

From: Chubon, Robert A. (1994) *The Social and Psychological Foundations of Rehabilitation*. Charles C Thomas, Publisher

## **Chapter 21**

### **TUMULT, TRIUMPHS, AND UNCERTAINTIES**

The tumult began one fall day in 1954. Following a momentary miscue on a trampoline, I literally plunged into the world of disability and rehabilitation. As the crowd of students, teachers, physicians, and others, all visibly shaken, stared at the ambulance as it sped away from the high school gymnasium, I had no idea of the drama that was about to unfold. The tentative diagnosis of a cervical spinal cord injury had little meaning in those early hours and days, but the drama was there. That it was high drama is evidenced by the numerous books and movies depicting the struggle that ensues spinal cord injury, such as *Born on the Fourth of July*, and *Waterdance, and Passion Fish* that have recently appeared in theaters. With regard to this book, however, it was the time when the life event occurred that matters most.

It can be argued that the contemporary rehabilitation movement came of age in 1954. The passage of the Hill-Burton Act followed by other milestone legislation impelled an array of programs, professions, and facilities directed at salvaging the likes of me. Little did I realize that I was about to become an embodiment of the history of contemporary rehabilitation. As the past four decades of rehabilitation history have unfolded, I have been witness to the evolution from several vantage points. My journey began by experiencing disability firsthand and confronting the emerging rehabilitation system as a rehabilitant. Subsequently, my tenure with disability has led me through a gamut of experiences, including that of a professional rehabilitation counselor, administrator of a rehabilitation facility, and most recently, a rehabilitation educator-researcher in a university. Those experiences and perspectives have shaped this book. That is important because, as one of my former English professors stated, "you write what you are." It is my hope that this sharing of some of the highlights of my experience with disability will enhance the reader's understanding of what I have written.

By the 1950s enough of the World War II medical experience with acute spinal cord treatment had filtered out to the broader medical community to enable it to save my life, but barely. Because of the desperate measures atmosphere surrounding my initial treatment and my total ignorance of severe disability, I had resigned myself to the fact that I would lead a relatively bedridden, drastically shortened life. Fortunately, I was rescued

by one of the early state vocational rehabilitation agency counselors who succumbed to persistent pleas from my high school's nurse, who in turn, had been moved by stories of both my plight and that of my burdened family. The counselor's lack of professional training and experience with severe disability were compensated for by his compassion, enthusiasm, all willingness to take risks. Without precedent, he quickly set an emerging bureaucracy in motion. I am reminded of the influence of McCarthyism at that critical time, having had to sign a loyalty oath by grasping a pen in my mouth to attest that I was not a member of the Communist Party or other organization intent on overthrowing the U.S. government, to become eligible for agency services.

In the fall of 1955, I found myself at the Kessler Rehabilitation Institute in West Orange, New Jersey, one of only a couple of such programs established for civilians at that time. Even with my teenage naivete, I realized that this prototype facility and its founder and my physician, Dr. Henry Kessler, were special. Even in that early rehabilitation era, the rudiments of a comprehensive interdisciplinary team approach to confronting disability were well established and under the direction of a masterful helmsman. Although rehabilitation-related knowledge has since mushroomed, and additions and refinements of the process have taken place, the underlying concept of rehabilitation had been well-conceptualized and put into practice by those early proponents such as Henry Kessler and Howard Rusk.

Most crucial to reshaping my outlook and engaging me in the physical restoration program, however, was the exposure to others with similar disabilities at Kessler, some of whom were in advanced stages of their rehabilitation. Being among peers ended the terrible aloneness that I had been experiencing, and witnessing the accomplishments of those who invested themselves provided me with concrete evidence of my own potential. I savor the memories of the sports-like competitiveness that permeated the rigorous, difficult, and sometimes painful therapeutic regimens we were put through. To be sure, it was challenging, but the creative approaches of the staff turned much of it into spirited fun.

Where early history shows through, however, was in dealings with the psychological, vocational, and social impact of disabilities. I still carry darkside memories of the all too common Dear Jane letters that were written by my older spinal cord injured peers. There seemed an almost inevitable day when the spinal cord injured males wrote a letter to their significant others. In it, they offered an uncontested parting of the ways so the wives and girlfriends could salvage their lives. These otherwise

determined men concluded that they were no longer capable of being adequate providers, parents, and lovers. As their action came to light, they were consoled by both the staff and peers who assured them that it was the honorable, manly, and otherwise appropriate thing to do.

Concluding that the good things in life are no longer in one's future has a profound negative impact on motivation. If one no longer feels capable of getting married, raising a family, or holding a decent job, life loses much of its purpose and there is little to strive or struggle for. Whatever motivation remained among many of the rehabilitants at Kessler largely emanated from an avoidance mindset, i.e., the desire to avoid the worst possible fate - spending the remainder of one's life in a nursing home or chronic care hospital for the indigent. That negative motivation easily wore thin from time to time, and for a few of my peers, the erosion was sufficient to turn their thoughts into a self-fulfilling prophecy. Despondency allowed their worst imagined fear to come true.

The fear of lifelong institutional care was heightened by the experiences and stories of those rehabilitants at Kessler who became ill or required surgery. Although we were all adolescents or adults, we were transferred to a nearby charity-supported children's hospital on such occasions. At deplorable conditions existed there. Nursing staff expressed fear of going to the basement service areas because of rats. Beds were so crowded in the wards on which we stayed that they had to be shifted one by one to enable staff to have enough room between them to make them up each morning. Registered nurses were a rarity. I still have difficulty understanding why such atrocious, inhumane conditions existed.

On the other hand, I am here today because of the dedication registered nurse who was assigned to the ward on which I stayed for a couple of weeks. When I developed a post-surgery infection with high fever, she stayed at my bedside for nearly 24 hours straight sponging me with ice water and alcohol. I struggled to survive because of her extraordinary effort. She was willing to make any possible sacrifice necessary for my recovery. The experience was an unforgettable lesson. I learned that no matter how despairing things might seem, there is reason to hope and that there are people who truly care. Out of the worst of predicaments, good can emerge. Most importantly, I realized that I was still valued.

The efforts of the Kessler staff were sufficient to convert me from a bedridden invalid to a relatively effective manual wheelchair user complete independence in activities of daily living. My stay at the facility concluded with the establishment of a vocational goal. The vocational counseling approach relied upon in those early days can best be described as *pigeonholing*.

I digress to mention that I never completed high school because I was viewed as too severely disabled to have potential and beyond benefit of even homebound instruction. There was no *Education for All Handicapped Children Act* or mainstreaming. With pigeonhole counseling, a few jobs had been identified as being ideal for persons with various disabilities. For example, film developing in darkrooms was a prime field for persons who were blind. Accounting, small engine repair, and drafting were suited to males who used wheelchairs, while tailoring and secretarial work were appropriate for women using wheelchairs. Counseling was a matter of fitting people with disabilities into the most appropriate slot. To round out the approach, vocational rehabilitation centers were being developed to provide the training in these fields, together with supportive services necessary to sustain those who were not totally independent in self-care.

Because my high school career objective was engineering, it was ultimately determined that drafting was the best available match or pigeonhole for me. At a time when I was considered too severely disabled to complete high school, the idea of going to college was viewed as fantasy. In fact, even the proponents of a technical education-based drafting career expressed reservations about the probability of success because of my marginal hand writing ability and independence in self-care.

Under the continuing sponsorship of the state vocational rehabilitation agency, I went to Woodrow Wilson Rehabilitation Center in Fishersville, Virginia, which was one of the prototype vocational rehabilitation centers. At that time, the Center was part of a converted World War II temporary military hospital contained within a huge complex of military reserve, high school, technical school, and staff residential facilities. Hundreds of persons with physical and mental disabilities from all across the country were attending the trailblazing facility. It was still racially segregated in part; there were African-American workers performing low level jobs such as orderly, but African-Americans with disabilities were not accepted for rehabilitation.

The early Woodrow Wilson facility, which bore no resemblance to its contemporary replacement, imposed Parris Island-like survival demands on students. Despite the primitive living conditions and other hardships at the scantily funded facility, I successfully completed the 18-month program. However, my sense of accomplishment was quickly replaced by despair. Upon returning home, I found that there was little need for draftsmen in the small community near my parents' farm. Being partially dependent, I could not move elsewhere. Independent living programs and personal care assistants were nonexistent. Like a blow to the head, I

was confronted with the shortsightedness of my vocational rehabilitation counseling.

I spent a couple of years of relative idleness while living with my parents, occupied by a ham radio station, selling tooled leather handbags that I learned to make in occupational therapy, and an occasional free lance drafting job. Again, however, my life took another unexpected turnabout. One spring day in 1960, my vocational rehabilitation agency counselor was in the area and dropped in for a visit. After a short time commiserating over my predicament, he stated that he knew of nothing else that could be done for me, other than arranging for an overdue medical check-up. He suggested that I have this done in Pittsburgh at a hospital rehabilitation medicine unit that was about to be opened. His rationale was that it would be a mutually beneficial undertaking; I could get my check-up, and while there, I could also do some surveillance. He wanted me to evaluate the facility and share my observations with him for future reference. I accepted his offer, not because I was especially concerned about my medical status [suicidal thoughts were frequent] or interested in my mission, but rather to give my parents a respite. Little did I realize the significance of this coincidental event.

My arrival at the new Hill-Burton funded rehabilitation medicine unit of the St. Francis General Hospital was greeted by an eager staff, freshly indoctrinated in rehabilitation practices and principles, and Tom Hohmann, M.D., a protege of Howard Rusk, groomed to direct the programs. Their enthusiasm, penchant for innovation, and general sense of adventure were contagious, and mutual admiration quickly evolved. They were eager to learn the details of my experiences and expressed admiration of my survival skills. I am still not certain how they managed to manipulate my scheduled 4—7 day check-up into a month-long stay. They were exasperated by my lost opportunity to pursue a college education-based career. From their standpoint, such a career was critical to earning sufficient income to be freed of dependence on my parents, as well as realizing my potential.

Despite the formidable obstacles that were acknowledged, and caught up in a swell of emotion, idealism, and adventure, we decided the time had come to test the waters and attempt to remedy the situation. An effort was mounted to resurrect my college plans. To be frank, I was filled with misgivings, relatively certain that the effort would end up as another trial balloon that would eventually burst. Despite the odds against succeeding, I accepted the challenge, recognizing that it was “the only game in town.”

At the onset of our deliberations, the University of Pittsburgh was targeted for integration. Its selection was based on pragmatics. The University was near the hospital, making it conveniently accessible to the staff. They foresaw the need to assume responsibility for providing

whatever support I might need, and selection of a nearby university or college was critical. Additionally, the Pitt campus was concentrated and relatively well-suited to wheelchair travel. The University also offered a wide-ranging curriculum that would maximize career track options.

The next hurdle to be tackled was that of finding financial support. At that point, my parents were heavily in debt due to the expenses incurred from my medical care, which far exceeded coverage provided by the family's basic hospitalization insurance policy. The only alternative appeared to be the state vocational rehabilitation agency. However, when approached, agency representatives declined any substantial involvement, emphasizing that I had been provided training and that the effort had been unsuccessful. I had been given a chance and "blew it." In essence, I was no longer considered to have vocational potential. Apparently, my disability resulted in the revocation of any right to fail, regardless of the circumstances. However, after much pressure and negotiation resulting in a commitment by the hospital to employ me upon graduation, the agency relented and agreed to sponsor me for training again.

Again, the hospital's commitment to hiring me rested on fortuitous circumstances. The hospital administration agreed to the condition, contingent on identification of a legitimate future job slot from me. That task was relegated back to the rehabilitation unit staff. After considerable deliberation, the only anticipated future college education-based position opening in the rehabilitation unit was that of a rehabilitation counselor. Because the profession had just been born and few training programs were operating, none had yet been hired for the rehabilitation unit. However, the staff psychologist, in particular, recognized the potential benefit of having the added expertise available to the team, and was strongly prepared to advocate for creation of a position slot.

Some of the staff were discouraged by the revelation of that single job possibility. The discouragement stemmed from the fact that the nature of rehabilitation counseling was substantially different from my previously expressed engineering and science interests. Consequently, it appeared to be a prohibitive mismatch. After a couple of days of reflection, however, my survival instincts took over. I had little understanding of what the profession entailed but understood that its people orientation was radically different from that of my previous career objective. In a desperate attempt to remain in the game, I concocted a story describing how I had developed an interest for people as a result of my circumstance and experiences, and how my interest in "things" seemed to have declined. My tale was convincing to all but the psychologist, who openly expressed skepticism. It took a couple of carefully faked interest inventories to convince him that the change really occurred. To

rationalize my actions, I fantasized that if somehow I did get into the field, I might be able to assist a few other persons with disabilities in avoiding pitfalls I had experienced. I reasoned that if, as a result of my effort, just one person might eventually be helped, it would be worthwhile and satisfying. Coincidentally, a rehabilitation counselor training program had recently begun at Pitt, given impetus by a start-up grant from the federal government.

The next step was to gain admittance to the University of Pittsburgh. Although we had anticipated problems, those encountered were considerably different from the expected attitudinal barriers. At that time, there were no ramps, reserved parking places, or disabled student services office. Nonetheless, with surprisingly little persuasion, University officials considered my application and shortly thereafter, I received notice that I had been accepted for admission. On the other hand, the University officials apparently were so distracted by my disabled status that they overlooked the fact that I had not graduated from high school. They simply glanced at my SAT scores, cumulative grade average, and class standing when they evaluated my academic qualifications. Since they had formally notified me of my acceptance, to avoid further embarrassment, they permitted me to remedy the problem by taking a few sections of the G.E.D. exam, which I managed to pass. Thus, I became the first full-time, wheelchair-using, residential student at the University of Pittsburgh in the fall of 1961.

When settling in during the week before classes were to begin, I became awakened to the immensity of the challenge. There was a seemingly endless onslaught of architectural barriers and personal care problems. There was, however, an overriding ramification of my situation. It was made clear to me that any future consideration of vocational rehabilitation agency sponsorship of others with severe disabilities to attend the University, as well as the University's willingness to admit them, was contingent upon my success. That was an almost overwhelming responsibility with which to be burdened. It raised my already high stress level exponentially. I was prepared to accept personal failure, but when I had contrived my career interest change story, I had not imagined taking on a burden of that magnitude.

My undergraduate years at Pitt were like a roller coaster ride, with a seemingly endless series of high and low points. The dormitory in which I first resided had approximately 10 steps at the most accessible entrance, and I had to seek out bystanders to carry me up or down when coming and going. Fortunately, the football team was housed in the same dorm. Although their win-loss record was not impressive, the elevator or lift service they provided for me was impeccable. Classes posed similar accessibility problems at times, requiring that I be carried up long flights

of stairs or across ice-clogged streets in the winter months. On the positive side, the Allegheny County Visiting Nurse Association rallied to my need and became a pioneer in providing intermittent attendant care.

Somehow I survived the first semester, which was regarded by all to be a milestone. In fact, another spinal cord injured quadriplegic had been prepared for admission by the St. Francis staff, and he became my roommate at the onset of the second semester. Academically, I struggled, having been away from studies for several years and lacking a complete high school education. Having to rely on my slow writing and typing abilities exacerbated the problems. But I persisted and the conditions at Pitt began to change dramatically. There was a steady influx of other wheelchair using students, and at the beginning of my junior year, approximately 10 of us were moved into one of three newly erected dormitories which had been had been ramped and had reasonably accommodating facilities. Moreover, arrangements had been worked out by the vocational rehabilitation agency for those of us in need to hire student attendants to provide various support services. Also, procedures were implemented that enabled necessary classes to be moved to accessible classrooms. I must mention that the University implemented the campus changes voluntarily, as they occurred before the Rehabilitation Act of 1973 was enacted.

With year-round enrollment, my targeted graduation date from undergraduate studies was December, 1964. Early that year, I applied for admission to the graduate program in rehabilitation counseling at Pitt. However, I did not receive notice of acceptance as expected. Eventually, during a follow-up call to the program chairman, he intimated that my application precipitated a controversy among the faculty. Apparently a few of them had raised a general objection to admitting persons with disabilities. They expressed doubts that persons who were themselves disabled could maintain the *objectivity* essential to engaging in a professional relationship with clients in similar circumstances. They concluded that the likely biases and emotional involvement of persons with disabilities would render them ineffective practitioners, and argued that they should not be permitted in the field. Ultimately, those few faculty did not prevail, but it enlightened me to the pervasiveness and sting of prejudice

After gaining admission to the rehabilitation counseling program, my self-confidence and sense of mission grew enormously. Perhaps the best evidence of my growth was the fact that during the Thanksgiving holiday break of my last semester, I married a coed, whom I first met in the cafeteria nearly two years earlier. Further, following the ceremony, we departed on a brief honeymoon in the hand control equipped automobile in which she had patiently helped me learn to drive.



Upon graduation, I immediately began my job as a rehabilitation counselor as planned and never looked back at my earlier career objective. I truly seemed to have found my calling. After I had served for approximately two counseling positions, however, Tom Hohmann concluded that the rehabilitation unit had evolved to a point where he could no longer cope with both the administrative demands and his medical oversight and practice responsibilities. Hence, he asked me to assume the administrative responsibilities, and my career took a new turn. The following few years were exciting for me. I was able to tap my creativity implementing new programs and directions for the unit.

During the early 1970s, however, outside pressures under the rubric of accountability began to occupy a major part of my time. By the late 1970s, I began to feel suffocated by never-ending battles with Medicaid, Medicare, and other bureaucracies over reimbursement practices and policies. It was also apparent that the steady influx of bureaucracy-generated controls was having an increasingly stifling influence on the innovativeness and enthusiasm of the staff. Rehabilitation appeared to be losing some of its capacity to implement the highly individualized, creative and sometimes extensive programming essential to the restoration of persons with severe disabilities.

As an adjunct to my administrative role, I had gotten involved in a number of educational activities, including lecturing in some of the rehabilitation-related professional programs at the University of Pittsburgh. This involvement had always been enjoyable, but as the situation in the rehabilitation medicine unit stabilized and became increasingly driven or controlled by government regulations and policies, it became the highlight of my activities. With the support of many colleagues and friends, I then decided to embark on an academic career which would enable me to devote the greater part of my time to sharing my insights and experiences.

When I returned to the University of Pittsburgh in 1976 to assume full-time doctoral study in the rehabilitation counseling program, it was apparent that dramatic changes had occurred. The program in which some faculty once had attempted to shun me, welcomed and treated me as someone of notable value. There were curbcuts, ramps, an office for disabled student support services and a transportation system. And even convenient parking! In sum, my doctoral study was an experience that I will always savor.

That brings my story nearly up to date. I chose to bring my experience to South Carolina, which by all standards is a poor state struggling to bring its human services up to standards. To many South Carolinians, rehabilitation is still an unknown concept. I am here disseminating the

concepts so capably espoused by Henry Kessler, Howard Rusk, and those other pioneers.

The message I send students and others who are willing to listen is a somber one. As I have pointed out throughout this book, many recent changes are having a stifling effect on contemporary rehabilitation efforts. The constraints imposed by a limping economy, bureaucratic proclivities, and other interrelated factors all militate against effective rehabilitation.

In too many quarters, rehabilitation has become rushed and constricted, with little opportunity for the creativity and experimentation that salvaged me. Although medical practice can now help the body heal more quickly than ever, facilitating the healing of the mind has not kept pace. The healing of tissue and adjustment to major insults are not the same. Establishment of a new physiological homeostasis can sometimes take years, and bringing the mind back into harmony is no less a task.

Although rehabilitation must be efficient, it cannot be rushed. I ponder the chances I would have entering the rehabilitation system today. Many of the rehabilitation measures that were most beneficial to me resulted from trial-and-error and experimentation that required extended periods of time. Innovation and persistence are critical to the successful rehabilitation of persons with severe disabilities.

On the other hand, some of the supports that I received over the years, which were critical to my triumphing over disability, were fortuitous, rather than planned. However, most of the shortcomings of the rehabilitation system that I experienced are attributable to the limited knowledge and understanding that existed in an earlier rehabilitation era. Although knowledge of disability and rehabilitation have increased substantially over the past several decades, there remain many cracks in the system that continue to deny individuals their rightful opportunity to prevail over disability. Those of us who are rehabilitators have a responsibility not only to vigorously promote and apply what works, but to search out and correct deficiencies in both the system and professional practice. I hope this book will help.