A Disabled Woman’s Journey

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**Abstract:** This is the story of the author’s journey from an early childhood characterized by severe physical and cognitive disability to an adulthood devoted to challenging distorted views of disabled persons. The author’s goal is to be among the disability studies scholars who impart at schools and at places of employment understanding of and respect for persons with disabilities

**Key Words:** Cretinism, Peer Abuse, Disability Studies

I embark on revealing my own experience with both physical and psychiatric disability with one purpose. That is to emphasize the dire need for disability studies to be integrated not only in the college-level curriculum, but in the curriculum and lesson plans from high schools down to primary schools. Such programs would make it possible for disabled children and adults to be perceived as part of a diverse population rather than as objects of derision. True access involves not just open doors but open arms.

About six months after my birth, at the end of 1944, my mother was confronted with an infant who did not eat, defecate, or show any intellectual growth. On the basis of one course in college physiology my mother suspected I had a non-functioning thyroid gland. No physician would believe her. She was told to go back to the kitchen. In 1946 she took me, by this time a bloated blob with a protruding tongue, to Duke University. There my mother was vindicated when I was diagnosed as a cretin, a person without a functioning thyroid. If not diagnosed in early infancy, the infant becomes a cretin dwarf, physically and mentally retarded. Upon diagnosis, I was immediately given desiccated thyroid which replaces the thyroid hormone. Within one month my appearance was normal. Due to the lateness of the diagnosis, the prognosis was guarded. “She will be physically normal, but probably mildly retarded. Ultimately it is up to the mother and God.” One of the physicians, however, gave my mother some hope when he told her of a rehabilitated cretin infant who became a doctor.

My mother and father clung to that hope even though I could not walk and was incontinent until I reached the age of four. My parents read to me constantly. Then a spark was ignited in my dim awareness and I began to read. By the time I was eleven I could read books on psychiatry in my parents’ library. Due to my lagging physical prowess no children would play with me. Books became my consolation. I erected a fortress of fantasy to survive.

From the time I was seven until I was fifteen, I was persecuted by my cousin Judy and by school children. After a dance recital in which I tried my best, my cousin laughed at me and said I moved like a cripple. After school I would hide behind the trees to avoid the taunts of the other children who called me “freak” and “cripple.” At summer camp my ineptness caused my teammates to lose baseball games. For this I was beaten brutally and often scratched and bitten. The brutality of my peers must be viewed in the light of the times. It was the 1950s, a decade of rigid conformity. I recall my neighbor’s daughter had epileptic seizures as a young child. The children in her neighborhood would kick the girl when she lay on the ground after a seizure.

Although I never fought back, I was consumed by hatred and revenge. I prayed my tormenters would die. To this day, I disintegrate emotionally when I am demeaned by others. Suddenly I revert to the anguished child hiding behind the trees. I can never forgive a blow to my ego.

In high school I began to sing and act in plays. This was the only happiness I knew. Despite my clumsiness on stage, my acting and singing talent moved the audience deeply. Admiration soothed, and to this day soothes, the deep wounds beneath the surface. Thus, I decided to become a star and to teach a lesson to all the children who had humiliated me.

When I left my hometown and went to college, I no longer had to engage in sports. For the first time I had friends. My singing was also admired; however, a small role in an opera revealed again my problem with clumsy movements and inability to take stage directions. I was nevertheless unwilling to face the reality that a stage career was out of the question for me.

After I had been graduated with honors from college in 1966, I went to Germany to train my voice further and to forge a career. Within a few months I saw singers far more talented than I could not find steady jobs. I became a medical translator and teacher of English and translation methods. Moreover, I developed my talent for singing in many voices and languages. After a few years in Germany I had a full-time career as a teacher and two part-time careers. I felt fulfilled professionally and garnered a great deal of admiration. Nevertheless I was plagued by depressions which I could not understand. I began to read books on psychology, especially the work of Alfred Adler. I then came to understand how correct my father was when he said that even if we do not live in the past, the past lives in us.

In 1973 I returned to New York, found a job as a translator with a publisher and went to graduate school. By 1986 I had been awarded a Master’s degree and a Ph.D. in German literature. Before I sat for the orals, I noticed I was gaining weight and had trouble staying awake to study. My hair was growing sparse and I had trouble retaining information. My “thyroid specialist” had not given me enough medication. Without any medication, I would have reverted to a vegetative state. It is important for people with disabilities not to place unquestioning trust in our “expert” physicians. We often know our bodies and minds better than anyone else. Another physician had overdosed me and I nearly died of high blood pressure. I now know the signs of both extremes and my current physician listens to me, rather than basing her prescription solely on the blood tests.

With my thyroid once again functioning, I passed my orals with flying colors and then wrote my dissertation. The doctoral degree did not yield the results I had envisioned. For several years I taught German as an adjunct, but I could not find a full-time job. During a German session of the 1990 Modern Language Association I was told by a professor of German that my credentials were outstanding but I would never find a full-time job. “You are a woman, middle-aged, and from New York,” he explained to me.

Due in part to my frustration at not finding the professorship I sought, my recurrent depressions became increasingly severe. Since 1988 I have been under the care of a psychiatrist. Although my medication keeps me quite stable, a severe blow to my self-esteem triggers a break-through episode. Despite the distress I have never been rendered dysfunctional.

By 1990 my publisher employer was selling the firm. Thus, I decided to go to law school and become an attorney in the area of employment discrimination. My special interest was in disability discrimination. From 1987 on I had been publishing articles on various aspects of disability. The story of my rehabilitation came out in 1987. By 1991 I had published in the medical journal *Epilepsia* a study on the depiction of epilepsy in literature and film. Owing to this research I gained international recognition in the epilepsy community. Although I have no seizure disorder, I identified deeply with the stigma and rejection most people with epilepsy experience both professionally and personally. The success I had with my research gave me the courage to embark on a law career at the age of 48.

At law school I initiated the first “Society for Disability Law” and did my writing requirement on the epilepsy defense. Upon graduation from law school I worked pro bono on my first case. She was a criminal defendant who had terminal lupus. I succeeded in obtaining a dismissal of the indictment in the interest of justice. Until I found a steady job, I earned my living as a free-lance legal researcher and writer. Most of my assignments involved disabled clients.

Finally I found a position as Disability Rights Coordinator at a major New York City criminal justice agency. I still work there and derive a great deal of fulfillment from my job. Despite the paramilitary nature of the agency I still manage to accommodate a significant number of employees. When I cannot provide the accommodation an employee seeks, I try to soften the blow by strategizing with the respective person as to what new career path might be appropriate. Sometimes I just listen to the employee cry out the pain.

At present I am also pursuing a graduate degree in forensic psychology. Continuing my studies is a joy, rather than a burden. I ski with my mind. My intelligence is a miracle and I never tire of proving myself worthy of that miracle.

Reading through my psychology journals, I came upon an issue devoted to disability. This was when I read of the remarkable pioneering work of Dr. Simi Linton and her colleagues. Suddenly I knew what to do when I retire from the City: The revolutionary movement of disabled academics as well as grass roots fighters is my home of the future.

It is February 7, 2004. As I write this account, I am recovering from hip replacement surgery. After the initial agonizing pain, I began rehabilitation at the Rusk Institute of New York University Hospital. There what had initially seemed to be a great misfortune turned out to be a blessing in disguise. Before my injury I had sympathy with people who use wheelchairs. However, it was only when I could not move, could not go to the bathroom or dress myself that I came to appreciate the courage entailed in fighting for access. Today putting on my socks and taking a shower on my special bench are victories. All of this I had taken for granted until my fall. Now I cannot go down the stairs to the subway. Now I must often in vain hail taxis which will not stop when they see me with my walker. I called Simi Linton from the hospital and told her what insight I was gaining from my experience and how much my determination to be an active part of the disability rights movement had increased. At Rusk Institute I made another discovery. I felt completely at home with my fellow patients. We were the majority in this setting. Our physical and occupational therapists were young men and women who gave us unceasing encouragement and showed unending patience.

There are an increasing number of people who feel the old and disabled are a drain on society. These “Darwinians” believe the world should belong to the strong. During my most recent attack of depression, a young man told me he would assist me in suicide if it were legal. He informed me that “since all depressed people are weak and will eventually commit suicide, they should be helped to do it efficiently so that their organs can be harvested.” And yet, it is the existence of the weak and needy which brings forth compassion in the strong who can see beyond cold financial considerations in regard to the elderly and disabled.

When I was about fourteen I wrote a poem called “Lonely Child.” Although I lost the words to the poem, I still recall that depicting that forlorn little girl, once myself, constituted an act of healing. Today participating in a course on disability studies is healing. Writing this essay is healing. Pain is rendered productive in service of transformation. Like a fearful horse I often wade in the quagmire of old injuries. Yet, I know I must rise above the past so the lonely child dwelling within me may find peace at last.

My journey continues towards my goal of becoming part of the disability studies community. The inclusion of disability studies will enable others to view disabled persons as part of a mosaic in which beauty is found in asymmetry as well as in symmetry. Incorporating disability studies into the lives of children and adults will bring us all one step further in the journey towards our own humanity.

**Irma Jacqueline Ozer** is a Lecturer/Researcher on Disability Rights at the New York City Department of Correction. Because of her childhood experiences, her studies and employment have been devoted as much as possible to disability issues. Her singing and acting background has been utilized in singing cabaret benefits for disabled homeless persons. She is presently pursuing a degree in psychology to be utilized in counseling disability groups and further research on the treatment of the physically disabled by psychologists.