Rehabilitation *into* Independent Living

30th ANNIVERSARY ISSUE OF REHABILITATION GAZETTE

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REHABILITATION GAZETTE
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Edited by

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Gazette International Networking Institute
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With Gratitude

Special thanks to the forty contributors who have so generously shared their experiences to provide us with this retrospective and introspective account of their rehabilitation into independent living.

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From the Editor

To celebrate its 30th anniversary, the *Rehabilitation Gazette* presents this extraordinary collection of life experiences written by individuals with a disability. Most of the 40 writers have been disabled more than 35 years, and many of them are ventilator users. They include polio survivors and individuals with other disabilities.

Their experiences were written as guidelines for professionals and other individuals with a disability who seek to learn how rehabilitation evolves into independent living, to learn how these individuals "got here from there."

They recall and analyze the factors that contributed to their success: (1) support systems — family, friends, attendants, and self-help networks; (2) education and employment; (3) equipment — commercial and adaptive; (4) transportation; (5) participation of vocational rehabilitation and other agencies; (6) creation of disability rights; (7) travel; and (8) hobbies and recreation.

The story of the *Rehabilitation Gazette* is interwoven with my life. Because polio caused the deaths of two sisters and a brother, I have been involved with individuals with a disability since 1949. During the decade of the 1950s, I worked as a volunteer at Toomey Pavilion, one of the 16 regional respiratory polio centers. After the centers closed, I started a little newsletter, the *Toomey j Gazette,* in 1958 for the local polio survivors. The newsletter evolved into an annual journal, the *Rehabilitation Gazette,* which includes the experiences of individuals with all types of disabilities worldwide.

Because of these life experiences in the *Rehabilitation Gazette,* thousands of other individuals with a disability have attained independent living through rehabilitation. The writers and the editors hope that this collection will be equally valuable to the present generation of professionals and individuals with a disability.

Gini

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Phone saleswoman. Uses voice-operated computer.

Polio. Ventilator user.

"There are some basic factors which have helped me to achieve my present independence. These are: adaptability and assertiveness; balance and bounce; coping and challenge. Besides, of course, continual support and guidance from wonderful friends and family."

It is not easy trying to figure out how I, a quadriplegic with respiratory polio, came to be living by myself in my own apartment, and what factors and forces have brought me to this present state of independence. There are some basic factors which have helped me to achieve my present independence. These are: adaptability and assertiveness; balance and bounce; coping and challenge. Besides, of course, continual support and guidance from wonderful friends and family.

Being a gregarious and social person by nature has also been very helpful in utilizing these qualities. From an early age I was brought up, though severely disabled, to be taken into the community and encounter what every other non-disabled child would. My mother "dragged" me, loaded down with supportive braces head-to-foot, everywhere she went. I was thus forced to encounter and adapt myself to all kinds of people and situations. Being an assertive person herself, she taught me not to be afraid of speaking out or finding ways to accomplish what was needed. I have always interacted with people who presume that I am capable of making decisions and using my mouth and mind to make my needs known.

I find that my A-B-C's are often working in conjunction with each other so no one aspect takes precedence. Learning to "bounce" back after a particularly difficult phase of my life, such as the death of my mother, was not always swift or easy, but I did it. We all have our own ways of returning to a more stable state, but we do it differently. I have never been one for moderation or balance. So it has been difficult for me to balance between overstressing my present physical weakness with my need to be on the go constantly.

I have always been involved in some sort of work, be it selling magazines, Christmas cards, and presently telephone sales. I cannot be idle for long and I feel that this natural drive to be interacting with the world has also been a major factor in my present independence.

My having to deal with the insidious late effects of polio has brought into play every strength and ability I have to cope. The challenge of altering my long-standing daily routines, such as getting out of my iron lung in the morning, not to return until bedtime, for instance, has now evolved into taking a couple hours' "tank-break" after an afternoon of phone work so that I can function less fatigued in the evening. I am presently utilizing a voice-activated computer system which does my writing for me, thus saving my limited left arm.

For me, variety has always been very important — whether it be food, music, or attendants. I presently have four different attendants who rotate throughout my week, some being around for my work time, others solely for my play time. I also have consciously developed a back-up system for those wonderful occasions that we all know about. Adaptability has played a strong part in my not going totally crazy some days. A great deal of my time is by necessity spent in organizing and keeping track of my pragmatic world. Like, do I need to do laundry? What's for dinner tomorrow? Who's going to wash my floor Thursday? So I value highly my "play time." I am continually going out (I think I must have some gypsy blood) to museums, concerts, movies, parks. If it's free or cheap, I'll be there. A very wise person once said, "It's not easy having a good time." But I certainly try. Life would be boring, if not useless, if I didn't do so.

It was a gradual progression from living with my immediate family, to living with my grandmother and brothers, to just my grandmother, to being on my own. During these stages I gradually had to learn, often by necessity, how to hire and manage attendants. It is a fine art trying to get someone to do what you want and have it be a pleasant experience for both. There is nothing wrong with a little positively motivated manipulation.

I am presently on the board and have become actively involved in my regional independent living center. It has been a source of satisfaction to feel I have some input into helping other persons with disabilities lead their own self-directed lives. It seems very natural for me to run my life, but there are times when I have needed guidance through the maze of living independently. I'm constantly learning from others how to manage both myself and my world. I have always been one to ask for all the help I can get, either from people or social agencies. I need all the support I can get.

It has never occurred to me not to be in charge of my life. I do value and need others' input. But it really is my life I'm dealing with and, in many ways, this can be harder. I ultimately have the total responsiblity. I think that's what independent living is all about. 福

Lawrence C. Becker

College professor.
Philosopher. Ethicist.

Polio. Ventilator user.

"My family always assumed that if I lived I would have a full and productive life; that I would go to college; that I would find a way not only to go to college but to have a career that I wanted."

In one incarnation or another, Gini's magazine has been an important part of my life since the early 1950s, when the *Toomey j Gazette* was my favorite among the newsletters circulating from hospital to hospital. In those days, the magazine was a long way from its current glory, but I read it eagerly. When it comes across my reading board now, it goes on top of everything else.

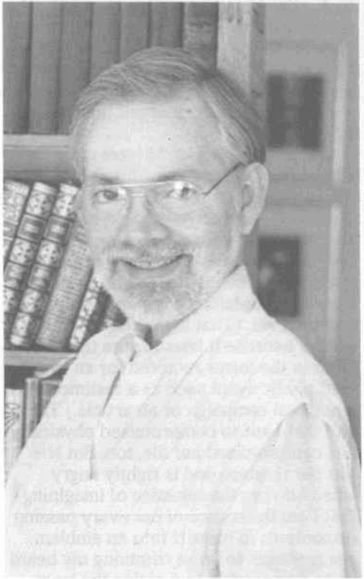
The priority I give to the *Gazette* would surprise my friends, I think, as much as it surprises me. For the past thirty-six years I have fought hard against being identified as a *handicapped* boy, son, student, man, philosopher, teacher, husband and so forth — as hard as I have fought against the limitations imposed by my body. And my insistence on excluding the most obvious fact about my life from every public description of me has some of the effects of denial, both on the inside and on the outside. So much so, in fact, that a severely disabled friend once accused me of trying to "pass." That remark still stings — not only because the charge of self-deception is hard to take, but also because it suddenly illuminates for me the absurdity of my walking around, arms dangling, breathing like a frog, acting like 1952 was a very good year.

For the record: 1952 was a very bad year for me, except that I survived it. It's a familiar kind of story, and can be told very briefly. In August of 1952 I walked into the hospital in Hastings, Nebraska, with what turned out to be a severe case of high-spinal polio. My arms failed first, then my respiratory muscles, then my legs. Two and a half years later I walked out of the respiratory rehabilitation center at St. Joseph's Hospital in Omaha, having regained the use of my legs (but not my arms) and enough accessory muscles to breathe on my own during the day. We also thought that I had regained enough strength to sleep without a respirator, but that turned out to be false. Three months of sleep apnea convinced me to stop lying to the doctors and stop arranging to have my blood gases checked when they would be likely to look reasonably good. (Fifteen-year-old boys are a cunning lot, especially in areas where they have only a vague understanding of physiology.) So I went back into a chest respirator for the nights, and that has not changed over the years. In fact, the only major physical changes since 1955 have been a gradual increase in strength and stamina until perhaps 1971, when I broke my femur in a fall, and a gradual decline in the strength and reliability of my legs between the mid '70s and mid '80s. In 1984 I began to use a wheelchair intermittently, for excursions, and now use one for everything except getting around inside the house or office. I have a foot-controlled Electric Mobility three-wheeler for trips around the campus, and a (foot-powered) E&J Companion chair for use in the classroom and for travel. A wheelchair is safer than walking alone, is less tiring, and restores some of the mobility and independence I had from roughly 1957 to 1974. Otherwise I am in good health, and am working harder than ever. (I am a professor at Hollins College, where I have taught philosophy since 1965).

There are three things at the heart of my life, and I was advised strongly against all of them: philosophy (it would impoverish and depress me); teaching (there was too much discrimination against the handicapped); and marriage (it would be unfair to anyone foolish enough to agree). I list those in the order in which I ignored the well-meaning advice. It doesn't seem possible to say which has been the most important. If I had done what rehabilitation psychologists and some friends advised, I would now have a J.D. rather than a Ph.D., a partnership rather than a professorship, and a farm in the country rather than a house in the suburbs. Charlotte would (if she remembered me at all) think I was stupid for never having proposed. I would have travelled more widely, but I wouldn't have had the luxury of sabbaticals. I might have written contracts for books, but probably not the books themselves. I would, I suppose, still be 49 years old in that other world, but nowhere near as happy.

There is no secret to this sort of success-without-arms story. Every reader of the *Gazette* knows that the ingredients are first, second, and last a family that somehow adjusts lovingly to its bad luck and resolutely sets out to keep their horizons wide, and their expectations of each other high. My family simply always *assumed* that if I lived I would have a full and productive life; that I would go to college; that I would find a way not only to make a living but to have a career that I wanted. What polio had changed was the way in which I would have to work all that out, the extent to which I would be dependent on them, and the degree of difficulty of it all. They coped with this in a way that was largely invisible to me and created an environment in which there weren't any excuses available to me for doing less than what was clearly possible. My mother, in particular, had an astonishing amount of patience and good cheer. She arranged for me to have a conventional life, adjusted for the lack of arms.

My mother's resolve weakened a bit when it came time for me to go to graduate school. I'd lived at home through college, gotten graduate fellowships, enrolled at the University of Chicago, and (through intermediaries) found a dorm room and several students to be my



attendants before she quite grasped the risks. I never did grasp them. I just took them, more or less blindly. Everything worked there, and almost everything worked smoothly — as it did in getting a job and starting out as a teacher. I screened out the unpleasantness and took a day at a time, with an occasional nod to what is now called strategic planning. From this vantage point the things I did from 1961 until 1967 look pretty unsafe. But that's what middle-aged men are supposed to think about their youthful exploits.

Charlotte Burner and I were married in 1967. Life with her feels a lot riskier than life as a graduate student, but that is an illusion. It is objectively safer; subjectively more gripping. An unconventional life, in a conventional setting, adjusted for the lack of arms. What isn't an illusion is Charlotte's unfailing companionship, wit and intellect. (That is true but sounds stupid, because it tries to sum up a love affair in the forms required for an irrelevant public event such as a testimonial or a political campaign or an article.) The fact that I am so compromised physically has compromised her life, too. But she has her reasons, and is rightly angry when I do her the injustice of imagining that I am the source of her every passing discontent. To make it into an emblem, she manages to make trimming my beard seem comparable to mowing the lawn: boring, intermittently oppressive, but ultimately routine.

The rest was (and is) work. That and what the psychologists call adjustment. The letter inviting me to write this reminiscence suggested that I try to articulate something about the adjustment part also — something, I assume, beyond the obvious. I'm reluctant to try this, since most of the readers of this journal have already worked these things out for themselves long ago. But the truth is that my ability to cope has been shaped decisively by several discrete events — several discrete utterances, actually — that I have never before tried to write down. I'll try to make them interesting — and short.

Some things are not within your control. On a day in September 1952, after my fever went down, my doctor decided to see whether I could still breathe on my own. He walked into my field of vision in the mirror of the iron lung, made eye contact briefly, said good morning, took out his pocket watch, and without warning went to the foot of the lung and turned it off. It was as if he had pushed my head under water.

Within a day or so, as I now believe, I independently rediscovered most of the truths, and all of the errors, of an ancient and famous book of stoic philosophy called the *Enchiridion.* It was written by Epictetus, a Greek who had been a Roman slave, and propounds the idea that human beings can control the quality of their lives by controlling their emotional and intellectual responses to events. Some things are within your control and others are not, Epictetus said, but your evaluation of them, and your emotions, are always within your control. (If that sounds familiar, it is. Every recent decade has seen a name brand of psychotherapy based on the idea of rational emotional response.) Practicing this doctrine has some ugly side effects, as Epictetus is honest enough to state baldly, but the overall results are persuasive for someone in an iron lung. It turns out that although it is true that some things are not within your control, you can't really know what the interesting ones are until you try them. That is a fine form of irony.

Never use THE fact. One of the first trips I made in a wheelchair was a forced excursion down the hall from my idling iron lung (I was due back within the hour) to see another juvenile male who had had polio. The nurses didn't know that he and I had been seventh-grade enemies. They rolled me into his room, and he graciously allowed me to wait while he dictated (to a patient Greylady) a letter to his girlfriend. It began with the words "I guess now that I've had polio . . ."

I wanted to throw up. Until then I had of course been considering the possibility of writing several such letters, like a good little opportunist. But that scene drove the thought, and all of its variations, permanently out of my mind.

Don't patronize people with no feet. This is complicated. It begins with a visit from a woman paraplegic who had just gotten leg braces and learned how to heave herself to her feet. In the flush of her triumph someone told her to wheel down to my room (where I was gasping like a minnow, immobile on the bed) and show off her new talent. She did, against her better judgment, and we were both stricken by the cruelty of the comparisons that are forced on the sick in order to exhort them into greater efforts and better spirits. ("I complained bitterly because I had no shoes, and then I saw a man . . .") I just cried and turned my head away. She came back later, without the well-wishers, and helped me put this principle into words.

Being easy to love. This was not a discovery. It was a slap in the face. (That is too mild. I was floored by it, and still am.) An ancient married man on a rocking bed, with a level gaze fixed somewhere on the footpedal of my wheelchair, said "I may not be able to keep the wolf from the door but I can make myself easy to love." The hideous brilliance of that principle — its danger and its inescapable logic — is worth a lifetime.

Putting polio at the periphery. This is the last one, mercifully. It took longer to learn, though I heard it repeatedly, in different words, from many friends who had reason to know. It is only half true, but still worth acting on. Stated as a parody of another famous philosopher (Kant), it is this: Act as though your biographer will have no evidence, not even a hint, of the fact that you were crippled.

That puts some things (work, mostly) into perspective. It is also bracing, makes one a more pleasant conversationalist, and (whatever its cost in absurd pretense) yields good results, mostly. I promise.

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Charlotte Becker

Librarian. Lawrence's wife.

"You certainly have a right to a life of your own."

I am a pusher.

As a pusher, I have learned a few things. Since these things are difficult to summarize, I will enumerate some of them.

I have learned that successful push-relationships are like successful marriages: you work at merging your rule books. This is most easily done when the rule books are in agreement from the very beginning, which is why people tend to marry people from similar backgrounds. There was, of necessity, a disparity between my rule book and Larry's. Mine was ordinary; he had had to write a highly complex and sensitive appendix to his book. I continue to find it difficult to assimilate some of this appendix. "Never make polio an excuse" translates, for me, to "Never make Larry's condition an excuse." How do you turn down an invitation to someone's utterly inaccessible house? (Our friends understand the problem and make allowances.) What do you say when you disappear twice a day during your coffee break?

The most troublesome rule is: "Don't ask people to go out of their way to accommodate you." I can apply this rule in personal relationships but not in our relationships to institutions. The College has been extremely good to us. No one asks me why I leave the library twice a day for my coffee breaks. (Admittedly, I want to tell Larry the latest gossip as much as I want to give him a pit stop.) But the College also has its blind spots: Every time a building goes up which is inaccessible or requires grinding a wheel chair over gravel paths or through a back door or across dangerous parking lots, I get . . . exercised.

One thing I had to *un*learn was that wonderful old saw: a couple is the sum of its parts. WRONG! Larry's physical disability does not require that I be twice as strong as a regular person so that the two of us average out as normal. That is only common sense. Larry's patience and his unflappable steadiness do not license me to be a brute or a ditz. That is pretty obvious, too, but not as comfortable to live with.

I have learned that successful pushers walk a very thin line which lies between being a selfless appendage and being a selfish creep. Having your own identity is important for at least two reasons. If you don't, your pushee may well feel responsible for your being an amorphous blob — after all, you're probably too busy with his life to have a life of your own. This means that if he's a decent sort, he'll feel bad about having deprived you of your selfhood and he'll try to make it up to you. He'll do this by killing himself in order to succeed. (Succeeding for two.)

The other reason is that you certainly have a right to a life of your own. (Even if you are intent on being thoroughly selfless, having a life of your own makes you a much more entertaining person to be around.)

I learned that once I had an identity, I had to figure out how to project it. I had to establish a "public image." As a feminist who spends a lot of time around impressionable college women, I am concerned with how others perceive me. I feel compelled to provide a good example of the balanced life. This is especially difficult to do when I am at Larry's professional meetings and am no longer in my own context. For starters, I learned that it

helps to have my name tag read CHARLOTTE BECKER, not MRS. LAWRENCE BECKER. That's the easy part.

But what does a civilian say to philosophers (or engineers or editors or ad execs)? While I am conversant with philosophy, I can't pretend to be a philosopher. Once, just a few years after Larry and I got married, I found myself talking at one of these meetings to an aged, venerable philosopher about our mutual interests. At subsequent meetings, we resumed our conversation about the Virginia mountains, renovating old houses, his amateur string quartet . . . It turned out that I had made friends with a giant in 20th century philosophy.

Once I discovered that even the greatest philosophers are three-dimensional beings, I felt fairly comfortable at Larry's meetings. As a librarian, I can talk with scholars about the pros and cons of online catalogs. I can also talk about cabinet making or opera or delphiniums or 19th century literature. ("Is George Eliot's ending to *Adam Bede* a cop out?") I have a persona!

May I hasten to add that it's not always a good persona. I have learned that *pushers aren't saints.* When I was about ten years old and found out that I was short, I also discovered — through an unfortunate fluke — that one way for short people to be noticed was to be perverse. This has its drawbacks. One of them is taking cheap shots. Pushers are ideally situated for taking cheap shots.

Cheap shots are great good fun until you fire them off, and then you feel like dirt. One of my favorite, and more reprehensible, shots was at a woman who had just returned from a marriage enrichment weekend with her husband. She was extolling the virtues of couples showering together. Golly, was she a sitting duck! I opined that, for me, a solo shower was a rare and guilty indulgence. Cheap shots are not social accidents, they are intentional misdemeanors.

I suppose that what I have learned is that there is no calculus which defines a good life, not even for pushers. We muddle our way through the days, trying to learn from our mistakes and enjoying — immensely — the funny or wonderful things which come our way. 福

Bud Blitzer

Retired businessman.

Polio. Ventilator user.

"I tried to make a mental list of options. I could come up with only two: try or give up. Giving up had such a terminal ring to it, that I decided to try."

Polio flattened me on August 15, 1952. This was not, however, the beginning of my struggle for independent living. That started when I was still in high school, and it continues to this day. My story is about some of the new dimensions that chronic disability added to this struggle, and how some coping mechanisms rescued me along the way.

At onset, I was 26 years old. After one month of acute care and 14 months of rehabilitation at Rancho Los Amigos, I returned home to my wife and our two children in Los Angeles with a strange new assortment of muscles. While I could walk short distances with assistance, I was essentially wheelchair-bound. I could, however, use my legs to propel the wheelchair, mostly backwards. While this kept me better informed about where I had been than where I was going (a recurring theme in my life), at least I could move myself around. My trach had been closed, I had enough biceps and finger flexion in my left arm to eat precut food without assistance, and scribble short notes if a pencil and pad were within my reach. With the help of my remaining abdominal and sterno muscles I had a sitting VC of 1700, which proved adequate to meet most of my breathing and talking needs through the day. At night I slept with a chest cuirass. So equipped, I re-entered the world I had left behind 15 months before, wondering how I could possibly hold a family together and provide for them when I could no longer even take care of myself.

One thing I had going for me was motivation. It started in late 1952, as I lay in an iron lung at Rancho. At some point it became increasingly clear to me that this was not the measles and, while I could not yet know which lost functions I would ultimately regain, clearly I would not ever be whole again. I could not cope with that new reality. Just wondering if I would ever get out of the iron lung proved overwhelming to me, so I tried to make a mental list of my options. I could come up with only two: try or give up. Giving up had such a terminal ring to it, that I decided to try. Although I did at times review that decision, I never changed it, and it became my most constant motivator.

One of the next problems I thought about was how to earn some income. I had always wanted to be in my own business and had, in fact, opened one barely six months before polio struck in 1952. But it was shaky then, and I suspected that my prolonged absence battling polio could do little to strengthen it, so I didn't see it as a reliable source of income to return to. I considered getting a job, but having abandoned high school to join the army, I was short on education and long on handicaps. This did not sound to me like a formula for success in the job market. Maybe if I could only hang on for a little while longer, I might be able to alter the business to make it more profitable and, at the same time, friendlier to my new limitations.

After much mental huffing and puffing, a new business was born in March 1956. We would try to design and sell unusual kinds of ceiling surfaces like luminous, mirrored, wood, etc. through architectural and interior design specifiers. I often wondered if part of the inspiration might have come from lying on my back for weeks staring at the faceless hospital ceiling above me.

The new business immediately began generating its own motivators. First there was survival, then growth. I needed growth for many reasons. One was that my attendant only got me up at home and delivered me to the office. I then had to depend on the office people to take care of my personal as well as my business needs. One of the most basic was help going to the bathroom. Being prudish by nature, I felt this required the services of a man. One day, when the company was still small, the need arose, but all of our three men were out. Luckily, my insurance agent dropped in just in time to avert a mishap, but I subsequently decided to try to make the company big enough so that this would not happen again. When we finally sold the company in 1984, we had 85 employees, of whom more than half were of the male persuasion. Motivation sometimes springs from the most unexpected sources.

Aside from long prison time, I can imagine nothing that can organize and train the mind better than chronic disability. Much that others do routinely requires thought and planning. My training started in the iron lung as soon as my head cleared. When I could not deal with the uncertainties and realities of my new situation, I forced my mind to think about other things. I began using this discipline as a defense against insanity and depression, trying to make it my major preoccupation. Soon I had most of my open time divided into compartments, with a different subject assigned to think about in each compartment. With practice it began to work so well, that I sometimes resented being interrupted by visitors, some of whom had travelled considerable distances to see me. I suspect that most chronically disabled people develop that same skill for the same reasons I did. That may partly explain why there are so many helpless looking people practicing law, medicine, psychiatry, psychology, engineering, politics and urban planning, doing creative artwork, founding and running institutes, teaching, writing, and lobbying in Washington, just to name a few such people I know myself. I also discovered an added benefit from the same unwanted source. In the game of business, while my competition was out playing golf, I was busy thinking up our next new product or strategy, and apparently it paid off.

Bud with his wife, Dalia, and their dog, Bamber.

My highest equipment priority (after the ventilator) has always been the telephone. It is my contact with the outside world, as well as my front line defense against the problems of finding myself alone and helpless. Every telephone company with which I ever dealt was always generous with its help, even to the point of assigning people who took a personal interest in me and often, on their own time, made special devices for my use. Starting in 1954 with a simple wall-mounted hand set which required no hands, to a knee-operated push-button switch panel through which I could gain access to all phone lines, and finally a speaker phone, they kept me current as the company grew and new equipment appeared. Those same two men watched over me for more than 20 years, and I owe them a lot. Other devices that made an important difference in my life were a foot-actuated bidet that eliminated the need for toilet paper, a foot-actuated dictation machine set up by IBM people so I could dictate letters and take telephone "notes," and more recently a new electronic automatic-dial telephone and the single-finger mode computer I'm using to peck out this paper. Whenever I could identify a repetitious problem, I found it generally paid to launch an aggressive search for a solution.

My first marriage ended in divorce 25 years after it started. Our inability to adjust our relationship to the changes resulting from polio was a major factor. But in the course of this change I discovered that people in wheelchairs can court, too, and in all modesty, my results were spectacular, as anyone who knows my wife Dalia will attest. We've been married now for 18 years, and she has brought a measure of peace and contentment to my restless life that is well beyond anything I could have hoped for.

I learned the benefits of networking from Gini Laurie. I don't know how she found me, but some time in 1958 an issue of her *Toomey j Gazette* arrived mysteriously in the mail. I began to read about how other people were coping with problems just like my own, and I felt less isolated. Over the years I've exchanged ideas with her readers, and eventually met many of them personally at her G.I.N.I. conferences. We now count some among our most cherished friends. I cannot overstate my deep appreciation to Gini for the benefits I've received from her lifelong commitment to helping the disabled.

Writing this paper recalled to me some of what I was feeling 30-odd years ago as I struggled to cope with the new burdens of disability. I could not then picture myself even lasting this long, let alone enjoying a good quality of life. My thoughts were more about adjustment, acceptance, and survival. Slowly, and with the help of family, friends, and even strangers, I overcame enough of the barriers of disability to replace my feelings of deep self-doubt with a measure of self-confidence. At 63, I am feeling more robust and energetic than I did two years ago, when my health appeared to be declining. My days are filled helping one of my old associates start his own business in which I have an interest, trying to speed the development of a workable and affordable nose mask, doing a little traveling, sharing the simple pleasures of life with Dalia, and still engaged in the struggle to live as independent a lifestyle as our limitations allow. I still think life played a dirty trick on me when I was chosen for the gift of polio. And yet, I sometimes wonder what I would have missed had it been otherwise. 福

Doris Brennan

Advocate. Founder of independent living center. Writer.

Spinal cord injury. C4-5.

"Rehabilitation was the focus of our lives . . . Trying to do and outdo each other, we also came to rely on one another for what we later came to know as peer support."

Lying on a Stryker Frame, weights attached to wires in my head, unable to move, those words, spoken to my mother and me by a bespectacled intern sounded ludicrous. I was paralyzed from the neck down because a tree got in the way of the van in which I was riding. I had just recently been weaned from an iron lung. I couldn't move a muscle. How in the world could this doctor say "There's a lot she'll be able to do without the use of her hands!"

That was in 1954 — 34 years ago. My life and times in the ensuing years have proven that intern to be prophetic. There was and is a lot I am able to do without the use of my hands!

So, when and how did I become a believer? At the time of my spinal cord injury, survivors were few and far between. The acute hospital I was taken to after the accident expected my imminent death daily — for the five months I was resident there. So they gave me free reign to enjoy my "last moments on earth" by killing me with kindness. I ate if and as I chose. Was turned if and as I chose. And had well over the traditional hospital limit of two visitors at a time into the midnight hour. I did a lot of talking, lost a lot of weight and developed lots of bed sores, but I certainly didn't do much else without the use of my hands — or legs, for that matter.

My family were believers from the start. They had never had any experience with disability, long-term or short. But reality was their long suit. Given whatever facts that were available from my doctors, they accepted the reality of the permanence of my disability, kept hope that the return would be greater than the doctors expected, and went on from there, helping me to deal with the drastic changes my life would take. My parents, my older sister and her husband, and my younger brother KNEW I would be able to carve a meaningful life without the use of my hands and legs, and they were going to be there to help make it happen.

Since "news of my imminent death was greatly exaggerated" at the acute hospital I had taken residence in, they decided I had overstayed my welcome and shipped me off to Highland View Hospital, the local rehabilitation facility. Stories I had been told about the beautiful grounds and the balconies off each room and the various therapies I would undergo had me fantasizing a spa-like existence which would result in my "walking off into the sunset," cured, healed, whole. After all, my only experience with disability came from the movies, and 34 years ago, movies all had happy endings! In "Heidi," Shirley Temple did what no doctors could do and helped her friend walk, and Gary Grant saw Deborah Kerr miraculously emerge from her wheelchair for a grand reunion in "An Affair to Remember." Could I expect less!?

The experiences of the next few years in and out of the rehabilitation hospital and the friends I chanced to meet during these and the ensuing years gave me the answer to that question. It was yes and no. "Walking off into the sunset" — that was not to be. But a life of fulfillment, satisfaction and quality — that happened.

Encouraged by my family, spurred on by two great occupational therapists who became close friends, and buoyed by a couple of fellow quads who "had been there," my first encounter with the "rehabilitation process" showed me that there could be life after disability.

At the time of my hospitalization, Highland View, having only recently been opened, was changing from an old folks infirmary to a rehab facility. As a result, there were only a few young people scattered on the different wards. There were a few polio survivors along with three or four quads, several paras and a few 14- and 15-year-old kids with cerebral palsy. Fortunately for all of us, the idea of an holistic approach to the rehabilitation process was gaining acceptance, and this forward thinking brought about changes to set up one ward for the younger patients.

Rehabilitation was the focus of our lives, and everything we did centered on that process. We worked together in groups in therapy. We also had group and individual sessions with the psychologists. All this togetherness spurred competitiveness and camaraderie among the group. Trying to do and outdo each other, we also came to rely on one another for what we later came to know as peer support. We even came to understand the idea of empowerment, before thoughts of "patients' rights" came into vogue, and motivated by the rebels among our care-givers, we established a Patients' Council to deal with problems and grievances.

My friends in Occupational Therapy looked into their mixed bags of devices and embryonic technological hardware and found ways for me to use splints with attachments to feed myself, type, play games, work with ceramic tiles, and most importantly, put on my own lipstick. (Only someone who has gone through the ordeal of having lipstick applied by an array of nurses and aides who "can't color inside the lines" will understand the magnitude of this last achievement!) My dentist friends came up with a wondrous mouthstick which enabled me to turn pages, dial phones, paint, and type. The mouthstick remains my faithful companion to this day and is the device which carries me through the many phases of my work. Accomplishments added to my validation as a person and became the building blocks of my ever-improving self-esteem.

Going home for the first time caused mixed emotions. I was ready for my next steps which I hoped would be school, but I was also a little fearful of leaving the safe and supportive environment of the rehab hospital. During my two-and-a-half-years in the hospital, I had gone home on weekends, gone out with friends to restaurants and malls and to see films and attend concerts, so being "out in the world" with my new self presented no fears. The idea of "being on my own" away from the friends who knew, understood, and accepted this new me was scary. Once I was back home with my family, all of my fears evaporated, and I got on with the task of living.

I would like to say that my plans to go back to school materialized at that time, but alas, I had no income and no prospects. I had never heard of the Bureau of Vocational Rehabilitation, and even if I had, in 1957 they were not offering much in the way of services to quadriplegics. Going back to school, if it was ever to be, would have to wait for another time. In the meanwhile, life went on. Books, music, family, and faith became the bottom line of my existence. It is said that "When God closes a door, He opens a window." With that as my philosophy, I pursued my "windows" with pleasure and enthusiasm.

Since school was not in the cards for the time being, the traveling library and "talking books" became my campus, allowing me to read and listen to literature great and not so great and chronicles of times past and present. Opera, one of my great passions, had been a sometimes pastime before my accident, for who could spare three to six hours of a Saturday afternoon listening to the Metropolitan Opera broadcasts, let alone stack LP's on a stereo for a three+-hour stint? Now time was mine to apportion as I pleased, and blocks of it were devoted to listening to opera, reading about opera, and falling in love with a great and gorgeous tenor.

Around this time and for several years beyond, our family was expanding with new nephews and nieces. I took to "Aunting" quite naturally, and purposed to become one of the "world-class aunts!" Since the traditional "aunting" pastimes of teaching the nieces and nephews to ride bikes or swim were impossible, I created some new traditions of my own which relied on "time" and imagination. My wheelchair became the focal point of some great pretending that had us involved in "Man from U.N.C.L.E." and "007" intrigues with the good guys, the bad guys, and the ever-present secret code tapped out on my trusty I.B.M. and hidden in obscure corners of the house. Twenty years later, the secret messages still surface occasionally, as an unused drawer or obscure nook is turned out for whatever reason.

My close-knit family and their unflinching support, understanding, and acceptance gave me a real sense of my value and worth as a person and as an integral member of our family. I was never made to feel that I was a burden or that, because of my disability, should revert to being treated like a child. My life was mine to direct. Decisions about my life were mine to make, and right or wrong, I was allowed the freedom to make choices. During my intermittent hospitalizations, I encountered friends and acquaintances for whom life was not so pleasant. They were the ones with no families or families who, for various reasons, couldn't provide the supports necessary to help them live a life of quality outside of an institution. This realization became an important "window" that has loomed large in my 34-year odyssey to find meaning for my life on this earth.

The '60s and early '70s were a time of discovery and the beginning of activism for me. Overtures by the National Paraplegia Foundation (now known as National Spinal Cord Injury Association [NSCIA]) to establish a chapter in the Cleveland area piqued my interest, and seeing this organization as a group working for change, I became one of the founding members. Through membership in the NSCIA, I became more aware of national issues and concerns relating to disability. Of course, *Toomey j Gazette,* which I had been receiving since its first mimeographed issues, kept me abreast of people-issues and how individuals with disabilities were managing to live lives of quality and independence. More and more I saw possibilities. Less and less was I willing to accept limited options for community living for my many friends and acquaintances who were locked into institutions.

As my involvement with NSCIA grew, so did my activism. Because we were the only disability group around, our phone numbers became the ones to call for information about disability-related concerns. We were called on to assist families of people who had recently experienced spinal cord injury and to provide peer guidance to the disabled person. We were asked about the full scope of life's circumstances and situations of people with disabilities and their families. Although we were able to assist many of the people who sought our help, frustrations kept mounting about the vital areas of concern with which we could not help. Accessible, affordable housing was almost non-existent in the Cleveland area, and Ohio had no paid in-home attendant services. Transportation options consisted of ambulances and a private transportation service that cost $50 a round trip, and employment opportunities for people with disabilities were few and far between.

> *"Accomplishments added to my validation as a person and became the building blocks of my ever-improving self-esteem."*

A growing awareness about what was happening in other parts of the country to address these kinds of problems and the frustrations about our inability to help our people locally motivated us to try to find solutions to these community needs. Our success in advocating for and getting a curb cut ordinance in the city of Cleveland gave us a heady feeling that working together, we could make a difference. We therefore focused our energies on the problem of housing and home services for people with disabilities, and using Gini Laurie's book on the subject as our Bible, began the journey which led to the establishment in 1980 of Ohio's first independent living center.

When the independent living center in Greater Cleveland, Services for Independent Living (SIL) was funded under the Rehabilitation Amendments of 1978, I left my position as board chair and took on the position of executive director. During the next five years, we opened the door to greater numbers of accessible, affordable housing units, brought about a state subsidy for attendant services, enabled large numbers of people with disabilities to achieve independent lifestyles in a community setting, and promoted barrier-free design through cooperative efforts with a variety of local community resources. We also worked with local school systems and developed an independent living curriculum which is being used in hundreds of schools throughout the country.

In 1986, a new "window" of opportunity was offered to me. I was asked by Lutheran Employment Awareness Program (LEAP) to develop new programming to open doors to employment for people with disabilities. Working with LEAP, which is also a consumer-controlled program with a board and staff reflecting a majority of disabled persons, we took a three-pronged attack to fight the problem of unemployment by educating consumers, building awareness among businesses about the benefits of hiring qualified employees, and advocating removal of barriers.

During my time at LEAP, we have made inroads in employment opportunities for people who have never before worked as well as people who have been out of the workforce for many years because of their disabilities. Using individualized and group peer interaction, we help improve self-esteem, assist with developing career goals, and prepare job-seekers for the job search and maintaining the job once employment has begun. Our work with employers centers on marketing the abilities of our program participants and informing employers about tax incentives available to them if they hire employees with disabilities. During the past year or so, we have become the local resource on current and proposed changes in the Work Incentives, and have been conducting workshops to explain the changes throughout Ohio for consumers with disabilities and their families.

The advocate's journey that began over 20 years ago has given me a rewarding life of public service and personal pleasure. It has opened doors to involvement with national, state, and local groups and organizations which have been "windows" of enlightenment and opportunity. Along the way, I have met and worked with national and international advocates who encouraged and inspired me to face each challenge as it came along and to believe that perseverance and hard work would win the day. I know not what the future holds, but I know much needs to be done before citizens with disabilities will be treated equally and justly. For as long as I am able I will be counted among the ranks of disabled advocates, working to bring about independence, productivity, and full integration for all citizens with disabilities.

> *"There's a lot she'll be able to do without the use of her hands."*

It seems the intern who told us that "She'll be able to do a lot without her hands" some 34 years ago had insights we never dreamed of. Thanks to friends, family, and peers I encountered along the way, life has been rewarding, challenging, and filled with opportunities to grow and learn. To them and to the faith that was instilled in me during my early childhood and which sustains me to believe that there is a place and purpose for me in this life, I say thank you for being there when I needed you.

Thanks also to Gini and the folks at G.I.N.I. for recognizing and encouraging talents that I didn't know I possessed. They are a world treasure we should all be proud of! Congratulations on your first 30 years! We look forward to a future of growth and continued leadership which will bring about "first-class citizenship" to people with disabilities everywhere.

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Ida Brinkman

Wife, mother, grandmother. Volunteer.

Polio. Ventilator user.

"I learned long ago to laugh at myself."

Labor Day of '53 marked the onset of my polio. Needless to say, it is not one of my most cherished holidays — although the people that I've met since then have added a very special bonus to my life.

I was diagnosed with three types of polio and was completely paralyzed except for the big toe on my left foot. I was trached immediately and put in an iron lung. Toomey Pavilion was my home for two years and the patients, doctors, nurses, therapists, volunteers, etc., became an integral part of my family. We shared the painful moments as well as the happy ones. The volunteers helped make our lives bearable by supplying entertainment and many times just by being good listeners. I realize now that the spinals, trachs, blood tests, and other badly needed procedures, as well as hot packs and therapy, were not always graciously received. And when I look back to the many long hours of work, the psychology and wisdom that was poured into our care, I appreciate the tender loving care we received. I send out many belated, loving thoughts and thanks to those who really cared and were involved with us.

Ida and her daughter (left) Bonnie's Bluebird troup in the 1960s.

The wards were not entirely filled with

despair as there was a great deal of frivolity such as: mousetraps placed in the bottom of iron lungs awaiting an unsuspecting nurse; full bedpans kicked off of beds (of course, I *never* took part in this!); unmentionables being hung on a male patient's bed (his wife was an extremely jealous woman); notes placed on a patient's body under a nightgown when said patient was due for a complete physical. And — since I learned long ago to laugh at myself — I remember sailing down the hall on a gurney in my birthday suit! The hall was loaded with visitors. My sheet had gotten stuck in the iron lung and with my breathing ability being nil, they simply hurried me on down the hall to a bathtub. I didn't speak to anyone for a week, but when they pinned the title "LADY GODIVA" on my bed, I forgave them and broke out in laughter.

I remember the wheelchair drag races that caused many a good nurse to turn gray. And the time a new black aide turned off my rocking bed and was unable to turn it back on. She proceeded to turn white, and I turned black!

Then there was the nurse who would travel between four patients and feed them while each patient was on a rocking bed. Each bed was rocking on a different cycle. The result was a very unsynchronized nurse!

I have had to change from a chestpiece to a P.V.V. machine. I was very angry at first, but it has proven to be my salvation.

I left the hospital for home sweet home in August of '55 after telling a very naive aide that I was to be towed behind a car in my iron lung. She, however, got even with me by putting a "loaded" bedpan in the van I was going home in. The group in my van that day looked at one another very suspiciously all the way home!

I became a born again Christian in 1960, and the good Lord has seen me through many a difficult trial. He blessed me with a good hubby who has been faithful and tireless. It hasn't been an easy road for him. However, he has carried his responsibilities admirably. Our children, David, Dean, and Bonnie, managed to grow up quite normally under the circumstances. They withstood umpteen housekeepers and nurses and readily accepted their electric momma. Loving discipline was a must. They all learned to cook and clean along with nursing chores. We tried to give them a balance of good times combined with their required duties.

My left leg eventually regained some movement and hubby Johnny rigged up a special shoe for my left foot, enabling me to play shuffleboard with the kids. Since we had an iron lung and a rocking bed in our living room, we had linoleum floors — just perfect for hopscotch and roller skating.

I remember a grade school teacher who came to meet me, planning to reprimand me for not attending PTA meetings. She had no idea I was disabled. The poor lady almost fainted! I checked the mirror as soon as she had gone — she must have thought those notes I wrote with a pencil in my mouth were from jittery nerves or alcoholism. Not so at all!

Thanks to the good Lord, our children turned out fine after all. Dave, our oldest, presented us with two beautiful grandsons. He is employed by the government

Ida and her husband, John.

and resides in Virginia. Dean works for my hubby in a tool and die shop. Our daughter Bonnie and her hubby own a microfilming company, and they gave us a darling granddaughter named Amy.

In my early years of polio I did some TV monitoring with a typing stick in my mouth, sold some carpeting, etc., helped out with PTA calls, and headed up a polio drive. I was called upon to phone elderly shut-ins that lived alone to check on them for their families. My hubby coached Little League baseball games while I typed up the rosters. We attempted many small trips and outings successfully.

Today I am involved in a Bible study group, and I write to many shut-ins in nursing homes. I am an avid reader, enjoy music and plays, and carry on a large correspondence with friends and relatives. I praise the Lord for my beautiful family and friends and for the great zest for life that He has given me.

Life is precious, regardless of the circumstances, so count your blessings, keep your sense of humor, love one another, and hang in there!

God bless you, Gini, for loving us so and for going to bat for us, encouraging and helping us in so many ways. We love you!! 福

Richard Daggett

Advocate. Volunteer.

Polio. Ventilator user.

"My functional limitations prevented me from doing many so-called 'normal' things, but they allowed me the time to pursue some very rewarding ones."

I turned 13 on June 14, 1953. A few days later I graduated from the seventh grade and went with my family on a camping trip to the eastern Sierra. We got home in time for me to sign up for a continuation of my swimming and saxophone lessons at Downey High School. At least that was the plan . . . Things didn't work out exactly as planned.

The first indication I had that something was wrong was waking Friday morning, July 17th, with a stiff neck and back; not just sore but really stiff. Putting my clothes on was very uncomfortable, so I just stayed in bed until mid-morning. My mother called my father at work, and they took me to see our family doctor. He did some tests and said I should be taken to the County General Hospital. At General they gave me more tests. It seemed that every time a different doctor came by he would ask me to try sitting up without using my arms. This seemed to have some special significance. I did this about a dozen times during the day. In the evening they did a spinal tap and that night my legs began to ache. Shortly after midnight I started having trouble sitting up. I don't remember anyone telling me that I was suspected of having polio, but by now I knew that whatever it was I had it for sure. Over the next few hours I was started on intravenous feeding, given a tracheostomy, and placed in a tank respirator. I couldn't breathe, swallow, or move more than the big toe on my right foot.

After three weeks I was transferred to Rancho Los Amigos, one of 16 regional respiratory centers in the United States. After about two weeks at Rancho I was assigned a physical therapist.

The first order of business was to stretch muscles that had tightened from disuse. Since the only things that I could move were the toes on my right foot, there was a lot of stretching to do. Over the next eight months I was gradually weaned from the respirator, and not long after that my tracheostomy was closed. By early summer of 1954 I had been fitted with leg braces and had my own wheelchair, which I propelled with my right leg. My legs continued to show improvement, and I began to use the wheelchair less and less. After two spinal fusions in the fall of 1955 to halt my increasing scoliosis, I was discharged from Rancho.

"Mainstreaming" was not common in the public schools at that time, and I continued my high school studies with a home teacher. I graduated with an honors certificate from the California Scholastic Federation and took several college level science courses.

Although I was fairly functional, I had limited use of my upper extremities and continued to wear leg braces. My biggest problem was restricted pulmonary function. Even on my best days I had a vital capacity of less than 25% of normal. This made full-time employment difficult. It was to my advantage to continue in a shared housing arrangement with my parents. I needed help with cooking, putting on my braces, and I did not drive.

It is often said that all clouds have a silver lining. That might be an exaggeration, but in my case it proved to be true. My functional limitations prevented me from doing many so-called "normal" things, but they allowed me the time to pursue some very rewarding ones.

Before I had polio, my family had always spent part of the summer in our travel trailer. This is one of my fondest memories of childhood. When I was once again able, we resumed this practice. In 1962 my father took early retirement, and we purchased an Airstream travel trailer. This trailer was large enough to allow longer trips comfortably. One year we were gone from home for eight months and covered over 23,000 miles.


Richard presenting G.I.N.I. recognition to Dr. Jonas Salk in 1985.

In 1964 the carbon dioxide level in my blood began to rise, and it was decided that I should use a portable respirator at night. I was fitted with a Monaghan 170C and a cuirass. The trailer made it possible for us to continue traveling. It was much more convenient with my equipment in the trailer than it would have been transferring it from car to motel room every night.

Between trips I began active participation in our church and several civic and disability-related organizations. I could schedule a number of hours a week in volunteer activities without becoming overly tired. At various times I served as president of the Methodist Men's Club, a member of the Disabilities Task Force for the Los Angeles Health Planning and Development Agency, and a delegate to the Downey Coordinating Council. I was honored by being named Citizen of the Year for 1982 and received a resolution of commendation from the California State Assembly.

It seemed logical to devote part of my time to Rancho Los Amigos. I was a patient there for almost three years and lived less than a mile away. I began as a member of the Rancho Advisory Council and now serve as an Administrative Volunteer. This past year (1988) was Rancho's one hundredth anniversary. I was asked to serve on the Centennial Committee as a representative of the thousands of polio survivors who received treatment there.

Since 1981 I have been President of the Polio Survivors Association, an organization devoted to improving the quality of life for disabled polio survivors. Little was known about the late effects of polio when the association was incorporated in 1975. We started with a core group of about sixty members, mostly respirator dependent "alumni" of Rancho Los Amigos living in Los Angeles County. As more polio survivors are experiencing problems, our goals have expanded to include research and referral and our membership has grown to include people across the United States and several in Canada and Europe.

I noticed an increase in fatigue in the early 1980s and began using an electric wheelchair to reduce the strain on my legs. The wheelchair allowed me to commute from my home to Rancho several times a week.

Late in June of 1984 I felt I was coming down with a cold. With me a cold usually has three stages: three or four days of congestion and discomfort, three or four days of gradual improvement, and another week to get back to normal. This cold, or whatever it was, just did not respond to my usual treatments. After about a week I still felt miserable and made an appointment with the pulmonary office at Rancho. The way I was feeling it didn't surprise me that my CO_2 was elevated. What did surprise me was that it had shot through the roof. My CO_2 had been running about 55, which is somewhat higher than normal, but it had not given me any problems. Now it was about 80. My blood oxygen level had fallen dangerously, too. Obviously, I was not getting adequate ventilation. The next day I once again became a Rancho in-patient.

For two weeks we tried several respiratory options, at first concentrating on the use of a positive volume ventilator (PVV) with a "mouth seal." I just couldn't seem to tolerate it. It might have worked if my pulmonary function had been in better shape. Even using my chest respirator full-time didn't seem to help. To compensate for my reduced ventilation, I was given oxygen. After much thought I decided that another tracheostomy would be the best choice for regaining my pulmonary health.

This decision was not made in a vacuum. For several years I had been what could be described as a good candidate for a trach. While not overly concerned, the doctors had kept a very close watch on my CO_2. This was coupled with a borderline vital capacity of 900 to 1000 milliliters (about 20 to 23 percent of normal).

Having made the decision, I was sent to surgery. I was relieved to learn that this tracheostomy, unlike my original one in 1953, was going to be done under general anesthesia. I didn't look forward to a repeat of my earlier experience with a tracheostomy done under local anesthesia.

I was released exactly eight weeks after being admitted to Rancho. The new trach and the weeks in bed, coupled with some of the late effects of polio, have caused a change in lifestyle. I have reduced my activities to compensate for my lower energy level. I was probably pushing my limits anyway. Over the years I had been very involved with a variety of volunteer organizations. I needed to learn to be more selective and conserve my energies for those things that I felt were most important.

As president of the Polio Survivors Association I've received thousands of letters from other polio survivors relating their experiences. A few individuals seem to be resentful of the advice that they were given years ago. They were told to be as active as possible, and now they feel that this advice has caused their current problems. While I can sympathize with them, I strongly disagree with this attitude. Even knowing what I know now, I doubt that I would have done things much differently. I enjoyed my activities. They added immeasureably to my life. I'm a richer person for the people I've met and the things I've done. A person can't dwell on what would have been, because none of us knows what would have been. You just have to do what you think is best at the time and move on. Life has many challenges, but it has many more rewards. 福

Soley Dietz

Wife. Volunteer.
Polio. Ventilator user.

"Patience and determination became the key words."

The year is 1954, and with youthful exuberance we are determined to hitch to a lucky star and, together, locate the worldly fortune that was solely ours to conquer. Our dreams were big, and what a comforting thought it was, knowing that we had a whole, long lifetime ahead to make them all come true. Each and every day held great promise as our varied individual interests — golf, bowling, church activities, bridge, traveling — were joyfully shared. Meanwhile we still kept involved with our separate work challenges. A full and scintillating life it most certainly was in all ways.

To mark our second wedding anniversary, a special trip was planned, a drive to the eastern shore of Maryland to spend a week with family and enjoy the serene, picturesque beauty that only the Chesapeake Bay area can offer. It was customary, on occasion, to enjoy a good game of "Scrabble," and it wasn't until a few weeks later that we were to learn the signficance of my Sam's draw — "N.Y. DOOM" — without yet having the opportunity to arrange his letter tiles!

Upon returning to our home in Fredonia, New York, I was feeling quite poorly and was soon to be diagnosed as having the old-fashioned "grippe." Within less than twenty four hours, though, it proved to be a totally different story as the bulbar polio virus attacked my entire being, and my Sam prayerfully looked on as the doctor, in a seemingly futile manner, attempted to assist me in winning my battle to live! From there, the series of events were critical ones that I was to learn about three weeks later, when I awoke to find myself within the confines of an iron lung, paralyzed from the neck down, and unable to express my needs due to an open trachea. Praise God, we do, that "back then" they weren't so eager to consider "pulling the plug"!

This disruptive event brought about extreme feelings of anguish and frustration as our projected lives and future dreams were seemingly shattered. We were literally in the throes of a "doom's day" episode. Where it would lead us was anyone's guess, for the doctors gave no hope of survival as the whirring noises of the ancient but ever faithful iron lung kept constant rhythm, enabling my body to continue functioning. There were numerous harrowing moments when "port holes" were mistakenly left opened, causing great panic and leaving Sam to keep a constant vigil, instructing each nurse's shift on the "Do's" and the "Do Not's" in iron lung survival.

The ability to swallow was no longer my pleasure to enjoy and after many painful, futile attempts to remedy this situation a nasal gastric tube became my additional lifeline companion for the next seven months.

While isolated in a private room at the Buffalo General Hospital for over four months, there remained within my mind recurring thoughts that "this" was not a permanent situation, and that "soon" it would disappear and I would be up walking around and breathing on my own. Realism hit home when I was later transferred to a rehabilitation clinic. There I was to share a large room with nine other "victims of polio," which quite traumatically allowed me to see the extreme severity of it all.

Perhaps it is interesting to note that the clinic was not particularly overjoyed about opening their doors to this sickly specimen of the female gender, for the doctors still considered me hopeless with the capacity of a mere vegetable. Sam had to exercise his vocal chords consid-

erably, stopping just short of bribery, to get me admitted into their inner circle. It was a "turning point" in our young lives, and one in which our vision was later to be sharpened into areas that may have otherwise lain dormant.

It was the beginning of a three-year uphill struggle, during which time we both would become adept at calling on our inner strength to provide an attitude that would bring back a sense of purpose and meaning to our personal world. A laborious involvement where patience and determination became the key words, and "victories" were measured in small increments. The ability to master once again the art of swallowing was truly a welcome accomplishment when once again taste was mine to enjoy and savor!

As I watched the weeks turn into months, I frequently became discouraged at the seemingly little progress that was being made. Sam decided to make a list of my accomplishments to help boost my spirits on those dismal occasions. The "list" has yellowed with age, but its power still exists today as it continues to give me direction and purpose within my unique sanctuary of life.

After nearly one full year of calling the "tank" (i.e., iron lung) my home, and viewing my world in a "reversed mode" through its attached mirror, I felt it quite difficult to conjure up enough courage to leave the security of its confining walls.

It had become like a warm cocoon, and everything on the outside was both foreign and terrifying to me, leaving little or no desire to venture out. Many tears were shed while being weaned from my seemingly safe haven, but thanks to the strict and sometimes cruel-like regimentation of both nurses and aides, I am today free from the cumbersome "tank" and able to feel secure, and made more mobile through the use of first the Huxley shell, then the smaller looking Monaghan shell, the Emerson rocking bed, and also the intermittent positive pressure hose (used by mouth) which allows my body freedom to be bathed, et cetera.

This accomplishment then provided me with the opportunity to pursue other challenges such as daily physical therapy sessions, where pain was the dominant factor while therapists attempted to stretch my motionless limbs, along with occasional gurney-rides to the soothing warm atmosphere of the Hubbard tank for more helpful exercise sessions.

The most momentous and difficult act took place soon thereafter when I made a bold attempt to bid farewell to my trach, providing great consternation and legions of unsettling moments until I mastered the art of dealing with mucus. It was indeed a scary thought that I might possibly "drown" in my own juices! This victory enabled me to pursue successfully the art of "gulping" or "frog breathing" (as it is commonly referred to within the esoteric polio circle) which had previously been a frustrating, elusive act. Four minutes isn't long perhaps for most, but it meant crucial time needed away from breathing equipment when being transported or in a crisis to yell for help!

From this point on, each accomplishment was considered a milestone as both physical and occupational therapists tirelessly and repetitively assisted in awakening new interests that had been thought impossible feats. That uncertain feeling when being first placed in a wheelchair, and months later joyfully realizing that my tolerance actually extended to two hours. An ancient electric IBM typewriter was placed over my bed on top a high stand, and for the first time I awkwardly attempted to "type" with a mouthstick, little realizing the struggling weeks of practice that were to follow would actually reveal a whole new productive life to me. The next acts to pursue were mouthstick painting (what a special feat to stay within the lines) and reading a book by turning the pages with yet another type of mouthstick. To be followed then, on occasion, by the unique opporturity of testing out a "motorized feeder" that had been developed at the Clinic.

After three long years of rehabilitation, I was eagerly looking forward to returning to home life. The momentous time arrived when my Sam prepared the way for us to continue our "lucky star" search, accompanied by an entourage of necessary breathing equipment. Traveling was then done on a "sawed off" chaise shoved into the back of a station wagon, where I quickly discovered how a loaf of bread must feel on its journey to the market!

There were considerable hurdles to meet and overcome, such as "live-in" attendant/housekeepers (today known as "caregivers") and a proper, comfortable, "sitting" arrangement while attempting to blend in with our livingroom decor. The latter, perhaps a womanly whim, consisted of such usable carriers as a "Simmon's Adjust-A-Bed" (slip cover made to fit fashionably at sitting position), the "Lazy Boy chair" (still comfortably used on occasion), and the best find of all, a "Contoured Lounge" that has both a vibrator (helps keep the kidney stones on the move) and a heater. This especially has allowed me to feel as if I had joined the "normals" once again!

Over the years we've met various obstacles in attempting to locate and keep agreeable personnel to ease Sam's heavy burdens and allow him to carry on with peace of mind while at the office or traveling on business. The sometimes exasperating situations that have occurred throughout the years are far too many to single out at this time, but the important thing we recall is that when one "door" was closed to us, God always made certain another was opened. We started out thinking that older women would be more reliable and competent (and there were a few that we still enjoy as close friends). However, in the early '60s, we were to be enlightened when we "welcomed" a nineteen-year-old into our circle of family. From then on, we've continued to be blessed with a variety of youth, each of whom is truly an "adopted daughter" in our hearts. Being fully involved with each along the way, we've received an added bonus in watching our circle grow to include son-in-laws and grandkids galore . . . all of which rounds out our lives and keeps us ever thinking young!

Since that fateful happening in late September of '56, not only did my lifestyle change, but also our perspective in looking ahead to that "dream" that was still there waiting to be sought. Yes, what appeared to be an ending, was merely the beginning of an interesting and fruitful adventure that was to take us to nine different home locations. Each move was unique in itself, providing opportunities for me to continue to discover and test many hidden talents.

It was a caring, young Lutheran pastor that was to awaken my interest in writing when, upon meeting me, he asked if I would contribute a "column" for a newsletter he was instigating for our local Sewickley, Pennsylvania, church. Other opportunities to share my faith took off from there, as my Sam's opportunities in business kept us on the move. Along the way, there was occasion to graduate from number painting; grow spiritually through stimulating weekly home Bible study sessions; remain an "efficient" housewife; and be active in our church "caregivers" program (these activities made feasible through a head-operated speaker phone); and "give birth" to a college sorority alumnae group — all allowing the feeling of productiveness to return. These last few years have also been enriched through my involvement with the Laubach and Literacy Plus organization, as varied nationals enter my inner sanctuary and, together, we share our lives, with verbal skills getting top priority in weekly two-hour sessions . . . surely satisfying my insatiable thirst for teaching all these many years!

It has most certainly been a full and challenging 32 years for both of us, and quite grateful we are to Gini for asking me to join in this momentous 30th anniversary of the *Rehabilitation Gazette,* for it has allowed us to pause, reach back, and count our many blessings and achievements that otherwise might never have been "if" polio hadn't entered our personal world. We've added up considerable mileage, going through two specially equipped motorhomes, and found that nothing was impossible along the way if we kept God uppermost in thought, relying solely on Him for our strength and direction.

Although my limbs still remain lifeless and my vital capacity nil, I continue to wake each day with a thankful heart, for each is an added bonus that others predicted would never be. My inspiration is kept alive through two channels: a personal friendship with Jesus Christ, and my husband, Sam, whose unique specialness, in his faithfulness to a loving lifetime commitment, has provided me with encouragement and kept me going.

It is now my sincere wish that this "reaching out" will provide a bit of insight both to those who are free from disabilities and to those, like myself, who must learn to survive in spite of an unpredicted "incapacitation." Indeed, within each of us there is a whole person longing to be free from infirmities." Empathy should be practiced often and wisely so that our earthly journeys can be kept in perspective, keeping hope ever present in our hearts, for . . . "but by the grace of God, there go I." 福

Gloria Finkel

Wife, mother, grandmother.
Bookkeeper.
Polio. Ventilator user.

"Inside I was still the same, but I was treated very differently by others. However, I have found that people tend to accept you as you accept yourself."

Today, I am 56 years old, a wife, mother, and grandmother and have had polio for 34 years. I have been asked to reflect on these years and, perhaps, share the wisdom that has enabled me to reach the point in life where I am today. After much soul searching, I have reached the embarrassing conclusion that much of my life has been governed by lack of intelligent fear or, more succinctly, "dumb luck." After graduating from high school, I worked as an EKG technician for one year, enrolled in college, attended one day, and at age 18 left to get married. I swear I didn't have to!

My husband-to-be, Shel, was working his way through his first year of dental school and when he had a few days off for spring break, we made this mature decision. Others followed. Although I worked at the hospital during the day while Shel attended school and we both worked nights calling square dances and teaching folk dancing, with typical lack of good sense we decided to have a baby — the happiest decision we ever made! Our beautiful daughter was born in Shel's third year of dental school.

In 1954, Shel graduated and, called upon by his country to save America's teeth, was commissioned a lieutenant in the United States Air Force. Although we natives of New York City requested a state-side assignment, we nevertheless were sent to Valdosta, Georgia. All went smoothly for a while. We even began to learn the native language and learned to sleep in all that quiet!

A few months later, our whole life changed. I got polio. There really is no way to prepare for something like this. To anticipate all the tragedies that can possibly befall us would dampen our enjoyment of the present. The Air Force air-evacuated me to Montgomery, Alabama, where I was put in an iron lung. I spent the next nine months there.

The hardest and most painful part of the following months was not seeing my one-and-a-half-year-old baby. However, it also gave me a very strong motivation for getting out of the lung, if possible, so I could go to Warm Springs for rehabilitation and then home. I was very fortunate. Although all my breathing muscles, except a small part of my diaphragm, were gone, I was able to breathe enough using my abdominal muscles to get out of the lung. At Warm Springs, although both my hands and arms remained paralyzed, I learned to walk.

When Shel was discharged from the Air Force, we went back to and settled in Montgomery, Alabama. I looked strange, and still do, but now I'm used to it. It was very difficult, having to adjust to a new role in life. Inside I was still the same, but I was treated very differently by others. However, I have found that people tend to accept you as you accept yourself and over the years I have made many good friends who, while not forgetting my disability, relegate it to an unimportant part of our relationship.

The fact that my disability is not always visible can create some embarrassing situations. Even my daughter, who should know better, sometimes forgets. Recently in a department store, she darted into a dressing room, leaving me with my two-year-old grandson and calling out over her shoulder, "Watch

Adam." Well, I did. I watched him methodically and systematically pull out and spread out on the floor every sock that his little arms could reach from a large display case. Meanwhile, the salesgirl and other customers were watching me in fascinated disbelief as I just stood there with an inane smile on my face.

People always say to the disabled, "How brave you are! I could never do that!" Yes, they could. We didn't bravely choose our disability. We had no choice and, frankly, I don't like it.

My condition presents its own unique problems. Over the years, I have learned to write with my feet; actually, I'm left-footed! It doesn't look great but neither did my handwriting. The only problem is convincing my pre-school grandchildren that, when they go to school, the teacher will think it odd if, when told, "It's writing time," they pull off their shoes and socks, put their notebook on the floor, and stick a pencil between their toes!

I think this is a good place to say that I may be writing about independent living under false pretenses. For 37 years, I have never had to be alone. I have had the good fortune to have a husband who has always stood by me, helped me, and taken care of me. In Montgomery, we just live day-by-day and deal with each problem as it arises. There are no guidelines. Since my daughter is now grown, I spend my days doing office bookkeeping (at home), reading cookbooks, shopping, faithfully watching "All My Children," and my favorite of all, keeping one or more of my grandchildren.

Although my general health was good, I was bothered by the fact that, after several attempts, I was still unable to get health insurance. Finally in 1970, I wrote a letter to the insurance company in which I stated, "I am paralyzed, not sick, nor have I been for 15 years." I got my policy! I eventually needed it. About six years ago, I was told by my gynecologist that I needed a hysterectomy. Because of my past respiratory history, he sent me to Birmingham for surgery where a pulmonologist was called in. It was a terrible experience, even though the surgery itself was fine. The pulmonologist tested my blood and told me that I would have to be hooked up to an oxygen tank 24 hours a day for the rest of my life. After surgery, he left me on the ventilator, tube in throat, for five days and then yanked it out. I felt I couldn't breathe. My Montgomery internist said to forget it, that I'd been doing fine for years, so I did.

"We just live day-by-day and deal with each problem as it arises."

A couple of years later, my hands and feet began to swell. I was told that it's a common occurrence in polio patients. During the day, I had difficulty focusing my mind and would doze off frequently. At night, I couldn't sleep. I thought all this was psychological, especially since I had been told nothing was wrong when I had consulted a throat specialist several years earlier about my having difficulty swallowing liquids. My condition quickly worsened, and I wound up in the hospital emergency room with pneumonia. Another pulmonologist was called in and after intensive treatment I was sent home with my basic problem (as I subsequently learned), underventilation, unrecognized.

Then good fortune smiled at me! My local newspaper had a one paragraph filler article about Gini Laurie. I phoned, she answered, and my life was literally returned to me. She immediately recognized my condition and put me in touch with a doctor very knowledgeable about respiratory problems associated with polio. Sleep tests revealed that I needed mechanical ventilation at night. Although it does not do the best job, I chose the rocking bed because I thought it afforded me the most physical freedom. Several times during the day, I use a small Bantam Respirator for deep breaths. Shortly after beginning this regimen, I experienced a dramatic change. All my swelling disappeared and much of my

energy returned. At present, I am looking for an alternative to the rocking bed but now, thanks to Gini and G.I.N.I., I can make an informed choice. That knowledge is very comforting.

Also very comforting is knowing that I am not alone out there; that there are valid reasons for (and solutions to) many of my problems; that there are professionals, who care and are willing to share their experience and knowledge. However, I have learned that the ultimate responsibility for my health lies with me.

In the spirit of sharing, I'd like to share my well-meaning, worried mother's sage advice as she watched me take my first steps at home the day I returned from Warm Springs: "Be careful. Don't forget to always walk close to the wall." I really hope this motherly advice helps someone out there; I could never figure it out myself. 福

Jack Genskow

University professor. Registered psychologist. Advocate. Husband and father.

Polio. Ventilator user.

"It's never the problem, but rather the way you react to it that makes all the difference."

Where was I in 1958, and how did I get here from there?

1958 was a year of beginnings for me. I finished my last long stay in the hospital three and one-half months (added to 20 months earlier), and began life "outside" as a person with a disability. My college class at Yale graduated, and I started back to school. I left my brother's farm, where I lived after leaving the hospital the previous year, and moved with a student attendant to the University of Illinois campus for the summer. In August, I moved in with my Dad, and started as a sophomore at the University of Wisconsin, Milwaukee. Most importantly, my future wife, whom I'd known as a student nurse, and I had our first date. Not long after that we made a commitment that if I could earn a bachelor's degree, and thus could probably hold a job, then we would get married. It proved to be a strong motivator!

To set the stage for these beginnings, let me backtrack to August, 1955. I was 19 and working at my summer job as a horseback instructor at a girl's camp in central Wisconsin. I had completed my first year on scholarship at Yale University and I looked forward to returning. At the Milwaukee suburban high school I went to, I had been student body president, lettered in football and volleyball, and elected to National Honor Society.

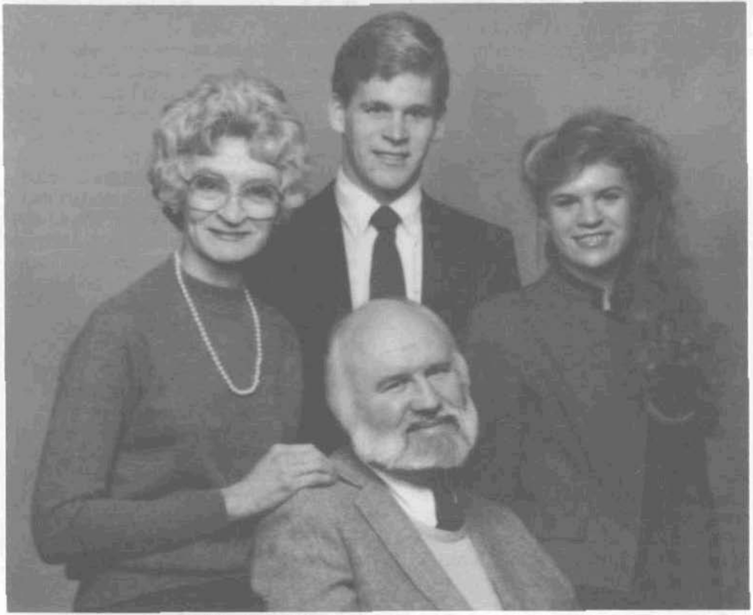
So one day I was young, athletic, with many friends, three more years ahead at Yale, with an ideal summer business, and what looked like a bright future. The next day I was part of the 1955 polio epidemic in an isolation hospital in Milwaukee, in an iron lung, and almost totally paralyzed from my neck down. In those initial months, I focused so much on recovering breathing ability, that I don't remember really grieving my physical paralysis. By the time I was out of the iron lung and onto a rocking bed and chest respirator, I had essentially adjusted to the paralysis. While there were low times, most often the focus was positive and hopeful.

Between August 1955 and April 1958, I was in six hospitals. I remember feeling that in the hospital it was as if I were a baby. The iron lung was like a great iron womb, from which I was reborn again into infant status. Almost all our own care was done for us — turning, bathing, bed pans, even breathing — and we were the focus of all this attention. The goal of the hospital treatment wasn't so much to help me take care of myself as it was to make it easy for others to care for me. Independent living philosophies in medical facilities were still in the future, and in some places, still are.

College was definitely the way to my future, but Yale would not accept me back because of my physical condition, and their inaccessible campus. We visited the University of Illinois campus, which was wheelchair accessible, but rehabilitation director Tim Nugent thought I was too severely disabled to go there except for a trial summer session. He did give Roy, my brother, some advice, however; stop coddling me, and be realistically demanding. It was important for both of us to hear.

Then Illinois DVR counselors visited me at the farm and decided I was too severely disabled to benefit from services sufficiently to gain employment. So after 20 months in six hospitals, living on a farm, being turned down for services by Illinois DVR, denied entrance to two colleges, were back to where we started in 1958.

So where am I now, in 1988? Lil and I



Jack with his family, (left to right) Lil, Ken, and Karen.

celebrated our 27th anniversary this year. She has been, among other things, mother, chauffeur, homemaker and handyperson, school and Planned Parenthood volunteer, a registered nurse in hospitals and a public health agency, and my intimate friend and partner. Our daughter, Karen, recently received her M.A. degree; she was elected to Phi Beta Kappa, and was a National Merit Scholar. Our son, Ken, was in the top 10 of his high school class, and will graduate in December in engineering from the University of Illinois; he's applied to the Peace Corps. My family's been an incredibly enriching and enabling part of my life.

Professionally, I have a Ph.D. in Counseling/Rehabilitation Psychology, and am a registered psychologist. This year I was promoted to full Professor at Sangamon State University where I am in my tenth year as tenured faculty. I am on the Board of Directors or Advisory Councils of community, state, national, and international organizations, including chairing the Advisory Council of the Illinois Department of Rehabilitation Services — the agency which originally turned me down for services. I also worked for IDORS for 12 years as a psychologist and program director. I've held elected offices in state and national professional organizations, and in 1986 was awarded a World Rehabilitation Fund Fellowship to study in Denmark. I'm 52, my health is good, and I enjoy the process of my life.

And how did I get here? The key elements to me are these. First, a strong and dependable social support system, including especially my family and friends. My family and friends have literally been there when I needed them from early support in the hospital to present day mainstream living. The support has been as extensive as living with my brother's family or my Dad after the hospital, to as simple as a neighbor providing a quick home repair, or a colleague giving me a lift to work. Lil, of course, and the kids, have been my most constant support. But many people, each significant at some point in my life, but all providing on-going support, have literally made my accomplishments and my life possible.

Second, the kind of person I was and the experiences I had prior to polio affected the way I reacted to it. I'd had a secure childhood, successful adolescence, good academic preparation, opportunities for self-initiated and self-directed activity, and a generally positive self-image. I did not feel depreciated as a person because of my physical disability, and my sense of worth remained intact. I learned it's better to do things for myself, if possible, than to wait for someone else to do it for me. When UW-M questioned my attending there, for example, I called the University Provost personally and he accepted me.

Third, supportive services. When I lived with Dad, a nurse from the VNA came Monday, Wednesday, and Friday to bathe me, and to assist with my bowel needs. The Wisconsin DVR paid my tuition, and for part of the Handi-Cab service that took me to and from school. The March of Dimes, which paid most of my hospital bills not covered by insurance, provided me with a rocking bed, chest respirator, and other medical equipment. They have continued to assist in providing breathing aids.

Fourth, a university experience and education are important influences. At UW-M friends hauled me up and down flights of stairs between classes and sometimes I hitched rides. There were no electric chairs then, and I was pushed everywhere. While I did not socialize much with students away from the university, they were a convivial group to interact with and the university was a good setting to get used to functioning as a person with a disability. I was admitted to graduate school at the University of Illinois after we were married, and it was much different; almost all buildings were accessible, wheelchair buses ran routes, motorized chairs and wheelchair repair became available. Most importantly, the professional areas of study and faculty were open without discrimination, as was availability of scholarships and assistantships. Lasting friendships were established.

One reason I decided to get a Ph.D., rather than to stop at an M.A., was I thought that due to my disability, I would have to be overqualified to be competitive with able-bodied job applicants. This didn't prove to be true; I was hired at the Ph.D. level at once. Education is a great equalizer.

Fifth, while my degree of paralysis is extensive, I am fortunate in what is left. I have retained use of both hands, my right forearm and biceps, my neck, and sufficient breathing to be on my way during the day. (If I become unconscious, I stop breathing.) These abilities have enabled me to use a motorized chair, to talk and communicate, write and type, use a telephone, and thus to earn a living. Although many of my muscles are paralyzed, locomotion is only one part of the body's functioning; the rest of mine has worked well, and my health has been good. I strongly believe a positive attitude promotes good health.

My sixth reason is a process reason so obvious that its almost overlooked. Successful independent living begets more successful independent living. By living in a home, in a community, having children in the school, going to parent-teacher meetings, church, movies, shopping, a job, etc., etc., "like everyone else," one has the opportunity to participate in everyday living. Social and vocational opportunities develop either spontaneously or through planning, and by keeping oneself open to the possibilities, good things happen.

Finally, I believe that it's never the problem, but rather the way you react to it that makes all the difference. 福

Iva Sue Grover

University professor. Wife.

Polio. Ventilator user.

"That's the only therapy I ever used — living."

If I were to describe the last thirty years in a phrase, I guess it would be, "Never say never!" Every time I say that, I do it. Unconventionally, perhaps, but I do it nevertheless.

Thirty years ago I was 17 and a junior returning to high school. I got polio on Halloween 1955 and was one of the very lucky ones. I had just begun my freshman year. They pulled me through a severe case of bulbar (some say I was too stubborn to die), packed me into an iron lung that I couldn't seem to get the hang of until one of my nurses pumped on my chest until I did, and acquiesced when I insisted on learning how to aspirate myself.

By 1958 I had spent nine months in three hospitals without seeing home, had a tracheostomy for breathing, a gastrostomy for eating, a long leg brace for walking, and a very supportive network of family and friends. When things got tough they advocated for me, long before advocating was acceptable. The one thing that I knew was certain in all of the uncertainty of those serious and often critical times, was that if my family said they would be there, they were there!

At home I was expected to contribute to the family effort. It didn't matter whether I was in a wheelchair. I would get help when I needed it, but my jobs were my responsibility. As I got more mobile, my jobs became more complex and I was encouraged to figure out ways to do them when the usual way wasn't possible. Mother held her breath more than once as I did something that looked precarious. But she usually kept quiet and let me try it.

So in 1958 I headed back to Granger High School. I found many ways I could participate in school activities. 4-H was also very important to me. I decided to hang around for a second senior year since I wasn't ready physically to go off to college. It was a wise decision. My grades were good and I won a scholarship and enough grants to finance half the cost of attending the University of Puget Sound in Tacoma, Washington. Vocational Rehabilitation funded the other half.

I majored in Business Administration and had the support of a wonderful group of college friends. I struggled a lot with what I would do after I graduated. The business world seemed awfully big. I had always loved libraries, so I went to the School of Librarianship at the University of Washington.

In 1966 I was finally ready to meet the world, both physically and psychologically. For me, psychological readiness is as critical as physical readiness. If my head and heart don't agree, it simply won't work. I'm a firm believer that everyone has their own timeline.

For thirty years I have continually encountered the inevitable question by medical practitioners. "Why do you still have an open trach?" The only answer I have is, because years ago I decided to live life to its fullest. I continue to maintain a fully open trach, otherwise I couldn't do anything else to contribute to society but sit and breathe. It hasn't been a problem for me. In fact, that decision may be one of the reasons I am NOT experiencing underventilation now. I have a one-way valve, that allows me to breathe in as if it were open and out as if it were closed, but I use it sparingly since it fatigues me quickly.

I am an avid traveler, frequently alone since many of my friends don't have the benefit of an academic calendar. My first overseas trip was to England and Scotland in 1969. I have been to Europe, Mexico City, Canada, and Hawaii. I'm returning for Christmas in Yucatan and

Chiapas this year. I prefer making my own itinerary over packaged tours whenever possible. People everywhere have been gracious and helpful. I use a cane on hills and rough ground. It's cheap insurance and invites help when I need it.

My work has taken me from Washington to Montana and back to the Puget Sound area, all challenging, gratifying, learning experiences. I returned to Tacoma in June 1971. I also met my husband, Bob Jahns, there. Now marriage was one of the things I thought I probably would never do — nor did he. But as I said, never say never!

I joined the faculty of Whatcom Community College in Bellingham, Washington in 1974. My job there has been exciting and challenging for almost 15 years. I never thought the same job would fulfill me for more than five or six years. See, never say never! But Whatcom is an unusual school and there is great variety in my responsibilities as Coordinator of Learning Resources.

Three years ago I bought a townhouse condominium. It's by a beaver pond in the city of Bellingham and tonight a tiny fawn just wandered by my back door. When I bought the house, I thought carefully about what I wanted that would suit my lifestyle and long term needs: a garage, one-floor living, space for guests or caretaker if needed, minimal yardwork.

Knowing the needs of my lifestyle means understanding my body. I have always confounded doctors by sharing with them what my body tells me, instead of expecting them to tell me what they think my body is doing. I trust that knowledge, but I also know when I need an expert opinion. And the experts I consult today are not always allopathic practitioners.

I have utilized the services of a variety of alternative health practitioners over the last eight years, receiving the most benefit from rolfing, homeopathy, massage, and acupuncture. I use them to enhance the good health I already have. If I were to get pneumonia, I would see my GP, but when I fall down and bruise my knees, I see my acupuncturist.

After much consideration and the recommendations of two friends whom I respect highly, I had a series of sessions with a local certified rolfer. He had had polio himself as a youngster. It was interesting that about halfway through the series of ten treatments, I realized I was walking differently. It was as though after thirty years, the top and bottom halves of my body were connected again.

Now I'm not advocating that everyone should see a rolfer. I am suggesting that you can investigate the many respectable and reliable alternatives out there. There are no quick cures in any type of health service. Be careful, but don't be afraid. Likewise, when you make the decision, be responsible for it. You always have the right to say no.

Would I have envisioned myself here thirty years ago? NO. But then I had no vision at all of where I would be, or even IF I would be here in thirty years. I had no great fantasies. My one goal when I first became ill and for the first year was simply "to go home." To do that I learned to walk and stabilize my respiratory infections. Then came "to go to college."

To do that I learned to eat and gave up the leg brace after surgery to fuse the ankle of my drop foot. Next it was "to go to work." Ironically that meant going to graduate school, so I added an element that had never occurred among the possibilities before. I also gave up the need to get sick and whatever that brought me. It was in the middle of graduate school that I had my last pneumonia and I have rarely had even a cold since.

"We may have been victimized by a disease, but we are not victims. The choice is ours."

When I went to work, my goals were similar to any other young person's. An apartment, a car, a stereo, travel, friends, and fun. Then one day the almost impossible dream that had been set aside materialized. I met someone who was interested in sharing my life, and I got married. The goal then became "to help build a successful business which would become my husband's career, while maintaining my career as a librarian." We had ten adventurous years together before we divorced in 1984.

I attained all of that simply by pursuing a new goal as each one was reached. Actually, I usually started on a new goal before my current one was totally complete. But isn't that how life is? My husband often said, "You'll never be satisfied." And he was right. There is always something more to learn, some new challenge, something more to experience. My beliefs about many things have changed over the years.

One of the ways I have changed is that I could never abide physical therapy. Recently I've begun taking yoga, and for me it is the best kind of therapy. I honor my body and I also challenge it. But rather than it being a regimen imposed by a therapist, it is a meditation between me and my body. It also produces amazing results. I remember at the Swiss workshop where I first did yoga, I turned my first somersault in thirty years (with a little help from my teacher). It was such a moving experience I sat in the middle of the floor and cried with joy. I was afraid to do it, but I did, and I felt full of wonder!

So here I am 33 years later, still learning, still rehabilitating just as the result of daily living. That's the only therapy I ever used — living. Living means change. Everything we do has the potential to be a contribution or a detriment. E.F. Schumacher had a point when he extolled that less is often better. We don't have to be superhumans to be worthwhile, a lesson I am still working on. We may have been victimized by a disease, but we are not victims. The choice is ours.

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Robert E. Hitz

Insurance agent. Music teacher and instrument repairman.

Marie-Strumpell arthritis.

"The application of effort, spirit, and determination can make independent living possible for many people who might have been written off in the past."

When the *Rehabilitation Gazette* was founded in 1958, the word "rehabilitation" was still more of a hope than a reality. Family and friends of seriously disabled people were compassionate and wanted to be helpful. The medical people charged with technical care were greatly frustrated when they had done their best to restore physical function in a patient but still could not send him forth into the world to work and play, to earn and enjoy, as he would have in a more standard body.

Everyone involved in the problem of disability wanted to help, but they were largely shackled by the attitudes of the past. "The poor fellow has a problem and can't be expected to do things to help himself or to help others."

Often the physical dysfunction also isolated the person so that it was typical for a disabled person not to have contact with others who were struggling with the same problem. This reduced the sharing of information and the encouragement gained by sharing the successes of others.

My own disability began twenty years before the advent of the *Rehabilitation Gazette.* I got my first crutches and an accurate diagnosis of Marie-Strumpell arthritis in 1938. No one knew how to alleviate the disease, but it could be very accurately described. The cartilage in all of the joints of the spine and hips were wearing away and soon the inflamed joints would be raw bones moving against each other. That painful stage would end when the joints had grown solid. Then there would be no motion and the inflammation and pain would subside.

During the years when the joints were acutely inflamed, both hips and spine tended to draw up into the fetal position. The spine wanted to pull forward into a question mark position and the hips would have drawn up into a seated position. Neither position was desirable, so I wore a heavy metal brace to keep my spine erect, and I used traction to pull the hip joints down into a straightened position which would later allow me to stand erect.

Thus, the decision was made to live the rest of my life standing erect or lying down but never would it be possible for me to sit in a chair again. I have not regretted the decision. It was right for me.

When the acutely painful stage of the disease was over, I had to learn to live in a RIGID body, doing all things standing or lying down. I only travel by ambulance and do not leave my home often because I cannot sit or negotiate stairs. It is a very different life.

I am house-confined because chairs and stairs begin as soon as I leave home. I operate my teaching and insurance business in my own home where I have lived alone for the last 10 years. Those stories have been recounted in earlier issues of the *Gazette.*

Our goal now is to recognize the great contribution that the *Gazette* has made in its 30 years of dedicated effort to serve the causes of all of us as we fight to gain more independence, and, as the years take their toll, to maintain what we have already attained.

In 1938, when I had to face my diagnosis, prognosis, and use of crutches and braces, when I had to face an entirely new life in which every facet is effected by the limitation imposed on my body by this implacable disease, Cleveland and Cuyahoga County were considered to be in the van of rehabilitation efforts. Bell Greve, who was building an international

reputation in social work and rehabilitation, was fighting to improve the Association for Crippled and Disabled, which later became the Cleveland Rehabilitation Center.

My doctor sent me to that group for advice. The interview only convinced me that my problem was personal and would have to be solved by me. The rehabilitation people could offer no road map to a useful life. They couldn't even point to a starting place.

Obviously, the place to start is where you are, but it was a lonely feeling to have people who claimed to know about rehab come up dry. I had never known anyone with my problem but had seen what "bed-fast" means to an arthritic. Terror of the bed was my first spur to keep active and to work to limit the concessions demanded by my body. Usefulness was the second aspect of my rehabilitation. Usefulness maintains personal pride and is essential to earning a living. My chief assets were the logical thought processes developed while obtaining an engineering degree and a wide acquaintance with people who could supply information on almost any subject.

My physical goal was to prevent distortion of the body and atrophy of any muscle that could be exercised.

I had some help with the planning of an exercise program and even muscles and joints that seemed less important were regularly flexed or merely tightened and relaxed to maintain tone.

Part Two of my program was to find a way to be an useful citizen and earn a living. Library research taught me that most achievements only require excellence in a few skills and talents. The sought-after achievement needs to be matched to the abilities still existing.

I considered hobbies and secondary interests for which I still had the required abilities and tried to engage in them.

My hobby skills of playing musical instruments were still with me, so I taught people to play clarinet and sax, privately. I could still understand mechanical devices so I learned to repair instruments in my home. Both enterprises were successful to a degree but were limited in scope, so I explored the field of insurance and eventually build up a successful insurance agency which I am still operating.

The *Rehabilitation Gazette* found me in 1958 and revealed a whole new view of disability and rehabilitation to me. I was no longer alone. I read about other people who were forced to rebuild their lives on a new pattern. Their way of solving problems gave me new ideas. I developed concerns for their problems and their solution. I could ask questions. Someone often had the answers.

I felt a sense of community with those whose stories I read and tried to help other people with their problems. For 30 years the *Gazette* has been giving us a chance to be part of something. The *Gazette* has encouraged the new thinking that we can overcome the limitations of imperfect bodies. The application of effort, spirit, and determination can make independent living possible for many people who might have been written off in the pessimism of the past.

Other publications are joining the chorus and carrying this same message to those who need help and to those who spend their efforts helping us. Because the message of the *Gazette* is being heard, there is hope where none existed before.

Who knows what this "Voice of Hope" and confidence can accomplish now?

Sherry Hurst

Volunteer elementary teacher.

Polio. Ventilator user.

"I try not to think of the things I am unable to do. I prefer to focus on all I can do."

In 1958, I was six years old. I had bulbar polio at the age of three and one-half in October 1955. My family lived in Abilene, Texas, at the time, but they moved to San Antonio in April 1956, shortly after my transfer from an Abilene hospital to Gonzales Warm Springs. I spent the better part of the next two years at Gonzales being stretched, fitted for equipment, and taught how to function with all the new contraptions used for coloring, eating, etc. When I first had polio, I used an iron lung for two months, was gradually weaned to a rocking bed for another month, and then "graduated" to a regular bed with no breathing assistance by the time I moved to Gonzales. However, while at Gonzales in December 1957, I caught a cold that rapidly developed into pneumonia and was placed back in the iron lung. Gonzales wasn't equipped to handle respiratory cases, so we made an emergency trip to the Southwest Respiratory Center at the old Jeff Davis Hospital in Houston (this moved a few years later and became T.I.R.R.). And so, in January 1958, my family began a long and fruitful partnership with the people at T.I.R.R.

My parents realized early on that my mind was going to be my most valuable asset in life, so in September 1958, I started first grade. However, I was unable to attend school. So an intercom system was set up by the phone company, and I began my academic career in a one room schoolhouse — our kitchen. In 1959, Daddy, who was a professional Scouter with Boy Scouts of America, was transferred to Austin. I used the intercom system in combination with visits by a homebound teacher twice a week during second grade. When I was ready to start third grade, we learned of a pilot program for handicapped kids at an elementary school in Austin. The school offered classes structured for emotionally impaired, for hearing impaired, and for those who were orthopedically impaired — CPs, spina bifida, post-polio, etc. There was also a complete physical therapy department with a full-time therapist and a dormitory-like room where any special ed child who needed to could lie down during the day. The orthopedic students were divided into two classes with a teacher and a full-time aide. There was a maximum of ten students in each of these classes ranging across three grade levels. This was great. I could go to school, be with other kids, and still have my P.T. and a rest in the afternoon. The school system also provided transportation, and some of my happiest memories of the third and fourth grades at Casis are the rides to and from school on the bus.

This program lacked academic challenge for me, however, and in fourth grade I was allowed to go around to the "regular" wing for my social studies. This worked so well that the next year in fifth grade I would have been allowed to mainstream for even more subjects, but we moved. This time we were transferred to Texas City, not known at that time for its advanced experimentation in educational programs for the handicapped. My parents were faced with a dilemma — no homebound teachers in Texas City; no special ed classes in the public schools; not enough money to afford private tutors; not enough educational expertise on their part to teach me themselves; and the doctors discouraged any thoughts of attending "regular" public school.

We were able to work out a deal with the schools where I would attend school as long as my presence wasn't disruptive and no special considerations had to be made regarding academics. Well, I started school and did wonderfully. We didn't inform the doctors until after my regular checkup, which was one of the best I had ever had. I came home exhausted the first couple of weeks, but mainstream classroom education was the best thing that ever happened to me. The intellectual stimulation of healthy competition with thirty other kids, for me, could not be matched. Also, the socialization was very important. I learned I could get along in a world structured for the able-bodied. Not only could I get along, but I could be successful. From this time on, I attended public schools with little, if any, special consideration in Texas City, Carlsbad, New Mexico, and Lubbock, Texas. My remaining school years were filled with the usual ups and downs of a teenager's life.

Both of my parents worked for much of my childhood, so finding adequate attendant care has been a part of our lives for many years. Until my junior year in high school, we tried various routines including a housekeeper/attendant during my elementary school years and a part-time attendant for morning and evening hours in junior high. Then the first day of my junior year in high school (twenty years ago this week), I met Celia Gutierrez. My mother had contacted one of the business colleges here in Lubbock about finding someone who would be interested in a live-in position in return for room and board. Celia was from Odessa. She had just graduated from high school, was leaving home for the first time, and needed a place to live while going to business school. The arrangement was a perfect match for both our needs. My mother is an R.N. and, at that time, worked the 11 p.m. – 7 a.m. shift. Celia would get me ready for school, as well as herself. Then, she would drop me off at high school before going to her own classes at the business college. In the afternoon, Celia would pick me up after she had finished for the day. It wasn't long before we had become best friends, and Celia was more a part of the family than

In 1958, Sherry at a Texas Respiratory Center (T.I.R.R.).

Sherry working with one of her students.

live-in attendant. Even though she is two years older than I, Celia and I did a lot of growing up together. As the end of my junior year approached, we started making plans for the two of us to attend college together. Celia had always wanted to go to college but had never been encouraged. You see handicaps come in all forms. Some, like mine, are very obvious. Others, like the financial and cultural ones Celia had experienced, are more subtle. We banded together, helping each other to overcome the barriers we faced.

My senior year in high school was spent preparing both Celia and myself for college. While she worked to pay off loans she had gotten in order to go to business school, I tutored her, somewhat, in the college prep classes I was taking in high school. Finally, all our efforts were rewarded. In September 1970, we began our freshman year at Texas Tech University.

In 1971, Celia and I parted as roommates but not as friends. We had both learned a lot as pioneers that first year. We were instrumental in the ramping of much of the campus, and because of our needs in class scheduling, much thought was given to the actual physical placement of classes. The remainder of my years at Tech consisted of a succession of live-in roommates, some who were supplemented with daytime and weekend relief attendants. I received some financial assistance from Texas Rehabilitation Commission, but the majority of my college expenses, including attendant salaries/room and board, were paid for by student loans and my parents. After four years of undergraduate work, I received a bachelor's degree in psychology. I returned as a graduate student and earned a teaching certificate in secondary education with psychology and English as my teaching areas. After two years of substitute work, I again returned as a master's candidate in English. While a graduate student, I taught freshman English classes as a T.A. (teaching assistant). Later, I got a position teaching English classes at the Lubbock campus of South Plains College in Levelland, Texas. I finished 33 hours towards my master's degree.

At this time, I am unemployed; however, my days are quite full as a volunteer in the Lubbock Independent School District. Celia, now Celia Glick, asked me three-and-a-half years ago to come help her in her fourth-grade room by using my skills to work one-on-one in developing reading and language skills with her predominantly Spanish-speaking students. What started as a couple of hours once or twice a week has grown to thirty hours a week as volunteer chairperson. I am now chairperson of the volunteer program at one elementary school and volunteer manager working with the chairpersons of seven other elementary schools. This past spring I was nominated by the Lubbock School District as volunteer of the year in the parent/community volunteer category. I was one of twelve semi-finalists out of over a thousand national entries. I was the only Texan to be recognized. Congressman Larry Combest presented me with a Congressional certificate of excellence for my efforts. Being a volunteer is very rewarding, and because I can set my own hours, this position suits my needs very well.

> *"I live one day at a time."*

As I have been writing this piece, I have been searching for what deep words of inspiration I live by and could pass on to others. The only thing I can say, however, is that I live one day at a time. I try not to think of the things I am unable to do. I prefer, rather, to focus on all I can do. You know in horse racing they handicap the best horses. Maybe if we who are physically challenged kept that thought in mind, we would change the perceptions of physical disabilities in the minds of those whose lives we touch. I don't think of myself as handicapped and neither do those who are around me.

Celia Glick

After twenty years of friendship, Sherry Hurst has impacted my life forever. At first sight, I saw Sherry as a severely handicapped individual who had a very sweet personality. For a time, I helped her with all her personal needs, and she showed me her appreciation by showing me that she has the same feelings, emotions, and thinking processes as everyone else. Sherry and I have developed a wonderfully close relationship. We treat each other equally, as friends should. However, Sherry has inspired me to strive for greater goals in my life. She has also taught me the skills of patience, persistence, and ingenuity. I believe I have helped Sherry adopt an even more positive attitude towards life by including her in my life and by accepting her as she is, unconditionally. We are both enriched by our friendship! 福

Cass Irvin

Editor, *The Disability Rag*.
Advocate.
Polio.

"The world needs to know what the disability situation really is and the role society has in keeping us 'confined.'"

The first piece I ever had published was published in the *Rehabilitation Gazette.* The article was called "The Radicalization of Cass," and it was written for an edition of the *Gazette* that focused on disabled women. The article was about my realization that no matter how hard I worked in my chosen field (then it was teaching), I could never earn enough money to pay the expenses of living on my own with a disability. I realized that society was structured in such a way that I could only excel so far; I realized that "overcoming" had nothing to do with my disability and everything to do with my "social/economic status." In this society, the social and economic status of disabled people is very poor.

When I wrote that article (in 1977), I realized if I did not get involved to change society's perceptions of disabled people, then I would become a victim of the trite but true slogan, "If you're not a part of the solution, you're a part of the problem."

I wrote "The Radicalization" two years after I had became involved with the disability rights movement. But my "involvement" with the *Gazette* began much earlier.

I had polio when I was very young, during the polio epidemic of the early 1950s. Being disabled in those days was very different than it is today; it was much more isolating than it is today.

I spent a lot of time being "rehabbed" at Warm Springs, Georgia — the "in place" for people who had had polio. In those days this publication was called *Toomey j Gazette* and it was provided as a resource to those who were new to disability. I read it some, but I was not involved with disabled people then or the disabled community and, since my mother kept pointing out to me that I was different than most disabled people, I made no effort to get involved. Warm Springs was very important to me. I knew that I loved it there, but I was a child (later a teen) so I didn't understand why. I didn't know about "peer support." I did not have disabled peers at home. I found it very traumatic to switch back and forth from being a disabled person among disabled people, as I was at Warm Springs, and being a disabled person all alone — as I was when I came home to Louisville.

I realize now that being at Warm Springs was important to me because I was with *my own* people there. But that isolation from peers while at home influenced my life more.

Having parents who believed in higher education was another influence. When a friend in college said she admired me for going to school "in spite of my disability" ("handicap" in those days), I did not know how to respond. Being in college had little to do with something in me. I went to college not because I was an overachiever, not to prove I could "overcome." I went to college because my mom, dad, uncles, and aunts had, my sister did, and my brother would — my family all went to college. It was expected.

I went to a very small college, so I was not lost in the masses (a good influence). After I graduated I tried to get a job teaching. No one would hire a teacher in a wheelchair (a bad experience!) So I persuaded my state VR agency to pay for a master's degree (that was unusual — in those days).

Before completing my master's degree, I moved out of my parents' house to live on my own. Independent living centers were new, and we didn't have one here. But there were people (family counselors, social workers, etc.) who helped me become "independent," who did not act like this was an impossible situation.

My parents were not among those people, but since they had the means, they supported me financially the first couple of years. (Being dependent on them was another influence in my life.) Soon I was teaching college, but I couldn't earn enough money to be financially independent. I became involved with a disability rights organization to try to change things. I wanted to become involved with the solutions.

This was in the seventies. I remember reading *Rehab Gazettes* because I had begun to get involved with a disability organization and as I read I thought, "Boy, those people are lucky. They have attendants, they have jobs. They are really independent. I wonder if that will ever happen for me?"

I became somewhat liberated by this involvement, but I still bought into society's stigma about disabled people, and I had become involved with that organization with the stipulation that I would be on the Board of Directors of the organization — not a part of the general membership. I did not want to associate with disabled people.

Remember, I had always been told by my family that I was different, I was not like other disabled people. So I was not comfortable with disabled people. I did not understand the "peer" concept.

Deep in my soul, I knew something was wrong, but I still did not know how to articulate — or understand — my feelings. There was a void, a loneliness, something missing from my life, but I did not know what it was.

Two things happened to me that showed me what I was missing.

First, I read *The Feminine Mystique* and I found that women had already discovered what I was just beginning to learn: they had a problem with no name. They felt an isolation, an aloneness, they couldn't explain. They were living the lives society proclaimed for them but they weren't satisfied. Their husbands, their kids, their squeaky clean houses were not enough for them.

Choices were missing for them. Making decisions, on their own, for themselves, was missing. Feeling happy about themselves — just being themselves (not someone's wife or mother) was not something they were allowed to be. *The Feminine Mystique* and the women's movement helped women realize that they can make choices, they should make choices and not let society dictate what women will be, what roles they must choose.

I wondered what the world would be like if disabled people were given choices.

The second thing: I gave a speech at Women's Equality Day in 1981. As I worked on it, I tried to think of ways to get my audience involved with the disability rights movement.

What could I say to make them realize that we are like them; what could I do to "overcome" the stereotypes of disabled people I knew they had. What did they have that made them strong, that made the women's movement strong — the thing we didn't have?

It has camaraderie. It is love for each other and camaraderie. It is the knowledge that they are all sisters and what happens to one can — and does — happen to them all. Whether they are rich or poor, educated or not, they all have been discriminated against, they all have been held down. The struggle for equality for women is their struggle and they fight side by side.

In my speech I told them they needed to bring their disabled sisters into the women's movement. I told them that disabled women did not have those feelings of camaraderie with anyone and we needed it.

That's what had been missing from my life and my work in the movement. That's what society had taken from me.

Society had taught me that disabled people were to be looked down upon. Disabled people are helpless, they are not capable, they need to be taken care of, they are burdens, they are of little or no value (except to be inspirations).

But disabled people was *me*! If I thought disabled people had no value, then I had no value — no matter how much I overcame!

When I was at Warm Springs I lived with people like me. Soon I forgot they were disabled, but I never forgot they were like me and I liked being with people like me. When I came home I was never with people like me and I felt I didn't fit in. (Usually the environment was inaccessible — so I literally did not fit in!)

When I gave that speech, I realized I had some responsibility to "overcome" the stigma myself. I had to put my intellect and my emotions together. I had to find that camaraderie for myself among my people. And once I did, I knew I would be alone no longer.

Today? Today I live in my parents' home — not with my parents (my mom is in a nursing home; my father retired to the lake). There is something about living in this house that is spiritual to me. There were so many trials here and so much pain here. When I lived here, I was a backroom person: I went to school, I had somewhat of a social life, but, for the most part, when I was home I was in bed; I did not spend time in the living room, the dining room, the kitchen. I didn't tell my friends about this. I tried to act "normal."

This was a place that confined me. I couldn't grow to maturity here. I could not be my own person here, disabled or not. I couldn't live my own life here. So I fought to leave.

I have come back "home" as a successful person living independently, being in charge of my own resources and making a home for myself. I have my own "family:" a man I have lived with for 13 years, a live-in attendant, my cats.

> *"Society had taught me that disabled people were to be looked down upon."*

After living on my own in apartments for ten years, I am happy to be home. But it is different. I have taken a place that used to have bad, bad memories and isolation and turned it into a place where there is happiness, where there is fullfillment, and where there is success.

It's been over ten years since I wrote "The Radicalization of Cass." A lot has happened since then. I have my own publication, *The Disability Rag.* It is a magazine created out of a need to connect with other disabled people, to see if the isolation and frustration those of us in Louisville, Kentucky, felt as activists was felt by others. It was created to be a forum for those activists. And for parents who want their disabled children to grow up unconfined. And for backroom people who have to know they are not alone, or isolated, even if they cannot leave their bedrooms.

I am still writing about the disability experience. I am more involved with advocacy than ever before, knowing that those two things need to go hand-in-hand: the world needs to know what the disability situation truly is and what role society has had in keeping us "confined."

I think society's view of disability has changed, and I think I helped.

So has the *Rehabilitation Gazette.*

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Judd Jacobson

Businessman. Owner of travel agency. Husband.

Spinal Cord Injury. C5.

"One must use one's own good judgment in order to pick and choose among the many options that are available now."

I heard about *Rehabilitation Gazette* when it was first called — *Toomey j Gazette.* That was in the late 1950s. It was my first exposure to a support group outside of my own family, and it was wonderful!

I was a C5 quadriplegic struggling in a world that was not accessible and using rehabilitation techniques that were primitive by today's standards. Today I am a successful businessman with a pretty, vivacious secretary, and I work in a very attractive office in my home overlooking a golf course. I consider myself very lucky. I am also proud of myself because I have never received any subsidies or benefits from the government or insurance. I did it all with the support and guidance of my family and my wife.

Yes, it was tough going and still is. Medical care is now readily available and that problem has been solved. My biggest problem today is recruiting and retaining good nursing assistant care at night as my wife has developed rheumatoid arthritis. She is still active but not able to assist me. I believe this is the number one issue facing severely disabled people for the rest of this century.

I can only take credit for having the perseverance and creative ability to take advantage of the opportunities and then stick to it as I took one day at a time. My opportunity was first in the form of selling magazine subscriptions over the telephone as originally suggested to me by my sympathetic local Methodist minister.

My second opportunity was a career in local radio broadcasting and advertising sales. It opened the world to me. Our local radio station was aware of my ability in public speaking and my voice which had what they said was good "tone." I built this into a full-time career which included organizing and operating travel tours for the radio station which I escorted. Imagine! I was a quad in a wheelchair with an attendant escorting forty able-bodied people on tours to Hawaii, the Caribbean, Mexico, throughout the U.S. and Canada, as well as Europe. This career made it financially possible to leave my parent's home and become totally independent in a specially designed duplex where I provided my attendant's family with a free duplex apartment in return for taking care of me.

After thirty-eight years of radio broadcasting, I retired and started a new career as an owner of Minnesota Home Elevator Company. I started this company from scratch, installing and servicing residential elevators, stairway elevators, wheelchair lifts, and similar equipment in public buildings as allowed by code in the state of Minnesota. We are now one of the top twenty distributors for the Cheney Company of New Berlin, Wisconsin.

I want to make it clear that none of this would have been possible without the love and support of my father and mother. My mother took all the physical care of me for seventeen years. My father had no medical insurance and was forced to pay all bills in cash.

One of the prime factors in maintaining my health and ability to work full-time has been my strong emphasis on daily hygiene and careful attention to skin breakdowns and muscle stretching. I have also had an annual checkup at the Mayo Clinic in Rochester, Minnesota. Whenever a new rehabilitation technique for spinal cord injuries was developed, I tried to take advantage of it by agreeing to a short hospitalization in Rochester to learn how to use it and evaluate its effectiveness. I have not always accepted every new fad because some were obviously very experimental and could cause permanent damage. Once the leading rehab physician at the Mayo Clinic pleaded with me to sever my spinal cord at my pelvic level in order to eliminate spasticity in my legs and hips. Today this technique has been abandoned. One must use one's own good judgment in order to pick and choose among the many options that are now available.

I live in a large home which was built for me with a large bathroom that includes a drive-in shower and wheelchair lavatory equipped with a shampoo spray and soap dispenser. My bedroom has a ceiling-mounted track with an electric hoist on a trolley that lifts me and transports me either to the wheelchair or toilet. There are no steps or even a threshold at any of the entrance doorways into my home. I also have a large whirlpool spa in the lower level of my home with a hydraulic hoist to lift me from the wheelchair into the spa. The entire home has a magnificent view of the golf course.

None of this would have been possible if I hadn't been fortunate in marrying Barbara Williams of Chester, England, twenty years ago. I met her on Poipu Beach on the island of Kauai in Hawaii. I was escorting a radio travel tour at the time, and she worked for TWA and lived in Hawaii. She agreed to marry me and open her own travel agency in Owatonna, Minnesota, which is called Travel Headquarters, Inc. We have an internationally famous division called Flying Wheels which is for the severely disabled and operates escorted tours all over the world. We also do independent travel. Another division for the ablebodied is called American Rail Magic Tours. This is a nationally advertised escorted tour business operated through Amtrak. The income from this business is now my major source of financial support and is managed by my wife.

Judd with his wife, Barbara.

Gini Laurie has been an inspiration to us all. However, her major focus has been on post-polio and the aging effects we are seeing today.

According to the Mayo Clinic, I am the second longest surviving quadriplegic anywhere. My friend, Jim Swenson of Rochester, Minnesota, has the longest record. He is a C-6 quad which helps account for that. I am hoping that the professionals in rehabilitation will soon start similar research into the aging effect on spinal cord injuries.

Gini Laurie is a walking, talking, earthly saint who has already earned her halo in heaven. Her work in our lives will go on for generations to come. I salute you, Gini, and I hope that you enjoy good health right up to the hour and minute of your departure from our planet. You do not deserve any of the pain and suffering that you have helped alleviate in the lives of thousands of your admirers. 福

Dick Jaskela

Teacher. Photographer.

Polio. Ventilator user.

"From that moment I never again approached a person of authority without a clear plan of what I wanted to do and how I was going to do it."

Gini has asked me, and I would never deny Gini anything in my power to grant, to write about my evolution during the past thirty years. The mundane facts of my 24-year-old life in 1958 were that I had lived in a nine-by-ten-foot converted sewing room for seven years, that I was attached to a respirator 24 hours a day, was confined to bed at least 18 hours a day, had the use of my hands and forearms and little else. I was being supported by my mother, a nurse's aide, and my grandmother, a charwoman. Oh yes, the local welfare agencies contributed the munificent sum of $24 a month for my bed, board, clothing, sundries, and entertainment. And for this largess had to endure the indignity of a humiliating monthly inquisition to assure the Welfare Department I was not lavishing their money on lewd and lascivious living. I had a tenth grade education and no funds for a tutor, and the City of Ashtabula had no provision for educating someone in my condition. I maintained my sanity by reading (the library would deliver carton loads of books every two weeks) and by teaching myself to draw and paint. The smartest thing I did during that time was to NOT have a TV set in my room.

Of all my pre-polio friends only one was able to deal with my disability and remain a friend. In 1958 he met a fellow, Frank Uvena, and introduced him to me, and my life was set on a new path. Frank was earning straight "A's" while attending Ohio University on the G.I. Bill, and during semester breaks, he would leave his textbooks with me to read. I had been a mediocre student more interested in girls and sports than academics and had no clue as to the depth of my intellectual capabilities. I discovered that I understood the material in the texts and that I could hold my own in discussions with Frank.

About the same time, Kent State University opened a Regional Campus in Ashtabula. In spite of my physical limitations and working class background (no one in my family had graduated from high school), I began to dream about attending college.

The Ohio State Bureau of Vocational Rehabilitation (B.V.R.) was confounded by the seriousness of my disabilities and had no idea of how to acquire training leading to employment for me. When I approached them with the proposition of attending Kent State, they fell all over themselves finding objections to my plan. They pointed out that I did not have a high school diploma and that my grades were not impressive; I could only be in the wheelchair six hours a day and had no means of transportation; the classrooms of Kent State were not wheelchair accessible as they were on the second floor of an elevatorless building; and what course of study would I pursue, and to what end, and if I managed to complete the studies, who would hire me with all my limitations? They concluded that they could not justify the required expenditure.

For the next two and a half years I talked to everyone I came across about getting the opportunity to acquire an education because, like Jack London, I realized that if I was ever to improve my lot in life I would have to become a brain merchant. Finally several prominent families decided to pool their resources and finance my education for one year. The University reluctantly agreed to admit me as a provisional student if I could get medical clearance. I went to Metro Hospital in Cleveland for an evaluation and virtually everyone there tried to dissuade me from my dream. I convinced them to not doom me to failure before I had the chance to succeed or fail on my own, and they wrote a half-hearted statement that clearly echoed their reservations yet did not deny me my opportunity.

At this point I began to take control of my fate as I realized if I were to make my way through the maze of life, I would have to learn to steer my own course. From that moment I never again approached a person of authority without a clear plan of what I wanted to do and how I was going to do it. I discovered that "authorities" were greatly relieved when I had a program all thought out, so they would not have the responsibility of making complicated decisions.

It was my good fortune that I had an athletic cousin, Lee Ranta, ten years my junior, who had just graduated from high school and was about to attend Kent State. He offered to transport me to and from class, carry me, my wheelchair, and respirator up and down two flights of stairs every day for a couple of years. I am forever indebted to him for his generosity and continuing friendship. After one term, I was an "A" student, had made several friends, and was dating a wonderful, talented woman.

My life had changed immeasurably for the better, and I was already a success as I had purpose and direction. I did not dwell on the vague goal of employment in the distant future; I quite happily took each day as it came and only planned one school term at a time. If the process had led to nothing tangible, my new life as a nonentity, it would have made the effort worthwhile.

"Do not listen to the naysayers; follow your dream."

After my first year at Kent State, B.V.R. concluded that I was salvagable and paid for my tuition, books, and attendant care during the remainder of my education as long as I kept making acceptable grades. I attended Kent in Ashtabula for three years. One year, after Lee had moved on to Ohio State University, I was transported to class by taxi. The taxi driver was not allowed, because of insurance liability, to carry me into the building, so he would deposit me in front of the building. I would sit there until some benevolent students came along and volunteered to carry me up to the second floor classroom. With the rigors of Northeastern Ohio winters, wind howling, snow blowing, and the temperature near zero, it was at times challenging. I also owe a debt of gratitude to the many students who were so generous to me. I earned academic and writing honors each year I was in attendance.

I joined Lee at Ohio State University for one year. We lived in the center of a black ghetto because it was the only place we could afford: the lower half of a two-family house for $40 a month. The drive to and from Columbus became too arduous, so the following year Lee and I transferred to Kent State. Our standard of living improved dramatically as we and two friends rented a winterized cottage on the shore of beautiful Lake Stewert. I earned my B.A. in 1967 and my M.A. in 1968.

The six years I spent attending several universities were wonderful years of growth with the glory of building friendships, the pain of losing friendships, the thrill of successes, the satisfaction of accomplishment, making mistakes that hurt loved ones (the agony of which still haunts me today). But oh, the good times far outweighed the bad, and I would eagerly do it all again if given the chance.

At the age of 33, teaching classes at Kent State in Ashtabula where I began my education, counseling students, serving on committees, and writing articles became regular events in my routine. My social life consisted of making friendships, dating, attending plays, parties, picnics, concerts, dances, and many evenings of stimulating conversations. In addition I became involved in politics by directing local campaigns and contributing whatever I could to state and national candidates I believed in. I also served on the Board of the Governor's Committee for the Handicapped and gave talks on problems of the disabled to the nondisabled and pep talks to the disabled, and served on the Mayor's Advisory Board. Seeing that I had the reins of my life firmly in hand, I decided to find out if I had any business acumen and engaged in four businesses in ten years: a service station, an auto parts store, a health club, and a photography studio. Only one was barely successful, so I concluded that I was not endowed with talent for business. Being a professional photographer was the most rewarding. My life was full, rich, and satisfying.

Dick using his van lift.

From the discontented man living in a nine-by-ten room being supported by my mother, grandmother, and welfare to living alone in my own home (the only house in Ashtabula I wanted), being self-supporting and contributing to society has been an exciting journey. I take some pride in my accomplishments and in the manner I have conducted my life. Has the experience brought wisdom? Well I have learned a few things that I would like to pass on. Do not listen to the naysayers; follow your dream. If you fail at first, pick up the pieces of your pride and start again with a new endeavor. Do not shy away from asking for assistance when it is truly needed, but never ask for help when it is not absolutely necessary. Find a cause outside yourself that you can contribute to or a person you can help.

The most important thing I have learned is attitude. Present yourself to the world with a positive, enthusiastic attitude and good things, good people, and good fortune will gravitate to you. Simplistic? Perhaps, but it works; it worked for me. 福

June Isaacson Kailes

Director of independent living center. Advocate. Wife.

Cerebral palsy.

"Assertiveness is a survival skill when one lives with significant disability, because one is constantly confronted with 'you can't get there from here.'"

In 1958 my role model was a young adult in my neighborhood who had CP. He combed the neighborhood going house to house selling pencils. In 1958 I was nine and I knew beans (shit!). The difference between now and then is that I didn't know I knew shit and now I know. I thought I knew more than my peers because I learned to type at the age of eight as a means of compensating for my motor loss which greatly slowed my ability to write. This opened up a whole new world of things I could send away for, and pieces of education that I could acquire long before my peers. If I only had a computer back then I would have been light years ahead!

At the end of second grade I was transferred from a "special school" to a regular public school. In other words I was mainstreamed (but the word hadn't been popularized yet). This transfer was initiated by a wise second grade teacher and not by my parents who were apprehensive about such a move. I did not receive any counseling preparation for such a move, thus all my fears, apprehensions, hurts, and other reactions were never verbalized, although they were present in many of my troubled thoughts. From then on through high school I had no contact with others who had disabilities. I believe it would have been helpful to have had friendships with other kids with disabilities, just to share some of the unique experiences that no one else, including family could really identify with or understand. In 1966 I wrote a telling line, "At this time in my life, I am more certain about my limitations than my abilities."

My mother was always the more liberal and permissive parent, thus I would have to give credit to her for my early moves toward independence.

Quote from mother: "We took each day as it came." She remembers that it was strongly impressed upon her that her attitude toward me would be the most important thing of all. "When you first came home from the hospital and things seemed so tenuous . . . the nurse used to say to me that my attitudes and thoughts would be the most important things for you to grow with. Her words were: 'If I planted potatoes, I would get potatoes, but if I planted flowers, we would get flowers.' We got flowers."

She often buffered my father's restrictive and strong over-protective leanings. I see my learning how to drive as a major turning point in my seeking independence. I secretly feared that I could not drive and it was urgent that I find out whether the fear was valid or not. Hence, the day I turned sixteen I commenced a campaign to try to get my driver's license. This was flatly denied by my father. I was frantic! At that point, my mother did something for which I shall be eternally grateful. She sensed the urgency of my need and secretly took me for driving lessons, sometimes using a portion of the grocery money to fund these lessons. I obtained a license within three months.

It was only after I got to college and beyond that I felt the camaraderie and special support that comes with sharing feelings and experiences with other folks with disabilities. I think for me it probably would have been helpful if there had been more open communication about my disability as I was growing up. It would have probably forced me to learn to deal with my feelings and people's questions at an earlier age. It would have probably also helped me to be somewhat more tolerant of people who stared.

Before going away to college, I only superficially accepted my disability. In most situations I actually denied its existence and became frustrated and annoyed when anyone drew attention to it. I had convinced myself that it was not noticeable and, therefore, it was disturbing when someone referred to it. In elementary and high school, acting as if my disability did not exist sometimes left me with feelings of inferiority and failure because this act of self-deception was not always convincing. I hated and resented people who would stare at me, and I thought they were inconsiderate and cruel. I often wanted to retaliate in some punishing fashion and sometimes would act this out to embarrass the starer or at the very least return their icy stares.

I never discussed my disability because of my strong desire to be accepted, treated equally, and considered "normal." Society's message was clear to me that this status would not be given to anyone with a disability. I felt that only by meeting standards which I considered to be those of "normality," could I totally be accepted by the world.

College was a blossoming experience for me, a period of real self-exploring and identity building. The decision to leave home was mine. Parental reaction followed its usual pattern with my mother saying, "Go," and my father warning about the competitiveness and horrors of New York City. The separation was untraumatic. For the first time I was not living under the shadows of two very verbal and community active parents. I became me and not so-and-so's daughter, the girl everyone admired and respected for her achievements, but the girl whom few really knew or took the time to know.


June in 1953.

My college years changed my feelings and self-perceptions about me and my disability. Stepping into positions of leadership in college also helped me to learn who I was and what I was capable of. I avoided, at first, extensive contact with students who had disabilities as I feared such relationships might be stigmatizing and imprisoning and I did not want to be considered one of "those." Gradually I developed friendships with students who had disabilities and began to realize that my denial only resulted in putting a strain on myself and my interpersonal relationships. Suppressing the reality of my disability only led to persistent and exaggerated feelings of failure and inferiority. By not permitting myself to join in activities with other people with disabilities, I reinforced a sort of self-imposed marginal being, not fully belonging to either group, people with or without disabilities. Through continued friendship building and eventual dating of some students with disabilities, I developed a clearer understanding of them and, through them, a better understanding of myself. I learned that my denial and concealment were not answers to really coping with disability. Only through a realistic recognition and evaluation of my disability, and integrating it into who I was could I truly accept myself and ascertain my identity.

Leaving New York for California was another major milestone. Leaving New

York meant leaving many close friendships, male and female. It meant leaving people who could be relied on for many happy social activities and support when personal difficulties arose. My parents' reactions again followed the usual pattern, with my mother saying, "Do your own thing," and my father issuing earthquake, fire, smog, mud slide, and freeway warnings in his own loving way.

Things I've learned/or my limited words of wisdom: Assertiveness is a survival skill when one lives with significant disability, because one is constantly confronted with "you can't get there from here." You need to feel fine about asking for what you need.

When one lives with disability, peer support is essential because no matter how good your friends without disabilities are, they cannot truly understand the total experience unless they have been there.

In terms of disability rights: The sobering part is that it is painfully slow, nothing happens overnight. I am the impatient type and because I know that life is short, this snail-paced progress is frustrating. Only when I look back ten years can I see inklings of progress and how many sets of ten years are there in one's life?

June with her husband.

To force myself to look at the big picture, energy is not infinite, time is uncapturable but it can be planned, therefore it is imperative that energy be focused on activities that get the biggest bang for the buck. I used to think nothing about spending hours looking for the best deal no matter how small the item!

We were all told that, "When you get older you can't do as many things as you could do when you were younger," but many of us didn't expect that would be exaggerated to a variety of degrees when we have lived with disability for a good portion of our lives. Given this emerging reality I feel that one shouldn't put off what one may not be as capable of doing as one gets older. Don't put things off like vacations, enjoy them, and take them frequently — especially those that take "high energy." 福

Todd Keepfer

Teacher. Husband and father.
Polio. Ventilator user.

"Dr. Anderson left me with prophetic advice, 'Todd, your most important consideration is your breathing, and it will always be.'"

This fall will be my 25th polio "anniversary," five years short of the *Rehabilitation Gazette's* 1958 debut.

Nineteen fifty-eight was a very good year for me. I was a junior at Penn State majoring in zoology and entomology and thriving on the excellent hunting and fishing in the Nittany Valley. The fall and winter of 1960-1961 were periods of escalating highlights in my life. I bagged a bear during Pennsylvania's short season and collected a nice buck a week later. My fiancé, Pat, and I were engaged. (Little did I realize what a faithful and supportive wife I had chosen!) I visited a local agricultural research station and left hours later with job in hand. I graduated from Penn State and began work.

Pat and I purchased a small mobile home and were married on February 17th. Thus began nearly two years of commuting to work for both of us. During this time our first son, Scott, was born.

While on our first vacation in 1962, we stayed with a college friend who was working as a park ranger on the Blue Ridge Parkway. I became enthused about ranger work, applied, and within three months accepted a position as park ranger in the Great Smoky Mountains National Park in Tennessee.

In September 1963, I came down with the "flu" or something. Pains in my back worsened, a local clinic diagnosed kidney infection, prescribed sulfa drugs, and I was sent home. The next day I was worse and neighbors insisted I go to Fort Sanders Hospital in Knoxville, Tennessee. There I gradually became weaker and began to have difficulty breathing. A spinal tap confirmed something very wrong and as my breathing failed I was rushed to the University of Tennessee Hospital, the only place where an iron lung was available.

After weeks in the iron lung the hospital staff began a campaign to "wean" me from the lung. I panicked when they tried. I could not breathe on my own. The staff was not experienced with polio and it was decided to fly me to Talmadge Memorial Hospital in Augusta, Georgia. I was under the care of Dr. Frank Anderson.

Dr. Anderson's knowledge and conservative approach were fundamental to my recovery. He immediately told us that the iron lung was my best friend and to expect to spend months in it and recover slowly.

The long recovery process began. During all this trauma and turmoil my wife stayed close by, supported by family, friends, and often concerned "strangers." Pat found a room near the hospital and stayed with me continually. Without her strength and presence I would not have had the drive to endure the long days and nights. I gradually began to leave the iron lung for physical therapy and heat wraps, breathing with a mouth-held, positive pressure ventilator.

Gradually, I moved to the rocking bed and eventually spent day and night bobbing up and down. Sometime early in 1964 I was able to spend short periods of time without breathing aids and slowly began to sit up to build up my tolerance. Having dropped from 155 pounds to 89 pounds — there was little padding to sit on. Next, I was introduced to the chest shell and soon left the rocking bed behind. I learned to feed myself with the aid of "feeders" and lap board.

Finally, the early summer day came when I was able to spend a few hours "outside." This gave Pat and me some hope even though the future seemed very uncertain.

After a few lengthy setbacks we began to plan on going "home" — home was to Pat's parents in New Jersey. Her parents still had two children at home and had kept Scott while we recovered. Now they provided a home for us. Late summer 1964 we made the long train ride from Georgia to New Jersey with equipment in tow. I was breathing with the chest shell at night and with a positive pressure respirator during the day.

Before leaving Augusta, Dr. Anderson left me with prophetic advice, "Todd, your most important consideration is your breathing, and it will always be. Don't every forget that and don't let anyone convince you differently."

A year passed. Our second son, Jim, was born and I had "recovered." Recovered? I could sit up all day, feed myself, shave, groom, and breathe without aid for a few hours. All other needs had to be met by others.

What was I to do for a living? Friends and staff from the Great Smokies and the National Park Service had been very supportive and now they came through again. They offered me a teaching position with the newly-created Job Corps program in the Great Smokies. In December 1965, we returned to Tennessee. Twenty-three years later I am still a teacher with the Job Corps program.

I enrolled in night class at the University of Tennessee, aiming toward a degree in education. Those early days at work were "new ground" and I was blessed by working with people who seemed to know how and when to help. They included me in many activities that were "impossible" by carrying me and my "stuff" around. They assumed I could. So I did! Their support made my working possible. Our first Job Corps center closed and we transferred to one in North Carolina.


Todd with his wife, Pat.

By the early 1970s I could "outbreathe" my chest shell and respirator and discontinued their use. Everything was fine but when I wheeled myself a few feet I became very tired. People began to notice that I was "working at" breathing. I went to Augusta for a quick checkup and was still there several weeks later. My blood gasses were so "out of whack" that a spell in the iron long was needed to rest my mental "thermostat." The careful fitting and monitoring of a new chest shell was needed before Dr. Anderson was satisfied that I could return home and take care of myself.

Upon our return home, we found a motorized wheelchair in our living room, given by friends, acquaintances, and anonymous others. The impact of the motorized chair was tremendous. I was able to go many places without help and I did not exhaust myself pushing about. So my problems were finally solved, right? Wrong! Over the next few years I began to have trouble sleeping, began waking up with headaches, began falling asleep during the day, and even started talking nonsense. To make matters worse, I didn't realize how bad I was and I insisted I was fine. Dr. Anderson had passed away and we turned to local doctors for help.

In the fall of 1977 I spent a spell in the hospital using the chest shell, adjusting pressures and padding and taping leaks until my blood gasses were more normal. We looked forward to spending the holidays with family and friends, although my condition had begun to deteriorate again. The day after Christmas I "zonked out" and was rushed to the University of Pennsylvania Hospital in Philadelphia where an iron lung was available. After a stint in intensive care in the iron lung, I was "weaned" to carefully monitored chest shell use and released.

By the next spring, however, I was on a downward slide again and after consulting several specialists, whose solutions ranged from implanting phrenic nerve stimulators to gulping blood thinners and heart stimulants I turned to Carlton Bishop, my respiratory equipment "guru" for advice. His advice was, "Todd, quit messing around and get back in the iron lung." I believed him, got a doctor's prescription, the lung was delivered, and I promptly slept for three and one-half days.

At last my troubles were over, right? Wrong again. After about three years, my "bad gasses" symptoms returned. This time we fortunately found a young pulmonary specialist who was interested, a good listener, open minded, and a problem solver. The solution, which seems to have maintained my health since then, was to increase the lung pressure considerably, use positive pressure frequently to expand the chest wall, and use supplemental oxygen at night.

Over the years it has not been the lack of intensive physical therapy, the absence of muscle strength, nor the lack of exercise that has hampered me, but as Dr. Anderson wisely cautioned, it has been my breathing limitations.

"My primary inspiration through the years has been the love and support of my wife. Without her the story would be quite different."

How have I made it this far? People say I am brave, strong, determined, and such. I will admit only to being stubborn and patient. My primary inspiration through the years has been the love and support of my wife. Without her the story would be quite different. My two sons have helped me relive many things and where my travel ended, their paths carry on, giving me a continual source of inspiration and satisfaction. Our families have always been here when needed, and that is a great understatement. Friends, old and unexpected, have helped so often. Classmates and professors at Western Carolina University, where I earned a master's degree in counseling in 1985, are examples of the caring people who made things possible. Above all, without the support, expertise, and long-time financial assistance of the March of Dimes, I would not be able to write this story now.

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Audrey J. King

Psychologist. Advocate.

Polio. Ventilator user.

"I was encouraged to be independent and self-sufficient before I was disabled and this attitude did not change after."

August 1958-1962, Ottawa: It had been six years since I'd attended a regular school and six years, almost to the day, since I became ill with polio as a nine-year-old in England. Now, on a summer day my mother pushed me in my wheelchair to a newly completed neighborhood high school to ask if I could attend. Although the special elementary school for crippled children had for several years emphatically refused to accept me because I was "too disabled," this principal welcomed me with open arms. A ramp was built at the school entrance, upstairs classes rotated down, school secretaries met my daily bathroom needs, and classmates pushed me from class to class as well as to and from school every day.

It was a difficult adjustment. After years of hospitalization, the move to Canada, and the loneliness of education by visiting tutor or correspondence, I was shy and filled with adolescent self-consciousness and doubt. The school was large and my erratic education had placed me ahead in some subjects and behind in others. Nevertheless, I was thrilled. I had finally made it back to the "real" world and was determined to stay there!

But within a few months I was falling asleep at school and having a difficult time waking up in the mornings. Everyone, including me, believed it was only school exhaustion. But summer brought a worsening of the symptoms, and I was sent home early from summer camp, rushed to hospital, and placed in an oxygen tent, whereupon I promptly stopped breathing. To my horror, I awoke once again in an iron lung and when I returned home several weeks later, I reluctantly took with me a cuirass for nightly ventilation. As a teenager I despised this dependency and was mortified when friends discovered my dark "unmentionable" secret. Nevertheless, the improved oxygenation it brought gave me renewed vigour.

About this time my parents bought me one of the first electric wheelchairs. Overnight my personality changed. My shyness disappeared and my confidence grew as I now became more able to mobilize myself.

September 1962-1967, Ottawa: Carleton University was only two miles from my parents' home. It was surprisingly accessible for the time, although no sympathetic stiff could be found willing to assist with bathroom needs. I quickly learned to be a "camel." My father drove me to and fro, lifting me from car to electric wheelchair, which had to be left on the campus because it was not easily portable. My mother eventually took a job with the university so she could also chauffeur.

It wasn't until my second year in psychology that I learned I had passed a "silent" probation period. Several faculty members had apparently believed I would never be employable and had accepted me only conditionally. Somewhat shaken by this, I studied even harder and achieved scholarship grades which enabled me to complete my degrees without financial dependence on parents or government vocational assistance for the disabled.

During 1967, my last summer in Ottawa, I was hired by the federal department of Health and Welfare. It was a surprise to learn that my always supportive parents didn't find it convenient to drive me across town twice a day. Just as room and board had been expected during my periods of student employment, so too was some self-reliance and responsibility with respect to organizing transportation. I placed an ad and soon found a fellow employee living nearby who was willing to lift me in and out of his car and drive me every day for a modest amount of money. I constantly worried about whether I was paying him enough and whether he was getting tired of helping me. It was an important first training experience. That summer was the beginning of proving both to myself and the world that I really was truly employable. What a positive stepping stone into the future!

October 1967-1979, Toronto: My father had retired from the Canadian Army in 1966 and was now working for the Ontario government in Toronto. The family plan was to move to Toronto when my master's studies were finished. I wrote hundreds of letters to school boards, agencies, and industries in Toronto seeking employment, always mentioning my disability. Few places replied. Ironically, the last letter I sent was to the place where I wanted to work the most but felt I had the least chance of being hired: The Ontario Crippled Children's Centre (now called the Hugh MacMillan Medical Centre). I was hired without hesitation and have worked there to this day! I loved it so much that at first the weekends frustrated me enormously!

As the months went by, I began to finally really believe I was clever and capable and competently able to achieve whatever goals I set. I also began to see myself in comparison to other disabled people and realized how very severely disabled I was. It shook me to think that I had never been aware of this and had never perceived myself in this light. Neither had my parents. It frightened me to think what might have happened had some well meaning rehabilitation professional made me aware of the serious physical limitations I actually had. Would the knowledge have prevented me from achieving what I had accomplished?

I continued to despise the cuirass and always wondered if I really needed it. Toronto, being a major North American medical centre, seemed like an appropriate place to check this out. Before I knew it, I had survived major spinal surgery, having been told I would not live more than a few years unless I had my spine stabilized . . . but may well not survive the required surgery, or if I did, would probably be permanently dependent on full-time ventilation. I survived the surgery, and the orthopedic surgeon unilaterally decided I had been "psychologically dependent" on the ventilator all these years. He weaned me off it, and I was soon getting morning headaches which I did not then recognize as symptomatic of underventilation and which he did not consider significant.

I was thrilled to be free of the encumbrance of my equipment. As soon as I was "up" again and back at work full-time, my sister, mother, and I returned to Britain for a vacation, the first of many such vacation travels.

I managed both full-time employment and an increasing commitment to speaking engagements and community work on disabled issues without nighttime ventilatory assistance for seven more years. In retrospect, the symptoms were increasingly obvious. I fell asleep at work, sometimes even in the middle of assessments. Instead of seeking help I complained to the Public Health department about stale air and our whole department moved to superior offices with windows as a result!

Finally, when I began to fall asleep in the middle of telephone conversations and while crossing the street, I decided to see a doctor. I was admitted to hospital immediately in severe cardio-respiratory failure . . . and not a moment too soon! The solution was, of course, a return to the cuirass. I was utterly depressed for several months. No knowledgeable physical or emotional support existed. The cuirass did not fit, giving me pressure sores, and attempts to make new ones were unsuccessful. No one told me such machines required maintenance, let alone how I was expected to accomplish this. I realized fairly quickly that if I were to survive, I had to seek my own resources and find my own solutions. I have fortunately been able to do this, particularly since the first G.I.N.I. conference in 1981, largely by networking with my fellow Western Canadians and international post-polio respiratory peers.

Between 1967 and 1974 my brother and two sisters married and left home to raise their families. In 1979 my father died, leaving my mother and me to manage on our own. We bought our first condominium together, and I bought a van with a lift, which eliminated the need to be transferred. Usually I had depended on the parallel Toronto public transportation system for wheelchair users which had been in existence since 1975, but having my own van meant that friends and family members could drive me with greater spontaneity and freedom.

January 1980 — present: In 1985 we bought a larger condominium under construction which was closer to shopping and to my place of work. Before moving in, I improved the accessibility by having the contractor lower counters and light switches, install an automatic door opener, and lifts over the bathtub and bed. My mother, now 74, was still able to drive me and to lift me, but she was becoming increasingly arthritic and extremely hard of hearing.

A new government program for "Outreach Attendent Care" came into existence about this time, and I was able to obtain three hours of attendent assistance per day, not enough to enable me to live on my own but enough to free my mother from her many years of loyal physical support and enough to enable me to stay with her and increasingly support her dependency needs, in turn, as she ages.

Within the last few years I have been actively involved in many government and community committees which are addressing the needs of the disabled. I have found time to write and illustrate several books and articles and occasionally find time to paint, cartoon, and make greeting cards as well as socialize with friends and family and enjoy my six nieces.

Since finally switching to positive pressure ventilation earlier this year, many of my lingering problems with the cuirass have finally disappeared. I am much less preoccupied with this necessary side of my existence and have a much more positive, outspoken, and healthy attitude about it than I did 15 years ago.

I consider my life during the past three decades to have been an interesting, challenging, and exciting experience. There are people from my 1952-54 hospital days who would be quite astonished to know that I am still alive, let alone all that I have been able to accomplish. How I would love to meet them now and share with them my news!

I believe the continuous support of my family over the years has been absolutely fundamental to all that I have achieved. I was encouraged to be independent and self-sufficient before I was disabled, and this attitude did not change after. Although I was supported physically, I was not rendered dependent or overprotected. I was expected to accomplish and achieve just as before, and this was what I wanted. These were our inherent family values. 福

John Leibold

Attorney. Advocate.

Polio.

"Perhaps it was not only fear, but also pride and ambition the same factors that would have motivated me had I not been disabled."

Memories and Musings of John W. Leibold, September, 1988: For years, I thought my principal motivation for becoming an extraordinarily active disabled person was fear. Fear of having no one to care for me, fear of being unprovided for by others, fear of nursing homes, fear of being left to rot. But as I think of it in a more philosophical mood, perhaps it was not only fear, but also pride and ambition — the same factors that would have motivated me had I not been disabled.

I had polio at age 16, almost 17, with one year of high school to complete. I completed it while at Children's Hospital in Columbus and at Georgia Warm Springs Foundation. Thereafter, I was educationally dormant for a time while attempting to achieve maximum recuperation of health, strength, and muscle activity.

Two years after my high school graduation, I commenced college education, taking one quarter by correspondence and then finishing my bachelor's degree and my law degree in resident attendance at Ohio Northern University. I then served some three and one-half years as an Ohio assistant attorney general, and nine years as staff attorney in the Ohio Department of Education. I then left state service and entered the private practice of law in July of 1969 and have practiced solo since that time. For six years, while in state service and in private practice, I also served as a solicitor for a village near this city.

My office building is attached to my residence by a safe, warm, and secure enclosed passageway. I have two elevators in my home and one in my office building. I have a garage attached to my residence where I house two wheelchair vans. I carry travel lifts in both vans and use a hydraulic lift in my bathroom. I have remodeled my home a number of times to make it more comfortable, larger, and more accessible.

When I contracted polio, I lived at home with my parents and one brother. I had two older brothers and an older sister who were married and away from home. I had a very prevalent, pervasive fear that my family (brothers and sister) would never take care of me, and so I felt it absolutely imperative to get out and learn how to make a living by myself. That is what initially prompted me to go to college.

Near the end of my law school career, I had an opportunity to become involved in politics by campaigning for Bill Saxbe, who was then running for Ohio Attorney General. I campaigned for him, and through that effort as well as through friendships established in law school, I was able to obtain my first job as an Ohio Assistant Attorney General. I have remained involved in Republican politics ever since. I have several times sought Republican endorsement for judgeships but have not yet succeeded.

Shortly after commencing work in my first job, I married Mary Alice Leeper, and that marriage lasted 23 years. We had no children. The marriage ended in divorce, and I married Beeyun Ding. This marriage was blessed with two beautiful children: Chase Ding Leibold, born December 21, 1982, and Yvette Hope Leibold, born September 16, 1984. This marriage also ended in divorce.

I consider myself to be very fortunate to be on good, friendly terms with both of my former wives. I employ Mary Leibold to perform some accounting-type tasks in my law office. Beeyun Leibold is part-owner and operator of a Chinese restaurant in a shopping center fairly close to my residence. I visit the restaurant for meals at least once a week, and an added benefit is that I see my children whenever I visit the restaurant. I have my children for visitation a month or more each summer, every weekend, some of the holidays, and whenever else I want to see them. My former wife, Beeyun, and I cooperate fully for the care and benefit of our two lovely children. Whenever she has transportation problems or babysitter problems, I exert my maximum effort to give assistance.

I employ a housekeeper who also provides some of my care and a driver-aide who provides a large amount of my care, as well as other driver-aides who are back-up care persons.

The achievements in my life of which I am most proud are: (1) my two children and (2) the fact that I wrote and lobbied through the Ohio Legislature the first statute requiring accessible public buildings in the state of Ohio. The latter effort was initiated at the suggestion of the Ohio Easter Seal Society. This accessibility law provided the foundation for gradual improvement of accessible construction throughout public buildings in the state. I have remained active with Easter Seal, having served nine years on the Board of Trustees of our very large and active Columbus Easter Seal Society. I have been very active in serving as trustee for a number of disability related, non-profit corporations in Columbus and Central Ohio. I have been moderately active in bar associations.

> *"I am extremely grateful for having had such loving and giving parents. They blessed me with the gift of a strong constitution."*

I am extremely grateful for having had such loving and giving parents. My parents left the family farm and built a home in the Village of Ada, Ohio, so I could live at home during my college and law school years. In those difficult days of stingy vocational rehabilitation programs, it would have been impossible for me to attend college and law school without the support, love, and care of my mother and father. In addition to these gifts, they blessed me with the gift of a strong constitution.

I believe I am correct in my recollection that my entire monetary assistance from vocational rehabilitation during my college and law school career totalled $1200. My father died while I was in law school, and his brother, Fred Leibold, provided some financial assistance to enable me to complete my law school and pay the expenses of taking the bar exam.

I think it is no secret that I am aggressive, tenacious, and thorough in my practice of law and that my aggressiveness spills over into many aspects of my personal and private life. Combined with other personal traits such as a compulsion to attempt to achieve perfection and a compulsion to be prepared for and to provide for every foreseeable contingency has probably served to make me both a trying and difficult spouse and perhaps a trying and difficult employer.

My law practice has evolved to a kind of specialized practice in civil litigation or civil trial work. My penchant for detail and organization has served me well in learning how to prepare and present trials.

I feel I have denied myself lots of pleasures and joys of life by being an overachiever, one who must always excel and surpass. I wish I could be more laid back. I wish I could enjoy small talk more. I wish I could enjoy cocktail parties more. I wish I were not so serious.

And yet, through all of these conflicting wishes and impulses, I am looking at the possibility of enjoying a new law partnership with a young and vigorous attorney who is chock full of ideas for related and unrelated enterprises. I am thrilled at the prospect of new fields to conquer and new legal battles to fight.

I have been attacked by the insidious arthritis, and I have pains here and there. I have fallen out of my wheelchair and broken both of my legs (two years ago), and have some consequences in steering my foot-controlled electric wheelchair. But I don't detect any serious or substantial weakening or other of the ramifications of post-polio syndrome.

I feel that my family life has suffered both from my attitudes associated with disability as described in this autobiography and also from the demands of my profession. I have a strong desire to regain a satisfying marital existence, though I don't want it at the cost of losing the closeness with my delightful children. Their squeals and laughter are such delights to me. When I visit their mother's restaurant and my four-year-old daughter hears the first sound of my electric wheelchair and screams, "Daddy, Daddy!" all the disorganization of my family life seems obliterated, and everything seems well. 福

John with his children, Chase and Yvette.

Bente Madsen

Advocate.

Muscular dystrophy.

"Life as a disabled person seems for me just as good and full of experiences and challenges as for everybody, but it is much more difficult to reach the same independence and quality of life."

I was born in Denmark in the summer of 1949 as my parents' first child. I was about half-a-year when my parents discovered that something was wrong with me and about three years old when the doctors agreed. They told my parents that I would die of an infection and breathing problems before I was five years old. My parents could not understand that. They knew that I could not walk and needed help for almost everything, but I was never sick. I was bright and happy and did not look like a child who was going to die.

When I was about seven years old, it was necessary to use a corset because I began to develop a scoliosis, but I did not feel that my spinal atrophy was worse because I was able to manage the same things as before.

I have two younger sisters who do not suffer from spinal atrophy. My mother did not work but had to stay at home especially to take care of me. My father worked as a hospital porter. At that time the county did not support families who wanted to have their disabled child at home. I went to the same public school as my sisters later did.

I did well in school and had a lot of friends there. I liked to sing and for many years I was singing in a choir. I wrote songs and I liked to listen to the music of the '60s with my friends.

My childhood and youth were not different from my friends. They treated me in the same way as they treated everybody else. I was in their homes and they were in my home. I participated in all the activities, went to the parties, concerts, and I must say that I was fully integrated in life.

In my childhood we never talked about my disability at all. I had never met somebody with a disability before I left school and got a job as a clerk at the Orthopaedic Hospital in Copenhagen. In this period I did not feel like a disabled person and therefore I was not active in the organization of disabled. I did not like to be together with disabled — I earned my own money and was not dependent on the social system. I did not worry about the future or about the situation of disabled people.

I had never been sick with an infection or had breathing problems before I was 24 years old but then I suddenly caught a cold. I did not have muscle power enough to cough and during a few days I got a pneumonia, came to the intensive ward where they treated me with a respirator and a tube through the nose (nasal tube) for two or three weeks.

After a month I began to work again but I did not feel well. It was almost impossible to wake up in the morning, I had a headache, I could not eat because I felt sick, I could not concentrate on anything, I could not remember anything, I fell asleep while I was talking, my periods stopped, my hair fell off, and I got incontinent. I was tired to the bone but I could not sleep because of nightmares of the dead.

For all these symptoms I got a lot of medicine. I got medicine for the blood pressure which was high because of the breathing problem, medicine to make it easier to breathe, for the heart, medicine for my sickness and other kinds of medicine that I cannot remember any longer.

During that year I was treated with a respirator and a nasal tube four times

Bente with two of her attendants, Klaus and Peter, on their trip across the United States.

about fourteen days each. I was at the hospital most of that year. The symptoms came sooner and sooner after the respirator treatments and much worse. At last I was unconscious. Nobody told me or my family at any time what was wrong and I did not know anything about a tracheostomy and a permanent respirator as a possibility for survival.

One day I woke up at another hospital with a tracheostomy and after some weeks I felt that my body began to work again. It was a wonderful experience. I had been fired from my work because of too much illness and days off. Then I got the disablement pension from the county. I got no counseling about ventilator use and I did not know any ventilator users so I had to find out everything myself. I was so happy to get enough air and I felt that I could manage everything.

When I later asked the doctors why they did not tell me about a tracheostomy and a permanent respirator, they answered that it had been difficult to find a solution for me. Some of the doctors thought that it was impossible to live a life of quality with spinal atrophy and as a permanent respirator user. Other ones thought it was possible and wanted to give me the chance.

I was afraid to breathe by myself because it had been so terrible an experience not to be able to breathe and I loved my respirator and the feeling of getting air enough without thinking about every breath, to sleep without nightmares of the dead, and to feel how my body began to work again. Using my respirator all the time I felt much better, had much more power and energy. I could talk loud and clear without getting tired and after one-and-a-half years in the hospital system, I felt that life was waiting for me again.

I did not have any mental problems at all although I had to go to a special nursing home for ventilator users. I lived at the nursing home for six years and that was my first contact with the social system and here I began to be active in the Danish Association of Muscular Dystrophy and the National Organization of Disabled and I began to give lessons about life in a nursing home. In this period I found out that it was difficult to be disabled and you had to fight for your own rights in life even in the Danish welfare system.

In 1980 the Danish government decided that independent living should be possible for everybody. Then I wanted to go out of the nursing home and live in my own apartment as I did before. Since I have lived independently with support from my own helpers 24 hours a day. The county pays the salary of my helpers, but I hire them myself and I have the possibility to fire them if it does not work out. In my situation it is necessary to have five helpers working 24 hours a day.

It was a big change in my life from nursing home to independent living because I was not used to having people around me 24 hours a day. Therefore it is very important for me to have helpers with almost the same age, intellectual interests, and appetite of life as me.

I have the full responsibility of my life and the function of the helpers is to do what I physically cannot do (personal help, housecleaning, cooking, shopping, driving my van, secretary work, and taking care of my equipment.)

I am active in the organizations and give lectures to doctors, nurses, and teachers on the psychological, social, and educational aspects of living with a disability. I plan courses, participate on panels about breathing problems, and work as a counselor for persons with muscular dystrophy and breathing problems.

> *"My childhood and youth were not different from my friends'. They treated me in the same way as they treated everybody else."*

Besides giving lectures, I like very much to go around like people without disability to enjoy movies, theaters, exhibitions, restaurants, and jazz-houses. I like to travel and to find my limits. During my career as a respirator user I have found out that there are a lot of things you cannot do because of your physical disability but nothing you cannot do because of your tracheostomy. It is most important for me to know everything about the respiratory equipment as well as the helpers ability to solve problems e.g. using the ventilating bag if the respirator breaks down or to use it when and where it is impossible to use the respirator (swimming pools/seabath, some kinds of transportation, public entertainments, etc.)

From my point of view, disability means to be dependent on public authorities and other people 24 hours a day to live as everyone else. It is necessary to have the courage and energy to fight for your rights as well as it is necessary to be open about your private life to the authorities.

Life as a disabled person seems for me just as good and full of experiences and challenges as for everybody, but it is much more difficult to reach the same independence and quality of life. Because of the system (public authorities, doctors, social workers, etc.) it is difficult to be as spontaneous as I want to be!

Whatever I want to do I have to plan and organize down to the smallest detail, which is funny but takes a lot of energy and time. 福

Lynn Martinka

Retired business accountant.

Polio.

"Education is one of the key ingredients in overcoming any and all obstacles."

Back in the fifties, those disabled were considered second-class citizens with no real potential or purpose to serve in society. Through the insight of several special caregivers and close families of those disabled, the vast number of us created a voice to be heard and reckoned with. I can still hear the whispered advice uttered to my parents to put me in a place where I can be cared for along with others suffering the loss of some or all use of their bodies.

Today, some thirty plus years later, I look back down the long bumpy road I traveled with love, determination, and hard work. I became educated, self-supporting, and independent. After relocating to the Southwest, leaving family and friends, fearful yet proud and encouraging, I established a lifestyle less demanding physically, yet a challenge of my talents and abilities.

Recently, the onset of post-polio syndrome along with damage caused by a benign tumor removed from the auditory nerve, has led me back to being semi-dependent and no longer able to maintain employment. This brought me to another major adjustment in my lifestyle. I no longer had financial freedom or earning power being dependent on Social Security and Disability Pension from my employer. A limited budget meant housing and medical expenses have to be closely monitored. Mentally, I had to find a new purpose to my life after being employed in an exciting field of business accounting for all of my adult life. This took time to consider my strength and energy levels not only now but in the future as the normal process of aging took its toll. I found the answer in volunteer work in a field unrelated to my previous work positions.

I wanted my time to be spent doing for others while enjoying and growing into new fields for myself. Since living in Arizona where the horse is king, I have always had the desire to ride and to feel free of all disabilities. The power and strength of the horse takes over and I can run, climb hills, or walk peacefully through the sun with the wind in my hair. Working with the group for Therapeutic Riding has brought new joy and a special relationship of animal and human contact. This, along with my close association in the Polio Echo Support Group, fills my days and keeps me active both mentally and physically.

Education is one of the key ingredients in overcoming any and all obstacles. Just because the body is impaired in some way does not mean the mind is also. Obtaining the facts, then taking that knowledge and applying it demonstrates the power of the human species. Determination to continue to find new ways to obtain the goals desired is another important factor. If I found myself dead-ended on one project, I stopped to look around for another means to get the end result I wanted. Never give the impression of defeat. Keep looking for the help or answer to the problem. It is out there somewhere!

One important lesson I learned early in my teen years when everyone is trying to be a part of a group, all looking and acting alike, is that it is O.K. to be different. Take that uniqueness and develop it into an outstanding asset. Knowing who and what you are is the foundation you build on. Accepting your limitations and developing your talents within that realm will enable you to reach your goals.

Professional rehabilitation services were not readily available or as varied as today to cover all the many concerns of the person who is trying to find their way

out in society. I found it to be a trial and test effort to see what or how to best assist each and every individual problem. This laid the groundwork and foundation for today's many specialized groups who learned from our mistakes and errors to better serve us now. Yet, I still find a great need to educate and train those interested in searching for better and new means to reach our independent goals.

We have come a long way in establishing ourselves as productive and important members of society, but we must not rest on our laurels. It is through our continuing efforts to support each other in solving problems and seeking help that we will share the benefits of a better life for all.

Learning to function again after losing any or all body powers is a team effort. Yet maintaining control and being in charge creates a positive feeling that keeps the spirit alive. Close family and friends are needed for encouragement and praise. Tough times and rough goings are part of the process where this support is critical to the success and degree of progress made. Seek out and surround yourself with positive, upbeat, and happy people who will inspire and motivate you to your greatest potential.

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Karen McKibben

English professor.

Polio. Ventilator user.

"I fear disuse and yearn to strive to the utmost of my capabilities."

I don't know exactly why I choose to quote from Tennyson's *Ulysses* when I wrote my high school class's valedictory speech. Caught up in the times, the closing of the '50s and the opening of the '60s, I was undoubtedy attracted to the resolute optimism and wistful idealism expressed in those very Victorian lines. Most likely, though, I simply searched through my high school literature text for an appropriate quotation to express the customary sentiments as my classmates marched off into what they hoped would be a glorious future. On graduation day all eighteen-year-olds and their parents are filled with optimism and a certain amount of idealism. Accordingly, I warned my classmates not to slip into complacency: "How dull it is to pause, to make an end,/To rust unburnished, not to shine in use!" And then I concluded by urging them, "To follow knowledge like a sinking star,/Beyond the utmost bound of human thought."

For me, however, the lines might have been a bit more quixotic than usual for high school valedictory speeches. My own particular future seemed rather circumscribed after a bout with polio at the age of eight had made me quadriplegic and partially dependent on respiratory equipment. Still, now that those lines can be placed in the context of 25 years of experience, their selection seems less of a quixotic hope for the future than a prophetic expression of the restless striving for self-fulfillment that would be developed through my own small quest, a quest for an independent life.

The optimism underlying that quest may well have been a legacy of the 1950s. Seen through the mitigating haze of memory, the decade seems to epitomize the belief that all problems, global and personal, can be overcome. With the marshaling of funds by the March of Dimes campaign and a national commitment to eradicate polio, a vaccine was indeed developed, and the periodic epidemics were finally stopped. When the unleashing of nuclear energy seemed to threaten the nation with annihilation, communities optimistically built shelters and devised evacuation plans. When the Soviets shocked the world with the launching of Sputnik, the American people set out to meet the challenge by studying more math and working to fulfill President Kennedy's commitment to land a man on the moon within ten years. Even my home town of Los Alamos, New Mexico, was founded on the optimistic mission of developing the atom bomb in order to end WWII.

Seen also through the mitigating haze of memory, my own personal experience now seems to be characterized by the same kind of pervasive positive attitude. When the onset of polio in 1952 left me almost completely paralyzed and dependent on an iron lung, everyone seemed to believe that this problem could be overcome. Certainly, by 1954 when I was finally admitted to Rancho Los Amigos, the medical professionals seemed to exude an absolute confidence that, with determination, paralyzed muscles could be regained, retrained, or at least braced into useful positions. And if muscles could not be recovered fully, then a little hand surgery and a spinal fusion could at least make what was useful more useful. And always an infinite array of medical equipment could be used and improved.

Thus, the iron lung was replaced over the years by a series of progressively smaller and sometimes more effective respiratory equipment progressing through a rocking bed, various shells,

Huxley positive pressure ventilators, and now Lifecare's latest volume ventilator. The original, standard wheelchair was replaced in 1959 with the first of three increasingly efficient versions of motorized wheelchairs. And there was a seemingly unending succession of adaptive devices, some more whimsical than useful, that were tried and occasionally adopted. It seems that in the 1950s and early 1960s Rancho had institutionalized the idea of progress to a greater extent than even Tennyson and his fellow Victorians.

Although less dogmatically decreed, the idea of progress also seemed to permeate my family's life, not just as an official response to the problem of polio but as a general family attitude. My father, a physicist whose approach to any problem is mechanical, began to make devices of various kinds. My mother, a home economist whose approach to any problem is organizational, began to arrange house and family affairs in order to include all the paraphernalia and added duties that polio brought into the household. As a result and despite the isolating properties of wheelchairs, adaptive devices, and quadriplegia, I remained a full family member, traveling with the family on vacations, attending community events, earning Girl Scout badges, and quarreling with my brothers.

Since in the 1950s and early 1960s schooling for the severely disabled was strictly a private affair, my parents, in cooperation with the public schools and the local telephone company, arranged for a speaker system that enabled me to attend public school by voice if not in body. From fourth grade through high school this system enabled me to take advantage of the community's advanced educational program. School work had always been attractive but, after polio, it became a primary source of self-fulfillment and hope for the future. Looking back, I'm impressed that so many people, even complete strangers cooperated in the belief that, with help, someday I could find not only self-fulfillment but also a way to contribute to society.

Thus, when I was graduated from high school in 1962 and quoted Tennyson's lines about not wanting to "rust unburnished" and yearning "To follow knowledge like a sinking star," I was not insincere. I did and still do to this very day fear disuse and yearn to strive to the utmost of my capabilities. However, at the graduation ceremony I undoubtedly did not realize how much of this optimistic enthusiasm was imparted to me by all those who had so enthusiastically contributed to my welfare. Indeed, in the years following graduation, I began to doubt seriously whether I was capable of doing anything without a whole community holding me up.

Because Los Alamos is a small, isolated community, the only college classes my support system could provide were a few night courses attended primarily by teachers needing re-certification credits. For the first time since third grade I began to attend class in person. And, if that were not intimidating enough, I found myself competing face-to-face not with my own age group but with experienced adults — all seemingly quite comfortable in classrooms and confident, or at least complacent, in their abilities. It took a couple of years of these cold, night classes for me to realize that maybe, just maybe, I could indeed handle more challenges at colleges in nearby communities.

Relying once again on my parents, especially my mother's unreserved stamina, for the 35-mile commute, one way, to the college of Santa Fe and the 100-mile commute, one way, to the University of New Mexico, I at last began to experience the anxiety and exhilaration of an academic life, a life where intellectual self-reliance was fostered and thoroughly tasted. By the time I received my B.A. in English from the University of New Mexico in 1971, I began to realize that I did indeed yearn profoundly "To follow knowledge like a sinking star." The quixotic dream of an independent life began to take on an intensity born of my own desires, not just my community's hope.

However, now it was well into the 1970s, and the atmosphere of optimism was fast slipping into the hopeless quagmire of the Vietnam struggle, leaving only a kind of bitter and lonely altruism to linger in young hearts. More significantly, it was time to realize that depending on others cannot make dreams come true. The only way to fulfill dreams is to pursue them with an Ulysses-like commitment that counts not costs, but struggles.

For me, the choice became clear. I could stay in the relative comfort and security of my family and my hometown, accepting the limitations to the dream of an independent life which that choice would mean; or I could take the risks of leaving home, moving to another state, and encountering the unknown. Fearing that the former meant that I would "rust unburnished," I choose to "follow knowledge like a sinking star," and attend graduate school at the University of California at Riverside.

". . . it is the struggling and the striving that give value to one's existence. . . ."

Now in 1988 I am still at the Riverside campus of the University of California, having earned a Ph.D. and beginning my third year as a Lecturer in the English department there. Like all quests, mine for independence and self-fulfillment was fraught with struggles, with unreasonable professors and requirements, with maintaining independence itself. Perhaps, I might have found just as good a life remaining, like Ulysses's son in Tennyson's poem, in the harbor and "in the sphere/Of common duties." It too is a noble life although I do not think I could have understood that way when I wrote the high school speech or certainly when I decided to move to California.

Probably, too, I still believe, although with less fervor, in questing and appreciate that it is the struggling and the striving that give value to one's existence, not the goals or small achievements one might accomplish on the way. Consequently, the lines I did not quote in the valedictory speech, because I could not quote them when I was eighteen and just starting out on my quest, now seem more meaningful than the ones I did quote:

I am a part of all I have met;
Yet all experience is an arch
  wherethrough
Gleams that untraveled world
  whose margin fades
Forever and forever when I move.

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Susan O'Hara

Former teacher. Director of disabled students' residence program.

Polio.

"The electric wheelchair changed my whole social relationship to whomever I was with. Instead of doing something for me, they were doing something with me."

In 1958 my mother was younger than I am now, I hadn't heard of contact lenses or microwaves or velcro, and I'd never seen a curb ramp. I didn't know I would teach history in high school for thirteen years, direct a disabled students' program at a university, or spend some time in France. Maybe even more important, I had no idea that I would someday discover a way to live on my own.

I was a sophomore in college then and, as I recall, quite settled into a reasonable pattern of living with the effects of polio. I'd had polio three years earlier and it was in 1958 that I decided to give up trying to walk, even in therapy sessions. The decision sounds momentous but it came about gradually and eventually seemed obvious. In physical therapy I had been using long leg braces, with a corset for stability, one of the two crutches tied to my right hand because of poor grip, a helmet in case I fell on my head, and always two therapists for substantial support. To this day, I can't decide if all of that was ridiculous or a necessary attempt to explore all possibilities.

So in 1958 the business of living life from a wheelchair was resolved. The whole matter evoked the memory of those first few days after my polio diagnosis in 1955. It had been only a week into my hospital stay when I realized I might not walk again. "Yes," my doctor said, "you might be right." His enduring gift to me was a prayer that made great sense to me: "Oh God, give me the strength to accept what I cannot change, the courage to change what I can, and the wisdom to know the difference." I spent the next five months in the hospital trying to "change what I could," recovering enough movement to be able to sit up, keep my balance, and eventually switch to my "good" left hand to feed myself.

My parents' response to the complexity of severe disability was the same as for any: Whatever it took, they would see it through. Once the permanence of my situation became evident, they built a 65-foot ramp to the house, added a bedroom to the downstairs, traded their car for one that would accommodate a folded wheelchair, and for many years did all of my personal care. Their common sense and generosity was, and is, one of the major influences in my life.

My family and I somehow made it through that early period without much of the stress being held to public view. I graduated from high school with my class and at the last minute decided to try going to college in the following fall.

By 1958 we had developed a workable routine. I say "we" because so much of what I could do was intertwined and dependent upon the strong support of my family — my parents, my three younger sisters, and brother. Family and friends drove me the daily ten miles to the college campus; I usually asked one of the other students to meet me at the one accessible door at the back of the main building, and push me to my first class. I took oral exams with professors the first year, before I could write well enough with my left hand. Fortunately, I liked to read and my memory was sharp, so I did all right. Several possibilities never occurred to me: living on campus, independent travel to school, owning a motorized wheelchair, or of course what the personal computer of the future could do for written assignments.

It was that same year that I took my first plane flight — alone. A good friend at a Minnesota college invited me to visit. My usually supportive parents resisted this one but I really wanted to do it. It was a bold adventure in those days but it was so successful that I did it more than once.

It took six years to finish my bachelor's degree as a part-time student. I majored in history and spent a part of the last year student teaching at Nazareth Academy, a Catholic girls' school two blocks from home in LaGrange Park, Illinois. To my great surprise, when I gingerly approached the principal about a full-time teaching position in 1962, she acted like it was the most natural of ideas and hired me soon thereafter. She suggested that I also start a master's degree in counseling because she foresaw a need for more counselors on the staff. To me this was more than a suggestion. It was an unexpected invitation to carry my own weight on the staff as a full participant, without regard to my disability. I could not have wished for a greater compliment.

I spent ten wonderful years teaching and counseling at Nazareth, finishing my master's degree during summers at Loyola University in Chicago. Opportunities for responsibility were always there. I became chairperson of the Social Studies Department, the coordinator for Public Relations, the chairperson of the Faculty Council. And I loved the high school kids. They responded by willingly pushing me where I needed to go, distributing class materials, being "scribes" at the chalkboard. The only accommodation to my disability that was necessary was to waive the job of escorting students down the stairs during fire drills.

In the late '60s, my sister Peg returned from her first trip to Europe and said she saw no reason that I couldn't plan a similar trip. I could barely believe it — that kind of travel had seemed so remote. My sisters and some friends and I went to Italy, France, and Ireland in 1967, 1969, and again in 1970! More trips to France in the 1980s resulted in the fun of seeing my articles on access in France published in newspaper travel sections in the United States and Canada.

The 1960s had been rich and full. My personal care had always been assured, thanks to my family, but its permanent relentlessness demanded constant vigilance. In a continued attempt to balance the work load, particularly for my mother, we tried live-in helpers — one from Norway, two who had graduated from a home for children without parents, one from a residential school for adult retarded people — with varying degrees of success. It was never easy to integrate a live-in employee into family life and sometimes it was more trouble than it was worth. By the end of that decade, I think we were all silently wondering how and where I would live if I outlived my parents or their capacity to care for me. In 1970 I began to look into the cost of nursing homes. The future in that regard scared me and depressed me.

It was at exactly that time, 1970, that my sister Liz left home for graduate work at the University of California in Berkeley. Once in Berkeley, she noticed about a dozen students in electric wheelchairs on the campus and one day asked one where he had gotten his chair. He told her about the group of disabled students (mostly quadriplegics) who lived in a wing of the hospital on campus and about the brand new Physically Disabled Students' Program at the university. The idea of disabled people living away from home, hiring part-time attendants, and getting around under their own power gave her an idea.

I'd been teaching for nine years but when Lizzie returned to the Midwest for Christmas, she proposed her idea: that I become a student again and spend a summer in the Residence Program in the hospital at Berkeley. The decision to try that in the summer of 1971 was the major turning point in my life.

Three factors in those ten weeks revolutionized the way I lived: a borrowed electric wheelchair, four part-time attendants, and a conversation with John Hessler, the founder and director of the Disabled Students' Program at Berkeley.

The electric wheelchair changed my whole social relationship to whomever I was with. Instead of doing something for me (pushing my wheelchair), they were doing something with me (going to a movie or whatever). I felt incredibly and unexpectedly free. That feeling was intensified by a second factor — the local custom of employing several part-time attendants, rather than one. I no longer needed to get to bed early in order to allow a single attendant time to sleep and get back in time to get me up in the morning. Now I could hire a late attendant for evenings and a morning attendant for any early hour I wanted, and a different set of attendants on the weekends. When one was absent, I could call on one of the others to substitute. Multiple attendants increased my freedom and independence in a critical way.

My conversation with John Hessler that July day in 1970 was the moment that I decided to move to California for good. John assured me that this new way to live independently was not a fly-by-night idea, that there were people fiercely dedicated to the concept whose own lives would be on the line if the idea failed. I was impressed that people with more severe disabilities than mine were living such independent lives. I was convinced.

Susan with sisters, (left to right) Peg and Liz, in France.

The rest of the story is simple. I returned to Illinois to teach one more year and applied for teaching positions in California during that time. I was thrilled when I got word that Holy Names High School in Oakland hired me. I moved to Berkeley in July 1972, found an apartment, hired attendants and a cook, and rented a van to get to work. I first thought I couldn't live completely alone so I found a young woman to share my apartment.

After three years, when my roommate moved on, I knew I could live alone and did. For meals, I asked my morning attendant to prepare simple dishes that I could bake or steam on a tabletop oven and burner set on low tables that I'd designed for my kitchen. Since then meals have become even easier with my microwave oven.

I also changed jobs that year. I became the coordinator of Physically Disabled Students' Residence Program at the university, the very place I'd started from in 1971. The program was moved to the residence halls, fully integrated with other university students. For thirteen years, I enjoyed facilitating the transition to independent living, much as it had been done for me.

At the present time, I'm the acting director of the Disabled Students' Program at the university. This means teamwork with a staff of 25 and service to 450 students with a wide variety of disabilities.

Looking back over 30 years has been an unexpected pleasure. It's been an extraordinary time to be a person with a disability. It's been a time of opportunity, packed with living, struggle, anxiety, satisfaction, ideas, excitement, stress, love, fun, laughter, and we can't forget technology.

Many thanks to Gini Laurie for her idea of a retrospective and her unflagging love for her friends and readers. And congratulations on keeping the family together with thirty years of the *Rehabilitation Gazette!* 福

Yukiko Oka

Former teacher.
International advocate.
Polio.

"To help other disabled persons would be the best way to repay the kindness and care that have been shown to me."

Thirty years ago, I was a fifth-grade student of the primary school. Disabled children have been usually asked to go to a special school. Fortunately, I was allowed to receive a normal education at a Roman Catholic private school ever since I entered primary school. My education up to the graduate school level was in an integrated environment, which gave me an opportunity to grow as a full person.

Compared with my nondisabled friends, it was obvious that I had some limitation due to severe paralysis of the left limbs and slight paralysis of the right limbs as a result of polio. However, disability was quite naturally accepted as one of my traits by my friends and even by myself by the time I reached adolescence. Then, it gradually became a cause of an inferiority complex. I could recover from the depth of pessimistic feeling with my parents' encouraging words that I was a charming and attractive lady.

Without any particular direction in mind, I took positions given by my supervisor and friends after graduation. My income at that time was quite good, as lecturer of an English course at the Japanese Red Cross Central Nurses' College and as an assistant at the graduate school of the University of the Sacred Heart, and, sometimes, as an English-Japanese translator and interpreter. However, there was always some dissatisfaction with my life. Although, I could fully participate in society and I felt deeply indebted to a lot of people around me for what I was, it was impossible for me to express my appreciation to every one of them. How could I thank them? Then I found that for me to help other disabled persons would be the best way to repay the kindness and care that had been shown to me.

Looking for an opportunity to tell fellow disabled people that they were not discriminated against but loved, I was introduced to a volunteer group, Japanese Red Cross Language Service Volunteers. Together with other nondisabled volunteers, I too had been a volunteer English instructor for seven years at the English Club of the National Rehabilitation Centre for the Physically Handicapped. It was a surprise and shock for me to encounter institutionalized disabled persons. The majority of these disabled persons in the segregated circumstances became accustomed to a controlled way of living, though it was their hope to become independent again in their own communities. The more I understood their situation, the stronger my desire became to work for them. At the same time my realization of how blessed I was to have been brought up in an integrated circumstance became stronger.

The Sixth Pan-Pacific Conference of Rehabilitation International was held in Seoul, Republic of Korea, in 1977. I attended as a simultaneous interpreter. Rehabilitation experts from Asia whom I met there agreed that importance should be placed on my increased involvement in the work with other disabled persons and that disabled people should not be isolated from the rest of society.

In 1980 I made up my mind to work in the disability field. My mother, who wanted me to retain physical and financial security in the famous university, was strongly against my decision to resign from the University of the Sacred Heart for which I had worked for nine years.

I was the first employed by the newly established Japan Council for International Year of Disabled Persons (IYDP) as a public relations officer to explain the theme of IYDP through the TV, radio, and newspaper. Everyday was full of interesting events and exciting projects. I organized several activities which included: A seminar, "Towards an Open Society." Two wheelchair attorneys — one from Japan and the other from the U.S. — discussed how to remove architectual and attitudinal barriers in the society. I was also given opportunities to attend many international conferences which included the 14th World Congress of Rehabilitation International, Winnipeg, Canada, 1980; Second Steering Committee Meeting of Disabled Peoples' International (DPI), Oakland, USA. 1981; Third DPI Steering Committee Meeting, Toronto, Canada, 1981; and First DPI World Conference, Singapore, 1981.

At the end of the 1981 IYDP, I found myself very tired — too tired to get up on Sundays in order to go to church. Then I became unable to work for two months because of fracture of my left foot caused by daily hard work. It should have been the sign given by God to me who could not afford to talk with Him at all through daily prayer. It was not difficult to leave the Japan Council for IYDP, since I was fully convinced that God wanted me to have a more relaxed life. Several months were spent to recover from fatigue. As soon as my body regained energy, I received many offers to participate in disability-related programmes.

The first and unforgettable programme was the Second World Council Meeting of Disabled Peoples' International (DPI) in 1982. The five-day conference with 19 delegates held in Tokyo and Hiroshima gave incentives to the stalemated disabled people's movement in the post-IYDP year. Since I had been actively involved, right from its preparatory stages in DPI it was a great honour for me to organize the peace demonstration of disabled persons and the announcement of the peace statement in Hiroshima.

DPI urged disabled people all over the world to unite in organizations of their own and to join the DPI in the common struggle for full participation and equality with fellow disabled citizens. In order to realize the DPI goals, it was also important that women with disability participate in activities together with men. In this respect, as a woman myself, there were many things I could do to further develop DPI and to work with disabled persons in the Asia-Pacifc region, which has more than 60 percent of the world's disabled population. During my four-year service at the DPI Asia-Pacific Regional office the regional network of the self-help groups of disabled persons was expanded through the conduct of the leadership training seminars in Thailand, Australia, Bangladesh, and Japan.

When the DPI Regional Office got information that the UN Economic and Social Commission for Asia and the Pacific (ESCAP) was interested in appointing a disabled person to a newly established position, I never thought it would be I who was nominated by DPI. In my case, three discriminatory elements — women, disability, and Asian — turned to be positive and made me accepted by ESCAP in 1986. The experience at the DPI Regional Office was of great help to make ESCAP a regional focal point in the field of disability.

For the last two years I have been implementing an assistance programme to develop national disability prevention and rehabilitation programmes, in which I personally emphasize establishing and strengthening organizations of disabled persons. The countries visited were Bangladesh, Bhutan, Indonesia, India, Republic of Korea, Lao PDR, Nepal, and Pakistan, among which disabled persons in Bhutan and Nepal started to form their own self-help groups.

My contract with ESCAP will expire at the end of May, 1989. It is my sincere desire that expertise gained in ESCAP will be further utilized to empower disabled persons especially in Asia. 福

Ingolf Osterwitz

Consulting psychologist. Advocate.

Polio.

> *"Gini and her friends have shown me and my friends a way we will continue to follow I am obliged to them in friendship and gratitude."*

I was born on October the 8th 1940 in Potsdam which lies in the German Democratic Republic. My parents were farmers. In 1953 my parents moved to the Federal Republic of Germany. Here I started an apprenticeship as chemical assistant at the age of 15.

In September 1959 I got polio. I had pain in my legs and I wasn't able to move them. At the hospital, always the same question, "Why did it have to catch me?" A question for which there was no answer. I became depressed and aggressive at the same time because of this terrible fate, which condemned me to stay in bed, unable to make a single move, while my friends could enjoy the good weather and go for a swim.

Terrible also was the isolation in a single bedroom. Friends and relatives were only allowed to come to the window. I felt left alone and badly affected by the virus. If it didn't become better, life wouldn't have made sense any more. I wished death to come. My respiration became worse, each breath was an effort and, moreover, pain was in all muscles. Lying on my back staring at the white ceiling, the warm summer days were endless. I hated my bed and my inability to move and envied the people outside. To be alive and to move, how wonderful must that be.

Shortly before New Year's Day 1960 I was placed in a rehabilitation hospital. It was regarded as the best institution for polio survivors. Rehabilitation included a lot of physical therapy, bathing in hot water in order to overheat the body and to create an artificial fever. I enjoyed the treatment because it was a way to get out of bed. I especially enjoyed the water therapy. I realized that I was still able to swim although I could only move my left arm and the right underarm. My legs and my trunk muscles remained paralyzed. My general condition became better and also my state of mind.

I experienced a lot of support and love by my girl friend, Renate, who visited me almost every weekend. She stayed in a hotel. Unfortunately the hotel wasn't accessible; I really would have liked to make love with her and to take up our sexual life again. She was very attractive to me, I loved her closeness and tenderness. Her body was soft and very female. The paralysis and the long stay in hospital had made me unsure if I was still interesting for a woman at all. Unfortunately, we didn't get any further than secret caresses in the hospital which only spurred on the desire but weren't relaxing or satisfying for either of us. Our friendship lasted until my discharge after one year. One day she declared that she could not imagine living together with a man who is paralyzed. We never had the opportunity to try out how our love sexually could have been performed. Still today I think of her with gratitude and I have a loving feeling for her who had a lot of love and care for me in hard times.

The intensive physiotherapy treatment didn't bring much change. I learned to handle a wheelchair and went out for little excursions in the hospital area. My left arm was quite intact, the right upper arm remained mainly paralyzed, as did the rest of the body. With the remaining functions I learned to dress. Getting from the wheelchair into bed and the other way around still wasn't possible. Neither did I manage to use the toilet without help. I had to be lifted onto a special chair and placed with the chair above the toilet. In the beginning this procedure satisfied me. I didn't have to do my business in bed, which had always annoyed me and was very unpleasant. Concerning intimacy, you are totally at the mercy of the frequently changing personnel. Georges Simenon once wrote that he could only let himself be washed by a very familiar person. I can understand this feeling very well. One is deprived of one's physical integrity.


Ingolf with his son, Tilmann.

With many tricks and with a lot of practice I tried to manage my activities of daily living and I succeeded in dressing myself and getting into a car. But it was years until I was able to pull my wheelchair into a car.

A crucial experience in the clinic was the acquaintance with a young man who also had polio but not as gravely as I. His arms were not affected. He attended a school in order to make the "Abitur," the qualification that is required to attend a university. His aim was to study. How often had I been dreaming of that, even before I had polio. I often talked to him in order to learn how one could attend a school in a wheelchair and afterwards go to university. I got to know all the details on how to attend to a boarding school for disabled and nondisabled pupils. I was still in hospital when I sent a postcard of application to that school. The headmaster of the school arranged the financing for me by the social service. Today, I must say, this young man in a similar situation was a good peer counselor. He was a role model. What he had achieved, I wanted to achieve as well. And so my way was clear. It was a pleasure to have found an aim. During the time in hospital I read a lot and brushed up my general education.

The boarding school had a very strict course. I was depressed by the fact that we had to go to bed at 9:30 p.m. It was nothing like an independent lifestyle although most of us were grown up. I felt locked up. It wasn't possible to live somewhere else because there was a lack of accessible apartments. We also had never heard of personal assistance. It was beyond thinking. "Those who need help to be mobile and for the activities of daily living belong in a nursing home." And that was also the way the official rehabilitation agencies thought and acted.

At that time, 1963, I had my first contact with Gini. I got hold of her periodical, *Toomey j Gazette*, spring-summer, 1963. Only my knowledge of the English language was too poor. With great effort I could read some of it. I was enthusiastic about the private engagement for polio survivors. There were no such activities in Germany and, with envy and admiration, we looked at the possibilities of the social activities of single people.

At first at the boarding school I needed private tutoring in English. My teacher was the daughter of the headmaster. I helped her with chemistry because before I got polio I was a chemical assistant. In these hours together we learned to know each other and fell in love. She was a cheerful girl with long blond hair and an attractive body. I was proud to have such a girl as a friend. Unfortunately, for so-called pedagogical reasons, the educators tried to disrupt our relationship. They didn't succeed. On the contrary, this brought us closer and closer together. We could only see each other at certain times. The regulations of the school left no scope. Several times they threatened to throw me out. The teachers at school supported me and protected our friendship. Here for the first time it became evident to me how dangerous rehabilitation institutions are for the personal development of disabled people. Again and again the educators tried to disrupt the establishment of normal human relations between disabled and nondisabled people, not only in my case.

Looking back I don't have much regard for them. Today I know that the rehabilitation was organized in a wrong way and the attitude of the educators was a result of a structure that didn't meet our needs. We felt the vague desire for an independent life. We had no philosophy, no models, and on top of that, no social power to fight for it. Everybody tried to make us believe that we should be grateful because, after all, we were privileged as we had the opportunity to attend school. Primarily, our life was directed towards high performance at school. In spring 1965, I made my "Abitur" as the best of my year.

About 14 days after this great event, I had a serious traffic accident on my way to university. A friend drove against a lamppost and I sustained several fractures and had to be in traction. The dreams of freedom and studying were over. I had to stay in hospital for nine months. This was a sinister time and often without hope. Lying on my back in severe pain cost me my physical and psychological energies. After an operation during which the left kneecap was removed, the knee could be bent again, and I was able to sit in the wheelchair. Two days after my dismissal I went into my car and within a few weeks I had my driving license. I felt the old power returning and was looking forward to the time of my studies.

In hospital I decided to register for psychology. My girl friend, Barbara, registered for pharmacy in the same city, Münster. Unfortunately, we had to live in different dorms. The separation of men and women was normal in student residences in 1966. It was only at the end of the '60s that a radical change took place because of the student revolt.

I lived in a residence which was only partly accessible via a steel ramp. I had a car which I could drive myself but I couldn't pull the wheelchair inside because the car was too small. According to the regulations of the social service, I wasn't allowed to buy a bigger model although it would have cost very little and would have raised my mobility — a totally incomprehensible act by the authorities. I made arrangements with other students and we went to the seminars together. They helped me to take my wheelchair out of the car and to get up the many steps to the university buildings. Often we studied on our own, which was more effective. Moreover, many lectures were boring and disappointing.

We often had our doubts about psychology and I was toying with the idea of studying chemistry. But I didn't dare to change my subject because I thought I lacked the required mobility to work in a laboratory. Today I know that with a certain amount of personal assistance I could have studied chemistry. At that time there was no way to get personal assistance. Either you made it on your own or it was not possible. That was the philosophy.

In 1970 I graduated in psychology. I had occupied myself intensively with behavior therapy and nondirective counseling. I got a job where I could work in this field. I had to leave Münster and moved to Mainz where I worked in a therapy center for disabled children. Barbara stayed in Münster in order to continue her studies. For the first time I lived completely on my own. I had a new car and so I was able to pull the wheelchair inside.

In 1971 Barbara and I married. Weekends I drove to Münster (which takes about six hours) where we had an apartment. It was a strenuous time with a lot of work. The center where I worked was only partly accessible. I decided to start working in Heidelberg for the "Stiftung Rehabilitation" (Foundation Rehabililtation), a center for the vocational rehabilitation of disabled adults. Here I had better conditions, total accessibility and I could decide myself the way I wanted to work. I worked as a consulting psychologist with the emphasis on psychotherapy training in social competence, and vocational counseling. Together with other disabled people from Heidelberg I founded "Gruppe 73" (Group 73). We set up a transportation service and, later, an attendant care system. That was the time when we tried to apply the findings and concepts of our American friends to our country. A political representation of our interests and the development of self-determined lifestyles were our aims. What a wonderful and fertile time for my development.

In 1974 our daughter, Nina, was born, two years later our son, Tilmann. From 1975 on we all lived in Heidelberg and a wonderful time began. Barbara decided to take up another study; she wanted to become a physician. Today she is a gynecologist. Studying, working, and educating the children is a lot of work. We got much support from our neighbors, who often looked after the children when Barbara went to the lectures. Therefore, they became very sociable. Both are open minded, active, and passionate athletes. A nice experience for all of us was a trip to California last year and since that time the English language is spoken very much in our family. When I see my children running around, I wish I were more mobile and could run together with them across the beaches and through the woods.

Another step in my career was the work in the management of a big center for vocational rehabilitation. In 1980 I was offered a chair at Hildesheim. My field is rehabilitation psychology and social work with disabled people. In my teaching and research work I feel committed to the independent living paradigm. This approach is very interesting for the students and many graduates work in ambulant and alternative services. Together with some friends we have founded a new initiative for disabled people called Avanti. We fight for more mobility and accessibility and are setting up a center for information, counseling, and attendant care services.

Gini and her friends have shown me and my friends a way, which we will continue to follow. I am obliged to them in friendship and gratitude. 福

Vera Overholt

Elementary school teacher.

Polio. Ventilator user.

"Because of the watershed of polio in my life . . . I too can sympathize with all types of disabilities, be they emotional, spiritual, or physical. People need to know that someone cares."

I have fond memories of Cleveland in 1958. I believe this is due largely to Gini's contribution to the children and adults who had contracted polio and were in the Cleveland Metropolitan Hospital at this time. She would always bring a sunny smile and some story about her cats. Nothing was ever too much trouble or a bother for Gini! Needless to say, we loved her. We still do.

We children would look forward with anticipation to her visits. She always brought fun and excitement with her. There was an aura of mystique and originality about her. She gave her life to us. I think we would have given our lives for her.

I was almost four years old when I contracted polio in 1952. I spent one and a half years in Aultman Hospital in Canton, Ohio. I was allowed to return home for a while, but the doctors referred me to Cleveland Metropolitan Hospital for further therapy and braces. I remember the hot, steam packs and the ambitious nurses frantically wrestling with the hot packs machines. I do believe the heat and steam did loosen my muscles so therapy could work better, even though we hated those horsehair blankets.

I was six years old in Cleveland. I needed to go to school. How I looked forward to the first day of school. Our schoolroom looked a little different from the regular schoolroom today. There were rows of beds instead of desks. Our teacher, Miss Buck, was from Germany. Miss Buck was our friend as well as our teacher. I believe she was instrumental in instituting in me a love for animals.

We had a small alligator in our classroom and other small pets. I find even today I do things in the classroom as Miss Buck did, like bringing pets into the schoolroom.

I was fortunate when it came to family. I had 10 brothers and sisters. All of them are very talented and supportive. I belong to a strong Mennonite family and have a mother and father who dearly love me. They are responsible for the optimistic outlook I usually have on life in general. They are hopeful and helpful — why shouldn't I be? Since I had so many brothers and sisters, I now have 27 nieces and nephews. They are a big help to me. They make wonderful traveling companions. They help me in my speaking engagements, often participating in the program itself. They help me prepare my schoolroom for the first day of school and do many other things, too numerous to mention.

My father knew the public school in Hartville, Ohio, had too many steps, so he donated the land for the building of our own private church school. Now his little girl could go to school. I had a bed in school until eighth grade. As time went on, we moved to Minerva, Ohio, a town 35 miles away from our former location. I had four years of high school with tutors at home. These were good years. I was a very motivated person and was honored to be inducted into the National Honor Society at Minerva High School.

Now I wanted to go to college. My sister, JoAnn, took me many exciting days to the classroom at Kent State. She would carry my books and sit beside me and dig out my paraphernalia whenever I needed it. (Thanks, JoAnn!)

I can't lift my arms and have varied breathing problems. I frog breathe almost all the time. Thank God for the frog breathing invention. (I learned it in Cleveland.) I now use a chest respirator at night. I had decided way back when I was in the eighth grade that I must get off the iron lung. If I did not, there would be no long distance traveling for me, and I knew I wanted to go to Europe someday. But first, I had to learn to use my chest respirator. It took weeks and weeks of trial and error. I'd begin the night with the respirator, but halfway through it I'd have to go back into the iron lung. Eventually I became acclimated and accustomed to the chest respirator, and it has become a dear friend indeed.

After I was weaned off the iron lung, I could go abroad. In 1975 we planned a great trip to Europe. "Flying Wheels" wrote up a lovely and practical itinerary which my two sisters, Lena, JoAnn, and I, could follow easily. They were absolutely fabulous with their directions. We sailed on the *Queen Elizabeth II* and flew back. A terrific four-week vacation.

A little now about life today: I have been teaching 18 years in elementary education. I have been lucky. I belong to a Mennonite church which hired me when I was 22 years old. The school is small. I have an average of 18 students each year. The families are good, old families. We have no drug problems, etc. The parents usually uphold the teachers and the principles of the school. We have a high academic standard of which we are proud. This excellence is achieved, by and large, by having small classes where each pupil receives individual attention.

Vera, on left, with her mother and five sisters.

I do not have the severe difficulties to battle as the teacher in the public school system. We have a lovely school, set back in a woods, so we have a natural setting for our nature walks. I use my golf cart to go on these hikes. It has become a yearly event. We pack our notebooks and pencils onto my golf cart. Everyone gets in line and off we march to the woods and up over the hill behind the school. We sit in various places. Some children prefer to sit by themselves to write, for that is what we are going to do — write poetry. They write what they see and hear. The poems must rhyme and they must have correct meter. But this is *not* terrifying to the children. These third through fifth graders have done it many times before throughout the year in the classroom. They love it. I do, too! After everyone has written and read (their poems) aloud to the class, and they have passed inspection, we play a game of ball. I am the umpire. My philosophy of school is, "when we work, we work hard, and when we play, we play hard."

When I sit back and wonder how I managed and coped all these years without the full use of my limbs and lungs, I almost panic, thinking of all the things that might have happened had I not met the right person at the right time, or even been at the right place at the right time. But I don't think it was mere chance either. God has been good to me, a real friend. Because of the watershed of polio in my life, I have become a stronger person. Because of the many kindnesses of people everywhere, children and adults alike, I too can sympathize with all types of disabilities, be they emotional, spiritual, or physical. People need to know that someone cares. Those of us who have been affiliated with Gini Laurie know that she most certainly does. God bless her. 福

Mona Randolph

Volunteer.

Polio. Ventilator User.

> *"Without God, His words, His committed people, and the resources I was given, I would be neither alive, nor well, nor living happily."*

My planning, in 1956, was for a December wedding, not an enforced vacation in an iron lung. In my numbed bewilderment, I believed excellent hospital care in Kansas City and hard work at the fabled Warm Springs, Georgia, would let me "conquer" polio.

Yet, recovery was limited and tortoise-speed slow. Seven months after being stricken, when I was weaned from the lung, I traveled to Georgia. Six months later, I could breathe without assistance, the Warm Springs experts had crafted personal appliances with which I could feed myself, and I had adapted to a wheelchair. Impatient, believing I could resume the life I had known, I begged to be graduated home.

There the loving welcome of my stable family and church friends comforted and encouraged me. Dad was a devoted, fun-loving provider. Mom was and is a dynamic person, continuously laying down her life for family and friends. My only brother was and still is a great friend on whom I can depend for understanding, practical help, and good humor.

During the next 16 years living with my parents, I worked part-time at home (invitation business, painting commissions, etc.) and studied voraciously. Thanks to family chauffeur services, we also shared cultural, civic, and social activities.

My most active life, however, was in my imagination, where visions of being "independent" ran like magnified background movies.

In the early '60s an excellent rehab publication, the *Toomey j Gazette,* introduced me to other real polio survivors who were succeeding at real tasks. This both humbled me and brought new hope. Until then, I related only to former friends, refusing to acknowledge much in common with disabled people.

Appropriating my own reality was extremely difficult. The sparkling self-delusion of regaining complete mobility had melted in the Georgia sunshine. Despite lingering grief over having to relinquish control of my life, and guilt over having interrupted my family's lives, I felt constrained to be unfailingly cheerful.

Disdaining what I mistakenly labeled self-pity, for years I deprived myself of the health-promoting process of grieving. But dark moods accompanied my vain attempts to appear "O.K." Frequently, subterranean pits of despair would bubble up noxious clouds to obscure my vision.

After a season of mourning a broken romance, at Christmas time, 1968, I developed severe bronchitis. Depressed, fearful, and lonely, I began a newly serious search for God. Reality as described by Jesus was so appealing that I began to desire the Kingship and counsel of this great Father/Saviour/Standby God. A life-threatening choking episode, during which I was convinced He heard my desperate plea for breath, persuaded me to accept the Lord's solemn covenant offer. Here was quite enough identity, self-esteem, and purpose to last a lifetime.

As a radical believer, I viewed everything differently. Because "Reverence for the Lord is the beginning of wisdom," I had much to learn and unlearn.

Ironically, I soon met and conversed with some physically disabled people (even liked them) and attended their next meeting. From that group grew a National Paraplegia Foundation (NPF), chapter which was effectively active in this area for several years.

Other major changes began when my dad was terminally ill in 1972. He arranged for us to move from our home of 30 years to a more accessible and easily maintained co-op town house. His death left a large gap in my life.

Mona and her husband, Mark, on their wedding day.

The next year when Mom was considering remarriage, we faced a dilemma about my care. She would need to travel with her husband-to-be, and I was not a very portable child.

This was my big moment to make the giant leap of faith out of the nest. A long-cherished dream came into sharp focus: an experiment in Interdependent Christian Living. After much consulting with God and counting the cost, I determined to stay in Kansas City. Negotiating with Mom, I tried to persuade her that she deserved retirement after 16 extra years of my second "babyhood" and to accept my blessing for a new life.

Besides the obvious primitive survival instinct, my primary motivation for independent living (and the propelling force behind it) has always been the desire to translate my beliefs into daily living. The success of that 1973 experiment became a point of honor to win for my Lord. While it was sometimes hard on the nerves not to know where my next bed pan was coming from, that first year was good for my faith. God keeps his promises. He is faithful.

Living out my faith also has required much seeking, perserverance, and adaptability on my part. The practical problems of help, financing, and housing are the sometimes grim reality of responsible adulthood.

Securing basic daily care has always been a large problem. A variety of part-time helpers, aged eleven through eighty, have kept me fed, clean, and clothed. Some have also graciously helped with extra projects by being my hands and feet.

Forty different people have lived with me since 1973, with various levels of commitment to the household and my care. One faithful friend stayed six years. Most of these individuals have been responsible and enjoyable people who appreciated the peace and harmony of our home. The problem people have been good for growth of character.

Because of this continual change, I learned to adjust to people moving in and out. Disorientation and insecurity could be expected, accepted, and ignored in the knowledge that "life is dynamic, not static."

Income was from Social Security payments as my dad's disabled child (newly available in 1972), plus some benefits and dividends Mom let me use, plus gifts and services from generous family and friends, and contributions from able housemates. Even though part-time help sometimes cost 50% of my income (the entire SSD amount), amazingly, my needs were always met, I was always able to tithe, and often had something left for a "kind act to others."

My fourteen years' housing history includes moving four times, buying two houses, selling one, renting a town house, and helping friends buy a home where I lived with them. Of all these roof-over-the-head solutions, I prefer the security, freedom to alter my environment, and the good feeling of investment that are benefits of owning a home.

There have been some disappointing health problems. After 20 years of happily doing without my "yellow submarine" (iron lung), in 1976 I had to return to it for sleeping. Bouts with infection have been temporarily inconvenient, discouraging, and debilitating.

But improvements in strength and coordination have allowed me to shelve some equipment so important at first, and an electric wheelchair has opened a new era of mobility. Since 1980 I have participated in two weddings (besides my own), explored many new places, and gleefully "danced."

An important person appeared in 1979. Mark Randolph had attended some of our dinners for ever-starving bachelors and eventually was added to the draft list of "lifters." He was an unusually polite, intelligent guy (a computer application engineer), with a bizarre sense of humor (like mine), and was a lonely newcomer, so I offered friendship (strictly platonic, I declared.)

Although we were very different in aptitudes and interests (besides the gulf between my severe disability and his robust strength), we complemented one another, felt accepted and appreciated when we were together, grew more and more comfortable with each other, so we began "dating." Finally we admitted to ourselves that we were IN LOVE. Oh, no! What to do about it?

After four years together, I knew he would surprise me if he ever asked me to marry him. And he did. On my 50th birthday, August 26, 1986, he startled me with The Big Question. We were married the day after Christmas, December 26, 1986, in a small family ceremony at my brother's home.

Though I can't say our marriage has been constant bliss — I have had to endure some old but now new frustrations over not being able to serve my husband with my own hands; Mark has had to come to terms with sharing his time, energy, and income with a needy person (we lost my SSD income and Medicare when we married) — I can say we are successfully adapting.

Life now is full, rewarding, and meaningful. New areas of service are opening all the time. (Having found it hard to have to receive so much service, which I could never repay, I greatly enjoy serving others.) I feel more complete and joyful than I ever have (even B.P.), and we're both still happy to be together after all these years.

While it may seem overwhelming to choose your own lifestyle and to implement your choices, it is definitely worth the effort!

So, remembering how I got from there to here, I have no secret formula to divulge, no delusions about being a self-made specialist who pulled myself up by my own hand-splint straps. Without God, His words, His committed people, and the resources I was given, I would be neither alive, nor well, nor living happily in Kansas City. 福

Susan Ray

Writer of educational and promotional materials. Advocate.

Polio. Ventilator user.

"My doctors once admitted that they had some early doubts about a respirator user traveling. But we and other self-directed guinea pigs had settled that question for them."

History. Since I was only four years old, my memories of the acute stage of polio are dim: telling my cousin to even up my socks before I went to the hospital . . . my aunt trying to comb tangles out of my hair after two or three weeks in the iron lung . . . my parents crowded in with me in an Army plane with a special tank flying from Lubbock, Texas, to a new polio hospital in Houston . . . my terror when the people at that new hospital took my red oxygen funnel away . . . having a blood transfusion because I wouldn't eat the hospital food, and then Mother being allowed to bring me a home-cooked meal each day . . . talking with but seldom seeing the other children in tanks in my ward . . . the Episcopal priest who taught us to sing "Eensy-Weensy Spider" . . . Eugenia, the nurse's aide who brought us milkshakes at bedtime . . . my fifth birthday party . . . the huge Army transport plane that flew me in my Emerson tank back home to Lubbock.

I was unaware of my parents' fears — fears that I would not live or, if I did, what kind of life there would be for me and our family. I took for granted the fact that my mother, baby brother, and grandparents moved to Houston — not knowing how long I would be there — while my father had to stay in Lubbock pastoring a growing church. And I had no concept of the frightful epidemic raging in the country.

I took polio in February 1952. Our local hospital barely knew what to do for me; but they did, thankfully, get me transferred in just a month to the brand new, innovative Southwestern Poliomyelitis Center. The problem was that by summer this new building and caring staff were being overwhelmed with ten or twelve new patients a day! My mother volunteered to help in my ward, doing simple things we children needed.

In July, my doctor told my parents she had reached a reluctant decision — I had to go home. It was against their policy to release anyone who could not breathe unassisted. But someone had to go. Mother had had hours of ward experience, and I'm certain my father showed his usual "can do" attitude. So we went home.

For me it was a good decision. Our church, with the help of others, built a parsonage with a big pink room for me and my tank. Daddy, adding welding to his mechanical skills, built me a child-sized chair to sit in while using the chest-shell (cuirass). With puppets and other diversions, Mother taught me to tolerate the rocking bed. (I had almost blacked out on one in the hospital.) And when Daddy built a small rocking chair, I loved it!

Soon time came to return to Houston for a checkup. But how to go? "Why don't you build a little tank to fit into our station wagon?" said Mother, half joking, half desperate. So Daddy got the help of a sheet-metal shop and a mechanic friend to build an "iron lung"! After a final all-night work session, they made me try it in a black, unpainted state. Then they hurriedly painted it yellow to appease me, and we took off on the 600-mile trip.

At one point, the tank suddenly stopped, causing panic. But it was a short panic, for Daddy found the switch accidentally turned off! When we arrived in Houston, the doctors pronounced me looking fine and my parents looking terrible. When a reporter asked Daddy what medical advice he had for building the tank, he realized, "Oh, we didn't think to ask for any. I just talked to all the mechanics and machinists I knew!"

Mother was concerned about a bad habit I'd developed, a sort of gulping. Dr. Pfeiffer watched me and exclaimed, "Thank goodness! This five-year-old has learned to frog-breathe on her own, when I spend hours trying to teach adults!" With that encouragement, my "bad habit" changed our life. Instead of ten minutes, I could breathe alone for one hour, then two, even three if needed.

Travel for pleasure became possible. We visited grandparents and took a brief vacation. Friends and strangers (I'd become a local celebrity) helped us buy and remodel a new station wagon. Daddy built better travel equipment. And in 1955 we went all the way to Florida.

I had been coast to coast, up on Pike's Peak and down in Carlsbad Cavern long before anyone heard of accessibility standards. Many a startled waitress, sightseeing guide, and fellow tourist have gladly lent us a hand. My doctors once admitted that they had some early doubts about a respirator user traveling. But we and other self-directed guinea pigs had settled the question for them.

I was lucky to be living in Lubbock when I turned six in 1954, because that school system was a pioneer in homebound education. Dear Miss Katie Bell Crump came every day for an hour or two of lessons and left other assignments for Mother and me. With my right arm supported by springs and slings I can move it over a limited area; so Daddy built a desk with motorized panels to move my paper around for coloring, drawing, and learning to write.

Teenage Susan dressed up for a church banquet. This travel chair is still her current one.

In 1956 we moved to San Antonio. At that time the school system there had no provision to educate handicapped children, and had no interest in trying. So my mother went to our neighborhood school, got the textbooks and advice from some of the teachers, and began teaching me herself. That is the way I completed high school in Grand Prairie, Texas (near Dallas). The principal granted me a diploma because he knew I had done the work well.

I took a few college correspondence courses. But since I was already receiving opportunities to begin a writing career, I felt no need to continue college studies.

As a child I showed an interest in and aptitude for writing, and my parents encouraged this as a promising area for my future. When I was 13, a man who worked with electronics wired a second-hand IBM typewriter to a small remote keyboard Daddy built, and this opened a whole world for me. I am now on my third typewriter. With more than twenty years' experience, I'm a recognized author of educational and promotional materials for the Southern Baptist denomination.

I also have many other interests and activities. A product of the '60s, I'm still a crusader for disarmament, the environment, campaign reform, the rights of Indians and farmworkers, etc., etc.! I'm not an activist for disability rights; I feel I promote that just by being me.

I love Spanish, although I'm ashamed to admit how little I speak. A highlight of my life was the six years I belonged to a Spanish-language Baptist church. There I first taught children (in English!). Happily, I've belonged to three churches that let me do whatever I felt I could do without making a big deal of it. My favorite examples are the times I would mind from 5 to 15 children, sometimes ranging from 5 to 15 years of age, during one-to-two-hour church business meetings. By the end I was tired, hoarse, and muddle-headed! But no one fretted over me; they just cheerfully loaded me into the car! My efforts were appreciated, but not unduly nor embarrassingly so.

Equipment Evolution. My first travel tank is now my faithful home tank. Travel tanks are now fiberglass and plywood. One rides in a small homemade trailer; the other stays in our remodeled, secondhand RV travel trailer.

Cars have gone from that first wood-paneled Ford to station wagons with doors rehinged to open the whole side; to two-door cars with the front passenger seat removed; now to a customized van with Golden Boy lift.

We've had several species of travel chairs. Since I no longer rock, my home chair now raises and lowers, with neck and knee lifts attached, for dressing. Alas, my hot-rodding motorchair days are passed!

In 1961, I had to switch from the chest-shell to mouth-held positive pressure — a wonderful change! A simple holder keeps the mouthpiece in reach. With a Thompson Bantam respirator, we gained so much freedom. (I fear now that these sturdy little units may be replaced with over-sophisticated, new-fangled ventilators!)

My motorized writing desk became a painting desk and now, with a revolving hoop added, is an embroidery/sewing desk. Years ago I abandoned a page-turner for a mouthstick. I have a phone gadget and a tape-recorder gadget.

"I'm not an activist for disability rights. I feel I promote that by just being me."

We built our new house with special touches from my special, raised bathtub to a "loading dock" platform in the garage.

For the future, who knows? A word-processor? A pneumo-suit or nasal mask for travel? My long-dreamed-of device to augment my arm movements?

Musings. I've been called an oldtimer since I was sixteen. That's when I went to Houston for a checkup and a new nurse would not accept my word for what pressure and rate settings my tank should have. A long-time aide pulled her aside and said, "Look, Susan Ray is an oldtimer, and these old-timers know what they need!"

Ever since the days of the *Toomey j Gazette,* Gini and *Rehabilitation Gazette* have meant so much to us "old timers." But I'm happy that they have given us a new name, "polio survivors." It fits us. We and our families are determined, problem-solving, survivor types. I sense that maybe we are a little different from many who have become disabled in recent years. We were pioneers. And I have the mixed feelings of any oldtimer who worked to make life better for those to follow and then regrets that they have less of a rugged, pioneering spirit.

Of course, things are changing for us polio survivors. I used to feel a guilty reassurance when I heard about progressive paralyzing conditions with a twinge of fear. Oh, how right that twinge was! Although I've not had any definite muscle loss, I have had a couple of scares from the specter of post-polio syndrome.

I cannot estimate the dollar value of the help March of Dimes gave me from 1952 until 1986. But now that Medicare, my father's insurance, and my parents are paying for rented equipment, I am more acutely aware of the high cost of anything medical. I wonder how much of that cost is justified. I feel somewhat trapped and threatened by the prices and the system.

Susan embroidering while using oral positive pressure.

With my father retiring, we have moved to be near my brother and his family. We have a good home-health aide and can afford to pay her. My parents have worked at saving for my future care.

I am more fortunate than many people, both disabled and nondisabled, in having a good family and lots of friends, financial security, a productive and satisfying life. I feel many of the uncertainties that many other disabled people feel; yet these do not dominate my life. Whatever the future, I know that family, friends, and the Lord will see me through. 福

Thomas W. Rogers

Polio. Ventilator user.

Insurance and mutual funds salesman.

> *"A multiple assistant (attendant) approach keeps you busy scheduling, but the benefits of working with several different people are stimulating."*

As I reflect on the last 35 years it all seems to be an evolution of adapting to changes. First, let me clarify that I have been extremely fortunate to have had strong parents, both financially and psychologically, who were able to absorb the initial shock of my polio condition and the annual cost thanks to an early boast by the March of Dimes.

I had two brothers — one was married and living away and the other one was in college. My younger brother married and eventually moved to Minneapolis while my older brother lived in the Chicago area. Although not living in our hometown of Moline, where I resided with my parents, both brothers answered every call for assistance when necessary. My younger brother is a doctor and to this day we still keep in close touch by phone and spend time together twice a year. My older brother has since passed away, but he was a frequent companion after he retired.

Moline, Illinois is a town of 40,000 where I have lived all my life as had my parents during their adult years. Both parents came from extremely tight, large families who all helped when they could and a lifetime of friends and assistants who have helped along the path — each one enriching my life.

My father was an engineer by profession and my mother had a spirit of independence and a belief that anything was possible. Together the two of them provided a rich, fun, merry, fascinating life at a sacrifice to their own life styles, but they never let me feel that I thwarted them at any time.

Polio hit me in the fall of 1953 and left me a breathing impaired quadriplegic. After a succession of three hospitals I finally came home about a year and a half after onset having been weaned from an iron lung to a rocking bed. During this time I developed great proficiency in frog breathing and was able to go all day and only used the bed at night for sleeping.

Originally we used nurses for the morning routine but found we could train aides as time went on. We advertised in the paper stating clearly what we needed and have generally been pleased with the results. My favorite morning nurse answered an ad in 1959 and has been with me ever since. She started out working six days a week and today it is more often five with part-timers filling in on her days off. As the years went on it became more difficult for my parents to put me to bed so I often used neighborhood high school students to handle the job. Once proficient it never took them more than 20 minutes.

My family had a cabin in Michigan where they spent their summers after my father retired and I went with them. This gave my nurse a chance to spend her summers with her family. We duplicated the help situation up there which also served as vacation time and a break for those in Moline who care for me.

In later years my parents went to Florida in the winter, first for a couple of weeks and then for three or four months. I would remain at home and use nursing students from the local college, young college couples, or non-nursing college students who would move into the house and provide the on-going support that my parents played. This was the proving ground for living on my own. Now both parents have been gone six years but I am still in the same house living with my support staff.

Today I have one full-time morning nurse who works four to five hours, five to six days a week. She takes care of the laundry, is my ace in the hole and part-time supervisor of my college students. She sees that they are well versed in all the medical problems. One full-time secretary who works 60 to 65 hours a week takes care of afternoons and early evenings when we work together. My office is my home. One full-time night aide who is a college senior and has been with me for 2½ years. His time is from 10 p.m. to 8 a.m. He throws me in bed and answers night calls. In addition there are six part-timers that fill in on relief. If I can't find a substitute — which is very rare — the regular full-timers will work.

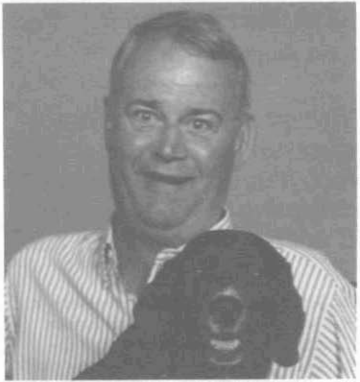
Help and How I Find It. Neighborhood high school boys have the strength to push my wheelchair so I start them with that activity and driving and they grow used to handling me. Later we can work them into the morning routine or evening routine and they become the part-timers to fill in for the regulars. Some of them have been with me as long as ten years and now, after college, have full-time jobs and family — but still they will fill in for a couple of days a month. Another source of help is the nursing program at the local community or four year colleges that are offering nursing curriculum. These students often need a place to live and are interested in the experience. They move into my house with a bedroom of their own and work the night shift. This requires only one-half hour of their time and being called once or twice a night. For this I pay all of their food costs when they eat at my house plus they do the grocery shopping, keep their room, handle the trash, etc. They also learn to fill in for the morning nurse on days they do not have classes or are free on the weekends. When anyone leaves I always ask them to try to find a replacement. This is particularly helpful in the college group. They can usually tell the prospect exactly what they think of the job and it alleviates the fears of a new recruit to hear it from their peers. They are aware of the situation and will screen the prospects even before they recruit them. They will know whether the candidate is capable of handling the job much better than you do in one or two interviews. My present student is a computer major but has amazed me with his capabilities.

During the summer I still move to the family cottage in Michigan and there I have a nurse who has been with me about 15 years and a secretary who has been with me about 17 years. They enable me to run my business from Michigan.

Education and Business. My education consisted of one year of college engineering when polio hit but as soon as possible I went to work studying economics, business law, and statistics from a teacher friend at the local community college who dropped by once a week to check my progress.

My interest was always in financial affairs and I started selling mutual funds and insurance for Waddell and Reed, Inc. of Kansas City. They are still in the business today as is A.L. Williams, Inc. — both selling term insurance and mutual funds. They both are strictly commission employers, and you are paid only for what you produce — but they will help you prepare for your test for licensing. In addition, they will help with sales material and the art of selling. Both companies perform a real service to their clients so you can be proud of your product. Concurrently while I was with Waddell and Reed I was reading law under the auspices of a local lawyer and who happens to be my favorite person. He did his best to make me a lawyer, but I found the world of finance just too attractive.

In 1966 I wanted to branch out, with the help of an uncle and a friend who were both in the security business, I opened my own firm and became a member of the National Association of Securities Dealers. Today I work about 60 hours a week with one full-time and one part-time secretary. My full-time gal has been with me 22 years and luckily lives next door. My part-time gal is 85 years of age and has been with me over 15 years. We are not the fastest nor the most profitable but we find what work we do very interesting and it does make me self supporting.



Games. Bridge, chess, backgammon, hearts, poker, and almost any other card or board games provide a great deal of fun. Early in my polio years I took bridge lessons and found the game fascinating and an area where I can participate as well as any able-bodied person. With aid of a card rack I play cards at least seven times a month and would play more if my business didn't usurp my time. It is a marvelous way to meet people and spend an enjoyable evening. Through the game, I have met hundreds of interesting people who have become my friends.

Health. I have been blessed with excellent care and tremendous support. I was 19 years of age at the time when polio hit, 6'3" and 190 pounds. Up to about five years ago I felt I could do most anything. Lately I need a portable respirator during the slow times of the day. Three nights out in a row requires a break. The doctor has prescribed more pills and has instructed me to be more careful in what I eat. My slim years have disappeared and I weigh as much as I did before polio but it isn't placed very well and it makes breathing and handling more difficult. Unfortunately I have a healthy appetite.

My goal in life was to make it until 50. Having obtained that mark, I asked the Lord, for a ten-year extension and the calendar tells me that is half gone. I am drafting another ten-year extension which I hope will be approved in five short years. I want to travel around the country in a mobile home adapted to my peculiar needs. To do that I will have to curtail some of my business activity. That means I will have to retire from the daily brokerage business but, hopefully, I can retain some of the activity. A rut is hard to change.

Travel. In addition to Michigan I do spend a month in Florida in April in the Sarasota area. At present I travel straight through in a Dodge van with a Braun lift with the aid of my nurse and two drivers. It takes about 24 hours. My nurse stays with me in Florida. There again I have a local gal who helps in the mornings and a driver who have been with me for several years. Each originally answered a newspaper ad. Florida has become the center of much of my business activity so it is largely a business trip with vacation overtones. The drivers fly back after spending a week with me and return by air to drive me home. I used to fly until I found breathing a little more difficult. After acquiring the van, I wanted it in Florida and that prompted the non-stop trip. I just lay back in my wheelchair with a portable Bantam Positive Pressure Respirator and we are there in about 24 hours. There is room on the floor to put a mattress down for the spare driver so that he can obtain some real sleep. The drivers trade off frequently. I have made one trip to Colorado Springs using the same technique.

A multiple assistant approach keeps you busy scheduling, but the benefits of working with several different people are stimulating. It also helps them and you by preventing burnouts and over-exposure. From this group have come some very close friends who have kept in touch over the years. They all have different approaches, but they are all living interesting lives and together they bring you a rich tapestry. 福

Rev. Robert J. Ronald, S.J.

Jesuit missionary priest.

Polio. Amputee.

"Acceptance of disability does not mean liking it. In fact, it doesn't even mean accepting it. What I accept is not the disability, but life."

1988 is also my thirtieth anniversary. In September 1958, just five days before turning 26 and seven days before the start of my second year of Chinese studies in Hsinchu, Taiwan, in preparation for missionary work, I woke up in the middle of the night with severe pain in my spine. Within two days I could not walk. Though polio changed my life in a million ways, I am not so sure it changed me. If I am better or worse, it is not the polio that did it, but the ways I responded to the polio.

No one ever responds to reality as it really is but as it is interpreted to be, and my first interpretation of polio was quite mild and ill-informed. I had never before been close to anyone with polio. While never believing I would recover fully, neither did I ever imagine, even for a moment, that I would stay severely disabled. After all, it was President Roosevelt's disease, and it didn't seem to have stopped him very much. This mistaken expectation was reinforced by the first person with polio I met. Mr. Watts, an American pilot for the Chinese C.A.T. Airline who had gotten polio two or three years earlier than I, came with his wife to visit me soon after my admission to the Seventh Day Adventist Hospital in Taipei. Coincidently he had occupied the same hospital room, and his condition had originally been just as bad as mine then was. Now he came in walking with forearm crutches and leg braces, and I immediately jumped to the conclusion that at the very least I would improve just as much as he had.

Six months later when my doctor told me in no uncertain terms that I would always have to use a wheelchair, the impact hit me hard. I remember telling someone later that same day that I would never be able to return to Taiwan nor could I ever become a priest. By this time, however, I was back in the U.S. at St. Mary's Hospital in San Francisco and had already made the acquaintance of some polios in wheelchairs who were doing quite well. So it was not too long before I began to see that I too would still be able to do many things. Eventually I was telling everybody, "If I have to sit in a wheelchair, I might just as well sit in Taiwan as in California." In other words, I decided to pick up the pieces of my life where I had left off when polio struck.

Reflecting on what happened I offer the following analysis:

When I began to see (interpret) polio and my disabilities as irreparable damage, saw myself as destroyed, my life ruined, my abilities taken away, my ambitions thwarted, these black thoughts were reinforced with equally black emotional reactions of grief, anger, and inferiority, which impelled me to correspondingly negative behavioral responses of mourning, resentment, hostility, and withdrawal. As long as my attention concentrated only on the losses and limitations and my feelings were similarly oriented, there was no energy left nor any inclination for me to break out of the vicious circle of self-pity, hopelessness, and distress.

Today my physical condition and limitations are nearly the same as they were then, but what has changed is the interpretation of what the disability means to me. At its worst, polio was an evil destroyer and I its helpless prisoner without hope of escape. Now, however, polio and its limitations are seen by me chiefly as an unwelcome but tolerated presence that causes me a great deal of inconvenience, but is not allowed to interfere with what I want to get out of life. Ronald's Rule One: "Every barrier has the potential of beginning a detour to something good."

A person who suddenly and unexpectedly loses a leg does not jump up and down on the other one shouting joyfully, "Look everybody, I've still got a good one left!" Rather, pain and sense of loss completely absorb the attention. Only when shock and grief subside does the person begin to think about the other leg and start to face life again. This is the essential first step toward eventual rehabilitation. The second step is finding a new goal for one's life that is worth striving for and which one believes is attainable even with the disability. The rest is just lots of hard work interspersed with all the friends and fun and rewarding accomplishments that can be squeezed in together with all the occasional frustrations and temporary disappointments that inevitably spice things up along the way. Ronald's Rule Two: "You have to look away from trouble to see around it."

Acceptance of disability does not mean liking it. In fact, it doesn't even mean accepting it. What I accept is not the disability, but life. I have committed myself to living the fullest possible life and to doing everything in my power to make sure that my disability does not stand in the way.

Rehabilitation is hard work, but my rehabilitation was relatively easy because I did not have to experience a lot of the difficulties or obstacles that so many other polios have had to contend with in their rehabilitating. In many ways polio found me with a "silver spoon" in my mouth. Among my blessings are the following:

Financial security. Belonging as I do to the Society of Jesus, a large international body of priests and religious, my medical expenses were all taken care of, and I could purchase whatever special equipment was needed in order to study and work with the least amount of restriction. I also received assistance from the National Foundation to help in my rehabilitation at the Warm Springs Foundation and an ample traineeship from the government when it came time for me to study rehabilitation counseling. Finally, my job as a rehabilitation consultant in Taiwan provides a salary sufficient for my ordinary living and traveling expenses.

Emotional and psychological support. From my family, my Jesuit superiors and colleagues, and all the medical and paramedical personnel, I always received encouragement. They accepted my aspirations and paved the way for me to do the things I wanted. Even my mother who is always urging me to slow down, take better care of myself, and preserve my energies has accepted, albeit it with mountains of reservations at times, even my wilder schemes.

I have no idea what course my life would have taken had I not gotten polio. I strongly suspect it would have been a lot duller and I would not have done half as many things or gone half as many places as I have since getting polio. In fact, every single thing in my life that I now enjoy, my job, my travels, even the priestly work in the parish where I live, is being done as a consequence of my polio. It has opened doors and provided opportunities I never would have had as an ordinary able-bodied run of the mill Jesuit. Ronald's Rule Three: "Even bad things that happen can make good things happen, if you keep moving."

> *"Though polio changed my life in a million ways, I am not so sure it changed me."*

Work. At the time I got polio I was already halfway through seminary studies on the way to becoming a priest. Fortunately, most of the things a priest does can be performed sitting down. Thus I was spared the necessity of having to change my occupational goals. At the time I was ordained, Church Law forbade the ordination of persons with disability, so I needed a special dispensation from Rome. As related to me, the only question Rome raised when the matter came up was, "Will he be able to do priestly work?" Since the answer was yes, the dispensation was granted. It was also quite unusual for a disabled person, particularly one in a wheelchair to be assigned to a foreign mission and probably had I not already been in Taiwan before polio, I would never have been sent back. The mission superiors only requested the doctor's assurance that there would be no special medical complications or problems for me in Taiwan. Ronald's Rule Four: "The measure of value is the contents of the package, not the wrappings."

Companions. As I look back now over the first years after my return to Taiwan and especially the four years I studied theology in the Philippines, I feel very embarrassed at all the trouble and inconveniences I must have caused because I always insisted on going everywhere and doing everything that my fellow Jesuits were doing. Actually I am very grateful to God for blinding me at the time to the occasional grumbling and resentment that others sometimes expressed because of my presence (as I have since been told), because had I known, I would probably have missed out on a lot of wonderful experiences. Fortunately, I always had a number of special friends who always championed my cause, taking me places and pushing my wheelchair without hesitation or regret. Nowadays I am much more sensitive to potential inconveniences for others and sometimes stay at home when I would rather be gadding about. But the truth is I still have the same thirst for travel and doing things that I had then and am always on the lookout for persons and occasions that will make my ambitions possible. Up to now, God has provided very consistently and well an unending series of opportunities and friends to help me participate in all the activities that have enriched my life and enabled me to do so many things for others. Ronald's Rule Five: "You have as many hands and feet as you have friends." But beware of Ronald's Rule Six: "Frazzled hands fracture friendships. Don't overstretch your strength or that of your friends. Even God rested on the seventh day."

Openness, flexibility, optimism, adventuresomeness. Before polio ever hit, I was blessed with a temperament that was open to adventure, not afraid of change or unwilling to try things difficult or new or tiring. Murphy's Law that says, "If anything can go wrong, it probably will," has always for me been followed by Ronald's Rule Seven: "For every door that closes, another one opens somewhere else." This new door may or may not lead to the same place, but if it doesn't, then Ronald's Rule Eight follows: "No matter where you find yourself, you can always find something satisfying." This is true because of Ronald's Rule Nine: "Happiness is not something you find, but something you create for yourself out of the responses you make to whatever circumstances surround you." There may or may not be a pot of gold at the end of every rainbow, but Ronald's Rule Ten states: "There is a rainbow in every shadow, because every shadow needs light in order to be cast."

Religious faith. Whether or not one believes in a personal God, it is impossible for anyone to face the difficulties of life with dignity and constancy without having a philosophy of life, a rule of conduct, a valued purpose of some kind.

> *"No one ever responds to reality as it really is, but as it is interpreted to be."*

For those of us who believe in God, at least the Christian God, Yahweh, Allah, the Supreme Lord of Heaven, life has value because it has a destiny beyond the vicissitudes of the present. My worth as a human being is not measured by how many pounds I can lift or how many things I can buy or how much power I have over others. I believe that the only thing God is asking of me is to do the best with what I have in whatever circumstances I find myself. God does not guarantee that the "good" will not suffer but that greater good will eventually come out of whatever is suffered. Which is the greater miracle: for God to run interference in our lives so that we never stub our toes on anything painful, or for God to give us the strength to face disappointments and pain with inner peace and determination always to make the best of what we have? I don't face my polio alone.

I do not know what the future has in store for me. I have managed to get a lot of satisfaction and enjoyment out of my "polio-ed" past. I look forward to more of the same even if the so-called post-polio syndrome stirs up trouble. Says Ronald's Rule Eleven: "It's not the pot that makes your food tasty, but what you put in the pot." 福

Phyllis Rubenfeld

Associate professor.

Polio.

"My parents have always been the moving force for me."

What a miraculous jam-packed 30 years! I earned a doctorate in 1984, and it astounds me to think back to the late '50s when I came off of home instruction, after receiving only 1½ hours of instruction per week for five high school subjects and was thrown into college. I was not only expected to compete with people whose school had never been interrupted, as mine was for two years when I was hospitalized, but was also expected to socialize when I had been relatively isolated during this time.

Undergraduate school was difficult at best for the first two years. Most knowledge is cumulative — it is a step by step process so when this process has been significantly interrupted, catching up often is difficult or impossible. The desire to be part of the social mainstream also created tension, since socializing is learned behavior. Given this adversity, what made it possible to go ahead? What made it possible to dream of attending a graduate school of social work and becoming a social worker to help those neighbors who lived in the same ghetto as I did in Brownsville, Brooklyn?

My parents were my strongest supporters. In their minds there was nothing I couldn't do. My college graduation was guite an 'honor' for them since they both were from Poland and neither completed more than third grade. With their support I graduated from Brooklyn College.

Undergraduate school was not without much difficulty regarding access. One incident remains most vivid. Since I am unable to raise my arms, I was told that I could not take chemistry and that "...people such as myself should not be in college." A professor of mine overheard my rather cryptic response to the Dean who told me this and offered an alternative (today known as reasonable accommodation).

There was a snag in entering New York University Graduate School of Social Work. I was told by a counselor from the New York Office of Vocational Rehabilitation that I was unqualified to attend social work school because I was unable to jump! To this day I do not know what jumping has to do with social work. Feeling that I had nothing to lose, I threatened to file a lawsuit. I did not know the implications of my threat, but it worked. I was admitted to social work school and graduated at the top of the class.

Following graduation I became extremely involved in the peace, black power, welfare rights, and disability rights movements and travelled extensively throughout the United States, Europe, the Middle East, and the West Indies, as well as attending a doctoral program at Teachers College/Columbia University. In 1984 I received an Ed.D. in Special Education. In November 1988 I was promoted and tenured in the rank of associate professor at Hunter College in the Department of Academic Skills.

What allowed me to move from an underprepared student from home instruction to an associate professor? My parents have always been the moving force for me. When I feared failure in school my parents would discuss my feelings with me, usually concluding with a lecture on the importance of not feeling sorry for myself and focusing on the positive rather than the negative, and encouraged me not to complain but to study. I came to believe them.

My political ideology and activities come from my father. He was very interested in politics and discussed current events with me. When I participated in peace demonstrations, for example, I didn't tell my mother because she was afraid I might be pushed. I did tell my father, though; he made me promise that I would hold onto a friend and not insist on being too independent, and he wished us luck. When I came home and told my mother, she was upset, but happy that I didn't fall. My parents treated me with respect and a deep abiding faith that I could do what I wanted to, and they encouraged me.

My attitude towards travel also comes from my parent's philosophy of life. There are many buildings that I may not be able to investigate thoroughly or even get into because of architectural barriers but rather than saying, "Why go?" and brooding because my inability to do what others do reminds me of my disability, I go ahead anyway and enjoy what I can do.

Looking back 30 years isn't easy because there were many difficult times. But there have also been great times and many substantial accomplishments. I have learned that one must take chances and not be afraid, and perhaps because of my philosophy, family and friends continue to be supportive. When I look at my parents, who were immigrants, and think how terrifying it must have been for them to come and find their way in the United States and how well they handled it, I know that I am a product of their strength, determination, and refusal to be licked. With this background to build on, I hope the next 30 years will be more fruitful in terms of family, friends, and career.

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Dottie Santa Paul

Activist. Employee of actuarial firm.

Amyotonia congenita.

"I pray my life will glorify the Lord."

In 1958, which was when the *Gazette* was born, I was ten years old and living in Gloucester, Massachusetts. I was in the fifth grade and attended public school. A taxi transported me to school at the expense of the city. I had a wheelchair, and the other students would all want to be my helpers. I remember the kids as being friendly, and they never treated me badly because I was different. My family was supportive and accepting, and I never questioned their love for me.

My mother searched far and wide for someone or someplace which could improve my medical condition. She had a strong never-give-up faith which I inherited. I got tired of all the places and doctors because they never seemed to help. My mother died just before I turned 13, and the searching pretty much stopped. Maybe that was in part because the last place she found to take me was a place that really did help me and, at least in my eyes, made up for all the others. It was a rehabilitation center in New Hampshire.

My stay there was over a year and was a very definite transition time in my life. It wasn't so much the physical that was important. It was that my world opened up. I began to be aware of disability and accept that my disability wasn't going to be outgrown. At the same time, as I watched what others achieved, I came to realize that my disability did not have to hold me back. Although not realizing at the time, I can look back now and see that time as when I really started to grow as a person.

My dad remarried, and I came home to an extended family. My new mother helped with my care. I had two new sisters, making three in all.

My high school was not accessible, so I went to classes through telephone intercom.

The first year in high school was hard because it was a searching kind of time. I did not have the stimulation of being at the center, and although I got out some, it wasn't nearly enough for my needs at the time. I also had heard very negative things about my "disease." I picked up the idea and became convinced that I would die before I was 20 years old. I thought, "What is the sense of trying to do anything if that is true?" I didn't want anyone to know my thoughts, so I never stopped trying, but at the same time I entered into a secret depression. I don't think anyone ever really knew my feelings at this time. I shared them with no one.

At the time it seemed like a long time that I felt that way, but now as I look back, I wasn't then, and I'm still not, a person to stay depressed. I got through that time (with no scars). We moved to a better house in a better location within walking distance to the beach. I got out a lot more. Whenever I could get someone to take me to the ocean, I'd be there. It was so beautiful, so healing.

The students and teachers came more and more; not so much to help with academics as to be my friends. They were truly great friends and still are. They took me lots of places. I began to attend church every Sunday, and that had a later impact on my life.

So my relationships increased, my horizons broadened, my skies brightened. A friend gave me a sample copy of the *Gazette* when I was about 16. As I read about people who were as disabled or more so than myself living on their own, a dream began which eventually developed into a goal. If they could do it, so could I. I already had a great interest in "penpalling," so I started writing to the people in the *Gazette* and to Gini to learn more. Everyone was so helpful and encouraging to me, and I thrived on getting to know new people.

In 1966 I graduated from high school. It was fine for a while. My friends still came. I filled my time working on a correspondence course in bookkeeping, writing letters, and some creative writing, and doing some craft projects. I made jewelry and my mother would sell it to her co-workers. It wasn't much money, but it seemed like a lot compared to nothing.

My dream/goal grew in me. Once I remember sharing it with my dad. He said, "I hope you do, Dottie." But I don't think he really believed it would happen. What I wanted then was a motorized wheelchair. I figured I could do about anything if I had one of those. I wouldn't have to wait for people to push me everywhere. But it was to be a while before that desire would be granted.

We moved again. The house was nice and in some ways more accessible — such as to get in and out. But in other ways it was less accessible. The bedrooms were upstairs, and my dad carried me. I really wanted to be out on my own but didn't know how to make it happen. We checked and visited various institutions, and I ended up going to a nursing home in November of 1969 when I was 21. I was quite an optimistic person and both my aunt, who has M.S., and my grandfather were there, so I entered with a hopeful attitude that I would have lots of people contact and that, since it was pretty accessible, maybe I'd get out more. But from the first day it was clear that this was an institution indeed with all the regimentation and rules to go with it. Still, I decided to make the best of it, but I have to say it was absolutely the most difficult 26 months of my life. It is not easy to be 21 years old and live with 99 other people an average of 40 years older than yourself.


John, her fiancé, and Dottie.

In January of 1970 a generous cousin made it possible to purchase a motor for my chair. It was the type which you could put on and off, so though not all that durable for outside distance, it increased my mobility 100%. Also, in January 1970 I started to "attend" college using the same intercom method as in high school. This was a challenge indeed with my roommate listening to soap operas right behind my chair. I persuaded the powers that be to set up a desk under the stairs in the stairwell. That's where I studied, by the light of a little window with bugs all over it. I didn't care. At least I could be alone for a few minutes at a time. The students and teachers were again great, but since the college was in another city, I didn't have the degree of contact as in high school.

In the spring of 1971 a disabled friend started to encourage me to live on my own. She lived on her own. She was a strong person who knew a lot of the right people. She was also politically involved in disabled issues and gave me a taste of all that. My dream/goal was strengthened.

In the fall of '71 some pieces started to come together for me, and my goal really took shape. There were so many factors, though, that it seemed when I got one thing, something else would fall through. The big three were (1) an apartment, (2) attendants, and (3) money. The first two would keep falling through as I fought City Hall to support me. This just wasn't done in the city where I lived. After a long struggle, I finally persuaded the city to support me. Instead of feeling victory, I felt discouraged because I didn't have an attendant then, and the apartment I had secured with my last penny was about to be lost for lack of rent payment. (I couldn't get any money from the city until I actually moved out.) It seemed impossible. I felt my strength and momentum ebbing. Still, I decided to set a specific time, and if it didn't happen by then, perhaps I would have to give up. I prayed. I turned it all over to a God I was yet to know. I said, "You do it." Fourteen minutes before my deadline I got a phone call from a seminary student. She agreed to be my live-in attendant (and a much greater friend) without our even meeting. She was the beginning of a miracle. That was in December 1971, just before Christmas. In the following weeks everything fell into place and on January 15, 1972, I moved from the nursing home into an incredibly beautiful and huge house overlooking the ocean. Harmony and Deb moved in with me. None of us had any money, but the landlady was great and gave it to us very reasonably, plus the city housing authority gave me a monthly grant that covered 90% of the rent. At that point I thought I had died and gone to heaven.

I thought I couldn't have been happier. Six weeks later, on February 29, 1972, my friends introduced me to the best friend a person can have, Jesus. It was the beginning of a new life.

I grew fast. I became involved with the seminary community and developed many new relationships. I finished college with a B.S. in social work. Church was my central community then as it is still today. I was also involved in some disability projects, teaching Sunday school and counseling.

Over the next four years I learned a great deal. Our little family grew and changed. I had many people from all over the world live with me. They were also my attendants, and all of them were great friends. All of my influences were positive.

When I graduated from college, I was able to purchase a second hand VW van with Babar the elephant painted on the side. All my friends drove it. We went everywhere. I started to travel. Had my first bus ride, my first plane ride.

In 1976 God called me to move to California. That is a long and exciting story in itself, especially with the Lord as my travel agent. I had never been here before, but I loved California instantly. The Lord gave me great roommates, one also disabled and from Massachusetts, and we are still together today, and our other housemate was with us for over eight years. We had a great house and a whole community of friends.

I went back to school and got my master's in health services administration with an emphasis in services to the disabled, especially in independent living. Living near Berkeley was a great asset in this since it is probably considered a Mecca for disabled persons.

In 1980 I started working in San Francisco, commuting everyday on the BART (Bay Area Rapid Transit) which is accessible. A year and a half later I started working with DREDF (Disability Rights Education and Defense Fund) in Berkeley.

In 1984 my roommate, my fiancé, and I purchased a house near a shopping center and BART station. Since October 1985 I've been working in an actuarial firm in Berkeley. I commute everyday alone on BART. I enjoy my job very much. One of my most useful work "tools" is a bamboo stick with a bent nail on one end and a rubber tip on the other end. I don't think I could live without it.

This year I took over the reorganizing of the International Correspondence Club for the Disabled (ICCD).

I pray my life will glorify the Lord, and I truly thank Him for all the people He has put in my life over the years. As I see it, the most important ingredients to success in anyone's life, disabled or not, are faith in God and good committed relationships. They are intricately woven together in my life, and I wouldn't be who I am without either one.

If I can help anyone with the transition to independent living, or if anyone would like details on the ICCD, or just to correspond as a friend, I would love to hear from you and will answer all letters. 福

Walter Sawyer, Jr.

Income tax preparer

Polio. Ventilator user.

"Sometimes we worry so much about the future we miss some of the opportunities to enrich our lives today."

Congratulations to the *Gazette* for surviving for thirty years and performing a valuable service for all your readers. My past thirty or forty years do not seem exceptionally worth writing about but after receiving your request I can hardly refuse.

Biographical information: Name: Walter Sawyer, Jr.; Born: 1932; Education: Started 11th year of school. Later took H&R Block Tax Preparation Correspondence Course; Respiratory Polio: October, 1947; Hospitalization: Four months in local hospital; Two years in iron lung center, Baltimore; Physical condition upon leaving center: Total paralysis from shoulders down; could breathe unassisted all day using neck muscles, rested and slept in iron lung every night. Had some movement in arms and hands but couldn't do anything except turn pages of books and magazines. Could not breathe while sitting up, so days were spent lying nearly flat in bed, reading, listening to radio, and watching TV that the community bought for me.

I returned home in January 1950. I was discharged from the center and sent home to live with and be cared for by my family. My family at that time consisted of Mother, Father, and a younger brother and sister. Three older sisters were living away from home with families of their own. My brother left home in 1956, and my last sister left in mid-sixties. My home was a large, isolated farm house and nearest neighbor was one-half mile away. Visitors were nearly non-existent except when one of my sisters came.

The Changes Begin. In early 1957 the National Foundation offered me a chance to go to a Respiratory Rehab Center in Buffalo. At first I rejected the idea completely. Then a very dear respiratory friend in Florida urged me to go as she had just recently been to one of them and they helped her a lot. And she assured me the centers now were nothing like the hated Baltimore center. Also, it was quite obvious to me that my physical condition was rapidly worsening and I could only breathe three or four hours until having to go back into the iron lung. So in July 1957, knowing absolutely for certain there was no way they could help me and expecting the worst, I reluctantly headed for Buffalo.

I was a teeny-tiny bit wrong about what could and could not be done at such a center staffed by skilled, knowledgeable, and caring people using up-to-date respiratory equipment. Within four months I was weaned from the iron lung and was using chest shell respirator, rocking bed, IPPB by mouth and learned to "gulp" or "frog breathe" while observing another patient doing it. For many years I never actually used gulping very much, but since my neck muscles are weaker than they were, I am forced to rely on gulping more and more.

After several weeks of physical therapy and some rather painful stretching, my stiff joints would bend enough to permit me to sit, so I was fitted with a supporting corset and by using IPPB was able to sit up again after ten years of lying nearly flat. When I became able to sit erect enough to use my arms, my chair was fitted with ball-bearing tip feeders, and with their help I was able to feed myself, write, and hunt and peck on an electric typewriter. After being there one year, I once again returned home, a completely changed person.

Now it was time to do something worthwhile, but what could it be? Local Lions Club bought me a used IBM typewriter. A friend suggested that since I could type, perhaps if I had a mimeograph machine I could get work making copies of forms, letters, programs, etc. At that time money was worse than just scarce for the Sawyers, but somehow $100 was found to buy the machine and a few supplies. Fortunately it did work out okay: I typed the stencils, and mother cranked the machine to make the copies. We continued doing this up until just recently but have now discontinued this as nearly every business, church, and organization has it's own copy machine. This business never made a lot of money but what it did make, especially in the '60s, was very helpful in paying household expenses.

The end of 1959 we moved from the farm because of my father's failing health. We moved to a village of some three dozen houses and still live there but not in same house. My father died in 1967, and in early '70s the Sawyer finances turned a lot better, and in 1972 mother and I designed and had built a small house that was suited to our needs and desires. Mother and I still live in it and she, at age 84, continues to take care of me.

In the '60s, needing more work and income than provided by the mimeographing, I sold magazine subscriptions, greeting cards, imprinted paper forms, and wedding invitations and accessories. The wedding business was very good for quite a few years, but then the company I dealt with changed from using small catalogs with reasonably priced items to very large catalogs with prices to match! That eventually put me out of that business, and I discontinued the other businesses for various reasons mainly because in 1970 I got into a new activity that I am able to do, I like doing, and it does make a nice profit.

"To do all these things and so many more without having to ask someone to do them for me makes living more enjoyable."

In late '60s I prepared my sister's tax returns and decided if I was able to do hers, maybe I could also prepare tax returns for others. I took the H&R Block correspondence course ($100), and it was the best investment I ever made. Since then my tax preparation business has grown and grown, and I now have more business than I can handle alone.

In 1969 I received a small inheritance from an aunt, and when I asked some friends about the best way to spend this little unexpected windfall, a disabled friend said there was only one thing to do and that was to get an electric wheelchair, and other disabled friends agreed. I got very lucky and found an electric E&J that had only been used a few months, just like new except for the price and that was an unbelievable $425! New ones were nearly $2,000. So I bought it, and what a fantastic change it made in my life!

We built a little platform under the seat of the chair, set my positive pressure Bantam on it, and attached a 50-foot extension cord. I can move around in my room, go to the table to eat, and even go outdoors to sit on the porch or go down the ramp to the sidewalk for a change of scenery or visit with next-door neighbors. By connecting the Bantam to the chair battery, the extension cord can be disconnected, and I can travel beyond its 50-foot limit and still have the Bantam operate. How fabulous it is to be able to do such simple little things as moving my chair so as to face people I am talking with; moving just enough to reach something that is only inches from my fingers; moving from sun to shade; moving out of a draft while outdoors; moving from typewriter to computer here in my room. To do all of these things and so many more without having to ask someone to do them for me makes living more enjoyable and less demanding and dependent upon those around me.

Three years ago the Sawyer finances had improved to the point where we could spend some money without the danger of having to go hungry so we bought a new Dodge van with a customized six-inch raised roof which permitted me to sit erect in my wheelchair. We do not use the van an awful lot, but it sure is nice to have when we do go out, and our only regret is not buying it ten years earlier. (Sometimes we worry so much about the future we miss the chance to enjoy some of the opportunities to enrich our lives today.) Not having a lift in the van; we use a folding ramp of plywood which works fine.

The latest change in my life happened a few years ago when something called the late effects of polio came along. I used to think it didn't really exist, but now I am a believer.

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Clair Schnitz

Tutor.

Polio. Ventilator user.

> *"To me, 'independent living' does not mean living alone."*

How did I do it? I am not sure. I know there was some doing on my part, especially in the later years, but most of that long thirty-four year journey here from there has been accomplished not so much by doing as by letting life's force, good and productive and creative, flow through me. But then letting is a form of doing, I suppose.

At the beginning I spent a great deal of time — about twelve years after the onset of my disability — just existing. Perhaps it was a necessary time of grieving or healing or simply a time of maturing (I was almost twelve when I had polio). I sometimes even suspect that such a period of time in limbo — though maybe not one quite as extended as mine — is required for the psyche to adjust to life's new reality. During those years I took absolutely no responsibilty for my life; I just rested and read, observed what others did, and wondered. I was well cared for by a loving mother, protected, and pampered by a wonderful father, provided with friends and interests by sharing siblings. And still I felt helpless and lonely.

Gradually, however, life's flow was building up behind the dam of my passivity and began leaking through it — at first in tiny, infrequent drops, then in streams, and finally in a rushing torrent. And now that flow moves rather freely, naturally — always bubbling, sometimes even roaring unexpectedly, not unlike the proverbial mouse that I was and am.

Enough philosophy! Let's get down to particulars.

When I had polio in 1954 at age twelve, the prognosis was not good. In fact, my parents were told that I probably would not live more than two years due to the severity of my respiratory involvement. I am certain that this medical opinion had subtle effects on both my initial rehabilitation and on family attitudes after my return home from the hospital. Hospital rehabilitation included weaning from the iron lung, learning to use a mouthstick for turning pages and typing, and sitting in a wheelchair. However, wheelchair-sitting for a couple of hours four or five times a week — optional at best — was recreational or therapeutic, not a way of living. For everyday life there was bed and Barker Loafer, a kind of cozy indoor lawn chair that was great for comfortable corner-sitting, but an impediment to mobility and convenient daily functioning.

I look back on the Barker Loafer as a symbol of my life at that time. Home from the hospital, I spent my days lying back, stationary, reading, enjoying only that part of life that came to me. Rehabilitation did not include even the slightest psychological preparation; never once did anyone mention the necessity of helping me prepare for a creative, productive life in spite of a severe physical disability. The attitude was rather one of sheltering, protecting, caring for me, making me happy. (Of all the obstacles in my journey's path, that attitude has been and is still the most difficult to overcome). My high school education was seen as a pastime, good for me because it kept my mind occupied, not because it would prepare me to meet some difficult challenges as a disabled adult, and even when I started at the university in my late twenties, some saw my educational efforts as a hobby.

My paralysis happened long before disabled youngsters were mainstreamed in public school systems, so I completed grades six through twelve in the homebound program. Having a "private" teacher who came twice a week for an hour and a half, I learned to be an independent, self-motivated student, skills that later proved valuable in my university studies and my tutoring work with individual students. However, that mode of education isolated me even further and held back my social and psychological development.

Clair and her mother (at left).

After high school I continued vegetating for another six long years, a period that came to an end when a Texas Rehabilitation Commission (T.R.C.) counselor, a member of my church, reached out to me and gently pushed me into thinking about what I intended to do with my life. At that time T.R.C. provided me with a headset and telephone that I could dial with a mouthstick and urged me to seek a telephone sales job. By chance, or maybe through fate, I secured part-time work doing television-viewing surveys. The first break in the dam had come; I was never again to be that passive little girl waiting patiently for the world to come to her.

After that first work experience, I became the initiator of my own future plans, and I found support and help at every turn from family, friends, my counselors at T.R.C., and my professors at The University of Texas at El Paso. When I needed a portable electric typewriter that I could operate with a mouthstick, T.R.C. lent me one; when I wanted to take college courses to qualify for the public schools' tutoring list, T.R.C. petitioned the university on my behalf, found professors willing to participate in the "experiment" of my telephone-intercom higher education, and paid for the telephone lines, books, and tuition. Family, especially my mother, saw that I was ready by class time and set up for note-taking.

By the time I had earned my degree in English, I had also developed a moderate part-time tutoring business, which has continued to the present. At first I worked exclusively with college students in English composition; however, in the last few years I have worked in language arts and remedial reading with younger people at the elementary and secondary levels. I work out of my parents' home, and my students come to me. Although my tutoring earnings fall far short of supporting me, I love my work. I love my students, and I love the feeling of self-worth that teaching gives me. It is a profession that keeps me in constant touch with other people, easing the sometimes overwhelming isolation inherent in severe disability. My work brings me the greatest happiness.

In the midst of all of this growth and success, however, came some severe and difficult physical set-backs associated with polio and aging. Since my initial rehabilitation in 1954, I had used only the chest shell as a respiratory aid — sleeping in it and using it for a few hours in the afternoons. In 1970, though, I began having serious health problems — headaches and drowsiness (sometimes so severe that I would fall asleep during a meal) — which eventually left me hospitalized in a comatose state. At that time my respiratory problem was corrected by using a larger chest shell, higher pressure, and oxygen during my free-breathing time. During the next twelve years I fluctuated between periods of stability and mechanical hyperventilation and hypoventilation.

After having pneumonia in December of 1981, my condition rapidly deteriorated. By September of 1982 I was in ICU in a coma again. My condition was much more serious this time; in fact, the doctors told my family that I would live only a few days. However, once more I rallied and was transported by air ambulance to Houston's T.I.R.R., where I went back into the iron lung. Adjusting to the tank (iron lung) was not too difficult for me as long as I believed my stay in it to be temporary, but when doctors or respiratory therapists talked about the possibility of my continuing to use it for sleeping, I balked, crying, and swearing that I would rather die than return to using the tank after twenty-eight years. Understandably, they soon stopped approaching the subject. Physically weakened, I went through a time of depression, feeling that the life I had begun to enjoy was over, that I would no longer be strong enough to study or paint or teach.

"Rehabilitation did not include even the slightest psychological preparation; never once did anyone mention the necessity of helping me prepare for a creative, productive life in spite of a severe physical disability."

By the time I left T.I.R.R., I was ventilating sufficiently with the chest shell, but I had no respiratory reserves and knew that El Paso had no iron lung available in case I were to catch a cold. This knowledge, combined with my parents' encouragement, led me to the decision to start sleeping in the tank at home in December of 1982. The improvement in my health was so immediate and obvious that the adjustment was relatively easy for me. Admittedly, sleeping in the tank has complicated my personal care, but rather than limiting me, it has brought me a new independence that results from good health and greater physical stamina.

In addition to the changes brought about through personal development in the last thirty years and, more recently, by good health, my life has been markedly improved by the use of good equipment and by the availability of services for the disabled. My really useful pieces of equipment range from a simple cut-out cardboard box and rubber bands that I use as a paperback-book holder for the iron lung to the marvelous technological miracle of my Sip 'n Puff Recliner wheelchair, which I have been using for only a year now. The rest of the list is long and includes mouthsticks that my mother makes with plastic tubing and mouthpieces cast in a local dental lab; a speaker phone; a Radio Shack push-button on/off control for lights and TV; a Hoyer patient lift; and a computer. Thirty years ago I never imagined such equipment, much less that I would have access to it. As an aside, there are a few techniques that have proved helpful to me in securing and using good assistive devices: an honest awareness of my own physical abilities and needs; a certain inventiveness, the ability to apply everyday items to those needs; and constant assimilation of information on new products for not only the disabled, but for the general consumer as well.

As for services for the disabled, today I have free morning attendant care seven days a week, a benefit undreamed of in the early years when my mother had sole responsibility for my personal care, an obligation that she undertook alone for twenty years with very little respite. With the help of the efficient, dependable women who get me up in the morning and of aides from a privately paid nursing agency who put me to bed at night, I am able to keep a regular living and working schedule. Furthermore, I enjoy the use of a local wheelchair transport system that takes me to medical appointments, shopping, or visiting. Thanks to this service, I am able to get out of the house; at least once a week I meet a friend for lunch, take in a movie, or just look around the mall. Attendant care and transportation are primary keys to the independence I now have.

Finally, no account of my journey from that helpless, hopeless beginning of life with a severe disability to my current state of stability and productivity would be complete without a discussion of my ultimate support system, my family. I simply would not be here were it not for the lifetime of love and devotion given me by my parents. They have provided me with everything from food, shelter, and day-to-day care to those even more basic needs — a sense of security and a feeling of self-worth. My mother took care of me unaided for twenty years, but rather than leaving me totally dependent on her, she taught me the importance of good physical care and led me to expect that kind of care, necessary requirements in taking responsibility for my own care and for training personal attendants. Because of my parents' loving, unqualified acceptance of me and my disability, I have a firm foundation of self-acceptance that allows me to be open, out-reaching, cooperative, and, when necessary, even a little assertive — all valuable in successfully dealing with other people.

For me those words — "dealing with other people" — succinctly define the term "independent living." Without others I cannot live; with them I not only can live, but can be productive and fulfilled. To me, "independent living" does not mean living alone. It does mean taking complete responsibility for myself and making effective use of all available resources, both human and mechanical. It means asking for and gratefully accepting help from others and joyfully giving back what I can. It means becoming a part of a loving whole — family, friends, care providers, sometimes even strangers. As paradoxical as it sounds, independent living for the severely physically disabled results not so much from self-sufficiency as from the ability to work well with others.

Getting here from there has been a long journey, a journey that continues and still holds the promise of new challenges and greater victories. 福

Floy Schoenfelder

Office manager. Accountant. Wife and mother.

Polio. Ventilator user.

"That is the secret of successful rehabilitation. They made me feel needed."

"Please, God," I prayed, "if it has to happen to one of us, let it be me because I can take it better myself than to see my husband or our little boy crippled and paralyzed."

We had been married only five years, and Dennis was not yet three years old. Polio was epidemic and terrorizing people in the United States and all over the world. Like other mothers, I had worried about my child. At that time we were living in a trailer parked on Bud's parents' property on the outskirts of Rapid City, South Dakota. Both of us were working to save enough money to go back to Los Angeles.

God must have heard me because within two days I had a classic case of bulbar-spinal poliomyelitis. I was totally paralyzed and flat on my back in a huge wheezing iron lung in the hospital corridor. They could not get my Emerson tank through the door of any room.

"If she lives, she will be just a vegetable," I heard the doctor say to my husband and mother. I thought, "Oh no! I'll make medical history and be back to work in a few weeks."

After more than thirty years, I am working again, though my profession had to change from hairdresser to office manager. I work in our home office from my power wheelchair, type with one finger on each hand, and do computer accounting. I do not need the strength to lift heavy ledgers. My body is about as active as a carrot, but I can use my hands and forearms and I wasn't "brain damaged." I use a Portable Volume Ventilator with a mouth-breathing device for sleeping and resting. My wheelchair, power bed, electric typewriter, computer, lifter, a sling for the shower and five well-placed telephones around my home and office are all just tools that help me do what I do. I don't "do windows."

My father, a retired teacher who died two years after I had polio, was confident that I would walk again. I have, in a way. I have to let my "fingers do the walking" as they say in the telephone book. My mother, also a teacher, was able to face the truth of my permanent paralysis. She died years later knowing that she left me a brother and four sisters who can't do enough for the baby of the family.

I am sure I could not accomplish "so much with so little" without the physical, mental, and spiritual support of all my family and friends. My husband never doubted that I could fight my way back to usefulness. To accomplish at least some little thing every day has been my special effort. Even to let the dog out is a triumph. I do not enjoy being waited on except as necessary. I have achieved my goal, to the point of exhaustion and now the doctor advises me to rest a lot to avoid the late effects of polio! There is so much to do that I find it difficult to take time to rest.

Ten months after my onset, I chose to go to Rancho Los Amigos Hospital in Downey, California for further treatment and rehabilitation. I spent three years there. When I was discharged with a Monaghan respirator and chest shell, I had lost over 40 pounds of body weight from a petite size 7. My appetite was all gone and it took me twenty years to get back to my normal weight of 104 pounds.

Bud brought roses to accompany me home. He was still my best friend, though I offered to let him go. My mother would take care of me, she said, but Bud would not hear of it. His answer was "This happened to us, not just to Floy, and she is not going to get away so easily!" He had brought his parents to West Los Angeles so his mother could care for Dennis while he worked. Our son was already in the second grade. "We need you to help raise Dennis," Bud said. That is the secret of my successful rehabilitation. They made me feel *needed.* My husband has done the greater share of my personal care ever since. We have had many housekeepers and caretakers, but through medical problems, laughter and tears, Bud has always been there for me.

My position in my family seems quite secure now and I doubt if they could manage without me! Who would make all the purchase orders and invoices for our aircraft repair company? Who would type all the checks for the bills and employees? How would my helper, Doris, plan shopping lists and meals without my input and who else could answer the phones day and night and keep up with the accounting and correspondence? Anyone who takes over my activities certainly will have a struggle.

I remember our first post-polio vacation. It was summer of 1958. Bud wanted to take Dennis (who was born in Los Angeles) back to South Dakota again and introduce him to the pleasures of hunting and fishing. We had a big white station wagon and a small dog. With my breathing equipment and wheelchair, could we travel? He saw no problems.

My brother, always extremely protective of me, was shocked. "Surely, you aren't going along! You can't sit in the car all those hours." "So what else is new?" I scoffed, "and what would I be doing at home?" I really *was* a little apprehensive but Bud provided the bravado.

Floy taking a day-time rest with oral positive pressure.

We had a marvelous trip and I saw Yellowstone for the first time. In Rapid City it was gratifying to show that first doctor that even a "vegetable" can have fun. He showed absolute amazement at my progress.

My husband flies small planes, and wanted to share this joy with me. He learned to leap up on the wing with me in his arms and drop me into the navigator's seat. We can leave my chair at the airport for short trips. If you have wings, you don't need a wheelchair. On my first flight my brother, often our co-pilot, worried that I would suffer from lack of air up there. He has been up too high without an oxygen mask a few times, so thinks he knows how I feel. I am used to being short of breath, and found I didn't need oxygen any more than the others. My skill at frog breathing sustains me. We have had many great trips over most areas of the western United States. I take my lightweight folding chair if we want to get out for lunch and my respirator for overnight.

During Dennis' growing up years, I took part in everything as a spectator. In all their activities he and his dad needed at least one enthusiastic "fan." We went through the Cub Scout stage, the boating, water-skiing years, the motorcycle phase, the auto-building, racing-trophy-winning episodes. After college came the Army Reserves for Dennis, where our son learned that his loving and caring family was great to come home to. We had purchased a home in Northridge, a suburb of Los Angeles.

When Dennis hunted for a job, I helped with resume writing. He took pilot training while employed by local aircraft industries. Later he and his dad rebuilt a WWII fighter plane for fun and profit. I was always available for observing, making lists, criticizing, and handing out free advice. Before Bud retired from Chrysler service management, he obtained his Aircraft Airframe and Powerplant license by going to night school. We established a family partnership business and our son experienced marriage and divorce. At this point, I am not married to a grandfather!

Although I had graduated from high school with excellent grades, and held hairdresser and cosmetician licenses in both South Dakota and California, I never got to go to college. We lived just a few blocks from UCLA for over twelve years and I wished I could attend. However, I could not go alone. It seemed that the university may as well have been a million miles away. Now we live two miles from Cal-State Northridge, and I have enjoyed a few courses by going with friends who take a liking to my mechanical lifter. I opted for free-lance writing and more difficult subjects like accounting and flight navigation, while my friends usually take the "sand-box" classes! I like to study and it is fun to be able to read more than the clock on the airplane's instrument panel.


Floy with husband, Bud.

In 1978, along with several other post-polio persons and the guidance of a local businessman, I helped to establish and name Polio Survivors Foundation, a California non-profit corporation. I like that word "survivors" and am thankful to G.I.N.I. for helping to spread its use in other areas. I am still serving as a director of PSF. It is primarily for the members of our local association and seeks to help other survivors of catastrophic polio with emergency needs. We also distribute new and used medical equipment to any who have use for items donated to the Foundation. This activity is volunteer work but very rewarding to me because I believe that the reason we are living is to help each other. Over the years the directors have had many interesting fund raisers and we have been successful.

Last year, it occurred to me that I should not be so dependent on Bud. I wanted to attend the 50-year reunion of my high school class in Rapid City, and he was busy the same week at the Reno Air Races. Why miss something that meant a lot to me? My helper, Doris, was delighted to fly with me and we spent a full week having a great time. We toured the Black Hills in a rented car and spent a whole day at Mount Rushmore. We visited many of my old friends and even called on that doctor, now in his nineties, who said I would be a vegetable. This time he squeezed my hand with tears in his eyes. I'm sure he thinks of me with pride as his medical miracle.

No matter what has happened to you, look for ways in which you can make a difference in the lives of other people. It is easier than you may think because just to listen is perhaps the greatest skill you can develop. Notice how many people knock themselves out to help you. Be thankful and appreciative, but do let them help. It makes their day. 福

Diane Rice Smith

Poet. Drives car with foot-controlled steering.

Polio.

"Looking back on where I was in life 30 years ago, it seems it was a giant leap to get where I am today. But that's not true. Getting here from there took a million tiny steps."

It is definitely "in" to be an old polio in 1988. We are hot! Research is being done all over the world on how we've coped, what our motivations for rehab were, what we've learned. The mail and phone keep us busy with interviews. We're celebrities . . . well, almost.

Putting thoughts together has been good for me. It has brought a wider perspective to my rehabilitation and to what I have learned in the past thirty plus years of disability.

Polio at age ten changed my life completely. Physically I would never be the same, nor would my view of the world. But that's not all bad. With disability came a forced passage into areas many normal people take years longer to reach. For instance, patience has to be developed early on, or frustration is intolerable. Waiting to be fed, bathed, dressed, brushed, combed, turned, lifted, driven, scratched at first seems endless, but patience comes somehow, and waiting for anything becomes just a part of life.

No doubt, my coping ability was enhanced by my superb rehabilitation. I spent five months at Warm Springs, Georgia. The Warm Springs philosophy of disability was "not to concentrate on what you have lost, but on what you have left. No matter how physically limited you may be, there are many ways to do things, and we'll help you explore those ways." Further, they taught that you must expect the best of yourself and work toward that. "You probably can do anything you want, though the ways you will do them may be unique. The end, not the means, is the object."

My involvement was mostly arms and shoulders, though I also wear a long leg brace, so tying shoes, buttoning a blouse, and brushing hair were challenging goals that became major achievements. Special hand braces were designed to assist me, as was a portable feeder. These devices are still indispensible. Reinforced by these accomplishments, I began setting new goals and reaching them often. This has continued throughout my life.

I had school at home by private tutor as the schools didn't have elevators in those days. My friends visited often and I went to parties and school functions. Finally, I attended school my senior year with help up and down steps, and I decided to take a few post graduate classes the next year to further my socialization.

Going to college was a major entry into the real world for me. I went trusting it would work out, and it did beautifully. My silent fears of how I would physically manage were allayed quickly by the perfect roommate. Unknown to me until I arrived at Southern Illinois University, she helped when I needed her, but never intruded on my new found independence. The exhilaration of living on my own was incredible. As the year progressed, I fell in love with someone back home and decided to get married after one year at college.

My fiancé also a polio survivor, and I, built a house to fit our special needs. Following six months of planning and building, we moved into our very functional home where I still live.

Bob and I had fourteen extremely happy years together before his death. As all disabled people know, adaptability is an essential characteristic. So, again, with the help and support of family and friends, I adjusted to another way of living. Though I continued to have a live-in helper, I was on my own in new ways I hadn't known before. I was making all decisions, planning my life, and coping with loss. I took part-time jobs — phone oriented — read, studied, and began to develop further my interest in politics.

In 1979, then Congressman Paul Simon offered me a staff position on a Special Education Subcommittee. I was to be involved in the Equal Education of Disabled division. This offer was not only flattering, but something I longed to do. After much consideration I accepted the job. My dad went to Washington, D.C., with me, and I began working in a House of Representative's office. I was surrounded by an attorney, a budget advisor, and various other very experienced personnel. Even though I expected the best of myself, I was surprised by my ability to fulfill the job. However, after the six-week trial period I could feel that burnout would come early for me. The physical demands were more than I was able to handle fulltime. Reluctantly, but realistically, I chose to come home. It was a difficult choice but the right one, and I continue to be grateful for that experience.

The next great event in my life happened in 1983 while I was attending the G.I.N.I. International Polio Conference in St. Louis. I met a woman whose involvement was very similar to mine, and she could drive a car! She described the foot-operated steering controls, told me she drove in Los Angeles freeway traffic and assured me I could do it too. A yearning to drive had been a part of me since I was sixteen years old. And now there seemed to be a possibility. Thinking of the unique ways I had discovered to accomplish many daily living activities, excitement mounted. I use a buttonhook to button my blouse. I hold my handsplint strap in my teeth to give my arm wider range in cooking, hair drying, and lifting objects. Why not driving with foot-control steering? My new friend supplied me with the number of a man who could adapt a car for me. I called him in California, bought a car, and within five months I was driving! In three more months I had my driver's license and was driving anywhere I wanted. I drove nondisabled friends to appointments, picked up their children at school, and took my turn driving to group functions. And I drove myself to St. Louis for the 1985 G.I.N.I. Conference, a triumph I will never forget.

Last year my live-in helper of 21 years died suddenly. I had been very dependent on her. And now what would I do? Opting to try it on my own — this time the real thing — I have been living alone, except for three hours help each morning, for a year. Though I miss Geneva, I feel freer than I ever have. I am working harder, but it's worth it. After all these years I am living independently!

Looking back on where I was in life 30 years ago, it seems it was a giant leap to get where I am today. But that's not true. Getting here from there took a million tiny steps. It took disappointments, hurts, losses, triumphs, spiritual growth, and it took living in hope. It took coming to terms with priorities in my life, and acceptance of many things I didn't like. And most important, it took risk. Without risk I would still be in a hospital bed. I wouldn't have walked, gone to college, gotten married, gone to Washington, D.C., driven, nor would I be living alone. I would not be "in life."

My motivation has been just that, "to

be in life." To be part of the community, the church, the world, to express my femininity and sexuality, to relate to men as a woman, to relate to everyone as a whole person . . . "to be in life."

Disability has taught me that life is full of compensations. Loss is balanced in many ways by being open to life and being aware of how we are all connected, one to another.

Last year I compiled the poems I had written over the past twenty years, and with urging and editing help from my father-in-law, a book was printed. It was a rare, thrilling experience to see my name on the cover of a book. People actually bought it. And they were not all family and friends. But one of the things that gave me the most satisfaction was an article that appeared in the local paper about the book. In the story there was not one mentien of my disability. That told me clearly that finally I was seen as a person, separate and distinct from my disability. Who I am today is certainly based in part on having been disabled. But the whole person is inside, and the trick is to get people's vision there without being slowed or stopped by the exterior view of disability.

I am happy to be where I am in 1988, and who knows what a million more tiny steps will bring.

I am healthy. I am content. And I am an old polio celebrity — well, almost. 福

Mary Lou Spiess

Tutor. Dress designer. Wife and mother. Advocate.

Polio. Ventilator user.

"I decided I would go anywhere, anytime, with anyone who wanted to take me."

The year is 1928; the place, a small town in Northern California. "Hi, Mom and Dad. Here I am — all seven pounds of me." Are you ready? You've named me Mary Lou, but you really should have named me Jane, Calamity Jane, that is. Most of the details of my calamities are unimportant. Suffice it to say that I spent a great deal of time in bed with respiratory illnesses, was hospitalized four times with a broken arm which mysteriously refused to heal and remains deformed to this day, and had an esophageal restriction which caused untold embarrassing trips to the bathroom during meals. Albeit rather minimally, I was disabled as a child.

OK, now to the important stuff, how my parents handled all this. Their attitude in my presence was always matter-of-fact. So you/we have a problem. We'll deal with it together. I was neither coddled (which would have been easy) nor ignored. If I were not in bed, I was to do my chores. If I were in bed, unless very ill, my mom saw that I kept up with my school work. There were responsibilities, there were no excuses, and through it all I knew I was loved. For example, upon breaking my arm a second time, Mom told me she would replace one of my chores, sweeping, with a one-handed job and, of course, I could drop my piano lessons for the duration. I said, "No thanks, I'll figure out how to do them." Guess what? You *can* sweep one-handed, and I had a ball playing music written for the left hand alone!

My parents, I feel, had almost everything to do with turning disabilities into challenges in my young life. Though it cost them dearly financially and emotionally, I was never made to feel guilty or restricted. To illustrate: the special joy of my young life, closely followed by dropping out of acacia trees and scaling cliffs, was swinging and swaying on a platform three stories up in our backyard fir tree. When someone asked my mom how she could let me do that she answered, "I just don't look!" This, of course, was after Dad had determined that I was reasonably safe. She taught herself to say "you can" not "you can't;" she taught me to say "can do" not "I can't." Besides giving me the freedom to be me, they lovingly, but firmly, disciplined and expected my best. Anything else would have caused a far greater handicap!

That was the end of my first rehabilitation period. Who were the important players? My teachers, who were willing to adapt; my brother, who treated me like a normal, annoying older sister; parents, who neither ignored nor coddled; and the friends, who supported them in a myriad of ways; and God, without whose sustaining love none of us would have triumphed.

During the next few years (1946-1955) I did what most young women from educated families did. I worked, studied (B.A., Elementary Education), married (Hal Spiess, 1951), and had a child (Michael, 1953). In late 1955 while Hal was finishing college following a hitch in the Navy, I was homemaker, child-care provider, teacher, and *pregnant.* But, after all, I was only 27 and invincible, wasn't I? Wrong! I became host to a whole army of polio viruses. Not quite all "can-do's" are good. Suffice it to say that I walked into the county hospital in November 1955 and in spite of all my determination, did not walk out. I was so fortunate to have excellent, caring doctors and nurses, plus an ever present family. My mom simply moved to our town for a couple of months. She, Hal, and Mickey were at the hospital daily while I fought for my life. Churches prayed and God was there. All of our families, some at great sacrifice, gathered in a donated house nearby that Christmas. With all this support to add to my own faith and will, I *had* to pull through!

Mary Lou with granddaughter, Kate.

After five months and the loss of my baby, I was transferred to Fairmont Hospital near Oakland, California. The medical care was basically good, but routine. What was outstanding was the general attitude of the staff. The wards were our home. We could have visitors, even our young children, at any time. We had entertainment, and lots of impromptu high-jinks. The staff sometimes took us on outings (or facilitated others doing so) and gave parties. The rehabilitation worker put us to work; i.e., "You have a teaching credential, get down to the children's ward and help those kids!" Morale was high. Another strength of the staff was to use those who were making it at home, when they returned for check-ups, to counsel patients who had negative attitudes.

One of the weaknesses, I believe, was inadequate counseling for patient, family, and hometown doctor before release from the hospital. We needed more information on living at home. We also needed periodic counseling after we were home so pressures couldn't build up too high and blow the family apart. Another was occupational therapy. All they could think of was typing. I hated typing. Why type when my handwriting was as good as theirs, and many times faster than typing. Show me how, surely; but don't dwell on it. What I wanted to do was sew, embroider, draw, paint, cook, and teach . . . all things I taught myself early on.

So now I was home, almost totally paralyzed and tied to a respirator for the rest of my life. Well, I figured I could raise and otherwise enjoy young Mickey. Later I would listen to his joys and woes — help with homework. At least I would be there for him and my husband until Mickey was raised. The doctors had given me 10 years; I figured fifteen or twenty. As for me, I'd do artsy/craftsy things, write letters, read, watch TV, do puzzles — a lot of fun things I'd never had time to do after I grew up.

Disaster, none of my clothes fit! Oh, well, I would not be going out anyway. I gave away my dresses, accessories, and high heels as well as my sewing gear. Sewing and designing clothes, mostly for myself, had been a lifelong passion. Thank God for my mom — she just hung onto the stuff, and went looking for a sewing machine. What she found was a concerned salesman and a Singer Featherweight. I wore it out over the next 25 years! Of course, Mom returned my notions and fabrics, and we learned how to make clothing that works. I now have an Elna Stella.

Getting out took more nerve. We were aware that I would be treated like a freak. Having folks come to the house was OK. They *chose* to see me. Coming home from a tea one day, mom said she'd seen another woman using a respirator while dressed to the nines. So, say I, if she can do it, so can I! Soon after a fellow church member offered to take me to the Christmas Tea at our church. With a reassurance practice beforehand, we journeyed forth in his station wagon — no problems. After that, I made the most important decision, other than deciding to live, of my post-polio life. I decided I would go anywhere, anytime, with anyone who wanted to take me! What adventures I have had! They have been limited primarily by time, money, and responsibilities, as are everyone's, but not because I was not willing to try.

At home, my rehabilitation worker was an older man who pegged me perfectly. Had he not pushed me to use my teacher training as a tutor, I should probably never have gotten up the nerve to do so. Had he pushed too hard, I'd have balked. Instead he quietly and effectively knocked down my self-imposed barriers until I said, "Yes," when a teenager asked for help with algebra! In 1957 California would not allow me to return to the classroom. Now I wouldn't want to. Tutoring has the joys and rewards (not monetary) of teaching without most of the hassles. I have influenced the lives of over 1000 students and their families over the past 30 years. I was there for Mike and Hal and had no hassles over transportation!

A room and bath had been built in my parents' home while I was at Fairmont Hospital. It served as home for three years. Everyone shared responsibilities while Hal finished college. When Mike was six, we moved into our own home a few blocks away. By then, I could handle Mike with my voice, my housekeeper, and my neighbors. These wonderful people reported to me, when necessary, to keep him safe.

For the next seven years we had a relatively ordinary middle-class life, church on Sunday, frequent drives, and holidays with extended family; working with Scouts, church youth, Mike's school, and attending classes ourselves. Mike spent a lot of his time making robots for Mama (He now has an M.S. in Agricultural Mechanics!). We fished and hiked; visited, picnicked, and explored; but seldom overnight — no iron lung; no sleep. I found in those early years that two things are essential: the ability to laugh, especially at yourself and the ability to make others comfortable with you. On the latter I would try to make the first move; people are often afraid of hurting you.

1966: a banner year! We finally made a portable lung from an idea we read about in the old *Toomey j Gazette,* now the *Rehabilitation Gazette.*" What a whole new world opened up! I have not used a chest-piece since 1957. Instead, I use mouth-positive from a P.V.V. Our son invented "drive-in air," a boom holds a dangling hose, so I can come and go from it all day as I go about my work in my power chair. It made me far more independent. I still use the iron lung at night; homemade "coffin" when traveling. Over the past twenty years "Mommy's Mummy" has made it possible to camp/travel up and down the West Coast and as far east as Michigan. I've traveled by car, truck, boat, horse trailer, aerial tram, train, river ferry, Piper Cub, and jet airliner. I've sat by fishing streams and "hiked" mountain trails — wild ones. We've camped in the wilderness and hobnobbed with the wealthy at major hotels (accessibility conferences). What fun we have had!

Moving to a city (pop. 200,000) in the late '60s has been most freeing. Our new church gave me my first power wheelchair. With that, the ability to frog-breathe all day, and lift-equipped city busses, I was able to take care of my own errands as well as much of the family business for many years. Because I could be on my own, I became far more active in church/community affairs. Through the late '70s and early '80s Hal and I were very active members of state-wide advocacy programs: writing, speaking, testifying, attending hearings, reading draft regulations and laws, and serving on endless committees. We've enjoyed helping people make their facilities accessible to persons with disabilities. It's been a great combining of skills, and a great adventure! Disabled does *not* mean incapable!

With age has come the need to slow down. How we are enjoying the next generation, especially our foster daughter's little Morgan (18 months) and our own little Kate born last March! Now is it time for artsy/craftsy things? I doubt it! 福

Joyce Ann Tepley

Social worker.

Polio. Ventilator user. Wife.

"The unsung heroes are my parents."

Like so many of us, I got polio as a child. I will never forget the nightmare evening spent in the dark ward of the Cleveland, Ohio, City Hospital after the ordeal of having a spinal tap to diagnose the disease. I was nine years old. It was the summer of 1952. Just the day before, I was feeling fine, riding my bicycle, and running with my friends in a game of tag. By the next night, I could hardly move. A few days later my brother, who was only eight months old, was also admitted. The acute state of the illness was more critical for him because he was so young, and because the virus affected his right arm near his throat. Fortunately he was strong enough that his breathing was not affected. Our parents were able to take him home soon after onset with instructions for physical therapy.

The treatment then was rest, "hot packs," and splints. The "instruments of medical torture" were frightening, but bravely I endured them because the hope was held out to me that I would overcome the disease. I remember how triumphant I felt a few weeks later when I could raise my head from the bed. Shortly after that I was able to sit up in a chair for short periods of time. My arms were unaffected. Even though my legs and back were paralyzed, I could comfort myself with the knowledge that I was lucky enough not to have to live in an iron lung, like some of the friends I had made in the hospital. After a couple of months I was transferred to a residential children's rehabilitation facility called Rainbow Hospital. It was quite a distance from home, so it put more of a strain on my parents.

At the time, I had no idea how difficult the whole ordeal was for my mother and father. They never showed me the fear they had that I would not be able to walk. They protected me from their financial worries. They were always encouraging. They made enormous sacrifices in time and effort, driving for two hours each day they came to see me. They did not want me to feel neglected. Over the years I have received much recognition for what I have been able to do with my life "despite my disability," but the unsung heroes are my parents.

After months of physical therapy I graduated from a wheelchair to a back brace, long leg braces, and two canes. One of the hospital experiences that stands out in my memory was learning how to fall, then get up by myself from the floor. I have fallen down many times over the years but never gotten seriously injured. The practice must have formed a protective pattern in my brain that has served my body well. My medical team was terrific. If it was not for my orthopedic physician, Dr. Myron Pardee, the nurses and physical therapists, I would never have reached the level of functioning I have been able to maintain for so long. I had a "crush" on Dr. Pardee. He was so kind and reassuring. I was lucky to have a competent and caring doctor throughout the eight years of my rehabilitation. Dr. Pardee retired a few years ago. I hope that he knows what a difference he made in one little girl's life.

During the fall and winter of 1952 my life settled into a comfortable routine of eating, sleeping, physical therapy, and school held in the hospital. I was able to go home for a few days at Christmas time. What a homecoming that was! I was overwhelmed with presents. There was one particular present I received from an unknown benefactor that I still treasure. One of the night nurses used to read us Raggedy Ann and Andy stories. I looked forward to it each time she was on duty. We had a Christmas tree surrounded with presents in the ward. The presents were collected from a volunteer group who wanted to make sure we each got something for Christmas. There was one box that stood out. It was the biggest of all of them. I had my eye on it. Was I surprised when it was handed to me just before I left for home. When I opened it on Christmas morning it was a Raggedy Ann doll. Her face is now stained, her red hair is faded, her original clothes are quite worn, but after thirty-six years, she still has her heart painted on her chest that says "I love you." She was a comfort to me.

By the spring of 1953 the hospital had done its job well, and I was ready to go home. It was just before Easter. For the first time since the day I got polio I was scared. I was leaving the shelter of the hospital life and going back to the real world. I could feel secure in that world because it had changed very little. However, I had changed a lot. Though my family did everything they could to help me adjust to my new physical limits but still live a full life, I struggled for a long time with a strong feeling of not being good enough. I felt different and damaged. Though my physical rehabilitation was impeccably good, little attention was paid to my feelings. I know now, after years of psychotherapy, that I suppressed my grief and anger. I remember being continually complimented about my brave smile and cheerful disposition. Only my diaries knew how depressed and ashamed I felt. I was different. I had heard that some neighbors were fearful about having their children play with me. People stared at me. I eventually began to force myself to overcome my shyness.

While I was trying to learn to walk without my braces, my brother was learning to stand up using my wheelchair pedals for support. His right arm was completely paralyzed and his muscles were quite atrophied. He did not know any different, and being a typical boy, he took a lot of risks. Even though we had physical limits, our parents wanted us to have a normal childhood. We swam in the summer and went sled riding in the winter. We were expected to do certain chores. A good education was emphasized and provided for. In the fall of 1953 I entered the third grade in our parish school. Some years later I learned that my parents had to do some fancy convincing of the school principal to let me in. They had not had a disabled child in classes before, and it was way before the time of mainstreaming. Our parents did not want us to go to a "special" school for "crippled children." They wanted us to deal with real life situations and not be sheltered. In retrospect I am grateful for the sound education I was given, but there was also a high expectation put on me to develop my mental abilities since I did not have a strong body. I therefore overcompensated and pushed myself too hard. Because I was the only disabled child in school for many years, my self-consciousness increased.

By age 11 I had strengthened my left leg enough to walk without a a brace. My doctor recommended experimenting with only a knee brace for my right leg. I did not need to wear my corset anymore. My family was hoping I could continue like that for the rest of my life. My grandmother, a devout Catholic, was praying for complete recovery. I tried to believe a miracle could happen, but that summer I was playing on a park merry-go-round when someone came along and spun it very fast. I was not holding on tight enough and got thrown off. I landed on my left knee. My femur was broken, and I spent the rest of the summer in traction. After that length of time in bed, my muscles had atrophied more, and I became too frightened to try walking without my brace. So I went back to wearing a full-length brace. The knee brace did not work out either. It cut into my shin. By age 12 I was wearing two full-length braces with knee pads and no knee locks. I was only using one cane to walk and did not need the wheelchair anymore.

My back was developing a curvature. Dr. Pardee wanted to do a spinal fusion. Many children I knew in the hospital had had several tendon transplants by then. I do not know how they survived it because my one surgery was ordeal enough. I had to lay flat on my back on a Stryker Frame for months. My father got permission to build one in his spare time at work, so that I could spend my convalesence at home. Once again my mother became my nurse. I finally returned to school wearing a heavy plastic back brace for the next two years. This time my classes were upstairs. The only accommodation made was an eighth-grade boy assigned to carry me down the two flights of stairs during fire drill. I was embarrassed.

After my family got me through the surgery, my brother had to have a pin put in his shoulder because there was no muscle to keep it from dislocating. We received considerable help from the March of Dimes and Society for Crippled Children. If it was not for them, my parents would have been bankrupt. Each year my mother participated in the Mother's March in our neighborhood. One of the services provided us was two weeks at Camp Cheerful during the summer. I went when I was fourteen and fifteen. It was the highlight of my childhood and the beginning of my adulthood. So much of my adolesence I was haunted by feelings of inadequacy and lack of self-confidence. But at Camp I felt normal. I won the Best Camper's Award in my last year there.

I worked very hard in high school to maintain an A average. I went to a brand new, all girls' Catholic school. Being the first class we got to set the traditions.

Again I was the only disabled student and felt the pressure to keep up. I suffered a lot from bouts of bronchitis, but I would not slow down. Besides school I was taking swimming lessons, guitar lessons, Hungarian lessons, volunteering for the Red Cross at the Veterans Hospital, and participating in every school play and choir performance. I did the same thing when I went a thousand miles off to college. Now, I would not attempt to walk up and down stone steps without a railing numerous times a day. The campus was small and fairly accessible, but there were no elevators or ramps. It was 1961. At least I did not have to battle snow storms in Florida.

It was a big risk to go away so far to college, but my parents continually encouraged my independence. I was growing in competence and experience in taking care of myself. I received some financial help from Vocational Rehabilitation, but my parents paid for almost everything. It required quite a bit of sacrifice on their part since it was a private Catholic college. I graduated with a degree in social work and was listed with Who's Who in American Colleges and Universities. I knew from the start that I wanted to have a career in helping people. My family and the church influenced me to choose something that would return the help I had been given. My vocational rehabilitational counselor tried to persuade me to follow in his footsteps. However, my social work professor, Sr. Elaine had the greater influence. I have never regretted the decision.

I went on to graduate school in Texas with a mental health stipend and in 1967 started my career working for a mental health clinic in Dallas. I have been in Dallas ever since. In the meantime my brother took a little longer to find his "niche" in the working world. Once he decided, however, he went on to get his doctorate. He is now a senior scientist doing research at Arecibo Radar Installation in Puerto Rico and busy raising a family.

From age 15 until my early 40s I have been stabilized in my disability. I have tried to think of it as merely an inconvenience. I was active in the disabled rights movement as president and founding board member of our Dallas center for independent living. Through that experience I learned to take pride in myself as a disabled person. I am now 45 years old. In the last four years I have experienced greater fatigue, more muscle weakness, pain in my arms, increased curvature of my spine, and labored breathing. I got involved in the local post-polio support group and was encouraged to make some necessary lifestyle changes. I traded in my sloppy old steel braces for more supportive plastic ones. I can now wear tennis shoes for the first time in my life. I bought an electric three-wheeled vehicle for long distances and cut way back on my schedule to allow more time for rest. The most difficult change I have had to make is getting used to using a respirator at night.

Traveling back in my mind to that life-altering day in 1952, I can see a world filled with the richness of many people who have helped me make my dreams come true. Part of that early encouragement came from a little magazine called, the *Toomey j Gazette*, published from a lady's house in Chagrin Falls, Ohio. Even though I lived nearby, I did not get to meet Gini Laurie until 1985 when I attended the polio conference. Congratulations, Gini, for over thirty years of faithful service. This grown up little girl appreciates you more than she can ever say. 福

Ray Youdath

Newspaper circulation manager. Husband, father, and grandparent.

Polio. Ventilator user.

"Without her (my wife) there is no me."

Trying to describe my life, motivation, and the secrets to my "success" could lead me to paint a picture of great accomplishment. A beautiful, devoted wife, three big, healthy children, their spouses and fabulous grandchildren, a comfortable home, a pond to sit by, and a pontoon boat to speed around the lake. In truth, I was just very lucky.

The day before I got polio I was on top of the world; out of high school, a new 1950 Ford convertible, and a family evergreen nursery. I was six-foot-six, broad shouldered and good looking (or so the girls told me, especially my mother and sister). No one felt more blessed. Then, polio! I spent the first six months in an iron lung. I was slowly weaned from it; just missed the need for a breathing machine. On to Warm Springs. After several fruitless months they sent me home. This was 14 months after onset of polio. Prognosis: sit in a chair with overhead feeders. I was unable to use the bathroom, dress, or get in and out of bed myself, and, naturally, not drive. After four years, luck popped its head up.

A friend sent a therapist to evaluate me. He was taught at the California Rehab center in Santa Monica. Their treatment was unorthodox. They believed in hard exercise, even to very weak muscles. I went to C.R.C. for 18 months of stretching, modification, and hard work. They were the right combination for me. I improved enough to use the bathroom, get in and out of bed, dress and undress, without help and, best of all, drive. I didn't have the strength to pull my chair into the car.

At this time I learned a couple of important lessons in life. I was still self-conscious about going out in public. I met a girl who graduated from Vassar. I would get in my car, she would put my wheelchair in, wheel around the car, jump in (strong arms), and put her chair in. I'd start the car and away we would go.

One afternoon, in the lobby of C.R.C., a tall, sharp-looking cadet she knew from Annapolis, dressed in white, walked in to see her. He professed his love for her and vowed to jump off the Santa Monica pier if she would not marry him. She told him to jump!

I was impressed. I learned a big lesson: a wheelchair is a handicap only if you let it.

Naturally, there are many real obstacles in the life of a severely handicapped person. Although I tout my optimism, attitude, and fast boat, the main ingredient in my "success" story is a gal named Marilyn — my wife. She made it easy for me to live with my handicap. We went many places and did many things. This may sound unusual, but I would be surprised when I would see our reflection in a store window. With Marilyn, I never thought of myself as being in a chair. She always made me feel that she was lucky to have me. Her attitude never changed. She not only did all the wifely things there are to do with three children and a house, but also all the things an able-bodied man would do around the house and yard. I would have to be a Rembrandt with words to paint a word picture showing all that my wife means to me. Without her there is no me. There is one handicap that gave me problems; too little education! I was lucky to get a job at the Cleveland Plain Dealer. Once you get your wheel in the door, you have a chance to prove yourself, but just getting in is tough. I started as a phone person. Ten years later I became circulation office manager. Things would have been much easier with a college degree, plus opportunities would have increased with other departments. Salary is important, but more so is medical insurance and building for Social Security. A college degree by itself isn't enough today.

About 10 years ago, burning the candle at both ends, a lung infection and an auto accident took its toll. Since most of my muscles were borderline, I started losing some functions, the worst of which was breathing. I wound up having to use a rocking bed. Now, traveling became a problem. I began to realize how fortunate I was for 27 years of mechanical-free breathing. Through trial and error, I found I could use an exsuffulation belt. Laying on my side, with the bladder tucked under my abdomen, with my corset on, I can get through the night.

I am a contrary thinker, and some may take exception to my next thoughts.

The mind is more important that we think. The more we think we are bound to get worse, the worse we will get. Naturally, you can't be stupid and ignore obvious things. If I had listened to the experts all the time I would never have gotten as far as I have. The times I have listened, against my better judgment, have cost me dearly. I also believe tightness has a bigger effect on post-polio than is recognized. Also, the human system is designed to slow down while sleeping. I believe when breathing is controlled mechanically at a high rate all night, the next day the body will demand the same amount of oxygen. The more it gets, the more it will demand. Today's technology should allow a monitor to judge the body and slow the speed and depth of breathing at night. So much for my soapbox.

Ray and his family, (left to right) mother-in-law, wife Marilyn, David's wife, Dave's daughter, son David, son John, John's wife, Debie's son, daughter Debie, Debie's husband.

Although breathing is getting to be more of a struggle, I have little to complain about. I am now sitting at my desk, with my good friend "Tiger" (a Manchester terrier) curled up asleep in my lap. I look outside at our pond and watch the rain dance on the surface. I think to myself, is this the day a scientist will find the thing that will get dead nerves to work again? I'll be sure to watch the evening news to check. As I said, I'm not short on optimism. 福

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