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### Star Performances: Ed Roberts on the Speaking Circuit, 1983-1995

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## Star Performances: Ed Roberts on the Speaking Circuit, 1983-1995

### Comments

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# Star Performances: Ed Roberts on the Speaking Circuit, 1983-1995

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## Keywords:

Ed Roberts; performance; celebrity

## Abstract

This article uses historical research methods to explore noted disability rights leader Ed Roberts' performances on the speaker circuit between 1983, when he left his position as director of the California Department of Rehabilitation, and his death in 1995. This article examines how he managed his performed identity, his self as presented on stage, in order to be a disability star. Using his own life story as a poignant example, he narrated an autobiography of how a paralyzed man could live a vigorous, successful, indeed a joyful life. His personal stories communicated his lived experiences of battling discrimination and stereotypes. Roberts skillfully and strategically marshalled his own growing celebrity as the most prominent disabled American while he promoted the cause of civil rights for disabled people.

Disability rights activist Harriet McBryde Johnson (2003) was worried about losing her independence. A disabled woman who used a wheelchair, she was living on her own. But she feared that her medical condition would deteriorate or she'd run short on the funds needed to pay for necessary support services, and she'd end up in "the disability gulag," (Johnson, 2003, p. 59) ~~the~~ ~~has~~ ~~about~~ ~~45~~ ~~of~~ ~~in~~ ~~stitution~~ ~~with~~ ~~each~~ ~~whose~~ ~~"~~ ~~disability~~ ~~people~~ ~~,"~~ ~~he~~ ~~is~~ ~~changing~~ ~~everything~~ ~~that~~ ~~exists~~ ~~."~~ ~~When~~ ~~she~~ ~~attended~~ ~~John~~ ~~Ed~~ ~~Roberts~~ ~~speaking~~ ~~and~~ ~~literally~~ ~~turns~~ ~~her~~ ~~life~~ ~~around~~ ~~is~~ ~~not~~ ~~what~~ ~~he~~ ~~has~~ ~~done~~ ~~.~~ ~~Not~~ ~~what~~ ~~he~~ ~~is~~ ~~saying~~ ~~.~~ ~~Not~~ ~~who~~ ~~he~~ ~~is~~ ~~.~~ ~~It's~~ ~~his~~ ~~presence~~ ~~."~~ ~~While~~ ~~his~~ ~~body~~ ~~is~~ ~~"~~ ~~frail~~ ~~"~~ ~~and~~ ~~"~~ ~~decrepit~~ ~~,"~~ ~~Roberts~~ ~~is~~ ~~also~~ ~~"~~ ~~tough~~ ~~and~~ ~~amazingly~~ ~~funny~~ ~~."~~ ~~He~~ ~~takes~~ ~~a~~ ~~"~~ ~~bad-boy~~ ~~delight~~ ~~in~~ ~~truth-~~ ~~telling~~ ~~"~~ ~~and~~ ~~he~~ ~~is~~ ~~filled~~ ~~with~~ ~~"~~ ~~hellcat~~ ~~gusto~~ ~~for~~ ~~proving~~ ~~the~~ ~~world~~ ~~wrong~~ ~~."~~ ~~Concisely~~ ~~capturing~~ ~~the~~ ~~experiences~~ ~~of~~ ~~many~~ ~~disabled~~ ~~people~~ ~~,~~ ~~family~~ ~~members~~ ~~,~~ ~~advocates~~ ~~,~~ ~~and~~ ~~professionals~~ ~~who~~ ~~observed~~ ~~an~~ ~~Ed~~ ~~Roberts~~ ~~performance~~ ~~,~~ ~~Johnson~~ ~~(2003~~ ~~,~~ ~~p.~~ ~~62)~~ ~~concluded~~ ~~,~~ ~~"~~ ~~A~~ ~~life~~ ~~like~~ ~~his~~ ~~can~~ ~~turn~~ ~~a~~ ~~life~~ ~~like~~ ~~mine~~ ~~upside~~ ~~down~~ ~~."~~

Stardom was anything but a possibility when fifteen-year-old Roberts first returned home from San Francisco Children's Hospital after eighteen months of polio treatment and rehabilitation. He attended classes at Burlingame High School via a two way audio hook-up installed in classrooms and the Roberts' home by volunteers from the local Sorooptimists Club. The polio virus left his athletic body paralyzed from the neck down except for slight movement capacities in his left hand and foot. His damaged neurological system abandoned the diaphragm muscles of the abdominal and thoracic cavity, rendering him unable to breathe. Lying in an iron lung with only his head visible, the six foot one, eighty-five pound adolescent listened to high school lectures on

a speaker and tapped a pedal with his foot to speak to the teachers and classmates (Roberts, Z., 1994; Roberts, Z., 1996; Roberts, Z., 2018).

During his senior year, Roberts' mother Zona insisted that he attend class in person. She reasoned that neither Ed nor she would have much of a future if he remained on eternal convalescence in the dining room. The thought of rolling into the high school frightened Roberts. His father Verne had helped him attend high school football games by parking the family station wagon at the base of the end zone, allowing him to remain concealed from the fans in the bleachers. He wrote a regular column about the team for the school newspaper. But he did so without allowing his classmates to see his body or wheelchair. Roberts understandably feared that his friends and neighbors, upon seeing his muscular frame reduced to a gaunt shell propped up by a corset in a wheelchair, would stare at him like a side show oddity (Roberts, Z., 1994; Roberts, Z., 1996; Roberts, Z., 2018).

On the traumatic first day back in high school, his brother Ron, three years younger but by then also a senior, pushed Ed's wheelchair into the commons area where hundreds of students gathered for lunch. "My worst fear," Roberts later recalled, "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). His darkest fears came true that day. Driven by what Chemers (2008, p. 31) calls "prurient curiosity," tantalized by the desire to see a polio ghost of a boy, the high school students stared at him. When he looked back at them, they turned away (E. Roberts, 1994; E. Roberts, 2007).

Two factors working in Roberts' favor in those initial weeks on the high school campus were his push wheelchair and his brother Ron's social stature. It would be another decade before electric wheelchairs would hit the market. The push wheelchair required someone to accompany him from classroom to classroom throughout the day. Much like Ed, Ron was an outgoing, handsome young man who excelled at sports and understandably attracted a fair amount of female attention. He was a well-known athlete on the school campus, a standout on the tennis and basketball teams. Ron's presence at the helm of the wheelchair allowed Ed to meet and charm the young women who quickly volunteered to take over duties ferrying Ed about the campus. The enjoyment of female company undoubtedly contributed to Ed wondering if being the most visibly striking and unusual person at Burlingame High School and the object of tremendous visual curiosity might lead to something more livable than stigmatization and humiliation. Perhaps, the grandiose teen imagined, all eyes might be cast upon him as he entered the room not because he was physically grotesque or strange but because he was a star (Ed Roberts, 1994; M. Roberts, 2018).

In his frequent re-tellings of this episode of his life, Ed Roberts boasted that he suddenly decided through the volitional flip of a cognitive switch that his high school classmates ogled him because he was a celebrity. He simply dropped stigma and chose stardom. More truthfully, becoming a disability star, a renowned figure soaked in the adoration of thousands of fans who were drawn to his public persona as a new and exciting kind of disabled person at the forward crest of a new civil rights movement, required years of intentional and effortful development by Roberts (E. Roberts, 1994; E. Roberts, 2007; King, 1990).

Stigma is, in the writings of the sociologist Goffman (1959, 1963), a product of a mode of social presentation occurring in interaction that actively devalues a person's status. Stigmatization involves the feelings, thoughts, and behaviors of both the targeted person and those who participate by way of interaction. But what Roberts realized, as if he were the top student in Goffman's class, was that stardom too is manufactured by the management of identity, through the social practices and attitudes of those involved. Stigma and stardom both required voluminous, almost involuntary acts of social attention. Roberts understood as a high school senior in a wheelchair that his classmates had placed him under a bright spotlight on a theatrical stage. Reflecting the conventional view of disability in the 1950s, they cast him in a role and a narrative that he viewed as intolerable. He made it his goal to rewrite the stigmatized script in order to create himself as an elevated rather than a denigrated figure, accepting the over-attention while remaking his own social status.

This article focuses on the presentations and speeches Ed Roberts made between 1983, when he first left his position as leader of the California Department of Rehabilitation, and his death in March, 1995. He undoubtedly made many speeches before 1983. But January, 1983 was the moment when, freed from the state agency leadership position he held for eight years, he devoted himself fully to spreading the liberating message about what he had experienced and learned about independent living. During the final thirteen productive years of his life, Roberts traveled the United States and the world, teaching audiences about the possibilities of a new freedom for disabled people. Using his own life story as a poignant example, he narrated an autobiography of how a man with an unmoving body mobilized by an electric wheelchair and oxygenated by a portable ventilator tube at the corner of his lip could live a vigorous, successful, indeed a joyful life. His personal stories communicated his lived lessons of battling discrimination and stereotypes at every turn. Logging over fifty thousand airline miles per year, appearing in at least twenty-nine states and ten countries on four continents, Roberts skillfully and strategically marshalled his own growing celebrity as the most prominent disabled American to promote the cause of civil rights for disabled people (Oda, 1996). His friend Chris Parames described him as the "master of his craft...a performance artist whose starring vehicle was the story of his life." (Parames, n.d., p. 4). He was a showman, storyteller, provocateur, comedian, salesman, egalitarian, and, by self-conscious design and with unhesitating relish, celebrity.

This article uses historical research methods, chiefly drawing from interviews and archival documents, to explore Roberts' performances on the speaker circuit. Focusing mostly on his busy schedule of domestic presentations across the United States, this article examines how he managed his performed identity, his self as presented on stage, in order to be a disability star. He was widely recruited by disability advocates, professional groups, and community organizations to speak to large audiences, typically in the hundreds, and regularly received large speaking fees (paid to the World Institute on Disability) of up to \$3000 (Haugen, 2019; Colorado Interagency Conference, 1990). Performing often and in many venues, he became the star of the growing disability rights movement in the United States.

## **Disability Stardom**

The tradition of disability stardom in the United States likely begins with the mid-nineteenth century headliners of prominent, national freak shows. While most freak show performers toiled

in the relative poverty and obscurity of traveling dime shows, side shows, storefronts, and circuses, a few disabled stage performers such as Charles Sherwood Stratton (Tom Thumb) and William Henry Johnson (Zip What is It?) achieved fame and wealth under the management of ambitious theatre producers like P. T. Barnum. The complex and elaborate staging strategies of early freak shows narrated ambiguous character identities across a cultural landscape of stigma and acceptance, deviance and normality, producing a combination of anxiety and exhilaration among large audiences (Bogdan, 1988; Thomson, 1996; Koppers, 2004; Chemers, 2008).

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) fabricated and typically fraudulent displays of human differences for monetary profit. Stigma, elaborately adorned and ornamented, was sold in ways that left audiences perversely amused yet also comforted by the reified safety of bodily, racial, and sexual norms as well as their own unthreatened status. Audiences experienced an up-close, confrontation with staged bodily displays felt to be beneath common decency and beyond imagination, "a type of theatricalized transgression...(that) challenges boundaries of gender, sexuality, and race" Yuan (p. 370). Apprehending a freak involved a brief, semi-intimate interaction with "a cultural transgressor," (Yuan, p. 375), a live yet contrived blurring and subverting of conventional cultural norms, resulting in the sort of excited psychological perturbation that can only be resolved by either running away quickly or immediately lining up to attend the show again.

Ed Roberts exhibited himself and his own life in relation to common experiences of stigmatization through similar performance techniques, but to dramatically counter-political ends. His autobiographic stories reconstrued stigma not as a natural outgrowth of a disabled body but as a social act carried out upon a disabled person, as an interpersonal insult perpetuated by stigmatizing people who typically didn't know better. His performative life story featured his struggles – actions of cleverness and courage - to defeat those who unthinkingly and cruelly enforced stigma and limitation on disabled people. In his public performances, Roberts embodied a repeatedly and persistently devalued character refusing lesser status and thereby living a successful and full life. "Never was a big star more frail," wrote Harriet McBryde Johnson (2003, p. 62). He dreamed up and delivered himself as a star by taking intentional advantage of the culturally conditioned feelings of pity and anxiety felt by the audience confronting his displayed frailty while arming his performance with the liberating message of the disability rights movement (E. Roberts, 1987; E. Roberts, 2007).

### **"When others speak for you, you lose"**

Roberts rolled off an airplane in Melbourne, Australia in January, 1983, to a bevy of reporters and exploded with "a loud yell...and a machine-gun pace story of love, pain, strength, radicalism, sex, and a new life for the world's disabled." (Molloy, 1983, p. 1). Liberated from his eight year post as director of the California Department of Rehabilitation at the end of Governor Jerry Brown's second term, in his own words "battered" by the experience of being a disabled man leading a largely intractable disability service bureaucracy, Roberts enthusiastically dove into his post-government life (Molloy, 1983, p. 1). He was alive and free, and he had something to say. He immediately set the distinct tone and purpose for the next thirteen years of touring and performances with a triumphant speaking tour of Australia. The media and government leaders

received him as an esteemed international diplomat. He made an address on independent living to the directors and administrators of the national rehabilitation service (Leeman, 1983). Leaders in Victoria arranged for his consultation on early childhood service programs (Hoff, 1983). Melbourne government officials took him on ceremonial tours of local hospitals and rehabilitation facilities. His visit to the polio respiration ward of Fairmont Hospital left the patients excited about the possibilities of living in the community with a portable respirator. He was like the first man in town who owned a gas-powered automobile, driving down Main Street, honking his horn, encouraging the citizenry to graduate from their horse and carriage lives (Reid, 1983).

The single speech of that Australia tour that provides the most insight into Roberts' thinking about himself as a public speaker and his sense of purpose was given at the first National Assembly of Disabled Peoples International (DPI) in Melbourne. DPI was a fledgling international group of disability activists, a group of upstart disabled people from around the world who broke loose from the straitjacket of the professionals in Rehabilitation International. Roberts had already taken a leadership role on the DPI World Council. His speech, though less biographic than what would become his standard talk in the upcoming years, featured The Artichoke Story, a pithy, humorous, corny morsel of memoir that called disabled people to rally together and be defiant in the face of the usual affronts.

When I was fourteen, I got polio. When the doctor took my parents aside, my mother asked, "Will he live?" The doctor looked at her and said, "You should probably hope he dies, because if he lives he will be nothing more than a vegetable for the rest of his life." Well, I'm here today as an artichoke. You know they're a little prickly on the outside with a big heart and I'd like to call on all the vegetables of the world to unite. (E. Roberts, 1983, p. 7)

This brief story would become a staple of his performative repertoire, one of about dozen experiential narratives that were regular bits in his routines over the years. Speaking to a friendly audience, to what he viewed as his own people, he declared the commitment of his public work: to remake himself with humor and intentionality while unifying all disabled people, like the Karl Marx of the disability revolution. "No one else will do it for us," he preached to the activists, "(W)hen others speak for you, you lose" (Roberts, 1983, p. 7). Disabled people needed to speak for their own rights and needs, and that was what Roberts unflinchingly did.

## **Autobiography as Teaching**

The content of Roberts' presentations consisted primarily of brief episodes of his own life story choreographed to teach lessons about the power of independent living, how virtually any person with a disability could live a rich, satisfying life in the community if the necessary services and supports were not only available but were controlled by the disabled person. The key was to wrestle control from the many institutions, organizations, and professions that provided assistance to disabled people, but, in Roberts' narratives, hold them back by making the most important life decisions for them. In the film *Freewheeling*, Roberts explained:

Independent Living is a psychological idea much more than a physical concept. I'm paralyzed from the neck down, but I am completely in control of my own life. I make decisions about what

I want. And when you begin to believe that it is very empowering and powerful. And then it becomes, it catches on with other people. They see well, if he can do that, why can't I? (Page, 1995)

The path to securing this control and using it to forge your own life, Roberts taught, was a personal and political struggle demonstrated in his own life story. He optimistically evangelized what he had lived and what the Berkeley Center for Independent Living sought to promote, which was the value of the struggle for disabled people to make the most important decisions about the daily and long-term character of their own lives.

Roberts highlighted and dramatized autobiographic selections that portrayed him as the target of political oppression based on his disability. His standard series autobiographic stories depicted the perpetrators of injustice as narrow-minded, foolish, and insensitive. In each tale, confronted with forces of cruelty, Roberts and his allies – frequently his mother Zona and members of the Berkeley disability community – fought for the unquestioned American values of freedom and equality. Typically, the dramatic conflict was resolved with a victory for Roberts and therefore disabled people everywhere.

Roberts' purpose was to both celebrate his own achievements but also to hold those accomplishments up as examples of what disabled people could and should do by uniting and advocating for themselves. His approach nurtured and even assumed commonality and unity across different types of disabilities, often understating confounding factors such as race and gender in the telling of a simplified, generic disability narrative. Given his own experiences at the Berkeley CIL and the California Department of Rehabilitation, Roberts was fully aware of the complications of unifying all disabled people (as well as the elderly) under a common umbrella and identity (California Department of Rehabilitation, 1981; Leon, 2000). The earnest plainness of his personal narratives embraced and encouraged a singular notion of disability across impairments and demographics, a performative strategy that positioned his own identity as symbolic of all disabled people.

One stock tale recounted how Roberts graduated from Burlingame High School in a suburb of San Francisco. He had completed all of the academic courses needed for a high school diploma. But the Principal informed Roberts and his mother Zona that he could not graduate until he fulfilled two additional requirements, physical education and driver's education. This story spotlighted the ridiculousness of the school leaders requiring a paralyzed man to engage in physically impossible activities. At one point in a heated exchange between the school leader and Zona, the Principal said, "You wouldn't want a cheap diploma, would you?" (E. Roberts, 2007, p. 19). Zona threw the man out of her house. Mother and son took the issue to the next meeting of the school board, where they easily prevailed (E. Roberts, 1994, 2007; Oda, 1995).

Similarly, Roberts' story about getting admitted to the University of California, Berkeley, involved a battle with both university administrators and a state rehabilitation counselor. Roberts had proved his academic talents by earning good grades and an Associate Degree from the College of San Mateo. When he applied to the University, an administrator rejected him because of his disability, saying "Well, we tried cripples, and it failed" (E. Roberts, 2007, p. 29, Shapiro, 1993, p. 45; Oda, 1995). A rehabilitation counselor, a man who had a disability himself, turned



Roberts down for state educational funding, declaring him "infeasible," not able to be employed due to the severity of his disability (Roberts, 1994, p. 27). Roberts and his mother Zona, with support from instructor Jean Wirth and Dean Phil Morse of the College of San Mateo, argued that his community college record demonstrated his capacity to succeed at Berkeley. They were able to convince the university and rehabilitation administrators to change their initial decisions (Roberts, 1994; Oda, 1995).

These two examples and the Artichoke Story demonstrate the standard narrative tropes that repeat in many of Robert's autobiographic presentations. The path to Roberts' successful participation in society is blocked by foolhardy public administrators who unthinkingly accept the conventional cultural assumptions about disability. As Roberts (1987, p. 3) observed, "(S)ome people who choose to go into professions are so wound up in trying to help, and, in a sense, take over for you." Those people have low expectations for the lives of disabled people, and they assume that only a nondisabled persons or professionals have the competence to take charge of a disabled person's life. This sets up a fight. Roberts and his supporters battled with the administrators or professionals, claiming that Roberts was deserving due to his prior achievements, talents, and hard work. He was the misunderstood and maligned character fighting for the respect he deserved. The story concluded with a Roberts triumph, a victory for the righteous cause.

Roberts undoubtedly lost many struggles in his life, particularly during his time directing the California Department of Rehabilitation. His eight years leading the largest rehabilitation agency in the country rarely provided content for the victorious life stories Roberts performed on the stage. The plot line for his performed personal narratives generally involved conflicts ending in his hard won victories, clearly demonstrating to the audience that Roberts' status and celebrity were the product of many years of struggles against the forces of disability discrimination, and passionately calling for the audience members to take up the same challenge of pursuing a life battling for disability rights.

## **Here, There, Everywhere**

Reaching out in every direction possible, Roberts accepted invitations to speak to a stunning array of different organizations. He carried a heartfelt message about independent living and the powerful but overlooked talents of disabled people, and he was willing to preach to anyone who would pin a microphone on his lapel. Audiences as divergent as Girl Scouts and meat packers enjoyed the autobiographic tales of the smiling man in the big wheelchair. In March, 1984, he gave a talk to the Girl Scouts of Denver about the implications of the independent living movement for public education. He was a strong, early proponent of what is now called inclusive education, teaching disabled students and nondisabled students together (E. Roberts, 1984). In February, 1993, Roberts was the invited keynote speaker at the Reno convention of the Western States Meat Association, an industry group of meat processors and distributors. Speaking in a convention that included sessions on nutrition labeling and reducing packaging waste, Roberts updated the audience on the labor law implications of the Americans with Disabilities Act (ADA) (Nowak, 1993).

University conferences and courses frequently invited Roberts to be a guest speaker. He gave a keynote address at the University of California, San Francisco's 1985 "Mind and Medicine" conference, speaking on the emotional life of people with physical disabilities (Slobin, 1984). His 1990 keynote at a Syracuse University conference explored how people with severe disabilities could live independent lives when provided with adequate supports such as personal attendant care (Racino, 1990).

In the late eighties, Roberts was a regular contributor to a Stanford medical school course on the psychiatry of physical disability, often appearing in guest speaker lineups with academic luminaries such as Albert Bandura and Irvin Yalom (Spiegel, 1988; Stanford Psychiatry Program, 1990). He also established strong connections with faculty and students at San Francisco State University (SFSU). He served on the Advisory Council of the SFSU Supported Employment Training Specialist Program (San Francisco State University, 1988). In 1993, presenting as part of an SFSU counseling course on "Employment and Disability," a class specifically for disabled students to learn how to navigate the harsh job market, he critiqued the common myths about disabled workers, portraying them instead as capable and consistent employees too often overlooked by companies (San Francisco State University, 1993). He taught SFSU special education students about the disability rights movement in spring semester, 1995 (San Francisco State University, 1995).

Local churches and civic organizations also hosted Roberts' presentations. The devoutly secular activist spoke at the "Second Annual Celebration of the Wholeness of the Family of God" at Christ Community Church in Carmichael, CA in October, 1983 (Jones, 1983). He taught a workshop for disabled people about how to hire and manage their own personal assistants in June, 1992, at the San Francisco Unitarian Church (1992). The Kiwanis of Santa Ana, CA and the Rotary Club of San Carlos, CA invited Roberts to teach their members about the independent living movement (Headland, 1985; Snider, 1992). Raymond Snider (1992), leader of the Rotary Club, described the impact of his luncheon speech: "I received nothing but positive feedback from the members...I'm sure after your talk that we are all now more conscious about the needs of all disabled people and realize that they are, in fact, JUST LIKE EVERYONE ELSE (caps original)."

## **Supporting Local Disability Rights Organizations**

Frequently, the agencies and organizations that hosted Roberts' talks used his fame to bring new energy and excitement to their local disability rights activities. He was a celebrity who gave additional weight and credence to their work. "Your presence will be a real boost for our activities and program," wrote a Michigan independent living center leader in anticipation of Roberts' visit. "I'm seeking your input and guidance," she requested after lamenting the lack of activism among the disabled population and the poor responsiveness of disability service providers. She wanted Roberts to reenergize a politically dormant disabled citizenry while "get(ting) the 'bureaucrats' to act in a more cooperative manner" (Wall, 1991).

Rosemary Creston (1984), the head of disability services at Colorado State University, commiserated that she was "frustrated by the conservatism," the patronizing attitudes and the slow pace of change on her campus and in the local community. She wrote Roberts a five-page,

single spaced letter detailing the many attempts to improve access and support for disabled university students and local disabled people in the community and public schools. Anticipating Roberts's upcoming campus presentation entitled "Beyond Disability," she hoped that his presence could revive stalled social change efforts: "I feel your presence here can do much to break the shell by which we seemed to be surrounded."

In some cases, local disability activists attributed specific victories and advances to Roberts' recent visit to their cities. Kirk MacGougan (1990) of the Albuquerque Coalition for Disability Rights (CDR) boasted to Roberts that "two city councilors who heard your speech have presented a bill to retrofit Albuquerque's main line haul buses. Obviously, your visit to (Albuquerque) had an impact on accessibility projects on which the CDR has been working." Georgia Keough (1991) of the Kalamazoo Center for Independent Living credited Roberts' complaints about poor access and service in the local airport with a groundswell of criticism resulting in architectural revisions: "The airport is in the process of renovating to increase accessibility."

When Roberts spoke to the Iowa Protection and Advocacy (P & A) Services in Des Moines in fall, 1993, the organization was gearing up for a class action lawsuit against the State of Iowa. They were working to close large institutions for persons with intellectual disabilities in favor of local community residential support options. P & A Director Sylvia W. Piper (1993) asked if she might "consult with (Roberts) regarding the campaign," seeking his wisdom and experience in the development of an effective legal strategy. Roberts was viewed as a high-profile expert whose skills of strategy and activism could be applied to virtually any disability issue.

## **Struggling with Disability Service Professionals**

Not all audiences greeted Roberts as the celebrated conqueror of disability discrimination. Perhaps the most challenging audience for Roberts to win over were the disability service professionals, the special educators, rehabilitation counselors, psychologists, and physicians. He made relatively few presentations to these groups by comparison to his many speeches to the friendlier, disability rights and advocacy organizations.

Over many years Roberts developed a rocky relationship with the professionals who specialized in disability services. As Director of Rehabilitation in California, he had achieved a mixed reputation among the career professionals who provided employment support services. He believed that professionals who traditionally controlled services and finances should greatly relinquish control to the 'consumers,' the recipients of the services, thereby allowing those persons a greater sense of autonomy, freedom, and responsibility. This shift was at the heart of the independent living concept that he pursued fervently (California Department of Rehabilitation, 1981). He also pushed the agency to halt the practice of "creaming" whereby rehabilitation counselors worked primarily with people with milder or more temporary impairments in order to boost their successful outcome statistics. Roberts installed policies that pressed counselors to serve clients with severe disabilities that had often been overlooked. These priorities and policies won over some progressive rehabilitation counselors who wanted the agency to be more ambitious, but many career bureaucrats viewed Roberts as an odd, radical intruder who knew little about their professional work. This was not surprising given that many

of the stories that he told in agency meetings about his own life experiences depicted professionals as foils who cruelly tried to block his path to success (Collignon, 2019; Jiminez, 2019; Leon, 2018).

In fall 1986, Roberts' friend Jean Kohn of the University of California, Berkeley, School of Public Health sent him information about the Fourth Pan American Conference on Rehabilitation and Special Education in Acapulco, Mexico. Perhaps thinking the sunny destination would be an added enticement, Kohn encouraged Roberts to ask the conference organizers if he could speak.

I realize that most of the people at this meeting will be professionals, and one of the major effects I can see of your participation is to shift the emphasis from 'doing for the disabled population' to 'the disabled population taking charge for itself', a view many professionals have trouble with...If your phone call does nothing more than remind the program coordinator that every international meeting about disabled children should have representatives of that group and their families present, you will have done a service (Kohn, 1986)

Even if the conference turned him away, Kohn hoped that Roberts' request would notify the professional group that disabled people deserved to and expected to have a real voice in their own lives. Roberts made a presentation at the March, 1987 conference, one of the few times he was not the keynote speaker. His talk focused on how the life experiences and lessons learned of disabled adults who had worked in the independent living movement could serve as wise advice for disabled children and youth in their quest to live independent lives (Castillo, 1986).

Audiences of professionals often viewed Roberts with a degree of impatience and skepticism. His presentation on "supported work, a new pathway to competence" at the 1992 Building Partnerships that Lead to Supported Employment conference hosted by the Rehabilitation Research and Training Center at Virginia Commonwealth University received tepid reviews (Brown-Glover, 1992). By comparison to the common professional presentations with Powerpoint slides and empirical evidence, Roberts' life stories came off as disorganized, anecdotal, and rambling. Rehabilitation professionals appreciated that he provided "much insight to seeing the world (and our field) through the eyes of those with disabilities," but he seemed to make the same point over and over (Brown-Glover, 1992; Virginia Commonwealth University, 1992). Stories about "Ed's personal struggles with the system and his success" were difficult to listen to because they painted the rehabilitation counselor "as the bad guy" (Virginia Commonwealth University, 1992).

Similarly, the professional audience who heard Roberts' presentation at the 1990 Building Blocks for Tomorrow conference in Colorado Springs found him to be "very inspiring" but also tedious. The forthright charisma and hard-earned wisdom that disabled people and the families of disabled people heard in Roberts' stories of disability rights struggle were largely absent from the experience of the Colorado state employees. They complained that he was a "long winded speaker" who was "repetitive" and prattled on "about a half hour too long." One commentator captured the feeling of many with the observation that "Ed makes a fine point early in his presentation but seems to reiterate this point continually." While Roberts may have been speaking about a revolution in disability services that placed the disabled consumers at the steering wheel of multiple forms of paid assistance in order to elevate their lives to new levels,

what the professionals chiefly heard were sappy stories with little relevance to the real work of rehabilitation (Colorado Interagency Conference Evaluation, 1990).

One episode that perhaps captures much of Roberts' stormy relationship with service professionals was a conflict with the organizers of the American Association of Spinal Cord Injury Psychologists and Social Workers (AASCIPSW) conference in Las Vegas in late 1992. In his many engagements, Roberts consistently asked conference organizers to pay not only his speaking fee (often waived or reduced for groups that could not pay) and his travel expenses, but also the travel costs and daily wages of his personal attendant. Historical records indicate that conferences and organizations routinely paid for the travel and \$100 per day salary of his attendant without question or complaint. But the AASCIPSW repeatedly refused to compensate Roberts' personal attendant (Gordon, 1992). Roberts wrote a strong letter asking the group "to appeal your decision not to compensate WID (World Institute on Disability) for my personal assistant. ...It is impossible for me to travel and speak without the assistance of an attendant; this personal assistant works 24 hour shifts and is with me at all times" (E. Roberts, 1992). The conference hosts denied Roberts' urgent appeal. But Roberts persisted. A month after the conference, he invoiced the AASCIPSW for an additional \$100 per day for the attendant services. The conference organizers lashed back, not only refusing to pay the bill but also charging Roberts for his phone calls from the conference hotel (Beyda, 1992).

## **Elite Circles**

By the early 1990's, greatly due to national media attention, Roberts was famous beyond disability rights and services circles. Since his early days as leader of the Rolling Quads student group on the University of California, Berkeley, campus, Roberts had a knack for seeking out and using the print and broadcast media to further both the disability rights cause and his own celebrity. He was named a MacArthur "genius" Fellow in 1984 for his influential work as leader of the Berkeley CIL and the California Department of Rehabilitation. He had successfully secured state funding to launch a set of ten independent living centers across California, and he was an important lobbyist winning the federal funding of independent living centers across the country in 1978 (Danforth, 2018; Leon, 2000).

The peak of Roberts' national celebrity came when Harry Reasoner profiled him on the popular television show *60 Minutes* in 1989, portraying him as the charismatic and driven leader of the American disability rights movement. Televised during the final political drive toward the passage of the 1990 Americans with Disabilities Act (ADA), Reasoner delivered an angry and captivating Roberts spinning his usual collection of autobiographic stories into the living rooms of millions of Americans who rarely thought with disability politics. Ever provocative, Roberts used the national stage to promote the oft-ignored sexuality of disabled persons by telling of his own sexual activity. He had married Catherine Dugan in 1976, and his son Lee was born in 1978. Reasoner joyfully joined in the boundary-breaking fun, asking, "You made a child in roughly the same way that we all try?" Roberts roguishly laughed and replied, "And I enjoyed it." (Roberts, 1989).

The following year, Roberts again reached a mainstream American audience in an in-depth, hour-long radio interview on the nationally syndicated *Larry King Show*. He gave the King listeners a down-to-earth description of how disability discrimination works in everyday life.

One of the things that happens in this country, when somebody becomes disabled, they hear the worst. They hear the worst predictions. Unfortunately we don't let people define their own limits. When I asked questions....Would I ever work? Would I have sex? Would I be able to live a life? All the answers were 'No,' and it really was wrong (King, 1990).

The messages Roberts received when he first became disabled repeatedly and erroneously told him to give up. His experience-built advice as displayed in his autobiographic stories told Americans to throw aside old, prejudiced ideas about disability.

Two events in 1993 again placed Roberts into the national spotlight. Cable News Network (CNN) reporter Larry Wood profiled Roberts' activist work to influence federal disability policy, and a popular book about the disability rights movement entitled *No Pity* by National Public Radio and *US News & World Report* journalist Joseph Shapiro (1993) was released.

The CNN report examined the World Institute on Disability (WID) efforts to promote California's successful model of funding personal assistance services. WID had produced a study examining costs and benefits of these services in California and New York. Roberts traveled to Washington, D.C., to lobby Senate and Congress for additional federal funding. He spoke passionately to the profound impact of personal assistant services, how disabled people otherwise isolated in nursing homes or institutions became contributing citizens with these needed supports (CNN, 1993; Leon, 2000, p. 151).

Shapiro's (1993) *No Pity* characterized Roberts as the central figure in the birth of the American disability rights movement in Berkeley, California. The book retold many of Roberts' standard stories in the broader context of the movement, positioning Roberts as a heroic political father figure. Designed to inform the lay public about disability rights progress and issues, *No Pity* quickly became a favorite in the disability advocacy community across the nation (Parames, n.d., p. 1; Stein, 1998, p. 183; Brown, 1994).

Roberts' growing fame launched him onto the speaking rostrum with numerous celebrities of the political left, including politicians, activists, and artists. A benefit dinner for Central American humanitarian aid in early 1990 featured Roberts with Tony Award-winning actor John Randolph, noted Chilean novelist Isabel Allende, and Weavers folksinger Ronnie Gilbert (Veterans of the Abraham Lincoln Brigade, 1990). The following October Roberts shared the stage with farmworkers rights activist Cesar Chavez to discuss the question "Can Democracy Replace Autocracy?" at the Public Citizen conference honoring Ralph Nader's twenty years of activism (Public Citizen Conference, 1991). Six weeks later, Roberts and Congresswoman Maxine Waters were keynote speakers at a California conference in celebration of thirty years of the independent living movement (Rouse, 1991).

After the ADA was signed by President George H. W. Bush in July, 1990, Roberts was frequently an honored invitee at annual ADA celebrations. In July, 1993, President Bill Clinton

hosted Roberts, ADA architect Justin Dart, and Gallaudet University President I. King Jordan among a select group of leading disability activists at a White House celebration of the law's third anniversary (White House, 1993). Congresswoman Nancy Pelosi and Roberts led a San Francisco march from city hall to the federal building site of the famous Section 504 sit-in for a disability rights rally that involved gay rights activists and service employee union leaders (San Francisco March, 1994). In July, 1994, Roberts and Justin Dart served as grand marshals of the New York City Disability Independence Day March in Manhattan (Zames, 1994).

## **Favorite Audiences**

Not surprisingly, regardless of his renown or opportunities to speak to multiple audiences, Roberts felt the greatest comfort and support when he presented to disability advocacy groups consisting largely of disabled persons and their family members. He knew that the audience was more prepared to receive his message and celebrate his achievements. The majority of his performances in the United States was delivered to these groups. For example, in October, 1987, Roberts gave the keynote address at the convention of the Coalition of Texans with Disabilities (1987) in Houston. The conference theme was "A Decade of Disability Advocacy." The Association of Independent Living Centers in New York brought Roberts to Albany in November, 1989, to speak to their theme: "Independent Living 89: Celebrating 10 Years in New York State" (Jones, 1989). In winter, 1992, Roberts packed a series of consecutive Ohio engagements into one trip. He gave the keynote address to the educational inclusion advocates at Ohio TASH (The Association for Persons with Severe Handicaps) in Columbus and then traveled quickly up to Toledo to give two speeches at the Ability Center of Greater Toledo. His first talk for the Center staff and board members was entitled "Independent Living: Where Are We Going," and a second presentation "Taking Control of Our Own Lives!" offered advice to disabled Ohioans served by the Center (Abell, 1992; Grunden, 1992). Within disability activist circles, he was cherished, and he felt at home.

Undoubtedly, the audience Roberts most enjoyed and the venue where his stardom shined brightest was the Partners in Policymaking (PIP) program initiated with federal funding by the Minnesota Developmental Disabilities Council in May, 1987. PIP was a cohort-based training program designed to teach people with intellectual disabilities, their parents and families, as well as adults with a variety of disabilities, how to advocate effectively for services and funding at the local, state and national level. The multi-meeting educational programs featured a small faculty of experienced activists and advocates teaching families and disabled people how to fight against the stubborn, calcified service delivery systems that frequently ignored the voices of those they served (Zirpoli, Hancock, Weick, & Skarnulis, 1989; Governor's Planning Council on Developmental Disabilities, 1990). By the early nineties, PIP had taken up the cause of inclusive education, showing parents how to push school administrators for more integrated placements for their children (Partners in Policymaking, 1993). Roberts joined the main program faculty at the start and remained active as a regular instructor as the program went national over the next eight years. He was a favorite of PIP sessions, presenting at dozens of training meetings from California to Florida, from South Dakota to Delaware.

Following his many presentations in the workshops, PIP participants flooded Roberts with letters and cards expressing heartfelt adoration and gratitude. An Iowa mother of a disabled daughter wrote,

I wanted to tell you how much I appreciated the insights you gave on the power of disability. I really needed that infusion. Strong as I am sometimes, sometimes I am not very strong. Sometimes I get tired of fighting for everything for Sarah....Once in a while I even catch myself feeling sorry for Sarah. I quickly recover and Partners is there to pick me up (Williams, 1993).

Katie Snow, mother of a boy with cerebral palsy and a passionate disability rights advocate wrote, "(Y)ou inspire me to greater efforts" (Snow, 1992, 1993). A mother from Delaware asked, "Are you tired of hearing that you are an inspiration? Well, you inspired me" (Lemon, 1993). A participant in an Austin, Texas training told Roberts, "I want to thank you for the tremendous difference you have made in my life....I admire you more than I can say (Coles, 1993). A Connecticut mother declared, "I think you are to the Independent Living Movement as Martin Luther King was to the Black Equality Movement" (Watras, 1993).

Jamie Wolfe was a disabled woman who worked as a social worker, activist, and disability studies instructor at the University of Delaware. She wrote to Roberts about how she had advocated to have greater control over her own services for years only to be told by friends and family members that she was being too demanding and selfish.

I was supposed to be grateful for any type of help I got. People 'took care' of me out of the goodness of their hearts. It didn't matter that my clothing were on backwards or I was sitting on my head in my wheelchair. Someone helped me. That's all that mattered (Wolfe, 1993).

But when she heard Roberts speak, in that moment, she knew she had been right all along.

While I was listening to you I finally realized I can take my personal experiences and education, and not only help people with disabilities take control of their lives but to take control of my own as well (Wolfe, 1993).

Roberts validated Wolfe's beliefs and her efforts, and she felt suddenly that her years of assertive advocacy had been validated (Wolfe, 1993; Miller, 2006).

After Roberts presented in Hartford, Connecticut in late 1993, the hosts gave him a gift. It was a painting by an artist living in a state institution. Ramona Watras (1993), a disabled woman who attended the PIP training that day, wrote to Roberts that she was disappointed because the painting was "depressed and lifeless," representing the unfortunate circumstances of isolation experienced by the artist. Instead, Watras wished that Roberts had received a painting displaying the vibrancy and freedom of the independent living concept that he taught.

If I were to present you with a gift, it would represent all of the activities, occupations and values that all people like I would like to obtain....a three by four foot montage of many men, women, and children from the Greater Hartford area (with various types of disabilities) enjoying life to its



fullest. It would include bright colors and happy, smiling faces to reflect the positive and determined attitude that supports this important movement (Watras, 1993).

Such a painting would reflect the tableau of possibility and vigor that Roberts expressed in his performances, the rich life the Roberts life narrative represented, and the life that any disabled woman "would like to obtain" (Watras, 1993).

## **Conclusion: The Limitations of Stardom**

The working assumption that fueled Roberts' speaking tour for the final thirteen years of his life was that raising himself to celebrity status and promoting the cause of disability rights were synonymous. This assumption was implicit in his autobiographic storytelling style of presentation, using his own experiences, struggles, and victories as examples to energize and instruct others. His life was held up as an instructive example of the pervasive power of prejudice, the need to fight for justice, and the potential of a disabled person living well in the community. Fame was a product of his success that gave him a prominent public platform to teach about independent living and disability rights.

For lay groups such as the Kiwanis, the Girl Scouts, Western States Meat Association, or the Christ Community Church, Roberts' life story could open their hearts and minds to what might be possible for disabled members of their family or community. Perhaps they would become more supportive when their state or local government considered issues of access and service funding. Maybe they would gain a different appreciation for the friend, family member, or community member with a significant disability. For disability advocates such as the independent living centers in Kalamazoo and Toledo, Roberts' narratives might bring needed sustenance to beleaguered and weary activists struggling on the seemingly unending road toward greater access and acceptance. Perhaps they celebrated Roberts' stories and felt his powerful presence as Harriet McBryde Johnson and Jamie Wolfe did. For the professionals such as the physicians, psychologists, social workers, special educators, and rehabilitation workers, maybe Roberts' tales meant more than just a moment of inspiration. Perhaps they heard lessons about how professionals can work to shift control of services and supports over to disabled people in order to live and participate more fully.

But one cannot help but notice that Roberts' stories – the content and the general message – changed little between 1983 and his death in 1995, a period of over a decade that included the passage of the strongest disability discrimination law in American history. Even during a time of great progress in the movement, the daily issues, concerns, and challenges changed little. The obstacles, problems, and discrimination remained formidable and pervasive. Part of the reason Roberts continued to speak widely across the United States and the globe over these many years was the intransigence of the cultural, economic, and institutional barriers faced by disabled people. In the small towns and the large cities, his message remained new and fresh and provocative. Roberts' celebrity, while a noteworthy advance for disabled people, signified the end of ableism no more than Barrack Obama's presidency indicated the conclusion of racism. Change came at a painfully slow pace.

To the end of Roberts' life, his only answer to this enduring problematic was to continue doing what he knew best, making presentations, telling his stories, and fighting for justice. As one PIP participant encouraged at the bottom of her thank you card to Roberts in late 1993, "P.S. Keep giving 'em hell" (Shipman, 1993). He did so with the fierce passion of a political activist and the pronounced stage presence of a theatrical star.

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