

REHABILITATION GAZETTE

International Journal for Independent Living
by Disabled People 1985/Volume 26

Special Features:

Institutionalization vs.
Independent Living

GINI

Gazette International Networking Institute
St. Louis



Polio Support Group
Guidelines

Spinal Cord Injury
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CITICORP awards \$25,000 to Gazette International Networking Institute (G.I.N.I.).

Left to right: Jonathan Graves, G.I.N.I. Board member and CITICORP Vice-President; Judith Raymond, G.I.N.I. Executive Director; and Gini Laurie, G.I.N.I. Chairman and Founder.

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In September 1984, our Gazette International Networking Institute (G.I.N.I.) was awarded a \$25,000 grant from CITICORP. The grant will enable us to place on-line our extensive database on polio, spinal cord injury, ventilators, and independent living to provide easier access to an ever-increasing national and international audience.

During the past year, we expanded the G.I.N.I. Board of Directors and hired Judith Raymond as our first salaried executive director. Judith is a long-time volunteer with the *Gazette*, and her experience as a former director of an Ohio public library fits well with G.I.N.I.'s objectives.

We are seeking corporate and foundation funding to increase the circulation and publication frequency of the *Rehabilitation Gazette*, publish G.I.N.I. handbooks on specific aspects of living independently with disability, and expand the services of G.I.N.I.'s information clearinghouse.

The Board, Judith, and myself look forward to G.I.N.I.'s exciting future.

Gini Laurie
Chairman/Founder

Rehabilitation Gazette

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Volume 26 1985

Rehabilitation Gazette (formerly *Toomey's Gazette*) has been published since 1958. Its aim is to reach, to inform, and to dignify people with disabilities throughout the world. The *Gazette* reaches 85 countries. It has been translated into five languages and is currently available in Japanese.

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Cover: Designed by Cynthia Hewett, the cover reflects G.I.N.I.'s new logo. The "foo" sign is a Chinese character which stands for health, prosperity, and all good wishes. It has long been a symbol of *Rehabilitation Gazette*.

*Disabled

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Subscription rates to *Rehabilitation Gazette* are new to *Gazette* readers. In the past, the *Gazette* gently requested a donation from its readers. Many readers who could not afford the *Gazette* received it free, and the *Gazette* existed thanks to the generosity of those readers who made extra donations.

Times have changed. Now, we must set a subscription rate for individuals of \$10 per issue and a rate for libraries, independent living centers, hospitals and other institutions of \$20 per issue. As always, anyone who cannot afford to subscribe to the *Gazette* will receive it without charge.

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Last Rights

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INSIGHTS

I had to make the decision twenty minutes after I returned from three weeks' leave. Three weeks of sand, surf, ice creams for the dog and deliciously burnt barbecue sausages. I was relaxed and brown. People said I looked exceptionally well. I almost looked forward to going back to work despite the half-hour crawl through the traffic.

The hospital where I have worked for the past ten years is old; its rambling buildings scattered through grounds softened by trees and beds of roses. Not most people's idea of a modern hospital, I imagine, but I like where I work, largely because of its eccentricity; I can no longer see myself in the impersonal bustle of an urban teaching hospital. But then, I sometimes really wonder what I am doing practising medicine at all.

The telephone rang while I sat at my desk looking despondently at the pile of junk mail which had accumulated in my absence. Half of it was already in the metal waste bin, the rest separated into piles. The smallest pile consisted of hand-addressed envelopes, certain to prove the most entertaining. I was leaving these until last.

"Can you come down to Ward 9 straight away, please, Doctor?" The voice from the switchboard was friendly. "Did you have a good break?" But I was already half-way down the stairs. I knew that urgent calls from the Respirator Ward meant trouble.

Mary was dying. I took one look at her grey, clammy face; the eyes were glazed and almost closed, and I knew I had five or ten minutes at the most. "Dave, get the emergency trolley, will you? Nurse, give me a hand getting this collar off. I can't get a decent fit with the mask. Oh, before you go, Dave, open the lid up — thanks! What do you think, Paul?"

Paul's eyes were troubled and the hand holding the opened lid of the wooden respirator was white. His balding head glistened with sweat. "I thought you should come down," he said. "Not too good, is she?" He didn't look di-

rectly at me as he spoke. Paul, old boy, I thought, you are getting past it. You really shouldn't be doing the wards any more. Better stick to administration. Leave the patients to us younger guys. But then I caught a glimpse of my own greying beard in the overhead mirror attached to Mary's respirator to allow her to watch television. "Thanks for your help, Paul," I said, puffing oxygen into Mary's lungs as she lay like a beached seal. "Thanks a lot."

I knew we couldn't leave Mary where she was. She had been in an iron lung for thirty-one years, ever since that first devastating epidemic of poliomyelitis way back in the fifties. We don't call them iron lungs any more, I thought, because they are made of plywood. Like a cheap coffin. It had very nearly been hers.

"Hi, Jan. Look, it's about Mary. We are going to have to get her across into I.C.U. Have we got a bed?" I briefly explained what my thoughts were to Jan, the sister-in-charge of Intensive Care. Mary had developed pulmonary oedema and needed to be on a different type of respirator to survive. Her lungs were waterlogged. She would need a breathing tube passed through her mouth into her windpipe.

"Damn you. All right, give me ten minutes," she said. I knew Jan resented the old polio patients coming across to Intensive Care. She resented them because they openly expressed their fear and hatred of the unit. They knew that being sent to I.C.U. meant you were going to die. Most of them had said they were never going there under any circumstances. Ironical, because I.C.U. had in fact been the original polio ward, hurriedly and rather clumsily transformed into an acute care ward when it became obvious that funds would never be available to build a new unit. However, I knew that Jan would find a bed. She always did.

During the next two weeks I spent many hours talking with Mary's daughters. They wanted to know whether she would ever be able to speak again. I didn't know. "I don't know," I said. "What about the stroke, Doctor. Will that get any better?" Once again I cursed Paul for his failure to tell me that Mary had had a stroke

while I had been on holiday. He had known. When I called down to the ward he had been too flustered to tell me about it; he had pressed the emergency button before considering the consequences. Now we had Mary on a respirator, a tube down her throat and an intravenous drip running fluids and drugs into her arm. With diabetes, long-standing paralysis from polio, kidney stones the size of walnuts, and now a serious stroke, and her two charming daughters believed that I was about to turn all this around and give their mother back her voice. "There is a chance she will be able to speak when we pull out the tube." Never take away hope. It is the one thing that people cling to in adversity," our lecturers used to tell us at medical school. I always tried to give myself this hope first, so that I would sound convincing.

I looked at Mary. She was ugly. Saliva drooled down her chin, a result of her inability to swallow, as well as paralysis of half of her face. Her eyes were turned always to one side. Much of the time they were deliberately closed. She was shutting herself off from the deadly reality of Intensive Care.

"I am going to send your mother back to Ward 9." I told them that she would feel more comfortable there. After all, it had been her home for the past thirty years.

Mary's friends were awaiting her return. They had written a card with "Welcome Home, Sweetheart" and pinned it to her respirator. Elsa and Liz, whose respirators abutted Mary's, wanted to know how she was. "She can't speak," I explained, "but when I take the tube out of her throat she may be able to say something after a day or two." I didn't feel very confident. I was beginning to realise that Mary's stroke had caused permanent damage to her ability to swallow and that she was unlikely to be able to talk normally, if at all.

It was Elsa who finally broached the subject I had deliberately avoided discussing with them. "Will she have to have a tracheostomy?" she asked. Elsa was out of her respirator lying on a reclining bed. She was lucky. She had learnt how to breathe using her throat and tongue muscles and only needed to go into her respirator at

night. She didn't have a tracheostomy. This was an operation that none of the patients wanted. It involved making a small hole in the windpipe and placing a curved tube into it through which the patient could breathe. It was a simple procedure, but one with enormous implications. Mary had said for years that she would rather die than have a tracheostomy. I think they all believed that it was like making your will, or writing your own epitaph, an admission of impending mortality. I dodged Elsa's question. "She's got away with it so far," I said. "She's coming across tomorrow morning. We'll just have to see how she goes."

When I pulled out Mary's tube the next day she was able to respond with a lopsided smile. She was back home, her body snug inside the wooden respirator, surrounded by get-well cards and the concerned faces of familiar nursing staff. She was still unable to swallow. I wondered how she could breathe with the saliva collecting in her throat, but somehow she seemed to manage. I left detailed instructions for the attending nurses, but as I went home that evening I had serious qualms for her well-being.

My worst fears were confirmed when I visited the ward next morning. Mary's respirator was empty. She was back in the I.C.U., a tube once more in place to allow her to breathe. She had almost died for the second time the previous evening, while being visited by her daughters. One of my colleagues had arrived to find the two of them fluttering distractedly around her respirator. He had little choice but to reinsert the tube immediately.

I eventually performed a tracheostomy on Mary three weeks after my return from holiday. At first I tried to wriggle out of it. I convinced myself that it was going to be too difficult technically; that I would have to call in an experienced surgeon to help me. I asked him to look at her neck. I thought it was going to be too hard to get at the windpipe — she had been flat on her back

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for so many years that her neck was rigid. The surgeon disagreed. "You've done more trachies than I have," he joked. "You'll be O.K." I was stuck with it.

A tracheostomy operation is a piece of live theatre. The actors wear green gowns, gloves, and masks. Everyone knows the patient will die without the operation. The lights are turned on. There is a busied hush. Instruments click and gleam in the circle of light. There is a little bleeding. The hole is made in the windpipe. A great sense of relief. A life has been saved. The ritual cleaning up begins.

On this occasion I left with a headache and my hands were trembling slightly. I walked slowly across to the sitting room and made myself a cup of coffee from the vending machine. The cup rattled as I carried it back to the armchair, and coffee slopped into the saucer. I remembered Mary's face when I told her she would need a tracheostomy. I know she understood, but to this day I don't know if she really wanted me to do it.

Mary went back to Ward 9 for the second time attached to a Bird respirator. When I first came across a Bird I wondered about the name. They are certainly small, green, and noisy, but otherwise bear no resemblance whatever to our ornithological friends. I have become quite fond of these rugged little machines over the years. They are the workhorses of the intensive care unit, very tough and simple and forgiving to use. We had one sitting neatly on its chrome-plated stand amongst the "coffins," the ugly plywood boxes we call the Tanks, most of them over thirty years old and needing a coat of paint. The little Bird looked somehow sad and out of place.

Mary lay on an ordinary hospital bed, her tracheostomy tube attached to the Bird by a three-foot length of plastic hose. Although she couldn't speak, we could read her lips and conversation was usually possible. Her saliva still had to be sucked from her mouth almost continuously, and she was fed through a fine plastic

stomach tube which was taped to the side of her nose.

I had discussed Mary's tracheostomy with my medical colleagues. I had been open about my reluctance to perform the operation. I pointed out that Mary was unable to be her own advocate. Was it reasonable to perform the operation when I knew what strong views she had previously held on the subject? But if I didn't do it, I would have been left with little choice but to switch off her respirator. My friends showed their obvious concern, but they didn't know the answer either. The decision was mine.

Several days later I sat at my desk pulling my fingers through my beard as I tried to concentrate on a submission I was writing. My mouth was dry and I decided to go and get a drink. The telephone rang as I got up to leave. It was an unfamiliar voice. "Doctor, can you please come down to Ward 9?" "What's the problem?" I said. The voice sounded Asian. "It's Mary. She wants us to turn the respirator off."

I sat down and slowly replaced the receiver. For a minute or two, I didn't move. I thought of Mary's face that morning — unsmiling, withdrawn, eyes closed against the world. She wants to die, I remembered thinking with sudden pity. And now she is actually asking us to help her. Asking *me* to help her. For there was absolutely nothing that she could do about it herself. She was completely paralysed below the neck. We would go on feeding her down the tube and breathing her with the Bird even if she desperately wanted just to be allowed to die in peace.

I had spent three weeks keeping Mary alive. Could I now go down and turn off her respirator in cold blood? I opened the door, walked along the corridor, and began descending the stairs one at a time. I recalled the recent symposium I had attended on euthanasia. There had been learned papers on the Living Will and the Right to Die, mainly from armchair philosophers and lawyers. No one had all the answers, of course, and there was no one to tell me what to do now. How can I go into that ward and turn it off, just like that? Surely, the relatives would have to be involved — but then, it *was* Mary's life, not

theirs. Would I give her some morphia first, to make it easier — for me?

The short walk to Ward 9 took me much longer than usual. It was a lovely summer morning, the sky a resounding blue. Butterflies dreamed erratically over the blossoming shrubs along the path. As I entered the cool, dark ward, I shivered slightly.

Mary's bed and her little green Bird were just inside the door. I can recall every detail. The white uniform of the wide-eyed Chinese sister, very still against the dingy yellow paint. The other patients going on, ostensibly, with their daily routine, ordering lunch from the menu, checking off their tattslo to numbers, talking in punctuated voices against the regular sighs and groans of their respirators. The color television, picture reversed to allow them to watch in their overhead mirrors, blaring out a commercial for somebody's margarine. Mary lying grey and silent, looking at me as I gingerly approached her bed and sat down beside her helpless body. "Sister said you wanted me to come down?" I looked her in the eyes, wanting to get this over with as quickly as possible.

Mary was unable to make a sound, but the movements of her lips were unmistakable. "Turn it off." And again, "Turn it off." I had been hoping that there had been some mistake. Perhaps the Asian girl had misunderstood. Now there was no doubt. There could be no other interpretation.

I stood up and walked out to the office, hands thrust deep in the pockets of my white coat. What now? Suddenly I felt that something was very wrong. Something about Mary's face made me turn around and stride back to stand by her side. "Mary, do you know what you are asking? Are you seriously wanting me to turn your respirator off?" As I spoke I pointed at the little Bird as it sighed quietly and rhythmically next to her bed. Mary followed my gesture with her eyes, then looked up at me and vigorously shook her head.

"Turn off the television," she mouthed. The sound from the set above her bed was loud and strident. I looked across at the Asian sister, who moved softly around the bed and reached up to

the array of buttons. There was sudden silence. Mary's expression was almost impossible to read, but I thought I saw in her eyes something which may even have been the beginning of laughter.

As I left the ward I was paged on the intercom. "Ring Intensive Care, will you, Doctor?" The patient with tetanus had arrived. I put down the telephone and turned towards the I.C.U. It was going to be another late night.

It was one month later, while I was finishing lunch, that I heard that Mary had died, quietly and without warning, while the nurses were adjusting her position in bed. Her two daughters bumped into me in the corridor a short time later. They looked sad, but peaceful. "Thanks for looking after Mum," one of them said. I watched them as they walked on towards the ward. I stood there for some time. Then I turned away, shrugged, and looked at my watch. I was already late for a lecture.

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Institutionalization VS.

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Erasing the Scars of Institutionalization

by Prudence Sutherland

SPECIAL

FEATURE

My experience in independent living falls into three stages: preparation, moving, and what is known as "doing it," which is the day by day running of your own life in the community with the aid of Personal Care Attendants (PCA) and other support systems.

For me, the preparation for independent living began with my decision to leave the health care facility in which I was a patient and to live in an apartment in the community. The decision had been long in coming. I had always assumed that independent living was not for me, not so much because of the severity of my physical handicap—others more physically disabled than myself were "doing it"—but, because I had always been something of a scatterbrain, my mind adrift in the gossamer realms of philosophy and poetry, leaving the mundane routines of life to those whom I sensed were more competent to deal with them.

Besides, I had always had a tendency toward loneliness and, whatever the drawbacks of the health care facility, at least there were always plenty of warm bodies around. The relative isolation of an apartment did not appeal to me.

For some years I took pleasure in the relative freedoms my health care facility allowed its patients. As time went on, however, those freedoms were severely diminished. A casualty of cost-containment policy, my chronic disease hospital transformed itself into a short-term rehabilitation hospital. The quality of life for the patients plummeted.

I, too, had changed. I became more and more aware that, under a sweet-smiling veneer of cordiality, the staff regarded the patients, not as human beings like themselves but, rather, as specimens to be charted, medicated, and psychologically maneuvered into doing what was deemed therapeutically sound. I saw, too, that

patients, with some exceptions, had developed in response to their institutionalization a passivity and a preoccupation with the routines of their nursing care and were consequently uninterested in their fellow patients. What the staff had become angered me; what the patients had become frightened me. From the time I woke in the morning until I fell into an uneasy sleep late at night, I was extremely frustrated and depressed.

Suddenly a turgid wave of bitter anger at my handicap engulfed me. Cut off from life and weird, because a few cells in my brain had been dead when I was born, while my able-bodied friends freely congregated to enjoy themselves—I hated it all. Self-pity can be lethal; it can also be the impetus to growth. My latent anger terrified me. I had always thought of my handicap as a gift by which I had come to know extraordinarily good people and through which I had gained tremendous insights. I did not want to hate that gift. I did not want to be bitter. At that point I saw clearly what the environment of the hospital was doing to me. There were no longer any two ways about it: I had to get out.

That decision was the start of the preparation stage in my independent living. The next step was to enroll in the necessary training. A number of the patients at the hospital were taking courses in independent living skills offered by Independence Unlimited, a Project of New Horizons, in Hartford. A considerable part of the preparation stage involved finding out what was and was not available, what could and could not be done, and what were my own abilities and limitations.

Since a number of patients were to be trained at the same time as myself, the team from I.U. held our classes at the hospital once a week. Initially we were taught in a group, but gradually this method gave way to one-to-one sessions with each member of the team. The group sessions frustrated me, because there were as many levels of competency as there were people, and a lot of time was spent on details which I considered myself to have mastered. I was, if anything, overmotivated. I had a great sense that this was my last chance to make

Prudence Sutherland, poet and writer of science fiction, spent 10 of her 39 years in a chronic hospital before moving to her own apartment. She studied philosophy and anthropology at Central Connecticut State U. Disabled by athetoid cerebral palsy, she writes with a headstick.

Independent Living

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something of my life and that I had better do my damndest. The thought of failure was unbearable.

It was unfortunate that the group situation added to my apprehension, for my anxiety was already monumental. The very course material frightened me. Interviewing a potential PCA who was intent on ripping off my stereo, sending home a drunken PCA at ten in the morning and thus being without aid until seven in the evening, firing a PCA caught stealing — Jesus!

A rather major area was omitted from the team's discussion of PCA management, namely, that of computation of the weekly payroll. In my case the omission was fortunate, for had I had the necessity for all that math flung in my face right then, I probably would have given up the idea of independent living. My attorney explained both the legal ramifications and the mechanics of withholding social security and employment taxes. I have mastered math on the typewriter quite adequately and kind of enjoy working out the problems. Before I type or dictate the checks, I have a trusted PCA go over my work with a calculator. Having a PCA help with the payroll is not suggested procedure, and one must use keen judgment when choosing the PCA who is to help with that responsibility. Yet you have no business hiring a dishonest PCA whatever his or her duties.

The enormity of the tasks involved in independent living and the potential for serious mishaps assaulted me with a nagging depression. My caseworker assured me that my depression was not pathological and expressed repeated admiration of the way I kept making an all-out effort even though I was depressed. Nothing was going to stop me.

Despite my depression, there were many moments of humor which made the weekly I.U. sessions highs for me. The members of the team became my personal friends, and our relationship was no longer that of client and caregiver. These friendships helped me to see that I was a real person instead of a pathological specimen. My relationship with the caseworker who has C.P. was, and remains, especially meaningful. Much less disabled than myself, she is married

and has an engaging twelve-year-old son. Again the rebellion against the accident of my dead brain cells rose within me. Yet she and I were able to talk about my envy of her and, with such sharing, a deep, abiding bond of affection developed between us. My sessions with the team were marked by laughter and camaraderie.

In an effort to complete more of the preparation on my own, I asked one of my friends to take me to inspect some apartments especially designed for the handicapped. Torrent House (which fast became known in I.U. circle as Torment House), a housing complex in Plainville, had a number of such units, available under Section 8 housing, and they were our first stop. The



Prudence Sutherland.

tiny, box-like rooms dismayed me; the crampedness would drive me berserk in no time. As an accommodation to the handicapped, the toilet was especially high. The only problem was that I need an especially low toilet. I was discouraged, and our next stop, housing for the handicapped in Wethersfield, did nothing to renew my enthusiasm. Again the cubicle-like quality dismayed me.

I was sitting in my room one mid-June Friday afternoon when both caseworkers appeared,

barely able to contain their glee. "We think we've found you an apartment, and right now we're going to kidnap you to take a look at it." We drove to a newly rehabilitated block in Hartford and there, at the top of a gently sloping ramp, was a luxuriously rambling apartment, with long hall, modern kitchen, and four huge rooms with sedate woodwork. Other than the ramp, the apartment had no special adaptations. The toilet seemed perfect. I fell in love with the apartment immediately, although I had a cloying suspicion that it was too good for me.

My mother was rather overwhelmed. "I sort of knew this was in the offing, but it all seemed so ephemeral." My caseworker liked that word. My mother arranged to come down the next week to meet with my caseworker and inspect the apartment. When my mother came, my caseworker did a yeoman job of reassuring her that independent living was a viable alternative and was not some harebrained scheme her daughter had pulled out of her typing helmet.

Now began the most crucial part of the preparation stage. The patient who had first put me in touch with I.U. helped me place an ad for PCAs in the classifieds, took the phone calls which came in response to that ad, and translated my speech during the ensuing interviews. Without his help my independent living would be but a dream.

Although in our I.U. sessions we had done vast amounts of role-playing, the real interviews came as a shock. I.U. had not prepared me for the fact that the majority of applicants would see me as mentally retarded and not in charge of the situation, as if the interview were an elaborate exercise in make-believe. An interview still saps all my energy, for, besides the strain involved in dealing with a total stranger, you must be alert to every little detail about the applicant which might indicate the kind of PCA he or she would be. Even today, with numerous interviews behind me, the process exhausts me.

Before the August date on which I was to move, I had hired three extremely competent and affable PCAs; my schedule called for four.

Many disabled people have only one or two regular PCAs. I prefer to spread the work among a greater number of PCAs; this not only saves wear and tear but provides me with a wider spectrum of social stimulation, very necessary in apartment living. I have fifty-six hours per week of PCA care, out of which, in principle, I recommended that no PCA work more than sixteen hours.

I am fortunate enough to be able to pay my PCAs well. A good PCA is worth nuggets and should be treated as such. A bad PCA should be fired as soon as possible. Furthermore, if PCAs are well paid there is less turnover, which makes the need for recruitment and interviewing less frequent. Sadly, the majority of the disabled have no control over what they pay their PCAs, as the funds come from the government and are usually the minimum wage. A good PCA works hard at a job which requires much skill physically and psychologically, yet their contribution is widely regarded as menial labor.

Part of my instruction in PCA management involved several "PCA Manuals," handbooks published by various Centers for Independent Living located in many parts of the United States. With the exception of their guidelines for writing a PCA contract, I have found these manuals, for my purposes, essentially worthless. Basically the manuals portray the PCA as a person wary of being overworked by an insensitive, tyrannical employer. This may be the reality of many such relationships. While "doing it," however, I have never come across one single problem to which any PCA manual had the solution.

Next to the question of hiring PCAs, my biggest problem was finding someone who would sign the checks I wrote. In my case, the problem was finally solved only because I had the right connections and was able to find someone who is willing to perform the services for a nominal fee. Yet the problem remains an aching gap in the support system required by the disabled who live independently. Those who perform the services professionally charge prohibitively. Some disabled people resort to the use of a rubber stamp to sign their checks, dangerous as the method is. Some widespread and practical

solution to the problem of how the severely disabled are to sign checks must be achieved if these people are to live successfully in the community.

The team from I.U. took me on several shopping excursions to furnish my apartment. I hired one of my PCAs, her boyfriend, and a van for a day (afterwards they refused to accept the pay!) to check out the Salvation Army Thrift Shop, and my mother generously both procured most of my kitchenware and saw that a driver delivered my meager furniture from storage in Cambridge, Massachusetts.

Music has always been extremely important to me. At the hospital, however, I could never hear the lyrics properly, because of the patients' blaring television sets. I was bound and determined to purchase a decent stereo before I acquired the washer and dryer my mother had recommended in its place. After all, one of my PCAs had said she would take my laundry home, but had not volunteered to stay all day to sing to me. The Friday before I moved, the O.T. and I set off by ourselves to explore Sears audio center. Buying the stereo was indeed exciting, and with it we bought my faithful if somewhat erratic clock radio.

I also acquired another longtime dream, a sleeping bag for nightly use. A sleeping bag eliminates the need for my PCA to tuck in my covers, a maneuver which, due to my thrashing, may come undone in the middle of the night and cause much cursing. Furthermore, my bed does not have to be made in the morning, which makes a big hit with the PCA. In this, as in other aspects of my plan for independent living, the I.U. team fully encouraged me to do my own thing as I had designed it, and their expressed confidence in me vastly increased my confidence in myself.

The preparation stage had ended; the moving stage was now to begin. The greatest two faults in my moving stage were that, at the time of my actual move to the apartment, I did not have a roommate, and none of my adaptive devices had been installed. I worked out a convenient arrangement to have my roommate work

a number of hours a week as my PCA. Since services performed at night constitute PCA care, I find it only fair to pay my roommate for offering such services, which are then less grudgingly given. If you pay a PCA to live on the premises, you may take half that pay plus half the rent plus half the utilities as a tax deduction. Again, most disabled individuals cannot afford the luxury of paying for night services.

It was a few weeks after my move before a roommate presented herself. To fill the gap, members of the I.U. team at first took turns staying overnight with me. To me, initial round-the-clock coverage like theirs should be a vital part of every transfer from institution to community. In such a transfer you undergo a malaise similar to cultural shock. The sudden aloneness combined with the simultaneous shouldering of numerous responsibilities can be, at the least, disorienting, and, at the most, devastating.

Initial round-the-clock coverage was imperative in my case because of my lack of adaptive equipment. My list of devices included an electronic door-opener for the back door, an adapted phone, a bathing device, and supports for the toilet which proved unnecessary. Ideally, my move should not have taken place until I had all those devices; however, the times were far from ideal. We had the dismal alternative of having me wait ten months in the harmful environment of the hospital.

I was extremely lucky in that the devotion of the I.U. team and of my PCAs and of my sister, who stayed with me the second week after I moved, enabled me to make it through the first few months without the devices. At first, of course, I was unable to let my PCAs in, hence somebody had to be here at the times a PCA was expected. The O.T.'s strict injunction never to let PCAs have housekeys was rapidly abandoned; we have not been sorry. A number of PCAs stayed overnight with me and were duly compensated.

By October a device with which I could answer the phone was installed; by November I had

the door-opener; by January the phone had been adapted so as to allow me to make phone calls, and by June a specially invented horizontal shower was in daily use. Not a long time to wait for so much freedom and joy.

The final and ongoing stage is "doing it." I have been "doing it" for over a year now. Some aspects of "doing it" have been easier than I had anticipated, others harder. My PCAs are far from the silent paranoids portrayed in the PCA manuals. They are definitely on my side, warm, friendly, and supportive.

An interesting facet of independent living, which is essentially an adult activity, is that at times I feel the need to be nurtured, rather like a child, to be spoken to softly, to be reassured that I am doing a good job, and to be gently led to make improvements in my life. In a way, this is the antithesis of the self-direction which is the guiding principle of independent living. Yet another major principle is self-acceptance, the recognition and affirmation of your personality traits, your strengths and your weaknesses. I must accept my need for nurturing and not view that need as detrimental or regressive. A small number of my PCAs, to whom I have become exceptionally close, have fulfilled my need for nurturing.

One of my worries has been PCAs who give too much; they work during their coffee breaks, work overtime and refuse payment for it, and do not let me pay them for the gas used when I have them drive me places in their cars. Good-hearted people like that are so easily taken advantage of that I must be scrupulous in my fair treatment of them.

On the other hand, through a kind of lethargy, I tend not to ask for help that may be legitimately asked of a PCA. The lethargy is only one of the scars left on me by institutionalization, scars that will take a long, long time to heal. My perception of myself and of the interaction between myself and my environment has been made faulty by years of restriction and dehumanization which, in turn, has warped my interaction with others. Institutionalization and

the effects of my disability have blemished my perception of every aspect of my existence from that of my body image to that of my destiny. I must accept this. I still experience pain when someone says to me, "You're acting so gauche because you've been institutionalized," as if that had been a shameful circumstance. Yet the judgment is valid, and I am fortunate that my friends are so honest with me. Rather like the effects of living through a war, the marks of institutionalization must be worked on actively through the healthy experiences and normal relationships which independent living makes possible. Psychic rehabilitation takes time, and that its outcome will be fortuitous must be accepted on faith.

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Living in an Institution and Changing It

A tiffany lamp lights Clayton May's room. If you visit him, he'll probably offer you a drink from his liquor cabinet, cooled with ice from his fridge.

The surroundings are so cosy that you will find it hard to believe that you are in a hospital. But Clayton has been a resident of the polio wing of the Aberhart Hospital in Edmonton for 10 of the 25 years he has been living in institutions.

Situated opposite the University of Alberta Hospital, of which it is a part, the Aberhart Hospital is an old TB hospital surrounded by hills and trees.

Of its eight residents, seven use respirators at least part of the time. The hospital also runs a respiratory home care program, and a number of other beds are kept for people with respiratory problems who need short-term treatment.

The residents, like all polio survivors in Alberta, are covered under the Polio Act which provides them with a guaranteed income and hospital accommodation and treatment at no charge.

The wing is almost completely free of the

regimentation and sterility usually associated with long-term care hospitals. Residents have their own furniture. If you tour the rooms, you will see carpeted floors, antiques, stereo systems, a benjamin tree, and even an aquarium.

Many of the people run businesses. Clayton is currently a broker for a vegetable grower.

One of the standard complaints of residents in chronic care wards is the rigidity of the hospital time table. Staff are often unable to accommodate people who want to leave early in the morning and return late at night. If they are not there for meals they simply have to go without.

This is not the case at the Aberhart Hospital where people may go out early and return late at night. If meals are missed, they have access to a microwave oven.

Dr. Neil E. Brown, the wing's administrator, says that there are few limits "providing residents do not infringe on other people's rights and freedoms." He adds that there has to be a certain amount of give and take between staff and patients. "If someone comes in at 2 a.m., they cannot expect the night staff to drop everything and put them to bed immediately."

Several of the residents have cars and many of them are frequent travellers. An executive director of the Canadian Wheelchair Sports Association, Gary MacPherson frequently flies across the country.

In 1983, residents of the unit travelled to St. Louis for the Rehabilitation Gazette's International Post-Polio Conference. Clayton and Gary have also organized two trips to Hawaii for the group.

How did such freedom come about? According to Dr. Brown, "It was more evolution than revolution. When people started asking for fridges and furniture in their rooms, we said, 'Why not?'"

Dr. Brown says that staff attitude is an important part of the way the hospital/wing is run. "Staff listen to residents and often act as patient advocates. They're like members of an extended family."

Clayton and Gary have pushed for many of the changes over the years. According to Clayton they "developed a philosophy of doing things

first and asking for permission later. It's easier to get forgiveness than permission. When staff found out things didn't come to an end when we did something new, they were willing to give us more freedom."

There appears to be very little turnover among the staff, who are frequently doing small favors such as washing and shopping for residents. Every Thursday afternoon residents and staff get together for a tea.

However, patient's privacy is respected. When someone's door is shut, staff do not come in.

Obviously, the wing is not without its problems. Dr. Brown says it is often difficult to maintain the home-like atmosphere when there are



short-term patients coming in who need active care. Clayton would like to see people socialize more while Gary feels there is still not enough privacy.

Despite some complaints, both men want to continue to live at the Aberhart Hospital. Gary sums up his feeling, "I'm single, I have my own private room and come and go as I please, but

△ Clayton May, Alberta, Canada.

when necessary I can quickly go from a living situation to a medical one."

Could units similar to the polio wing be developed in other hospitals? Dr. Brown believes that they would work well in chronic care hospitals. "However, they would be difficult to establish in active treatment hospitals without special funding."

How can residents of chronic care hospitals establish greater freedom? According to Gary, "There's strength in numbers. Just let administration know what they can do to make the place more livable. Then keep hammering away."

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Can Life Be More Livable in an Institution?

by Audrey J. King, M.A.



Audrey J. King, M.A., wheelchair by respiratory polio, is a consultant in the Psychology Department, Ontario Crippled Children's Centre.

Admission to an institution often means fear and despair, especially for those physically dependent persons whose minds remain alert and active. In return for the physical care provided by a

chronic care facility, residents usually surrender personal freedom and control of their lives.

We know that not every chronic care "patient" has the potential or the interest to become a fully functioning self-actualized person. But many, regardless of severity of physical limitation, do, and much latent potential actually goes unrecognized because of the lethargy and apathy that so quickly engulf a person once control of self is surrendered. Rules and schedules, established by the administration to maximize staff efficiency and trim costs, must be strictly adhered to. Personal privacy and opportunities for self-expression are sacrificed as rooms are often shared with others, not of one's choosing. Space is limited and the decor reflects the sterility of the institution.

Must institutions continue to be cold, impersonal human warehouses? Why aren't we looking at the reasons why people dread long-term care hospitals, and advocating changes? Why aren't we lobbying to improve the lives of those who remain in institutions year after year — people with active minds, forced into hospitals because the community has failed to provide sufficient living options for them. We have paid more attention to the psychological needs of animals in zoos than people in chronic care.

Making institutional life more palatable does not mean upgrading the bricks and mortar, and it goes beyond improving the staff/patient ratio. It requires careful consideration of the relationships between staff and patients. There must be respect for the basic physical, environmental, and emotional needs inherent in every human being. Improvement requires recognition of the fact that true independence is a state of mind, and not of body. Institutions must give physically dependent persons the opportunity to exercise their basic human rights and freedoms in a setting which is, after all, their only home.

"Not possible," you say? It is possible, and it has been happening for many years in the polio wing of the Aberhart Hospital in Edmonton. Much is to be learned by their example.

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Two Views Opposing Segregated Housing

Judy Heumann

Housing for people with disabilities is one of the most crucial issues to be addressed by the leaders of the independent living movement. People with housing problems are coming to the offices of independent living centers who need accessible housing that is also affordable.

People may want to move out of the family home, a nursing home, or another institution. People may want to move from one place to another for various reasons: they have married and need a larger home; they have become disabled and need to move from their home into an accessible home; they are moving from one area to another area, etc.

Many of these individuals need housing help; they are not in need of independent living skills training. They may also need other support services such as attendant referral, but are able to live in their own homes without additional training.

How can the independent living movement address the housing need? Should funding be sought for transitional living programs? Should funding be sought to build housing units for disabled people? Should funding be sought for internal and external modifications on buildings? Should policies be changed at the local community level or the state level or the national level?

The independent living movement must address the long-term implications of the housing issue. Is one of the goals to ensure maximum integration of disabled people? And what is the definition of integration to be used? Is compromise possible? Is the construction of facilities that will not allow non-disabled people to rent in the housing complex facilitating integration?

If we are willing to support "separate but equal" facilities, who fights for a broad-based governmental policy which demands that the housing needs of disabled and elderly people be addressed with the goal of integration? Why do we seek 202 funding for construction of segregated housing units instead of lobbying for fed-

eral and state funds to modify people's existing dwellings or increasing rent subsidies so that people can stay in their current dwellings? Are those of us in the independent living movement who support the construction of these dwellings actually going to live in them?

Recently, in Berkeley, California, the Gray Panthers and the city government aligned to develop 202 housing for the elderly and disabled. This ghetto, when and if constructed, will have 169 units and cost at least \$9 million. Of these units, 10% will be for disabled people and the remainder for elderly people. Only 10% of the units will be accessible. Only one two-bedroom unit will be available, and that is reserved for the manager. It is not centrally located near shopping centers.

Disabled individuals in Berkeley met many times with the developer, arguing for a smaller building with fewer units, for all the units to be made accessible, for more two-bedroom units, but to no avail. The response was that the present federal regulations would kill the project.

We decided in part to have these discussions because of our hope to either file a lawsuit against the 202 projects because of their segregation policy or advocate federal legislation to change the policy of renting to only disabled individuals. We decided we would attempt to get a facility built which could in the future be useable by all people. The tragedy is that other human beings are going to have to live in this ghetto who wouldn't prefer to, but will, only because it is affordable and minimally accessible.

If \$9 million were given to non-profit community-based service organizations for the elderly and disabled, hundreds of ramps could be built, hundreds of interiors could be modified, and hundreds of rents could be subsidized to allow people to live with dignity in an integrated setting within their communities.

In 1954, the Supreme Court ruled in *Brown vs. Board of Education of Topeka, Kansas* that "separate but equal" was not equal. This case began to put an end to segregated educational facilities and programs for black children.

Thirty-one years later, too many of our leaders are still rationalizing why "separate but

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equal" housing facilities must be accepted. Too many are still saying that while it is not ideal, there are few alternatives.

The leaders of the movement must state finally that they will not tolerate segregated housing for any reason and put their energies behind an effective program which will ensure that reasonable, affordable, accessible, integrated housing is developed for all people within our country.

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Colleen Starkloff, P.T.

Housing for the disabled is big business for some agencies and organizations. It means federal construction dollars for the developers and guaranteed rent payments through rental subsidy dollars for the owners. For some groups, such as social service agencies or parents' groups, it is protection and the future for their disabled clientele or their sons and daughters. For many parents, it is the answer to the question, "What will happen to them when I'm gone?" But, for thousands of people with disabilities, housing is a dead-end street.

Unfortunately, the problem of housing for the disabled has been dealt with in the same way as other disability issues in the past. Out of well-meaning concern for the disabled, organizations, agencies, groups, and corporations have devised a concept of an accessible environment, specially designed for disabled persons alone, or the disabled and elderly collectively.

Some of the buildings have as many as 100 or more units, while others are as small as 12 units. Some offer group meals, transportation services, organized recreation, 24-hour attendant services, or any combination of these. Some offer none of these.

However, all offer some degree of accessibility — from minimal access (according to the U.S. Department of Housing and Urban Development's minimum design standards) to maximum

access with variable height countertops and cabinets, modern appliances, useable storage, and wheel-in showers.

This type of housing provides a residential complex for a group of people, all of whom need accessibility. It is easier for the developers of these complexes to build one building with many units than it is to go out in the community and make many scattered units accessible. It is easier to provide services if everyone is in one place.

There is an unfortunate and outdated notion that disabled people need to be around other disabled persons for moral support because they have so much in common.

It is true that a large number of people seek out such housing because they want to live among the disabled. However, if one looks at their reasons and observes what happens to them after they have lived there awhile, one may begin to understand why disabled leaders are so opposed to segregated residences.

People who have been in special programs and overprotected all their lives feel that it would be safer to live in a housing complex for the disabled. Safer because everyone else is disabled, and, presumably, will understand and accept them. And safer because they have had little interaction with non-disabled people and the real world.

But, after living in such housing, they become disenchanted. It is not all one big, happy family. They find that they do not necessarily have things in common with their disabled neighbors. They find that they are lonely and that there is nothing to do. The personal growth that most people experience through daily interactions with others is missing. In short, they find out that lack of accessible housing was not really the whole problem, and having an accessible apartment, therefore, is not the whole solution.

People who have been isolated, overprotected, discriminated against, and stripped of their dignity and self-esteem are not suddenly going to be happy, contented, productive citizens just because they have accessible housing.

The fact that these complexes are filled up is testimony only to the fact that there simply is not enough affordable, accessible housing

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available. Growing numbers of people with disabilities are leaving their families' homes or institutions to live independently in their communities. Unfortunately, many are relegated to segregated public housing since that is where the greatest number of accessible apartments with affordable rents are to be found.

Transitional housing is related to the segregated housing issue. This is housing which is usually organized by a non-profit organization, such as a social service agency for the disabled, a rehabilitation institution, or even by some independent living centers. Its purpose is to provide housing and training in daily living skills or independent living skills in order to prepare a disabled person to live in the community. The length of time that a person stays in transitional housing varies according to the program set up by the operating agency, but it is intended to be temporary.

There is much controversy within the independent living movement with regard to the value of transitional housing. From my experience, I believe transitional housing is unnecessary. It is just one more delay in getting on with real independent living.

In transitional housing, supportive services are provided, including attendants. The operating agency oversees the program. It is safe. It is a protected environment that still is not the real world. If an individual has been dependent on a rehabilitation facility, nursing home, or parents and family members at home, he or she will simply transfer dependency to the transitional living facility, forestalling the ultimate confrontation with the realities of community living or the responsibilities of true independence.

Disabled leaders around the world concur. Ed Roberts, co-founder of the Berkeley Center for Independent Living, reminisced recently about his experience in California in the late 60s. "When we first began organizing ourselves, we thought that transitional housing was the way to go. We abandoned it when we realized that it was not reflective of what it was really like to live in the community. People had to start all over again after leaving a transitional program. It made more sense to start right away by changing the environment they were presently in or creating a

new one. The experience gained through that process is invaluable for self-reliance and self-advocacy, and does not relegate one to dependency on a program all the time."

The recent experience of HAIL (Holistic Approaches to Independent Living), the independent living center in Denver, demonstrates what Roberts was talking about and provides an excellent example for those contemplating starting a transitional living facility or presently running one.

When HAIL first began a transitional living facility over three years ago, they contracted for five apartments in a HUD 202 apartment complex. Mark Johnson, who was responsible for the operation of the program, explained what happened. "Initially, we felt we were meeting the needs of the individual and the family. Although true, it was also easier for us to have people in one place and provide services. As more people with head injuries successfully re-entered the community, we began to question the need for our transitional living program. We began to provide transitional services instead of maintaining apartments. After demonstrating to ourselves and the community at large that we didn't need it, we closed the transitional living program after three years of operation. In those three years, we strengthened our intake, independent living services, and case management."

HAIL has demonstrated that a well-developed service delivery program makes a transitional living program unnecessary.

Charlie Carr, Executive Director of the Northeast Independent Living Program in Lawrence, Massachusetts, points out another pitfall of transitional housing. "In order to maintain the apartments, you get Medicaid reimbursements, which come with certain restrictions. In order to maintain a cash flow, you have to keep the 'beds' filled, which can restrict the flexibility of your program. It becomes a 'tail wagging the dog' situation. There is no question that it is harder to help a person get out into the community without transitional living, but if we are really going to help people learn to take control over their life situations, we cannot use transitional housing."

Max Starkloff, Executive Director of Paraquad, Inc. and President of the National Council of Independent Living Programs, developed a HUD Section 202 apartment complex in St. Louis in 1976. He is adamant about what his experience has taught him.

"Segregated housing doesn't work. There is no form of segregation that works. You cannot segregate people and expect them to grow and be productive members in our society. The isolation already experienced by millions of people with disabilities is magnified by segregated programs.

"If we don't take a stand right now against segregated housing or any other form of segregation of the disabled, we will continue to send a message to society that it is all right to separate and develop specialized services for people with disabilities. The independent living movement nationwide is demonstrating every day that disabled people, no matter how physically disabled they are, can live independently and in a totally integrated environment."

Segregated residences and transitional living facilities are no more than simplistic answers to a very complex problem. Disabled persons seeking community living and independence can accomplish their objectives through the services offered by non-residential, community-based independent living centers that are directed and staffed by people with disabilities.

At these centers, one can find peer support and role models who can provide valuable services. If one only needs accessible housing, the center makes a housing list available. If one needs preparation for community living, services such as attendant management, budgeting, daily living skills, self-advocacy, attendant and housing referral, etc., may comprise a program which enables that individual to create a new lifestyle. Peer counselors show the way, step-by-step, and the disabled person begins at once to pursue independence.

Although independent living centers and other disabled advocates have had a dramatic impact on housing issues, there is still more to be done. HUD needs to lessen the amount of paperwork and restrictions surrounding Section 8 rent subsidies, so that more landlords of pri-

vate housing stock might be encouraged to accept Section 8 tenants.

Disability organizations need to educate their communities on the importance of integrated housing and push for dollars, currently spent on residential and transitional facilities, to be used to encourage more integrated housing.

Organizations running transitional and segregated housing facilities could provide a greater service to their clientele if they would put their energies and dollars behind programs that would enable disabled persons to develop self-sufficiency and independence.

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Independent Living Centre in New Zealand

by Vivian Naylor

The concept of independent living, from its roots in Berkeley, California, in the early 60s, is now spreading worldwide, and New Zealand is no exception.

Since September 1981, Auckland has been the base for a unique facility in New Zealand. The Independent Living Centre there combines the advantages of a permanent exhibition of a wide range of aids and equipment, together with a comprehensive information service.

More than 500 aids, which help relieve difficulties experienced in all facets of daily living, are currently exhibited at the Centre. They have been donated by their manufacturers, importers, and inventors, and are for display purposes only. None are for sale or hire. Occupational therapists are available to give unbiased advice as to the most appropriate aid to suit a particular problem or disability. There is no sales pressure, as the Centre gains nothing financially. Having a variety of similar aids in one place saves the disabled person the hassle of exploring the market. Information is given on where the aid can be purchased, its price, and any grants for which the applicant may be eligible. Apart from a

central display of aids, there is a demonstration kitchen, bedroom, and bathroom. A unique telephone assessment facility, worked in conjunction with the Post Office, demonstrates equipment suitable for both physically and sensorily handicapped people.

In addition to the display, a register is being developed of existing and potential inventors of aids. The register also includes resources within the community where such aids could be made or adapted for a particular individual.

Information is a vital prerequisite for independent living, and it must be readily accessible. The Information Service at the Centre sees itself as a first port of call, preventing the tedious and exasperating runaround so frequently experienced by disabled people. Whether newly disabled or the parent of a newly disabled child, chasing information and advice can be an intolerable and often impossible burden.

Queries are on a wide variety of topics; local, national, and international: from accessible restaurants in Sydney to financial help on buying a car; from wheelchair hiring in Honolulu to possible local employment outlets; from accessible holiday accommodations in London to where a publication can be obtained. One inquirer wanted to know if a certain station on the BART system was accessible.

Additional functions include setting up education and public awareness programs as the need arises; counseling services; serving as liaison with libraries and appropriate community agencies; and researching areas of social policy and advocacy where necessary.

We launched a Dial-a-Ride pilot scheme, and this is proving invaluable. No form of public transport is accessible, and financial help from the government is only available to those who are gainfully employed. It is estimated that 11 in 1,000 New Zealanders cannot use public transport.

Apart from the above mentioned services, the Centre houses the local chapters of the Arthritis & Rheumatism Foundation Inc., the Spastics Society, and the Multiple Sclerosis Society. The meeting rooms and facilities are available to member organizations and, for a fee, to outside bodies.



Vivian Naylor with wheelchair manufacturers at the Independent Living Centre in Auckland.

The fact that other organizations are housed at the Centre illustrates the unity which is beginning to emerge within New Zealand among disabled groups. Initially, the concept for such a facility came from the Auckland Co-ordinating Council for the Disabled. A concerted effort of fundraising, through telethons, service clubs, charitable trust funds and private enterprise made the Centre a reality. Fundraising is an ongoing concern, with some government assistance through subsidized employment schemes.

With the merger of Rehabilitation International NZ, National Council for the Disabled, and Disabled Persons International, disabled people are more readily able to voice their needs and opinions at government level. Information services are also better co-ordinated, resulting in less duplication of effort.

If *Gazette* readers are thinking of visiting New Zealand for a holiday, please write to the Centre for accommodation and traveling assistance. We would like to hear from similar Information Centres in other parts of the world, for such a link up would help disabled New Zealanders travelling to other countries. 福

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SCI Mother: My Pregnancy

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Lee Bryant, R.N., C7-8 (incomplete) quad due to an automobile accident in July 1978, was born in 1953. She received her nursing degree from Southeastern Missouri State U. Lee married Tom Bryant in December 1977.

Some of my experiences with pregnancy are relevant to me as a spinal cord injured woman while some are relevant to all disabled women. I'd like to share my adventure in the hope that I may give someone else the encouragement necessary to try pregnancy.

I knew there was no physical reason why I couldn't become pregnant. However, I didn't become pregnant the minute I quit using my birth control device. My husband, Tom, and I relaxed and enjoyed my being free of another form of medical intervention. When I least expected it, I suddenly realized I might be pregnant. I missed one menstrual cycle, but I waited another two weeks to use an early pregnancy test, which was as positive as I expected.

In September 1982, I wrote my personal physician in St. Louis (120 miles away) with the good news. His main concern was that I stop taking all my medications immediately because of possible side effects on the fetus.

I was living in Rolla, Missouri, a small college town with a 100-bed hospital, and I felt sure there was a well-qualified doctor locally. I found a wonderful doctor with thirty years of active practice and an electric lithotomy table. Finding that type of exam table was pure luck since diagnosing pregnancy, besides urine tests, requires a full pelvic exam.

The electric lithotomy table is an exam table that folds and tilts in such a way as to present itself like a highbacked arm chair. With the pushing of the controls, the chair/table rotates from vertical to horizontal and unfolds flat in the leg section into an exam table. It has calf supports instead of stirrups. All I had to do was transfer to and from wheelchair and chair/table for examinations.

I read up on pregnancy to prepare myself. A book I had on female sexuality and spinal cord injured women warned of: increased possibility of pressure sores; increased chances of urologic

infections; problems maintaining adequate nutrition for the developing fetus and mother; autonomic dysreflexia masquerading as eclampsia (a serious and nasty complication in pregnancy); and physicians who want to perform cesarean sections because they wrongly believe the uterus is paralyzed because the patient is.

During my rehabilitation process, I had asked the doctors about pregnancy and was warned with very stern looks and negative body language that I shouldn't even think of it. Later I became friends with an orthopedically disabled woman who uses a wheelchair. She had given birth "naturally" during the mid 60s and 70s. She had told me that although with each of her pregnancies, there was talk of a cesarean section, it was not needed and in general she had no real problems. Talking with her had given me great confidence.

I remembered from my nursing lectures the comparison of the automatic function of the uterus to the heart. When the uterus decides it's time to kick in and work, it does. However, during second stage after approximately half of the baby is out of the uterus, the uterus cannot shrink fast enough to finish pushing the baby by itself and needs help from the rest of the body. It was for that part of the delivery my obstetrician warned me that he might need to use a low-end forceps delivery. My doctor viewed a cesarean for me as a *last resort*.

Anesthesia was another area for concern. Epidural anesthesia is famous for eliminating all sensation to the pelvic region and leaving the mother alert. My doctor and I agreed during our first conference that I didn't need or want any form of anesthesia that involved my spinal cord.

Areas of concern were diet, water weight gain, bladder infections, and low blood pressure. My goal was to stay as healthy as possible and to have a healthy baby.

Diet was a big problem. No one in rehabilitation ever discussed how many calories a day I needed to avoid weight gain and maintain good nutrition. Most obstetricians prescribe prenatal vitamins. Protein requirements are high for women, but for pregnant women the need climbs

and Delivery

by Lee Bryant, R.N.

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even higher. I learned exactly how much milk, eggs, yogurt, cereal, and/or cheese I had to eat each day to maintain an adequate protein intake.

A common problem is water weight gain. The ideal is low water retention, low blood pressure, and a healthy baby. The body increases its blood volume by approximately one-third because that's where the body is feeding two. I avoided salt, sugar, and fats to prevent the retention of fluid. My blood pressure stayed low and I didn't spill protein into my urine. I gained 30 pounds and lost 40 within ten days of delivery.

For once in my life I was drinking enough fluids, 6-8 glasses of water or milk a day. I use an indwelling catheter and the "crud" rate increased early into my pregnancy so I increased my catheter changing schedule to once every two weeks.

Getting weighed at regular intervals was necessary. I weighed myself at home, and then reconciled the home scale with the office scale. Tom weighed me on his weekends home, and I faithfully reported the amount to my doctor. When Tom was available, we'd do a spot weigh at the office.

Overall, I found these special problem areas to be normal areas for concern that just needed twice as much attention and planning on my part.

Tom and I wanted to enjoy as much of the labor and delivery together as possible. I started looking for a childbirth class when I was four months pregnant.

Tom was 4½ hours away in Fayetteville, Arkansas, attending another college to finish his degree faster, so he was only home every other weekend and school holidays from January through June. The local public health nurse who conducted childbirth classes took us under her wing and we began lessons in my fifth month on weekends when Tom was in town. In May, my eighth month, Tom and I were able to attend two regular childbirth classes together.

The highlight of such classes tends to be a tour of a maternity unit, a chance to imprint the memory cells with which door to enter and how to tell the hospital "we're here." For me, the tour



Lee and Tom Bryant with daughter Christine Marie, born June 16, 1983.

awoke all sorts of fears buried from long in-hospital rehabilitation. I talked with the class leader, who in turn talked with the head floor nurse, who then had an inservice class for her staff to make them more sensitive and aware of my possible needs. The head nurse also set aside a bed in the largest room to give my wheelchair negotiating space.

Finally my due date came. Labor started on June 16, 1983. I called Tom and told him to come home. Because of the 4½ hour drive, I didn't want him to come home for a false start so I asked that he call halfway home. Two and a half

hours later when he called, I knew I was in full labor and ready to leave for the hospital as soon as I got off the phone.

I drove to the hospital, suddenly becoming aware of how exhausted I felt. What I didn't know was how fast a labor I was having. When I got to the maternity floor I collapsed into the care of the staff, too weak to make the last transfer from wheelchair to bed by myself.

I began doing slow controlled breathing to stay calm, since I could feel my contractions and was subconsciously worried, but the controlled breathing was working. I had managed to talk my doctor out of an enema and into agreeing that a suppository would be effective enough, but even that doubled my blood pressure and gave me one grand slam of a headache. This is when Tom arrived.

My membranes were still intact and bulging with every contraction, so the doctor tore them and I was complete in 45 minutes. As the baby continued into transition, second stage, and began to crown, I was still in the labor bed. The baby was putting pressure on the nerve group going into my right leg, causing a nasty shooting pain with every contraction. Tom and I were breathing in harmony, and he would help me position my right leg to minimize the discomfort. I couldn't have kept count without him. Things were going so well we began to think we could deliver in the labor bed, but when I would bear down the baby's head would barely crown. The fetal monitor showed the stress the baby was experiencing so we all quickly agreed to try the delivery table.

With the delivery table to hold onto and Tom to coach and support my shoulders, my bearing down brought excellent results. I delivered without forceps, but did get a pudendal block for the episiotomy, headache, and leg pain. Suddenly we had a beautiful baby girl who squalled like a cat. We were able to hold her

in the delivery room. She had lots of hair, measured 21" long, and weighed 7 lbs., 12½ ounces. We named her Christine Marie.

Six and a half hours of labor had produced a remarkable baby girl and the end of my pregnancy. I was no longer a mother-to-be; I was a new mother. My pregnancy had served to take me through a transition. It was my rite of passage, a rewarding experience that I'm ready to attempt again, as soon as this baby is older. 福

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ED: G.I.N.I. is gathering material for a handbook on the experiences of SCI women with pregnancy and delivery. The editors would appreciate contributions from *Gazette* readers around the world. Address: 4502 Maryland Ave., St. Louis, Missouri 63108.

Religion and Disability

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How Shall the Door Be Opened?

by The Reverend Nancy Chaffee, M. Div.

I was ordained an Episcopal priest on April 10, 1984. Historically, the church has ordained persons with hearing and vision impairments, but rarely have they ordained persons with more visible physical disabilities. My disability is cerebral palsy. Although it is very mild, it is visible in my hands and somewhat in my speech. This was an outstanding event in my life, but also in the life of the Church. The Church is making a statement which says that we recognize and accept the abilities, gifts, and potentialities of persons with disabilities. It is at last a liberation from the old law of Leviticus which says that the blemished shall not approach the altar of God.

The medical profession determined at birth that I would never walk or talk. They continued their doom and gloom throughout 13 years of schooling, telling my parents I would never make it. Yet I went through regular school without any difficulty, receiving above-average grades. My classmates assisted me in the lunch line; my teachers tolerated poor handwriting until I learned to type. My friends of today are some of those classmates; their sense of my presence among them in school is that it helped them to accept the diversity of people and life.

After 12 years of marriage and two healthy children, I decided to attend college so that I could have a career. Although I had worked as a secretary part of those years, finding employment had become impossible due to the attitudes of employers who were confident that I could *not* work.

I had decided that since I enjoyed writing perhaps I could write at home and earn a living without being refused employment. So I applied both to a community college and to the Office of Vocational Rehabilitation. I was accepted by the school, but not by OVR. They stated that with cerebral palsy I could not learn or probably hope to find employment. Their expectations did not match mine. Through the efforts of the school's financial aid director, I was able to begin school, and we secured the aid of OVR later. I at-

tended that school for 3½ years, taking creative writing through the Women's Studies program, a program which exposed me to the academic knowledge of oppression.

I graduated with an A.S. degree and a desire to continue my education. Too many new horizons had opened before me; I had begun to discover other interests and a desire to do counseling work in the area of grief and terminal illness. One of my professors at the community college



The Rev. Nancy Lane Chaffee.

Photo by: Ray Axelson

happened to be an Episcopal priest to whom I had addressed questions of interest and concern. Through him I learned of new possibilities and was encouraged to pursue them. I also came to the Episcopal church as a result.

I was accepted at once by Wells College in Aurora, New York, for the B.A. program in religion, which provided opportunities for grief counseling. Once again, OVR said no, and another struggle ensued, and was won.

Wells was a major turning point in my life. The professors there treated me as a capable, thinking adult. They expected me to be able to learn and to use the tools of that discipline to grow, to achieve, and to claim my gifts and use them. What an experience that was for me!

I began to feel very capable, and to at last feel I could say what I wanted to be. I wanted to be a priest; I wanted to answer the call which I knew I had had at the age of 16.

I had many reservations about being taken seriously by the Bishop. So I was prepared to work in terminal illness, providing sacramental ministry and counseling in a quiet, out-of-the-way place, where I would not preach, be at the altar, or be in a parish. I went to the Bishop, asking to proceed through Canon 10, whereby one does not attend seminary, works out of their home parish in the community, and is not paid! But the Bishop said no. He said instead that I was to go to seminary and to seek the ordinary route to ordination.

At the end of my first semester in seminary, I took the psychological tests which are required by the Commission on the Ordained Ministry. Shortly after, a letter arrived with the recommendation that I was suited for ministry, but that I did not accept being disabled. I was furious. How dare they define me or my experience. It was true that I did not always like being disabled, but that was not the same as not accepting it.

I was not accustomed to having my experiences affirmed, so I decided I had to check them out, and had to arm myself with scholastic ammunition that would not get shot down. I enrolled in the seminary class on Ministry with Persons with Handicapping Conditions, taught by the Rev. William Gaventa. The required reading list was all new to me, and I literally dove into those books with a hunger to learn. Those books affirmed my experiences, experiences which I had denied as well, e.g., embarrassment, shame, fear, feeling that it was up to me to accept the ridicule, the discrimination, and the negative remarks and/or expectations of others. At last I was discovering that I did not have to, that I had a right to be angry about those things which hurt, and yes they did hurt! To be a person is to have the right to hurt, to be angry, and to have desires and hopes as everyone does.

Most significantly the books explained the

difference between liking and accepting disability. One does not have to like having cancer, or pneumonia; one does not have to like losing a loved one through death or divorce. But nevertheless we do have to accept these things. Just so with disability; we do not have to like it, but we accept it by getting on with the business at hand, living life in the best way we can, whatever that may be for us. Acceptance does not come with being perfect. Perfection is a limitation, and it prevents the power of God from working in and through us. *We are the image of God.* God is not limited to that which we call perfect. How liberating that was for me, to know that I was in the image of God! I did not have to be ashamed, I did not have to feel less than I was.

Nevertheless, there will always be those days of frustration, pain, and grief for the real or perceived image of who/what we would like to be . . . more able, better-abled, etc. There is a tension between liking and not liking, between accepting and not accepting. We are frail human beings . . . *all of us* . . . not always able, not always (if ever) perfect. Grace makes it possible for us to walk that fine line. Grace lifts us out of the self-pity. It meets us at the point of real discouragement and propels us forth anew.

Presently, I am Director of our Diocesan Ministry with Persons with Disabilities. I spend most of my time preaching to the churches in our diocese about developing their own ministry with persons with disabilities. I also do workshops and lectures on consciousness-raising, etc. We stress the need for accessibility in our architecture (e.g., buildings), our communications (help for the hearing and vision impaired), and in our attitudes. The demands on this office and the response are overwhelming.

Persons with disabilities have been too long shut out of our church life, our community life, and our corporate life. They are eager to be a part of the ongoing life of the church, to participate by sharing their gifts and abilities with us and for us. Disability is not something particular to a few, but is a universal condition, for it will affect most of us in some way. For too long the church focused on disability as sin, sickness, or the shame of "differentness." We are moving

toward healing, toward acceptance of the diversity of God's people, and toward affirmation of all God's children.

My ordination, the being of a priest, has come about because of the affirmation and positive attitudes of many who accepted me and encouraged me to develop spiritually and academically. My limitations are accepted for what they are, merely more visible and perhaps somewhat different than those whose limitations are invisible.

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Address: The Rev. Nancy Lane Chaffee, Director, Office of Ministry with Persons with Disabilities of the Diocese of Central New York, Box 261, DeWitt, New York 13214.

Relations Between Disabled Persons and Their Churches

by *The Reverend Nancy Chaffee, M. Div.*

The clergy are a large, but often untapped, resource for disabled persons and their families. Finding ways to enhance the roles of church and clergy in the lives of disabled persons is the goal of the Project on Disability and the Clergy. Dr. Louis J. Heifetz and Dr. Stephen T. Murphy, associate professors at the Division of Special Education and Rehabilitation at Syracuse University's School of Education, are collaborating on the Project.

One of the Project's first steps is to examine the great variety of ways in which the clergy has been involved with families of disabled persons and with their secular service providers. With this information, it would be possible to identify factors that promote the successful involvement of the clergy, and other factors that interfere with their successful involvement. The ultimate goal of the Project on Disability and the Clergy is to publish materials for disabled persons and their families, for clergy, and for secular professionals, enabling them to work more productively, complementing and enhancing each other's efforts.

Now in the early stages of its work, the Project would like to hear from anyone whose personal or professional experiences might shed some light on ways to increase the involvement of church and clergy with disabled persons. The experiences of families, friends, and clergy of all faiths would contribute greatly to the work of the Project. Anyone interested in participating should send name and mailing address to Project on Disability and the Clergy, P.O. Box 261, DeWitt, New York 13214.

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The Healing Community

by *Gini Laurie*

The Healing Community is a national, ecumenical resource center for religious groups concerned with increasing awareness, involvement, communication, and integration of persons with disabilities.

The center was founded in 1973 by Rev. Harold Wilke, who currently serves as its director. Dr. Wilke, who was born without arms, is an ordained minister, author, professor, lecturer, editor, husband, and father of five sons.

Dr. Wilke formerly headed the United Church of Christ Council for Church and Ministry. He has taught at the Menninger Foundation School of Psychiatry, in the Department of Psychiatry and Religion at Union Theological Seminary, and has spoken in 37 countries and all 50 states.

A board comprising world leaders in religion and rehabilitation sets its policy and works with local units across the country. Its purpose is "to help congregations become accessible in attitude, architecture, and communication to persons with disabilities."

Information on creating local units and a list of the publications by Dr. Wilke is available from Healing Community, 139 Walworth Avenue, White Plains, New York 10606. Two publications are especially useful to congregations planning to make their facilities and programs accessible: *Creating the Caring Congregation* and *The Open Congregation*.

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Polio Survivors

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Bill Pirtle

Emma and I had been married a year and we had a 2½ month old son when I contracted polio in 1952 in Burlington, Iowa. We moved to Bartonville, Illinois, for treatment at the Institute of Physical Medicine and Rehabilitation, and Emma got a job with the *Masonic News* while I spent two years undergoing therapy.

The state Division of Vocational Rehabilitation paid my tuition at Bradley University and I graduated with a construction engineering degree.

My first job was as a draftsman. For five years, my fellow employees lifted me (I'm 6' 4")



Bill Pirtle, Mayor of Bartonville, Illinois.

Photo by: Linda Henson,
Peoria Journal-Star

from my car into my wheelchair and carried me up two flights of stairs. Now I am an engineer for a heating and ventilating company.

Things are different today. Everything is much more accessible. Nobody has to carry me up and down. People are more understanding, not sympathetic. People today understand that disabled doesn't mean you can't work. We've all come a long way.

I am the mayor of our town (6,200 population) as well as a member of the board of directors and past president of the Institute. I am also a member of the Forest Park Foundation and I've served as president of our school board.

Our son, Bob, is 31 years old and married to a great gal. He is a sheet metal worker and owns and operates his own business.

Our daughter, Betsy, is 29 years old and is married to a Methodist minister. They have twin sons, Jamie and Joel, age 7, who are our great pride and joy.

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Address: Bill Pirtle, 3935 South Paramount Road, Bartonville, Illinois 61607.

Kim Stevens Husby

I had polio when I was three years old in October, 1948. I was hospitalized for only nine days. My neck, back, and legs were stiff. I had pain and fever and was unable to walk. Hot packs were used and physical therapy was prescribed to strengthen my legs. That winter I couldn't hold my ankles straight enough to ice skate well but I struggled on.

I have struggled with life for as long as I can remember. I have given up, given in, and given out. I never could manage to hold a very good job because I felt I should start at the top. I simply did not understand why I couldn't belong and be appreciated, so I began to increase my drinking to ease the pain and loneliness. In March of 1977, I finally drank myself right into a hospital where I almost died.

In June of 1977, after ten years in Seattle and being newly sober, I returned to my hometown in South Dakota with my two daughters. My parents loaned me enough money to get an apartment and I began to look for work.

After what seemed an eternity, I got a full-time job as an employment counselor. I earned more money than I ever had before and received several achievement awards.

In February of 1979, I started having serious problems with my lower back and had to quit working. I had never been able to sit or stand too long and, after my first daughter was born, I spent some time in traction. There had always been a weakness there and when it got too bad, I would have terrible headaches from the muscle spasms. I spent a week in the hospital with trac-

tion and medication. Several months of physical therapy followed, mostly deep heat and massage to stave off the muscle spasms.

Unable to find work, I was forced to rely on Aid to Dependent Children (ADC) and food stamps to support my girls. \$321 per month and \$118 for food were barely enough to allow for necessities, let alone the many other expenses of raising children and running a household. My rent alone was \$210 and I lived in constant anxiety about my financial condition.

In May of 1980, when I began to experience severe pain and cramping in my lower legs and lower arms without apparent cause, I also began to experience frustration and hopelessness. After months of pain and loss of sleep, I went to the hospital for tests. A neurologist did a spinal tap, and muscle activity tests were performed. When nothing conclusive was found, I was again told it must all be in my head. So I saw a psychiatrist and he gave me a clean bill of mental health.

In October I received a notice that the \$321 ADC I was attempting to survive on would be reduced by 10%. With the help of a long-time human rights advocate, we held meetings with other ADC recipients to try to stop the reduction and invited the news media. We printed fact sheets to educate the community about life on ADC. I spoke before community groups. I was interviewed by radio, TV, and newspapers.

At the end of November, I spent a week at the Mayo Clinic being thoroughly evaluated and tested, physically as well as psychologically, and received medication to stop the problem with my legs and arms. I could not get them to definitely connect my prior polio with my current problems but, at that point, just having some relief was enough so I could continue my involvement with the welfare rights.

I attended a legal services conference in St. Louis in December of 1980. In January of 1981, I went to the State Capitol of South Dakota where I lobbied and testified before subcommittees. In March of 1981, I went to Washington, D.C., to participate in a National Anti-Hunger Coalition conference. I enrolled in a two-year degree program at a local community college to become a paralegal, a lawyer's assistant.

Very unexpectedly, my daughter announced her pregnancy, and after the initial shock wore off about being a very young grandmother, we went about our business. (My grandson is now almost three and beautiful!)

Soon after I started my internship in a local law office, the sitting I had done in school and



Kim Husby fought cut-backs to welfare mothers and has organized the Tri-State Polio Survivors Association in South Dakota. Kim with her daughters Erin and Kris, and grandson Jesse.

now at the desk finally took its toll. I went into the hospital again for traction, but was able to return to work in about 10 days, this time with a drafting table in my office so I could stand and do my work if necessary.

In the fall of 1983, a sales opportunity opened and I changed fields. In March of 1984, I married a man who is sensitive, kind, and gentle. He is also ambitious and unwilling to settle for a life without growth.

In May my back did it again and I treated it with traction rented from a local medical supply house and medication from my doctor for the pain and muscle spasms.

While I was in bed trying to undo the knots

in my back, I read an article on polio in *Newsweek*. I called Mayo Clinic, my neurologist, the newspaper, and the TV and radio stations. I want to educate the physicians and the community and organize a support group.

I am getting weaker; the problems in my legs seem to break through the medication some nights, but I can still walk and I can still use my arms. I am fortunate and as long as I am still able, I will continue to do my best to share what I have.

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Edna Maree Moore



E.M. Moore presenting one of her paintings to Texas Governor Bill Clements in 1981. The painting now hangs in the Governor's Mansion in Austin.

I had polio the summer of 1937, at age 5½. My entire body was affected but I did regain almost full use of my right arm. I was treated at Texas Scottish Rite Hospital for Crippled Children in Dallas.

My early years were lived when no one ever thought of disabled people being able to participate in normal activities. Schools were not ramped and many were two or three stories high. It was impossible for me to attend public school. I was tutored at home by my family, and I read and studied the textbooks of my brother and sister. Then I went through school again with a

younger sister. I ran the gamut of arts and crafts trying to find something that I could do.

In 1954 my family moved to the Arkansas Ozarks and I had the opportunity to study oil painting with artist Glenn Swedlun in Eureka Springs, Arkansas. I found I had a talent for color. Painting has been so easy for me; it's as though I have an angel on my shoulder guiding my brush. I studied with Swedlun for four years. He not only taught me to paint but also how to promote and sell my work. He made me what I am today professionally.

We moved back to Texas in 1958. The Texas landscape had more grayed tones than the Arkansas hills I had been taught to paint. I developed my own colors and style to depict the drier, dustier Texas landscapes. Much to my surprise, people liked what I was painting, and I sold my first painting in 1959. I now exhibit and sell in galleries throughout Texas and the Southwest.

I have taught art classes, in my home, for the last twenty years. I have given lectures, art demonstrations, and workshops for art groups throughout many states. I am fortunate I can make a living doing something that I enjoy so much. I am very proud to have E.M. Moore paintings in many prominent places, but the one I am most proud of is hanging in our Texas Governor's Mansion in Austin.

After twenty-five years of art, my life is taking a slightly different direction. Last summer I had very serious surgery and almost died. Life now has a new meaning for me. My priorities changed. I wanted to get out and see what the rest of the world was doing. I did just that and liked what I found outside my studio walls. I now volunteer in the offices of the Texas Department of Human Resources Regional Office. I find it very enjoyable to be with people. I work half-days and continue my art business, too. I have worked very hard for twenty-five years to build a name for myself in the art world and certainly want to keep that going.

I wear bilateral long leg braces and a back brace. I did not realize until recent years that I do have a slight breathing problem. An evaluation in 1984, by a pulmonary specialist, showed that I breathe mostly with my left lung. My right diaphragm muscles do not work well and I breathe at about 50% capacity. So far I manage

with no breathing aids. I tried walking with crutches for a while but decided that was too slow. Then, I went to a manual wheelchair for many years but found that was too much for my weak muscles. For the past six years I have used a motorized wheelchair and a van with a lift and hand controls so I can drive myself. For the first time in my life, this has given me independence as I never dreamed possible. I require assistance dressing and undressing and need help which is provided by my mother and my aunt. The three of us make our home together. Many of my activities would be impossible without them.

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Pat Reardon

(Excerpts from an interview
by Dolores Thompson.)

Pat Reardon, who contracted polio in 1955 at the age of 22 months, is experiencing post-polio problems at the age of 31. After a few days in an iron lung, Pat gradually progressed. By age fifteen, he could walk without braces or other assistive devices.

Pat spent eleven years at the Massachusetts Hospital School, then went to Hilton Head Island, South Carolina, where he got his diploma at a public high school. After that, he enrolled in Massasoit Community College in Brockton. He studied three years and then dropped out. Pat traveled to Europe with a disabled friend. Their disabilities were such that they were able to assist one another.

In 1978, Pat applied for a job as a switchboard operator in a large company. The firm seemed hesitant to hire him — they had no other disabled employees. When Pat did the usual follow-up call after the initial interview, management told him they were not hiring. Pat knew the company was in fact hiring people and training them, and asked to see their affirmative action plan. When they admitted they did not have one, Pat told them he was going to report them. Within two days, he was hired. The only concession in terms of special adaptations for his

disability was a small foot stool to raise his knee, which in turn supported his elbow allowing him to do his work.

Pat stayed there for two years, but left because there was no place for advancement. The only time that the company seemed to single him out was when they approached him about promoting his role as their disabled employee.

Next, Pat became an in-take worker at the Community Service Center for the Disabled. He worked with his peers to help them better cope in such areas as finances, independent living, and emotional adjustment. He then worked for Able-Disabled Advocacy, helping other disabled people in sharpening their skills; this time with the major emphasis on job placement. Pat says proudly that the agency had a high percentage of successful placement.

Pat has a deep, resonant voice which has enabled him to work effectively in radio and television. He first worked in radio as a jazz disc jockey for a campus radio station. Pat did one radio program later which focused on disability awareness in Canton, Massachusetts. There he interviewed both disabled and able-bodied people for their opinions on how they viewed disability. One of the participants was the mayor who used a wheelchair for one day.

From radio, Pat went into television narration. In San Diego, he narrated a documentary film on three aspects of disability awareness: education; adaptation; and recreation. This film was done in conjunction with the International Year of Disabled Persons. Pat was selected as the San Diego County representative in the worldwide effort to focus on disabled awareness.

Pat noticed general weakness in his body in 1979 but feels it may have started earlier. Now, he cannot walk as he once did. He experiences muscle pain. Whenever he goes anywhere that requires a lot of walking, he uses a wheelchair.

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Address: Patrick Reardon, 4437 Kansas Street, San Diego, California 92216.

Mildred Byrd

Unlike most of the polio survivors in the *Gazette*, the polio bug bit me in 1910. I was eleven months old, so I never really learned to walk. Polio affected my legs, back, and left arm. The disease was not understood at that time, so nothing was done to correct my paralysis until I was almost six. My parents moved to St. Louis, and I entered the St. Louis Children's Hospital (part of Barnes Hospital). Two years later, after many operations and much rehabilitation, I was equipped with two leg braces and crutches. I remember how proud my family and I were that I could finally "walk."



▶
Millie Byrd, champion bowler.

At age eight, I was allowed to start school in the first grade. The other children accepted me after they got over my being "different." I was determined to catch up with my age group and ten years later, I graduated from high school at age 18. More operations had been performed during summer vacations.

After graduation, I worked a year doing hand sewing in a children's dress factory and saved some money. With help from my parents, I went to a small Methodist college in Wilmore, Kentucky. I only finished two years as the 1930s were depression years. I worked a while, then married and subsequently divorced.

I returned to St. Louis and got a job in the same factory, taking a secretarial course at night school. I passed a civil service examination and, since this was about the time of Pearl Harbor, I easily got a job as a clerk-typist in the Finance Office of the Army in St. Louis.

During this time, I became a charter member of the Mid-West Polio Association. I met my present husband, Bob, there. Later we discovered that he was disabled by encephalitis at age 5, not by polio. We were married in 1944 and in 1947 our son, Roland, was born.

We bought a small neighborhood grocery store in Coffeyville, Kansas, and tried to make it work, but finally had to give the store up. We moved to Wichita when Bob took a job as a machinist at Beech Aircraft.

We had started a disabled club in Coffeyville and it is still going strong. We also helped start a club in Wichita, and though we are not too active in this club, we are both active bowlers in a league of 52 disabled bowlers. I bowl with an aluminum ramp, but Bob can bowl by standing at the line.

Bob is still working for Beech and we are active in many things. I have arthritis in my shoulders and have given up the crutches for a wheelchair. We live very independently and still do most of our work ourselves. We celebrated our 40th wedding anniversary on Easter Day, 1984. We have lived happy and productive lives. 福

Address: Mildred & Bob Byrd, 2157 Bedford Rd.,
Wichita, Kansas 67207.

Sandy Goldstein

Right before my sixth birthday, during a hot summer in Kansas, I came down with polio. That was nearly 35 years ago. I was left with both legs paralyzed and scoliosis of the spine. I get around very well with a wheelchair, drive my own car, and I do most of my own housework — time and stamina permitting. My life has been full, and I have remained active through the years. After high school, I attended business college for a year. I worked in Kansas City, Missouri, for about five years and those were the years, in the 1960s, when being disabled and finding a job were very difficult.

It was in 1967, in Kansas City, that I met my first husband. He was in the Army and the thrill of my life came when I flew to Honolulu, Hawaii, to marry the special man who later became the father of my son. I had a hard time making that trip, as the airlines in Kansas City didn't want to let me fly alone in case of an emergency. Finally, I found an airline that agreed to take me.

We were transferred to San Antonio, Texas, in 1971 and in 1977 my husband died. At 34 I found myself in shock and afraid of the future. Those first few months were very hard on both myself and my son. He was only eight and couldn't understand why his daddy had to die. We managed on our own with very little help from friends and practically none from family. I knew that I had to manage on my own, and I kept busy and tried not to think about being scared. The loneliness was unbearable at first; I felt as though a part of me had been ripped away.

Later on, I felt that I very much needed someone in my life again and I remarried, but that ended in divorce as I couldn't live with a man who drank too much alcohol. I think, in some ways, the divorce was much harder to go through than the death was.

In October 1981, I had two surgeries on my back and I was in the hospital for a month. My scoliosis was increasing and my doctor performed a spinal instrumentation and fusion. It has taken a long time to recover from those 14 hours of surgery. It has been nearly three years now and I am finally nearly free of soreness and pain if I don't overdo.



Sandy Goldstein, corset-maker

Life is easier for me now with loads of experience behind me. I am happy and I keep busy with my son and activities and with our business ventures. Life really does begin at forty!

My son, Mark, is a tall young man of 15. He has taken on the responsibilities of an adult at times and he is a great help around the house. I have tried to teach him to be self-sufficient, to respect others, and to be helpful.

My son and I are in business (MARK I ENTERPRISES), and I work from our home making custom-made lumbosacral supports and corsets, and doing repairs and alterations. People are referred to me mostly by doctors and brace shops. I enjoy what I am doing and it gives me a great feeling of satisfaction to know I'm helping others with something they need so badly. 福

Address: Sandy Goldstein, 11013 White Sands, San Antonio, Texas 78233.

Polio Support Group

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One day a month in communities across the United States, groups of men and women gather to discuss how they deal with the late effects of polio. They are part of the growing number of support groups which aid people whose needs are not met through established health care and social service programs.

Polio support groups are vital to persons experiencing post-polio problems who need information, medical treatment, and emotional support. Nancy Frick, a polio survivor who spoke at "Polio Update, 1984" at Helen Hayes Hospital last October, describes the need firsthand. "Because of real physical distress from an unknown

and solutions, and to find relief and comfort through the interchange.

This interchange is the essence of the support groups and the dominant purpose of the groups. Other purposes include the education of the medical community and the general public, encouragement of research into the late effects, the promotion of worldwide immunization against polio, and the relating of polio problems to the problems of other aging disabled persons and to all aging persons.

Gazette International Networking Institute (G.I.N.I.) has acted as the coordinator of support groups around the country when they formed after the *Gazette's* first international post-polio conference in Chicago in 1981, and has organized the Greater St. Louis Polio Support Group and a national coalition of polio survivors.

The following is a summary of suggestions for organizing future polio support groups, based on the experiences of these first groups. **Nucleus.** All it takes is a phone call by one or more polio survivors for the initial meeting. Others can be reached by arranging announcements on local TV and radio stations and notices and feature articles in local newspapers.

Sponsors. Ask local voluntary organizations, hospitals, medical societies, and independent living centers or rehabilitation institutes to be sponsors. Build as broad a local base as possible. Form a consortium of sponsors. Start with Easter Seal Society's local chapters. They can be very helpful in providing a meeting place, sending out notices, and assisting with publicity and names of survivors, as can March of Dimes chapters. Hospitals, medical societies, and rehabilitation centers are invaluable as a source of speakers and as potential location for a polio clinic.

Place and Time. Try Easter Seal Society's local chapter and/or March of Dimes local chapter first, then ask other sponsors. Check out the location before the meeting to ensure both accessibility of the meeting room and adjacent restroom facilities, and accessibility of the garage for vans with raised roofs.

Start with a meeting on Saturday morning at 10:30 a.m. Ask the survivors to bring a brown bag lunch so those who want to stay on and talk



St. Louis polio support group meets at the Easter Seal Society of Missouri.

source, persons who had polio went to all types of physicians only to learn the medical community had no idea what was happening to them. Often these people were told nothing was wrong, that they would get used to pain or even that they were 'crazy.' Conversely, others were diagnosed as having multiple sclerosis, amyotrophic lateral sclerosis, and even muscular dystrophy.

"In short, no real medical assistance was available to thousands of persons experiencing very real, dramatic, and debilitating problems. In addition, these persons had to deal with the psychological trauma created by having a new disability on top of an old one . . . alone and with no idea of what was happening to them."

Support group meetings are an outlet to vent feelings, a place to share mutual problems

Guidelines

by Gini Laurie and Judith Raymond

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among themselves can. Then plan monthly meetings with occasional social events such as a Christmas party for the December meeting, a summer picnic, etc.

Refreshments. Have coffee available before the meeting. Serve soft drinks and coffee at lunch. Bring an extra lunch for the speaker. Ask someone to bring cookies for dessert.

Spirit. Keep the meetings informal, casual, friendly, and small. A group larger than 30 people inhibits the ease of interchange. For large metropolitan groups, perhaps a solution would be a formal presentation to the whole group by a special speaker once every quarter or every other month, with smaller groups organized geographically by suburb meeting monthly.

Try to avoid an auditorium and a lectern. Meet in a comfortable circle with the speaker seated in the midst.

Remember that it takes time to establish a foundation of trust and cohesiveness among attendees; time to feel at ease with one another.

Speakers. The speaker's warmth and concern are of the utmost importance. Look for a physician or a physical therapist who had polio. If not, feel your way until you find a professional person (physiatrist, neurologist, pulmonologist, orthopedist, or physical therapist) who will talk and listen, not pontificate. Plan for no more than 5 or 10 minutes of opening remarks, then allow the speaker 1 to 1½ hours of questions and discussion.

First Meeting. Set the pattern for future meetings with name tags and a sign-in list for attendees to provide name, address, and phone number. Distribute a page listing a choice of topics to be covered in future meetings: adjustment; aging; bracing; diminished function; equipment; exercise; fatigue; health maintenance; immunization; muscle weakness; nutrition; pain; resources; respiratory problems; and stress. Leave a space for checking interest in a swimming program. Start the meeting by asking each person to introduce him or herself and tell the year polio was contracted and which hospital, respiratory or rehabilitation center where treatment was undergone.

Organization. Most groups confine their activities to mutual support and sharing. Officers, by-

laws, dues, and non-profit tax-exempt status are not necessary for a successful support group, but a few have elected to organize. One group meets only via mail, coordinated by a polio survivor working in an independent living center.

Funds. If the group is not formally organized with membership dues, ask each attendee to contribute at least \$1 at every meeting to cover mailing notices, coffee, and soft drinks.

Notices and Minutes. Mail out notices two weeks before the meeting. The notice can be as simple as a single mimeographed sheet, or a postcard, listing the speaker and the affiliation. Try to repeat the names of the sponsors.



Dr. Oscar Schwartz, fourth from left, answers questions during St. Louis polio support group meeting.

More elaborate newsletters will develop as the group assumes its own peculiar nature and increases its sophistication.

For those who are unable to attend meetings, the group may decide to tape the session and make the tape or a transcript of the information available. The other alternative is finding a dependable and competent group member to serve as a recorder.

Swimming Programs. Swimming is one of the best forms of exercise for polio survivors. Easter Seal and similar organizations should be approached to sponsor a swimming program, after the locations of accessible, heated, supervised swimming pools have been determined.

Brace-Makers Directory. Use the collective experience of the group and the advice of physical therapists and orthopedists to compile and distribute a list of local cooperative and

reasonably priced braccemakers.

Physicians' Directory. Compile and share a list of the local physicians and physical therapists whom the group members have found the most concerned and knowledgeable.

Polio Clinic. If the group has involved a broad range of sponsors and has reached the local medical community, a clinic will evolve naturally in due course. Ideally, the support group and clinic should work in tandem, sharing, exchanging, and reinforcing.



Address: G.I.N.I., 4502 Maryland Avenue, St. Louis, Missouri 63108.

• Information •

Handbook on The Late Effects of Poliomyelitis for Physicians and Survivors, edited by Gini Laurie, Frederick M. Maynard, M.D., D. Armin Fischer, M.D., and Judy Raymond. ©1984. 48 pages. \$5 postpaid (\$6 outside U.S.). *Proceedings of Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability, May 6-8, 1983, St. Louis.* ©1984. 72 pages. \$15 postpaid (\$16 outside U.S.). *Rehabilitation Gazette* (Volumes 23, 24, 25) \$8 each postpaid. Available from G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108. (314) 361-0475.

Late Effects of Poliomyelitis, edited by Lauro S. Halstead, M.D., David O. Wiechers, M.D. ©1985. 236 pages. \$1795 postpaid. Available from Symposia Foundation, 1480 NE 129th St., P.O. Box 611857, Miami, FL 33161.

Proceedings from Polio Update 1984: A Medical Education Conference For Health Professionals and People Who Have Had Polio. Helen Hayes Hospital, Friday, October 12, 1984. 12 pages. \$2.00. Available from New York Easter Seal Society, 2 Park Ave., Suite 2000, New York, NY 10016. (212) 532-8830.

Oakland Post-Polio Western Conference, 1984, December 1-2, 1984. Audio cassette tapes. Tape #P1 Aging with Polio, Degenerative Arthritis. Tape #P2 Osteoporosis, Scoliosis. Tape #P3 Exercise & Energy Conservation. Tape #P4 Breathing, Pulmonary Complications. Tape #P5 Late Progressive Weakness. Tape #P6 Attendant Care. Tape #P7 Respiratory Information, Coping. Tape #P8 Physical Therapy Workshop, Technical Aids. \$7 each postpaid, or \$52 for entire conference. Available from Stuart Sweetow, Audio Visual Consultants, 1440 Broadway, Suite 422, Oakland, CA 94612. (415) 839-9745.

Polio Clinics • Polio Support Groups • • Resource People •

ARIZONA

* Anna Servino, 1035 E. Carmen St., Tempe, AZ 85283. (602) 838-1344.

ARKANSAS

* Delbert O. Lewis, Arkansas Dept. of Human Services, P.O. Box 3781, Little Rock, AR 72201. (501) 371-2687.

CALIFORNIA

† Sheldon Berrol, M.D., Rehabilitation Medicine Service, GC4, San Francisco General Hospital, San Francisco, CA 94110. (415) 821-8642.

* Peter Belton, 1015 Duncan, San Francisco, CA 94131. (415) 647-0597.

* Richard Daggett, Polio Survivors Association, 12720 La Reina Ave., Downey, CA 90242. (213) 923-0034.

** D. Armin Fischer, M.D., Chief, Chest Medicine Service, Rancho Los Amigos Medical Center, 7601 E. Imperial Hwy., Downey, CA 90242. (213) 922-7556.

** Jacquelin Perry, M.D., Dir. of Pathokinesiology, Dir. of Rocker Polio Clinic, Rancho Los Amigos Medical Center, 7601 E. Imperial Hwy., Downey, CA 90242. (213) 922-7177.

* Renah Shneider, 350 Vernon, Apt. 101, Oakland, CA 94610. (415) 832-2574.

** Stanley K. Yarnell, M.D., Dept. of Physical Medicine and Rehabilitation, St. Mary's Medical Center, 450 Stanyan St., San Francisco, CA 94117. (415) 750-5762.

COLORADO

* Colorado Post-Polio Education Foundation, Marlene Harmon, 2986 S. Garfield, Denver, CO 80210. (303) 758-4688.

- ** Yagada Franotovic, M.D., Spalding Rehabilitation Hospital, 1919 Ogden St., Denver, CO 80218. (303) 751-9800.

CONNECTICUT

- † Ruth Gregory, State Co-Ordinator, 1830 Nichols Ave., Stratford, CT 06497. (203) 375-5084.
- * Judith Grosner, Southern Connecticut Polio Support Group, 175 Dahl Ave., Stratford, CT 06479. (203) 375-6532.
- * Lucy Yannis, Northern Connecticut Polio Support Group, 46 Sprague St., Hartford, CT 06106.

DISTRICT OF COLUMBIA

- * P-Polio, 5432 Connecticut Ave., N.W., Suite 204, Washington, DC 20015. (202) 244-5700.

FLORIDA

- † Douglas Roy, M.D., 9 Skidmore Rd., Winter Haven, FL 33880. (813) 324-4120.

GEORGIA

- ** Larry McKinstry, M.D., Medical Director, Roosevelt Warm Springs Institute for Rehabilitation, P.O. Box 1000, Warm Springs, GA 31830. (404) 655-3321.

ILLINOIS

- * Easter Seal Society of Lake County Post-Polio Support Group, Joseph Quinn, 1125 N. Milwaukee Ave., Libertyville, IL 60048. (312) 367-1750.
- † Allen Goldberg, M.D., Medical Director, Div. of Respiratory Care, Children's Memorial Hospital, 2300 Children's Plaza, Chicago, IL 60614. (312) 880-4630.
- * Illinois Information Center, Holly Donohue, 2308 Marshall Pkwy, Waukegan, IL 60085. (312) 336-8261.
- † National Easter Seal Society, 2023 W. Ogden, Chicago, IL 60612. (312) 243-8400.

INDIANA

- † Tony Lies, 1140 Hillcrest Rd., South Bend, IN 46617. (219) 267-4590.

KANSAS

- * Alice Mary Blodgett, Kansas Easter Seal Society, 3701 Plaza Drive, Topeka, KS 66609. (913) 267-4590.

- * Anita Siler, Independence, Inc., 1107 W. 27th St., Lawrence, KS 66044. (913) 841-0333.

KENTUCKY

- † Cass Irvin, 304 Kenwood Drive, Louisville, KY 40214. (502) 363-3606.

MARYLAND

- ** Mary Jay Bullock, O.T., Rehabilitation Medicine Dept., Osler 1, Johns Hopkins Hospital, 600 N. Wolfe St., Baltimore, MD 21205. (301) 955-6214.

MASSACHUSETTS

- † Francis Curran, M.D., Dept. of Pulmonary Rehabilitation, Lakeville Hospital, Lakeville, MA 02346. (617) 947-1231.

MICHIGAN

- * Ann Arbor Polio Survivors Support Group, Liina Paasuke, Room EL 3001, Box 050, University Hospital, Vocational Rehabilitation, Ann Arbor, MI 48109.
- † Central Michigan Polio Registry, P.O. Box 552, Mt. Pleasant, MI 48858.
- * Detroit Polio Survivors Support Group, Dolores Wehr, March of Dimes, 17117 W. Nine Mile Rd., Suite #820, Southfield, MI 48075. (313) 423-3200.
- † Grace Joppich, B.S.N., 720 E. Orchard Drive, Traverse City, MI 49684. (616) 946-5126.
- * Lansing Polio Survivors Support Group, Charlene Bozarth, 4815 Arapaho, Okemos, MI 48864. (517) 332-3789.
- ** Frederick Maynard, M.D., Physical Medicine and Rehabilitation, E3120, University Hospital, 1403 E. Ann St., Box 33, Ann Arbor, MI 48109. (313) 764-9401.

MINNESOTA

- ** Mary Codd, M.D., Dept. of Physical Medicine, Dept. of Neurology, Mayo Clinic and Mayo Foundation, 200 1st St., SW, Rochester, MN 55905. (507) 284-2044; (507) 284-8388.
- ** Richard Owen, M.D., Medical Director, Sister Kenny Institute, 800 E. 28th St. at Chicago, Minneapolis, MN 55407. (612) 874-4492.

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MISSOURI

- * Cape Girardeau Polio Support Group, Miki Gudermuth, 1314 Brookshire Rd., Cape Girardeau, MO 63701. (314) 334-1959.
- † Gini Laurie, Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, MO 63108. (314) 361-0475.
- * Greater St. Louis Polio Survivors Support Group, Easter Seal Society of Missouri, Larry Fletcher, 10000 Watson Rd., Suite 18, St. Louis, MO 63126. (314) 821-6001.
- † Oscar A. Schwartz, M.D., Department of Pulmonary Rehabilitation, St. Mary's Health Center, 6420 Clayton Road, St. Louis, MO 63117. (314) 768-8414.

NEBRASKA

- * Nancy Carter, 5647 S. 148 Plaza, Omaha, NE 68137. (402) 895-2475.
- † Terrence Connelly, 402 Beverly Drive, Omaha, NE 68114. (402) 391-7195.

NEW JERSEY

- † Theodor & Shari Dukes, 315 Ewing St., Princeton, NJ 08540. (609) 921-8729.

NEW YORK

- ** Augusta Alba, M.D., Dept. of Rehabilitation Medicine, Goldwater Memorial Hospital, Franklin D. Roosevelt Island, New York, NY 10044. (212) 750-6777.
- † Harriet Bell, Polio Information Center, 510 Main St., Suite A446, Roosevelt Island, New York, NY 10044. (212) 223-0353.
- * Eileen Healy, New York Easter Seal Society, 2 Park Ave., Suite 2000, New York, NY 10016. (212) 532-8820.
- * Easter Seal Society Polio Survivors Group, 974 Kenmore Avenue, Buffalo, NY 14216. (716) 876-6804.

OHIO

- ** Susan L. Hubbell, M.D., Ernest W. Johnson, M.D., Dept. of Physical Medicine and Rehabilitation, Ohio State University, Dodd Hall, 472 W. 8th Avenue, Columbus, OH 43210. (614) 421-3801.

- * Carolyn Melvin, 103 Center St., Coal Grove, OH 45638. (614) 532-7572.
- * Diana Oglesbee, Polios United for Research and Education, 1063 Tabor, Kettering, OH 45420. (513) 254-7917.
- † David O. Wiechers, M.D., 3994 The Old Poste Road, Columbus, OH 43220. (614) 876-2215.

OREGON

- † Glen Reynolds, M.D., Emanuel Rehabilitation Center, 3001 N. Gantenbein Avenue, Portland, OR 97227. (503) 280-4400.

PENNSYLVANIA

- * Delaware Valley Polio Survivors Association, Arnold Snyder, 530 E. Vernon Rd., Philadelphia, PA 19119. (215) 844-5500.
- † Gerald J. Herbison, M.D., Dept. of Rehabilitation Medicine, Thomas Jefferson Hospital, 10th & Walnut Streets, Philadelphia, PA 19107. (215) 928-6567.
- ** Magee Rehabilitation Hospital, Dr. William Staas, Jr., Medical Director, 6 Franklin Plaza, Philadelphia, PA 19102. (215) 665-5099.
- † March of Dimes, 1229 Chestnut St., Suite 101, Philadelphia, PA 19107. (215) 972-0866.
- ** Moss Rehabilitation Hospital, Resource Center, 12th & Tabor Rd., Philadelphia, PA 19141. (215) 329-5715, ext. 2233.

SOUTH DAKOTA

- * Kim Husby, Tri-State Polio Survivors (Iowa, Minnesota, South Dakota), RR 4, Box 19, Sioux Falls, SD 57107. (605) 338-2894.

TENNESSEE

- † Robert Christopher, M.D., Physical Medicine and Rehabilitation, University of Tennessee College of Medicine, 800 Madison Ave., Memphis, TN 38163. (901) 528-5768.
- * Deborah Cunningham, Easter Seal Center for Independent Living, 1177 Poplar Avenue, Memphis, TN 38105. (901) 726-6404.

TEXAS

- * Dallas Area Post-Polio Association, Carol Williams, 7306 La Cosa, Dallas, TX 75248. (214) 386-9427.

- † Justin Dart, Jr., Star Rt. 1, Box 9, Fort Davis, TX 79734. (915) 425-3437.
- ** Lauro Halstead, M.D., T.I.R.R., 1333 Moursund St., Houston, TX 77030. (713) 797-5900.
- * Texas Polio Survivors Assoc., Marie Goodwin, President, P.O. Box 35688, Houston, TX 77235. (713) 729-4037.

UTAH

- † A.A. Boston, M.D., 468 Bringham Circle, Providence, UT 84332. (801) 752-3679.

VIRGINIA

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- ** Marvin Brooke, M.D., Dept. of Rehabilitation Med. RJ-30, University of Washington, Seattle, WA 98195. (206) 543-3300.
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- ** Jane Clay, RN, University of Wisconsin Hospital and Clinics, Highland Avenue, Madison, WI 53792. (608) 263-6542.
- * Bill Hoefer, 552 W. 23978 Glendale Rd., Waukesha, WI 53186. (414) 542-1660.

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- ** Neil Brown, M.D., Respiratory Home Care Program, Aberhart Centre, 11402 University Avenue, Edmonton, Alberta T6G 2J3. (403) 432-6048.
- ** Rubin Feldman, M.D., Physical Medicine & Rehabilitation, University of Alberta Hospital, 8440-112 St., Edmonton, Alberta T6G 2B7. (403) 432-8467.
- † Gary McPherson, Aberhart Centre, Room 7127, 11402 University Avenue, Edmonton, Alberta T6G 2J3. (403) 438-5520.

British Columbia

- † Joy Lynn Kjellbotn, Pearson Hospital, Ward 7, 700 W. 57th Avenue, Vancouver, British Columbia V6P 1S1. (604) 321-3231.

Manitoba

- † Joseph Kaufert, Ph.D., Dept. of Social & Preventive Medicine, University of Manitoba, 750 Bannatyne, Winnipeg, Manitoba R3E 0W3. (204) 786-3798.

Ontario

- † M.G.P. Cameron, M.D., University Hospital, 339 Windemere, London, Ontario N6A 5A5. (519) 663-3513.
- † Audrey King, M.A., Ontario Crippled Children's Centre, 350 Rumsey Rd., Toronto, Ontario M4G 1R8. (416) 424-3827.
- * Ontario March of Dimes, 60 Overlea Blvd., Toronto, Ontario M4H 1L1. (416) 241-4887.

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Access to College Campuses: AHSSPPE

by Alfred H. DeGraff

Until the mid-sixties and early seventies, attending most campuses with any significant disability was an education in itself. One soon acquired field experience as a politician, a jester, and an overall strategist. These skills were learned in the process of conning and cajoling campus faculty and staff into providing accommodations to one's special academic needs. Very few campuses featured any form of formal support service for disabled students who needed "enabling accommodations." These disabled students were on their own in combating barriers of architecture, a lack of technological advances, and, most of all, negative attitudes.



Alfred H. DeGraff has served for more than 10 years as Director of Disabled Student Services at Boston University. He also is President of AHSSPPE. DeGraff became a C-5 quad from a diving injury in 1967, and then entered his freshman year of university studies.

In sharp contrast, today's typical college scene is quite different. Whether a vocational-technical school, a 2-year community college, a small college, or a large university, most post-secondary institutions have recognized that disabled students are not after special favors and waivers, but simply want accommodations which enable equal access to competition . . . equal competition in the academic classroom, in

addition to the equal chance to participate in the recreational and cultural activities of a full campus life.

Most campuses have formally designated professionals to coordinate these services. From college to college, the name of the program, staff size, and variety of available services all differ according to institutional size, geographical region of the country, budget, administrative commitment, and, of course, number and scope of disabled students who attend classes. For this article, a campus office or department will be generically referred to as a Disabled Student Service (DSS).

"How do I find interpreters for my lecture class, and when does the University pay for them?"

"A class I wish to take next semester is now scheduled for an inaccessible building; how easily can the class be relocated so I can attend it in my wheelchair?"

"How can I tell the instructor of my law course that I have a learning disability and therefore write more slowly than other students? I need more time to finish essay exams."

"I am a quad and have trouble writing; how can I get the notes for each of my classes?"

"As a blind student, how can I use the track at the Physical Education Center?"

These are typical questions being heard today by the professionals who staff these DSS programs. The professional expertise required for providing these services is becoming increasingly complex. In the early days, these people studied ways to build ramps over steps, along with how to select the specific support services which should be offered at any individual program. Today, in addition, they are researching such topics as the different methods for the delivery of those selected services; methods which promote skills of independence and self-sufficiency, instead of those which encourage a student's dependency on maternalistic campus programs. International data banks are being established to record, store, and disseminate research results. Publications of various types are being developed to further facilitate the sharing of program innovations and accommodation ideas. Na-

tional and regional conferences bring professionals together to develop new accommodation ideas, delivery methods, and departmental management strategies.

The field has truly become a profession, and a profession which soon found the need to form its own organization: Association on Handicapped Student Service Programs in Postsecondary Education (AHSSPPE).

AHSSPPE (pronounced "ah'-spee") is a national, nonprofit organization of professionals and students from across the U.S., Canada, and other countries. It has rapidly grown from a small group of concerned program directors who met for a conference in 1978. Today, the Association has almost 600 members who represent over 350 campuses throughout 49 states, 5 Canadian provinces, and other foreign countries. Last year, AHSSPPE's membership increased by 33%. Between $\frac{1}{4}$ and $\frac{1}{3}$ of the members are, themselves, disabled; a factor which helps the organization remain truly accountable to the needs of the disabled students which it serves. It has been estimated conservatively that the information available to the membership may benefit as many as 10,000 college-oriented disabled individuals across the country.

The overall objective of the Association is "promoting equal access for disabled students in higher education." It strives to strengthen professionalism, expertise, and competency of individuals who are interested and involved in services for students with disabilities. Several goals have been directed toward the overall objective:

- 1) to encourage the development and expansion of a communications network for those people professionally involved in programs for disabled students;
- 2) to facilitate the collection and dissemination of information on post-secondary education and the disabled student;
- 3) to develop the capability to make timely and meaningful responses to issues and concerns affecting the educational resources and environment of students with disabilities;
- 4) to train personnel about the many avenues of support services necessary for the successful academic and social integration in post-secondary institutions;
- 5) to explore areas of qualifications of indi-

viduals working with disabled students on campuses; and,

- 6) to serve as a resource to individuals currently in the field as well as other individuals and organizations interested in the field.

Benefits to members include the *Alert*, a newsletter, the *AHSSPPE Bulletin*, a journal-like quarterly; the information retrieval system, a comprehensive listing of member resources; the *Annotated Bibliography*, a compilation of published resources; the *Conference Proceedings*, a reference to information from the presentations made at each annual AHSSPPE conference; and the *Membership Directory*, which facilitates rapid communication among members.

In addition, AHSSPPE holds a national conference each year. The most recent conference was held in Kansas City, Missouri, from July 30-August 2, 1984. Over 300 members attended ses-



◀
AHSSPPE conference
registration.

sions for 4 days. Sessions addressed methods for accommodating students with impairments of ambulation, hearing, sight, speech, and learning disabilities. Also included were topics of grantsmanship, conducting faculty in-service awareness, cooperative education, coping with chronic illness, specialized career counseling, pre-college assessment centers, alcohol/drug abuse in disabled students, sexuality and the disabled, special concerns of black and Hispanic students with disabilities, the head-injured student, rehabilitation technology, and managerial skills for the service provider. Parts of the conference were featured on ABC's "Good Morning, America."

The next conference takes place in Atlanta, Georgia from July 24-27, 1985. Further details

about memberships and upcoming conferences are readily available from the AHSSPPE Business Office at P.O. Box 21192, Columbus, Ohio 43221, (614) 488-4972.

In summary, the question might be asked at times whether sufficient rationale exists for the considerable effort and expense of "promoting equal access for disabled students in higher education." There are many such rationales, which are based on ethics, legislation, tax return of gainfully employed citizens, and simply the ever-increasing population of academically qualified people who happen to have disabilities.

Perhaps an equally impressive rationale came from a television commercial several years ago. The scene was an elaborate science laboratory with many counters full of active experiments with bubbling liquids of various colors. Standing at one counter was a tall woman in a white lab coat and goggles. The commercial's narrator said, "Our firm hired Dr. Jones because she is a well-educated, brilliant researcher. Dr. Jones is deaf . . . but we didn't hire her ears, we hired what is *between* them!"

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Address: Alfred H. DeGraff, Boston University, Disabled Student Services, 775 Commonwealth Ave., Boston, Massachusetts 02215.

Texas Colleges for the Ventilator Assisted Student

by Sue Sortor, R.R.T.

Several of our former patients at Dallas Rehabilitation Institute attend or have attended each of these colleges with favorable comments.

East Texas State University is located in Commerce, Texas, which is about 2½ hours from Dallas. It offers a support program for disabled students which includes transcription, test administration, note-taking, and readers. Students are otherwise mainstreamed into the college.

East Texas State has three counselors specifically to assist disabled students. There is

housing designed and designated wheelchair accessible, and equipped to house an attendant.

Attendants are either hired by the college or the student. Financial support is often provided by the Texas Rehabilitation Commission for in-state residents. The counselors automatically seek financial support for all students accepted by the college and in need of special services. Contact Tom Lynch, Mach III Special Services, East Texas State University, Commerce, Texas 75428. (214) 886-5834.

A program closer to Dallas is the University of Texas in Arlington, directed by Jim Hayes. Presently, 72 disabled students are enrolled at Arlington, but not all live on campus. There is about a six-month waiting list for housing. The program is very similar to East Texas State in that students are mainstreamed. The college provides necessary support services which include a full wheelchair repair shop on campus, and attendant care. Contact Jim Hayes, Office of Handicapped Services, P.O. Box 19348, University of Texas, Arlington, Texas 76019. (214) 273-3364.

Texas Jaycee Campus of Victoria College is a community college near Houston. Warm Springs Rehabilitation Hospital is located adjacent to the school. This college was designed specifically for the disabled student.

In addition to earning an academic degree, the program demands that students learn how to live as independently as possible. Strong emphasis is placed on learning the skills needed for living with only part-time attendant care.

Counseling and career guidance is provided to assist students in choosing appropriate four-year institutions at which they may continue their education. If continued education is not feasible, appropriate vocational training programs are recommended after completion of the junior college program. Attendants are on duty 24 hours to assist students in activities of daily living. The level of attendant care received by each student is determined during an evaluation period. Contact Texas Jaycee Campus, P.O. Box 58, Gonzales, Texas 78629. (512) 672-2831, Ext. 270.

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Address: Susan Sortor, R.R.T., Dallas Rehabilitation Institute, 7850 Brookhollow Road, Dallas, Texas 75235.

Sue Sortor, R.R.T., is director of respiratory therapy at Dallas Rehabilitation Institute. DRI is one of the few rehabilitation facilities for the ventilator-assisted spinal cord injured. Respiratory therapists at DRI teach glossopharyngeal breathing so a patient can breathe on his/her own during the day and use a ventilator only at night. DRI tries to prevent unnecessary tracheostomies.

Notes on a Trip to Europe

by John Hessler

It had been fifteen years since my last trip to Europe. My decision to go again filled me with feelings of excitement and trepidation. I once lived just outside of Paris for a year, had traveled around parts of Europe, and so knew of the variety of activities to do and sites to see. I wanted to renew old friendships with the people and the country. I also wanted to visit some relatives whom I had never met.

At the same time, I remembered that getting around older cities was not as easy as it is in California. I am a C5-6 quad and here I have an electric-powered chair, a van that is modified so that I can drive it, the curbs are mostly ramped, elevators are large, and bathrooms are often accessible. In Europe, an electric-powered chair might be a cumbersome, useless object; a modified van seemed out of the question, and I was more likely to run into cobblestones than curb cuts.

I knew one thing for certain: a successful trip would require careful planning. My wife, Jean, our close friends, Shelly and Claire Weissman, and their daughters, Barbra and Gisela, and I would be traveling together for a month. We formed an ad hoc committee on The Trip. Besides being an excellent excuse to get together for dinner, lunch, cake and coffee, the races, travel shows, you name it, we found this an excellent way to understand what we each wanted from the trip. We had long and interesting discussions about what we liked or didn't like, how fast or slow we wanted to travel, and what we felt was worth seeing. We also would decide what needed to be done and who would do it.

Then, at the next meeting, each of us would report on our progress. I consider these meetings to have been part of the trip, and a most enjoyable part at that.

We left San Francisco on June 17, 1984, and arrived in Paris the next day. The plane took off four hours later than scheduled, so we arrived in the middle of the night. We were tired, cold, and

hungry, but hopeful. We had a Volkswagen Vanagon waiting for us in Paris and a rented chalet in Switzerland. These had been arranged for during our year of planning.

Since the van was leased in his name, Shelly went to the nearby van headquarters (a large hotel, open all night) and signed the necessary legal papers allowing him to drive internationally. He was back in about half an hour with the van. Our spirits rose and we knew that transportation would not be a problem for the rest of our trip. We put our baggage in the van. Then we placed the 5-foot folding ramps we had carried in our duffel bag against the side of the van. A few of my companions pushed and pulled my wheelchair with me in it into the van. I fit perfectly, as we knew I would, since we had experimented back home with an identical van and with these ramps. All six of us and our baggage fit beautifully in the van and we headed south to the French countryside and then east to Biel, Switzerland, where the chalet in the Jura mountains was waiting for us.

We had already been up 28 hours and we

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John Hessler mountain climbing to a ski lodge in the Jura mountains with the help of friends.



and imposing monasteries. We stopped at a roadside restaurant and had freshly baked baguette (long thin loaf of French bread) and fresh French cheese. Since we were driving much of the time on the auto-route, we were glad that we had French francs since it cost a couple of hundred francs to cross that area of France to get to Switzerland and there was no convenient place for us to exchange our dollars.



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John arriving at ski lodge.

had another 20 hours to go before we would be in our own "home." As one person drove, the rest of us napped or slept depending on how tired we were or how excited we felt. I for one enjoyed the red sunrise over the green and misty French countryside, dotted here and there with villages.

One of the real pleasures of driving through the French countryside is the fact that the mountains, valleys, and meadows are lush with green grasses or heavily forested with spindly pines. It seems that every valley has an ancient village, its church spires marking the center of town. And on every other hill there is an ancient castle or chateau. There are wonderful roadside inns with cafes or restaurants serving a wide variety of delicious food and drink.

The first city that we visited in France was Dijon. It was early morning of our first full day in Europe and we were hungry for breakfast. If it seems as though I talk a lot about food during

this article it is because that is one of the most delightful and interesting parts of a visit to central Europe. There are accessible cafes and restaurants everywhere. The food is almost always excellent. And away from larger cities the service is almost always friendly and helpful.

Dijon, like every other city that we visited, was a mixture of the ancient and modern. The architecture, especially that of the older buildings, was beautiful but the traffic was noisy and the streets were full of cars going dangerously fast. The air on the main streets was almost unbearably. We went to the downtown area where the sidewalks were wide and smooth. In some places the street came to the level of the sidewalks, making it very easy to cross from one corner to another. But most of the sidewalks and most of the buildings required a lift up of at least one step, if not more. Being in my push chair made it easier for us to enter buildings and I'm sure that we visited many more places, not only in Dijon, but in every other city than we would have had I been in an electric-powered chair.

From Dijon, we headed into the French Jura mountains and crossed into Switzerland in the early afternoon. It was a sunny, comfortable day with cool breezes. It was the first border that we passed on our trip. We, of course, had to pass through the customs gate at DeGaulle airport and show our passports. But this was our first time to cross a border. We were not apprehensive but we did expect at least to have to show our passports and perhaps have some of our luggage searched. When the border guards saw that our Volkswagen van had a Belgian license plate (we had leased the van from a Belgian company) they waved us on through without asking even for our identification. At every border crossing we were either waved right through or merely had to show our passports. Only when coming back into France were we stopped a second time by a second border check several miles into France. That last time we were made to show not only our passports but also the international insurance on the van and the other papers that were required to drive the van.

When we finally reached Biel, 48 hours after leaving our homes in Sacramento, the six of us were delightfully happy to get to our chalet in the

mountains and to discover that the chalet was indeed accessible, although it was up a steep road and required a push up a steep driveway, through a thicket of bushes and trees. I had a ground floor bedroom with a bed seven feet long. I was able to stretch out and sleep and did so until 3:00 PM the next day.

We spent the next eight days visiting Claire's family, the German and French-speaking city of Biel, and the mountains, meadows, and lakes of the region. Claire is from that area of Switzerland and has many relatives there. They took turns showing us around the area, entertaining us at their houses, and taking us out to the local restaurants, shopping, and recreation areas. The downtown area is quite accessible with low curbs and many easily entered stores and shops. The lakefront has a large park, and I saw several young people in wheelchairs and on crutches who were enjoying the scenery and the evening coolness alongside Bielersee, the large lake on the southwest corner of Biel.

The least accessible place that I visited in Biel was that of Pro Infirmis, the local social service program for disabled individuals. I had to have an able-bodied person go up two flights of stairs to let the service providers know that I had arrived for a meeting with them. It had been arranged by phone. A pleasant young man came down to greet me and to unlock the one-story outdoor elevator that would make it possible for me to attend the meeting in a conference room. I learned that Pro Infirmis had been around for 60 years or more and that it had 40% government funding, but I never found out why in all those years Pro Infirmis hadn't come up with a policy to guarantee disabled Swiss citizens access to all its offices. Or, for that matter, why the disabled in Switzerland would let them get away with such discrimination. Ironically, the Pro Infirmis representative handed me a book on accessibility in and around Biel. It was good.

The highlights of our stay in Biel always seemed to have included using the 5' portable ramps or lots of muscle power, whichever seemed to be most useful at the time. One day we took a round-trip boat ride on Bielersee (Lake Biel), which is connected by canals to

Lake Neuchatel and to Murtensee. Entry to the boat was quite easy, since the dock and ramp were all at the same level. However, once on the boat, I had to go down five very steep steps. The ramps came in handy and so did the strength of my friends and the boat stewards. When we got to the other end of the three lakes, we had lunch in Murten, a ring-walled city perched on top of the steep hill.



Another highlight during those first few days was the wedding reception for Claire and Shelly (they decided to redo their marriage vows). The reception took place in a ski lodge perched on the side of one of the famous Jura mountains. The ramps came in handy getting in and out of the van, as they always did every day. However, getting up to the lodge required the brute strength of five strong young men who literally picked up my chair with me in it and carried me up a steep mountain slope and across a grassy meadow to the lodge. Getting up the one step into the lodge of course was a cinch.

The hundred or so participants at the lodge were in high spirits, and after consuming an enormous amount of food and drink began to

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John outside chalet in
Switzerland.

sing, of all things, American songs. I was delighted but somewhat embarrassed that I did not know as many words to the songs as the young Swiss seemed to. When the older folks began to sing, the music and songs became decidedly Germanic. The music and singing went on for hours and culminated in a dance with people holding hands and following in one long line through the ski lodge and out into the meadow and up the hills. It was a "lustiges" afternoon and evening.

Coming down from the lodge we took a steeper but shorter slope. But by now we were experts and made it down quickly and easily. Again, five men holding me and my chair up off the ground walked through thick grass until we reached the dirt and gravel road below.

It was with some sadness that we left in late June. Claire's family had treated us so well, and we loved living in the chalet in the mountains. But I was anxious, too, to go to Austria and to visit relatives of mine that I had never met.

We left on a beautiful alpine summer day with wildflowers in every field, crystal clear sky, and views of snow-capped mountain peaks to the east of us, to the passes that we would soon be crossing.

On our way to Austria we stopped at Brienz, Switzerland. There is a magnificent outdoor museum there which covers hundreds of acres of rolling forested hills. The museum is made up of a number of different styles of houses as they are found in Switzerland. I was told that the houses at their original sites were to be torn down because of some new construction (e.g., highways) and that the houses were taken apart stone by stone, log by log, and rebuilt at this museum. The result is quite extraordinary. It is a feast for the eyes and is done so well that it is very easy to see how people have lived in Switzerland and what they have done to make theirs the good life. For example, in one house a man baked fresh loaves of bread in a large stone oven. In another house a man and his wife made flit lace for curtains and clothes, while in another room a woman worked on a loom as big as the

room that it was in and made beautiful traditionally patterned cloth. My wife, who is a weaver, bought some of the cloth and is making a skirt out of it.

Entering the houses and moving from one part to the other was not easy in the wheelchair. However, with the help of Claire, Shelly, Jean, Tildi (Claire's sister) and Barbra, I was able to get inside several of the houses and visit the various rooms. At one house the caretaker even had a set of ramps to get up one step; however, there were two steps to get into the house. To visit most of the houses, we had to go either up or down somewhat steep dirt and gravel roads. This was not difficult if we took our time and rested. And there were several resting spots on the way.

It was in Brienz that we learned a lesson in accessibility that would prove to benefit us several more times during our trip. The best hotel that we could find had a first floor that was up six very steep steps. Again, the ramps helped us and we were able to negotiate those steps easily. However, on the first floor was the restaurant and lobby. To get to our bedroom, we had to use the elevator. The elevators in most European hotels or buildings are very narrow and not very deep. We discovered that if we removed the pedals from my chair and put a belt around my knees so that I could put one arm under the belt, holding my feet up off the floor while I held my body back with the other arm around the back of the chair, I could be pushed into most elevators with enough room for one person behind me. I must add that I am 6'7" and weigh 230 lbs., so my chair is rather large since it was built to fit me. But I think most people in American chairs would find difficulty in using an elevator without doing something like removing the front pedals. In another elevator in another city I had to take the push rims off the wheels of the chair to get in and use the elevator.

The trip across Austria continued our visual, sound, and taste odyssey. The country itself is long and narrow with impressive mountains, fast running streams, fertile valleys, and an unending supply of guest houses, all with restaurants on the ground floor. This means all the sleeping rooms are at least up one flight of stairs. So when we reached Innsbruck we found a hotel, used the

ramps for the three entry steps, and resorted to our old elevator trick. In Innsbruck we also discovered the only curb cuts on our whole journey.

Farther east, in a small town named Lienz, the local tourist bureau (we always went first to these bureaus, which were usually very helpful) directed us to a guest house that was built on the side of a hill. Several sleeping rooms were therefore made accessible by driving up the hill and behind the building.

In early July we arrived in Graz, a busy commercial and industrial city situated not far from the Yugoslavian border. My cousin Georg lives there with his wife, Margrit, and their daughter, Danielle. We met in person for the first time (we had written and I had called him). He spoke English very well and I felt relieved not to have to rely entirely on my 20-year-old German, even though I had brushed up on it in California and had improved on that somewhat as we crossed Switzerland and Austria. In a nearby restaurant we talked, drank a locally brewed beer, and ate typical Austrian dinners of *Wienerschnitzel*, dumplings, sausages, potatoes, and fresh vegetables. We finished up with *Kaffee mit Schlag* (heavy whipped cream) and a baked dessert made of whipped egg whites, sugar, and fresh berries. It was the richest dessert I've ever had.

A few days later, Georg and family met Jean and me in Lindabrun, a small village south of Vienna. There we had an all-day feast and party with more relatives at what was once my great-grandfather's house, Georg's mother and father live there now. The house is located on a small hill overlooking farmland and forested hills. It made me quite emotional to realize that my ancestors had sat where I was sitting and had enjoyed the view that I was enjoying.

The days at the end of our trip went all too fast. We had a wonderful time in Vienna at the *Volksoper* (Folks Opera) where we saw the "Merry Widow" performed. There are spaces reserved for disabled individuals and the ushers are courteous and helpful. In Salzburg, on the way back to Paris and our plane, we visited the Altstadt. It was generally accessible with handicapped parking and a portable ramp for the steps into the cathedral.

Back in Paris, we spent four days eating well, resting, and waiting for our departure date. I had the pleasure of meeting two different times with Philippe St. Martin of the *Groupement pour l'Insertion des Handicapes Physiques*. We discussed in French the independent living movement and compared progress, or lack of it, in our two countries. We agreed to exchange ideas and information and parted, I think, having lifted each other's spirits about the Movement.

We arrived in San Francisco safe and tired after a long and cramped flight. When I got off the plane, my electric-powered chair was waiting. As soon as I could, I sped off up the jetway ramp and left all the walkies behind. I had had a great time on the trip, but it was good to be home again where the environment was conducive to my freedom.

If I had it to do over again (and I do plan to go back someday), I would still plan ahead as far as possible. The two things I would change are: 1) I would make sure that I did not try to visit too many places. It was difficult on me and the people with me to move so often. 2) I would take a lightweight portable power unit for the chair. There is no substitute for being able to be on one's own from time to time. Either way, though, it is well worth the trip.

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A China Experience

by Ruth Diehl

Our China experience was both adventure and challenge from the beginning. My husband Bob and I have travelled to many distant and unique places, and we viewed China as another potential adventure but never questioned our ability to travel there.

Unfortunately, this view was not shared by the Chinese embassy which felt that someone in a wheelchair would not be able to get around in

than denying disabled travelers, because many disabled people are experts at overcoming obstacles and should be allowed to make an informed choice.

Our three-week China tour was organized by Pastor Furber of St. Mark's Church in Illinois. Bob and I were accompanied by his mother, Anna Cramer, and an old friend, Don Gugel. Our itinerary took us from Beijing to Xian to Hangzhou to Shanghai to Guilin to Guangzhou to Hong Kong.

We rode on a variety of large tour buses. My husband would just pick me up and carry me on, and as long as he held up and we could find a seat by the door, we managed very well.

Our first hotel in Beijing (Peking) was typical of all the others we would encounter. The entrance had a few steps, but once we were inside there was an elevator to our room. The lobby also had an occasional step or two to the dining area and shops, but with my husband's help, this was not a significant obstacle.

Beijing has 4.3 million bicycles and they are the major mode of transportation since Chinese people are not allowed to own cars. I wondered what this would mean for disabled people. I soon discovered an occasional hand-driven tricycle and assumed they were for people who couldn't use their legs.

The Great Wall is one of the most awe-inspiring sights I have ever seen. It was a great enough feat to just get up the flight of uneven steps to get on the wall, especially when those steps were crowded with people who couldn't quite figure out what we were doing with that strange-looking chair.

"Spirit catchers" became a familiar sight as we travelled through China. These are raised door sills which stand about 10 inches high and are intended to keep the evil spirits out. Needless to say, these spirit catchers are also wheelchair catchers, but my husband, with the help of another man, just lifted me, chair and all, over the sills.

The train to Shanghai had a few steps to board and the aisles were too narrow for my chair, but I was placed in the first seat and it was a comfortable ride.



Ruth Diehl and her mother-in-law in China.

China. I spent many anxious and discouraged moments when I was told that the embassy was denying my visa because of my disability.

I decided I was going to fight this decision, and I still marvel at the support I received from both friends and strangers. For the first time in my life, I called upon my Congressmen in Wisconsin to help me, and in fact, this seems to be what turned the decision around.

In retrospect, I can respect the concern of the Chinese embassy because, as they warned me, there is very little in China that is easily wheelchair-accessible. However, I hope they will change their policy to one of warning rather

For a cruise on the Li River, we descended two flights of crumbling stairs to get to the boat launch, and then had to cross over several boats to get to the one we would take. Once on board the boat, there were two levels. One level, where we entered, had tables for tea and lunch. The other level was upstairs and a bit hard to negotiate with a wheelchair because of the narrow passage at the base of the stairs, but well worth the effort. It had an open deck and an outstanding view.

In Guilin, just outside the gate of our hotel, we saw a disabled man, an amputee, who was strapped to a little platform with wheels. He pushed himself along with a couple of irons with his hands. He stared at me curiously as I did at him, both probably thinking the other certainly had a strange way of getting around. Their society does not frown upon staring at something unusual and I found I was a true novelty for the Chinese.

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Travel with a Ventilator to Hawaii

by Nathalie Nelson

After I spent a year recuperating from two consecutive bouts of pneumonia, my brother suggested that a visit to the Hawaiian Islands might be a good change. I readily agreed, but after booking flight-hotel packages, I had second thoughts. The pneumonia had weakened my breathing tolerance and walking ability and the "what if's" plagued me until I actually boarded the plane with my brother and an attendant.

I travelled with two LP-4s, 2 aspirators, and a battery pack for the LP-4, using canvas travel bags for the equipment. Seat space was at a premium, and there was scarcely space for our feet let alone my LP-4 ventilator and battery pack. However, the five-hour crossing went smoothly.



◀ Nathalie Nelson with brother Bob and attendant Emily at Hanalei in northern Kauai.

When we landed, an airport attendant was waiting with a wheelchair and lift. While we waited for the rental car, I noted a sign which read, "No corrosive materials allowed on board the planes," and I realized I should have mentioned the battery at the Los Angeles terminal.

Our lodging on Kauai was a simple Polynesian cottage located where the Wailua River empties into the Pacific. From that base, we drove the country roads and witnessed Hawaii's immense and varied beauty.

Once, the car keys were locked inside the car along with my aspirator. I became increasingly congested and a concerned policeman called an ambulance to the site. Unfortunately for me, their aspirator wouldn't function, which necessitated an expensive trip to the local emergency room.

Another bad moment occurred when we made a sharp turn and the already loose water humidifier tipped over, causing water to be pumped into my lungs. We quickly suctioned it out and I was fine again, although a bit shaken.

At the end of our wonderful week, we reluctantly packed our clothes and tucked in the shells and coconuts we had collected on the beaches. It was hard to leave Hawaii's incredible paradise.

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My Sacrifices to India's Art

by Ala Wokoun, Ph.D.

To ride on an elephant and to see my article in the *Gazette* were not my only ambitions for my tour of India. My interest in Indian art and architecture did not end with my visit to Taj Mahal with its marble-lace beauty. I enjoyed that jewel of Islamic architecture, but at the same time I overshadowed it. How? The wet, white marble stairs of Taj Mahal's entry were so slippery that I had to mount the stairway on all four limbs. I became a greater sensation for passers-by than the magnificent Shah Jahan's mausoleum

stadiums. Photographs of super gates covered by that astonishing sculpture told me too little about the individual statues. For 35 years I had longed to see these South Indian, many-storied galleries of innumerable sculptures. In 1973, I finally stood in front of a typical South Indian temple in Madras.

South Indian Hindu temples are spacious areas with many courtyards, many-columned low shrines, sacred lakes, and some towering gopurams. Although the gopurams were built to serve as gigantic gates and striking sculptural advertising of the Hindu religion, the desired gopuram of the Kapaleeswarar temple was some way from the present "porter's lodge." Here visitors of the temple had to take off all their leather things, especially shoes, because cows are sacred animals for Hindus.

I am unable to walk without surgical boots and therefore tried to enter the temple area wearing them. I was stopped by an old sacrificer of that Kapaleeswarar temple, who pointed to my shoes. Because he spoke English, I tried to explain to him that I cannot walk in socks and that, in addition, my right boot is connected with my supporting orthopedic apparatus. I argued in vain. The priest said he was sorry for my handicap, but mentioned strict religious regulations. Our agreeable guide from the Tamil travel office in Madras, Mrs. Ahalya, threatened to make an official complaint if he would not make an exception for me. She negotiated in vain with the pedantic sacrificer, although she certainly had superiority in kilograms. Then she, too, disappeared into the temple area because our group had been given only one hour to visit.

I was so near to my aim of many years, yet instead of viewing the details of the temple's gopuram from its foot, I lost valuable time in discussion with the stiff-necked man wrapped in a bed sheet. I told him that I had flown from Central Europe to India just to see the architecture. He said he was moved by my interest, but had to follow the rules concerning my leather shoes. Indian worshippers, who were going to the temple, gathered around us. They interceded on my behalf, but in vain. My situation seemed hopeless.

In the meantime, an additional younger worshipper in a white toga came to us and listened



Ala Wokoun, Ph.D., Czech artist, raconteur, and world traveler.

that was built for his most favorite wife. That evening, it was unfortunately impossible to repeat Richard Halliburton's rich experience at Taj Mahal because the moon was covered by the less romantic "kitchen smog" produced by cow-turd fuel in nearby slums.

Nonetheless, I was interested in South Indian Hindu temples, especially their many-storied gates — gopurams, which are slender, truncated pyramids covered by thousands of statues. They represent colorful events in the rich Indian mythology. The many rows of statues on later pyramids suggested spectators in

with evident sympathy to my interest in gopurams. He disappeared quickly after saying something to the old priest. Soon he reappeared carrying two parcels of wide white ribbons. He began to wind the bands round my shoes and legs up to the knees. At last the old priest allowed me to enter the temple area. It was not easy. My legs were now thick like an elephant's with plaster dressings like those of surgical patients in crazy comedies.

But the old sacrificer was by me again and drew me from the pyramid of statues to a low temple building with an explanation that, first, I had to sacrifice to Shiva, one of the most important gods of Hindu religion. I was more attracted by Shiva's son Ganesha, who is depicted with an elephant's head on a human body and, in addition, is humanized by a respectable belly.

Drawing by Ala Wokoun of himself at shrine in India.



At the place of sacrifice the unforgettable old priest took out some corns and told me he would sacrifice them on behalf of me. But at the same time he demanded Indian money for it. With hesitation, I gave him a rupee for his forced sacred spectacle just to get rid of the sacrificer. He reacted scornfully that one rupee was too little. I answered that I had no more money. The priest objected that the other tourists could pay for me when they returned from their walk to more distant shrines. Meanwhile, he let me get closer to the desired "ant-hill" of statues. The many meters of ribbons around my legs began to unwind until I dragged them behind my feet like comets' tails. The old sacrificer disappeared for a while. The young priest, thanks to whose ribbons I had been permitted to enter the temple, rejoined me and explained the sense of gopuram's sculptures. Further, he did not squeeze any rupees from me.

I was sorry that I had so little time for examining the crowd of statues, because our group of tourists was returning to the temple's exit. The old priest reappeared and was demanding more rupees for my involuntary sacrifice. Fortunately, our kind guide, Mrs. Ahalya, rejected his demands and triumphantly broke his spirit. She showed him a paper saying that I could enter the temple with my leather shoes. Unfortunately, it was late and the next day we had to leave Madras. In spite of coming evening darkness, I saw how the sunburnt dogmatic old priest paled.

I have expected that god Shiva would punish me because I saved my limited amount of tourist rupees and sacrificed to him only one. According to Hindu mythology, Shiva is not only a god for creation but, at the same time, a god qualified for destruction, too. Yet up to now, I have not been worth his revenge.

(Translated by the author from his prepared manuscript of a Czech book of his travels to different parts of our world. Illustration by the author.)

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A Gentleman Farmer with ALS

by Rena Groth

We live in Burton, Ohio, a farming township 40 miles east of Cleveland. My husband Quentin, age 64, has had amyotrophic lateral sclerosis for 7½ years. We have been married 44 years and have two children. Quentin retired at age 57 from Eaton Corporation as Vice-President of International and bought a farm which he equipped with tractors, beef cattle, etc. Eight months after retirement, Quentin was diagnosed as having ALS. He gave up his cattle, but will not give up the farm or tractor. He says he will drive that tractor one day.



At first, Quentin had only to be on a ventilator when he slept. During the day, he would throw his shoulders back to take air into his lungs, and then throw them forward to expel the air. Now, he is on a mechanical ventilator 24 hours a day. He cannot talk, but we read his lips. When he wants our attention, he makes a noise with his mouth that sounds like "pt-pt." One "pt-pt" is "yes," two "pt-pt" is "no," and three "pt-pt" means "I need you." Quentin is also a severe diabetic, needing 3 injections of insulin a day.

I took care of Quentin the first 2 years he was on the ventilator full time. I was completely exhausted. He then had pneumonia because I couldn't clap him and give him range of motion. For the last 2 years, we have had private duty nursing for Quentin every day from 8 to 5, then a nurse in for an hour to prepare him for bed. We are lucky our hospitalization pays for this.

Since we have nursing for Quentin, he can now sit up in his wheelchair for 7 to 8 hours. Our doctor from Cleveland Clinic says he can feel movement in the muscles of Quentin's arms and shoulders. Quentin can shrug his shoulders and, if you hold your hand under his elbow, he can move his arms from side to side. He can also move his legs from side to side if you hold your hand under his knees. This is all new within the last 2 years.

Quentin's wheelchair is equipped with a battery, ventilator, and suction machine. We have a van with a wheelchair lift, so we are able to take him on excursions.

We also have a 33' motorhome with a wheelchair lift and hospital bed all equipped just for him. We built a new room on our home with all windows for Quentin. We have our beds there; otherwise it looks like a living room. He doesn't miss much that goes on. Between TV, watching the birds on the feeder, reading (he has a reader that he can turn pages with by blowing in and out of a mouthpiece), watching the farmers work their fields, and company, Quentin doesn't have enough time in a day to get everything done.

He gets very upset when he hears of people who say they would rather die than go on a mechanical ventilator. He says it is not the end of the world. There is too much to enjoy as long as you don't feel sorry for yourself. Quentin is much loved by everyone. He is always smiling, never complaining or demanding. He says from his Adam's apple up, he is perfect. Because of Quentin's positive attitude and cheerfulness, we have a lot of company. Quentin's life is full. He enjoys everything and calls these last 7½ years a bonus. 福

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Quentin Groth, Burton, Ohio.

Stephie's Story

by Stephanie Rivard

I don't remember anything about my automobile accident, but I was hit broadside by an eighteen wheeler on June 21, 1982. I suffered a devastating head injury, lung and kidney injuries, broken arm, wrist, and fractured pelvis. I was life-flighted to Hermann Hospital where I remained in a coma for three months.

I came out of my long coma on September 20 able to read, but unable to walk or talk. My left arm would not move at all and my left leg was very weak. My right eye did not open much, and when it did open, I had double vision. I could hold my head up pretty well, but I could not do simple things like rolling over. My long rehabilitation was just beginning.

I was an in-patient in T.I.R.R. and Medical Center Del Oro Hospital. I had the same schedule every day. Physical therapy, speech, and occupational therapy from 9:00-11:00 in the morning. At 11:30 I went back to my hospital room to have lunch. After the therapy, I would sometimes wish that I would die over lunch, so that I would not have to endure the afternoon. But the routine was always the same. I was finished with therapy by 4:00 p.m. every day and, by that time, I felt like a first-grader at the end of a school day.

I would start off excitedly for my room. My mom and dad would be in my room waiting for me. Seeing them made a celebration inside of me. I had a deal with myself. During the day, I would do anything anyone asked. The evening, with my parents, was my only time. I had set the night aside for me. We would go down to the cafeteria for dinner. I loved this, for I would see people other than Mom or the therapists. My parents would talk to other parents, while I sat and smiled at everything. When a person cannot talk, they learn fast that responding with a simple smile cures a lot of problems.

I left the hospital in February 1983. I have almost regained full speech. I walk with a cane when I am alone. When I am in therapy, I walk free.

The accident taught me a lot about friendship. The therapists have been better friends to me than my girlfriends. The encour-



Stephie Rivard remained in a coma for three months following a head injury.

agement from my parents was reinforced by the therapists.

I finished high school. For the first half of the year, I was going to school for data processing, but I found that I really liked staying home. My government teacher, Juanita Ridgeway, taught me data processing, too. After completing the year as my high school teacher, Mrs. Ridgeway decided to retire and to tutor me at Lee College in Baytown, where I plan to learn to become a physical therapist.

My family has changed. From a father who works, to a father who makes a daily trip to the hospital. From a mom who was a maniac about cleaning our house, to a mom who did not care about the house so she could prepare herself to go to the hospital.

I have older twin sisters: Kathleen and Teresa. On May 11, 1984, Kathleen was life-flighted to Hermann Hospital. She had been at college, celebrating the completion of the last examination of her sophomore year. She received a severe head injury from an auto accident and remained in a coma for 5 weeks. Kathleen emerged from her coma with fewer physical limitations than I did. She still needs speech and physical therapy.

This is a story about how my family and I have coped. Our story is not yet done because the story, and the coping, continue.

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Address: Stephanie Rivard, 10443 Rocky Hollow, LaPorte, Texas 77571.

Mike Scott, Karate Expert

by Rosalie Scott

Michael Scott, disabled by cerebral palsy, is now a karate black belt instructor.

Mike's disability is slight and as a child he had trouble with balancing since the lower extremities were spastic causing tight tendons and muscles. His intelligence was not impaired. Cerebral palsy is not a disease — it is a condition that, with proper therapy, patience, love, and will power, can be alleviated.

From birth on past teen years, Mike faced many obstacles and was discriminated against. His childhood friends sometimes left him out of fun and games due to his slow coordination. Even the public school system held Mike back from his full potential.



Mike Scott, black belt karate instructor.

It was not until junior high school that Mike was treated with proper respect and told that "handicapped" is just a label. Mike became more independent. At first, I was overly protective but learned to let Mike do everything possible for himself.

Mike made great progress by the time he reached high school. He was ready for the challenge and learned to drive an automobile. He also attended a vocational school and learned electronics. At graduation, he joined his classmates as they all marched down the hall to receive their diplomas.

By graduation, Mike had learned to do twenty push-ups, and his own therapy with stretching exercises and weights. Mike enrolled at another career center and became an electronic technician. In his job, Mike began to socialize with his co-workers and finally felt as though he fit in.

In addition to working full time during the day, Mike spent two nights a week in karate class. He is a fifth-degree black belt, master of the arts in Shinto Ryu karate, and in 1984, Mike became a black belt instructor. One of his pupils is a nine-year-old boy and they performed a kata for a cerebral palsy telethon. Mike still belongs to the Y.M.C.A. where he does workouts and body conditioning.

In karate, Mike's "canes" are used to demonstrate a side kick. Mike assists in judging karate tournaments and has driven as far as North Carolina to participate in the martial arts.

A good attitude, plus dogged determination, has brought Mike Scott a long way at the age of 29. To Mike, achievement is the utmost. And he has two karate trophies to prove it!

福

Address: Mike Scott, 2603 Lincoln Ave.,
St. Albans, West Virginia 25177.

Don't Give Up

by Norma Jean Puetz

Ralph and I were married in September 1950. Like all young people in love, we were going to sail through life, doing all the fun things together. We both came from large families and our "own" family was a must in our planning. In 1952, we had a beautiful baby girl followed in 1953 by another daughter and, in 1954, yet another daughter.

I was twenty-three years old when my health gradually began to go downhill. I couldn't understand what was happening to me. My hands, shoulders, and feet ached and swelled. I had a low-grade fever that rose every afternoon. The doctors diagnosed rheumatic fever.

In 1957, our first son was born. In August of that year, I went to the Mayo Clinic, where I was diagnosed as having rheumatoid arthritis. I was instructed on controlling and relieving the pain with rest and aspirin, and taught suitable exercises, massages, and heat treatment.

I traveled to the Mayo Clinic regularly in the years to come. I learned that my body had broken down all over at the same time, so corrective surgery was begun in 1961 and was still being done in 1984.

In the early 60s, my knees were operated on and the synovial membranes were removed, but, since they do grow back, surgery had to be repeated several times. In 1972, I received artificial knees, but in 1975, an infection developed in the left artificial knee joint, which resulted in the joint having to be removed and the leg fused. The year ahead brought more foot surgery and two artificial hips. In between these surgeries, other illnesses struck: Felty's syndrome, thyroid trouble, congestive heart failure, pneumonia, and ulcers. My last major surgery was a neck fusion from 3 to 7 vertebrae.

I wear braces on both legs but I can walk short distances around the house. For longer trips, where I must stand longer, I use a wheelchair.

I can dress myself but it takes two hours without help. I crochet, paint, do needlework, and type. My hands are very crippled and all my fingers have been fused. I cannot lift heavy objects. However, I can do simple cooking, use the microwave, and wash dishes.

We remodeled our home to make life easier for me and for all the family. We have electric chairs throughout the house. My husband has built my bed high so that I can get off of it by myself. I have a wheelchair (which I try to avoid using in the house); an elevator to lift me into the house; a van with a hydraulic lift, and an electric 3-wheeler golf cart that I can drive around our small town. One of my special aids is a pillow of hard, very lightweight styrofoam.

There have been periods during which I have functioned almost normally, thanks to the steady, loving support of my husband and the



◀
Norma Jean and Ralph
Puetz with grandson
Jason.

help of loving parents and friends. Our children, which number six, were taught how to help around the house and take care of their mother.

In 1980, I opened a crafts and antique shop, Ne Ne's Oldees, but Goodees Shop, with the help of my daughter, Marge. I try to go down there every day to help in its management.

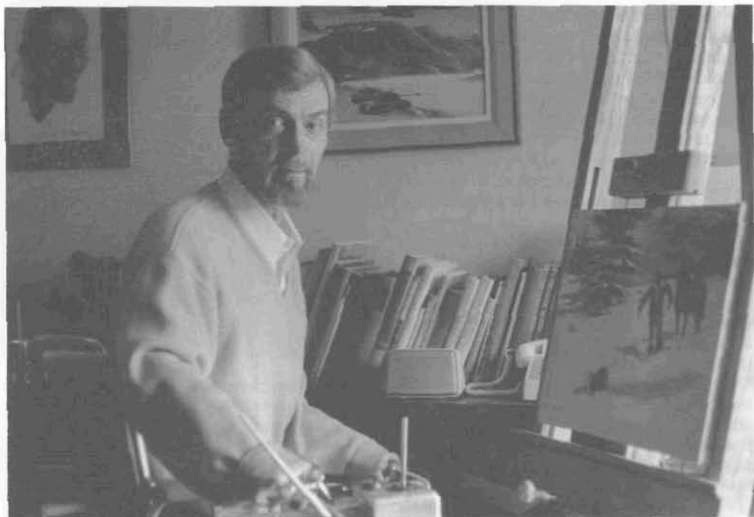
I was not taught how to handle my disability, mentally or emotionally, only how to deal with my physical problems. I searched in those early 60s to find help in books and magazines, not only for myself but for my family, too. The strain on loving family members of anyone with a chronic illness or disability is great. I found so many ideas in the *Gazette* and *Accent* magazines that were helpful to me.

When I first became ill, an aunt said, "Norma Jean, it all depends on you. You can be a happy, smiling person even if you are in pain or you can be unhappy and sorry for yourself. You make your own life."

I have tried to do this. I have many wonderful friends, a devoted husband, and a warm, loving family. I have suffered much pain. I have experienced much joy and happiness. I am looking forward to the future and I am smiling. 福

Address: Norma Jean Puetz, 107 N. Madison,
Fowler, Indiana 47944.

Western artist Paul
Schlueter.



Western Artist *Paul Schlueter*

Oil painter Paul Schlueter is a native St. Louisan who works and resides at his apartment-studio in the St. Louis Central West End.

Schlueter has Buerger's disease, a rare illness which blocks the blood supply to the limbs, which then die from lack of blood and must be amputated. The disease does not affect the trunk or vital organs.

Since his diagnosis, Schlueter has undergone 18 operations. He has no left arm, only half of his right arm, and paints with a loop attached to a prosthetic device attached to his right elbow. His legs were amputated at the knee. He gets around in an electric wheelchair.

Schlueter distinguished himself during the Korean War as a Marine and later attended Washington University School of Fine Arts in St. Louis and the Chicago Art Institute.

A former commercial artist who was always doing work on the side, Schlueter is happy to return to painting. He has been accorded various awards including scholastic invitations to the Ringling School of Fine Arts in Sarasota, Florida, and the Chautauqua Institute in New York.

His work has been exhibited at the St. Louis Art Museum and one-man shows in the St. Louis area, and is represented in private collections. 福

Address: Paul Schlueter, 4545 Forest Park Blvd., #117, St. Louis, Missouri 63108.

Ordinary Moments

By Alan J. Brightman. University Park Press, 300 N. Charles St., Baltimore, MD 21201. 1984. 160 pp. \$8.95. *Ordinary Moments* is just eight people with something to say . . . and a ninth who benefited enormously from listening to them.

Alan Brightman has a Ph.D. in Education and is Director of Educational Projects, a non-profit organization which trains special education professionals and parents of disabled children.

In the first few pages of the book, Brightman speaks of individuality and commonality, uniqueness and ordinariness. How natural is the author's approach to disability and how unnatural is the general public's.

Through the personal accounts of eight disabled people living in a society which is for the most part unfamiliar with disability, Brightman hopes his readers will come to see disabled people as ordinary human beings. He wants to change society's misconceptions of disabled people as either heroic or tragic beings set apart from able-bodied people. The individuals discuss happy times and sad times. They share their joys and excitements, their angers and frustrations. I feel each one of us can benefit from the approach the book takes. It is simple and honest.

Reviewed by Lucy Dolan

Voices from the Shadows

By Gwyneth Ferguson Matthews. Women's Educational Press, 16 Baldwin St., Toronto, Ontario, M5T 1L2, Canada. 1983. 192 pp. \$8.95. Through her personal account of learning to adapt to her disability and through the collection of interviews of forty-five women with varying disabilities from all social, economic, and educational backgrounds, Gwyneth F. Matthews gives her readers some feelings, attitudes, fears and joys which concern the lives of disabled women in Canada today.

Matthews provides her readers with a very candid and open account of her experiences after becoming disabled. Her determination to live a productive and fulfilling life challenges

some of the stereotypes society has about disabled people.

Matthews addresses issues about the disabled population which the public can no longer ignore. Areas covered in the interviews include sexuality, accessibility, motherhood, housing, education, employment, and social assistance.

How can society's view towards disability be changed? Matthews says, "Everything comes down to information, understanding, and integration."

Reviewed by Lucy Dolan

The Cripple Liberation Front Marching Band Blues

By Lorenzo Milam, Mho & Mho Works, Box 33135, San Diego, CA 92103. 1984. 218 pp. \$9.95. This is a personal account of the author's emotional response to polio. With wrenching detail, he describes the pain and anguish he suffered at the hands of incompetent medical and therapeutical persons, as well as the changes wrought in his own life.

This is not a straight narrative, but one that is filled with metaphor, simile, imaginative personification and hyperbole, images piled one upon another. It is bitterly subjective. Milam tells of his hospitalization at the onset of the disease, recuperation in a nursing home, and rehabilitation at Warm Springs, Georgia. Only at the latter was he able to find a measure of satisfaction, as he regained use of his arms and partial use of his legs, although he continues to walk with braces and crutches.

His subsequent education, marriage, and divorce are treated cursorily. Much space is devoted to a sojourn in Spain where he settled to escape and to write.

The language of the book runs the gamut from the poetic to the medically technical to the scatological. It is a story told with brilliance, dulled only by too many rubs.

Reviewed by Theodore Solomon

Multiple Sclerosis

A Guide for Patients and their Families edited by Labe C. Scheinberg. Raven Press, 1140 Avenue of the Americas, New York, NY 10036. 1983. 268 pp. \$9.50. It is somewhat difficult to ignore the many times we are referred to as "MS patients" rather than as persons who have MS. But grit your teeth and read on, because this book is comprehensive. It is designed to aid those with MS to live life to the fullest through the use of coping techniques, adaptive means, and home and workplace modifications.

Questions you might have had, do now have, or someday may have are answered in a thorough and understandable manner. There are 16 chapters in the book, each written by knowledgeable health care professionals. Some of the areas covered are: Drug Therapy; Bladder and Bowel Management; Social Adaptations; Vocational Issues; New Treatments; Available Services. An annotated bibliography is also provided.

Put this book on the shelf next to Miriam Ottenberg's *The Pursuit of Hope* for easy reference.

Reviewed by Margie Goodwin

The Disabled and their Parents

A Counseling Challenge by Leo Buscaglia, Ph.D. Slack Inc., 6900 Grove Rd., Thorofare, NJ 08086. 1983. 393 pp. \$14.95. Leo Buscaglia is a humanist. He has written books and made appearances on TV extolling love and caring and civilized behavior. He is primarily an educator who believes in human life.

This book is a definitive study of counseling for the disabled and their parents, with the focus on their needs and rights. That, he says, is the purpose of counseling in particular and education in general and not, as one educator seemed to think, the preservation of an expensive facade and well-organized program.

The book is a comprehensive description of many angles of vision, some of which are related directly by disabled persons, their parents and

counselors. Buscaglia maintains his theme that these people need help and should be encouraged with guidance to help themselves.

Rehabilitation should develop the physical and mental skills of individuals who are disabled, and direct these skills toward independent living and equal, productive membership in society.

Reviewed by Theodore Solomon

Able Scientists — Disabled Persons

Careers in the Sciences by S. Phyllis Stearns, Ph.D. Published for the Foundation for Science and the Handicapped, Inc., John Racila Assoc., Inc., 1820 Oak Brook Rd., Oak Brook, IL 60521. 1984. 65 pp. \$12.95. There is an old saying: "It couldn't be done, but the darn fool didn't know that and went right ahead and did it." The people in Phyllis Stearns's book of biographical sketches are no fools. Instead, they managed to fool the experts who would have placed them in preconceived niches according to their disabilities.

In overcoming the handicaps of rigid rules, physical structures, and negative attitudes, they used a number of strategies: perseverance; aggressiveness; humor; and hard work.

They managed to succeed in their endeavors, sometimes after years of failure and rejection. In spite of their disabilities, they earned advanced degrees and established themselves in scientific and technological careers. The author, herself born with cerebral palsy, went on to a distinguished career as a radiobiologist.

Robert P. Larsen, who became a Ph.D. and an analytical chemist, notes the crux of the problem. "The barrier was not the disability per se, but the inability of able persons — the counselors, the educators, the employers — to appreciate that careers in science are primarily intellectual endeavors, not physical ones."

The struggle of these able scientists with disabilities will continue to confound the experts like the bumblebee which flies in defiance of those aerodynamic principles that proclaim it cannot be done.

Reviewed by Theodore Solomon

Physical Disability, a Psychosocial Approach

By Beatrice Wright, Ph.D. Harper & Row, 10 E. 53rd St., New York, NY 10022. 1983. Second edition. 520 pp. \$24.95. This classic work, which has been revised to include current research findings and new topics, should be read by everyone, disabled or not. The author writes with understanding and empathy, keeping jargon to a minimum.

Wright believes in coping rather than succumbing, and in the disabled having an active role in their lives and their communities. She offers numerous suggestions and examples for parents, teachers, and professionals.

The Aquarian Conspiracy

Personal and Social Transformation in the 1980s. By Marilyn Ferguson. J.P. Tarcher, Inc., 9110 Sunset Blvd., Los Angeles, CA 90069. 1980. 448 pp. \$8.95. The spirit of the sixties is alive and well and in the process of transforming our lives, attitudes, relationships, and institutions. That is the message of the ideas embodied in what might best be called the "human potential movement."

Ferguson shows how the "Aquarian" values which emerged in the 1960s — values such as self-fulfillment, tolerance, peace, love, cooperation, and a simpler lifestyle — are infiltrating the fields of medicine, education, business, and politics. The key idea of this movement is that by changing ourselves in ways which enhance our personal awareness and growth, we will eventually transform our entire society. In fact, society can only be changed one person at a time, from the bottom up and not from the top down.

Surprisingly, Ferguson's thesis is based on new theories in physics and brain research. Briefly, these theories argue that the physical world we think we see is in fact not at all solid, but a constant and harmonious flux of energy patterns which our brains interpret as solid objects. Ferguson also observes that the brain itself is a system of constantly changing waves of energy. It is during awareness-raising states,

induced by Transcendental Meditation, deep relaxation, LSD, or other techniques, that our brain waves are most harmonious, and thus most receptive to the energy patterns of the reality underlying the world of appearances.

As a result of this higher state of awareness, we can break through our cultural blinders and realize the potential of which we are capable. As our own awareness and attitudes change, we realize that we can bring our lives in harmony with the real, rather than the culturally induced, world. Our behavior becomes more natural, more loving, more compassionate, and more rewarding both to ourselves and to others.

A short review cannot possibly do justice to the richness of this book. It draws on the ideas and experiences of numerous individuals and groups, from Hermann Hesse to the holistic medicine movement. Implied throughout is a rejection of the materialism and competitiveness of modern society. The Aquarian Conspirators draw on ideas from Eastern religions, mystics, and Romantic thinkers — as well as from current writers — to forge a simpler, more harmonious view of the world, in which individuals cooperate on equal terms and in mutually beneficial ways.

Oddly, disabled persons are not discussed in this book. The independent living movement seems like an excellent example of the principles of the Aquarian Conspiracy, but Ferguson does not appear to be aware of it. Nor is she aware of other concepts and programs developed in recent years by disabled persons which fit the process of personal growth and social cooperation (such as networking) that she regards as the heart of the Aquarian Conspiracy.

This is not the sort of book one walks away from unchanged. Too many exciting possibilities are presented; too many issues are discussed only briefly. It left me eager to read some of the sources upon which this book is based.

Reviewed by Richard Bopp

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Book Reviewers



Lucy Dolan

Lucy Dolan, C5-6 quad (incomplete) due to a mountain climbing accident in Jackson, Wyoming, in July 1979, is finishing her degree at the University of Missouri at Columbia. She majored in history and is now taking additional courses to be certified in elementary education. Address: 2 Spoede Acres, St. Louis, Missouri 63141.

Margie Goodwin was diagnosed with M.S. in 1977. She teaches high school chemistry in St. Louis, where she resides with her husband, Dick (C5-6 quad). Address: 1614 Liggett Dr., St. Louis, Missouri 63126.

Theodore Solomon contracted polio in 1930 when he was a year old. He uses braces and crutches and has a hearing loss. Ted is a clerical supervisor for the Ohio Department of Welfare. He enjoys reading, writing, chess, and fishing. Address: 2023 Marlow Rd., Toledo, Ohio 43613.

Richard Bopp, disabled by transverse myelitis, is Documents Librarian and Associate Professor of library administration at the University of Illinois library. Rich has received master's degrees in both history and library science. He resides with his wife, Susie, and three children at 1713 Georgetown Rd., Champaign, Illinois 61820.

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Pen Friends

"I would like to correspond with some disabled persons in the U.S.A. My age is 30. My hobbies are stamp collecting, corresponding, singing and indoor games." *Calvin Green, Cedar Grove, Mandeville P.O., Jamaica, West Indies.*

"I live in Seoul, Korea. I'm a 28-year-old male, disabled by polio. I would like to exchange letters with a girl like me. I'd like to know her age, hobby, and so on." -151-, *Lee Keun-Myeong, 877-13 Bong-Cheon 4 Dong, Gwan-Ag Gu, Seoul, Korea.*

"I have lost two of my friends in the States and hope that others will take up correspondence with me . . . I have passed another year without any major catastrophe and I wish I could help some people in the year to come." *Latha Arunachalam, 27A, Seventh Street, Tatabad, Coimbatore 12, South India.*

"I was born with cerebral palsy. For 24 years I have been happy. I have three sisters and one brother. We are a very close family . . . I want to know about cerebral palsy and to write to others with it." *Lori D. Cleesen, 1101 Avenue B, Rock Falls, Illinois 61071.*

"I want correspondence with disabled people. I am hard of hearing and have a slight speech defect . . . I am single male. I weigh 190 lbs. and I am 6'3" tall. I want to exchange photos and viewcards." *Robert Wittnebel, 7177 Country Club Road, Oshkosh, Wisconsin 54901.*

"I am a cerebral palsy man. I would like to write to somebody in Kentucky or anywhere south who would like to do something in art." *Kent Caswell, 135 Colorado Street E., St. Paul, Minnesota 55107.*

"I was born with cerebral palsy. I'm 37 years old. I use a wheelchair. I enjoy rock and roll music, Talking Books, and corresponding by typing or talking on cassette tapes to people with my own disability, especially males. I love to keep busy — the busier, the happier I am . . . I live at home with my parents." *Mary Catherine Sirakas, 7668 Westchester Drive, Belleville, Illinois 62223.*



Anna Jimae Trantham,
Texas

"My husband and I are both disabled. He has retired from Goodwill. I'm a homemaker. I enjoy pen friends, cooking, baking, liquid embroidery, talking on the CB, and writing letters. I'm planning to learn how to drive, and I'm studying to become a Handi-Ham." *Anna Jimae Trantham, 1720 North Howard, Sherman, Texas 75090.*

"I have cerebral palsy. I want pen friends who are disabled, too, because I don't have anyone to talk to who knows how it is to be disabled. I'm 18 years old. I love to write letters. It's easier than talking." *Katie Fairburn, 712 North 5th Avenue, Ann Arbor, Michigan 48104.*

"I am disabled with muscular dystrophy. I am 25 years old and work in a travel agency. I look after an organization, G.I.H.P., in Orleans devoted to the integration of disabled people. . . . I should like to have an American pen friend, age 20 to 30, man or woman, disabled or able-bodied." *Dominique Dupuis, 8, rue St. Loup, 45130 Charsonville, Meung-sur-Loire, France.*

"I am 42 years of age and would like to write to others with congenital heart disease. I also had a stroke which damaged the right side of my body and I'm in a wheelchair due to the lack of oxygen. I hope to get my poetry on music. Meanwhile, I am getting my book on my life typed. The title is 'The Magic Flute.'" *Sharon Browman, c/o Arlinda Cosby, 1700 Santa Clara Avenue, Alameda, California 94501.*

"Like post-polios, my prenatal virus attack, (cocksackie A2) which damaged my muscle nerves (4 limbs in my case) 58 years ago, now ages me exceptionally because I do everything with my teeth. I still answer letters needing information about arthrogryposis. . . . I am an artist." *Viola M. Henne, 2206 N.E. 88 Street, Vancouver, Washington 98665.*



Electric Scooter Wanted

"I was born in Vietnam in 1970 and had polio when I was two. I use braces, crutches, and a body jacket. I'm in the ninth grade in high school. I would like an electric scooter or wheelchair now and a small van when I go to college. I collect stamps and write to pen friends. I speak and write French and I like to read." *My Lam Hau, Rt. 3, P.O. Box 165-P, Hammond, Louisiana 70401.*

Aging Polio Survivors

"I turned 70 this January, in wheelchair for 33 years, post-polio quad. I am healthier than all my 'normal' friends. I know so much more than I did years ago when I wrote the article on nutrition in the *Gazette*." *Mrs. Ruth Anne Black, 2431 Benjamin Drive, Mountain View, California 94043.*

"I am age 50, use a wheelchair because of polio at age 12. Married, with a son of 15 and a daughter 10 years old. I am secretary of a group calling itself H.U.H.O. (Help Us Help Ourselves) made up of disabled persons, mainly children. We hope to equip a day centre and also purchase walking aids. . . . I wonder if *Gazette* readers can offer any suggestions of ways to raise funds." *Muriel Willes Balchin, "Kingshurst," St. Pauls District, St. Helena Island, South Atlantic.*

"My mother and I moved here four years ago. This house is great for wheelchair living. I have an electronic typewriter, electric wheelchair, and lifting hoists for our house and our car. We do much more traveling now within Australia. The group of Baton Twirlers I coach were swamped in the State Championships. I would be delighted to hear from my old *Gazette* polio friends." *Mary Guy, 23 Norman Circle, Glenorchy 7010, Tasmania, Australia 7010.*

"The General Secretary and National Chairman of the British Polio Fellowship spoke of plans to provide continuing care for all polio-disabled people in the years ahead at our lunch meeting of B.P.F. members and other polio-disabled people from Cumbria and North Lancashire. I found their reassurance very helpful." *Anne Dobson, Ghyll Cottage, Ings., Kendall, Cumbria LA8 9PU, England.*

"I was delighted with the 25th anniversary copy of the *Gazette*. I have passed it around to interested persons here at the hospital. Polio is very much a forgotten disease here and old polios a forgotten breed. I celebrated my 'Silver Anniversary' of polio on September 13, 1984. Physically, I feel a lot better than 10 years ago, and certainly

My Lam Hau, Louisiana

do a lot more. . . . As for living at home for those of us who use respiratory aid, our medical people think 'institutional,' and the social services department isn't going to legislate for such a minority group, even though we could live at home at less cost to the state. . . . Congratulations on your new G.I.N.I. organization." *Ethna O'Dowd, Ward 7, Cherry Orchard Hospital, Dublin, 10, Ireland.*

"Best wishes to your new G.I.N.I. magazine and your Institute for disabled persons' problems and solutions. . . . Our monthly magazine for disabled, *Elan*, published my 87 lines about your *Gazette* jubilee, where your self-sacrificing gigantic work for polio survivors and your special congresses about post-polio problems and living of disabled were mentioned. . . . Recently, my correspondence with Dr. Nagai developed so that we know more about Japanese disabled's possibilities. . . . This year my polio has its 40th anniversary, but its direct consequences are not worse than 20-30 years ago." *Dr. A. Wokoun, Cabařovická 1333, 182 00, Praha 8, Czechoslovakia.*

French Exchange Student

Translation: "I would like to come to the United States for one year and arrange an exchange with a disabled student who would like to stay in my apartment and use my attendant and housekeeper, while I would stay in their apartment. . . . I am completing studies in psychology, subspecialty of pathology and clinical psychology. I am disabled physically and have to use an electric wheelchair as I have a disease which involves my muscles." *Catherine Estienne, Bois d'Arcy, Apt. 302, 33400 Talence, France.*

Belize Para Wants ROHO

"The ROHO you got for me years ago started to leak all over so I keep in bed most of the time. . . . I would like to correspond with paraplegics like myself who suffered an accident. I enjoy reading letters." *George Wade, 14 Sarstoon Street, Belmopan, Belize, Central America.*

Portable Respirator Wanted in Hungary



János Horváth, Hungary

"My name is János, age 38. In 1959 I fell ill with the disease Heine-Medin (polio) and I became paralytic of breath. I spent 12 years in hospital, and since then have been living at home. . . . In the hospital where I was treated lives a friend who wears an iron lung at night, György Kárpáti, age 26. Family ties he has developed recently would make it possible for him to go home if he had a portable chestpiece respirator. If anyone can help with the acquisition of such an instrument, please let me know. . . . I would like to correspond with my foreign fellows." *János Horváth, 1162 Budapest, Békés Imre u. 119/a, Hungary.*

György Kárpáti, Hungary



Can anyone identify this mystery man? He was photographed at the Pacific Missile Test Center, Point Mugu, California.

Official photograph, U.S. Navy



Mystery Man

If anyone recognizes the gentleman in the wheelchair, please send his name and address to the *Gazette*. He was photographed at the Navy Air Show, Pacific Missile Test Center, Point Mugu, California.

Leper Colony Library

"On behalf of my disabled Hansenite inmates of this isolated island, I beg of you to send newspapers, magazines, books, and a vacation and camping directory for our Reading Center."

Remarcelito Butiong, Culion Leper Colony, Palamar 2913 Philippines.

Stamp Collectors

"I write for the Société d'Etudes Philatéliques de Paralysses. We are a group of young French disabled. For our studies, we need stamps and postcards from U.S.A." *J. Despréaux, "Le Solail Levant," 20 rue des Aubépines, 42700 Firminy, France.*

Hemophillic in India

"From childhood I am suffering frequent heavy bleedings and consequent anaemia. My joints have been affected due to arthritis causing difficulty in movement . . . I am keeping myself fit with periodic transfusions of blood and anti-hemophillic factor. They cost me a lot, and the Red Cross and Lions Club occasionally help. . . . I request financial and medical information on the latest medicines." *V. Krishnan, S/o. S. Vasudevan, Kilayur (Post), Nagapattinam Taluk, Tamil Nadu, India.*

SCI Wants Information

"I am a T6/T5 paraplegic since May 31, 1983. . . . I try to exercise mentally. I feel that the answer to the spinal cord lies within the cord itself and the healing involves development of the subconscious mind. Do any readers know of good books that deal with the subconscious mind or where I can have experimental or exploratory surgery?" *Archie T. Birch, P.O. Box 187, Langston, Oklahoma 73050.*

Wants Barrier-Free Housing in South

"I have had rheumatoid arthritis since the age of three. I use crutches and a wheelchair. I am now 63 and I would like to move to a warmer part of the country. I can manage well when things are accessible. I shall appreciate advice and information." *Jennie Cheszun, 22 Booth Street, Nashua, New Hampshire 03060.*

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The Elswick Envoy

by Carol Raugust

December 8, 1984, marked a milestone ... I received, from California's Department of Motor Vehicles, the pink slip certifying my ownership of the first British Elswick Envoy in California. It has been twenty months since the actual purchase order was placed, fifteen months since I initiated importation, and nearly nine months since I watched it emerge from the cargo bay of an Air Canada jet at San Francisco International Airport.

Several obstacles accounted for the delay. The Envoy does not meet California's exceptionally high air pollution standards. I sought legislative assistance in obtaining an exemption, and, with much help from the news media, finally got clearance for one car "on an experimental basis." The path is now clear for others to obtain similar clearances on a case-by-case basis for Envoys in California, thanks to A.B. 2794 written by Assemblyman Bob Naylor.

Another problem was more mundane. California also requires a "Certificate of Origin," a sort of birth certificate, to complete the registration process. Few clues were offered for tracking down the proper document, and, as far as the manufacturer was concerned, the shipping invoice and bill of sale were sufficient. On the federal level, prospective buyers need to do business with the Environmental Protection Agency (EPA) and the Department of Transportation (DOT). Federal law provides that every individual may import one vehicle which does not meet EPA pollution standards. The feds have been particularly considerate about granting exemptions for the Envoy because of its special purpose. However, many racing sports cars have been imported under this statute, and pressure for new restrictions is building.

DOT oversees issues related to auto safety. Elswick has done its best to bring the Envoy into compliance with DOT specifications. Indtec, their U.S. distributor, has succeeded in obtaining temporary exemptions for DOT requirements the manufacturer has not yet met. Until standards are relaxed or the Envoy is upgraded, buyers may be asked to assume responsibility



The Elswick Envoy.

for assuring DOT that specifications will be met to the best of one's ability. For example, some of the dash controls are required to have better labels; a simple task if you have a Dymo label-maker and a camera to prove the labels have been added.

Since this car is an import, U.S. Customs is necessarily involved as well. I found them to be most helpful in cutting red tape. They were instrumental in securing a ruling that the Envoy may enter the country duty free as a medical appliance.

Once I mastered its idiosyncrasies, I enjoyed a kind of freedom with my Envoy I had never known before. It does for my power wheelchair what the battery pack and motors did for my "push" chair, only more so.

For the first time, I am able to understand the psychology behind car commercials designed to appeal to body image. Seven months and nearly 5,000 miles behind the wheel have not diminished the thrill of being able to go where I need to, when I am ready to go; the joy of making appointments I know I can keep; the pleasure of being able to window shop at any village center I happen to pass.

It's a relief to know that even when my E & J blows a transistor, I can still make it home. I have a beautiful sense of functioning easily and inconspicuously in a world designed and built primarily for the able-bodied. I am out of the car and

ready for action in less than one minute. Getting back in and started up requires only slightly longer.

Inside, the car is very basic. The floor-mounted automatic stick shift sits on the right. Originally it was difficult for me to manage, but the optional adaptive handle brought it within easy reach. (Installation was a little tricky.) The transmission is different in that it responds to two different modes of driving. When driving in town with a gentle touch on the gas, it goes through all the gears before reaching 20 mph. On the other hand, one has the option of the "jack-rabbit" start, in which case it remains in the lower gears until reaching 30-35 mph. This is more suitable for entry into traffic on the super highways. One drawback of the transmission is that there is no parking gear. The hand (parking) brake is also floor-mounted on the right within easy reach.

Though I am used to driving with foot controls, I find Elswick's hand controls very acceptable. The gas pedal and power brake are activated by two levers concentric with the steering wheel. These levers are lifted towards the driver when used. Thus, the driver has the asset of being able to keep both hands on the wheel whenever circumstances warrant. The hand controls on my car do take advantage of my strong left hand, but do not cause fatigue.

Elswick offers power steering which I found too sensitive at first. Now that I have learned to use it properly, I like it. It's great to make a complete U-turn in 25 feet or slip into a parallel parking space — frontwards.

The four cylinder, 1000 cc., 39 hp. engine gives me about 30 miles to the gallon. It is rated at 0 to 60 in 27 seconds and pretty nearly lives up to the claim. Elswick delivered my car tuned for 97 octane gasoline. The best I can get is 92 octane, so it does "ping" a bit. Parts are available in foreign car specialty shops and salvage yards, provided you have the patience to search them out. For some reason, the serial numbers on items such as the air filter cartridge are missing from catalogs in this area. On the other hand, the Envoy is so unique as to excite the interest of sincere British Mini hobbyists who have been only too happy to do whatever they could to

offer the benefit of their experience. I recommend this resource for locating a mechanic who takes pride in his work. Commercial garages, for the most part, are less flexible, often too busy to be bothered, and unwilling to assume the risk, real or imagined.

Elswick was helpful in providing a supply of oil filters and belts with my car. They claim that no part should be more than a week away, but so far I have found the shop service manual to be unavailable.

The Envoy's large windows provide superb visibility. The interior rearview mirror, however, vibrates badly on the road. Possibly a different type of mounting would help that. The side windows slide forward and back, rather than up and down. I find this very convenient and a good source of ventilation minus the annoying drafts found in other cars. The rear window comes complete with washer, wiper, defroster, and defogger. The front has one single-speed wiper equipped with a window washer.

The driver is intended to sit center front in a wheelchair which has been specifically crash-tested with the Envoy. Driver safety is very important to the manufacturer, as it should be to the owner. The tie-down is therefore wired into the ignition system as a precaution, and serves as an anti-theft device as well. Other chairs may fit, but are used at the owner's risk. The tie-down system and alternative chair have to be redesigned to fit each other.

The driver enters by means of a folding ramp at the rear. The ramp may be made less steep by simply pushing a button. (There is one on the rear door and another one on the dash.) Grab bars are mounted on the two folding rear jump seats to assist the driver who uses a push-type chair. I am impressed by the comfort of the jump seats, but passengers riding too together can't afford to be shy about intertwining their knees — there is not room to do much else.

Cargo space is limited. The spare tire lies just to the driver's right. I managed to install a small fire extinguisher between the tire and the rear seat. On the left side, there is space for one large suitcase, but one must be creative in securing it. Once I purchased two cases of oil and simply asked the sales person to load them beside

my chair once I was in place. Then I drove home and found a friend to do the unloading. The dashboard is flat and convenient for carrying casseroles to pot-luck dinners — if you drive carefully. Some space is also available on the front floor by your feet. This could be considered an advantage of not having foot controls.

Elswick does mention the fiberglass body, but many insurance companies are not interested in writing policies for fiberglass cars. I spent a great deal of nervous energy locating insurance coverage. Presently I am with Utica, but have a quote from State Farm that looks like a better bargain. It is a good idea to check with your own agent or broker.

The Elswick Envoy is not the ultimate answer for everyone's mobility needs. No car can be. But for my purposes, it is the best thing on the road today.

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Address: Carol Raugust, 26724 Lauderdale Avenue, Hayward, California 94545.

ED: As this issue went to press, Barry Newman, President of Indtec, Inc., U.S. distributors of the Envoy, informed us that Elswick had removed the car from the U.S. market due to problems with product liability. Newman will continue to fight for the Envoy. For more information on the status of the Envoy, write Newman at Indtec, Inc., P.O. Box 570, Ramsey, NJ 07446 or call (201) 746-0682.

The Escort Chairman, based on the Ford Escort, is similar to the Envoy, but unfortunately is unavailable in the U.S. *Gazette* readers in Europe and England can contact Gowrings Mobility International, The Grange, 18-21 Church Gate, Thatcham, Berks, RG13 4PH England.

An excellent article, "Mini-vans: panacea or passing fancy" by William Fryckman and Susan St. Amour, appeared in *Mainstream*, December 1984. *Mainstream's* address is 2973 Beech St., San Diego, CA 92102.

Oral Positive Pressure Adaptations



Orthotic collar hose support.

Orthotic Collar Hose Support

Lightweight, comfortable collar made of ABS material by orthotic engineer Howard Campbell at Ohio State University for Imogene Pritchard. "Gene" is a polio survivor who needs a positive pressure tube close to her mouth during the day.

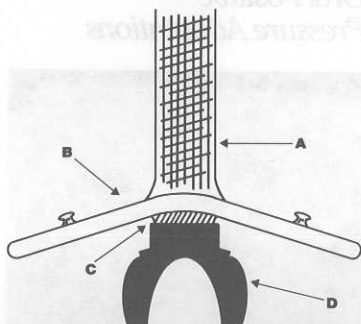
Address: Gene Pritchard, 472 West Eighth Avenue, Columbus, Ohio 43210.

Over-the-Shoulders Hose Support

Bud Dabney, an "upside-down" polio survivor (ambulatory with paralyzed arms), has devised a shoulder holder for his positive pressure tubing to relieve weight from his neck and keep the mouthpiece in one place near his mouth. The support consists of a $\frac{3}{8}$ " plywood platform 3" X 6 $\frac{1}{2}$ " with a clamp for the flex-tube. Steel wire (#9) slips into slots in the plywood and extends over the shoulders. Padding covers the portion of wire which rests directly on the shoulders. Bud estimates cost at \$25-\$30 and will share the blueprint.

Address: Bud Dabney, 8354 Edgedale Road, Baltimore, Maryland 21234.

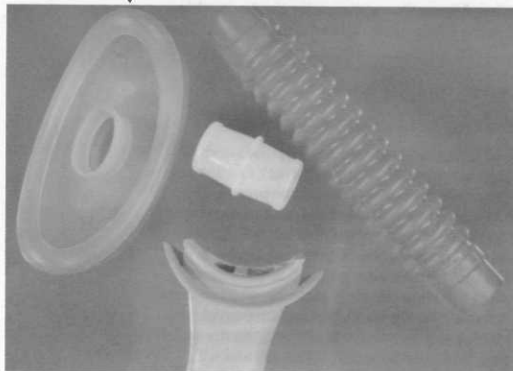
Figure 1.



Lipseal and Diving Mouthpiece

An adaptation to the Puritan Bennett lipseal increases its sealing ability without having to tighten the head straps. A mouthpiece from scuba diving gear or from pulmonary function equipment is used. The illustration in Figure 1 demonstrates the set-up.

Figure 2.



A section of ventilator tubing (A) is attached to the Puritan Bennett lipseal (B). A tubing adaptor (C) is used to connect the lipseal to a diving mouthpiece (D). The photograph in Figure 2 demonstrates the parts of a pulmonary function mouthpiece. The mouthpiece aids in keeping the mouth closed and the lips stabilized.

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Address: Oscar Schwartz, M.D., St. Mary's Health Center, 6420 Clayton Road, St. Louis, Missouri 63117.

Center for Computer Assistance to the Disabled

by John Dycus

Ronald Ballard and Larry Adrian make a living with their computers. Eric Reed writes music with his. Billy Yaws does simple programming and plays computer games.

All four men are disabled. Ballard, Adrian, and Reed are quadriplegics, the result of accidents. Yaws was born with a birth defect that left him severely disabled with limited use of his hands.

All four men have been helped by the Center for Computer Assistance to the Disabled (C-CAD), a Dallas-Fort Worth non-profit agency.

"When people say we're doing a good job, I can't help but remind them how much more we need to do," says C-CAD Board Chairman, Jack Kishpaugh, himself a quadriplegic. "Then I think of 'superquads' like Ronald and Larry and realize that everything we give out comes back to us many times over. Our small efforts have paid off in big ways."

Ballard runs a collection agency from his home — all correspondence, billing, and recordkeeping accessed via mouthstick on a Morrow computer fitted with a 10-megabyte hard disk.

Adrian, who holds degrees in sociology and computer science, works for a company he was introduced to through Operation Link, a Chicago liaison between employers and homebased programmers. He was introduced to Operation Link through C-CAD.

Reed motors his sip-and-puff wheelchair around the Stephen F. Austin College campus in Nacogdoches. Although a business major, he retains a keen interest in computer-aided music composition, instilled when a therapist introduced him to C-CAD.

"We have received 78 computers in the year and a half that we've been operating, but we don't have sufficient peripherals, software, or people to help all our clients grow beyond a basic level," Kishpaugh says. "Everyone should be brought along with additional training."

But a computer and its software can get expensive. Assessment and training are non-existent on a large scale. Without these, the disabled user has no proven talent to showcase. That's where C-CAD comes in.

The Center will one day teach programming and computer-use courses specifically for the disabled. It will also attempt to place those students with prospective employers. It is already developing customized hardware and software designed to overcome clients' handicaps. One doesn't need ten nimble fingers to manipulate a keyboard, if a mouthstick or other prosthesis will work.

"It's almost impossible for a disabled person to find someone who can even place a power-supply toggle on the front of an Apple unit," says Board Member and computer science professor, Rusty Hollingsworth. "With the Center, a technician can do that in a matter of minutes at virtually no cost and enormously simplify the client's use of the equipment."

Consider what the Center's advisor Dr. Richard Roa's minimum-keystroke text generator did for Jean Riley's productivity.

Ms. Riley, an Arlington artist and writer with cerebral palsy, has great difficulty in typing. Dr. Roa's software cuts the number of keystrokes needed to yield about 400 common words. Her computer types a one- or two-letter abbreviation, corresponding to a word stored in memory. The computer matches the abbreviation with a word or phrase and displays it on the screen.

"For a long time I had wondered how typing could be made easier for people who have difficulty using their hands," says Ms. Riley, who supports herself by freelancing. "Typing can be so time consuming."

Roa, a bioengineer with Baylor Medical Center in Dallas, has extensive knowledge of electronic and computer programming. Ms. Riley had the idea for abbreviating words and the need.

C-CAD's Chairman Kishpaugh believes the computer center will improve the odds of such collaborations happening again.

"Computer technology is growing very, very quickly, but we're still caught in a 'black box syndrome,' with many people saying that 'we don't understand these machines,'" he says. "But all the disabled have to do is relate their needs to us, and we'll try to bring the two worlds together."

Those worlds came together in 1981 during the Johns Hopkins' First National Search for Applications of Personal Computing to Aid the Handicapped. From more than 7,000 entries nationwide, the most inventively useful would be detailed in printed proceedings.

Approximately 35 projects were chosen for demonstration at a regional competition at the National Aeronautics and Space Administration in Houston. Judges picked Roa's text generator among the top 15. Jack Kishpaugh's "Mobile Computer Skills Evaluation Unit" was judged to be 10th best nationally.

The evaluation unit involves a modified Texas Instruments 99/4A computer, an Epson MX-80 printer, and Universal Data Systems' 103JLP telephone modem, all donated by the manufacturers. A disabled user's motivation and aptitude can be determined within a few hours.

"You see a potential candidate for a job market, a loyal, fantastically productive employee, especially if he has access to the tools," Kishpaugh says. Larry Adrian, for example, works from his home. His employer saves on office costs and has an employee who can work at low-demand times on the mainframe and data bank. Adrian saves on transportation, wardrobe, food, and time spent commuting.

The movement, if that's what it is, seems to be growing. Approximately 100 major corpora-

tions and labor unions comprise the Industry-Labor Council, a national non-profit organization committed to employment of the disabled.

Developments similar to C-CAD are occurring in St. Paul and Chicago, and Kishpaugh notes that organizations in Baltimore, San Diego, Los Angeles, and Portland tend to "copy what we're doing, but that's great, we like them to do that. There's nothing proprietary about this."

Kishpaugh utilizes a 16-function environmental control system operated either by a radio device when he's in his wheelchair or by breath-activated diaphragm switches when he's lying down.

Until the system was replaced this fall, one puff on a tube triggered a rotary mechanism that produced the desired function. Once the function was found, a sip on the tube kicked it in. Kishpaugh controlled his phone, lights, TV, bed positioning, even door latches this way. Now these items and more — every electrical outlet, every device in the apartment — are controlled by a state-of-the-art, voice-activated system.

Tape recorder switches were too small and close together for a person with no finger use. Kishpaugh glued wide lucite strips to the switches and works them with a mouthstick or the rubber-tipped steel rod he has strapped to his right wrist.

He couldn't roll the carriage on his IBM Selectric, so he replaced the small, smooth end knobs with knurled giants indented deep enough for his wrist splint to push.

He couldn't load 5 1/4" floppy disks into his TI drive unit, so he turned it on end and now slides a disk up a homemade lucite ramp and, snap, into the spring-loaded opening.

Kishpaugh took his first computer course in 1979 at Texas Wesleyan College in Fort Worth. He found the computer to be an intellectually stimulating companion. "Someone who's disabled spends a lot of time alone. You can get off by yourself with one of these devices and, before you know it, you're doing magic — and you've hardly touched your potential for doing something productive."

"The disabled are a tremendously underutilized resource, at a time when computer costs are coming down and demand for computer skills is very high. There's a 40 percent shortfall of technician/programmer demand over supply. Why can't a physically impaired person, who's otherwise very capable, be equipped to write programs in his home and send them to the company via a telephone hookup?"

Then the Texas Rehabilitation Association's 1982 Handicapped Texan of the Year answers his own question: There's no reason, as he sees it. No reason at all.

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Address: The Center for Computer Assistance to the Disabled, 2501 Avenue J, Arlington, Texas 76011, (817) 640-6613.

Computers and the Disabled: Update

by William Kaiser

Much changed in the computer world in 1984. The article I wrote in Volume 25 of the *Gazette* was barely printed when Texas Instruments stopped making the 99/4A computer. Thousands were sold out at prices as low as \$49.00. If anyone has the old 99/4A and needs locking shift and control keys, Texas Instrument will still exchange your unit for one that has been modified. Call Greg Nестеby at 800-842-2737. And you can get more information on 99/4A equipment and software that is still available from: Re:Able, Box 384, Bellflower, CA 90706.

Apple Computer has come out with the Apple IIe and IIc. The IIe has the same variety of hardware and software for use by someone with a disability as the old II+.

Another new computer that I've developed a nice relationship with over this last year is the Epson QX-10. The benefit this system offers someone with a disability is found in a uniquely designed keyboard and in the "ValDoc's" software that comes with the QX-10. On most



computers if you want to write a letter you load a word processor program and write. If you next want to file information you have to store the letter, take out the word processor program, and load a different program that handles information. The QX-10 does both at the same time, and more. The "ValDoc's" software starts with a good word processor, and you can leave in the middle of writing at the push of a key and access an address book, appointment or note book, draw graphs, or send and receive mail, and still go right back to writing. The keyboard was designed to work with "ValDoc's." It includes special keys for printing, word processing, type style, help, and even an "undo" key to correct mistakes. It is close to ideal for someone with a disability in a business environment.

Another new computer uses a touch screen to input information in addition to the keyboard; simply touch an area of the screen of the TV and the computer performs a predetermined task.

Touch tablets are like touch screens, except these tablets can lie on tabletops or be held on laps. When a finger is moved over the surface, a similar line appears on the screen. Touch tablets can also be used to interact with computers in

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Bill and Cathy Kaiser (son John peeking under Cathy's arm) in their new store, Bellflower Video and Computer, 16412 Bellflower Blvd., Bellflower, CA 90706.

special ways. One new product has the alphabet, shapes, and color areas on the tablet. When a letter, shape, or color is touched, it appears on the screen. Touch tablets can be especially useful with disabilities like cerebral palsy where fine motor control is not possible. (Re:Able will focus on this area in an upcoming issue.)

My book, *Computers and the Disabled*, has been delayed due to the truly massive amount of information that has been gathered, and I thank all of you who have already written with news, experiences and questions, and look forward to hearing from more *Gazette* readers. Another reason for the delay is the video and computer store my wife and I were asked to open late last year. Bellflower Video and Computer has become a second home since then. My wife runs the shop as part of Creative Management Concepts, her management consulting firm, and I step in occasionally as technical consultant.

Resources and things: *Closing the Gap*, Box 68, Henderson, MN 56044. CTG is a bi-monthly newspaper with a focus on special education and computing. Includes news, articles, and reviews. Subscription is \$15.00 a year (\$33.00 overseas). Publisher Delores Hagen is also author of *Microcomputer Resource Book for Special Education*, an excellent book of practical and education applications, available from Reston Publishing.

Re:Able — The international newsletter of computing and the disabled. Applications, news, equipment and software reports aimed at use by the disabled, hardware adaptation, question-answer. Providing extensive information on computing and the disabled for the professional, disabled, and business communities. Bi-monthly newsletter—\$18.00 a year from Re:Able Publishing, P.O. Box 384, Bellflower, CA 90706.

A Beginner's Guide to Personal Computers for the Blind and Visually Impaired. Reviews of six talking computer systems and special features of each, plus information on programming, software selection, data banks, and clubs. Braille or cassette version \$6.00, available from Braille Press, 88 St. Stephen Street, Boston, MA 02115.

Talktex 64 is like the Talktex for the Vic-20 reported on last year and is a cartridge for the Commodore 64. The Talktex speaks each word on the computer screen, allowing telecommunications and computer use by the blind. \$199.00 from Duffy Engineering, RFD 1, Box 387A, Nashawena Rd., Mashpee, MA 02649.

SpecialWare Directory. A comprehensive reference of special education software. LINC, 3857 N. High St., Columbus, OH 43214.

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Address: William Kaiser, P.O. Box 384, Bellflower, California 90706.

Accessibility

"Guidelines for Improving Access for Disabled People." Brochure prepared by the Royal Association for Disability and Rehabilitation (RADAR). Outlines the basic principles for those responsible for planning and building in developing countries. Bilingual in English and French. Available free from ICTA Information Centre, Box 303, S-161 26 Bromma, Sweden.

Adoption

Adoption of special needs children who cannot be returned to their biological families is a project of the American Bar Association and Dept. of HHS. Contact Ellen Segal, ABA, National Legal Resource Center for Child Advocacy and Protection, 1800 M St., N.W., Washington, DC 20036.

Advocacy

Disabled Persons Advocacy Division of the Office of the Illinois Attorney General appointed a Consumer's Task Force comprised of recognized experts in their fields of disability. They identified priority issues of housing, employment, education, transportation, voters' rights, accessibility, health, mental health, and insurance. Write Elaine Hirsch, Chief, Disabled Persons Advocacy Division, Offices of the Attorney General, Room 806, 160 N. LaSalle St., Chicago, IL 60601.

ALS

ALS Society of America (ALSSOA) and National ALS Foundation have merged to form the ALS Association. Rochelle Moss, Executive Director of National ALS, will be the new Executive Director of the ALS Association, 185 Madison Ave., New York, NY 10016.

Arthritis

The Arthritis Information Clearinghouse offers a new type of publication — a biblioprofile, which includes a brief report of current thinking on a particular medical subject followed by a short bibliography. Materials are free from the Clearinghouse, P.O. Box 9782, Arlington, VA 22209.

Attendants

"Working Together: Disabled People and Their Attendants Talk about Attendant Care" is an audiovisual production which includes a slide/tape presentation with printed manual and printed script. Available from Access to Independence, Inc., an independent living center, 1954 E. Washington Ave., Madison, WI 53704. Total cost of the package is \$175.

Attitudes

"Responding to Disability: A Question of Attitude" is a 38-page booklet illustrating potentially awkward and uncomfortable situations involving people with disabilities. Designed as a discussion starter for attitude training workshops. Contact the Minnesota State Council for the Handicapped, 208 Metro Square Bldg., St. Paul, MN 55101.

Braille

Western Union will mail telegrams in large print or in braille throughout the continental U.S. Rate is \$2 for the first 25 words and \$1 for each additional 25 words. Call your local Western Union office.

General Electric (GE) will provide a service technician to put braille knobs on GE Hotpoint ranges and home laundry equipment for visually impaired consumers. Braille panels for microwaves are available

also. Write GE Consumer Relations, Appliance Park, Louisville, KY 40225.

Children

SKIP (Sick Kids (need) Involved People) is a national, non-profit organization of families and public and private health care professionals devoted to supporting and facilitating home care for technology assisted children. This new population of children includes ventilator assisted children with respiratory disabilities, children with nutritional disorders dependent on parenteral nutrition, and children with kidney disease dependent on dialysis. Contact Karen Shannon, SKIP, 216 Newport Dr., Severna Park, MD 21146 for information on state chapters.

The Vanderbilt University study, "Public Policies Affecting Chronically Ill Children and Their Families," is scheduled to be published in the fall of 1985. Tentative title for the final two-volume report is *Constant Shadow: Childhood Chronic Illness in America*. Contact May Shayne at the Institute for Public Policy Studies, Vanderbilt University, 1208 18th Avenue South, Nashville, TN 37212, (615) 322-8524 or the publisher, Jossey-Bass, 433 California St., San Francisco, CA 94104.

Clothing

Adaptive Apparel, Inc., P.O. Box 3497, Lawrence, KS 66044. Easy-to-fasten closings, extra room for movement. Fashions for both men and women.

Access Activewear, P.O. Box 15891, San Diego, CA 92115. Sportswear for men and women.

Dressing with Dignity, 2430 Central Parkway, Cincinnati, OH 45214. Men's and women's fashions.

Fashion Able, Box S, Rocky Hill, NJ 08553. Men's and women's apparel.

Gwynedd Designs, P.O. Box 17872, Milwaukee, WI 53217. Fashions and accessories.

Laurel Designs, 5 Laurel Ave. #6, Belvedere, CA 94920. Vinyl rain pouch and limited apparel for wheelchair users.

Pirca Fashions, 901 Third Ave., Sacramento, CA 95818. Fashions for women.

Sears' Home Health Care Specialog. Free from any retail store. Adaptive clothing section.

Style Craft Co., 1306½ S. Roxbury Dr., Box 35869, Los Angeles, CA 90035.

Communication

Rehab Technology System controls telephones, television, lamps, etc., and signals for assistance. Easy-to-use, no-frills device from Rehab Technology Inc., P.O. Box 185, Aviston, IL 62216.

Words +, Inc. Personal computer-based augmentative communication aids. Words + infrared switch can be operated by any body motion, even eyeblink and eye movement, to operate communication aids. Words +, Inc., P.O. Box 1125 Stewart Court, Suite D, Sunnyvale, CA 94086.

Computers

Personal Computers and Special Needs by Frank Bowe. 171 pages. 1984. \$9.95 paper edition from Sybex, Inc., 2344 Sixth St., Berkeley, CA 94710.

Personal Computers and the Disabled by Peter McWilliams. 416 pages. 1984. \$9.95 paper edition from Doubleday & Co., Garden City, Long Island, NY 11530.

Lift, Inc., a not-for-profit corporation, trains and hires severely disabled individuals to work as computer programmers from their own homes. Contact Donna Kozberg, Eastern Region Director, Lift, Inc., P.O. Box 1072, Mountainside, NJ 07092.

Critically Ill

The Rights of the Critically Ill by John Robertson. An American Civil Liberties Union Handbook. 192 pages. 1983. Ballinger Publishing Co., 54 Church St., Cambridge, MA 02138.

Dating Services

Handicap Introductions, P.O. Box 48, Coopersburg, PA 18036. \$25 application fee guarantees six matches in a three-month period. Nationwide. Independent Introductions, One Penn Plaza, Suite 100, New York, NY 10119. New York City metropolitan area, nominal cost.

Touching Disableds, P.O. Box 2908, Anaheim, CA 92804. \$5 for mail order dating service for disabled and non-disabled.

Dogs

Support Dogs for the Handicapped, Inc., P.O. Box 10607, St. Louis, MO 63129.

Guide Dogs for the Handicapped, The Maxwells, 16081 Montgomery Rd., Johnstown, OH 43031.

Employment

Job Accommodation Network (JAN) is a new information network for employers operated by the President's Committee on Employment for the Handicapped. JAN is a database of specific information about how tasks can be performed by disabled individuals. Write Job Accommodation Network, P.O. Box 468, Morgantown, WV 26505, or dial 1-800-JAN-PCEH.

Putting Disabled People in Your Place: Focus on Paraplegia and Quadriplegia is a new publication from Mainstream, Inc., on hiring and placing individuals with specific disabilities. Practical advice on interviewing, accommodating, and supervising. Available for \$7 postpaid from Mainstream, Inc., 1200 15th St., N.W., Washington, DC 20005.

Films

Rehabfilm Newsletter, a quarterly from a division of *Rehabilitation World*, reviews audiovisual materials as they relate to disabled individuals. Subscription prices and information on the International Rehabilitation Film Festival 1985 are available from Rehabfilm, 1123 Broadway, New York, NY 10010.

"Tell Them I'm a Mermaid." A musical-theater half-hour documentary on the private world of seven women with physical disabilities, enhanced by an original music score and unconventional choreography. For rental, Embassy Pictures, 1901 Avenue of the Stars, Los Angeles, CA 90067.

Gardening

"Tools and Techniques for Easier Gardening" evaluates enabling garden tools and presents techniques developed with the assistance of horticultural therapists, gardening experts, and gardeners with physical disabilities. This handsome booklet is available for \$3 from Gardens for All, 180 Flynn Ave., Burlington, VT 05401.

"Gardening for Handicapped and Elderly Persons" is a bibliography published by the National Library Service for the Blind and Physically Handicapped, available free from the Library of Congress, Washington, DC 20542.

Genetic Disorders

National Foundation for Ectodermal Dysplasias. A rare genetic defect which affects children till adulthood. Symptoms are bad teeth, absent or poor sweat glands, impaired nerve endings, sparse hair follicles, missing nails and toenails, and other abnormalities of the outer skin. Contact Mary Richter, NFED, 108 N. 1st, Suite 311, Mascoutah, IL 62258.

Charcot-Marie-Tooth (CMT) Newsletter is a new quarterly published by Linda Crabtree, 34-B Bayview Dr., St. Catharines, Ontario, L2N 4Y6, Canada.

A rare genetic disorder, Prader-Willi syndrome, affects approximately 2,000 in the U.S. Studies indicate that the figure might be higher since many may not have been diagnosed or have been misdiagnosed. Symptoms are slight retardation, emotional instability, and obesity. Write Prader-Willi Syndrome Association, 5515 Malibu Dr., Edina, MN 55436.

Head Injury

National Directory of Head Injury Rehabilitation Services is a comprehensive tool available for \$43.50 postpaid from National Head Injury Foundation, 18A Vernon St., Framingham, MA 01701.

Drucker Brain Injury Center at Moss Rehabilitation Hospital has been awarded a grant for \$150,000 over a three-year period for research in the analysis of functional skills, studies of learning capacity for persons with organic brain damage, measuring brain injury rehabilitation outcome, studies of brain-behavior relationships, and studies of long-term social and societal needs of head injured individuals. Nathaniel Mayer, M.D., is director of the Center, Moss Rehabilitation Hospital, 12th St. & Tabor Rd., Philadelphia, PA 19141.

Housing

Housing and Home Services for the Disabled: Guidelines and Experiences in Independent Living, written by Gini Laurie in 1977 and published by Harper & Row, is still a classic text on the subject. Available for \$34 from bookstores or directly from distributor J.B. Lippincott, East Washington Square, Philadelphia, PA 19105.

Incontinence

Help for Incontinent People was organized in 1983. The HIP Report is a free quarterly newsletter available from HIP, P.O. Box 544, Union, SC 29379.

Independent Living

Challenges of Emerging Leadership: Community Based Independent Living Programs and the Disability Rights Movement. Final report of a five-day conference held in East

Lansing, Michigan, in August 1982 sponsored by the Mott Foundation. Attendees were leaders in the independent living movement. The report provides a basis for future action in the following areas: technical assistance, networking and communications, leadership development, research and policy analysis, and long-term planning. 1984. 62 pages. \$4.95 plus postage and handling. Publications Coordinator, The Institute for Educational Leadership, 1001 Connecticut Ave., N.W., Suite 310, Washington, DC 20036.

Independent Living and Policy Changes: Reflections on a Decade's Progress. Report identifies changes in rehabilitation services, transportation, housing, employment opportunities, elimination of architectural and communication barriers. Send \$5 to Independent Living Research Utilization (ILRU), P.O. Box 20095, Houston, TX 77225.

Proceedings of the International Conference on Rural Rehabilitation Technologies. Technology and the unique needs and resources of disabled individuals living in rural areas. 1984. 285 pages. \$30.00 ICRRT Headquarters, Publications Secretary, Box 8103, University Station, Grand Forks, ND 58202.

National Council on the Handicapped has approved Independent Living Center Evaluation Standards developed with the assistance of Berkeley Planning Associates. The standards are to be used in conducting the national evaluation of the Independent Living Program. Available from Berkeley Planning Associates, 3200 Adeline St., Berkeley, CA 94703 or the National Council on the Handicapped, 800 Independence Ave., S.W., Suite 814, Washington, DC 20591.

Independent Living Aids

Technology for Independent Living Sourcebook. Edited by Alexandra Enders, O.T.R. The *Sourcebook* continues and updates the materials and information in *Technology for Independent Living Resource Guide*. The *Sourcebook* has added sections on control, communication, and microcomputer applications. 1984. 265 pages. \$25.00 Rehabilitation Engineering Society of North America (RESNA), Suite 402, 4405 East-West Highway, Bethesda, MD 20814.

Why Didn't Somebody Tell Me About These Things? By Lou Hamilton. An illustrated collection of ideas and resources for persons with ALS and other disabilities. 139 pages. Spiral-bound. \$750 postpaid from Kansas City ALS Patient Services Fund, 5350 W. 94th Terrace, Suite 207, Prairie Village, KS 66207.

The Electronic Industries Foundation established a non-profit Rehabilitation Engineering Center to facilitate the transfer of research designs and newly developed assistive devices to private industry for production and marketing. EIF/REC is supported through NIH. Write EIF/REC, 1901 Pennsylvania Avenue, N.W., Suite 200, Washington, DC 20006.

Information Sources

ICTA Information Centre. International Commission on Technical Aids operated by the Swedish Institute for the Handicapped and Rehabilitation International. Publishes *ICTA Inform*, a quarterly newsletter free from ICTA, Box 303, S-161 26 Bromma, Sweden.

British Database on Research into Aids (BARD) for the Disabled contains information on design and

development work of technical aids, prototypes, as well as research projects on the use of aids, surveys and evaluations. BARD will concentrate on aids not commercially available. Write BARD, the Handicapped Persons Research Unit, Newcastle-upon-Tyne Polytechnic, No. 1 Coach Lane, Coach Lane Campus, New-castle-upon-Tyne NE7 7TW, United Kingdom.

Gazette International Networking Institute (G.I.N.I.) is an information clearinghouse on polio, spinal cord injury, and other neuromuscular disabilities and diseases, ventilators, and all aspects of living independently with a disability. Computerization of G.I.N.I.'s files is soon to begin to make the material more widely available to independent living centers, health care professionals, researchers, and students.

Legal Information

Mainstream, a monthly newsletter from The Legal Center for Handicapped Citizens, covers issues and cases currently in the news. Write to the Center, 1060 Bannock St., Denver, CO 80204.

Know Your Rights: The Disabled Voter's Guide by Barbara McGarry, Editor, American Foundation for the Blind, 15 W. 16th St., New York, NY 10011. A state-by-state guide to registration assistance, accessibility of polling places, personal assistance in the voting booth, and availability of absentee ballots for the disabled. Free.

Microfilm

Rehabilitation Gazette is available on microfilm (100-foot reel or cartridge). Includes all the out-of-print *Toomey's*. Positive or negative mode. \$50 including postage.

Rehabilitation Gazette is also available on open reel or cassette, free from Johanna Bureau for the Blind and Physically Handicapped Inc., 30 W. Washington, Chicago, IL 60602, or the Division for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20540.

Organizations

Appropriate Health Resources & Technologies Action Group Ltd. (AHRTAG) is an independent charity set up in 1977 as an information and resources centre on primary health care in underdeveloped countries. It publishes *Aids for Living*, a newsletter on low-cost technologies for the prevention of disability and rehabilitation. Write AHRTAG, 85 Marylebone High Street, London, W1M 3DE, United Kingdom.

The Sibling Information Network has been established to assist individuals interested in the unique needs of families of disabled persons. Write Dr. Thomas Powell, Dept. of Psychology, Box U-64, The University of Connecticut, Storrs, CT 06268.

Formed in 1981, The Third World Group for Disabled People is training medical and para-medical workers going overseas to work with disabled people to extend basic rehabilitation services in remote rural areas, and also train local rehabilitation workers. The group has recently published *A Cry for Health: Poverty and Disability in the Third World*, edited by Oliver Shirley. Available for £2.50 from Third World Group for Disabled People, 16 Bath St., Frome, Somerset, BA11 1DN United Kingdom.

Pain

National Chronic Pain Outreach Association, Inc., has introduced its first newsletter, *Lifeline*. For subscription information, write NCPO, 8222 Wycliffe Court, Manassas, VA 22110.

Parenting

Parenting Children with Disabilities: a Professional Source for Physicians and Guide for Parents by Peggy Muller Miezio. 201 pages. 1983. \$14.95 from Marcel Dekker Inc., 270 Madison Ave., New York, NY 10016.

Peer Counseling

The Peer Support Training Manual has been developed by Access to Independence, Inc., an independent living center in Wisconsin. The 50-page manual sells for \$10.00 postpaid from Access to Independence, Inc., 1954 E. Washington Ave., Madison, WI 53704.

"Peer Counseling: as a Movement, as a Rehabilitative Service" is a *Rehab Brief*, February 1984, Vol. VII, No. 2, free from PSI International, Inc., 200 Little Falls St., Suite 104, Falls Church, VA 22046.

Radio Show

Judy Heumann does a weekly radio show on public radio in California which covers a wide range of disability issues. Judy is co-director of the World Institute on Disability. The 28-minute programs are available for other public radio programs by contacting Nancy Angelo, Pacifica Radio, Pacifica Program Service/Radio Archives, 5316 Venice Blvd., Los Angeles, CA 90019.

Recreation/Sports

Parents' Guide to Accredited Camps, 1985. Directory of camps serving persons with disabilities. Refer-

ences indicate which camps mainstream or which are restricted to specific disability. Available for \$8.95 from American Camping Association, 100 Bradford Woods, Martinsville, IN 46151.

"Recreation for the Handicapped," available from the Missouri Dept. of Conservation, lists areas accessible to the disabled hunter, fisherman, or sportsperson. Special permits are available also. Write the Department, P.O. Box 180, Jefferson City, MO 65102, and departments in other states for their policies.

Scuba diving classes taught using the buddy system. Students include paraplegics, hemiplegics, amputees and quadriplegics. Write Handicapped Scuba Association, 1104 El Prado, San Clemente, CA 92672.

University of Alberta offers a Disabled Scuba Program consisting of classroom and pool sessions for diver certification. Contact Bob Coakley, Alberta Division of Canadian Paraplegia Association, 18131-107 Ave. Edmonton, Alberta T5S 1K4, Canada.

Respite Care

Respite Care: Principles, Programs, and Policies by Shirley Cohen, Ph.D., and Rachel Warren, M.S. Respite care for parents of severely disabled children. Available for \$18 from United Cerebral Palsy Associations, Inc., 66 E. 34th St., New York, NY 10016.

Safety

"Employers Are Asking . . . About the Safety of Handicapped Workers When Emergencies Occur" is a brochure to help safety-conscious employers include disabled people in their emergency management plans. Free from Presidents

Committee on Employment of the Handicapped, 1111 20th St., N.W., Washington, DC 20210.

Sexuality

"Disability and Human Sexuality: an Introductory Guide." April 1984. The WHOLE PERSON, Inc., 6301 Rockhill Rd., Suite 305E, Kansas City, MO 64131.

The Sex and Disability Resource Manual. \$9 from UCP Association of San Francisco, Golden Gate Theatre Building, 25 Taylor St., San Francisco, CA 94102.

"Sexuality and Disability." Spring 1984. Single issue \$2.75. *Rehabilitation Digest*, Canadian Rehabilitation Council for the Disabled, One Young St., Suite 2110, Toronto, Ontario M5E 1E5, Canada.

Shoes, Orthopedic

Prescriptions filled for all types of foot conditions. Guaranteed fit. Schoolcraft Shoe & Boot Repair, 223 N. Grand, P.O. Box 461, Schoolcraft, MI 49087.

Sign Language

National Technical Institute for the Deaf at Rochester Institute of Technology has developed *Basic Sign Communication Vocabulary*, a new dictionary to complement any sign language curriculum. Available for \$15 postpaid from NAD Bookstore, Dept. NR, 814 Thayer Ave., Silver Spring, MD 20910.

Spinal Cord Injury

Spinal Cord Injury: An Illustrated Guide for Health Care Professionals. By Marcia Hank, B.S.N., and Anne Scott, B.S.N. A multidimensional approach to working with spinal cord

injured individuals in the acute care, rehabilitation, and community settings. Psychological, medical, and therapeutic aspects of spinal cord injury management. 1983. 158 pages. \$15.95. Springer Publishing Co., 200 Park Avenue South, New York, NY 10003.

Twenty-four hour hotline for people needing information about spinal cord injury. Dial 1-800-526-3456.

Stroke

Stroke Connection is a newsletter published 11 times per year by Courage Center. Available free from Courage Center, 3915 Golden Valley Rd., Golden Valley, MN 55422.

Travel

A Guide for the Disabled Traveler. The United States, Canada, and Europe. By Frances Barish. Advice from an experienced wheelchair traveler on getting there, getting around, orientation, and where to stay. 1984. 362 pages. \$10.95. Frommer Books, Simon & Schuster, 1230 Avenue of the Americas, New York, NY 10020.

When planning to visit the Senate on a trip to Washington, make an appointment at the Office of the Sgt.-at-Arms. Special tours are available for those with visual or hearing impairments, and for wheelchair users. Write Special Services Office, Office of the Sgt.-at-Arms, U.S. Senate, Room S-321, the Capitol Bldg., Washington, DC 20510.

Ventilator Assisted Living

Brook Lodge Invitational Symposium on the Ventilator-Dependent Child. October 1983. Final report available from Children's Home Health Network of Illinois, E. 65th St. at Lake Michigan, Chicago, IL 60649.

Ventilator Assisted Care Program at Children's Hospital in New Orleans provides discharge planning, training, and on-going consultation with hospitals, families, and communities to enable a ventilator assisted child under 22 to live at home. Contact Kathryn Kirkhart, Ph.D., Program Coordinator, Children's Hospital, 200 Henry Clay Ave., New Orleans, LA 70118.

Gazette International Networking Institute (G.I.N.I.) is an information clearinghouse on ventilator assisted living. Chairman Gini Laurie has collected information for more than 35 years on people living at home with a ventilator. The experiences of polio survivors who are ventilator assisted can be transferred to spinal cord injured, muscular dystrophy, and the new population of technologically dependent children. For details about using the archives/research center, contact G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108, (314) 361-0475.

The Surgeon General's Regional Seminars on Ventilator Assisted Children and Adults have been held since December 1983 in St. Louis, Chicago, New Jersey, and Dallas. The next one is planned for Atlanta, Georgia, during November 1985. The proceedings of the St. Louis seminar were published in *AARTimes*, April 1984, available for \$3 from American Association of Respiratory Therapy, 1720 Regal Row, Dallas, TX 75235.

For details of the Atlanta seminar, contact G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

Volunteers

"New Resource: Volunteers Who Happen to be Disabled" is a special report from the President's Committee on Employment of the Handicapped. It highlights the positive benefits of volunteering and includes tips for attracting disabled volunteers for low budget community organizations. The booklet also offers a list of words to be avoided, such as "suffers," "victim," "crippled," etc. Free from PCEH, 1111 20th St., N.W., Washington, DC 20210.

Women

A self-defense catalog for women is available from Hatpin, P.O. Box 6144, Santa Fe, NM 87502.

Handicapped Organized Women (HOW) is a non-profit support group for women with physical disabilities. Write for information on local and national dues to HOW, Inc., P.O. Box 35481, Charlotte, NC 28235.

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Periodicals and Newsletters

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AARTimes. American Association of Respiratory Therapy. 1720 Regal Row, Dallas, TX 75235. Monthly. \$25.

* *AADC News*. American Association of Disability Communicators. 2100 Pennsylvania Avenue, N.W., Suite 232, Washington, DC 20037. Quarterly. Membership.

* *ACCD News Net*. American Coalition of Citizens with Disabilities, Suite 901, 1012 14th St., N.W., Washington, DC 20005. Bi-monthly. Membership.

* *Accent on Living*. P.O. Box 700, Bloomington, IL 61702. Quarterly. \$6.

* *Achievement*. 925 N.E. 122nd St., North Miami, FL 33161. Quarterly. \$3.

American Rehabilitation. Rehabilitation Services Administration, 330 C St., S.W., Washington, DC 20202. Quarterly. \$11.

* *The Braille Forum*. 190 Lattimore Rd., Rochester, NY 14620. Bi-monthly. In braille, large print, cassette, open reel tape, sound sheet. Free.

* *Breaking New Ground*. Farmers with disabilities, Dept. of Agricultural Engineering, Purdue University, West Lafayette, IN 47907. Quarterly. Free.

* *Breakthrough*. Osteogenesis imperfecta. P.O. Box 838, Manchester, NH 03105. Quarterly. Free.

Bulletins on Science & Technology for the Handicapped. American Association for the Advancement of Science, Project on the Handicapped in Science, 1515 Massachusetts Avenue, N.W., Washington, DC 20005. Quarterly. Free.

* *The Bumblebee*. 412 Woodward Blvd., Pasadena, CA 91107. Quarterly. \$2.

* *COPH Bulletin*. 1814 Welwyn, Des Plaines, IL 60018. Quarterly. \$3.

Computer-Disability News. The National Easter Seal Society, 2023 West Ogden Avenue, Chicago, IL 60612. Quarterly. Free.

* *The Deaf American*. The National Association of the Deaf, 814 Thayer Ave., Silver Spring, MD 20910. Monthly. \$10.

* *Disability and Chronic Disease Newsletter*. Irving Kenneth Zola, Ph.D., Dept. of Sociology, Brandeis University, Waltham, MA 02254. Quarterly. Free.

* *The Disability Rag*. Box 145, Louisville, KY 40201. Bi-monthly. \$9.

* *Disabled USA*. Superintendent of Documents, U.S. Govt. Printing Office, Washington, DC 20401. Quarterly. \$11.

* *Foundation For Science And The Handicapped*. 236 Grand Street, Morgantown, WV 26505. Monthly. Membership.

* *Friedreich's Ataxia Group in America*. Box 11116, Oakland, CA 94611. Free.

* *The Handicapped Coloradan*. Box 133, Willard Hall, University of Colorado, Boulder, CO 80309. Monthly. \$5.

Healthline. 1320 Bayport Avenue. San Carlos, CA 94070. Monthly. \$24.

In The Mainstream. Mainstream, Inc., 1200 15th Street, N.W., Washington, DC 20005. Bi-monthly. \$40.

* *Insights*. Spina Bifida, 343 S. Dearborn, Room 319, Chicago, IL 60604. Bi-monthly. Membership.

International Rehabilitation Review. Rehabilitation International, 25 East 21st Street, New York, NY 10010. Quarterly. \$20.

* *Itinerary*. P.O. Box 1084, Bayonne, NJ. 07002-1084. Bi-monthly. \$7.

Journal of Rehabilitation. National Rehabilitation Association, 633 S. Washington St., Alexandria, VA 22314. Quarterly. \$35 to non-members. Included in dues for members.

* *Kaleidoscope*. Literary/Art Magazine. United Cerebral Palsy and Services for the Handicapped, 326 Locust St., Akron, OH 44302. Bi-annual. \$8.

* Written by disabled individuals/organizations.

- * *Link and Go*. Committee on Personal Computers and the Handicapped, 2030 West Irving Park Rd., Chicago, IL 60618. \$8 membership.
- * *LINKS*. The National Association of Private Residential Facilities for the Mentally Retarded, P.O. Box 160274, Sacramento, CA 95816. Monthly. \$45. \$10 for parents.
- * *The Mainstream*. 2973 Beech St., San Diego, CA 92102. Monthly. \$12.50.
- * *NAPH National Newsletter*. 76 Elm St., London, OH 43140. Quarterly. \$6 membership.
- * *NCH Reporter*. National Council on the Handicapped, 800 Independence Avenue, S.W., Suite 814, Washington, DC 20591. Monthly. Free.
- NRA Newsletter*. National Rehabilitation Association, 633 S. Washington Street, Alexandria, VA 22314. 8 issues yearly. Membership.
- * *National Hookup*. 32 Margaret Dr., Loudonville, NY 12211. Bi-monthly. \$6.
- * *New World for the Physically Handicapped*. P.O. Box 1965, Reseda, CA 91335. Monthly. \$10.
- * *Open Channels*. National Stroke Association, 1420 Ogden Street, Denver, CO 80218. Quarterly. \$10.
- * *PCEH Perspectives*. The President's Committee on Employment of the Handicapped, Washington, DC 20210. Bi-monthly. Free.
- * *Paraplegia Life*. National Spinal Cord Injury Association, 149 California Street, Newton, MA 02158. Quarterly. Membership.
- * *Paraplegia News*. Paralyzed Veterans of America, 5201 N. 19th Ave., Suite 111, Phoenix, AZ 85015. Monthly. \$12.
- Programs for the Handicapped*. Clearinghouse on the Handicapped, Office of Information and Resources for the Handicapped, Room 3119, Switzer Bldg., Washington, DC 20202. Bi-monthly. Free.
- * *Rehab Brief*. Bringing Research into Effective Focus. PSI International Inc., 200 Little Falls St., Suite 104, Falls Church, VA 22046. Monthly. Free.
- Rehabilitation Digest*. Canadian Rehabilitation Council for the Disabled, One Yonge Street, Suite 2110, Toronto, Ontario M5E 9Z9, Canada. Quarterly. \$9 (outside Canada, add \$3 postage).
- * *Rehabilitation Gazette*. Gazette International Networking Institute, 4502 Maryland Ave., St. Louis, MO 63108. Annual. Back issues \$8 each. Current issue \$10 individual, \$20 institution.
- Rehabilitation Literature*. National Easter Seal Society. 2023 W. Ogden Ave., Chicago, IL 60612. Bi-monthly. \$21.
- Rehabilitation World*. Rehabilitation International USA, (RIUSA). Circulation Department, 1123 Broadway, New York, NY 10010. Quarterly. \$40.
- * *Reports*. Council for Disability Rights, 343 S. Dearborn, Chicago, IL 60604. Monthly. \$10.
- * *Sports 'N Spokes*. 5201 N. 19th Ave., Suite 111, Phoenix, AZ 85015. Bi-monthly. \$6.
- * *Synapse*. The American Society of Handicapped Physicians, 137 Main Street, Grambling, LA 71245. Quarterly. Membership.
- * *UC People*. United Cerebral Palsy Association, 66 E. 34th St., New York, NY 10016. Bi-monthly. Free.
- * *Walking Tomorrow*. The American Paralysis Association, 275 One Lincoln Central/LB 58, 5400 LBJ Freeway, Dallas, TX 75240. Monthly. Membership.
- * *Word from Washington*. United Cerebral Palsy Association, UCPA Governmental Activities Office, Chester A. Arthur Building, 425 I Street, N.W., Suite 141, Washington, DC 20001. Bi-monthly. Free.
- * Written by disabled individuals/organizations.

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(Conference audio and video tapes are available.)

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*Handbook on the Late Effects of Poliomyelitis for Physicians and
Survivors*, Edited by Laurie, Maynard, Fischer, Raymond, ©1984.

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Higher Education of Quads by correspondence, telephone, and attendance. Volume 5, 1962. Reading aids. New approaches to attendants. Self-aspirator.

Quads and Their Families. Volume 6, 1963. Marriage and adoption. Camping and vacations. Wheelchair cushions. Australian fiberglass lung. English chair/bed.

Traveling Quads. Volume 8, 1965. Medical engineering — arm aids, foot-operated aids, multi-controls. Quad driving. Foot-controlled steering. Ramps. Lifts. Adoption. Housing.

Vocational Rehabilitation and Education. Volume 9, 1966. Employment experiences of quads. Wheelchairs — respiratory, self-reclining, climbing, foreign. Remote-controlled typewriter. Association of Mouth and Foot Painting Artists.

Quads at College and at Work. Volume 10, 1967. Citizens band radio. One-hand typing. Curb climbing and chin-controlled wheelchairs. Frog breathing. Portable lungs. Sex.

Quads in Their Communities. Volume 12, 1969. Ramps for home and car. Home care services. Wheelchairs. Typing aids. Bathroom equipment. Photography. Living in Mexico.

Independent Living by Quads. Volume 13, 1970. Community service projects. Mouthstick typing. Cushions. Bath lifts. Tie-downs. Hydraulic tailgates. One-armed fishing. Chess.

Quad Artists and Pianists. Volume 15, 1982. Amateur radio. Rehabilitation centers. Worldwide religious groups. Housing and home services. Talking eyes. Portable ramps. Reclining and travel wheelchairs. Wheelchair pilots.

Social Security and Medicare. Volume 16, 1973. Sex. Vans. Lifts and hand controls. Amyotrophic lateral sclerosis. Family reactions to quadness. Amputees. Living with a kidney machine. Cerebral palsy. Writing as a career. Yoga, Zen, and Sufism. Automatic telephones. Foreign periodicals.

Hobbies for Quads. Travel to Mexico, Canada, and Europe. Volume 17, 1974. Travel with respirators. Recreational vehicles. Rehab Act of 1973. Bill of rights. Coalitions. Education and employment of quads. Adjustments to spinal cord injury. Biofeedback. German breathing treatment. Charcot-Marie-Tooth syndrome. Vans and lifts. Remote controls.

101 Employed Quads. Volume 18, 1975. SSI. Multiple sclerosis. Data processing. Telephone services. IRS regulations on attendants. Camera for quads. Step-vans, lifts and ramps. Word board. Tie-down. Wheelchair narrower. ACCD.

Vocations and Avocations for Quads. Volume 19, 1976. A quad's view of understanding depression — helping with grief. Teaching blind persons to type. Employed quads. Independent living. Tennis. Skiing. Self-help organizations. Wheelchair loader. Step-vans. Hitch-hiking through Europe in a wheelchair. GPB for quads. ROHO cushion.

Employed Quadriplegic Women. Volume 20, 1977. Rehabilitation in the Navajo Nation. Independent living programs. Wheelchair lifts for vans. Battery charger. Camper-pickup with lift. Self-operating electric hoist. Vocational rehabilitation rights. Traveling quads.

Note: "Quad" is not used in the specific spinal cord injury meaning of quadriplegia or tetraplegia (an injury at the neck level), but in the general meaning of a severely disabled person who has little or no use of arms or legs because of injury or disease — such as arthritis, amputation, cerebral palsy, multiple sclerosis, spinal cord injury, polio, muscular dystrophy or any other neurological disease.

Spinal Cord Injury Centers. Respiration

Equipment. Volume 21, 1978. Twentieth anniversary issue. A deaf Japanese student in the U.S. Don't be left without your RIGHTS. Disabled in Protestant churches. Indian sign system. Voice-activated telephone. Housing and home services. Portable iron lung. Pissing cross country. Suspension arms. Traveling quads.

Nutrition. Independent Living Programs.

Volume 22, 1979. Diet: A key to better health for SCI. MS diets. Lifestyles. Attendants at home and at college. Building a quad's own home. Mensa. Oral hearing-impaired adults. Computer programming training. Travel by a quad to 68 countries. Legbag control. Foot control driving. Pushbutton driving.

Post-Polio Aging Problems. Volume 23, 1980.

Respiratory rehabilitation. Disabled Peoples' International. Adoption. Independent living. Housing and home services. Religion and rehabilitation. The *Gazette* editors' 1980 study tour of independent living in Europe. Travel in Europe for respirator-users. MS in Britain. Hand-cycling. Alert systems. Respirators. IYDP: Watch our words. U.S. periodicals.

Gazette's Post-Polio Conference in Chicago.

Volume 24, 1981. Oral positive pressure. Making a cuirass shell. Adoption. Self-hypnosis. Learning disabilities. Coping with hospital care. Sexuality. Independent living centers. Independent lifestyles of persons with arthrogryposis, myasthenia gravis, Charcot-Marie-Tooth, SCI. Reclining wheelchair. Ceiling hoist. Lifts. VA-tested van lifts. Computers.

Second International Post-Polio Conference.

Volume 25, 1982. Twenty-fifth anniversary issue. Living independently with severe disability. Twenty-five years of experience as polio survivors in Canada and the U.S. Cerebral palsy challenges. Adjusting to myasthenia gravis. Traveling quads. Portable rocking bed plans. Mouthsticks/page turners. Ventilators. Lifts and ramps.

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In addition to the special features listed above, all the issues contain first person accounts of the experiences of quads (severely disabled individuals) in obtaining higher education, training, or employment, review of books of special interest, and excerpts from readers around the world seeking pen friends.

G.I.N.I. Photos

- 1 Gayla Hoffman, President of G.I.N.I., and Art Hoffman, Vice-President of G.I.N.I.
- 2 C. Everett Koop, U.S. Surgeon General, and Gini and Joe Laurie during the Surgeon General's First Regional Seminar on Home Care for Ventilator-Assisted Children and Adults, December 1983, in St. Louis.
- 3 Bob Tanton, C5-6 quad, artist and long-time *Gazette* illustrator, with adopted daughter Arianne.
- 4 Stuffing party for the polio conference packets, January 1985. Margie and Dick Goodwin, *Gazette* volunteers, stamp the "foo" sign on the Brown Bags.
- 5 Jack Genskow, G.I.N.I. Board member, and wife Lillian.
- 6 Ed Roberts, Co-Director of World Institute on Disability and recent MacArthur Fellow, and Gini Laurie confer during the Western Post-Polio Conference in Oakland, California, December 1984.
- 7 Judith Raymond, G.I.N.I. Executive Director, at the keyboard of the *Gazette's* computer.
- 8 Joe Leone, Secretary of the G.I.N.I. Board of Directors.
- 9 Dr. Pradip K. Mallick, Nandita Mallick, and Gini Laurie during the Mallicks visit to 4502 Maryland in August 1984. Dr. Mallick, C5-6 quad, is Research Officer at the National Institute for the Orthopaedically Handicapped in Calcutta, India.
- 10 Al Kemp, Regional Director, Region VII, Department of Health and Human Services, visiting the *Gazette*, December 1983.
- 11 Cindy Hewett, graphic designer for the *Gazette*.
- 12 Dr. Mallick, Ted Marcilliat, Ann Sheehan, and Lucy Dolan.



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omnes unius
aestimemus assis.
soles occidere et
redire possunt:
nobis cum semel
occidit brevis lux,
nox est perpetua una
dormienda.
da mi basis mille,
deinde centum,
dein mille altera,
dein secunda centum,
deinde usque
altera mille,
deinde centum.
dein, cum milia
multa fecerimus,
conturbabimus
illa, ne sciamus,
aut ne quis malus
invidere possit,
cum tantum sciat
esse basiorum.*

Catullus



Ave Atque Vale

JOSEPH SCOTT LAURIE III

May 11, 1908 – March 24, 1985

We mourn the loss of the *Rehabilitation Gazette's*
co-editor, the *Gazette* family's big-hearted "Papa Joe,"
and Gini's beloved husband of forty-seven years.

Ave Atque Vale