

Rehabilitation Gazette

International Journal for Independent Living by Disabled People
Volume 25

A black and white photograph of a woman with short dark hair and glasses, wearing a light-colored striped blouse with a ruffled collar and a pearl necklace. She is seated in a wheelchair at a desk, smiling at the camera. Her left hand is on a large, vintage-style rotary telephone. On the desk in front of her are several papers, a white disposable cup with a straw, and a small potted plant. The background shows a wall with various papers and a framed certificate.

**Special Features: 25th Anniversary and
Gazette International Networking Institute (G.I.N.I.)**

**Second International Post-Polio Conference and
Symposium on Living Independently with Severe Disability**

HAPPY
25TH
ANNIVERSARY

REHABILITATION

When Joe and I celebrated its 20th birthday in the 1978 issue, it was "a time to look back and remember with long-time readers." In photos and words, we told how the Gazette began, started, evolved, and lasted for 20 years.

The Gazette began before I was born, when polio caused the deaths of three of my siblings (two sisters and a brother).

It was started in 1958 as a continuation of my volunteer work at the Toomey Respiratory Polio Center as a means of communication and sharing among polio survivors.

It evolved from polio to include all disabilities, expanded from a newsletter to a journal reaching 83 countries, from encouraging living independently to nurturing the independent living movement, from local to international problems and solutions.

It has lasted because it has been a home-based volunteer project, operating on a small budget, without salaries or overhead, supported by its readers' donations.

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GAZETTE

So it might have continued for a few more years. But the Gazette's St. Louis post-polio conference in May and the Charles Kuralt Sunday Morning TV program in June were powerful catalysts to self-searching and action.

A month after the conference, Joe and I spent a weekend "retreat" with the board of directors, looking back and planning for the future.

Together, we reaffirmed the unique value of the Rehabilitation Gazette. It is all the people who are part of this international journal and information service. It is a living network, an international communications system.

Together, we created exciting plans to perpetuate and expand the Gazette, which for 25 years has been the hub of that network.

To reflect our plans for the next 25 years, we changed the name to:

**Gazette International Networking Institute
(G.I.N.I.)**

We will change from a totally volunteer operation and seek individual, corporate, and foundation contributions in order to add a salaried executive director and secretary to assist Joe and me.

We will continue to publish the Gazette and hope to make it quarterly.

We will continue to be "the glue that has held 'the polios' of the world together" and to work with persons of all disabilities and all ages.

We will continue to serve all respirator/ventilator-dependent persons.

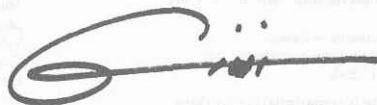
We will computerize the network, the files, and the library and establish an international data bank.

We will improve information gathering and sharing as an automated clearinghouse.

We will sponsor the Rehabilitation Gazette's Third International Post-Polio Conference and Symposium on Living Independently with Severe Disability in St. Louis on May 10-12, 1985.

We will organize the multitude of services of the Gazette, existing and future, into an Institute.

Together, Joe and I and the Board feel confident of the Gazette's future for many years.



The "foo" sign is a Chinese character which stands for health, prosperity and all good wishes. It has long been a symbol of the Rehabilitation Gazette.

Rehabilitation Gazette

Annual International Journal for Independent Living by Disabled Individuals

Volume 25 1982

Rehabilitation Gazette (formerly the *Toomey J Gazette*) has been published once a year since 1958 by a volunteer staff. Its aim is to reach, to inform and to dignify people with disabilities throughout the world.

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Cover: Nita Weil is Director of Volunteers at The Institute for Rehabilitation and Research in Houston, Texas. Nita, one of the productive and creative polio survivors who are celebrated in this issue, has been reporter-dependent fulltime since 1952. See page 33. Photo by Houston Chronicle.

Donation for this 25th Anniversary Issue:

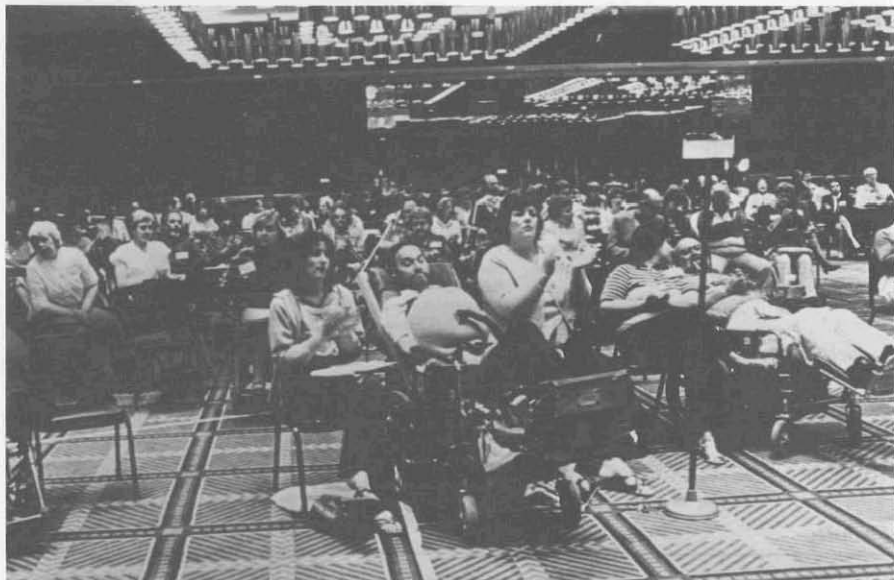
\$10, domestic or foreign postage is included. Extra contributions are tax-deductible.

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- 1 **25th Anniversary of Rehabilitation Gazette.** Announcement of Gazette International Networking Institute — (G.I.N.I.)
- 3 **Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability** by Gini and Joe Laurie
- 21 **Polio Clinics and Support Groups**
- 23 **Poliovirus and Immunization** by Marilee M. Thome
- 24 **25 Years of Experiences as Polio Survivors in Canada and the United States.** Vignettes of 27 individuals. Thirty-Year Polio Survivor by R.B. (Bob) Gordon. Hanging onto the Coattails of Science by Alice Loomer, Ph.D. I am Still the SAME Person by Audrey King, M.A.
- 36 **Reflections/Perspectives:** The Psychological Barrier by Theodore Solomon. The Magic of Motivation by Carole Ann Parsons.
- 39 **Computer-Assisted Living** by William Kaiser
- 42 **Trends in Home Health Care.** Medicaid Waivers. Surgeon General's Workshop on Children with Handicaps and Their Families. Brook Lodge Symposium. By Judy Raymond.
- 44 **Future Concerns:** Is Apathy Growing on the College Campus? by Valerie Brew Parrish. Independent Living: An Advocacy Base or Service Provider? by Charles Carr.
- 46 **War and Peace: Adjusting to Myasthenia Gravis** by Rachelle Kess, R.N.
- 48 **Cerebral Palsy Challenges:** The First and Greatest Challenge by Rose Ann Stanowski. The Right to Be Challenged by George D. Green. The Road to Independence is Paved with Help by Jim Hammit. No Longer a C.P. by David Morton. I Try to Help Other People by William E. Tubbs.
- 53 **Coping with Chronic Pain** by Marilee M. Thome
- 54 **Travel.** By Bus in a Wheelchair by Eileen Van Albert. Using a Respirator on Trans-Atlantic Flights by Anne Isberg. Israel: A Dream Come True by Renah Shneider. My Trip To Israel by Selma Z. Sack.
- 56 **Books.** Reviews by W. Danforth Hayes, Joyce Kniffen, Theodore Solomon.
- 60 **Friends Around the World**
- 62 **Equipment** by Joe Laurie. Communication: Using a Microfilm Viewer as a Reading and Reference Device by John Dalhaus. Text Generating System by John Dalhaus. The Story of Blissymbols: A New Language by Fred Murray. Respirators/Ventilators: Go Positive with Face Mask and Mouth-piece by Adolf D. Ratzka, Ph.D., Learning to Use a Portable Volume Ventilator (PVV) by Paul K. Longmore. Making a Custom Fit Polyethylene Cuirass by Audrey King. Frog Breathing with Gary McPherson. Foot-made Portable Respirator by Louis Dabney. Manufacturers of Respirators/Ventilators. Mouthsticks/Page Turners. Miscellaneous Readers' Ideas: Wheelchair Office and Bed Rack for CB and Ham Radio by James Thompson. Swimming. Mobility.
- 73 **Potpouri** by Gini Laurie
- 78 **U.S. Periodicals and Newsletters**
- 79 **An' A Tac on My Tires** by Audrey J. King
- 80 **The Gazette Marketplace**
- 81 **Available Back Issues**

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GLOBE-DEMOCRAT Photo by John Bloomquist

These were among the more than 400 participants in the conference.

Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability

**May 6-8, 1983, Sheraton-St. Louis Hotel
St. Louis, Missouri**

**By Gini and Joe Laurie
Conference Chairmen**

A brief summary of the sessions which will be reported in depth in the published proceedings. The C.V. Mosby Company volunteered its expert editing assistance. Details for ordering the complete proceedings are on page 80.

Agenda

Friday Afternoon and Evening, May 6

Results of 1981 Polio Conferences

4:00 pm Opening Session
6:00 Dinner

Polio Immunization and Research

7:15 pm Worldwide Immunization
8:20 Recent Poliomyelitis Research

Polio Rap Session

9:15 pm to 11:15 pm

Saturday Morning, May 7

Positive Attitudes and Health Maintenance

9:30 am Positive Attitudes and Wellness
10:45 Health Maintenance—General
12:00 Lunch

Saturday Afternoon, May 7

Long-Term Respirator Maintenance

1:15 pm Health Maintenance—Respirator-Users
2:15 Respirators/Ventilators
3:15 Home Care Programs for Respirator-Users

Post-Polio Action Plans

Saturday Evening, May 7

Celebration of Rehabilitation Gazette's 25th Anniversary

6:30 pm Reception
7:30 Banquet

Sunday Morning, May 8

Essentials of Living Independently

9:30 am Personal Assistants—Prevention of Burnout
10:30 Mechanical Assistance—High and Low Technology

Rewards of Living Independently

11:30 Family Life, Natural or Adopted Children, Sexuality, Fertility
12:30 Lunch

Sunday Afternoon, May 8

Independent Living

1:30 pm The Independent Living Movement
3:00 Rap Session on Independent Living Centers
4:00 Adjournment

Forum for International Interchange

4:15 to 6 pm

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**Respirator-dependent

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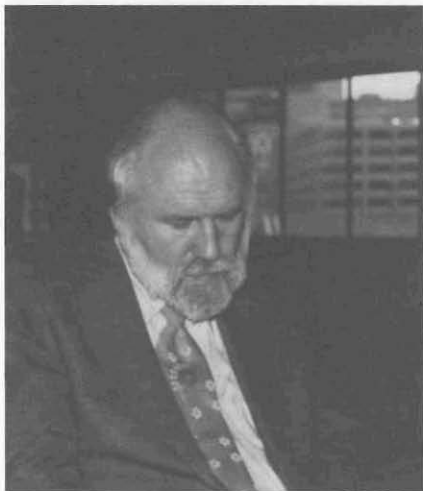
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*Disabled

**Respirator-dependent



Jack Genskow, Ph.D., program adviser and speaker.

The Planning

In January, 1982, our neighbors, Gayla and Art Hoffman and Colleen and Max Starkloff, and Mickie Martin, the *Gazette* librarian, suggested a 25th anniversary party for the *Gazette* in 1983. We loved the idea but we felt that if there were a real anniversary party there would be so many old polio friends that it should also be the Rehabilitation *Gazette's* Second International Post-Polio Conference. Thus the conference was conceived.

The Program

As we planned the program, Gini recalled the *Gazette's* role of observer during the last 25 years and realized that the story of "the polios" living independently was also the story of the involvement of the independent living movement — a story that has value for all disabled persons.

The program reflected this involvement. It shared the experiences of polio survivors with cost-effective home care, positive attitudes, health maintenance, attendants, mechanical assistance, long-term respiratory maintenance, and family life experiences.

In addition, the program summarized developments and research since the 1981 conference, called attention to the problems of worldwide immunization, and included time for action plans and a rap session.

We created the program with the invaluable guidance of Jack Genskow, Ph.D., an associate professor at Sangamon State University in Springfield, Illinois, and a respiratory polio quad. The program also reflected the contributions of Judy Raymond, Mickie Martin, Robert M. Eiben, M.D., Frederick Maynard, M.D., Max and Colleen Starkloff, Audrey King, Judy Heumann, and many others whom we saw at conferences and meetings throughout the year.

The Volunteers

With the exception of printing, typesetting, and recording, all the work was done by volunteers or donated by companies. Southwestern Bell Telephone Company funded the programs and invitations. Donna Johnson wrote the script of the history of the *Gazette* for the Saturday night anniversary dinner. Money, Marbles, and Chalk produced and presented the show.

The Lauries were chairmen. Gayla and Art Hoffman were vice chairmen. Mickie Martin planned the sightseeing and wrote an accompanying guide. She and Colleen Starkloff surveyed the accessibility of nearby restaurants and directed the sightseeing tours. With Jeremiah Sheehan, Mickie created an accessibility map of downtown and worked with Ann Sheehan to design the banners and scrapbook displays. The dinner-committee volunteers were joined by other volunteers who came from Ohio and California to help — Kem Mahan, Judy Raymond, and Marty Stitt from Ohio, and Marion Greene from California.

The Funding

Once again, there was no federal or other source of funding. The faculty and the participants paid their own expenses or made arrangements to have them paid by universities, hospitals, social welfare agencies, fraternal organizations, and airlines.

Once again, you, the *Gazette* readers, responded to a second "Brown Bag" appeal. A total of 330 brown bags "bagged" \$11,000. Your donations paid for printing and mailing and supplemented travel and hotel expenses for participants and faculty who, otherwise, could not have attended.

In addition, Justin Dart, Jr., and Art Hoffman headed the Finance Committee that raised \$10,000. The committee members were Clarkson Carpenter III, Charles E. Claggett, The Rt. Hon. the Earl of Dunraven, Lady Hamilton, O.B.E., Most Reverend John L. May, Archbishop of St. Louis, D. Elliott O'Reilly, M.D., William M. Landau, M.D., Itzhak Perlman, The Hon. Sir Peter Ramsbotham, GCMG, GCVO, James Roosevelt, and Jonas E. Salk, M.D.

Gayla Hoffman headed the Anniversary Dinner Com-



Planning: Donna Johnson (left) writing the script for Saturday night's show. Art Hoffman and Mickie Martin discuss fund raising.



Early arrivals: Some registrants from England, Sweden, and Germany arrived a week early. Standing: Gini Laurie (L) and Judy Raymond (R) who came from Ohio.



Registration: Marion Greene registers Dr. Geoffrey T. Spencer from England. Marion came from Napa Valley, California.



Registration: Three dedicated volunteers — Mickie Martin, Gayla Hoffman, and Judy Raymond, and Dr. Irving Kenneth Zola.

mittee which raised another \$2,500.

The Hotel

The Sheraton-St. Louis Hotel is a model of both attitudinal and architectural accessibility. The management and the staff were understanding, friendly, and helpful. All the rooms have 36" wide entrance doors and 29½" wide bathroom doors. There are 24 special "wheelchair" rooms on the fourth floor with lowered peepholes, raised beds, grab bars near the toilets, and 31½" wide bathroom doors. All public rest rooms have one wheelchair stall and one lever faucet. For the conference, one phone in each bank of phones was lowered and ramps were added to the main dining room. The downtown location, next to the Convention Center, and near the Arch, simplified sightseeing and dining. (The City of St. Louis was helpful and, at the last minute, finished pouring the concrete for the final ramps that made the nearby area accessible.)

The Faculty

The international faculty totalled 64. Of these, 39 are disabled and 14 of these disabled use respirators. There were 20 physicians (3 are disabled and 1 is a respirator-user) and 18 professors, nurses, lawyers, social workers, occupational and physical therapists (12 are disabled and 3 are respirator-users). Of the 26 other faculty members, 24 are disabled and 10 of the disabled are respirator-users.

The Participants

A total of 439 registered. Of these, 201 were disabled (158 by polio, 43 by other disabilities — SCI, MS, CMT, CP or blindness). The other 238 were professional persons and families, friends, or attendants of the disabled registrants.

They came from around the United States and around the world: 24 from Germany, 1 from Sweden, 4 from England, 2 from South Africa, 1 from Japan, 7 from Australia, 1 from India, 2 from El Salvador, 2 from Mexico, and 30 from Canada.

The Respirator-Users

Once again, Lifecare Services, Inc., solved the rental and maintenance problems of respirators with efficiency and reassurance. Their representative, who worked with us from the initial planning, came to the hotel months in advance to check the size of the elevators and doors for iron lungs and rocking beds. There were 40 respirator-users, including 2 oxygen-users. Most of them used their own portable respirators. Lifecare brought 2 rocking beds and six lungs, plus an extra lung for display outside the meeting room.

Impact

The letters from the participants have been warm and enthusiastic in their praise of the significance of the conference and its effects on their lives.

"The conference was successful," said Richard L.

Bruno, Ph.D., of New York City, "in linking like-minded researchers who are interested in first defining and then studying the problems of old polios."

"What a wonderful event," said Selwyn Goldsmith, RIBA, of London, "a unique international congregation of friends, colleagues and admirers . . . a lovely gathering of people . . . valuable and enjoyable." Another Londoner, Dr. Geoffrey Spencer, described it as a "magnificent conference." Adolf Ratzka, Ph.D., of Sweden, termed it a "most memorable meeting of people."

"The weekend's experience simply overwhelmed me," said Doris Brennan of Cleveland, Ohio. "The information imparted was so valuable. The opportunities cannot be measured. It was a triumph of caring and sharing." To Val Parrish of Carbondale, Illinois, "It was electrifying."

"I have never before," said Alice Mary Blodgett of the Kansas Easter Seal Society, "been to a gathering where canes, crutches, walkers, and wheelchairs caused traffic jams." "The planning and logistics behind those three wonderful days must have been staggering," said Richard Daggett of Downey, California.

"I learned many useful things," said Nancy Frick of New Jersey, "that are proving most helpful not only professionally but also personally . . . I had a sense of peership and camaraderie never before felt."

"A totally successful meeting," said Justin W. Dart, Jr., of Austin, Texas, "of considerable significance in the maturing process of the disability rights and independent living movements, and the cause of progressive rehabilitation."

"My entire group and I," said Darlene Odynski of Edmonton, Alberta, "came back inspired and with many ideas. It was good to see and talk to people from all parts of the world sharing a common interest."



Joe and Gini Laurie receive President Ronald Reagan's Distinguished Service Award from Justin Dart, Jr.

Photo by Stewart Halperin



Dinner guests: Sunny Weingarten, Vera Overholt, and Speed Davis.



Mickie McGraw, President, Gazette International Networking Institute, "I know that Gini and Joe are proud, not of their own accomplishments, but of those of each of us — their family."



Nancy and Jack Quigley. Jack presented a Certificate of Commendation to Joe Laurie from their fellow alumni of Amherst College.

"Tremendously helpful and informative," said Lucille Owen of Toronto, Ontario. "It's given me renewed vigor to tackle some post-polio difficulties I've been experiencing . . . It was a particular pleasure to meet people whom I'd read about in the *Gazette*."

"The marvelous people," said John Dycus of Arlington, Texas, "made the conference a festive time of discovery and enlightened friendship. I found my own self-worth increased in light of another's accomplishments — 'if he can succeed, I can succeed.'"

National TV Coverage

Sally Manns, a conference participant, wrote to Charles Kuralt about the conference and the volunteer work of the *Gazette* editors. Her enthusiasm so effectively aroused his interest that he sent Pauline Canny, Frank Currier and a camera crew to St. Louis several days before the conference to cover the preparations at the Lauries' and the opening night and first day of the conference. CBS showed the 10-minute feature on "Sunday Morning with Charles Kuralt" on June 19, 1983.

German Documentary

Dr. Adolf Ratzka of Sweden arranged with an old friend, Hans Peter Meier, a lawyer and movie-maker in Munich, to bring a film team to make a documentary of the conference. The documentary will be about 60 minutes in length and will focus on the medical and technical aspects. The team arrived a week before the conference and covered the planning work at the Lauries' as well as every detail of the conference. The team followed two respirator-dependent participants, Susan Ambrecht and Dr. Ronald Doneff, to their homes after the conference to show the German viewers that even very severely disabled persons can be active, high-powered, and successful citizens.

25th Anniversary Dinner

On Saturday night, May 7, friends from St. Louis and friends who had come to St. Louis for the conference gathered to celebrate with the Lauries the 25th anniversary of the *Rehabilitation Gazette*. Chairman of the dinner was Gayla Hoffman and Mistress of Ceremonies was Karen Foss of St. Louis's NBC TV-News.

Highlights of the evening were two presentations: a Certificate of Commendation from the Executive Committee for the Alumni Council of Amherst College to Joe Laurie by Jack Quigley, another Amherst graduate, and President Reagan's Distinguished Service Award to both the Lauries by Justin Dart, Jr., Vice Chairman of the National Council on the Handicapped.

The love and warmth at the dinner were touchingly recalled by John Dycus of Arlington, Texas, "I saw human potential celebrated and never so vividly as the Saturday night dinner when the Lauries' extended family was returning their love as hard as they knew how. It was an unforgettable experience."



Karen Foss, KSDK-TV, Mistress of Ceremonies of the anniversary dinner.



Joe Laurie, one of the volunteer photographers.

Second International Post-Polio Conference



Opening session: (L-R)
Robert M. Eiben, M.D.,
Sheldon Bernal, M.D.,
Frederick M. Maynard, M.D.,
Allen I. Goldberg, M.D.,
Geoffrey Spencer, F.F.A.R.C.S.,
Gini Laurie,
Jack Genskow, Ph.D.,
Stanley K. Yamell, M.D.,
Renah Shneider,
William M. Landau, M.D.

Opening Remarks

Gini welcomed the participants as pioneers, as the representatives of all persons with severe disability "who wish to live on today's frontier of independence." The polio survivors of the 1950 epidemics were the pioneers whose self-directed lives at home demonstrated that home care cost one-tenth to one-fourth less than hospital care and who were the leaders of the independent living movement. The respirator-dependent polio survivors who have lived independently and productively for 25 to 30 years are role models for all respirator-dependent and all severely disabled persons.

The following six goals for the conference were presented:

- (1) Influence the development of home-care programs for respirator-dependent persons and for personal-care attendants for disabled and elderly persons;
- (2) influence the development of a national and international network for all respirator-dependent persons to coordinate services, treatment, funding, information, and equipment;
- (3) focus attention on the physiological and psychological effects of aging on the larger group of polio survivors, estimated at 300,000, who are not respirator-dependent, and relate the findings to all elderly persons;
- (4) disseminate medical information to the medical profession on the changing needs and changing technology of all polio survivors (specifically, arrange for the publication of

the *Physician's Handbook on Polio* which the *Gazette* is correlating with Dr. Armin Fischer at Rancho Los Amigos Hospital);

- (5) reactivate the general public's awareness of polio, hasten worldwide immunization and alert travelers to checking immunization status;

- (6) enrich the independent living movement by demonstrating the relevance of the longtime independent living experiences of polio survivors to all disabled and elderly persons.

Results of the 1981 Post-Polio Conferences

The *Gazette's* First International Post-Polio Conference in Chicago and the Post-Polio Symposium II in Oakland heightened awareness of the aging problems of polio survivors among the medical community and disabled individuals. Post-polio clinics were set up; additional conferences were held in 1982 and 1983; and an increased number of polio survivors sought information and checkups. The Chicago proceedings were published and are available from the Rehabilitation Institute of Chicago.

Developments for the long-term respirator-dependent person were reported by Dr. Augusta Alba: the number of vendors of respiratory equipment in New York City increased; regular respiratory therapy visits in the home were organized; a discharge planning manual was created; more hospital and community facilities became available; increased competition improved the portable volume ven-

tilator; more scholarships for the training of personnel in techniques of care were established; and Alba's article in the *Gazette* on the use of mouth intermittent positive pressure ventilation for sleep triggered a deluge of letters and phone calls.

Dr. Spencer discussed the disturbances of breathing during sleep. He found Dr. Alba's methods excellent for preventing excessive rise of carbon dioxide levels for people who develop abnormally high carbon dioxide levels during sleep. These methods help eliminate the danger that the high levels might not return to normal by day causing the individual to have some daytime tiredness, headache, and even insomnia.

Dr. Allen I. Goldberg was involved in the planning of the Surgeon General's Workshop on Children with Handicaps and Their Families, which was held in December 1982 at The Children's Hospital of Philadelphia. The conference was convened by Surgeon General Everett C. Koop, M.D., to consider ways of assisting the family to care for respirator-dependent children at home.

Dr. Fredrick M. Maynard referred to the sessions on polio held at the American Academy of Physical Medicine and Rehabilitation in Houston in November 1982 and the conferences held by nursing organizations in Michigan. He mentioned increased interest in ventilator-dependent spinal cord-injured persons at centers and hospitals, and also the change in Michigan in the willingness of third parties to pay for their home care.

Drs. Yarnell and Berrol, who with Renah Shnaider, organized the Oakland conference, felt there was a significant need for training of post-polio survivors in basic health care and for providing information on the resources of the community. Dr. Yarnell has set up a polio clinic and Ms. Shnaider is developing a support group to meet once a month to broaden the base of information and funnel this information back to the clinic.

Audrey King, M.A., worked with the Ontario March of Dimes to organize a Post-Polio Workshop on April 22, 1983. At the workshop, a commitment was made to compile an Ontario registry of post-polio people and their family physicians.

Worldwide Immunization

Though vaccines have dramatically reduced the incidence of polio in the United States, the panelists — Father Lewis, a member of an order with missions in South America, Africa, and the East Indies; Mrs. Chaukar, a social worker in India; Dr. Spencer of London who has treated polio throughout the Middle East as well as Europe; and Dr. Lusk, whose specialty is infectious diseases — warned that polio is still endemic in much of the Third World and that there are many sociopolitical problems involved in worldwide immunization.

The magnitude of the disease is understated because of the underreporting of paralytic cases and the high proportion of unrecognized cases. Dr. Spencer quoted the estimate by Professor Hucklestep that there are 5 million new cases of polio in the world each year. The National Institute

for Allergy and Infectious Diseases estimates 1 of every 200 children born today will suffer paralytic polio.

Unimmunized adults planning to travel to areas in which polio is endemic were advised to be immunized with the Salk (killed) vaccine.

"Vaccine is available," said Dr. Lusk, "technology and know-how for delivery of the vaccine is available; what appears to be lacking is commitment of political leaders. Therefore, it seems to be reduced to a 'people issue'." He urged polio survivors to use their influence to eradicate the disease.

Recent Poliomyelitis Research

Joseph Kaufert, Ph.D., a rehabilitation epidemiologist at the University of Manitoba in Winnipeg, reported on his current follow-up survey of 1,500 nonrespiratory and 186 respirator-dependent polio survivors, documenting the effects of aging and changing family support systems. There was much lower reporting of age-related changes within the nonrespiratory group: about 20% reported significant changes in energy levels, and about 25% had significant arthritic and secondary limb effects.

"Some polio survivors experience not only residual weakness from the initial illness," said Dr. Dalakas of the National Institutes of Health, "but they also develop later in life a new progressive weakness. The mechanism of this new muscle weakness is unknown. Three basic possibilities have been raised, but none has been proved scientifically. One is the natural predisposition to deterioration that has



Dr. Frederick M. Maynard checks Dr. Ronald H. Doneff's respirator.

been linked to the genetic background of the patient; the other is an acceleration of the aging process; and the third is reactivation of polio. At the National Institutes of Health we have started to study post-polio patients to understand the mechanism of this new syndrome."

The panel and the audience concluded that "post-polio muscular atrophy" should be used rather than "post-polio syndrome." It is very, very slowly progressive. It is a degenerative problem, common in the general aging population. No one can predict who is going to develop the weakness and who won't. "There is no doubt," said Dr. Spencer, "that people with polio get weaker as they get older. So do we all. People who are already weak notice this earlier."

Positive Attitudes and Wellness

Jay Bullock, an occupational therapist at The Johns Hopkins Hospital, summed up her experiences, "A positive at-

(Right) Gini Laurie with Dr. and Mrs. Lauro S. Halstead of TIRR, Houston.
(Far right) Renah Shneider of Oakland and Augusta Alba, M.D., of New York City.



titude to health is maintained by planning a program adapted to your needs and accepting the fact that some aspects of life will change as we age."

"In terms of positive mental attitudes," said Dr. Maynard of the University of Michigan, "and how they affect wellness, the following are the most important: (1) belief and hope — belief that things can be better and hope for relief or improvement in the future; (2) control and self-direction — control over the way you experience disability and willingness to assume self-direction, which reflects self-esteem and self-confidence and is related to survival and success; (3) good health — something to be tended to by proper diet, exercise, and rest and by avoiding excessive drinking, smoking, and similar social habits; (4) the ability to plan ahead and think for the future; (5) flexibility and adaptability — a willingness to reorder priorities; (6) humor — especially the ability to see humor in your own situation; and (7) being open for whatever comes along in life — not blaming people but rather forgiving people and yourself."

"My reflections relate to attitudes," said Mickie McGraw, art therapist at Highland View Hospital in Cleveland, "my own and those of the professionals around me. (1) Learn about compensating. It is a part of coping and the way one learns to live with limitations. We have all done it

before and we can do it again. (2) Do not automatically relegate all of our manifest symptoms to post-polio problems. Our nondisabled peers experience limits and losses of their own. We are special, but we are not alone. (3) Relate to yourself as a whole person. Do not focus on your disability. Set the example for your physician and your friends by your own attitudes and they will follow suit. (4) Balance — physical and psychic — is essential. It requires self-knowledge and self-control and preserves our ability to maintain control of our lives. (5) We should listen to our bodies' messages and acknowledge our physical vulnerability. Our spiritual invulnerability is our ability to adapt . . . and the ultimate key to freedom within limitations. We must keep faith with the collective will to survive, which is the call and spirit of this conference."

"Wellness is not a state," said Dr. Zola, a sociologist at Brandeis University, "that is an absence of disease. It is not a state. It is a process, a continuous process . . . the aspect

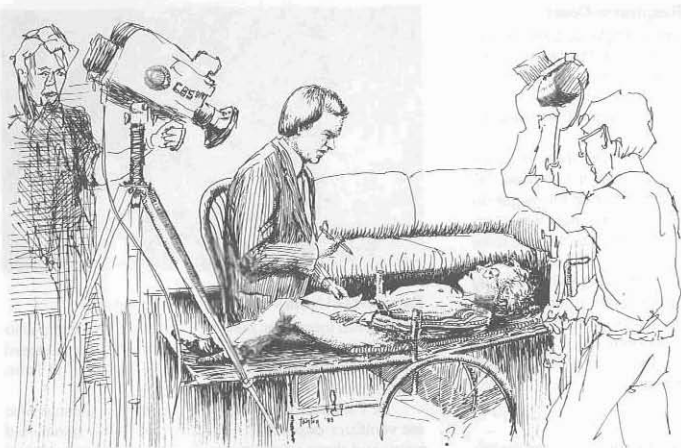


of wellness must in some way be concerned beyond an individual's life-style, beyond individual behavior. It has to involve social and political spheres. . . . For all of us, the nature of wellness or health must involve a certain kind of social support. . . . One needs social support all the time, and part of a network of social support is a realistic perception of the environment out there."

Health Maintenance — General

"The new post-polio syndrome is real," said Dr. Berrol of San Francisco General Hospital, "but there are many other causes for progressive weakness that occur to the post-polio person as a result of the aging process and as a result of some of the residual deformities that occur secondarily to the disability rather than as the onset of a new syndrome. The new syndrome is there but these other issues are far more common."

A dermatologist, Dr. Doneff summarized basic skin concepts, emphasizing common sense and simple, inexpensive management. "Oily skin is associated with polio and many other neurologic diseases. . . . Two important things: flaking does not always mean dry skin; and virtually all 'complexion' problems are due to oiliness and blocking of the pores of the face and upper torso by old oil and cellu-



Frank Currier interviews Susan Ambrecht during the filming of the conference for the CBS TV program, Sunday Morning with Charles Kuralt.

Drawing by Bob Tanton, Jr.

lar material. . . . Your best friend here — in fact, your best friend as a general rule throughout your life, when talking about the face and scalp or 'complexion' — is frequent, gentle washing with soap and water. . . . The best treatment for acne is gentle soap and water washing no more than two or three times a day. . . . Dry skin does not need oil. It needs water and the prevention of evaporation. The simple solution is to decrease bathing, to decrease the temperature of the bath water, to use soap only where it is needed, and then to use hydrating soaks or applications of water and to trap that water immediately with a moisturizing cream or oily cover (a moisturizer containing lactic acid and/or urea or Vaseline)."

Dr. Cameron of the University of Western Ontario called attention to the fact that we are perpetually reminded of the various health hazards. One of these is smoking, another is obesity, and the third is salt intake. "People smoke for a variety of reasons," he says, "including peer pressure, the tranquilizing effects of the tobacco and, eventually, metabolic dependency. Breaking the addiction can be painful and depressing. . . . Moderate obesity is as much a cosmetic problem as a health problem. If you like the way you appear, then you don't need to do anything about it. . . . You should not add salt to your food, although you do not need to cut it out completely."

Linda Hennig, M.A., R.N., of the Dallas Rehabilitation Institute emphasized preventive health practices and health maintenance needs. Concentrating on the problems of women, she said, "Breast self-examination is considered to be the most effective way of detecting early breast cancer. In fact, 95% of all breast cancers are found by women themselves or their sexual partners and about 84% of breast cancers can be cured if they are detected early. . . . For women who have experienced disability, the ability to perform self-breast examination may be significantly altered. . . . At our

Institute, we developed a modified technique for those who could not perform the standard technique and taught a family member or other person if they were totally unable to perform the technique."

Dr. Yarnell of San Francisco discussed exercise, emphasizing the need to suit exercise to individual differences. "General conditioning exercises or aerobic exercises," he said, "to maintain endurance and the overall tone of the cardiovascular system are good for post-polio people. The best is swimming, which exercises the muscles and stresses the heart appropriately. And, don't worry about the temperature of the water. . . . Another important form of exercise is stretching and range of motion, stretching not just your limbs, but your chest wall and abdominal musculature. . . . Don't overexercise your muscles. Know your level of fatigue. . . . Don't flog yourself using a manual chair, change to a motorized chair. Think of the change as a matter of conserving your energy and conserving your joints."

Respirators/Ventilators

The efficiency and the specific uses of the various types of respirators/ventilators — iron lung or tank, cuirass, chestpiece, or chestshell, plastic wrap or poncho, rocking bed, volume or pressure respirators/ventilators, and pneumobelt — were discussed in detail by Mr. Killam of Lifecare, Dr. Johnson, and Dr. Alba.

"The mouth," said Dr. Alba, "is one of the best forms of using positive pressure, as I discussed at length in Volume 24 of the *Rehabilitation Gazette*. . . . The mouthpiece that is presently the most convenient is the Bennett Lipseal. Adolf Ratzka is working on a form-fitting one that has promise."

Home Care Programs for Respirator-Users

Three comprehensive programs in England, Canada, and Australia were described by Dr. Spencer, Ms. Odynski, and Dr. Newton-John. The three programs include home visits, respirator maintenance, a team with medical supervision, telephone consultation, and a flexible approach to meet individual needs.

"Home artificial respiration," said Dr. Spencer, "is totally different from intensive care respiration in the hospital. All the problems of cross infection and other things just do not exist in the home. The users at home must be the experts in their own care. If they're not, they're not safe to be at home."

Bill Tainter added, "The key to living independently with a respirator is to receive adequate orientation and training about your personal care needs relative to the respirator. The key to moving out of institutions on your own is the availability of viable options and disabled peer models — the essence of independent living."

Respirator-Users — Polio

"The early warning signals," said Dr. Alba, "of need for initiating respiratory aid or for increasing aid are increased fatigability, falling asleep during the day, and increased swelling of the ankles. . . . When you have these warnings, you should hook up with a local hospital and have a respiratory evaluation or go back to a center that can do it for you. If you have respiratory involvement, you should have an annual appointment for a checkup."

Respirator Users — Children

Dr. Alba described the program at Goldwater Memorial Hospital for eight respirator-dependent children. To provide stimulation to the children who have little or no interaction with their environment, other children from the area and "grandparents" from a skilled nursing facility are brought in as volunteers. To mainstream education, a trained aide accompanies the child to a nearby school.

Dr. Faure described the psychological advantages and cost-effectiveness of the home care programs for ventilator-dependent children on which she and Dr. Goldberg have worked at The Children's Hospital in Philadelphia and Children's Memorial Hospital in Chicago. These are in the process of being expanded around the country.

Respirator-Users — Amyotrophic Lateral Sclerosis

"We try," said Dr. Alba, "to give our ALS people as optimal a life as possible. . . . Many of them have been capable of doing some wonderful things. . . . We give them and their families a choice of whether or not they want to prolong life with a tracheostomy and to decide whether they want to be resuscitated if they have a mucus plug or cardiac arrest. We try to keep them as well as everyone else. We don't have any additional sympathy because they are dying. . . . eventually we are all going to end up dying."



Respirator-Users — Spinal Cord Injuries

Dr. Alba has found that persons with spinal cord injury who come from an acute care center with a tracheostomy regard it as an "umbilical cord" and they do not want to learn mouth positive pressure or frog breathing.

Dr. Parsons contrasted the experiences of persons who are ventilator-dependent because of high level spinal cord injury and those who have polio. The mortality for spinal cord injury is high, maybe higher than post-polio persons because of the problems of neurogenic bladder, pressure sores, renal failure, respiratory complications, and disconnection of the mechanical ventilator from the tracheostomy tube. As an example, Craig Hospital discharged 41 spinal cord-injured persons on ventilators between 1974 and 1982. . . . Thirty percent were alive 3 years after the injury and 17%, 5 years after injury. "There was a clear pattern," he said, "to suggest that those who died spent more time in bed than did the survivors, and those who died spent a great deal less time out of the house than did those who survived."

Tracheostomy

Historically, persons disabled by polio in the United States have been tracheostomized less than those in other countries or those disabled by spinal cord injuries. A variety of opinions concerning tracheostomies were presented. A brief summary of some of the opinions expressed: Dr. Alba: "If an individual has repeated difficulty in handling secretions we may have them tracheostomized. . . . From the



Planning German TV documentary at the Lauries' before the conference. Hans Peter Meier of Munich, Adolf Ratzka of Stockholm, and Gini Laurie.



(Far left) Bavarians meet in St. Louis: Eveline A.M. Faure, M.D., Chicago, and Gertrud Weiss, Science Editor, United States Information Service, West Germany.

(Left) Hospitality suite: Hugh Newton-John, M.D., of Australia (Olliva's brother) and Audrey King of Canada.

practical viewpoint, a shortage of caretakers to do postural drainage and suctioning may be the reason for going to a tracheostomy." Dr. Brown: "At the University of Alberta Hospitals 55% of the patients with respiratory poliomyelitis have tracheostomies . . . 39% of these patients have required reestablishment of their tracheostomy within the past 5 years. Notwithstanding the benefits of a secured airway, complications such as localized sternal infection, bronchitis, formation of granulation tissue, and persistence of hypoxemia and hypercapnea can occur." Dr. Johnson: "Too many tracheostomies are done. . . . Even a high quad who has a perfectly normal diaphragm will often be tracheostomized in an emergency room even though he may not need it."

Frog Breathing

Glossopharyngeal breathing (GPB) is familiarly known as "frog breathing" because it resembles the gulping of the frog. Audrey King described how she had learned GPB after Dr. Alba told her about repeating the word *gup*. As a result, she has significantly increased her vital capacity. Gary McPherson showed a videotape, "Frog Breathing with Gary McPherson." (Details for ordering the videotape are listed in the Equipment Section under Respirators/Ventilators.)

Surveys

"Without preliminary information," said Dr. Halstead, "about who is having problems and what kind of problems they are having, it is going to be difficult to disseminate to the medical community and the lay press in a credible fashion the seriousness of the problems polio survivors are having."

Polio survivors can help secure this information by sending for and filling out one or more of the surveys being distributed by:

- Lauro S. Halstead, M.D., The Institute for Rehabilitation and Research, 1333 Moursund Street, Houston, Texas 77030. In addition to compiling and analyzing data from their questionnaires, Dr. Halstead and Dr. Wiechers of

Ohio State University are trying to raise money for a research symposium for clinicians and researchers to exchange and accelerate research on polio problems.

- Richard L. Bruno, Ph.D., Department of Rehabilitation Medicine, College of Physicians and Surgeons, 630 West 168th Street, Box 28, New York, NY 10032. If you live in New York State, send for his questionnaire.
- Harriet Bell, 510 Main Street, Suite A446, Roosevelt Island, New York, N.Y. 10044.

Post-Polio Action Plans

Following Jack Genskow's summary of the polio-related sessions of the conference and a report of the Action Committee chaired by Father Lewis, the conference participants concluded that:

- Polio is still endemic and epidemic in many parts of the world.
- Insufficient research is being conducted regarding the many unanswered questions about the long-term effects of polio on polio survivors.
- Available knowledge on current health problems of polio survivors is not sufficiently disseminated among health care professionals.

To develop action plans, the participants voted unanimously to empower Gini Laurie to appoint a Steering Committee of 15 members and to charge the Committee with developing action plans for:

- Urging the World Health Organization, governments, and agencies to promote immunization programs against polio.
- Insisting to governments in countries where polio has been controlled that travellers to nonpolio-controlled countries be immunized.
- Urging the United States government to enforce its polio immunization policy.
- Making governmental representatives aware of polio and post-polio problems via the Conference proceedings and hearings on research, information, training, and funding or programs to address these problems.
- Clarifying the current policy of the March of Dimes toward polio survivors.
- Forming local support groups through independent living centers, local chapters of organizations such as the National Easter Seal Society, and rehabilitation centers.
- Forming alliances with other respiratory and chronic disability populations.
- Enlisting the support of Disabled Peoples' International, Rehabilitation International, and similar organizations.

The above resolutions are a general charge to the Steering Committee. The Committee will report back to a Third International Post-Polio Conference to be held in 1985. *Rehabilitation Gazette* will serve as the international clearinghouse and coordinator of persons interested in sharing information and forming support groups.

Symposium On Living Independently With Severe Disability



Session on the independent living movement: (L to R) Renah Shnaider, Judy Heumann, Adolf Ratzka, Douglas Martin, and Bob Gorski.

Personal Assistants

Ed Roberts, one of the founders of the first Center for Independent Living in Berkeley, called his assistants, "the key to my life." He explained, "I have always had multiple assistants . . . several people coming in and out of my life. . . . If you are going to be strong and free and independent you need to make the choice as to the kind of person you want to live with you or to work for you."

California began an attendant care program in 1958. This year the maximum benefits for a severely disabled person are around \$900 a month. The total cost of the program is around \$225 million — probably the largest of its kind in the world.

Unpaid Personal Assistants and Prevention of Burnout

"Unpaid assistants," said Jack Genskow, "are people who care for disabled persons for relationship reasons — family ties, friendship, love, marital commitments. . . . There are several components of burnout — low energy, chronic fatigue, emotional exhaustion, depression, helplessness, and even entrapment. . . . It is insidious, it creeps up on you . . . it is a general erosion of the spirit. . . . Burnout occurs when one person does all the receiving without recognition of the needs of the person giving." He suggested several strategies to prevent burnout: keep communications open, develop an effective social support system, share what you're really feeling, rotate duties, and get away when the situation is stressful.

Peg Leonard, a longtime *Gazette* friend, died just before she was to have attended the conference. Her paper had been taped by a friend because Peg had been having problems with her voice. "Having been hospitalized," said Peg, "for three years, I appreciate the superiority of good home care as compared to a communal setup. . . . The privilege of being the sole patient means one has certain responsibilities to exercise extreme thoughtfulness."

Paid Personal Assistants

Adolf Ratzka of Sweden contrasted the usual agency-run system, which has a tendency to overprotection and limitation of initiative, to the disabled-directed system which he and a few others use. "To the disabled individual," he said, "the way attendant services are organized is at least as important as the number of hours of assistance. . . . If somebody is to be trained, it should be the disabled person. Motivating and directing another person take some psychological and educational skills, which have to be learned."

Gill Whitworth described the unique attendant care system Dr. Spencer organized for a few respirator-dependent polio survivors through a London hospital. "It is extremely important," she stated, "to maintain your privacy. . . . A lot of us are putting up with a lot of things. It is a question of how much quality of life you expect and demand."

Jan McMurphy, who has been working as an attendant for six years, defined an attendant's work. "Do anything,"

she said, "that makes it possible for your employer to live independently in the home. . . . The most important things about being an attendant are joy, pride, and maintaining a sense of humor. . . . To be an attendant you just have to be an extremely responsible person and have a professional regard for confidentiality. . . . My employers have trained me. . . . I am an extension of the employer's body and that's why it is such a close relationship."

Mechanical Assistance

"The problem," claimed Theodor Dukes, "is not what kind of additional technology we need but how can we make the technology available. . . . My arbitrary definition of low technology is that it is below \$1,000; above that amount it is high technology. . . . In the future, microprocessor technology could make maintenance of respirators much less expensive. . . . The computer is of utmost significance to the disabled in the areas of education, communication, and work opportunities."

John Dalhaus described the microfilm viewer which he has developed for his quadriplegic brother-in-law. (The viewer is featured in the Equipment Section of this issue.)

Bob Gorski shared a list of the computerized data banks currently available. He discussed two organizations of the disabled which specialize in computers — COPH-2 and Handicapped Source — and the advantages and disadvantages of working at home. Working at home is less stressful but it cuts down on interaction with other people; there may be additional tax write-offs but insurance will be higher.

Dr. Oldroyd described the small tabletop robot he has been using in his work at Washington University. "My interests are primarily in the computer-to-robot connection," he said, "and how to make robots work. . . . The technology is available and all the components are present, it is a matter of putting the components together and getting enough people producing the kind of software needed to tie them all together at inexpensive prices so that disabled people can use them productively in simple kitchen and bathroom chores."

Disabled Parents

"Disabled parents must develop a strong fortitude in dealing with the public," stated Val Parrish. "The public is often-times shocked, awed, outraged, and baffled when they see a disabled couple raising a family. . . . Children of disabled parents grasp early in life that there are many solutions to daily difficulties. This positive approach can only enhance their outlook on life. . . . The important factor is the love that is felt and shared."

Adoption

"The adoption of 15 children in our 25 years of marriage," said Grace Sandness, "has been a really exciting experience. . . . When we started, nobody else was doing it. . . . If you find an adoption worker who treats your disability as just another facet of your life-style and not as the dominant

thing, then you have a good chance. . . . In parenting, most of your problems are just extensions of so-called normal problems and the disability doesn't make any difference. . . . If anyone wants help with adopting, just write to me at



Ed Roberts, co-founder of the first center for Independent Living, "Personal assistants are the key to my life."

9965 Quaker Lane, Maple Grove, Minnesota 55369."

The disabled father's role in raising an adopted daughter was discussed by Max Starkloff, "She has never responded to my disability in anything but a very natural way. . . . The important thing is to compensate for those things you cannot do and to let the child get to know you very well." Colleen Starkloff suggested finding an agency to act as an umbrella, then developing a resumé and distributing it to physicians, social workers, and other people who might know of a child who will be adoptable.

Marilyn Potter, who has worked in adoption in Ontario for 23 years, added, "Parenthood is a process of mutual nurture. . . . Years after adoption, the children say that what really mattered was the parents' appreciation of them as they were as a person. . . . and their relationship of caring and hope and expecting."

Sexuality

Yvonne Duffy discussed the difficulties of people who were disabled in finding out anything about sex. "My mother told me about the birds and bees at the usual time but told me not to bother because I wouldn't be able to do it anyway. . . . That kind of false information can hurt us. We should make sure that present-day disabled children have a really good factual sex education program."

Fertility

In his presentation on fertility for spinal cord-injured persons, Dr. Halstead recommended research on the impairment of sperm production and on ways of optimizing the production of quality sperm. "We need," he stated, "to initiate and continue a discussion of the humanistic and ethical issues involved in manipulating nature in ways that impact on people's lives in very far-reaching and yet very personal ways."

The Independent Living Movement

Gini Laurie related her observations of the experiences of polio survivors living independently to the independent living movement.

"The foreshadowings of independent living," she said, "were in California in 1953 when Los Angeles County realized that its Rancho Los Amigos Hospital had 158 respirator-dependent polio survivors unnecessarily occupying \$37-a-day hospital beds when they could be cared for at home for \$10 a day.

"Consequently, a home-care system was set up. In effect, the system was 158 one-person self-directed independent living centers. Other polio centers around the country copied this money-saving plan and sent their patients home, many of them with about \$300 a month from the March of Dimes to hire and train their own attendants.

"This utopia lasted about six years until July 1959, when the success of the vaccines curtailed donations to the March of Dimes. The centers were closed and home care funding stopped.

"Dr. Leon Lewis, the medical director of the Respiratory Center at Fairmont Hospital, and the polio survivors of the San Francisco Bay area led a successful campaign to effect attendant care legislation in California.

"Thus in 1960 the way was paved for the independent living movement started a decade later in the same area by one of Dr. Lewis's ex-patients, Ed Roberts.

"Ed Roberts and John Hessler made the big leap with their Center for Independent Living from one-person independent-living systems to a system of services for all disabled persons of all ages. But their system of services might have stayed in California if there had not been developing simultaneously a spirit for human rights expressed in coalitions of all types of disabilities and in specialized and generalized disability publications."

Phyllis Rubinfeld related that the American Coalition of Citizens with Disabilities was founded in 1974 by a group



The John W. Leibold family from Columbus, Ohio: Master Chase Ding, Bee Yun, and John, an attorney and one of the moderators.



Phyllis Rubinfeld, American Coalition of Citizens with Disabilities, and Martha Ross Redden, Ph.D., Project on the Handicapped in Science, American Association for the Advancement of Science.



Gazette artist Bob Tanton and Father Patrick Lewis of San Francisco.

of disabled people who recognized that all people with disabilities must work together to secure independence and civil rights. The veto of the Rehabilitation Act of 1973 by President Nixon and the demonstrations in 1977 to implement Section 504 were the catalysts that strengthened "the movement to seek full, civil, and human rights for all people with disabilities."

The history of the independent living movement was told by one of the founders, Ed Roberts. "One of the reasons," he said, "that the movement is becoming so powerful and political today is that we started it to help ourselves become independent. . . . In 1970, when John Hessler and I started the first Center for Independent Living in Berkeley, we never dreamed how far it would go. . . . From the beginning, we were political. Now the 23 centers in California are the most important political network in our state and the state is putting up about \$4½ million for the centers' core money. . . . It all begins with a very positive attitude that says disability is not the most important thing. . . . motivation is, the belief in yourself. . . . If we could organize all disabled people and elderly and children and all who are devalued, we could be one of the most powerful forces on earth."

The philosophy of the independent living movement was summarized by another of the movement's leaders, Judy Heumann. "The philosophy of the movement is a civil rights movement," she said, "a movement of freedom for all people. . . . We are working to do away with the past history of discrimination against disabled individuals. We must empower ourselves and all disabled people. . . . We must make sure that there is no disability group that we consider to be inferior to any other disability group. . . . The centers are vehicles to enable people to become free, to provide innovative programs to ensure that no one needs to be living in an institution."

Jim DeJong described the importance of the recent development of the National Coalition of Independent Living Programs (NCILP) as a means of trading information and technical assistance as well as of developing the political aspects of the movement.

The future of the movement was visualized by Ray Zanella and Irving Zola. "The movement," says Zanella, "is the active expression of consumerism and of our own civil rights. . . . As it grows, we must watch out that there are enough people to develop within ranks to replace the leaders, that we do not sell out and become bureaucratic, that we realize vocational rehabilitation is a component of independent living, and that we are not pigeonholed and directed away from controlling our own lives."

Dr. Zola emphasized, "We are a political movement because we are interested in promoting change in attitudes, in barriers, in opportunities. . . . We are political because we speak of the quality of life. . . . of economic priorities. . . . We are political because the professions out there are in certain ways fighting over us and our turf, because in some states we are fighting over who has control over the personal care attendant, because we must be aware of the peril



(Left) Selwyn Goldsmith, England. "A unique international congregation of friends, colleagues, and admirers."

(Below) Rosina Grosse and her husband, Ron, from New South Wales, Australia. Rosina uses an iron lung at night.



of pitting one disease group against another. . . . We are political because we must organize into a political constituency with votes to whom the government must be responsible and accountable."

Forum for International Exchange

Each speaker summarized the status of disabled persons in his/her own country.

Australia. "The consumer movement, said Rosina Grosse, "is in the embryonic state in Australia. . . . When some of us went to the Disabled Peoples' International Congress in Singapore we were inspired to make a total commitment to the new concept of independent living. . . . There will be much achieved in Australia in the next few years."

Canada, Manitoba. Theresa Ducharme described the problems she encountered when, after being hospitalized for many years, she wished to marry and move into the community. Her solutions were the basis of a new government home care program that funds individuals to hire and train their own attendants.



Gary McPherson, Edmonton, Alberta, Canada, presented a videotape on glossopharyngeal "frog" breathing.



Mrs. M.A. Chaukar, Bombay, India, Lillian Genskow, Springfield, Illinois, and Yukiko Oka, Tokyo, Japan.



Joseph M. Kaufert, Ph.D., rehabilitation epidemiologist, University of Manitoba, performs magic tricks in the hotel's hospitality suite.

Canada, Ontario. "In terms of independent living centers," said Audrey King. "Canada is not as advanced as the United States but many of the problems are very similar: A lot of professionals are trading on the phrase *independent living*. . . . There aren't enough disabled people involved actively. . . . What the professionals say the disabled need is totally different from what disabled people say they need."

El Salvador. "The people live mostly with their families," said Eileen Giron, "and they are taken care of by them. . . . Most of them live in very bad conditions. They don't have any wheelchairs, so they have to stay at home in bed and they are considered as sick people and not able to do a job. . . . Rehabilitation services and education are only in the capital city."

England. "There are dilemmas," stated Selwyn Goldsmith, "in both cultures. . . . In the United States it is about equal treatment and normalization; on our side, it is about special treatment. . . . We have been shifting our orientations in Britain . . . about programs of house renovations and about assisting people to remain in their own homes where they can be supported with the services coming in from the outside rather than the service being provided in-house."

Germany. August Rüggeberg arranged an international independent living conference in Munich in 1982. As a result, his organization, VIF, is planning to adapt American concepts of independent living centers to Germany. "We have learned during this conference," he said, "the importance of international exchange of experience and people. . . . We in Germany are well prepared to receive disabled people and we are very much interested in sending disabled people to other countries to learn what independent living means around the world."

India. "The movement of rehabilitation started about 30 years ago," stated Mrs. Chaukar, "and it is gaining momentum but the efforts are concentrated only in the large cities and have not reached the rural areas. The International Year of the Disabled awakened the interest of the government in the welfare of disabled people."

Japan. "Situations are different in each Asian country but most still have a large family system," said Yukiko Oka. "This year Judy Heumann had seminars in the five largest cities in Japan so we are informed about the American centers and the concept is ideal. However, I think we should seek an Asian type of independent living."

Mexico. Mrs. Eileen Van Albert, the doyenne of disabled persons in Mexico, has lived there for 21 years. She has watched the ebb and flow of disabled persons moving to Mexico because of the cheap attendants, then leaving when costs were inflated.

South Africa. "We don't have any government funding," said Kathy Jagoe, "so people tend to go it alone. We are having our first Congress of Disabled People in September this year. It will be the first time all disabled people of all races will get together and start talking about issues that affect all of us."

Sweden. Adolf Ratzka discussed the gap between the disabled and the rest of the population. "Only 20% are employed," he says, "compared to 68% of nondisabled in the same age bracket; the disabled are four times as likely to be socially isolated. . . . Most of the leaders of the disabled movement in Sweden are nondisabled. . . . Too much research is carried out on issues relevant to us without consumer control. . . . I am appalled at all the begging and all this gratefulness to the March of Dimes and similar organizations because you happen to get a respirator. . . . I am surprised that nobody at this conference has proposed a resolution that what you need is national health insurance."



Kathy Jagoe (C5-6), social anthropologist at University of The Witwatersrand, Johannesburg, South Africa.



August Rüggeberg brought his guide dog, Xenia, and a large delegation from West Germany to learn how to adapt American concepts of independent living centers to Germany.

Polio Clinics and Support Groups

One of the most important mandates of the St. Louis conference was to set up local support groups and to make the general public and professional community aware of polio. Some of the registrants started support groups after they returned home. Some of the medical personnel, who had started polio clinics, augmented them with support groups. All of them will be sources of support and information for other polio survivors in the surrounding area.

Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, Missouri 63108 (314-361-0475), will act as the clearinghouse of information on local, national, and international support groups and clinics. If you know of any groups or clinics being created, please advise so the information can be shared in the next issue of *Rehabilitation Gazette* and through the network.

ARKANSAS. Delbert O. Lewis, Rehabilitation Services, Arkansas Department of Human Services, 1401 Brookwood Drive, P.O. Box 3781, Little Rock, Arkansas 72203.

CALIFORNIA — SAN FRANCISCO AREA. Stanley K. Yamell, M.D., Department of Physical Medicine and Rehabilitation, St.

Mary's Medical Center, 450 Stanyan Street, San Francisco, California 94117. Once-a-month polio clinic. Support group through Renah Shnaider, 350 Vernon, Apartment 101, Oakland, California 94610.

CALIFORNIA — LOS ANGELES. Richard Daggett, President, Polio Survivors Association, 12720 La Reina Avenue, Downey, California 90242. Well-established organization. Write for dues and meeting information.

CALIFORNIA — LOS ANGELES. Rancho Los Amigos Hospital, 7601 East Imperial Highway, Downey, California 90242. Rancho has maintained a polio clinic since the 1950's. The Pulmonary Clinic, directed by D. Armin Fischer, M.D., meets every Monday between 1 and 5 p.m. In between times, a nurse practitioner is available for telephone consultation. The Polio Clinic, directed by Jacqueline Perry, M.D., meets every other week.

CALIFORNIA — FRESNO. Norma Depoyan, 4931 East Platt Avenue, Fresno, California 93727.

CONNECTICUT. Eleanor Thompson, RFD #1, Berkshire Road, Sandy Hook, Connecticut 06482.

DISTRICT OF COLUMBIA. Bob Gorski, Editor, *Disabled USA*, The President's Committee on Employment of the Handicapped,

1111 20th Street, N.W., Room 600, Washington, D.C. 20036. Regular monthly meetings through local independent living center.

GEORGIA. Ann A. Bailey, M.D., Roosevelt Warm Springs Institute for Rehabilitation, P.O. Box 1000, Warm Springs, Georgia 31830. Clinic.

KANSAS. Alice Mary Blodgett, Kansas Easter Seal Society, 3701 Plaza Drive, Topeka, Kansas 66609.

MICHIGAN — ANN ARBOR. Frederick M. Maynard, M.D., Physical Medicine and Rehabilitation, University of Michigan Hospital, Box 33, 1403 E. Ann Street, Ann Arbor, Michigan 48109. Post-polio evaluation program at the University Hospital, allied with support group at local independent living center.

MICHIGAN — TRAVERSE CITY. Grace Joppich, R.N., 720 E. Orchard Drive, Traverse City, Michigan 49684. Lectured on polio to nursing students and arranged extensive publicity about support group.

MISSOURI — ST. LOUIS. Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, Missouri 63108.

NEBRASKA — OMAHA. Terrence M. Connelly, 402 Beverly Drive, Omaha, Nebraska 68114.

NEW YORK — BUFFALO. Susan N. Siegel, Program Coordinator, New York Easter Seal Society, 974 Kenmore Avenue, Buffalo, New York 14216. Monthly meetings to educate the medical profession and polio survivors, to develop a swimming program and a list of physicians.

NEW YORK — NEW YORK. Augusta Alba, M.D., Goldwater Memorial Hospital, Franklin D. Roosevelt Island, New York, NY 10044. One-day respiratory and general evaluation. Phone 212-750-6777 between 3-5 p.m., except Tuesday.

OHIO — DAYTON. Connie and Gregg Johnson, 5301 Rexford Drive, Dayton, Ohio 45432.

UTAH. A.A. Boston, M.D., 468 Bringham Circle, Providence, Utah 84332 or Mrs. Roberta Ivory, 270 West 3900 South, Nibley, Utah 84321.

WISCONSIN — MADISON. Patricia A. Giese, R.N., Rehabilitation Clinic, University of Wisconsin Hospital and Clinics, 600 Highland Avenue, Madison, Wisconsin 53792. Monthly Polio Clinic in the Rehabilitation Center and support group through local independent living center. In first year, 25 polio survivors evaluated. Staff: psychiatrist, nurse clinician, registered respiratory therapist, and physical therapist. Evaluation procedures: scoliosis and chest x-rays, muscle testing, mobility evaluation, joint contracture measurement, pulmonary function studies including arterial blood gases and spirometry, equipment evaluation, and influenza and pneumonia vaccination. Findings and recommendations are discussed and included in written summary report. Follow-up appointments scheduled as needed, usually on outpatient basis. The charge is \$350; Medicare pays 80%.

CANADA — ONTARIO. Ontario March of Dimes, 90 Thorncliffe Drive, Toronto, Ontario M4H 1M5. Committee and workshop on post-polio.

CANADA — ONTARIO. Canadian Rehabilitation Council for the Disabled, One Yonge Street, Suite 2110, Toronto, Ontario M5E 1E8. June 1983 annual meeting and conference included post-polio experiences.

CANADA — ONTARIO. M.G.P. Cameron, M.D., F.R.C.P., University Hospital, 339 Windermere, London, Ontario N6A 5A5.

CANADA — ONTARIO. Audrey J. King, M.A., Ontario Crippled Children's Centre, 350 Rumsey Road, Toronto, M4G 1A8.

CANADA — ALBERTA. Neil E. Brown, M.D., F.R.C.P., Medical Director, Respiratory Home Care Program, Aberhart Hospital, University Hospital, Edmonton, Alberta T6G 2J3. One-day seminar.

CANADA — MANITOBA. Joseph Kaufert, Ph.D., Department of Social and Preventive Medicine, University of Manitoba Faculty of Medicine, 750 Bannatyne, Winnipeg, Manitoba R3M 0T5.



Audrey King, Consultant, Psychology Department, Ontario Crippled Children's Centre, Toronto, Ontario.

Poliovirus and Immunization

By Marilee M. Thome

Paralytic poliomyelitis, which once attacked more than 10,000 persons per year in the United States, has been virtually eliminated in this country since the development of successful vaccine and immunization methods. The disease has been compared to smallpox, which also affects only humans, and has apparently been eradicated around the world; this is a worthy goal for polio, but thus far unobtainable.

Polio is transmitted only from human to human, through the shedding of the virus from the alimentary tract of the affected individual. Unlike smallpox, which is an illness whose victims are always readily identifiable, large numbers of persons are exposed to polioviruses and experience a very mild, non-neurologic illness, or even not becoming at all ill, though they may still be contagious to others. Smallpox was eliminated by identification of cases and rapid vaccination of all human contacts, in addition to systematic immunization of large population groups. This method is much more difficult to apply with polioviruses, as the disease is hard to identify unless neurologic symptoms appear. Spread of the disease is enhanced by poor sanitation, crowded living conditions and low standards of personal hygiene. In certain tropical and subtropical areas, paralytic poliomyelitis is still a problem of endemic proportions. The World Health Organization Expanded Program on Immunization, which began in 1974, has as one of its goals the immunization of all the children in the world against six diseases, including poliomyelitis, by 1990. Cuba, Puerto Rico, and some Central and South American nations have already successfully overcome the disease through huge, well-organized immunization programs, showing that such triumphs are possible.

There are two types of polio vaccine currently in use, both "trivalent," or containing three polioviruses. Oral polio vaccine (OPV), which came into use in 1961, and inactivated or "killed" vaccine (IPV), given by injection. OPV also may be referred to as "Sabin" vaccine, and IPV as "Salk," after their developers.

OPV has several advantages: being given orally, it is easier to administer on a large scale and to the very young. It is a live vaccine, and multiplies in the gastrointestinal system's epithelial cells, thereby giving "extra protection" of immunity to any so-called "wild" polioviruses to which the individual might be exposed. It is also believed to give quicker protection and much more lasting protection than IPV. However, since it is a live vaccine, use of OPV carries with it the small but very real risk of actually inducing poliomyelitis in those receiving it, or in non-immunized contacts of the vaccinee. In the past ten years, figures for vaccine-associated cases of paralytic polio have averaged about seven per year. In spite of this risk, such medical groups as the American Academy of Pediatrics have studied the problem carefully and continue to recommend use of OPV in infants and those under eighteen.

For unknown reasons, persons over eighteen years of age are more susceptible to vaccine-induced poliomyelitis. Parents who have never been immunized or have been only partially immunized, and who have young children scheduled to receive OPV, should, according to most medical experts, receive a full course of IPV as a precautionary measure. This is also true for persons planning to travel to an area where polio is still a problem. Any person with a deficiency of the immune system, either genetic or drug-induced, as in cancer chemotherapy, should never be given live vaccine, nor should anyone who is pregnant.

The latest policy for immunization against paralytic poliomyelitis for those residing in this country is:

1. Primary immunization of infants: 3 doses of OPV, at age 2 months, 4 months and eighteen months, approximately.
2. Primary immunization of older children and adolescents: 2 doses of OPV at 8-week intervals, followed by a third dose 6-12 months later.

On entering school, another single dose of vaccine is considered desirable as "insurance," to provide complete immunity. According to the American Academy of Pediatrics, anyone who has not received a full course of oral vaccine may still be susceptible to one or more poliovirus types, and should receive OPV to complete the schedule even if IPV has been received previously.

It is difficult to find reliable figures for immunization levels among the adult population. Those who received OPV may still be well protected. However, one author estimates that 35 to 40% of U.S. adults over 35 years of age have either "lapsed" immunity or have never acquired immunity. Surveys or interviews which rely on ones' memory are not useful, as most individuals can recall only vaguely their "childhood shots." Since vaccination for polio is now a prerequisite for school admission in all fifty states, it is not surprising that a survey in 1978 showed that 92% of children entering school had received three or more doses of vaccine, which is good news. With the continued research and aggressive campaign against polio now going on in developing countries, we may hopefully look forward to a world protected against paralytic poliomyelitis in the future.

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- Fulginiti, Vincent A. The Problems of poliovirus immunization. Hospital Practice, Aug 1980, pp. 61-7.
- Horstmann, Dorothy M. Control of poliomyelitis: a continuing paradox. Journal of Infectious Diseases 146 (4): 540-51, October 1982.
- ED. NOTE: Rodney H. Lusk, M.D., Division of Infectious Diseases, St. Louis University School of Medicine: "I reviewed Ms. Thome's article on polio and immunization and feel that it is an excellent discussion of this topic. . . (In addition) You should heavily rely on the details of the most recent reference from the Public Health Service. At the present time that reference is, 'Recommendation of the Immunization Practices Advisory Committee (ACIP) on Poliomyelitis Prevention,' Morbidity and Mortality Weekly Report, 1982; 31:22-34."



Photo by Phil Goodis

Ladies' side of the L-shaped ward of the Pearson Polio Pavilion in Vancouver, British Columbia. Joy Lynn Kjellbotn says, "The open ward is safer as we save each other's lives at times by noticing something the staff might not have seen or heard."

25th Anniversary Feature

25 Years of Experiences as Polio Survivors Canada

Edited by Gini Laurie

This special feature resulted from our request for "Then-And-Now" stories and photos of *Gazette* readers over the last 25 years to display in scrapbooks at the St. Louis conference.

These photo-stories were excerpted from the scrapbooks to give *Gazette* readers who did not come to the conference glimpses into the lives of many fascinating individuals. They are affirmations that severely disabled individuals — including those who are quadriplegic and respirator-dependent — can live full and productive lives.

They are "case histories" of 25 to 30 years of experiences with various types of respirators, of returning to respirators years after initial weaning, and of the importance of attendants, families, and friends in maintaining independence.

The biographies of present and former residents of Pearson Polio Pavilion, 700 West 57th Avenue, Vancouver, British Columbia, are especially interesting. They were enthusiastically gathered by Joy Lynn Kjellbotn.

Pearson, originally a large tuberculosis facility, is an extended care facility for the elderly with six wards. Pearson Polio Unit was built on the extensive grounds of the TB hospital by the British Columbia government in 1955 for treatment and long-term care of polio survivors. (In 1953 in B.C. there were 787 cases of polio and 26 deaths.) Originally, the polio unit was two wings totalling 55 beds. Now the respiratory unit is one L-shaped wing, a three-bed ward and two single rooms. There are 24 residents — 14 "old" polios and 10 muscular dystrophy and high-lesion quads. The other original wing is used for therapeutic day care to help keep people living at home. The per diem cost in the respiratory unit for fiscal year 1982/83 was \$275.40. Those who can afford it pay \$7.50 a day, the rest is paid by the government's medical plan. All the respiratory equipment is provided, as well as electric wheelchairs, cushions, etc.

Each person has a bed, bedside table, and other cupboard space and a locker for clothes. All have their own TV, stereo, and tape decks. Some have environmental control units. There is a portable pay phone or one may have a private phone.

A doctor visits every weekday and on weekends someone is on call. Specialists are provided as necessary and eye and dental care are available. The unit is not equipped to handle acute care. Anyone who is gravely ill is transferred to the intensive care unit of the general hospital until well enough to return.

The unit is on the ground floor with access to a large private patio. There is a ham radio room and a darkroom. The hospital owns a big bus equipped for respirators and there are weekly bus trips. There is a large recreation program and parties. Six residents own their own vans. The city has a disabled transit service at a cost of \$1 one-way to any place in the city.

Within the last decade an attendant care program and small group homes were initiated. The Long Term Care Program places individuals out of institutions and provides homemakers for up to 120 hours a month. The homemaker is paid by government funds. The Handicapped Resource Center, directed by Les Watson, a former Pearson resident, provides placement in group homes where three

to four residents pool finances and attendant hours. The residents are responsible for running the homes. The H.R.C. pays for the attendant. Residents pay 30% of their income with a rental subsidy making up the difference. The unemployed receive a handicapped pension from the government which is about \$575 a month at present.

The evolution of the Long Term Care Program in Vancouver is an interesting parallel to the evolution of an English program. Until the early 1970s there were 17 respirator-dependent polio survivors at Phipps Ward at South Western Hospital in London. Then, Dr. Geoffrey T. Spencer, anaesthetist and consultant at St. Thomas' Hospital, initiated a three-year research project to move them into the community with supportive care services. The project has continued and now maintains nearly 300 respirator-dependent persons of all disabilities in their homes throughout the United Kingdom. The program provides attendants, runs a home respirator maintenance service, and schedules home visits by a doctor, nurse, or social worker when necessary.

JOY LYNN KJELLBOTN

Ad reviewer. (Respiratory polio quad since 1953 at age 11.) ♦
"Although modern technology has given us an improved quantity of life, we must strive to further increase the quality to make the effort worthwhile." Pearson resident from 1955 to 1956 and 1973 to the present. "I was home for 17 years, moving back to Pearson when my parents retired . . . Being the second oldest of six children, I was an active participant in helping raise the younger ones. . . . This provided me with a degree of fulfillment that has enabled me to adapt to an institutional environment, without a trapped feeling of having to 'get out and try it on my own.' . . . I spent three years at the Crippled Children's School in North Dakota and three years studying art by correspondence. I was very active in community work, clubs, and church. . . . After two months in the lung, I learned to sleep out full-time. Although my vital capacity is limited, I manage to get by without a breathing aid by making sure I get adequate rest. My ability to frog breathe has literally 'saved' me many times with colds and even an attack of pneumonia. My biggest problem is lack of stamina. . . . My hobbies include reading, writing poetry, painting, playing the piano, and dabbling in the stock market."

ROY CURLE

Ad reviewer and knitter. (Respiratory polio since 1960 at age 37.) ♦
"It frustrates me to see strong, able-bodied people abuse the wonderful gift of a healthy body." Pearson resident since 1970. "I was home with my family of five children after two years in hospital. At first I used the lung at night then I started using positive pressure part-time during the day to rest, gradually using it full-time. . . . I enjoy music, especially western, wrestling and other sports on TV and going out in my own van."





MUMTAZ "TAZ" PIRBHAI

Social worker. (Polio quad since 1954 at age one.) "We do not know just what we are capable of until confronted with the situation. When put to the test, the depths of our own resourcefulness are truly amazing." Address: 3410 — West Third Avenue, Vancouver, B.C. V6R 1L5. "I was born in Kampala, Uganda. . . . The family moved to Canada in 1972 when Idi Amin was in power. . . . I was admitted to Pearson. . . . I graduated from university with a B.A. and work as a social worker at Pearson. I have lived in a group home since 1974. I keep involved in community work."



ORVILLE McBRIDE

Ad reviewer and Avon salesman. (Respiratory polio quad since 1955 at age 13.) "Instead of sitting thinking about what you like to do — if it is at all possible — make it happen. If one avenue closes — open another." At Pearson since 1956. "I use the lung for sleeping, the chest respirator while on the bed and the pneumobelt while sitting up. I am very proficient in frog breathing. . . . I am co-owner of a 1981 Chevy van. I spent a one-month summer vacation down California way in 1981 and went north and east in Canada. I copied a plywood lung I saw in the *Gazette*. I carry it in a trailer behind the van and use it for sleeping. It is powered by the motor for the chest respirator. . . . I dabble in the stock market. Also, I very much enjoy gambling and go to the track as often as possible. Dining out, movies, concerts are also part of my social scene."

KEITH "KELLY" GREEN

Industrial leather contractor. (Respiratory polio since 1952 at age 34 with full use of legs and limited use of arms.) "Never be stuck just because you can't do something the way you used to." Pearson resident since 1970 with long vacations at home. . . . "Individuals shouldn't be afraid to use respirator assistance when they begin to feel weak. Once you get adequate ventilation, you realize how well you really can feel. . . . My strong family support has given me the incentive to want to strive to accomplish things." <



BRIAN FITZGERALD

Licensed ham radio operator. (Respiratory polio quad since 1960 at age 27.) "I believe that when a person becomes disabled, he loses self-confidence and should be encouraged, even pushed into some suitable training." Pearson resident since 1960. "I was living with my wife and two sons, working as an auto-body man, when I contracted polio. . . . I use the rocking bed for sleeping and the chest respirator for daytime breaks. While I am up, I frog breathe. Fortunately, I have never had a trach. I operate an electric chair by mouth as well as type, turn pages, etc. I am on the radio most evenings and have met many people through this hobby. . . . I enjoy various outings, theatre, concerts, visiting and, of course, my four grandchildren."

JUNE MEWHORT

(Respiratory polio quad since 1953 at age 23.) At Pearson since 1960. "By being disabled we do miss out on many things. Yet the kindness and consideration that we receive from others compensates in some small measure. . . . After several years at home with my husband and son, I ended up with pneumonia and a blocked lung and moved to Pearson. . . . In the early 1970's I switched to positive pressure via trach full-time. . . . I knit with a mouthstick and enjoy reading and music. . . . I live one day at a time and look forward to tomorrow." ◇



MARGARET "PEGGY" WESTERGARD

Painter. (Respiratory polio quad since 1960 at age 30.) "This is certainly not the kind of life I would have chosen, but since it is the one I'm living — I'm going to *live* it." At Pearson since 1960. "I was living with my husband and seven children when I contracted polio. . . . At first, I used the lung, rocking bed, and pneumobelt. In 1978, I learned the use of portable positive pressure which gave me much more freedom. Since then, I have travelled extensively. . . . I use a foot control for my electric chair and type and paint in oils with my foot. (I got the idea for my foot adaptation for painting from the old *Toomey* j *Gazette* and I have corresponded with an Italian pen pal I 'met' through the *TjG* 18 years ago.) . . . My hobbies are stamp collecting and entertaining my eleven grandchildren." ◇



SYBIL HALLADAY

Artist. (Respiratory polio quad since 1960 at age 16.) "Free at last from institutional life — a dream come true." Address: 9374 Ashwell Road, Chilliwack, B.C. V2P 3W1. At Pearson from 1961 to 1980. "In 1979 a friend, Marie, and I took a camping tour of seven U.S. states. I slept in my recliner wheelchair and we ran the respirator and suction off the car battery. We had a list of respirator-users en route we got from the *Gazette*. If all else fails — head for the nearest big hospital's intensive care unit. . . . In 1980, Marie and I bought a house 65 miles from Vancouver. I have a TOSC remote control unit. I use a mouthstick for typing and drawing. . . . I heartily recommend to anyone remotely considering it, to put forth the effort to live independently." ◇



JEANETTE ANDERSON

Artist and reviewer. (Respiratory polio quad since 1955 at age 16.) "It is vital to have ongoing and varied interests that can be continually expanded." At Pearson since 1955 except for travel and holidays at home. . . . "I use the lung for sleeping and positive pressure when I travel or go home. I'm planning to switch to positive completely. . . . I use a mouthstick for turning pages and writing and painting. . . . I am very fortunate to have a close-knit family and their full support." ◇



AUDREY SETTLER

Part owner monument business. (Ambulatory respiratory polio since 1954 at age 21.) "I am living a very fulfilling life. I could never be as contented and happy without the help of my husband, my family, my friends, the professional people, and faith." Address: 12840 King George Highway, Surrey, B.C. V3T 2S9. "Six months after onset I was using the rocking bed at night and back at work. . . . I was married in 1968. I do the bookkeeping and sales of our business. . . . We have a portable rocking bed that is only two feet wide. . . . I do handwork — crocheting and needlecraft."



LES WATSON

Director, Handicapped Resource Center. (Respiratory polio quad since 1952 at age 4.) "We are probably not here for a long time, so I am going to make sure that it is a good time." Address: 4678 Main Street, Vancouver, B.C. "I came back to the hospital in 1965 because my breathing was deteriorating. In 1975 my trach was replaced and I now use positive pressure for sleeping and manage without aid all day. . . . Our center manages 23 adult group homes and maintains information services. . . . In 1978 I moved into a group home. This year my friend and I purchased a house. I have a van equipped with a hoist. . . . My social life is very full. I am in partnership in a couple of race horses. I also indulge in the traditional wine and women and have a great many friends who enjoy going out."

BRIAN CRUIKSHANK

Law student. (Respiratory polio quad since 1953 at age 8.) "The permanence of one's physical condition is matched only by the resiliency of the human capacity for responding to adversity and getting on with the task of living." Pearson resident since 1953. "Within first few years, had pneumonia twice, two trachs. . . . In 1962, I regained my vertical position with Harrington rods. . . . Now I am up all day, frog breathing to assist my very limited neck breathing. I use a Bantam respirator for sleeping and seldom need suctioning. . . . I'm also very adept with a mouthstick. . . . I completed high school through correspondence, obtained my amateur radio licence, worked for the Department of Consumer Services, and enrolled in university in 1975. . . . During the years 1975-1980, I attended a local community college part-time and continued to work part-time. I also travelled extensively, going to Winnipeg in 1974, Barbados in 1976, Hawaii and Europe in 1977. For those trips I took a Bantam respirator for sleeping. . . . In the fall of 1980 I was accepted by the Faculty of Law at the University of British Columbia and am now within a few units of my law degree."



DAVID YOUNG

Artist. (Respiratory polio quad since 1955 at age 19.) "Life outside an institution is so much better. Life in an institution is staying alive — it isn't living." Address: Simonn Sound, B.C. "I was at Pearson from 1955 until 1976 when I left to get married. While at Pearson I painted and typed by mouth. I designed and had made a portable rocking bed. I also created an electric easel and a self-feeder. At home, I designed a lift for getting from bed to chair. I use a remote control to operate the lights, radio, typewriter, with options up to 16 appliances. My wife and I work on a health line business from our home. I'm still selling my paintings. . . . After 20 years of institution, it takes quite a while to become strong of spine to handle any given situation."

Thirty-Year Polio Survivor

by R.B. (Bob) Gordon

Since polio hit me in 1953, at the age of 19, my life has been divided into three distinct phases.

The first phase covered about four years of hospitalization at Pearson, and involved learning how to shed the respirator, increase my wheelchair hours and overall endurance, and accept my physical restrictions psychologically.

The second phase, which lasted approximately twelve years, was marked by my first opportunity to work and achieve economic success, by driving lessons and the purchase of a car, and by rehabilitation for independent living, (see the 1970 *Rehabilitation Gazette*).

The third phase began in 1969, when I left the hospital for independent living in my apartment. While I saw this as an exhilarating and challenging move, I was also very much aware of the potential pitfalls it contained. However, good luck was with me, and I managed very nicely with the help of some good friends. The apartment manager relocated the kitchen stove, and I learned how to cook a little. He also persuaded a neighbor to trade parking stalls with me so that I could park closer to the door. Some of my neighbors also helped with the shopping. For the first time in my life, I felt free — free from the restrictions of living according to other people's rules.

I soon learned, however, that freedom goes hand in hand with responsibility, for one year later I married a fun-loving girl, and soon we were on our way to starting a family. (I'm not paralyzed all over.) Our daughter Kari was born in 1971. We bought a modest home in the suburbs on a one-acre lot, and were blessed with friendly neighbors.

The double load of home ownership and family support led me to put much more effort into my job: I worked longer hours, and took home extra paperwork. Naturally, this drastically curtailed our social life, and my wife, who had always been a career girl, became disenchanted with our domestic scene. Unfortunately, our relationship suffered, and our marriage was soon on the rocks.

In no time at all, I found myself part of that rapidly growing group known as "single parents." This, undoubtedly, was the biggest challenge that I have ever faced. Obviously, my first concern was to find a live-in housekeeper capable of responsible child care. This I did, starting with very limited funds and very little else to offer. Since then, I have maneuvered my way through ten years of child rearing with a dozen or more housekeepers — some great, some not so great, all with problems, and most of them short-stayers. Obviously, I worry about what kind of effect this environment is going to have on my daughter. Only time will tell.

I like to think that I have a very good relationship with Kari. I've made every effort to keep her surroundings stable in spite of the high housekeeper turnover. She maintains a



Bob Gordon, "In no time at all, I found myself a single parent. . . . Parenting has been a richly rewarding experience."

good average in school and she's active in ice-skating, ballet, gymnastics, and trampolining. While she's still at the carefree stage of life, she is probably quite a typical "only child."

Fortunately for me, my mother is still around (at the age of 83), and she has been invaluable in helping me bring up Kari. Although parenting has provided me with my fair share of trials and tribulations, it has been a richly rewarding experience. I would recommend everyone to try it if at all possible. Picture a baby not much bigger than your hand, absolutely, totally dependent upon you. Then imagine what it is like to see this infant develop physically, intellectually, and emotionally. It's a miracle.

Life has become easier for me as my employment has advanced and my pay has increased. I started work as an estimator for a refrigeration and air-conditioning contractor. Then I was promoted to sales engineer. This raised my earnings to a salary and commissions basis. I found the commissions a great motivator, and benefitted substantially from them. After a while, the original owners of the firm sold out



"My daughter, Kari . . . I like to think that I have a good relationship with her. . . . I've made every effort to keep her surroundings stable in spite of the housekeeper turnover."

to the employees: I was able to purchase a major shareholding in the new company and, in the process, became one of its directors and officers. The company has since enjoyed considerable growth, and it is now the largest firm in the industry in Western Canada.

Estimating is one job classification that should be given more consideration by people with physical restrictions. If you can sit at a desk, write, use a telephone, turn pages, then you can learn to be an estimator. Estimators for trade contractors will have to learn how to read blueprints, understand written specifications, and become familiar with the systems installed. Any technical training or trade experience will of course help. The work can be done in your home, as the plans and specs can be brought to you, or at the office. On-the-job training is best if you can find the right employer.

Currently, we are enlarging the house, and remodeling to provide greater wheelchair freedom, more space for Kari and her friends, a solarium with a swim-spa and a double garage. Most of my spare time is devoted to my garden and yard. We are creating a mini-park, with wheelchair paths, waterfalls, a winter creek, fishpond, and a great variety of shrubs, trees, and flowers. While I have enjoyed a reasonable degree of success, my lifestyle has remained fairly conservative. I'm satisfied with the comforts of home, a good meal, and a glass of wine.

What does the future hold? My plate is pretty full at the moment, but if I'm allowed to continue, there are still things to accomplish. Maybe then I can take time to try hydroponics, sketching, photography, music and reading.

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Hanging Onto The Coattails of Science

by Alice Loomer, Ph.D.

The gulf between science and the disabled is heartbreaking. Modern technology is capable of making the blind almost as if they could see, the deaf as if they could hear, and us as if we could walk. If they have the actuators and servo-mechanisms to walk a LEM on the moon, they also have the hardware to walk (and climb and sit) a quadriplegic on earth by automating braces and crutches, for example. But the gap between what is possible and what is likely will continue, for many reasons (some of which we can, perhaps, change).

We are brainwashed by the conventional. We often humbly accept what is as what must be. Starting one's thinking from scratch is very hard. It took me 40 years to realize I didn't have to put up with miserable tucked-in bedclothes. Now, I sleep comfortably, my way, with a firmly anchored bottom sheet and a small light-weight throw that's easy to handle.

The disabled, by and large, have been given little knowledge of science and technology, and have been so little encouraged in inventing, that they cannot design for themselves nor guide those who could. The same is often true of rehabilitation centers. Even in one's own town, there are craftsmen and experts ranging from telephone technicians to model plane clubs (experts in remote controls) whose help is lost because neither the disabled nor their rehabilitation centers see the possibilities.

Scientists and technologists have trouble picturing our real needs in practical (and cheap) terms, as they also do with those of the Third World. They are as brainwashed by the esoteric as we are by the conventional.

Manufacturers and distributors. Not only are we a very tiny market (how many bicycles and motorcycles to one wheelchair?) but for promotional and sales and service purposes,



Dr. Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University; then psychotherapy practice in New York; writer, now partly retired consultant, Halifax, Canada; and since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

manufacturers need products so complicated that they have exclusive rights.

We, on the other hand, need equipment so simplified that it can be made from cheap, readily available parts and serviced by local repairmen, family, friends, neighbors (or oneself).

What's to do about it? Perhaps a lot more of what many readers are doing right now:

- Whenever we see a product that's clearly not user-oriented (like most reclining backs and adjustable foot boards); or equipment that could have used standard parts but didn't, we can protest to manufacturers.

We can keep reminding governments that simple design faults that bar us from independent living are costing the country millions of dollars annually. The conventional

electric wheelchair is an engineering disgrace, as well as being thirty years behind the times: No appliance outlets. No provision for heated foot blankets and jackets, and not even a heated cover for one's driving hand. No user-operated back and leg rests. No power loading and unloading. No quick, easy handyman repairs.

- We can write to science, technology, and manufacturing journals and conventions asking them to be alert to any of their new developments that might have spin-offs in our direction. We ourselves can be alert to new discoveries, inventions, and products intended for other uses.
- We can learn to improvise, invent, supervise, or do more of our own construction. Like most people with polio, that most whimsical of diseases, I have an unreasonable pattern of weaknesses. If limited to commercial equipment, I would have been very helpless, so we (my family and I) were forced to develop all kinds of things: kitchens, hand controls, van lifts, even urinals. (There's nothing like a paper coffee cup, a small garbage bag, a bunch of Kleenex, and a rubber band!)

My first wheelchair was made by my teenage brother from a kitchen chair and his old bicycle — it worked fine until I outgrew it. My last is concocted out of an old E and J frame, a set of motor wheels installed by an apartment handyman, and wiring controls, figured out and put to-

gether by me. Its craftsmanship is deplorable, but it's the only wheelchair that could have kept me away from nursing homes and attendants. It stays on the road. (In twelve years, the longest it has ever been broken was 24 hours, once.) I made it. So I know how to fix it. It's easy to add conveniences.

I may have had to grit my teeth, I may have had to drive myself to learn about motors and wiring and relays. I may have failed almost as often as I succeeded, but I have equipment that fits me.

So I guess I'd better keep on saying, "There ought to be a way," and beating my brains out to find my own little bridges to science and technology.

Dr. Loomer is a mixture of things: rehabilitation psychologist, 10 years, New York University; then psychotherapy practice in New York; writer; now partly retired consultant, Halifax, Canada; and, since age 9, full-time schemer, improviser, inventor, and finagler to beat the rap of polio and lead her own life, her way.

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I Am Still the SAME Person

by Audrey King, M.A.

I became a polio quadriplegic in 1952, at age 9, while in England with my parents. I spent two years in hospital, the first six weeks of this in an iron lung. When I was finally discharged, I was able to sit with a brace and use my right hand well enough to write and draw.

Frequent respiratory infections prevented me from attending the school for crippled children in London. On returning to Canada in 1956, the Ottawa "special" school wouldn't accept me because of the severity of my disability.

It was six years before I was able to re-enter the regular educational stream. Academic progress was interrupted by the onset of respiratory insufficiency and a return to the iron lung and cuirass in 1958. Nevertheless, I was able to graduate as the top grade 12 student of several thousand and I went on to achieve an Honours B.A. and Master of Psychology from Carleton University in Ottawa.

Except for absences related to health and surgery and a two-year sabbatical for doctoral studies in special education at the University of Toronto, I have been a full-time consultant within the Psychology Department at the Ontario Crippled Children's Centre in Toronto since 1967. My duties include counselling, assessment, behavioral consultation and program development with orthopedically and neurologically impaired children.

During the last ten years, I have served actively with community organizations such as the Ontario Federation for the Physically Handicapped, the Clarendon (Cheshire Homes) Foundation and the Ontario Advisory Council on the Physically Handicapped.

I have lectured widely on topics relating to the disabled and have written articles for many professional journals and magazines.

I have travelled widely throughout Canada and the United States, to various Caribbean countries, and I have returned to Britain as a tourist. When time allows, I enjoy crafts and painting of all kinds. I am an ardent cartoonist and contribute regularly to various magazines.

My widowed mother and I live in an architecturally adapted condominium.

I would sum up my "key to success": "Strong family support combined with the belief that I am still the same person; therefore, the same personal goals and ambitions that existed before becoming disabled still apply."

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Photo: Houston Chronicle

Nita Weil, Director of Volunteers, The Institute for Rehabilitation and Research, Houston, Texas.



Photo: Marvin M. Greene, The Plain Dealer

Kathleen Monahan, an attendant paid by the Ohio attendant care program, assists Susan Armbrecht with her telephone sales work.

United States

NITA WEIL

Director of hospital volunteers. (Respiratory polio quad since 1952 at age 22. Pneumobelt full time by day and chestpiece at night.) Address: The Institute for Rehabilitation and Research, 1333 Moursund Street, Houston, Texas 77030. At onset, she was doing some modelling and had just had twins, Shelley and Bill. She lives in a nearby apartment with an attendant. In 1959 she became a receptionist for the Institute for Rehabilitation and Research (TIIR). In 1968 she was promoted to director of volunteers. At that time, there were 60 regular volunteers. Today, she directs more than 90 volunteers who give 20,000 hours a year. She has organized fund-raising activities that have earned more than \$1 million. She is founder and fund-raising chairman of the Coalition for Barrier-Free Living, an advocacy group. She helped write a Houston guidebook for the disabled. Over the years she has received several dozen awards, plaques, and citations, including the Houston Association of Volunteer Administrators Award and the Handicapped Professional Woman of the Year Award. In May 1983, Texas's First Lady, Linda Gale White, presented her with the 1983 Governor's Award for Outstanding Volunteer Service.

SUSAN ARMBRECHT

Telephone salesperson. (Respiratory polio quad since 1945 at age 6. Oral positive pressure at intervals during day, iron lung at night.) Address: 15983 Nelacrest, Cleveland, Ohio 44112. From her home, she has done abstracting, stenotype transcription, sold magazines and cards, and held a number of telephone jobs. Her present employment as a sales representative of a moving company makes the most of her attractive voice and manner. For the past 20 years she has lived in her own apartment by creating a "one-person independent living center," meeting her needs with the assistance of family, friends, part-time attendants of all ages, and the Visiting Nurse Association and Cleveland Homemakers. "It was like being on a treadmill to coordinate everyone." Since the recent enactment of the Ohio attendant care program, she has full-time attendants to supplement family and friends. "I have gained a degree of independence I once thought impossible."

MARY JANE FAULL

Part-time hospital lab clerk. (Respiratory polio quad since 1948 at age 11.) Address: 605 South Throckmorton, Sherman, Texas 75090. After spending a month in an iron lung, she transferred to Scottish Rite Hospital for hot packs and surgery. Since 1967, she has been using a breathing aid. She has use of her left hand and partial use of her left arm and leg. She has worked as a lab clerk since 1967 at the hospital where she was born.



RUTH DAVIS

Wife, mother, grandmother, and international correspondent. (Respiratory polio quad since 1953 at age 30.) Address: 9316 Snow Road, Parma, Ohio 44130. Ruth and her husband, Glen, have raised their three children who are now married and have children of their own. (One of the grandsons, Tim, is in this 1972 photo with Glen and Ruth.) Ruth's rocking bed is her office. She types with a mouthstick and operates the phone with her foot. She uses a chestpiece for eating and sleeping. For 25 years, she has been the *Gazette's* United Kingdom correspondent, gathering news and exchanging letters, photographs, and stamps.



RICHARD DAGGETT

Community service volunteer. (Respiratory polio quad since 1954 at age 13.) Address: 12720 La Reina Avenue, Downey, California 90242. He spent his first six months in a tank respirator. After three years at Rancho Los Amigos Hospital he returned home to live with his parents. He uses a Monaghan 170-C with cuirass at night. President of the Polio Advisors Association and a member of the Advisory Council of Rancho, he is active in his church and in many community and volunteer activities. Hobbies: photography, history, and caravan travel (member of Airstream club).



JEAN DOYLE

Wife, mother, homemaker, and teacher. (Respiratory polio quad since 1953.) Address: 86 North 7th Avenue, Des Plaines, Illinois 60016. She and her husband, John, met while they were attending college. She graduated with a B.S. in math and he graduated from engineering school at Northwestern University. Their son is working toward a Ph.D. in community psychology at the University of Virginia. Over the years she has changed from an iron lung to a rocking bed, from a Monaghan chestshell to a pneumobelt and added a blower. She has a motorized wheelchair and an environmental control system which she operates with a micro-dec and a sip and puff tube. In 1980 the Jaycees named her "Teacher of the Year."



JUSTIN W. DART, JR. ⚡

Vice Chairperson, National Council on the Handicapped. (Polio quad since 1948 at age 18.) Address: 2012 Lear Lane, Austin, Texas 78745. After earning a M.A. degree from the U. of Houston and attending the U. of Texas Law School, he became an entrepreneur, business executive and author in Mexico, Japan, and the United States. He has organized employment opportunities, transitional independent living, sports, and civic-religious activities for disabled persons. Recipient of numerous academic honors and scholarships, he is an active member of many disability and human rights organizations. He is a member of the Texas Governor's Committee on Employment of the Handicapped.



ROBERT GORSKI ⚡

Editor, *Disabled USA*. (Polio para since 1951 at age 2.) Address: President's Committee on Employment of the Handicapped, 1111 20th Street, N.W., Room 600, Washington, D.C. 20036. While attending the University of Southern California he worked with a graduate student, Adolf Ratzka, to change the ways in which disabled people are disadvantaged by society. He worked at Westside Community for Independent Living and lobbied with disability groups. In 1981, he moved to Washington, D.C., and became editor of *Disabled USA*.

VERNA JEAN EDMISTON

Wife and mother. (Respiratory polio quad since 1954.) Address: 5710 DeMilo, Houston, Texas 77092. At the onset of polio she had two daughters, ages 5 and 18 months. They are now grown and have children of their own. Attendants have been their biggest problem and an unending expense. She still uses breathing equipment but other aids, such as an electric wheelchair, electric bed and van lift, have given her freedom. She and her husband enjoy travelling and have seen most of the U.S. in the last few years. She has many hobbies — especially stamp collecting. "All in all I do enjoy life, but I owe it all to a belief in God, my wonderful husband and our two daughters." ⚡



IDA BRINKMAN ⚡

Wife, mother, and grandmother. (Respiratory polio quad since 1953 at age 28.) Address: 224 East 326 Street, Willowick, Ohio 44094. After two years in the hospital, she returned home to raise her three children. She can use her left big toe and has a little left leg movement with which she turns on lights, radio, cassette, TV, record player, blanket, and operates the phone from the controls on her rocking bed footboard. She reads and types with a mouthstick and does a bit of painting. For travelling, she uses a chestpiece and a car aspirator her husband made out of a peanut butter jar. "I finally came to the conclusion that you have to concentrate on what you do have and forget what you don't have. I'm blessed with a loving family and friends." ⚡

RENAH SHNAIDER

Commissioner on the Oakland Mayor's Commission on Disabled Persons. (Polio quad since high school.) Address: 350 Vernon #101, Oakland, California 94610. She was born and grew up in Detroit, Michigan. After graduating from Wayne State University she worked as a receptionist for a year, then returned to the university where she earned a M.A. in rehabilitation counseling. In 1963, she accepted a position as a rehabilitation counselor in the Los Angeles area. Three years later she transferred to the Oakland office. In 1981, she coordinated a post-polio symposium in Oakland.



Stanley K. Yarnell, M.D., San Francisco, and Renah Shnaider.



RAY YOUDATH

Circulation office manager, *Cleveland Plain Dealer*. (Respiratory polio quad since 1950.) Address: 9905 Knollwood Drive, Mentor, Ohio 44060. After 8 months in an iron lung at Toomey Pavilion in Cleveland, he went to Warm Springs for six months. In 1954, he went to California Rehabilitation Center in Santa Monica for 18 months of hard work to learn to dress, drive, and transfer. In 1958 he and Marilyn were married. He is 6'7", she is 5'9", their daughter is 5'10" and their sons are 6'3" and 6'8". In 1978, he started becoming lethargic. In 1979, he wound up in Cleveland Clinic with respiratory failure and he was trached. After a month he went home and, eventually, the trach was removed. Now, he uses a rocking bed at night.



SALLY MANNS

Out-patient clinic of the Sister Kenny Polio Foundation. (Polio quad since 1953 at age 17.) Address: 27333 Arbonway #46, Southfield, Michigan 48034. She spent the first four weeks in an iron lung and two and a half years in hospitals — the University of Michigan Hospital, a polio clinic in Oklahoma, and the Sister Kenny Polio Hospital. In 1956, she and a good friend opened a small business which they sold after three years when she started to work for the Sister Kenny Foundation. She drives a van and enjoys concerts, movies, and plays. She has driven and flown to many parts of the U.S. and Canada, including four trips to Hawaii.



The Psychological Barrier

by Theodore Solomon



Theodore Solomon contracted polio when he was a year old in 1930. He uses braces and crutches and has a hearing loss. He is employed as a clerical supervisor by the Ohio Department of Public Welfare.

Physical barriers are a terrible imposition on the disabled. Perhaps I was more fortunate than many. With my braces and crutches I managed to get where I wanted to go most of the time — whether by stairs or bus or car. I even walked. It wasn't always easy. I took countless flops on the snow and ice — like the time I kept sliding down on frozen rain going from my doorway to the car in the street, to be helped by two school girls, only to drag them down with me. That was and still is a problem. Psychological barrier is something else. It can be a good deal more agonizing.

The shift from grade to high school was an especially bad time for me. I went to Charles Feilbach School my first eight years. It was a wonderful school for the disabled long before anyone thought about mainstreaming. But I was eager to go to the high school where my five brothers had gone. But the change was not at all what I expected. I was the only disabled student in the school. Some accommodation was made at first for classrooms on the upper floors, but I soon discovered that I could climb the stairs myself by doubling up my crutches and hanging onto the bannister — and getting to classes on time. By the third or fourth year I felt more at ease. After all, I was an upperclassman by then.

Beginning at the University of Toledo, however, I experienced the same pangs of difference. I can remember riding the buses or walking down the halls in a pit of depres-

sion. With the benefit of hindsight, I can say now that the feeling was largely of my own making. If you want to feel miserable about something like that, you have every opportunity to crawl into a shell of loneliness — or, as Cyril Connolly once called a “womb with a view.”

I began to come out of it when I met a friend with whom I shared interests that transcended physical limitations. We both talked about being writers, about God, about philosophy, literature, about changing the world for the better — things that made my disability seem to disappear. Certainly, he made little mention of it. There was no need. It was insignificant when you were trying to save the world. I don't mean to say I forgot altogether. It was a gradual adjustment of an inner kind, in what William James called our passionate nature. In high school we used to talk about “poise.” The word was easily defined, but inner attainment was more elusive. I once read someone called it “amiable contempt.” For a definition it helped, but it took a long time to realize, to become embodied in the psyche, the passionate understanding.

The big break came when I gradually extended my consciousness beyond my own inner world. I became aware of other people, not simply as objects that react to me, but as human beings with feelings of their own. I thought many times about the little old ladies who gave me their seats. They had troubles and needs too. Our weaknesses and infirmities are matched by others in different loca-

tions. An arm for a leg, or a limb for a mental handicap. People with seemingly perfect bodies and beautiful faces may well be missing something. In comparing ourselves with others we come to understand that "normal" people do not exist. You have only to listen to anyone for five minutes to learn of their financial plights, their marital woes, their wayward children, their incorrigible illusions. We are all subject to "the heartache and the thousand natural shocks that flesh is heir to."

If everyone was going to be miserable at least part of the time, regardless of their "healthy" or "normal" qualities, then maybe it was all right to laugh or be a philosopher. But I didn't exactly turn into a ghoul, like one of Charles Adams's cartoons. I could still feel miserable too. But at least I understood the feeling was "in." And, anyways, part-time was enough. There are too many things to enjoy in life: fresh air and birds and sunsets and evening stars, baseball games, movies, books, learning something new, babies, and, of course, sex. None of these are full-time either. And, yet, Benjamin Franklin had it right when he wrote in *Poor Richard's Almanac*: "Human felicity is produced not so much by great pieces of good fortune that seldom happen, as by little advantages that occur every day."

So now I work and drive my car and sing along the highway, curse the reckless drivers (sometimes myself for being one), and dream impossible dreams, just like anyone else.

It seems that my life has been a constant struggle between opposite needs: to accept the help of others and to do what I could for myself. As a polio case when I was a year old I never knew any other condition. I needed my parents, of course, as all babies do; or, for that matter, as all people need each other. We are all interdependent. But during my childhood I didn't know anything about that. I had all I could do to fight this inner conflict between needing others and standing on my own two feet, such as they were.

I remember riding on the bus and hoping that no one would offer me a seat. Invariably some little old lady would get up and insist that I take hers. Sometimes I did and sometimes I flatly refused. In either case I always felt wretched. I could stand up — if I had something to hold onto besides my crutches. They alone were not stable enough on a swaying, jerking bus. I never developed a great love for buses as such. But as transportation, that was something else again. I had places to go and things to do.

When I was younger my brother Morris pulled me on a wagon or sled, or I rode on the bars of his bike. I couldn't ride a bike myself. I also rode in the cars of my older brothers. And how I loved all of it. I did get rides, to be sure, though sometimes I had to beg for them.

Naturally, when I learned that I could ride the bus — and before that the streetcar — first with my parents, then with Morris (how I still remember the thrill of my first trip to a downtown movie!) and finally all by myself. For 5¢ (later, due to inflation, you know — 10¢) and a penny transfer, I could ride anywhere in the city. When I was 12 years old, I came to a fateful decision. This was during World War II,

and while we managed to survive the Great Depression, we were not rolling in wealth. I still depended on begging (though I imagine with a little more dignity) and an occasional offering from one of my brothers. I was determined to do something about it. So one day when my mother was out I wrote her a note: "Ma, I'm going downtown to sell papers."

I trundled off on my crutches to the bus stop on La-grange Street. I got on the next bus and arrived in time for the noon edition of the Toledo Blade. A friend of my brothers, all five of whom sold papers, was a circulation manager. His name was Butch O'Desky. A big gravel-voiced, but kindly man with twinkling blue eyes, bellowed at me: "Hello, Billigan!" He knew who I was — I think by the family nose. To Butch, we were all "Billigan." He promptly gave me a corner downtown in front of the old Civic Center Restaurant on Superior and Jackson streets and soon after that, an even better spot, Lasalle and Koch's Department Store (now Macy's).

I sold papers at two places, the employees' entrance and another one down the block where customers left the store and often bought the paper in the afternoon. It was really a two-boy operation, but I handled it myself — except for one problem. People would pay at the other entrance by throwing their money on top of newspapers that lay on the sidewalk. Generally, the people were honest, but the same could not be said for a few kids that roamed the downtown area.

At the employees' entrance there was an old silver-haired watchman named Mr. Hewey who took a liking to me. He solved my problem by attaching a lock to a cigar box with a slot cut in it and fastening the box to a pillar by the other entrance. Mr. Hewey did other things for me too. The fact that his opinions were somewhat strange didn't really bother me. He hated Roosevelt ("that yellow dog"). Now, Roosevelt was then (and still is) a hero to me. But I learned that you don't have to agree with everything a person says to appreciate his heroic qualities.

I worked hard that summer and the following winter until I was forced to quit due to surgery on my feet. The excitement of riding buses soon gave way to a grim feeling about getting to and from school and to my father's tailor shop where I worked a couple of years later. Waiting for buses, sometimes six a day, in the hot sun or in the winter blasts of wind and snow was not exciting. I longed for a car of my own and a way to drive it. Years later when I did get a car and learned to drive, the wheels never stopped turning. I drove all around the city, parts of Ohio and Michigan, to California and Nevada.

The Magic of Motivation

by Carole Ann Parsons

Carole Ann Parsons with some components of her "essential support system": her sister and nieces (right) and her parents (far right).



My adolescent world exploded when I contracted polio and was rushed into an iron lung. Nine months of anguish, disbelief, and tears followed.

My parents, sister, brother, friends, and religious faith provided a vital, essential support system. I am utterly convinced that my survival would have been questionable without that multitude of support.

Thousands of post-polio persons have had similar experiences, have survived, have gathered every valuable ounce of strength and determination, and have continued as a loving, caring, contributing "being" within a marital, family, friendship, or community structure.

To those who have made "the magic of motivation" an implicit part of their lives, what have been the significant factors encompassing a severe disability and successful living as opposed to mere existence?

I feel unequivocally that a support system, whether it be a parent, a spouse, a sibling, or a friend (medical or social), is crucial in a crisis situation as well as continued life evolution.

Religious faith may also play an important role. In my case, a tenuous faith became stronger, providing sustenance and the realization that I was grateful to just be alive.

Another significant variable, I believe, is "cope-ability"—an undefinable, marvelous quality or ability to deal effectively, patiently, and compassionately with a devastating disability. Within the round of "cope-ability," there are such qualities as a formidable stubbornness, an unwillingness "to give in" or to accept defeat.

Such a personality must be extremely motivated by life challenges! Surely this mixture of factors must also include one's personal philosophy. As the years have flown by, my "Reverence For Life" has evolved into a mature philosophy that dominates my world.

I have severe respiratory involvement necessitating the use of a rocking bed, a chest respirator, a positive pressure machine, and a pneumobelt portable respirator. Pulmonary infections often result in brief séjours in the iron lung. Parenthetically, I have discovered the Ultra-Sonic vaporizer to be life saving when I have a "bad cold."

My hobbies include reading voraciously (favorite authors—T. Caldwell, P. Gallico, V. Holt, and H. Fast), writing poetry, painting and teaching watercolors, preservation of wildlife, tutoring French, and collecting miniature animals.

My college years at the University of Wisconsin-Madison were exciting, challenging and always interesting. Because I was using minimal respiratory equipment, those years were physically demanding and difficult. Often I was short of breath! At that time, I felt very strongly about being independent of respiratory assistance. How foolish!

Three years later, I began to develop respiratory fatigue with disastrous results! The recuperative process required two years. Now I am using assistance most of the day and I feel terrific!

Because attendant funding was unavailable in Wisconsin during my university years, I chose to live in a nursing home a half-hour from campus. Emotional survival in such a sad and depressing atmosphere was directly related to all-day classes and home vacations. Oral exams, carbon copied notes, tape recorder, cooperative professors, volun-

teers, and friends were invaluable. Finally, I received a Bachelor of Arts degree in psychology (1970) and a Master of Science degree in social work (1972).

After graduation, I returned to my family in Lake Geneva to search for a social-work consultant position. I



volunteered at a local rest home for a year, then worked at the Lake Geneva Nursing Home for a year. Because I have a very basic need to help others, that time of my life was especially fulfilling. Currently, I am a guest lecturer at the University of Wisconsin School of Nursing. An extremely challenging, stimulating experience!

Through the years my parents have remained an incredibly strong, loving support system. (Yes, we have our differences of opinion, but our individualism and mutual respect allow for these differences.) They have shared my laughter, my pain, my frustrations, and my happiness! The word "burden" has never occurred to them. When I lived in a housing complex (1978-1980), loneliness and isolation engulfed me! I could not cope with segregated living and the poor quality of live-in attendants available. Now I am independently living with my family again, enjoying their companionship and care.

Certainly my disability is an enormous inconvenience, but *not* a tragedy! I am fervently in love with life — rainbows, pussywillows, blue skies, and sunshine!

And, I love the *Rehabilitation Gazette*. Happy Anniversary! Each issue I receive offers inspiration, motivation, an awareness of shared life-styles, and a veritable resource of ideas. Most important, you have given me a very special gift — encouragement!

Address: Carole Ann Parsons, 5206 Trafalger Place, Madison, Wisconsin 53714.

Computer-Assisted Living

by William Kaiser

There is good news coming from the front lines of the computer revolution. In recent years advances have been made that open the door for the disabled to fully enter the computer world, increase their independence, to realize greater self-fulfillment and more fully share with others.

The computer affects everyone, but it offers so much for those with disabilities. With software like "Screenwriter II," a powerful word processor for the Apple computer. It offers scan and search features that easily locate chapters, words, and verses at the push of a few keys, making the study of God's word easy for those with severe disabilities. It is available from Bible Research Systems, 9415 Burnet Rd. #208, Austin, Texas 78758.

Another powerful word processor called "The WORD Processor" is the Bible on disk for the Apple computer. It offers scan and search features that easily locate chapters, words, and verses at the push of a few keys, making the study of God's word easy for those with severe disabilities. It is available from Bible Research Systems, 9415 Burnet Rd. #208, Austin, Texas 78758.

Education is easier and more interesting with programs like those from Edu ware, (28035 Dorothy Dr., Agoura, California 91303). Their fractions and algebra software offer a new visual way of learning.

Even in recreation the computer offers almost unlim-

ited opportunity. For example: Infocom, (55 Wheeler St., Cambridge, Massachusetts 02138) creates the wildest text adventure games ever seen. "Zork I, II and III" and "Dead-line" are stories and you can tell the computer what to do, where to go, what to look at. Sir Tech (6 Main St., Ogdensburg, New York 13669) has a different type of adventure game called "Wizardry." In "Wiz" you create a band of adventurers and travel through underground mazes (displayed on the screen) fighting battles, finding weapons and treasures.

These types of games can be played slowly; by keyboard, mouthstick, and other special input. They offer amazing challenge and excitement, taking days, even weeks, to complete.

Systems News: The Apple II+ is the most versatile computer for the disabled. A beginning system with disk drive and monitor can be found under \$1,500.

On the horizon, IBM is coming out with a lower priced model called the Peanut. It could have great potential for the disabled if it becomes as widely received and supported as the Apple has been.

For a more economical beginning, Atari's new 1200 and Texas Instruments' 99/4A also offer potential for the

disabled. The 1200, after a rebate, is about \$200 with 64K of memory. The 99/4A is about \$100, but only 16K. Both come with BASIC. Disk drives and more memory add significant costs. However, both units have many programs on cartridges which plug into the computers, allowing some use without disk. (If this is new, try the book *Your First Computer* from Sybex, 2344 Sixth St., Berkeley, California 94710.)

The Apple II+ is the only popular computer currently compatible with voice input equipment like the Shadow/Vet (Prentke Romich Co., 8769 Township Road 513, Shreve, Ohio 44676). Once programmed to your voice, the Shadow/Vet translates your words into instructions, allowing use of a word processor, games, anything the keyboard can do. The Shadow/Vet and other voice recognition systems being developed are a major step toward greater independence. With systems like this almost total environmental control by voice is possible, even by an otherwise unclear voice.

Communication is a vital part of life, but for the disabled it is often frustrating or impossible. The computer is changing this with products like the Echo II, a versatile Apple speech synthesis unit made by Street Electronics Corp. (1140 Mark Ave., Carpinteria, California 93013). It speaks what is typed on the computer screen, allowing someone who is non-vocal to generate computer speech. Besides being able to make instructional programs that talk, the software includes a program that allows a blind user to hear any part of the text on the screen, making word processing, programming, and data management accessible to those with vision impairments.

TI and Atari also have speech capability with additional equipment. TI makes very effective use of its speech in its educational software. TI also makes a portable device called Voicaid that provides a limited vocabulary.

Communication with other computers is also possible, and popular. Hayes Micromodems (Hayes Microcomputer, 5835 Peachtree Corners East, Norcross, Georgia 30092) make telephone use easy (they even dial and answer the phone for you). The modem connects your system with other computers around the country, and there are many computers (and people) to communicate with. *The On-Line Computer Telephone Directory* (P.O. Box 10005, Kansas City, Missouri 64111) lists over 300 free systems you can access. Also, there are large public information systems which charge a modest membership fee and small hourly rate.

Delphi (3 Blackstone St., Cambridge, Massachusetts 02139, Phone: 617-491-3393) is probably the most people-oriented of these systems. I've spent many enjoyable hours on the conference line talking (typing actually) to other users (often several at a time) around the country. One user, who has become a much treasured friend during conversations deep into the night, is blind and uses a Talktex (see below) to connect with Delphi. Delphi also offers electronic mail, a reference library, bulletin boards, games, and more. If you join Delphi, be sure to mention my



user name "Kaiser," and send me a note by e-mail when you log-on. I'll be running a special interest group for disabled users, and conferences for professionals to share the latest information.

Talktex is a new product that attaches to a Vic-20 computer. The Talktex speaks everything that goes to the screen, including regular software. The Talktex sells for only \$899 and the computer it connects to is under \$100. Write: Duffy Engineering, RFD #1, Box 387A, Nashawena Road, Mashpee, Massachusetts 02649.

More good news: *Re: Able* is a bi-monthly newsletter on computer-assisted living published for the professional community and the disabled. *Re: Able* explores the newest in computer equipment and new technology. Each issue details advances in equipment and applications, with emphasis on the usefulness to the disabled. Evaluations of hardware and software, products, books, and resources provide the professional with information vital to serving the disabled. It is also an excellent reference for someone with a disability who wants to be a part of the computing world.

Upcoming issues will include features on voice synthesis and voice recognition equipment, multi-tasking computers, remote keyboards, video game therapy, portable communication aids, independent living and environmental control, the P.H.O.E.N.I.X. Training and Development Center, computer networks and listings of hundreds of information services, seminars and conferences. Subscriptions are \$18 per year (\$21 overseas). Send to: *Re: Able*, P.O. Box 384, Bellflower, California 90706.

As editor of *Re: Able* I would like to hear from every reader — let me know about your experiences (and non-experiences) with computers. I need your thoughts, ideas, suggestions, and dreams. Your letters (or tapes) will help in the efforts of *Re: Able* to help manufacturers to improve the designs of new equipment, and also will provide informa-



(Far left) William and his family (L to R): his wife, Cathy, with the dogs, Fonzie and Bree, Eric, John, William, and Danny. (Left) William Kaiser working with Apple II+ system. Computer eases physical inability caused by muscular dystrophy.

tion for a book I am writing about the importance of computers for those with a disability, due to be published in 1984. Also, if you are buying equipment, write and let me know. I have sources for very low prices on most products.

A new remote control keyboard made for the Apple by Key tronic (P.O. Box 14687, Spokane, Washington) sells for about half of what others have charged for "disabled" keyboards and it has many more features. Retailing at \$298, it has an added numeric keypad, special BASIC programming keys, and Key tronic has started producing keyboards with locking shift/control/escape keys for mouthstick and other single-digit entry.

Texas Instruments will sell special 99/4A's that have locking keys, or will modify one already owned by someone. Contact: Texas Instruments, Consumer Relations, c/o Tom Shields, P.O. Box 10508, MS 5828, Lubbock, Texas 79408.

Smith Corona's TP-1 (soon to be upgraded into TP-2) is a compact, easy-to-use, letter quality printer that performs excellently. It is selling in some areas for under \$600 which makes it an incredible bargain.

KY Enterprises (3039 East Second Street, Long Beach, California 90803) produces modified controls for the Atari and Colecovision video games and Atari computers. Modifications include use by mouth, tongue, and head.

COPH-2 is an organization of disabled computer users. Membership is \$8: COPH-2, Membership, 2030 West Irving Park, Chicago, Illinois 60618.

Communication Outlook is a quarterly newsletter focusing on communication aids and techniques. Available for \$12 (includes membership in the International Action Group): Artificial Language Laboratory, Computer Science Department, Michigan State University, East Lansing, Michigan 48824.

Reference books: *The Elementary Apple*, *Kids and the Apple*, *Kids and the Atari* (Datamost, 9748 Cozycroft Ave.,

Chatsworth, California 91311). *The Apple II Users Guide* (Osborne/McGraw-Hill, 630 Bancroft Way, Berkeley, California 94710). *Apple Software 1983*, *Atari Software 1983* (The Book Company, 11223 S. Hindry Ave., Los Angeles, California). *Discovering Apple Logo* (Addison-Wesley, Reading Massachusetts 01867).

Software news: Datamost has a beautifully animated game for the Apple; "Swashbuckler" features a figure that you control in sword fighting. Datasoft (9421 Winnetka Ave., Chatsworth, California 91311) has excellent software for the Atari; games like "Canyon Climber" and "Zaxxon," and a super word processor, "Text Wizard." Broderbund Software (1938 Fourth St., San Rafael, California 94901) offers "The Arcade Machine," a program that lets you design your own arcade-style games on the Apple. They also have an easy word processor suitable for even children to use called "Bank Street Writer." Quality Software (6660 Reseda Blvd., Suite 105, Reseda, California 91335) has "Beneath Apple Manor" where dungeon paths are revealed map-like on screen with each step. The game is adjustable for different skill levels. Sierra On-Line has several fascinating picture/text adventures like "Cranston Manor" where you search for treasure in a old house and the caverns beneath. All are suitable for mouthstick play.

There is much more. A whole world more, but it will have to wait 'til next issue. Happy computing.

Address: William Kaiser, 9451 Olive, Bellflower, California 90706.

Trends in Home Health Care

by Judy Raymond

MEDICAID WAIVERS

In November 1981, President Reagan interceded in the case of Katie Beckett, a 3-year-old disabled child. Medicaid rules permitted payment of Katie's care in a highly intensive tertiary hospital, but could not pay for care if Katie were taken home. Reagan granted a waiver to permit payment for Katie's care at home. Katie Beckett publicized a health care delivery system which was not providing the best of life-sustaining technology in the least restrictive environment.

The Federal government has now made an effort to restrain the rising cost of medical care by initiating an alternative program for institutional care. Under Title XIX Medicaid waivers, states are permitted to waive certain requirements, such as income eligibility, which had previously prevented states from providing Medicaid-reimbursed noninstitutional care.

To qualify for a Home and Community-Based Waiver, states must:

- ensure safeguards for health and welfare,
- provide individual assessment of need for inpatient services for those requiring care provided by an intermediate care facility,
- inform recipients of the alternatives available under the waiver,
- determine that average per capita expenditure *does not* exceed institutional costs.

The services which may be covered include case management, homemaker services, home health aides, respite care, occupational and physical therapy. The Home and Community-Based Waiver is to serve individuals who receive or qualify for Medicaid benefits in an institutional setting. Eligibility is based on financial standing and the individual's health care needs, but eligibility requirements for programs vary substantially from state to state.

The Model Waiver is simpler and will allow states to cover small groups under Medicaid with coverage limited to disabled children and adults who would otherwise be ineligible for Medicaid services while living at home.

The waivers decrease costs and at the same time improve health care. Their potential and implications for all those concerned with home and attendant care, especially independent living centers, are unlimited.

SURGEON GENERAL'S WORKSHOP ON CHILDREN WITH HANDICAPS AND THEIR FAMILIES

The disabled comprise the fastest growing segment of our population. The number of children with chronic physical or mental disabilities has doubled from 1 million to 2 million in the last twenty-five years. Medical, surgical, and technological advances have saved the lives of children who would have died in years past. Children with multiple dis-



Judy Raymond, longtime Gazette volunteer, represented the Gazette at the Brook Lodge Symposium on the Ventilator-Dependent Child. "The problems and solutions for ventilator-dependent children relate to all who are severely disabled."

abilities now live. The ramifications for health care needs of these disabled children, dependent on technology for daily living, are far reaching and complex.

Pioneering efforts of doctors, nurses, allied health professionals, state agency officials, insurance and hospital administrators, social workers, and parent advocacy groups have made it possible for ventilator-dependent* children to live in the community with significant savings. Yet now this growing population needs regional coordinating organizations to maintain and refine current strategies for providing community-based health care, to guide and support parent groups, and to educate the professional and private sector about the dynamics of community-oriented care.

The Surgeon General's Workshop on Children with Handicaps and Their Families convened in December 1982 in Philadelphia to investigate ways to lessen the handicaps imposed on disabled children and their families. The workshop focused on the unique problems of the ventilator-dependent child as a specific example of the disabled child. The acceptance of the responsibility for insuring that all care alternatives be available to ventilator-dependent children

*Ventilator-dependent is the term currently used for respirator-dependent.

and their families was a major issue.

Over 150 participants — doctors, nurses, social workers, therapists, insurance and hospital administrators, state agency officials — explored the progress in programs in Illinois, New York, and Pennsylvania which document both the remarkable growth and development of ventilator-dependent children when they go home from intensive care units and the cost effectiveness of that move.

Participants examined approaches to service delivery; institutional, public and private organizational roles and limitations; standards; regionalization; abuse; professional and public education; research; and financing.

Among the recommendations presented to the Surgeon General were:

- development of regional systems,
- definition of the scope of the problem,
- development of model standards for quality assurance,
- revision of medical education curricula,
- identification of potential abuse,
- support of research,
- improvement of financing.

Although the workshop concentrated on ventilator-dependent children, the problems and solutions relate to all who are severely disabled.

Surgeon General C. Everett Koop assured the participants of his commitment and that funds would be available for a small number of demonstration projects for regionalized systems. Under Title V, Special Projects of Regional and National Significance (SPRANS) grants were awarded Louisiana, Maryland, and Illinois.

To further implement the recommendations of the Surgeon General's Workshop, a first regional workshop will be held in St. Louis, December 13, 1983.

ED. NOTE: *Report of the Surgeon General's Workshop on Children with Handicaps and Their Families* is available from National Center for Education in MCH, 3620 Prospect St., N.W., Washington D.C., 20007.

The proceedings of the Surgeon General's Regional Seminar on Home Care for Ventilator-Dependent Children and Adults in St. Louis in December 1983 will be published in a special issue of *AARTimes*, the official magazine of the American Association of Respiratory Therapy, Box 35886, Dallas, Texas 75235.

BROOK LODGE SYMPOSIUM

The Symposium, graciously hosted by Upjohn HealthCare Services in the relaxed setting of Brook Lodge in Augusta, Michigan, October 16–18, further implemented the recommendations of the Surgeon General's Workshop.

A small, select group of health care professionals, state agency officials, and recipients of the SPRANS grants shared experiences and information on clinical and program planning in discharging ventilator-dependent children for home care.

Mark Merckens, M.D., Chronic Illness Unit, LaRabida Children's Hospital, Chicago, stated that "We are dealing with a paradigm of illness . . . that is, children with severe chronic illness who are high-technology dependent."

In a presentation about a World Rehabilitation Fund Fellowship studying home care services for ventilator-dependent people in England and France, Allen Goldberg, M.D., Medical Director of Children's Home Health Network of Illinois (CCHNI), compared the problems the polio patients faced in the 1950s. Modern critical care and rehabilitation medicine evolved from the response to the polio epidemics.

The multidisciplinary approach to that crisis, involving the family in decisions and risk taking, with regional centers for care, rehabilitation, and research, resulted in tremendous savings of money while providing a greater degree of self-sufficiency for ventilator-dependent people than had ever been thought possible. This same multidisciplinary concept of care involving the family will work again for the ventilator-dependent child.

Intense group discussions concentrated on:

- ethical policy issues,
- philosophy and responsibility for discharge,
- medical and social assessment for discharge,
- discharge planning and post discharge evaluation,
- home care case management,
- attendant care,
- community based services and support groups,
- rechanneling of acute care dollars,
- financing and Medicaid reimbursed noninstitutional care — waivers,
- equivalent liability for all levels of caregivers,
- alternative placement such as foster homes.

Respect for and deference to the value of the family and confidence in it to deal with the responsibility for the child was an issue heard over and over. Respect for the capabilities of other professions was stressed. Doctors need to accept that they may not be able to cure but must pass the child on to other levels of care providers.

Dr. Robert Ketrick, Children's Hospital of Philadelphia, Ventilator Dependent Children Home Program, reaffirmed that medical paternalism must be avoided. "The rigidity of the disciplines must be overcome so that all involved in the care and responsibility of the child will also be involved in the decision making," said John Hartline, M.D., Neonatology Services at Bronson Hospital in Kalamazoo. Shared family and community responsibility was also emphasized by John Dyer, M.D., Chief of Maternal and Child Health, Region V.

There was little doubt that transfer from ICUs to home care accelerated the growth and development of the ventilator-dependent child. The answer to "What is best for the child?" is most definitely and positively home care.

Children's Home Health Network of Illinois (CCHNI), established in 1983 by Children's Memorial Hospital, LaRabida Children's Hospital and Research Center, and State of Illinois Division of Services for Crippled Children (DSCC), has developed a regional program to support the transfer of hospitalized children with prolonged ventilator dependency to their homes or alternative homelike settings. Representatives from CCHNI reported on their discharge planning and plans for a pediatric home care model for

chronic illness services. They are evaluating the effect of the program on the comprehensiveness, continuity, and cost of services, and its impact on the children and their families. Savings of 75% of acute care inpatient costs have been documented by CHHNI.

Competing priorities for the health care dollar require everyone's efforts for more workable interstate Medicaid transfers with the suggestion that Maternal and Child Health should take the lead in encouraging the states to find the mechanisms for these transfers.

Income eligibility waivers, enabled by the Omnibus Reconciliation Act of 1981, are vital to prevent families from reaching poverty levels before they can qualify for Medicaid and home care reimbursement.

Unfortunately, Crippled Children's Services and Public Aid programs vary from state to state to an astonishing and frustrating degree. Agencies involved with providing services to disabled children must recognize that services needed by the ventilator-dependent child differ only in the technical nature and complexity of services. Programs and services must be family oriented, multidisciplinary, and coordinated. According to Dr. Edward Lis, Illinois Division of Services for Crippled Children, the programs must be more involved with discharge planning and case manage-

ment. Departments of Public Aid and Crippled Children's Services must work together creatively.

The general public must be educated about this new category of disability and the growing population of high technology children. The successful, safe and productive aspects of home care for the child and the family must be made known, along with the necessity for the removal of the legislative and financial barriers to that home care.

The Brook Lodge Symposium aired the frustrations and hopes of the participants in dealing with the bureaucracy of paperwork and lack of creative funding to accomplish the simple goal (yet complex task) of sending a child home to be with his family.

Brook Lodge established a communications network of people/institutions/agencies involved in the discharge and home care of ventilator-dependent children and affirmed a core group of dedicated, caring people who know that it can be done.

ED. NOTE: The final report on the Brook Lodge Symposium will be printed and distributed by Upjohn Health Care Services, 2605 E. Kilgore Rd., Kalamazoo, Michigan 49002

Future Concerns

Is Apathy Growing on the College Campus?

by Valerie Brew Parrish

Banner headlines from coast to coast once proclaimed the disabled as a new militant advocacy group demanding basic civil rights under the law. The momentum of this powerful movement spurred legislators into action and for the first time in history, the disabled population was viewed in a new light. Legislators became convinced that disabled persons would no longer be treated or tolerate the status of second class citizens. Employment, education, housing and transportation became issues that could no longer be put on the back burner. Disabled persons on college campuses and around the nation were loudly telling the public that they had a right to the same privileges enjoyed by all Americans.

The culmination of the efforts of the civil rights movement occurred in May of 1977 when the Rehabilitation Act of 1973 was signed into law. Courageous disabled persons had literally camped out for days at Health, Education, and Welfare offices in many cities until this important piece of legislation became the law of the land.

A new era was beginning to take shape on the American scene as a result of the Rehabilitation Act. Universities were required to make their campuses accessible. Discrimination and segregation were prohibited in any facilities receiving Federal monies. Curb cuts began appearing even in

rural areas. Housing complexes began making modifications and employees were mandated to actively recruit, employ, and promote qualified disabled applicants for employment.

Nostalgic memories of the impetus that sparked the White House Conference on the Handicapped have dissipated into the sad realization that most disabled college students today have become apathetic. Activism on the college campus has been replaced by sanctimonious displays of Miss Wheelchair America Pageants.

The decade of the '70's seemingly paved the way for social reform for the disabled. Will the decade of the '80's quash the dreams of equality that so many disabled persons fervently fought so diligently to secure?

The golden age of the 1980's dawned brightly for the disabled population. All facets of life appeared to be greatly improved. Complacency dangerously crept into the disabled camp.

Advocates for accessibility suffered a major defeat on the Southern Illinois University campus when disabled students informed the administration that the automatic doors being considered for the recreation center would not be needed although members of the student Handicapped

Rights Organization had recommended their installation.

In a letter to the recreation department, disabled advisory recreation members stated they did not mind asking for assistance with opening doors because it provided them with an opportunity to interact with able-bodied students. The letter also stated that the number of disabled students who would benefit from the automatic doors did not justify the large expense that would be incurred by the university.

The letter concluded that automatic doors and lowered elevator panels should be delayed until the continuing expansion of this new building, paid for solely by student fees, is completed and that such an expenditure be carefully considered in relation to benefit and gain. It is difficult to fathom the reasons or logic that would compel disabled students to thwart plans of accessibility.

Why is apathy growing on the college campus? The implementation of Section 504 of the Rehabilitation Act of 1973 enabled disabled persons to have a choice of post-secondary institutions to select to pursue a college education. Perhaps apathy abounds on the college campus because too often coordinators of Disabled Student Service Programs are persons without disabilities and the issues so vital to the survival of the disabled become superficial compared to the mundane daily routine of running an office.

The coordinator should be a strong advocate of disability issues. Disabled students must be made aware of the legislation affecting their lives. The disabled and nondisabled coordinator alike should take an active role in both local and national consumer organizations and strongly encourage the disabled college students to do the same. Each Disabled Student Service Office should maintain a library or browsing room where disabled students would have access to publications related to disability issues.

Several years ago while I was attending a conference in Washington, I had the pleasure of meeting a coordinator

of a Disabled Student Service Program from a university located in Minnesota. The coordinator enthusiastically informed me that every year the staff and disabled students combine their efforts in promoting fund-raising activities so that the disabled students can travel to Washington to attend conferences. The coordinator felt that disabled students benefited from this experience in many ways. Exposing disabled students to pertinent conferences heightens their awareness of the issues. Furthermore, it allows them an opportunity to meet and interact with disabled leaders who serve as excellent role models.

Perhaps, most importantly, it allows the disabled person to realize that his or her opinion has merit, and by uniting and working together positive changes can and do come about. Unfortunately, it may not always be feasible to fly disabled students to Washington to attend conferences. Nevertheless, other viable options can be sought to make students aware. Coordinators can invite notable leaders to the campus to meet disabled students. The old fashioned "rap" session can be used whereby disabled students can get together and exchange ideas.

Disabled college students symbolize youth and fresh vitality to conquer the problems of today and the future. Apathy, like an infectious disease, spells destruction for the disabled population. The time has come for disabled college students and all disability groups to unite together in promoting a better world for us all tomorrow.

Valerie Brew Parrish is a Placement Specialist for the disabled students at Southern Illinois University and has a master's degree in higher education. She is an "upside-down polio" — she has use of her feet, but not her arms. She and her husband, Rick, who is blind, are the proud parents of a daughter, Tara. Address: Carbondale Mobile Homes, Lot 466, Carbondale, Illinois 62901.

Independent Living: An Advocacy Base or Service Provider?

by Charles Carr, Independent Living Center, Lawrence, Massachusetts

The independent living power base originates from the leaders who got together in the late sixties and early seventies to develop disability rights legislation as well as independent living services.

It was at this time in the growth and development of the movement that there was a serious difference of opinion concerning the future direction of centers for independent living. Will we compromise our advocacy efforts through the provision of services?

Trying to pepper services into an advocacy base is very awkward and sometimes impossible. Conversely, service providers that try to inject advocacy into their operations, meet with dismal failure.

The leaders of the movement that sought a better qual-

ity of life for disabled people and felt that services were a means to that end, should get together and rethink some of the basic and inherent problems in the existing operation of community-based centers for independent living.

The advocacy versus service provision dilemma has not gone away, but, in fact, has intensified.

If we do not take notice, we will eventually be choked off by our service provision arm that starves for money and lacks philosophical direction.

The basic tenets of this movement consist of self-help, self-direction, and a rebellion against institutional and medical environments that were oppressive and socially irresponsible.

War and Peace: Adjusting to Myasthenia Gravis

by Rachelle Kess, R.N.

Droopy lids provided the first clues. Before long, I noticed other disturbing symptoms. I found that doors now seemed too heavy to open and that I could no longer finish brushing my hair, chewing a meal or climbing a flight of stairs. But, with a bit of rest, each of these "lows" was followed by a "high," a period of pep and energy which reassured the part of me that had to believe that nothing serious was wrong. I was basically unconcerned until my first episode of breathlessness. Panic followed when the shortness of breath progressed to respiratory failure and the transient weakness to paralysis.

I was imprisoned — expressionless — within an un-moving body, seemingly oblivious to the frantic activity going on around my hospital bed. Some caretakers unfamiliar with my illness pinched or slapped me to "wake me up." But, concealed beneath the poker-face, were fear and frustration. I was alert and very aware that I was totally dependent upon man and machine, both fallible. I was unable to swallow my saliva, change from an uncomfortable position, scratch an annoying itch, call if someone had forgotten to switch on the alarm that would attract others if my respirator tubing became disconnected. My muscles refused to budge, but the wheels of my mind would not grind to a halt. There was no way I could fall asleep and later awake to find everything back to normal.

I had developed myasthenia gravis, a chronic neuromuscular disease characterized by fluctuating weakness of diverse groups of muscles, periods of remission, and periodic "crises" during which there is paralysis of those muscles used in breathing. As an R.N., I had no difficulty understanding the disease process or recognizing that mine were signs and symptoms of severe myasthenia.

Unfortunately, intellectual understanding and positive test results did not facilitate my adjustment to this potentially life-threatening condition. Between "crises," between bouts of weakness and air-hunger, I convinced myself that I'd never have another attack. I disregarded symptoms until I sensed that control, consciousness — life itself — would soon slip away. Again and again, I drove myself to exhaustion, trying to prove that I had not entered the world of the disabled and dependent. But each attempt to maintain this denial led to an exacerbation of symptoms and to nightmarish emergency interventions which mercilessly exposed the reality I was trying so desperately to refute.

Furious at my myasthenia, I lashed out instead at the physicians who'd diagnosed me, who'd "pronounced" me myasthenic and insinuated that, with my nursing background, I should be better prepared to deal with the diagnosis. I hated being viewed by them now as an arrangement of body systems — a case, not a person.



*Rachelle Kess, R.N.,
"Paradoxically, the disease
which periodically shut my
lids opened my mind's eye
to new vistas and sharpened
my focus on important
issues."*

It was painful to note the attitude changes that occurred as soon as the hospital gown became my uniform and bed rails went up between my former colleagues and me. I resented their distancing themselves and telling me that "I'd have to learn to live with" what felt unendurable — without offering concrete ideas that could have helped me do so. Despair set in, my anger intensified, my behavior became increasingly hostile and nonsensical, and I managed to alienate members of the "helping professions" when I most needed help.

Alone, I pondered my predicament. Two brutal words — myasthenia gravis — had dashed my dreams and I was helpless under their weight. Now, the ME as all knew me was no more. People were seeing me at my worst as I'd hoped they never would. I could not deal with the forced dependency. But I very much wanted to live, to beat the "enemy" responsible for the death of my secret hopes and aspirations. I began to read all I could find written on the subject of myasthenia; I searched for a hospital with a cure, an article detailing a solution, a doctor who could perform miracles. I found none, of course.

What I did find was just short of miraculous — a handful of physicians and nurses who linked life support and emotional support, who meshed intensive care and intensive caring, who cared for and about "the patient." They personified competence, provided a sense of security. They treated me not solely as a myasthenic, but as an individual who had opinions, feelings, concerns and interests unrelated to my illness. Though I was dependent upon them to a great extent, I did not feel totally "out of control" because, whenever possible, they involved me in decision making and problem solving. They were practical, totally honest and honestly hopeful as we discussed possible solutions to my difficulties. We joined forces and were partners in battle.

Of course, even the most compassionate professionals

could not be all-knowing and all-powerful. They could not alter the harsh realities of my existence. The disease would not be vanquished. Complications would arise to intensify my misery.

The very drugs used to control my illness themselves induced severe disorders, including infection, deterioration of bone and gastrointestinal bleeding. There also were "little" problems that loomed large in my mind such as my tracheostomy, a life-saver when respiratory muscles were on the blink, but a source of distress when I was well enough to shower and then would suffer the shampoo-seasoned droplets that seeped into the opening in my neck, drenching my lungs.

Feelings of depression did not let up. What kind of future could I look forward to, I wondered, now that I could not work or mingle with others? I was going nowhere (literally and figuratively) while the healthy were producing, progressing and passing me by. Frustration was my regular companion because the smallest task could demand such effort. More than anything, I felt isolated.

Survival had become my career — and it was a lonely occupation. Old friends no longer shared similar concerns. I was busy feeling sensitive about cortisone-induced body changes, embarrassed if fluids regurgitated through my nose or words came out slurred, ashamed if my posture was poor and my gait unsteady.

I knew that what would be harrowing for me would become tired news to others. How many times would I feel like describing what it's like to feel starved for oxygen? How could I explain the terror, the fear someone in charge might foul up or show up a bit too late to keep alive my own crucial brain cells?

I swallowed the fears and pain and anger to the point of satiation. I became fed up with self-pity and inertia. I realized how dangerous was my defeated spirit, my pessimistic attitude, my unwillingness to redefine my limits. I wondered why it was that, when others needed my "ministrations" as nurse, I thought no ill of them and yet, for myself, being on the receiving end — being the trusting, dependent patient — seemed unacceptable, impossible. I questioned what self-pride was all about if it might rob me of my will and ability to go on. Were independence and perfection to be considered absolute ideals if they could cause exhaustion, despair or even death?

I reviewed my old set of standards, examined the roots of my fears, and recognized that I had better modify my thinking and learn to live with the disease which might be here to stay. The M.G. would not rule my life, but I would have to begin to consider its demands and the limitations it imposed. The course of my illness might determine my schedule of activities, but I'd not allow it to program my moods or limit my range of interests.

Fear of being stopped in my tracks by a "crisis" could not keep me from getting started on projects important to me. I had to keep in mind that while I might miss the roses

and scent of newly cut grass this June, a remission might arrive next year with spring. My objective had to be to make the most of each day until then, whatever my physical state.

To occupy myself during the "bad times," I could listen to music or to thought-provoking National Public Radio broadcasts. Recordings could be obtained of some of the conferences I was unable to attend, Audio Digest Foundation tapes could keep me up to date on news in the health field, and "Talking Books" could fill my ears — at no cost — compliments of the Library of Congress. Also, exercises could maximize the strength of unaffected muscles. And certainly there was ample opportunity to daydream and devise solutions to recurring problems, such as my "trach troubles." Why not use the long hours to formulate short-term goals that could be reached between the inevitable "crises" — concoct exciting plans for the "good days?"

In those precious days between "crises," when the "old me" returned for an indeterminate length of time, I'd have to guard against my desire to make up for lost time, my tendency to wear myself out. I'd try to continue on my own at home, writing health-related material (or doing some Japanese brush painting or "working out," or . . . or . . .) whenever the muscles would comply. For safety purposes, however, I'd have an emergency communication system in operation at all times so I could call for help when unable to speak or move about.

And call for help I would, long before my life was in danger. I'd learned, at long last, the importance of communicating my needs, of finding a healthier balance of dependence and independence. It finally became obvious how sensible it was to request assistance, if only to conserve some of my limited energy — or to get a bit more pleasure out of life.

Three years of illness made me keenly aware of the importance of living each day to its fullest, appreciative of all the beauty therein. It taught me to value pure being, to be more tolerant of imperfection — both in myself and in others. The M.G. experience helped me to discover small joys previously unnoticed and to appreciate trustworthy, caring people I had not known before. It showed me the importance of assuming an active role in sickness and in health, proved how advantageous it can be to view difficulties as challenges rather than obstacles. Myasthenia has forced me to sift out the trivial from the important. It has taught me to smile when the muscles would, say "I love you" when I was able — for no one could foretell when another opportunity would occur.

Experience convinced me that I'd continually be confronted by disease-related changes and physical losses for which I'd grieve. The recurrent realizations of loss could make me hit rock bottom, could make me call for good support systems to cushion the painful jolts. Yet I learned that I was incredibly resilient and that I could bounce back.

Strangely, illness taught and reinforced lessons that

health could not. Paradoxically, the disease which periodically shut my lids opened my mind's eyes to new vistas and sharpened my focus on important issues. It changed my perspective and enlarged my scope of values. A condition that appeared senseless would bring me to my senses. What could not be changed brought about great changes in me. What was seemingly meaningless could bring deeper meaning to life. . . .

So, after battling my illness for so long, I quietly gave up the fight. I know that I will never come to love my "stop-and-go, on-again, off-again" life style. My desire for a total cure will persist. I will never grow fond of "the invader," but armed now with the insights it has given me, I am able to make peace with this "enemy" of mine and to make peace with my new self. At last.

Rachelle Kess, R.N., 154 West 70 Street, New York, New York, 10023

Cerebral Palsy Challenges

The First and Greatest Challenge

by Rose Ann Stanowski

I like to compare the following events of my life as a person with cerebral palsy to that of a baby who skips the stage of crawling and goes straight from the crib to walking.

Since the death of my parents in 1974 I lived in nursing homes. I was determined to get back to the normal life I lived at home. So, on February 21, 1979, I moved from the safe, loving cocoon of a nursing home in New Jersey into my own apartment in Staten Island, New York.

The "crawling stage" would have been a group home, but there was not an opening, so I plunged into the greatest risk a disabled person could take. On that cold day with snow on the ground, I arrived in a van at the apartment. But my attendant was not in sight! The kind driver found her in a phone booth.

I assured him I would be all right. In an almost empty apartment with only a few pieces of used furniture, I started my new role of employer. I had no experience but I had read a little about what people had done before me.

I had my own priorities and I laid down some ground rules. The care of my body came first before the care of the house. I had specific jobs for my attendant to do each day that would still give her enough time for herself. I had a time set for everything, even fun times, times for just dropping everything and going for a walk to enjoy the autumn leaves.

I think we started off on the right foot even though I was scared stiff that she might walk out on me. The nurses back at the home were afraid for me. I lived with this fear for the whole year. The only one to call daily was my kind bus driver. I got little moral support, a lot of criticism, and negative feedback. My attendant was good to me in many ways but she carried a chip on her shoulder about her ancestors being slaves and many times she took it out on me and on my friends. Yet, this didn't stop me. I did what I set out to do and there were many rewarding days of having my own "pad."



Rose Ann Stanowski, "I received a letter of acceptance from Hofstra University. . . . But the Vocational Rehabilitation in New York and here in St. Louis would not sponsor me. . . . I'm at the nursing home now."

The day after we moved in, I had another "cradle to walking" stage experience. I started my first day of college. I was nervous! My only previous experience with school was two weeks of grade school in a special school. All the rest of the time I had been tutored at home.

I had wonderful teachers and a counselor who gave me much of their time. They encouraged me and told me that I worried too much.

I started on a liberal arts program, hoping to major in psychology and become a counselor for people who have lost their loved ones or who have emotional problems.

For the first time in my life I came home with five books on one subject. In the beginning, my stomach would turn somersaults and I would think that I couldn't make it. But I finally learned study habits and I studied from 3 to 11 and on weekends. I had to prove to myself and to all the "doubting Thomases" that you can do anything if you just take that first step.

During my first semester, students would push me to classes. Then in May I got a motorized chair and it gave me

my first taste of independence. I loved it! Just roaming the campus and getting to my classes could be an adventure.

That summer I was supposed to go to summer school. But, instead, at a Fourth of July picnic, I fell out of my wheelchair and broke my knee. It was a lesson in pain and compassion. I used the recuperating time to practice driving my wheelchair so I wouldn't bump into school doors and desks.

I became a better student in my second semester. I had a goal to reach. I wanted to attend Hofstra University on Long Island. I wanted to experience the full campus life — both study and play. I wanted to live in a dorm. Many people said I wouldn't make it. I went back to the College of Staten Island and, at the end of December, received a letter of acceptance from Hofstra University. Proud and happy, I knew my hard work had paid off. Another first, a challenge accepted and reached.

But . . . the Vocational Rehabilitation in New York and here in St. Louis would not sponsor me. They both said my speech problem is too great to be a counselor. Ironically, I solve most of my problems by talking on the phone.

I faced the most agonizing decision of my life — that of risking getting funds for college in New York or returning home to a nursing home in St. Louis.

I'm at the nursing home now.

The faith and love my parents had for me now shines through in my friends, and I know one day I will be a counselor.

Where one door closes, others will open.

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The Right to be Challenged

by George D. Green

I am 53 years old — and cerebral palsied. I was born and spent my childhood in Cambridge, a small town in southwestern Ohio. My early education was in a special class for the disabled in that city. My last two years of grade school were spent as a member of a special experimental class of ten CP's from across the state.

By the end of the second year, I was ready for high school, however, they didn't want to extend this class beyond the grade school level. The rural school board wouldn't send me a home tutor and I couldn't board a school bus and go from class to class. So that was where my formal education stopped — without a high school diploma! Even though I came from a family of college graduates.

Since our home was across the street from the grade school, I started a small store in the living room of our home. I carried school supplies, candy, pop, etc. I also established a magazine-subscription agency but I had to depend on my dad to make out the orders because I could not operate our manual typewriter.

The IBM office sold me an old model electric for a low price and a machine shop made a finger guide out of clear plastic. What a joy it was to type a decent looking letter for the first time in my life!

I am very thankful that my parents didn't take the attitude of "why bother to educate this child, he can never lead a normal life and will probably die young." On the other hand, I wish now that I had taken the study of spelling and English grammar more seriously because of my present inclination to become a writer.

You may be wondering what happened to my store. First, the school moved the seventh and eighth grades,



Bea and George Green,
"We both like the idea of
being as independent as
possible."

which included the kids with the most spending money, to another school. Then, one day when I was alone, two kids came in, filled their pockets and walked out without paying. Dad and I were so mad that we complained to the school principal. That was a big mistake because he made the rule that no child could leave the school grounds at noon or during recess. I finally had to get rid of my remaining stock and close the store.

Meanwhile, with a friend at Goodwill, I had set up an

Ashtabula Handicraft Club. That led to a newsletter I started and a part-time position as a public relations writer for Goodwill. I held that job for eleven years.

The big turning point in my life was going to Easter Seal's Camp Pittenger in McCutcheonville, Ohio. During my first session I learned that there was a little grocery in town run by Bea, a CP gal, who would come out for the camp's evening programs. I met her when I ordered a battery for my radio.

That was in 1966. We were married in August 1976. The one hundred and ninety miles between our homes and the health of both of our parents were the factors in our courtship. My mother had died in 1954 of cancer. Dad and I batched it for over twenty years.

After our marriage, I accompanied Bea to the store every day, unless it was extremely cold weather or I was ill. While my poor speech and poor use of my hands prevented me from waiting on trade, I could keep eyes on the shelves to see what was to be ordered. In time, Bea taught me her bookkeeping system. From then on, I was in charge of keeping the day-by-day records. Since I didn't have a calculator with a finger guide, it certainly sharpened my mental math. During the five years that I was in the store with Bea, I enjoyed it, especially getting acquainted with the people of the community.

Periodically over the years, Bea developed foot trouble while walking on the concrete floor of the store. In the spring of 1981, her foot problem returned. When our chiropodist saw the condition of her feet, he told her to get off her feet even if we had to sell the store. In July of that

year, we sold the store. She had been in business for 31 years. The store still bears the name, "Bea's Superette."

In the next few years, we hope to do a little traveling and see some of this great country. Besides traveling, we both like the idea of being as independent as possible. Bea drives the car. While I need help to eat, I can dress myself. Bea enjoys cooking, does all the housework and cares for our police dog.

At 56, she is a lifelong resident of this community. She graduated from high school and received a B.S. degree from Heidelberg College in 1949. At one time she wanted to become a physician and specialize in cerebral palsy. But doctors talked her out of the idea. After completion of school, she was unable to find employment, so her parents bought the grocery store and assisted her in the business as long as they were able.

My main ambition is to write two books. I have the plots pretty well worked out in my mind but, at my present writing speed, it is questionable if they will ever be finished. If they are ever written, I hope these books will shock some people out of their A.B.S.O.S. (Able-Bodied Sense of Superiority). They will show that disabled persons have the right to be challenged and to develop and utilize their talents and their abilities to the fullest extent possible in order to make their own way in life.

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The Road To Independence Is Paved With Help

by Jim Hammitt

In my position as an Independent Living Services Coordinator for an independent Living Program in the Los Angeles area, I am contacted daily by people who want assistance in finding housing. Sadly, when we begin to discuss their individual needs, it often becomes apparent that they are not really ready for housing assistance. They don't know what they want and they have no realistic idea of what they can afford, what they can physically handle, or what they will eventually do when they change their environment. Most are simply looking for an escape from their present situation. They have not really thought through what moving to a new environment will require of them.

The individual must consider: What do I want out of life? What are my abilities and capabilities? What are my financial resources? What are my limitations and how can I manage my life so as to overcome and go beyond those limitations? All of these considerations require individual decisions and you must take responsibility for making these



Julie and Jim Hammitt, "The independence process is being nurtured and accomplished through our marriage."

decisions yourself. If you are not ready to do so, then don't be ashamed to ask for help. Many Independent Living Programs offer peer counseling and/or rap groups which give you an opportunity to discuss your questions and needs with other disabled persons who may have worked through similar dilemmas. Their input is intended to assist you in eventually making your own decisions; they are not there to tell you what you should do.

Many people fall into the trap of thinking that independence is being solely dependent upon oneself for everything in life. However, true independence is being able to recognize our need for dependence upon people in some areas, and being able to allow others to be dependent upon us in some ways, thus creating interdependence.

My own road to independence began early in life. My parents raised me as a boy with a disability rather than as a disabled boy and my self-image resulted from emphasizing my abilities rather than my limitations. This was a long process and there were many detours along the way. I hated myself and my disability for a long time, but I always had a basic feeling of security because my family accepted me and believed in me.

When I first became an active member of the disabled community, many of my peers did not understand why I continued to live in my parental home. However, I was at that time working on other areas in my growth toward independence and this could not have been accomplished if I had put my energies into leaving home at that time. My first job greatly nurtured my growth toward developing the life-styles that I was seeking.

I have found that development of friendships has been very important to my personal, social and vocational growth. One of these friendships evolved into something that I dreamed of but never really expected to have — a happy married life. My wife Julie and I met on the bus when I first went to work at MAINSTREAM and for several years our friendship consisted of a few hours a week chatting on the bus. When our relationship suddenly changed to a romantic one, we were as surprised as those around us.

For the past two years, we have been learning the meaning of independence through interdependence. We share chores around the house and yard according to our individual capabilities so that neither of us feels disproportionately dependent upon the other. We also share the financial burdens of our life together by working full-time. However, our interdependence does not end with these chores and responsibilities. We have found that our greatest strengths and contributions to each other are in those qualities that cannot be measured by physical capability. Although one of us is disabled and the other is not, our interdependence has allowed both of us to achieve and experience many things that neither of us could have done alone.

In our case the independence process is being nurtured and accomplished through our marriage. However, many other people find their way to independence through interdependence in a non-marital relationship with a significant other, in a roommate situation, or through interaction

with friends and family members. In other words, the details are not important — what is important is that you are in control and that you make the decisions that affect your life.

Jim Hammitt, director of a literary service agency, was the founder and editor of Mainstream, coordinator of services at the San Gabriel Center for Independent Living, and a member of the Board of Directors of United Cerebral Palsy Association. He has received many awards, including the 1980 Governor's Trophy from the California Governor's Committee for the Hling of the Handicapped. Address: 4203 Yuleton Avenue, Covina, California 91722.

No Longer a C.P.

by David Morton

I am no longer just cerebral palsied, I have become a person. I did not discover a new operation to correct my disability nor make a pilgrimage to a holy shrine for a miraculous cure. Instead, I finally realized my cerebral palsy is as much a part of my person as my physical, psychological, and spiritual makeup.

Admitting to be a person has been a frightening experience for me. I have used my disability as a distorted "macho" image. No longer could I project an image of a man who had "overcome" disability by self-determination and could cope with all problems without any assistance. Although I am proud of my personal achievements and can handle many of my problems, I recognize everyone is dependent upon others in many daily situations. I guess my acceptance of my being a person has been revealed in a series of humorous episodes during my life. Thus, my humor has made me more of a person than any therapy could.

My boyish smile gave me the chance to become the 1954 Easter Seal Society of Iowa poster child. I remember trying to maintain my balance as I attempted a smile while I posed in parallel bars wearing full-length braces. However, the photographer caught the impish smile of a young lad whose braces would not have prevented me from climbing a tree if I was given the chance.

I felt the problems of my teens were special to me because of my disability. My family had moved to Chamois, Missouri. My parents managed one of my grandfather's funeral homes in Osage County. The front porch had a ramp, where the caskets were taken to and from the funeral home.

The Fourth of July, 1967, was my own Independence Day. I had become bored with our family gathering. So, I quickly rolled myself down the ramp and started exploring the town. To my surprise, Chamois lacked the modern convenience of street curbs. Thus, I had the freedom of going

anywhere in Chamois. This freedom gave me the opportunity to attend public high school.

My humor played an important role in letting people accept me as a person. While I was taking a stroll one afternoon, I went by the high school coach's house. The coach saw me as he was washing his car. He asked if I was planning to go out for track as I was the fastest person he knew in the wheelchair division. My reply came the following day when I dressed in a sweat suit and appeared in the gym to announce that I was ready for track. This stunt was rewarded by the only track letter ever presented to a disabled student at Chamois High School.

My family moved to St. Louis which gave me the chance to attend Meramec Community College. Like any young man in college, I was fortunate to date several girls. I recall an incident where I had managed to date a girl with long brown hair. After a wonderful evening, I wished to thank her by a kiss without being too obvious. Well, I tried gently to put my arm around her neck. Unfortunately, I caught a handful of her hair and I could not let go. My attempted kiss became a painful task of untangling her hair from between my fingers.

My college years were devoted to learning to write scripts. I had a few of my plays performed giving me a chance to make friends with those studying theater arts. Often, I would be invited to cast parties. During a party, we were very drunk causing us to play silly games. One game was trying to see how many people could fit in a bathtub. There were a few surprised looks when I climbed out of my wheelchair and crawled into the tub with my other drunken friends.

Despite my heavy "cerebral palsied" accent, I earned a bachelor's degree in speech and drama as well as a master's degree in mass media. I have become a free-lance writer and playwright. In the spring of 1980, I started to live independently in an area of St. Louis where a writer has a feast of people to study and write stories. I decided to write a short book on the people who worked on Euclid. While I wrote the book, I hired Jane Yates Offutt as an attendant. I discovered she enjoyed to write. So, I invited Jane to become my translator when I interviewed the people for my book. Well, our relationship developed into romance and I proposed marriage to Jane on September 18, 1981.

And what do we do now?" I exclaimed to Jane when we finished walking up the aisle at our wedding. My question relieved the tension of the people as we heard some laughter from our guests. I feel Jane answers my question when things go wrong. I usually blame my disability for any problem. However, Jane replies, saying, "Stop blaming everything on your disability. . . . Just be a person!" So, I am no longer just a C.P. I have become a person. . . . And it's great!

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I Try to Help Other People

by William E. Tubbs

I was born with cerebral palsy on August 23, 1913, in Elizabeth, New Jersey. Nothing unusual showed up until my parents noticed that I was not creeping or crawling the way a child should and my mother had to prop me up with cushions so I could sit in a chair.

They started taking me to physicians all over New York and New Jersey. I was in St. Barnabas Hospital in Newark, and, even there, they could not tell what was wrong with me. In 1918-1919 I was in a school that had mostly mentally deficient children. They did not do any treating of my condition. They just tried to take care of me and all the rest of the children. The school had a camp near the ocean and Mother used to come and take me to the beach where we had wonderful experiences.

About 1920 I was taken to an osteopathic hospital in York, Pennsylvania. In those days the osteopathic doctors were not looked upon with great favor. It was at that hospital with Dr. Crandall that I gained the best and most effective treatment, which was later undone by a doctor in New York City.

There, at the Hospital for Joint Disease, I was put into casts by the Chief of Staff of the Medical Department. The restriction of my legs and arms did not allow me any motion and soon I got the reputation of being the worst child in my hospital ward. Then the doctor discovered that he had made a mistake and so he removed the plaster casts and gave me a course of exercises. These exercises are what is now known as physical therapy.

Meantime my father and mother had agreed to disagree. They divorced and Grandmother arranged with two great-aunts to take Mother and me as boarders. We had a lot of good times together from 1924 to 1928. When I was 15 and getting too much for Mother to handle, we looked for a place for me to stay. A friend of our family recommended Cathcart Home in Devon, Pennsylvania. I went on a six-month probationary period and we found that it fitted us perfectly.

I made many friends, became a member of Devon Boy Scout Troop 50 and went as high in rank as I could, becoming a Scout Counselor of Chester County (Chester County Council). Just recently I have become one of the Assistant Masters of the Troop. My main goal is to help boys pass their merit badges and see that they reach the rank of Eagle Badge.

In 1980, I passed my 50th year at Eliza Cathcart Home. They threw a big shindig on April 8 with a party in the chapel. Many friends came and Representative Dick Schultz sent his man from Paoli to hand deliver a special letter and medal, the Congressman's Medal of Merit, for my civic service. In addition, House of Representatives and

Senate of Commonwealth of Pennsylvania sent a citation. Devon Scout Troop 50 gave me a beautiful citation and the Ladies' Committee gave me a beautiful plant.

In February of 1981, I received another award — a plaque honoring my 51 years of service with Devon Scout Troop 50. Further, my name is on the official plaque of Devon 50's Cabin.

So, even though I'm disabled with cerebral palsy, I have the ability to use my hands and to think and talk. I manage to do things that are valuable. After all, that's all that counts — to help other people and not be a drag on anyone.

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Coping with Chronic Pain

by Marilee M. Thome

All of us have most likely experienced pain. Pain is the body's warning signal that "something is wrong," such as when we are suddenly injured, but, pain can recur chronically even when little more can be done to alleviate it, with the possible exception of drug therapy.

The experience of pain has many meanings:

Feeling It — the physical sensation, which varies in intensity for each of us, and may interrupt our thoughts or activities.

Awareness of It — being reminded of our illness or disability; being fatigued or depressed by the continuing quality of it, reducing our activities in an attempt to decrease it, etc.

Isolation of It — frequently we do not "share" our pain or let anyone else know it is occurring, because we do not want to make situations unpleasant for others, or to be a "bother," or to call attention to ourselves as "sick." Although some people with chronic pain may seem to "use" it to seek sympathy and attention, most remain silent.

Dr. Ronald Melzack of the University of Toronto, an expert in evaluating and treating chronic pain of all kinds, believes two factors contribute much to our experience of discomfort, and to its intensity:

Attention — for those with chronic, repeated pain, whether abdominal cramps, backache, nerve compression or phantom limb, paying attention to the body part where the pain is felt has been demonstrated to actually increase the experience of pain.

Expectation — watching and waiting for the pain causes us to tense up, to be "on the alert," much as we might when approaching the dentist's office to finish having a root canal done! This may happen to us when we prepare to go out, to eat, to go to bed, or at any time we associate with previous pain.

None of this is intended to say that pain is not real or not there, but is meant to suggest that our experiencing of the pain can be intensified by our attention to it, our awareness of or our concentration on it, and our expectation of its return.

It is exciting to consider the possibilities this information offers us because there are many things we can do to change or modify our attention and expectation of the pain. Whether or not we can make it disappear, we can:

1. Practice *distracting* ourselves with other pleasant activities of our choice (make a list!) to remove our attention from the discomfort and thereby decrease its significance.
2. Decide *we are in charge*, and do everything we can to manage the pain, especially with *non-pharmaceutical methods*:
 - a. Progressive relaxation exercises
 - b. Self-hypnosis
 - c. Abdominal breathing
 - d. Biofeedback
 - e. Acupuncture/akupressure
 - f. TNS — Transcutaneous Nerve Stimulation, in which small, painless electrodes are attached to painful areas of the body and are electrically stimulated. This "scrambles" the pain signals to the brain, preventing it from being received.

Any of these methods, in addition to getting a good massage, gentle swimming or sitting in a whirlpool, etc., can assist us in relaxing and avoiding the chain of events which comes with pain: *pain — tension/anxiety — more pain*. You may think of many other ways to relax, but the whole point is to de-stress yourself and increase your ability to tolerate the discomfort you do have without giving it complete control of your life and activities. The advantage of non-chemical methods of working with pain are the lack of side effects and the absence of potential for addiction found in narcotics. Pills of some kind may also be needed at times, but make it your goal to use as few chemicals as possible.

Take pride in how well you function with chronic illness or disability which makes pain and limitation; take time every day to appreciate yourself, to take stock of all that you do and all you accomplish, and make sure to do something special just for you!

TRAVEL

By Bus in a Wheelchair

by Eileen Van Alburt

When I decided to attend the *Gazette's* Post-Polio Conference in St. Louis and visit relatives around the U.S. by bus, I asked Gini to find out about the bus companies' latest policies on attendants and handling wheelchairs.

She told me that on Trailways an attendant may ride free if you have a statement from your doctor about your disability and that the drivers will help get you on and off the bus and that, on Greyhound, the attendant could also ride free with a doctor's statement but that the drivers were not allowed to touch the passengers.

My attendant, Teresa, and I rode the bus from Guadalajara to McAllen for 18 hours. Not a bad trip as we slept. In McAllen, Trailways would not give Teresa free passage because the letter was from a Mexican doctor. So I paid only to Houston and flew from there to visit relatives in Iowa and Wisconsin.

The next bus trip was from Fond du Lac to Eau Claire. In the Greyhound station, I didn't say a word about a free attendant. The clerk volunteered. So Teresa rode free and the driver lifted me into the bus.

Then we flew to Phoenix and bused to Anaheim, California, on Trailways. Here again, the clerk volunteered the information that Teresa could go free. No question about a letter from a doctor.

The drivers on our shuttle buses from our hotel to Disneyland and Knotts Berry Farm were helpful and pleasant. No problem for them to lift the chair — with me in it — into the bus. We used the wonderful city buses with lifts when we were visiting Selma Sack.

We learned that one never knows what to expect. Authorities make the rules and the clerks use their own judgment. I still think it is a good idea to keep your luggage

weight low and to not expect too much from strangers. If strangers do help, that's a special gift. Travel with a companion who can cope with the unexpected, good or bad, is a definite plus.

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Using a Respirator on Trans-Atlantic Flights

by Anne Isberg

The airlines must give you special approval long before you show up at the airport! It is important to understand the concerns of the airlines and then work out from that basis.

I use a PULSULA respirator manufactured in Denmark. It has a 24-volt, DC motor, uses 100 watts, has an input for 24 volt DC and 220 AC. This respirator has been tested for interference on aircraft radio systems.

The airplanes have power outlets but not all of them are working during the flight. Most outlets work with standard U.S. plugs. The power of the planes is 115 volt AC 400 hz and that is why the airlines don't like standard transformers as they are rated for 50-60 hz.

On recommendation from an engineer with PanAm, we purchased a Sola Power Supply rated for 120 watts at Newark Electronics. It has an input for 115 volts AC, 500-400 hz and an output of 24 volt DC.

We carry a 30-foot extension cord since the outlets that are powered during flight are usually in the First Class section.

Both PanAm and Scandinavian Airlines System (SAS) have power packs that they install for you and, although this does not cost extra, arrangements have to be made way ahead of the flight. British Caledonian has also cleared me to travel with my respirator and Sola Power Supply.

The airlines take my electric-powered wheelchair without any extra charge. They take the batteries because they are sealed marine batteries. There is not much disconnection as we have made a terminal panel that is easy to get to. The wheelchair goes in the baggage compartment. I use a small collapsible transfer chair that is folded and stored with the suitbags during flight.

Address: Miss Anne Isberg, Castbergvej 20B, 2500 Valby, Copenhagen, Denmark.



A Disneyland friend with Eileen and her attendant, Teresa.

Israel: A Dream Come True

Renah Shnaider



Cathy Creese and Renah Shnaider at the Western Wall in Israel.

Israel was the best, the most exciting trip I have ever taken. The sense of history in that glorious country is not to be believed. Almost every experience was a peak one for me. I did everything, including ride the cable car at the Masada. It was all so thrilling — a dream come true.

The only unexpected and temporarily sad event of the trip came on my third night in Israel, when I fell out of my wheelchair into the street. I broke the tibia and fibula of my right leg and was rushed to the hospital in amazing pain. The place they took me was like something out of a 1920s novel and the dialogue was in a foreign language that I couldn't understand.

Fortunately, David, my traveling companion, saw me through the ordeal with great support, love, and tenderness. Fortunately, too, the severe pain began to ease after eight hours or so, and David encouraged me to ask the doctors for a discharge after I had been there one night and one day. He felt that they had done all they could for me there, and that I would be better off back at the hotel where he could take care of me. The doctors agreed and discharged me the next day.

We had to adapt my chair so that I could keep my leg straight out, and use cabs large enough to take me extended full-length in the back seat. Yet we rejoined our tour a day earlier than we had planned, thanks largely to the encouragement of a cousin of mine, who is a doctor in Tel Aviv.

My lifestyle was different — my right leg was in a long cast and I was totally dependent on David — but that didn't deter us one bit. We did and loved everything. In fact, Israel was not hard for me to cope with because I had someone there to help me.

Address: Renah Shnaider, 350 Vernon, Apartment 101, Oakland, California 94610.

My Trip to Israel

Selma Z. Sack

I just returned from a two-week vacation to sunny, warm Israel. I was very surprised to find Israel so peaceful and quiet. I did expect to see or hear bullets and soldiers.

It took 14 hours (flying time) from New York to Israel. Gad, it was murder sitting still so long. I am glad that I have an urostomy, as getting to the bathroom on a plane is next to impossible.

The tour was from Flying Wheels. The group consisted of six wheelchairs and six pushers.

The terrain was very bad for wheelchairs. I was really worried about my wheels bending or breaking. All the streets and roads have cobblestones with rocks of all different sizes and shapes. One of the gals in our group met with an accident. The front wheel of her chair got stuck between rocks causing the chair to flip over. She fell out of her chair and broke her leg near the knee. In Tel Aviv she went to the hospital where her leg was put in a cast from toe to crotch. Cast and all, she continued on with the tour.

I arrived in sunny Ben Gurion Airport, a bit on the tired side. A van with a portable lift drove us to our hotel in Tel Aviv. This van had one English-speaking tour guide and one driver. They both stayed with us for the entire two weeks.

The next day we drove to Nes Ammin, lower Galilee, and picturesque Jerusalem. We visited many churches. (Four men had to lift each wheelchair as every building had stone steps.) We saw beautiful, old churches in Nazareth. We then drove on to see the Jewish Museum, the Holocaust Museum, a large kibbutz, the Arab market place in the Old City, Wailing Wall, Dead Sea and Olive Wood Mountain. We saw many archeological digs. We then proceeded on to Haifa, Tiberias, and Hadassah Hospital, where they have stained glass windows painted by Marc Chagall. On the roads we saw herds of camels and goats.

I am just about getting over my "jet-lag." I am glad that I went to see this interesting and historical country.

Address: Mrs. Selma Z. Sack, 1052 Redwood, Apartment #6, El Cajon, California 92020.

BOOKS

It's A Lovely Day Outside

By Pamela La Fane. Victor Gollancz Ltd., 14 Henrietta St., London WC2. 1981. 159 pp. (\$5.95) Beginning in 1939, in an England at war, Pamela La Fane chronicles her struggle to be her own person in spite of rheumatoid arthritis which kept her in institutions for nearly thirty years. From the age of eleven until she reached the age of sixteen, she was treated in children's hospitals where she continued to be educated. Then she was sent back to London to exist in a "chronic sick" hospital where "no one gets better." Here she was surrounded by aged patients and uncaring nurses. Despite these difficulties, she managed to take a correspondence course, embark on a writing career and make a number of close friends. Finally, in 1969, with help from many quarters, she was able to leave the hospital and establish a home of her own in a small apartment which seemed like a castle.

Pamela's story is amazing. The spirit, that kept her hoping when there literally was no hope, shines through in all her writing. The callousness of many of the health workers who surrounded her through those years is depressing, a discouragement offset only by those in later years who showed astounding insight and persistence in helping Pamela realize her dream.

Although at times the story can be extremely depressing, especially for those who have had similar experiences in institutions, in the end it is a testimony to the triumph of the human spirit over almost insurmountable odds.

Reviewed by Joyce Kniffen

The Making of Franklin D. Roosevelt

Triumph Over Disability. By Richard Thayer Goldberg. Abt Books, 55 Wheeler Street, Cambridge, Massachusetts 02138. 1982. 224 pp. (\$16.95) The result of an enormous amount of research, Dr. Goldberg's book is the fascinating story of FDR's encounter with polio and the effects this disease had on his life. Amassing innumerable details from letters, books and personal interviews as well as from medical records, the author shows how FDR's struggle to deny and then to accept his disability changed him as a man and a politician. He also explores FDR's development of and continued involvement with the Warm Springs Foundation and its treatment of polio patients.

The full extent of FDR's disability was kept hidden from the public as much as possible. Dr. Goldberg questions whether, in this age of television cameras, a disabled person could ever become president again. Dr. Goldberg is Director of Research for the Massachusetts Rehabilitation Commission.

Published on January 30, 1982, to coincide with the celebration of the FDR Centennial, this scholarly work is a

rewarding study of an important figure in American history. It is interesting for both historians and disabled persons.

Reviewed by Joyce Kniffen

Missing Pieces

A Chronicle of Living with a Disability by Irving Kenneth Zola. Temple University Press, Philadelphia, Pennsylvania 19122. 1982. 246 pp. (\$14.95) If William James was the philosopher who wrote like a novelist, *Missing Pieces* by Irving Kenneth Zola should be on the best seller list. The middle two-thirds of the book reads like an exciting novel. It tells of Zola's stay at Het Dorp, an experimental village for the disabled near Arnhem, Holland. How these people live and their relationship with the Administration which acts for their well-being, carries overtones of Aldous Huxley's *Brave New World*.

Are the residents really happy? Is the Administration, in fact, a sinister force which reduces them to a status of well-kept children? Is the Administration really the black knight in a game of benign domination?

Zola raises these questions, while conceding that, for the most part, Het Dorp is a success. If the questions are not so easily answered, it is because the problems of the disabled extend beyond the Village to society as a whole. Affected not least of all is the author. A sociologist who is himself disabled, Zola is on leave from Brandeis University outside Boston. He wears a leg brace and a back support and uses a cane. For his week-long residency, he forces himself to live like the others and use a manual wheelchair, no small feat on these hilly streets.

The interaction becomes more than a give and take of personal information between him and the residents, while the Administration, which he had planned to be his primary source, avoids him. With refreshing candor, Zola not only braves the exhausting streets in his wheelchair and the perplexities of his apartment, he also confronts his own prejudices and assumptions. He is chagrined to discover that he had never identified himself with the disabled, that, as one who had "made it and passed," he avoided associating with others who had not. While defending their views and sympathizing with their conditions, he ruefully admits it was always *their* views and conditions, not *his*.

The residents are like characters in a novel with feelings and emotional responses of qualitative mix. They come alive.

Sexuality is a sub-plot in the story. Zola draws a sharp point by showing that society considers it vaguely immoral for the disabled to expect sexual fulfillment. Sex is a biological drive that is suppressed in a civilized society and reserved for a proper circumstance. And the disabled are somehow relegated to the conception of impropriety.

But sexuality is only a tip of the iceberg. And, in fact,

the disabled are made invisible by keeping them off the streets, by pretending that theirs is a problem to be solved by telethons for the poor unfortunates. The world belongs to the healthy and everyone else is abnormal. Abnormal is equated with inferior. The media, for the most part, represent the disabled as people who can invariably improve through exceptional courage and extraordinary effort.

In essence, Zola is saying that debilitation is a condition we must all face at one time or another. We need to recognize and avail ourselves of the "differently abled," as Yvonne Duffy terms them in her book, *All Things are Possible*, in the same way that all people should be cherished for their human potential and because they, as well as prime physical specimens, are an inseparable part of our humanity.

Reviewed by Theodore Solomon

The Music Came From Deep Inside

A Story of Artists and Severely Handicapped Children by Junius Eddy, McGraw-Hill Book Co., 1221 Avenue of the Americas, New York, New York 10020. 179 pp. (\$16.95) They don't make good poster children. These and others described in Junius Eddy's new book are afflicted with Down's syndrome, Apert's disease, rubella, cerebral palsy, and birth damage. Most are mentally retarded, with multiple physical defects and emotional complications. According to Eddy, there are an estimated 460,000 youths who live in this "twilight world." Many live in or attend institutions where they are helped by dedicated teachers and therapists.

Milestones of progress are measured in "quarter inches or less." Toilet training, eating with a spoon, drinking with a cup, learning to say a few simple words take up much of the time. At first, it seems like an impossible task. Repetition and patience often change the prognosis to possible. The teachers are characterized by "loving toughness." But there are limits of endurance. After five or six years they are often "burned out." Many leave on sabbaticals; some return, some do not.

In 1978, the National Committee on Arts for the Handicapped began a project to improve the lives of these damaged children. Teams of artists were sent to three pilot centers to help "the last of the least," as Wendy Perks, former NCAH executive terms them. Art for the profoundly retarded? Not always in the conventional sense. Finger painting is done with chocolate pudding. Dance varies from the truly creative to scooting on the seat of the pants. Yet, response of any kind, even in quarter inches, can signify change.

Eddy reports that the artists' entry into this special world was sometimes resented by the teachers, but a fresh, invigorating air was injected. Music, dance, drama, and puppetry were cast like seeds to chance. The formal events were interspersed with improvised, highly creative approaches to stimulate the children's interest and elicit their

response. The actors dressed in costumes and mingled with the children, who were encouraged to participate — put on the king's crown, crawl into the tube-tunnel "snake," wear body paint. Small groups were the ideal arrangement. When the puppet show was over, the kids were urged to hold the soft, cuddly "animals." For some, the touchstone was music or dance; for others, glued-on blocks or newspaper dragons.

The culmination of each project was the Very Special Art Festival, a day-long "show and tell" of what the children had learned and how their lives were enhanced. The artists exploded briefly on the scene with their specialties. The teachers were inspired to continue where they left off. Was the project a success? Yes, there was some physical improvement and in self-help and affective relationship. Statistics and subjective opinion reported in this intriguing book indicated the experiment was worth continuing in the regular programs of the institutions.

Junius Eddy and Roger Vaughan were chosen to record the project, and this wonderful book is the result. Vaughan's photographs and Eddy's words, along with generous quotations of teachers, artists, and NCAH executives, form a highly readable and perceptive account of these children and the heroic efforts to improve their lives.

Reviewed by Theodore Solomon

A New Life for the Handicapped

A History of Rehabilitation in India. By Kamela V. Nimbkar. Nimbkar Rehabilitation Trust, Amerind, 15th Rd., Khar, Bombay 400052, India. 1980. 374 pp. (Rs. 40.00, \$10.00) As a history of rehabilitation in India, this account connects with rehabilitation all over the world. While mainly of interest to specialists in the field, it has a number of descriptions and anecdotes to interest general audiences.

Mrs. Nimbkar's life is detailed in only a few pages. One wishes there were more. She was an American of Quaker descent who married an Indian engineer, settled in India, and returned briefly to the U.S. to study occupational therapy. In India, she founded two schools for occupational therapy, the first of their kind in Asia, and "retired" in 1957. In fact, this marked only the broadening of her activities into the larger field of rehabilitation. She co-founded the Indian Society for Rehabilitation of the Handicapped, founded the Nimbkar Rehabilitation Trust, and the *Journal of Rehabilitation in Asia*. She worked for years as editor of the *Journal*, served on numerous boards and commissions, and participated in conferences and workshops throughout the world. Mrs. Nimbkar died at the age of 79, shortly before the completion of this history.

One marvels at the dedication of this woman and the individuals (many of whom are delineated here, including Gini and Joe Laurie) who have devoted their lives to help-

ing the disabled through education, occupational therapy, physiotherapy, employment, prosthetic/orthotic devices, and other services. This is a never-ending struggle to engage the interest and financial resources of countless people in government and private life.

Reviewed by Theodore Solomon

Ordinary Lives

Voices of Disability and Disease. Edited by Irving Kenneth Zola. Apple-wood Books. Cambridge/Watertown, Massachusetts 02139. 1982. 221 pp. (\$12.95) Before they can begin she has to tell him: empty the catheter bag, lift her from the wheelchair onto the bed, undress her. "Don't be afraid," she reassures him. "I won't break." Then, he has to tell her what he is doing because she must visualize; she cannot feel. It is a strange sort of lovemaking: only kissing and touching and hugging. But is it really so strange? Are the passionate undulations of the movies and books any less artifice than braces and catheters?

Neither sex-hyped heroic characters nor people in all walks of life comprise the entire cast. There are those who live by the sound of a different drummer: for example, the ones who do not march or walk or hear. Irving Kenneth Zola's collection of stories, essays, and poetry relates how people with disability and disease manage their lives "with no battles won or lost."



Irving Kenneth Zola, Ph.D., of Brandeis University, author of *Missing Pieces and Ordinary Lives*.

The theme that runs through all these stories is one of search and discovery, learning and adjustment to life with a disability.

Disability does not signify decay or incompetence or inferiority, but quite simply the inability to perform in a cer-

tain conventional manner — not precluding performance — but, with the ingenuity that marks *Homo sapiens*, performance in a different and often better way.

This collection is a story that needs to be told to all people who take courage by the courage of others, but who should also realize that strength lies in knowing the worst as well as the best. And what it means to be different.

Reviewed by Theodore Solomon

Parkinson's: A Patient's View

By Sidney Dorros. Seven Locks Press, Inc., P.O. Box 72, Cabin John, Maryland 20818. 1981. 220 pp. (Cloth \$14.95, paper \$9.95, plus \$1.50 postage/mailling.) This is probably the best, the most revealing insight on Parkinsonism, the chronic and conceivably incurable neurological ailment that, at any given moment, lies in wait in the genes of over 500,000 American men and women as they approach their 60s.

Various identified by palsied hands, shuffling feet, muscle-rigidity spells and the soul-tremors of depression, Parkinsonism was theoretically isolated from historic "trembling palsy" in 1817. But it has been pointedly addressed by medical and pharmacological science for only the past 20-odd years.

The unique value of Dr. Dorros' book arises from its being the work of a former career publications executive with the National Education Association who — progressively slowed by the disorder which began at age 36 and forced by this into early retirement — was for 12 years a key "experimental patient" at the National Institutes of Health. There all the major treatments contrived for Parkinson's since 1961 were tested on him.

Determinedly active today in helping promote regional mutual-support groups for fellow Parkinsonians, Dr. Dorros found that his physical impairments stretched the writing of these highly personal pages into an eight-year project.

His account, reporting his triple traverse of extremes of bodily incapacitation and stark depression, includes the conjecture that his Parkinson's onset at age 36 may have been due to the stresses of his excessive zeal for NEA promotion . . . to the extent of his being an admitted workaholic.

So here we have, well told, the Dorros discoveries in Parkinson's Land, largely a terra incognita before 1960. He has not only been there but has also returned with intellect unimpaired . . . and a knack of conveying to the concerned reader the contours of that territory, its lows and its highs.

There is no obscuring cloak of martyrdom. Rather, Dr. (D.Ed.) Dorros reveals a wonderfully objective sense of perspective . . . which is, at the same time, to be as admired as a blessed sense of humor.

It all serves to qualify his book as a sure claimant for the eyes and hands of every prudent, maturing, rank-and-file and literate person in America. It's not only that, but also a key resource for every informed pastoral counselor, family physician, neurologist, therapist and psychiatrist . . . or the concerned and puzzled relative of any one of us uncoun-
tained, patient Parkinsonians. For the too-resolute "closet Parkin-

sonian," it could be quite invaluable.

Further, the author of this book's obvious companion-volume, Dr. Roger C. Duvoisin's *Parkinson's Disease: A Guide for Patient and Family* (Raven Press, 1140 Avenue of the Americas, New York, New York 10036, 1978.) provided Dr. Dorros with "encouraging comments and suggestions upon reading the manuscript at two different stages." Dr. Duvoisin rates as one of the nation's top neurologists, as well as being endowed with clarity of reportage.

Reviewed by W. Danforth Hayes

Serving Physically Disabled People

An Information Handbook for All Librarians. By Ruth A. Velleman. R.R. Bowker Company, 1800 Avenue of the Americas, New York, New York 10036. 1979. 392 pp. (\$17.50) This book is an attempt to bring together in one volume some basic information about the needs, in regard to library services, of persons having different disabilities. The author gives some facts that should help librarians make their services more accessible to the disabled population as well as enable librarians to assist this group in finding information about other needed services.

Well organized, clearly written and well annotated, this volume is of interest primarily to librarians but could be useful to anyone interested in the needs of the disabled population, especially someone doing research in this field.

Reviewed by Joyce Kniffen

The Unexpected Minority

Handicapped Children in America. By John Gliedman & William Roth, for the Carnegie Council on Children. Harcourt Brace Jovanovich, Inc., 757 Third Ave., New York, New York 10017, 1980. 525 pp. (\$17.95) This is a study of handicapped children in relationship to society as a whole. The authors compare the handicapped with racial minorities. They also compare them with normal children in their social, personality, and intellectual development. They attempt to show that, while all children go through difficult periods of growth, the handicapped are often stunted by the dichotomy between the home, where they are loved and protected, and outside, where they are reviled. In education and medical treatment, they are often considered objects without feelings or personalities. Reference is made to the doctor/patient relationship in which the patient must obey without question the all-knowing technician. Educationists often perpetuate the status of the handicapped by emphasizing training that will lead to positions inferior to their potential.

Discrimination is cited in diagnostic procedures and evaluation. All disabled job seekers are painfully aware of employers who refuse to hire them, not for lack of ability, but because they do not want them in sight, although this reason is rarely given.

The designation "handicapped" covers a wide latitude of physical and mental disorders, and it is impossible to fit all into convenient categories. The authors stress the need for further research and classification. Every effort should be

made, including legal coercion, to raise the handicapped to their highest potential for humane reasons and so that they can make their valuable contributions to the social and economic fabric of society.

Reviewed by Theodore Solomon

Book Reviewers

William Danforth Hayes . . . B.A. cum laude Amherst College 1931 . . . graduate study Harvard 1937-38 . . . news staffs and desks of three New England dailies . . . retired 1976 from Worcester Telegram . . . Colorado native . . . married 1939 . . . four children, ten grandchildren . . . member Scottish Rite Masons, Appalachian Mountain Club . . . baritone, hike leader, traveler . . . to Scotland for "roots search," to Ireland as Friendship Force goodwill ambassadors . . . activity limited by Parkinson's Syndrome. Address: 40 Romola Road, Worcester, Massachusetts 01605.

Joyce Kniffen has been quadriplegic from polio since 1959. She received a B.S.Ed. degree in 1975 from Abilene Christian University and she has begun work on her master's. She is a teacher and head of the academic department of The Bridge in Abilene. Address: Route 2, Box 45, Clyde Texas 79510.

Theodore Solomon contracted polio in 1930 when he was a year old. He uses braces and crutches and has a hearing loss. He spent three years at the University of Toledo, made a brief sojourn to California and Nevada, then returned to Toledo where he is employed as a clerical supervisor by the Ohio Department of Public Welfare. He enjoys reading, writing, amateur acting, and chess. Address: 2023 Marlow Road, Toledo, Ohio 43613.



Theodore Solomon, Gazette book reviewer.

Friends Around The World

"As a physical therapist with practice in São Paulo, I am interested in receiving pertinent literature concerning disabilities that require wheelchairs and other aids, as well as their possible adaptations for home usage." *Marli Viotti, Rua Jeronimo da Veiga 428-42, São Paulo S.P., Brazil 04536.*

"I safely returned home, after a week stay with Ed Roberts. I enjoyed very much meeting you *Gazette* people. Thanks to Tanner Chrisler for showing me St. Louis. Besides, I learned a lot about the American way of doing. *Nao Ishizaka, Kanouzan, Jishsudai, Fetsu, Chiba, 299-16, Japan.*



(L to R) Akiko Saito, Gini Laurie, and Nao Ishizaka. Nao, a Japanese advocate for the disabled, visiting the Lauries in St. Louis.

"I am certain that the Post-Polio Conference was successful. I was unable to attend, for I was invited to give a talk at the Asia-Pacific Rehabilitation Conference in Kuala Lumpur shortly before the St. Louis meeting. My opinion as regards the emerging roles for the disabled person was well received there. . . . I am looking forward to a day when I can make a trip to the States with my attendants to visit you and express my gratitude in person. I am also happy to tell you that the support was finally found for publishing the next *Rehabilitation Gazette* in Japanese. The Showa Ikeda Memorial Fund will aid us for half of the expense and Tokyo Colony the remainder." *Masao Nagai, M.D., 29 Kitamachi, Shinjuku-Ku, Tokyo 162, Japan.*

"Tahanang Walang Hagdanan (TWH) provides rehabilitation and training for paraplegics and other severely disabled people. In addition to its live-in transition center in Manila, TWH has started regional group living arrangements. . . .



William Norcio and Rosa Licliocan, residents of Sinag-Tala Cheshire Home in Manila, Philippines.

Two of our people, who are residents of Sinag-Tala Cheshire Homes, are pictured above. William Norcio was left abandoned in the National Orthopedic Hospital and became one of the first Cheshire Home residents in 1966. Rose Licliocan is disabled by muscular dystrophy. She and the other residents make sewing kits for big hotels, rag dolls, and other hand-crafted items." *Sister M. Valeriana Baerts, ICM, Tahanang Walang Hagdanan, Inc., P.O. Box 3565, Manila, Philippines.*

"I got your address from the GIHP bureau in Paris . . . I am deeply interested in magazines dealing with the problems of disabled peoples . . . I am a medical doctor and I'm 34 years old. I am a specialist in internal diseases but I am interested in rehabilitation as I am afflicted by polio paresis of my leg . . . I would like to correspond in either English or French." *Joanna Scieszka, ul. Sowinskiego 19/13, 40-022 Katowice, Poland.*

"I am a physically disabled writing from West Malaysia. I came across clapping my eyes on *Rehabilitation Gazette* magazine. Please kindly rush me with appropriate information." *L. Alages Varan, 123, Buntong Satu, Sg. Part Road, Teluk Krui, Ipoh, Perak, West Malaysia.*

"I am a quadriplegic because of a diving accident in 1964 when I was 23 years old. I was in various hospitals and now

I am living at a Cheshire Home in South Africa . . . I have an electric wheelchair which I operate with my usable arm. I learned to use my mouth to make model ships and aeroplanes. I have various instruments and tools to use with my mouth. I also play my tape recorder when I'm in my wheelchair by using surgical forceps to lift the tapes and put them in the recorder. . . . I am taking lessons in art and would like to correspond with another artist. . . . I hope someone can help me obtain a certain model aeroplane. It is a tri-pacer, a plastic assembling model, with a 1/72 or 24th scale." *Mr. Melly Willmans, Summerstrand Cheshire Home, P.O. Box 13148, Humewood 6013, Port Elizabeth, South Africa.* "I am in the process of compiling a 'Where to Find Assistance' info sheet for disabled persons in my area. I would appreciate it if organizations of the disabled would forward their publications and related information to help us obtain services for disabled persons in my community." *A. Perumal, Physical Planning Committee, Goldsteps Training Centre, Private Bag X29, Tongaat, South Africa.*

"We have a fully accessible bungalow in North Wales that will sleep a family of six. It is available for rent by the week. Write to us for a free brochure and details." *Tom and Lynne Dowling, 27 Mappas Road, Great Sutton, South Wind L65 7BQ, Wales.*

"I am a quad, 27 years old, 6 ft, 165 lbs, male. I get very lonely. All my friends have married and moved away. My Mom would like to write to mothers. We both get very depressed." *Terrey Better, 7791 Denise Cr, La Palma, California 90623.*

I am disabled for 9 years as a result of a stroke after the birth of my youngest son. I have no use of my left arm and the stroke also left me legally blind. I am 39 years old, a widow of 4 years, and I have 4 children, ranging in age from 9 to 18. I enjoy reading, arts, crafts, and music . . . After my husband's death, I managed our apartment from a wheelchair. Then about a year ago I entered a nursing home. . . . I want to live independently in the community and I would like to be in touch with other stroke people who have gone on to lead productive lives." *Jackie Melvin, 5025 McCook Avenue, East Chicago, Indiana 46312.*

"I am 25 years old and I have cerebral palsy. . . . I am very interested in corresponding with disabled people from other parts of the world. . . . I do not like to think of myself as disabled. So many people ask me if I would like to walk. Strange as it may seem, it scares me when I think of walking. Although my body is disabled, my mind and heart are very much alive and healthy. I love all people. I have adjusted to my way of life." *Shawn Nevins, Oak Forest Hospital, 159th Cicero, Oak Forest, Illinois 60452.*

"I enjoy your magazine very much . . . I have had cerebral palsy since 1945. I had speech therapy but it did not help much. I can say some words but not clearly. I can type. I help the Spinal Cord Injury Club and I work for the rights of disabled persons. I get talking books on cassettes." *Larry Murphy, Holiday Home Health Care Community, 1201 West Buena Vista, Evansville, Indiana 47710.*

"I have written to Guy Papelard (1980 Gazette) to let him know that I would love to work with him on this side of the Atlantic in organizing an exchange program between American and French disabled persons and that disabled French visitors are welcome to 59 Tahattawan Road." *M.E. Fol, Ph.D., 59 Tahattawan Road, Littleton, Massachusetts 01460.*

"I enjoy gardening, camping, fishing, music, creative writing, art, crocheting, and sewing (make all my own clothes). I would like to meet a nice disabled man, age 50 to 60. I would relocate for Mr. Right or he could live with me in my residence. I am a very decent, respectable, warm, loving, slim woman. I am blonde with blue-green eyes and I'm considered pretty." *Roberta Carpenter, Apt 121, 27727 Michigan Avenue, Inkster, Michigan 48141.*

"I am a paraplegic (T12). I've been in a wheelchair for a year and a half. . . . I would like to hear from other disabled people. I want to work as a counselor but I don't know how to go about it. Maybe by writing to other people I can find the way." *Judy Baños, 1900 West Church, Apt #20, Carlsbad, New Mexico 88220.*

"People think we are freaks. We are not. My legs are in full braces. My spine was broken in an auto accident a year ago. I am on crutches and have a wheelchair. . . . I'm very lonesome and I'd like to write to other disabled people, both amputees and spinal injuries." *J. Cannon, #504, 3280 Nostrand Avenue, Brooklyn, New York 11229.*

"I am a registered nurse and have had multiple sclerosis for about four years. . . . Fred and I were married after I discovered I had MS. . . . I have produced a tape that deals with emotional-psychological aspects of coping with MS. The title is 'MS — Why Me?' and I sell it for \$9.95. I also offer counseling services to individuals with MS by cassette." *Carole Dandino, 31 St. Anthony Lane, Scotia, New York 12302.*

"I am a bilateral amputee and I work extensively with the disabled. . . . I am an oncology counselor and involved in grief and loss training for professionals, paraprofessionals, and significant others." *Joy Carr, 747 N. 135th, Suite 103-B, Seattle, Washington 98133.*

EQUIPMENT/READERS' IDEAS

by Joe Laurie

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.

Communication

Using a Microfilm Viewer as a Reading and Reference Device

by John Dalhaus

In August of 1981, my wife's eighteen-year-old brother, Mike VonAlst, broke his neck in a diving accident. The (C-4) spinal cord injury resulted in paralysis from the neck down. Since his accident, I have been developing devices for Mike's use. Being involved in the micrographics industry, I decided to look for a microfilm viewer to adapt for his use. This effort was successful. I would like to share what we've learned with *Gazette* readers.

WHAT IS A MICROFILM VIEWER? A microfilm viewer (also known as a roll-film reader) is a device for viewing 16mm microfilm, one frame at a time. Roll-film readers accept 100-foot rolls of film, and are either motorized, or operate via a crank. The most common roll-film readers contain a viewing screen approximately 12 inches high, by 12 inches wide. On film, the original page was reduced 24X by a microfilm camera. The microfilm viewer enlarges the microfilmed image to its original size. Their ease of operation makes roll-film readers ideal for use by the physically handicapped. Without modifications, most readers can be operated by advancing and rewinding the film reels using a mouthstick. I am in the process of modifying a motorized reader for sip-puff operation. This will include forward and reverse operation via one tube, and fast forward and reverse with another tube.



Mike VonAlst uses his mouthstick to advance to the next page on film. Used roll-film viewers such as this are reasonably priced.

Another advantage of a roll-film reader is the quantity of information easily accessible. One 100-foot roll of microfilm can contain more than 3,000 pages (8½" by 11") of reading and reference material. The user can have quick access to phone numbers, addresses, lists, and an entire dictionary on a single reel. A student can have text and reference material on film for study at home. A telephone solicitor can have product information and client lists easily accessible. The system is not ideally suited for information requiring frequent updating. However, microfilm can be cut and spliced to add and remove selections. For the user requiring quick access to more information than available on a single 100-foot roll, at least one manufacturer of readers offers a 1,000-foot reel attachment. Also available are portable readers that open and close like a briefcase.

Microfilm readers can also be used by the visually impaired. By the proper selection of a reader lens, magnification of the image is achieved.

COST OF MACHINES AND FILM. New 16mm roll-film readers start at about \$400 for a non-motorized version. However, used machines can be found for about \$75 and up. The National Micrographics Association can provide a list of companies dealing in new and used equipment.

For custom filming of printed materials, check the yellow pages listings under "Microfilming." Costs can vary, and are dependent on the size of the job, and the quality of the material to be filmed.

University Microfilms International offers over 1,100 popular, currently published journals on microfilm at a nominal cost. As an example, "Better Homes and Gardens," from January 1981 through December 1981, is available for \$16.90.

Microforms International Marketing Corporation lists rare and unusual collections on microfilm.

I am able to film a limited amount of material through the generosity of micrographic equipment owners.

The readers also provide the user with a possible source of employment while at home. This involves viewing microfilm to detect errors occurring during filming or processing. (See page 46 of the 1971 *Rehabilitation Gazette* for additional information.)

SUMMARY. Roll-film readers provide quick and easy access to thousands of pages of printed material. Readers and filmed materials are available at affordable prices. A machine can be used "as-is," or modified as required by the user. Materials on microfilm can be tailored to the users' study, business, and leisure requirements.

I would like to hear from those interested in using roll-film readers. Perhaps a group of users could be formed to exchange filmed materials and ideas.

ADDITIONAL INFORMATION. John Dalhaus, 2815 Orchid Court, Highland, Illinois 62249. Mike VonAlst, 790 North Walnut Street, Breese, Illinois 62230. National Micrographics Association, Services to the Handicapped Committee, 8719 Colesville Road, Silver Spring, Maryland 20901. University Microfilms International, 300 North Zeeb Road, Ann Arbor, Michigan 48106. Microforms International Marketing, Fairview Park, Elmsford, New York 10523.

REHABILITATION GAZETTE ON MICROFILM. I put every issue of the *Gazette* on microfilm for Mike and he found them an invaluable source of information on adapting to severe disability. He was especially interested in the personal accounts of other disabled persons and in the many ideas for mouthsticks and remote controls.

If a library or an individual would like to have the whole 25 years of the *Gazette* on one tape, it can be purchased from Gazette International Networking Institute, 4502 Maryland Avenue, St. Louis, Missouri 63108, for \$50. On the tape are all the rare out-of-print *Toomey* j's, as well as the latest issues.

They are available on one 100-foot reel or cartridge. Positive or negative mode optional. (They are not available on microfiche at this time.)

If a library is interested in having individual issues on microfilm, please send your request to University Microfilms International, 300 North Zeeb Road, Ann Arbor, Michigan 48106.

Text Generating System by John Dalhaus

I have developed a system which allows a physically disabled person to generate, display, edit, and print out text. Unlike other text generating systems, the device is small (8" x 8" x 5"), and simple to set up and use. The device is ready for use as soon as power is switched on. It can be powered by the 110-volt wall adaptor or from the DC voltage available from an electric wheelchair. The printer may be connected and disconnected easily.

Input to the device can be any type of switch that the user can operate. An advantage of the single-switch system over the use of a mouthstick is that an arrangement such as a breath-operated switch causes less fatigue.



Mike VonAlst's breath-operated text generating system.

The predecessor to this device was a regional award winning system in the Johns Hopkins First National Search for Applications of Personal Computing to Aid the Handicapped contest. Details of the system are available from John Dalhaus, 2815 Orchid Court, Highland, Illinois 62249.

The Story of Blissymbols: A New Language By Fred McMurray

A new method of communication for severely disabled persons was researched, established, and promoted by a remarkable Canadian woman, Shirley McNaughton.

Before 1971, Shirley McNaughton was a quiet, sedentary Ontario school teacher. She was relatively unknown and led a sedate life with her environmentalist husband and two small sons. And was untraveled. "I'd never seen Ontario let alone the rest of the world!"

After the early 70s, life for Shirley McNaughton became frenetically hectic. She's still married to the same man and her two sons are now at university. But she has become one of the most sought-after educators in the world of disabled education. She's in constant global demand and travels year-round conducting seminars and giving lectures.

The story of Blissymbols, as McNaughton tells it, is mundane. With a Gallic shrug she will say there's nothing to it.

Shirley McNaughton graduated from the University of Toronto in 1953 with an honors degree in psychology. The

next few years were spent as a personnel representative for Simpson-Sears, running a nursery school in Brampton and teaching music in the Carl Orff 'Music for Children' system. She has a music degree. This was followed by three years of kindergarten work.

In 1968, Shirley McNaughton became a teacher at the Ontario Crippled Children's Center. During 1971 she began to teach children with non-functional speech habits. "I'd had a fair amount of activity in this field before 1971 but it was all reception. The children couldn't speak to me. Communication was one sided. They would indicate responses with eye signals. We had to guess their wishes by question and answer methods. It was frustrating."

The pupils were cerebral palsy patients who spent their lives in wheel chairs. They couldn't talk.

Cerebral palsy is a condition in which brain damage affects motor functioning of the body. In 8% of cases inability to speak is added to walking impairment and limited head and hand control. The effect on a child can be devastating.

In the fall of 1971 Shirley McNaughton became frustrated by the inadequate teaching methods then used with severely disabled children. She requested and received time off from teaching duties to find or develop a new method. An advisory team was formed. This consisted of two teachers, a rehabilitation engineer, a speech pathologist and a psychologist.

The hunt was on for a new teaching technique.

The evaluation team held meetings each Friday to sift through findings. They quickly decided to make their own symbol system.

For help they obtained Elizabeth Helfman's book, *Signs and Symbols Around the World*. Mrs. Helfman referred to another book, *Semantography*, by one Charles Bliss. This obscure volume, said Mrs. Helfman, contained a symbol system created by Bliss.

A pamphlet written by Bliss was located, but a lengthy search for the book was fruitless until a single copy was found at Laurentian University in Sudbury, Ontario.

To Shirley McNaughton it was like a shaft of light in the dark. "We instinctively knew our search was over. We had found the answer to our problem. It was an intensely emotional moment."

A word ought to be said about Charles Bliss. By all accounts Bliss, who now resides in Australia, is a most unusual person.

Charles Bliss was born in Austria of the imperial Hapsburgs during the closing years of the last century. He graduated as a chemical engineer in Vienna. Then Hitler annexed Austria in 1938 and interrupted a successful career. Charles Bliss found himself in a Nazi concentration camp because of his Jewish faith but was fortunately and unexpectedly released in 1939.

He wanted to get his wife away from war-rumoured Europe and they journeyed to China. There Charles Bliss became fascinated by the centuries-old Chinese symbol language. He dreamed of developing a universal symbol

system based on the Chinese model. A book on the subject, *Semantography*, was completed.

At the conclusion of World War II, the couple settled in Australia and he set about finding a publisher for the book. This, alas, took three years and even after publication the book appeared destined to be buried in obscurity. That is, until 1971, when Shirley McNaughton rescued it from the dim recesses of Laurentian University for a purpose never dreamed of by Charles Bliss.

Charles Bliss gave permission to the Ontario Crippled Children's Center for the use of his symbols in teaching the disabled. In his honour the new method was to be known as 'Blissymbols.'

Work was begun. A 60 by 50 centimeter display tray with symbols displayed thereon was designed. The tray was 400 brightly colored symbols arranged in rows. These depict different facets of life experience. Nouns are yellow, verbs green, conjunctions white, and adjectives blue. The students point to the symbols which express their thoughts. The messages are readily understood. A major advantage of Blissymbols is that ability to read is not required. Only symbols are necessary for communication.

Severely disabled students who cannot use their hands have technical aids to help them use the charts. These include levers, knobs, touch plates, and joy sticks. Coding systems are employed by which eyes, hands or feet can indicate symbols.

After the forming of the symbols chart came the problem of implementation. Barbara Royds, an OCCC colleague, recalls: "Shirley had a child for almost a year in a basement room teaching him the Blissymbols. We were skeptical but results were astounding. She's a genius for what she has done for the children."

Results were astounding. What Shirley McNaughton had done was to revolutionize the teaching of the severely disabled. Using Blissymbols, she had developed a method of teaching that would discover in these children high intelligence, ameliorate social relationships, and make lives inestimably happier. Parents would discover in their children hidden talents and experience much less frustration in coping with their inevitable moodiness.

Shirley McNaughton gave them hope.

Workshops for local instructors began in Toronto. Then commenced on a regular basis for teachers, speech pathologists, and therapists from around the world. Every spring, summer and fall they come for four-day workshops and seminars from across Canada, every state in the U.S., Sweden, Germany, the United Kingdom (there are now 1,600 qualified instructors there), Trinidad, New Zealand, and the rest of the 52 countries which correspond with the Blissymbols Institute.

Shirley McNaughton, who had not even explored her native Ontario before 1971, now travels and lectures and promotes Blissymbols in almost every country of the free world.

Address: Fred McMurray, 39 Randolph road, Toronto, Ontario M4G 3R8, Canada.

REHABILITATION WORLD

Summer 1983 issue is devoted to "Communications Aids for People with Speech Impairments." It is an excellent means of catching up on the latest developments in the field. Individual subscriptions are \$25 year. Write to Circulation Dept., *Rehabilitation/WORLD*, 1123 Broadway, New York, New York 10010.

COMMUNICATION OUTLOOK

Another important publication that tracks developments in the field of communication enhancement. Quarterly. \$12 year. *Communication Outlook, Artificial Language Laboratory, Computer Science Department, Michigan State University, East Lansing, Michigan 48824.*

MINISPEAK

A versatile, humorous language system that can be used by all educational levels. An information and storage system based on logical concepts and symbols. Lightweight. Portable. *Prentke-Romich Company, 8769 Township Road 513, Shreve, Ohio 44676.* Request the catalog of their other products.

TELEPHONE AIDS & SERVICES

The Touch-a-matic 12 Dialer will dial any of 12 frequently called or emergency numbers with just a touch on a button. Numbers can be changed as you wish. Works with any desk model rotary or push button phone equipped with modular plug-in. Check with the Phone Store or your local telephone company. Also, ask for the latest booklet on aids and services.

TACTILE COMMUNICATOR

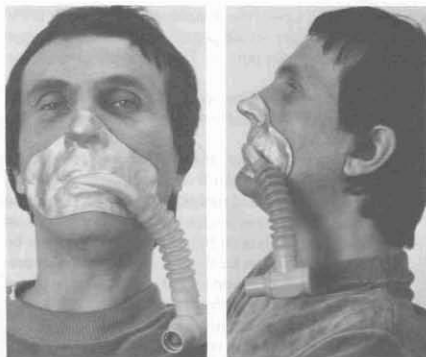
Designed for persons who are deaf and deaf-blind. It transmits information such as a doorbell, TTY, telephone ring, a fire alarm, and a smoke detector. Basically a radio paging system, it consists of a small portable receiver that can be put under a pillow or worn on a belt or in a pocket, and a transmitter that transmits a vibratory sensation that can be felt in the receiver. About \$300 from *Herb Cohen-Research Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, New York 11050.*

Respirators/Ventilators

Go Positive With Face Mask and Mouthpiece

by *Adolf D. Ratzka, Ph.D.*

When you don't get enough air with your negative pressure equipment and/or its bulk weighs down your high-flying dreams of mobility, it is time to look into using a small and quiet, positive pressure ventilator. In many parts of the world, however, night-time positive pressure use is known only via trachea and that is a price not many are prepared to pay. It is only in the U.S. apparently that people sleep with positive pressure using mouthpieces. If one has not been



Early prototype of the Ratzka face mask and mouthpiece.

using a mouthpiece for day-time ventilation over years, however, it will be very difficult to switch to positive pressure sleep. About 4 years ago I tried. After months of too little sleep, I gave up and started to look into face masks and different types of mouthpieces. The mask and mouthpiece shown here are only prototypes and leave a lot to be desired. I know of several persons who work along the same lines and there must be many more. In St. Louis we were three showing our contraptions, next time I hope we will be more.

FACE MASK. There is a whole flora of masks used in connection with anaesthesia and intensive care. I must have tried about a dozen but none really worked. Usually, in order to get enough air down my lungs without noisy air leaks that kept me awake, I had to tighten the head gear so hard that I developed pressure sores on the bony areas of my nose. Adaptions, for example, from fitted pieces of dental acrylic to protect these areas were not satisfactory, since they got displaced when I moved my head during sleep. I also tried industrial and diving full-face masks. I have an industrial mask that I can sleep with for about a week before a pressure sore develops on my forehead.

The mask shown here is made of plastic, foam rubber padding, and soft chamois leather. The purpose of the leather is to provide a seal against the skin as the pressure builds up inside the mask during inhalation. I have slept with the mask several weeks at a time, but it still does not seal sufficiently without too much pressure on my face.

(The work on the mask is supported by a grant from the German foundation Stiftung für Bildung und Behindertenförderung, Stuttgart, to my friend Ernst Hörmann who built it.)

EXTENDED MOUTHPIECE. The purpose of the extended mouthpiece is to try to eliminate some of the drawbacks of standard mouthpieces. Referring to Dr. Augusta Alba's article in this Journal (Vol 24, 1982) and her presentations in

Chicago and St. Louis, the disadvantages of mouth IPPV sleep with standard mouthpieces such as the Bennett Lipseal or the angular pipe by Thompson seem to be the following:

- The method depends on a conditioned reflex where the sleeper tightens jaws and lips and closes the soft palate to prevent air leakage.
- Those who do not learn to close the soft palate need some type of nose clip which can cause pressure sores.
- Persons using standard mouthpieces for sleep must be free of heavy sedation and/or alcohol at bedtime, must not have high levels of carbon dioxide, and must not be acutely ill. The reason for these contraindications is presumably the risk of dropping the mouthpiece or of not closing mouth or nose without waking up.
- In order to compensate for leakage through mouth and nose, high air volume is required. Some of the smaller portable volume ventilators may not deliver enough air at one stroke. Pressure ventilators, on the other hand, use more energy (which matters if you run the unit off a battery) and tend to be less reliable. High air flows can cause air to be blown into the stomach.
- Since so many factors affect air leakage, it seems likely that the amount of air that does reach the lungs can undergo variations during the night which would affect the level of blood gases. By the same token, the constant automatic adjustments required by the sleeper to maintain a certain air intake will probably affect the quality of sleep. (For that reason comparisons of the various ventilation methods should include monitoring blood gases and the relevant brain waves.)

An improvement over the available standard mouthpieces would then have to have the following properties:

- The unit must not fall out of the sleeper's mouth.
- No conditioned reflex should be required to seal off mouth and nose.
- Air leakage should be negligible.

After some preliminary testing the extended mouthpiece shown here seems to meet these requirements. The unit cannot fall out of the sleeper's mouth, since it is firmly secured to the teeth of both jaws by the dental piece. The teeth are imbedded in the form-fitted dental piece about halfway up to the gums which allows the user to remove the mouthpiece without using his or her hands and precludes involuntary loss of the mouthpiece. The guard around lips, cheeks, and part of the nose prevents air leaks. As the pressure builds up inside the mouth during inhalation, the lips are pressed against the guard and form an effective seal. The same happens to the sides of the nose. There is a slight air leak at this point but I do not experience it as a problem, since the leak does not make a noise nor does the air draft bother my eyes. One way to reduce the leak at this point is to increase the pressure of the sides of the nose against the guard. This is accomplished by building up the inside of the guard at these points by one or two millimeters. The guard also prevents the cheeks from being blown up — what might be called the Satchmo effect.

CONSTRUCTION OF EXTENDED MOUTHPIECE. The dental piece is made of 2 mm hard dental acrylic. It consists of two horseshoe-formed pieces which have been cast after the user's upper and lower jaw teeth. Such pieces are normally used to prevent somebody from grinding his teeth. The two pieces are fused together leaving a gap at front for air intake which is about 3 mm high and extends across the incisors up to and including the canines. For proper fit and positioning of the jaws it is probably best to leave the construction of the dental piece to a dental technician.

For building the rest you need plaster of Paris, two-component dental acrylic available from a dental lab supplier, and a modified pressure cooker for hardening the acrylic (polymerization). We replaced the cooker's safety valve by a regular bicycle tube valve for that purpose. The material is hardened while still on the plaster form (to prevent it from getting warped) in the cooker at a water temperature of some 40 to 50°C and approximately 2.5 kg air pressure. One of the advantages of dental acrylic is that you can add it and harden it as often as necessary.

To make the connecting piece for the flex hose you need first a wax core as shown in the drawing. The wide end of the core is flattened and fills up the gap in the dental piece. Cover the wax with 2 mm thick two-component acrylic paste and harden it. A safe way to remove the wax is to dissolve it with Toluene.

The guard is also made of dental acrylic by pasting an about 3 mm thick layer of acrylic onto a plaster of Paris positive of the lower part of your face. Leave a hole for the connecting piece. Since acrylic will tire with time, one way of insuring the guard's proper fit around the cheeks is to imbed a pre-bent flat piece of metal into the acrylic.

The two parts of the mouthpiece can now be fused. Put the dental piece and the guard in their proper position. To secure them in this position use plaster of Paris. After the plaster has hardened, remove mouthpiece from mouth and fuse guard to connecting piece with acrylic paste.

If the diameter of the connecting piece is too small or the gap in the dental piece too narrow, there will be problems with using an on-line active humidifier: back pressure will build up in the humidifier and the valve will not function during exhalation.

FUTURE DIRECTIONS. For a more natural way of breathing one could conceivably have the air stream enter both mouth and nose. This might be done by adding two small tubes onto the outside of the guard where they run up from the flex tube to the nostrils. In fact, the ideal solution might be to have some mechanism built in by which the user can distribute the air flow between mouth and nose.

(My friend Mike Crisp, who did most of the work, and I received support for the extended mouthpiece from the Swedish Association of Traffic and Polio Injured.)

Adolf D. Ratzka, Ph.D. (respiratory polio quad) has been disabled since he was a teenager in Bavaria. He graduated from the University of California at Los Angeles and received his Ph.D. at the University of Sweden. He is a Research Economist, Royal Institute

Learning to Use a Portable Volume Ventilator by Paul K. Longmore

For the last twenty years I had used a negative pressure respirator with a grid and wrap. Aside from being extremely uncomfortable, it seemed to be accelerating the stiffening of my rib cage. Year by year I had to turn the pressure up in order to be sufficiently ventilated. The only alternative, one that I feared, was trach positive. Thus, when Rancho Liaison Nurse Bill Prentice talked to me about another alternative, a mouthseal with a portable volume ventilator (during sleeping hours), I was eager to try it.

Following several sessions with an orthotist to adapt a leak-proof headgear, I went to Rancho as an in-patient so that the volume of air I required could be determined. Monitoring the level of CO₂ so that it would be neither too high nor too low, the pulmonary staff determined the proper adjustments of volume and pressure on a Lifecare Portable Volume Ventilator (PVV). At first the amount of air I was getting seemed uncomfortably low, but the machine measuring my CO₂ indicated that I was getting plenty of air. Bill Prentice and Dr. Harry Rice suggested that the volume seemed insufficient simply because I was used to a positive pressure respirator that pushed the air forcefully into my lungs. In time, they assured me, I would adjust to sleeping with a respirator that relies on volume rather than pressure.

Indeed, it took me about a month to adjust to the new equipment. This was not only because of the difference between volume and a pressure ventilator, but also because I changed the way I lie in bed. Without the uncomfortable grid and wrap, I no longer have to sleep on my back. Once again I can sleep comfortably on my side and move around much more easily.

Other adjustments also had to be made. The mouthpiece causes moisture to collect on my lips. My lips became chapped within a couple of days. Also the straps, especially where the snaps are attached, chafed against the side of my face. Dry red blotches began to appear there. I have solved both of these problems by smearing vaseline on my cheeks and lips at night and using a skin moisturizer twice a day. To avoid infection, have the jar, the hoses, and the mouthpiece cleaned every day.

The PVV has other advantages. It is considerably quieter than the Huxley, not to mention the vacuum cleaner noise of a Monaghan 170C. For the first time in twenty years I can now hear night sounds. The PVV is also, as its name says, "Portable." It weighs only 26 pounds. I have yet to take a trip with the new equipment, but I expect travel to be much easier than with the old machine. An additional advantage to me is being able to remove the headgear myself, allowing me to get out of bed when I choose.

The Lifecare PVV is much more convenient, comfortable and efficient than my old negative pressure respiratory

equipment. I recommend it for anyone using negative pressure who finds that arrangement increasingly difficult. I particularly urge it if someone fears that eventually he or she will have to resort to a trach.

Reprinted from *Polio Survivors Newsletter*, July/August 1983.

Paul K. Longmore (respiratory polio since 1953 at age 7) is finishing his Ph.D. in American history at Claremont Graduate School and working with Prof. Harlan Hahn on the first disability studies program at the University of Southern California. Address: 1437 North Avenue 47, Apartment 7, Los Angeles, California 90042.

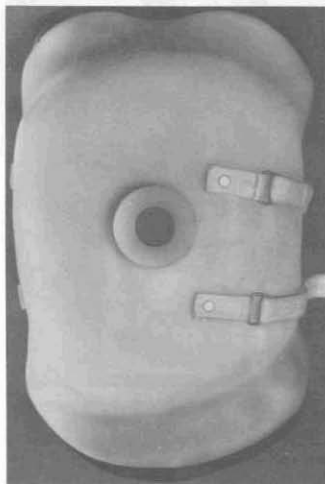
MAKING A CUSTOM-FIT POLYETHYLENE CUIRASS

"An individual custom-fitted chest piece for scoliotic persons who use negative pressure ventilation can be made from polyethylene by an orthotist. Once a plaster cast is made to duplicate one's unique body deviations as well as allowing adequate room for chest expansion (see Dr. Spencer's article in *Rehabilitation Gazette*, Volume 24), polyethylene material can be drawn in around the cast in a chamber which combines heat and negative pressure.

"Once the polyethylene has cooled, the edges are trimmed and padded with 1/2" neoprene rubber which is glued to the polyethylene. The rubber along the lateral edges is extended to fit under the back.

"Extra thicknesses of rubber can be spliced onto the edging whenever required for a snugger fit or to relieve pressure areas.

"Velcro straps which fold back on themselves through metal fasteners are attached with speedy or dot rivets. The coupling ring of rubberized plastic is attached by rivets and machined to the right side to accept the hose.



Audrey King's custom-fitted polyethylene cuirass.

"A chestpiece made in this manner is light, flexible, exceptionally durable and offers comfort of fit. The neoprene rubber does tend to split over time, if subjected to bending and stretching. However, the edges where the polyethylene meets the neoprene rubber can be covered with thin strips of leather which help to prevent this cracking of the rubber." *Audrey King, Suite 2204, 75 Graydon Hall Drive, Don Mills, Ontario M3A 3M5, Canada.*

FROG BREATHING VIDEOTAPE. "Frog Breathing with Gary McPherson" is available in 1/4" VHS or 3/4" pneumatic. \$85 Canadian and \$75 United States currency, including a script for teaching purposes and mailing charges. Make payable to Respiratory Therapy — Aberhart, Account #0943, University of Alberta Hospitals, Aberhart Centre, 114 Street and University Avenue, Edmonton, Alberta, Canada T6G 2J3.

FOOT-MADE PORTABLE RESPIRATOR. "I wanted a smaller respirator I could use with my chestpiece for travel so I made one out of the parts I had bought from the Monaghan company over the years for their M.H.R. (S). First, I marked off a place on the floor for all the parts I would need and then moved them around until they took up the least space. I had a relative cut an old table top to fit the space.



Bud Dabney's granddaughter totes his foot-made respirator.

"I gathered the tools I can use with my feet — an electric drill and socket wrenches — and in three days I had it bolted together and in operation. I had a relative put a switch in the motor wire and make a handle for one person and two side handles for two people. It weighs about 65 pounds so even my granddaughter can carry it. It can operate on its side or flat on its three casters. I figure this home-made M.H.R. cost me about \$425 spread out over many years.

"It is an easy respirator for me to work with because it does not have a cover. With my feet I can easily change the hose from the cylinder to the valve, change the belt, and make rate adjustments. I can lift it with my right foot." *Louis "Bud" Dabney, 8354 Edgedale Road, Baltimore, Maryland 21234.*

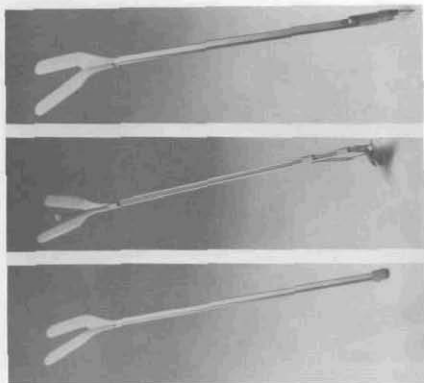
MANUFACTURERS OF RESPIRATORS/VENTILATORS
Dr. Augusta Alba of Goldwater Memorial Hospital compiled the following list for the May 1983 conference in St. Louis;

- The Cuirass Shop, Bob Waind, 1131 East 16th Avenue, Denver, Colorado 80218. Cuirass shell (chest piece).
- J.H. Emerson Company, Bruce Van Lenten, Respiratory Equipment, 22 Cottage Park Avenue, Cambridge, Massachusetts 02140. Emerson volume ventilator, rocking bed, iron lung, poncho.
- Life Products, Inc., Richard Apple, P.O. Box 3348, Boulder, Colorado 80307. LP-3, LP-4, LP-5 (near future).
- Lifecare Services, Inc., James Campbell, 5505 Central Avenue, Boulder, Colorado 80301. PVV (LP-3), CAM-10 (Standard Bantam), PLV-100 (near future). Lifecare has representatives with 24-hour service in St. Paul, Grand Rapids, Chicago, Houston, Cleveland, Kansas City, KS, New York, Augusta, Denver, Oakland, Seattle, Detroit, Boston, Baltimore, Omaha, Los Angeles, Phoenix, and San Diego. Write to Mr. Campbell for the addresses and phone numbers.
- Thompson Respiration Products, Inc., Harris Thompson, 1680 Range Street, Boulder, Colorado 80301. Minilungs M-3, M-15, M-25, M-25 Assist Bantams GS, GT, Compact C (metal case), Chest respirator maxivent, M-3000 XA-minilung.

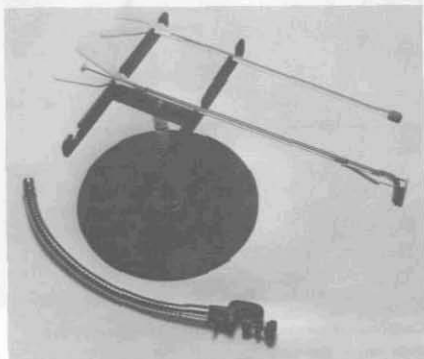
Mouthsticks/Page Turners

NEW MOUTHSTICKS AND DOCKING STATION

Whether you are an experienced mouthstick-user or a neophyte, the manufacturer asks that you measure the length according to its method: the total length of the mouthstick plus the length of the biteplate. Measure from the lips to end of the stick. The average adult mouthstick ranges from 12" to 18" long. If you have any questions, call or write Adlib Incorporated, P.O. Box 905, Lakewood, California 90714. (213) 420-9448. Request the free brochure.



Adlib's mouthsticks: (Top) Pencil automatically advances lead; (Center) Pincer operated by tongue; (Lower) Page turner/typing wand.



Adlib's mouthstick station for tabletop and gooseneck for lapboard.

MORE MOUTHESTICKS. Back issues of the *Gazette* presented many creative, home-made mouthsticks that will be reprinted. In addition, several manufacturers will send brochures of their mouthsticks. Write to Bell Easy Reading Aids, 5435 North Artesian Avenue, Chicago, Illinois 60625. Maddak, Inc., Pequannock, New Jersey 07440.

EASEL MOTORIZED FOR MOUTHESTICK. Arthur Heyer, an engineer and C4-5, designs custom-made easels to be used from wheelchair or bed. With a touch of a button, the easel moves up, down, and sideways. For an estimate, send your requirements to Extensions for Independence, 635-5 North Twin Oaks Valley Road, San Marcos, California 92069.



Joni Eareckson's motorized easel created by Arthur Heyer.

PAGE TURNERS. Most of the following manufacturers make page turners that can be operated by mouthstick, foot, elbow, head, or breath. Most of them will turn the pages of any size book or magazine. Some turn forward only; others turn backward too. Send for brochures and prices but don't buy immediately if you are newly disabled. Call your local Public Library's Service for the Blind and Physically Handicapped and borrow one first. Then wait. Most long-term quads prefer the independence and simplicity of using a mouthstick directly to turn pages.

Manufacturers: Cleo Living Aids, 3957 Mayfield Road, Cleveland Heights, Ohio 44121. Dickey Engineering, 3 Angel Road, North Reading, Massachusetts 01864. Fashionable, Rocky Hill, New Jersey 08553. HB & D Products, 2008 Donna Drive, Laguna Beach, California 92651. Lakeland Tool Works & Products, P.O. Box 1224, 21 Birnamwood Drive, Burnsville, Minnesota 55337. Maddak, Inc., Pequannock, New Jersey 07440. J.A. Preston Corp., 71 Fifth Avenue, New York, New York 10003. Touch Turner Co., 443 View Ridge Drive, Everett, Washington 98203. WTB, Inc., 1259 Millikin Place, N.E., Warren, Ohio 44483. Zygo Industries, Inc., P.O. Box 1008, Portland, Oregon 97207.

Miscellaneous Readers' Ideas

Wheelchair Office and Bed Rack for CB and Ham Radio

by James Thompson

I had polio in 1954; paralysis was total. Eventually, movement returned to my left arm and hand so I can eat, type, and write. In my vertical days I was a mechanic. After I was horizontal, I tried a gift shop and accounting, without success. Then, a reconditioned Royal electric typewriter was given to me in 1959 and our local dealer provided the opportunity to start a typing business which grew into stencil duplicating and into selling printed stationery, cards, and advertising specialties. I had to cut back in 1975 but I still sell wedding invitations and pursue many hobbies.

I can sit at my desk for 6 to 8 hours. My desk is home-built. It is on rollers and has a folding leaf extension. It has an accessible file and stationery compartments, pen holder, Touch-a-matic dialer, Touchtone telephone, an IBM correcting Selectric typewriter, and a four-sided copy/book rack on a swinging cantilever that extends over the typewriter. I use a lightweight telephone headset clipped to my glasses at all times.

I sleep on a rocking bed and spend a lot of time on it during the day. I had a frame made which slips into pipe sockets attached permanently to the lower bed. The frame holds a reading rack and cassette tape player.

Next to my pillow, I have switches that let me control my rocking bed, a blower, reading lamp intensity, electric blanket, and three other devices.

A caster-mounted cantilever rack holds CB and amateur radio equipment over my bed. The top shelf contains SWR/power meter and CB radio at left, amateur radio transceiver on right. Bottom shelf holds electronic keyer and antenna tuner. Double paddles to operate keyer are mounted on the board in my lap. A lever-operated switch for my CB boom microphone lays on my chest. A small speaker mounted on a post near my left ear is connected to the ham rig. My telephone headset clips to the same headband that holds my CB boom mic. The base on which the rack is mounted has two 12-volt storage batteries for ballast and to supply power.

Any questions about my equipment will receive a fairly prompt reply. My phone is 219/872-1939 and my address is 204 Johnson Road, Michigan City, Indiana 46360.



Cantilever rack holds CB and amateur radio equipment over rocking bed.



Copy board of over-bed reading/recording rack moves on rails.



James Thompson's custom-made desk and four-sided copy/book rack.

BRACES AND CORSETS FOR POLIOS. "I had polio at age 4 in 1930. I have outlived my physicians and several generations of 'brace men.' Can any readers suggest sources for bracing and corset fitting? I wear a right leg brace and a Hoke-style canvas corset reinforced with steel. I've tried to have a new leg brace and corset made locally but, despite the very diligent efforts of the orthotists, I have greater discomfort and more fatigue than before." *Florence Lockridge, 4117 Adams, #206, Kansas City, Kansas 66103.*

INNOVATIONS FOR RESPIRATORY POLIOS. "I would like to share some adaptations, innovations, and designs discovered through the years: GLASS HOLDER which attaches to the top of my rocking bed is a tall, plastic traveling mug with a lid. ROHO CUSHION lets me sit straighter and for longer periods of time. DECORATED CHEST SHELL has a lovely painted design of flowers, a heart, and a butterfly, thanks to a good friend. Because I require more back support than the pneumobelt corset provides, I adapted the front panel to my back brace." *Carole Ann Parsons, 5206 Trafalger Place, Madison, Wisconsin 53714.*

PORTABLE ROCKING BED PLANS. "I had the bed constructed about four years ago by a welding shop. The total cost was \$784, of which Medicare paid 80%. The gear box was donated by the National Foundation and the motor was a spare we had around." *Jean Doyle, 86 N. 7th Avenue, Des Plaines, Illinois 60016.* The *Gazette* has a set of the plans you may borrow.

UNIQUE TOOLS. Free brochure of gadgets and tools Mad Eagle Aeronautical Engineering Co., 292 Bridge Street, South Hamilton, Massachusetts 01982.

CATALOG OF COMFORTS. Aids for easier living for everyone. Free catalog from Comfortably Yours, 52 West Hunter Avenue, Maywood, New Jersey 07607.

NEW SEARS CATALOG. Sears has expanded its health items to include clothing, beds, bathing aids. Free from Sears, Roebuck and Co., Sears Tower, Chicago, Illinois 60684.

A GUIDE TO CONTROLS: SELECTION, MOUNTING, APPLICATIONS. Illustrations and descriptions of most frequently used commercially available controls. \$10 including postage from Ms. Bobbi Reagan, Rehabilitation Engineering Center, Children's Hospital at Stanford, 520 Willow Road, Palo Alto, California 94304.

Swimming

SELF-OPERATED POOL LIFT. The company that makes the water-operated bathtub lift has created a pool lift that operates by connecting a garden hose to a water faucet. The unit is self-operated, rising, lowering, and turning automatically by upper and lower control levers. There are two models — one portable, the other permanent. Free brochure from J.E. Nolan & Company, Inc., Box 43201, Louisville, Kentucky 40243.

FIBERGLASS POOL STAIRWAY. Transfer starts outside the pool at wheelchair seat height on gradually sloping stairs into the pool. Rail and hand stabilizers assist descent or ascent. Adaptable and portable. Free brochure from Northern Plastics Corporation, 6733 Myers Road, East Syracuse, New York 13057.

Mobility

VA STANDARDS GUIDE. *Program Guide: Add-On Automotive Adapted Equipment for Passenger Automobiles.* Guide developed to meet the need for minimum safety and quality standards. It covers VA standards and test criteria and a complete listing of VA approved devices with photographs and names and addresses of manufacturers. Useful for vocational rehabilitation agencies as well as veterans. Free from *Program Evaluation Service (074), Veterans Administration, 810 Vermont Avenue, S.W., Washington, D.C. 20420.*

AUTOMOBILE FOOT-DRIVING CONTROLS. Engineering service available. Free brochure of improved models from Cameron Enns, 13637 S. Madsen Ave., Kingsburg, California 93631.

ARROYA VI-SKI/SLED. Peter Axelsson, SCI, pilot, swimmer, sailor, and photographer, redesigned the "pulk" sled while a student at Stanford U. He has formed a company to sell the Arroya VI. Free brochure from *Beneficial Designs, Inc., 5858 Empire Grade, Santa Cruz, California 95060.*

SIT-N-SKI. A ski sled for use on both cross-country and downhill ski runs. Free brochure from Mountain Man, 720 Front Street, Bozeman, Montana 59715.

MOTORHOME LIFT. Designed to fit standard 30" door and take up the minimum of interior space. Free brochure. Handicaps, Inc., 4335 South Santa Fe Drive, Denver, Colorado 80110.

PROTOTYPE VAN WITH RAMP. Industrial design students have created modifications which could be made to the new mini-van that Chrysler will have on the market in 1984. Details available from Douglas Fetterman, Industrial Design, Michigan State University, East Lansing, Michigan 48824.

MODULAR WHEELCHAIR RAMP SYSTEM. Abbey Medical carries the DuraTech system of ramps. They are steel framed and have plywood surfaces. They can be bolted together for a straight ramp or angled to a platform. Optional hand rails. Free brochure from Abbey Medical dealers.

FREEDOM CHAIR. Electric-powered indoor/outdoor vehicle climbs curbs, crosses fields, and clears a 28" doorway. Bright red, five-speed transmission, power steering, large flotation tires. Free brochure from Custom Design Industries, 46976 West Bursley Road, Wellington, Ohio 44090.

WHAT TO LOOK FOR IN A POWER DRIVE WHEELCHAIR. Informative booklet. Free. Ask for brochure of Solo Power Pak. Solo Products, Inc., 2435 Front Street, West Sacramento, California 95691.

SOUTHWARD TRAVELIFT. Combination manual wheelchair and passenger seat. Can be installed in any two-door bucket-seat auto, including subcompacts. Works on electrically operated swing-lift mechanism. Brochure from Golden Boy Sales Corp., 2920 West Central, Santa Ana, California 92704.

KIT FOR REMOTE-AREA WHEELCHAIR. An Australian biomedical engineer has designed an inexpensive wheelchair that may be made from a kit or ordered assembled. The construction booklet is free to disabled individuals who wish to build a chair for their own use but the chair is protected by patent from commercial production except where license to manufacture has been granted.

The essential components — bicycle wheels and ordinary PVC plumbing pipe — are obtainable from local stores for no more than \$100. The kit-made chair does not have arms, the footplate and back rest are fixed to the main frame and it is not collapsible. It can be assembled in about 2 hours.

The manufactured model has removable plates and back rest, arm rests, and it is narrower and collapsible. It sells for \$250.

Both models are rust resistant and lightweight and can be adjusted for use on sand, "a major obstacle for wheelborne people in remote areas and developing countries." These same features make it suitable for use as a shower chair and a swimming pool chair.

The kit and chair are described in a free brochure from the designer, Robert Bosshard, Biomedical Engineer, Spinal Unit, Royal North Shore Hospital, St. Leonards 2065, New South Wales, Australia.



Australian plastic wheelchair made from a free kit for under \$100.

WHEELCHAIR III. Report of a Workshop on Specially Adapted Wheelchairs and Sports Wheelchairs. The report includes examples of the new technology: the "smart wheelchair" which uses a microcomputer and a sensing device and can be attached to any wheelchair and the omnidirectional wheelchair which can move sideways. \$10 from Rehabilitation Engineering Society of North America, Suite 402, 4405 East-West Highway, Bethesda, Maryland 20814.



Frank Engel, the Gazette's exuberant postman.

Accessibility

The Planner's Guide to Barrier Free Meetings. If you're planning a conference, buy a copy and photocopy the relevant pages for the conference site people. Saves a lot of hassle. \$11.95. Barrier Free Environments, Inc., P.O. Box 30634, Raleigh, North Carolina 27622. From the same source: *Catalog File of Architectural Products for Accessibility.* \$25.

Access Symbol labels. 1½ inch. Blue or white with adhesive back. 48 labels for \$3. Bob Peters, Symbol Specialties, #1 Timberlake Road, Bloomington, Minnesota 55437.

Adoption

National support group for parents who adopt a disabled child will provide lists of family groups and a newsletter. Write to NACAC, 1346 Connecticut Avenue, Suite 229, Washington, D.C. 20036.

The Loving River — a journey in prose and poetry . . . about adoption, disability, about this complex business of living. By Grace Sandness. \$5 including postage. Balance Beam Press, Inc., 12711 Stoneridge Road, Dayton, Minnesota 55327.

Advocacy

Find out how to get services by being assertive and how to organize and move bureaucracies by sending for the free list of publications of the Coordinating Council for Handicapped Children, Room 412, 220 So. State Street, Chicago, Illinois 60604.

Attitudes

Improving Communications about People with Disabilities. Attractively illustrated 20-page booklet presenting guidelines for the media adopted by a United Nations Seminar held in Vienna in 1982. Limited number free from United Nations, Division for Economic and Social Information, Department of Public Information, New York, New York 10017. \$5 from Rehabilitation International, 432 Park Avenue South, New York, New York 10016.

Blind

The First Steps: How to Help People Who are Losing Their Sight. Practical, down-to-earth suggestions. \$8.25 including postage from Peninsula Center for the Blind, 2435 Faber Place, Palo Alto, California 94303.

Children

The Chronically Ill Child and Family in the Community. 30 pages. 75c. *Preparing Your Child for Repeated or Extended Hospitalizations.* 16 pages. 75c. Both from Association for the Care of Children's Health, 3615 Wisconsin Avenue, Washington, D.C. 20016.

The Able Child/TAC, 154 Chambers Street, New York, New York 10007. The Able Child has a wheelchair accessible play area and professional advisers to select toys and play equipment. TAC is a resource center with aids for all ages. Free catalog.

Children and Youth

National Information Center for Handicapped Children and Youth, James Murphy, Information Services Manager, P.O. Box 1492, Washington, D.C. 20013. Three-year funding by U.S. Department of Education. Collects and disseminates information through newsletters, workshops, and other links with people.

Welcome Aboard

Tips for Welcoming Young People with Disabilities in Youth-Serving Programs. Free from National Easter Seal Society, 2023 West Ogden Avenue, Chicago, Illinois 60612.

Clothes

Laurel Designs, 5 Laurel Avenue, #1, Belvedere, California 94920.

Caradine of California, P.O. Box 22754, San Diego, California 92122.

Pirca Fashions, 1810 4th Avenue, Sacramento, California 95818.

Cook Books

Easy Cooking. 97-page collection of recipes submitted by AOL magazine's readers. \$3.90 postpaid from Cheever Publishing, Inc., Accent on Living, P.O. Box 700, Gillum Road and High Drive, Bloomington, Illinois 61701.

Deaf

What You Should Know About TDDs. Free brochure on selecting telecommunications devices. Public Information Office, Rochester Institute of Technology, National Institute for the Deaf, One Lomb Memorial Drive, P.O. Box 9887, Rochester, New York 14623.

College and Career Programs for Deaf Students. Lists of federally funded post-secondary and graduate programs throughout the United States and Canada. \$3.50 from Gallaudet College, Center for Assessment and Demographic Studies, Kendall Green, 800 Florida Avenue, N.E., Washington, D.C. 20002.

New Trends for Instructing Deaf People. Free catalog of resources from the National Technical Institute for the Deaf, One Lomb Memorial Drive, P.O. Box 9887, Rochester, New York 14623.

Developmentally Disabled

Request the free list of publications from Center of Residential and Community Services, 207 Patee Hall, 150 Pillsbury Drive, S.E., University of Minnesota, Minneapolis, Minnesota 55455. Latest publications: *Sourcebook on Long Term Care for Developmentally Disabled People*. \$4. *Mentally Retarded People in State Operated Residential Facilities: Year Ending June 30, 1980*. \$3.

Reaching Out: Achieving Community Involvement with Developmentally Disabled Children. \$9.95 prepaid. Willoughby by Wessington Publishing Company, P.O. Box 911-R, Mercer Island, Washington 98040.

Disabilities, Miscellaneous

Myoclonus Families United — National Organization for Rare Disorders, Attn: Mrs. Sharon Dobkin, 2153 East 22nd Street, Brooklyn, New York 11229. Consumer oversight group of organizations that serve individuals with rare disorders and their families. Central clearinghouse for research, treatment, and legislation.

Multiple Sclerosis: The Facts. By Dr. Bryan Matthews. 103 pages. 1980. Practical and well written by a neurologist at

Oxford. Covers diagnosis, treatment, theories, diet, and everyday life. \$6.75 from Oxford University Press or Ontario Division of Multiple Sclerosis Society of Canada, 130 Bloor Street W, Suite 700, Toronto, Ontario M5S 1N5, Canada.

A new series of health publications offers practical self-help information presented in plain English. They are paperback and average about 100 pages. They are all a great bargain at \$3.95 each. The author is a medical writer, Ms Ada P. Kahn. The four titles are *Arthritis*, *Diabetes*, *Headaches*, and *High Blood Pressure*. Order from Contemporary Books, Inc., 180 North Michigan Avenue, Chicago, Illinois 60601.

Education

Directory of College Facilities and Services for the Handicapped. Edited by C.S. McGeough, B. Junjohan, J.L. Thomas. 360 pages. Comprehensive guide to more than 2,000 colleges and universities in the U.S. and Canada. Valuable resource for vocational rehabilitation and high school counselors. \$80 from the Oryx Press, 2214 North Central at Encanto, Phoenix, Arizona 85004.

Scholarships for Respirator-Dependent Persons. Lifecare will award four annual scholarships of \$2,500 each. Forms, with a sponsoring letter, must be received by December 31. Awards will be made in April for the fall semester. Details available from Lifecare, 5505 Central Avenue, Boulder, Colorado 80301.

Employment

Speaking of Employment... A Symposium on disabled people in the workplace. \$9. Medical Standards for Employing Handicapped People: Some Perspectives on Affirmative Action, \$1. *Insuring Handicapped People: A Contract Compliance Guide*, \$1. 503: *A Law Meaning Job Rights for Handicapped*. Free. Mainstream, Inc., 1200 15th Street, N.W., Washington, D.C. 20005.

Internships for disabled people during June 1984-May 1985. Information from Disabled Visitor Services, The Metropolitan Museum of Art, Fifth Avenue and 82nd Street, New York, New York 10028.

Job Tips for People With Mental and Emotional Problems. Planning for a Job: Tips for Disabled Students. Marketing Your Disability and Yourself. Single copies

free from the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

LINK, a national model job development and placement project, is funded by the Department of Labor and directed by Mainstream, Inc., 1200 15th Street, N.W., Washington, D.C. 20005. Prototypes are being set up in Dallas and the Washington, D.C., area.

Adapting Work Sites for People With Disabilities: Ideas from Sweden. 260 pages. Illustrated. Available from The Swedish Institute for the Handicapped, Box 303, S-161 26 Bromma, Sweden, for 45 Kroner and from the World Rehabilitation Fund, 400 East 34th Street, New York, New York 10016.

Films

"Life Another Way." A 57-minute film of the life and family and community involvement of Beryl Potter who slipped and fell in 1965, causing thrombophlebitis which resulted in the amputation of both legs, right arm and the sight of the right eye. For rental or purchase, Mrs. Marilyn Currie, 147 Benjamin Blvd., Scarborough, Ontario M1K 3P4, Canada.

"A Portrait in Courage." 28-minute film of the life of Stanley L. Obritzki, Jr., a quad from an automobile accident. \$25 rental. 16mm color with sound. Write to Stanley at RD 1, Box 458A, Jackson, New Jersey 08527.

Head Injury

National Head Injury Foundation, Inc., 280 Singletary Lane, Framingham, Massachusetts 01701. Central clearinghouse, support group network, rehabilitation, and research. Free brochure.

Getting Our Heads Together: A Helpful Handbook for Families of Head-Injured Patients. 48-page booklet. \$3.50 from Public Relations Office, Thoms Rehabilitation Hospital, One Rotary Drive, Asheville, North Carolina 28803.

Incontinence

Female incontinence is a major and degrading problem. *A Gazette* reader, Patricia Etue, is on the track of every hint of a solution. If any individual or company creates a device, please send a sample to her at 5582 Lockhaven Drive, Buena Park, California 90261. Any device that really works will be headlined in the next issue and promoted around the world.

Independent Living—Historical Perspective

"Physical Disability and Public Policy" by Gerben DeJong and Raymond Lificez. SCIENTIFIC AMERICAN. June 1983. Vol. 248. No. 6. Pgs 40-49. An important analysis of federal disability laws, history of the independent living movement, and statistics on disability. The authors conclude "the civil rights of disabled Americans require a more accessible environment."

Independent Living for Physically Disabled People. By Nancy M. Crewe, Irving Kenneth Zola and Associates. 1983. 406 pages. \$19.95. Jossey-Bass Inc., Publishers, 433 California Street, San Francisco 94104. A significant contribution to the independent living movement! The book traces the history of the movement, presents models of services and programs, and assesses the future of the movement.

International Perspectives About Independent Living. Proceedings of a one-day conference in April 1982. \$3.50 from University Center for International Rehabilitation, College of Education, 513 Erickson Hall, Michigan State U., East Lansing, Michigan 48824.

Independent Living Aids

A Handbook for the Disabled. Ideas & Inventions for Easier Living. By Suzanne Lunt. Charles Scribner's Sons, 597 Fifth Avenue, New York, New York 10017. 1982. Homemade devices, commercial equipment, guide to wheelchair selection, ideas for all ages. \$17.95.

Designs for Independent Living. Excellent, free, 25-page booklet. Plans and modifications. Selection, position, and installation of major home appliances in a kitchen or laundry. Whirlpool Corporation, Benton Harbor, Michigan 49022.

Handling the Handicapped: A guide to the lifting and movement of disabled people. Published by the Chartered Society of Physiotherapy. Useful information for family and instructing attendants. \$9.25 including postage. Springer Publishing Inc., 200 Park Avenue South, New York, New York 10003.

1982-83 Buyer's Guide to commercial products, services, publications, organizations, films. \$10.65 including shipping.

Accent Special Publications, Gillum Road and High Drive, P.O. Box 700, Bloomington, Illinois 61701.

Technology for Independent Living. Edited by Sandi Enders, OTR, and the faculty of a Workshop on Technology for Independent Living presented at the Fifth Annual Conference on Rehabilitation Engineering. Intended primarily for use by professionals. \$20. Three-ring binder. Rehabilitation Engineering Society of North America, Suite 402, 4405 East-West Highway, Bethesda, Maryland 20814.

Rehabilitation Engineering Project, Service Delivery Model and Evaluation (PDD 82-7-2). Final report of a three-year project; it includes the California Information Broker Project and an evaluation system. Available from Rehabilitation Engineering Section, Department of Rehabilitation, 830 K Street, Sacramento, California 95814.

Independent Living Programs

The Economic and Societal Benefits of Independent Living Services. Report includes case histories and background information on 23 independent living centers in Minnesota, Illinois, Indiana, Michigan, Ohio, and Wisconsin. Available from National Clearing House of Rehabilitation Materials, 115 Old USDA Building, Stillwater, Oklahoma 74078.

Independent Living Evaluation: Washington State Data System and Data from the First Year of Title VII. 1982. \$10. Available from Debra Wilkerson, Department of Rehabilitation Medicine, RJ-30, Seattle, Washington 98195.

Centers for Independent Living. 1982. Available from D. Zimbras, DVR, P.O. Box 7852, Madison, Wisconsin 53707.

Programs for People: The California Independent Living Centers. 1982. Available from Gene Hinkle, Statistics, Program Evaluation and Research Section, California State Department of Rehabilitation, 830 K St. Mall, Sacramento, California 95814.

Evaluating Independent Living Programs. June 1983. Free 4-page summary available from Institute for Information Studies, 200 Little Falls Street, Suite 104, Falls Church, Virginia 22046.

Rehabilitation for Independent Living: A Selected Bibliography 1982. Single

copies free from the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

Independent Living Services — Attendant Care

Position Statement: Every person has a right to live as independently as possible. Persons who, because of physical functional loss, cannot themselves perform tasks of personal care and daily living, have the right to be provided that assistance through a Personal Care Attendant in the location of the disabled person's own choosing.

We call for legislation and public funding of a statewide program which will:

(1) Provide money to severely physically disabled people who have a functional loss of two or more limbs and who need assistance with tasks of daily living.

(2) Provide an amount of money to such individuals to enable them to hire a Personal Care Attendant; an amount adequate to accomplish tasks required. This amount must be sufficient to enable a disabled person to hire an attendant at the minimum wage.

(3) All disabled individuals shall be eligible, regardless of income.

(4) The disabled participant shall be responsible for selecting, employing and terminating his/her attendant.

(5) Money shall be paid directly to the disabled participant to employ the attendant of choice.

(6) An attendant care program shall be operated through a non-profit agency controlled by severely disabled individuals, and one which has experience working with severely disabled people. — *The Disability Rag*, P.O. Box 145, Louisville, Kentucky 40201. June 1983.

The Consumer's Guide to Attendant Care. Guidelines for record keeping, hiring and firing. \$5. Postpaid from Access to Independence, 1954 East Washington Avenue, Madison, Wisconsin 53704.

Personal Care Attendant Manual. Compiled by Center for Independent Living of Greater Bridgeport, P.O. Box 3366, Bridgeport, Connecticut 06605. 84 pages. \$7. A very comprehensive guide!

Independent Living Services — Housing

Housing Services for People with Physical Disabilities. Tips for conducting a needs assessment and locating existing housing. \$12. Postpaid from Access to Independence, 1954 East Washington Avenue, Madison, Wisconsin 53704.

Information Sources

ACCESS-INFO. Telephone tape information service provides 3-5 minute taped messages on the subjects of disability and rehabilitation in the Los Angeles, California, area. A joint venture of the Daniel Freeman Memorial Hospital, Department of Rehabilitation, and the Westside Community Independent Living Center. Call 213-673-9090 or 213-272-4636.

Directory of Information Resources. Free from Arthritis Information Clearinghouse, P.O. Box 9782, Arlington, Virginia 22209. A directory of 67 private and government organizations from whom information on arthritis is available.

Mainstream Information Line (202) 833-1162 is on call 9 am to 5 pm (EST), Monday through Friday, for questions on issues concerning disability.

Resource Directory 1982-1983. Higher Education And The Handicapped. A comprehensive guide to the major areas of concern. Useful to disabled individuals as well as education and rehabilitation personnel. 23 pages. Free from Health/Closer Look Resource Center, P.O. Box 1492, Washington, D.C. 20013.

National Rehabilitation Information Center (NARIC) is rapidly expanding its information on commercially available rehabilitation equipment and aids through ABLEDATA. For a list of Information Brokers and information on the Training Workshops, write to Marian Hall, ABLEDATA System Manager, NARIC, 4407 Eighth Street, N.E., Washington, D.C. 20017.

NCHRTM Memo. Free newsletter of rehabilitation training publications available from National Clearing House of Rehabilitation Training Materials, Oklahoma State University, 115 Old USDA Building, Stillwater, Oklahoma 74078.

Polio and severe disability information network worldwide: *Gazette International Networking Institute*, 4502 Maryland Avenue, St. Louis, Missouri 63108. Phone: 314-361-0475. Free brochure.

Directory of Resources for Adults with Disabilities. 114 pages. Free from William R. Langner, Division of Adult Education Services, Room 5624, R.O.B. #3, Washington, D.C. 20202.

International

15th World Congress of Rehabilitation International will be held in Lisbon, Portugal, June 4-8, 1984. Brochure from Secretariado Nacional de Reabilitação, Av. Conde Valbom, 63-5, 1000 Lisbon, Portugal. The president, Col. João Vilalobos, who uses a wheelchair is the founder of Portugal's leading organization of persons with disabilities.

For a free list of publications of previous international congresses and seminars, write to Rehabilitation International, 432 Park Avenue South, New York, New York 10016.

A Voice of Our Own. Proceedings of the First World Congress of Disabled Peoples' International held in Singapore from November 30-December, 1981, are available from University Center for International Rehabilitation, 513 Erickson Hall, Michigan State University, East Lansing, Michigan 48824. Every disabled person in the world who reads this will feel great pride.

World Rehabilitation Fund, 400 East 34th Street, New York, New York 10016, is a superb source of publications on developments in rehabilitation around the world. Ask for the free list of monographs.

Learning Disabilities

Syracuse University Press, 1011 East Water Street, Syracuse, New York 13210, has published several monographs on learning disabilities, including *A System of Marker Variables for the Field of Learning Disabilities* sponsored by the International Academy for Research in Learning Disabilities at \$16.20. Another is *The Struggle from Adolescence toward Adulthood* on learning disabilities and special education at \$9.95.

Report from the Study Group on Rehabilitation of Clients with Specific Learning Disabilities. 91 pages. \$4.50. #1188 from Arkansas Rehabilitation Research and Training Center, Publications Department, P.O. Box 1358, Hot Springs, Arkansas 71901.

Mental Illness

The Caring Family: Living with Chronic Mental Illness. By K.F. Bernheim, R.J. Levine, C.T. Beale. Common-sense advice from three professionals. \$13. Random House.

Families in Pain: Children, Siblings, Spouses and Parents of the Mentally Ill Speak Out. By Phyllis Vine. The experiences of 17 families, a list of resources, a

summary of treatment in the United States, and a table of drugs make this a comprehensive handbook. \$15. Pantheon.

Organizations

Disabled scientists, engineers, and science students, who would like to be listed in the *Resource Directory of Handicapped Scientists*, write to Project on the Handicapped in Science, AAAS, 1776 Massachusetts Avenue, N.W., Washington, D.C. 20036.

Disabled physicians, health professionals, or any individual who would be interested in becoming a dues-paying member and receiving the publication, *Synapse*, write to Mary Lewis, The American Society of Handicapped Physicians, 137 Main Street, Grambling, Louisiana 71245.

All disabled individuals are welcome members of American Coalition of Citizens with Disabilities, Inc., 1200 15th Street, N.W., Suite 201, Washington, D.C. 20005.

Periodicals, New

Joyful Noise. Editor, Brad Chaffin, 5500 Monroe Avenue, Evansville, Indiana 47715. The editor, who is disabled by multiple sclerosis, was a high school music teacher for 25 years. Quarterly. \$6 a year to Gazette readers.

Focus. Newsletter of library service to older adults and people with disabilities. One page. Monthly. \$6 a year from Eunice G. Lovejoy, 172 West Main Street, Westerville, Ohio 43081.

Breaking New Ground. Newsletter for disabled farmers includes adapted equipment, resource information, and special events. Free from Bill Field, Department of Agricultural Engineering, Purdue University, West Lafayette, Indiana 47907.

Recreation/Sports

Wilderness Inquiry II conducts year-round trips into the Midwest and Canadian wilderness for people of all ages and all abilities and disabilities (blind, deaf, or wheelchair). Brochure from Wilderness Inquiry II, 3255 Hennepin Avenue South, Suite 230, Minneapolis, Minnesota 55408.

Freedom on the River—rowing program for persons with disabilities is directed by Doug Herland, a former crew coach. Information Services, University of Michigan, 6008 Fleming Administration Bldg., Ann Arbor, Michigan 48109.

Training manuals on pulk and Nordic skiing, ice sledging, kayaking, relaxation techniques, fitness courses, medical self-

care and other healthsports and life enhancement activities. \$5. Vinland National Center, 3675 Ihduhapi Road, Loretto, Minnesota 55357. Free newsletter, *Vin-Lines*.

Oakland, California's Water Safety and Boating Program includes courses in sailing, canoeing and rowing. Office of Parks and Recreation W.S.B.P.D., Sailboat House, 1520 Lakeside Drive, Oakland, California 94612.

Special Recreation Digest. New national and international quarterly devoted to rights and needs of people who are disabled. \$28 year. Free list of other publications. Special Recreation, Inc., 362 Koser Avenue, Iowa City, Iowa 52240.

Parents' Guide to Accredited Camps. The annual guide, available in January, includes a state-by-state listing of 2,200 camps for persons of all types of disabilities. \$5.95, includes postage. ACA Parents' Guide, 110 Bradford Woods, Martinsville, Indiana 46151.

Ski for Light International. Week-long program at Lake Placid in 1984. Sighted guides teach blind people to ski on a one-to-one basis. Apply to Grethe Winther, P.O. Box 2971, Reston, Virginia 22091.

Recordings

Voice-Indexed Concise Heritage Dictionary. 219 sides of 55 cassettes recorded in 4-track, 1 1/2 inches-per-second. \$82.54 from the American Printing House for the Blind in Louisville, Kentucky. Available for use at the 160 cooperating libraries serving the National Library Service for the Blind and Physically Handicapped of the Library of Congress.

Choice Magazine Listing. Recorded 8 rpm magazine anthology of articles, fiction and poetry selected from 100 contemporary periodicals. Bi-Monthly. Free to those unable to read regular print because of visual or physical handicap. Dept. RG, P.O. Box 10, Port Washington, New York 11050, or call 516-883-8280.

Rehabilitation

Rehabilitation in the Public Mind. Strategies of Marketing. A Report on the Seventh Mary E. Switzer Memorial Seminar. Edited by Leonard G. Perlman, Ed.D. 88 pages. One of the five invited papers is "Strategies of Marketing With Persons With Disabilities" by Gini Laurie. The report is \$10. Make a check to Switzer Memorial Fund (Monograph #7), National Rehabilitation Association, 633 South Washington Street, Alexandria, Virginia 22314.

REHABILITATION GAZETTE

Rights

Masterplan for Affirmative Action for the Disabled. A "how to" manual for municipal governments. \$2.50. Make check payable to Vocational Rehabilitation Grant—City of New Haven. Mail to Ismael R. Chavez, Director of Handicapped Services, 1 State Street, New Haven, Connecticut 06511.

National Center for Handicapped Rights, Inc., P.O. Box 1122, Atlanta, Georgia 30301. James L. Cherry, J.D., Ph.D., Director

Free 90-minute, tone-indexed cassette tapes of Section 504 and Title VI of the Civil Rights Act of 1964 recorded at a speed of 1 1/2 IPS on four-track monaural in exchange for a 90-minute cassette tape in a stamped, self-addressed mailing case. Send tape and specify which tape to Director, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, S.W., Washington, D.C. 20201.

Sex

Sexuality and Sexual Assault: Disabled Perspective. By Virginia W. Stuart. Describes sexuality, rape, incest, defense against assault, and recovery from assault as related to persons with disabilities. 92 pages. \$4 from Dr. Charles K. Stuart, Learning Support Services, Southwest State University, Marshall, Minnesota 56258.

The Sex and Disability Information and Referral Service, Denise Sherer, Coordinator, 2nd Floor, United Cerebral Palsy Association of San Francisco, 814 Mission Street, San Francisco, California 94103. In addition to disseminating information, UCP is compiling a directory of persons with expertise in sex and disability. A referral manual will be published in late 1983 and will be available at cost.

Shoes, Mismatched

If your feet are different sizes and you want to find a sole mate, write to Jeanne L. Sallman, Odd Shoe Exchange, RR 4, Indianola, Iowa 50125. \$15 registration fee; plus annual dues of \$7.50.

Spanish Language Publications

The Braille Forum. Free. Selections from this monthly English publication now available in Spanish on 8 1/2 rpm flexible discs. Mary T. Ballard, Editor, 190 Lattimore Road, Rochester, New York 14620.

Travel—Employment

Bed and Breakfast Service (BABS). In this nationwide network of Referrers and Hosts there are money-saving and money-making opportunities for persons with disabilities. Referrers provide information on local Hosts' homes including wheelchair accessibility, foreign languages. Hosts rent rooms for \$15 night single and \$18 double. For information on joining the organization: Dolores Herrmann, BABS, P.O. Box 5025, Beltingham, Washington 98227.

Travel

Travel for the Handicapped. Free pamphlet from United Airlines, Consumer Affairs Department, P.O. Box 666100, Chicago, Illinois 60606.

Consumer Information About Air Travel for the Handicapped. Free pamphlet available from TWA's reservation clerks or ticket agents.

1981/1982 International Directory of Access Guides. If you're planning a trip, start with this and send for the relevant guides. International Rehabilitation U.S.A., 20 West 40th Street, New York, New York 10018.

Avis, Budget, Hertz, and National rent cars with hand controls *if* they are given advance notice. Arrangements can be made through your local branch office.

Mobility International, P.O. Box 3551, Eugene, Oregon 97403, offers a range of services including a newsletter, information, and educational exchange.

London guide: William Forrester, 1 Belvedere Close (off Manor Road), Guildford, Surrey, GU2 6NP, England. First person in a wheelchair to become a registered guide. An historian, he will work with an individual or a group.

The Itinerary. The magazine for travellers with physical disabilities. An excellent new bi-monthly. If you are planning to travel, you will be wise to start a subscription and gather all the issues. \$6 year. Whole Person Tours, Inc., 137 West 2nd Street, Bayonne, New Jersey 07002.

Florida wheelchair bus tours to Disney World, Circus World, Busch Gardens and Seaworld, etc. Wheelchair Wagon Tours, P.O. Box 1270, Kissimmee, Florida 32741.

London Tara Hotel, Scarsdale Place, W8 has 10 accessible rooms available through The Visitors' Club, Juxon House, St. Paul's Churchyard, London EC4. A year's membership is one pound (about \$2).

Travel—By Air with a Powered Wheelchair

The Air Lines Pilots Association, 1625 Massachusetts Avenue, N.W., Washington, D.C. 20036, issued new recommendations in July 1982, "Pilot's Guide to Hazardous Materials," which were published in *Air Line Pilot*: wheelchairs powered by lead-acid wet-cell batteries may be carried with the battery not removed under the following conditions: the vehicle (wheelchair) must be loaded and secured in an upright position, the battery must be secured to the vehicle, battery terminals and cables must be taped and battery caps must be tight.

A non-spillable battery that can be used safely close to delicate electrical circuitry without fear of damage is being produced by Gates Energy Products, Inc., 1050 South Broadway, P.O. Box 5887, Denver, Colorado 80217.

Typewriters

IBM's Handicapped Purchasing Program offers rebuilt, used typewriters at a low price to individuals who have a letter from their doctors indicating they are disabled and would receive therapeutic benefit from a typewriter. Call your local IBM or write to IBM, 10100 Santa Monica Blvd., Suite 2100, Los Angeles, California 90067. Attention: Dave Kelley.

Veterans

Federal Benefits for Veterans and Dependents. 1982. 73 pages. \$4. #1S-1 from Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

Women

No More Stares. 128-page book celebrates growing up female and disabled in America. By Ann Cupuolo Carillo, Katherine Corbett, and Victoria Lewis. \$5 prepaid from DREDF, 2032 San Pablo Avenue, Berkeley, California 94702.

Free publication from The Fleming Center, Inc., 3613 Haworth Drive, Raleigh, North Carolina 27609, describes their program for women and their partners.

U.S. PERIODICALS AND NEWSLETTERS FOR PERSONS WITH DISABILITIES

Prices indicate a one-year's subscription.

\$\$\$ Periodicals by Disabled

ACCD News Net. American Coalition of Citizens with Disabilities, Suite 201, 1200 15th St., N.W., Washington, D.C. 20005.

Accent on Living. P.O. Box 700, Bloomington, IL 61701. Qtrly. \$5.

Achievement. 925 N.E. 122nd St., North, Miami, FL 33161. Qtrly. \$3.

The Bumblebee. 412 Woodward Blvd., Pasadena, CA 91107. Qtrly. \$2.

COPH Bulletin. 1814 Welwyn, Des Plaines, IL 60018. \$3.

The Deaf American. The National Association of the Deaf, 5125 Radnor Rd., Indianapolis, IN 46226. Monthly. \$10.

Itinerary. P.O. Box 1084, Bayonne, NJ 07002. Bi-monthly. \$6.

Link and Go. Committee on Personal Computers and the Handicapped, 2023 West Irving Park Rd., Chicago, IL 60618. \$8.

The Mainstream. 861 6th Ave., Suite 610, San Diego, CA 92101. Monthly. \$10.

NAPH National Newsletter. 76 Elm St., London, OH 43140. \$6 incl. dues.

National Hookup. 32 Margaret Dr., Loudonville, NY 12211. Monthly. \$6.50.

New World for the Physically Handicapped. P.O. Box 1567, South Gate, CA 90280. Monthly. \$10.

Paraplegia News. 5201 N. 19th Ave., Suite 108, Phoenix, AZ 85015. Monthly. \$12.

Rehabilitation Gazette. Gazette International Networking Institute, 4502 Maryland Ave., St. Louis, MO 63108. Annual. Back issues, \$8 ea. Vol. 25, \$10.

Reports. Council for Disability Rights, 343 S. Dearborn, Chicago, IL 60604. \$10.

Sports 'N Spokes. 5201 N. 19th Ave., Suite 108, Phoenix, AZ 85015. Bi-monthly. \$6.

Free Disability Group Newsletters

ALLSSOAN. Amyotrophic Lateral Sclerosis Society of America, 15330 Ventura Blvd., Suite 315, Sherman Oaks, CA 91403. Qtrly.

Avenues. Arthrogryposis multiplex congenita. Bi-yrly. 5430 E. Harbor Heights Dr., Port Orchard, WA 98366.

The Braille Forum. 190 Lattimore Rd., Rochester, New York 14620. Monthly. In braille, large print, cassette, open reel tape, sound sheet.

Breakthrough. Osteogenesis imperfecta. Qtrly. P.O. Box 838, Manchester, NH 03105.

Friedreich's Ataxia Group in America. Box 11116, Oakland, CA 94611.

Insights. Spina bifida. 343 S. Dearborn, Room 319, Chicago, IL 60604.

Free Periodicals

Breaking New Ground. Farmers with disabilities. Dept. of Agricultural Engineering, Purdue U., West Lafayette, IN 47907.

Crusader. United Cerebral Palsy Assoc., 66 E. 34th St., New York, NY 10016.

Disability and Chronic Disease Newsletter. Irving Kenneth Zola, Ph.D., Dept. of Sociology, Brandeis U., Waltham, MA 02254.

In the Mainstream. 1200 15th St., N.W., Washington, D.C. 20005.

Programs for the Handicapped. Clearinghouse on the Handicapped, Office of Information and Resources for the Handicapped, Room 3119 Switzer Bldg., Washington, D.C. 20202.

\$\$\$ Periodicals

American Rehabilitation. Rehabilitation Services Administration, 330 C St., S.W., Washington, D.C. 20201. Qtrly. \$8.50.

Disabled USA. Superintendent of Documents, U.S. Govt. Printing Office, Washington, D.C. 20402. Qtrly. \$9.60.

Rehabilitation Literature. National Easter Seal Society, 2023 W. Ogden Ave., Chicago, IL 60612. Bi-monthly. \$21.

Journal of Rehabilitation. National Rehabilitation Association, 633 S. Washington St., Alexandria, VA 22314. Qtrly. \$30 to non-members.

An' A Tac On My Tires

by Audrey J. King

I wonder if a psychiatrist can help me? You see, I've got this awful identity problem. I don't know whether I'm a person or a vehicle, or both . . . or which of these I am when. I don't know whether I, as a person, control my life through the powered wheelchair I live in, or whether I'm just the body in a vehicle which goes around running my life for me. It's all so confusing!

I think the problem began on my first day of employment. Halfway through the day some essential synapse in my control box (excuse me — the chair's) broke and I began relentlessly going around and around in frantic circles. What better literal demonstration could there possibly be of the confusion and panic felt by a new employee on her first day?

Most people have distinctive "gait" patterns. I have a distinctive "whirr, squeak and rumble" pattern which varies according to the state of health of my vehicle and the mood with which it is driven! Problem is, unlike footsteps, my approach and departure noises (excuse me — the chair's) are so unique that I'm never permitted the luxury of slipping by undetected or being mistaken for someone else.

When I enter a meeting late or leave early, my arrival and departure never occur silently and unobtrusively. Thus I am often teased about being an "attention seeker," or of having an "inflated" sense of power. Is this really fair? Surely such comments should be applied to the chair rather than being a slur on my character.

It is quite true that one's mood can be expressed through the operative style of the wheelchair. Restlessness and boredom can be recognized by slow, random, purposeless circles and zigzags. Anger is expressed by short, sharp, abrupt movements which often speedily plow down furniture and people who happen to be in the way. Fatigue and depression are demonstrated by a slower speed and lethargy such that people stop and ask "is your battery dead?" They're inquiring about the health of your chair, of course, not yours! (Or is it yours?)

As your chair approaches its senior years, it is often the state of the chair's health and functioning which gives rise to altered behaviors and personality disturbances in you, the person. A flat tire cannot help but produce that "let-down" or "deflated" feeling, so often described as depression. "Low acid" levels in defunct batteries frequently produce "high acid" levels in one's duodenum and an associated ulcer-prone personality. Sometimes I think a sphygmomanometer would be far more useful than a hygrometer! When the diagnosis indicates "dirt in your potentiometer," "faulty Woodruff keys," and "dead cells in your battery," how can a person feel anything else but "terminal"? The tendency to give someone a belt back when told, "Oh, and you also need a new belt!" is strong indeed at times like these! What to do? Sometimes going to the local bar and getting thoroughly "tanked up" seems to be the only way to

get enough "pick-up" to see you through the rest of the day!

Problem is, even getting down the street to the bar poses yet a whole new set of identity problems. My friends say, "Come on, let's walk rather than drive. It's such a nice day." I follow on their heels, willingly, tongue hanging out . . . feeling quite confused again. Surely, in spite of their instructions, I am driving? I'm certainly not walking! Or is it that I'm rolling? . . . or trundling? . . . or R.P.M.ing? I'm sure I don't know.

I should go on the sidewalk with the others. After all, I am a person and they are my friends. Problem is, I can't get down the curbs at the corners, so I head for the nearest driveway and onto the road. I'm a vehicle after all, it seems! The "King-of-the-Road" feeling that I experience must surely be proof of this! I find myself maneuvering along the crest of the road so gravity cannot pull me into the nearest drainage ditch. I cannot signal with my arms; neither are there signals on my chair. Reality suggests that I really am rather small and vulnerable as I alternate from one side to the other according to the dictates of my schizophrenic vehicle/person personality. I must keep reminding myself that I'm not an "all-powerful, super mini-compact" and I should refrain from "playing in the traffic." I'd better listen to those terrified bystanders and "put the brakes" on such inclinations!

I go through the park with my friends. Suddenly a sign appears. *No motorized vehicles allowed.* Does that mean me? I am mindful of the fact that, if I go back on the road, I could be summoned to court and charged with driving an unlicensed vehicle on the road. It has happened before. This sign reminds me of others I have seen in stores: *No carriages, carts, etc.* Dear me! Is it me that's not wanted . . . or just my chair?

Sometimes I really feel quite tired as I try to solve the dilemma of who and what I really am. Colleagues ask "What's pneu with you?" and I immediately glance at my tires expecting to find a tack. My boss compliments me for being so "well spoken" and the warm glow of satisfaction I feel comes, not from the words of praise, but rather from the fantasy that my spokes are plentiful and secure and my hubs will revolve safely in the middle for yet another day. My adversaries say I'm "outspoken" and "full of hot air." The wrath I feel comes not from the insult I've heard but rather from a mental image of ripped out spokes and exploded tires!

Surely, somewhere, there is a psychiatrist who can help me get a handle on this problem. I must, somehow, acquire a clear, unconfused sense of identity before my next trip to the gas station so that I can react calmly and appropriately when the attendant says, "I'll be there in a moment to service you."

THE MARKET PLACE

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The Rehabilitation Gazette's Third International Post-Polio Conference and Symposium on Living Independently with Severe Disability will be in St. Louis on May 10-12, 1985.

Forthcoming Publications:

Proceedings of the Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability

Physician's Handbook on Polio

Rehabilitation Gazette on Microfilm

25 years of the *Gazette* on one 100-foot reel or cartridge — all the rare out of print *Toomey's* as well as all the *Rehabilitation Gazettes*. Positive or negative mode. \$50 including postage.

Rehabilitation Gazette on Open Reel or Cassette Free from Johanna Bureau for the Blind and Physically Handicapped, Inc., 30 West Washington, Chicago, Illinois 60602, or the Division for the Blind and Physically Handicapped, Library of Congress, Washington, D.C. 20540.

The "foo" sign is a Chinese character which stands for health, prosperity and all good wishes. It has long been a symbol of the Rehabilitation Gazette.

Foo Sign Posters

Silk-screened on heavy stock suitable for framing. Size 24" x 36". Dark green, beige, Chinese red. Designed by Cynthia Hewett. \$20 including postage.



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Moss green with the "foo" sign silk-screened in Chinese red. S.M.L. Designed by Cynthia Hewett. \$8 including postage.



Audio and Video Tapes of the Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability are available from Audio Visual Service Center, 2232 Welsh Industrial Court, St. Louis, Missouri 63141. Attention: Tim North.

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Available Back Issues of Rehabilitation Gazette

Gazette International Networking Institute

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HIGHER EDUCATION OF QUADS by correspondence, telephone, and attendance. Volume 5, 1962. Reading aids. New approaches to attendants. Self-aspirator.

QUADS AND THEIR FAMILIES Volume 6, 1963. Marriage and adoption. Camping and vacations. Wheelchair cushions. Australian fiberglass lung. English chair/bed.

TRAVELING QUADS Volume 8, 1965. Medical engineering — arm aids, foot-operated aids, multi-controls. Quad driving. Foot-controlled steering. Ramps. Lifts. Adoption. Housing.

VOCATIONAL REHABILITATION AND EDUCATION Volume 9, 1966. Employment experiences of quads. Wheelchairs — respiratory, self-reclining, climbing, foreign. Remote-controlled typewriter. Association of Mouth and Foot Painting Artists.

QUADS AT COLLEGE AND AT WORK Volume 10, 1967. Citizens band radio. One-hand typing. Curb climbing and chin-controlled wheelchairs. Frog breathing. Portable lungs. Sex.

QUAD HOMEMAKERS Volume 11, 1968. Tenth anniversary issue. Home-based businesses. Quad driving. Wheelchairs. Mouth-operated phone. Music therapy. Remote controls.

QUADS IN THEIR COMMUNITIES Volume 12, 1969. Ramps for home and car. Home care services. Wheelchairs. Typing aids. Bathroom equipment. Photography. Living in Mexico.

INDEPENDENT LIVING BY QUADS Volume 13, 1970. Community service projects. Mouthstick typing. Cushions. Bath lifts. Tie-downs. Hydraulic tailgates. One-armed fishing. Chess.

QUAD ARTISTS AND PIANISTS Volume 15, 1972. Amateur radio. Rehabilitation centers. Worldwide religious groups. Housing and home services. Talking eyes. Portable ramps. Reclining and travel wheelchairs. Wheelchair pilots.

SOCIAL SECURITY AND MEDICARE Volume 16, 1973. Sex. Vans. Lifts and hand controls. Amyotrophic lateral sclerosis. Family reactions to quadness. Amputees. Living with a kidney machine. Cerebral palsy. Writing as a career. Yoga, Zen, and Sufism. Automatic telephones. Foreign periodicals.

HOBBIES FOR QUADS. TRAVEL to Mexico, Canada, and Europe. Volume 17, 1974. Travel with respirators. Recreational vehicles. Rehab Act of 1973. Bills of rights. Coalitions. Education and employment of quads. Adjustments to spinal cord injury. Biofeedback. German breathing treatment. Charcot-Marie-Tooth syndrome. Vans and lifts. Remote controls.

All issues from Volumes 5 through 24: \$8.00 per issue, including postage.

Note: "Quad" is not used in the specific spinal cord injury meaning of quadriplegia or tetraplegia (an injury at the neck level), but in the general meaning of a severely disabled person who has little or no use of arms or legs because of injury or disease — such as arthritis, amputation, cerebral palsy, multiple sclerosis, spinal cord injury, polio, muscular dystrophy or any other neurological disease.

101 EMPLOYED QUADS Volume 18, 1975. SSI. Multiple sclerosis. Data processing. Telephone services. IRS regulations on attendants. Camera for quads. Step-vans, lifts and ramps. Word board. Tie-down. Wheelchair narrower. ACCD.

VOCATIONS AND AVOCATIONS FOR QUADS Volume 19, 1976. A quad's view of understanding depression — helping with grief. Teaching blind persons to type. Employed quads. Independent living. Tennis. Skiing. Self-help organizations. Wheelchair loader. Step-vans. Hitch-hiking through Europe in a wheelchair. GPB for quads. ROHO cushion.

EMPLOYED QUADRIPLÉGIC WOMEN Volume 20, 1977. Rehabilitation in the Navajo Nation. Independent living programs. Wheelchair lifts for vans. Battery charger. Camper-pickup with lift. Self-operating electric hoist. Vocational rehabilitation rights. Traveling quads.

SPINAL CORD INJURY CENTERS. RESPIRATION EQUIPMENT Volume 21, 1978. Twentieth anniversary issue. A deaf Japanese student in the U.S. Don't be left without your RIGHTS. Disabled in Protestant churches. Indian sign system. Voice-activated telephone. Housing and home services. Portable iron lung. Pissing cross country. Suspension arms. Traveling quads.

NUTRITION. INDEPENDENT LIVING PROGRAMS Volume 22, 1979. Diet: A key to better health for SCI. MS diets. Lifestyles. Attendants at home and at college. Building a quad's own home. Mensa. Oral hearing-impaired adults. Computer programming training. Travel by a quad to 68 countries. Legbag control. Foot control driving. Pushbutton driving.

POST-POLIO AGING PROBLEMS Volume 23, 1980. Respiratory rehabilitation. Disabled Peoples' International. Adoption. Independent living. Housing and home services. Religion and rehabilitation. The *Gazette* editors' 1980 study tour of independent living in Europe. Travel in Europe for respirator-users. MS in Britain. Hand-cycling. Alert systems. Respirators. IYDP. Watch our words. U.S. periodicals.

GAZETTE'S POST-POLIO CONFERENCE IN CHICAGO Volume 24, 1981. Oral positive pressure. Making a cuirass shell. Adoption. Self-hypnosis. Learning disabilities. Coping with hospital care. Sexuality. Independent living centers. Independent lifestyles of persons with arthrogryposis, myasthenia gravis, Charcot-Marie-Tooth, SCI. Reclining wheelchair. Ceiling hoist. Lifts. VA-tested van lifts. Computers.

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

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Photo by Stewart Halperin

Joe and Gini Laurie, volunteer editors of the Rehabilitation Gazette, accept President Reagan's Distinguished Service Award presented by Justin Dart, Jr., Vice Chairman of the National Council on the Handicapped, on the 25th anniversary of their international journal for persons with disabilities.