We moved, not a great distance, but far enough that I would go to a different high school with students who had no idea that I was legally blind. Passing as fully sighted became my strongest desire and I went about it with a devastating single-mindedness (Michalko 1982, 1998, 102–27). I knew, on some level, that I had been trying to pass since the line drive hit me in the cheek, but now I was fully aware of it and relentlessly pursued the life of a sighted adolescent. I employed every interactional strategy possible to pass myself off as someone who was totally sighted. I could see, even if it was just a little, and I *was* sighted. That was *my self*, my identity, and even though blindness was creeping its way into me, I held it in abeyance on what I quickly came to experience as the interactional battlefield of passing. I now made conscious use of the taken-for-granted character of sight left over from my days as a fully sighted child. But the skill I cultivated most desperately was that of observation. I came to see sightedness as a culture with customs, folkways, and gestures—with its own language. That I did so was something I realized only later in life. Nonetheless, I imitated this culture to perfection. For all practical purposes (Garfinkel 1967), I was a high school student who was sighted.

But my identity as a sighted adolescent went far beyond its interactional accomplishment. Regardless of any legal definition, I was not

blind; I was sighted; that was me. My passing was motivated by the adolescent desire for normalcy, by the desire to be “one of the guys.” But there was more to it than that: I wanted to be me, my sighted self.

Blindness continued to threaten this sighted self, which I clung to as tightly as I could, constantly battling the blindness that was slowly entering me. I could still see and no matter how little, that was the “I” I was and for which I fought. Sightedness and blindness could not co-habit my identity. I was one or the other but not both. One of them would have to die and I was doing my best to kill blindness before it killed me.

I was as certain that I would “go blind” as I was that I would die. But blindness was far closer to me than death. My life as “one of the guys” was what blindness threatened. Once blindness took over my self, it would destroy any semblance of normalcy I had. Passing allowed me to keep blindness a secret from all other students in the high school. And it allowed me to keep blindness a secret from me as well. My passing was truly an act of repression.

Disability, Lennard Davis (1997, 1) writes, is “always an actively repressed *memento mori* for the fate of the normal body.” Steeped as it is in the biomedical understanding of the human body, disability reminds us of the body’s fate, that the body is “normal” only temporarily. First the sight goes, then the hearing, then the rest of the body. Our sense of normalcy weakens in the remembrance of our fate. But the “normal body” is only the beginning of normalcy. Seeing line drives and blackboards, reading books, making eye contact all spring, or so we think, from the sense of our bodies as normal. The normal stuff of everyday life is threatened when our bodies lose a sense of their normalcy. Thus, disability also actively represses the fate of everyday life. Passing, then, is an act of repression because the presence of disability in everyday life reminds us of the fragile character of social interaction and threatens its existence (Goffman 1963).

It is small wonder that many of us who are disabled subscribe to the “person-first” ideology. We place the common ground of personhood before the not-so-common one of disability. Choosing personhood over

disability emphasizes both the strength of personhood and its separation from the body. As much as we want to repress any memory of the fate of our bodies, we also want to be reminded of just how strong personhood is in the face of this fate. Disability can be our reminder. For disabled people, interaction with a nondisabled person is often a struggle to present the self (Goffman 1959) as *person* as the primary actor in this interaction and to disavow the “deviant” character of disability (Davis 1961). But suggesting that disability is merely a secondary feature of one’s identity and that we are persons *first* and persons *with* disabilities disavows both deviance and disability. It refocuses attention from the disability to the person who happens to have it. For example, a few days after the hotel clerk told me that the hotel did not rent rooms to blind people, Tanya and I had dinner with friends and I told them about this incident. They were, of course, surprised that such a thing could happen in Toronto and asked whether I was thinking of legal action. During our discussion, one of our friends said, “And he didn’t even know you.” What she was implying was that the hotel clerk rejected not me but blindness. The clerk did not know the person behind the blindness; blindness came before the person. If blindness were put in its “proper place,” our interaction would have been person-to-person rather than person-to-blindness. And so, my friend thought, if our interaction had been face-to-face rather than on the telephone, the clerk might have “seen” that I was indeed a person first and was in control of any of the negative aspects of blindness.

We often reason that interaction between disabled persons and nondisabled ones would diminish the fear of disability and the negative attitudes the nondisabled persons might harbor about it. Such interaction could change the thinking of nondisabled persons who imagine life with a disability only in negative terms. The hotel clerk, in my experience, responded to me on the basis of a version of blindness as an imagined life. Perhaps he could not imagine being blind in a hotel or perhaps a previous blind guest had set a room on fire and the clerk was stereotyping—if one blind person sets a room on fire, they’ll all do it. Whatever the interpretation, the clerk’s imagined life of blindness did

not include hotel accommodation. I or, as my friend implied, my blindness was not welcome in his hotel.

This incident illustrates yet another feature of disability; not only does it repress our memory of the fate of the “normal body” but it also engenders a *memento vivere*, reminding us of the good fortune of a “normal life.” Seeing a disabled person often evokes admiration, especially if the person is seen as overcoming his or her disability. This admiration is often extended to the most basic accomplishments. I recently attended a university convocation where an address was delivered by a woman upon whom the university had just conferred an honorary doctoral degree. In her address, she said that one of her mentors was a blind man who is married and has a family and a job. Her comments were greeted with resounding applause. There was no applause for the fact that the blind man was a mentor. Conversely, disability can also remind others of their good fortune and generates such adages as, “There but for the grace of God go I.”

The person-first ideology grows out of these collective representations of disability but has not been able to rid the collective of negative representations of disability. We are still feared, we are still applauded for simple accomplishments, we are still not the type of person anyone wants to be, and we are still not welcome. The image nondisabled others have of disability does not yet include any association with “the good life.” Lauri Klobas (1988) suggests that the image of disability represented in film and television has not changed much since the inception of those forms of entertainment. In contrast, she shows how the images of race and gender have changed positively over the decades. She is disturbed but not puzzled by her finding, which she considers self-evident, a “fact of disabled life.” The media continue to employ images of disability, she points out, as part of an effort to demonstrate all conceivable foibles of individual and collective life. But we are still not welcome. And this fact ought to be both disturbing and puzzling. Klobas should be more interested in why disability is so resistant to changes of image and why the media resists changing the image of disability.

Choosing Disability

The biomedical paradigm claims disability for itself and treats disability as the continuous struggle of the “normal body” with itself. What is considered normal about the body is a product of the measuring of human achievement (Davis 1995; Thomson 1997a). Normal hearing, normal seeing, normal walking are achieved when the conception of the “normal body” is evoked as a method for understanding the body that quits hearing or seeing or walking, or the body that simply quits (Canguilhem 1991).

The biomedical paradigm sees disability as something wrong with the biological body and thus constructs disability as a medical problem. In other aspects of life as well, according to this paradigm, disability is a metaphor for a problem. I encountered one in Toronto, where I heard a traffic report on a local radio station announcing that a “disabled streetcar” was holding up traffic on Queen Street. This disability resulted in a traffic problem. The same evocation of normalcy exists in this example as in the example of disability as a medical problem. Like the body, the streetcar is not doing what it normally does and thus is causing problems. The disabled streetcar now represents a technical problem and the mechanics take over. If they cannot fix it, the streetcar is removed from the street. Medical doctors likewise take over the problem of disability. If they cannot fix it, the disabled person may not be welcome on the streets.

No one is likely to choose disability according to this sense of the world. The biomedical paradigm represents the dominant way of understanding the body and of defining what is normal and what is abnormal, particularly in Western cultures. Still, many of us live disabilities. Our lives are influenced by the ways our culture represents disability. We are living examples of those representations.

Choosing or reclaiming disability (Linton 1998) begins with the attempt to understand the representations that our culture has ready-made for us and to grasp the relationship between them and our individual and collective identities. With Arthur Frank (1995, 27), we must

recognize that “the body is not mute, but it is inarticulate; it does not use speech, yet begets it.” The body says nothing and so we speak on its behalf. This speech is found in the various interpretations societies develop regarding the body, which include definitions of what is a “normal” body and what is a “disabled” body. Disability is an example of the speech that the inarticulate body begets. Choosing disability also involves resisting the formulation of disability as a medical problem.¹ This resistance within the disability movement and Disability Studies has resulted in alternative, and even competing, interpretations of disability. But more important, it has allowed disability to be seen as worthy of choice.

I believe that disability is indeed a choice. This sentiment may be discomforting or even nonsensical to those who treat disability as a medical problem, but to those of us who are disabled as well as those of us who are engaged in Disability Studies, this sentiment is essential. Any political struggle involving disability and any connection we make between identity and disability necessarily begins with a conception of disability as choice. Thus, I begin my argument with the assumption that disability finds its sensibility within the ways in which a collective conceives of what it means to be human and how it makes a place for the individual in what it socially organizes as a human community. Making a place for difference, including disability, is a feature of every culture and society and my aim is to interrogate this “making” in relation to disability. I do not begin by defining disability but instead, along the way, I allow its meaning to emerge as I work through the various conceptions of disability that exist in collective life.² Disability is not a static entity amenable to definition in the empirical sense; it is a “fluid and shifting set of conditions” (Shildrick and Price 1996, 93). My aim, therefore, is to use the shifting set of conditions of my life and my society to capture the meaning of disability. This is not a book based on personal experience, however, because my experience, and anyone else’s experience for that matter, is embedded in a collective.

In *The Mystery of the Eye and the Shadow of Blindness* (Michalko 1998), I explore the meaning of blindness. Using the heuristic device of “stages,” I show how we come to form understandings of our blindness

within our culture and how we then live our lives in and through these understandings. I also show how the dialectic between sightedness and blindness acts as a primal site for the development of such understandings.

In my second book, *The Two in One: Walking with Smokie, Walking with Blindness* (1999), I make extensive use of my experience with my guide dog Smokie, uncovering the world that Smokie brings to me as he guides me through it to develop the idea of guide as teacher. I try to show how the relationship that Smokie and I have is a derivative of the one between nature and society. There are many interpretations of nature and of society and there are many interpretations of the relationship between the two, just as there are many interpretations of blindness; within this manyness a blind person lives his or her life.

In this book, building on the ideas I raise in my first two, I focus on disability as a political act that is suffered by both disabled people and nondisabled ones, albeit differently. Suffering here does not refer to the conventional sense of “suffering a disability” but refers instead to the suffering of the multitude of interpretations of disability, the political acts that culturally organize and define disability—the suffering of our society’s choices made in regard to the meaning of disability. The animating question I use to understand disability in this way is that raised by Irving Zola (1982, 244): “Why [has] a society been created and perpetuated which has excluded so many of its members?” Disabled himself, Zola asked this question of his society almost twenty years ago with regard to its exclusion of its disabled members. He did not expect an answer. Instead, he meant to issue a challenge to his society and to its nondisabled members as well as to those of us who are disabled. It is relatively easy, suggests Zola, to ask questions about matters of accessibility and their costs but not so easy to ask why these questions are necessary in the first place.

Why are we excluded? This is the question I asked myself after hanging up from my telephone conversation with the hotel clerk. Why was I not welcome in his hotel? Why does my society, *still today*, exclude so many of its members? As personal as this question might seem, it is a social and political one. Exclusion, intentional or not, is a

political act and, therefore, a choice. Zola's society, as well as my own, has chosen to exclude its disabled members. In this exclusion, society has decided to include disability in particular ways, which I interrogate throughout this book.

This book is about the decisive character of exclusion and inclusion. It is also about the version of disability that must be chosen in order to see exclusion as an oriented and thus political act. Seeing exclusion as a choice is possible only when disability is understood as a choice and as a life worth living. I attempt to trace out the path that leads to exclusion and I also try to find the one that allows us to pose Zola's question. I welcome all readers, disabled or not, to join me in this quest.

A final note: throughout this book I make extensive use of my own experience as a blind person. I also make use of the experiences of others, some of whom are disabled, some not. To protect the identity of these people I have altered their names as well as other features. I use their experiences to narrate the life of disability as it emerges in the midst of our society. Whatever disability can teach us about itself and our society originates in the stories I explore in the following pages.