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## Teaching and the Experience of Disability: The Pedagogy of Ed Roberts

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This article was originally published in *Canadian Journal of Disability Studies*, volume 9, issue 5, in 2020.  
<https://doi.org/10.15353/cjds.v9i5.705>

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CANADIAN JOURNAL OF

# Disability Studies

Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

*Canadian Journal of Disability Studies*

**Published by the Canadian Disability Studies Association**

**Association Canadienne des Études sur le handicap**

**Hosted by The University of Waterloo**

[www.cjds.uwaterloo](http://www.cjds.uwaterloo)

# **Teaching and the Experience of Disability: The Pedagogy of Ed Roberts**

Scot Danforth  
Attallah College of Educational Studies  
Chapman University  
[danforth@chapman.edu](mailto:danforth@chapman.edu)

## **Abstract**

Ed Roberts was a renowned activist considered to be one of the founding leaders of the American disability rights movement. Although he engaged in numerous political strategies, his main form of activism was teaching in his prolific public speaking career across the United States and around the world. The content and methods of his pedagogy were crafted from his own personal experiences as a disabled man. His teaching featured autobiographic selections from his own life in which he fought and defeated forces of oppression and discrimination. This article examines Roberts' disability rights teaching in relation to the experiential sources, political content, and teaching techniques.

## **Keywords**

Ed Roberts, American Disability Rights Movement, Teaching

## **Introduction**

Before he became a leader of the disability rights movement at the University of California, Berkeley, in the late 1960's, Ed Roberts was a teacher. As a graduate student, he taught political science to undergraduates, running small discussion sections for large lecture courses. Roberts (1995, p. 53) described this experience, "(I)t was wonderful". He enjoyed the rich social interactions, the students' vigor, and the excitement of new ideas. When he finished his Ph.D. coursework, rather than completing his dissertation research, he continued to do what he found fulfilling. He taught at two alternative junior colleges in the Bay Area (Z. Roberts, 1995; M. Roberts, 2018).

In 1973, Roberts became director of the Center for Independent Living Center (CIL) in Berkeley. He served as director of the California Department of Rehabilitation from 1975 to 1983, the first disabled person to hold the post. He used his state agency position to establish the first eleven independent living centers throughout California, and he was instrumental in the national lobbying effort that added independent living center funding to the 1978 renewal of the federal Rehabilitation Act. A recipient of the prestigious MacArthur Foundation "genius" fellowship in 1984, he leveraged the award funds to co-found of the World Institute on Disability (Leon, 2000, 2018; Z. Roberts, 1995, 1996, 2018).

Roberts was a well-rounded disability activist who capably employed all the tools of grassroots political action (Danforth, 2018). He planned and carried out protest marches and sit-ins. He canvassed the legislature hallways of Sacramento and Washington, D.C., buttonholing lawmakers for passage of important bills. He made thousands of phone calls to political contacts of every stripe. He especially enjoyed working the media, giving interviews to newspaper and

magazine reporters, captivating audiences on television and radio (E. Roberts, 1994; Z. Roberts, 1995, 1996, 2018).

But education was Ed's primary activism. "I don't see myself in the same way as the radicals in the streets," he explained, "My job is to teach" (E. Roberts, 1994, p. 55). A prolific public speaker, he traveled widely across the United States, Canada, and around the world, presenting at a variety of venues, including conferences, independent living centers, community organizations, and churches (Danforth, in press). Often logging over fifty thousand annual miles, he taught the independent living concept that he and other Berkeley disability rights activists developed (Oda, 1995). With his life and his words, he delivered radical lessons about disabled people fighting for their rights to equality and inclusion, asserting control over their lives, and living far better than the suffering most assumed synonymous with disability (E. Roberts, 1994).

This article uses historical research methods, including archival documents and interviews, to examine the pedagogy of noted disability rights leader Ed Roberts, closely scrutinizing the experiential sources, political content, and teaching techniques. He taught from his own life experiences as a disabled man, narrating his autobiography as the central pedagogical example, delivering a countercultural message about how disabled people can live full, rich, enjoyable lives. Exhibiting his life story as a provocative object for examination, illuminating and utilizing social stigma as a strategic tool, framing his own lived experiences as emblematic of the struggles and opportunities of all disabled people, Roberts created a narrative pedagogy of social change.

This article begins with the experiential roots of Roberts' teaching, three life-changing experiences that formed the foundation of his pedagogy. Then it navigates the contours of Robert's personal theory of stigma and stigmatization, concepts that allowed him to fashion a life

and pedagogy opposing disability oppression. This leads directly into an analysis of teaching techniques, how Roberts publicly staged his own body and articulated narratives from his life story that reanimated theatrical techniques developed many years earlier by American freak shows. Beginning lessons with an intentional dive into social stigma, the disability rights activist created his own updated version of the freak show presentation strategies, seeking the elevation of the status of disabled people as a political group fighting for justice.

### **Three Foundational Life Experiences**

#### ***Death, Life, and Control***

When Roberts contracted the polio virus at age fourteen, he spent nine months supine in an iron lung at San Mateo County Hospital. In addition to paralysis, he experienced stomach pain, indigestion, and a weak appetite. The medical solution was a private duty nurse devoted solely to his individual care and the daily task of cajoling the boy into accepting enough food into his body. The nurse was too forceful with her encouragement to open wide to the approaching spoonful. Ed refused to eat. His body weight, already greatly reduced by the loss of muscle mass, dropped over a number of weeks to just over fifty pounds (Z. Roberts, 1995).

“(T)he more she wanted him to eat,” his mother Zona observed, “the less he wanted to eat” (Z. Roberts, 1995, p. 57). Without purposeful intention—as Ed noted later, “It wasn’t a conscious effort”—one nurse became his sole object of resistance and the singular human activity of eating encompassed the totality of his emotional pain. Confused, angry, embittered, Ed pitched every fiber of his being against the encapsulation of every loss and indignity he had suffered (E. Roberts, 2007a, p. 15). After laying still watching a host of white-clad nurses and

physicians scurry around and over him for months, the bedridden adolescent asserted fierce control over the one life activity he could. As Roberts later explained,

I wanted to die. You're 14 and you're paralyzed from the neck down and you're in an iron lung - you have all these people around you, doctors and nurses, and their job is to save life. You have to be pretty creative to commit suicide... I was just totally depressed and not knowing what the hell my life was going to be all about. (E. Roberts, 2007a, p. 15)

Without question, he had adopted the common cultural view that paralysis required that his life be confined to misery. "I had totally accepted the whole idea that being crippled was terrible, the worst thing" (E. Roberts, 2007a, p. 16). He had no positive disabled role model to look to. He had no access to any depiction of living with a severe disability that offered anything other than unhappiness.

Fearing for their son's life, Verne and Zona Roberts contacted Dr. Gene Gordon, a psychiatrist and family friend. Dr. Gordon visited Ed in the hospital, talked to him and assessed the situation. He recommended immediately discontinuing the private duty nurse. Whether Ed decided to eat or not, Dr. Gordon reasoned, the choice had to be his. The Roberts followed his advice, and the nurse was released (Z. Roberts, 1995, 1996, 2018).

Young Ed, for the first time since his illness, found himself in the surprising position of having unencumbered authority over the direction, and indeed the very existence, of his own life. "All of a sudden I was on my own, and I had to make my own choices...I chose life" (E. Roberts, 2007a, p. 15). It was not only a momentous turning point in his life as a newly disabled man. He would later realize that it was the beginning of his work as the leader of the independent living movement, starting with the personal realization that living without some degree of control over one's life is not really living at all. "I had to begin my own life...if you had people taking

care of you, making all your decisions, what is there to life, really?” (E. Roberts, 1989). Fifteen-year-old Ed decided to take charge of his own life, a move he later learned was politically challenging for disabled people given the widespread paternalism of the professions and organizations that controlled most forms of assistance.

### ***Confronting Stigma***

When Ed came home from San Francisco Children’s Hospital, he attended high school classes on a two-way audio hook-up installed in classrooms and the living room of the Roberts family home. Prone in an enormous iron lung, the six foot one, eighty-five-pound adolescent heard lectures on a speaker and tapped a pedal with his foot to speak to the classmates and teachers (Z. Roberts, 1994, 1996, 2018). For his senior year in 1958, Ed’s mother Zona decided that he would attend class in person. Ed was very scared. He feared that the other students would stare at his thin, limp body propped up by a corset in a wheelchair (Z. Roberts, 1995, 1996, 2018).

My worst fear and one of the reasons that I had not come out at all was that I was terrified of being stared at. That just indicated to me how awful it was and how ugly I was. I didn’t want to put myself down in the process. (E. Roberts, 1994, p. 20)

Without what he would later call a helpful “kick in the butt” from his mother, Ed would have avoided the miserable experience altogether (E. Roberts, 2007a, p. 16).

Before he first rolled onto the high school campus, Ed was already aware of the corrosive content and ubiquitous power of the dominant cultural meanings about his paralyzed body. Years before his illness, while attending a county fair, riding high on his father’s shoulders, Ed noticed a woman with cerebral palsy using a wheelchair. When his inquisitive eyes followed the woman, wondering about her body and the wheelchair, Ed’s father shouted at him, “Don’t stare!” Verne

Roberts was merely passing on the conventional knowledge and cultural sensibility that was self-evident to any American in the decades after World War II, that physical disability was a source of fear and shame. Stigma was as thick in the culture as oxygen was in the air, invisible but prevailing as if it were a requirement of nature itself (E. Roberts, 2007a).

On the first day on campus, Ed's younger brother Ron, also a senior, pushed his wheelchair into the commons area where hundreds of students gathered for lunch. As expected, the high school students stared at Ed. When he looked back at them, they turned away (E. Roberts, 1994, 2007a; M. Roberts, 2018).

But Ed quickly realized that the profound sense of discomfort felt by the other students didn't necessarily extend to him. "Something remarkable occurred to me... it didn't hurt. For people to stare at me did not hurt me. It had been such a fear that I thought it would" (E. Roberts, 1994, p. 19).

Stigma was performed in a social interaction that could be split into two different sides, one a set of feelings and actions on the part of the stigmatizers, the starers and gawkers who unknowingly enacted the dominant cultural meanings about disability. The other side occurred in the devaluing and deflating experience of the stigmatized person. Ed noticed to his surprise that the former could occur without the latter. The feelings of pity, shame, embarrassment, and fear felt by his high school classmates were just their own (E. Roberts, 1994, 2007a).

(M)aybe it wasn't all my problem, because when I looked back, they would look away.

As I thought about that, why was I taking all this on as my problem when wasn't the fact they stared also their problem? It was an interesting feeling. (E. Roberts, 1994, p. 19)

This innovative feat of self-preservation and self-valuing became a prime feature of Roberts' approach to life and teaching.

Roberts developed a useful working theory of social stigma. The average person in society experiences an automatic emotional, cognitive, visceral response to dramatic bodily difference. Without intention or volition, she is trapped within a symbolic matrix of cultural meanings about divergent bodies that rarely arises to a state of self-reflection and awareness. Normal bodies are assumed to have certain appearances and functionalities, and conversely stigmatized bodies lack those valued appearances and functionalities. Stigmatized bodies constitute personal failures, incurring unavoidable embarrassment and shame. An inevitable and seemingly unchangeable social hierarchy exists between the elevated normal bodies and the devalued abnormal bodies, thereby instituting a ranking in society between what Thomson (1997, p. 8) later called a “normate” and the disabled person. All these cultural meanings are experienced as self-evident, as anthropologist Clifford Geertz (1975, P. 22) observed when he wrote, “Truth is as plain, as the Dutch proverb has it, as a pikestaff over water,” or as Americans commonly say, as plain as the nose on your face.

Ed knew that even people who are family members of disabled persons or who have disabilities themselves were typically not immune to the cultural power of stigma. For example, when he was first assessed for rehabilitation services, the counselor who initially declared him “infeasible” was disabled himself.

His disability had hurt him a lot more than mine had hurt me, even though mine was a lot more disabled. He was a pretty down kind of guy. I think that it limited him more than it limited me (E. Roberts, 1994, p. 27-8).

The counselor limped, a relatively lesser bodily impairment by comparison to the quadriplegic Roberts. But the counselor’s depressive mood and belief that Ed’s paralyzed body rendered him unable to work or go to school were indications of the extent to which he had succumbed to the

pervasive cultural complex of meanings concerning disability. “Society’s expectations of us—very low expectations—have tremendous power over us” (E. Roberts, 2007b, p. 35).

Teaching disabled and non-disabled audiences as well as families of disabled persons, Roberts knew that the symbolic matrix of meanings, attitudes, feelings, and beliefs surrounding disability were not easily overcome. “Our number one issue is still old attitudes towards us, and those old attitudes see us as helpless and unable” (Page, 1995, n.p.). The standard cultural scripts encouraged disabled people “to have no expectations, “to believe that we will not work or participate in our... in our communities when in fact we’ve discovered that the reality is just the opposite” (E. Roberts, 1989, n.p.).

One reason for Ed’s strident optimism was his knowledge that because stigma as a social response to bodily difference is cultural, it is therefore learned. And it can be unlearned. His oft-told story about how his father warned him not to stare at a disabled woman at the county fair served as an example of how he had been enculturated as an American child into the conventional complex of stigmatized meanings about disability. The deep cultural meanings about human bodies was passed on from generation to generation, instilling an unquestioned understanding of what divergent bodies mean, including how one should feel and think about them and interact with them.

We don’t understand how we inculcate prejudice in people, but we do it. And prejudice is the worst thing around. In my case, I call it “handicapism.” It’s an -ism like sexism. It puts you apart, makes people think that you’re something other than what you are – that you’re weak, sick, and unable (Pfaff, 1985, p. 4).

Ed viewed the inculcation, this process of ubiquitous social learning, as a form of mass deception occurring casually in our midst. “(O)ur society has been brainwashed to fear us. People literally

*fear* us because of our disabilities. They have terrible misconceptions about who we are” (Tao of Ed, p. 25). Roberts’ pedagogy was a lifelong effort to correct those misleading and painful misconceptions.

Ed worked tirelessly to convince disabled people to throw off the illusion, the cultural lie, that their lives could not be rich and fulfilling (McBryde Johnson, 2003; Wolfe, 1993).

Why do we build self-hatred around this stuff, and actually be the people, become the people, who put us down? Today I try to teach that you make choices about how you feel—whether people stare at you or not. Misery is optional. (E. Roberts, 2007a, p. 17-18)

### ***Disability Solidarity in Berkeley***

During Roberts’ first year attending the University of California, Berkeley, he was the only disabled student living on an empty floor of Cowell Hospital, the campus infirmary. Dean Arleigh Williams arranged with Dr. Henry Bruyn, the medical director, to house Ed and his iron lung. The following year Roberts was joined by John Hessler, a tall man who had suffered a broken neck in a swimming accident in the San Joaquin River Delta and spent five years languishing at Martinez County Hospital. The two became fast friends and budding political comrades, working with Dean Williams and staff members across campus on creating greater architectural access for wheelchair users (Danforth, 2018).

Funded by a federal grant, the California Department of Rehabilitation (DR) increased the number of disabled students at Cowell Hospital in early 1968. By November, 1970, the program rolls had jumped to eighteen students. DR attempted to control costs in the expensive project by tightening the rules on the Cowell students, creating a series of intensive cost-benefit requirements designed to move the students through to graduation and employment more

quickly. Enforcing those new rules fiercely, the DR counselor ejected two of the disabled students from the program.

In September, 1969, Roberts and a group of Cowell residents calling themselves the Rolling Quads summoned Dr. Henry Bruyn to a meeting. “We’re organized and we’re taking over,” Roberts announced triumphantly (Bruyn, 1999). The disabled students had cultivated deep friendships over nightly discussions around an enormous dinner table on the hospital ward and over beer at a local pizza parlor. Uniting in a battle against the University and DR, they demanded that the reinstatement of the dismissed students and the removal of DR counselor. Convincing local newspapers to cover the story in a sympathetic way, Roberts and the Rolling Quads won their first disability rights battle (Berkeley Daily Gazette, 1969; San Francisco Chronicle, 1969). The students were reinstated, the counselor transferred, and the Rolling Quads gained greater control over the Cowell program (Danforth, 2018).

This first victory taught Ed that dramatic social change occurred when disabled people unify for a common cause. Leading the Rolling Quads, he not only felt that he was no longer alone in his experiences of rejection and devaluation. He discovered that an alliance among disabled people framing their concerns as political, viewing their destiny as shared rather than individual, gave them new power.

We began to be perceived as political animals. That changes the perception of you to (being) powerful. As you begin to get more and more empowered, you see yourself as powerful too. We realized that the only way to change things was politics (E. Roberts, 2007, p. 43).

This life experience set Roberts on a path of political work, crafting a new civil rights movement for disabled people that greatly mirrored the political movements of African-Americans and women in the United States (Danforth, 2018).

### **Teaching Strategies**

Roberts developed a pedagogy that employed performative strategies originally developed by American freak shows in traveling dime shows, side shows, storefronts, and circuses. Popular across the United States from the mid-1800s until at least the 1930's, freak shows were "formally organized exhibition(s) of people with alleged and real physical, mental, or behavioral anomalies for amusement and profit" (Bogdan, 1988, p.2). Oddly salacious performance characters consisting of unique bodily differences and foreign racial/ethnic identities were fabricated and displayed for monetary profit. Stigma was elaborately adorned and ornamented, leaving audiences amused, titillated, but also comforted by the familiar safety of the bodily, racial, and sexual norms of their own lives and communities. Experiencing a live (staged) freak involved a brief, almost intimate interaction with "a cultural transgressor" (Yuan, p. 375), provoking a fever of psychological perturbation resolved only by fleeing or immediately lining up to buy another ticket.

Noting that Ed's pedagogical practices—his theatrical showmanship, visual and linguistic rhetoric, and techniques of identity management—echoed the strategic stagecraft of historical freak shows does not imply that he was knowledgeable about or supportive of freak shows as a way of representing disability or publicly displaying disabled people. What it observes is that freak show producers and Roberts began with a similar understanding about how audience members experienced a severely impaired person through the common experience of social

stigma. Chemers (2008, p. 25) has commented that “a ‘freak’ cannot exist in the absence of pre-existing social stigma,” the dominant cultural meanings animated and energized in the staged interaction with the audience. Ed and the freak show producers knew well that audiences would stare, gawk, and turn away while experiencing an array of negative feelings and attitudes.

As Ed learned in high school, he had the students’ eyes, their attention, and that nameless, uncomfortable sensation in their gut. He discovered that he could utilize their fixated attention by refashioning that gaze of tragic pity into something more useful to his disability rights cause. Chemers (2008, p. 25) explains that “freakery requires conditioned theatrical conventions that often enter into subversive dialectics with that stigma.” The audience experienced an involuntary flood of thoughts and feelings that could be managed or manipulated by the performers to seek certain, pre-planned ends. The goal of American freak shows popular until the 1930s was to bring hidden levels of suppressed cultural judgments and sensibilities about human bodies to the uncomfortable surface, thereby titillating, teasing, and invigorating audiences.

Ed began with the same initial baseline of social stigma and used updated versions of freakery tactics to pursue radically different goals. He didn’t want to empty the pockets of his audience. He wanted to lead their minds and hearts to a profoundly expanded understanding of political freedom that included persons typically viewed as defined and defeated by their own failed bodies. He wanted to win them over to the social cause of seeking dignity and inclusion for disabled people in society.

Two features of freak show staging and performance rhetoric organized and animated Roberts’ teaching. First, at the very beginning of each presentation, Ed employed what Bogdan (1988, p. 107) called “the exotic mode” of presentation through which freak show performers

focused the audience's attention on "their anomalies as well as their 'strange ways,'" heightening the observer's interest and fascination with the appearance and operation of the unusual body. Ed developed a powerful visual rhetoric directing attention to his large wheelchair and the degree of his bodily impairment, drawing the audience into the very symbols of stigma they might have assumed or even hoped a quadriplegic speaker would avoid.

Second, Roberts created a disability rights version of what Bogdan (1998, p. 108) termed "the aggrandized mode" of performance. In the freak show tradition, the aggrandized presentation mode "emphasized how, with the exception of the particular physical, mental, or behavior condition, the freak was an upstanding, high-status person with talents of a conventional and socially prestigious nature" (p. 108). Ed certainly provided information and told stories that elevated his social status far above what one might expect of a paralyzed man. For example, he told audiences of the joys of fatherhood, demonstrating a sexuality and social position not expected of a man with his bodily condition.

But the mainstay of his teaching was a series of autobiographic accounts that positioned himself as an oppressed political figure fighting against discrimination, battling for justice and inclusion (Oda, 1995; Roberts, 1987, 1989, 2007a, 2007b, 2007c). While standard freak show performers achieved status in overcoming their bodily limitations, Roberts rose up by fighting and defeating the political forces that burdened disabled people. His many life stories that served as the centerpiece of his narrative pedagogy depicted himself as struggling for justice and freedom against people whose actions were built on prejudiced misunderstandings of disability. He portrayed himself as exemplary in pursuing his own freedom while also serving as the representative for all disabled people.

### **Exhibiting Body and Wheelchair in the Exotic Mode**

Roberts' teaching performances updated the freak show technique described by Bogdan (1988, p. 105) as the "exotic mode" of presentation. In the early freak shows, this mode consisted of the performer strategically stressing "the culturally strange, the primitive, the bestial, the exotic" in order to emphasize "how different and, in most cases, inferior the person on exhibit was" (p. 108). Bodies with physical features including impairments (e.g. missing limbs) as well as racialized aspects (e.g. dark skin, kinky hair) were the showman's template for the production of human curiosities. The goal was to call the audience's attention to aspects of the performer's body and identity that were the site and source of the greatest discomfort and anxiety. Roberts developed a series of performative maneuvers that effectively locked the visual focus of the observer on his wheelchair and his frail body.

Deaf actor Terry Galloway (2009, p. 158) once described the emotional and cognitive state of persons confronted with disability as an "epic absence of imagination," a thought-blanching state dominated by the stale cultural narrative of disability stereotypes. The stigma-delivering person's understanding of disability clung to thin notions of tragedy, pity, and isolation. The key strategy for the performer was to grasp that deer-in-the-headlights moment of effusive pity, a kneejerk social response when thought was dulled and static, to use that instant of heightened vulnerability as an occasion to turn the conventional political asymmetry around, giving the disabled person the upper hand.

As Roberts told audiences, "I can be paralyzed from the neck down and be up here in control of all of you" (Oda, 2003, p. 25). He often boasted jokingly, "If I look them in the eyes and they look away, I got 'em" (Weick, 2019). He knew how to use the oppressor's experience in the stigmatization interaction as a strategic opportunity. Whether meeting with the leader of an

affluent private funder such as the Charles S. Mott Foundation or presenting to a conference sponsored by the Massachusetts Department of Rehabilitation, Roberts' first performance move was wordless motion. He drew the audience's attention to his wheelchair and his respirator, to his impaired body and the devices that commonly invoked tragic tales of loss and woe. Joan Leon, his frequent partner in fundraising efforts for many years, described this opening ploy of his fundraising pitch.

The funny thing was he would use his wheelchair. He'd come in, and the person we had come to see was usually--I could watch their eyes go immediately to the wheelchair.

Then he'd lower his feet up and down. Sometimes he would flick his light on. He would push this thing back. He would play with it. It would just mesmerize someone. (Leon, 2000, p. 23)

Before Roberts launched into his life narrative, he skillfully entranced the fund leader in the negative cultural aura of the wheelchair, the ultimate symbol of physical disability. While the philanthropist most heartily hoped to avoid the awkwardness and discomfort that might occur in meeting with a paralyzed man in a wheelchair, Roberts immediately danced the symbols of stigma in his face.

Roberts frequently employed the same theatrical staging at the start of a speech to a large audience, moving his giant wheelchair back and forth like a hypnotist swinging a gold watch on a chain. He paired this with a statement of gratitude thanking his personal attendants by name for caring for his body, helping him travel many miles, and making his presentation possible. At the start of the teaching, these strategies highlighted the nature of Robert's bodily condition, a man fed and bathed by care workers, and set the stage for the autobiographic narrative Roberts was about to deliver (Oda, 1995, p.4; Parames, n.d., p. 4).

The viewing audience was stunned by his appearance and dropped quickly into a mini-fugue state awash with culturally prescribed emotions and beliefs. They were captured by the dominant cultural meanings—pity, shame, fear, sadness—concerning a polio-paralyzed body in a wheelchair. As if drenched by a sudden rainstorm of negative social understandings, attitudes, and emotions, they experienced an overwhelming combination of discomfort and revulsion. One might assume that the audience was not at all ready to learn, not prepared to use their cognitive abilities to consider new information or concepts. But Roberts (1987, 2007a) found them ripe for what he quite openly described as manipulation. They were vulnerable in the moment, and Ed was ready to take full advantage. His teaching yanked them firmly away from the brainwashing misconceptions of disability prejudice and invited them to share in provocative stories of a paralyzed man fighting for justice in an unjust society.

Roberts often taught other disabled people that an attitude of pity was a weakness waiting for the skilled disabled person to use to strategic advantage.

(W)hen people stare at me, when they look at me, as so different that, in a way, they want to feel pity, or feel sorry for me.....I can probably get anything I want out of them, because I can manipulate the hell out of them. While they see me as weak and unable, I'm not, and I come on strong and capable while they're staring at my wheelchair and my respirator and feeling entirely sorry for me. I can use that. It's a very powerful tool, and it's something we should teach people to use practically. (E. Roberts, 1987, 2007a)

Properly managed, the social interaction of impaired body and interacting person producing stigma could be commandeered by the crafty performer and pushed forward toward ends that upended the semiotics of stigmatization itself. The purpose of this maneuver was not charity or

profit but justice, strategically winning the staring or pitying person over to support the equality and dignity of the disabled person.

### **Narrating Life Stories in the Aggrandized Mode**

The original purpose of the aggrandized mode in the early freak shows was to offer elements of a normative identity, whether true or false, that ran directly counter to the totality of the freak presentation (Bogdan, 1988, 1996).

The thrust of the aggrandized mode was to claim that the exhibit...in spite of his or her particular physical, mental, or behavioral anomaly, was an outstanding person...Such attributes as social position, achievements, talents, family, taste, intelligence, and physiology were fabricated, elevated, or exaggerated, and then flaunted (Bogdan et al., 2012, p. 11).

For example, two nineteenth century women performers both known professionally as the “armless wonder,” Frances O’Connor and Ann E. Leak Thompson, posed for promotional photographs emphasizing their normal abilities. O’Connor held a teacup with her foot, showing off her physical and social grace. Thompson posed with toes grasping scissors while doing intricate needlework (Bogdan et al., 2012, p. 11, 14).

Ed Roberts’ pedagogy employed features of this aggrandized tradition, raising his status through examples of normative achievements and activities that seemingly defied his bodily paralysis. He often told audiences of his marriage and his son Lee. He described career accomplishments such as earning a graduate degree and leading the Berkeley CIL and the California Department of Rehabilitation. He regaled listeners with surprising physical exploits, swimming with dolphins and whitewater rafting trips. At some presentations, he gave dramatic

self-defense demonstrations of karate skills that he had developed in training with instructor Tony Johnson (Campbell, 1990; Goode, n.d.).

But Roberts' use of the aggrandized performance mode pushed far beyond the traditional freak show ends, for he did not merely intend to convince audiences that a disabled man was capable of a few conventional attainments. Persuading audiences that disabled people could match nondisabled people on dominant social norms such as appearance, activity, or intelligence ignored daily political realities of disabled people. The challenges confronted by disabled Americans and their greatest achievements, as detailed repeatedly in Roberts' many stories of his own experiences, were political. The primary obstacles to participation and success for Roberts and for disabled people were "the old attitudes of patronization," the same cultural norms of discrimination and stigmatization that Roberts confronted in high school (Roberts, 1981). The life of a disabled person, if lived according to the teachings of Ed Roberts, was a series of righteous battles for justice.

Roberts (1987, 1989, 2007a, 2007b, 2007c; Oda, 1995) highlighted autobiographic selections that portrayed himself as the target of political oppression due to his disability. He was not a victim of polio, as he once fiercely barked at radio interviewer Larry King (1990). He was a proud and persistent fighter for the civil rights of a devalued people. His public presentations told a standard repertoire of about a dozen stories about his life that portrayed the perpetrators of injustice as uninformed and foolish. In each, confronted with forces of cruelty, Roberts and his allies—in the early years his mother Zona and later members of the Berkeley disability community—fought for the American values of freedom and equality. By the end of each story, the dramatic conflict was resolved with a victory for Roberts and disabled people everywhere.

Roberts taught that his path to successful participation in society was blocked not by his own body or illness but by foolhardy public officials and professionals who unthinkingly perpetuated discriminatory attitudes about disability. Roberts was the misunderstood and falsely maligned character fighting for the respect withheld from people like him. The story line involved political conflicts concluding with his hard-won victories, not only teaching the audience about Roberts' many years fighting against the forces of disability discrimination but also displaying the pursuit of political justice through struggle as the model life for disabled people living in an oppressive society. In 1992, he advised an audience of disabled people and family members completing training in disability advocacy strategies in the Partners in Policymaking program, "Now it's time to go out there and question authority and create a new way for people with disabilities to be free" (Haugan, 1992). This was the prime lesson of his many autobiographical narratives.

### **Education Yet to Be Done**

In June, 1992, Roberts received a letter from Katie Snow, a Colorado mother of a son with cerebral palsy and a fierce disability rights advocate (e.g. Snow, 1993). She and Ed were regular faculty members in the Partners in Policymaking program, providing disability advocacy training across the country (e.g. Zirpoli et al., 1989). Snow related a story about a discussion she had with a participant in the Partners training in Dallas. The woman was a member of the Arkansas Developmental Disabilities Council, and she "had an adult daughter in some kind of institution & sheltered workshop." She approached Snow and exclaimed, "You people scare me!" Snow explained, "She's very frightened when she hears people like me talking about closing institutions, workshops, etc., but what will happen to her daughter?"

Snow tried to reassure the woman that closing state institutions and sheltered workshops meant transitioning adults with intellectual disabilities to “options and choices for community living, employment, etc.” The woman was not easily comforted. She demanded, “Well, what about that Ed Roberts sitting up there saying ‘Just shut them all down!’?” (Snow, 1992). Despite Snow’s repeated efforts to explain that “we weren’t talking about throwing people out on the street,” the Arkansas mother remained disturbed by the blunt, radical tone of Roberts and others at the meeting. Katie Snow (1992) concluded in her letter to Ed, “It’s scary to think of how much education is yet to be done—and to think that you’ve been doing this for how many years???”

Katie Snow was correct that, by the early 1990’s, Ed Roberts had been teaching audiences about independence and disability rights for two decades. She was also correct that, although landmark civil rights legislation such as the 1973 Section 504 and the 1990 Americans with Disabilities Act seemingly ushered in a new day of inclusion and equality for disabled Americans, Ed’s teaching changed little. It didn’t need to. The social problem at the center of his teaching, the “old attitudes” that he often groaned about, remained doggedly persistent in American society.

Katie Snow made one last statement in her letter to Ed that captured his attitude about this apparently depressing situation, “I love the challenge ahead!” She and Ed both found joy and purpose in the fight itself. Ed’s teaching celebrated the many times he defeated disability discrimination. While his tales featured the victories, no student of Roberts could overlook the many, obvious defeats that Ed and disabled people everywhere experienced daily. It was only against the enduring and painful backdrop of those numerous losses that Roberts’ tales of disability rights battles won had any meaning. The unspoken sub-text of every Ed Roberts autobiographic narrative about his own personal struggles to overcome ableism was the reality

that Ed and other disabled people had little choice but to fight every day. Teaching in that struggle was the challenge that gave him energy and purpose.

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