

# Ira Holland: From Rebirth to Eternity

by Ira Holland

***"Living in the community has enabled me to maintain friendships, expand my understanding of the world, work and travel. There is literally no limit to what can be accomplished."***

**In 1955, I began my odyssey from active teenager to someone who was permanently disabled.** In 1955 I was 15 years old, a junior in high school ... athletic, active, in excellent physical health and working on Cape Cod as a Counselor at a Sailing Camp, when the last of the major Polio epidemics struck Boston. A youngster of seven was admitted to the camp in mid-August and he became ill two or three days later. I joined a number of the other counselors in attending to him, and on the third day, as he was having difficulty breathing and walking we summoned a physician and it resulted in his transfer to a hospital. He was diagnosed with Polio. In the interim, I had been exposed to the virus for a number of days and within a week I became ill with similar symptoms. A spinal tap, at the local hospital indicated that I had Polio and I was transferred to a major treatment center in Boston. There were no portable ventilators at that time, and the ride by ambulance was a torturous, endless, journey into darkness. My breathing diminished to the point where I was semi-conscious, I was a quadriplegic with an elevated temperature of 104°. When at last we arrived, at the Haynes Memorial Hospital, in Boston, I felt that I was a few minutes from death. I was placed in an Iron Lung and awoke more than a week later surrounded by thirty or forty other similar machines.

**After three months in the Boston institution I was transferred in the Iron Lung by truck with a generator a doctor and a nurse to the Goldwater Hospital on Welfare Island in New York City.** The March of Dimes or National Foundation operated a Polio rehabilitation center in this facility. After a very brief meeting with my family, who lived in New York, I was transferred to the Iron Lung belonging to the new facility, and the Iron Lung I had traveled in from Boston, a trip that took nine hours was returned in the truck to its original facility. So at the age of 16, I had a birthday in October I was to begin to live a new life, and I would spend the rest of my life as a quadriplegic, forever dependent upon mechanical ventilation. I wondered if there would be any real life for a quadriplegic who was dependent on a machine for the very breath of life.

**The Iron Lung was in 1955 the only viable means of sustaining a ventilator dependent person.** The smaller portable ventilators that would eventually come into being were still being developed in the research and development departments of J.J. Monaghan and Company and Thompson Respiration Products, Inc.

A bellows-like device rhythmically moved back and forth driven by an electric motor. The patient's head protruding from the cylinder, and a sponge rubber collar isolated the body. Inside the chamber, a vacuum was created that provided fifteen breaths a

minute. I lived within this device for more than six months and finally emerged when the first Thompson "Portables" and Monaghan "Universals" became available. I was released from a ventilator that offered no hope of mobility or a functional future, and anxiously attempted to adapt to the Cuirass an early creation of the Thompson and Monaghan Companies. The Cuirass was worn like a breast plate. This rigid device fit over the chest and abdomen and left a space of four or five inches between the chest wall and the top of the device. The device resembled a turtle and so the name Turtle Shell became popular. It was in essence, a small Iron Lung that worked on the same negative pressure principle. The ventilator that powered the Turtle Shell, was by no means portable, it removed the air from the Shell by means of a six-foot tube resembling the hose of a vacuum cleaner. As crude and cumbersome as it was, it allowed me the freedom of leaving the confines of the Iron Lung and permitted me to be placed in a severely reclined wheelchair. And so with the device weighing nearly 50-pounds and batteries weighing another 50-pounds on a cart that was positioned behind my wheelchair, I was able to leave the confines of my hospital room, for the first time in nearly a year. I was able to enjoy going outside onto a porch and sitting in the sun. I was encouraged by the fact that I was now able to at least see a part of the world that had been hidden. To see people walking, children playing, boats passing on the river surrounding the hospital. My apprehension was quieted only by the fact that I had been told that smaller more portable devices would soon be available enabling me someday to regain access to the world.

**I was terribly afraid that the device would fail it was new and unfamiliar.** The Iron lung was so large it seemed impervious to failure. Sitting in the sun, I convinced myself that at the age of sixteen there was a lifetime ahead of me, but I could not spend it on the porch of a hospital watching the world go by. In the company of twenty other people disabled by Polio, using ventilators, I forced myself to go forward, to use whatever devices were introduced and to ultimately escape the institution with the new and smaller ventilators that were promised.

**Within six months, the Thompson Company introduced a small black Samsonite overnight case that contained a ventilator.** The doctors and therapists demonstrated the device to me; I was to breath with a tube that was to be held in my mouth. I was told that this tube would create a flow of air generated by the black Thompson ventilator that was to be known as the Bantam. I could now take off the uncomfortable Turtle Shell, and using the positive pressure generated by the Bantam, I could now actually go home for a weekend. The Bantam was dependent upon a set of batteries that were large and extremely heavy. I was told that they had to be charged on a regular basis to provide the external power the Bantam would require, whenever it was not plugged into the AC current.

**In the months that followed, a number of devices, each somewhat more comfortable, were introduced.** Jack Huxley, an engineer whose wife contracted Polio and was now ventilator dependent, was encouraged by his wife to develop an innovative means of providing ventilation. The Pneumobelt was a creative and liberating device. A rubber

bladder was placed inside a corset worn around the waist. A special ventilator that was developed by Mr. Huxley rhythmically inflated the bladder enabling the person to breathe without having a tube in their mouth. When I first saw it, I was afraid to try it. How could such a device enable me to breathe? It was explained to me that it would only work when I was in the sitting position. The doctors and therapists placed the belt in its proper position, lifted me into the chair, turned on the ventilator and with a quiet hum the belt began the process of inflating and deflating, and as if in a dream, I began to breathe.

I had no understanding of how it did what it did, but it worked. Soon I was able to spend many hours in the chair going outside the hospital, even going to a movie, something I believed would never happen again. Ultimately, a pattern developed whereby I would use the belt during the day in the chair and the Turtle Shell or the Bantam in the evening. Always sleeping with the Turtle Shell. New and smaller ventilators were developed, batteries that enabled the ventilators to operate for 10, 12, 14 hours were developed, and I forced myself to adapt to each change as it enabled me to liberate myself from that yellow hulk that waited in the corner, always there as though it were waiting for me to fail.

**As months and then years passed, new ventilators and accessories became available from established manufacturers**, e.g. Emerson, Monaghan and Puritan Bennett. New medical equipment developers made ventilators that were to ultimately permit me and a host of other post-polio patients to leave the confines and protective walls of the institution and venture out to our homes, with some of us setting up homes for the first time.

My family drifted in and out, young friends from school visited in a most uncomfortable and increasingly short manner. They were going on to college, jobs, and marriage, and saw me as a static, unfortunate individual. Not knowing what to talk about, and uncomfortable with their own wellness they soon stopped coming.

My family came regularly as though they had no choice. My brother was off to college and my parents were obsessed with the fact that they would have to spend the rest of their lives visiting Ira in a City institution. But the worst was yet to come, the National Foundation had determined that with the advent of the Salk vaccine, respiratory centers in the United States would be diminished; the Goldwater center was being phased out, as Polio was no longer a public health threat. The National Foundation was now encountering financial problems. People did not contribute to eradicate a disease for which a vaccine had been developed. It was determined that those Polio patients who could go home with family and some minimal assistance provided by the National Foundation would in fact go.

The first time I was discharged, my experience at home with my family was nothing short of horrendous, my parents had vacated their bedroom, which was the largest of the three bedrooms in the house and had an air conditioner and my hospital bed

installed. A small sleep sofa was placed next to my bed and my "attendant" who was paid by the National Foundation worked Monday through Friday, 24-hours a day. The weekends were left to my father and my mother who admonished me not to have a bowel movement or have me require anything except a bath of my arms and legs, "your father is tired and has neither the energy or the ability to do much more than that for you." So began a four-year odyssey that culminated in my attempting to starve myself to death without any awareness by my parents who were overwhelmed with the prospect of now having Ira in their home and under their supervision. In those four years, I was not permitted to get out of bed. I was left in the company of a home attendant who was a Christian Scientist. She actually attempted to convert me, and seeing no hope in that pursuit, she actually would occasionally turn off the ventilator and encourage me to "try to breathe," "pray ... if you are sincere, God will hear you and help you." I spoke with my parents about this abuse and they dismissed it because Mrs. Brown spent 80% of her time helping in the house and was unavailable to me. She ironed and cooked and cleaned and generally was very supportive and assistive to my parents.

**I spent the next four years in bed, not getting up once, except when illness forced me to go to a local hospital, it was a blessing to get out of there.**

Unfortunately, I recovered and returned to my "prison." My only contact to the outside world was the television as my parents had decided that a telephone was a waste of money ("who would he call anyhow?"). Eventually, the stress and day-to-day boredom resulted in my deciding to simply not eat more than one egg a piece of toast and a cup of tea. A few months of this and I was virtually delirious.

**In the interim a telephone device, crude and virtually unusable though it was, enabled me to call Dr. Augusta Alba** who had been my physician at Goldwater Hospital. "I am dying, if I stay here any longer I will be dead," I told her. She asked what was happening and she asked me to return to Goldwater Hospital. "Can you have someone bring you here or shall I call an ambulance?" I asked my father and he agreed to bring me back to Goldwater. "Thank God Ira will no longer be a burden to us." I overheard him telling my mother.

**I arrived at Goldwater weighing 58 pounds.** I required intravenous supplement feeding. After a few weeks, the therapists and nursing staff carefully put me, where I had not been for four years ... in a wheelchair. Using one of the newer portable ventilators I was for the first time in many years permitted to go outdoors. It was an overwhelming experience; I sat in the warm sun facing the water and trees for a while. It was difficult to believe that there was a life outside of that bedroom in which I had lived for four years.

**I remained in Goldwater from 1961 until my eventual discharge to my own apartment in 1976.** Fifteen years were to be spent in the institution. As in the movie "One Flew Over the Cuckoo's Nest," there was in fact a life to be lived in the hospital. I met people and became friends; I met young women and developed romantic relationships.

I tried cigarettes, whiskey and marijuana all in an attempt to make up for the years in which I had wasted in that damn bedroom.

**With the advent of new ventilators, portable equipment that was actually portable and batteries, though heavy, were still able to enable me to travel in a van to places where I may hear concerts in the park or spend an afternoon in the country.** Therapists became friends and I met their friends. New Years Eve was finally a real night to celebrate, not one to go to sleep at 8:30 or 9:00. When I was 25 I ingested a bottle of Scotch with some friends and woke up with a terrible, terrible hangover in the middle of the night. Certain that I had died, I couldn't figure out why I was still disabled. I tried calling for a nurse and one arrived explaining that I was just "stinking drunk."

**It took a long time to get back to myself, but I did eventually, met a wonderful girl, Victoria, who I married in 1967.** We went to college, Long Island University, a process that took six years to complete. Using portable respiratory equipment I was able to travel to Brooklyn with Vicky and finally had the fullness of accomplishment, a graduation with honors in 1973. Ventilators became more sophisticated and I was able to use smaller ventilators that ran for hours and hours on batteries that did not require two strong men to lift them.

**After graduation, I was confronted with the fact that there was not an enormous market for ventilator dependent quadriplegics with a degree in Psychology.** The question remained what would I do now that I had graduated from college? I had always found law to be intriguing. A friend and my college advisor suggested that I take the LSAT (Law School Aptitude Test). I took their advice and after spending hours in my room at Goldwater with my college advisor, overseeing and administering the exam, which literally took some 7 or 8 hours, I waited for the results. Much to my surprise, I did quite well. In fact, I was subsequently accepted at New York Law School and St. John's University.

**While at Goldwater I developed a business.** I sold Amway, a company that specialized in making everything. I would order my supplies by telephone and they were delivered. I delivered to the multitude of nurses and therapists, kitchen and ancillary staff that worked in Goldwater. I actually carried the samples on my lap tray using a portable ventilator, which had to be charged at lunchtime. When I finally left Goldwater in 1976, with Vicky, I was the proprietor of some 500 customers and was making some good money. In fact I was reluctant to leave, what would become of the 500 customers?

**Over the years, I met and came to know a man who was to become my closest friend, Ed Litcher.** Ed had begun coming to Goldwater as a volunteer in the Catholic chapel. Soon Ed was to become a close friend of Vicky and myself, spending virtually every evening and weekend with us. Were it not for Ed's help and understanding, were it not for his patience and ability with disabled people and his understanding of portable ventilators, batteries and all that we depended on, life would have been very much different. It was Ed who enabled us to get out, to go places, to run the Amway business,

to understand our needs as regards living as disabled people, it was Ed who learned to switch batteries and ventilators when the need arose. Ed had become a very essential part of my life. Without Ed's assistance, we would never have been able to leave Goldwater and to make the transition to an apartment as easily as we did. Not to say that there was not a great deal of anxiety that ensued. Ed virtually moved us from hospital to home make certain that all of the essential elements of the ventilators were working properly and were implemented.

Until I was disabled, at the age of fifteen, I had of course always lived with my family. But over the course of the next 21-years, my family situation had changed radically, my parents and my brother left New York and moved to Houston, Texas. If I was to change my life, I had no choice I had to find a way to live independently in my own apartment with a personal care assistant.

**In the late 1960's and early 1970's the State of New York had developed plans to put housing on what was then called Welfare Island.** Once these plans took shape, I began to make my move to acquire an apartment in this new development. I developed a committee of disabled people in the institution and spoke with the institution's social service department. Attempts to use the institution's official discharge programs proved less than helpful. Ultimately, Victoria and I and another disabled couple, Tom and Nancy, snuck out of the hospital to get and sign our leases. With leases in hand, we returned to the hospital to announce our now concrete plan to begin independent lives.

That last night in the hospital was a sleepless one. For all the lousy food, hostile caregivers, waiting indefinitely for everything from meals, to getting off the bedpan, the hospital offered security. There was always a built in solution to any ventilator problem. Whenever I went to school or to any other function, a nurse always accompanied me, with a backup ventilator, batteries, a manual ventilator, and usually a mechanic or his assistant. The bus that took me would wait until I was finished and then take me back to my sanctuary. Now I was confronted with the stark reality of leaving the institution without any backup except that which I had the foresight to develop and implement myself. My caregivers were hired and trained by me. My meals had to be determined by myself. No dieticians would direct the preparation and variety that would be wholesome and attractive.

Doctors and Registered Nurses, mechanics and generators were all to be left behind. It was frightening, my parents offered no support, and advised me to stay in my "little safe corner of the world." However, I had decided that life after 21 years in the institution had to change. I had to make the step toward independence. Change of any sort is always a challenge and often a threat. But often that change is essential if one is to continue to live as an adult person. Anxiety and apprehension overshadowed my move. In much the same way that changing from one type of ventilator to another makes a ventilator dependent person apprehensive. There is always a sense of confidence in that which you know. The unknown, be it a new apartment, a new way of living for a

ventilator dependent quadriplegic, or the necessity of changing from a ventilator that you have used for twenty years to a new type of breathing device are all anxiety producing events. But changes had to be made. **With my wife Victoria and my friend Ed Litcher at my side, in 1976 I was took my giant step to reenter the real world after my 15-year hiatus.**

Shortly after moving, Victoria had expressed the desire to develop a program that would assist people with disabilities, and at almost the same time, **an opportunity availed itself for Ed, Vicky and myself, to create a new home care company.** After much discussion, we came up with an idea that was unique. We would provide home care with a twist. It was to be called Patient Managed Home Care and the twist was that in our agency we would permit the client to select, train, and supervise, and if necessary dismissing the home attendant. We came up with all manner and sort of ideas, we would mail the payroll directly to the client, we would make the client the employer with the agency becoming the employer of record, and so Concepts of Independence for the Disabled, Inc. was born in my living room. We solicited the service of an attorney who lived in our building to be the one to incorporate us and we began a three-year struggle with the city and state officials, none of whom believed that there was any chance of quadriplegics using ventilators, to operate a real business. Unfortunately, Vicky died of cancer in 1979, never living to see us open the doors to an organization that she inspired us to create.

In 1980, after endless meetings with innumerable people we finally were given our first contract with the proviso that "if we did not enroll 100 clients in our first year, we would not be permitted to continue." Well we did, Ed became Program Director and we got an office on 14th Street in Manhattan. **Beginning with five clients and a staff of five, we were "Concepts of Independence."** We continued to grow, elected a Consumer Board of Directors, hired staff and consultants and after some 14 years we had 400 clients. In 1994, our program's first President Sandra Schnur became ill and passed away. After the Sandra's death, I was elected President/CEO and I took the company in a completely different direction. I decided that we were ready for relocation and we moved to the Wall Street area, which at the time was very hungry for new tenants. I was able to negotiate a lease for virtually half of what we had paid on 14th Street, and I soon began the process of aggressively expanding the program. During this period we were able to work with State Legislators and Advocates to expand the legal definition of our program to enable Consumers to receive high level home care services and to formally incorporate it into the list of Medicaid services available to Consumers across the State of New York.

It was during this period that we worked with the Human Resources Administration, the Alzheimer Association, Sick Kids Need Involved People and other organizations to develop a system that would allow people who were not independent to participate with the aid of a surrogate. It was this combination of factors that enabled Concepts to grow from a sleepy program serving about 400 clients to an important provider of home care services serving more than 1200 Consumers and employed more than 2400 personal

assistants in New York City and several upstate communities. Included in our program's design we provided extensive benefits to our employees and their families, including Blue Cross Medical Insurance, a dental plan, a pharmacy plan, and as vision plan.

**The program we started in 1980 became the foundation for what was now called the Consumer Directed Personal Assistance Program.** Ed and I worked seven days a week on the program, rarely taking vacations, as we worked on this program we were able to prove to the City and State officials that we could save many millions of Medicaid dollars by empowering and protecting Consumer autonomy.

After working for Concepts for 20 years, I at the age of 61, felt that we had accomplished what we had set out to do, so in March 2001, Ed and I left Concepts and we began to direct our attentions elsewhere. In September 2001, I began consulting with Millennium Respiratory Services, Inc., and working with manufactures such as Puritan Bennett and Respironics to assist ventilator-assisted people in the community; while Ed began to develop a new we based advocacy business Consumer Directed Services.

**Using portable ventilators has enabled me to pursue an active functional life, proving that ventilator dependent, severely disabled individuals can continue to provide productive and functional service to society.** The technicians and therapists of Millennium Respiratory Services, Inc., in conjunction with today's modern technology enabled me to go much further than you can imagine. Today's technology and knowledgeable therapists can permit individuals such as myself to live in the community and manage occasional hazards and blackouts that this situation can entail. Living in the community has enabled me to maintain friendships, expand my understanding of the world, work and travel. There is literally no limit to what can be accomplished. The equipment exists the technology exists; a companies such as Millennium Respiratory Services, Inc. exist to enable the technology to serve the client so that truly miraculous things can be achieved.

**Living as a disabled person I have learned that we must each devote ourselves to the fact that we have but one life.** Live it to its fullest. Go to ballets, plays, ball games, movies, vacations, go to work, to school. Regardless of your disability or lack of one, all things are possible, if you have the initiative to accomplish them. Watching television and sitting in the street are not going to fill you with enthusiasm or make a productive person of you. Take the next step yourself. Don't sit and wait for the magic cure to come by, busy yourself, devote yourself, and take advantage of the many miraculous changes that have enabled us to go forward. *Avail yourself of what is today available.*