Special Features: Independent Living

The Polio Conference — A Blueprint of Creative Cooperation
For All People Who are Disabled
Next issue will be Volume 25. Will you help us make the twenty-fifth anniversary issue the best ever? We'd like to do a big international "Then-And-Now" feature on your lives over the last 25 years ... with photographs and stories of your education, employment, families, children, grandchildren, generosity, amphibious adaptations you have made to clothing, equipment and housing... your creative ways of finding, keeping, funding and firing attendants... examples of what the Toomey J Gazette and the Rehabilitation Gazette have meant to you in the way of ideas, equipment, coping, models, friendships, motivation, travel... the humorous and tactless remarks or reactions of people to you or your respirators... And, we'd also like "Happy Anniversary" letters from our professional and other nondisabled readers from around the world. We'll start working on the issue right away, so, start sending us material NOW!

Gini's dream came true. The October 1981 Gazette/RIC international polio conference was a superb success. Thank you, Gazette readers, for responding with such generosity to the Gazette's "Brown Bag" appeal for funds to help support the conference.

Your warmth and generosity are typical of the warmth and fellowship that pervaded the conference, as Gazette readers met for the first time other readers whom they had "met" on the pages of the Gazette, "Gini and the Gazette," says one participant, "have been the glue that held the poles of the world together for almost a quarter of a century."

There was sadness too. Sue Williams, a very special Toomey and Chagrin Falls friend and one of the early members of the Gazette staff, died of a heart attack the week before the conference. She was excited and happy about attending the conference as a representative of the Vermont Center for Independent Living, and looking forward to reminiscing at the "Brown Bag" Toomey dinner: "Ave atque vale!"

It was a happening of significance for all disabled persons and for everyone, young or old, who face the limitations of aging or seek self-directed healthful living. Whether you had polio or not, read the special feature on the conference — especially "Rx: Know Yourself" and Mickie McGraw's "Warnings!"

Breathing problems? If you were weaned from a respirator long ago and are now experiencing breathing difficulties, check with the nearest resource person listed in the conference section on page 36 and go to a pulmonary specialist for an evaluation. If you live in the East, note especially the one-day evaluation program developed by Dr. Augusta Alba at Goldwater Memorial Hospital in New York City. It is one of the few centers with personnel experienced in respiratory polio. An evaluation will help you now and give you and your doctor a future reference point.

$$$$$. The price of the back issues has been reduced to encourage new readers to discover the wealth of information contained in them. But alas, the price of this new Gazette must be raised a little to meet increased postage and printing expenses. Perhaps, only new readers will notice the increase because most of you long-time readers have been giving far more than the minimum and have kept the Gazette going with your generosity.

Gazette membership. New Readers, when you ask to be put on the Gazette mailing list, you automatically become members of its resourceful community, entitled to its free international information service.

Alumnae awards and reunions. During the year, Gini received two gratifying alumnae awards, the Trés Bien Award from the Alumnae of the Sacred Heart and the Distinguished Alumnae Award from Randolph-Macon Women's College, and Joe celebrated his 50th reunion at Amherst College.

English representative. Jo Sandiford is continuing to help the Gazette in England. You may send your payment by cheque or Postal Order to Mrs. J.D. Sandiford, 55A South Street, Havant, Hants., England PO9 1BY. Special price of £1.50 from disabled individuals and £3.00 from all others — plus 50 pence postage.

Recordings. The following sources have superb collections of books and magazines on open reel or cassette, including most of the back issues of the Rehabilitation Gazette. Both are responsive to new requests from those who are blind or physically unable to handle books. So if you need this issue recorded, get in touch with the Johanna Bureau for the Blind and Physically Handicapped, Inc., 30 West Washington, Chicago, Illinois 60602 or the Division for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20540.

Donations are tax-deductible as permitted by law, if they exceed the suggested donation per copy and if they are made payable to Rehabilitation Gazette, Inc. They are most welcome, for the Gazette, staffed by volunteers, is entirely supported by its readers and friends.

The Gazette editors found the following gem in The Bumblebee, a newsletter of biofeedback in a letter from a spinal cord injured gentleman telling of his arrival in India, "To describe the Bombay Airport is impossible ... After Sabena reported my wheelchair was hopelessly lost, an airport official came on board and asked me if I couldn't make an exception and walk just this once, otherwise they didn't know how to get me off the plane."
Community Living

by Mary Devlin

"Phuong, will you please cook dinner tonight?"
"Yes, yes, I understand. I make chicken curry, yes?"
"Thank you Phuong, that will be fine. Yes, Hieu and Ti, you may take the ball and go out on the lawn to play." The two Vietnamese children, aged 6 and 8, after only 5 weeks in the U.S. understood better than they spoke. They had asked permission through signs and pointing. What was I (in a wheelchair or on crutches) doing with a Vietnamese family in my home?

It all began back in 1966 when my mother died leaving me the sole owner and occupant of a Cape Cod house in a suburban Philadelphia area. It has two bedrooms on the first floor with a full bathroom, and the same on the second floor. There were several options open. I could sell the house and move to a small apartment, or close off the second floor and remain here. In both cases I would be alone. Or I could ask someone to share the house with me. I had a friend living nearby who was unhappy with her apartment. I asked her to share with me, at least for awhile, and fortunately she agreed to try the arrangement. She moved into the second floor. We shared the kitchen and the cooking and ate together when we were both home. It was a happy choice, for although both of us had been a little hesitant about the adjustments we’d have to make, it turned out that our similar interests more than compensated for minor inconveniences and the differences in our temperaments.

I was still teaching at the time, although a few months earlier I had had to go on crutches, after trying a long brace, intensive therapy, and taking all sorts of tests. Yes, the late-onset syndrome (Rehabilitation Gazette/80) had started catching up with me in the early sixties. I had had polio in 1927 and recovered enough that I walked with a double adductor limp, wore a short brace for drop foot and carried a cane for assistance over rough terrain. Muscle power had been gradually diminishing, my knees had gone into recurvature over 25%. No one had a definitive answer as to why, or what could be done. My friend, Jo, working at that time in a general hospital, had had some experience as a rehab nurse at Magee. She knew when to help — when to let me “do-it-myself.” From ’66 to the spring of ’68 I continued teaching, but my arms were carrying me and I was getting very tired. I took sick leave for the remainder of the term and then retired from the Philadelphia school system in June, earlier than I had planned. We reorganized things, I took over all of the cooking, Jo took on more outside work, planting a vegetable garden.

In 1970 when my aunts in Florida needed assistance, Jo quit her job and drove down with me. We stayed for six months, until Aunt Helen died and we had found an excellent housekeeper for Aunt Kitty, then ninety-three. On our return we found that Jo’s Aunt Nan was ill, so we took her to live with us to recover. She stayed three years before moving to a retirement home.

Then a friend who was having difficulties at home asked to stay with us. She shared our home for about three months until her problems were ironed out. She and all of her family are still among our closest friends.

Another friend, in somewhat similar circumstances, later on stayed with us for several months. In late 1979 I started teaching English to four young men, Vietnamese refugees, who came to my house daily. After two weeks, Thao, the oldest asked if he could live with us so as to improve his

Mary Devlin (right), disabled by polio, shares her home with her friend, Jo (left), their Vietnamese “family” and friends.
English faster and be ready for a job. We agreed to try it. In January of '80 he obtained employment and has been working ever since. It was his wife, two children and a brother who joined us in April of '81, after eleven months in a Japanese refugee camp. It was a bit crowded the weeks they were here, as we searched for a suitable house or apartment, but never dwell. Jo and I were suddenly instant grandparents. Thao had long since been our son, and now Phuong was our daughter. She loves to cook and so we alternated American and Vietnamese meals.

Along with our temporary family members we somehow seem to run an open house. Jo and I each have a single brother and we include Tom and John in all holiday activities and that sometimes includes their friends. Jo also has two married brothers. Bob, her twin, and his family (wife, two sons, five daughters, four grandchildren) consider our home the place to come for R. and R. Bob is a retired colonel in the reserves and they are all military minded to some extent. Sometimes it is for a day — sometimes for a longer stay depending on their need. Jim, her oldest brother, and his wife are frequent visitors. My cousin, Dot (incidentally our next door neighbor), and her family consider this a second home.

It is the place to come for assistance with school work, for first aid attention, to get needed supplies or just to chat. Another cousin of mine, originally from this area but now a Floridian, and his family make our home their headquarters when they get up this way. Long ago we had made one of the first floor bedrooms into an activity room, but it can be instantly changed back with a sofa bed and a cot.

There are disadvantages of course to this kind of shared living. It takes constant adjustment to others, their likes, dislikes, methods of doing things. It takes the reorganization of living areas while still making it possible for me to navigate. Back around 1974 I invested in a wheelchair and now use it around the house about 50% of the time. It takes accepting others with a nonjudgmental attitude, no prying, no sermonizing — just a lot of love and caring.

But the advantages are far greater. At least they have been for me. From the beginning I had confidence in Jo's knowledge and ability to judge whether I could or could not participate in various activities. I have certainly done any number of things since she has been living here that I would not otherwise have thought to attempt. Sharing jobs and responsibilities lets each of us do the things we can do, and not feel inadequate when we have to ask for help. So if I need assistance in going somewhere, or help to get something from a high shelf, I know that Jo or whoever is helping me, may in turn ask me to do something for them that I can do. Each person who has lived with us, for either a long or short period has contributed something unique and so enriched our lives as well as increasing our circle of friends. My brother and I, both single, are the surviving members of our extended family. The brothers, sisters, cousins, friends, nieces, nephews, and grandchildren of our extended family are numerous.

As I write this, Jo and I and our toy poodle, Mori, are the only occupants of our home. We are taking a "break." I am still teaching English to Vietnamese. This year I've had three young women — all mothers — coming to my home. Last evening one of them wondered if I could help the children over the summer months. I don't know what the future will bring. I know it won't be dull.

One of the fears I had when Jo first came to live with me was that my problems in getting around might limit her. In some ways it undoubtedly does, but usually she comes up with a solution that includes me and doesn't limit her, so I have ceased to be concerned about it. At the same time we have both retained our other friendships and go our separate ways whenever special interests come along. I'm still driving and love it. Several years ago we sold our two cars and bought one between us. Jo now works as a rehab nurse in a small nearby hospital so if I need the car, I drive her to work and arrange to pick her up. If I don't need it, she takes it. I have a hand control on the brake that does not interfere with her using the brake in the usual manner. One car has cut our expenses considerably.

For anyone in circumstances such as mine I heartily recommend sharing. I recommend it to my retired friends, not just to disabled persons (though aren't we all disabled in one way or another — emotionally, mentally, physically — and therefore dependent on one another). As my strength decreases and I have to limit my outside activities, I don't feel as if the world is passing me by — it just moved in with me. We hear so much today about the evil in the world — not enough is ever said about all the wonderful people out there. All we need to do is open ourselves to them and let them walk into our lives.

Mary Deulin, retired home economics teacher, has been disabled by polio since 1927. She has evolved her own version of community living by sharing her home with many friends. Her address is 8003 Southampton Avenue, Wyndmoor, Pennsylvania 19118.

Jesuit Volunteer Corps:
Advocates/Attendants

by Ray McCarthy and Tom Hutchinson

"Mainstream and integrate persons with disabilities into diocesan life." With this in mind, Bishop John S. Cummins inaugurated the Department of the Disabled at Catholic Charities in the diocese of Oakland. In order to accomplish this goal the Department attempts to remove the barriers, attitudinal and architectural, that prevent persons with disabilities from participating fully.

The permanent staff at the Department consists of the director, Ray McCarthy, and a senior secretary, Marge Polley, who are both disabled. The remainder of the staff is
made up of two Jesuit Volunteers. These young people are part of a volunteer program administered by the Jesuit Order. They have donated their time and talents for a year of service to worthy social organizations. The two volunteers in our office, Janet Bartush and Tom Hutchinson, are typical of the members of the Jesuit Volunteer Corps. They both graduated from universities in the Midwest and left their family and friends to work for social justice. Janet and Tom both chose to work with disabled persons as advocates. Our Jesuit Volunteers live within the communities that they serve. Janet and Tom live near downtown Oakland with four other volunteers in a Christian community. They strive to live simply and integrate Christian values throughout their community life.

This Department tries to utilize a holistic approach in our ministry with disabled persons. We feel that we should work toward freeing disabled persons of all the barriers that keep them from becoming totally independent. Only if people are free to choose their actions can they fully accept the church of their choice. If it were not for the Jesuit Volunteers this approach would be a near impossibility. Janet is in charge of education and recreational outreach. She organizes disabled persons to participate in monthly meetings to have lunch, take in a movie or some other type of entertainment, and just to sit and socialize for a bit. Janet also tries to educate nondisabled persons about disabled persons and their attitudes, feelings, wants, and hopes. Through this she hopes to remove the attitudinal barriers that can separate nondisabled persons from those persons who have a disability. Tom is involved with legislative issues concerning disabled persons and advocating for their rights and privileges in the areas of transportation, housing and employment. Tom is also politically organizing the disabled persons of the Diocese into a viable voting bloc to accomplish these goals.

One of the Jesuit Volunteers accompanies Ray on all his on-site visits to parishes and schools. On one of these recent visits, once again the pastor assured us that there was no need for a ramp at his church that has several steps, because of course, "We have no disabled people who come to Mass." When we try to point out that they are unable to get into church the good Father assures us that anyone is allowed to go into his church for the church doors are never locked.

"But, Father, they can't get in," we retort, "the disabled persons are there but they can't get in because of the steps!"

"Well we have plenty of people who can carry people in wheelchairs up the stairs," he replies.

Finally we explained about independent living, doing things for oneself, and how dehumanizing it is to have one's fanny hauled up and down steps. After all this he consented to having a ramp built.

We feel the biggest stumbling block of disabled persons is the ignorance of others. This problem is faced daily with a sense of humor and a thoughtful urging to accept persons with disabilities for what they are, persons. We try to impress upon people that they have far more in common with disabled persons than there are differences.

How long have you been in a wheelchair is a question often asked of Ray. His usual tongue-in-cheek reply is "Since about seven o'clock this morning."

"Should I call you handicapped or should I call you disabled?" is also met with a gentle reminder that, "you can call me Ray."

Through instances such as these we hope to educate those who are ignorant and to bring about a barrierless society.

Ray McCarthy, disabled by Friedreich's Ataxia, is president of the national organization, Friedreich's Ataxia Group in America, Inc. His address is P.O. Box 11116, Oakland, California 94611. Tom Hutchinson is a nondisabled Jesuit Volunteer.

Cooperative Services

Access California has created a system in which both disabled and nondisabled persons volunteer to provide and receive services on an organized exchange basis. The mutual-help system, known as the Volunteer Exchange Cooperative (VEC), is a special project of the City of Oakland Social Services Department.
The creators and directors of the service system are Debee Norling, VEC Coordinator, who has impaired vision, and Marilyn Golden, Access California Project Coordinator, who is wheelchair bound because of T-10 paraplegia.

"The idea began," says Norling, "when we realized that many of us were already using a similar informal exchange (blind people doing laundry for quadriplegics in exchange for reading services, for example), and we decided to extend the benefits of this mutual help on a broader and more organized basis that includes both disabled and non-disabled people."

"The purpose is not to resolve crises," says Golden, "but rather, for people to continue their self-management and share their competencies. The level of skills exchange may be simple, such as housework, typing, reading, etc. or higher-level skills such as plumbing, photography, translating, etc."

Membership is free but it requires a commitment of two hours of service. It starts with registering and filling out a Skills/Needs form which lists the individual's proffered skills and needs. (Disability, age and address are not included in the list.) The skills and needs information, with names and telephone numbers, is printed on a list that is updated every six months and shared among members.

After a prospective member has worked for two hours for another person on the list or in the VEC office, membership is confirmed. The new member is assigned a membership number and given five coupons, good for one hour of labor each.

Coupons are simply a way of measuring and verifying units of work. They circulate from person to person and are used repeatedly. Each volunteer pays in coupons and, in turn, is paid in coupons.

"When arranging work with someone," says Norling, "be sure that both of you clearly communicate the time and place of work, how the work is to be done, and generally what you each expect to occur. The actual exchange of coupons is to be decided and carried out between the two of you — our office will not arbitrate on this matter."

"It is not necessary," she says, "for a perfect exchange of skills or hours to occur between you and another person. For example, you do not have to do typing for the same person who gives you harmonica lessons or a massage."

The goal of the cooperative is to put into circulation thousands of coupons facilitating an even flow of give and take between volunteers — that is, people helping each other. The cooperative enables people to have a substitute for cash in the exchange of services.

"Our purpose," says Golden, "is to promote greater independence and cooperation in the face of economic hardship. We believe that decreased financial resources do not necessarily result in people leading less active, productive lives. This independence is especially important to those of us who are disabled. Other skills banks have discriminated (out of ignorance) against people with disabilities."

"This cooperative," she says, "starts with the resources of disabled people and expands to serve everyone. We began in October 1981 and within three months we had more than 50 members. We hope that the VEC grows until it includes many people with a variety of skills to exchange."

"We had valuable advice from David Tobin, the director of a national barter project, National Center for Citizen Involvement, P.O. Box 4179, Boulder, Colorado 80306. If you wish to start a similar service, write to him for information and technical assistance. We will be glad to share our experiences. Our information is available in braille, large print and on tape. Write to: Debee Norling, VEC Coordinator, or Marilyn Golden, Access California Project Coordinator, Access California, Room 614, City Hall, 1421 Washington Street, Oakland, California 94612. (Voice or TTY: 415-273-3723)"

Independent Lifestyles

A Life of Uncertainty . . . and Confidence

by Richard E. Bopp

I am very fond of a recently released film, "Pins and Needles," produced by Genni Batterham, a young Australian woman who has multiple sclerosis. The film touches on many important aspects of her life with MS, but the central focus is the uncertainty with which Genni and her husband must cope because of the unpredictable nature of MS. Handling the uncertainty of a chronic illness can be as difficult as handling the physically disabling effects of that illness.

This is a situation with which I can identify, because I see many uncertainties in my own life, and because I was once diagnosed as having a rare and severe form of MS.
called Devic's Disease (or neuromyelitis optica). The diagnosis was apparently in error, as I have had no change in my condition (paraplegia at T-1 level) in twelve years. But the cause of my disability is still not known, nor can it ever be known.

In May 1969 I was in basic training at Lackland Air Force Base in Texas, when, following several days of cold and flu symptoms, I suddenly lost feeling and movement in my legs and, subsequently, most of my trunk as well. The doctors were not sure what was happening, or if I would survive, but I did survive. They gave my condition the name “transverse myelitis, etiology unknown,” and sent me off to the Veterans Hospital in Long Beach, California for rehabilitation. Transverse myelitis, which is also rare, is an inflammation of the myelin sheath which surrounds the spinal cord; the cause of this inflammation is often not known.

It was at the Long Beach VA hospital that a neurologist thought I had Devic's Disease and submitted me to every test available to try to prove it. Unfortunately for him, he couldn't (one article in a medical journal down the drain!). Unfortunately for me, since my disability had an organic cause rather than a traumatic one, I was not admitted to the famous SCI unit at Long Beach VA. Instead, I was put with the MS and Parkinson's patients on the neurology ward. There I learned a lot about MS, but did not receive the excellent care and training I could have received. As it turns out, physically I am no different from a spinal cord injured person whose level is T-1, but because of a techni-cality, I could not benefit from one of the best rehab centers in the country.

For several years after my illness, I did not know what the future would hold for me. Each time I caught a cold or flu virus, I feared it would lead to further paralysis (or death), since that was how my paralyzing illness had be-

gun. And, like many paralyzed individuals, I suffered in those first years from a succession of pressure sores and urinary infections. Under these conditions, I was uncertain whether I could return to work or lead a normal life. Fortunately, those early problems and fears have disappeared, and I am living a normal life and working full-time as a librarian at the University of Illinois at Urbana-Champaign. I no longer worry about my physical health. I have learned from my experience to take life as it comes and not be concerned about "the long run." As Lord Keynes once said, "In the long run, we're all dead." I just hope that the end of my "long run" is a long way off.

Another area of uncertainty for me has been my vocation. Before joining the Air Force, I was in the Ph.D. program in history at the University of Missouri-Columbia. After my rehabilitation, my wife and I returned to Columbia, where I resumed my history studies. I passed the Ph.D. comprehensive exams and began writing my dissertation. That was when the doubts set in. I faced a year or two of intensive research and writing, and what would I get out of it? Ph.D. graduates were entering other careers in droves, because there were no jobs for them in the teaching field. So I gave up my plans for college teaching and entered the Master's program in library science at the University of Illinois.

Compared to history, I found library school incredibly dull. Nevertheless, I completed the program in 1974, and have had some interesting library jobs since then. Most recently, I was the project librarian for a two-year grant to develop a comprehensive collection of books, journals and films about physical disability for the Library of the Health Sciences at the U. of I. But I am not satisfied. I think librarians basically serve and assist the people — scholars, professionals, etc. — who are doing the real work in the world. So I have been thinking seriously about going to law school.

One's identity is tied to a large degree to one's vocation. Since I don't know for sure what I'll be doing in the future, part of my identity is up for grabs, and I have had to learn to live with this uncertainty.

Another part of my identity is finally beginning to settle down — my identity as a disabled person. When I came to the U. of I., I was somewhat intimidated by the disabled students here and the Rehabilitation-Education Center which guides them. There is a great emphasis here on physical activities — on wheelchair sports, on mastery of one's chair, on physical independence. This is an area in which I do not excel, and there were times in the past few years when I wondered if I were a failure as a disabled person. I was assessing my self-worth solely in terms of how I had handled my disability. Fortunately, with a little help from my friends,” I now view myself and my disability differently. I value more highly those qualities which are a more essential part of me than my disability is. This is the source of my confidence in myself and in the future. It has only happened recently; I could not have written this account two years ago.
Foremost among those friends who have helped me is my wife, Susie. We had been married only four months when I became disabled. She could easily have left me, as many people have left their disabled spouses. But from the beginning, she maintained that she did not marry me for my physical capacities, but for the "me" within. To borrow from Tom Helms, she married the driver, not the car (Against All Odds, pp. 43-44). She has had her doubts about me at times, but never because of my disability. She has doubted me only when I have forgotten how to be a caring, concerned and sensitive spouse. And it is by seeing myself as a person who is kind, intelligent, interested in other people and in helping them that I have accepted myself as a disabled person. To me, the ability to listen to the frustrations or share the joy of another person is more important than the ability to get myself and my wheelchair up a 6-inch curb. No doubt some people can do both well — right now I'm happy to try to do just one well.

My family is also a source of confidence for me. Susie and I have two children, and a third is due in June of '82. I try to be a good father, and people tell me I'm succeeding. It takes time and patience, but where better to invest my time than in the development of a human being who is in my care? I think it is a tragedy and a travesty that so many children in our society are neglected by parents who consider their careers more important than their children.

My other "friends" who have helped me define myself as a disabled person have been the disabled people whose stories I have read. People like Tom Helms, author of Against All Odds (Warner Books, 1978), and Richard Brickner, who wrote My Second Twenty Years: An Unexpected Life (Basic Books, 1976). And finally, Barry Corbet, who talked to 54 spinal cord injured people and recorded their ideas and lifestyles in Options: Spinal Cord Injury and the Future (available free from the National Spinal Cord Injury Foundation). Reading these autobiographies has helped me to see that, for better or worse, I'm the same person I was before my disability; that my disability is only a part of my meaning as a person; and that there is no single "right" way to be independent. We disabled individuals are each unique, with talents and interests unrelated to our disability. Yet we have much in common, much to share. There is much we can learn from each other. I have found that reading about the lives of others gives me a new perspective on myself, one that is more healthy than the one I had before.

I hope to keep learning. I would like to write in next year's Gazette about the autobiographies of disabled people which I have read. In writing their stories, these disabled people have reached a better understanding of themselves. They have learned from their experiences, and have shared what they learned. I thank them for that.

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Jeannie Ledoux and her mother, "Instead of being on supplemental security and food stamps, I earn my own money now."

I Am Myself, Me ... Independent
by Jeannie Ledoux

I am a French Canadian, born in Drummondville, Quebec, in January 1945. I have five brothers and sisters. I was born with arthrogryposis and missing my left leg below the knee. Many operations were performed on me in Montreal until, when I was four years old, my family moved to Massachusetts.

My parents bought a home in the country in Westport. The doctors in Canada said that I would never walk or feed myself but Mom can't take "No" so she took me to Easter Seal and they paid for my surgery and I stayed at Lakeville State Sanatorium from age five to seven. I spoke only French so the doctors and nurses taught me English. They were loving, gentle and warm and sort of adopted me. I became confused about home and hospital. I thought hospital was home and I went to my family's for holidays.

At seven, I started to walk with a brace on my right leg and a peg leg below my knee on the left. I left the hospital and went home. I went to public school for nine months but the teachers and the bus driver could not accept me.

So I was tutored at home, two mornings a week, for an hour. They said they took me through the 4th grade but I didn't get an education. I never went any place. I looked out the window at the chickens, geese, ducks, turkeys, sheep and our horse. I stopped walking.
When I was 11, I went to a medical center in Boston and had surgery on my right hip. I was in a body cast for months. Then another hip operation. Altogether in Canada and Boston I had 29 operations. Finally, at age 13, I took my first step on crutches. When I got out of the hospital I was determined to keep on walking no matter what happened.

My brothers and sisters were starting to get married and have children and I became aware of being a teenager. I went to a nearby Catholic school but I did not like it because I had to start back at the first grade. I was unhappy and ill at ease with such young kids.

My doctor in Boston encouraged me to be a teenager. "You have a big mouth, use it," says he.

So I told the family I did not belong with the kids and I wanted to grow up as a teenager. I stopped school and I taught myself to read and write. I began to act like any normal red-blooded American teenager. I started smoking, I bought cosmetics. I went to a recreational center for disabled in New Bedford. I learned to swim at the YWCA. I started to go bowling and met blind people and all types of disabled people.

I discovered my singing power. I sang like a crazy nut. I thought I wanted to be a singer so my parents gave me singing lessons. I sang at wedding receptions. I sang both country and western. I sang solo and with a group. I went on dates to movies and on hayrides with disabled boys and other boys. I fell in and out of love. I went steady for a year. And I fell in love.

In 1972, after my parents separated, my mother, who had been a diettian at a hospital, decided to retire and move to Missouri to be near my sisters. It was sad to leave my friends. It was sad never to enjoy lobster again.

Mom bought a house in Fenton, which is near St. Louis. I made new friends. I joined an Easter Seal group of young disabled adults. I became a member of the disabled group, Victim Missionaries, at the Shrine of Our Lady of the Snows in Belleville, Illinois. I became more religious. I met people who are worse off so I thank my lucky stars that I am myself, me.

In 1974 the most exciting thing happened. I went to Europe on a pilgrimage to Lourdes with the Victim Missionaries. I went by myself. I never dreamed I would be so independent. My roommate took care of dressing me and putting on my braces. Everyone was glad to have me along because I could talk French. We went to Paris and Rome where I have a cousin who is one of the Pope's secretaries.

I got introduced to Gini Laurie and her Rehabilitation Gazette when a friend gave me a pile of them to read. I met her at an Easter Seal meeting and I started to call her. She suggested I write to another Gazette reader, Jim Wallace, in Saskatchewan, Canada, because he also has arthrogryposis. For a year we wrote and we became good friends. In the 1979 Gazette there was an article about me that brought me many more friends. So Mom gave me a tape recorder and now I write on tape. If anyone else wants to write to me, I will be happy to respond on a cassette. I am a people-lover.

Best of all, in 1979 Gini recommended me for a job. I had told her how much time Mom and I spent watching TV so she wrote to Robert A. Damers of Lynch Transcription Service in New York, who hires people to monitor commercials on TV, and told him about me. I thought she was kidding. Then I was afraid that he would not hire me because of my lack of education. But after he called and talked to me he said I was hired if I would get the state vocational rehabilitation bureau to buy the monitoring equipment.

Good luck started to happen.

My rehab counselor, Jim Hurley, reopened my case. I had to have a doctor check me for voc rehab. (I almost gave it all up because I didn't want more exams and shots. But Gini and Jim talked me into going on.) Voc rehab bought the audio/video equipment and set me up in business.

Now, I'm a business woman. Independent. My first job is very rewarding. I love it. So far, I've pleased Mr. Damers. He is very understanding of the disabled. When the check arrives I go to the bank and put it in. Instead of being on supplemental security and food stamps, I earn my own money.

Last year, even more happened to me because of the 1979 Gazette article. A counselor of the Girl Scouts in St. Louis read the article and asked me to be a counselor at its summer camp. I helped others adjust by telling them about how I have learned to accept my own disabilities. I feel like a mother to them.

I go to monthly meetings at the shrine. I love to go to ball games and movies. I only go out with men who are gentlemen. I will stay pure until I am married. I dream that some day I will marry someone who can fulfill my life and I'll fulfill his life. I dream about traveling and going to Disneyland in Florida. I dream about starting a club for other people with arthrogryposis or for all types of disabled people.

Anyway, I enjoy living and laughing and loving many people. My mom most of all because she has done so much for me.

Jeannie Ledoux, disabled by arthrogryposis and a below knee amputation, works at home monitoring TV commercials. Her address is 25 Linda Court, Fenton, Missouri 63026.
Coping with Laughter and Poetry

by Aimee DiCarlo

I am twenty-one years old and I graduated from New Castle High School in Pennsylvania in 1977. I always took it for granted that I would graduate from college some day. Everyone in my family did, and I assumed that I would too. I was accepted at, and planned to attend Duquesne University, in the nursing program for the fall of 1977. However, in my last month of high school, I became very ill.

At first the doctors were not sure just what was wrong with me. But after a few days, I was diagnosed as having myasthenia gravis, a very serious neuromuscular disease — the one which makes it a real chore to hold your eyelids open. The doctors started a course of treatment, which involved heavy doses of steroids, and I felt pretty good for awhile. So I began school in the fall almost as if nothing had happened. But after a month or so, I became so weak and ill that I was forced to leave school.

The doctors thought a thymectomy would help. So in the fall of 1977, they performed this operation, which is the removal of the thymus gland. This really seemed to help and for a while I felt great again. So I started back to Duquesne again for the spring semester of 1978. Things were going great, but towards the end of the spring semester I started to have trouble with my hands trembling and feeling numb. I began school in the fall, but my hands soon became worse, and I began to develop other symptoms that were not myasthenic. I was forced to leave school and return home. Soon after, my walking started to leave me, and by the end of December of 1978, I was diagnosed as also having multiple sclerosis.

My illness became so serious, that I was forced to use a wheelchair, and during the winter of 1979, I spent two months at Harmarville Rehabilitation Center. While there, I had an interview at Westminster College, which is only eight miles from my home, and was accepted for the fall semester of 1979.

When I first went to Westminster and began accounting classes, I was on crutches, and since then, my walking has continued to come and go. It fluctuates from causing me to use a wheelchair, crutches, or a cane to allowing me to get about without assistance.

I have been trying to go to college since 1977. I am still trying. At present, I am still a second-semester sophomore. I am going to school very slowly. I have found out over the years that if I try to push too hard, I just make myself sick. But I will eventually graduate, because it means so much to me. In the meantime, I have been going to Partial Hospitalization Program three times a week at our local Human Services Center. I am very pleased to have been elected president of this group.

I have not really accepted my illnesses, but I am learning to adapt. I can do many things, but I have to do them in special ways. I have to realize my limitations, and accept myself for what I am. I have found two ways to express my emotions.

The first is for other people. It is laughter. Most people shy away from others who have a lot of problems, because others' problems make most people very uncomfortable. For openers, I usually introduce people to my crutches, which are "Ping and Pong," identical twins. When I am able to make light of and laugh at my troubles, people seem much more eager to be around me.

The second way is for me. I can let all my secret emotions out by my secret love — poetry. Through my poems, I can let all my pain escape from my mind. I feel much better, because I can free my mind of my deep troubles.

I like reading about how other people cope. I hope other Gazette readers will write to me. My address is 306 Fairfield Avenue, New Castle, Pennsylvania 16105.

Growing Up a Stutterer

by Lisa Fay

Most people see me as an attractive woman with brown curly hair and brown eyes and one who wears stylish clothes. It is only when I speak that they learn that I'm disabled because I stutter.
Stuttering is very painful for me to discuss at the age of 25, but I am talking about it so that I can possibly save others from going through the same experiences I did. I also want to educate the public on what stuttering is really about.

The worst part about being a stutterer is that I never know when I am going to stutter. I may be talking well, and then suddenly block in the beginning, the middle, or the end of the word — sometimes it is all three.

Sometimes, I cannot understand words or cannot say them so I block. Often, the words and the sounds which are hard for the child to produce are the same ones the stutterer struggles with. I hate terribly when I stutter on the most personal description of me, my name — and it is such a short one too.

When I stutter, I am usually gasping for air like a panting dog. People react by walking away, ignoring me or avoiding eye contact. If people see a blind person or someone in a wheelchair, they stop to help them — with me, they are horrified.

After I stutter, I feel like a ruptured sewage tank, leaking anger. What really need is a hug. This unpredictability is nerve-wracking and delays my personal adjustment and social growth in this fast-paced world.

My other disabilities don't bother me as much. I can accept the fact that I limp a little when I get tired and that I don't hear too well.

Stuttering is not disfiguring nor does it mean a loss of body part. The anatomy of communications is usually intact. What it does involve is dysfluency of time. Some experts may disagree with my definition, but they have no problem identifying the disorder when they see it.

Stutters are known for prolonging words or blends, eye-blinking, twitching, licking the tongue, blocking and facial contortions — unfortunately, I do all of the above.

I don't remember just what incident prompted stuttering, but I do recall my mother taking me to speech therapy at age six for articulation problems. Prolonging vowels was emphasized at that time and still is the method most used. Stuttering therapy began for me when I was about eight or nine years old. My childhood was severely limited by defective speech. Other kids laughed at me, mimicked my stutter or refused to let me play with them — adults were no better.

My mouth felt like an animal trap most of the time. The more I tried to open it, the more it slammed shut. There were times when I didn't talk for weeks, and my family always complained that they didn't know me. How could I tell them with such a trap for a mouth?

Ironically, anger gave me peace. I never stuttered when I swore. When I couldn't talk, I became violent. Throwing, banging, breaking objects, punching a window and kicking an office partition are a few of the many physical outbursts I and others attribute to not talking.

My family has not always been receptive to the stuttering problem. They never failed to remind me that "if you can't say it, don't say it at all." That message still rings in my ears today. Their attitudes are no different than those reflected in society.

They often discouraged me from using the phone, so it was not until I was 22 and out of school that the phone became a regular commodity in my life.

Teachers either ignored me or were hell bent on having me speak in order to prove that I am like everybody else. Many never knew I stuttered until I gave a speech because I never said anything — by that time, it was too late.

I would not hesitate to take a stuttering child out of the public school where the stress is so great, and substitute temporary or long-term respite or medical care. This way the problems of stuttering and/or family difficulties are addressed early in the child's life which may alleviate unspoken miseries later.

What hurt me most as a child and still hurts as a 25-year-old adult is people saying that I stutter on purpose. How could I be stuttering on purpose when I have spent 13 years in speech therapy trying to stop it? Stuttering is like diabetes. There is no cure, only control.

I paid a visit to the Massachusetts Rehabilitation Commission in 1972 when I was 17. My parents got the papers ready and I became eligible in 1973. They accepted writing as an obtainable goal for me.

When I finally got a steady vocational rehabilitation counselor, I tried to tell him just how stuttering affected my life. Keeping friends was difficult and my education suffered immeasurably, as I rarely spoke. I told him that, without help, my potential as a writer would be forever limited as communication skills via speaking are absolutely essential.

He turned a deaf ear to my pleas, saying it wasn't a real
problem since I never stuttered badly with him. This was partially correct since I had grown accustomed to him. But he never saw me in new social situations, schools, parties and family gatherings, where I never failed to bomb.

The issue slipped for several years but then showed up greatly when it came time for work after I graduated from Framingham State College in 1978. I stuttered terribly during all of my 50 interviews — I had no problem getting the interview as I had a good resume.

I was beginning to wonder if I was in the wrong program. After all, MRC was obligated to provide services to those who have the most severe handicaps. If stuttering isn't considered a serious disadvantage, then I don't know what is. Nothing is so central to personality development as speech. Very little of life exists without it.

The statistics on stuttering are alarming. Approximately 1,400,000 persons stutter, with males outnumbering females four to one. The annual cost of treating all speech disorders totals $500,000,000. Lost earning powers on all speech disorders run approximately $2,000,000,000 per year.

After a number of additional false starts, I was referred to Emerson College's Robbins Speech and Hearing Clinic where I have been since 1977. Since that time I have made slow progress but they recently informed me that they cannot help me anymore. The main reason for this failure was lack of intensity. Therapy must be intense and continuous to be successful.

I am now in psychotherapy and the therapist cannot seem to understand the emotional stresses of stuttering. He seems to think I can stop stuttering instantly like turning off a T.V. set. He prefers to say, "You do it to yourself, Lisa."

The fun of companionship, the satisfaction of earning a living, the winning of an acceptable mate and the pride of self-respect and appreciation come hard to those who cannot talk or have difficulty talking.

Medicaid pays for these speech therapy and psychotherapy sessions as part of my rehabilitation as a writer. I am fortunate to have this advantage and make the most of it. I know that I could not do it any other way.

All I really want to be is a person, not a patient. I desperately want to be able to speak in a normal way and so I will keep trying. I am determined to make a therapy program work for me.

Now, there is another program starting at New England Rehabilitation Hospital in Woburn, Massachusetts. The treatment consists of 10-hour-a-day sessions for three weeks. I'll keep on trying — maybe this one will work.

Lisa Fay, "I have a B.A. in liberal studies from Framingham State College in 1978. During my collegiate years, I went abroad to study in London." Address: 6 Joel Avenue, Walpole, Massachusetts 02081.

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Just Me

by Flo Puffer

I was born on January 1, 1918 and my parents first noticed something was wrong when I couldn't sit up at six months and didn't walk until I was four years old. It was then that they learned that I had cerebral palsy.

At six years old, I started first grade. My brother, Howard, looked after me during the two years I was in the first grade. Then I moved to Minneapolis and lived with my grandparents while I attended Michael Dowling School for the disabled and John Marshall High School. I graduated in 1938 at age 20.

For two years I went to the General College at the University of Minnesota. Later I took an indexing and filing course at a business school. I worked for Goodwill Industries and NYA.

At age 24, I decided I would like to get married and raise a family just like any other woman. At a camp for disabled people, I met and fell in love with one of the counselors, Ivan Puffer. We were married six months later on New Year's Day — coincidentally, my 25th birthday.

Our first son, Hale, arrived in December 1943. We were happy at first and two more babies came, Rickie and Renee. But, as the years went by, Ivan developed a codeine habit from taking cough medicine for his cough due to heavy smoking. The bills piled up and Ivan became mean and then stopped working. So, in 1950, I got a divorce and went on welfare and raised the three children by myself.

Today I have many hobbies to keep me busy. I babysit for my neighbors and for Renee, collect autographs of famous people who helped me overcome my shyness and speech defect. I write play reviews for Minnesota Mirror, the newsletter of a disabled organization. I like to read new books and I have recently learned to bowl.

I have done everything that I set out to do and I am happy saying, "I can do anything that an average person can do!"

Flo Puffer, disabled by cerebral palsy, has raised three children and accomplished many of her lifelong goals. Her address is 3355 Virginia Avenue South, St. Louis Park, Minnesota 55426.
Independent Attitudes

Renegotiation of Society's Handicaps

by Jody Paimour

Independent living is a fast growing philosophy among disabled people. It calls for all services to be geared toward developing deinstitutionalized environments that encourage even severely impaired people to make the many decisions affecting their own lives.

Lord knows a lot of government money has been spent on disabled people. Billions more have been given in our name. And many important civil rights laws and regulations are now on the books. However, much of this money and many of those laws have been developed without truly involving disabled people in determining how to use it wisely. Public policy has yet to focus on the concept of Independent Living for Disabled Americans.

Only in such an independent environment can disabled people grow out of childlike dependency into adult maturity, or return to their pre-accident or pre-disease social status. Only in an environment of accessible domestic, recreational and vocational opportunity can disabled people live with the self-respect and dignity that is possible for all other men and women.

Exciting, hopeful things are happening in Independent Living Centers now springing up in cities all across America. Disabled people and their families are beginning to believe in the possibility of independent living and productive social contribution that hardly anyone visualized in earlier generations. A new breed of self-confident, knowledgeable and articulate disabled people is coming into the mainstream of American life.

It is critical that this Independent Living philosophy be spread throughout the huge community of 35 million disabled Americans, for even the best-intentioned Federal laws and regulations must eventually be implemented locally. That implementation will require sophisticated disabled advocates. Struggles can be won in Washington, but lost when it comes to putting actual policies into practice.

In the past, practical policy toward disabled people at the local level has resulted from innumerable individual negotiations between disabled citizens and authorities. Too often, we have bargained poorly over the applications of community resources, and come away with little of value to ourselves or to future generations.

Existing disability programs are vital to the very existence of many disabled Americans. Yet one must also wonder how many billions of dollars could be saved if these programs were aimed toward integrating disabled people more fully into the mainstream of society.

The national budgetary crisis thus contributes to the need for disabled people to renegotiate the handicaps we have been given, and to fight for those rehabilitation and self-help programs that can and do save every community a great deal of money.

The need to implement and enforce existing regulations means we must reopen these negotiations not only at the national level, but in offices, schools and city halls across the nation. Our primary targets for renegotiating fairer handicaps are the managers of all the institutions within which we must make places for ourselves — the work places, schools, churches, shops, community and recreational areas. Traditionally, they have all been rather inaccessible to us.

For many disabled people who still believe they have no rights, or who are too embarrassed to claim them, negotiating can be a pretty scary concept. Considerable moral maturity and political sophistication is required, since proper channels too often seem designed for people to drown in before their grievances are resolved.

Nevertheless, we must master the ability to be neither too servile, nor too surly; neither too accepting of whatever is offered, nor too demanding without regard to broader considerations of fairness, expense and potential backlash. Otherwise, tricky professional manipulators will continue to outmaneuver us.

We should remember that principles of good management are on our side as we enter employment negotiations, for example. Wherever leaders work to encourage the development and high performance of subordinates, they create handicap systems of a sort, giving help and responsibility according to the subordinates' increasing abilities and natural limitations.

The best managers have already rid themselves of a host of prejudicial assumptions about women, Blacks and other minorities. The time has now come for a similar paring.
away from our society's perception of physical disability the popular assumption that we are also emotionally and intellectually impaired. In the instances where those problems occur, they more likely arise from the unjust social handicaps we have been given than from our inability to live with our physical disabilities.

Exposing managers and administrators who set the tone in their organizations to competent and productive disabled people should be a prime objective for those working to open opportunities to us.

It is obvious that if disabled people's place in society is to be renegotiated, today's generation of disabled Americans must be the vanguard. But where are we to develop the skills and independence necessary for this task?

The failure of established authorities to open up career development paths for disabled people has left our dispersed community with few of our own kind in positions of authority and influence. We have few institutions of our own — such as the Black church or Jewish synagogue — around which to gather our numbers, deliberate about our problems and unite in self and community developing action. Without such shared institutional and community experience, there is little hope for us to develop leaders rooted in our real life problems.

How much more bereft can one be than to stand alone and untutored in the life he must face? Perhaps the small Independent Living groups with their peer counseling and head-on facing of disability realities might generate the leaders and the new culture we need.

But what, you might ask, of the dozens of charitable and disability-related organizations that exist at national, state and local levels? The public already supports these private organizations generously. They are widely publicized and seem to be somewhat democratically controlled by the people in whose names millions and millions of dollars are raised annually.

It is true that such charitable organizations are potentially powerful centers for disabled people. As of now, however, in too many of them, disabled people are seen as hardly more than excuses for transfer payments from a wonderfully generous public to physicians, researchers, appliance manufacturers and association staff members. Rather than Independent Living, they approach us from a medical model perspective in which we are treated as sick and dependent — as patients, rather than agents or actors.

The managers of such organizations define their goals primarily as fund-raising, and not in broader terms of cultural leadership and development. Often their success at raising money enhances their organizational power in such a way as to destroy, with pity-arousing telethons, any community spirit in their constituency. Too often, they strengthen the very cultural attitudes toward disabled people that have always inhibited our full participation in society. They have made people pity us and open their wallets to us without ever believing in us or being proud of us. They never challenge and encourage us to live as fully and maturely as we can.

Having become involved prior to this era of greater self-assertiveness among disabled people, many on the staffs of these organizations — like dependent mothers — have a hard time encouraging the independence of people whose incapacity has provided sustenance and given meaning to their lives.

The boldest mark against such organizations is their miserable record in hiring and developing the very people in whose names they raise their own operating costs.

Yet any effort by disabled people to assume greater authority and participation in these organizations poses a delicate problem. The strategic knot we must untie is how to wage campaigns for greater influence without souring the public's support for these organizations, and without being unkind or unjust to the people who have built them in our names.

These groups, after all, have helped support technological advances which benefit many. They helped author the legislation that promises support in the renegotiation of our place in society. For all of this, we owe them our thanks and respect.

Yet, even after these accomplishments, disabled people are still isolated and ashamed when we ought to be proud of ourselves and organized. We ought to run our own affairs and encourage one another, but we do not.

Each of these organizations has lists of thousands of unactivated, unchallenged disabled Americans and other volunteers. With so much to be done, why should so many people be lacking direction, and waiting in vain for a chance to contribute? These dinosaur organizations could be brought to life to become organizing, educational and support centers for a renaissance of activity, learning and hope among disabled Americans.

Clearly, we need leadership from both disabled and nondisabled persons, but the requirements are stiff: exceptional belief in what disabled people might become; courageous hearts and inquiring minds to identify and combat the fears, prejudices and policies inhibiting us; and an entrepreneurial spirit to break through inept, wasteful procedures to create effective new programs.

We should not be deluded into thinking that there are adequate numbers of managerially-trained disabled people ready to help change the direction and spirit of these organizations. The talent is there, but the experience and cultivation has not yet been acquired. The Independent Living movement might become the starter motor that gets the huge engine of these private associations in motion for the development — and not just the maintenance — of the disabled.

Perhaps in struggling to renegotiate our own social handicaps, we will create new processes for overcoming the often relatively minor disabilities that block all people from exercising their far more important abilities. We disabled — who are so often forced to acknowledge our weaknesses and ask for assistance — cannot easily avoid becoming point-men and women in the struggle for greater justice for everyone.
To achieve this, we need opportunities that will increase the practical wisdom of our members; and we need the support of a respectful society that promotes people's productiveness rather than stigmatizes them for their differences.

We disabled people have a lot more going for us than we have been led to believe — and a lot less about which to be ashamed. Fairer handicaps will allow us to demonstrate that.

We're game.

The question is, will others let us play?

Jody Paltmou, "I'm a 36-year-old white male with Charcot-Marie-Tooth, who uses a wheelchair... I have B.A. and M.S. degrees and all but dissertation in philosophy for a Ph.D. ... I am presently a management analyst and consultant working on issues of humanizing and teach social justice courses part-time at American University." Address: 3700 Massachusetts Ave., NW, Apt. 121, Washington, DC 20016.

**Altering Attitudes**

by Jacob Oser, Ph.D.

We who are disabled frequently feel left out of things. We see the world buzzing with activity, and we are usually on the outer edge — lonely, neglected, wishing we could reach out and make contact with other people. But there is a barrier, invisible but unfortunately obstructive, that impedes our communicating with those we meet.

Most people in our society are taught not to pry openly into other people's problems, not to ask embarrassing questions, not to stare. The easiest way out of an awkward social relationship with a handicapped person is to ignore her or him, doing nothing more than cast furtive glances. Children are less inhibited and stare openly.

In my own case, my tongue and lower jaw were removed more than four years ago because of cancer. I take all my food and drink through a tube inserted for each meal into my stomach. I do all my communicating by writing. I did not learn hand-sign language because not many of my friends and relatives would understand me that way.

I wrote an article titled "Oral Cancer: Coping with the Changes," which was published in the August 1979 issue of American Journal of Nursing. I duplicated this article and distributed it widely. Here I shall give one example of the dramatic difference it made.

My wife and I attended her fortieth college class reunion. In the past I had seen only one of her college classmates, who is an editor and whose lecture I once attended. In a roomful of strangers I could expect to be alone. People would wonder about me and my situation, but they would not ask me questions. That would be considered by our society a rude intrusion into a private matter. It would be easier to ignore me.

But my wife sent my article to a few of her classmates. Someone had the inspiration to duplicate the article and send it to all the people who were coming to the reunion. They all knew much about me when they came to the affair, and they wanted to meet me and talk to me when they got there. I was surrounded by a circle of interesting, friendly and warm women and men.

This system to help break down barriers can be used by others. Not everybody can be lucky enough to have articles published describing their situations. But suppose someone in a wheelchair is attending a class. The instructor can have that person write an autobiography of a few pages which can be mimeographed and distributed to the class. The same can be done for disabled people attending meetings of social, cultural and political organizations. New channels of communication are thereby created, and a difficult life can become more tolerable. The disabled person is not likely to push his or her autobiography toward other people — it is up to some other member of the group to promote this project. It should also be shared with friends and relatives. They also hesitate to ask questions but often respond warmly to such a document. It clears the air to resume their previous relationships.

Jacob Oser, Ph.D., Professor of economics (emeritus), Utica College of Syracuse University, had his tongue and lower jaw removed more than four years ago because of cancer. Address: 1055 South Street, Clinton, New York 13323.

**Must I Mourn?**

by James H. McGrath

When I was given the opportunity to contribute a short article of the kind which you would like to have found at some particular stage of rehabilitation," an issue concerning my psychological adjustment came to mind.

The story begins in July of 1980 when my vacation ended abruptly with an accident which damaged my fourth and fifth cervical vertebrae. The events which followed the accident are familiar to quadriplegics who have had a spinal cord injury: hospitalization, a fusion and rehabilitation time adjusting to a wheelchair, becoming accustomed to non-functional fingers and trying to resolve medical complications.

During the first weeks of hospitalization, as I began to assess my situation, I realized a tragedy had befallen me and that my life was to be dramatically changed. Although I occasionally found these thoughts depressing, at no time did I experience an overwhelming emotional upheaval. There were no sustained periods of depression. There was no uncontrollable gloom.

Months after my injury, while in the rehabilitation institute, I began to worry: Shouldn't such a tragic and life-altering accident produce a dramatic emotional crisis? Am I
unconsciously putting off such a crisis? Is a period of debilitating gloom soon to overcome me? I left "looking over my shoulder" still worrying that I might see a cloud of depression about to engulf me.

At home, I began reading. I subscribed to five or six of the monthly magazines and newspapers listed in the Rehabilitation Gazette (this proved invaluable). And I asked my librarian to order a steady stream of OT, PT, nursing and rehabilitation books (also a must). It was in one of these books that I found an idea that threw some light on my worry that I had not become "sufficiently depressed."

The idea was called the requirement of mourning. Apparently, people associated with the severely injured commonly expect or require the injured person to be emotionally debilitated with depression or mourning for what has been lost. Yet, contrary to these expectations, the injured person often has no such reaction. According to my reading, neither clinical observation nor psychological testing has found significant evidence that injured persons typically were overwhelmed with grief or mourning.

Reflecting on this idea, I made an important discovery. For the most part, I had no recollection that the hospital or rehabilitation staffs had imposed on me the requirement to mourn. At times, some members of my family seemed to — during visits, sometimes I was the one who ended up consoling them. Ironically though, it wasn't others who imposed a requirement to mourn; but rather, as the previous paragraphs suggest, I was the one who imposed the requirement on myself. What I mean is this: I had not experienced extreme grief or mourning; my reading had reported that this is often the case for severely injured people. But, by worrying that I "should" grieve or mourn, I was doing what my reading reported others often do — imposing a requirement of mourning. I had committed the mistake of requiring myself to mourn.

Having realized this, I now look over my shoulder for that engulfing cloud of depression far less often. Of course there is no guarantee that it will never come, nor could there be one. I had excellent medical care, a strong personal background, an abiding and loving wife, supportive family and friends and an injury that left hope for returning to my profession. Perhaps under less fortunate conditions things would have turned out differently.

But, I can report that it is possible to suffer a tragic, life-altering injury, to assess the significance of the injury and yet not to undergo a severe emotional upheaval.

James H. McGrath became a C4-5 quad in an accident in July 1980. His address is 1114 Oak Ridge Drive, South Bend, Indiana 56617.

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Adjusting to Public School

by Kevin Riggs

Having had cerebral palsy since birth I prefer a wheelchair for longer distances even though I can walk with crutches.

When I started first grade in a special school for the disabled in 1968, my parents told me that I should feel fortunate to have such a school in town. I did, in fact, feel fortunate and could not imagine myself attending my neighborhood school and being taught in the same class with my nondisabled peers.

However, all that changed four years later when I enrolled at my local elementary school, Warren Elementary. The principal at the school for the disabled felt I had the potential to make it in a public classroom, even though I would need help from fellow students because I am not totally independent.

The teachers helped me adjust to the new environment. Since I had already mastered basic techniques for doing such things as math problems on the typewriter (I don't write well), many problems solved themselves and the teachers did not mind adjusting to my methods.

The students were also helpful. Whatever job needed to be done, I could always find a student to do it — in fact, I had so many wanting to help that the students took turns pushing my wheelchair.

While the number of eager helpers eventually decreased a little, I always found people to meet my physical needs.

I have gained many close friends in the process. I've never regretted my lack of disabled friends because my nondisabled friends have treated me as a person with the need to receive and give love. They've allowed me to give and receive on countless occasions. Some of my friendships lasted from the fourth through the twelfth grade and beyond.

Although my experiences in public classrooms have been mixed, the good times outweigh the bad. If I have learned anything from my years in public school, it is that the similarities between the disabled and the nondisabled outnumber the few differences.

In the fall of 1981, I began attending Georgia State University. I am presently pursuing a Commercial Music/Recording associate degree — I may also try to earn my B.B.A. as well.

I am convinced that all the ramps and elevators (and other devices) will never take the place of the help and guidance that the nondisabled can give to the disabled and the love and friendship that we, the disabled, can give to them.

I shall welcome correspondence from other disabled people (students in particular). My home address is 2962 Medinah Court, Atlanta, Georgia 30341.
As I have become more involved in the administration of Independent Living Programs, I have grown increasingly concerned about the accountability and management of our programs. This accountability is most important to consumers of our services, but is also important to current and potential funding sources. One of my favorite analogies on this subject is the relationship of Independent Living Programs to consumers. In many cases, these programs are demonstrating how to ask for help to their consumers. So, if Independent Living Programs need help with administrative issues, they also should be able to ask for help. From what I have seen over the last four years, Independent Living Programs are having difficulty doing this.

Most Independent Living Programs have similar philosophical bases but management techniques (or the lack thereof) vary widely. Of the 20 programs I have visited or with which I have worked, a majority of directors have ignored or not clearly recognized several factors which demand the attention of management: a) the limited time available for Title VII Part B grants; b) the positive impact that sound internal organization has on services provided, public relations, and the potential for funding; c) the fact that Independent Living Programs are competing with existing and traditional service providers for limited dollars; d) the need for effective communication at all levels of organization and how such communication becomes a major part of the management structure; and e) how important money is in relationship to quantity and quality of services provided.

Many program directors (and perhaps, Boards of Directors) have seemed reluctant to admit their lack of management skills and their need for help. I have attributed much of this attitude to the fear of becoming bureaucratic or too much like traditional agencies. I think this is an invalid fear and would like to point out some benefits that management has to offer Independent Living Programs.

I believe that on-the-job experience is crucial to understanding the need for management but it is not solely sufficient. Understanding the need should translate into a request for help with specific questions to be asked, perhaps of Board members, professionals, educators, or consultants. Once a program's philosophy is set, management should be the next step in program development. The establishment of a management structure begins with a 5-step planning process:

1) Defining the mission — What is the program’s philosophy and main effort?
2) Setting a goal or goals — What should happen as a result of the program’s efforts in 5 years?
3) Listing the objectives to reach the goal(s) — How will the program address the goals during the first year, second year, etc.?
4) Developing action steps — How can each yearly objective be met?
5) Assigning responsibilities for action steps — How many and which staff or volunteers will be necessary in order to complete each action step?

Objectives should be quantifiable from top to bottom, i.e., from the Board of Directors to staff to the program’s consumers. Most important, this planning process should be written down. A written plan not only helps the Board and director review progress, but also helps the entire staff understand their role(s) in the overall scheme of the program and how they contribute to meeting larger goals.

As the plan begins to take shape, a program’s Board of Directors and chief executive officer (staff) should begin to address the need for management policies. Policies are simply pre-determined methods of action. They can be rigid or they can allow for great flexibility. They are developed (and written down) in order to be prepared for any eventuality. The areas where policies are needed are as follows:

1) Governance — Who has ultimate authority and responsibility for the program? How will the program be governed? What state or local laws must be met by the governing body? What is the relationship between the Board and the staff?
2) Legal — What federal, state, and local laws must be addressed by the program? What are the legal implications of the program’s services? How will the
Innovations

Adaptive Equipment Center/ David Tyrey

Opportunities Unlimited, Independent Living Center of Mid-Missouri, Inc. was funded in the fall of 1981 as a referral and information agency which will eventually expand to include an eight-county area.

One important aspect of Opportunities Unlimited’s service delivery system will be providing assistance to disabled children and adults in the selection of necessary adaptive equipment. The center will stock a large assortment of various types of adaptive devices, which will be solicited from manufacturers and providers as sales demonstrations. Participants will then, with the consultation of the Adaptive Equipment Coordinator, be able to evaluate the effectiveness of a piece of equipment and select necessary modifications before purchasing the item directly from the supplier.

The Division of Special Education of the State of Missouri is strongly in support of the component and has pledged its financial, as well as staff support. The Division will provide the salary of the Adaptive Equipment Coordinator and other expenses of this component.

Strong support has been pledged by a number of departments of the University of Missouri. Members of these departments interacted to form a task force in 1979-80 to establish a similar adaptive equipment center. This project was not funded by the State of Missouri, but the members of the task force have pledged their support of Opportunities Unlimited’s program on an informal basis.

Opportunities Unlimited will establish fee-for-service arrangements with school districts throughout the state, and this component will contribute to the economic viability of the center independent of Title VII funds.

This component could also be expanded to include a wheelchair repair service, pending negotiations with the Electrical Engineering Department of the University of Missouri—Columbia, which currently provides this service. This will provide an additional income-producing activity for the center.

Opportunities Unlimited will provide a much needed service and provide a much needed closure of gaps in service for severely disabled individuals in the mid-Missouri area. In addition, the Adaptive Equipment component will provide a greatly needed benefit to the school age children of the entire state of Missouri.

Address: Dave Tyrey, Director, Opportunities Unlimited, Independent Living Center in Mid-Missouri, Inc., 111 South 9th Street, Suite 211, Columbia, Missouri 65201.

The Free University/ Barbara G. Hummel

"Where can I find a good place to get my wheelchair fixed? And what parts of it could I fix myself?"

"How did you adapt your kitchen so you could cook?"
"What is Medical Assistance and what will it cover?"
"If I take a part-time job, how will it affect my benefits?"
"My attendant and I aren't getting along. How can I make myself more clear?"

These are just a few of the different kinds of questions disabled people may have as they pursue living independently. Access to Independence, an independent living center in Madison, Wisconsin, decided to provide a forum where disabled people could share and learn this kind of practical information. Out of this idea came the Free University, a series of workshops taught by disabled people in the community on different topics related to independent living.

In planning for what workshops would be offered, disabled people were surveyed as to what they'd find most interesting and helpful. From these preferences, a variety of topics were selected, including attendant management, housing information and rights, sexuality, appealing service decisions, environmental controls, assertiveness training, leisure time planning, adapting kitchens, and using TTY's. Since March 1981, 36 different workshops have been offered with a total attendance of 375. This number includes registrations from 135 different disabled people, plus some family members, attendants, and service providers. Access has contracted with 36 different disabled individuals to teach these workshops; at times, there have been other people with special expertise who have served as co-instructors. Access is committed to paying disabled people who are selected as instructors, acknowledging the expertise they have to offer. Instructors are not full-time employees, but are paid for the specific workshops they do.

Workshops are typically two hours long. Some topics, like attendant management, have involved a number of sessions over several weeks; others, like massage, consist of only one session. Workshops are scheduled at different accessible locations throughout Madison, and interpreter services and/or taping of materials are also available with advance notice.

Sometimes workshops have developed into full-blown projects. For example, in conjunction with a public cable TV station, Access developed a workshop which enabled disabled people to plan and produce their own TV program. A core of people got together and decided upon a program idea that involved elementary school age children talking with disabled adults about disability, feelings, and other information they wanted to know. The production will air as a half hour show in spring of 1982. This opportunity to get a taste of TV production has led to an appetite for other TV related projects with the station, including plans to televise other Free University workshops in order to reach people unable to come to the workshop sites.


Apprenticeship Program/Eileen S. Berkley
Beth Lindl exemplifies a program that's working at Access to Independence, an independent living center in Madison, Wisconsin. Beth, severely disabled with muscular dystrophy, started working as an apprentice to the Executive Director in March, 1981. Like the 11 other apprentices who have worked at Access, Beth was not paid a salary for her part-time work but did receive on-the-job training. She assisted the director in preparing grant proposals, fringe benefit programs and quarterly reports. Also, she became familiar with the center's bookkeeping and filing systems. She gained experience in running staff meetings and helping to coordinate staff activities. These were all objectives that Beth and the director had agreed to when she started her apprenticeship. Her long-term goal was to gain the qualifications needed to fill an administrative position in a small organization. Beth is on her way to achieving this goal — when a part-time housing counselor position opened up at the center, the director immediately hired Beth. Her skills and her charm have proved to be a real asset.

Access developed the apprenticeship program for two main reasons. First, Access wanted to increase the number of disabled persons on its staff. By receiving firsthand job experience over several months, the apprentices will be better able to compete for jobs that become available within the center. This program can then address the problem that centers staffed primarily with nondisabled people may have: qualified disabled persons are not applying for available positions.

A second reason for the program is simply to provide valuable job training and the practical experience of working in an office, providing direct services or doing clerical or administrative work. Apprentices who are seeking employment in other organizations receive job referrals, job counseling, assistance with the application and letters of recommendation from center staff. This is often in conjunction with services from a vocational rehabilitation counselor.

Based on his or her interest and skill level, each apprentice is matched with one staff member within the center. The apprentice must possess at least a minimum level of skills. For example, the apprentice assigned to work with the clerk typist must already possess typing skills. An apprentice who will work with the independent living counselor must be able to relate well with others.

The program allows for quite a bit of flexibility for both apprentices and staff. Apprentices are encouraged to concentrate on particular facets of the work that are most interesting or will provide opportunities to develop specific skills. Staff members are free to "borrow" other apprentices (upon mutual consent) to work on special projects or activities.

"This experience came at just the right time for me," said Beth. "I had graduated from college and taken some time off before attempting to enter the work world. It really
The Residence University to participate in 1962-1981. Susan son gave dependent according to early students who lived in three percent are living in their Program at the University of Independence. The experienced except end of the school year—re-positioning at night and danf lomia palsy, cent had participated in the Physically Disabled Students' Residence Program at the University of California in Berkeley. Prior to admission to the University, almost all students were dependent on families or medical facilities. Today, ninety-three percent are living in their own apartments or homes, according to a 1981 survey of former participants.

More than 115 severely disabled students have used the program as a stepping-stone since its start in 1962. Seventy-five former participants responded to a detailed questionnaire on their present status and on changes they have made. Eleven participants are deceased.

The Program began twenty years ago with a handful of students who lived in a wing of the campus hospital in the early 1960s. The students located and hired part-time attendants for personal care and did not use the hospital staff except for on-call emergency services at night. In 1975, the Program left the hospital and was integrated into the University residence halls. At that time a full-time coordinator and support staff were hired, under a grant from the California State Department of Rehabilitation. Since then, one experienced staff member is on duty twenty-four hours a day to provide assistance while students learn to use the campus and community resources. Staff members acquaint students with the now formally established attendant referral service, and help with interviewing, hiring, and training of attendants. A staff member is available for re-positioning at night, helping with meal trays, for emergencies, and for the many unpredictable needs that arise. Almost all students move out to private apartments at the end of the school year.

Over the twenty years, sixty-four percent of the participants have had spinal cord injuries, twenty-five percent had a form of muscular dystrophy and the remaining eleven percent had other disabilities, such as cerebral palsy, post-polio, rheumatoid arthritis, and osteogenesis imperfecta. Recent years show an increase in students with the latter disabilities.

Eighty-one percent of the respondents presently employ part-time attendants. This contrasts with fifteen percent who did so before coming to the Residence Program. Almost all employ three or more attendants each week, reflecting the Program's philosophy that a system of multiple attendants allows the residence independence. Each attendant is ill, allows for adequate days off for attendants, and for more freedom for the disabled person. Respondents locate attendants through attendant referral service, Disabled Students' Program at the University, and through the Center for Independent Living in Berkeley, word of mouth, and newspaper advertisements.

Fifteen percent of those polled drove their own cars or vans before the Residence Program. Thirty-seven percent currently do. Use of public transportation increased from three percent to twenty-one percent. City buses in Berkeley became accessible in June, 1981, after this survey was completed. More than the twenty-one percent are now using public transportation.

Approximately thirty percent of the respondents are currently students at the University. Thirty percent have graduated with Bachelor's, Master's, or Jurisprudence degrees. Majors were diverse: architecture, political science, law, English, psychology, social welfare, French, economics, computer science, business administration, public health. Ten percent transferred to other universities; fourteen percent withdrew from school. About half of all respondents received further education or training after leaving the University of California. Over ten percent of that additional training was in the computer field.

Another thirty-four percent of the respondents are employed full time; six percent work part-time. Some are employed in state government: Director and Deputy Director of the California State Department of Rehabilitation; Chief of Operation and Policy of the California Department of Health Services; Director of Developmental Disabilities, Nevada. Many are in the field of data processing: programmers, analysts, program managers at such firms as International Business Machines, Standard Oil, Fireman's Fund. One is employed in the Mayor’s Office of Los Angeles, one is in real estate, and one is a proofreader and librarian for Kaiser Aluminum Chemical Corporation. The University employs several former participants: a drafting technician in architecture, a computer specialist in graphics, an accountant/an analyst and the coordinator of the Residence Program. One operates a telephone answering service, one is self-employed in wood crafts, another is the manager of Driving Aids, Inc. Several are counselors in the field of disability.

In an open-ended question on “Most important things learned” in the Residence Program, respondents ranked independent living skills and attendant management first, followed by peer relationships, improved self-image, and learning to deal with bureaucratic agencies, wheelchair mobility and health/disability management.

For information on the Residence Program and financial aid, inquirers should contact: Susan O’Hara, Coordinator, Physically Disabled Students' Residence Program, University of California, 2515 Channing Way, Berkeley, California 94720.
Research and Demonstration

Holistic Approaches to Independent Living (HAIL, Inc.)
Barry Rosenberg, Director, 816 Acoma, Suite 100, Denver, Colorado 80204.

In November, 1981, HAIL was awarded a three-year contract by the U.S. Department of Education to demonstrate model approaches for improved delivery of independent living services.

Phase I, the first year, will be devoted to developing a comprehensive needs survey to find the major needs of disabled persons and to develop ways of tapping limited resources to meet these needs. It will also include assessing available resources, designing a model non-residential skills training program for persons with severe disabilities at risk of institutionalization and identifying independent living programs in a 15-state region. The 15 states are Arkansas, Colorado, Iowa, Kansas, Louisiana, Missouri, Montana, Nebraska, New Mexico, North Dakota, South Dakota, Oklahoma, Texas, Utah and Wyoming.

Presently, HAIL is seeking persons who would be willing to fill out the comprehensive needs survey form or who would be willing to be interviewed. If you are interested, get in touch with Barry Rosenberg.

Phase II will involve the implementation of the training program and the provision of technical assistance and training to the independent living centers in the region.

The training and technical assistance components of Phase I and II will be geared to the production of topical monographs of independent living services such as attendant care, housing and housing referral, financial management, counseling, skills training, employment, recreation, and transportation.

A regional resource center of programs and funding sources will be established and a grants exchange network will be developed.

Phase III will be a regional demonstration of the model's impact.

Research and Training Center on Independent Living.
James F. Budde, Director, The University of Kansas, 348 Haworth, Lawrence, Kansas 66045.

In November 1981, the R&T Center was awarded a contract to study the independent living field — the needs, the current state of theoretical development and available resources.

The study of independent living will be limited to two core areas: foundations for independent living and independent living services.

The foundations core will contain two studies: identification of psychological and environmental determinants of independence and identification of influences of family and significant others.

The services core will focus on two problem areas: peer helpers and program evaluation.

Oddity . . . or odyssey . . .

That is the question

J. David Corrigan, S.J.

“. . . whether 'tis nobler to suffer
the slings and arrows of outrageous fortune
or take arms against a sea of troubles
and by opposing
end them . . .”

Some people make history by taking a stand on some vital current issue. By contrast, I seem to make my mark when I’m sitting down. Such was the case last April when I sat down to discuss the results of my learning disability tests with Betty Lingren. Many of my suspicions were pinpointed, but I shall never forget Betty’s question, “Where have you been for the last 15 years?”

Now I truly felt that I could ask the question behind the question, “Fifteen years? How about the last 30 years?” Yes, from grade school, through high school, on into my Jesuit training and job assignments and even during my
sabbatical experience — a hidden power kept displacing and pursuing me down the labyrinthine ways of the times, the spaces and the very breath of my life.

Going way back, I can remember how painful and humiliating it was in the latter days of grade school to stay after class and try to work out word problems without assistance. “Never,” said I, “will I ask a question about math again.” During my high school days, I was too naive to realize that six or seven hours of homework was inefficient even at a Jesuit high school. Agonizing through algebra, geometry, physics and English composition was the price you paid for the big brass ring of academic success. Surely, such stresses were growing pains and the ache of all would soon be past history.

From 1952 to 1967, I moved from one stage of Jesuit training to another. Again, the monster inside kept dragging my self-esteem — down, down — as I sought to analyze English literature, to comprehend philosophy and finally, understand and begin to live theology. From the academic side, the ’60’s exerted such demanding pressures that I sought counseling. On the spiritual side, the unique Suscipe of Ignatius — give all to the Lord — kept drawing me more to this deep spiritual source.

From 1967 till now, there have been a succession of diverse and challenging assignments. As I changed from the role of teacher to retreat master to campus minister, the monster continually haunted me all the way. As the monster roared, I would run again. Finally, last April at Skyline College, I stopped running and began to walk again. I enrolled in the Learning Center there. Now, thank God and others, the inner roaring is lessening as I learn more about myself as a classic L.D. learner.

And tomorrow? What will it bring? Somehow I sense that with the sky as the limit, I have many miles to go before I sleep. One thing I do know is that the oddity of the past is behind me. The odyssey of learning anew is ahead of me. Other learners like me will need help to know that their oddity is not like their odyssey... that will be their question and that will be my life... my work my service.

Address: Rev. J. David Corrigan, S.J., P.O. Box 28530, San Jose, California 95159.

A View of Self-Hypnosis

by Margery Halford

During the past year an old problem with pain in a hip and leg returned. It became so continuous while sitting up that I was almost unable to keep on working. Always before, without giving it any particular thought, I had been able to block it out while I was working. My principal work is musical research, editing and writing about music. It is so engrossing that when I look up from an 18th century manuscript and see cars whiz by the window, it sometimes seems anachronistic.

Other than blocking it out, the pain was always relieved when my feet and legs were repositioned, and there was never any pain when lying down. I reasoned that it was not caused, therefore, by an infection or something more serious. But it reached the point where I sometimes had to call a neighbor and ask to have my feet moved, and then it reached the point where even that did not stop the pain for more than a very few minutes. I tried to understand why I was no longer able to block it out, and failed completely. I decided that, for me, the answer would be to learn self-hypnosis. I knew nothing about it at all except that it is a means of getting in touch with the unconscious, and that it must be the answer to phenomena such as the yogi walking on hot coals without pain or scarring. This was a solution I was sure I could use.

When I read, at the suggestion of a friend, Healing From Within by Dennis Jaffe (Alfred A. Knopf, New York, 1980), I began to get an understanding that gave me enough courage to tell my husband what I wanted to do. Of course it was obvious to both of us that the very first step had to be consultation with a doctor. I went to a specialist in physical medicine and rehabilitation, but I did not have the courage to tell him what I really wanted to do. I am very aware that the medical community at large has a very mixed view of hypnosis as a medical tool.

After a discussion and examination, the doctor was able to rule out organic or progressive disorders and to determine that the pain seemed to stem from pressure from sitting in the same position for so many consecutive hours. There were no easy solutions to this problem because I am alone all day while my husband is at his office and I can neither shift my body weight in the chair nor reposition my legs, and feet significantly enough to make much difference in weight distribution. We agreed to try to find a non-narcotic and non-habituating medication that would kill pain and not produce unpleasant side effects.

During the next few weeks, while trying different medications, I made up my mind to take the plunge. I was afraid to try hypnosis by myself because I understood that the rate of breathing slows down during the process of becoming deeply relaxed. Since I use a respirator, the prospect
frightened me. I made an appointment with a qualified hypnotherapist who was recommended by a friend who works in the medical community. I did not omit any details from my discussion with him. I may have told him considerably more than necessary, but I felt it was important for him to have as much information as possible.

He talked to me about the nature of hypnosis, what it is like to be in a trance and what to expect, then explained in detail exactly what he was going to do. He also said that even if he were to drop dead while I was in a trance, nothing adverse could possibly happen — the trance would simply end itself naturally. The breathing would be no problem, because he would instruct my unconscious to make no changes in it.

He then induced a light trance and taught me the "glove anesthesia" technique for control of pain. My hand became numb and I transferred the numbness to the hip and leg. He gave me several post-hypnotic suggestions including a strong feeling of well-being and energy, and asked me to give myself whatever post-hypnotic suggestions I wanted. Since I needed to lose some weight, I suggested that I not overeat. Then he roused me from the trance and we discussed it in detail. I knew exactly what had happened at all times and I felt perfectly marvelous. He said not to discontinue the medication until I felt confident that I could control the pain without it. There was no pain for the remainder of that day. The medication was then taken worked some times and not others. At dinner time, I was scarcely hungry and ate very lightly.

During the succeeding days, I tried self-hypnosis with varying degrees of success. The therapist had told me that, initially, I might have no more than 2 percent success, but that it was a positive step in the right direction. He taught me other techniques during the next sessions, and in a few weeks I was able to discontinue all medication. I was losing some weight, I had a tremendously high energy level, there was a strong and almost constant flow of creative ideas (an essential part of my work) and everyone I saw said how much better I looked. I rarely had any pain.

I phoned the specialist and told him what I was doing. He was delighted! My personal physician gave me a general examination and I told him. He said that although he knew little about hypnosis, he was in favor of a technique that enabled me to control pain. I keep in touch with him, and discuss anything new that I want to try to correct with hypnosis. This is essential because the pain mechanism is designed to let the conscious mind know there is something wrong with the body that needs attention.

I had read about endorphins, the natural chemical anesthesia manufactured by the brain, and discussed this subject with the therapist. When I woke one morning with a splitting headache, I induced a light trance and asked the endorphins to rush in there and relieve the headache. It disappeared almost instantly. I mention this to underline the fact that the power of the unconscious is awesome. The motto should always be, "Be careful what you ask for, you might get it."

I have from 95-98 percent success in eliminating the specific hip and leg pain entirely. I use imagery liberally. For example, I see the numbness of anesthesia encasing my leg from toes to hip like a transparent sheet. When it is in place, I slip a little piece of cloud under my feet. I can visualize delicious meals without wanting to eat more than just a small amount. I see my skeleton hanging from the skull so that the slumping straightens out and I am sitting more comfortably and straighter than before.

Creative use of imagery is a practice everyone can indulge in with beneficial results. I realize that many people are not able to concentrate in a manner which makes self hypnosis possible for them. And unfortunately, hypnosis often invites quackery. Its legitimate use is invaluable. I emphasize that care should be exercised in selecting a medically responsible hypnotherapist whose reputation can be verified.

I converse with my unconscious and with God on a daily basis. My perceptions, attitudes, perspective on life and my ability to produce worthwhile work have all benefitted along with a general improvement in my health and happiness.

Margery Halford, "The power of the unconscious is awesome."
Adoption by Parents with Disabilities

Grace Sandness

If we are honest about our own strengths and weaknesses and willing to make the effort, we adults with disabilities can pioneer in an area which yields both personal satisfaction and service to others — parenting through adoption. But we must have courage because the seeking is a struggle, often fraught with discouragement, and our acts of adoption are often criticized and doubted. We must have wisdom, because to adopt and parent successfully we must know what works and what doesn't work — what to attempt and to refrain from trying.

Twenty-three years ago, my non-disabled husband, Dave, and I first explored the possibility of adopting. Married less than a year, we knew we weren't yet ready to be parents, but we fully intended to adopt someday. However, the agency director we talked with obviously had trouble imagining that a frail polio quad with respiratory problems could be a mother. I remember his words: "Be glad you have each other. Don't try to be parents, too."

About four years later our first child arrived, through the faith and endorsement of a woman who knew from experience that miracles do happen. We had found the opportunity to seek out Bertha Holt, who, with her husband, had begun the Holt Adoption Program to seek families for G.I. babies, byproducts of the Korean War. With her help we adopted, first a malnourished five-year-old girl who was mildly cerebral palsied, and, second, a four-year-old "sister" who had some paralysis from polio.

After that it was easy. Our third, a tiny Mexican-Black girl, was physically normal; her only handicap was being born a minority-race child. Each one who followed was considered, for some reason, hard to place. That was, surely, an important factor in our being allowed to adopt at all.

As our family grew, we began to receive pleas for help or advice. People with lesser disabilities than mine were being refused by agencies around the country. There was really nothing we could do for them then, because prejudice was too great. But we were able to continue because we'd proven we could succeed, or at least hold our own, as parents.

Our most painful turn-down came after eight adoptions, when a judge in India refused us because, he said, I couldn't manage a family because I was "crippled." Though we dearly wanted eleven-year-old Sheela, paraplegic from polio, the story of our refusal made a good anecdote at adoption meetings. By that time Dave and I were both deeply involved as adoption counselors for CROSSROADS, the adoption agency we'd helped to bring into existence. It was in many ways a dream come true, for CROSSROADS emphasized homes for children with special needs and would work for people like me.

That is where we are today — involved and excited about the possibilities with CROSSROADS, especially when it involves the families and children who concern us most. Four of my client families have one partner with a wheelchair — one client is blind. Though a small beginning, it yields immense satisfaction — in a way it is the
fulfillment of a plan greater than we could have conceived.

Our family today is the result of eighteen years of adopting. Our newest daughter is paraplegic, the result of child abuse. When she came, at seventeen, we became a two wheelchair family. Most of our twelve (including three "adopted in spirit") have some sort of physical or emotional disability.

Usually the decision was mutual and deliberate. We felt we had the knowledge and resources needed to cope with each child's unique situation. Twice we have had to regret our decisions — during trying times — but these were cases where the full extent and impact of the problems were not known before placement.

There seems to be a fallacy prevalent among adoption workers today: special-needs kids for special-needs parents. Ridiculous! This viewpoint also calls for placing children with severe physical, mental or emotional problems with single adoptive parents, simply because nobody else wants them. Such placements are fair to no one. Having to be content with second-best is the worst possible way to begin a relationship. Any child needs to feel wanted — not just "settled for."

I do feel that people who have adjusted to handicapping conditions have learned something which can be beneficial to a child who still has that rough road to travel. The disabled often have more empathy and coping skills for dealing with such problems than so-called normal people do. We've found this true in our own experience. Our orthopedically handicapped children, as well as those with heart-related limitations, have been easy to handle, simply because we have learned to live active lives in spite of the limitations my own disability imposes.

Our familiarity with Crippled Children's Services and DVR has been invaluable. Without them, our kids could not have done as well as they have. Dave's skills have evolved from building ramps and parallel bars to installing hand controls in cars. The ease with which we've been able to handle physical maintenance has made the more important matters of self-acceptance, competence and preparation for independent living easier to deal with.

In some ways — both good and bad — each child has been a model for some other family member. Where compensating for and "doing" in spite of a handicap are concerned, I've consciously tried to be an example. This is the most valuable strength I can foster in any of our children.

Each of us has strengths to bring into an adoption situation, but inevitably some situations will frustrate and threaten to defeat us. Here are some ways I've found to avoid such situations. These may start you thinking.

Adopt young. My strongest attachments have been formed with children young enough to ride in my lap and cuddle in bed. Touching and caressing are vital to building strong relationships. If a child is beyond the lap-riding stage it's often awkward to find a common ground for expressing affection, but if you begin early you can find some way to maintain it beyond childhood. Being a quad is an added drawback in this area. Learn to be a nuzzler.

Watch out for discipline. If you can't follow through on discipline, especially during the "getting-to-know-you" stage, have someone around who can. The reputation for being a pushover can haunt you into eternity. Force yourself to avoid making threats or promises you can't carry out. A good way to let off steam in the "needing-to-threaten" area is to make ridiculous statements. "I'm so mad smoke's coming out my ears!" is effective with little kids, "I feel like running you over and flattening you like a rug!" or something similar is fine with children old enough to know you can't (or don't really want to) do it. Generally, withdrawing from the arena is best. A wheelchair need not make you a captive audience for an acting-out child unless you let it. (I learned that the hard way.)

Remember, you're okay. Don't be dismayed when your child becomes embarrassed because you're "different." Every child goes through a stage when individual differences of any kind seem to threaten his evolving self-concept. Let your child know you're okay with yourself and don't need the approval of anyone else — including him. If you're not okay with yourself, think carefully before attempting adoption.

Children are quick to sense weaknesses and use them. Likewise, don't let yourself be put on the defensive because your child's adopted. You are the real parent if you feed, clothe, worry and love, because you are the one with the commitment. Kids need a hook to hang their problems on — if not adoption or disability, then something else.

Now, if you're still interested in adopting, what's the process? In most states you need a homestudy, done by a licensed adoption agency. Though you cannot be legally denied service by a public or private agency because of your disability, you will be at the mercy of the adoption worker to whom you're assigned. It's wise to learn an agency's or worker's track record for serving persons with disabilities before applying. Agencies such as CROSSROADS, designed to place children with special needs — children handicapped by age, race, sibling status, physical or mental condition, etc. — are usually more open than others to serving non-traditional clients. (Call your state's commissioner of child welfare to locate such agencies, or write NACAC, 1346 Connecticut Ave. N.W., Suite 229, Washington D.C. 20036.)

The homestudy process varies among agencies. At CROSSROADS we ask each client to write a rough draft of his homestudy, including what he feels is important — values, strengths, parenting skills, etc. You should include additional material concerning what you feel is unique about your situation — information necessarily better expressed by you than through a worker's interpretation. For example, I asked my blind client to write out her special techniques for infant and child care — already proven successful in raising her own "homemade" child. This is mailed with each copy of her homestudy sent out in our child search. If you seek an American child, your homestudy may be one of a dozen or more, or only a few, depending on the attractiveness of the child or the special
circumstances or degree of expertise sought in the potential adoptive parents. Whenever sent, it will be your chief representative, containing the only information about you a placement committee may have before making its decision.

After you’re approved, finding a child can represent a further problem. Sources are many and varied — from Latin American lawyers charging exorbitant fees to U.S. agencies offering subsidies for older children. However, no foreign agency or judge or American adoption worker is compelled to place a child with you when a so-called “normal” family is available. That’s a fact of life — a discrimination not covered by any equal opportunity act I know of. Your success may depend on selling yourself totally with your worker so that person can wholeheartedly endorse you as a potential parent. But even that may not outweigh the cultural prejudices of some foreign officials (such as our judge in India).

Though transracial adoption of infants is still possible, if a same-race family is not available (and you can pay a $2,000 to $3,000 fee), the reality of adoption today is the “waiting child.” About 130,000 of them, from birth to eighteen years, have been shoved around, battered and abused, dumped by irresponsible adults or shifted from foster home to foster home. Our newest daughter was in fourteen homes. Your agency should have exchange books from various states, filled with their pictures. If not, ask where you can see some. They’re an education.

The guideline “adopt young” may not be important to you. Close, beautiful relationships can be formed with children like these. Physically or mentally handicapped, emotionally traumatized, or often just rootless and hungry to “belong,” they offer both challenge and fulfillment to anyone confident enough to say, “yes, I’ll try.” That could be you — but not necessarily.

If you decide to adopt, decide first where your strengths and weaknesses lie and proceed accordingly. Then, do not accept any placement unless it meets your criteria. Be flexible where you feel comfortable doing so, but remember — you’re the best judge of what you can handle.

Adoption seldom just happens. It takes planning, work and dedication, both before and after the fact. If successful, the parenting that follows can be frustrating and agonizing; that commitment must be permanent. We non-traditionals say we’re just like other people. We can prove this by putting our commitment on the line — knowing what we can handle and avoiding what we can’t. Because we’re pioneers, we must work harder and do more to prove ourselves equal. But, as in other areas, we can succeed in adoption. With courage and wisdom...

Editor: Grace has written and published two very informative and helpful books on adoption. In Beginnings ($5.95) she tells of the experiences of CROSSROADS clients and in Brimming Over ($3.95) the delightful story of the Sandness family. Add 75c postage and send your check, payable to Mini-World, to her at her home address, 9965 Quaker Lane, Maple Grove, Minnesota 55369.

Grace Sandness, “A respiratory polio quad since 1950, I now use a pneumobelt by day and a trach-connected respirator at night. I am 49, married for 23 years, and have 13 adopted or semi-adopted children, ages 9-30, most with some form or degree of physical disability. My husband, Dave, is a psychologist who works in private practice and with our local school district. Professionally, I am an adoption counselor for Crossroads, Inc., a licensed adoption agency dedicated to the placement of children with special needs.”

Sex

Let’s Tell the C.P.’s About Sex

by David L. Morton

Society’s attitude toward sex and sexuality leads many of us cerebral palsied individuals to believe we are not sexual beings. Advertising, books, magazines, movies and television depict a sexually active person as the perfect “10.” Thus, many of us do not attempt to seek mates because we feel we will be rejected for not coming close to the perfect image.

Too often, our parents take the “Peter Pan” attitude toward dealing with our sexuality. They equate our long dependency upon them with an eternal childhood and they feel no need to provide sex education.

Consequently, when we decide to live independently and pursue a productive life, we feel too frustrated, afraid or ignorant about sexuality to seek an intimate relationship.

One way of combating this low self-esteem is to project a positive self-image. Good grooming can be the first step. A good personality is another way. If we are warm and caring toward a potential mate, we will have an easier time.

Asking for a date can be a tricky deal. Usually, we should take a longer time to get to know another person before asking for the first date than a nondisabled individual and we should not feel rejected if we are refused.
If a relationship grows from friendship into romance, we have the responsibility to make our partner feel comfortable with trying alternative methods of sexual expression. Kissing, hugging, caressing and intercourse will need practice and patience by both partners.

In some cases, when one or both of us is cerebral palsyed, we might feel the demands of marriage are too difficult and prefer a long-term relationship.

Others may choose masturbation and fantasy as an alternative to an intimate relationship and they should not be discouraged.

The time has come for parents, teachers and professionals involved in independent living programs to realize that sexuality is our right as human beings. We should be able to express our sexuality within our abilities and our limitations. Although we may be unable to feed or dress ourselves, we are capable of being lovers.

David Morton is cerebral palsyed. He has a B.A. degree in speech and drama and a M.A. in mass media. Address: 4545 Forest Park Boulevard, St. Louis, Missouri 63108.

All Things Are Possible

Yvonne Duffy

My book, All Things Are Possible, was conceived in the summer of 1976, near the end of a long but stormy love relationship with a fellow writer who remarked casually one night as he was going out to see another woman, “You think and talk so much about your sexuality as a disabled woman you ought to write about it.”

Intrigued by the idea, I found myself a few days later at the University of Michigan’s Graduate Library checking the card catalog to see what had been written on the sexuality of disabled women. Beyond a few articles in various professional journals dealing primarily with the child-bearing abilities of women with spinal cord injuries, there was virtually nothing. So, there was, in fact, a need for such a book.

I decided to use my skills as a fiction writer to give an impressionistic sketch of what a group of orthopedically disabled women were thinking and experiencing at a given space in time.

To find the women, I wrote letters to the editors of all the periodicals I could find that might be read by the Differently Ableled, informing them of my intentions and requesting volunteers. I received letters from ninety women, seventy-five of whom answered the first questionnaire. Thirty-nine of these also responded to the additional verbal questionnaire. To give a more complete picture of lesbianism, two respondents were added later, resulting from the distribution of twenty-two revised questionnaires at the first Disabled Lesbian Conference held in August, 1981.

Two groups are underrepresented: black women and those confined to institutions. From the several inquiries addressed to nursing homes, I received only one reply, scrawled on the bottom of my letter, stating that that institution’s patients were “not interested in sex.”

In today’s society, there are many obstacles to be overcome in order for men and women to be able to relate freely and openly with each other. “I think men and women have been raised to behave in ways that cause each other pain,” says one respondent. “Men and women have been trained to act very differently, and when we’re together it’s really hard to be real people.”

I think there’s a growing awareness that we are all just people attempting to grow and love in what often seems to be an alien world, and this acceptance can only be good for those of us who are Differently Abled. Meanwhile, the current transition of changing roles is a difficult period for male-female relationships.

Of course, being a Differently Abled woman can add other complications to the already complex process of forming love relationships. It is clear that Differently Abled women do not have the same social opportunities in high school as do their able-bodied peers. Our first dates occurred on the average of almost four years later than theirs, and fewer of these dates were with friends from school.

A partial reason for this can be attributed to the fact that of the sixteen women who indicated “other” sources of their first dates, seven had home teaching and four had attended special education facilities for at least part of their education. It is extremely important, therefore, for Differently Abled adolescents, as well as we, older women, to extend our social circles as wide as possible. For teenagers, this may mean joining Girl Scouts, church groups, community activities, arts and crafts classes at the YMCA, or special interest groups, such as recycling projects.

Involvement in political activity is also a great way to meet new friends. Besides already sharing an enthusiasm for your particular candidate or issue, working together on a common project makes it easier to break the ice and start conversations. There are always lots of telephoning, addressing envelopes, writing speeches, leafleting, etc., that we can do as well as anyone. A side benefit not to be overlooked is that one usually meets the candidates and may have opportunities to influence them on issues and legislation of importance to all Differently Abled persons. One must also be able to face disappointments, however, because for every victory there’s a wake on the other side of town or the state. Since my first political experience of backing George McGovern, I’ve helped make my doctor a Michigan senator and worked on lots of local campaigns.

The point of all this is that the more we’re in circulation, the more men we will meet, some of whom are likely to be mature individuals who can appreciate the valuable things
we wish to share. Even if we don't meet the man of our dreams right away, we will, undoubtedly, develop lots of good friends with whom to spend spare time, of which there won't be so much left anyway. For sure, it may be tougher for Differently Abled women to initiate and maintain relationships, but it can be done.

My book, *All Things Are Possible*, covers a wide variety of experiences with many aspects of sexuality by women with orthopedic disabilities. It may be ordered from A.J. Garvin and Assoc., P.O. Box 7525, Ann Arbor, Michigan 48107 for $8.95 plus $1.15 postage/handling.

Yvonne Duffy has been “Differently Abled” (polio quad) since she was two years old. She has a B.A. in English literature from the U. of Michigan. She is a writer, researcher, counselor, lobbyist and public speaker. She lives alone with her cat, Mignon. Student attendants come several times a day to help with meals, transferring, etc. Address: 720 E. Ann Street, Ann Arbor, Michigan 48104.

Female Sexuality

Following Spinal Cord Injury

by Lee H. Bryant, R.N.

There is a wealth of information in the book, *Female Sexuality Following Spinal Cord Injury*, concerning the effects of spinal cord injury on the body, mind and spirit. It was reassuring to read the ideas and opinions of other disabled women, to feel that I was not alone in being ignorant and confused as I went through the rehabilitative process. This book tries to provide answers that most medical professionals seem not to know or will not provide. The author of the book is Elle Friedman Becker. It costs $10.95 from Accent Special Publications, P.O. Box 700, Bloomington, Illinois 61701.

I was asked to review this book about nine months after my spinal cord injury, and now I’m ready to try, a year later. The first chapters discussing physical changes due to spinal cord injury went very fast. Those informative chapters were answers to several questions and gave insight into my new physical self. Working into the third chapter was slower because I identified with what was written. Someone had noticed the silent problems within the rehabilitation programs — the blank wall of sexuality — a wall that patients beat their brains against and get next to no help in overcoming.

The fourth chapter of interviews with 15 spinal cord injured women by another spinal cord injured woman was page-a-day reading. The frank discussions of their sexuality and sex lives had enormous depth and great impact. I didn’t feel alone anymore. I wasn’t the only woman who felt ignored by the textbooks, disliked by the professionals and misunderstood by family and friends. Some of the interview material was repetitious, but that might help those working with disabled women understand them. Reading those interviews I saw myself and other women I had met — I cried and laughed and felt good about myself again.

Although the focus of this book is spinal cord injured women, it talks about all mobility impaired women when it examines our sexuality. It is hard to feel feminine in a wheelchair or in leg braces with crutches; and yes, Doctor, there is more to sexuality than being able to get pregnant.

Lee H. Bryant, R.N. (C5-6 incomplete). She and her husband, Tom, are studying engineering at the University of Missouri. Address: 1101 McCutchen, #3-105, Rolla, Missouri 65401.
“Our society would be very grateful if anyone would send us copies of books on rehabilitation.” Nana Opoku Ayegemang, Secretary, Society of Friends of Mentally Retarded Children, P.O. Box 1124, Humasi, Ghana, West Africa. Reference #SFMC/3/79.

“Having just been confirmed with M.S., I am interested to know what you do in the States in order to see what can be done ‘Down Under.’” Mrs. Anne Loubine, Royal Geelong Yacht Club, P.O. Box 156, Geelong 3220, Victoria, Australia.

“Some interested members of our community have set up an association to help the isolated disabled persons in our area toward leading more normal lives as our area is far removed from our capital city and there are very few opportunities … We are also trying to establish a co-operative workshop … I feel it would be a great help if we can obtain literature from other countries showing the things being done there.” Mrs. Glenda Eichells, 112 Membury St., ROMA, Queensland, Australia 4455.

“I was one of the founders of a disabled/able-bodied people group. We started publishing a monthly newspaper. It has articles for and about disabled. It’s not the Rehabilitation Gazette, but the spirit of it is the same.” Martha Do Nascimento Paro, Rua Joao Ramalho, 195 Apt. 102, Perdizes — 05008 — Sao Paulo, S.P., Brazil.

“I am working as Research Officer in National Institute of the Orthopaedically Handicapped … Last year we arranged ‘Gateway to India Project’ where, probably for the first time in India, leprosy victims sat together to discuss their problems. It is felt that disabled people should be integrated … In last June we have formed National Association of the Orthopaedically Handicapped. I am the Chairperson and Chief Coordinator.” Dr. Pradip K. Mallick, c/o N.I.O.H., B.T. Road, (Bon Hoogly), Calcutta, India 700090.

“I’ve been having a lot of cervical spine trouble and, indeed, the orthopaedic consultant confirmed bad disc degeneration and maybe arthritis as well. Prescribed gentle neck exercises and infra-red heat treatment to ease pain and discomfort … Hope your polio conference has some information for all of us old polios … Had a great time at Dublin Theatre Festival and managed to see 14 productions in three weeks … My night classes on ‘The Philosophy of Art’ have me thoroughly confused. I’m beginning to ask, ‘Do I exist? If not, who’s writing this letter? Regards and love from (I think) Ethna O’Dowd,” Ward 7, Cherry Orchard Hospital, Ballyfermot, Dublin 10, Ireland.

“We would like to call your attention to a new independent journal, Rehabilitation Outlook, which has begun publication in Israel. It is the first of its kind here and is aimed at 350,000 Israel’s disabled population, as well as the many thousands of professional and paramedical personnel involved in rehabilitation services.” Dr. Alan Kirshenbaum, Editor-in-Chief, Technion-Israel Institute of Technology, Faculty of Industrial Engineering and Management, Technion City, Haifa 32000, Israel.

“Since I returned to Japan, I have been trying to write articles about my personal experiences in the United States and Europe … I am deeply interested in doing research on the sociological and psychological aspects of educating hearing impaired children (and also disabled persons as a whole) in their own classes or schools … I would appreciate very much any help with this subject … A community college for the deaf will be established on the campus of Tsukuba University in the spring of 1983 with approximately 200 deaf students and 80 staff. I was asked to join the staff.” Tetsuji Tomikawa, c/o Mr. Kuniko Tomikawa, 2-1-12 Tsukushi-za, Yotsukaido-cho, Inba-gun, Chiba-ken, Japan 284.

“While I was going through your interesting Gazette, I found a very important title, Housing and Home Services for the Disabled by Gini Laurie, published by Harper & Row. I’d like very much to satisfy my curiosity and quench my thirst for knowledge by reading it. Please send me two copies.” Mohammed Alsatan, Regional Center for Mobility Interfor the Handicapped, P.O.B. 44062, State of Kuwait. (The second printing is available for $26 from Harper & Row, Medical Department, 2350 Virginia Avenue, Hagerstown, Maryland 21740. 800-638-3030)

“I am back in the missions and also working with the Christian Fraternity of the Sick and Handicapped (Fraternidad Cristiana de Enfermos) here in Mexico … In October I attended an ‘Encuentro Nacional’ in Torreón and Father Salvador Ribera, a Carmelite (and a quadriplegic), was presiding at all the sessions. He is the National Assessor for the Fraternity in Mexico … Some 35 disabled people from all over Mexico attended.” Bro. James Mc—
How to Get On an Elephant
Ála Wokoun, Ph.D.

Although I am “only” a paraplegic, walking one yard behind high crutches, I meet some barriers, which flavour my passion for traveling. Readers of the 1986 issue know how I nearly throttled an Egyptian camel when I fell headlong from his high hump.

I had not taken a lesson from that landing into golden sands of the Sahara and wanted to ride on an elephant during my travel to India some years later. I presupposed that the broad elephant’s back is more hospitable than the miniature saddle of a dromedary.

Nevertheless, I had feared another problem, before I saw the elephants for tourists in Amber. How shall I get on the high back of an elephant? I cannot climb the hill of meat up like a mountainer. The elephant cannot lift me up by his trunk, because I am not by far so slim like a princess or a slender she-tamer. I also cannot climb a ladder to the elephant’s back. To my sorrow I had seen such ladder at the side of a carved ivory elephant with the Emperor Shahjehan. My crutches unfortunately have no reactive rockets to push me upwards. How shall I conquer the back of an elephant?

My fear was groundless. At the elephants’ station in Amber there was a solid ramp like a railway ramp or port pier, to which the elephants for tourists were drawn near like a freight car or a ship. From that platform I sat down on a bench, which covers the elephant’s back, so simply as I sit down on my couch at home. Amber’s barrier for disabled persons was not the elephant’s height, but some stairs to that platform. Fortunately from some time I know how to surmount stairs by mounting them backwards.

My landing to any chair does not suggest a landing of a small feather. If I sit down anywhere, I rather imitate a hard landing of a parachuter. But the elephants of Amber evidently were the most still elephants in the world and stood like the large stone elephants at Ellora without movement. When I had landed on the elephant’s couch, his mahout attached me to it by a thick wire, so that I could not fall even if I wanted. My ride on the elephant was fascinating but no heroism or heartrending adventure for immodest readers.

Ála Wokoun, an artist, uses crutches because of polio. His address: Odesitadel Chabatovická 1333 182 00 Prague 8, Czechoslovakia.

Caffrey, S.M., Apartado 58, Aposao el Grande, Guanajuato, Mexico.

“I am 40 years old, married with children. I was involved in a hit-and-run motor vehicle accident, and as a result I am now a quad with a C5-6 injury. I have been doing nothing since my accident in February 1973. This is because we do not have any rehabilitation centres in this country, and we are not provided with jobs, as they are hard to come by.”


“In 1927, an association for disabled persons was established in Holland. The name of the association is AVO-Nederland (Actio Vincit Omnia = Labour overcomes everything).

1981/VOLUME 24
"AVO-Nederland would like to hear from disabled persons who plan to travel to the Netherlands and to know what they want to see and do here. We will try to help."
C.F.J. Vuister, Managing Director, AVO-Nederland, P.O. Box 850, 3800 AW Amersfoort, Netherlands.

"As a disabled visitor from Norway — on my way 'Around the World' with my wheelchair — I have been much impressed by the informative writings published in the Rehabilitation Gazette and appreciate making its/your acquaintance," Ms. Solheig Fowler, Kongelenen 10A, N-4620, Vagsbygd, Norway.

"Hello, I'm looking for friends. I'm a survivor of the 1953 polio outbreak in northern Ohio. My interests are many — reading, movies, football, sewing, going for drives, crocheting and my job. Hope to hear from lots of you people out there." Sandra (Sandy) Brunn, 10 Madison Street, Norwalk, Ohio 44857.

"I am a registered nurse and writer, currently disabled by myasthenia gravis. I would like to develop a guide for health professionals describing how they can better help patients deal with the psychological impact of chronic, disabling and/or recurring diseases. If you are coping with such a condition, I would appreciate communicating with you about your experiences and feelings. How have physical illness and/or disability affected you emotionally? What factors facilitated your psychological adjustment? What stages did you go through since the onset of your condition? What role did doctors or nurses play in making things more easy (or difficult) for you? What have you always wanted to tell your health care workers, but never had the chance (or guts) to say? Please write me. (Of course I will give you due credit in my final work.)" Rochelle Kess, R.N., 154 West 70 Street, Apt 4H, New York, NY 10023.

"I would like your readers to know that I am available to help in the designing and fabrication of devices which their particular disability demands but which might not be commercially available." Steven Kanor, Ph.D., 101 Lefurgy Avenue, Hastings-on-Hudson, New York 10706. Dr. Kanor, a medical engineer, is a consultant to United Cerebral Palsy of Westchester.

"I've had an experience with our post office that proves the people there do try to get the mail delivered even if it means solving puzzles.

"The puzzle began with an article I had written for Wider Horizons, an English magazine for disabled persons. In the article, I gave detailed, nostalgic directions for finding the old Davis family home in Jackson, Ohio. An English reader of the magazine pounced on the article as a way to find someone in Ohio who might be able to find out why her sister in Mansfield, Ohio, had stopped writing.

"She addressed the front of the envelope with the incomplete address in the article, 'Mrs. Ruth Davis, Parma, Ohio, U.S.A.' and on the back, she wrote a note to the Parma Post Office with clues to find the Davis home. The clues, of course, were the directions to the old Davis home in Jackson: 'Take road from town leading south, cross railroad tracks, turn left at cornfield ... Pass old schoolhouse ... Turn right at the fork, over the creek and up the hill.'

"The branch manager, a letter carrier, and a Parma resident joined in the sleuthing. They studied maps and they followed the Jackson directions. By a strange coincidence, the wrong clues led them to our former home right here in Parma. From there, a former neighbor directed them to our house. I tracked down the sister in Mansfield and let the lady in England know that her sister was recovering from a stroke." Ruth Davis, 9316 Snow Road, Parma, Ohio 44130.

Post office super sleuths Jim Comodeco, branch manager, and Joan Lear, letter carrier, deliver THE letter to Ruth Davis (right). Photo: Cleveland Press.

Frank Engel, the Gazette's postman, shares our enjoyment of your letters and postcards from around the world.
International Conference on Respiratory Rehabilitation and Post-Polio Aging Problems

Cosponsored by Rehabilitation Gazette and Rehabilitation Institute of Chicago

Wednesday, October 14, 1981

SESSION 1 — The Past: The Experiences of the Polio Epidemic
Henry B. Betts, M.D., Medical Director, Rehabilitation Institute of Chicago
Gini Laurie, Editor/Publisher, Rehabilitation Gazette, St. Louis, Missouri
Alton L. Goldberg, M.D., Medical Director, Division of Respiratory Care, Children's Memorial Hospital, Chicago, Illinois
David Dickinson, M.D., Chief, Clinical Affairs, University of Michigan Hospital, Ann Arbor, Michigan
Augusta Alba, M.D., Associate Director, Goldwater Memorial Hospital, New York University Medical Center, New York, N.Y.
*Ronald H. Doreff, M.D., Dermatologist, Hobart, Indiana
*Jack K. Geraske, Ph.D., Sargent State University, Springfield, Illinois
*André Dessertine, Foyer d’AEP, Evry, France
*Audrey J. Ring, M.A., Ontario Crippled Children's Centre, Toronto, Ontario, Canada
*Adolf Ratzka, Ph.D. candidate, Stockholm, Sweden
*Rev. Patrick Lewis, C.S.Sp., M.S.W., Coordinator of Services to the Handicapped, Archdiocese of San Francisco, California

SESSION II — The Present: A Crisis? The Need to Develop Cost-Effective and Personalized Services for Polio Survivors
Ernest Johnson, M.D., Chairman, Department of Physical Medicine, The Ohio State University Hospitals, Columbus, Ohio
*Alice Nolan, R.N., Goldwater Memorial Hospital
Ann A. Bailey, M.D., Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia
*Margaret Pfleumer, Research Associate, Northwestern University Rehabilitation Engineering Program, Chicago, Illinois
*August W. Christman, Executive Director, Illinois Council, Congress of Organizations of the Physically Handicapped, Chicago, Illinois
James Campbell, President, Lifecare Services, Inc., Boulder, Colorado
Joseph Kauffman, Ph.D., Associate Professor, Department of Social and Preventive Medicine, University of Manitoba Faculty of Medicine, Winnipeg, Manitoba, Canada
*Russ Besson, Lifecare Services, Inc., Pacific, California

Thursday, October 15, 1981

SESSION III — The Present: Technological Issues Are Past Techniques and Practices Developed During the Polio Crisis Applicable to Meet Present Needs?
John O'Connor, Vice President and General Counsel, National Foundation March of Dimes, White Plains, New York
Augusta Alba, M.D.
Ernest Johnson, M.D.
*Theodore Dukes, Dynast, Inc., Research and Consulting, Princeton, New Jersey

*Herbert S. Morrill, Down East Electronics Mfg. Co., Falmouth, Maine
*Carleton Bishop, Lifecare Services, Inc., Augusta, Georgia
*Robert B. McCown, Ph.D., Staff Scientist and Engineer, Inter-magnetics General Corporation, New York
*Eugene F. Murphy, Ph.D., Rehabilitation Engineering Research and Development Service, Veterans Administration, New York, N.Y.

SESSION IV — The Present: The Regional Approach to Meeting Needs of Polio Survivors Outside of the Medical Center
Augusta Alba, M.D.
*Judy Heumann, Deputy Director, Center for Independent Living, Inc., Berkeley, California
*Val Brew Parish, Associate Director, Career Planning and Placement Center, Southern Illinois University, Carbondale, Illinois
*André Dessertine

Friday, October 16, 1981

SESSION V — Premature Aging Problems of Polio Survivors
Allen I. Goldberg, M.D.
Frederick M. Maynard, M.D., Assistant Professor, Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, Michigan
*Ann A. Bailey, M.D.
Mary Jay Bullock, O.T.R., Rehabilitation Medicine Department, The Johns Hopkins Hospital, Baltimore, Maryland
Augusta Alba, M.D.
*Harriet Bell, Patient Advocate, Goldwater Memorial Hospital
D. Amlin Fischer, M.D., Chief, Pulmonary Service, Rancho Los Amigos Hospital, Downey, California

SESSION VI — The Future — Can Modern Organizational Approaches Today Meet the Challenge of Complex Problems of Tomorrow?
Henry B. Betts, M.D.
*Linda Bienick, Staff Assistant, Continental Bank, Chicago, Illinois
*André Dessertine
Matthew Lee, M.D., Goldwater Memorial Hospital
*Judy Heumann

C. Everett Koop, M.D., Surgeon General, Deputy Assistant Secretary of Health, United States Department of Health and Human Services

*Disabled
THE CATALYSTS. In recent years, an increasing number of you, polio survivors of the '50s, weaned from respiratory aid and "on your own" for twenty-plus years, have found yourselves becoming increasingly tired and irritable. If you were lucky you had an experienced physician from the old days or found one through referral from another survivor, LifeCare or the Gazette. With such help, you changed your lifestyle to ease tensions or learned "frog breathing" or started to use a respirator at night and you found renewed energy and zest.

Many more of you, who have never had respiratory involvement, found yourselves with increasing weaknesses, often in the "good" limb that had served you so well for so many years. Each one of you seemed an isolated incident, until you read Larry Schneider's article, "Those Passing Years," in the '79 Gazette. It triggered many of you to write to the Gazette in agreement with Schneider's suggestion that the Gazette, "which seems to be the last polio link," should act as a national directory of "Simpatico" and experienced doctors.

Schneider's article served as a catalyst for NBC's "Prime Time Saturday" program of July 1980 on premature aging of post-polio people. The program caused a deluge of letters to the doctors at the hospitals mentioned on the program — Roosevelt-Warm Springs Rehabilitation Center, The Institute for Rehabilitation Research, and Rancho Los Amigos Hospital — requesting more information.

To lead this search for information, the Gazette started gathering material for a special feature on post-polio aging. The doctors on the TV program and disabled individuals were asked to write articles. Alice Mailhot (polio quad) offered to work with her doctor, Frederick M. Maynard, M.D., University of Michigan, on an article, "Age and the Old Polio." Concurrently, Theda Carle (respiratory polio quad) was working on a similar article at the University of Washington with her doctor and a therapist.

Meanwhile, an anesthesiologist's meeting in October 1980, brought Dr. Allen Goldberg and his wife, Dr. Evi Faure, to St. Louis and a visit with the Lauries. As a pediatrician and an anesthesiologist, respectively, they were concerned about the number of children who were being kept on respirators in intensive care units instead of being sent home. Dr. Goldberg had arranged for a few children to go home with respirators when he had worked under Dr. C. Everett Koop, Surgeon in Chief at Children's Hospital in Philadelphia.

As Gini described her years of experience with polio survivors on respirators living productive lives at home there began the flicker of an idea for an international conference of Gazette readers, both survivors and physicians. The conference would be an exchange of information to study the problem of post-polio aging and a means of helping people of all ages and types of disabilities to live at home with respirators.

Spurred on by the enthusiasm of Dr. David Dickinson, former Director of the Ann Arbor Regional Respiratory Center, and Dr. Maynard, the Lauries began to seriously plan the conference.

THE PLANNING. Chicago was decided upon as the site of the conference since Dr. Goldberg was treating hospitalized children on respirators there, working toward a home care system, and he interested Dr. Henry B. Betts, Medical Director of the Rehabilitation Institute of Chicago, in co-sponsoring the conference with the Gazette. A start-up planning committee was formed (Dr. Faure, Dr. Goldberg, Gini and Joe Laude, Don A. Olson, Ph.D., and Margaret Pfommer) and many trips to Chicago resolved the details and the problems. Dr. Goldberg and Margaret Pfommer concentrated on the program and the Lauries worked on gathering the speakers and participants.

A Blueprint of Care
For All Who
By Judy Raymond
concerned medical, professional and voluntary organizations made very welcome and vital donations.

THE HOTEL. Marcia Bristo, Access Living of Metropolitan Chicago, suggested the American-Congress Hotel as suitably accessible. The hotel management was more than accommodating, making adjustments and adaptations wherever necessary. With cheer and precision, Bruce Pendleton made countless trips to and from the airports in a lift-equipped van. With skill and efficiency, Dr. Olson's staff coordinated registration and the hotel and transportation arrangements.

All the gaps were filled by the enthusiastic work of Dr. Goldberg's volunteers from the Chicago area and the Gazette's volunteers who came from Ohio, Missouri, Arizona, and California to help.

The problem of respiratory equipment — unique to this conference — was solved with great efficiency and assurance by LifeCare Services, Inc. Jim Campbell, President, and his representatives not only made arrangements to have iron lungs, rocking beds, and respirator motors in place in the respective rooms but also maintained a 24-hour equipment repair and replacement pool in the hotel.

THE PARTICIPANTS. When the proceedings are published you will be able to read what was said at the sessions, but you should also know what a vital part you had, not only in making the conference happen, but in making it a happening of great significance. This significance is enthusiastically expressed in letters from your conference and the medical people who attended. They tell of the warmth and love that permeated the days and nights of the conference, during and between sessions, and that still continue to pervade memories and lives.

"I felt," says Jenny Reitzinger (polio quad) of California, "I met 200 strangers and went away with 200 friends."

"It is unique," says Otto Bong of Germany, "how these polio people fit together at the conference, like a family ... It is unbelievable what a deep relationship I have to the people at the conference when I have only seen them for three or four days."

"I'll never be the same," says Susan Armbricht (respiratory polio quad) of Ohio, as she left. "This conference will change my whole life. Now I know that if I can follow Dr. Alba's advice and get used to oral positive pressure, I'll be free to go where I want to go." She echoed the thoughts of many who attended. Although she and many others there were disabled by polio and require a respirator at night, their experiences of increasing potential are relevant to all people with disabilities.

Conference participants included experts from the medical community — doctors, nurses, occupational and physical therapists; equipment specialists; insurance people; and individuals with disabilities actively involved in issues related to independent living in their own communities. Registrants tallied 160 on Wednesday and Thursday and about 200 on Friday. A total of about 70 registrants were in wheelchairs and 30 of them use respirators, full or part-time.
Both the medical experts and the polio survivors participated as peers throughout the sessions. The intense commitment by all who were working together to identify the problems and develop the solutions demonstrated the tremendous growth possibilities of strong disabled advocacy. "All participants," says Dr. Jack Genskow (respiratory polio quad), "became both experts and listeners — individuals who shared and listened. There was a definite sense of community."

THE IMPACT: "I had many questions answered and found I am not alone in my fears." Similar thoughts were echoed by many participants and the sharing of experiences became the real lagniappe of the conference. Informal sessions continued day and night during and after meals and in rap sessions with Drs. Alba, Goldberg, Maynard and Spencer.

The Gazette's Suite 700 was the place to gather from Monday noon to Sunday morning where "old" Gazette friends, who had "met" on the pages of the Gazette, actually encountered each other and cemented friendships.

"We are all amazed," says Dr. Ron Doneff (respiratory polio quad), "by what all the rest of us had accomplished in our 25 years with polio ... We can show that a fellow who is put back to work contributes a lot more than he would drain out if he were left in his bed disabled."

"The entire three-day experience," says Dr. Maynard, "was truly inspiring, most notably for the opportunity to experience firsthand the constant celebration of the human spirit in the face of adversity. It is difficult for me to express my feelings about what it is like to be with a group of more than two dozen ventilatory-dependent people all at one time in a large room."

"I believe," he says, "the most powerful message generated by the conference is that the human spirit is not only capable of surviving but can truly flourish and grow to tremendous power in spite of severe restrictions to the physical human body. I believe it is very important for health care professionals, and perhaps especially physicians, dealing with chronic disease and disability, to know this truth by directly experiencing it."

"What was especially gratifying," says Shari Dukes
(polio quad) of New Jersey, "was that the organizers and the physicians as well, so naturally mingled with us, leveled with us. It means a lot to have physicians talk to you about your problems in such an informal atmosphere, without holding back. It truly was a barrier-free environment in more than one sense of the word."

"I have been so excited," says Audrey King (respiratory polio quad) of Toronto, "since returning from Chicago. There is so much that needs to be done with the 'forgotten population' in Ontario . . . hope to improve respiratory home support service and to put on a conference next year . . . I'm keeping in touch with the other Canadian participants, Dr. Neal Brown and Joe Kaufert and I've borrowed equipment so I can learn to get used to positive pressure."

"The air was crackling with energy," says Jynny Retzinger (polio quad) of California. "Friendliness, helpfulness and humor flourished and it was organized and disciplined."

"I have never been with a more dynamic group," says Jay Bullock, physical therapist. "To meet doctors from the U.S. Centers who can deal with the problems of polio made me realize that we need a definitive list and some way to share their information. But the people at the conference who had lived with the effects of polio for many years outshone even this illustrious group of professionals."

"In the past," she says, "they led the way in proving that, when given adequate help, they could take charge of their own lives. They have made independent living work. Again, they have come forward to demand that the medical profession be responsive to their changing needs . . . they need to find those in the medical profession prepared to deal knowledgeably with their medical and emotional needs. I believe they have the right to expect this."

"This conference may prove," says Dr. Goldberg, "to be a turning point for many involved people, policies and programs. From the conception — a dream of Gini's — it demonstrated that when people work together, by a process of mutual respect and sharing, anything worthwhile can be accomplished. A spirit of being together, needing each other, led to a cooperation which overcame every barrier: funding, accommodations, transportation, required services, etc. . . . The most important thing I learned is that polio survivors are leaders. They must organize and take action to help themselves and others with disability."

PROFESSIONAL UNAWARENESS. Both disabled individuals and medical experts agreed that the medical profession no longer understands the needs of the person disabled by polio. Many participants shared the fact that they had been labelled "hypochondriac" or "neurotic" by their physicians.

Photographs by Otto Bong, Alice Burkhardt, Evi Faure, Kent Gilbert, Gayla Hoffman, Joe Laurie, Rehabilitation Institute of Chicago.
NETWORKS. There was constant emphasis on the need for gathering and supplying reliable information to both disabled persons and the medical community. "The long term results," says Dr. Eugene Murphy, "should be beneficial not only to post-polios, but to many other groups with other disabilities."

"Society tends to equate ability," says Marilyn Saviola (respiratory polio quad), "with physical ability and maneuverability. If one is less physically able, does one become less human? . . . We have many networks, informal networks throughout the country. We have the spinal cord injury centers, we have the Rehabilitation Gazette, we have the centers for independent living. We have our own informal networks. We have to somehow or another develop a networking system that, when someone is in trouble or in doubt or in fear, they can plug into these systems from many different levels . . . nationally, regionally, and locally. We have to come up with a method of addressing this, otherwise, at the next conference, there will be a significantly lower number of us present."

PUBLICATION NETWORK. Publications and organizations of disabled persons are a very important link in a self-help network. The following editors, who attended the conference and who represent most of the leading U.S. publications of the disabled, are valuable resource people. (Their

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Rehabilitation Gazette Polio/Respirator Resources

Until a structured network of information is created, those listed below will be helpful or be able to suggest someone nearer to you who can help with polio-related or respirator problems. Further, if each of you will share your own experiences and your experiences with doctors and hospitals that understand polio survivors and respirator-users, the Gazette will organize them and continue to coordinate a people-to-people, do-it-yourself network. Call 314-361-0475 or write to 4502 Maryland Avenue, St. Louis, Missouri 63103.

GREAT BRITAIN: Geoffrey T. Spencer, FFARCS, Consultant, St. Thomas' Hospital, Phipps Respiratory Unit, South Western Hospital, London, S.W.9, 9NU England. Dr. Spencer has created and directs a hospital unit and a comprehensive home care system with systems of medical management and equipment maintenance for 280 persons of all disabilities who are dependent on respirators. He has vast experience and concern to help respirator users living or travelling in western Europe.

CANADA: Audrey J. King, Ontario Crippled Children's Centre, 350 Runnymede Road, Toronto, Ontario M4G 1A8, Joseph Kaufert, Ph.D., Department of Social and Preventive Medicine, U of Manitoba Faculty of Medicine, 750 Bannatyne, Winnipeg, Manitoba R3M 0T5, Gary McPherson, 1017 6th Street, Aberhart Hospital, 11402 University Avenue, Edmonton, Alberta T6G 2J3.

U.S.A. If your problem is respiratory, start with the nearest Lifestyles representative who will have had extensive experiences with polio survivors, doctors and hospitals in your area.

EAST: Augusta Alba, M.D., Associate Director, Goldwater Memorial Hospital, New York University Center, Franklin D. Roosevelt Island, New York, NY 10044. Dr. Alba has arranged a special one-day evaluation program for polio survivors (212-750-6777. Call between 3:5 to 6:00 pm.). Lifestyles: 165 Beale Street, Quincy, Massachusetts 02269 (617-472-0700) and 62-26 Myrtle Avenue, Glendale, New York 11385 (718-381-7018). Theodor and Shari Dukes, 315 Ewing St., Princeton, New Jersey 08540 (609-924-4512).

MID-ATLANTIC: Mary Jay Bullock, Rehabilitation Medicine Department, Osel I, The Johns Hopkins Hospital, 600 North Wolfe Street, Baltimore, Maryland 21205. Lifecare: 607 Beaver Court, Joppa, Maryland 21085. (301-679-0409)


MIDWEST: Lifecare: 2 W. Wilson Street, Batavia, Illinois 60510 (312-879-1822), 32486 Center Ridge Road, North Ridgeville, Ohio 44039 (216-337-2161), 2713 Grand River, Redford, Michigan 48240 (313-338-0104), 775 Leonard Street NE, Grand Rapids, Michigan 49503 (616-456-5003), 621 Martha Street, Omaha, Nebraska 68105 (402-334-4328), Allen I. Goldberg, M.D., Medical Director, Division of Respiratory Care, The Children's Memorial Hospital, 2300 Children's Plaza, Chicago, Illinois 60614. Frederick M. Maynard, M.D., Physical Medicine and Rehabilitation, University of Michigan, E312 University Hospital, Box 43, Ann Arbor, Michigan 48109. Terry L. Lies, 1140 Hilcrest Road, South Bend, Indiana 46617.


care services, employment, etc., of Goldwater's polio survivors.

Dr. Bailey's survey of about 400 former Warm Springs polio people is still under way.

Joe Kaufert, Ph.D., an epidemiologist, reported on a 1980 study of 186 respiratory polio survivors in Manitoba, ranging in age from their early 30's to late 70's.

The comments and explanations of the impact of aging at the conference led him to re-examine the information collected in the study and suggested new areas to be explored.

A re-examination showed that the majority of the 186 had stated they maintained a stable functional level. The minority, who reported worsening conditions, were of no particular age group. "The impact," he says, "of the aging process on respiratory function requires much further research."

EQUIPMENT: John O'Connor, vice president and general counsel of the National Foundation March of Dimes, "We still serve the respirator equipment needs of approximately 700 post-polio patients around the country from our Georgia pool and Lifecare services." There was strong feeling that the March of Dimes should do more than provide equipment and should become actively involved in meeting the present "creative crisis" needs of polio survivors. "We can't let the March of Dimes forget us," says Judy Heumann, "since they are there because of us."

addresses are listed in the Periodical List at the end of this issue.) Accent on Living, Ray Cheever; Achievement, Connie Lamps; COPH Bulletin, Rose A. Wilson; Disabled USA (President's Committee on Employment of the Handicapped), Robert Gorski; NAPH National Newsletter (National Association of the Physically Handicapped), Sister Mary Matilda Handle, R.S.M.; National Hookup (Indoor Sports Club), Georgean Davis; Paraplegia Life (National Spinal Cord Injury Foundation), Ann Ford; Rehabilitation Gazette, Gini and Joe Laurie.

PROCEEDINGS: The Rehabilitation Institute of Chicago will be publishing the proceedings. Neither the date nor the price is known yet. So, if you wish to be advised when they are ready to order, send your name and address to the Gazette, which has a list of people to be notified, or to Don A. Olson, Ph.D., Director, Education and Training, Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, Illinois 60611.

SURVEYS: "What wonderful work has been started," says Harriet Bell. "I know it will not lose momentum." Harriet and Chick Weiner are continuing to circulate the questionnaire which was printed in the 1980 Gazette. (If you have not filled one out, write to Harriet Bell, Patient Advocate, Goldwater Memorial Hospital, Franklin D. Roosevelt Island, New York, NY 10044 or Chick Weiner, 277 West End Avenue, New York, NY 10023.)

Alice Nolan, R.N., is working on a study of the home

1981/VOLUME 24
Front: L-R: Gill Whitworth, England; Dr. Alba; Adolf Raiska, Sweden; Stewart Anderson, Scotland; Susan Ambrecht, Ohio; Marion Greene. Back: L-R: Dr. D. Armin Fischer, California; Judy Raymond, Ohio; and Mickie Martin, Missouri, in the Gazette’s Suite 700.

Jill Smith, Access Living, Chicago, and Isabel Doneff, Indiana.

Joe Laurie, Gazette Editor, and Don Piron, U of Syracuse, N.Y.

Mickie Martin and Judy Raymond, Gazette volunteers, baked 1000 cookies. “Loaves and fishes” meals were created in the Suite 700 kitchen.
Rehabilitation Gazette's Brown Bag dinner: Gini Laurie; Kent Gilbert, California; Robert Gorski, Editor, Disabled USA.

Dr. Rothenberg and Evi Faure, M.D., Illinois.

Jan Service and Susan Ambrecht.

André Dessertine, Eury, France, and his brother-in-law, Joachim Rothenberg, M.D., Lyon, France.
Herb Merrill (respiratory polio quad), engineer, "Life-care is trying to repair the old equipment and keep it going because Drinkers, Emerson, Monaghan... have all stopped making respiratory equipment."

Bob McCown, Ph.D. (polio quad), physicist, "We need wheelchairs, lifts, etc. that can be repaired anywhere, that are going to continue running for years and are easily maintained in any environment... made of standard parts... utilizing as many parts built for the ordinary consumer market as possible."

Theodor Dukes (polio para), instrumentation control consultant, "The most important aspect of technology is to provide for the replacement of lost functions... with the underlying assumption that everyone wants to be and should be as independent as possible."

ADAPTING LIFESTYLES. Making value judgments and adapting lifestyles to osteoarthritis, tendinitis, bursitis and the other limitations that accompany aging are of vital importance.

"If something changes your level of function," says Jay Bullock, physical therapist, "some depression is perfectly in order and normal... You came through the first time, you can come through it a second."

"Know yourself," she says, "be assertive with your doctors and therapists. Tell them exactly how you usually do your activities and negotiate around your own condition... Learn to do your own pacing."

AGING PHENOMENA. The conference sought to identify the extent of the problem as well to develop potential solutions. Much useful information was shared about the management of restrictive respiratory insufficiencies, especially from an equipment and home maintenance perspective. Current research and treatment approaches to post-polio loss of strength and endurance provided reassurance and information.

Dr. Maynard discussed research efforts currently under way to define the aging phenomena, noting that all body functions normally decline with age, and that changes in all nerve cells normally occur. The changes seen in the muscle fibers of a disabled person complaining of loss of strength and decrease in endurance are the result of aging superimposed on previous residual nerve cell damage from polio.

"We need to investigate," says Dr. Maynard, "what can be done for the loss of anterior horn cells with normal people in aging, and I think the post-polio people are an excellent group in which to study this phenomenon because you have become a laboratory group of people who are, perhaps, aging more quickly in their forties or fifties or sixties.

"There is tremendous variability," he says, "in the course of weakness, it is far from inevitable, and it is only very slowly progressive... Keeping in general good condition and taking time to rest may be the real answers for a lot of people that have slow progressive weakness."

Dr. Fischer emphasized that people's difficulties are compounded because many disabled persons won't return to rehabilitation centers where they could be reassessed and put on individual programs. "I believe," he says, "all parties present at the conference agree that we need data which are not yet available... Until then, there is no consensus that the syndrome is more than the effects of aging (and overuse?) in compromised muscles."

ADVOCACY. "We have to be outspoken advocates," says Judy Heumann. "This conference has begun to allow us to discuss and to articulate many issues and has also allowed many of us who have been very strong advocates to get together. The most important thing that will come out of this conference is that we maintain strong linkages among ourselves.

"As advocates," she says, "we have more to do than we had to do ten years ago because ten years ago we did not have the legislative pieces that we have fought so hard to get. Now they are being whipped away from us... It is our responsibility to go back and talk to other disabled people... parents... professionals... to get involved in the 1982 elections... to stop accepting what is going on right now."

Judy Heumann, Center for Independent Living, Berkeley, Calif.
there will be a Magna Carta which gives them the opportunities which I think they deserve."

IMMUNIZATION. "We must," says Dr. Bailey, "make the public aware of the need to prevent occurrence of new cases of polio through adequate immunization."

"... in a developing country like India," wrote Dr. A.K. Muhkerjee, who had hoped to attend the conference, "poliomyelitis is still a major cause of disability. The All India Institute of Physical Medicine and Rehabilitation is treating 2500 polio patients per year." All international travelers, leaving the country, are urged to check the status of their polio immunization.

ACTION PLAN. There was a consensus that there must be a system to assist all respirator-dependent individuals to lead productive lives in their own homes. Suggestions were made for a new nationwide voluntary organization with significant disabled representation, perhaps as a unit of an existing one, such as the March of Dimes, or as a separate entity: to manage services; to coordinate federal, state, and voluntary funding; to disseminate information; to provide consultation through a WATS line for individuals and their physicians; to furnish transportation for those who need evaluation; to utilize the existing network of equipment distributors; and to establish regional centers within existing institutions with existing staff.
Rx: Know Yourself

Practical Medical Advice for Everyone

The value of preventing problems by self-directed, healthful living was stressed by Drs. Alba, Bailey, Doneff, Fischer, Goldberg, Johnson, Maynard, Spencer and all the other physicians who participated. Following is a digest of their practical, down-to-earth recommendations and admonitions.

- Aging. "Life is a disease," says Dr. Spencer, "with a mortality of 100%. . . . We should be able to talk about getting old without feeling scary."
- Alcohol. Avoid it. It may inhibit swallowing, interfere with nutrition and cause falls. If you do drink, do not drink just before bedtime if you have any respiratory insufficiency.
- Calcium. If you are post-menopausal, you should drink about a pint of skim milk every day.
- Colds. Drink lots of fluids. Put humidity in the air. Rest. These old-fashioned remedies will do more for mucus and raising secretions than medications.
- Constipation. In addition to eating bran, use a stool softener, like Colace. Avoid laxatives.
- Diet. Keep it sensible! Supplement with one-a-day vitamins and minerals.
- Exercise. Do it in moderation, never to exhaustion or pain.
- Feet swellings. Use Jobst stockings — most support hose won't help. Be sure you do not have anything tight about your abdomen or upper thighs. If you sit up very straight and wear a brace, have elastic put on the lower part of the brace or tilt your chair.
- Frog breathing. You can learn this very valuable technique by saying the word "gup" or "gulp" way back in your throat — at the rate of 100 times a minute with a stop every 12-15 seconds. Do it about once every 2-3 hours during the day for 5 minutes.
- Hypertension. Nothing about polio would predispose you to hypertension. If you have a history of high blood pressure in your family, start on a low salt diet early in life.
- Kidney stones. They are more likely to occur in people who are flat on their backs. So, if you have to stay in bed for a while, get yourself turned from side to side regularly.
- Maintenance. Find a good knowledgeable physical therapist and/or physician. Best to go to a place with a rehabilitation-medicine focus and see a psychiatrist and a pulmonary specialist. Have an evaluation while you are feeling well so you have a baseline. Discuss hospitalization arrangements, too, while you are well so you and they won't be unprepared if there is an emergency.

- Neck arthritis. Looking up at people from sitting low in a wheelchair can lead to nerve damage and secondary weakness in the hands. Don't worry. Don't suffer. Discuss the problem with a physical therapist or a physician.
- Rest. Take time to rest. Nap during the daytime. Shorten your days. Take longer vacations.
- Respiratory aid at night. If your breathing muscles are paralyzed or distorted by scoliosis, you underventilate during sleep and your CO2 level rises. It is as if you rose to an altitude of 10,000 feet or higher each night. You waken with a headache, slowed mental concentration and short of breath. With an appropriate breathing aid at night, you will rest your breathing muscles and have much more energy.
- Sedatives. Tranquilizers. Pot. There is a very large risk in taking any of them if you have any respiratory insufficiency.
- Sex. Same as everyone else. Age need not diminish.
- Skin problems. If you have fungus under your nails, use Lotrimin.
- Sleeping. Get comfortable. If you are skinny, add 2" soft foam between your sheet and mattress. Use your bed only for sleep. Don't lie on it. If you sleep on your side, keep your arm in front, not under your chest wall which may cause numbness in your arm.
- Sleeping pills. Avoid them. No sleeping pill has an effectiveness after 2-3 months.
- Smoking. Do not smoke if you have any respiratory insufficiency. Smoking causes mucus. Ask people around you not to smoke; their smoke will affect you.
- Swallowing problems. Chew thoroughly. Think about what you are doing. Sit up straight and lean your head forward.
- Swimming. One of the most excellent forms of exercise.
- Veins. If they have trouble finding your veins, have the physical therapy department apply hot packs for about 20 minutes.
- Vaccines. If you have respiratory susceptibilities, get both the flu and pneumococcal vaccines every fall.
- Weight. Keep it down! Overweight compounds all kinds of problems. It seriously influences your capacity to breathe and involves hypertension, cardiovascular disease and diabetes. If you are in a wheelchair, you may have to take as little as 800 calories a day to avoid gaining weight.
Warnings!

Mickie McGraw

Learn to live with your limitations.
Learn about coping, about compensating.
View the post-polio problems as a natural aging process made more difficult by limited reserve.
There is nothing mysterious or magic about the problems and it should not be labelled a "syndrome."
Urge your doctors to respond to you as a whole person, and not focus solely on your disability.
Don't lose belief in your invulnerability.
Balance is essential.
Do not push yourself.
Learn what you can do and do not lose control.
It is no longer necessary for people who are disabled to prove they can do it better.

Mickie McGraw has been disabled by polio since 1953 when she was a teenager. A victim of the 1950's medical pattern, she was weaned from a respirator and sent home. She soon lost her good disposition and began to fail in school. At about this time, underventilation was discovered by the respiratory centers and she was brought back to the Toomey center, reevaluated, fitted with a chestpiece for night use and advised to learn her limitations and keep within them. Thenceforth, she graduated from art school, earned a B.F.A. and pioneered an art therapy program at Highland View Hospital. Because she "practices what she preaches," she did not push herself to the utmost to attend both an art therapy conference in Detroit and the polio conference in Chicago that almost coincided. Instead, she shared these cogent and pertinent thoughts. Mickie has been an important member of the Gazette staff since it began in 1958. She is president of its non-profit corporation.

(See cover photo, Gazette, 1975.)
A European View of the Conference

Adolf Ratzka

The most significant outcome of the conference to me was highly personal. I saw many disabled individuals older than 1 and with more severe breathing problems whom I nevertheless could accept as role models. They appeared to carry on an active and interesting life compensating their respiratory difficulties with modern, truly portable equipment. Seeing a whole ballroom full of such exceptional individuals the prospect of my becoming increasingly dependent on equipment did not seem so scary anymore. Who knows, it might even lend my image a touch of eccentricity as it does to Dr. Huff&Puff (alias Dr. Ronald Doneff)!

It became very clear to me that in this game you have to be an equipment freak. In most of Europe positive pressure equipment is used in connection with tracheotomies which means that polios will switch to positive pressure on their deathbed only. Thus, many of my fellow post-polios continue with leaking chest shells getting chests as flat as pancakes and hypventilation on top of it or spend fun-filled nights in their iron lungs. The great advantages of positive pressure equipment — ventilation intensity and mobility, however, can be fully exploited only by those who have learned to sleep with mouthpiece or face mask (unless you go in for a trache which has its drawbacks).

Ninety percent of Dr. Alba's patients at Goldwater Memorial learned to sleep with a simple mouthpiece after a year and after having had a mouthpiece during the day for quite some time.
For me the transition from chest shell to mouthpiece sleeping seems very tough. I've had more luck with face masks. My latest model (which I had along in Chicago) is a regular industrial-type full-face mask. The only modification consists of plugging the exhalation valve. I can sleep with it a maximum of a couple of weeks until my forehead has a fully developed pressure sore. So nighttime use is the bottleneck of positive pressure equipment and it is strange that the manufacturers have not realized this and come up with better solutions. I also wonder how U.S. manufacturers market their products in Europe as there is no information on or service for U.S. positive pressure equipment.

Medical advances have added years to our lives. The question now is how to add life to those years. In that sense I missed references to the non-medical aspects of our lives. Man does not live by respirator alone, we need a whole range of supportive services to enable us to live like other folks, such as accessible housing and cities, education, jobs.

Nobody at the conference mentioned anything about the need for a national health insurance. Instead some speakers suggested another March of Dimes drive to draw the public's attention to our plight and away from other — as it were — competing disability groups. Such a strategy is undignified and self-defeating in the long run. In some countries it has long been recognized as a basic civil right to receive the appropriate medical care, including technical aids, regardless of income or cause of affliction. In the U.S., such a system is either associated with the stigma of a public handout (reserved for the deserving poor and who wants to play that part) or socialism. As long as we disabled are begging for what we need to live instead of claiming it as our right we will be objects of charity and not equal and fully participating citizens.

Adolf Ratzka (respiratory polio quad) has been disabled since he was a teenager in Bavaria. He graduated from the University of California at Los Angeles and is now working on his Ph.D. in urban planning from UCLA at the University of Sweden.

Post-Polio Symposium II
Oakland, California — November 14, 1981

By Gini Laurie

The positive spirit of the first post-polio conference reappeared in the second conference, which Renah Shnaider arranged at Laney College through the Oakland Commission on Disabled Persons. Renah, Judy Heumann and a few other polio survivors had participated in the Gazette's Chicago conference, but most of the participants and all of the medical personnel were from the San Francisco Bay area.

Medical personnel: Sheldon Berrol, M.D., Ralph K. Davies Medical Center, San Francisco; Marilyn Dilsaver, O.T.; Elaine Huddon, P.T.; Allen Lifshay, M.D., Alta Bates Hospital, Berkeley; Leonard Polcoff, M.D., Pacific Medical Center, San Francisco; Stanley K. Yarnell, M.D., St. Mary's Hospital, San Francisco.

Polio survivors panel: Judy Heumann, Joe Koontz, Jim Leinen, Esther Reynolds, Renah Shnaider, Mary Lou Spieass.

"Many theories," says Dr. Yarnell, "may explain the phenomenon of weakness or deterioration of strength occurring 20-30 years after the onset of polio, usually in limited muscle groups.

"The late weakness may have nothing to do with polio," he says, "but may be caused by overwork weakness, pinched nerve root, medication, or compression and be

Stanley K. Yarnell, M.D., St. Mary's Hospital, San Francisco, speaking at the Oakland conference.
relievable by rest, traction, surgery or other appropriate treatment. A host of musculoskeletal problems may occur as a result of long-standing muscle imbalance and weakness: osteoarthritis, scoliosis, bursitis, osteoporosis, hypertension, skin problems, swollen legs, purple feet (try Jobst stockings), indigestion, constipation — try Colace or Metamucil as stool softeners — you’re getting old when you think more about your bowels than sex.”

Drs. Yarnell and Berrol emphasized that the problems must first be recognized, that many M.D.s blame too much on polio and that it is the survivors’ responsibility to bring them up to date.

“There are many treatments,” says Dr. Yarnell, “many common sense things that can be done to alleviate symptoms. You may have to start doing things in a different way. Keep an open mind! You need psychological flexibility. You must maintain good general health with diet and exercise.”

“Quadriplegics can get into a horrendous state,” says Dr. Lifshay, pulmonary specialist, “with a single cold. Respiratory polios should work with their doctors so that at the onset of a minor respiratory infection, it will be dealt with as a serious problem and treated with antibiotics and postural drainage (chest tapping to remove secretions).”

“Polio survivors should not become fatigued because you are more prone to respiratory infections if you have too little rest,” says Dr. Lifshay. “Using night respiratory aids allows the chest muscles to rest so that they can function during the day. If you have any respiratory problem, you should have baseline pulmonary tests done. Then your doctor will have a comparison if you develop symptoms later.”

The panel of polio survivors discussed their worries about diminishing function, weakness and pain, as well as the lack of polio-experienced, open-minded doctors and the unawareness of hospitals that will not allow attendants or family members to continue their care during hospitalization. They confirmed their improvement after consulting doctors and therapists and changing their lifestyles. For instance, several have more energy and chest expansion after changing from a manual to a motorized chair.

“Conserve your energy,” concludes the medical personnel. “Prioritize your activities. Balance your lives without causing damage and problems. Avoid fatigue. Exercise to build endurance, not strength. Keep track of your medical records. Teach doctors and hospitals and therapists about your individual needs. Be assertive about your care!”

Editor: Joe and I had the pleasure of attending this Oakland conference and of seeing the ripple effect from the Gazette/RIC Chicago conference. We hope there will be many more around the country and the world.
Since 1964 the majority of the patients with neuro-muscular disease followed at the Howard A. Rusk Respiratory Center at Goldwater Memorial Hospital have been breathed at night with mouth intermittent positive pressure ventilation (IPPV). The reasons for this choice of ventilation are mainly the portability of the respirator and the large volume of air that can be delivered per breath.

Mouth IPPV at comparable positive pressures gives you the same tidal volume that the iron lung does at negative pressures. However, the respirators used for mouth IPPV can be set at much higher pressures than the iron lung. For this reason much more air can be obtained with mouth IPPV than with use of the iron lung. This is of utmost importance for disabled persons with stiff lungs, scoliotic rib cage and/or respiratory infection.

**IPPV During the Night**

"We have learned that even patients with no vital capacity can be breathed during the night with a mouthpiece such as the Bennett lipguard strapped to the mouth. They become conditioned to take sufficient air in their sleep from a cycled respirator with a fixed rate and a pressure set high enough to compensate for some leaks. This technique does not work if the patient must initiate the respiration. They apparently seal the mouthpiece with their lips and teeth during inspiration exactly as they do when awake, and the soft palate does not leak in sleep if it is not incompetent when the patient is awake."

About a third of the persons who use mouth intermittent positive pressure ventilation during the night do so using the same mouthpiece they use during the day. They may keep it in the immediate vicinity of their mouths by using a baby bottle holder, or a gooseneck, or pin it to the bed sheets or their clothing, but they do not strap it on. The rest use the Bennett lipseal.

**The Bennett Lipseal**

Catalogue #: 0730.

At Goldwater we remove the plastic strap that goes behind the head at the level of the mastoids and add two straps from the corners of the lipguard — one going above the ears, and the other going around the head at the level of the mastoids. These are 3/4 to one inch in width and of canvas with Velcro closure. This method has served us well for more than fifteen years.

More and more respiratory disabled persons are using this method of breathing in the community. Here in the United States the vendors for respiratory equipment tell me that instead of adding canvas straps they simply add a second plastic strap, and patients feel secure using the two plastic straps at the level of the mastoids.

**Problems with the Bennett Lipseal**

*Anchoring of the Lipseal.* We have had some persons with beards and moustaches which interfere with a snug fit around the mouth. For some we have made an additional strapping that goes up across the top of the head and then is anchored by an attachment to the straps at the back of the head. This creates a regular head harness and is used if the lipguard tends to slip down from the upper lip.

*Allergy.* An occasional person is allergic to the type of plastic used in the lipguard and has padded the inside with other materials.

*Bitting.* Some who use the lipseal eat the soft plastic tubing which stabilizes the rigid plastic mouthpiece that is inserted through the center of the lipseal. We have inverted this tubing for one person and added another piece from rubber hosing used in the laboratory — so that if it is eaten away by bitting it can easily be replaced without replacing the entire lipseal.

*Absence of Teeth.* We have had one middle-aged female quadriplegic polio who fell and knocked out all of her upper incisors. She continued to sleep with the lipseal during the healing process and since, without difficulty.

We have one lady in her seventies with amyotrophic lateral sclerosis who is quadriplegic but still has good bulbar function, and slight function in one hand. With the use of the sling she operates a motorized wheelchair. She is edentulous. She is using mouth IPPV 24 hours a day. She has less than five minutes of free time off the respirator. She has been able to use the Bennett lipseal for mouth IPPV during the night for 27 months without difficulty.

*Need for a Nose Clip.* We have had one middle-aged adult male quadriplegic polio who gave up the use of the chest piece ten years ago for mouth IPPV for sleep. He has been able to use this method only because he uses a noseclip during the night. Otherwise the air would escape from his nose because of an incompetent soft palate in sleep.

We have a young adult scoliotic moderately obese quadriplegic female polio who has mild weakness of her soft palate from the polio. She needed to close her nose with the index and middle fingers of her right hand when she used mouth IPPV during the day. She gave up the use of the chest piece, and began using the mouth IPPV for sleep more than five years ago. She continued to pinch off her nose with her fingers during sleep for a year or more after she began to sleep this way, but at the present time she no longer needs to do this.

More recently we have had two persons with polio who have used mouth IPPV with the lipseal for fifteen years who have now experienced leaking of the inspired air from
the nose during sleep. In both, nasopharyngitis was present. The young adult female quadriplegic polio needed the noseclip for about two weeks this fall during an acute upper respiratory infection. She was aware of her not getting enough air as soon as she fell off to sleep when she did not have the noseclip in place. The middle-aged adult male quadriplegic polio has had leaking of the inspired air from the nose along with a blowing out of nasal secretions during the night intermittently for a period of five months. He obtained a noseclip from the respiratory equipment vendor two months after this started and used it off and on since to prevent the secretions from escaping, but did not realize he was also leaking the air he needed for breathing. He frequently wakened during the night for his wife to clean his nose. He began to fall off to sleep during the day while he was using his small mouthpiece without the lipseal. When he slept during the day, he was so tired that he was seen not to use his mouth IPPV effectively. His wife had intuitively put him back to bed each day for a nap of two hours on the lipseal mouth IPPV and he would be more alert for the rest of the day. The patient gradually developed right-heart failure and massive generalized edema. He has required hospitalization for the management of nephrotic syndrome and superimposed respiratory infection. In the hospital while he was slightly obtunded he was using his noseclip both day and night. As he improved on diuretics and steroids, he continued to use the noseclip during sleep. However, his nose had become quite sore from the pressure, and his wife had substituted cotton pledgets in his nostrils covered with surgitape to seal his nose. This method has been very comfortable for the patient in the past three weeks and provides a good seal. If the leakage of air through the nose in sleep persists, the alternatives for the patient are to continue sealing off the nose and use mouth IPPV, to use face mask IPPV, to consider the use of the iron lung or its equivalent the poncho, or to have a tracheostomy for tracheal IPPV.

Vital Signs, Inc. (East Rutherford, N.J.) has just produced a single use nonconductive face mask with low pressure seal (product #5250) with an equalizer headstrap with constant cartridge assembly (product #9100.) We have not had enough experience with the mask and headstrap to determine whether some modifications are needed for long term use, but it appears promising.

Learning to Sleep with Mouth IPPV
Since the article quoted on the first page of this paper was written we have had an occasional person who has required more time to be able to sleep this way. If you use the mouth IPPV while awake during the day with a simple mouthpiece for several hours, your ability to use it during the night will improve.

Case Illustration 1. One person started to use aid 20 years after he had had polio. He had to leave the hospital with a rocking bed for sleeping nights. He used the mouth IPPV during the day. He then began practicing using it while he napped in the afternoon. He would be babysat at these times by a neighbor. He continued to practice for almost six months before he was able to return the rocking bed and sleep exclusively on mouth IPPV.

Case Illustration 2. Another person could be ventilated only by the iron lung, the rocking bed, or mouth IPPV. She did not want the bulkier pieces of equipment. She could not use the mouth IPPV in her sleep. She went home using a Bennett face mask with the head harness with which it comes. She also needed a size 28 French Bardex nasal airway in one nostril because she was breathing primarily through her nose and did not have an adequate airway without it. She slept this way for almost two years, and gradually used her mouth IPPV for longer and longer periods in the evening. About two years later she was able to discard the use of the face mask for mouth IPPV and has been doing well since.

Complications from Mouth IPPV
Aerophagia. Occasionally persons who use mouth IPPV in their sleep get air in their stomachs. However, they find it a small price to pay for the comfort of being free of the bulkier respirators. In the morning they find with getting up in the wheelchair, they will gradually lose the air from the abdomen — probably by the passage of flatus.

Tension in Jaw and Lips. Those who do not use the lipseal are usually sleeping with an angulated mouthpiece that practically falls into the mouth when the head is supine. The lipseal comes with a straight mouthpiece. Substitution of an angulated mouthpiece for the straight mouthpiece in the lipseal may provide even better acceptance, but I have not tried it as yet.

If you add the lipseal to the mouthpiece you will find it more comfortable because you won’t have to grip it so strongly. You can relax your jaw and lips intermittently. You will not be afraid that you will lose the mouthpiece.

Drying of Mucous Membranes. We use a Bennett Cascade heated humidifier (Catalogue #: 001750) set at the arbitrary setting of 2 or 3 during the night and have had no problem with humidification. We do not keep a thermometer in the line to monitor the exact temperature, but it is not more than 80 degrees Fahrenheit. An occasional person will require a setting of 4. Some use a setting of 2 or 3 most of the time, but if they become ill with a respiratory infection they will turn the setting up to 6 or more for half hour intervals for increased moisture to loosen secretions.

Portable Ventilators
Portable pressure or volume ventilators are the most practical respirators to use although console models can also be used. The portable volume ventilator can present a problem. The unit, the first model of which became available in 1978, does not have the high flows that the portable pressure ventilator, the Thompson bantam, has. You should set the unit at a tidal volume of at least 1500-2000
which "riderabie" occurs when the Vital Capacity providing mechanical breathing aid but whose breathing is weakened. A person with muscular dystrophy whose cheeks were weak and therefore considerable amount of air escaped around the mouthseal. He had to use the Thompson bantam or portable pressure ventilator because the high flow allowed him to fill up his cheeks with air, and the pressure of his cheeks inside the mouthseal provided a better seal than the mouthseal alone. He was not able to do this with the volume ventilator because of its lower flows.

Since the method depends on a conditioned reflex which is present in sleep, persons on mouth IPPV without a face mask must be free of heavy sedation and/or alcohol at bedtime, must not have high levels of carbon dioxide in the blood (over 55 mm Hg; normal below 43 mm Hg), and must not be acutely ill.

How to Make a Cuirass Shell That Works

Dr. Geoffrey Spencer, O.B.E., F.F.A.R.C.S.

The cuirass shell is a convenient and well tried device for providing mechanical breathing assistance, particularly at night, for people with restrictive respiratory insufficiency such as follows poliomyelitis. "Restrictive respiratory insufficiency" occurs when the Vital Capacity (biggest possible voluntary breath without fog breathing) is greatly below normal. A cuirass doesn't help people with lung disease (Chronic Bronchitis).

As a rough general guide, the size of the vital capacity determines what sort of breathing aid is most suitable. A fit young man usually has a vital capacity of over 5 litres. A paralyzing illness can reduce the vital capacity to about 2 litres without causing serious breathing difficulty. Between 1½ and 2 litres breathing assistance is usually only needed during chest infections or other intercurrent illness. People whose vital capacities are below 1½ litres sooner or later come to need mechanical breathing aids at least during sleep.

The standard methods of mechanical breathing aid for use during sleep are:

The Rocking Bed: A large cumbersome bed which is popular because it leaves the patient unencumbered and accessible. It provides only a moderate amount of breathing aid but is particularly suitable for patients with a paralyzed diaphragm but whose breathing muscles are otherwise largely unaffected. Such people can usually breathe well when upright but have trouble on lying down when their vital capacity falls sharply, often to well below 1½ litres. A rocking bed allows them to sleep easily and comfortably but is not easily transported when travelling. It provides insufficient breathing aid for people whose vital capacity is much below 1 litre.

The Iron Lung: An efficient breathing machine which is usually necessary, at least for sleeping, for patients whose vital capacity is between 1¼ and 1½ litre. The Iron Lung is large, cumbersome and unsuitable for travelling. It also imprisons the patient and so cannot be used by people who have to sleep alone.

Tracheostomy and Intermittent Positive Pressure: If the spontaneous vital capacity is less than a quarter of a litre this is undoubtedly the best method. Suitable apparatus for home I.P.P.R. via a tracheostomy is less readily available in America than it is in England which is why many American polio sufferers with very low vital capacities get by with Iron Lungs at night and various positive pressure mouthpiece aids by day.

The Cuirass Shell: This classification leaves an obvious gap for people whose vital capacity is between a half and one litre. This is where the cuirass shell should fit in. People whose vital capacity is outside these limits can often use a cuirass for limited periods when travelling or on holiday, its


2Thompson minilung M-15, M-25, M-3; Life Products LP-3, LP-4.

Dr. Alba is Associate Director, Department of Rehabilitation Medicine, and Associate Professor of Clinical Rehabilitation Medicine and Dentistry, New York University Medical Center, Goldwater Memorial Hospital, Franklin D. Roosevelt Island, New York, NY 10044. (Call between 3-5 pm Eastern Time: 212-750-6777.)

Dr. Khan is Supervising Physician, Howard A. Rusk Respiratory Center, Goldwater Memorial Hospital.

Dr. Lee is Director, Department of Rehabilitation Medicine, and Professor of Clinical Rehabilitation Medicine and Dentistry, New York University Medical Center, Goldwater Memorial Hospital.
great advantage being that it is easy to put on and carry about, particularly if driven by a small Monaghan (Life-care) or Thompson pump.

So why aren't cuirass shells more widely used?

The Cuirass Shell was developed for people who had recently had polio. They were made in various standard shapes and sizes. The trouble is that few people who had polio badly enough to need a cuirass remain a standard shape for more than a few years. Nonstandard people — now the majority of potential cuirass users — need to have their cuirass specially made from a plaster cast of their torso. Even then the plaster cast needs to be carefully made if the subsequent cuirass is to fit and work properly.

Ten years ago we started using cuirass shells to help severe scoliotics (“hunchbacks”) to breathe at night. Whatever the cause of the scoliosis, if severe, the breathing problems are similar to those of polio. No scoliotic is a standard shape, so we had to make special casts and shells.

After various trials I found that Bob Waind of “The Cuirass Shop,” 1131 East 16th Avenue, Denver, Colorado 80218, could make the best shells and seals. Bob used to work for Monaghan’s. When they gave up, he started out on his own and has a new shell which is an improved version of the Monaghan with a neoprene, non-inflatable seal. When we first started working together, although Bob made excellent shells, they still didn’t always fit. I visited him in Denver and worked out how to make casts of the patient so that his shell would work. Since that visit we have made over fifty special cuirass shells together. Although we don’t always succeed, about 95 percent of our shells work well and are regularly used by patients, some of whom are very strange shapes indeed.

When I came to the recent Polio Conference in Chicago I was surprised to find how few people used a cuirass. My surprise disappeared when I saw one truly appalling cuirass shell made in wire reinforced fiberglass with no seal. It was quite the wrong shape and obviously providing inadequate breathing aid. Few people seemed to know about Bob Waind or how to make plaster of Paris molds.

Bob Waind makes the cuirass shell from the outer surface of the plaster cast by pressing it down into a trough of plaster. If the plaster cast is too thick the shell comes out too big. The dome of the shell is then made by gouging further into the trough of plaster after the cast has been removed — like casting a church bell. We have occasionally had to return shells when the dome was too shallow allowing the patient’s chest or clothes to touch the inside of the dome at peak inspiration. This is particularly liable to occur in patients whose trunk is badly distorted by scoliosis.

The quarter-inch plaster of Paris mold is fragile. If broken in transit to Bob Waind the shell is never right. To prevent this we pack our casts in polystyrene granules in wooden crates and send them to Denver by air freight. Finally, it is worth pointing out that cuirass shells cannot be used by patients with absent sensation over the trunk, such as follows spinal cord injury. The seal just causes sores.

Editor: When this article by Dr. Spencer arrived this issue was almost finished and there was just enough space left over for the article and three reduced photographs. The detailed instructions and the 26 step-by-step large photographs are available on loan from the Rehabilitation Gazette to anyone who wants to make a plaster of Paris mold.

Dr. Geoffrey Spencer, O.B.E., F.F.A.R.C.S., is Consultant in Charge, Phipps Respiratory Unit, South Western Hospital, St. Thomas’ Hospital, London S.W.9 N.U., England. He has created and directs a hospital unit and a comprehensive home care service system of medical management and equipment maintenance for 280 respirator-dependent persons of all disabilities.

Glossary of SCI terms. Paraplegic (“para” — a person whose legs and part of whose trunk or torso are paralyzed as a result of spinal cord injury (SCI) or disease. Quadriplegic or tetraplegic (“quad” or “tetra”) — a person whose legs and a part of whose trunk are paralyzed and whose hands and arms are partially or completely paralyzed, depending upon the level of injury or extent of the disease. If it is an injury, the level of injury to the spinal column is indicated by letters and numbers. For example, C5-6 means the injury occurred at the level of the fifth and sixth vertebrae of the neck, T2 at the second vertebra in the thoracic or chest area, and L3 at the third vertebra in the lumber or lower back area. Usually, there is loss of function below the level of injury.

50

REHABILITATION GAZETTE
The Rehabilitation Gazette does not accept any advertising. The gadgets and devices presented here were gleaned by the editors from readers' letters and other sources. They are presented as ideas for the readers to pursue on their own by sending for brochures and latest prices. The Gazette does not specifically endorse any product nor accept responsibility for any approximate price listed.

**Mobility**

Gene Nelson, engineering design consultant, became a C-6 quad twice — the first time from a football accident in 1936, the second time in 1956 from arachnoiditis at the site of the original injury. In between, he was ambulatory, obtained a degree in mechanical engineering, worked at an aerospace firm, married and raised four children.

In the 1974 Gazette, Nelson mentioned his well-engineered home and described his project to develop and market a reclining, powered wheelchair.

Since then, he has embarked on a new career as a professor of mechanical engineering at his alma mater, San Diego State University. The Departments of Industrial Studies and Mechanical Engineering are using two of his experimental designs as student training projects and seeking funding for the construction of prototype models to be tested by disabled students on campus and evaluated by Sharp Hospital and the VA Hospital.

**Experimental electric powered reclining wheelchair.**

**ELECTRIC POWERED RECLINING WHEELCHAIR.** The design will incorporate a reclining backrest, pivoting at the approximate location of the hip joint, and a seat that will tip up on the front and move slightly forward during the first half of the recline cycle. The seat will then return to horizontal and move forward at the full recline position. This coordinated movement will retain the occupant in the chair without sliding out or being subjected to shearing forces on the back or buttocks.

**AUTOMOBILE CONVERSION FOR OPERATION FROM WHEELCHAIR.** The study will investigate the feasibility of using a compact, front-wheel-drive auto, modified to provide increased head clearance, and equipped with a rear entry, elevator or ramp system, locking restraint behind the steering wheel, and driving controls for operation with limited muscular capability.

**CEILING HOIST.** "I have a commercial 500 lb. chain hoist as used in auto shops for lifting motors out of cars. Available at any machine supply dealer under "Hoist" in the yellow pages. The track is normally used for sliding garage doors, and is available from building hardware suppliers. It comes with brackets for mounting to wood or metal beams. Mine was built during construction by running a heavy wood beam across the upper portion of my bed at a 7° elevation, and hiding with the ceiling plaster. It rolls into a closet during the day. The sling is a variation of the helicopter rescue sling used by the Navy. A smooth, plastic-covered chain sling fits under my arms. Another chain with a large tubular hook tucks under my knees, so, when lifted, I am in a seated position for my wheelchair or shower chair."

For brochures and further details, write to Gene Nelson, Professor, Department of Mechanical Engineering, College of Engineering, San Diego State University, San Diego, California 92182.

**HOISTS AND THEIR USE.** Here is another of the practical and comprehensive studies of equipment which Lady Hamilton, Chairman, Disabled Living Foundation, has instigated. The 318-page book was written by Miss Christine Tarling, an occupational therapist, and illustrated by Mr. W. Brennan. Though the hoists described may be manu-
Communication

HEADPOINTER(PRINTER FOR NONVERBAL PERSONS. A new optical headpointer, developed at the U of Tennessee Rehabilitation Engineering Center, has been incorporated into a strip printer by Prentke-Romich. When the headpointer, which is mounted on the side of the head, is directed at a panel of letters and numbers, the characters selected are printed on a narrow strip of paper. The printer weighs six pounds and is operated by batteries. For more information and brochures of other environmental control systems, write to Barry A. Romich, President, Prentke Romich Company, RD 2, Box 191, Shreve, Ohio 44676.

TALKING BOARD. A 14 x 18 inch board, named for the late Hal Roe, who was cerebral palsied, cost $7.50, but the charge will be waived for persons who can't afford it. The board is produced and distributed by a Masonic Grotto in St. Paul. The Grotto provides the raw board and the members of the Grotto prepare the board for printing. "At the moment we have boards in the British Isles, New Zealand, Australia, all the provinces of Canada and the 50 states. We keep a little stockpile of boards with a friend in Belgium and he fills orders for Britain. Many of our sister Grottos around the country order boards for persons in their communities as a part of their local humanitarian projects." Fern Metcalf, Talking Board Committee, Ghora Khan Grotto, 2245 Fremont Avenue, St. Paul, Minnesota 55119.

TELEPHONE AIDS AND SERVICES. Telephone companies around the country are responding in a variety of ways to the needs of their customers for aids and services: Mountain Bell lists TDD before the numbers of hearing impaired customers in its telephone directory; Southwestern Bell allows a 35 percent discount in intrastate long distance and direct dialed calls to customers who use a teletypewriter device. It has also established an Operator Services Center which provides operator assistance for users of TDD or TTY; Pacific Telephone Company has a new service group, Handicapped Centralized Assistance Points, which provides individualized consultation on equipment and also offers MCM devices, similar to TTY's, which have readouts akin to pocket calculators; New York Telephone has rolled back its monthly charges for volume-control equipment; Illinois Bell opened an accessible Communications Center for the Disabled in its Chicago company headquarters that offers individualized bi-lingual consultation on its special products — which are offered at non-profit monthly rates — and toll-free numbers for voice and TDD. Call or write your local company and ask about its special services, discounts and booklets for its disabled customers. If your company has additional special services, let us know so that we can share them in the next issue of the Gazette.

INTERNATIONAL COMMUNICATION NEWSLETTER provides a
Reprint of an article from the May 1981 issue of Personal Computers.

**Computers**

Committee on Personal Computers and the Handicapped (COPH-2) has been organized by two disabled individuals, Tom Shwores and Margaret Pfrommer, to provide an information exchange among disabled individuals who use computers. The exchange will be effectuated through meetings, a newsletter and personal contact. Topics will relate the experiences of disabled individuals with computers: kinds of computer hardware and software most suitable, uses for school, work or play, software adaptations, uses by children and ways of locating educational materials. For membership information, write to COPH-2, 2030 Irving Park, Chicago, Illinois 60618.

Proceedings of the IEEE Computer Society Workshop on the Application of Personal Computing to Aid the Handicapped, $10 to nonmembers from Institute of Electrical and Electronics Engineers Computer Society Press, 10662 Los Vaqueros Circle, Los Alamitos, California 90720.

EDUCATIONAL SOFTWARE FOR MICROCOMPUTERS. "I am wheelchair'd by Charcot-Marie-Tooth disease and have been a full-time respirator user for the last three years. I am presently in a situation that may be of value to other Gazette readers. Krell Software is at present the largest manufacturer of educational software for microcomputers in the United States. Consequently, we are in a position to donate computer programs to Gazette readers who may be able to use them. More important, we have a top notch marketing organization and can both publish and distribute computer programs written by Gazette readers. If there is anyone out there who is interested I would personally be glad to offer whatever assistance I can." Edward Friedland, Ph.D., Krell Software Corp., 21 Millbrook Road, Stony Brook, New York 11790. (Dr. Friedland, former professor at U of California, Berkeley, Senior Scientist at Brookhaven National Laboratory and Senior Staff Officer, National Academy of Science, is author of Krell's College Board Preparatory Series.)

PERSONAL COMPUTERS. A clearly written 10-page resource guide, Personal Computers for the Physically Disabled, is available free from Apple Computer, Inc., 10260 Bandley Drive, Cupertino, California 95014. It answers many questions and lists sources for additional information on uses by people who are physically disabled or visually or hearing impaired.

CONTRACT SOFTWARE BY DISABLED PROGRAMMERS. A new company, Disabled Programmers Incorporated, trains and employs programmers, primarily disabled, and seeks contracts on a time and material basis. For a brochure, write to Tom Puorro, DPI, One West Campbell Avenue, Suite 35, Campbell, California 95008.

**Respirator**

RESPIRATOR HOSE EXTENSIONS. "Since polio in 1953 I have used a chestpiece with a Monaghan hospital respirator. I have no use of my arms but I can walk all around our two-story house with my hose extensions connected to the respirator motor in the basement. I have gradually added 6' hose extensions so I now have 36' of hose extensions hooked together. I'm getting all the air I need as long as the motor is in good condition. (I check it very often for leaks in the hoses and gaskets.)

"I buy regular plastic vacuum cleaner hoses from the Montgomery Ward catalog for $7.95 each. I tried the hoses that are used to vacuum swimming pools but they didn't work as well. My long hoses will work with either a Monaghan or a Huxley. If you want to add hoses, you will need a couple of old Monaghan end fittings or a small piece of tubing which you can find at most hardware stores.

"I keep the motor in the basement, which means the noise stays down there, oil doesn't drip on your rug, and, when it is worked on, the mess stays in the basement.

"I have become rather handy with my feet. I do jig-saw puzzles, wash and dry clothes, mop floors, dust and polish furniture, use an electric jig-saw and drill, and I type. If the weather is nice, I can get out because I have a positive pressure Bantam respirator that works in the car.

"If anyone wants more information about hoses, I will be glad to help." Bud Dabney, 8354 Edgedale Road, Baltimore, Maryland 21234.
The Best Years of My Life
By Harold Russell with Dan Ferullo. Paul S. Eriksson, Publisher, Battell Bldg., Middlebury, VT 05753. 1981. 178 pp. ($11.95) Harold Russell has crammed a lot of living into the years since 1944 when he had both hands blown off in an explosion at an Army camp. This book, written with the help of Dan Ferullo, a journalist, is the entertaining account of those years. During this time, Russell made three movies, winning two Oscars for his role in the film "The Best Years of Our Lives." As national commander of AMVETS and president of World Veteran's Federation, Russell traveled around the world, meeting such notables as Marshal Tito of Yugoslavia and Dag Hammerskjold of the U.N. All of this he did without hands, using special books with such dexterity that he was asked to make a demonstration film for other amputees.

Russell's book is exciting and fast reading although his use of the first person narrative is sometimes a bit awkward. This biography will be especially interesting to younger disabled adults who may not know what it was like being disabled before the beginnings of the civil rights for the disabled movement.

Brimming Over
By Grace Layton Sandness. Mini-World Publications, 9965 Quaker Lane, Maple Grove, Minnesota 55369. 1978. 303 pp. ($5.95) Dave and Grace Sandness are extraordinary people. Their story is amazing and inspiring. It begins with Grace's bout with polio which left her paralyzed at age eighteen. It moves swiftly through her early adjustment and her establishment of a greeting card line developed from her original pen-in-mouth drawings. But the story really begins with the introduction of Dave. These two caring people were soon married and over the next twenty-three years adopted seven children, among them two from Korea and one from Vietnam, several of them handicapped in one way or another. They also provided a temporary home for numerous "strays" and lonely souls. Additionally, they were instrumental in establishing a private adoption agency.

Grace Sandness tells the story of this loving family with honesty and openness. The troubled times as well as the joyous ones are there. Grace is not only a wife and mother but also an obviously talented writer. Throughout the book she maintains the suspense and excitement as this story of growing faith and commitment unfolds.

Comeback: Six Remarkable People Who Triumphed Over Disability
By Frank Bowe. Harper and Row, Publishers, Inc., 10 East 53rd Street, N.Y. 10022. 1981. 172 pp. ($12.50) Frank Bowe, an outstanding author who happens to be deaf, has written inspiring profiles of six people who also happen to be severely disabled. These six people have accomplished feats which would be outstanding even for nondisabled people. Their disabilities include paralysis, deaf-blindness and mental retardation. Their abilities have helped them become a political activist, a theoretical physicist, a sex counselor, a busboy in a restaurant, a poet and a neurochemist. Bowe has emphasized the abilities and accomplishments throughout.

In addition to six profiles, the book includes a foreword by Dr. William Glasser, author of Reality Therapy, a preface and final "Reflections" by Bowe, a list of agencies serving the disabled, and a brief bibliography. Bowe's final section contains a list of characteristics he believes the successful disabled person needs. These include drive, patience, sense of humor, education, rehabilitation, supportive parents, curiosity, information about disability, access to technology, realistic sense of self, practical and social intelligence and friendliness.

Dr. Bowe's portrayals are sensitive and well written. At times he does plunge so deeply into the details of physics and chemistry that the average reader may be lost for a few pages. But, for the most part, this book is interesting and inspirational reading.

Courtesy Needs of the Disabled Customer
Developed by Sue A. Schmitt. Stout Vocational Rehabilitation Institute, University of Wisconsin-Stout, Menomonie, Wisconsin 54751. 1980. 107 pp. ($10) This training manual for students preparing to enter the hospitality industry was prepared as a joint project of the Stout Vocational Rehabilitation Institute and the Department of Habitational Resources of the University of Wisconsin-Stout.

This project also produced a slide/sound series on accessibility and a coordinated videocassette providing pointers for serving the disabled in restaurants. The forty-eight slides are available for thirty dollars and the videocassette for fifty-five dollars. These materials can be used as a package for an educational course.

Divided into six chapters, this curriculum guide lists goals, materials and instructions for the teacher in each chapter.

The text is well-prepared, informative, and concise. It provides a good foundation to guide those who are training students to work in restaurants and hotels.

Driver Education for the Handicapped Manual
Prepared by David G. Krenzer. Materials Development...
In Ida: Life With My Handicapped Child, By Ulla Bondo, translated from the Danish by Elisabeth Mills, Faber and Faber, 99 Main Street, Salem, New Hampshire 03079, 1980. 128 pp. ($8.95) Being the parent of a disabled child can almost miraculously endow a person with the courage and inventiveness to cope with that situation. Or maybe it is true that God sends "special" children only to "special" parents who have the ability to adjust. In either case, Ulla Bondo has approached the loving and rearing of her Down's syndrome daughter, Ida, with a determination to help Ida develop to her fullest potential. In this book, she records for us her daily efforts in this direction.

Ulla Bondo has written in detail about the daily training of her mentally disabled daughter in hopes of helping other parents of similar children. She emphasizes the amount of patience and time required in teaching Ida the simplest tasks, such as eating with a spoon or using the bathroom. She records the family's frustration and exhaustion. However, she also shares the joy and pride that Ida has brought to their lives.

This story of a loved and loving mentally disabled child is a joy to read. The reader is made to feel he is part of the efforts to help this child. It is especially recommended for parents who are rearing a mentally disabled child but is rewarding for any reader.

In Your Dog — Companion and Helper, By Milo D. Pearsall and Margaret E. Pearsall, Alpine Press, Inc., 1901 South Garfield, Loveland, Colorado 80537, 1980. 190 pp. Two experienced dog trainers, Margaret and Milo Pearsall, enthusiastically draw upon their forty years of experience to present a guide for the layman to train his dog to be both companion and helper. The Pearsalls emphasize that their methods depend upon seeing situations from the dog's point of view.

The book moves step by step from preparing yourself for a pet to choosing the right dog and taking him home, house-training him and teaching him basic obedience. Of particular value are special sections on training dogs for the disabled using a walker or wheelchair, for the deaf and for the non-vocal deaf. The authors also provide guidelines for teaching your dog tricks, traveling with your dog and working on advanced training with your dog.

This book is fascinating reading. It opens up a world of possibilities to disabled dog lovers. The reader should be forewarned that he may be moved to explore this world by acquiring and training his own companion and helper.

In Options: Spinal Cord Injury and the Future, By Barry Corbet, National Spinal Cord Injury Foundation, 369 Elliot Street, Newton Upper Falls, MA 02164. 1980. 152 pp. (Free) This collection of profiles of fifty different spinal cord injured persons is designed to make the newly injured SCI aware of the many options still open to him. In addition, Barry Corbet, himself a paraplegic, offers some succinct advice and encouragement to those SCI's who may be isolated from others with similar injuries.

The profiles, based on interviews and written to a large extent in the interviewees' own words, are of persons who, despite their common injuries, have found widely diverse ways of coping with these injuries. Represented in the book are lawyers, teachers, farmers, social workers and almost any other profession that can be imagined. Through the wide range of choices presented here, the author encourages each individual to realize and develop his own options.

In Your Future, A Guide for the Handicapped Teenager, By S. Norman Feingold and Norma R. Miller, Richards Rosen Press, Inc., 29 East 21st Street, New York, N.Y. 10010. 1981. 177 pp. ($7.97 plus 60c postage) If you don't know what you want to be when you grow up or if you are grown up and want to be something besides what you already are, this book is for you. Dr. Feingold and Mrs. Miller have put together a practical guide to help both disabled and nondisabled persons select careers that are right for them, to get the training needed and to find the job that they have prepared for. The authors take the reader through each step of career selection and preparation.

They also include numerous examples of individuals who are pursuing rewarding careers. This guide is clearly and concisely written. It is illustrated by photos of various disabled persons, including one of the late Donna McGwinn, one-time book reviewer for this magazine.

Written by two knowledgeable authors, this book is informative reading. Every person, disabled or not, who plans to work for a living at any time, would do well to read it.

Joyce Kniffen has been quadriplegic from polio since 1959. She received a B.S.Ed. degree in 1975 from Abilene Christian University and she has begun work on her master's. She is a teacher and head of the academic department of The Bridge in Abilene. Her address is Route 2, Box 46, Clyde, Texas 79510.
Coping With Hospital Care

Edna Brean, R.N.

For disabled people, the problems of a safe hospital stay can be very serious. Someone admitted with pneumonia may be discharged completely cured, but with an absolutely ruined bowel program because [s]he “needed” enemas (how else can he move his bowels? He’s paralyzed!). Or someone who is disabled and deaf finds that he cannot sign flat on his back, and pencil and writing tablet do not help him because of his limited arm-hand function.

I have, in workshops for nurses and other health professionals, listed some problems which can be completely prevented if staff, especially those in intensive or pulmonary care units, know about them. I call this kind of teaching “buckshot technique” — that is, it's hit or miss. You are much safer if you know what should or should not be done to/for you in hospital. Hence this article.

The time to set this up is before you need it. Talk it over with your physician as soon as possible. Consider it part of your routine medical interview. One disabled friend took a checklist in for discussion and his doctor was impressed enough to make it part of the intensive care unit protocol at the local hospital. This checklist should be included in your medical folder and should accompany you to the hospital if and when you are admitted.

Here are some items for your list. They are intended to jog your memory and to help you come up with your own specific needs.

1. Any special dietary preferences, foods you don't tolerate too well, etc.
2. State the length of your successful management of your disability so staff can trust you as a source of information on your special needs. A thumbnail (be really brief here) and specific account of how you came to be disabled is useful to indicate what you have accomplished while disabled — from training your own attendants to getting a college degree or a permanent job. Do not assume that hospital staff members always see the person behind the disability.
3. Briefly outline your routine bowel and bladder management techniques. Especially ask your doctor to write that enemas must be avoided unless expressly ordered. For example, an enema is routinely administered prior to several kidney and X-ray studies — but your doctor may write an order contravening this in favor of a bowel program (suppository) instead.
4. A brief statement on your need to be turned with position changes, how often, and by what methods. Note which side (direction) you were on at last turning so that all available sides will be used in rotation. This should be a written schedule, and hung at your bedside if possible.
5. State the importance of regular and careful range of motion during your hospital stay. Quads with minimal arm strength can lose this during extended bed care if they are not ranged at least once daily. Also, joint contractures are always a distinct and unpleasant possibility if range of motion is not given regularly, or if position changes are not performed. Remember that if you are in an acute care unit, medical staff are very busy trying to save your life, hence these other considerations may not be so high on their agendas.

6. I'd like to engrave this one in marble: ask your doctor to write an order stating that your attendant be allowed to give you routine daily care even in an intensive care unit. This will give you real continuity of care and relieve the highly specialized staff from time-consuming and special “routine” care. Explain to your doctor the advantages to you and to the staff of this unorthodox plan. Explain that your attendant is already familiar with your daily care and can work unobtrusively and quietly.

7. Skin care for quads is really special. It means that you cannot be dragged up in bed by your arms (a time-honored hospital technique) and that this shears your skin, leading to serious damage. It means that you cannot be placed on a hard X-ray table (isn't that a redundancy?) without careful skin protection or you will pay a heavy penalty in pressure sores. It means that transfers from gurney to chair, to bed, etc., must be done carefully and that staff with sharp jewelry, broken or long fingernails (so fashionable now), etc., can unwittingly cause great harm to you. A foam rubber pad (even 1 inch thick) or a sheepskin, neither of which are X-ray opaque, can make a huge difference to you on those hard surfaces.

8. Staff should know if you have postural hypotension (that is, black out easily when in a sitting position) and how to avoid this when getting you up into your chair. State that your normal blood pressure is low by ordinary standards but OK for you. And state your typical blood pressure in numbers too!

9. Be sure to include with your checklist an explanatory sheet on autonomic dysreflexia if you are a high spinal cord injured person with this phenomenon. Do not assume that non-rehab hospital staff know about this problem. Make sure you discuss this with your doctor in advance so that treatment to relieve this paroxysmal and dangerous rise in blood pressure is prompt and accurate. Such explanatory sheets are available from rehab facilities which see many cord injured people, and you may request a sheet for your use. Also, do not assume that since much time may have passed since your spinal cord injury that you cannot ever get autonomic dysreflexia again.

10. Note in your routine bladder care whether you tolerate irrigation fluid administered rapidly or not, also whether you have a tendency towards bladder spasms and
what these are and how to relieve them. Bladder spasms certainly can bring on autonomic dysreflexia and they can mystify an individual with significant loss of sensation. Also, if you have successfully trained your bladder, or if you use an external collection device such as a condom catheter, emphasize the loss to you if you are automatically placed on a Foley (in-dwelling) catheter for "staff convenience." (If your attendant could "attend" you in the hospital, it wouldn't happen, would it?)

11. State whether you prefer warm or even hot water to drink — most importantly, if you cannot tolerate drinking ice water. (Ice water and hospitals seem joined at the hip, no?)

12. Note that you do not want injections in your hips or buttocks, but should be given "shots" when necessary above the level of your injury. That means in your arms or shoulders, probably.

13. Note that if you become nauseated from your illness or some medication, etc., that you will not be able to turn over to vomit, or even raise yourself on an elbow. Inhaling even a bit of stomach contents can be harmful to your lungs. (Aspiration pneumonia is harder to cure than regular [infection caused] pneumonia.)

14. List briefly any special equipment you use routinely such as Spenco boots, egg crate bed frame, waterbed, sheepskin, etc. Many of these items are covered by insurance especially if they are rented for your hospital stay. You may want to bring the more portable items with you.

15. A quad with severe respiratory complications may have a tracheotomy. Without a mouthwand and letter-board, (s)he cannot communicate at all. When one has a "trach," which is a temporary (usually) opening into the windpipe for breathing ease, there is no air crossing the vocal cords to make them vibrate and thus produce sounds. A non-disabled person can write messages; not so someone with weak upper extremities. Such isolation can be terrifying.

You can decide which of the above are useful and relevant for you; you may wish to add others or to modify these for your special needs. But look them over, and even better, discuss them with your doctor soon. Ideally, hospitals could have such checklists ready for admission of disabled persons. I would not wait for that wonderful day but would be ready with my own list and with my doctor's support and approval.

The key is to discuss it with your doctor early and have a concise typewritten checklist long before you have any need for it. One of our top local chest specialists, who has cared for many severely disabled people with pneumonia, etc., has already authorized the use of attendants in the intensive care unit. There have been no problems — in fact, the response from staff has been very positive.

Makes sense, doesn't it?

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Potpourri

by Gini Laurie

Accessibility


Adoptable Housing. By Jack Callin. 12-page booklet illustrating the absolute minimum needed to make ordinary housing accessible to disabled persons. $3 from Research Dissemination, Education and Training Center, Rehabilitation Institute of Chicago, 345 East Superior, Chicago, Illinois 60611.

Design for Accessibility, a traveling slide show, has been created by Rita McGaughy, environmental specialist at National Easter Seal Society, 2023 West Ogden Avenue, Chicago, Illinois 60612. Very informative! From the same address, a free pamphlet, Building Access.

The Planner's Guide to Barrier Free Meetings, By Barrier Free Environments and Howard Russell Associates. A practical and comprehensive guide. 73 pages, $11.95 from Barrier Free Environments, Inc., P.O. Box 30634, Raleigh, North Carolina 27612.

Accessibility Audit for Churches. Practical and basic guide to measuring and achieving accessibility at the lowest price. 40 pages. 1981. $2 from Service Center, General Board of Ministries, 7820 Reading Road, Cincinnati, Ohio 45237.


Accessibility Guidelines for Meeting and Lodging Facilities. By L. Thornton and T. Owens. 51 pages. 1981. $3 from Rehabilitation Continuing Education Program, P.O. Box 1358, Hot Springs, Arkansas 71901.

Addiction

Addiction Intervention with the Disabled. A newsletter, published quarterly. $4 from Dr. Alex Boros, Department of Sociology,
The Kurzwell Reading Machine, the "magic talking machine," which reads printed material aloud, is now available at some local libraries.

Books
Received too late for Joyce Kniffen, the Gazette's book reviewer, to include in this issue:


Cerebral Palsy
Cerebral Palsy: Hope Through Research. Revised and enlarged by National Institute for Neurological and Communicative Diseases. Free from UCPA, Public Relations Department, 66 East 34th Street, New York, NY 10016.


Clothes


National Odd Shoe Exchange, Ruth Rubin Feldman, 3100 Neilson Way-220, Santa Monica, California 90405, now charges $5 initial membership fee for its services to people whose feet are mismatched due to disease, injury, or amputation.

Clothes for Disabled People. By Maureen Goldsworthy. Instructions for adapting or making clothes for an individual disability. $11.95 from Batsford, North Pomfret, Vermont 05033. From the same source, Knitting & Crochet by Shelagh Hollingworth for $17.50.

Cookbooks

Cooking from a Wheelchair. By Phyllis Tamir, former food editor for The Cincinnati Enquirer. 42 recipes in large type. $5.45 including postage from Advocates for the Handicapped, 120 S. Ashland, Chicago, Illinois 60607.

Herbs and Doodles. By Mickie Martin, the Gazette's librarian. A salt-free, low fat collection of gourmet recipes and a guide to growing and using herbs. 45 pages. $3 including postage. The proceeds go to the Gazette, so make check payable to Rehabilitation Gazette and send to Mickie at 4502 Maryland Avenue, St. Louis, Missouri 63108.

Deaf/Hearing Impaired
Captioning: Shared Perspectives. Collection of papers presented at National Captioning Conference in 1978. $20.50 from National Technical Information Services, 5285 Port Royal Road, Springfield, Virginia 22151.

The Tutor/Note-taker: Providing Academic Support to Mainstreamed Deaf Students. $6 from Information Services, Alexander Graham Bell Association for the Deaf, Inc., 3417 Volta Place, N.W., Washington, D.C. 20007.

National Association of the Deaf Credit Union is now available to NAD members who wish to save and borrow money in small amounts. Information from Gus
Gentile, Manager, NAD Credit Union, National Association of the Deaf, 814 Thayer Ave., Silver Spring, Maryland 20910.

The Bell Telephone System has set up a nationwide, toll-free, 24-hour TTY directory assistance service. If you have a TTY, call 800-955-1155 for a phone number of any place in the country.

Captioned TV is IRS-deductible. Under Section 213 of the Internal Revenue Code, captioned TV adapters or the extra cost between an ordinary TV and a TV with built-in adapter are deductible as medical expenses. (Your local Sears store has both the Title Caption Adapter and the built-ins.)

National Easter Seal Society has installed a TDD, with the number 312-243-5880.

An Annotated Bibliography of Literature Related to the Employment of Deaf Persons, 1981. $1 from Rochester Institute of Technology, RIT Bookstore, One Lomb Memorial Drive, P.O. Box 9887, Rochester, New York 14623.


Dental Care

Special Report on Dental Care for Handicapped People. 24-page booklet available from U.S. Department of Health & Human Services, Public Health Service, Office of Dental Affairs, Parklawn Building, Rockville, Maryland 20857.

National Foundation of Dentistry for the Handicapped, 1726 Champa Street, Suite 422, Denver, Colorado 80202, has an extensive program that involves preventive dentistry, curriculum guidelines and publications.

Some Masonic organizations will pay for dental care for children. Check with your local or regional Grotto or write to Dr. George W. Thomas, 2500 Atwell Drive, Richmond, Virginia 23234.

Developmentally Disabled


Recession Survival Handbook: Resources for Victims of Financial Crisis. The booklet describes such basic needs as food, shelter, clothing. $1 from Michigan League of Human Services, 200 Mill Street, Lansing, Michigan 48933.

Financial Resources for Disabled Individuals. Published by the Institute for Information Studies. 75 pages. $1 from National Rehabilitation Information Center, The Catholic University of America, Washington, D.C. 20064.


Driving

The Handicapped Driver’s Mobility Guide. Revised 1981. Includes van modifications, foot and hand controls, ramps and lifts. 55¢ from your local American Automobile Association or the AAA, Traffic Safety Department, 8111 Getchouse Road, Falls Church, Virginia 22047.

Education


Teaching Chemistry to Physically Handicapped Students. Free from The Committee on the Handicapped, American Chemical Society, 1155 Sixteenth Street, N.W., Washington, D.C. 20036.

Disabled students from other countries will be welcomed at Southern Illinois U. at Carbondale. For information, write to Ron Blosser, Coordinator, Specialized Student Services, Woody Hall B-150, SIU, Carbondale, Illinois 62901.

Peterson’s Guides, P.O. Box 2123, Princeton, New Jersey 08540. Free catalog of guides to undergraduate schools, colleges, graduate study, correspondence and study abroad.

Publications of three conferences on disabled students in postsecondary education cover the impact of attitudes, attendant care, specialized services for learning disabled, head injured and deaf students, interpreters, transportation, etc. Excellent! 1977 Proceedings at $2.50; 1978 Proceedings at $3.25; 1980 Proceedings at $3.25 from Handicapped Student Services, Wright State University, Dayton, Ohio 45435.

The College Connection. How to Help Yourself into College. By Z.D. Schneider and B.G. Edelson. $3.50 from The College Connection, Box 43103 (R), Chevy Chase, Maryland 20815.

Looking for a college scholarship? Many are unknown and unused. For example, one college offers grants to ‘needy left-handers.’ You can have a computer search made to match you and a scholarship. A search costs $35 from National Scholarship Research Service, 88 East Belvedere, San Rafael, California 94901 and $57 from Scholarship Search, 1775 Broadway, New York, N.Y. 10019.

Employment


Unlock the Door to Employment for the Handicapped College Graduate. An impressive collection of resumes prepared by and available from Career Planning and Placement Center, Southern Illinois University, Carbondale, Illinois 62901.

Medicine and Rehabilitation, Box 297 Mayo, U of Minnesota, Minneapolis, Minnesota 55455.


Employing Seriously Disabled People in Data Processing. Free from the National Computing Centre Ltd., Oxford Road, Manchester M1 7ED, England.

Recruiting Qualified Disabled Workers, An employer’s directory to placement services in the Greater New York area. 160 pages. Limited number: free. (Thereafter: $5.95 + 50c postage.) From Products Manager, Human Resources Center, I.U. Willets Road, Albertson, New York 11507.


Families

Income Tax Deductions
Reprints of “Tax Deductions and Credits Available to Parents of Handicapped Children,” an article by Arthur Sauter, CPA, are available by sending a self-addressed stamped envelope to him at Deaette Haslins and Selis, 1950 IDS Tower, Minneapolis, Minnesota 55402.

Special Report: Taxes and Disability
Deductions for people who are disabled, their relatives and employers. Free from President’s Committee on Employment of the Handicapped, Washington, D.C. 20210.

Businesses which remove architectural barriers may deduct $25,000 of the costs per year, through December 31, 1982. Copies of the IRS regulations available from John Coulter, Office of the Chief Counsel, Internal Revenue Service, Washington, D.C. 20224.

Independent Living Aids

The Disabled Homemaker. By Hoyt Anderson, who is disabled by cerebral palsy. Contributions by several California disabled individuals. A helpful guide to living independently and performing or directing the chores and techniques of homemaking, dressing, raising children, etc. Paperback. 348 pages. 1981. $12.75 from Charles C. Thomas, 301-327 East Lawrence Avenue, Springfield, Illinois 62717.


Self-Help Manual for Patients with Arthritis. The title should be changed to “Self-Help for Everyone.” It’s a super bargain. 246 pages of aids and techniques and ideas. $3.50 from Arthritis Foundation, Suite 1101, 3400 Peachtree Road, N.E., Atlanta, Georgia 30326.

Independent Living Services
Environmental Accessibility and Independence Living Outcomes. Directions for Disability Policy and Research. By Gerben DeJong, Ph.D. This study, written by one of the most perceptive and sensitive writers on independent living, should be obligatory reading. 198 pages. $8 from University Center for International Rehabilitation, D-201 W. Fee Hall, Michigan State University, East Lansing, Michigan 48824.

Housing Services for People with Physical Disabilities. By B. Hummel and K. Houston. 38-page manual on meeting housing needs of clients of independent living centers through developing an information base and associated services. $12 including postage from Access to Independence, Inc., 1954 East Washington Avenue, Madison, Wisconsin 53704.


Independent Living Services — Attendees


Independent Living — Shared Housing

A Guide to Cooperative Alternatives. A valuable collection of resources and experiences for those who are considering shared living arrangements. Edited by Communities. Journal of Cooperative Living. $5.95 from Community Publications Cooperative, Box 426, Louisiana, Virginia 23093.

Community & Growth. Our Pilgrimage Together. By Jean Vanler, founder of L'Arche. Though directed to those interested in shared living, it has value to any family or group. 214 pages. $6.95 + 75¢ postage from Pecos Benedictine Abbey, Pecos, New Mexico 87552.

Information Sources

National Rehabilitation Information Center (NARIC) now has an online database that contains more than 6000 research documents and nonprint items, primarily resulting from government sponsored research, but also including commercial reference works. NARIC's newest resource is ABLEDATA, a nonbibliographic online database on rehabilitation products which lists and describes commercial aids and devices and which utilizes regional information brokers. For brochures and details: NARIC, 4407 Eighth Street, N.E., Washington, D.C. 20001 (phone: 202-635-5822).

Mainstream Information Center (MIC), 1200 15th Street, N.W., Washington, D.C. 20005, furnishes information on disability issues with emphasis on the employment of health care for disabled persons. Write or call between 9-5 EST, weekdays: 202-833-1162 (voice or TTY). The following publications are free: In The Mainstream bimonthly newsletter on affirmative action; Project HEALTH quarterly newsletter on equal health care and employment in the health care sector; Contract Compliance Guide series of brochures on handicap issues; There Ought Be a Law ... There is consumer-oriented series on Sections 503 and 402; The Federal Contractor's Guide To ... series designed for federal contractors.

National Center for a Barrier Free Environment, Suite 1006, 1140 Connecticut Avenue, N.W., Washington, D.C. 20036, now has a toll-free WATS line (800-424-2805) which provides consultation on accessibility with design and Information professionals.

The Council on Exceptional Children has a hotline for teachers, students, and researchers on services for disabled and gifted children (800-336-3728).


HEALTH/Closest Look Resource Center, Box 1492, Washington, D.C. 20013. National clearinghouse on support services for disabled students in postsecondary institutions in the U.S. Ask to be placed on the free mailing list to receive news bulletins and fact sheets. Phone consultations, voice/TTY: 202-833-4707. Director, Rhona C. Hartman.

Polio information network. An embryonic list of resource people around the U.S. is included in the report of the polio conference in this issue. With your help, we'd like to set up a people-to-people, do-it-yourself network to share your own experiences and your experiences with doctors and hospitals that understand polio survivors. So, send us your experiences. We'll correlate them and share them around. And, if you need information, write to Gini Laurie, Rehabilitation Gazette, 4502 Maryland Avenue, St. Louis, Missouri 63108. Our memories, library, and files of polio survivors date back to 1949.

National Office on Disability, 1575 Eye Street, N.W., Washington, D.C. 20005. Director: Sydney H. Kaspar. Privately funded, this office picks up where the IYDP left off.

International

Mobile and Mobility for Disabled People. By Ann Damborough and Derek Kinrade. A superbly comprehensive compilation of Information on every phase of mobility — cars, conversions, hire, holidays, driving, wheelchairs, etc. 349 pages. 1981. 75p ($1.50 + $1 postage) from The Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London WIN 8AB, England.


Living With Disability! How! By Jagdish G. Sambrani. 30 brief biographies of disabled persons. 125 pages. 30 photographs. 15¢ from Mrs. Uma J. Sambrani, 19/145 Unnatnagar III, Goregaon West, Bombay, 400 062, India.

Existing and Evolving Independent Living in Eight European Countries. By Gini Laurie. An expanded report of the Laurie's World Rehabilitation Fund study trip to Europe that was summarized in the 1980 issue of the Gazette. It is available on microfiche under the code number of F813. 20¢ from National Clearing House of Rehabilitation Training Materials, 115 Old USDA Building, Oklahoma State University, Stillwater, Oklahoma 74078.
Living Independently: Three Views of The European Experience with Implications for the United States. Lex and Joyce Frieden report on their experiences in Sweden and the Netherlands and Gini Laurie on “Relationships Between American and European Concepts of Independent Living.” Published by the World Rehabilitation Fund, this 63-page monograph is distributed free. The Gazette has a few left. If you hurry, we’ll send you one. Write to 4502 Maryland Avenue, St. Louis, Missouri 63108.

Learning Disabilities


Steps to Independence for People With Learning Disabilities. Published by Parents Campaign for Handicapped Children & Youths. Free from Closer Look, P.O. Box 1492, Washington, D.C. 20013.

Lefthanders
Lefty Magazine. 8 issues a year; membership, product information and window sticker for $15 from Lefthanders International, 3601 S.W. 29th Street, Topeka, Kansas 66614.

Rollerflex SL 2000F, 35mm reflex model has two shutter releases, one for righties, the other for lefties.

Legislation


Medical, Miscellaneous

Charcot-Marie-Tooth Seminar, conducted by Dr. Peter J. Dyck of the Mayo Clinic. Transcript $2 from Patient Service Coordinator, Muscular Dystrophy Association, 1800 Massachusetts Avenue, N.W., Suite 100, Washington, D.C. 20036.

Help Yourself! Blue Print for Health. 92-page booklet. Free from your local Blue Cross office.


Mental Illness

Madness Network News. A quarterly journal of the psychiatric inmates anti-psychiatry movement. 5 years a year from MNN, P.O. Box 684, San Francisco, California 94101.

Multiple Sclerosis
Learning to Live with MS. A 64-page book written by members of local chapters of The Multiple Sclerosis Society. £2.50, including postage. RADAR (Royal Association for Disability and Rehabilitation), 25 Mortimer Street, London, W1N 8AB, England.

Independence. Quarterly publication of the Self-Help Association for Multiple Sclerosis and Allied Disorders, 39 Darlington Street, Glebe, 2037, New South Wales, Australia. No price given. Articles and letters welcomed.

Publication Catalogs


Recreation/Sports
The Widening World of Sports & Recreation for People With Disabilities. 35¢ with self-addressed, stamped business envelope from National Easter Seal Society, 2023 West Ogden Avenue, Chicago, Illinois 60612.


Directory of Recreation and Leisure Services for the Physically Handicapped Within the Greater Los Angeles Area. A valuable model for directories of other areas as well as being useful to L.A. residents. 132 pages. $8.95 (including postage — $1 discount to disabled) from the editor, Mickey A. Christison, 11066 Gonsalves Place, Cerritos, California 90701.

Vinland National Center, 3675 Inshuapi Road, Loretto, Minnesota 55357, will send free information and a newsletter on its exciting programs of health-sports and recreation for people with disabilities.

Wheelchair Bowling. By Jim Lane. 96 pages. $7.95 from Wheelchair Bowlers of Southern California, 3512 Cadiz Circle, Huntington Beach, California 92647.

Fair Play, a booklet on the myths and misconceptions about disabled people, is available from National Therapeutic Recreation Society, 1601 North Kent Street, Arlington, Virginia 22209.
Respite Care
For This Respite. A comprehensive manual. Compiled by United Cerebral Palsy Associations and the Special Education Development Center of the City University of New York. The 134-page book describes both urban and rural programs. It includes possible sources of government support. $3 from the Professional Services Program Dept., UCPA, 66 East 34th Street, New York, NY 10016.

Rights
Lobbying for the Rights of Disabled People: Views From the Hill and From the Grass Roots. Published by the Institute for Information Studies. $1 from National Rehabilitation Information Center, 8th and Varnum Streets, N.E., The Catholic University of America, Washington, D.C. 20064.


Legal Rights Primer for the Handicapped: In and Out of the Classroom. By Joseph Roberts and Bonnie Hawk. 141 pages. $5 from Academic Therapy Publications, 20 Commercial Boulevard, Novato, California 94947.

Sex
Sexuality and Sexual Assault: Disabled Perspective. $4 from Dr. Charles K. Stuart, Learning Support Services, Southwest State University, Marshall, Minnesota 56258.

All Things Are Possible. By Yvonne Duffy. Sexuality of disabled women (see review in this issue). $8.95 from A.J. Garvin and Assoc., P.O. Box 7525, Ann Arbor, Michigan 48107.

Disabled Lesbian Alliance, c/o Connie Panzarino, R.D.1, Box 98, Monticello, New York 12701, provides mutual support. The alliance is forming a national network to work on relevant issues, starting a newsletter and planning a residential facility for disabled women. The May 1981 issue of the publication, off our backs, is a special issue on women with all types of disabilities. $1 from off our backs, inc., 1724 20th Street, N.W., Washington, D.C. 20009.

Spinal Cord Injury
1981 National Spinal Cord Injury Foundation Convention Journal. Another excellent issue! Free while they last, but send at least $1 for postage to Judith C. Gilliom, Editor & Publisher, Convention Journal, 901 Arcola Avenue, Wheaton, Maryland 20902.

Living with Spinal Cord Injury: Questions and Answers for Patients, Family and Friends. $1.50 from New York Regional Spinal Cord Injury System, Institute of Rehabilitation Medicine, 400 East 34th Street, Room R812, New York, NY 10016.


The Care and Management of Spinal Cord Injuries. By George M. Bedbrook, FRCS, FRACS. Sir George, Senior Surgeon, Spinal Unit, Royal Perth Rehabilitation Hospital, Western Australia, has created a superb book that will contribute greatly to the care of people with spinal cord injuries. Because of his sensitivity, the book imparts a feeling for the SCI person as a total human being. 1981. 351 pages. $41.30. Published by Springer-Verlag New York, 175 Fifth Avenue, New York, NY 10010.

Stroke

Home Care for the Stroke Patient: Living in a Pattern. By Margaret Johnstone. Illustrated, detailed program of position-
International Visitors at 4502
During 1981, the editors, Gini and Joe Laurie, welcomed Gazette friends with parties at their home. In a January snowstorm, Lord Crawshaw (T5-6), a keen horse rider from England, came to lunch and showed movies of his special jumping saddle. In torrid August, a group of Japanese disabled persons arrived. They were touring the U.S. under the sponsorship of The Mainichi Newspapers, the largest newspaper in Tokyo. At 4502, they had their first home-cooked American dinner and tasted their first U.S.-made Sake. Also in August, Otto Bong, a physical therapist from Germany, John Evans (C5-6) from England and Jane Kristensen from Denmark spent ten days visiting and studying independent living in the Gazette library.
(Photos by Gayla Hoffman and Joe Laurie)

Japanese tour group and Missouri friends: (above) Gini Laurie and Barbara Bradford; (below, L) Tamakasukuri Kosei, OTR; (R) Hiromu Sakamaki, Mainichi staff columnist, Max Starkloff, and Meiko Kitehara, interpreter and Sacred Heart alumna.

John Evans (above) and Otto Bong (below with Meaghan Starkloff) studied the cost-effectiveness and philosophy of independent living centers across the U.S., analyzing their potential for adaptation in England and Germany.

Barbara Perry Lawton, Gazette proofreader, horsewoman and botanist, Lord Crawshaw, skillful paraplegic horseman, and Shiva, the Laurie's afghan hound.
Available Back Issues

Volume 5. HIGHER EDUCATION OF QUADS by telephone, correspondence and attendance. Reading aids. New approaches to attendants.


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.

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.
Disabled American Freedom Rally

On August 30, 1981, about 25 members of the coast-to-coast caravan of disabled "Freedom Riders" arrived in St. Louis to spend the night and relax at St. Mary's on the Mount Rehabilitation Center.

Gazette volunteers were among those on hand in St. Louis to greet the "Freedom Riders" and to support them. (Right, Gini Laurie welcomes Eve Ceniber of Berkeley, California. Photo by Karen Eishout, St. Louis Post-Dispatch.)

The caravan, which left California on August 15, traveled in vans and cars festooned with "Disabled Americans Unite" signs. They crossed the country and rendezvous in Washington, D.C. on Labor Day for a three-day rally.

The caravan was led by Mike Pachovas (C-5-6). Its goal was to publicize the International Year of Disabled Persons and to protest government cuts in aid and services for people who are disabled.