FOUR

The Disability Experience: II. Affect and Everyday Experiences

This chapter continues the exploration of commonalities in the disability experience. The intent is for readers to feel as if they've had a good look around a usually sealed room. This inside look includes a discussion of the ways in which society prescribes and prohibits how people with disabilities are to behave and feel. Furthermore, if there is a "disability experience," how might this experience shape cognitions and world views? Finally, to whom can people with disabilities look as role models, and who chooses them? Clinicians will find that both their clients with disabilities and they themselves are hard pressed to find guidance from healthy and functioning role models with disabilities. This absence contributes to the isolation that is part of the disability experience.

PRESCRIPTIONS AND PROSCRIPTIONS

The able-bodied community imposes restrictions on the behaviors and affect of persons with disabilities. These restrictions include the encouragement of pluckiness, the prohibition of anger, and the presumption of mourning. In addition, this chapter discusses the effects of having a disability on one's privacy and personal power and control.

Regulation of Affect and the Requirement of Mourning

The requirement to regulate affect is a common part of disability. There is the dual requirement of what to be and what not to be: One must be cheerful; one must not be angry. This issue of forced cheerfulness has been addressed most eloquently in Hugh Gallagher's *FDR's Splendid Deception* (1985). Franklin Delano Roosevelt, a president with a profound disability, successfully hid the extent of his disability from the world. Gallagher contends that the price for this was a bargain FDR struck with the United States: We (the nondisabled) will let you (the disabled) live and work among us, provided that you never make us unduly aware of your disability or its attendant difficulties, and provided that you at all times appear cheerful. We have been stuck with this bargain ever since, and as yet have been unable to break free.

The FDR legacy is evidenced in a 1993 obituary taken from the *San Francisco Chronicle* (August 3, 1993). At the top of the obituary is a picture of an attractive young woman. The caption has her name, and in smaller letters it says, "She was paralyzed in 1985." This is her main identity. The title of the obituary is "Radio career cut by gunman's bullet": this model and disk jockey had to switch careers when she became paralyzed by "a gunman's bullet on a deserted highway in 1985" (Hallissy, 1993). She died of breathing problems related to double pneumonia, but this 28-year-old woman will be remembered "as a fighter who overcame the obstacles that paralysis put in her way and managed to live a happy and full life." A quote from a friend takes this theme over the top: "She never complained. She'd always have this big smile." And now we come full circle. Think of FDR. You probably envision him sitting behind a desk, his head thrown back, a huge grin on his face, and in one hand the cigarette in its long holder. Now, 40 years later, we have this young woman who "always" had this big smile. Disabled people are supposed to smile. In case we missed this point, the latest reminder comes from, of all places, Mattel toys. In May 1997 Mattel issued the first Barbie (actually, friend of Barbie, or FOB) in a wheelchair. Her name is "Share a Smile Becky."[1]

The flip side of this requirement of cheerfulness is the interdiction against anger. I strongly believe that for persons with disabilities, anger is rarely tolerated, accepted, or understood. The problem is one of decontextualized rage (i.e., rage seen as response to a single event rather

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[1] Barbie's "dream house" turned out not to be accessible: The doorways were too narrow for Becky's wheelchair. Mattel has pledged to make the house accessible. Life imitates Barbie.

than to a greater social history and context), viewing rage as a violation of the desired (cheerful) norm set for the group, and the assumption that rage for persons with disabilities indicates individual pathology, lack of adjustment, and failure to be appropriately socialized. Yet to understand persons with disabilities it is necessary to examine and understand the issue of their rage.

Anger among the disabled is a complex issue. First, we are mindful of the bargain struck by FDR that the disabled must remain cheerful and never be despondent, despairing, or angry. Second, in the same way that impairment is viewed as residing within the person and not in the environment or in society, so too the anger is seen as a reflection of the person, and of the person's disability. It is said to be either a stage of "adjustment," and patronizingly tolerated by others, or as a failure to appropriately go through the stages to reach the final plateau of "adjustment," and thus pathologized.

Third, anger suggests that we are not grateful enough. We, who depend to some extent on the assistance of others, cannot express anger because to do so would jeopardize our continued care. We "should" be grateful not only for others' assistance but also because we are so much better off than others with worse disabilities (able-bodied people can look me in the eye and say this, unaware of the irony). Like the big fish eating the littler fish eating the littler fish, we are always supposed to compare ourselves to the smaller fish, not to the next larger fish in the chain. By keeping us grateful not to be an even smaller fish (i.e., more disabled), those without disabilities protect themselves from our envy and resentment. We collude because we want "people to do things for me because they liked me rather than because they pitied me" (Zola, 1982b, p. 220).

Fourth, in addition to the prohibition of expressions of anger *by* persons with disabilities, we are faced with the unseemliness of anger *toward* persons with disabilities. "People are very wary about being openly angry or critical of someone with a chronic disease or physical handicap" (Zola, 1982b, p. 223). Perhaps the visible manifestation of disability is seen as implying a deeper characterological weakness, a basic flaw, such that anger toward us would destroy us.

To these two regulations (you must be cheerful, you may not be angry) we add a third: the requirement of mourning. Most of psychology views disability as a loss—a loss of the healthy or undamaged body, loss of function, loss of the wished-for perfect child. As such, the loss "must" be mourned before the process of "adjustment" to the real body, function, child can be negotiated. The possibility of mourning becomes the requirement of mourning. This does not mean that mourning does not or should not occur. Wright (1983) makes a useful distinction between the “requirement of mourning” and the “period of mourning.” In many instances persons who sustain a disability may well experience a period of mourning, with its components of sadness, loss, and grieving. But this is not inevitable or universal. Nonetheless, the requirement of mourning persists, and is particularly strong within the mental health community. The logic goes as follows: “You have a disability. Having a disability is awful. Therefore you must be suffering. I see you as suffering. Ah, but you are not suffering, in a situation in which suffering should occur. Why not? It must be because you are brave, courageous, plucky, extraordinary, superhuman.” Thus the requirement of mourning is coupled with the requirement of cheerfulness. Those are the choices: suffering, loss and mourning, or continual pluckiness. Virtually all persons with disabilities I know have been told how brave they were, sometimes for *simply getting up in the morning*.

Wright (1983) cites several motives for the requirement of mourning. One is the need to see others as devalued in order to maintain one’s own position of status or value. This is similar to the notion of cognitive dissonance. If I do/am *X*, then *X* must be valuable. You are not *X*, so to maintain my belief in the value of *X* the condition of Not-*X* must be devalued. A second motive “arises when the perceiver becomes threatened by the apparent adjustment of a person with a disability because one’s own ego is found wanting by contrast” (p. 81). To avoid acknowledging one’s own weaker ego, the perceiver needs for the person with a disability not to be coping well or living a life of quality and fulfillment. The thought arises: “If a person with a disability can do it even though he or she has a disability, why can’t I do it without the disability?” A third motive is to force compliance with codes of proper conduct, with the way one ought to act and feel, much like certain behaviors are seen as appropriate at a funeral. This idea is closely allied with the moral model of disability, the idea that the disability is a punishment for a sin. If it’s a punishment, then one “should” suffer, or what good is a punishment? These two aspects—the requirements of mourning and cheerfulness-comprise the essential paradox of disability.

The person with a disability who fails to conform to these requirements has “a bad attitude” or is “in denial.” Rehabilitation patients must simultaneously mourn their disablement and enter enthusiastically into their rehabilitation regimen. Hostility toward the staff is unacceptable. For the person with a disability the latitude for a normal range of emotions is curtailed. We are expected never to let the disability get us down. At the same time, people underestimate some of the effects of disability while overestimating the misfortune and suffering of persons with disabilities. Even family overestimate the degree of suffering from the disability. It often is assumed that there are higher levels of distress, anxiety and depression among persons with disabilities. It is vital for us as clinicians not to interpret the discrepancy between others' views and those of the client with a disability as denial on the latter's part. We must be mindful of the fact that persons with disabilities are more like than unlike persons without disabilities. Similarly, we should not underestimate the debilitating power of daily prejudice, stigma, and discrimination.

Privacy and Control

Being a person with a visible disability is to be stripped of many of the usual boundaries of self. Because a part of oneself (one's disability status) is apparent to others, one becomes "a person who can be approached at will" (Goffman, 1963, p. 16). A somewhat analogous situation occurs when a woman is in the third trimester of pregnancy. Acquaintances feel free to ask personal questions ("Was this a planned pregnancy?"). Indeed, perfect strangers come up and pat your belly, as if your stomach had pushed through and broken that invisible shield around your personal space. Something about the state of visible pregnancy invites such intrusions. This is what happens with disability as well—the personal questions, the intrusive touching. The exposure makes one subject to "the conversations strangers may feel free to strike up . . . conversations in which they express . . . morbid curiosity about [your] condition" (Goffman, 1963, p. 16). These invasions happen unpredictably, intruding into your day unbidden. One example: I get off my scooter in a shoe store to examine something more closely. A man nearby says to me, "Good for you!" and punches the air in front of him enthusiastically. Another example: I get to the checkout counter at the grocery store. The clerk, seeing me on crutches, asks, "What did you do to yourself?" (As if it were my fault.) I answer, "I had polio" and, as I knew they would, the people in line behind me go rigid with tension. My answer has made them uncomfortable. They identify with being in the position of the clerk who has asked a question that now is seen as thoughtless. Suddenly I stand there not as a mother buying fruit but as a "polio victim," the fact of my disablement a blinking neon sign. This can happen anytime, anywhere. It can happen once a week or twice in 10 minutes. It can happen in front of my children, who will learn through repetitions of this scenario that something is wrong with having a mother with a disability.

With this blinking neon sign on me it's hard to be invisible, or just one of the crowd. When I come late to a meeting *everyone* knows it. As another woman said, "being three feet tall and using a power wheelchair makes me stand out more than any rational person would ever care to do" (Collins, 1997, p. 12). Having a visible disability means always being noticed, standing out, being different, *everywhere you go*. People will respond to your differentness. Some people will want to soothe you (and assume you need soothing); some will want to heal you (embrace their religion and you could throw away your crutches); some offer redemption (Jesus loves you); and some need to tell you how really okay they are with you as you are, and in the telling prove the opposite ("Some of my best friends have quiggles"). But you just want to be left alone, anonymous, invisible, just once: "Sometimes we just want to fade into the woodwork and be anonymous—be not even a crip . . . " (Milam, 1993, p. 106).

Paradoxically, given how visible I generally am, sometimes I am completely invisible. For example, sometimes when people meet me for the first time I'm on my scooter. If at the second meeting I am walking (either on crutches or unaided), many times people simply don't recognize me. They think we've never met. I got encoded in their memories as a scooter, and they sure would remember a scooter if they saw it again. But they don't see *me*. One year my son's teacher, having met me on my scooter, kept trying to clarify at our second meeting (I was on foot) exactly what my relationship to my son was. I finally understood her confusion, and said "I'm his mother." Not the scooter; me. The reverse can also happen. I received a traffic ticket, and the officer saw me seated behind a steering wheel (and not on my scooter). I went to court to fight the ticket, and sat on my scooter through an hour of this officer citing details from each ticket he'd written. I thought I was doomed. However, when my name was called and I scooted to the front of the room, the officer looked confused, and told the judge he had no recollection of me (and thus the ticket was dismissed).

Often people make comments about the nature of the disability itself. Someone might say to me, "I saw you walking in the store the other day; you seem to be doing better" (honey, the "better" train left long ago). I could explain—that one doesn't get better, and in fact one gets worse from the combined effects of age and polio; that I always walk in that particular store because it's too crowded for my scooter; that sometimes I walk, sometimes I use crutches, sometimes I use a scooter, and the choice is often unconscious as I negotiate my way through the physical world. But I don't. You don't know me that well. I don't want to have this conversation with you. But I will take all the time needed to answer the questions of a child. If you are a friend of mine, ask me anything. It's not that I'm "oversensitive" about my disability. It's just that I don't want to share personal information with strangers any more than you do.

People want to let you know that you're not the first of "your kind" they've met. Just as the pregnant woman incurs stories of others' childbirth experiences, the person with a disability engenders stories of other persons with disabilities known to their interlocutor ("My uncle had a quiggle"). How is one to respond to this? Here the issues of privacy and regulation of affect collide. Get angry, and you confuse the other person; are seen as maladjusted, with a chip on your shoulder, stuck in one stage of "adjustment" to your disability; and are seen as representing your group, giving a worse name to persons with disabilities. Blow it off and it can be like an insidious bacterium invading your immune system. You could explain to the other person the effect of the remark on you, but really, when did you sign up for this career of disability educator to the world? You don't even remember this job having a booth on career day! So you say, "Oh really," in as disinterested a voice as you can muster, or try to joke ("Funny, you don't look like the nephew of a person with a quiggle"). No matter how you respond you are likely to enter the next encounter just a little more warily and be a little "overreactive" to the next person who has an uncle with a quiggle.

With the high degree of visibility associated with disability, a person with a disability is seen as a representative of the group. When attaining a high position, "a new career is likely to be thrust upon him, that of representing his category" (Goffman, 1963, p. 26). Conversely, one's failings or mistakes also can be misinterpreted as representative of the group. Thus the person with a visible disability is always an ambassador from the disablility community on assignment to the AB world.

All these incursions into one's privacy contribute to a sense of loss of control. The invasions of privacy occur at others' whims. They affect not only the person with a disability but also his or her family. Another factor in loss of control affects the person with a hidden disability, or with hidden aspects of the disability. This person has control over knowledge of the fact of the disability only as long as he or she tells no one. Once the information is divulged, the person loses control of the information, which then may be shared, misrepresented, recorded, gossiped about, and so on. A further factor in loss of control is that disability often involves living with a future course that is unpredictable. Persons with disabilities will respond to all of these demands of disability in myriad ways. In a testament to human resiliency and resourcefulness, there are many versions of making it work. This is the primary clinical mantra—do not insist on the response you think should be, or what you think it would be like if you had a disability.

EVERYDAY EXPERIENCES OF PERSONS WITH DISABILITIES

Okay, let's not be ridiculous—I can't really tell you about what it's like to have a disability on a day-to-day basis. But I can show how disability leads to certain kinds of experiences, and how those experiences in turn influence and shape the world view of the person with a disability. A pervasive part of the disability experience is dealing with others' attitudes toward disability. Negative attitudes toward persons with disabilities constitute a major obstacle to successful adjustment and rehabilitation (Asch, 1984; Schneider & Anderson, 1980; Tringo, 1970; Wertlieb, 1985; Wright, 1983).

Effects on Cognitions and Schemas

If there is a disability culture, that presumes some commonality of disability experience. These experiences are partly personal (i.e., the things that happen to oneself) but also events that happen to others with disabilities, events to which one resonates. This disability experience shapes one's perceptions of and stance toward the world. Let's approach this issue of how having a disability creates a different world view by analogy. Imagine you are from some small country far away, and you've come to visit and study the United States. You are interested in race relations, particularly between blacks and whites. Your research unearths two events: the Tuskegee study on syphilis and the Rodney King incident and subsequent trial resulting in acquittal of the white policemen. You might conclude that there is much racial tension in the United States, to put it mildly. If you, the visitor, were black, you might feel wary. And if you had a personal experience of racism here, these three events together—Tuskegee, King, and personal experience—would probably create in you a conceptual framework for thinking about race in this country. In other words, it doesn't take that many events or experiences to form your view, provided these events are emotionally powerful and personally meaningful. Then, even if most of your interactions with whites were positive, the overall effect comes more from those powerful negative events, which overshadow the positive experiences.

Let me use myself as an example to show how disability, like race, can frame one's world view. One day I came back to my car with my infant son and a cart full of groceries. I took my son up into my arms, and as I was opening the trunk a woman stopped and said, "May I help you?" I gratefully accepted. To my amazement, instead of helping me load the groceries she forcefully took my son out of my arms. Both he and I freaked, and I took my crying son back. The woman turned to walk away, saying, "I know, I know, you people like to do it all yourselves." This emotionally powerful incident might have remained an isolated one, but within the next few years I read about Tiffany Callo (which, whether accurate or not, I remember as the case of a mother with a disability losing custody of her baby in large part because of her disability) and then read a newspaper account of a Michigan case of two parents with disabilities who used personal attendants (they lost custody of their son because they were unable to care for him without assistance). I read in a scholarly journal that "disabled women are at risk for a range of undesirable outcomes, including . . . loss of child custody" (Kallianes & Rubenfeld, 1997, p. 203). Thus four events helped shape my view—one personal experience and three I read about that had personal meaning for me—that I, as a mother with a disability, could lose my child more easily than a mother without a disability.

This example shows how my perspective was shaped in one area. Suppose this process were repeated over many areas, as indeed it has been. Soon much of my perspective is influenced by my experiences as a person with a disability. In other words, it doesn't take many experiences or events to heavily shape my world view. Even if 99% of my experiences are positive, the 1% of negative experiences can have a greater impact if they are emotionally evocative, personally meaningful, powerful, and I have reason to believe that they are not isolated instances (e.g., by reading that they have happened to others). Over time my "reality" becomes discrepant with the AB one. Think of how many African Americans and Caucasians seemed to have such different responses to O. J. Simpson's acquittal. This gives the flavor of how two separate sets of realities coexist. Each side thinks the other side "just doesn't get it."

There is a second way that disability shapes perspective. Again, an example: I contracted polio in 1954, one of two isolated cases in the state of Michigan. A random event had happened to me. The occurrence of this event, the fact of its having happened, was a lesson to me: I learned that lightning can strike and having learned that could not unlearn it. This knowledge influenced how I viewed subsequent events. For instance, I was worried about having amniocentesis during pregnancy because of the risk of miscarriage (never mind the implications of doing tests for disabilities on my yet unborn child!). I was assured that the risk was very low and was cited statistics, which I didn't find in the least bit reassuring. Why not? Because in 1954 only two people in the state of Michigan contracted polio, and I was one of them—those odds were minuscule, but they happened. It was a lesson to me in another way: I knew that many other people had not learned that lightening could strike them, and I both envied and disliked them for this. And in an odd way I felt I had special knowledge and prized this specialness.

I feel "special" in other ways as well. Throughout my week I do things differently from nondisabled people. I park in designated areas. I enter through different doors to avoid stairs or heavy doors. I can't use the bathroom in one store because it's inaccessible but get to use the restroom next door because the owner makes an exception for me. I call a restaurant for a reservation and ask about their accessibility and then don't believe their answer so I go downtown to check it out for myself. Salesclerks in my local stores all remember me—I'm the lady on the scooter. I have a card in my wallet that identifies me as the proper owner of my handicapped parking placard. I avoid the art fair in my city's downtown because the crowds on the sidewalk make it hard to negotiate my way. I have some special skills related to my disability. First, I can identify fine gradations of pain, knowing when the pain crosses the line from nuisance to warning signal. From about 10 paces away from a curb I can tell if my right or left foot will be the one to go up (or down) the step and change the length of my pace accordingly so I go up (or down) the step with my "good" foot (I cannot do this consciously; if I stop and think about it, I lose this ability). I have well-honed skills in sensing nonverbal responses of others, sharpened by a lifetime of figuring out how people react to my disability. I have developed methods of managing stigma. And I know from the pain in my right ankle when the barometer drops and it's likely to rain.

I am not like everyone else. I am the exception. Things don't apply to me. This is a form of narcissism I sense in myself and others with disabilities. We are so used to pushing and shoving our way in, being our own advocates, being on the outskirts, being the exception, being different, that we start to think we are the exception in ways and situations other than those related to the disability. Clinicians must understand this process and not mislabel it as a personality disorder.

In this section on cognitive schemas we've seen that the world view of a person with a disability can be shaped by that experience in several ways. First, events important to the lives of persons with disabilities take on accentuated meaning, and it doesn't take many of them to have a profound impact on the person's organizing structures through which the world is viewed. Second, the fact of disability often forces an admission of personal vulnerability, an appreciation of how random events can happen to a person, and an altered relationship to probabilities. Third, having a disability means being the exception so often that it becomes a modus operandi. Fourth, being a person with a stigmatized condition hones skills in detecting nuances of nonverbal responses in others, and in stigma management. Finally, if you're lucky, you can "feel it in your bones" when it's going to rain.

But one thing people assume is an important and salient cognition for me turns out not to be. Many people who hear when I had polio are struck with the irony of my contracting it so soon before the polio vaccine was available. People assume I feel some bitterness about this timing when in fact the issues of "why me" or how narrowly I missed were never mine. I believe this attitude generalizes to other persons with disabilities. Issues of how close one came to not having a disability, "if only" I had done this, not done that, been in this place and not in that place—I don't believe these are common themes among persons with disabilities, at least not beyond the first year post-onset (but I can't be sure—no one's ever asked us, as a group, about this issue). I think it's able-bodied persons who are struck with this issue, in part because of their need to explain how such things happen (and hence couldn't happen to them, as discussed earlier). But as a person with a disability, getting deeply into the "if only"—therein lies madness.

Role Models, Mentors, and Heroes: Living in a Nondisabled World

If a child is the only one with a disability in the family, to whom does he or she look as a model? What are the norms for children with disabilities? Where are the role models for parenting with a disability? Who are our icons, our heroes? As it happens, this is a subject under great debate in the disability community. At issue is who gets to choose, "us" (i.e., persons with disabilities) or "them"—ABs?

This debate has become embodied in Christopher Reeve. The actor who portrayed Superman on film became quadriplegic in a riding accident in 1995. In an irony not lost on anyone, the embodiment of superhuman strength of heroic proportions became one of us. But then a certain uneasiness set in. Part of it was the typical perception that the rich really are different from us (the not rich). Whoever says you can't throw money at a problem doesn't have a disability. Disability is a problem that money can ameliorate tremendously: Wheelchair breaks? Buy a new one. Fatigue interfering with family life? Hire a cook. Can't drive? Hire a driver. House inaccessible? Work with an architect to design an accessible one. Money does wonders. Mr. Reeve has two full-time attendants and commands enormous fees for speaking engagements. The second stirrings of uneasiness came with the article about him in *Newsweek,* called "To stand and raise a glass." This was a quote from him, and his focus on *cure*, on eventually standing, on eventually holding a glass, is a message anathema to many people with para- or quadriplegia. The rallying cry of the disability community is "care, not cure," which means redirect funding to provide help with independent living now, for people who already have disabilities, and put less emphasis on fixing or preventing people like us. So when our most high-profile member called for cure, indeed, started raising money for a cure, we became wary. Then he appeared at the Academy Awards, and without speaking a word, his mere presence alone on a stage in his wheelchair brought thunderous applause. Frankly, it brought tears to my eyes. Why? I admired his courage *just for being there*, for having survived. (You see, those with disabilities are not immune to any of the same messages exerting pressure on us all.) And then all hell broke loose. Christopher Reeve was chosen (by ABs) to speak at the Democratic National Convention in 1994. Suddenly the Internet was awash with the topic. I received as many as 40 e-mails a day about this for several weeks. Debate centered on whether he was "our" spokesman, who gets to decide who speaks for us, and whether he was or he was not entitled to his views on living with a disability and the hope for a cure, and whether we were being harsh and judgmental. But we don't have a lot of spokespeople, people with disabilities who command much attention, so we have to be careful about who is in that role. If you only get 15 minutes in the spotlight, you want to use them well.

Air time—the medium of TV—is a powerful source of role models. There are four predominant roles for persons with disabilities on TV. The first and most ubiquitous is the role of villain, whose disability explains the villainy—the psychopathic killer with a club foot. The second and increasing role is a nonrecurring character on a sitcom whose raison d'etre is to be a person with a disability; the point of the character is the disablement, which serves as convenient metaphor. For example, in June 1997, the Nanny (played by Fran Drescher) dates a blind man (played by Jason Alexander) because she doesn't want guys to like her only for her looks. The role is played by a sighted man (you could tell; he had sighted mannerisms) and his function in the show is to make a point about seeing beyond appearances. His blindness is a symbol for inner vision. Fran realizes she has been using him, and returns to the sighted man. The function of the blind man is no longer needed. The third role is a relatively new one on TV. It began, as far as I can tell, with the sitcom *Murphy Brown,* which takes place in a TV newsroom. One of the employees of the newsroom is a man in a wheelchair, and he can be seen in the background going about his business, as would any employee. He has no lines, but the role is groundbreaking—just a regular guy doing regular work. There is a fourth role, though it is a rarity. It is a character with depth and multifacets, only one of which is the disability. The first such role was Lenny, a man with mental retardation, on *LA Law.* Another is a boy with Down syndrome who appears on *Picket Fences.* Thus we see four roles: villain, disability as symbol, background character, and well-rounded characters. The latter, by far the most important in creating positive models for persons with disabilities, is the newest and fewest.

Where else can we look for role models? Another example of a role model chosen for, but not by, us was Mark Wellman. (I don't know Mark Wellman. Nothing I say here is intended to be against him personally, only against the symbolism with which he was imbued.) Mark Wellman was a rock climber who became paraplegic in a fall. He continued to use his rock climbing skills and climbed El Capitan (a relatively sheer face of granite in Yosemite). San Francisco Bay Area news shows sent cameras to Yosemite to catalogue his ascent. Then, having spent the money to send crews there, they made a continuing story out of it. For a week we got Mark Wellman updates along with panoramic shots of El Capitan with two ant-looking creatures on it. Here's how he climbed: He had a partner who carried all the gear. The partner climbed up some, making a trail and carrying the supplies. He climbed back down for Mark, and helped him up to the next level. In other words, the partner climbed the rock twice and did so carrying all his own and Mark's gear. This is a pretty remarkable climbing feat. What was his name? I don't remember. And that's the point. No matter what that guy did, the media ensured that this was a Mark Wellman story. Nothing he did could compete with the crip on the rock.

So what's wrong with that? If a guy with paraplegia wants to climb a rock, isn't that his right? Of course it is. But do I need to climb a rock? As a matter of fact, I thought I did. When I was about 20 I climbed on crutches 3½ miles up to the top of Nevada Falls (Yosemite again). Being at the top was exhilarating. Climbing down the shorter but steeper route, however, it became clear that there had been a recent rock slide and the trail was obliterated, covered in rocks of various sizes. When using crutches, there is a moment of faith in which you raise your feet off the ground and put all your weight on the crutches. As I did this, the crutches would turn out to be on unsteady rocks, and I'd begin to slide down the mountainside. The descent was exhausting and nerve wracking, but I continued, having been convinced that there was no other choice. By midafternoon my energy was spent, and I still had the steepest part ahead of me and had to negotiate my way down past the falls on "the mist trail"—over 100 very steep, narrow, wet and slippery steps, between a wall of rock, covered with slippery and wet moss, and a waterfall rushing past in a crescendo of water and noise. I made a slow, treacherous, careful descent, while behind me a line of people backed up. I could hear them: "What's the hold up?" "I don't know, something seems to be holding up the line." "There's a girl there on crutches." "What's she doing here?" Well, what a good question. What *was* I doing there? My goodness, I was the crip on the rock.

That trip to Nevada Falls was a watershed (sorry) event for me. Raised to think I could do anything I set my mind to, I tested the boundaries of "anything" and found that there were limits. Wellman and Reeve (not coincidently two very good looking white guys), chosen as spokesmen for our group, are what we call "supercrips" or "overcomers." We hate that overcomer crap. Because most of us are just regular people. Itzak Perlman (one of my early heroes, in part because he always insisted that his TV appearances show him walking out on stage with his crutches) said that when he began playing violin professionally all the stories about him described him as a man who had polio and who also played the violin. It was only after he became one of the four premier violinists in the world did the stories switch to describing him as a premier violinist who also happened to have had polio. Most of us are not premier violinists. Most of us will never climb a rock. But we would still like to be thought of as people first, not as a disability. When we talk about using "people first" language ("person with a disability" as opposed to "disabled person"), this is what we mean. It's not semantics. It's a way of looking at us and seeing *us*, not the disability.

Roosevelt was a hero, one with tremendous resonance in the disability community. The debate over his memorial, over whether he would be depicted in at least one statue in his wheelchair (he wasn't) cut deep. As my friend (who had polio) said to me, "FDR delivered this nation from the depression and won a world war; what have *you* done for us lately?" FDR was a man of convictions, a leader, and a visionary, all during a time in which he had to hide his disability from public view. We're not likely to get another FDR anytime soon, and we hate to see his memorial robbed of its significance for people with disabilities. It isn't only the absence of his wheelchair (remember, Roosevelt *could not walk*) but the way in which the memorial ignores current issues of disability. The Braille on the memorial is as high as eight feet off the ground and is so large that the spacing of dots within a letter and between letters is nonsensical. Robbed of our past hero and robbed of our present participation, just what will the FDR memorial come to symbolize for us?

If we don't want ABs to choose our heroes for us, who would we choose? My first role model (I was about 7) was a colleague of my father who also had polio, which left him with considerable weakness and paralysis. I most vividly remember that he didn't have sufficient stomach muscles to produce a decent sneeze. He lived in a two-story house with an inclinator chair-a chair that travels on a rail up and down the stairs. He was married, had children, and had a career. He lived a "normal" life. It was my first example that people like me could be normal.

The disability community is full of heroes, people of enormous courage. My husband, who was diagnosed with MS just as he was hitting his professional stride, has continually altered his career path as increasing symptoms change his functioning, always doing what has to be done to remain a gainfully employed individual. He is not a hero in the conventional sense, yet he is a positive role model for others with disabilities. We must not focus so much attention on the rock climbers that we lose sight of the "profoundly ordinary" (Kirshbaum, 1994) persons with disabilities who are not premier violinists.

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