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ZONA AND ED ROBERTS: TWENTIETH CENTURY PIONEERS

by

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## ZONA ROBERTS: TWENTIETH CENTURY PIONEER WOMAN

### INTRODUCTION

I earned a doctorate in history from the University of Oklahoma in 1981. Unsuccessful in my job search, I accepted a one-year instructorship at my alma mater. At the end of that year, my department chair inquired if I would be interested in writing a history for and about a private association located in another part of the state. I grabbed the opportunity. A number of phone conversations ensued. The association's representative encouraged me to submit a proposal and then helped me to refine it. During another phone call I was hired.

At my first in-person meeting with my contact, I walked into the airport terminal using a pair of crutches needed because of a lifelong disability. A written contract never materialized. Within a week I was informed that my use of crutches caused the association to determine that I did not possess the energy or stamina to do the job.

Angry and frustrated, I drove to the local center for independent living, a community advocacy organization for people with disabilities, which I had learned about from two students, to see what I might do to rectify the situation. To make a long story short, there was nothing I could do. Although everyone, from my colleagues to the Oklahoma Human Rights Commission agreed that I had encountered discrimination based on my disability, I had no legal protections.<sup>1</sup>

That summer I volunteered most of my time at the independent living center. In the fall I was hired to fill a new full-time position. Since 1982 I have worked in the disability rights movement, but I have never relinquished my academic roots as a historian. I continue to speak and to write about historical issues from a disability-rights perspective and disability rights from a historical perspective.

In 1990, shortly after chairing two panels focusing on disability history and culture, I accepted a training job at the World Institute on Disability (WID) in Oakland, California. I knew about, and held in awe, many of the exceptional people working at

WID:

Judy Heumann, first lady of the modern disability rights movement, who had been a rebel since her New York City kindergarten had told her in the 1950s that she could not attend her neighborhood school because she used a wheelchair<sup>2</sup> and who, in the 1990s, was appointed by President Clinton to become an Assistant Secretary in the Department of Education; Simi Litvak, world-renowned expert in research about Personal Assistance Services, people aiding those of us with disabilities in tasks of daily living, such as getting in and out of bed, going to the bathroom, and getting to work; Deborah Kaplan, a disability rights lawyer, who had worked with Ralph Nader, and has become a leader in innovations concerning technology and disability; Hale Zukas, seen by the outside world as a quadriplegic unable to speak intelligibly, who had graduated in honors from Berkeley with a double major in Russian and mathematics; and Ed Roberts, WID President, an internationally respected activist, considered to be equivalent in stature to Martin Luther King, Jr. by many in the disability rights movement.

I had not heard about Zona Roberts, Ed's mother. As I got to know both Ed and Zona I started to have a better grounding in the evolution of the disability rights movement. In December 1996, Zona visited our new home in New Mexico to be interviewed at length for a project about Ed. At that time, I realized that Zona's tale was just as significant as that of her son.

A vibrant seventy-six year-old woman, whose age and gray hair belies boundless energy, Zona spent mornings ruminating thoughtfully for the tape recorder and afternoons touring southern New Mexico. When we came home, she wanted to go to the kitchen and cook, or play with our cats, before settling down for a quiet hour or two of reading.

When the interviews were completed, eleven hours of tape contained detailed, sometimes brutally honest, reflections about her life and times. I learned that Zona's life held fascinating detail before Ed's birth. She truly is a remarkable woman who is one of our century's pioneers and the sharing of her story will, I hope, become part of our

## BEGINNINGS

Howard Harvey, youngest of five children, labored in a mill near Portland, Oregon. He wooed and married Naida Post, a carpenter's daughter and an attractive woman with cultural ambitions centered around music and art. Teenage parents, nineteen year-old Howard and seventeen year-old Naida Harvey, shared the joy of their daughter Zona Lee's birth on April 1, 1920, in Portland, Oregon.

The exhilaration common to the arrival of a new baby did not last. Naida had two big problems with Howard. First, she was more ambitious than her husband. Second, she had a lifelong concern, sometimes bordering on paranoia, about contagious diseases, including tuberculosis (TB), which was rampant in Howard's family. Worried that Howard would contaminate herself and her daughter, the couple parted when Zona was an infant.

Naida's fears were not entirely unfounded. Howard died from TB when Zona was about nine. The dissolution of the marriage might have been perceived as a portent. Howard and Naida's new-born daughter experienced a radically different childhood than we generally read about in the history books for middle-class America in the early twentieth century.

Zona's early remembrances about life with Naida focus on two aspects of life: the men in their lives and what each of them had to endure to survive. In her biological family, both Zona's maternal grandfather and great-grandfather were carpenters, but they played less significant roles in her childhood than the women of the matriarchal family. Marriage was not a lifelong commitment in this family. Zona's grandmother married three times and Naida would eventually marry five times, four of those unions while Zona was still a child.

After Howard's departure, Naida at first gave piano lessons to survive, but she continued to seek companionship and security she believed would result from marriage. She got a job at the Montgomery Ward store in Portland and while working

there she met Leo Adams. When Zona was about four and too rambunctious for her grandmother to supervise comfortably Naida decided to marry Leo. She viewed him as quite a catch partly because he owned a home in Portland.

Zona remembers Leo as a jealous stepfather who became abusive. She recalls incidents when her stepfather placed a pillow over her face and threatened to choke her and when he struck her at the dinner table. During a trip to nearby Boise the family stopped at a dam and Leo held Zona over the edge. Her stepfather terrified her and what was perceived as contentions between Leo and Zona contributed to the fairly rapid dissolution of this marriage.

Naida then married Bob Baring, a music teacher, from Stockton, California, who'd been married before and was the father of two daughters. Naida and Zona joined Bob at his home in his Stockton when Zona was about seven or eight years old, then moved to the San Francisco Bay Area when Baring got a job at the College of San Mateo.

Baring, an only child, had been a violin protege, whose musician friends spoiled him. He spent more money than he earned. But he also had a more unsavory side.

It eventually became unclear if Baring had truly been divorced from his previous marriage when he met Naida. Complaints from students revealed he also was a child molester. In early adolescence, Zona, molested by a second stepfather, became bed-ridden, complaining to her mother about Baring. Naida responded what would they do without him? A doctor suggested Zona needed a change of environment so she was sent to live with relatives in Oregon. Her two years in this pastoral country setting freed her from the pressures of Naida's home. She recalls these years as two of the happiest and most serene of her childhood.

During Zona's Oregon sojourn Naida left Bob Baring. She got a job teaching ballroom dancing where she met George Stevens, known as Steve, an early San Francisco radical, with ties to communists in the area. Zona learned about their marriage from the wedding announcement. Steve seemed to be able to satisfy and placate Naida and this, her fourth union, would be her only long-term marriage.

Zona rejoined her mother and her new husband to begin her sophomore year of high school in Portland, where her mother and new stepfather had relocated. Steve, a writer, attempted to publish a magazine there. Zona hoped to finish high school in Portland, but that was not to be. The magazine never became established and the family moved back to the San Francisco area.

Zona's independence asserted itself at this early age. Having already lived away from home Zona felt capable of living apart from Naida and Steve. She chose to attend high school in Burlingame, south of San Francisco, because she liked that community. She left Naida and Steve to live as a domestic worker with a family in nearby San Mateo while she attended school.

While at Burlingame High School, Zona played in the orchestra and participated in drama. She wanted to participate in more extracurricular activities but had to work instead.

Zona had been attracted to the opposite sex from a fairly early age, having had boyfriends in Oregon. While still in high school, Zona met Verne Roberts through a mutual friend. Their first activity, more an outing than a date, they played tennis. The 5'10" or 5'11 Verne later told Zona he liked her legs.

Verne, four years older than Zona, happily left high school to work when his father became ill during Verne's senior year. When he and Zona met he still lived with his parents in Burlingame, sleeping on a couch in the living room.

Zona graduated from high school in 1938. She also became pregnant that year while dating Verne. They visited an abortionist, but Zona refused to abort her baby. She and Verne married on July 4, 1938. Naida was not particularly happy with the marriage, believing Verne was not good enough for her daughter.

After their marriage, the newlyweds returned from their honeymoon in Fresno to San Mateo where they rented an apartment for a couple of months. Then Verne's parents bought them a four room house for \$2500 across from Burlingame High School and near their own home.

## FAMILY LIFE

Verne's father, Walter, had worked for Southern Pacific Railroad as a machinist. Verne himself was on the Extra Board for the railroad, meaning that when there was work available he received calls to do odd jobs. Unfortunately, the jobs and the money evaporated during these Depression times. The couple applied for welfare. Verne applied for lots of jobs while waiting to hear about welfare. Zona remembers this as a horrifying experience. The morning the welfare worker was due to arrive, Verne got a job at a furniture store. He made \$25 week there before being called back to work at the railroad as an apprentice. Since he came in as Walter's son, railroad cohorts looked after him. He started as a machinist, then electrician, then diesel electrician. He rejected promotions to foreman, although he would sometimes fill the position on a temporary basis.

Edward Verne Roberts was born on January 29, 1939. Verne wanted to name a son, Ed, after his best friend. Zona preferred the name Michael, but Verne's parents, who had become very influential in her life, especially her mother-in-law, Katherine, who had accepted her into the Roberts family as one of their own, thought Michael was an Irish name and the Irish were denigrated in San Francisco.

Following a long labor, Ed was born, weighing a little over six pounds. Zona remembers looking at her child and thinking he looked like a rat with dark hair. She remained in the hospital for about a week after Ed's birth. She recalls having a difficult time remaining still while in the maternity ward. She tried to nurse Ed, but had little success because of a tooth abscess that hemorrhaged. Ed wasn't getting enough nutrition. Once the problem was discovered, Ed received food supplements which alleviated the situation. The cost for pre-natal care, delivery, and post-natal care was \$50. When Verne and Zona brought Ed home they put him in a bassinet next to their bed and Zona said, "Well, here we are--I don't know how we're going to do it, but we're gonna do it!"<sup>4</sup>

Creating family stability to avoid repeating her own chaotic childhood became paramount. Zona recognized deficiencies in meeting this goal, such as her initial lack of

cooking skill. At the beginning of her marriage her specialties were jello salads and cakes. Verne's mother always had a pot of soup going and Verne would frequently venture over there in the evenings.

Roberts' family gatherings, such as celebrations of holidays, often happened at her in-laws house, which Zona enjoyed. After several years, Verne questioned why they always spent holidays at his parents and one Thanksgiving in the mid-1940s Zona cooked chicken and then they went to the big football game, San Mateo High School versus Burlingame High School, right across the street.

Ed was an early walker and talker, saying "kitty-cat" when he was about nine months. He ran everywhere taking after his father who liked running so much that he once chased a dog around the block to get him back into the house. Ed was constantly putting his top teeth through his bottom lip while scurrying around.

A day after her twenty-second birthday, Zona gave birth to the family's second son, Ron, on April 2, 1942. He was a very blonde, gorgeous baby, similar to the Gerber baby. Ron tagged along with Ed when he went to the high school to play. One time Ron suffered a concussion when he was hit by a car while running after Ed. That was the first major trauma for either boy.

Ed began nursery school, then attended McKinley Elementary School. Still in constant motion, his motivation for going to school was the playground where he was the center of attention and activity. Ed did not sit still long enough to learn to read until the fifth grade.

Verne, fitting the middle-class stereotype of the day, spent much of his time at home in the garage fixing things or gardening. He was well-known throughout the neighborhood as someone who could and would lend a helping hand. He knew more about their neighbors than Zona did. Verne wanted Zona to be at home as well perceiving a homemaker as someone who literally remained in the home. Most of Zona's friends, also married to blue-collar workers, had similar constraints.

Despite Verne's preference, Zona managed to find many opportunities to become involved in her community. She would strategize ways to leave the house. Some of



these activities played formative roles in her later life and career choices. For example, she volunteered for Parent Teacher Association (PTA) activities, such as teaching sex education classes, and later became PTA President.

Their third son, Mark, was born when Ed was about twelve and Ron about nine. When Mark was about two months old, Zona and her friend Marge Caton applied to be census takers. Zona took the exam and got the job, but Marge was denied because she was Canadian, so while Zona went out, Marge took care of Mark and they then split the money. This emphasis on friendship and sharing remained a consistent pattern throughout Zona's life.

The couple's fourth, and final child, another son, Randy, was born about two and half years after Mark.

## POLIO

Life changed dramatically for the Roberts family in early 1953. Ed returned from a March of Dimes benefit baseball game saying he did not feel well. He planned to go out again that evening, but Zona refused to let him leave. That night, Ed came into his parents' bedroom and slept stretched out between their two beds.

The next morning Ed awoke with a fever, stiff, holding his spine very straight. A doctor came at dinnertime, looked at Ed, washed his hands, and immediately wanted to take Ed to San Mateo County Hospital. The physician believed Ed could have flu, meningitis, or polio.

Ed walked into the hospital. The doctor performed a spinal tap to detect meningitis. Ed got up once during his first evening in the hospital to go to the bathroom; two days later he was rushed into an iron lung when paralysis began and included his neck and lungs.

When Ed contracted the polio virus, the family had known only one other person who had polio and who had died as a result. They were petrified about what would happen to their son.

At the hospital, they could only visit Ed through the windows of his room. Ed's fever escalated at the end of the week, creating a life-threatening crisis. The physician suggested they call for a priest. Verne and Zona stayed at the hospital on Friday evening watching to see if a tracheotomy would be needed. Ed awoke at about 2:30 a.m., saw his parents and asked why they were still there. Verne and Zona believed then that the crisis had passed and went home.

Upon returning to the hospital the following morning, relieved that their son survived, the doctor, who lacked a warm bedside manner, asked Ed's parents how they would like it if they had to spend the rest of their lives in an iron lung? Zona immediately became concerned this physician would convey a sense of hopelessness. Her fears were somewhat alleviated when the same doctor suggested putting a clock in Ed's bedroom so he would be aware of the time.

Some Sister Kenny methods were practiced at the hospital, including exceedingly painful hot packs. Hospital personnel moved Ed in and out of the iron lung and eventually out of isolation into a ward with other polios, as they call themselves, of all ages and both sexes.

A new routine settled over the family. Zona would visit Ed in the afternoons, Verne in the evenings. Verne began to develop a nurturing side. His role was to be in the hospital every evening.

Verne had recently bought an insurance rider for 50 cents per month to cover polio for up to \$5,000. When he first entered the hospital, the family waited to find out if Ed had polio to know whether he would be a public patient or a private one, covered by the newly-acquired policy. Once the polio was identified, Ed became a private patient for two and a half months. Then the March of Dimes covered the remainder of the bills.

Medical practitioners of the 1950s believed that polio survivors should do their utmost to become independent of an iron lung. For someone like Ed, whose level of paralysis meant his lungs no longer had the capacity to breathe on their own, that meant a terrifying fear of lack of air. Could he tolerate being out of the lung? Only time

would answer that query.

Ed remained hospitalized for the greater part of two years. This time was crucial to see how the swelling would go down and what nerve endings would be corrected. Beyond two years there was no hope for further recovery.

During the first year, Verne and Zona took trips to the Russian River, a popular northern California vacation spot. One time they left for a week. Zona recalls she knew Ed could adapt to the polio when he handled that trip. She later learned from Ed that he thought those excursions abetted his recovery. The polio had caused enough pain in his life; if his parents sacrificed their lives it would be more than he could bear.

Ed remained at San Mateo County Hospital for about nine months. Although he recovered from the initial ravages of the disease, the hospital lacked a rehabilitation program to teach him how to live with the aftermath of polio. The family learned about such a program at Children's Hospital in San Francisco. Zona arranged to move Ed. On the day of the move, they got Ed and put him in the back of the station wagon to move him from one hospital to the other. Ed became furious for no apparent reason. All Zona could imagine was that Ed felt akin to a dog going to the pound, removed from familiar surroundings. For the first six hours or so Ed spoke to no one.

Zona had to learn to drive to visit Ed in San Francisco. She had started to learn once before, during World War II, but gas rationing prevented her from completing the lessons. This had not displeased Verne. Since he liked Zona at home, the freedom she would acquire from driving did not excite him. Zona had to plan how she would convince Verne that learning to drive and being able to visit Ed herself would be appropriate. This kind of strategic planning had become a part of Zona's life at which she was quite successful and it would be propitious not only for her, but for Ed's recovery and return to family and community life.

While in the hospital, Ed didn't eat well for a time. Speculation abounded about the cause, including frustration from being unable to feed himself. Zona attended a doctors meeting where she learned that with polio the hydrochloric acid of the stomach is almost depleted and digestion is difficult. But Ed's difficulty with eating was not

physical.

Zona observed a private duty nurse pressuring Ed to eat. Zona spoke to a psychologist who in turn conversed with the nurse about this pressure being too intense and counter-productive. She was removed. Ed still had to be fed, but his attitude changed when the pressure was off. He later made many public declarations about his lack of desire to eat until he was left alone to make the decision to survive for himself.<sup>5</sup>

While Ed resided in Children's Hospital a news story about the polio epidemic included a camera shot that panned over Ed while the newscaster described him as being unable to move. Zona, watching the story, for the first time cried about her son's polio.

The hospital was filled with polios, many without families. Ed, with obvious support from home, began to think that life as a polio survivor could be okay.

Rehabilitation work occurred during the nine months that Ed spent at Children's Hospital. He would, for example, try to feed himself with a sling but it would take most of the day for one meal. As he adapted to his condition, being fed by someone else did not seem as restrictive when he could put his energies to alternative uses.

At the end of two years, Ed prepared to return home. The prospect terrified Zona. She feared she would never be able to leave the house again. She shared these feelings with a nurse who expressed surprise that no one had spoken with her about the Polio Foundation, which provided and paid for assistance to families four hours per day five days a week. This enabled Zona to feel more confident about the many changes to come.

First and foremost, the house that the Roberts family lived in across from the high school was no longer adequate. It was not big enough to accommodate Ed's iron lung and associated paraphernalia. The family moved to a new house where a bed was set up for Ed in the dining room. With Ed's arrival from the hospital to the Roberts' new home a fresh routine began.

## POST-POLIO

The effects of the polio virus remained throughout Ed's lifetime. He retained some movement of two fingers on his left hand and two toes on his left foot. The rest of his body, including his lungs, remained paralyzed. Unable to breathe on his own for extended periods, he became, in the language of the day, a ventilator-dependent quadriplegic. This meant that both his arms and legs were paralyzed and that he required a machine, such as an iron lung or a ventilator, to assist him with breathing. Although he could not move, feeling remained.

Ed spent two years attempting to breathe without the iron lung, but it was a losing proposition. Although he learned to breathe on his own in what was known as "frog-breathing" it required an enormous expenditure of energy. When he finally surrendered to using the lung, he never regretted it. He felt most comfortable in this cocoon where he was not required to concentrate on breathing, but could focus his attention on other matters. The lung became a lifelong friend. He would enter the lung during the evening. Once daytime returned, he would leave the lung behind, either breathing on his own or using a ventilator.

Verne's mechanical and electrical ability made life easier for the family. He also had a knack to be able to awaken in the middle of the night, fix or repair whatever needed it, and go back to sleep.

The Roberts' post-polio routine included Verne arising early to go to work; a Mrs. Hibner arriving to provide assistance as promised from the Polio Foundation; Verne returning in the afternoon, and Zona serving dinner about 5:00. Verne often had soda crackers, coffee, or beer before dinner. This was also the time when Ed would be bathed. It took four people to lift Ed. Verne would support his head and neck, Zona his butt and knees, and two others on each side of his back. Ed's immobility had immediate consequences even in the sanctity of home. For example, at dinner, the family's pet cat, Tigre, would often lay by Ed's head and steal meat from Ed's fork before he could get to it.

A slew of immediate, medical problems plagued Ed after his return home. His face began getting big blotches because he wasn't getting enough oxygen. He also had a

cardiac catheterization because the left side of the heart had a little damage. A kidney stone caused Ed to go into shock and he almost died. He also developed a polyp behind the nose which eventually hemorrhaged and had to be packed with gauze. Each crisis was dealt with in its turn and Ed eventually acquired a routine of his own.

Ed, the only person in his school to contract polio, resumed his education at Burlingame High School at the age of eighteen. He joined brother Ron's class of sixteen year-olds, attending via a phone hook-up promoted by the phone company and provided by the San Mateo County Women's Club. It began with a phone connected to one room at the high school. When Ed pressed a bar on the phone he could be heard, when he released the bar he could hear, enabling him not only to listen but to communicate with his classmates. Hands-on tutoring was provided for Spanish and biology courses.

The phone hook-up also began what would become a lifetime of publicity about Ed. His picture and a short write-up appeared in the phone bill.

Zona thought she paid attention to her other three boys during these years, but remembers Ron getting caught stealing and stating that he was feeling neglected. About this time he started playing tennis at the high school and the family bought him a membership at the country club. Ron became co-captain of the high school tennis team and also played basketball. He didn't date or drink, but played poker. The two younger boys, Mark and Randy, attended Washington Elementary School.

Verne was a man who liked routine, including wanting to know where all his family members were. He liked barbecuing in their back yard, playing bridge, and generally being at home. He and Zona seldom went out together.

Zona still had her own dreams. Two things she always wanted to do were travel and go to college. At this juncture she didn't believe she would get to do either.

During his senior year, Ed sometimes went to sports events and wrote a sports column for the Burlingame Bee. He read with a book or magazine on an elevated bed tray and using a mouthstick so he could turn pages without assistance. He listened to the constant bustle of his busy home. He watched TV. Many visitors would come into

Ed's open area in the middle of the house. Since he could not escape, he learned how to tune out and fall asleep, which became a lifelong habit.

Once a semester Ed's class met at his house. During Ed's senior year Zona informed him he had to attend classes once a week at the high school. Ed was terrified; he had not associated with students since he had left the community as a star athlete in eighth grade. He was returning a cripple. His greatest fear was that he would be stared at. He was. His eventual response to being on exhibition became if everyone was going to be looking at him anyway he would be a star. But it was awhile before Ed would let people see him in public. Once when Ed was about nineteen and Mark pushed him along Burlingame Avenue, a man stopped to ask Ed what was wrong with him. Ed couldn't answer. At this juncture, he had no desire to be around other people with disabilities, not wanting to be identified as one of them.

Ed had wanted to be a Marine. He was an avid gun collector who persuaded Zona take him to gun shops. Ed even took a terrified Zona to rifle ranges where he would direct her in how to shoot. This and sports kept him in touch with the guys.

Ed graduated from high school, at the age of twenty, in 1959. But not without a fight. His post-polio paralysis prevented him from taking either physical education or driver's education courses. His high school counselor thought Ed should remain in school another year. Zona, determined that her boy would be as similar to his peers as possible and having done all in her power to achieve this end was mystified by this turn of events.

Zona contacted the principal about the inequity of the situation. He supported his counselor. Zona next called her friend, Mimi Haas, the mother of one of Ron's friends and a school board member, to see what could be done. A school representative met with Zona and Ed at their home and asked, "Ed, you wouldn't like a cheap diploma, would you?"<sup>6</sup> A furious Zona got in touch with the Superintendent of Schools, whom she knew from PTA work. She also called some of Ed's teachers. They planned to advocate for his graduation at a school board meeting. Before they could act, the Assistant Superintendent of Schools announced that everyone was proud of Ed

and granted the diploma.

At the graduation ceremony a fellow student pushed Ed across the stage. A big party followed at the Roberts' home. Zona believes Ed attained some of his own sense of determination from watching Zona persevere about his graduation.

Ed and Ron graduated at the same time. Ron ventured across the bay to attend the University of California at Berkeley. Ed enrolled at the nearby community College of San Mateo. To attend classes he was placed in a corset, which enabled him to sit up. A head brace came out of the back of the corset.

At first, Zona brought Ed to campus. They would solicit help from passers-by to get Ed in and out of the car on campus, learning to avoid the football player types who wanted to do it all by themselves without consideration of Ed's needs. Once at the college, Ed attended class by himself, with assistance from fellow students, to traverse the numerous steps. A fellow student was eventually hired to drive Ed back and forth to campus.

Ed spent three years at the College of San Mateo finishing two years of classwork. To complete assignments Zona wrote while Ed dictated. Ed speculated about a career as a sportswriter. Others discussed technical writing. He eventually chose political science as a major.

Ed earned no money either in high school or at the College of San Mateo. Zona thought the California Department of Rehabilitation (DR) might pay for some books and began an interaction with that agency that would eventually prove to be a watershed relationship for people with disabilities throughout the country. But that was still to come.

The most fortuitous development at the College of San Mateo for both Ed and Zona occurred when Ed enrolled in an English class taught by Jean Wirth in his second semester. Jean, like Ed, knew about difference. She had been six feet, five inches tall from the time she was twelve years old. She became his unofficial advisor after his class with her.

Jean asked Ed where he wanted to continue his education after graduating from



the College of San Mateo and he responded UCLA, because there was a program for veterans which he speculated would make it fairly wheelchair-accessible. Zona was surprised, since he had never discussed this with her. Jean dissuaded him from this idea because UCLA was a commuter campus and he would have to find housing, transportation, personal assistance, and friends away from the university. She suggested instead that he apply to the University of California at Berkeley (UCB) where there was an outstanding political science program.

Ed did just that and was accepted at UCB. The application form asked no questions that related to disability. The only hint was that Ed weighed only eighty-five or ninety pounds. Zona accurately predicted that school officials would guess Ed forgot to put a "1" before the other numerals.

Ed also applied to DR for financial assistance. The DR counselor informed Ed that he was too severely crippled to work and would therefore be denied services. Zona, Jean, and Phil Morse, Ed's official advisor at the College of San Mateo, then met with DR to advocate successfully for Ed.

While this was happening Jean, Zona, Ed, and Phil visited the UCB campus prior to the commencement of the school year. UCB personnel were shocked to learn that Ed was a post-polio ventilator-using quadriplegic and were at a loss about where he might be housed. His large iron lung wouldn't fit in a dorm room. Morse contacted the Dean of Men, who suggested they see Henry Bruyn at Cowell Hospital, the on-campus student health center.

Bruyn, a physician, had worked with polios and commented that they were becoming of college age and should be able to attend colleges. He thought Ed could probably live at Cowell. Successful negotiations to do just that continued throughout the summer.

#### EAST AND WEST OF THE SAN FRANCISCO BAY

EAST--ED ROBERTS: Zona stayed with Ed during his first week at UCB, while

both interviewed personal assistants. She then returned home and came back to Berkeley about one month later to see how Ed was managing. Ed would remain at Berkeley throughout most of the 1960s, but Zona had little to do with his life there. Just as she felt her role as Ed's mother demanded that she be present at earlier crises, like the onset of polio and the potential fiasco surrounding Ed's timely high school graduation, she realized the time had come to let Ed make his own way into the world and to return to her own life. A brief highlighting of Ed's impact while a student at Berkeley demonstrates how well Zona and the rest of Ed's circle of support succeeded in conveying to Ed a sense of power that augmented his own natural capabilities.

During Ed's first academic year, 1962-63, the same year that James Meredith integrated the University of Mississippi, he was the only student with a disability at Cowell, and, as far as we know, the first student with a disability of this significance to attend an American university. An area paper ran a story about Ed headlined, "Helpless Cripple Goes to School."<sup>7</sup> It caught the attention of a social worker in nearby Antioch whose client, John Hessler, had broken his neck while diving. Towering above six feet tall he was too big to be cared for by his parents and he lived in a nursing home. He attended Contra Costa College, going back and forth to the nursing home by taxi. His social worker spoke with Henry Bruyn, after reading the newspaper story, and John joined Ed at Cowell in the 1963-64 school year. He majored in French language and literature.

Bruyn began to garner a reputation for this program. Several more students arrived in 1965-66. Their arrival signaled a formal program for students with disabilities, who started to call themselves the Rolling Quads.<sup>8</sup> They were moved from the second floor to take over the entire third floor, with a nursing supervisor. Each student had their own room. There was a common room and a dining room where the Rolling Quads met together. Ed and John roomed next to one another. They stored beer in the shower. Ed was once disciplined by police for peeing behind bushes and was delighted to be perceived as a bad boy.

Ed's DR worker on this side of the Bay, Katherine Butcher, unlike his

geographically-appointed counselor in Burlingame, was supportive of his efforts and DR paid for tuition, books, and secretarial help. Toward the end of the 1960s, Ed's DR worker changed and the new one attempted to run things herself. She told Ed what to write for his thesis and told other students what classes they could take. The Rolling Quads organized and hit the papers about this worker and got her transferred, not only flexing, but beginning to understand their own power.<sup>9</sup>

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## TWO LIVES--TWO HOMES

Still in Sacramento and wondering what he would do after Jerry Brown's terms as governor were completed, Ed and two of his colleagues planned an organization called the World Institute on Disability (WID). Ed remained in Sacramento, trying to sell his house there, while WID began in Berkeley in 1983. This was a difficult time for him. It was not easy to find PCAs in Sacramento and now that he was no longer in state government he felt that Berkeley was where the action was. He finally decided to return to Berkeley to join WID prior to the sale of his house.

Zona asked Ed if he wanted to move in with her since she was alone and he was surviving on Social Security benefits because he no longer had a job. He moved into the living room once more.

Ed did not depend on Social Security for long. Within a year of his return to the Bay Area he received a call from the MacArthur Foundation, asking if he would be willing to accept what is commonly known as the "genius" Fellowship, a five year award that is designed to enable people of great vision to pursue their dreams without money worries. Part of the monetary award went to a university or a program of the recipient's choice. Ed used it as seed money for WID.

The first WID project (a place Zona never officially worked) concerned learning about the different kinds of personal assistance programs throughout the country. In fifteen years WID's expansion has been rapid and involves many projects, but the initial project remains an ongoing one.

After a few years, Zona began to chafe from her lack of privacy at home. Ed and

his PCAs had taken over the downstairs. Zona couldn't entertain like she had before Ed moved in. They had plans drawn up to expand the house, but the cost came in at \$90,000, in the California real estate market that had skyrocketed in costs since Zona had first moved to Berkeley. Zona suggested Ed look for a place to live since he had finally sold his Sacramento house, but he didn't have the money for a down payment.

They decided to look for another place together and found a house in Berkeley. It had a back apartment known as an "in-law unit" built twenty years previously. Zona provided the down payment and Ed paid the mortgage on the new house on Eton Street in Berkeley. They moved there in 1991.

Zona continued with her practice, traveling when she could to visit friends and family and when she had the opportunity to other international destinations. Ed continued his stewardship as President of WID and became an international traveler who garnered a worldwide reputation as the father of the modern disability rights movement.

On a March morning in 1995 Ed died from a heart attack or blood clot while Zona was visiting Ron and his family in Hawaii. Ed had just finished breakfast. Jonathan, his PCA, held up a pair of pants and asked Ed if those were the ones he wanted for the day. Ed dropped his mouthstick in an unusual way. By the time Jonathan got to him he was dead. There was no autopsy.

When Zona learned about her son's death, she immediately returned to Berkeley and opened up their house to their family and friends. Their home was filled with people, food, and memories. Within a few days a memorial service was held. So many people were expected that it was held at Harmon gymnasium on the UCB campus. Obituaries from all over the world recalled Ed's life and impact. Few mentioned Zona except as his surviving parent.

## LEGACIES

Legacies from the lives of Zona and Ed Roberts abound.

Just as the breaking of the color barrier at American universities in the 1960s led to nationwide integrated campuses, Ed's attendance at UCB has paved the way for thousands, if not millions of others. In 1974, Congress passed the Education of the Handicapped Act guaranteeing an equal education for all children with disabilities. College campuses across the world are now implementing disability studies programs.

PDSP was the first program of its kind. Now almost every university and community college has a similar program, no longer restricted to students with physical disabilities.

CIL was the first organization of its kind. There are now more than three hundred in the United States and many more across the world.

Ed became the first person with a disability of his significance to direct a state Vocational Rehabilitation agency. Many more have followed in his wheelspath.

WID has grown from its beginnings of three people in 1983 to an organization of dozens of employees known throughout the world for a multitude of activities.

The MacArthur Fellowship has been awarded to other disability rights activists since Ed received one in 1984.

Ed's legacy may live on most fundamentally in the individuals he touched. At a memorial service held at WID shortly after Ed's death, a woman related the story of how her parents had moved to the United States from the Far East after she became disabled. She ended up in a hospital in the Bay Area wishing she were dead. When asked if she wanted anything she made a request to meet Ed. He visited. While there she related her story and he began to cry. When she saw his tears that he could not wipe from his face she realized that she possessed physical capabilities that he did not. Yet he was a powerful, happy man in his huge, electronically powered wheelchair, breathing with the aid of a respirator. She wondered why she was lying in a hospital bed. She got up. She has since become a well-known artist in the Bay Area.<sup>13</sup>

Her story is one of hundreds, if not more, of the people Ed touched directly. Many more got out of their beds, or their nursing homes, or their lives of listlessness, after hearing Ed speak or seeing him on television or reading about him in the press.

Ed changed Zona's life in fundamental ways. She reminisced that she learned from Ed about inclusiveness, disability, connections, world-wide experiences, and being brazen. She also became aware of the importance of noticing and accepting differences. For instance, if someone doesn't notice a wheelchair the possibility of being run over by it is much greater than if someone pays attention.

Zona had both a mother's and a pioneer's impact on Ed. Aside from the remarkable life he lived, Zona believes Ed gained from her knowledge and compassion about love and loving. I believe he also gained a lust for life which he, like his mother, demonstrated for all the world to see.

Zona continues to live in Oakland. She rents the "in-law" unit as well as rooms in the front of her house. Ron and Mark are both alive and well. Zona has six grandchildren. She was present at the birth of each of them. Her desire and success in creating in her own family a stability unknown to her as a child remains her most important personal legacy. That she was able to achieve it in the face of Ed's bout with polio and its aftermath helped to give the world a human rights legacy.

My hopes are that the stories of parents who have been pioneers, like Zona Roberts, will become an everyday part of our history; that Ed's breaking of the educational barriers at an American university will be told in the same paragraph in the same textbooks with that of James Meredith, his historic counterpart; and that the struggles and accomplishments of the disability rights movement will take their rightful places in our national storytelling alongside those of the civil rights, women's rights and other minority rights movements of our country's illustrious, but not always so magnificent history.

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great difficulty, but need supportive counseling. All come via word-of-mouth. Zona is particularly supportive to women who are facing the same kinds of obstacles she once encountered as an abused child and as the wife of a man who did not want her to leave the house.

## TWO LIVES--TWO HOMES

Still in Sacramento and wondering what he would do after Jerry Brown's terms as governor were completed, Ed and two of his colleagues planned an organization called the World Institute on Disability (WID). Ed remained in Sacramento, trying to sell his house there, while WID began in Berkeley in 1983. This was a difficult time for him. It was not easy to find PCAs in Sacramento and now that he was no longer in state government he felt that Berkeley was where the action was. He finally decided to return to Berkeley to join WID prior to the sale of his house.

Zona asked Ed if he wanted to move in with her since she was alone and he was surviving on Social Security benefits because he no longer had a job. He moved into the living room once more.

Ed did not depend on Social Security for long. Within a year of his return to the Bay Area he received a call from the MacArthur Foundation, asking if he would be willing to accept what is commonly known as the "genius" Fellowship, a five year award that is designed to enable people of great vision to pursue their dreams without money worries. Part of the monetary award went to a university or a program of the recipient's choice. Ed used it as seed money for WID.

The first WID project (a place Zona never officially worked) concerned learning about the different kinds of personal assistance programs throughout the country. In fifteen years WID's expansion has been rapid and involves many projects, but the initial project remains an ongoing one.

After a few years, Zona began to chafe from her lack of privacy at home. Ed and

his PCAs had taken over the downstairs. Zona couldn't entertain like she had before Ed moved in. They had plans drawn up to expand the house, but the cost came in at \$90,000, in the California real estate market that had skyrocketed in costs since Zona had first moved to Berkeley. Zona suggested Ed look for a place to live since he had finally sold his Sacramento house, but he didn't have the money for a down payment.

They decided to look for another place together and found a house in Berkeley. It had a back apartment known as an "in-law unit" built twenty years previously. Zona provided the down payment and Ed paid the mortgage on the new house on Eton Street in Berkeley. They moved there in 1991.

Zona continued with her practice, traveling when she could to visit friends and family and when she had the opportunity to other international destinations. Ed continued his stewardship as President of WID and became an international traveler who garnered a worldwide reputation as the father of the modern disability rights movement.

On a March morning in 1995 Ed died from a heart attack or blood clot while Zona was visiting Ron and his family in Hawaii. Ed had just finished breakfast. Jonathan, his PCA, held up a pair of pants and asked Ed if those were the ones he wanted for the day. Ed dropped his mouthstick in an unusual way. By the time Jonathan got to him he was dead. There was no autopsy.

When Zona learned about her son's death, she immediately returned to Berkeley and opened up their house to their family and friends. Their home was filled with people, food, and memories. Within a few days a memorial service was held. So many people were expected that it was held at Harmon gymnasium on the UCB campus. Obituaries from all over the world recalled Ed's life and impact. Few mentioned Zona except as his surviving parent.

## LEGACIES

Legacies from the lives of Zona and Ed Roberts abound.

Just as the breaking of the color barrier at American universities in the 1960s led to nationwide integrated campuses, Ed's attendance at UCB has paved the way for thousands, if not millions of others. In 1974, Congress passed the Education of the Handicapped Act guaranteeing an equal education for all children with disabilities. College campuses across the world are now implementing disability studies programs.

PDSP was the first program of its kind. Now almost every university and community college has a similar program, no longer restricted to students with physical disabilities.

CIL was the first organization of its kind. There are now more than three hundred in the United States and many more across the world.

Ed became the first person with a disability of his significance to direct a state Vocational Rehabilitation agency. Many more have followed in his wheelspan.

WID has grown from its beginnings of three people in 1983 to an organization of dozens of employees known throughout the world for a multitude of activities.

The MacArthur Fellowship has been awarded to other disability rights activists since Ed received one in 1984.

Ed's legacy may live on most fundamentally in the individuals he touched. At a memorial service held at WID shortly after Ed's death, a woman related the story of how her parents had moved to the United States from the Far East after she became disabled. She ended up in a hospital in the Bay Area wishing she were dead. When asked if she wanted anything she made a request to meet Ed. He visited. While there she related her story and he began to cry. When she saw his tears that he could not wipe from his face she realized that she possessed physical capabilities that he did not. Yet he was a powerful, happy man in his huge, electronically powered wheelchair, breathing with the aid of a respirator. She wondered why she was lying in a hospital bed. She got up. She has since become a well-known artist in the Bay Area.<sup>17</sup>

Her story is one of hundreds, if not more, of the people Ed touched directly.

Many more got out of their beds, or their nursing homes, or their lives of listlessness, after hearing Ed speak or seeing him on television or reading about him in the press.

Ed changed Zona's life in fundamental ways. She reminisced that she learned from Ed about inclusiveness, disability, connections, world-wide experiences, and being brazen. She also became aware of the importance of noticing and accepting differences. For instance, if someone doesn't notice a wheelchair the possibility of being run over by it is much greater than if someone pays attention.

Zona had both a mother's and a pioneer's impact on Ed. Aside from the remarkable life he lived, Zona believes Ed gained from her knowledge and compassion about love and loving. I believe he also gained a lust for life which he, like his mother, demonstrated for all the world to see.

Zona continues to live in Oakland. She rents the "in-law" unit as well as rooms in the front of her house. Ron and Mark are both alive and well. Zona has six grandchildren. She was present at the birth of each of them. Her desire and success in creating in her own family a stability unknown to her as a child remains her most important personal legacy. That she was able to achieve it in the face of Ed's bout with polio and its aftermath helped to give the world a human rights legacy.

My hopes are that the stories of parents who have been pioneers, like Zona Roberts, will become an everyday part of our history; that Ed's breaking of the educational barriers at an American university will be told in the same paragraph in the same textbooks with that of James Meredith, his historic counterpart; and that the struggles and accomplishments of the disability rights movement will take their rightful places in our national storytelling alongside those of the civil rights, women's rights and other minority rights movements of our country's illustrious, but not always so magnificent history.



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1. A fuller description of this experience is found in Steven E. Brown, Investigating a Culture of Disability: Final Report (Las Cruces, NM: 1994), 69-70.

2. Joseph P. Shapiro, No Pity: People with Disabilities Forging a New Civil Rights Movement (New York: 1993), 56.

3. Zona Roberts interview by Steven E. Brown, Dec. 27-30, 1996, audiotapes (in Steven E. Brown's possession).

4. Roberts interview, side 2, tape 2.

5. Mr. Roberts. (circa 1988). Sixty Minutes. (Available from World Institute on Disability, 510 16th St., Oakland, CA 94612).

6. Roberts interview, side 2, tape 4.

7. Shapiro, No Pity, 45.

8. Brown, Investigating a Culture of Disability, 50-51, Steven E. Brown, Independent Living: Theory and Practice (Las Cruces, NM: 1994), 28-30, Shapiro, No Pity, 47-55.

9. Hale Zukas. "CIL History," presented at Independent Living Conference, October 21-23, 1975, Berkeley, CA. (in Steven E. Brown's possession).

10. Roberts interview, side 2, tape 6.

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11. Ed Roberts interview by Steven E. Brown, Sept. 8, 1993, audiotape, side 2, tape 1 (in Steven E. Brown's possession).

12. Zona speculates that the murderer himself is probably long dead. Roberts interview, side 1, tape 7. In another conversation about the murder, Randy was described as stepping between the girl and the gunman, who was aiming at his date. Lillian Gonzales Brown, personal communication, Aug. 15, 1997.

13. This story was related at a small memorial service for Ed held at WID on March 20, 1995 which I attended.

14. Roberts interview, side 2, tape 6.

15. Ed Roberts interview by Steven E. Brown, Sept. 8, 1993, audiotape, side 2, tape 1 (in Steven E. Brown's possession).

16. Zona speculates that the murderer himself is probably long dead. Roberts interview, side 1, tape 7. In another conversation about the murder, Randy was described as stepping between the girl and the gunman, who was aiming at his date. Lillian Gonzales Brown, personal communication, Aug. 15, 1997.

17. This story was related at a small memorial service for Ed held at WID on March 20, 1995 which I attended.