

# Rehabilitation Gazette/78



*20th Anniversary Issue  
Spinal Cord Injury Centers  
Disabled in Protestant Churches  
Respiration Equipment*



INTERNATIONAL JOURNAL AND INFORMATION SERVICE FOR THE DISABLED

**My Twenty Years in the Gazette Haus.** How good it is to be eager to be awake, eager to see what the day might bring and what treasures our friend, Frank the postman, might deliver to our door. And the pleasure of tackling these mail-borne problems has helped to wash away all the bitterness of that cataclysmic "early retirement" of half a score of years ago.

My twenty years in the Gazette Haus are actually only half that number. Though on the fringe of things, I did not really become involved until retirement. As I learned more about the magazine, and began to know more and more of its readers and contributors through our journeys to their lands, and theirs to ours, and became familiar with the inner springs of these sheets and realized the immense amount of work that Gini puts into each issue — and has been doing for more than 20 years — I know that we have come a long way. From an Ohio cat-house to a Missouri dog-house, with one dear old pussy and Beauregard Basset and Shiva Afghan, we have our umbilicus still attached to Mimi and Kybo, the Bassets, and our four-footed feline family, RU, The Duke of Zippity-Zap, Papa Chat, The Queen Mothah, and Mr. More, and the beginnings of the Gazette back in Chagrin Falls.

—Joe Laurie

**Congratulations** to our good friends, Fred Fay and Jim Jeffers, on the well deserved awards they received in 1978! Frederick A. Fay, PhD, (C5-6 quad), a psychologist and researcher at Tufts New England Medical Center, Boston, was named one of "The Ten Outstanding Young Men of America" by the United States Jaycees. James D. Jeffers (paraplegic), director of the Illinois Division of Vocational Rehabilitation and former director of the Architectural and Transportation Barriers Compliance Board, was named Handicapped American of the Year by the President's Committee on Employment of the Handicapped.

**Thanks again** to Ted Smith, graphics designer, for volunteering his expertise and talent to do the layout.

**And**, thanks to Fred Faust, Jr. and the staff of Just Your Type, Inc. We are grateful for their patience and understanding.

**Our new brochure** has been edited by our neighbor, Gayla Hoffman, and designed by Phil Casper of Omnibus Studio. Thanks to both of them for volunteering their creativity and skills.

**Purr! Purr!** Both the reviewers and our readers have been so warm in their praise of Gini's book, *Housing and Home Services for the Disabled*, that we continue to purr as we read such descriptions as "stupendous," "useful," "priceless," "a virtual Bible." Thank you! There are details of the book in the article on housing and comments in the Friends Around The World section. If you want to read it but not buy it, ask your local public library to get a copy

for you in print or as a Talking Book.

**English representative.** Jo Sandiford is continuing to help the *Gazette* in England. You may send payment for your copies of the *Gazette* by cheque or Postal Order to Mrs. J.D. Sandiford, 55A South Street, Havant, Hants., England. Tel. (07012 area code) Havant 75937.

**Japanese translation.** Dr. Masao Nagai, C5-7 quad, has the *Gazette* translated by the Red Cross Language Volunteers under his supervision. For a copy, write to him at 29, Kitamachi, Shinjuku, Tokyo 162, Japan.

**On tape and records.** Copies of the *Rehabilitation Gazette* on either open reel or cassette are available to any blind or physically handicapped person requesting them from Johanna Bureau for the Blind and Physically Handicapped, Inc., 22 West Madison Street, Chicago, Illinois 60602. (Phone: 312/332-6075). Also, contact your local public library or the Division for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20540.

**\$\$\$ or \$\$\$\$\$.** May we delicately remind you that the 1977 and the 1978 *Gazettes* are separate volumes and that you should send a remittance of \$3 for each copy if you are disabled, or \$5 for each copy if you are not disabled.

**Donations are tax-deductible** if they are made payable to Rehabilitation Gazette, Inc. They are most welcome, for the *Gazette* is staffed by volunteers and entirely supported by its readers and friends.

**Glossary of SCI terms.** *Paraplegic* — a person whose legs and a part of whose trunk or torso are paralyzed as a result of spinal cord injury (SCI) or disease. *Quadriplegic* (more correctly, *tetraplegic*) — a person whose legs and a part of whose trunk are paralyzed and whose hands and arms are partially paralyzed. 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 lumbar or lower back area. Usually, there is loss of function below the level of injury.

*Plegia* is the Greek word for "strike," *para* the Greek for "side," *tetra* the Greek for "referring to four," and *quadri* the Latin for "consisting of four." Thus *quadriplegia* is a mixture of Latin and Greek and *tetraplegia* is all Greek. The adjectives are paraplegic, quadriplegic, and tetraplegic. The nouns are paraplegia, quadriplegia, and tetraplegia. The abbreviated forms are "paras" and "quads."

G&J

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# Rehabilitation Gazette

International Journal and Information Service for the Disabled

Volume XXI

1978

*Rehabilitation Gazette* (formerly the "Toomey j Gazette") is published once a year by a volunteer staff. Its aim is to reach, to inform, and to dignify the disabled throughout the world

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(*Mexico*)

**Cover:** Gini Laurie, founder and volunteer  
editor of the *Rehabilitation Gazette*.  
Photo by J. Scott Laurie

\*Disabled

†Donna died of a perforated ulcer on  
April 9, 1978

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1958: "I began the *Gazette* with a borrowed typewriter, a dictionary, a notebook, and a volunteer staff of disabled friends."

## Twenty Years In The Gazette House

by Gini Laurie

Happy 20th Birthday, *Gazette*!

This is the 20th year of the *Gazette*, the 20th year our house has been the *Gazette* House. It is a time for celebration. A time to look back and remember with long-time readers. A time to recount with new readers.

What is the *Gazette*? How has it evolved over the years? How is it financed? Who are the writers? The staff? Who makes it happen? How did it start?

The *Gazette* masthead states that it is an "International journal and information service for the disabled." It is much more than that to its readers. It is the embodiment and reflection of the imaginative, practical, down-to-earth

life experiences of its severely disabled readers. For them, it is a form of group therapy by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. For many, it is almost an exclusive club. For its nondisabled readers, it is a source of reference material and insight into the interests and needs of disabled individuals.

How did it start? Directly, the *Gazette* began in 1958 as a little newsletter in a respiratory polio center. Indirectly, it started the year before I was born, when a polio epidemic in St. Louis hit the four children in my family. Two sisters died that summer, another sister was mildly disabled, and



a brother was very severely disabled. My parents started another family immediately and I was born the next summer. From the time I was mobile, I was my brother's auxiliary arms and legs. I didn't notice how disabled he looked. I thought he was supergreat and followed him like a shadow.

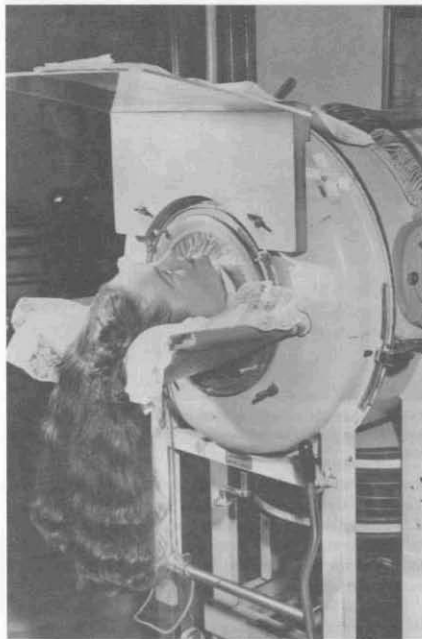
My brother died of pneumonia when he was 21 and I was 16. That experience with severe disability was never forgotten. In 1949, Joe and I moved from St. Louis to Cleveland, Ohio, for business reasons. We found an old house in the village of Chagrin Falls, a suburb east of Cleveland, and started to remodel the house, create an herb garden, and become involved in suburbia things. But these plans were slowed, for there was a ghastly polio epidemic in Cleveland that year and the newspapers were full of appeals for volunteers to help by learning to do hot packs. Naturally, I took the course, and I've never stopped volunteering with people who are disabled since.

For the next 10 years, I went once or twice a week to Cleveland City Hospital's contagious ward, the Toomey Pavilion, which became the regional respiratory polio center. I loved being with the patients. I came to know their families, their problems, and their joys. I shopped for them and ran errands. I fed, bathed, dressed, toileted, shampooed, shaved, manicured, read to, and wrote for. I did whatever needed doing and I tried to relieve the boredom and to make life as much fun as possible by giving birthday parties and decorating the wards for every holiday.

My strongest, warmest memories of my years in the Toomey Pavilion are of the close feelings of sharing and caring in the two big wards. Because of a permanent shortage of staff, the regular family visitors helped everyone and families came to know and to strengthen each other. The patients watched over each other. If someone made the major alarm sound — a "cork-popping," clicking sound (a sound that you can make by clicking your tongue against the roof of your mouth even if your trachea is unplugged and you are voiceless) — then everyone with a voice yelled, "Nurse!" I still love the sounds of the bellows of an iron lung and the pulsation of a portable respirator because I have had so many close friends attached to the swooshing and pulsing sounds.

When the patients left the hospital, they kept in touch and came to parties at our house — many became our closest friends. We ramped our house and built a small swimming pool with a hydraulic lift and heated it to a good warm temperature. Eventually, we had the annual get-togethers, the Toomey "Alumni" picnics, at our house, and the picnics grew to include not only the "old polios" but an assortment of people of all disabilities in northeastern Ohio. We had annual L.S.D. (Lick, Stick, and Dunk) parties when we readied an issue for mailing — we licked the stamps, stuck the flaps, and dunked in the pool.

By 1958, Salk and Sabin had almost eliminated polio and the wards began to empty, leaving only the few who came in for checkups, a bout of pneumonia, or to deliver



1949. "I started working as a volunteer with people in iron lungs. I've been volunteering with people who are disabled ever since."

a baby. I continued to volunteer regularly and became a peripatetic newsletter of what was going on in the lives of the "alumni." They were eager for news of each other and constantly called me or Dr. Robert Eiben, the medical director. Finally, he asked me and another volunteer, Flora Seielstad, to get in touch with the expatients and put together a little mimeographed newsletter. We created a staff of our disabled friends to report the diverse ways in which they and the other "alumni" were coping at home — with attendants, children, hobbies, home adaptations, housekeeping, families, jobs, recreation, school, and spouses — from their wheelchairs, rocking beds, chest-pieces, or iron lungs.

The first staff members were Susan Armbrecht, Ida Brinkman, Ruth Davis, Sally Russell, and Sue Williams. A few years later, they were joined by two other talented "alumni," Mickie McGraw and Donna McGwinn, then by Barbara Cory of Illinois and Bob Tanton of Alabama, then by the many other treasured people from all over the U.S. and around the world who are listed at the end of this article.

So began a little publication for the hospital staff and



1955. "When the patients left the hospital, they kept in touch and came to parties at our house — many became our closest friends."

the expatriates of Toomey Pavilion. It was named the *Toomey j Gazette*, in memory of the former director, Dr. J. Toomey. It was so popular that we sent it to the 17 other respiratory polio centers in the United States. Then to the respiratory centers around the world. Then it evolved to include all types of disabilities.

The first issues were mimeographed at the hospital. When the circulation started to zoom, it had to be printed. Unfortunately, that cost money — even doing it the cheapest way, by offset, which reproduced my typing on an antique Underwood. As the circulation grew, several unique ways of raising money were discovered. I made herb vinegars to sell. We had a surplus of Siamese kittens so we exchanged them for a \$25 donation to the *Gazette*. We did the same with their fathers' stud fees. I think it must be the only publication in the world that was once supported by tax-deductible cats and stud fees.

The *Gazette* was incorporated as a non-profit organization with a board of trustees that tapped a few family foundations for equipment such as typewriters and addressing machines. We stopped giving it away, except to those who could not afford it. We began to request a small donation from the disabled and a slightly larger one from the nondisabled. So we have continued. The backbone of our support comes from a few very special nondisabled friends and from many disabled individuals who have become successful in their professions or businesses or who are just extra generous. Our regular funds come from \$3 donations from disabled individuals and \$5 donations from libraries, hospitals, universities, rehabilitation centers, doctors, therapists, counselors, and nurses.

The secret of the *Gazette's* continuing independent existence on a shoestring is two-fold: no salaries (except occasional, part-time) and no payments for articles. Our



friends — nondisabled, Toomey "alumni," and other disabled individuals — volunteer their talents as artists, graphic designers, foreign correspondents, legal counsel, newsgatherers, proofreaders, typists, and writers.

The most exciting part of the *Gazette* has been watching so many people go forward from the initial stages of disease or injury, seeing them gather their forces and cope, going back to work, or changing work, or going on to finish school, getting PhDs or MDs or MAs in engineering, psychiatry, medicine, psychology, or social work, marrying, acquiring homes and families, traveling, living it up! It has been like having a worldwide family of friends!

The twenty years of the *Gazette* mirror the history of rehabilitation. It has recorded the changes in social security. It has explained how to earn disability payments after disability and how to obtain SSI. It has reported the amendments to the Vocational Rehabilitation Acts and tracked the teething of 503 and 504. It has followed the movements of the disabled toward forming coalitions and achieving rights, both in this country and abroad.

It has been reporting developments in housing and services for the disabled since 1958 and in independent living centers since 1972. This material on housing and independent living is now compiled in my book, *Housing and Home Services for the Disabled*, which Harper & Row published in 1977.

The twenty years of the *Gazette* have been innovative. In 1960, it organized the first International Paralyzed Artists Show, then shared the names of the 70 participants with the Kenny Institute, which developed its own annual show from this nucleus. Congress was influenced to pass the Talking Book legislation to include the disabled as well as the blind because Ruby Heine, a disabled reader in Nebraska, had the idea, the *Gazette* alerted its



"During the 1960's, we had L.S.D. (Lick, Stick, and Dunk) parties in our garden to prepare an issue for mailing."



readers around the country to express their views to their congressmen, and Mrs. Cyrus S. Eaton brought the proposed bill to the attention of influential congressmen. It published one of the first articles on sex and the disabled — back in 1967, long before it became popular.

The twenty years of the *Gazette* have recorded the ingenuity and creativity of its readers in the Readers' Ideas section, which reports their unique equipment ideas. Back before "group therapy" or "role models" were bandied about, the *Gazette* readers invented their own group therapy and created their own models out of necessity. The personal life experiences and the brief



1971. "Joe retired and joined me as a volunteer. Then we left our Box 149, Chagrin Falls, and moved back to 4502 Maryland, St. Louis."



letters in the Friends Around the World section triggered other readers to emulation. "If he can do it, I can do it . . . If she can do it, I can do it" drifts out of its pages to the readers. Many now travel, work, play, enjoy hobbies, and live independently and more fully because other disabled readers have ventured beyond the expected.

Where else except in the *Gazette* can an inventor find a market for a portable iron lung or a traveler locate someone with three rocking beds or a travel agency with



1978. "My Gazette office is a library/information service of specialized publications and data collected over the last 28 years."

expertise in travel with respirators? Where else can one find others with rare diagnoses such as syringomelia or dermatomyositis or Charcot-Marie-Tooth who would like to share experiences? Where else can one find a tooth-borne telegraph transmitter? Or a race horse owned by a group of hospital patients? Or foot-controlled steering? Or ways to learn frog breathing? Or dozens of different mouthsticks? Or a special issue titled "Quads on Quadrangles?" Where else can you find "upside-down" polios? Or hundreds of employment and life experiences of quadriplegics? Or characters who use a mouthstick for deep sea fishing, or jewelrymaking, or ham radio, or driving, as well as painting, typing, and reading?

The *Gazette* has come a long way from those first mimeographed pages of twenty years ago. Now it reaches thousands and thousands of disabled persons and professionals in 83 countries. Various issues are translated into Japanese, Portuguese, Spanish, French, and German.

Along the way, the staff changed the name from *Toomey's Gazette* to *Rehabilitation Gazette*. Some readers cheered. Others felt saddened.

Then, the house changed as well as the name. Joe "retired" in 1967. In 1971, we left the snows of Chagrin Falls and moved back to our home town, St. Louis. We brought the *Gazette* with us and Joe joined me as a full-time volunteer. Here, too, we found expert once-a-year volunteers to help with proofreading and layout, but we have not found the daily typing and library volunteers who did so much work in Chagrin Falls between dips in the pool.

The editing and researching are all still centered in our house. Somehow, Joe and I keep up with all the work this entails and with the lovely daily flow of mail.

We find time for wandering, too. We have met many of our disabled friends since we acquired a van, which we equipped for camping, and discovered this relaxing and relatively inexpensive way to travel. On our way to annual meetings of the National Paraplegia Foundation and the President's Committee on Employment of the Handicapped, board meetings of the American Coalition of Citizens with Disabilities, and assorted other meetings, we have zigzagged over most of the United States, Mexico, and Canada calling on our disabled friends and studying housing projects.

We have continued to amass an extraordinary library of specialized publications, periodicals, correspondence, information, and books and this house is now bulging. We have become an information center for the world. We





*The Gazette reaches thousands of disabled individuals and professionals in 83 countries and some issues are translated into five languages.*

find the answer to almost any question about living with a disability in our library or back issues or by referring the questioner to another disabled individual who has solved the particular problem.

The Library of Congress records selections on records that are available through local libraries. The Johanna Bureau for the Blind and Visually Handicapped, Inc. records each new issue on tape, either open reel or cassette, and offers them to any blind or physically disabled individual who requests them.

The *Gazette's* original aim is the same: "To reach, to inform, and to dignify the disabled throughout the world." I am still the catalyst, the catcher of straws in the wind, the gatherer and giver of facts. Though the house has changed, we still have *Gazette* friends from everywhere stop by to visit. They are an excuse for a party and they meet our St. Louis friends.

After twenty years, our house is still the *Gazette* House!





*Many now travel, work, play, enjoy hobbies, and live independently because other disabled readers ventured beyond the expected.*



*Every issue includes the imaginative, practical, down-to-earth life experiences of its severely disabled readers.*



*The Gazette has been cheering the movements of the disabled toward forming coalitions and achieving rights, both here and abroad.*



*The Gazette is a form of group therapy by mail, an invaluable source of ideas, inventions, and adaptations found useful by others.*

### Gazette Staff, 1958-78

Proudly and gratefully, we list the disabled and nondisabled staff members throughout the world who have worked as volunteers to give the *Gazette* its unique character. For various periods over the last 20 years, they have contributed their writings, their drawings, their office skills, or their special expertise. Some of these lovely people have departed this world. Many have gone on to their own pursuits. A treasured few are still contributing their talents, still working to create the *Rehabilitation Gazette*.



**Disabled**

Roy Abell  
Ann Adams  
Susan Armbrecht  
Alan Arnold  
Joan Barnekow  
Eleanor Billmire  
Bud Blitzer  
Helen Bourne  
Doris Brennan  
Ida Brinkman  
Elaine Brockway  
John Lyle Brownlee  
Darlene Calvert  
Merle Chisholm  
Jane Comstock  
Betty Lou Conrad  
Barbara Cory  
Doris Coutant  
Mary Ellen Davis  
Ruth Davis  
Ronald Doneff, MD  
Ralph Dosch  
Roger Duell  
Mary Jane Faulk

Burton Fern, MD  
Jack Fuller  
Ben Gerson  
Blanche Goldwater  
Lenny Goldwater  
Anita Good  
Jo Ann Goodin  
Esther Hammil  
Paul Hibbard  
Bob Hitz  
Duncan Holbert,  
MD  
Ira Holland  
Jim Hooper  
Jane Jeffris  
Doris Jones  
John L. Jordan  
Bill King  
Don Kollar  
Vince La Mielle  
Ealon Lamphier  
Gretchen Lees  
Tom Loehr

Charles Lyser  
Mickie McGraw  
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Margaret Norris  
Ron Perry  
Imogene Prichard  
Juanita Pusateri  
Jack Quigley  
Irene Ridgeway  
Sally Russell  
Jan Service  
Bob Smith  
Jean Stange  
Dana Stanton  
Helen Swanson  
Bob Tanton  
Betty Weisensel  
Lowell Weisert  
Cliff Westhead  
Nancy Westman  
Basil Wiley  
Sue Williams

**Nondisabled**

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Louise Bartholomew  
Jean Bohlin  
Willie Bjorkman  
Ruth Carlton  
The Close Family  
Dorothy & Ray  
Davis  
Junius Eddy  
Rhoda English  
Pearl & Paul Essert  
Marion Greene  
Ginny Hamann  
Nancy Hoover

Mary & Mike  
Huston  
Frieda Hutchins  
Margy Johnson  
Joan Kerber  
Ernest Kirschten  
Mary Lynch  
Kem Mahan  
Mickie Martin  
Nancy Martt  
Marge Mootz  
Brooke Owens  
Elise Palmer  
Frances Payne

Judy Raymond  
Maribel Reynolds  
Sally & Paul Schmidt  
Bea Shmock  
Martha Scott  
Flora Seielstad  
Ted Smith  
Timy Sullivan  
Debbie Tinajero  
Janet Williams  
Kristie Williams  
Bill Wingate  
Connie Winslow

### Foreign Correspondents

**Africa:** Ian Bompas, Peter Collis, & Enid de Groot; **Argentina:** Monica Le Monnier; **Australia:** Erich Krell, Ron King, & Max Rawson; **Brazil:** Marisa Do Nascimento Paz; **Canada:** Elaine Allison, Pierre Gariepy, Bob Gordon, & Jean Mead; **Republic of China:** Ronald Dickson; **Czechoslovakia:** Vladimir Kvapil & Alois Wokoun; **England:** Brigid Boardman, Paul Driver, Kenneth McDonald, Heather Ruffell, & Dr. & Mrs. H.B.C. Sandford; **Finland:** Madge Frey & Erkii Riihimaa; **France:** Jacques Fournier & Michel Le Saux; **Germany:** Marjorie Cappel & Jurgen Erbsleben; **Holland:** Theo Van Kooten; **Ireland:** Ethna O'Dowd; **Japan:** Tetuji Tomikawa & Masao Nagai, MD; **Mexico:** Gabriella Brimmer, Arturo Gomez, Arturo Heyer, & Eileen Van Albert; **New Zealand:** Ngaire Pascoe; **Switzerland:** Chantal Benn, Charles Froelicher, & Cyndy Pohlmann; **Tasmania:** Mary Guy

# A Deaf Japanese Student in America

by Tetsuji (Ted) Tomikawa

At the age of nine, I became ill with meningitis, which took my hearing. Arthritis left me with a deformed leg. From 18 to 25 years of age I worked in a small electric company near Osaka as an assembler of TV and radio parts. Then, for a year, I attended the National Institute for Hearing and Speech Disorders in Tokyo to get vocational training (typing). From age 26 to 30, I worked in a printing company as a photsetter and at the Japan Charity Plate Association as a translator.

I learned English by self-education. My English textbooks were *Reader's Digest*, magazines for disabled people (the *Rehabilitation Gazette* was one of them), and reports of conferences on education, rehabilitation, and welfare of the disabled. One of the reports mentioned the name of the Center on Deafness at California State University, Northridge, California (CSUN).

I was active in the All Japanese Deaf Association, where the leaders were increasingly concerned with the lack of services for the deaf in Japanese universities. But people, both hearing and deaf, did not show much attention to my idea of establishing a campus service for the deaf in colleges and universities in Japan. So I wrote a letter to the Center on Deafness at CSUN and told them about my experiences in Japan and asked about the way the deaf students studied with the hearing students at CSUN. The person who answered my letter was Dr. Ray L. Jones, director of the Center on Deafness. Dr. Jones answered my questions with long letters and pamphlets about the program.

Gradually I began to understand what the program offered. So I consulted with Mr. Justin Dart, Jr., a good American friend of mine who was living in Japan at that time. I have known him for a number of years and have a deep respect for him. We discussed a long time and our conclusion was that I should go to Northridge to study there and write my experiences and send them back to Japan in hopes of encouraging people to develop a program of higher education for the deaf in our colleges and universities in Japan. Happily, after further correspondence with Dr. Jones, I was accepted by CSUN. To express my appreciation to Dr. Jones, I brought him the new third volume of *Japanese Sign Language* to which I added the English equivalents for each of the Japanese signs — a work of many months done with great gratitude.

I entered CSUN in the fall of 1974 as a freshman. Immediately, I met with problems. In the first place,

English is a foreign language with me, so I had trouble not only with the lectures, but with reading textbooks and notes, and in communication with other people. Secondly, because I had not been prepared for college, I did not know how to study. Maybe I had as many problems as three American students put together.

Therefore, I depended on the Campus Services for the Deaf (which is a part of the Center on Deafness) probably more than any American student. One of the most important services is the provision of paid interpreters. These interpreters translate what the teacher is saying into American sign language. Unfortunately, for me, I didn't have time to translate the different words and sentences from sign language to English to Japanese, so I still didn't understand the lectures.

Another service that is offered is notetaking. Since the deaf student must concentrate on the hand movements of the interpreter, he can't look away long enough to take notes. So other students in the class are hired to do this for him. However, to make proper use of the notes, you must have understood the lecture. Since I didn't understand the lecture, the notes could not help me much.



Ted Tomikawa, pioneering deaf Japanese student at the California State University, Northridge Campus.



As the weeks went by, I became more and more confused. If things had continued like that, maybe I would have broken down completely. But, fortunately, Campus Services for the Deaf also provides counselors, who are skilled in the sign language and in dealing with the problems of deaf students. When I began to realize I couldn't follow the classroom lectures, I went to the counselors for advice each day. For me, the counseling system seemed like an oasis in the desert. Through that counseling system, I was helped and was able to get myself back up on my feet and on the road again.

Thus, a fourth service offered by Campus Services for the Deaf came to my rescue. This was the tutoring service. There are 23 tutors in the program. A retired teacher from the school for the deaf at St. Augustine, Florida, became my tutor. Each day I went to my tutor with the notes and we discussed what the notetaker had written. If I met with a problem I couldn't understand and my tutor couldn't help me, I went to my professor and asked. The professors were all glad to help me. In this way, I established methods of study.

By the time mid-term tests arrived, I was able to get a little better than average grades. I think the fact that a foreign deaf student is able to get good results in the tests shows that the well organized system developed at CSUN, consisting of tutors, counselors, interpreters, and notetakers, works well!

Now I am a senior and I hope to graduate in June, 1978. My major is psychology, which has a very good department at CSUN. My speed of reading English is still about one-fifth of American students, and my speed of writing in English is about one-tenth of my classmates. In addition to my weak English, I don't know mathematics at all. This made my study of statistics very hard. I still don't know most of American customs. This made my study of personality very difficult. Consequently, I must study three times more than American students.

I have travelled throughout the United States to study deaf education. Deaf people in America have a choice of

the program they like best. If they wish to study with other deaf people, they have Gallaudet College in Washington, D.C. If they wish to study with hearing people, and take advantage of the many different courses offered in a large liberal arts college, they have CSUN. If they wish to develop their technical and vocational skills, they have the Rochester Institute of Technology or similar programs in more than two dozen colleges and technical institutes around the country.

In Japan, there are no programs at all. Recently, social services for the deaf in Japan have begun to develop and produce some good results. But the people who provide services are almost all hearing people. I think that unless deaf people can take part in the program as educators and rehabilitation specialists, we deaf people can't become truly happy. How can we become specialists? It is only education which makes this possible. College is where the specialists are trained and in the colleges no services for the deaf are offered.

I feel that the first efforts in establishing higher education opportunities for deaf people in Japan should be concentrated on the liberal arts area. What needs to be done is to develop a program in existing colleges to help prepare deaf students for university training by having them study with hearing students.

I feel that this movement must come from deaf people themselves. We have 250,000 deaf people in Japan. Some brave deaf persons must begin by studying in a regular university and complete their program of study with the provision of basic supportive services such as interpreting and/or notetaking. Their success will open the door for many others to higher education.

Address: Ted Tomikawa, c/o Charles Dirks, 9421 Lassaine Avenue, Northridge, California 91324.

*Editor: Congratulations, Tetsuji, for your inclusion in the 1977-78 edition of Who's Who Among Students in American Universities and Colleges, in the U.S. Jaycees' 1978 Outstanding Young Men of America, and in The 1978 College Register!*

## Affirmative Action Programs in the Bell System

by Diane Schwillig

Bell System companies are committed to a long-standing policy of hiring and promoting qualified disabled people. No one is discriminated against because of mental or physical handicaps. Of course, opportunities for disabled people, as with all employees, depend on job openings and the needs of the business.

The approach to affirmative action programs in hiring the disabled differs with each Bell System company. But one company in the forefront is Michigan Bell, which is in the fourth year of its program. Dick Stone, general per-

sonnel supervisor, said the company has moved further along each year. This year, more than 5 per cent of all Michigan Bell new hires will be disabled people.

Michigan Bell has detailed the experiences of its severely disabled employees in a 23-minute film called "Everyday Champions." The film can be borrowed or purchased by contacting the Michigan Bell Audiovisual Department, 1365 Cass Avenue, Room 1900, Detroit, Michigan 48226, Attention: B.A. Tyll. Purchase price is \$200. A version signed for the deaf is also available.

"One of the keystones to our program is the relationship we worked out with the State Vocational Rehabilitation Services (VRS) people," he said. "They provide us with disabled applicants and help train them both before and after employment."

The arrangement Michigan Bell and the State VRS worked out was a new approach for the agency. As a result, the VRS now has a placement service, with employees assigned fulltime to large companies in the state. Other agencies Michigan Bell works with include the Division of Blind Services, State Department of Social Services, and Goodwill Industries in Detroit.

Another Bell System unit which has made notable progress in hiring the disabled is the Arkansas Area of Southwestern Bell. Jayne Mann, area employment supervisor, attributes their success to an active recruiting program. Organizations they work with include Arkansas Enterprises for the Blind (AEB), the Federation for the Blind, schools for the blind and deaf in Little Rock, and rehabilitation agencies throughout the state.

In addition to asking their help in recruiting employees, the company gets suggestions on adapting jobs to the limitations of specific handicaps, Mann said. As an example, the company is working with AEB and the Massachusetts Institute of Technology (MIT) to test a computer which allows blind people to work as Long Distance operators.

The modern Long Distance switchboard isn't really a switchboard at all. Instead of using cords and buzzers, it is a computerized console which signals the operator with flashing lights. The computer directs calls and provides billing information.

"An AEB employee heard about the work of an MIT technologist who was developing a computer to convert light signals to Braille," Mann said. "AEB came to us and offered to put up funds for the device if we would test it. We thought it would be a good thing for the company if it worked out, and it could provide jobs for many blind people."

The computer is still being evaluated, but it has been quite successful so far. This is in part due to the hard



Ann McDaniel, the first blind long distance operator, uses a computer, which converts light signals to Braille, and an abacus with which she stores telephone numbers and figure rates.

work of Ann McDaniel, the Southwestern Bell operator who is testing the machine and who has been blind since birth. She went to AEB in 1974 for their college preparation program, but decided not to go to college. She began working the switchboard at AEB, which led to her present job.

"I thought I would have to do a lot of hard work getting everybody to know me," she said. "But everybody is so nice, and the attitude toward my being blind is good. I've made friends with a lot of the other employees."

"Customers learned my operator number from stories in the newspapers and on radio and TV," she said. "Sometimes when I answer a call, the person will ask if I'm the blind operator. And a couple of customers have remembered my number and asked for me to place calls for them again, because they thought I did a good job before."

For more information, contact Diane Schwillig, Room 1212, Southwestern Bell, 1010 Pine, St. Louis, Missouri 63101.

## Quad Employment in Britain A Few Case Histories

by Roger Jefcoate

**BALLET CHOREOGRAPHER.** (Respirator user for over 25 years.) Elizabeth Twistington Higgins, 82 Patching Hall Lane, Chelmsford, Essex, England. Well known for her superb paintings (done with the brush held between her teeth), she has recently pioneered with her own ballet group, the Chelmsford Dancers. She was a ballet dancer before polio and now teaches with help from a high fidelity remotely controlled tape recorder and a portable voice amplifier. She is training dancers in the new tech-

nique of liturgical ballet (dancing in church). She uses a sip-operated environmental control whilst she is at home during the day and when she goes into hospital every night into her iron lung she also has a similar unit there. She recounted the story of her life in the autobiographical book, *Still Life*, which was published by Mowbrays, London. One of Britain's best known disabled people, Elizabeth and her team have frequently appeared on television and her story has been featured on radio.

**COMPUTER PROGRAMMER.** (Age 44, athetoid spastic.) Dick Boydell, Spastics Society's Further Education Centre, Oakwood, High Street, Kelvedon, Essex, England. With no written qualifications of any kind, he is one of Britain's pioneer computer programmers and a full member, as well as an honorary member, of the British Computer Society. The first athetoid ever to use electronic remote controlled equipment, he does it all with his right foot feeding an electronic typewriter with built-in word store which enables him, in effect, to type at speeds well above 50 words per minute. Wheelchaired, he moves around by pushing himself backwards with his right foot. His hobby is amateur radio. His story is described in a chapter of the book, *Despite Disability*, published by Educational Explorers, Reading. He has done programmes for the Ford Motor Company.



*Robert Bowell, income tax accountant.*

**COMMUNICATION COORDINATOR/SPECIAL EDUCATION ADVISER.** (Age 28, nonspeaking, athetoid spastic.) Glynn Vernon, 23 Holderness Drive, Sheffield, South Yorkshire, England. He was one of the first disabled students to graduate from the unique British Open University (where the courses and tuition come through the radio, television, and some postal services). With help from his wife, Gill, he runs the area teletype link service (deaf to hearing communication) and during the day is special education adviser to Rotherham local authority. Education of the disabled person is Glynn's great interest and the Lightwriter speech substitute device enables him to carry out this work.

**OWNER/DESIGNER EQUIPMENT COMPANY.** (Aged 30, severely paralysed by an undiagnosed virus condition whilst a university student.) Toby Churchill, Toby Churchill Limited, 20 Panton Street, Cambridge CB2 1HP, England. Because Toby was left without speech, wheelchaired, and with only control in his right hand, he and three friends designed and built the 'Lightwriter,' the first

truly portable speech substitute device. Holding 32 characters (up to half a sentence), it resembles a lightweight manual typewriter with keys laid out in the standard pattern. The all electronic control shows the user's message on a computer-like display. Toby runs his own company, which manufactures these and other devices for disabled people.

**INCOME TAX ACCOUNTANT.** (32 years old, disabled by amyotonia congenita.) Robert Bowell, Copper Beech, Parry's Close, Stoke Bishop, Bristol, England. Robert is a wheelchair user, with weak finger and arm movement; he weighs less than 40 lbs. Some years ago he set himself up as an accountant specialising in income tax affairs. He uses an electronic typewriter with a multiple splint mounted switch assembly (where the carefully mounted microswitches are set up in a three dimensional sense precisely to suit his residual ability). He was the first disabled professional to be given remote control equipment by the British Government.



*Toby Churchill, designer and manufacturer of the 'Lightwriter.'*

*Roger Jefcoate, Willowbrook, Swanbourne Road, Mursley, Milton Keynes, Bucks MK17 0JA, England, is a consultant to the British Government, UCP of New York City, and The Spastics Society on electronic aids and he conducts courses on aids and equipment for disabled children.*

## Don't Be Left Without Your RIGHTS!

### Become informed!

The new laws and regulations offer to the disabled equal opportunity and civil rights guarantees similar to those previously extended to minorities and women.

The new laws and regulations guarantee that if you are otherwise qualified — for a job, college, welfare, or other activity or service — disability does not count.

But laws and regulations must be enforced. Each of you can help make the agencies and institutions in your community aware of the problems of the disabled. Each of you can become a watchdog to ensure that the laws are enforced. And, each of you can be ready to file a complaint if you see or experience discrimination.

Each disabled individual is important to the effectiveness of the laws. Each of you should join with other disabled individuals to become more effective. And every organization should join with other organizations to achieve strength through coalition.

The American Coalition of Citizens with Disabilities (ACCD) has assumed the major role in promoting equal opportunity and civil rights for citizens with disabilities. Last spring, ACCD led the sit-ins that resulted in the signature of the 504 regulations by HEW.

ACCD informs its members on how to achieve rights through its monthly publication, *ACCD Action*. If you want to be informed on your rights as a disabled citizen, become a member and receive this publication by sending \$5 to ACCD, Room 817, 1346 Connecticut Avenue NW, Washington, DC 20036. Ask to start with the January 1978 issue. It has concise and clear statements on Sections 501 (federal employment), 503 (affirmative action), and 504 (discrimination).

The Department of Health, Education, and Welfare has worked with ACCD on booklets to explain the new laws on civil rights. Several other organizations have published guidelines. Send for all of these and watch for more:

- (1) *Accommodating Programs to People With Disabilities*. (2) *Your Rights As A Disabled Person*. (3) *Your Responsibilities to Disabled Persons as a Health Care or Social Service Administrator*. Free from Office of Public Affairs, Hubert H. Humphrey Building, 200 Independence Avenue, Washington, DC 20201. (*Your Rights As A Disabled Person* will be distributed in English, Spanish, and Braille through local social security offices.)
- Request the following free publications from Ms. Anne Beckman, Office for Civil Rights, Department of Health, Education, and Welfare, 330 Independence Avenue, SW, Washington, DC 20201: (1) *Fact Sheet. Section 504 of the Rehabilitation Act of 1973*. (2) *Federal Register* as of May 4, 1977 and January 13, 1978. (3) *Statement by David Tatel*, July 29, 1977.

The 8-page fact sheet is especially helpful. Note the deadline of June 2, 1978 for recipients of financial assistance from HEW to complete a self-evaluation process in consultation with handicapped individuals and organizations. See paragraph 84.6(c) of the Regulations. Don't wait! Contact your local Office for Civil Rights and offer consultant services.

- The Office of Civil Rights, which has responsibility for enforcing the regulations, has speakers available for groups around the country who can assure an audience of at least 15 or 20 persons. Contact Dorothy Dillard, Office of Civil Rights, HEW, 330 Independence Avenue, SW, Washington, DC 20201. Phone: 202/245-6480.
- *Rights Handbook for Handicapped Children and Adults*. Revised edition. 100 pages. \$2 from Co-ordinating Council for Handicapped Children, 407 South Dearborn Street, Room 1090, Chicago, Illinois 60605.
- *Handbook on the Legal Rights of Handicapped People*. Free from President's Committee on Employment of the Handicapped, Washington, DC 20210.
- *The Equality Issue*, a new publication of the Minnesota Department of Human Rights. Send 75 cents for the January 1978 issue, which summarizes the problems of discrimination against disabled persons and their rights under Minnesota law, to State Documents Section, 140 Centennial Office Building, St. Paul, Minnesota 55155.
- *Handicapping America*. By Frank G. Bowe, PhD, executive director, American Coalition of Citizens with Disabilities. Clear and straightforward. Details the barriers that infringe on the rights of the disabled and what is being done and is not being done to eliminate those barriers. \$10.70, including postage, from Harper & Row, Publishers, 10 East 53rd Street, New York, NY 10022.

### Recent Publications on Laws Relating to Barrier-Free Education

PUBLIC LAW 94-142. ALL HANDICAPPED CHILDREN ACT OF 1975. . . . to assure that all handicapped children have available to them, within the time periods specified . . . a free appropriate education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected.

PUBLIC LAW 93-112. REHABILITATION ACT OF 1973. SECTION 504. . . . No otherwise qualified handicapped individual in the United States, as defined in section 7(6), shall, solely,



by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

## Grades I through XII

*Barrier-Free School Facilities for Handicapped Students.* Educational Research Service, Inc., 1800 North Kent Street, Arlington, Virginia 22209. \$7. 89 pages. 1977. Brief summary of legislation and a reprint of the North Carolina State Building Code.

The Children's Defense Fund, 1520 New Hampshire Avenue, NW, Washington, DC 20036. Following publications are free: *How to Look At Your State's Plans For Educating Handicapped Children.* 21 mimeographed pages. 1975. Summary of legislation. List of States' special education departments. *Your Rights Under the Education For All Handicapped Children Act.* P.L. 94-142. 15 pages.

The Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091. Free brochures of their publications: *Procedural Safeguards P.L. 94-142-Guide for Schools and Parents.* Soundfilmstrips, audio cassettes, booklet. \$90. *Teaching Exceptional Children in All America's Schools.* \$15. *Special Education Administrative Policy Manual.* \$27.50. *Public Policy and the Education of Exceptional Children.* \$13.95. *A Primer on Due Process - Education Decisions for Handicapped Children.* \$4.95. *Financing Educational Services for the Handicapped.* \$4.95. *Digest of State and Federal Laws: Education of Handicapped Children.* \$15. *Legal Change for the Handicapped Through Litigation.* \$3.75.

*The Education for Handicapped Children Act: P.L. 94-142.* Free from Bureau of Education for the Handicapped, 400 Maryland Avenue, SW, Washington, DC 20202.

*Handicapped People in Society: A Curriculum Guide.* Developed by Ruth-Ellen Ross and I. Robert Freeland. Governor's Committee on Employment of the Handicapped, 81 River Street, Montpelier, Vermont 05602. \$6.50. 178 pages. 1977. A teacher's guide for kindergarten through high school. Empathic, comprehensive, delightfully illustrated. Excellent references and source materials.

*Your Responsibilities to Disabled Persons as a School or College Administrator.* Free from Office of Public Affairs, Hubert H. Humphrey Building, 200 Independence Avenue, Washington, DC 20201.

## Colleges/Universities

*Architectural Accessibility for the Disabled on College Campuses.* By Stephen R. Cotler, R.A. and Alfred H. DeGraf. Free from Stephen Cotler, State University Construction Fund, 194 Washington Avenue, Albany, New York 12210. 133 pages. 1976. (Supplement/update being written.) Very helpful publication. Clear and attractive. Covers a wide diversity of disabilities.

"Architectural Affirmative Action: A University with a New Concept." By Eric Gentile. *Amicus.* Vol. 2, No. 4, June 1977. National Center for Law and the Handicapped, Inc., 1235 Eddy Street, South Bend, Indiana 46617. Pages 31-36. Four years experience with accessibility at Michigan State University, using

Mr. Gentile's creative concepts, prove that compliance need not be a burden. He uses environmental design for greater and safer use for all people. For instance, a path ramp rather than a curb cut; a grade level approach (cost \$400) rather than a ramp and handrail (\$1000).

*The College Guide for Students with Disabilities.* By Elinor Gollay and Alwina Bennett. Abt Publications. 55 Wheeler Street, Cambridge, Massachusetts 02138. \$30. (Special price to students: \$18.50.) 545 pages. 1976. A detailed and comprehensive directory of the services and facilities of about 500 colleges. Lists sources of financial aid.

*The Disabled Student on American Campuses: Services and the State of the Art.* Handicapped Student Services, Wright State University, Dayton, Ohio 45435. 1978. In process.

*Getting Through College With A Disability.* A summary of services on 500 Campuses for Students With Handicapping Conditions. The President's Committee on Employment of the Handicapped, Washington, DC 20210. Free. 64 pages. 1977. Well organized information. Lists of guides to colleges and disabled students organizations included.

*Guide to Implementation of Section 504 at Colleges and Universities.* \$2.50. 1978. Payable to George Washington University. Order from RRRI-ALLB, George Washington U., Suite 704, 1828 L Street, NW, Washington, DC 20036.

*A Guidance Manual For The Physically Disabled Two Year College Applicant.* State University of New York, College of Optometry, 100 East 24th Street, New York, NY 10010. Free. 104 pages. 1976. A manual for students and counselors. Covers 48 agricultural and technical schools and 38 community colleges in New York State.

*Handbook of Special Information for Handicapped Students.* Guide to University of Wisconsin-Oshkosh. By Jon L. Van Dyke. Free from Dean of Students Office, U. of Wisconsin-Oshkosh, Oshkosh, Wisconsin 54901. 22 pages. 1977. Well planned handbook. Good model.

National Easter Seal Society for Crippled Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois 60612. Following reprints: "Barrier-Free Environments" by Margaret Milner and "Planning for Accessibility" by Rita McGaughey.

*One Out Of Ten.* By Larry Molloy. Educational Facilities Laboratories, 850 Third Avenue, New York, NY 10022. Free. 24 pages. 1977. Summary of the implications of the new laws.

*Planning for Accessibility: A Guide to Developing and Implementing Campus Transition Plans.* By Margaret Milner. Available from The Association of Physical Plant Administrators of Universities and Colleges, Suite 250, Eleven duPont Circle, Washington, DC 20036. \$3. 88 pages. 1977. Illustrated manual covers accessibility requirements, recommendations, and guidelines.

*The Preparation of Orientation and Mobility Maps for the Visually and Physically Handicapped.* By F. Cuthbert Salmon, AIA. School of Architecture, Oklahoma State University, Stillwater, Oklahoma 74074. \$3.50.

# Spinal Cord Injury Centers

by Gini Laurie

At long last, it is being recognized again that regional centers are the most effective and most economical means of treating the psychological and physiological problems of catastrophic disabilities that require treatment and rehabilitation by an array of specialists.

Before looking at the new regional spinal cord injury centers, glance back at the 1950's. Then, with the support of monies contributed by the American public to the March of Dimes, a comprehensive system of 17 regional respiratory and rehabilitation centers for poliomyelitis patients was developed at teaching hospitals of medical schools, totaling over 500 beds.

The centers demonstrated the tremendous value of an organized network of centers, staffed by medical and paramedical specialists.

The team approach and the munificent flow of monies enabled each center to reintegrate its patients into their communities, to work with their families, to adapt their homes, to assist with attendant care, to encourage educational and vocational rehabilitation, and to furnish a continuing source of information and support.

The centers were invaluable means of improving medical management, evolving vocational and psychological rehabilitation, utilizing group therapy, and developing new equipment.

In the 1960's, after Salk and Sabin conquered poliomyelitis, the financial support was channeled elsewhere and the centers were closed. It is tragic that the rise in the number of spinal cord injured did not coincide with the decrease in the number of polio patients for, if it had, the centers would have been a natural transition from polio to spinal cord injury (SCI). It would not have been necessary to "reinvent the wheel," to revive the center concept for SCI persons.

In 1970, the U.S. Department of Health, Education, and Welfare initiated the Regional Spinal Cord Injury Research and Demonstration System, which now includes 11 regional systems or centers. The first center, the Southwest Regional System for the Treatment of Spinal Cord Injury in Phoenix, Arizona, was established by Dr. John S. Young. He developed a National Spinal Cord Injury Data Research Center to include variables pertaining to SCI and to record accurate, actual costs. The national data center has demonstrated that the treatment of paraplegics and quadriplegics at a systems center saved 9.5% in the average length of hospitalization and an average cost of 18.8% (\$6000 per case) compared to the fragmented, unsystemized care that is otherwise prevalent.

New SCI cases occur at between 8000 and 10,000 cases yearly. The total number of SCI cases in the U.S. is estimated to be between 100,000 and 125,000. In 1974, the annual cost of care was estimated at \$2.4 billion, based on the average lifetime costs of a quad at \$325,000 to \$400,000 and of a paraplegic at \$180,000 to \$225,000. These costs have risen, not only because of inflation, but because SCI now live longer than previously and because the ratio of new paraplegics and quadriplegics is changing to an increasing percentage of quadriplegics.

Dr. Young estimates that the 11 established regional systems are able to accept approximately 750 new SCI referrals each year. He recommends that eventually there should be approximately 100 Regional SCI Systems in the United States. He estimates that five new model systems could be established every year and that with a national network of 100 systems the annual savings should total \$48 million in initial hospitalization and \$480 million in lifetime medical and social costs. "Though these are rough estimates," says Dr. Young, "they certainly support the need for development of a national network of Regional Spinal Cord Injury Systems at the earliest possible time. Not only can we afford this network, we cannot afford anything else."

Elmer Bartels, a C4-5 quadriplegic, who is Commissioner of Vocational Rehabilitation for the State of Massachusetts, emphasizes that loss in human and monetary terms as a result of poor or inappropriate care of SCI is astronomical. He advocates a system with the overriding goal that "the injured person should be able to have a future as a contributing member of society and should be able to take his or her place back in the community from which he or she came." He also advocates the rights of SCI to have questions answered honestly, to have contact with other SCI as models, and to have funds immediately available for treatment and equipment.

In the 1977 NPF *Convention Journal* (901 Arcola Avenue, Wheaton, Maryland 20902), Bartels compiled a list of basic functions and/or resources that should be part of the SCI system:

1. Prevention of injury and public awareness of SCI.
2. Emergency evacuation capabilities.
3. Acute medical facilities to handle the injured within the shortest time and to serve until the acute phase is concluded.
4. At least one active SCI post-acute medical/rehabili-

tation center providing medical care, social service, physical and occupational therapy, activities of daily living, urology, surgery, orthopedics, nursing, psychology, psychiatry, and adjustment to disability.

5. Various funding mechanisms to pay for services and equipment on a lifetime plan.
6. Vocational rehabilitation services.
7. Educational facilities.
8. Transportation resources including driver training.
9. Housing facilities for disabled and their families.
10. Continuing follow-up.
11. Monitoring, documentation, and research on the performance of the system.

The proof of the value of the team/center approach is demonstrated by the successful careers of respiratory poliomyelitis quadriplegics (individuals dependent upon respirators), who have attained higher degrees and who have been successfully pursuing professional careers for twenty years and more as physicians, professors, counselors, psychologists, lawyers, and engineers, as well as those in a wide variety of other occupations, including that of homemaker.

The need for centers is demonstrated by the contrast between the number of these poliomyelitis individuals living independently and the number of traumatic quadriplegics who are shunted into nursing homes after initial hospitalization because they have not had the benefit of the team expertise of a SCI center. Neither the average general hospital nor the average rehabilitation hospital has the staff or sufficient experience with SCI to offer the creative choices and guidance that are now available in the 11 regional SCI centers and that should be available in many more centers.

Two excellent sources of material on SCI for both laymen and professionals are the National Paraplegia Foundation (NPF) and the Paralyzed Veterans of America (PVA). Everyone who is concerned with SCI should subscribe to the PVA publication, *Paraplegia News*, 935 Coastline Drive, Seal Beach, California 90740 (\$4 year), and should become a member of NPF and receive its publication, *Paraplegia Life*, 333 North Michigan Avenue, Chicago, Illinois 60601. Both organizations will send a free introductory copy of their monthly/bimonthly publications and the NPF will send a list of bibliographies and other publications on SCI.

For professionals, two organizations offer specialized information. The American Spinal Injury Association is composed of specialty physicians interested in SCI clinical care and center development. The president is Dr. Paul R. Meyer, Jr. (address below). The International Medical Society of Paraplegia includes 600 physicians and other health professionals involved in SCI. Dr. R. Edward Carter (address below) is a member of the Council, the governing body of the Society. The official journal is *Paraplegia*, published by E. & S. Livingstone, 43-45 Annandale Street, Edinburgh EH7 4AT, Scotland.

Section 304(b) of the Rehabilitation Act of 1973 authorizes grants to States and public or non-profit

organizations, not to exceed \$250,000 per demonstration, for the purpose of paying part or all of the costs for special projects and demonstrations (and research and evaluation connected therewith) for SCI individuals.

Copies of the application and instructions may be obtained by writing to the Division of Project Grants Administration, Room 1427, MES Memorial Building, Washington, DC 20201. Technical consultation regarding application preparation, project development, and program details may be obtained from Mr. J. Paul Thomas, Executive Secretary & Project Officer, Medical Research Studies, Room 2328, MES Memorial Building, Washington, DC 20201.

Information about the SCI centers for veterans may be obtained from Emanuel Mannarino, M.D., Director, Spinal Cord Injury Service, Veterans Administration Central Office, 810 Vermont Avenue, NW, Washington DC 20420.

Additional information on the 11 existing SCI centers for civilians may be obtained from their medical directors, who were contacted for the information which is summarized on the following pages.

For both veterans and civilians, the existing SCI systems must be expanded so that all who are spinal cord injured receive acute care, rehabilitation, and lifetime follow-up at regional SCI centers.

## Regional Spinal Cord Injury Systems

I. ALABAMA. Model Regional Spinal Cord Injury Center, University of Alabama in Birmingham, University Station, Birmingham, Alabama 35294. Phone: 205/934-3450. Director: Samuel L. Stover, M.D.

- (1) Number of SCI beds and average cost per diem: No specific beds for SCI; 120 beds for all types of inpatient rehabilitation. Average: 20-30 paras; 20-30 quads. Average cost per diem: \$262. Room = \$125; doctor = \$12.
- (2) Apartments or facilities for independent living practice: No.
- (3) Recreational facilities: Outdoor recreational area including a half basketball court.
- (4) Driver training: Yes.
- (5) Other services and special facilities: Affiliated with Lakeshore Hospital, which is being developed into a vocational evaluation and training center for severely disabled.

II. ARIZONA. Southwest Regional System for the Treatment of Spinal Injury, Good Samaritan Hospital, 1033 E. McDowell Road, P.O. Box 2989, Phoenix, Arizona 85062. Phones: 602/257-2000 or 602/257-4533. Director: David J.E. Cheshire, M.B.B.S. (Lond), D. Phys. Med. (Eng), D.P.R.M. (Aust).

- (1) Number of SCI beds and average cost per diem: About 35 beds for SCI, but can be expanded since in close association with 700-bed general hospital. In 3-4 years will have own building and 100 beds. Average cost: \$200 for room, board, nursing, and physicians. Extra for major surgery or respiratory therapy. Average stay: 120 days for paras; 140 days for quads.
- (2) Apartments or facilities for independent living practice: No, but good arrangement with nearby accessible Holiday Inn.

- (3) Recreational facilities: Unheated open air pool. Various programs run by recreational therapist.
- (4) Driver training: Selected physical therapists do driver training on a dual-controlled, hand-controlled motor vehicle.
- (5) Other services and special facilities: Arizona Medical Evacuation System uses both fixed wing and helicopter aircraft. Good Samaritan Hospital has its own air ambulance. Counselors from Arizona Department of Vocational Rehabilitation work with local and out-of-state counselors to keep programs going.

III. CALIFORNIA. Santa Clara Valley Medical Center, Norman B. Nelson Rehabilitation Facility, 751 South Bascom Avenue, San Jose, California 95128. Phone: 408/279-5100. Director: Sheldon Berrol, M.D.

California Regional Spinal Cord Injury Care System. Director: Glenn G. Reynolds, M.D. Phone: 408/998-4554. Ext. 43.

- (1) Number of SCI beds and average cost per diem: 70 beds. Cost per diem: \$155 plus physician visits, therapies billed at \$30 per hour, and laboratory, x-ray, pharmaceutical, and other special treatment charges.
- (2) Apartments or facilities for independent living practice: No. A few in adjacent community available by select referral.
- (3) Recreational facilities: Active program to include swimming, other indoor sports, crafts, and programs in community such as ball games, and cultural and recreational activities.
- (4) Driver training: Recipient of a special grant from the California State Department of Rehabilitation in driver training.
- (5) Other services and special facilities: Special developmental projects funded by HEW for head injury, psycho-social, vocational, urologic, and skin pressure studies.

IV. COLORADO. Rocky Mountain Regional Spinal Injury Center, Inc., Craig Hospital, 3425 South Clarkson, Englewood, Colorado 80110. Phone: 303/761-3040. Director: Robert R. Jackson, M.D.



Robert E. Jackson, M.D., director, Rocky Mountain Regional Spinal Injury Center, and president, National Paraplegia Foundation.

- (1) Number of SCI beds and average cost per diem: 80-bed facility on the campus of Swedish Medical Center and a 20-bed sub-acute unit at Swedish; plus use of intensive care unit beds at Swedish. Cost per diem: \$200. This includes room, board, nursing care, medications, laboratory, therapy, physicians. Individual equipment extra. Average stay: 90 days for paras; 100-110 for quads; ratio about equal now, formerly 60/40 para over quad.
- (2) Apartments or facilities for independent living practice: 23-unit accessible apartment house within a block of the hospital. Used for families, re-evaluations, outpatients, and final training site. The units cost between \$17 and \$19 per day.
- (3) Recreational facilities: Five full-time people in the department. Use bus and van for events away from hospital — football and basketball games, concerts, downhill and cross country skiing, horse back riding, back packing and overnight camping, and kayaking. Small recreational pool at hospital; for team events use nearby fifty meter pool.
- (4) Driver training: Steering and hand control mechanism for pre-testing; use local driver's training program for specific hand control training. Expect everyone who is a C-6 last preserved segment and distal to be able to drive independently and safely.
- (5) Other services and special facilities: Dr. Jackson says, "Always open to ideas . . . built-in flexibility . . . the population we serve is healthy even though disabled. The result of that is that we have taken down every trapping of sickness where we can and go on as best we can with the business of living."

V. ILLINOIS. Acute facility: Northwestern Memorial Hospital, 250 East Superior Street, Chicago, Illinois 60611. Phone: 312/649-3425. Director: Paul R. Meyer, Jr., M.D.

- (1) Number of SCI beds and average cost per diem: 20 beds. Cost Pre diem: \$235. Attended by Orthopaedic and Neurosurgery Departments.

Rehabilitation facility: The Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, Illinois 60611. Phone: 312/649-4728. Director: Joel S. Rosen, M.D.

- (1) Number of SCI beds and average cost per diem: Approximately 50-70 beds. Cost per diem: \$176.
- (2) Apartments or facilities for independent living practice: Approximately 20 beds available on transition floor which simulate actual living conditions in the community.
- (3) Recreational facilities: Extensive daily and weekend in-house programs as well as bi-weekly out-trips.
- (4) Driver training: Full program in driver education, evaluation, and training available from two full-time instructors.
- (5) Other services and special facilities: Extensive research facilities available from the R&T Center #20, as well as the Rehabilitation Engineering Department.

VI. MASSACHUSETTS. New England Regional Spinal Cord Injury Center, University Hospital, 75 East Newton Street, Boston, Massachusetts 02118. Phone: 617/247-5124. Director: Murray M. Freed, M.D.

- (1) Number of SCI beds and average cost per diem: 24 beds. Average cost per diem: \$163 for semi-private room; \$198 for private; plus physician's fees.
- (2) Apartments or facilities for independent living practice: No apartments, but hotels are made available to the family.

- (3) Recreational facilities: Swimming pool, billiards, table tennis.
- (4) Driver training: Training is available.
- (5) Other services and special facilities: When air transportation is indicated, Coast Guard helicopters are used.

VII. MINNESOTA. Spinal Cord Injury Center at Minnesota, Box 297 Mayo, University of Minnesota Hospitals, Minneapolis, Minnesota 55455. Phone: 612/373-8990. Director: Frederick J. Kottke, M.D.

- (1) Number of SCI beds and average cost per diem: 20 beds. Average per diem cost for fiscal year 1977 — \$314.
- (2) Apartments or facilities for independent living practice: No, but there are facilities at Courage Center and elsewhere.
- (3) Recreational facilities: Three recreational therapists provide activities for young adolescents and children with SCI. For adults, the lounge has games, stereo, TV, radio, and a pool table; recreation is provided in the community, using a special bus — shopping, athletic events, picnics, etc.
- (4) Driver training: Training and equipment are provided.
- (5) Other services and special facilities: Program in Human Sexuality; Renal Function Laboratory; follow-up after discharge; consultation on access to housing; arrangements for special adaptations; Inservice Training Programs provided by SCI team to other hospitals and rehabilitation agencies providing care.

VIII. NEW YORK. Spinal Cord Injury Center, New York University Medical Center, Institute of Rehabilitation Medicine, 400 East 34th Street, New York, NY 10016. Phone: 212/679-3200. Director: Edward W. Lowman, M.D.

- (1) Number of SCI beds and, average cost per diem: Variable number of beds — usually 40-50. Cost per diem: \$225 is the average rate and includes room, board, and all rehabilitation services.
- (2) Apartments or facilities for independent living practice.
- (3) Recreational facilities: Facilities of the Institute of Rehabilitation Medicine including the therapeutic pool.
- (4) Driver training: Available.
- (5) Other services and special facilities: Close contact is maintained with the referring physician, who is sent a complete report including recommended regimen of treatment and plans for rehabilitation program. Discharge planning includes employment, mobility, housing, and post-discharge follow-up.

IX. TEXAS. Spinal Cord Center, Texas Institute for Rehabilitation and Research, 1333 Moursund Avenue, Houston, Texas 77025. Phone: 713/797-1440. Director: R. Edward Carter, M.D.

- (1) Number of SCI beds and average cost per diem: 17 at TIRR main building and 3/4 of 14 beds at Annex to TIRR. Cost per diem: \$250 (includes everything).
- (2) Apartments or facilities for independent living practice: No apartments connected with SCI center but TIRR's staff members have been among the pioneers in facilitating independent living.
- (3) Recreational facilities: On Saturdays there are in-house games, entertainments and out-trips to movies, games, ice hockey, etc.
- (4) Driver training: Driver education and training available.
- (5) Other services and special facilities: New Options, at TIRR Annex, is a six-week live-in program to help individuals acquire skills necessary for integration into the community.

X. VIRGINIA. Acute and rehabilitation phases: University of Virginia Spinal Cord Injury Unit, Department of Orthopedics and Rehabilitation, Towers Office Building, 1224 West Main Street, Charlottesville, Virginia 22903. Phone: 804/977-7154. Director: Warren G. Stamp, M.D.

- (1) Number of SCI beds and average cost per diem: (a) Acute care, 5 beds at \$111 base cost, plus \$175 for services (OT, PT, x-rays, respiratory therapy, operating room, medications, and supplies); (b) Intensive Care Unit, \$400 base cost; (c) Towers Rehabilitation Care Unit, 20 beds at \$115 base cost, plus \$75 for services (OT, PT, x-rays, medications, and supplies), total \$190. Physicians fees for both acute and rehabilitation: \$60 first day, \$20 per day thereafter.
- (2) Apartments or facilities for independent living practice: No apartments, but a nearby motel is available to the family.
- (3) Recreational facilities: Recreational therapy.
- (4) Driver training:
- (5) Other services and special facilities: Patient and family education and training, counseling, social services, vocational counseling.

Rehabilitation facility: Woodrow Wilson Rehabilitation Center, Fisherville, Virginia 22939. Phone: 703/885-7281. Director: J. Ellies Moran.

- (1) Number of SCI beds and average cost per diem: Dormitory beds (for those independent in self-care) number 400 and the cost is \$22 or \$23 per diem. Nursing Services Units beds number 88 and the cost is \$83 or \$84 per diem. 11% of clients are SCI.
- (2) Apartments or facilities for independent living practice: An apartment is available as are OT and PT services; family education is provided on a regular basis and included in the per diem.
- (3) Recreational facilities: heated pool with ramped access, gym, lighted tennis court, outside basketball and softball playing fields, 4-lane bowling alley, rifle and archery range, carpet golf range, pool and table tennis areas, arts and crafts, a lake with paddleboats and canoes, picnic and camping areas and an auditorium.
- (4) Driver training: Three instructors (one an OTR), a car, and a van with hand controls, 12 simulators, a filmed training program, adaptive equipment, an orthorator, and a multi-car driving range.
- (5) Other services and special facilities: Prevocational services include vocational evaluation and work adjustment training; 23 vocational objectives are offered. Supportive services include counseling and psychological services, recreation, academic instruction, and a student intern program.

XI. WASHINGTON. Spinal Cord Injury Center, Department of Rehabilitation Medicine, CC-814 University Hospital, University of Washington, Seattle, Washington 98195. Phone: 206/543-3600. Director: Justus F. Lehmann, M.D.

- (1) Number of SCI beds and average cost per diem: About 30 SCI beds. About \$110 for room and nursing services; physicians' fees extra.
- (2) Apartments or facilities for independent living practice: No.
- (3) Recreational facilities: Recreational therapists utilize the university campus facilities, including the pool
- (4) Driver training: Training includes simulators, cars, and vans.
- (5) Other services and special facilities.

# The Disabled in Protestant Churches

by Susan Ray

Churches, like all other institutions made up of people, are not perfect. They are not always quick to respond to the needs of disabled people, encourage their participation, make buildings accessible, or accept the disabled as leaders. Not always I say — but often. Many churches are coming to do all these things. As disabled people become more involved in all areas of life, I feel we will play a larger role in church life, too.

There are already hundreds of disabled persons who are active lay church members. This article, however, will focus on those who hold employed or ordained positions in various denominations; it is not a representative sample, only a group of persons known to myself, to Gini Laurie, and to *Gazette* readers such as Mrs. Jean Legried of Minnesota. This article will also give a few random examples of churches that are providing for the disabled, considering first the deaf, then the blind, and finally those in wheelchairs.

**THE DEAF.** Southern Baptists, to which I belong, have a well-established ministry with the deaf. Carter Bearden, Field Consultant for Deaf Ministries of our Home Mission Board, is a deaf man who has obtained degrees from New Orleans Baptist Seminary and Emory University. Led by the Home Mission Board, about 20 individuals or couples serve as missionaries for the deaf in half the states of the nation. They preach, counsel, conduct weddings and funerals, and train deaf Christians to be leaders in their churches. In several states, they hold religious camps or conferences for the deaf; the workers here in North Carolina produce a weekly televised devotional program, which is broadcast in a number of states. But primarily these workers encourage and help local churches to serve the deaf.

Over 600 Southern Baptist churches across the nation provide at least interpretation of the worship service or a sign-language Bible study class. Some also offer interpreters or sign-language sessions of other church activities. In a few cases, the deaf people form almost a separate congregation, providing most of their own leadership.

In 1973, the First Baptist Church in Danville, Ken-



Susan Ray using the miniature, remote keyboard her father designed.

tucky, had 25 Sunday School classes for 250 students from the state school for the deaf. Deaf members of Haverhill Baptist Church in West Palm Beach, Florida, are part of the total church family but lead their own program of church activities. A rather unique church exists in Oregon. The Evangelical Deaf Church began in the 1940's as an interdenominational church to serve all deaf people in Portland. After meeting in several churches' facilities, they purchased a small building downtown. In 1975 the church decided to affiliate with Southern Baptists. Both the first and the present pastor are hearing, but the other church leaders are deaf.

Lutherans also have a substantial deaf ministry. *The Deaf Lutheran*, a monthly newspaper, is published by the International Lutheran Deaf Association and the Board for Missions of the Lutheran Church-Missouri Synod. A recent issue told of Rev. Kjell Omahr Mörk, a native of Norway, who had just become the first deaf graduate of Concordia Seminary in St. Louis. In June of 1977 he was installed and ordained to begin his duties as pastor. Mörk served as vicar in the metropolitan Washington D.C. Churches of the deaf as part of his theological education.

*The Deaf Lutheran*, captioned filmstrips, and other materials for the deaf are available from Concordia Publishing House, 3558 South Jefferson Avenue, St. Louis, Missouri 63118. Information on how to begin a deaf ministry and on available materials is offered by the Southern Baptist Home Mission Board, 1350 Spring Street, NW, Atlanta, Georgia 30309. Two booklets of Sunday School lessons with a simplified vocabulary may

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*Susan Ray, respiratory polio quad, has been disabled since she was four. The daughter of a Baptist preacher, she has been active in the church all of her life. In addition to teaching, she has devoted 10 years to writing Southern Baptist materials. Address: 2208 Charlotte Court, Raleigh, North Carolina 27607.*

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be ordered every three months from the Baptist Sunday School Board: *Sunday School Lessons Simplified* and *Simplified Bible Study*.

**THE BLIND.** "Southern Baptists do not have a specific, denominationally oriented ministry with the blind at the present time, and some Baptists believe it is long overdue," said a North Carolina Baptist publication. One of those urging an organized emphasis, similar to that with the deaf, is Rev. Jay Waugh, a blind evangelist in Burlington, North Carolina. After graduating from Southern Baptist Seminary in Kentucky, he founded the Kinnett Memorial Baptist Church in Burlington, which he pastored for 17 years before beginning full-time evangelistic work.

Along with encouraging churches to seek out the blind in their communities and provide transportation and Christian materials, he says churches need to be taught to offer acceptance and association. "Sighted people have a way of keeping their distance — so do the blind," says Waugh. "My personal desire is to see that kind of ministry that makes people in general aware that we who have so-called 'handicaps' are still very much people with the same longings and desires as have our peers. We want to make our contributions as do our fellows. Baptists are losing some potentially great leaders whose abilities are wasting away."

The American Bible Society, 1865 Broadway, New York, NY 10023, has Bible portions in braille and on tape or records. The whole Bible on records costs \$38; in braille it costs \$129. Taped Sunday School lessons and other Christian materials, most free, can be ordered from Christian Education for the Blind, Inc., Box 6399, Fort Worth, Texas 76115. Two monthly braille periodicals are available free from the Baptist Sunday School Board, 127 Ninth Avenue N, Nashville, Tennessee 37234, (Write to the Braille Editor.) Each contains Bible lessons, Christian training material, and missionary information. *The Braille Baptist* for adults comes in either braille grades 1-1/2 or 2; the *Youth Braille Baptist* comes only in grade 2.

**PERSONS IN WHEELCHAIRS.** Many congregations and religious organizations welcome and benefit from the service of persons in wheelchairs. Although barrier-free church buildings are still few, more are being made at least partially accessible.

In 1956, the Crusaders Chapel was begun in Fort Worth, Texas, as a unique church of and for the disabled. (For more on this chapel, see the 1972 *Rehabilitation Gazette*.) Some churches supply homebound members with tapes of worship services.

The Lutheran Church-Missouri Synod has adopted a resolution to "renew its efforts and pledge its resources to a more complete ministry with handicapped people, providing them with the opportunity to study God's Word, to experience the fellowship of believers and the stewardship of God-given gifts and talents." The resolution specifically encouraged congregations to "provide barrier-free access

and handicap parking." David Beese serves as a worker/priest with the disabled for the Lutheran Metropolitan Ministry Association in Cleveland. Last fall the South-eastern Conference of the United Methodist Church sponsored three seminars in Florida to enable church leaders to "mainstream" disabled persons into their activities.

Of course, with or without special provisions, many people in wheelchairs do hold positions of leadership in Protestant churches and organizations. For example:

Larry Abbott and his wife are home missionaries under the independent Baptist Mid-Missions agency working on university campuses around Ankeny, Iowa. "A lot of our work is both with Bible study groups and personal counseling. We help local church people and their pastors in their involvement on a number of campuses."

Bob Bardwell is director of the Ironwood Springs Christian Ranch in southern Minnesota. He became a paraplegic from a construction accident just after completing his seminary work. "I have always worked with youth and enjoyed it. We are here because we love people, care where they spend eternity, what they do with their lives, how they get along with themselves and their neighbors." Goals include a retreat center for the handicapped.

Until her recent death, Bobbie June Slatten, disabled by respiratory polio, served Anglicans throughout the Oklahoma diocese as secretary for the Shepherd of the Good Mission.

Hoyle Allred, wheelchair'd by a stroke, continues to serve capably as Director of Associational Missions in Gastonia, North Carolina. With his wife as driver, he helps Baptist churches of the area to upgrade their church programs and leads them in mission work. "There are days when it seems I may be in one of the most meaningful (and useful) periods of my ministry."

Robert Lovering had polio in 1946 during his last year at Northwestern Bible School in Minneapolis. After his fiancée persuaded him to go through with their marriage, they sought missionary appointment as they had planned, but in vain. He finally found his place of service as a counselor for the Christian League for the Handicapped. He also worked for United Cerebral Palsy of Greater Minneapolis and the Minnesota Society for Crippled Children and Adults, plus remodeling his own home. Now living in Phoenix, Lovering has set up a non-profit corporation, Arizona Rehabilitative Counseling Services, Inc. The Baptist minister says, "In counseling or rehabilitation work it always seemed as though the positive effects of my disability outweighed the negative."

Dr. Helen Knubel, polio paraplegic since childhood, has served for 24 years as archivist for the Lutheran Council in the USA. Since retirement, she has continued to serve as a consultant, helping to initiate an oral history collection of taped interviews with past and present Lutheran leaders.

Anita Watson, disabled with cerebral palsy, attended Schaeffler College of Religious and Social Work. Intrigued with the idea of chaplaincy, she worked three

years at the Elyria Methodist Home for the Aged. For more education in the field, she then went to the Methodist Theological School in Ohio and trained at Riverside-White Cross Hospital in Columbus. As the first woman graduate of the new school, she was ordained as a Methodist Elder in 1964. However, a chaplaincy position has been hard to find. Meanwhile, she has filled in for her pastor at Cove Church in Lakewood, Ohio, and for a friend during recovery from surgery. She has helped with counseling, weddings, funerals, and has accepted invitations to preach all over Ohio, in Georgia and Florida — in fact coast to coast!

I myself had respiratory polio in 1952 at age four. I am a Baptist preacher's daughter and have been active in church all my life, except for a couple of years after having polio. For seven years I have taught children at our former church in Texas and our new one here in Raleigh, North Carolina. Both churches have given me an acceptance that let me do whatever I thought I should and could — even coping with a room full of children until I was hoarse, muddled, and exhausted! For ten years, my vocation has been writing Southern Baptist materials promoting stewardship and mission support — audio-visuals, articles, and two books. I work at home, by assignment, with a typewriter my father built with a miniature, remote keyboard.

**CONCLUSION.** I believe all the people named above would agree that for a disabled person contemplating a church-related vocation, the first considerations should be spiritual. Religious service should no more be thought of as “sheltered employment” for the disabled than as a refuge from the world for the able-bodied. If God calls a person, He will help in dealing with the physical limitations, either working around them or living with them.

Contrary to some folks' notion, a Christian with a disability is not automatically a “super-saint!” Neither do the disabled need a personal faith in Christ solely because they are disabled; they need it as all men do.

Let me add one more note. If you are not involved in a church but want to be, don't wait for someone to find you. Call some churches. Look around for a congregation that will meet your needs, make you feel at home, and let you be one of the family to the fullest extent.

## Retreat/Conference Center

by Shirley Locker

“It's a dream come true!” wrote one camper after she attended the opening in 1977 of Inspiration Center, the retreat and conference center owned and operated by the Christian League for the Handicapped in southern Wisconsin.

The first units of the camp were completed in 1975 — six cottages which have two large rooms for four joined

by a large bathroom. Each room has four comfortable (firm) beds, four dressers, and two night stands. There are two sinks in each room, and in each bathroom there are two toilets and one bathtub with shower. Beamed ceilings and panelled walls create a rustic and cozy atmosphere.

There are no steps in any of the buildings, and the doorways are wide. The various buildings are joined by level asphalt pathways 10-feet wide, good for wheelchair races or just wheeling with a friend.

The main lodge was completed in 1975. The dining room has a large stone fireplace on one end, providing focus for an informal lounge area. The main lodge has 16 sleeping rooms, 10 of which have private baths. Inspiration Center can house 110 campers altogether. A balcony surrounds one edge of the lodge, allowing campers to wheel or walk close to the trees.

The downstairs area, serviced by an elevator, is used by the Rehabilitation Department of the Christian League, but during camp sessions, the craft activity is also centered here. The rehabilitation center has an evaluation kitchen where campers can receive some hints on independent living.

Swimming opportunities are provided in the indoor pool of the CLH Occupational Home, which is on the same acreage. In the summer, a flatbed “open-air taxi” pulled by tractor transports campers back and forth to the pool. An outdoor pool at the campsite is in the projected plans for the future.

One of the main purposes of the Christian League for the Handicapped is to meet the spiritual needs of physically handicapped people, and therefore the chapel is a focal point of the lodge and of its planned program. The room is simple in design and has panelled walls and rustic chandeliers. A single antique stained-glass window is set in the front wall.

The Christian League for the Handicapped is a non-profit corporation supported by individual and organizational gifts and grants. Many individuals have given of



New conference and retreat center in Walworth, Wisconsin.

their time and know-how (such as the architect, who donated his services, and the men who hauled and assembled the local stone for the fireplace), and hundreds of people have contributed gifts ranging from \$1 to \$25,000.

Inspiration Center is located in southern Wisconsin in the Geneva Lake area. The entrance is at the corner of Highway 67 and County Road F, about one mile west of Williams Bay. The retreat center can be rented for retreats, seminars, conferences, and dinner meetings. For further details, write to Clark S. Dempsey, Camp Director, Box 98, Walworth, Wisconsin 53184.

## The Ministry and the Blind

by Arthur L. Jackson

As a young person, I soon became aware that working opportunities would be less for me because of my minimal visual ability. After working for ten years at various occupations with modest satisfaction, I felt called to enter the ministry. I enrolled at the Philadelphia College of Bible and the following year entered the Reformed Episcopal Seminary in Philadelphia. Before graduation, I served a small mission parish. When I graduated in 1964, I was assigned two additional congregations in the Mennonite Conference. In 1966, I was asked to pastor a suburban Mennonite church in Toledo, Ohio. I remained there until my move to Chicago in 1968, where I pastored until I retired in 1972 for personal reasons.

During my years of active service in the Mennonite Church, I found little discrimination because of my blindness. Rather, I found warm acceptance of my counseling and outreach activity by those rural and urban Mennonites whom I served.

Although the salaries were modest, the sincere manner in which I was received far exceeded that of other



Arthur Jackson, "During my service in the Mennonite Church, I found little discrimination because of my blindness."

denominations that were less favorable towards qualified ministers who are blind.

I acquired my M.S. in rehabilitation administration at Southern Illinois University and I am now employed as an instructor of the older blind at Black Hawk College in Moline, Illinois.

As I look back over my years as a minister, I feel that the ministry is a worthy field for the blind, even though it involves problems with travel and congregational politics. Now I yearn for a university campus where I might pursue my interest concerning the elderly and especially those with visual or physical impairments. Much of the peace that older persons possess can be traced to the religious peace that they may have gained in their earlier life, and much of their loneliness can be resolved by the personal nature that a religious identity can offer.

Address: Arthur L. Jackson, E4, Riverview Apartments, Rock Island, Illinois 61201.



# Housing and Home Services 1978 Supplement

by Gini Laurie

The *Gazette* first published information on housing for the disabled in 1958. In virtually every issue since then it has reported developments in housing and services in the United States and abroad. The information thus accumulated is now available in a comprehensive collection in my book, *Housing and Home Services for the Disabled* — subtitled, *Guidelines and Experiences in Independent Living* — which Harper & Row published in 1977. Details, including the table of contents, are at the end of this article.

To keep readers of the *Gazette* and of our book up-to-date on what is happening in the fields of housing and services, we present this supplement. It is a combination of an annotated bibliography and a list of relevant bits and pieces of information. We hope that our readers will continue to keep us informed about what is going on in their communities so that we can continue this supplement in future issues.

## Architects' Services

Barrier Free Environments, Inc., Suite 814, Wachovia Building, P.O. Box 53446, Fayetteville, North Carolina 28305. Architectural and design consulting firm for federal and state agencies, national organizations, and private industry.

Community Independent Living, Inc., P.O. Box 991, Monroe, Georgia 30655. Nonprofit firm composed of disabled and non-disabled social workers and architects.

Interface, Box 5688, Raleigh, North Carolina 27607. Custom-tailored home construction and modifications. Phone consultations. Advisory services. Designs for deafness awareness.

Sally Swanson Human Systems in Space, 4489 17th Street, San Francisco, California 94114. Design consulting firm. Free consultation on compliance with regulations and codes to business, industry, and schools. Construct and remodel homes for disabled. When Ed Roberts' home was remodelled, walls were opened or removed and his iron lung motorized so he could move through his environment.

Building Design Associates, P.O. Box 11954, Columbia, South Carolina 29201. Group of management specialists, architects, and engineers. Barrier removal services to public and private owners.

Design Center for the Deaf, Department of Environmental Design, Rochester Institute of Technology, College of Fine and Applied Arts, 1 Lomb Memorial Drive, Rochester, New York 14623. Provides special criteria of the hearing-impaired to archi-

texts and designers. Contains a data bank. Information by mail or phone (716/464-2653).

## Bathrooms

Acrylic, one-piece shower stall. Waugh Co., P.O. Box 12264, Jacksonville, Florida 32209.

Molded fiberglass, roll-in shower. The Braun Corporation, 1014 South Monticello, Winamac, Indiana 46996.

Complete bathroom package. One-piece, fiberglass shower stall, 18" toilet, and sink with lever-type fittings. Universal-Rundle Corporation, 217 North Mill Street, New Castle, Pennsylvania 16103.

## Building Codes/Standards

*Accessible Architecture: An Illustrated Handbook Based on Minnesota Building Code Chapter 55.* Illustrated and edited by Harold Kiewel and John Salmen. 1977. Sponsored by the City Council of Minneapolis on the Handicapped and the Advisory Committee to the Mayor.

Connecticut. Effective October 1977, most public and private buildings must be accessible. Regulations include new or renovated buildings, apartments, motels and hotels with more than four units. Public buildings include both State and municipal buildings.

New Jersey. The new regulations are available for \$2 from the Barrier Design Office, Division of Building and Construction, Box 1243, Trenton, New Jersey 08625.



*Universal-Rundle's complete bath for the disabled.*

Michigan. *Barrier Free Design. A Design Manual Based on the Michigan Construction Code.* By Georges Selim, P.E. Order from The Office of Disabled Student Services, 2211 Michigan Union Building, University of Michigan, Ann Arbor, Michigan 48109. \$8 (Payable to the U of Michigan). 180 pages. 1977.

ANSI. *Proposed: ANSI A 117.1 (1977) Specifications for Making Buildings and Facilities Accessible to and Usable by Physically Handicapped People.* \$3.25 from Syracuse University, School of Architecture, Research Office, 118 Clarendon Street, Syracuse, New York 13210.

## Hardware

Electric door and window openers: (1) Power Access Corporation, Box 139, Eatontown, New Jersey 07724. (2) Horton Automatics, 4242 Baldwin Boulevard, Corpus Christi, Texas 78405. (3) Prentke Romich Company, RD 2, Box 191, Shreve, Ohio 44676.

## HUD

To keep informed about HUD's programs, ask to have your name put on the mailing list for program announcements by contacting Press Release Center, Room 9239, HUD, Washington, DC 20410.

*HUD Programs.* Request #HUD-214-3-PA from Director of New Services, Office of Public Affairs, Room 9245, HUD, Washington, DC 20410.

*HUD Programs That Can Help The Handicapped.* Request publication #HUD-467-NNGOCP from the Office of Independent Living for the Disabled, Room 9106, Washington, DC 20410.

*Programs of HUD.* Published in September 1977, this 150-page compendium contains a one-page description of HUD's program's. Single copies free from Publications Service Center, HUD, Room B-258, Washington, DC 20410.

*Selected Publications Checklist.* Published January 1976. Request #HUD-170-1A-(2) from HUD, Washington, DC 20410.

*HUD and the Handicapped.* Guide to barrier-free design, including specifics on kitchens and bathrooms. Developed by area office of HUD in Minneapolis and the Handicap Housing Service, Inc. (HHS). Free from HHS, 230 Metro Square, 7th and Robert Streets, St. Paul, Minnesota 55101. (The executive director of HHS, Mary O'Hara, wrote, "I would like to hear from others who are concerned because HUD has not issued regulations or guidelines on housing for the disabled.")

## HUD, Section 8

Section 8 regulations for small group residences are available from Chief, Existing Housing Branch, Office of Assisted Housing Development, HUD, 451 Seventh Street, SW, Washington, DC 20410. An "independent group residence" is defined as "privately owned housing for the exclusive use of no more than sixteen eligible" elderly and disabled persons who require "a planned program of continuous supportive services or supervi-

sion, but do not require continuous nursing or medical care." For Section 8 purposes, residents may be considered as a family or as individuals.

Buffalo, New York, gives priority to persons who are disabled in allotting Section 8 rent subsidies. A coalition of organizations effected the priority.

Albuquerque, New Mexico. The local NPF/PVA Chapter assists with certification for Section 8.

## Independent Living

*Handicapped at Home.* By Sydney Foott. Published by Design Council, 28 Haymarket, London SW1, England. 1.85 pounds (about \$3.60 plus postage). Attractive and informative. Stresses careful planning and attention to details. Central theme is author's belief that independence is the driving force that enables a handicapped person to live a normal life. She warns against too much pampering. "It becomes fatally easy to take over from a disabled person, leaving him no responsibility for his own life . . . nothing should be dismissed as impossible or too difficult until it has been carefully considered."

*Home Management. One of the Equipment for the Disabled* series which has been revised and expanded. Contains guidelines for planning kitchen layout and equipment; suggests solutions. 5 pounds. Available from Equipment for the Disabled, 2 Foredown Drive, Portslade, Brighton BN4 2BB, England.

*Independent Living* by Susan S. Pflueger, with a foreword by Edward V. Roberts. Reviews pertinent legislative history, current issues, and estimates of target population. Presents major models of independent living. Free, while supply lasts, from Institute for Research Utilization, Washington Transportation Alliance, 719 Delaware Avenue, SW, Washington, DC 20024.

## Independent Living Learning

United Cerebral Palsy Association, 7117 S.E. Harold Street, Portland, Oregon 97206. Apartment Living Program trains for transition from a group home or foster care to an independent situation. Two specialists give training in cooking, shopping, money management, personal hygiene, housekeeping, and leisure activities.

New Options, TIRR Annex, 105 Drew Street, Houston, Texas 77006. Six-week, live-in program includes peer counseling, field trips, psychological assessment and consultation, transportation, financial and home management, social and functional skills, sexuality, exploration of vocational and educational opportunities, and group discussions. Details from Dr. Jean Cole, Project Director.

Worcester Area Transitional Housing, 507 Main Street, Worcester, Massachusetts 01608. Director: Donald Riel. 19 residents. Small, individual rooms with shared baths. Meals in a cafeteria. Section 8. Per diem of \$23.50 includes attendant care, counseling, training, transportation, room, and board. Majority from institutions. Ages 18-40.

## Kitchens

Geo. A. Moore & Co. Ltd., Attention: Ian Keen, Thorp Arch

Trading Estate, Wetherby, West Yorkshire LS23 7DD, England. England's leading manufacturer of contract kitchen furniture has developed a line of flexible kitchen cupboards and worktops. Attractive brochure! (Interested in export.)

### Legislation (Passed) Relating to Independent Living

California AB922. This important law, which became effective January 1978, removes disincentives by removing existing restrictions on income. As personal income increases, the State pays a smaller portion for support services, such as attendant care and Medi-Cal. Before, SSI benefits were terminated when disabled recipient earned \$200 or more; this resulted in immediate cut-off of attendant care and Medi-Cal. Under the new law, funds are available to employed persons no longer receiving SSI if they require at least 20 hours of care per week in their home and if their income is insufficient to pay for the services.

New York State S.6345. "Medicaid eligible persons who are in or who qualify for a nursing home or other health care facility may receive home care services instead. If it is appropriate to their needs, Medicaid will pay for up to 75% of the average cost in their county of the institutional care for which they qualify." The new law defines home care services broadly to include homemaker, housekeeping, personal care, and chore service. To be eligible, the program must be under governmental or voluntary nonprofit auspices.

A Medicaid regulation that can be used for statewide home care has been in effect since February 1, 1970, yet few States have utilized it. The regulation, 249.10 (b) (15) (vii) states that payments can be made for "personal care services in a recipient's home rendered by an individual, not a member of the family, who is qualified to provide such services, where the services are prescribed by a physician in accordance with a plan of treatment and supervised by a registered nurse."

### Legislation (Proposed) Relating to Independent Living

National: H.R. 8341. Introduced by Mario Biaggi of New York. Would provide home health aides funded by Medicaid to non-Medicaid eligible severely disabled individuals who could work or engage in gainful activity if they had such assistance.

State: H.R. 6577 introduced by the former Representative Koch of New York in April 1977. Would establish a system for promoting the creation of independent living centers within the Office of Human Development of HEW, making available \$250,000 for centers in each State.

### Mobile/Modular Homes

FHA loan insurance has been expanded to cover the combination of mobile homes plus their sites; mobile homes now eligible under the Section 235 Homeownership Subsidy Program.

Donnington Mobile Homes for the Handicapped, 52-60 The Broadway, Dicot, Oxfordshire, England. Sales manager and designer: Roger J. Sylvester. Standard models are 30', 36', and 43' x 10' wide.

Jafny Manufactured Homes, 2414 East F, Tacoma, Washington 98421. Mobile home called the "Barrier Breaker."

### Modification Services

Robertson Custom Aids Ltd., 777 Warden Avenue, Unit 11A, Scarborough, Ontario M1L 4C3, Canada. Manufactures, installs, and services lifts and elevators (4' to 30') and makes modifications to bathrooms, doorways, entrances, and kitchens.

R.J. Chairlift Company, Inc., 715 Fifth Avenue, Maywood, Illinois 60153. Vertical and stair lifts for residences and commercial buildings. Complete package of services for mobility.

### Remodeling Grants

Minnesota HF875. Provides grants up to \$5000 to low income residents for rehabilitation of their homes, plus an additional \$2500 for removal of architectural barriers if the resident is disabled. Grants to make one- and two-unit dwellings more accessible are available from the State-financed Accessibility Improvement Incentive Fund. \$500,000 was appropriated by the 1977 Minnesota legislature. Grants are distributed through local Housing and Rehabilitation Authorities. To provide technical assistance, MHFA contracted with Handicapped Housing Services, Inc., 230 Metro Square, 7th and Robert Streets, Minneapolis, Minnesota 55101. (612/222-1813)

### Resource Guides

*Resource Guide to Literature on Barrier-Free Environments*. With Selected Annotations. By the Architectural and Transportation Barriers Compliance Board, Washington, DC 20201. January 1977. 223 pages. Topics cover architecture, transportation, parks and recreation, standards, legislation, statistics, and human factors research. Appendices cover travel guides and periodicals and organizations related to environments or services. Very useful. Free.

*Barriers and Bridges. An Overview of Vocational Services Available For Handicapped Californians*. Attractive, well organized, comprehensive guide. Useful to disabled individuals and professional personnel anywhere. 149 pages. 1977. \$3 from California State Department of General Services, Office of Procurement, Publications Section, P.O. Box 1015, North Highlands, California 95660.

*Bibliography on Architectural Barriers*. Free from Reference Section, Division for the Blind and Physically Handicapped, Library of Congress, Washington, DC 20542.

*Home In A Wheelchair*. By Joseph Chasin. \$2.50 from the Paralyzed Veterans of America, 7315 Wisconsin Avenue, Washington, DC 20014. 1977. 32 pages. Basic and comprehensive.

*Design Criteria: New Public Buildings Accessibility*. 157 pages. Attractively illustrated. Clearly presented. \$2.60 from Public Buildings Service, General Services Administration, 1500 East Bannister Road, Kansas City, Missouri 64131.

*Open House - Preparing a Successful Home Environment for the Wheelchair User*. Free from Access Chicago, Rehabilitation Institute of Chicago, 342 East Superior Street, Chicago, Illinois 60611.



## Respite Care/Day Care Centers

*A Community Respite Care Program for the Mentally Retarded and/or Physically Handicapped. A Handbook.* By Deanna Shoob, Childcare Assistance Program for Special Children, Inc., Box 1217, Springfield, Virginia 22151. Excellent summary of a low budget community program that furnishes trained care in and out of home for disabled of all ages. Lists other respite programs around the country.

*Developing A Day Center For Disabled Adults: The Kenny Experience.* By Margaret Dawson. 40 Pages. Describes process of developing a center. \$3.25, plus \$1 on orders less than \$5. Publications, A/V Dept., #280, Sister Kenny Institute, Chicago Avenue at 27th Street, Minneapolis, Minnesota 55407.

In December 1977, HEW clarified Title XX funds for day care equipment and supplies, renovations, and minor construction. Details from Mrs. Jonnie U. Brooks, Office of Policy Development, Interpretation, and Coordination, DHEW, Mary Switzer Building, 330 C Street, SW, Washington, DC 20201.

## Services, Innovative

In a program called Easy Ride, ex-drug offenders receive training in driving and escorting disabled and elderly citizens on weekly errands. Program directed by Wildcat Corp., an ex-offenders' organization.

MS Chapters of the Atlantic Division, Canada, offer an annual course in home care for the relatives and friends of persons with MS. Wide range of topics, from aids to sexuality.

Self-help program of exchange of skills and talents. For details, send an addressed and stamped envelope to: Useful Services Exchange (USE), 1614 Washington Plaza, Wellborn Building, Reston, Virginia 22090.

*Homebound. Hopebound. Aimed Toward A Brighter Future.* 18-page booklet describes services funded by State of Alabama's program set up in 1975, including attendant care, transportation, home modification, and medical care and supplies. The program is administered by health teams of counselor, RN, PT, and secretary.

The Georgia Warm Springs Hospital, Warm Springs, Georgia 31830, has initiated a one million dollar, HEW-funded, project to research family acceptance and family involvement of the spinal cord injured. Director: Ernest L. Craft.

Access Real Estate, Richard C. Weir, Sea Realty, Montauk Highway and Mill Road, Westhampton, New York 11977. Free national central registry of wheelchair accessible homes. Transactions handled through licensed brokers at standard fees.

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a new book from Harper & Row

## Housing and Home Services for the Disabled

### Guidelines and Experiences in Independent Living

by Gini Laurie, Editor/Publisher and Founder, "Rehabilitation Gazette," with contributions by Donna McGwinn, Book Editor, and Joseph Scott Laurie, Co-Editor. Cartoons by Robert E. Tanton, Jr., Art Editor. Preface by Isabel P. Robinault, Ph.D., Supervisor, Research Utilization Laboratory, ICD Rehabilitation and Research Center. 415 pages and index. 131 illus. 9 cartoons. \$20. Published in 1977.

HARPER & ROW, Publishers, Inc., Medical Department, 2350 Virginia Avenue, Hagerstown, Maryland 21740. (Phone: 301-733-2700. Ask for Mrs. Taylor.)

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# Books

by Donna McGwinn\*

## The Body is the Hero

By Ronald J. Glasser, M.D. Random House, Inc., 201 East 50th Street, New York, NY 10022. 1976. \$8.95. Do you ever think about your body and all the wondrous, purposeful tumult going on within it? Ever since my body was paralyzed I have been more aware of it than before, but I was never as awed and grateful for its performance until after I read this book. This is a magnificent, importantly informative work that everyone should read.

It takes a bit of concentration to get into and flow with this book, but once you do you will find it exciting. The subject is the body's immune system, how you manage to protect yourself from constant external and internal attacks. There is suspense and drama in the story, especially in the mysteries of the body as explored by doctors who challenged prevailing medical theories to discover facts and cures that are responsible for many *Gazette* readers being alive today. These doctors persisted with their explorings despite ridicule and diatribe from their medical peers. Dozens of these fascinating human stories remind readers that the things they take for granted — moving, breathing, seeing, hearing, life itself — are possible only because of their ever-vigilant immune system and the dedicated efforts of doctors and researchers who care.

## Born on the Fourth of July

By Ron Kovic. McGraw-Hill Book Company, 1221 Avenue of the Americas, New York, NY. 10020. 1976. \$7.95. Quite a book. I read it in one night. A movie is being made from it. A lot of people are talking about it. It is earthy and bitter and will make a lasting impression. Throughout are the illusions and ironies of patriotism as experienced by one born on the fourth of July.

Ron Kovic makes us think again about Vietnam and what it did to him and thousands of others, to our country, our institutions, our beliefs and, indeed, our whole way of life. He begins his autobiography as a young Catholic boy with high ideals who aspires to be a Marine. This he achieves and goes to fight in Vietnam. There he discovers how glorious war can be — killing his own men in a panic, blasting off the heads and limbs of children and old men by mistake, carrying and bandaging shattered bodies and not being able to feel or move after a bullet tears through his lung and spinal cord.

After he leaves Vietnam the sobering lessons continue: hospitals are hell, people don't cheer when he rides as grand marshal in a parade, loving and lovemaking are traumatic, the war is insane, and when he protests against

it he is beaten and thrown into jail. If anyone wants to know how a wounded Vietnam vet feels and how he is different from wounded vets from other conflicts, he will find the answer in this book.

## Handbook for Helpers

By Lillian Petock Crowley, National Impediment Registry, Inc., Freedom Gardens, Mohegan Lake, New York 10547. 1977. \$5. Crowley has undertaken to inform those who help the disabled with the everyday tasks of living of the best attitudes and procedures for that service. Her effort is appreciated, for training can be energy- and patience-draining, and Crowley makes several good points that it is important for helpers to know. Also, I like the idea of a national pool of helpers toward which book profits will go. On the other hand, my feeling is that each person's needs and wishes are so personal that it is hard to generalize in a book of this sort. It is like having a handbook for housekeepers, cooks, secretaries, and valets.

## It's Hard To Leave While The Music's Playing

By I.S. Cooper, W.W. Norton & Co., Inc., 500 Fifth Avenue, New York, NY 10036. 1977. \$7.95. "Carpe diem — seize the day. Grab it, each moment." This was the philosophy of Louis Morell who at age 50 discovered that he had amyotrophic lateral sclerosis, a progressive, fatal disease that paralyzes the nervous system. It is sometimes known as Lou Gehrig's disease, named for the famous baseball player who was disabled by it.

The author is an internationally renowned brain surgeon. His medical knowledge is evident throughout this story that is told from the point of view of Dr. Daniel Carter, Morell's best friend. Dr. Carter is on trial for the murder of Morell in the opening pages.

Cooper's absorbing, dramatically written novel compels the reader to think about such things as friendship, duty, morals, purpose, love, and euthanasia. Its haunting title comes from the music of life and ambition that lure Morell toward the top. He is near the peak when he realizes he is going to die.

## Joni

By Joni Eareckson with Joe Musser. Zondervan Publishing House, Grand Rapids, Michigan 49506. 1976. \$6.95. An athletic, high-spirited girl of 17 breaks her neck in a diving accident at which point she begins "... an incredible adventure which I feel compelled to share because of what I have learned." *Joni shares her feelings and experiences honestly and in detail. The reader feels what it is like to be skewered to a Stryker frame with her*

\*Donna died of a perforated ulcer on April 9, 1978.

head shaved, to have friends shrink from her appearance, and to be frustrated in her desires to move or be held and loved.

The reader also feels Joni's change in attitude and spirit as she turns her life over to Christ and accepts the belief that there is purpose and meaning for her even though she cannot move or take care of her physical needs. Her relationships improve, she experiences the joy and sorrow of romantic love, and she develops her ability to draw and become self-supporting. A really good story, well-written, with many pictures of the author's family, friends, and art work.

### Winning

By Robin F. Brancato. Alfred A. Knopf, Inc., 201 East 50th Street, New York, NY 10022. 1977. \$7.95. It is hard to tell a story about life as a quad unless you've been

one, lived with one, or are an empathetic, skilled novelist. Brancato is the latter and presents this fast-moving, believable experience of a high school football player who tackles hard enough to permanently injure his spinal cord and become a quad. One area of concern, and it is a large area, is untouched by the author, and that is people upon whom one depends, either family or staff, who are uncaring, hostile, or dangerously inefficient.

Gary Madden goes through the various stages of adjustment to paralysis with the help of his parents, friends, girlfriend, and English teacher. His teacher encourages him to write a journal that charts his thoughts in the hospital and later in the rehabilitation center. In this way she learns that, despite his rehabilitation progress, he despairs that he will be nothing but a burden to those who love him. At this crucial point she assures him that many people need him, including herself.

## Travel

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### Security in Transcience

by *Andrea Cappaert*

When my friend, DaleAnn, and I knew that the time had come to leave our hometown in Michigan, we were ready to go within 24 hours. We threw our clothes in knapsacks, our knapsacks in Big Blue (a van borrowed from my parents that has space for my wheelchair and a backup to the car's battery for my respirator), loaded my iron lung into a rented U-Haul, found a driver on a bulletin board to share the 1200-mile drive, and set out for unknown and random New Orleans.

The next two weeks were an exhilarating struggle for survival. We moved down Airline Highway from the \$18 to the \$12 to the \$8 motel. Our search for less expensive quarters led us next to the cavernous basement of a boarding house jokingly called "The Palace" where DaleAnn swept ten years worth of cigarette butts into a corner for a rent reduction. Finally, with our last \$50 we rented a room on Carondelet Street.

Each move involved moving the iron lung (800 lbs., 7 ft. long, 3 ft. wide, and 5 ft. tall), and these moving escapades became our version of street theater. We had learned a lot standing in motel parking lots at 3 a.m. (no matter when we set out we seem to arrive at 3 a.m.) trying to recruit the three to five characters it takes to move the iron lung from a trailer into a room.

On our first move we made the error of selecting a pair of gentlemen emerging from the motel bar. By our third move, we concluded that truck drivers were our best risk. They pull in and out of motels at all hours and know how

to move heavy machinery without injuring themselves.

Our next challenge, now that a place to stay was resolved, was to replace our depleted stash of money. Of the two of us, DaleAnn was the more likely to find an immediate job. She was intrigued with the topless dancing jobs on Bourbon Street and we were surprised when the first joint she tried out in accepted her.

The eight-hour job created a dilemma for the two of us. We needed cash to hire helpers for me, to relieve DaleAnn of her full-time responsibility. But the catch was that we needed helpers immediately so that she could be free for eight hours to earn that money.

We agreed that I should not stay alone in the tiny room we had rented. Besides the monotony of it, there was no way that I could contact the outside world for help if I needed it. Southern Bell Telephone phone deposits make it rare for low-income people to possess telephones and with our combined resources of 74 cents we certainly fit that category.

To keep me from going stir crazy, we needed accessible public places with outlets to plug my respirator into. (Half of the French Quarter runs on European voltage; we never knew if an outlet would carry the correct voltage for the respirator.) We needed an assortment of part-time helpers. The transient on-the-road culture of the French Quarter was conducive to finding people to hang out with. I remembered the street people I'd met while working at a runaway center in my hometown. We looked in the phone book and, sure enough, there was a similar center in New Orleans. We were lucky to come in contact with a core gang who lived in a crumbling hotel on Dumaine Street. As I observed the chain of people flowing through this hotel I began to grasp the feeling of

security within transiency and I began to understand why my seasons on the road have been my most secure periods. The settled world forgets how immediate needs can be, but the road cuts through the layers of routine leaving needs bare as it cuts through mountains revealing the layers of rock.

Address: Andrea Cappaert, 839 Oakland, Ann Arbor, Michigan 48104.

## Wheelchairing Around Europe

by Eileen Van Albert

I left on May 29th and returned on July 28. I landed in Brussels, rented a Polo VW, and toured Belgium, Holland, West Germany (going through East Germany to Berlin with a three-hour bus tour through East Berlin), then via Hamburg to Denmark, Sweden, Norway, and England.

I had a great attendant with me. She is tall, blonde, strong, and so attractive in face and manner that we had all kinds of masculine help.

We took the Göta Canal boat trip from Stockholm to Göteborg. It lasted three days and two nights. I recommend it highly. People make reservations a year in advance but we were lucky and got one twelve days in advance. Of course, we had to take one of the higher-priced deck cabins. My attendant swung me from my wheelchair outside the bulkhead of our door to my lower bunk. The bathroom was down the way, so I used the waste basket.

Another tour, by bus and ferry from Oslo to Bergen, a few days in Bergen, then by train to Oslo, was as dramatic as anything I've ever seen.

We kept the Polo for five weeks, until we reached Stockholm. We used Avis rentals this time. We were advised to try Esso rentals next time because they are cheaper and the Esso and OK motels have at least one room in each place for wheelchairs.

Here in Guadalajara, I have a new guest residence for the wheelchair and have some openings for both men and women. Ken has some space too, but he takes men only. If anyone wants to stay here, call me for reservations at 21-38-22.

Address: Eileen Van Albert, Apdo. 5-208, Guadalajara, Jalisco, Mexico.

## The Galloping Wheelchair

by Selma Z. Sack

I did it! I finally did it! I rode in a public bus feeling like an ordinary commuter and not like a third-class citizen (something a handicapped person in a wheelchair is often referred to).

I have multiple sclerosis and I am in a wheelchair. I still

refuse to be a shut-in. I don't have a car so I have to rely on taxis to take me here, there, and everywhere. I live in El Cajon and use the Yellow Cab Service for my transportation.

I have often said to the various cab drivers, "Too bad this Yellow Cab does not go all the way down to San Diego as there are so many interesting things I would like to see but my wheelchair is holding me back." "Really" said one driver. "Don't use a pair of wheels as an excuse. If you really want to go alone you have to make a special effort, but it can be done."

On August 23, 1977 I called the Bus Transportation Corporation of San Diego to make a definite appointment for Bus #7 to meet me the following day (this bus has a wheelchair lift). I was told to meet the bus at the starting point — 69th Street & University Avenue in San Diego at 1:00 p.m. on the following day.

On August 24, 1977 at 11:45 a.m. I called the Yellow Cab Co., requesting a cab to take me to the end of the line where I was to meet the Dial-A-Ride cab. Then the Dial-A-Ride cab of La Mesa was going to take me to meet the "Special Bus" with a wheelchair lift.

In ten minutes the Yellow Cab was in front of my home. When I entered the cab I proceeded to give the driver the fare (one yellow ticket worth 50 cents). The driver was told by his dispatcher where I was going. In ten minutes we arrived in La Mesa to find the Dial-A-Ride cab waiting for me. My driver told the other cab driver that I had a wheelchair. Before I was able to move, the two cabs parked very close to each other thus making it easier for me to transfer. I took two steps while the drivers held me by my elbows, thus I was able to enter the awaiting cab easily. My wheelchair was also transferred to the trunk of the awaiting cab.

In the Dial-A-Ride cab I asked the driver what the fare was. I was told that it would be 65 cents one way, but he would give me a transfer to be used on the bus. When we arrived at the bus stop the cab driver said he had to leave, but that the "Special Bus" would come along exactly at 1:00 p.m. (in 40 minutes).

When the bus finally arrived it stopped near the curb. The bus driver pressed a button near the steering wheel and the steps moved down (similar to an escalator). Another step shot out (similar to a drawer) and I, in my wheelchair, feeling a bit nervous, got on this small platform. I was told to close my brakes. The platform then went up to meet the floor of the bus. I then unlocked my brakes and drove into the space reserved for a wheelchair. My back wheels were locked into place on the floor of the bus plus a seatbelt was put around my waist, then off we went. This took three minutes.

I then asked the driver what the fare was. I was told that since I had a transfer from the cab there would be no charge. It's all unbelievable!

I am glad that I wore my dark sun glasses as it hid the tears. This is the first time in 10 years that I have been able to ride in a public bus.

I asked the bus driver to stop at the Zoo stop. At my

stop the bus came to a halt near the curb. The same procedure occurred, the driver pressed the button, the steps turned into an elevator, and off I went. I was told to go straight ahead for two blocks then I would come to the Zoo entrance.

When I got off the bus I was lucky to see a young couple walking in the same direction as I. He asked, "Would you like a push?" "Yes," I answered, "that would be great." He then pushed me to the entrance, I paid my admission, and rolled in.

A park guide told me that I would be able to get on the sightseeing bus. At the bus depot I bought a ticket for \$1.50 and had a short wait for the next bus. When the bus arrived I was surprised at seeing the steps as I had expected to see a ramp or small elevator as the guide had told me that I would not have any trouble getting on. Two unformed guides lifted me out of my chair and carried me on to the bus and placed me in the first seat near a window. My chair was folded and left in the office at the depot until my return. As I saw two other folded wheelchairs standing there I felt my chair would be safe.

The ride through the zoo was interesting. Many of the animals were snoozing due to the heat of the day. That bus ride lasted about 40 minutes. When I got off the bus I paid a visit to a nearby restroom. It was clean and had one large stall for a wheelchair. I ate lunch at a nearby lunch stand that had tables and chairs outdoors. A waitress brought my food over to the table. I ate slowly, looked about, relaxed, then I started the trip back home.

On the bus going home the fare was only 15 cents. I was surprised to see the driver talk into a phone to his office dispatcher. The phone was just above the driver's head. After asking me if I wanted a cab, he relayed the message to the dispatcher. When the bus returned to 69th Street and University Avenue, I had a short wait of ten minutes before the Dial-A-Ride cab showed up.

I must admit it was a very strenuous day, but it was worth it. Now that I have found that I can use the bus I intend to do so again and again.

Address: Mrs. Selma Z. Sack, 1052 Redwood Avenue, Apt. 6, El Cajon, California 92020.

## Friends Around the World

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How to pass time? This question came to me when I came back from S.S.K.M. Hospital, Calcutta, after a three months stay as a C5-6 spinal injured patient to my home town, Puralia, with no clear idea about my future.

"All of a sudden I thought that I will have to make some arrangement for me. But that must be done by myself only. So I started communicating with people in the line of rehabilitation in my country and abroad. I wrote to Harper & Row Medical Book Department and the publisher sent my letter to Mrs. Gini Laurie of the *Rehabilitation Gazette*. So I came to know about associations like Rehabilitation International, journals like *Rehabilitation Gazette*, and disabled persons like Dr. Masao Nagai and Dr. Mary Verghese, who are still in their profession and doing great works in the line of rehabilitation.

"At the midst of negative and semi-positive replies of my letters I received a positive reply from one gentleman, whose address I had from an issue of the *Gazette*. Yes, he is Dr. Howard A. Rusk, MD, president, World Rehabilitation Fund. He offered me a fellowship from W.R.F. and, through Prof. M. Natarajan, arranged a training programme for me in rehabilitation medicine at Government General Hospital, Madras, under Prof. T.K. Shanmugasundaram, Prof. S. Soundar Pandian, Prof. I.S. Shanmugam, and Prof. K. Janardhanam. I shall be finishing my training programme in October 1978.

"After this I want to move from one end of my country to the other end, to meet people like me and their

families who think that after a man is disabled there is no other way out except for death. At this era of science, I know now that this does not stand. "But for these plans I am in need of a vehicle and finance too. It will be a great pleasure and I shall be thankful if any person or any association can help me in this.

"Lastly, no doubt it is true my family and my friends had to suffer a great deal. Without them it was not possible for me to keep my morale up and I would not have come to this present physical condition of mine.

"But I shall be lacking if I do not send my thanks through this article to the following associations and personalities: Leprosy Mission, Puralia; Harper & Row Publishers; Rehabilitation International; Spinal Injuries Association of England; Mr. Eugene J. Taylor; Mrs. Gini and Mr. Joe Laurie; Prof. M. Natarajan; Dr. W.G. Rama Rao; Mrs. Kamala V. Nimbkar; Principal, Madras Medical College; Dr. V.C. Jayram and his family; Mr. Vasudevan and his family; respected professors of Department of Orthopaedic Surgery, Physical Medicine and Rehabilitation, my trainee friends, staffs, and students of School of Physical Medicine."

Dr. Pradip Mumar Mallick, c/o Prof. I.S. Shanmugam, M.B., D.Orth., D. Phys. Med. (Lond), Department of Physical Medicine and Rehabilitation, Government General Hospital, Madras, 600 003, India.

"I have heard about the rehabilitating gazette and seen it from Dr. Mallick. I am a medical student. I met with an

accident which resulted in traumatic paraplegia. I would like to have an electrically powered wheelchair from the U.S. Will any philanthropists or any social service clubs, like Lions or Rotary Clubs, help me to get it as it is impossible for me to pay the cost along with the import and excise duties?" *M. Srinivasan, B.Sc., (M.B., B.S.), 14, J.P. East Street, Kumbakonam 612 001, India.*

"Through Mrs. Ida Daly from Seattle, we came to know about Gini Laurie's book, *Housing and Home Services for the Disabled*, and we were lucky to get a copy of it in New Delhi. We have to compliment you for this book . . . My husband and myself are about to join a training in Rehabilitation work with all kinds of disabled people with the goal later to start a new Rehabilitation centre somewhere in India." *Mrs. Doris Ngodup-Widra, c/o Library of Tibetan Works + Archives, Ganchen Kyishong, Dharamsala, Dist. Kangra, H.P., India.*

"I wonder if any American reader would care to exchange letters with me. I will be 52 this year and live in a bedsitter with my budgerigar. I was disabled through a fall downstairs in 1966 so I walk with the aid of a stick. I miss letters from the States. I used to hear from aunts in El Paso and Asheville and an ancestor of mine opened the Broadhurst Theatre in New York." *Miss C.W.M. Broadhurst, 20 Locksley Way, North Somercotes, near Louth, Lincolnshire, LN11 7QR, England.*

"I have returned safely from Manila and Hong Kong. Thank you very much indeed for giving the names and addresses of *Gazette* friends there. Your reply was prompt as before when you gave me names for my trip to Europe (*Rehabilitation Gazette*, 1972, pages 34-35) . . . In Manila, I visited Father James B. Reuter, S.J. at an auditorium where he was conducting a stage show by the disabled . . . In Hong Kong, Colin Chan, Jenny Lung, and their able-bodied friends met me at the airport and Colin arranged everything for me and called for me at my hotel every morning. He is really wonderful, a school teacher of 36, speaking good English, driving an Austin Mini with hand control, having a lovely wife, Merlin, and lots of friends. He did his best for me . . . I visited Mr. Siu Chow Chiu in his hospital." *Naoyuki Ishizaka, Kanouzan-Jishudai, Futtsu, Chiba 299-16, Japan.*

"Since my retirement from the Canadian Paraplegic Association, I have kept busy at a number of things without being tied down . . . The Association in Edmonton is in good hands and I am happy I made the change when I did. The Old Guard in CPA is moving on . . . My friends in the respiratory polio group continue to live life to the full. Gary McPherson is still the executive director of the Canadian Wheelchair Sports Association. He was presented to the Queen last fall when she was in Ottawa . . . The computer programmers are still active and the Pro-Data firm maintains its reputation for quality and performance . . . Henri Baril and Fred Kijek are still

scholars with the International Association of Mouth and Foot Painting Artists . . . A Recreational Centre for the Disabled is being built in Edmonton under the sponsorship of the Associated Canadian Travellers . . . Finally, a group of some thirty Edmontonians (half of them disabled) travelled to Japan last February in response to a visit made here by a group of Japanese some eighteen months previous. They were very well received and enjoyed their visit tremendously." *Pierre Gariépy, 11910-87th Avenue, Edmonton, Alberta, Canada.*

"The *Rehabilitation Gazette* is an excellent, informative resource for rehabilitation. I would like you to send a copy to friends in Bangladesh who are working on the only project in that country to help traumatic paraplegics and quadriplegics: Ms. Valerie Taylor, *Volunteer Services Overseas, P.O. Box 406, Dacca, Bangladesh.*" *Jill Jones, 1300 Oakland Road NE, #1414, Cedar Rapids, Iowa 52402.*

"I am an orthopaedically disabled person and I am 28 years old. I have been practising the chartered account-



"I lost my two legs in the Nigerian Civil War in 1969 . . . I started high school in 1974 . . . My wheelchair wore out, so I was forced to stop school and to confine myself indoors and pine away." *Vincent Nwiguwe, Champagne House, Box 688, Uwani-Enugu, Anambra State, Nigeria.*



tancy profession for the last four years . . . I would like to have a friendship through the post with other disabled persons who are auditors or CPA's." *T.A.P. Varadakutti, Chartered Accountant, 107-A, Lake View Road, West Mambalam, Madras 600033, India.*

"Just to let you know that my book, *Atlantic Rendezvous*, can be obtained through a regular outlet in the United States: Fowler, Dick & Walter, The Boston Store, 15-25 South Main Street, Wilkes-Barre, Pennsylvania 18703." *Bill Murray, Ballure, The Glen, Ramsey, Isle of Man, British Isles.*

"After 22 years, ten of us post-polio friends still continue to correspond regularly through two separate Round Robin letters. Each letter makes the rounds every three or four months, bringing news, snapshots, and clippings of mutual interest to all of those participating. It is a good way to keep in touch with old friends, with the least amount of effort.

"My personal involvement in the two Round Robin letters stems from the fact that, while in my early twenties, I spent many months on two respiratory polio wards: Colorado General Hospital in Denver (1952-54), and Rancho Los Amigos Hospital in Downey, California (1954-55). Many of my friends, both at CGH and at Rancho, indicated an interest in corresponding after their release. Thus, when I returned to my home in Wyoming in June, 1955, I spearheaded an effort to organize Round Robin letters.

While neither group, today, can boast of having all of its original members, all gaps left by those no longer participating have been quickly filled by others — friends from adjoining wards, out-patients, and volunteer workers, among them — each eager to help keep the letters flowing. The members of the Denver-based Round Robin group are Norman Winchester, Boulder; Mrs. Richard (Carol) Jensen, Columbia, Maryland; Mrs. Robert (Helena) Ritchlin, Denver; Mrs. Bart (Donna) Pekar, Denver; Mrs. Barbara Pickett, Longmont, Colorado. Those from Rancho days are Mrs. Donald (Carol) Doss, South Gate; Mrs. Mary Jane Robinson, Long Beach; Mrs. William (Ruth) Van Oosting (volunteer), Pico Rivera; and Mrs. M.K. (Daisy) Lowrmore (volunteer), Ventura.

"With one exception, all of those participating in these two Round Robin letters reside at home. Their release from institutional care came during the 1950's through a special program sponsored by the March of Dimes to return post-polios to home surroundings whenever possible.

"For the most part, our Round Robin participants have been privileged to live near-normal lives among family members and friends. Letters, therefore, are generally filled with news of latest family activities, such as reports of weekend or holiday get-togethers, or maybe word of a newly arrived grandchild! Our letters have kept our long distance friendships going although most of us have not

seen each other since our days together in the respiratory wards.

"For those unfamiliar with the concept of Round Robin correspondence, the mechanics are quite simple. First, a list (complete with addresses) of those persons wishing to be included should be established. Each person, beginning with the first listed, then writes a letter and sends it to the succeeding name on the list — much the same as in a chain letter, minus the promise of monetary reward or other good fortune. Once the Round Robin has made a full round, with each letter in turn having been read by all, the person having written first removes his/her old letter and replaces it with an updated one. Then, once again, he/she sends the Round Robin on its way.

"For the ten of us, Round Robin correspondence has proved to be an excellent way to keep in touch. Otherwise, we'd probably write but once a year — and friendships reduced to such infrequent correspondence soon wither and are lost.

"Anyone wishing to discuss further the subject of Round Robin letters, write to me: *Mrs. Edward G. Leonard, Jr., P.O. Box 681, Douglas, Wyoming 82633.*

"Thank you for putting in the notice about my pen pal club, Friendship's Door, in the '76 *Gazette*. I received so many responses — most from people who live overseas! *Maxine Gabe, 2671 Emory Drive East, Apt. L, West Palm Beach, Florida 33406.*

"I feel so fortunate that I had been in Rehab Nursing for a number of years before I had a below the knee amputation. I would like to try to be of some help to some of the amputees who think they can't do things . . . I would love to hear from any amputees (in New Jersey, especially) with questions." *Louise B. Quinn, R.N., 15 Ventosa Drive, Morristown, New Jersey 07960.*

"After years of having my physical symptoms misdiagnosed by neurologists as 'nerves' and being sent off for psychiatric consultations, I learned that I have had a rare disease since birth: dystonia musculorum deformans (Ziehen-Oppenheim disease). It began to show at age 16 when I became unable to control my right leg during walking. I went to college and majored in psychology, then to a school for occupational therapy . . . All this while my bizarre gait and other symptoms increased and I saw many neurologists until I met with several at the University of Pennsylvania who made the DMD diagnosis. Subsequently, I went to the Neurological Institute at Columbia University and then to St. Barnabas in the Bronx to consult with Dr. Irving S. Cooper, a super specialist in DMD. If anyone wishes to know more of DMD, they may write to me." *Selma Ephross, 15 Juniper Drive, Doylestown, Pennsylvania 18901.*

"Recently, our respiratory polio group in the San Fernando Valley formed a Polio Survivors Foundation. One of our goals is to awaken the United States to the

need for immunization against polio . . . I am an upside-down polio and thank you for all the wonderful help you have given us through the years." *Nathalie Nelson, 4901 Escobedo Drive, Woodland Hills, California 91364.*

"I am sending for my second copy of *Housing and Home Services for the Disabled*. It's a virtual Bible." *Viola Hamby, Arthrogryposis Association, Inc., 3204 K Street, Vancouver, Washington, 98663.*

"I love your new book. I talked our local library into buying a copy. Then I liked it so well I bought a copy for myself." *Adelaide Janzen, P.O. Box 5655, San Jose,*

*California 95150.*

"Aside from the practical ideas in the book, it does encourage one to go ahead and think about some possible solutions. Thanks for writing it; the book is fun to read as well as educational." *Al Holloway, 5580 Woodsdale Road, Hanoverton, Ohio 44423.*

"Gini's book should be a must to anyone wanting to be worth his salt as a social worker, architect, designer, draughtsman, politician. . . . They should have a copy, preferably on a chain, around their necks." *Erich Krell, 15 Tester Drive, Blackwood, South Australia 5051, Australia.*

## Equipment/Reader's Ideas

*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.*

### Respiration Equipment

Advancements Over the Years.  
Equipment Now in Use, and Most Recent Developments

by *W. Sunny Weingarten*

It was in 1929 that a Harvard student named Philip Drinker made the first tank-type respirator. Mr. Drinker received little in the form of monetary reward for his invention which was the forerunner to what is commonly called the "iron lung."

In 1937 John H. Emerson designed and had manufactured what was the first modern iron lung. Like its forerunner, the iron lung requires the patient's entire body to be enclosed, with the exception of the head, in a pressure chamber which provides both negative (pulling) and positive (pushing) pressure produced by a bellows made to work by a small electric motor.

Iron lungs provide ventilation by creating a uniform pressure over the entire chest, thorax, and abdomen, forcing the patient to inhale room air through the nose or mouth.

Iron lungs were first used during the 1930's by polio patients who had become paralyzed from the neck down, temporarily or permanently. The manufacture of iron lungs was discontinued in 1959, three years after the introduction of the "Salk" polio vaccine which eliminated

the disease.

In 1949, both Huxley and Monaghan received patents on the first chest shell-type respirator. The negative and positive pressure was produced and provided by a separate pressure unit that was similar to a vacuum cleaner. The shell covered as much of the patient's chest, thorax, and abdomen as was physically possible with straps to hold it in place. The larger the area covered the better the ventilation. These respirators were more portable than the 800 lb. iron lungs, with the shell, hose assembly, and pressure unit weighing less than 100 pounds. Shortly thereafter they were adapted to run two to three hours off of a 12-volt auto battery.

During the early 1950's, several companies fabricated what was called the "rocking bed." It has been manufactured and made available by the J.H. Emerson Co. since 1953. In order to provide ventilation the bed is set with the patient in a lying 30° footdown position. When the electric motor makes the bed rock to a 30° headdown position the patient's diaphragm raises and exhalation occurs more easily. When the bed rocks back to a 30° footdown position the diaphragm lowers, with



*During daytime hours W. Sunny Weingarten uses a LPS positive pressure respirator with a mouth tube. The unit will run over 24 hours on one charged auto battery and has a built-in charger.*

the help of gravity, helping the patient to inhale.

In the middle 1950's, the first intermittent positive volume ventilators were used in hospitals only. These units were and still are being used by victims of pneumonia, poison, electric shock, asthma, spinal cord injury, and neurological disorders all of which can cause weakness or paralysis of the breathing muscles. The positive or blowing pressure ventilates the patient by forcing air through a surgical hole called a trachea, located in the recessed area above the collar bone. The Bennett Co. has been the chief maker of these hospital units since their introduction; the Emerson Co. came into production a little later.

In 1956, the Thompson Respirator Co. developed the first portable positive pressure respirator called the Bantam, which weighed only seventeen pounds and worked by way of trachea or mouth, providing the same ventilation as a volume ventilator. At this time Thompson also came out with its own chest shell along with the pneumobelt, pneumo meaning lung. The pneumobelt helps in ventilation and consists of an inflatable bladder enclosed inside a corset wrapped around the waist. A separate pressure unit inflates the bladder and makes it press against the stomach area, forcing the diaphragm to raise, helping the patient to exhale. When the bladder deflates, pressure is released from the stomach area and, with the help of gravity, the diaphragm lowers, which allows easier inhalation. The patient must be in an upright sitting position so that gravity can provide a maximum pulling effect on the diaphragm during inhalation, otherwise quality of ventilation will be very low.

During 1961, Thompson bought rights to all of the Huxley cuirass chest shells and pressure units, and has since made available a more modern version of the positive pressure Bantam, the Mini-lung.

At the present time, there are approximately 5000 various pieces of respiration equipment being used in the

U.S. by about 2500 respiratory patients, an average of two pieces of equipment per patient. The 2500 patients are divided into the following three groups: neurological disorders, (MD, MS, etc.) 40% or 1000; polio patients, 35% or 875; spinal cord injuries, 25% or 625.

The following figures are for units used in a home-type environment, on a continuing basis, and excludes units used in a hospital-type environment on a temporary basis.

There are around 350 iron lungs in use today, mostly the Emerson type. They are used by individuals who are paralyzed due to polio, with those paralyzed by spinal cord injuries and neurological disorders using a small percentage of them.

The number of chest shell respirators currently being used has stabilized at 1000 with about 500 polio patients using them. Some patients, for the first time since becoming disabled, have gone back to the chest shell because their breathing muscles have become progressively weaker from inadequate ventilation. Also positive pressure respirators and positive volume ventilators will, no doubt, during the next decade, replace a high percentage of chest shells because they both provide a drastically higher quality of ventilation and are becoming much more portable.

Approximately 350 rocking beds are in use, mainly for polio patients with moderate breathing difficulties. These are usually used at night, during sleep.

There are about 400 pneumobelts being used equally by polio patients, the spinal cord injured, and those with neurological disorders.

There are about 2500 positive pressure respirators in use, 300 Monaghans and 2200 Thompson Bantams, all used through the trachea or mouth, and used equally by the spinal cord injured, polio patients, and patients with neurological disorders.

Positive volume ventilators in use number about 400 and are used almost entirely by patients with neurological disorders. Polio patients have been slow in discovering this excellent kind of ventilation. Positive pressure respirators and positive volume ventilators have about the same quality of ventilation as the iron lung, are more versatile in their applications, and more portable. Both provide identical ventilation but measure it differently. This area will definitely have the largest growth over the next ten years as more portable units are made and used for just about every kind of breathing weakness. Twenty years ago most patients with broken necks did not survive because of inadequate respiratory therapy and corrective surgery. Now it is common for high level traumatic quads, with the help of positive pressure respirators and positive volume ventilators, to not only survive but also to become highly rehabilitated and able to operate electric wheelchairs along with many other devices.

During the final three months of 1976, I had the honor of testing and using the prototype LP3 positive volume ventilator designed and developed by Life Products, Inc., of Boulder Colorado. Upon completion of the testing I purchased unit #1 which I have since used by mouth an

average of 35 hours per week throughout 1977. The LP3 is the first truly portable positive volume ventilator ever perfected. It can run over twenty-four hours on one charged auto battery, and can produce a tidal volume of 3000 c.c. It has an internal emergency battery which will run the unit for about one hour. The breath rate control is conveniently located on the front control panel. Unlike the Bantam and Monaghan 170C, the LP3 has a very natural, smooth, breathing pattern. I have used this unit exclusively on several two- and three-day trips, and have found it very adaptable. A Bennett face mask is needed for sleeping overnight along with a Bennett Cascade Humidifier, which eliminates severe dryness in the mouth and throat area. The artificial nose supplies adequate humidification for daytime use. The Sears Diehard 12 volt auto battery will last about two years in powering the LP3 and is easily mounted on a wheelchair along with the LP3.

After sleeping in the same room every night for 25 years I designed and had fabricated a mini-iron lung. I spent 30 days in testing and using it in place of the iron lung with total success. Because I have only one third of my breathing muscles, a chest shell, rocking bed, or penumbelt can't provide me with adequate ventilation. Since the iron lung is not portable and nothing was available that would provide comparable ventilation with complete pressure coverage, I designed the PortaLung.

The PortaLung is a tank type respirator without the bellows and motor found on the iron lung. The pressure, both negative and positive, is provided by a Thompson Portable or a Monaghan 170C pressure unit by way of a flex hose.

I have in just the past year traveled over 7000 miles in seven different states, including a two-week, 3600 mile trip to California, using the PortaLung without any problems. I used the PortaLung mostly at night for sleep; the LP3 while traveling and sight-seeing.

I have found the PortaLung to be equal in quality to the Emerson Iron Lung that I've used since 1949, with maximum pressure levels, 36 cm of negative and 23 cm

of positive. It is portable enough to be used in a van or station wagon, weighing about 100 pounds. The shipment cost by air to anywhere in the world is about half the cost of an airline ticket, and even less when shipped by truck.

Most of the above mentioned equipment is available through Life Care Services, 5505 Central Ave. Boulder, Colorado 80301.

For more information on the availability of Life Product's Inc., LP3 positive volume ventilator, and the PortaLung, please contact me. I will be more than happy to answer any questions concerning the applications of both respirators. Address: 401 East 80th Avenue, Denver, Colorado 80229.

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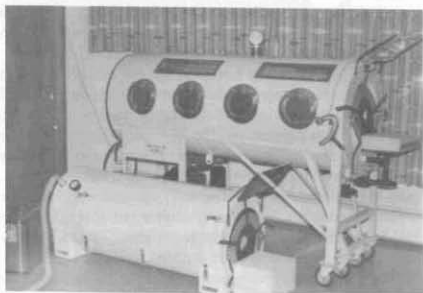
*W. Sunny Weingarten has been a respiratory polio quad since he was disabled in 1949 at age seven. He uses an iron lung 16 hours per day, mostly for sleep, and positive pressure during the remaining time. He sponsors and coaches Little League baseball, teaches the guitar privately at a local high school, and spends about 20 hours per week in reading and studying social work, political science, and Christian literature. He is part-owner of an advertising firm, has owned several race cars, and recently purchased a Cessna Skylane four-passenger airplane with a pilot friend.*

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*Editor: During the past year we have had a number of letters relating to respirators. Following are a few excerpts:*

"I have slept in a tank respirator almost 30 years. Sometimes when I was sick I'd turn the pressure up a little at night. It would feel so good I'd leave it at the higher pressure. Consequently, my pressure crept up. For the first time in 28 years, I went to Rancho Los Amigos' pulmonary ward last summer. They found that I was hyperventilated. Over the three weeks, they lowered the pressure till my test was in the normal range. Other readers might be interested in knowing that you can get too much air but you will not realize it unless you go to a hospital for a check." Patsy Wade, 420 Wynola Street, Pacific Palisades, California 90272.

"In 1949, when a sophomore in high school, I was completely paralyzed from polio and placed in an iron lung. . . . Now at age 43 and 29 years later I use, during a 24-hour period, a rocking bed and a penumbelt powered by a Bantam portable respirator for sitting in a wheelchair. When in bed but not rocking, I use a Zephyr positive pressure blower, complete with cascade, via long hose and mouthpiece. In addition, I use emergency and maintenance frog breathing and have an extra Bantam portable for traveling. With all these means of breathing I, when ill, prefer the iron lung and Zephyr positive pressure when the lung needs to be opened. Over the years, I have returned to the lung at the hospital for bouts of flu, broken ankle, smoke inhalation, and major surgery. When I am in the iron lung, I receive the most ventilation and feel secure and calm. . . . The newer pulmonary methods may be practical for new patients, but not for us oldtimers. Since I cannot use my hands, I must be able to use my voice to communicate my needs at all times. Once a nurse attempted to put a mask over my mouth and I went into a state of panic. . . . So, I say, Iron Lung Polios of the World, unite! Persuade your hospital to keep



*Sunny has designed and fabricated a semi-portable fiberglass "iron" lung, called the "PortaLung," which he markets on a custom basis. (Photos by Harley Fehlman.)*

an iron lung available for you!" Ruby Heine, 2885 Sharon Drive, Omaha, Nebraska 68112.

"I am a 25-year old man and I have had muscular dystrophy all my life. Last year respiratory difficulties made it necessary for me to undergo a tracheostomy. Since that operation I have felt that the quality of my life has vastly improved. I use respiratory equipment at night and sometimes in the day and often have to resort to a suctioning machine to clear my lungs. Since the tracheostomy my health in general has improved to the point where I am able to maintain my own apartment, with the occasional help of an attendant. . . . I wish to contact other people with muscular dystrophy as well as professional people and make it clear that respiratory problems in the long term are inevitable and that they are not insurmountable and can be dealt with in a satisfactory way." Glenn Wildenrad, 2406 Dana Street, Berkeley, California 94704.

"I use a Monaghan 170C portable respirator connected to my trachea because of polio at age 11. I use it all night. I have a job and get around pretty good. . . . My problem is I would like to locate manufacturers of other respirators that are portable and light, have positive pressure and automatic cycling. The problem with the 170C is carbon soot from the motor brushes that I have to worry about. I just hope the filters catch most of it and not my lungs. Monaghan knows of this problem but so far cannot solve it." Ronald Brekke, 1114 Park Ridge Boulevard, Park Ridge, Illinois 60068.

"I would like to hear from persons who use respiratory equipment. How do most patients get and keep their respirators repaired? I, for one, am refusing to sign my equipment over to Life Care, Inc. as their rates are very expensive. . . . I repair my four pieces of equipment myself. The National Foundation used to supply me with parts from Colorado. Now I am having a hard time getting parts from the manufacturers. . . . They have made little effort to provide good service manuals and parts for the local repairmen. . . . The average home respirator is no more complicated than a washing machine. . . . Thompson Respirator Products has a new portable respirator called the Minilung which has a very stable rate and pressure. Operation with a car battery is 16 hours. I have used the unit on trach positive. I found the unit so quiet that I heard noises in the night that I had never heard with my Monaghan 170C's." Jerry Daniel, Indian Lane, Langlois, Oregon 97450.

"Sometime in the Spring of 1977 the National Foundation turned all my respirators over to a company called Life Care Services and so now Life Care bills Medicare for the rental and servicing of each piece of equipment. Medicare will permit only three pieces of equipment so I kept my rocking bed, Thompson chest respirator, and Bantam. My iron lung, which I hadn't used in a long time, was hauled away. I didn't object to parting with it, especially considering the amounts LCS charges Medicare for rental. Would you believe \$66 each month for chest respirator, \$64 each month for rocking bed, and \$61 each month for Bantam? Plus, \$9 per month for the hose from Bantam to mouthpiece and \$18 per month for chestshell and hose?" Walter Sawyer, Jr., Box 90-Austinville, R.D.1, Troy, Pennsylvania 16947.

A lightweight "iron" lung in aluminum is made by a voluntary group of engineers, technicians, and tradesmen. Information 1978/VOLUME XXI

available from Dr. V.S. Ramsden, Technical Aid to the Disabled, 48 Fourth Avenue, Eastwood, New South Wales, Australia 2122 or Mr. Mark Dohrman, Lincoln Institute, 625 Swanston Street, Carlton, Victoria, Australia 3053.

"I am concerned about the safe use of gasoline powered standby generator equipment used to supply a continuous source of electricity for respirators during power failures.

"Because gasoline engines are all around us we forget the precautions that must be taken. Whenever there is liquid gasoline, there is gasoline vapor. This vapor is heavier than air and, therefore, tends to accumulate at some low spot. A small amount of this vapor can easily form a combustible mixture with the air at this low spot and then be ignited by a hot water heater pilot light or a spark from an electric fan or from an electric switch.

"These considerations, along with the well known dangers of breathing the exhaust gases (also heavier than air), make it most desirable that the engine be mounted outside the building and the generated electricity be brought inside by wiring.

"Gasoline should be stored in gasoline cans approved by Underwriters, outside the building, and in the smallest quantity that is practical." Robert E. Hitz, 1182 Warren Road, Lakewood, Ohio 44107.



*Editor: The Annual General Meeting and Conference of the British Polio Fellowship, which was held at Reading University on September 24, 1977, featured an address by Geoffrey T. Spencer, MB, BS, FFARCS on "Polio-myelitis and Breathing." Dr. Spencer is Consultant in Charge, Intensive Care and Respiratory Units, St. Thomas' Hospital, London. Following are excerpts from the November 1977 issue of The Bulletin of the BPF.*

"Polio was the first disease for which any attempt was made to prolong life once breathing had failed. It led to the development of artificial respiration without which no heart or chest operation would be possible today. The value of the work done on those early polios and the number of lives saved is incalculable.

"The iron lung dates back to 1930 and was first produced by a Harvard engineer named Drinker. Lord Nuffield equipped hospitals in this country with modified Drinker respirators in wartime and they were first used in the 1940s.

"The number of survivors was small. Probably the longest survivor has been in an iron lung every night since 1948 and quite a number since the early 1950s.

"In the severe Copenhagen epidemic of 1952, when they ran out of iron lungs, they called on an anaesthetist, Bjorn Ibsen, for help. He said, "Try what we do in the theatre short-term — make a hole in the windpipe and blow air into the lungs under positive pressure." They paid medical students 30 shillings for an 8-hour shift!

"After three months the patients who had got in first and been put in iron lungs had a mortality rate of 80%, while those who came in too late and had to put up with the medical students had a mortality of 40%.

"Respiratory insufficiency in a person who has had

polio is quite different from that which results from lung disease such as chronic bronchitis. The latter is in the lungs, the former in the mechanism — the lever power which operates the lungs.

"The lungs of a polio are essentially normal. They only become abnormal as a result of unnecessary neglect or misuse of treatment used for the respiratory difficulties of chronic bronchitis. Oxygen, which is used to treat respiratory diseases originating in the lungs, is harmful and dangerous to the polio person and will only make him worse because his breathing difficulties are due to an accumulation of carbon dioxide. A mild lack of oxygen produces a certain stimulus to breathing; take it away and the carbon dioxide rises still further.

"There are two sorts of muscles and nerves which control breathing — intrinsic and extrinsic ones. The intrinsic ones are wired in to an automatic centre in the brain which goes on functioning when you are asleep. The extrinsic muscles are not wired in to the automatic centre and cease to function while you sleep.

"If a significant number of the intrinsic muscles are not working, you can breathe by day by all sorts of tricks such as frog breathing, but you will need a bit of help at night. Without help you may have difficulty in getting off to sleep, you will wake up and not be able to get back to sleep and have a bad night followed by drowsiness and lack of concentration by day.

"Everybody's lungs change and deteriorate as they get older. In your 40's you cannot breathe as well as you could in your 20's. If you have impairment of the muscles, the normal changes due to age cause trouble.

"That is why, though the number of people having polio is going down, at the same time the number needing breathing aid at night is rising.

"You can stave off the necessity of seeking assistance with breathing at night by a variety of tricks. The most useful is frog breathing. Other simple measures are not to neglect coughs and colds and, if you can't frog breathe, to use positive pressure.

"The only way of measuring the efficiency of your breathing is to measure the carbon dioxide in the arterial blood.

"Providing you are in the hands of people who understand the changes in physiology as a result of polio, there is no reason why surgery should involve any higher risk than to anyone else of the same age. . . . The effect of obesity on breathing problems is profound.

"Polio is still endemic in Africa, South Africa, the Far East, and round the Mediterranean. Even the World Health Organization returns underrate the true situation and the travel agencies have a vested interest in suppressing the figures and will not advise travellers to be immunised. Another good reason to go on plugging the need for immunization."

## Miscellaneous Readers' Ideas

CUSTOM-DESIGNED OFFICE FOR A MOUTHSTICK USER. A.G. Garris, consultant, California Department of Rehabilitation, Rancho Los Amigos Hospital, says, "Enclosed are photos of Arthur Heyer's office which were taken by Angela Marquez, my secretary. Arthur designed everything in his office. He can function very well independently and perform necessary office activities. He designs similar

things for other severely disabled patients. In our TV tape of Arthur we tell counselors that there is no magic here, just the right equipment, suitably placed, a lot of practice, and motivation to use it. This should partially answer the question, What can a person with a mouthstick do?"

Arthur has been a C3-4 quad since 1965 when he made an unfortunate dive into a waterless pool at age 17.



Arthur Heyer files and extracts paper with his mouthstick.



His typewriter is on a Lazy Susan.



Trained as a mechanical engineer in Guadalajara, Mexico, he moved to California in 1975 with his bride, Flor. He is employed by the Neuromuscular Engineering Department, Rancho Los Amigos Hospital, 500 Hut, 7601 East Imperial Highway, Downey, California 90242.

As liaison engineer, he designed a prototype house in which patients and outpatients may see and test equipment. The house is the office for his program, Project Threshold Rehabilitation Engineering Service, in which he designs equipment according to individual needs.

Arthur's desk, shown in the accompanying photographs, illustrates his ability to engineer his environment to meet his needs. The desk is U-shaped. His files for larger papers are located in the left wing of the "U." He files and extracts papers with his mouthstick by using a ramp.

The typewriter is located in the center section, on a Lazy Susan, which he revolves with his mouthstick. His portable desk is "parked" on the right wing of the "U," beside the telephone. He uses the top for writing and sketching and the inside for storage.

Note that his V-shaped mouthstick makes it easy for him to talk while holding it in his mouth. His mouthstick holder is attached to his wheelchair, which he guides and reclines with his chin.

**PISSING CROSS COUNTRY.** "I was too young when I got polio — three years old — to remember how I learned to cope with not being able to get to a bathroom whenever I needed to. Undoubtedly, I wet myself a few times, learned to hold on for a long time in spite of discomfort, learned gradually to be very good at planning ahead, worried a lot. . . .

"Very little changed in that regard until I was in my late twenties. I went on a long cross-Canada camping trip with a friend through the Western provinces. It was a long way between service stations. We developed a habit of



Portable desk. He operates his wheelchair with his chin.

throwing modesty aside; we would pull over to the side of the road and, while she went into the bushes, I would open the car door, lift myself to the floor, pull down my britches, and pee over the edge. I was unprepared for the sense of liberation! Only those with a long history of miserable propriety could understand.

"Later, traveling alone, I grew bolder. . . . I pull over to the side of the road, slide forward in the seat, press a two-cup plastic measuring cup to my bottom, pee, and dump it out the car window. Over the years I have pissed along the highways of many scenic states, along the curbs of leafy suburbs, and in the parking lots of some of our finest supermarkets.

"I still feel a little uneasy about such primitive 'bad' behavior. But basically, it makes me happy. It feels a lot like stopping punishing myself." Eleanor Smith, Atlanta Rehabilitation Center, 1599 Memorial Drive, S.E., Atlanta, Georgia 30317.

**EASY-FEED.** The device consists of a plate, which rotates freely on a stand clamped to a table. The food is placed at the edge of the plate, which the user turns around with his mouth. 15.50 pounds. *Newton Aids Ltd., 2A Conway Street, London W1P 5BE, England.*

**SAAB ADAPTATIONS FOR DISABLED.** Especially designed hand controls and a seat which slides out and pivots are available from SAAB-SCANIA of AMERICA, Saab Drive, Orange, Connecticut 06477 and Scancar, Ltd., 860 Progress Avenue, Scarborough, Ontario, Canada.

**ARTHRITIS BOOKLETS.** Contact your local Arthritis Foundation chapter for booklets such as these: *Self-Help Devices for Arthritic Patients. Living More Comfortably With Arthritis. Home Care Programs in Arthritis.*

**TOILET PAPER SUBSTITUTE.** My brother adapted a simple household cleaning gadget, a plastic sponge on a straight, plastic handle, that I can use with my arthritic hands. He used a "Scrub Pal" made by Hi-Ko Products Co., Bedford Heights, Ohio 44146. He bent the handle by heating it over an electric stove burner, then attached with Epoxy cement an 8" strip of thin wood (such as an old ruler) to make a cross-shaped handle. For further information, send a self-addressed, stamped envelope to Lawrence J. Meinen, Route 3, Box 268, Chippewa Falls, Wisconsin 54729.

**INDEPENDENCE FACTORY.** "We are an all volunteer, non-profit organization which makes and designs self-help devices. Send us your special problems. There is no charge because we learn by solving problems. . . . We have a price list of the devices we make and sell and we have put many of our ideas into three manuals. Titled, *How To Make It Cheap*, Volumes I and II are \$1.50 each plus 30 cents postage, Volume III is \$2.50 plus 30 cents postage." Fred D. Carroll, The Independence Factory, Box 597, Middletown, Ohio 45042.

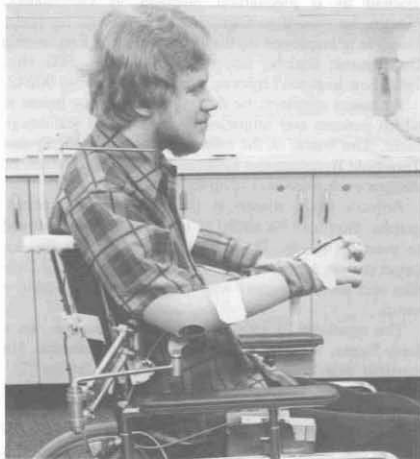
SWEDISH SUSPENSION ARMS. "The accident happened in June 1977 in northern Ontario. I struck a moose which landed on the roof of my car. The roof fell in on me and broke my neck. . . . I spent two months in Toronto General Hospital . . . I was flown to my home town, Pittsburgh, and entered Harmarville Rehabilitation Center (Box 11460, Guys Run Road, Pittsburgh, Pennsylvania 15238) for eight months of work.

"The person who helped me the most was an occupational therapist from South Africa, Miss Christa Meyer. Christa came to Harmarville to co-author a book about quads. . . . She started my therapy on Swedish Suspension Arms. As I progressed, Christa thought of new things to help me achieve independence. . . .

"Before the accident I was a senior psychology major at West Virginia University. While at Harmarville, I was able to continue my degree work by completing an independent study project under the supervision of a professor from WVU. With the help of the social service director, my personal social worker, and vocational counselor, I formulated a study about the changes of attitudes and values of patients at Harmarville. The professor from WVU came to Harmarville to see me and grade the report. I received six hours of credit for the study.

"Since I left Harmarville I have been living in a house with two other men. One cooks and the other does the dishes. Nurses come in the morning to exercise me and help get me ready for school and in the evening for general health care.

"I had hoped to return to WVU, but the campus is not accessible. I arranged to finish my studies at the University of Pittsburgh but my degree will be granted by WVU. . . .



Terry Moore, a traumatic quad, and the Swedish Suspension Arms.

It has not been easy to learn to ask for help especially from strangers. But I am learning that there is no need that cannot be met, if I open my mouth and ask." Terry Moore, 3254 South Park Road, Bethel Park, Pennsylvania 15102.

## Communication

AMER-IND: INDIAN SIGN SYSTEM. Madge Skelly, PhD, a professor of speech pathology at St. Louis University and a consultant at the VA Hospital and the State Hospital, has achieved international recognition as the creator of a special method of communication. The method is based on the Indian Sign system which Dr. Skelly, now 75 years old, learned as a child from her grandfather, a member of the Onondaga tribe. Indian Hand Talk is a signal system, based on action, which was created to provide a universal communication mode among the many tribes who did not share a common language. It was well developed long before Columbus arrived and early European voyagers communicated with the natives by this means.

While no more than 10 per cent of the sign languages developed for the deaf can be guessed, 90 per cent of the Indian Signs are guessable. Amer-Ind is used by those who have impaired speech or who have lost their speech through strokes or removal of their vocal apparatus or

who have failed to develop speech and language because of retardation.

Additional information may be obtained from: (1) an illustrated book by Dr. Skelly which will probably be published in June 1978 by the University Park Press, 233 Redwood Street, Baltimore, Maryland 21202; (2) Learning Resources Service, VA Hospital, St. Louis, Missouri 63125, has two series of video tapes — a video dictionary and orientation; and (3) for professionals, Dr. Skelly offers five-day workshops. Contact her at Executive House, 20-D, 4466 West Pine Boulevard, St. Louis, Missouri 63108.

VOICE-ACTIVATED TELEPHONE. "I finally have the no hands telephone of my dreams. The *Gazette* told me whom to call to get special telephone equipment but there were many detours between my first call and my final goal — a phone activated by voice command at night

from my iron lung or by touch button during noisy days.

At first, the telephone company sent a series of bright young men who had neither the experience nor the time. Finally, the Project Supervising Engineer, Robert L. Glyn, heard about my request and came to see me. He worked out a special design and provided the equipment, which has given me greater independence and security. The operators show such genuine interest that they make Dallas seem like a warm home town.

Mr. Glyn told me, "St. Louis handles devices for blind and disabled people. We'll send this new design in to St. Louis. If they think there's a need for it elsewhere, they'll publish it in a book so that anyone in the Bell System will have access to the information. The book is updated every five years. In the meantime, anyone interested can get in touch with the Southwestern Bell Telephone, 500 South Ervay, Dallas, Texas 75201. If no one seems to know what you're talking about, ask for Mr. Glyn and tell him Iron Lung Jeanne sent you." Alta Jeanne Drake, 3737 Purdue Street, Dallas, Texas 75225.

**A TREASURE OF BOOKS AND BOOKLETS.** The Trace Research and Development Center For the Severely Communicatively Handicapped, University of Wisconsin-Madison, 922 ERB, 1500 Johnson Drive, Madison, Wisconsin 53706, has an exciting and valuable list of aids and techniques. Many of the publications, such as the list of commercial switches, are useful for all types of disabilities.

*Interface Switch Profile and Annotated List of Commercial Switches.* 1976. \$1.25. The switches listed include push, sliding or trolley, pneumatic, breath, zero pressure, proximity, motion-detecting, eye-controlled, and optical. Other controls include joysticks, wobblesticks, air pillows, and squeeze bulbs.

*Annotated Bibliography of Communication Aids.* A 1974 summary of aids in the U.S., Canada, and abroad. \$3.50.



Jeanne Drake and the Bell men who created her voice-activated phone.

*A Portable Non-Vocal Communications Prosthesis for the Severely Physically Handicapped.* 1976. 75 cents.

In addition, the Trace Center has edited transcriptions of its National Workshop Series and they are published in a 228-page book. Titled, *Non-Vocal Communication Techniques and Aids for the Severely Physically Handicapped*, it is edited by Gregg C. Vanderheiden and Kate Grilley. A major professional treatise on the subject of communication, it is available for \$12.50 from Univerity Park Press, 233 Redwood Street, Baltimore, Maryland 21202.

**PHONIC MIRROR HANDIVOICE.** A portable, hand-held battery-operated electronic speech synthesizer that simulates the human voice. It can produce complete sentences and articulate almost every word in the English language with some inflections and tonal quality. Various models are designed to meet the range of learning ability. Information from HC Electronics, Inc., a subsidiary of the American Hospital Supply Corporation, 1740 Ridge Avenue, Evanston, Illinois 60204.

**EKOMI 2.** An electronic communicator which allows persons who cannot speak or write to express their thoughts by pressing the keys on the keyboard of a battery-operated device, it looks like and is about the same size as a standard pocket calculator. Manufactured in the Netherlands, it is distributed by Prentke Romich Company, RD 2, Box 191, Shreve, Ohio 44676.

**MORSE CODE CONVERTED TO VIDEO.** Al Ross, an electronic media producer at the University of Washington Child Development and Mental Retardation center, Seattle, Washington 98195, created a special device for a young man disabled by cerebral palsy. His device converts Morse code into letters at a rate of 8.4 words per minute and displays them on a video monitor.

**DICTATION MACHINE FOR MOUTHSTICK-USERS.** Sony Dictation Machine VR-35 was designed for the severely disabled. The control unit, which is actuated by voice and by a magnetic mouthstick, accepts any standard tape cassette. The dictating/transcribing unit may be operated manually by touching the unit with the magnetic end of the mouthstick. Contact your nearest Sony dealer or write Business Products Division, Sony Corporation of America, 9 West 57 Street, New York, NY 10019.

**INEXPENSIVE REMOTE CONTROLS.** For under \$20, the following companies sell small receivers which, when plugged into a wall outlet ahead of any electric appliance, will operate that appliance by a remote control switch from a distance of up to 50' from the appliance. Data-Link, Box 1145, 1282 Fayette Street, El Cajon, California 92022 and Hammacher Schlemmer, 147 East 57th Street, New York, NY 10022.

## Advocacy

New York State Advocate for the Disabled, Room 3712, 2 World Center, New York, NY 10047. 212-938-0186. Toll free number for rest of New York State: 800-522-4369 (except Nassau, Suffolk, and Westchester).

*Nursing Homes: Citizens Action Guide.* By Elma Griesel and Linda Horn. \$2.95 from Beacon Press, 25 Beacon Street, Boston, Massachusetts 02108.

## Art

The 15th Annual Sister Kenny Institute Art Show for Disabled Artists will be held from October 8-22, 1978. Two categories: artists who work with their mouth, foot, or forehead; or artists with disabled arms and hands. Details from Art Show Chairperson, Sister Kenny Institute, Chicago Avenue at 27th Street, Minneapolis, Minnesota 55407.

## Barriers, Architectural

*Barrier-Free Meetings: A guide for professional Associations.* By Martha Ross Redden et al, this valuable guide sheet should be required reading for every organization. It covers all stages of planning meetings. 73 pages. \$4 from American Association for the Advancement of Science, 1515 Massachusetts Avenue, NW, Washington, DC 20005.

*Barrier-Free Environments.* Community Development Series, Volume 33. Edited by Michael J. Bednar. A collection of essays by professionals in the fields of architecture, social work, and urban planning. The planning and design are performance-based rather than prescriptive. The emphasis of the book is on developing a philosophical approach to the integration of both physically disabled and mentally retarded persons. 278 pages, \$22. 1977. Dowden, Hutchinson & Ross, Inc., Box 699, 523 Sarah Street, Stroudsburg, Pennsylvania 18360.

*Update, 1977,* supplement to *Access to America, 1976,* to be published by early summer 1978. Access is a 300-page

compendium of federal and state legislation on barriers, curb cuts, license plates, and polling places. \$15 from Michigan Center for a Barrier Free Environment, 6879 Heather Heath Lane, West Bloomfield, Michigan 48033.

## Barriers, Attitudinal

*Social Barriers to the Integration of Disabled Persons into Community Life.* Report of an Expert Group Meeting in Geneva, 28 June to 5 July 1976. The 31-page booklet is available for \$3 from United Nations, Sales Section, New York or Geneva.

*People . . . just like you.* About handicaps and handicapped people. (An Activity Guide). Free from The President's Committee on Employment of the Handicapped, Washington, DC 20210. 36 pages.

## Blind

Brailled paper currency. Most Dutch and Swiss paper money is marked with Braille identification marks or dots. No U.S. paper currency has Braille dots because it is felt that the paper would not hold up under constant use. Why don't we use heavier paper?

The National Retinitis Pigmentosa Foundation, Inc., Suite 932, 393 Seventh Avenue, New York, NY 10001 urges all who have RP to contact the foundation and assist with research.

*Where Do I Go From Here?* A talking book for newly-blind persons. Information from Don Nold, Dialogue Magazine, 3100 Oak Park Avenue, Berwyn, Illinois 60402.

Richard J. Wright, a member of the science faculty at Valencia Community College, Box 3028, Orlando, Florida 32802, created methods by which blind students can participate in botany laboratories.

## Children

*A Reader's Guide For Parents of Children with Mental, Physical, or Emotional*

*Disabilities.* Comprehensive annotated bibliography and additional sources of information. 144 pages. \$3 from Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. Ask for 33X.

*Early Years.* By Morique Cornwell, MCSP, a physiotherapist and mother of two small children. For the disabled mother or father and their child from birth to nursery school. \$2.50. From Disabled Living Foundation, 346 Kensington High Street, London W14 8NS, England.

## Clothing

*Adapt Your Own. A Clothing Brochure For People With Special Needs.* Excellent source of ideas and further references by the creators of the *On Your Own* program. (The cover was designed by Bob Tanton, a C5-6 quad, who is one of the *Gazette's* staff artists.) \$1 from Office of Independent Study, Division of Continuing Education, P.O. Box 2967, University, Alabama 35486. Make check payable to University of Alabama.

Custom-made or sew-it-yourself kits of women's wash and wear clothes. Free catalogue from C.O. Smith, 7674 Park Avenue, Lowville, New York 13367.

## Coalitions, National

*Coalition Building.* A Report on a Feasibility Study to Develop a National Model for Cross-Disability Communication and Cooperation. By Frank G. Bowe, PhD. 66 pages. 1978. \$4 from American Coalition of Citizens with Disabilities, 1346 Connecticut Avenue, NW, Washington, DC 20036.

## Coalitions, State

United Handicapped Federation, 1951 University Avenue, St. Paul, Minnesota 55104. In October 1977, UHF initiated an interesting buying plan. For an annual fee, members may purchase prescription drugs, eye glasses, hearing aids, and renters' insurance at a reduced cost. A program is available at many of the local hospitals that will accept Medi-

care payments as full payment. In addition, over 100 retail stores offer a 5-20% discount to members.

## Consumer Information

*Medical Devices and Equipment for the Disabled: An Examination.* By Daniel Clearfield. 53-pages. \$3 from Disability Rights Center, Inc., 1346 Connecticut Avenue, NW, Suite 1124, Washington, DC 20036. The report, of particular value to wheelchair-users, should be read by all medical equipment manufacturers and distributors.

*Consumer Warranty Law: Your Rights and How to Enforce Them.* A Guide for Users of Medical Devices. By Belinda Bean and Susan Schapiro. 21 pages. \$5 from Disability Rights Center, Inc., (address above).

*The Best of Helpful Hints.* 86-page compilation of problem-solving hints. \$3.50 from Courage Center Auxiliary, Courage Center, 3915 Golden Valley Road, Golden Valley, Minnesota 55422.

## Deaf

Deaf college students are eligible for a summer program in computer programming offered by IBM in California.

*Speech and the Hearing-Impaired Child: Theory and Practice.* By Daniel Ling. Dr. Ling of McGill University is internationally known as a consultant and research worker. The text is clearly written; the book is attractively presented. Of value to parents as well as professionals. \$11.95, soft cover, from Publication Sales Department, Alexander Graham Bell Association for the Deaf, 3417 Volta Place, NW, Washington, DC 20007.

Universal Sign Language cards. International language game in 36 languages. \$1 from Special Industries, World Wings International, 1600 West Army Way, Seattle, Washington 98119.

## Dentistry

*Toothbrushing and Flossing. A Manual of Home Dental Care for Persons Who Are Handicapped.* By Paul Casamassimo, D.D.S. Techniques, aids, and adaptations, \$1.50. *Helping Handicapped Persons Clean Their Teeth.* 15 cents. Both are available from National Easter Seal Society for Crippled

Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois 60612.

*Journal of Dentistry for The Handicapped.* Published semi-annually by the Academy For Dentistry for the Handicapped, 1240 East Main Street, Springfield, Ohio 45503. \$15 per year for non-members. The summer 1977 issue contains the article "Providing Office Accessibility to the Disabled Patient."

*Dentistry for the Handicapped Patient.* 420 pages. \$29.50 from The C.V. Mosby Company, 11830 Westline Industrial Drive, St. Louis, Missouri 63141.

## Disabilities, Miscellaneous

*What Everyone Should Know About Cerebral Palsy.* Cartoon-style booklet tells the story of CP in simple, short sentences. 10 cents a copy or \$9 for 100 from: United Cerebral Palsy Associations, Inc., 66 East 34th Street, New York, NY 10016. We hope UCP chapters will buy it in bulk and distribute it gratis.

*The Epilepsy Fact Book.* Non-technical, concise publication. \$5.50 plus postage from F.A. Davis Company, Publishers, 1915 Arch Street, Philadelphia, Pennsylvania 19103.

*Legal Rights of Persons With Epilepsy.* State-by-state listing of laws. Free to organizations involved with advocacy and other services from Suzanne Turner, Epilepsy Foundation of America, 1828 L Street, Washington, DC 20036.

*Using Everything You've Got.* By Rev. Harold H. Wilke. Explicit details of ways of coping with the necessities of living without arms and hands by using ingenuity and a pair of well directed feet and toes. A delightful book by a delightful person! Available from The National Easter Seal Society for Crippled Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois 60612.

## Education

*Look out For Yourself! Helpful Hints For Selecting a School or College.* 80 cents. 16 pages. 1977. Public Documents Distribution Center, Dept. 10, Pueblo, Colorado 81009. Make check to Superintendent of Documents.

*Bibliography of Secondary Materials for*

*Teaching Handicapped Students.* Free from President's Committee on Employment of the Handicapped, Washington, DC 20010.

*Vocationally Oriented School Planning for the Handicapped. Kindergarten through Grade Twelve.* Developed under a Federal grant by the Windham Southeast Supervisory Union, Brattleboro, Vermont 05301. 236-page notebook.

The federal government offers five student aid programs: (1) Basic Educational Opportunity Grant up to \$1400. (2) Supplemental Educational Opportunity Grant up to \$1500. (3) Work-study program pays 80% of salary at a non-profit institution. (4) National Direct Student Loan up to \$1500 a year; and (5) Guaranteed Student Loan Program pays interest on \$1500 loan.

*The Handicapped Person in the Community.* Structured multi-media course, based upon texts, TV and radio, and group meetings at study centers throughout the United Kingdom. Details from Kirsty Wilson, Course Co-ordinator, The Open University, Walton Hall, Milton Keynes MK7 6AA, England.

## Employment

Tax Reduction and Simplification Act of 1977 (PL 95-30). Effective May 23, 1977. Employers may claim up to \$100,000 annually in credits based upon 50 percent of the first \$4200 paid to a disabled employee hired in 1977 or 1978. An additional 10 percent credit limited to one-fifth of the 50 percent credit, available for employees who have received vocational rehabilitation services, including those offered to disabled veterans.

*Get Yourself Going The Work-Easy Way.* An Action Handbook for the Handicapped Office Worker. By Henry Mara and Penny Thrift. Charming and useful paperback. 1 pound or \$2 U.S. From Disabled in the City, 40 Etherley Road, Tottenham, London N15 3AJ, England. 104 pages. (Both authors are disabled by multiple sclerosis.)

## Films

Jill Kinmont's life is continued in *The Other Side of the Mountain, Part II*, telling the story of her marriage. Previous movie recounted the accident that

made a ski champion a quad, and her subsequent teaching career.

**Epilepsy: The Invisible Wound.** Available free from: Epilepsy Association of Ohio, 5310 East Main, Columbus, Ohio, 43213.

## General

The 1978 International Disabled Expo is scheduled for August 10-12 at the O'Hare Expo Center in Chicago. The 1977 Expo was attended by 9137 professionals, disabled individuals, and exhibitors. 150 manufacturers were represented. The 1978 Expo will again be sponsored by the Paralyzed Veterans of America. Cassettes and written transcripts of the conferences are available. Information available from PVA/Expo, Box 1337, Hines, Illinois 60141.

Grantsmanship Center News Reprints, 1015 West Olympic Boulevard, Los Angeles, California 90015. *Program Planning And Proposal Writing*. 75 cents. How to Obtain Funding from Local Governments. 75 cents.

An anti-trust suit has been filed by the Western Law Center for the Handicapped and The American Coalition of Citizens with Disabilities against Everest & Jennings Co. The Department of Justice charges E&J with violations of the Sherman Anti-trust Act by restricting competition, denying consumers the benefit of a free market, and suppressing innovation and improvement in the design, construction, and sale of wheelchairs.

According to HEW, 16 million children under 14 years of age have not been vaccinated against polio. Current recommendations for vaccinating children against polio are: three shots at two, four, and 18 months of age. At five years — a booster.

**Motherhood: How to Cope.** By Morique Cornwall. Problems of mothers with physical disabilities as well as those who are blind or deaf. 2.50 pounds from Disabled Living Foundation, 346 Kensington High Street, London W14 8NS, England.

## Incontinence

*Incontinence: A Guide to the Understanding and Management of a Very Common Complaint.* By Dorothy

Mandelstam, MCSP, Dip. Soc. Sc. Illustrated by fashion designer Mrs. Brenda Naylor. Describes a wide range of appliances, clothing, methods, and gadgets. 1.75 pounds from Disabled Living Foundation, 346 Kensington High Street, London W14 8NS, England.

Adults' "dri-pants", urinals, snap-in pads, etc. are available from Piper Brace, 809 Wyandotte, Kansas City, Missouri 64105. Free catalog/price list.

DriPride underpants and disposable pads. Gerber Family Health Care, 445 State Street Fremont, Michigan 49412.

## Information

Ever wonder about the National Organizations that solicit your \$\$? The National Information Bureau, 419 Park Avenue, South, New York, NY, 10016 will send you the rating list of philanthropic organizations, if you request it on a post-card.

*Registration of Nordic Projects Relating to Disability.* 1977. By the Nordic Committee on Disability, Fack, S-161 25, BROMMA, Sweden. Exciting and valuable collection. Free! Covers many disabilities and many phases of coping with disability.

National Rehabilitation Information Center, P.O. Box 136, The Catholic University of America, Washington, DC 20064, was started in September 1977 with a five-year grant from HEW's Rehabilitation Services Administration. It will provide specific information services to the rehabilitation community, including rehabilitation professionals, disabled persons, and concerned members of the public.

The California Department of Rehabilitation has hotline telephones in Sacramento and Los Angeles for individuals who wish information about its services. Sacramento: 916-322-5066 (call collect) 800-952-5544 TTY. Los Angeles: 213-620-3353 (call collect) and TTY.

National Center on Educational Media and Materials for the Handicapped, The Ohio State University, Columbus, Ohio 43210. Free catalog lists audio-visual materials and publications in special education.

*Consumer Health Education.* A directory. 1976. Major voluntary health organizations in the U.S. Free from DHEW, Public Health Service, Health Resources Administration, National Center for Health Services Research, 6500 Fishers Lane, Rockville, Maryland 20857.

National Health Planning Information Center, Long-Term Care Component, P.O. Box 31, Rockville, Maryland 20850.

## International

*A Hit-And-Miss Affair. Policies for Disabled People in Canada.* By Joan C. Brown. Published in September, 1977 by The Canadian Council on Social Development, 55 Parkdale Avenue, Box 3505, Station "C", Ottawa, Ontario K1Y 4G1, Canada. 508-page study. Fascinating compilation. \$1. "Everywhere is the need to establish a system that will enable disabled Canadians to take their rightful place in society. . . . What is needed is the political will to act."

Rehabilitation International, 432 Park Avenue South, New York, NY 10016 would like to have disabled individuals participate in a survey of the rehabilitation process and the involvement of the disabled.

*Government Controls on the Health Care System: The Canadian Experience.* 1977. 17-page summary of a lengthy report. 35 cents from Superintendent of Documents, Public Documents Distribution Center, Pueblo, Colorado 81009.

*The Dimensions of Need.* By Pauline Faughnan. Interesting analysis of the needs of the Irish Wheelchair Association. Guidelines for the Association to work as a provider of services, an "awareness creator," and a mobilizer of local community resources. \$10 from Irish Wheelchair Association, Black Heath Drive, Clontarf, Dublin 3, Ireland.

## Legislation

California's AB822 provides that costs over \$200 for modifying a vehicle for use by a disabled person will be excluded from automobile license fees. The law is not retroactive, but at time of renewal a vehicle may be reappraised, excluding the cost for modifications.



The National Center for Law and the Handicapped is developing better State legislation on architectural barriers. Information on various State laws will be welcomed by Jill Robinson, NCLH, 1235 North Eddy Street, South Bend, Indiana 46617.

Minnesota SF922 imposes a \$10 fine on nondisabled individuals who park in spaces reserved for the disabled.

Minnesota SF1208 provides that polling places be accessible — governing bodies must select as polling places only those which have 31" wide entry doors, curb cut near main entry, ramps, and no barriers to booth.

Consumer Warranty Law Guide. The 22-page booklet explains federal and State warranty laws and procedures to use for seeking redress, with examples taken from actual complaints. The Disability Rights Center, which is affiliated with Ralph Nader, is selling the guide for \$5 per copy, with a special price of \$2 for individuals who cannot afford the higher price. Available from Debby Kaplan, Disability Rights Center, Inc., 1346 Connecticut Avenue, NW, Suite 1124, Washington, DC 20036.

### Library Services

Talking Books. If you are turning these pages with a mouthstick or a page turner or relatively useless hands you are eligible for Talking Books. Contact your local library or write to Division for the Blind and Physically Handicapped, Library of Congress, Washington, DC, 20540.

*Libraries for College Students With Handicaps.* Directory of academic library of academic resources and services in Ohio. 1976. *Libraries for People With Handicaps.* Information collected in a survey of 249 public libraries in Ohio. Both free from The State Library of Ohio, 65 South Front Street, Columbus, Ohio 43215.

*The Librarian and the Patient: An Introduction to Library Services for Patients in Health Care Institutions.* By Eleanor Phinney, the doyenne of special librarianship. The 352-page book is an encyclopedic compilation. 1977. \$20 from the American Library Association, 50 East Huron Street, Chicago, Illinois 60611.

### Periodicals, New

*ALPHE.* Assistance in Law for Physically Handicapped Elders, 624 University Avenue, Palo Alto, California 94303.

*International Journal of Rehabilitation Research.* Original articles will be published in English or German; summaries in English, German, and French. Quarterly. US \$14 or DM36.00 from G. Schindele Publishers, Rheinstrasse 5, 7512, Rheinstetten 3, Federal Republic of Germany.

*International Directory of Periodicals for the Handicapped.* Revised edition. \$1 from UCP of Tarrant County, Inc., 1300 W. Lancaster, Ft. Worth, Texas 76102.

### Rehabilitation, Miscellaneous

*Program Evaluation in Vocation Rehabilitation.* Fascinating bulletin. Free from Institute for the Crippled and Disabled, 340 East 24th Street, New York, NY 10010.

*Sheltered Workshop Study: A Nationwide Report on Sheltered Workshops and Their Employment of Handicapped Individuals.* Free from the Division of Evaluation and Research, Department of Labor, Room C-3315, 200 Constitution Avenue, NW, Washington, DC 20210.

### Religion

Correction: the Sisters of the Lamb of God have a new address: 1516 Parrish Avenue, Owensboro, Kentucky 42301. Addition: they will consider those with late vocations and both the disabled and nondisabled.

### Scientists

Project on the Handicapped in Science. American Association for the Advancement of Science is developing a directory of scientists with handicapping conditions. All handicapped scientists and graduate students of science are urged to contact Martha Ross Redden, Project Director, AAAS, 1776 Massachusetts Avenue, NW, Washington, DC 20036.

*Access to Science.* New quarterly. Aimed at improving opportunities for full participation of disabled students in college and university science programs. Free from Access to Science, American Association for the Advancement of Science, Office of Opportunities in

Science, 1515 Massachusetts Avenue, NW, Washington, DC 20005.

### Sex

*A Small Wind of Change.* Report of a research project by the Committee on Sexual Problems of the Disabled; project investigated the sex problems among 212 disabled individuals. Written by William Stewart. 2 pounds from National Fund for Research into Crippling Diseases, Vincent House, 1 Springfield Road, Horsham, Sussex, England.

Association for Sexual Adjustment in Disability (ASAD) resulted from a workshop held in 1975. The project included the publication of a newsletter, *Options*, that included *Options' Resource Guide to Sexual Adjustment in Disability.* Compiled by Barry J. Rabin, PhD. Fascinating collection of references. Available from Easter Seal Society, 1545 Wilshire Boulevard, Suite 600, Los Angeles, California 90017.

*Sex and the Disabled.* Edited by Dr. E. Chigier. This special issue of the *Israel Rehabilitation Annual* contains 20 papers by international professionals. \$8 from MERETZ, Tel Aviv, P.O. Box 344, Israel.

*Sex, Society, and the Disabled.* A Developmental Inquiry into Roles, Reactions, and Responsibilities. By Isabel P. Robinault, PhD. Drawings by Robert E. Tanton, Jr. 256 pages. 1978. Clear, comprehensive, well organized, attractive. Covers the life-cycle from infancy to the older ages. Harper & Row, Publishers, Inc., Medical Department, 2350 Virginia Avenue, Hagerstown, Maryland 21740.

Counseling for disabled women, individual or group sessions. Kay Harris Kreigsmann is establishing a counseling practice to deal with the problems of women, especially disabled women. Ms. Kreigsmann is wheelchair-bound by polio. Address: 5615 Ridgefield Rd., Bethesda, Maryland 20016.

### Social Security

The Social Security Administration has published a number of new booklets that will be helpful. Call or write your nearest office and request: *Disability Benefits for Blind People. Vocational Rehabilitation for the Blind and Disabled. Medicare for people under 65 with permanent kid-*

ney failure. Medicare coverage of kidney dialysis and kidney transplant services. SSI for disabled or blind children. A Guide to supplemental security income. What you have to know about SSI. How SSI can help. SSI for retarded people. Social services programs under Title XX of the Social Security Act.

Keep a copy of everything you receive from Social Security and of every letter you send. Keep an exact record of all phone calls. If you receive an oral decision, ask to have it written. If you are notified that you have been overpaid, ask the Social Security District Office for a waiver of repayment because you were not at fault and it would be a hardship to repay. If you were not overpaid or if the amount is wrong, ask for a reconsideration of overpayment. File an appeal! Don't just acquiesce!

### Spinal Cord Injury

*Exercises and self care Activities for Quadruplegic Persons.* \$5.95 from New England Chapter, Paralyzed Veterans of America, West Roxbury VA Hospital, West Roxbury, Massachusetts 02132.

*Spinal Cord Injury: A guide for Patients and Their Families.* \$2.50 from the Department of Public Relations, Northwestern Memorial Hospital, 250 East Superior Street, Chicago, Illinois 60611.

*Employment Opportunities for the Spinal Cord Injured Person.* Preparing yourself to Go to Work. Edited by Thomas R. Shworles and Richard J. McCauley. \$1 from National Paraplegia Foundation, 333 N. Michigan Avenue, Chicago, Illinois 60601. 23 pages. 1977. This pamphlet should be required reading for spinal cord injured and all who deal with them. A wealth of information and resources. A great bargain!

*How to Take Care of Your Skin.* By James Smittkamp. Excellent 8-page summary of daily routines and cushions, mattresses, and other equipment used for prevention of pressure sores. \$1 from National Paraplegia Foundation, 333 North Michigan Avenue, Chicago, Illinois 60601. Ask for list of NPF's other publications.

*Physical Medicine and Rehabilitation Approaches in Spinal Cord Injury.*

Edited by John G. Cull and Richard E. Hardy. Variety of professional contributors cover psychotherapeutic, vocational, and other aspects of SCI. \$15.50 from Charles C Thomas, Publisher, 301-327 E. Lawrence Avenue, Springfield, Illinois 62717.

### Sports and Recreation

Radio Camp, run by the Minnesota Society for Crippled Children and Adults, offers a week in the summer of intense study for a "ham" license or an upgrade to a higher class. Information from: Courage HANDI-HAM system, 3915 Golden Valley Road, Golden Valley, Minnesota 55422.

Wheelchair Square Dancing Instructions. Available on a 30-minute cassette for \$3 from: Colorado Wheelers, 525 Meadowlark Drive, Lakewood, Colorado 80226.

Tennis anyone? Jack Kenny writes, "The article about me in the '76 Gazette opened up contacts with rehabilitation people all over the world — New Zealand, Puerto Rico, Canada, and all over this country. . . . I have developed some new games. We have one that blind children really love. . . . The IRS just gave us tax-exempt status so we can now start fund-raising. Let me know of any programs that need equipment or games." Tamarack Foundation, Tamarack Tennis Camp, Franconia, New Hampshire 03580.

Outward Bound School. During the summer months, 10-day courses will include canoe travel in the wilderness, rockclimbing, and navigation for self-care disabled and hearing impaired individuals. Scholarships and tuition grants cover all or part of \$300 per course. Brochures from Ray Uloth, Project Center Director, Minnesota Outward Bound School, 308 Walker Avenue South, Wayzata, Minnesota 55391.

*Access to Recreation.* Report of a national hearing on recreation for disabled, held by A&TBCB in Boston in October 1976. 70 pages. Free from the Architectural and Transportation Barriers Compliance Board, Washington, DC 20201.

### Statistics

*Jobs for the Disabled.* By Sar Levitan, Center of Political Studies, George

Washington U., and Robert Taggart, National Council on Employment Policy. Study based on the Social Security Administration surveys of the handicapped population in 1972. The SSA survey showed that there were 7,700,000 adults between the ages of 20 and 64, based on a self-classification of being termed severely disabled if their handicaps prevented them from working regularly or not at all. 129 pages. Available for \$3.50 from the John Hopkins U. Press, Baltimore, Maryland 21218.

### Transportation, Public

Inter-city bus travel was made more accessible to the disabled by the rules of the Interstate Commerce Commission that went into effect on August 8, 1977. The rules prohibit carriers from denying transportation to any person on the basis of a handicap, physical disability, blindness, or because a person cannot board the bus without assistance. Carriers must provide assistance in boarding or carrying luggage.

Accessibility of stations and trains. Information available by calling toll-free 800-523-5720. Deaf travelers may use the teletypewriter free 800-523-6590. Transit authorities in Southern California, Dade County (Florida), and South-eastern Pennsylvania formed a consortium to pool their orders for the Transbus.

*A Study of Wheelchair Access to the Current Transit Bus Design.* Report of a study by AM General Corporation, 32500 van Born Road, Wayne, Michigan 48184 under contract with UMTA.

### Travel

*Guidebooks for Handicapped Travelers.* Free from President's Committee on Employment of the Handicapped, Washington, DC 20201.

Parking clearance sign to hang on the inside of a car or van window: "Please leave five foot clearance. Driver of this car uses wheelchair and needs five feet between your car and this car for wheelchair to fit." \$3.50, including postage, from Seton Name Plate Corp., 949 Boulevard, New Haven, Connecticut 06505. Order Sign Style SA-915.

*1978 Accessible Motorcoach Vacations.* Booklet describes escorted tours to Florida, California, Black Hills, Grand

Ole Opry, Yosemite, Niagara Falls, New England/Canada, and East Coast. Request from Barbara and Judd Jacobson, Flying Wheels Tours, Box 382, Owatonna, Minnesota 55060. Judd, a quad, has arrangements for '78 worldwide tours by air and cruise (Queen Elizabeth 2).

*Access to the World.* A travel guide for the disabled. By Louise Weiss. \$7.95. Chatham Square Press, 40 Broadway, 23rd Floor, New York, NY 10013.

*Dialysis World-Wide for the Traveling Patient.* National Association of Patients

on Hemodialysis and Transplantation, Inc., 505 Northern Boulevard, Great Neck, New York 11021.

*Access Travel: Airports.* 20 pages. Lists accessibility features of airport terminals around the world. Free from Consumer Information Center, Dept. 619-F, Pueblo, Colorado 81009.

Disabled Campers Club, 28, Coote Road, Bexleyheath, Kent, DA 7 4PR, England.

Mobility International, A. Lumley, Esq., The Central Bureau for Educational

Visits and Exchanges, 43 Dorset Street, London W1H 3FN, England. Information on travel and exchanges for disabled.

New English travel service run by and for disabled persons: Liberty Travel Service, 8 St. Giles Court, Dane Road, Ealing, London, W13, England.

#### Veterans

*Affirmative Action to Employ Disabled Veterans of the Vietnam Era.* Free from President's Committee on Employment of the Handicapped, Washington, DC 20210.

# 更生 復健服務中心

## China's Peregrinating Polio Priest

by Ron Dickson

Unlike the blind man on the corner who sang the Beale Street Blues, the news man on the corner in Martinez, California, didn't sing much. And his problem was cerebral palsy. Or so Bob Ronald suspects, looking back on his childhood from a few decades and three continents later, after a heap of experience with the halt and the lame.

At the time, though, Bob was only aware that the news dealer was different, as a schoolmate with a flail foot was different, or as a dog with floppy ears may be different from the run-of-the-kennel mutt: Only as one grew up, it seems, did one learn to discriminate, pity, or be embarrassed by the handicapped.

When Bob grew up, he had decided to study for the priesthood, a decision motivated in part by a desire to help people, although he never dreamt that it would be a particular kind of help for a particular group of people in a particular remote part of the world.

The area came first, when the Jesuits sent him to Taiwan, China. Here he settled down for a two-year intensive program of mastering the language.

His studies were half through and he could carry on a simple conversation in Chinese — talk about the lousy weather, for example — when, in the steamy summer of 1958, Bob took a week's vacation. One lazy morning, he woke up with a sore back. The soreness persisted for a couple of days.

Then his leg buckled under him — maybe he'd strained

a muscle. That night after dinner, he couldn't get up. They discovered it was polio after they got him to the hospital, where he stayed for a month. For thorough treatment, the Jesuits had him flown back to the U.S.

It was in San Francisco, California, not far from home, that therapy started on his affected muscles (and in San Jose that it continued) — both legs, both arms, one shoulder, back, abdomen, chest and assorted other spots. And it was in San Jose that the March of Dimes took over and whisked him off to Warm Springs, Georgia, for the full presidential treatment.

Over a year later, he got back to Taiwan and picked up where he'd left off, with modifications: a wheelchair and a remodeled room for sleeping quarters. There was more Chinese study, then a transfer to the Philippines for theological training.

In the Philippines, there was a major change in his awareness and his life when he met a Sister Baerts from Belgium. She helped the sick and especially the physically disabled, running a sort of one-woman counselling and rehabilitation service. Though he himself was in a wheelchair, Bob for the first time realized how much the disabled needed: physical rehabilitation, help with psychological, spiritual, vocational, housing, and other problems — problems that seemed to have been automatically taken care of for him. (Sister Baerts' activities, incidentally, have since expanded to include

housing for the disabled in and near Manila, including a projected "House Without Steps," where their families will live with the handicapped in a community of cottages.)

Realizing that his own disability would be a big advantage in rehabilitation work (the disabled would feel that he'd been that route himself, understood their problems, and really knew what he was talking about when he gave practical advice), Bob determined to become a rehabilitation counsellor.

He needed training, in techniques and goals. But where? He flew back to the U.S., following up correspondence and queries.

In California, he talked to a school official who, advising that "there's no better place for you than the University of Arizona," picked up the telephone and put through a call to his old classmate in Tucson: in three minutes, Bob was admitted to Arizona's rehabilitation counselling program.

A couple of years later, he was back in Taiwan, putting his training to use as a full-time rehabilitation counsellor at Veterans General Hospital (such extra-Ordinary employment is possible in the Order of Jesuits). This hospital, with the best staff and equipment in the country for rehabilitation purposes, was less than five minutes away, via powered wheelchair, from Bob's home and church.

As the years wheeled by, Bob realized he was serving largely an elderly clientele — stroke victims, for the most part. But he was not reaching many young adults whose needs — vocational, residential, psychological, social — were greater. Where had all the potential flowers of society gone?

The answer lay, in part, in the family-oriented Chinese social structure; lay, so to speak, in the back bedroom of the home, where the disabled person was cared for, sheltered from the shocks of normal life, and the public view. To learn how to help him, one had to learn more about the social context. A practical approach to understanding some of his problems was to take advantage of the hospital situation: Bob was to run surveys among patients, able-bodied, and hospital personnel of all ages and sexes to discover what blocks, what openings, what detours existed on the road to rehabilitation in a tradition thousands of years old, a tradition that was being assaulted by western Levi and bubble-gum culture.

In 1972 came a chance to see how other countries were doing, when Bob flew to the 12th World Congress of Rehabilitation International, meeting that year in Sydney, Australia. He got Down Under a week early for an associated seminar on vocational rehabilitation in Adelaide. And he flew over the Outback and beyond later, reaching the Indian Ocean at Perth and casting, en route, a critical eye upon Australia's rehabilitation facilities.

His reaction to Australia?

"A good place to be sick."

But the same was not true of other places. Before going back to Taiwan, Bob made the Grand and Not-So Grand Tour of Asia, visiting the Philippines (again), Malaysia, Indonesia, Vietnam, Cambodia, Thailand,



Father Bob Ronald, S.J. (in wheelchair) arranged this unprecedented camp-out in Taiwan for over 200 disabled.

Japan; sleeping in cities like Singapore, Kuala Lumpur, Jakarta, Saigon, Phnom Penh, Bangkok in hostels, hotels, monasteries, homes of friends of acquaintances made in Australia; riding in planes, trains, buses (including one fascinating 16-hour ride through the Indonesian countryside), taxis; following an international network of church and rehabilitation people that spread to relatives, friends, associated vocations. ("Now, when you get to Bangkok, call this number and ask for Eric: his brother-in-law is an orthopedic surgeon with the right connections, might even put you up for the night, would certainly invite you to dinner. . . .") And surviving adventures like being off-loaded after midnight in a strange town in a strange land, where there was nobody to meet him and nobody spoke English or understandable Chinese.

Every country, it seemed, had a showcase rehabilitation hospital, with trained personnel and gleaming equipment. One hospital. And teeming millions of people, many of whom had never seen a doctor or even a city. Asia was not a good place to be sick, unless you lived in the right place and knew the right people. The problems were just too great, but everywhere Bob met dedicated doctors, therapists, nurses, counsellors, and other health workers fighting against pestilence, apathy, and overpopulation.

He returned, refreshed and with new ideas, new friends, and new associations, to his own problems in Taiwan. It was only when he had met Sister Baerts in the Philippines that he had become aware that the disabled needed help; now, he realized, what they really needed was a chance to help themselves.

To give them this chance, one step would be to form a club or organization, run on very informal lines, where young adults could meet, socialize, develop self-confidence, have contact with the outside world, even get leads and advice on getting jobs and developing a life, perhaps a home, independent of the overprotective family. The goal would not be to disrupt the family



system, but to help the disabled person become a productive member of the family rather than a burden.

"Operation De-Handicap," whose Chinese name is based upon a folksaying that translates roughly as "help yourself to a better life" (operation sandal strap?), was started in 1973, with a full-time able-bodied director. The Chinese name has the positive flavor Bob wanted: He viewed his own polio not as disabling but enabling him to help others help themselves.

These days, Bob needed to get around, with a thousand extra demands on his time. He worked out an arrangement with a taxicab driver and his wife, who alternated in driving Bob wherever he needed to go.

One night, coming home late from a meeting, the wife was driving. It was her last drive. When she pulled around a curve in the road, she was confronted with two sets of headlights bearing down on her at high speed. She was killed instantly when a truck, passing on the curve, smashed into Bob's car.

And Bob? — both legs fractured, a hand smashed, internal injuries. There followed eight dreary months as a patient in the hospital where he worked. But he knew the staff, and even from his bed he could train others, keep in touch with his job and with Operation De-Handicap, and get some statistical work done.

He had been hoping to get back to the States for more study; then, when he was released from the hospital, there was a chance to leave earlier and get home to California in time to have Christmas with his mother.

But there was an unexpected (though not unwelcome) delay: The government announced that Bob was one of the few who had been selected to receive the annual *Hau Ren Hau Shr* ("Good Man, Good Works") awards, in recognition of his outstanding contributions to society. The awards ceremony was scheduled for December, nudging the holiday season.

Bob just made it.

Things at home didn't work out quite as he'd expected. First, one of the fractured legs was acting up. The medical solution: amputation. Well, he thought, the leg hadn't been of any use to him anyway.

Secondly, his study took a form he hadn't anticipated. He ran into a fellow-priest whose special concern was geriatrics, as Bob's interest was rehabilitation. Moreover, he had a car at his disposal, and four free months between assignments. Why not join forces and tour rehab and old folks' facilities in the U.S. and Canada? They'd learn more that way than they could in the classroom.

So, like the wandering scholars of the Middle Ages, they set out. They criss-crossed the continent, easy riders through 30 states and three provinces, staying in church residences as well as putting up (it seemed) in more motels than Lolita and putting up with more home-cooked vittles than a circuit-riding preacher. One stop was at the home of Joe and Gini Laurie and the *Rehabilitation Gazette* (Bob rates the cuisine three-star).

There were adventures — like the twilight race to the Canadian border before it shut down for the night and left 1978/VOLUME XXI

them stranded on the bleak Dakota plains; there were discoveries — like the home of the Sisters of Christ Crucified, where every Sister was disabled in one way or another; there was sightseeing — like a boat trip around Manhattan, and the first smoldering of autumn colors in New England; and there were surprises — like the time when Bob, phoning ahead to Washington, D.C. for accommodations at a Missionhurst establishment, identified himself as "Robert Ronald, from Taiwan," and was greeted with: "Hello, Bob! This is Father Paul — from Taiwan."

When Bob got back to Taiwan, Operation De-Handicap was lurching ahead, on crutches, wheelchairs, enthusiasm, and a couple of foundation grants. Part of the latter will help finance a new home base (Bob has found the ground floor of a building now under construction, which can be modified to suit and which is handily situated with bus stops near by).

Already, three other cities have offshoots, offshoots that are sprouting into independent growth: the Hsinchu branch, for example, has supplied 15 wheelchairs to those who need them, and has helped 30 people find jobs.

Before the typhoon season really got under way this year, Operation De-Handicap staged something unprecedented: a camp-out for the handicapped, many of whom had never spent a night outside of home or hospital. Buses were chartered and a pack of Cub Scouts enlisted to help with raising tents and scrounging firewood and scouring pots, and over 200 disabled took off on their great adventure.

The campground, it turned out, was near a military camp. Some off-duty soldiers wandered over to see what was going on, and pitched in with help and advice. After supper, there were songs and mosquitoes — sing-along with it.

The next day, one of the campers told Bob: "You know, we really appreciated that. It was the first time we had a chance to do something for ourselves. Even if we made mistakes, they were *our* mistakes; even if we burned the rice, it tasted great!"

"Have you eaten rice?" or "Have you had your fill?" is a standard Chinese greeting, equivalent to the western "How are you?" This camp-out left a couple of hundred of the disabled tired but with the appetite for adventure satisfied — temporarily.

For tomorrow, says Psycho-Social and Vocational Rehabilitation Consultant Robert J. Ronald, S.J., other plots and plans are bubbling on the back burner to help China's disabled help themselves to a fuller life.

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*Ron Dickson, a quad from a combination of polio and an unknown disability, is a writer and a librarian. A graduate of the University of Illinois, Champaign-Urbana, he moved to Taiwan in the late sixties. He is employed as a librarian at the National Palace Museum in Taipei. Address: Box 46-58, Taipei 104, Taiwan, Republic of China.*

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## Available Back Issues

Donation per copy: \$3 from the disabled  
\$5 from the non-disabled

*In addition to the special features listed below, all the issues contain first person accounts of the experiences of severely disabled individuals in obtaining higher education, training, or employment, reviews of books of special interest, and excerpts from readers around the world seeking pen friends.*

**1962. Vol. V.** Experiences of quads acquiring higher education by telephone, correspondence, and attendance. Reading aids. New approaches to attendants. Voice-spondence Club. Self-aspirator.

**1963. Vol. VI.** Quads and their families at home, marriage, and adoption. Housing around the world. Wheelchair cushions. Australian fibre glass lung. Vacations and camping. English chair/bed.

**1965. Vol. VIII.** Traveling quads. Medical engineering — arm aids, foot-operated aids, multi-controls. Quad driving — foot-controlled steering, ramps, lifts, aids. Adoption. Housing. Narrowers.

**1966. Vol. IX.** Vocational rehabilitation. Employment experiences of quads. Wheelchairs — self-reclining, respiratory, climbing, foreign. Remote controlled typewriter. Association of Mouth and Foot Painting Artists. Housing. Reading list for quads.

**1967. Vol. X.** Experiences of 23 disabled college students and 35 employed quads. Citizens band radio. One-hand typing. Wheelchairs — curb-climbing, chin-controlled. Frog breathing. Portable lungs. Sex and the disabled. Alien attendants. Housing summary.

**1968. Vol. XI.** Tenth anniversary issue. Homemaking experiences of severely disabled individuals. Home-based businesses. Quad driving. Wheelchairs and accessories. Mouth-operated phone. Housing in Mexico and England. Rehabilitation through music. Remote controls.

**1969. Vol. XII.** The quad in his community. Ramps for home and car. Home care services. Housing complexities. Wheelchairs. Typing aids. Bathroom equipment. Traveling and living in Mexico. Photography.

**1970. Vol. XIII.** Community service projects. Independent living by quads. Mouthstick typing. Cushions. Bath lifts. Tie-downs. Hydraulic tailgates. One-armed fishing. Chess by mail. Group tours.

**1972. Vol. XV.** Comprehensive rehabilitation centers. Housing and home services for the disabled in the U.S. Remote controls. Ramps. Amateur radio. Art, music, and religion. Architectural barriers. Education. Employment.

**1973. Vol. XVI.** Social security and Medicare. Annotated bibliography of sex. Vans, lifts, and driving controls. Communications. Curb-jumping. Mouthstick controls. Family reactions to quadness. Yoga, Zen, and Sufism. Periodicals around the world relating to disability. Veterans. Housing aid home services for the disabled in the U.S.

**1974. Vol. XVII.** Travel to Canada, Mexico, and Europe. Travel with respirators. Recreational vehicles for wheelchair. Rehabilitation Act of 1973. Bills of rights. Coalitions. Education and employment of quads. Volunteer projects. Adjustments to spinal cord injury. Biofeedback. German breathing treatment. Charcot-Marie-Tooth syndrome. New wheelchairs. Vans and lifts. Remote controls.

**1975. Vol. XVIII.** Compendium of employment experiences of 101 quads. Supplementary Security Income. Multiple sclerosis. The telephone: a genie of services. IRS regulations on attendants. Quad-adapted camera. Step-vans, lifts, and ramps. New word board. Inexpensive tie-down. Bargain wheelchair narrower. ACCD. Architectural barriers milestones.

**1976. Vol. XIX.** Vocations. Avocations. Understanding depression — helping with grief. Teaching the blind to type. Employment experiences of quads. Housing and independent living. Tennis. Skiing. Self-help organizations. ROHO cushion. Wheelchair loader. Step Vans. Hitch-hiking through Europe in a wheelchair. GPB for high level quads.

**1977. Vol. XX.** Compendium of employment experiences of 25 disabled women. Rehabilitation in the Navajo Nation. Independent living programs. Wheelchair lifts for vans. Improved battery charger. Inexpensive camper-pickup with lift. Self-operating electric hoist. Your state vocational rehabilitation rights. Paraplegics in prison.

**1978. Vol. XXI.** 20th anniversary of the *Rehabilitation Gazette* — a photo story. Experiences of a deaf Japanese student. Don't be left without your RIGHTS. Barrier-free education. The disabled in Protestant churches. Indian sign system. Voice-activated telephone. Latest in housing. Respiration equipment. New portable iron lung. Spinal cord injury centers.