

REHABILITATION GAZETTE

INTERNATIONAL JOURNAL OF INDEPENDENT
LIVING BY PEOPLE WITH DISABILITIES



SPECIAL FEATURES:

SYRINGOMYELIA

TRAVEL WITH A
VENTILATOR IN EUROPE:

Narrow Boating on
England's Grand
Union Canal

World Rehabilitation
Fund Study Tours in
France and Denmark

G.I.N.I.'s 1987 POLIO &
INDEPENDENT LIVING
CONFERENCE

Au Revoir

Best wishes and congratulations to Judith Raymond and Dr. D. Armin Fischer who were married on September 14, 1987, at the Church of St. Michael & St. George (Episcopal) in St. Louis.

Judith has been a very treasured member of the Gazette for 20 years. In May, 1984, she started as the Gazette's executive director and organized the formalization of the Gazette into Gazette International Networking Institute (G.I.N.I.), International Polio Network (I.P.N.), and International Ventilator Users Network (I.M.U.N.). She will continue to do editorial work for G.I.N.I. from her new home at 4635 Larwin Avenue, Cypress, California 90630.

Armin, chief of chest medicine at Rancho Los Amigos Medical Center in Downey, California, is well known for his knowledge of the breathing and sleep problems of polio survivors. He is a coeditor of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*.



D. Armin Fischer, MD, and Judith Raymond

Welcome

A warm welcome to new staff member Joan Headley, who joined G.I.N.I. on August 17, 1987, as director of G.I.N.I.'s International Polio Network.

Joan, who was disabled by polio in 1948, has been a high school biology teacher in Indiana for 20 years.

Joan is enthusiastic and committed to gathering and sharing information on the late effects of polio to help others as she was helped by the International Polio Network.



Joan Headley

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Syringomyelia

Syringomyelia in Paraplegics

by Bernard Williams, MD, ChM, FRCS

**SPECIAL
FEATURE**

Syringomyelia is a complication of paraplegia that can result in pain and loss of feeling or weakness of the upper limbs, sometimes leading to severe disability. Its early recognition is important, and knowledge of its occurrence should be more widespread.

The term syringomyelia means the existence of elongated tubular cavities within the spinal cord. The most common cause of such cavities is leakage (by a pumping action) of the cerebrospinal fluid, the clear, water-like fluid that normally bathes the outside of the cord, inside the cord. This produces extension of the cavities and destruction of the nerve tissues of the spinal cord with characteristic symptoms. Studying the nature of the pumping mechanism is difficult, but it seems probable that several mechanisms can be at work, sometimes more than one in a patient.

The most common form of syringomyelia is not caused by paraplegia and arises in patients who have deformities at the base of the brain. This group is "hindbrain-related" syringomyelia. These cases may be congenital or caused by birth injury, the late effects of meningitis, or brain tumors. Rare causes include inflammation of the coverings of the spinal cord, known as arachnoiditis, and also tumors of the spine; in both arachnoiditis and spinal tumors, the incidence of paraplegia is high.

In patients with spinal injuries, the condition is sometimes called "posttraumatic cystic myelopathy." To distinguish spinal causes, "non-hindbrain-related syringomyelia" is a useful term. For those cases occurring after fractures or spinal dislocations, "posttraumatic syringomyelia" is a widely used term.

In patients with posttraumatic syringomyelia, the nervous system is usually normal before the injury. It is the nature of the damage causing paraplegia that determines whether a pumping mechanism develops.

The simplest concept is that blood clots and damaged central cord tissues released at the time of the initial injury liquefy and cause a cavity, which then develops and spreads either upward,

downward, or both, chiefly under the influence of muscular straining such as coughing. The initial fluid in such a cavity is replaced and augmented by cerebrospinal fluid as the disorder progresses.

The majority of paraplegics do not have complications of syringomyelia because they were fortunate in not having much bleeding in the cord to initiate the cavitation. The fluid continues to get into the syrinx by either a sizable communication to the fluid outside the cord or seeping through the thinned and damaged tissues.

The incidence of the disorder in paraplegics is around 1% to 4%. It is probably more common in lower-level lesions and active persons but certainly occurs in sedentary and elderly persons with quadriplegia. It may occur after either complete or partial lesions. The disorder may start within the first year after injury but usually starts between the second and sixth years after the paraplegia.

The onset of symptoms may be slow and insidious or sudden. Often patients recall that the onset was brought on by a specific strain, such as coughing or lifting (Fig. 1). Pain may be accompanied by numbness or obviously disordered sensation. Pain and sensory disturbance may spread from the level of the paraplegia upward. Each ad-

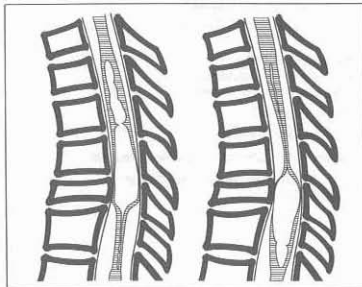


Fig. 1. Illustration of the mechanism by which straining aggravates syringomyelia. On the left the situation is shown at the height of a strain such as a sneeze. The fluid outside the cord is forced upward so that the lower part of the cavity is compressed and the upper part is enlarged. After relaxation, the pressure drops below the injury site and fluid tries to run downward, distending the lower part of the cavity. (Bones have a heavy outline; spinal cord is shaded.)

Dr. Bernard Williams is consultant neurosurgeon with the Midland Centre for Neurosurgery and Neurology in England.

vanice is sometimes associated with a strain. Alternatively, the disease may seem to jump upward, sparing part of the trunk. The altered sensation may start in the shoulder, side of the neck, or arm. Pain in the arms is common in paraplegics, who may strain joints during transferring, folding wheelchairs, etc.

The pain of syringomyelia is almost always one-sided and nearly always accompanied or soon followed by an upset of feeling. Sometimes this is numbness, but more commonly it affects the sense of temperature; hot and cold may be so disturbed that one feels like the other. Patients may therefore burn themselves without knowing.

If the disorder spreads, the area of pain or disturbed feeling may increase. Involvement of power may follow. It is always on the same side as the sensory involvement and its advance is commonly sporadic. Either the hand, elbow, or shoulder may become weak or start to let the patient down at critical times. In patients with partial paraplegia, there may be increasing leg weakness. In a few cases, the disorder may spread inexorably and involve all aspects of cord function including the initially uninvolved side.

Another feature that may indicate a developing cavity inside the spinal cord is disturbance of perspiration. Sweating is controlled by a complex mechanism and many paraplegics find their sweating patterns to be altered. The final pattern depends on level and completeness and may vary with such things as urinary infections. However, when syringomyelia develops in a paraplegic, there is often a marked change in the patient's usual pattern, with commonly excessive sweating, unprovoked by infection or overheating, followed weeks or months later by dryness. This phenomenon may occur above or below the level of the paraplegia depending on which way the cavities spread in the cord.

Downward extension of the cavity may improve the lot of the paraplegic if spasms are reduced. On the debit side, a well-balanced autonomic bladder can be upset, and in partial lesions there may be worsening of function in the legs, bladder, bowels, or sexual ability if syringomyelia supervenes.

Management of syringomyelia in a paraplegic is not clear-cut. One difficulty is that the progres-

sion of the disorder, if untreated, is unpredictable. Some patients achieve stability with only minimal problems, and it is therefore tempting to delay treatment by surgery until it is absolutely necessary.

The matter should be discussed with experienced medical personnel as soon as it is suspected, so neurological examinations can proceed and both the patient and surgeon can be involved in observation and decision making from the earliest stage.

Surgical treatment may take many forms. The aim of the surgery is to drain the fluid out of the cavity and keep it flat while it heals. The correction of the "pump" is therefore also important. Surgeons may decide to operate on the widest point of the cavity that is causing the trouble, commonly in the neck, or they may choose to intervene at the level of the initial fracture or dislocation (Fig. 2). Drainage tubes from inside the cord may be connected to sites within the spine, chest cavity, or abdominal cavity. Some surgeons prefer to put valves in such drainage tubes. Sometimes the cord is divided just above the site of the paraplegia. Most surgeons experienced with this condition have had some very satisfying results with improvements in symptoms and arrest in progression of the disease. Conversely, the disease sometimes appears to be unstoppable even after more than one surgical intervention. Drainage of the cavity only is probably not enough for most cases (Fig. 3).

Medical management is less likely to be successful than surgical treatment. Drugs have no curative value and the only nonsurgical steps that seem likely to be helpful are the avoidance of violent straining, such as may be involved in wheel-

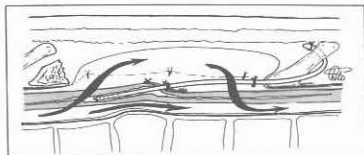


Fig. 2. Ideal situation after operation on the site of paraplegia. The syrinx cavity has been drained to the pleura (chest cavity outside the lung) and there is a free passageway for cerebrospinal fluid up and down the site of fracture (*heavy arrows*).

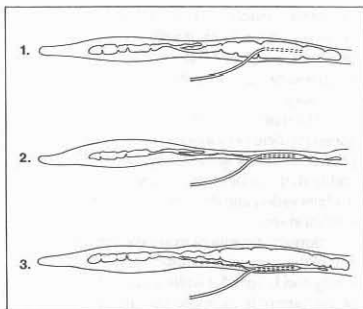


Fig. 3. An example of the difficulties if the cavity is partly drained but all of the cavity is not flattened or if the filling mechanism is not disabled. 1. Drainage that may produce good improvement. 2. Flattening and healing of part of the cavity. 3. The cavity may dissect upward alongside the healed part.

chair athletics. Competitive sports obviously are pleasurable and provide opportunities for social intercourse and travel; however, in the presence of symptoms of syringomyelia, any violent sport may be ill-advised and medical opinion should be sought.

Syringomyelia may be regarded as a serious complication of paraplegia and should be investigated carefully and documented at the first suspicion of its occurrence. Surgical treatment is well established and often spectacularly successful. The occurrence of difficult problems and sometimes relentlessly progressive disability that is resistant to treatment means that the condition should be treated with great care and respect and should be better known to patients, relatives, physicians, neurosurgeons, and lawyers concerned with compensation claims.

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The Maintenance of Function of People with Syrxinx

by Albert D. Anderson, MD

Loss of function is one of the bitter
components of disease.

— Is there a sweet one?

The event, whether abrupt or gradual,
comes as a surprise;

A moment when inability is irrefutable.

Sure you tell the doctor, but who is to

accompany you in this private descent?

Those who rush to inquire or do battle

are only observers, removed.

No one can go with you.

Whether loss of strength, motion, or skill.

Struggle, reach, do not surrender.

These writings, from someone intimately involved, are not intended as a frightening tally of the woes to be encountered as this disorder progresses.

They are meant to enable anticipation of coming events. Only then can an individual take preventive and coping action. For example, hypoesthesia and loss of position sense may cause a person to "lose" a limb. A hand may be caught between the spokes of a wheelchair, or left to the devastation of a bandsaw. One must learn to keep appendages in sight. Reader, observe the importance of constant visual monitoring!

The syndrome of spinal cord syrinx is caused by an expanding midcervical central cyst. A progressive weakness develops at and below the level of the site of encroachment; this may be symmetrical or asymmetrical. The trunk and limbs become overresponsive to what have been minimal, although noxious, stimuli.

The progressive dissociative sensory loss is insidious. The sense of temperature fades but touch remains. So slight is the loss in its early manifestation as to seem trivial. There is loss of the fine qualities of pain and lack of thermal awareness, and yet the person will experience touch, will feel the limb, will know of its existence. It is later that knowledge of the limb will recede. This is an excellent example of neuroanatomical localization through clinical appearance. For in-



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stance, the loss of superficial sensation in the face does not appear all at once, but descends from the numb forehead to the hypoesthetic malar region, to a chin without feeling as the cyst ascends in the rhombencephalon (hindbrain).

As part of the spinal cord picture, the strength of bladder contraction diminishes. Smaller volumes of urine initiate contraction. The result is frequent voiding. If there is not a significant residual (incomplete emptying), a man may solve the problem by wearing some form of external drainage. A woman faces the dilemma of using a catheter or a drug that diminishes bladder irritability. (This is an example of the necessity of seeking a specialist whose primary concern is not with the total experience of our disorder, but a fraction: in this case, the diseases of the urinary excretory system.)

The hindgut also loses its reflex motor abilities. The emptying mechanisms of the rectum require attention. The regimen of bowel toileting requires the judgment and management of someone experienced in bowel disorders of central nervous system origin. A stool of good volume and consistency must be presented to the hindgut, and emptying should be accomplished on a regular basis. It is to the benefit of a good bowel program, as well as to guarantee a good bladder flow (shown to be

of bacteriostatic value), that a minimum of 3 liters of fluid be taken orally. The judicious use of docosate sodium will keep the stool soft. Senna concentrate, at the dosage decided by the physician, should be taken at night, some 12 hours before the induction of evacuation by bisacodyl suppositories. A bowel program requires patience. The first rule: better out than in. Avoid constipation. Early attempts at regular emptying may result in "accidents," but incontinence padding is available.

The midcervical cystic collection ascends. Superficial sensory losses about the shoulder (shawl) are of diagnostic value, but are not of importance here. In the early days of the disorder, active hyperextension of the neck may produce an excruciating burning pain that darts down the midback (Lhermitte's sign), a frightening experience. However, it tells us what we already know: there is a disorder of the upper cervical cord.

Eventually, in the classic disorder, the cavitation reaches the hindbrain. In sequence, the nuclei are compressed, each yielding a clinical manifestation. Of significance are swallowing and speech difficulties. Swallowing may be improved by neck flexion and lateral rotation. However, it is the coordinate motion of the posterior oral musculature, in turn, that must direct a rounded mass (bolus) of food into a receptive esophagus and not into a larynx that is not in the digestive system. Incoordinate swallowing action that sends food or just saliva into the tracheal structures threatens aspiration and may require cuffed tracheostomy; in this case the responsible physician should seek an otolaryngologist.

Conjugate motion of the eyes permits binocular vision, and neural tracts running up and down the core of the brain coordinate eye movement. When these tracts are impinged on, there is a fine, jerking motion of the eyes. Pressure on the final motor pathways to the eye muscles results in double vision. One lens of a pair of noncorrective or corrective glasses can be frosted to yield monocular vision. Sudden, lateral motion of the head, or just the eyes, must be avoided because these will yield a pendular motion of the visual field and annoyance.

Ventilatory deficit resulting from neuromuscular disorder should be evaluated continuously.

When vital capacity is markedly reduced, the very presence of the oropharyngeal dead space may serve as an additional ventilatory work load. Consider tracheostomy. Some physicians are so concerned with the threat of pulmonary infection as to use intermittent antibiotics. An increase in sputum volume or change in color, or the occurrence of sputum odor, indicates a need for a culture.

Inability need not be an instant calamity. It is better to flatten the curve of unavoidable loss. Conventional techniques of the physical modalities are brought to bear on progressive motor weakness that occurs over the years. In response to those who might say "why bother?," consider the precipitous decline in strength, joint range of motion, and function that may occur in unattended progressive neurogenic paresis.

Under the supervision of a health professional specializing in restorative care, an exercise program appropriate to the grades of strength of the musculature of the trunk and extremities of the affected individual should be prescribed. I am biased toward the use of manual exercise because I feel strongly that a person undergoing a careful exercise program should perform under the close supervision of an experienced physical therapist. I do not approve of a trunkful of weights, sandbags, and over-door pulleys to every person on an exercise regimen. Certainly, no muscle with a grade less than Good should receive mechanotherapy. I am not certain of the preventive value of range-of-motion and stretching techniques to oppose muscle imbalances, spastic or flaccid. I feel more sure of the value of proper splinting. This holds particularly for paraspinal musculature and spinal curvature of paralytic origin.

A care program should include a regularly scheduled evaluation of self-care skills and ability to deal with problems of daily living and work performance. An interview is not sufficient. Evaluations should be performed by an occupational therapist. For example, shoulder forward flexors needed to reach a high closet shelf may be preserved, and loss of range of motion may be prevented by an appropriate exercise regimen. At a later date, the shelf may have to be lowered, but note the avoidance of an unnecessarily frustrating struggle in a dark closet.

Dr. Anderson acknowledges the editorial assistance of Sally Howard.

Function at home and work should be analyzed in terms of hand skills. With activities that can be demonstrated to relate to specific joints or truncal motion ability, substitutions and mechanical aids should be used and charted to permit review and demonstration of change over the years. Supports and positions can be devised by an experienced therapist that will place a joint in an optimum position for active function. Beware of splinting for cosmetic value only (for example, a dropped wrist makes a poor fist; simple dorsiflexion splinting is done for better grasp, not to make the hand look better).

It is no easy matter to keep up with an active person, but formal programming prevents or delays the scattered, unnoticeable loss of function. Bright persons will devise their own devices and substitute techniques to get around obstacles that occur at school, work, or play, but it is not necessary for a person to face challenges alone.

Williams¹ has shown that Valsalva's maneuver (straining) expresses cystic fluid beyond the level of the primary site. Other than precluding excessive static motions such as heavy lifting and wheelchair work, I cannot see the elimination of such straining as coughing, defecation, crutch walking, and wheelchair transfer. *And what of definitive therapy?*

A number of aspirations and/or shunting procedures have been devised to relieve or prevent the progress of the destructive cystic lesion. The necessity to know in order to take therapeutic action has brought neurosurgery to an exquisite knowledge of the dynamic neuroanatomy and neuropathology of syrinx. At the moment of diagnosis, every person with the disorder should be seen by an experienced neurosurgeon. This is essential if only to gain an awareness of the course of the disorder and perhaps to decide on wise intervention. Prevention is of greater importance. Cervical cord injury in the course of a difficult delivery is definitely one cause of this disorder.

The physician concerned with restorative care is often called on to assist impaired persons planning for their working future. We must have some knowledge of the probabilities of certain

organ system failures concomitant to particular clinical diseases. Restorative concepts do not require cure of a relentless disorder. Maintenance of function is a success — a victory.

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Williams B. Progress in syringomyelia. *Neurol Res* 1986; 8:130-145.

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The "504 Demonstrations" of 1977

by Mary Jane Owen, MSW

Each minority group in the United States, as it has gained self-awareness as a group, has found itself needing to look in two directions. While concentrating on future strategies and breaking new ground, it is also forced to trace its own historical roots and to claim its existence through time. The disability movement is no different. It has a history but the validity of its involvement in past events too often lacks documentation. The heroes are seldom recognized as such and too often forgotten. Too few have had the opportunity to participate actively in a broad social context and little energy has been devoted to the effort to document events from a disability perspective.

Ten years ago, from April 5 to May 1, 1977, there was a series of events in which people with a range of disabilities acted out their dreams for acceptance within their environments. The "504 Demonstrations" for regulations to guide federal protection of civil rights of America's "handicapped" citizens were played out against a background that tended to ignore their importance.

Precious few have done more than record some personal involvement; the rich tapestry of those events that preceded the signing of the guidelines for implementation of the Rehabilitation Act has not been illuminated. There are many ways in which 1977 proved a watershed year and events in many communities across the country galvanized activists in diverse ways.

Histories currently being written rarely give more than a paragraph to these realities and many claiming to speak with authority about the results of the "504" activities have neglected both the national political effects and the personal changes that a new sense of potency brought to people who had lacked a sense of value or unity of purpose.

The bone-chilling cold of the vast expanse of the converted car dealership forced us to huddle around a small electric heater. We had come, after hours, to plan a West Coast response to the Washington, D.C.-based American Coalition of Citizens with Disabilities, (ACCD) request that we plan some sort of rally or event to focus attention on the slowness of the Carter administration's campaign promise to move to formalize the civil rights protections for disabled citizens. Our passion ran

high and I remember assuring Judy Heumann that, if we planned to sit-in, I would be there as long as anyone. The others agreed. We would plan to stay ourselves and suggest to others that they come prepared for such an event, but not make a point of confrontation. We were not yet sure others would care to follow our example.

The New York Times and *The Washington Post* are two major newspapers that are considered reflective of the nation's concerns on a given day. Neither had a reporter with a disability perspective then, and one might question if either does today. In 1977, disability was covered as a special feature or a health report. The few items in either newspaper during April or May of 1977 did not look beyond official Washington bureaucrats for background on the issues. Good people whose jobs were in the caretaking area were seldom questioned; those affected personally by the protective legislation were apparently never considered for comments.

We were fortunate to have an accessible transportation system. The Bay Area Rapid Transit (BART) officials were notified that they might expect an increase in usage by wheelchair users. Every possible source of support was briefed; news releases and background information were distributed broadly. City, state, and federal political figures were asked to join with representatives of every possible minority group and disability classification to speak at a rally. Permission for a good sound system was applied for and a bull horn was borrowed. The agenda was set and rough guidelines for entering the building were laid out. (We marveled over a leaked memorandum from HEW officials recommending that the handicapped visitors be greeted with courtesy. There was a flavor of serving tea and cookies to the children before sending them safely home.)

Most of the planners already had friends or colleagues within the local political and media systems. As a former professor at San Francisco State University's Master of Social Work Department, I had a supervisory role with a number of graduate students who had been placed in local, state, and federal offices and had connections with both Mayor George Moscone and Congressman Phillip Burton.

Mary Jane Owen, who is visually impaired, is Executive Director of Disability Focus, Inc. in Washington, DC.

We needed every resource and connection. After sleeping the first night on the hard floors, mattresses were delivered from the supplies of the State Health Department. Food arrived from McDonald's, Delancy House's drug programs, the Black Panthers, and Safeway. The Mayor himself scolded the federal officials for ignoring the needs of the uninvited guests and brought in shower attachments to be used in the tiled restrooms.

Phillip Burton arrived from Washington at a critical point. The guard at the door was refusing to allow the entrance of members of the Black Panthers who were bringing in food. As a congressman, he used his authority to stress that we must be allowed to eat, but we had already anticipated a food shortage. Our peers in Washington had been forced to cut short their sit-in after a brief stay because they were allowed no food.

Some of us decided to call a hunger strike to confirm to ourselves and others our commitment to stay at any cost. We who chose that form of commitment were amazed at how much time the others had to spend with food: its preservation, preparation, and clean up. We were free to spend those hours in discussion, strategizing, writing, etc.

Once, we played the game of "Godmother," with the person designated as the Godmother offering each of the players one wish. Some wished for a favorite food; others for success in our goal of having "504" regulations signed. The last to present her wish was Cathy, a young woman who used crutches. "If I'd been asked before to make a wish, it would have been not to be a cripple anymore. I wanted to be beautiful. But now I know I'm beautiful, just as I am." I can never remember that evening without the passion rising up into my throat and, swallow as I may, the lump remains. She was a hero.

There were so many — Steve, who lay, day after day and night upon night, taping events around him on a recorder because he knew what was happening was important enough to risk his health; Jeff, who brought his guitar and proved to be a master cheerleader with chants on the bull horn — he wrote new words for old civil rights songs with which we loudly greeted federal employees in the morning; the members of the Butterfly Brigade, a gay street patrol that loaned us

their walkie talkies when the officials turned off our telephones; the deaf woman who entered the building to teach a class in sign language and stayed; the mentally retarded woman who always injected a note of realism into our too-abstract deliberations late at night when we talked of possible arrest or forceable removal.

We were *all* heroes and *all* suffered variously from the stress and strains of the confrontation and testing of our strengths. But no one who participated left that building the same as they entered. We built a community of concern. I entered the building an intellectual bigot and left after knowing the positive value of mental variety.

Today, histories of the civil rights of disabled people are being written without the benefit of the experiences of hundreds of people who went through those days gaining a sense of power. The growth of the minority mindset of the disability movement was fostered by these events and sacrifices. People placed their lives and health on the line and believed the potential gains were worth the risks.

That time *must* be remembered. The stories must be told. The passion must be passed on. 福

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Concepts — A Unique Approach to Personal Care Attendants

by Sandra Schnur and Ira Holland

Concepts of Independence, Inc., offers an opportunity for self-directing persons with disabilities to maximize their goals of living independently. If such an alternative were not available, these same people would be forced to receive services from an agency that does not consider their needs and strengths, only their physical limitations. As representatives from Concepts have said, "... without Concepts, one controlling health care institution would be exchanged for another." This statement reflects the reaction to conventional home health care systems that require passivity on the part of service recipients and a willingness to accept agency mandates. An agency can send any available personal care attendant with little concern for the working relationship.

In several states, the local department of social services has elected to fund personal care services for elderly and disabled persons. This is done in New York with Medicaid monies for persons whose income does not exceed \$417 per month, who are elderly or disabled, and who are authorized to receive personal care services. The Human Resources Administration is the administering agency for Medicaid and home attendant personal care services in New York City.



Concepts of Independence, Inc., Staff

Because of the threat of agency intervention and domination (i.e., workers who have an allegiance to the hiring agency, not to the consumer), a core group of severely disabled persons held a protest demonstration in 1977 outside the chambers of the New York City Board of Estimate which approves City contracts. People in motorized wheelchairs, most of whom had to have their ventilators plugged into corridor outlets, sat waiting to talk with Board of Estimate members.

The demonstration led to many meetings with City and State representatives, which took place over a two-year period. In 1979, this same core group of severely disabled persons developed and presented an alternative mode of service delivery to City and State representatives. The alternative is Concepts of Independence, Inc., New York City's only client-maintained plan. Its services are available throughout New York City's five boroughs; currently there are more than 250 people in the program. In order to become a Concepts member, a person must be Medicaid eligible, authorized to receive personal care services, and be deemed self-directing by the Human Resources Administration (based upon completion of a lengthy questionnaire).

Concepts members are as varied in age and lifestyle as is the general population, but all Concepts members have disabilities of varying severity. All Concepts members receive varying allotments of personal care attendant hours based on the recommendation of a team that includes a physician, medical social worker, and a Human Resources Administration caseworker.



Sandra Schnur, polio survivor, is President of Concepts, Inc. Ira Holland, ventilator user, is Vice-President of Concepts.

Concepts is a fiscal intermediary that receives Medicaid monies to administer personal care attendants payroll and benefits package. Upon hiring a personal care worker, it is the member's responsibility to enroll the person, to fill out and to submit weekly time sheets.

Concepts is unique in that it requires members (consumers) to interact directly on a one-to-one basis with their personal care attendants. Members of Concepts receive and distribute payment directly to the attendants, thus reinforcing the belief that the attendants are the employee of the consumer, not the agency. Concepts requires members to choose their own lifestyles. For Concepts members, this means assuming responsibility for recruiting, hiring, training, supervising, paying, dismissing, and developing a cadre of backup attendants.

Currently, Concepts offers its members recruitment assistance via a hotline with names and phone numbers of members seeking personal care attendants, that is heard by personal care attendants seeking employment when they dial the Concepts hotline number.

In addition, Concepts Board of Directors has written *Living Independently: A Consumer's Guide About Personal Care Attendants*. This publication offers advice on such topics as how to recruit help, developing emergency backup resources, how to interview, supervising your employee, lifestyle choices, evaluating your employee, and terminating your employee.

The ability to determine one's lifestyle as well as how, when, and with whom this will be accomplished has resulted in greater self-esteem and satisfaction for each Concepts member.

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Address: Concepts of Independence, Inc.,
853 Broadway, Suite 1404, New York, NY 10003.
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Concepts Board of
Directors meeting

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Disabled Peoples' International

by Diane Driedger

"Disabled people of the world — join us in our struggle. Join us in our struggle for full participation and equalization of opportunity." (DPI Singapore Declaration, 1981). Indeed, Disabled Peoples' International (DPI), an organization of people with physical, mental, and emotional disabilities, wants justice, not charity.

DPI has obtained consultative status with the United Nations, International Labor Organization, and UNESCO. It has been successful in airing human rights violations against disabled people at the United Nations Human Rights Commission. Perhaps most important, DPI has shown the world that people with disabilities are able to represent themselves effectively at the international level. DPI has been the catalyst for the building of organizations of disabled people in 100 countries around the world in the last 5 years.

DPI was officially born in December 1981 in Singapore. Four hundred disabled people from 51 countries attended the first DPI Congress.

The Constitution and Manifesto accepted in Singapore asserted the basic rights of disabled people as participants in society like everyone else: the right to education, rehabilitation, employment, independent living, and income security. The Manifesto also declared that disabled persons have the right to influence governments and decision-making processes through their own organizations. By the end of the Congress a new World Council was elected for DPI with 25 people, five from each of five regions of the world. This governing body would meet once a year in the next 5 years.

To be a full member of DPI, an organization must be national, and the majority of decision-making positions must be filled with disabled persons.

National organizations are involved in a variety of issues. They lobby their governments for increased access to public buildings, employment opportunities, public schools, and transportation. Although all these issues are important, perhaps transportation is most fundamental. The ability to live independently depends on whether one can leave home for work and recreation. If there is no affordable or accessible transportation for many

people who are mobility impaired, they will have difficulty finding and holding a job. In many North American and European countries, governments fund public transportation, such as bus travel, for disabled passengers. In these systems disabled people usually pay the same fare as nondisabled bus riders.

In developing nations in Africa, Asia, Latin America, and the Caribbean, a pressing issue for mobility impaired people is the lack of wheelchairs, crutches, and prostheses. Without these aids, people with a physical disability crawl, scoot on leather or bamboo mats, or remain bedridden in parental homes. Because of this, many disabled peoples' self-help organizations are initiating wheelchair factories operated by people with disabilities themselves, with local materials used to produce wheelchairs designed for the local terrain.

Not only have these organizations addressed the wheelchair shortage, they have started self-employment projects. In Jamaica the Combined Disabilities Association has run a wood products factory since 1983. It is an integrated factory in which half of the employees are disabled and the other half are nondisabled. In Zimbabwe, the National Council of Disabled Persons has started small animal and vegetable farming cooperatives.

DPI's "Self-Help Leadership Training Program" seminars enable disabled people who are experienced leaders and organizers in their countries to share their expertise in forming disabled peoples' groups and in lobbying governments for changes. Self-help organizations are a vehicle for disabled persons to speak collectively to governments, society, and service providers for improved job opportunities, accessible public buildings and transportation, and education. After a 2-week seminar, newly-trained leaders return to their countries equipped with tools to organize and build their own groups.

In addition to conducting a development program, DPI has addressed international issues. DPI helped shape the UN World Program of Action Concerning Disabled Persons and the ILO's Vocational Rehabilitation Convention. In both cases, DPI was successful in incorporating key elements of DPI philosophy into these documents. Most important, the documents assert that disabled

Diane Driedger of Canada is working on a history of Disabled Peoples' International for her master's thesis.

Nutrition for Polio Survivors

by Charlotte Gollobin, MS

peoples' organizations should be consulted on policies that relate to disabled persons.

DPI was successful as well in bringing human rights violations against disabled people to the attention of the UN Subcommission on Prevention of Discrimination and Protection of Minorities. DPI was successful in appointing a Special Rapporteur, or reporter, on the status of disabled peoples' rights.

Disabled persons' rights as human beings are violated in wars and armed conflict every day around the globe. Thus, peace is a disability issue for DPI. It called for peace in its International Peace Declaration, issued after the DPI World Council visited Hiroshima, Japan, the site of the first atom bomb blast: "The creation of disability and the ending of life by the waging of war gains pace . . . Let us insist that the \$600 billion now spent on armaments is diverted to socially useful projects."

DPI, as an organization purporting to represent all the world's disabled people, recognizes the need to increase the representation of certain disability groups. Persons who are deaf and mentally handicapped must be represented more equally. In 1985 DPI resolved to involve more women in its leadership. DPI's goal is to increase the participation and representation of women to 50% at all levels of the organization in the coming years.

The participation of all disabled people will strengthen self-help organizations worldwide. All over the world disabled people are organizing to speak for themselves with, in the words of DPI's motto, "A Voice of Our Own."

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Address: Diane Driedger, 249 Simcoe St., Winnipeg, Manitoba R3G 1V9 Canada.

During G.I.N.I.'s Fourth International Polio and Independent Living Conference in June 1987 in St. Louis, I discovered that most polio survivors do not have good diet regimens. Weight control and nutrition should be important parts of everyone's lives, but especially of polio survivors, many of whom are inactive, overweight, and perfect candidates for heart disease and other debilitating illnesses.

If one is overweight, one can begin to lose weight by cutting caloric intake by 3500 calories/week (500 calories/day). Diets high in fat cause increased weight, and the American Heart Association now recommends that diets contain no more than 30% of calories as fat.

However, some fat is beneficial. Fish contains oils that help lower triglycerides and prevent platelets from clumping, thereby lowering the risk of heart disease and atherosclerosis. Although olive oil doesn't lower cholesterol levels, it improves the ratio between high and low density lipoproteins and total cholesterol, thus lowering the risk for heart disease.

When one counts calories, one should be aware of portion sizes. It is helpful to learn what portion sizes look like so that when preparing food or dining in a restaurant, one knows how much to allow oneself to eat.

Protein and carbohydrates contain 4 calories per gram, and should be important parts of one's diet, especially complex carbohydrates, such as those found in vegetables, fruits, whole grains, and legumes. These foods also contain dietary fiber.

Diets high in fiber are associated with lower incidence of diabetes, appendicitis, hemorrhoids, diverticulitis, and colon cancer. High-fiber diets can lower cholesterol levels, slow the release of sugars into the blood, and prevent constipation. The amount of fiber per day one needs is 25-35 grams. The most popular fiber foods include:

Food (½ cup cooked)	Fiber (grams)
All Bran w/ extra fiber	13.0
100% Bran	9.1
Kidney beans	5.8
Pear	4.6
Sweet potato	4.2
Peas	4.1
Potato, baked	3.8
Apple w/skin	3.5
Orange	2.6
Rice (brown)	2.4
Carrots	2.3
Broccoli	2.0
Spaghetti	8

Pasta is a favorite fiber and complex carbohydrate food because it is healthy and not very high in calories if one avoids the creamy sauces. Pasta has been a staple of the Mediterranean diet for centuries, a diet that contains many foods known to help prevent heart disease. The Mediterranean diet consists of vegetables, fruits, fish, olive oil, small amounts of meat, pasta, bread without butter, and low-fat cheeses.

Everyone should be aware of the amount of salt ingested. The amount of natural sodium in most foods is more than enough without adding salt. Too much sodium can cause water retention as well as hypertension.

When one reduces the amount of calories, one also lowers the total food intake and therefore decreases the amount of essential nutrients ingested. Many people in the United States are marginally deficient in calcium, zinc, iron, magnesium, Vitamin A, B-6, and C. Certain age groups are more deficient in certain vitamins than others, and it is reasonable to suspect that polio survivors may be even more deficient. (I am not aware of any research being conducted on nutrients in relation to the late effects of polio.)

A multiple vitamin/mineral supplement each day can guarantee that one is receiving the recommended dietary allowance (RDA), but that is to supplement the diet, not replace it.

A multivitamin can provide vitamins such as Vitamin A, C, and E, that prevent the destruction of tissue. Oxygen, while burning the fuel from the food we eat to provide energy, can form destructive materials in the body. Vitamins A, C, and E, can prevent such formation.



Charlotte Gollobin, MS, nutrition consultant, is president of the American Nutritionists Association.

Carpal tunnel syndrome is a common ailment among polio survivors. New research indicates that certain B vitamins can be very effective in treating carpal tunnel syndrome if caught early enough.

Vitamin/mineral supplements should have 100% of the RDA for all listed ingredients. A good checklist should include Vitamins A, C, D, E, K, B-1, B-2, B-6, B-12, biotin, folic acid, niacinamide, and pantothenic acid. Minerals should include calcium, phosphorus, iodine, iron, magnesium, copper, manganese, potassium, chromium, molybdenum, selenium, and zinc.

Exercise should also be an important complement to any diet program. Even simple range-of-motion and stretching exercises can help burn off calories because they increase the metabolic rate. New research indicates that this increased rate continues for several hours after the actual exercise activity.

Polio survivors, as well as individuals with any disability, need to be especially careful of diet regimens. With advancing years, eating well and preventing extra weight from slipping on will aid polio survivors in maintaining fully functional weightbearing joints.

RECOMMENDED READING:

- Brody, Jane. *Jane Brody's Nutrition Book*. New York, Bantam, 1982.
- Hausman, P. *The Right Dose*. Emmaus, Pennsylvania, Rodale Press, 1987.



Address: Charlotte Gollobin, MS, 11510 Old Georgetown Rd., Rockville, MD 20852.

Congratulations



Berkeley Center for Independent Living Staff



John Hessler

Photo credit:
Harvey Zane Holland, ©1987



Ed Roberts

Photo credit: Benjamin Ailes

15th Anniversary

A coalition of people with severe disabilities founded the Berkeley Center for Independent Living (CIL) in 1972, continuing the model of living independently at home begun in the 1950s by polio survivors. CIL is now recognized worldwide as the inspiration and archetype for over 300 centers.

CIL's programs advocate for the rights of people with disabilities, nurture community support, and encourage people with disabilities to participate as fully productive members in the community. CIL's services focus on job development, living resources, integrated housing, peer counseling, and independent living skills.

The 15th anniversary of CIL in 1987 marks its successes:

- More than 136,000 persons with disabilities received direct services from CIL —
- More than 500 residential ramps built free of charge —
- More than 1,000 persons with disabilities placed in jobs.

Because of CIL's services and programs, people with disabilities are freed from dependence on families, friends, or institutions, and enabled to take charge of their own lives and to take risks. 福

Address: Michael Winter, Executive Director,
Center for Independent Living, Inc., 2539 Telegraph
Ave., Berkeley, CA 94704, 415/841-4776.

25th Anniversary

The University of California—Berkeley Physically Disabled Students' Residence Program marks its 25th anniversary in 1987. Established in 1962, the residence program began with one ventilator-dependent quadriplegic student, Ed Roberts, living in a special wing of UC—Berkeley's Cowell Memorial Hospital. A second quadriplegic student, John Hessler, joined Ed in 1963.

Both went on to work for the state of California; Ed as director of the Department of Rehabilitation and John as chief of operations for the Department of Health Services.

In 1975 the residence program moved out of Cowell Hospital into the university residence halls. Today the program provides special assistance to students with severe disabilities who are spending their first years in the residence halls. The program emphasizes independent living skills to students who have previously lived at home or in nursing homes, especially how to hire and train personal attendants for routine care.

In a recent survey of program graduates, many said the program had meant the difference between a restricted, dependent existence, and an active, independent life. 福

Address: Susan O'Hara, UC—Berkeley, Disabled
Students' Residence Program, 2515 Channing Way,
Berkeley, CA 94720, 415/642-0518.

Travel with a Ventilator in Europe

Narrow Boating on the Grand Union Canal

by Audrey King, MA

Unknown to many, an historic network of over 1500 miles of navigable inland waterways thread their way through the heart of Britain. Linking remote countryside with villages and major tourist attractions, the rivers and canals are a living and working inheritance from a bygone age. With no schedules and no telephones your time is your own to enjoy a unique escape from the trials of 20th century life. (U.K. Waterway Holidays, 1986)

A small news item in the *British Polio Fellowship's Bulletin* (Spring 1985) offering "accessible" canal boat vacations caught my eye as a unique opportunity. I sent the item to Chris, my British childhood friend, and asked her to inquire further. Several months later she telephoned, suggesting that I book my holidays and airfare to England, because the *Sheldrake* had now been officially reserved and arrangements made with St. Thomas' Hospital in London to borrow a Monaghan 170C ventilator, to enable me to breathe when asleep.

In April, Chris, husband Tim, and 12-year-old Katie drove to Nash's Mills, near Hemel Hempstead on the Grand Union Canal (that section of waterway between Birmingham and London). They learned how to operate and steer the 20 HP Lister Air-cooled diesel-driven boat and work the locks.

They inspected the *Sheldrake* and saw that, although the boat was narrow and long, tall people could stand comfortably, and six people could sleep and eat on two sets of built-in bunks, two fold-up sleeping shelves with mats, a drop-down table, and a folding table for use outside the boat. A gas-fueled heater, hot and cold running water, two cubic-foot refrigerator, dishes, and "accessible" flush toilet, sink, and shower were provided.

A removable section of deck rail and a small aluminum ramp enabled easy wheelchair access between canal bank and deck (although often this was not required). A battery-powered lift in the hatchway, easily accessed by removal of a set of hooked-on steps, enabled a wheelchair user to move easily between the deck and living quarters below.

We boarded the *Sheldrake*, armed with sleeping bags and provisions that wouldn't last the week. We weren't worried because we needed excuses to stop at picturesque canal-side pubs and historic villages along the way. I took up a navigational position on the fore deck with the appropriate section of Elwin & King's *Braunston to Brentford* historical guidebook unfolded.

Within ½ hour we had gone through several locks, passing the Nash and Apsley Victorian paper mills, cricket matches at Boxmoor, curious swans, and convoys of baby ducks and moorhens who were to escort us throughout.

We passed the Fishery Inn at Boxmoor, admiring the brilliantly colored flowers suspended in baskets from an overhanging upper level and easy canal-side access that would encourage us to stop on our return. We purred along before stopping finally at another canal-side pub, the Three Horses-shoes at Bourne End.

We moored on the opposite bank, intending to walk across the swing bridge, which we discovered was under repair. The wheelchair and I had to be carried up open plank stairs and across a temporary scaffold over the canal in order to enjoy a drink at the canal-side tables before supper. Never again! Needless to say our instincts for searching out accessible moorings beside accessible watering holes improved dramatically and, by the time we lunched outside the Globe at Old Linsdale on our return trip home, the *Sheldrake* was moored so close to us we could have touched her.

We moored at night along quiet rural sections of the canal. It was wonderful to wake up to a peaceful dawn at the foot of a farmer's field or to find yourself beside banks of tumbling wild flowers. Several times we saw herons taking flight as the sound of our motor broke their solitude.

A gasoline-fueled generator, chained to the back deck and sheltered under two bright red umbrellas, delivered, via extension cords fed along the side of the boat and into the cabin, the electricity my ventilator required to operate.

As the days passed we slowly climbed our way through an ever-changing landscape and 22 locks to the summit of the Chilterns, then down through more locks on the other side to the canal town of Stoke Bruerne.

Audrey King, respiratory polio survivor, is a psychologist with the Hugh MacMillan Medical Center in Toronto, Canada.

Audrey has just published a disabled fable, *There's Lint in Your Bellybutton*.

We settled into a comfortable daily routine, rising about 7 a.m., filling our stomachs with muesli (Swiss granola), and working our way through several locks before mooring for a “proper” breakfast in some attractive spot.



Audrey King on the deck
of the *Sheldrake*

We ate enormous quantities of food. Perhaps it was the amount of baked beans or the deliciously fresh bread and cheeses that we ate, or perhaps it was just the close-quartered congeniality, that seemed to make all of us progressively more flatulent and aerophagic. Certainly as the week progressed we chatted increasingly about the state of our collective “alimentary canal,” for *Sheldrake’s* manual had clearly warned that “effluent is captured in a holding tank on the vessel which has a finite capacity . . . whenever possible use public facilities to minimize the risk of your tanks prematurely becoming full. Given sensible use the toilet capacity is adequate for a week’s cruise.” This printed threat, hovering over every meal, was enough to make the calmest abdomen rumble. But finally it was Chris’ loose lasagna, dubbed the “*Sheldrake* slurry,” that did us in. With only 2 days to go we stopped for a pump out, breathed a sigh of relief, and . . . ate unashamedly all the way back to Nash’s Mills.

We went through 112 locks, covering a distance of only 94 miles. Opening and closing the lock gates and waiting for the locks to fill or empty usually took 10 to 15 minutes. The 14-foot-wide locks, narrow by European and North American standards, usually raised or lowered us by 6 to 8 feet, although one lock we went through changed our height by only 18 inches. The amount of water leaving (or entering) a lock each time can be as much as 56,000 gallons, so it is easy to appreciate why there are large reservoirs at the summits

feeding water into collecting side ponds beside the locks to keep the canal system open, particularly during dry periods.

Every day we took time to tie up, eat, explore, or shop in some historic village or town.

The larger town of Leighton Buzzard offered well-identified public washrooms for disabled persons ($\frac{1}{2}$ mile from those near the canal for non-disabled), a modern supermarket with checkout counter assistance for disabled persons, and many small specialty shops.

A 15th-century market cross, town hall, and the 13th- to 16th-century Church of All Saints provided historical interest. We attempted to enter this church, situated close to the high street in peaceful, secluded grounds, but it was entirely covered in scaffolding and an ominous sign warned: “All ye who enter here must wear safety helmets.”

Some of our most enjoyable expeditions were in less-populated areas. At Great Linford we moored beside manicured lawns sweeping gracefully up to a fine group of 18th-century manorial buildings. A gabled 17th-century almshouse block lies opposite, hiding behind it among the trees the 14th-century Church of St. Andrew’s.

Sometimes we walked several miles along country lanes to locate an interesting pub such as Ye Old Swan at Woughton-on-the-Green or up a long slow hill with fantastic rural views to discover a historic village such as Soutbury with its 14th-century houses and 18th-century Lovetts School.

We ferreted out the peaceful village of Willen, still hidden from the ominously close, ever-encroaching modern town of Milton Keynes. The Hospice of Our Lady and St. John’s nestles peacefully beside the Willen wild fowl reservoir. A peace pagoda with a huge golden Buddha dominates the crest of the hill overlooking the reservoir, its hundreds of steps flanked by pairs of white Chinese lions, the monument itself sitting against an enormous backdrop of thousands of cherry and almond trees. Beside the hospice is Saint Mary Magdalene’s Church, built centuries ago by a contemporary of Sir Christopher Wren.

Traffic on the canal was sparse, particularly on the long, peaceful stretches that were blended so well into the landscape as to feel like a river. We passed only a few other narrow boats each day.

(continued on page 23)

Rehabilitation Gazette

4502 Maryland Ave., St. Louis, MO 63108 U.S.A. • 314/361-0475

Rehabilitation Gazette, an international journal of independent living by people with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences. The *Gazette* has grown from a local newsletter to a renowned international journal reaching 40,000 readers in 87 countries (with translations in Japanese) and evolved to include other physical disabilities and the aging of all disabled persons.

Reflecting the imaginative, practical, and down-to-earth life experiences of its disabled readers, the *Gazette*

is a form of peer counseling by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. Personal experiences in the *Gazette's* articles motivate other readers to live full and independent lives.

The *Gazette* is read by health care professionals interested in creative rehabilitation and in gaining additional insight into the interests and needs of persons with disabilities, and, of course, by persons disabled by polio, spinal cord injury, cerebral palsy, multiple sclerosis, muscular dystrophy, ALS, or stroke.

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1985. Volume 26. Special feature: Independent Living vs. Institutionalization. Articles: SCI Mother: My Pregnancy and Delivery. Religion and Disability. Polio Survivors. Guidelines for Polio Support Groups.

1982. Volume 25. Special feature: Second International Post-Polio Conference, St. Louis. 25th Anniversary Issue. 25 Years Later — Polio Survivors in Canada and U.S. Cerebral Palsy Challenges. Myasthenia Gravis. Wheelchair Travel. Equipment: Mouthsticks/Page Turners, Ventilators, Lifts and Ramps. Portable Rocking Bed Plans.

1981. Volume 24. Special feature: International Post-Polio Conference, Chicago. Independent Living — Attitudes and Lifestyles. Independent Living Centers. Oral Positive Pressure. Homemade Cuirass Shell. Adoption. Equipment: Ceiling Hoists, Lifts, VA-tested Van Lifts.

1980. Volume 23. Special feature: Post-Polio Aging Problems. Respiratory Rehabilitation. Disabled Peoples' International. Adoption. Religion and Rehabilitation. Independent Living in Europe. Travel with a Ventilator in Europe. Equipment: Handcycling, Alert Systems, Shoes.

1979. Volume 22. Special features: Nutrition — SCI and MS Diets. Independent Living. Oral Hearing-Impaired Adults. Computer Programming Training. Wheelchair Travel. Equipment: Legbag Controls, Automated Urinator, Foot Control, and Pushbutton Driving.

1978. Volume 21. Special feature: Twenty Years in the Gazette House. Spinal Cord Injury Centers. Education and Employment. Rights and Legislation. Religion. Amerind — Indian Sign System. Equipment: Respiration Equipment, Portable Iron Lung, Suspension Arms. Pissing Cross Country.

1977. Volume 20. Special feature: Employment of Disabled Women. Rehabilitation in the Navajo Nation. Vocational Rehabilitation Rights. Equipment: Wheelchair Lifts, Battery Charger, Camper-Pickup with Lift, Self-Operating Electric Hoist.

1976. Volume 19. Special feature: Vocations and Avocations for Quads. Coping with Depression. Blind Typing. Quad Employment. Housing and Independent Living. Tennis and Skiing. Wheelchair Travel. Frog Breathing for Quads. Equipment: Remote Controls, Wheelchair Loader, Step-Vans, ROHO Cushion.

1975. Volume 18. Special feature: 101 Employed Quads. Multiple Sclerosis. IRS Regulations and Attendants. SSL. Telephone Services. Equipment: Quad Photography, Step-Vans, Lifts and Ramps, Word Board.

1974. Volume 17. Special feature: Wheelchair and Ventilator Travel to Mexico, Canada, and Europe. Hobbies. Rehabilitation Act of 1973. Education and Employment Biofeedback. Charcot-Marie-Tooth. Acupuncture. *German Breathing Treatment*. Equipment: Vans and Lifts, Remote Controls, New Wheelchairs.

1973. Volume 16. Special feature: Disabled Veterans. Amyotrophic Lateral Sclerosis (ALS). Kidney Dialysis. Yoga, Zen, and Sufism. Sex and Disability. Amputees. Equipment: Vans, Lifts and Hand Controls, Automatic Telephones, Chin Switch, Mouthstick Controls, Curb-Jumping.

1972. Volume 15. Special feature: Quad Artists and Pianists. Woodrow Wilson Rehabilitation Center. Housing and Home Services. Ham Radio. Equipment: Talking Eyes, Wheelchairs and Accessories, Remote Controls, Ramps, Wheelchair Pilots.

1970. Volume 13. Special feature: Independent Living by Quads. Community Service Projects. Mouthstick Typing. One-Armed Fishing. Chess by Mail. Equipment: Wheelchair Cushions, Bath Lifts, Hydraulic Tailgates.

1969. Volume 12. Special feature: Quads in their Communities. Education and Employment. Travel and Living in Mexico. Quad Photography. Equipment: Ramps, Wheelchair Accessories, Bathroom Aids, Typing Aids.

1968. Volume 11. Special feature: Ten Years in the Gazette House. Quad Homemaking. Homebased Businesses. Rehabilitation through Music. Equipment: Quad Driving, Remote Controls, Wheelchairs.

1967. Volume 10. Special feature: Quads at College and at Work. Sex and the Disabled. Citizens Band Radio. Friends Around the World. Frog Breathing. One-Handed Typing. Equipment: Chin-Controlled Wheelchair, Curb-Climbing Wheelchair, Remote Controls.

1966. Volume 9. Special feature: Vocational Rehabilitation and Education. Employment. Association of Mouth and Foot Painting Artists. Hobbies. Housing. Equipment: Wheelchairs, Remote Controlled Typewriter.

1965. Volume 8. Special feature: Travelling Quads. Biomedical Engineering. Housing. Education. Quad Drivers. Equipment: Lifts, Ramps, Wheelchairs.

1963. Volume 6. Special feature: Quads and Their Families. Marriage and Adoption. Camping. Vacations. Equipment: Wheelchair Cushions, Australian Fiberglass Iron Lung.

1962. Volume 5. Special feature: Higher Education of Quads. Correspondence Courses. Education by Telephone. Reading Aids. Attendants. English Views of Positive Pressure Ventilation. Self-Aspirator.

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(continued from page 18)

The Tring Cut, a 1½-mile section of the canal at the top of the Chilterns, was an exceptionally beautiful tree-lined glade that we had to ourselves for a good ½ hour because of our slow speed. Well-secluded from the highway and railway, which parallel the canal throughout, its ivy-covered banks tower some 25 feet high in places.

Although it never was crowded on the towpaths, the people we passed provided us with a slice of British life far more authentic and variable than one could ever hope to experience as a tourist. Well-dressed, rosy-cheeked children in hand-knit cardigans sat on the gate balance beams curiously watching us guide the *Sheldrake* through. Housewives in frocks proudly walked their well-groomed dogs. Mums, or perhaps nannies, with prams could be seen before lunch taking their infants on their daily constitutional. Factory and office workers scurried to and fro between noon and two o'clock in the town sections of the canal. Businessmen, smartly dressed and toting umbrellas, walked briskly home after work. Contented older couples, as well as love-smitten youngsters, strolled slowly, arm in arm, as dusk lengthened the shadows over the canal.

Anglers (fishermen) were spotted frequently throughout the route, rooted firmly to the secluded spots they had selected, bicycles propped against the hedge behind, tackle, wicker lunch boxes, and thermoses of tea in array. Long fishing poles propped on stands thrust lines well into the center of the canal, while partially submerged mesh baskets near the edge kept captive the bream, roach, or tetch of the day. Huge green umbrellas the size of pup tents provided shelter when it rained.

By mid-week we ascended the north side of the Ouse valley, crossing an aquaduct over the river Ouse between Wolverton and Cosgrove Village.

We arrived in Stoke Bruerne, Northamptonshire, just before noon, mooring the *Sheldrake* halfway up the seven locks and walking up the towpath into town because of the busy boat traffic. Stoke Bruerne is much touted as the southern showplace of the canal system with its attractive canalside cottages, historic Boat Inn, canal shop, and Waterways Museum.

The Waterways Museum, originally a 19th-century mill and grain warehouse, has three floors and is not particularly accessible to wheelchair users. However, once hoisted up the three front steps, I stationed myself beside a helpful museum curator and received much intriguing insight into the history of the canals and the way of life of two centuries of boatmen and their families.

We returned to the *Sheldrake* and worked our way through the rest of the locks to the entrance of Blisworth Tunnel. This tunnel, first opened in 1805, is one of the longest (3056 yards) ever built and is still in use. We turned the *Sheldrake* around in the winding (pronounced "winned-ing") basin at the tunnel entrance and began our leisurely return trip of 47 miles, looking forward to a repetition of the countryside sights and sounds.

Would I undertake such a holiday again? Certainly. The boats are easy to operate, although not designed for a wheelchair user to do so, perhaps because several able-bodied people are required to work the locks. The boats move slowly, so that if you do collide with another boat, as happened to us at Woughton-on-the-Green, nothing more serious than spilling your tea or being knocked off the toilet can occur.

If you're interested in such an accessible canal vacation, write to Reach Out for Kids, the Education Centre, Hall Grove, Welwyn Garden City, Herefordshire AL7 4PJ, England.

Family-size boats such as the *Sheldrake* are available, as well as a larger boat that can accommodate small groups. Reservations are usually required a year ahead.

For detailed maps and guides and publications relating to the routes and history of the canals, you should also write to the British Waterways Board, Canal Shop and Mail Order Department, Melbury House, Melbury Terrace, London NW1 6JX, England.

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Address: Audrey King, 255 The Donway West,
Apt. 319, Don Mills, Ontario M3B 3M3 Canada.

World Rehabilitation Fund Study Tour: Denmark

by Jack Genskow, PhD

Jack Genskow, PhD, Associate Professor, Human Development Counseling Program at Sangamon State University in Springfield, Illinois, was accompanied on the World Rehabilitation Fund Study Tour by his wife, Lillian, who is of Danish descent, and their son, Ken.

Going to Denmark has always been a family dream since my wife Lil's parents came to America from Denmark. The dream came true for us and our 20-year-old son Ken when I was awarded a World Rehabilitation Fund Fellowship to study older persons with disabilities and the independent living movement in Denmark during September and October, 1986.

Lil and I have traveled often in the United States, but we were amazed at the number of details involved in overseas travel, and we were at a disadvantage in having only 7 weeks to prepare for the trip.

We worked with Edna Cook of Flying Wheels Travel (P.O. Box 382, Owatonna, MN 55060, 1-800-533-0363), and she was indispensable in making arrangements with airlines and hotels. We found that it is better to have van rental and longterm (4 weeks) accommodations made locally by friends in Europe.

We confirmed arrangements with the airline one week before the flight. We had booked seats in tourist class next to the bulkhead for leg room, ventilator, battery, etc., but there was room in business class so we were allowed to sit there instead.

L to R: Bente Madsen, Lil Genskow, Jack Genskow in front of Copenhagen's Town Hall



I used my ROHO cushion in the plane seat and in the aisle transfer chair. Because of inaccessible restrooms on the plane, I limited my liquid intake the night before and did not drink on the plane.

We exchanged the liquid acid batteries on my motorized Everest & Jennings wheelchair for the gel cell batteries required by the airline, and also used one of the gel cells in the airplane to power my ventilator. We carried each battery in a canvas bag, using a plastic cord connected to each battery pole as a handle.

We found that charging the chair batteries the usual way did not work in Germany or Denmark, although the manufacturer claimed it would. We borrowed a 12-volt battery charger there, and each night charged one battery directly — not using the chair's circuits. When charging, the connecting cable between the batteries must be removed (bring along an adjustable wrench) and a record kept to ensure that alternate batteries are charged. Ken pushed the chair up a 5-story ramped tower in Copenhagen with the low voltage light blinking merrily the day after we had charged the same battery two nights in a row.

We adapted our Hoyer travel hoist for the flight by cutting off each leg about 4 inches above its attachment to the base and by inserting a solid metal piece into the base's 4-inch stub to fit into the leg when reassembled. The hoist collapsed relatively flat for packing when disassembled.

Voltage in England and Europe varies from 220 volts to 240 volts, with 50 cycles rather than 60. Adaptor plugs are vital, because foreign countries have different plug styles, sometimes even within the same country. Two California companies specializing in adaptor plugs are International Primary Power Components (707/523-0600) and Hybrinetics (1-800-247-6900).

A good transformer is essential for ventilator equipment. We used a Stancorp transformer, that was excellent, but it had a 3-prong plug designed to fit US 220-volt outlets. Unfortunately, the backs of all of the European adaptor plugs we could find only fit a regular United States 2-prong plug. Finally, two electricians made an adaptor by wiring a "female" 3-prong 220-volt plug to a regular United States 2-prong 110-volt plug. The transformer plugged into the 3-prong plug and the 2-prong plug fit the adaptor.

During the summer before the trip, I had changed from using a rocking bed for sleeping (chest shell for travel) to a positive pressure ventilator (PPV) and lipseal with scuba mouthpiece adapted by Oscar Schwartz, MD, of St. Mary's Health Center in St. Louis. It was a new and anxious experience to travel where no one was as familiar with the repair of our equipment as our local support systems.

We flew into Frankfurt on American Airlines (AA), because American had the shortest (8½ hours) nonstop flight between Chicago and Europe. The flight was smooth, and AA service for disabled passengers disembarking in Frankfurt and expediting through customs was highly efficient. We stayed at the Sheraton Airport Hotel, which was expensive but convenient, and drove the autobahn to Denmark the next day in a Peugeot Rancho arranged for by a friend through the German government.

Our time in Denmark was delightful. Lil's parents had 9 siblings who remained in Denmark so we had the special pleasure of meeting many relatives for the first time. We stayed on a farm near Sønderborg in the south with our relatives for 5 days, spent 3 days at a hotel in Aarhus, and 4 weeks at a conference center 15 miles south of Copenhagen.

Distances were short and traveling convenient. The larger ferries were fully accessible, and if we arrived a half hour early, had reservations, and had notified the ticket taker, our car was placed in a position where the wheelchair could be unloaded near an elevator. Trains in Copenhagen were also accessible if one could manage a 5 to 8-inch step from the platform, but not every train station was accessible.

We left Denmark and were driven to Hamburg to take the train to Frankfurt because Germany has an intercity train system adapted for wheelchairs. We notified the Red Cross (Rote Kreuz) the day before, and were met at the station by a man with a portable ramp. (We discovered that these trains did not carry luggage, so we carried what we could and sent the rest assured that they would arrive at the airport the next morning, which they did.)

The ramp was too wide for the train door, so Ken had to lift the rest of the chair the last foot or



Jack Genskow with son Ken and Peugeot Rancho. The rear floor of the car is lowered to the ground by pressing a button, and a small ramp extends for easy access.

so into the car. Once inside, the car was accessible, with a large bathroom and two spots for wheelchairs. In Frankfurt, the Red Cross again met us with a ramp that was again too large so Ken had to take me down the steps. The shuttle train had a 5-inch step at the main Frankfurt station and a 10-inch step at the airport station. A special freight elevator, or lift, connects the train area with the airport. We were eligible for a discounted train ticket from Hamburg to Frankfurt because we had flown into Frankfurt and used the train on the first leg of the trip.

People were the primary focus of the fellowship, and we arranged 31 interviews with persons from all strata of society, including the Third Mayor of Copenhagen, government officials, agency directors, career professionals, young and elderly individuals with disabilities, relatives, home helpers, etc.

Whether we were meeting with people on interviews or with family, we experienced a warm reception, often being offered soft drinks, coffee, Carlsberg or Tuborg beer, and the wonderful Danish smørebørd or open-faced sandwich.

There is a strong sense of pride in what the Danes are doing in their various programs for the elderly and/or disabled. Their sense of commitment to the rights of an individual to live a quality life as defined by that individual was evident. They expressed frustration in waiting for equipment for persons with disabilities and in waiting for placement in living facilities that are new and designed to meet the needs of the elderly and/or disabled.

Jack entering the Peugeot Rancho with Ken's assistance



Among the people who made an impact upon our trip were Bente Madsen, Kim Tinggaard, and Svend Due. They made arrangements for our stay, set up interviews, and often accompanied us to them.

Bente had lived in the Collective House, but learned from Gini Laurie that ventilator-dependent people with severe disabilities similar to Bente's can live in their own apartments with 24-hour attendant help. Bente applied her self-determination and assertiveness, and today — 6 years later — does exactly that. She has become an independent living advocate for others. (Following our visit, Bente found sponsors to enable her to attend G.I.N.I.'s Fourth International Polio & Independent Living Conference in St. Louis in June 1987.)

Kim, a man in his early 30s, is disabled as a result of a diving accident in his teens. He, too, had lived in an environment that restricted the independence he desired. Kim and his friend, Bent, also with a severe disability, convinced their community to build an experimental home to allow each of them their own living quarters combined with shared areas of kitchen, dining, laundry and utility rooms. Electrical doors, windows, ceiling hoists, etc. were built in. Each hired and managed his own attendant care. (We introduced Kim to Lil's cousin Lis, and, in their efforts to plan for our visit, "an affair of the heart" began. Today they share each others lives and will be living in their own home soon.)

Svend's brightness, humor, spontaneity, and accomplishments impressed us. He contracted polio in his teens and had used a ventilator for

more than 30 years. While living in a group home with other young persons with severe disabilities, he decided to become an architect and design homes that would provide an independent lifestyle for himself and others. He has been an architect for 6 years, has been married for 6 years, and has his own architectural firm.

The Danish national social policy is to promote independent living for the elderly to enable them to live in the community, not in nursing homes. The communities provide many services to the elderly according to need, including a basic pension and free medical service to everyone, home helpers, meals-on-wheels, rented apartments that cost no more than 15% of one's income, etc. Some sheltered housing with 24-hour nursing care is available.

In Copenhagen, we visited the oldest (circa 1960) "Collective House" in the world that provides apartments for persons with and without disabilities, a medical unit for ventilator users, and special programming for persons with disabilities. We also observed modern congregate housing especially for younger persons with disabilities.

However, we talked with many young persons with severe disabilities who chose to move out of these specially built and planned living centers to live independently. They do this with the aid of helpers whom they hire and fire, but whom the government pays. We observed that many individuals choose to live as independently as possible on their own terms, rather than to be restricted by a seemingly ideal government-planned program.

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ED Note: Excerpted from the full report, *Independent Living and Older Persons with Disabilities in Denmark (F57)* by Jack Genskow, PhD, as part of the International Exchange of Experts and Information in Rehabilitation sponsored by the World Rehabilitation Fund through a grant from NIDDR, available for \$2 (postpaid) from World Rehabilitation Fund, 400 E. 34th St., New York, NY 10016.

World Rehabilitation Fund Study Tour: France

by Marilyn Saviola, MA, CRC and Ann Johnson, MS, FNP

The purpose of our 3-week World Rehabilitation Fund study tour in France was to learn how ventilator users live in the community. The areas we studied included independent living, home care, accessibility, and transportation in and around the cities of Paris, Lyon, and Montpellier.

We were interested in the degree of integration, independence, and self-determination of individuals and in the roles played by government, family, and economics.

Our host organizations and agencies included Groupement Pour L'Insertion Des Personnes Handicapées Physiques (GIHP) and Association D'Entraide Des Polios Et Handicapés (ADEP).

Flying Wheels Travel (P.O. Box 382, Owatonna, MN 55060, 1-800-533-0363) made our travel arrangements. LIFECARE (655 Aspen Ridge Drive, Lafayette, CO 80026) made all the arrangements for the ventilators and converters, supplying ventilators that were made for European current. The only problem was with the converter, which was inadequate for the charger — we had to borrow a stronger French model. Also, we found TWA was not helpful with the ventilator and the 747 was too tight a squeeze for transfer and the ventilator.

The health care system in France is one of socialized medicine which provides all French citizens with the same level of government-provided services. As a result, the level of care which ventilator users in France receive is not as limited by financial constraints as it is in the United States.

After the acute phase of care in a hospital, the individual is transferred to rehabilitative care in an intermediate care facility which specializes in rehabilitation. When the maximum level of potential has been reached, the individual is discharged and receives a social security allotment from the government for living expenses and personal care services.

The person is either discharged to home to live with the family, if the family members can meet the personal care needs, or to a group living

situation known as a foyer, if more care is required than the family can afford or give.

Foyers are shared living situations where groups of severely disabled individuals live together and share services. These services include attendant care, housekeeping, and cooking. Foyers range from very restrictive environments to rather independent situations with only the sharing of attendant care.

The home care programs we visited in Lyon, Montpellier, and Paris were initiated to address the needs of ventilator-dependent survivors of polio epidemics. These programs have since expanded to encompass a wider variety of disabilities. The highly organized home care services include family counselors for assessment and support, technicians for ventilator repair, respiratory therapists, medical specialists as consultants, and nursing personnel.

The home care programs are also responsible for hiring, training, and supervising of the personal care workers who go into the individual's home or are available to individuals living in foyers. However, in the less restrictive foyers, the residents are responsible for the hiring, firing, and supervision of personal care workers.

In Lyon, the home care services are provided by ALLEP, a hospital-based system, which maintains about 650-700 patients at home. Technicians are available 24 hours per day and make home visits every 1-2 months to maintain and repair ventilators. A nurse specialist is responsible for overseeing the status at home. Annual medical exams are provided by general physicians who consult with ALLEP specialists when needed.

The APARD organization in Montpellier covers five counties of southern France. Patients come to APARD to be evaluated for home care feasibility. Technicians and nurses are available for home visits. House calls are made by local general physicians while specialists are available for consultation by phone.

In Paris, the provision of home health care is not connected to a specialist hospital but, rather, functions as a service to the ADEP foyers. For those individuals living with their families, the team approach is used to provide comprehensive home care services through physical therapists, respiratory therapists, and technicians. The same

Marilyn Saviola, MA, CRC, is executive director of The Center for Independence of the Disabled in New York, Inc. (CIDNY) and chairperson of the Statewide Association of Independent Living Centers. She uses a ventilator fulltime.

Ann Johnson, MS, FNP, is affiliated with the Manhattan Veterans Administration Medical Center's Hospital-Based Home Care Program.

services are available to those living in ADEP foyers. A general physician visits the foyer weekly and ADEP provides transportation to specialists' offices or a hospital.

One of the advantages of the French system is the continuity of care that exists following dis-



Marilyn Saviola

charge from the hospital into the community. Without these comprehensive home care services, ventilator users would have to be institutionalized in longterm care facilities.

The recipients of home care services, as well as the professional providers of the services, are generally very satisfied. However, the vast majority of ventilator users we met with indicated that they would prefer, if they had the option, to live independently rather than being limited by shared services.

"The vast majority of ventilator users we met with indicated that they would prefer, if they had the option, to live independently rather than being limited by shared services."

The sharing of personal care services may be more cost-effective, but it diminishes the individual's ability to live independently and still have all personal care needs met.

Although deinstitutionalization is of primary importance in France, it has not led to integration into community life. We did not see wheelchair users on the streets, even though we visited restaurants, tourist sites, and shopping areas. During our entire visit, we saw only one man in a wheelchair who was moving about Paris independently.

In the areas of public transportation and architectural accessibility, France does not have legislation that mandates accessibility. In the cities we visited, there was no accessible public transportation or paratransportation, nor legislation or incentives to achieve architectural accessibility, which seems to be haphazard and left to the goodwill of the builders.

Of all the places we visited, Montpellier was the oldest and the most inaccessible. The streets and sidewalks are so narrow they are almost impossible for a wheelchair or a van. The Lyon streets are often made of cobblestone and are hilly and narrow. By comparison, Paris is much easier for a wheelchair. The streets are wider and paved, and there is an effort to make cultural centers and tourist sights more accessible.

We explored a few of the Parisian tourist sights. The Louvre is currently inaccessible to wheelchair users, but alterations are underway to make it accessible by 1989. Notre Dame is accessible from the street level to the main floor, but to find an accessible restroom we had to go to a nearby hospital. The Eiffel Tower was accessible except for the upper level. Many shops and restaurants along the Champs-Élysées and the Seine are manageable with assistance up one step.

With the exception of the new high speed railroad trains, TGV, the French National Railways system is not accessible to wheelchair users. The TGV has a wheelchair area in the first class car that will accommodate two chairs. There is no tie-down system. There was an electrical outlet that could have been used, but it was not functioning and we had to use an extension cord to a plug in the restroom.

There were lifts available to board wheelchairs in Paris and Montpellier, but not in Lyon. De-boarding in Lyon was accomplished with the help of 8 strong men who lifted the chair off the train. For the return journey, we went to the station master 3 days before to help locate the unused lift and to instruct the staff in its use.

In France, the disability rights movement is not as well organized as in the United States, but the groundwork is being laid by organizations such as GIHP to raise consciousness levels and work towards legislative protections guaranteeing equal rights and more independence. As the disability rights movement in France develops and grows, so, too, will the levels of integration, independence, and self-determination increase for persons with severe disabilities living there.

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New York, NY 10003.

ED Note: Excerpted from the full report, *Community Living for Severely Disabled Ventilator Users in France* (F68) by Marilyn Saviola, MA, CRC, as part of the International Exchange of Experts and Information in Rehabilitation sponsored by the World Rehabilitation Fund through a grant from NIDDR, available for \$2 (postpaid) from World Rehabilitation Fund, 400 E. 34th St., New York, NY 10016.



Marilyn Saviola entering Renault van

"During our entire visit, we saw only one man in a wheelchair who was moving about Paris independently."

FRIENDS AROUND THE WORLD

Pen Friends

"I am a law student in Columbia. I was born in 1946 and was disabled by poliomyelitis at age 3. Now I use a right crutch. Most of my activities are intellectual. I would enjoy corresponding with other Gazette readers." *Tancredo Q. Herrera, Apartado aereo 968, Palmira Valle, Colombia.*



Tancredo Herrera

"I was diagnosed with ALS (amyotrophic lateral sclerosis) in 1971. I am happy to live with my family. For my wife, Renate, and the children it is self-understood to assist me in every respect. We try to participate in life in many ways. I am able to type using two keys on the board of a refitted teletype machine. My wife and I developed our own techniques for physiotherapy. We attend many theatre performances." *Jürgen Weise, Enzianweg 8, 8201 Thansau b. Rosenheim, West Germany.*



Jürgen Weise and family

"Many thanks for sending us another issue of *Rehab Gazette*, which we have been absorbed in reading as we have several disabled persons on our staff. Afterwards your good magazine goes to the Ferrer Hospital and the attached Ferrer Home for "Iron Lung" and other pulmonary-motored residents who eagerly read it." *Robert Pender, H. Odeon, Esmeralda 368, (1035) Buenos Aires, Argentina.*

"We are happy to let you know that we have launched a project for handicapped children in Calcutta. In 1986, our Indian Council of Sports for the Disabled organized many campings and outings. We hope to survey and research disability and rehabilitation facilities in and around Calcutta. We have many projects that need sufficient funds to proceed farther." *Tapan Kumar Dhar, 47/1A Palm Avenue, Calcutta 700019, India.*

Independent Living in Austria

"I enjoyed the rest of my journey in the United States. . . . I start my work on independent living, reading all the papers I photocopied while doing research at Gazette International Networking Institute's headquarters in St. Louis, and putting all the information together like a puzzle. Soon we start discussion about what we can learn from American centers for independent living and what changes we have to make. I'll send a report about what is going on in Salzburg." *Gottfried Wetzel, c/o Mobilier Hilfsdienst, Elisabethstr. 14, 5020 Salzburg, Austria.*

Used Equipment Needed for Mexico

Douglas Hewitt, a volunteer with Project Projimo, a nonprofit organization working with people with disabilities in western Mexico, is collecting all types of used orthopedic and ventilatory equipment to be redistributed and reused by people in rural Mexico. Any kind of orthotic aid — brace, cane, crutch — or ventilator — cuirass, pneumo-belt, etc. in good condition may be shipped to Hewitt at 14695 Poncho Conde Circle, Box 128, Rancho Murieta, CA 95683, 916/354-2934.

Polio Survivors

"South Australia experienced two major epidemics of poliomyelitis in the 1930s and 1950s. Many people were severely disabled, and many fought hard to maintain a place in the workforce and to uphold their independence. The late effects of polio are being experienced by Australians as well as polio survivors in other parts of the world, and we have formed The Poliomyelitis Welfare Association. I am travelling to G.I.N.I.'s Fourth International Polio and Independent Living Conference in St. Louis, Missouri, U.S.A. in June to bring back information for all of Australia." *Anna Young, 317 Glynburn Rd., Kensington Park 5068, South Australia, Australia.*



Anna Young

"I have lived in Switzerland since 1953. I am disabled by polio and use a ventilator. Recently, my family and I traveled to Florence, Italy, for the baptism of our newest grandchild. My daughter lives in beautiful countryside outside Florence, and the baptism took place in an old church high on a windy hill overlooking the city. The next day I visited the American Military Cemetery in Florence, an area that was liberated by the Sixth Armored Division (the Super Sixers) in July 1944." *Charles Froelicher, Steinhofhalde 18, CH-6005 Luzerne, Switzerland.*



Gloria Ramirez

Friedreich's Ataxia

"I wish to tell you I have received some copies of your magazine, and wish to thank you for publishing the information I sent you so I can have friends around the world.

"I recently celebrated my 27th birthday. My childhood was normal, except that I had a congenital heart condition that was never any trouble or worry. I have since learned that it is related to Friedreich's ataxia.

"When I was 20 years old, I gradually lost the use of my legs and arms and had problems with my eyes, due to the progress of the disease. But I have not given up my desire to overcome and to communicate with the world... it is possible to have a more direct relationship with people who are also disabled by Friedreich's ataxia?" *Gloria Ramirez, A.A. 1991 Armenia (Quindio), Colombia.*

PEOPLENET

PEOPLENET is a nationwide personals newsletter for men and women with disabilities who would like to meet other interesting men and women with disabilities. PEOPLENET is published quarterly and mailed only to other PEOPLENET members. Each issue contains the names, addresses, and phone numbers of members along with a 50-word description of who they are and with whom they would like to meet. PEOPLENET is \$10 per year and is available from Robert Mauro, 257 Center Lane, Levittown, NY 11756 or call him at Computype, 516/579-4043.



EQUIPMENT

Carchair

Carchair is now available in the United States (VA approval is pending for both the chair and the system). The carchair system enables an individual to be lifted into either front seat without any physical transfer. The individual remains in the chair throughout while the wheelchair locks into the car chassis to become the car seat (see Figure 1).

Carchair is being adapted for several full-sized American cars (Gresham Driving Aids in Michigan has used a Mercury and a Buick), but the manufacturer prefers the Nissan Stanza wagon because of its dual-sliding doors and pillarless construction.

The 1000-pound capacity lift, run from the car battery, operates by push-button control. The carchair reverses to the open door and hooks onto the system cone to be lifted (see Figure 2). The wheels retract and the footrest is removed. The carchair swings into the seatwheel and automatically locks into position.

The carchair system's advantages are that it enables persons to drive a regular car rather than a van, thus saving van gasoline mileage costs, and it enables the person with a disability, if he or she is not in the driver's seat, to be seated next to, rather than behind the driver.

The carchair system includes a power lift and three models of wheelchairs — self-propelled, attendant-pushed, and electric — that are more comfortable and contoured to the body.



Figure 1. Carchair system on passenger side



Figure 2. Carchair system with chairlift in operation

Economically, the carchair system plus car roughly equals van conversion costs, but the carchair provides a wheelchair. Persons with disabilities who are anticipating needing a wheelchair might be interested in investigating the carchair, BEFORE they purchase wheelchairs.

The following van conversion specialists are carchair dealers:

Advanced Mobility, Inc.
12555 Sherman Way, North Hollywood, CA 91605
818/982-1004

Driving Aids, Ltd.
215 Commercial St., Vallejo, CA 94589
707/553-1515

Driving Aids, Ltd.
2216-A Cemo Circle, Rancho Cordova, CA 95670
916/635-2765

Grayless Mobile Aids
1132 Basse Rd., San Antonio, TX 78212
512/732-1216

Gresham Driving Aids
30800 Wixom Rd., Wixom, MI 48096
1-800-521-8930

Rainbow Conversion
6834 N. 25th Dr., Phoenix, AZ 85017
602/433-1994

Write the manufacturer, Carchair Ltd., Robin Callow, Station Rd., Industrial Estate, Hailsham, Sussex, BN27 2ES, England or call England toll-free, 1-800-367-9291, but *please* remember to add 5 to 8 hours for time zones.

Hints for a Successful Van Conversion

by Scott McDonald and Greg Sacks

A van lift enables a person in either a manual or power wheelchair to gain access to a van. Lifts come in two styles, electric and hydraulic. An electric lift requires little maintenance and is not drastically affected by temperature. It does require a well-charged battery. A hydraulic lift requires more maintenance. Cold weather slows its operation, but it can be operated with a minimal drain on a battery. Either type can be mounted in the side or rear door.

Door openers come in two varieties, swinging door openers and sliding door openers. Swinging doors are generally recommended as they are mechanically more reliable than sliding door openers.

The type of seating that would be most appropriate depends on the ease of transfer from chair to chair without too much effort. A power seat can be adjusted for height and position automatically to best allow someone to transfer onto it. If a transfer is too difficult or impossible, two options can be considered for driving from a wheelchair.

A power pan is one method of getting properly seated so as to have a maximum field of vision. The power pan is simply an elevator mounted in the floor under the steering wheel. One simply drives onto it in a wheelchair and lowers it to an appropriate height. The power pan is best mounted in a Ford van, since undercarriage and body sit 4 inches apart, allowing the room needed for lowering the pan. In some cases a deeper pan is required, and cutting on the undercarriage may be necessary. Most dealers can effectively reinforce the cut away portion.

Lowering the floor on the van is the second option. Again the Ford is most easily converted. If a depth of more than 4 inches is required, the body can be raised to accommodate for that space. Modifications of these types are not limited to Fords, they're just easier to do. Dodge, Chevy,

and GMC can also be adapted; they require more extensive alterations to the undercarriage.

There is a variety of electric lock-downs on the market today, and one must determine which one will fit best the type of wheelchair to be locked down to prevent any shifting of the wheelchair while accelerating and breaking.

Zero-effort steering is available for a person who has limited strength. The steering column can also be extended to bring the wheel closer to the body. Another option for someone who has limited range of motion is the horizontal wheel. This option brings a 10-inch wheel into the lap and can be used with zero-effort steering for someone who has both limited strength and mobility.

Hand controls vary widely and are selected according to the degree of mobility and strength. A hand control that has vacuum assist requires very little strength to operate. Proper positioning of this type of control is very important since strength, range of motion, and balance need to be taken into consideration. The push-pull quad control, which has reduced effort for accelerating this unit, may be appropriate. The power hand control is the last option. Strength and good range of motion are a must for safe operation.

A quad console can be installed in a convenient location to allow someone with a severe mobility problem to reach the switch with little effort. An electric gear shift and emergency brake are also available options.

When having a van adapted, one must work closely with the dealer representative from the initial evaluation to the final fitting when all knobs and buttons are made accessible to the driver.

Most dealers have specific brands they handle. When trying to decide on which equipment would work best, have the dealer show some of his work. That's the only way one will know if it's appropriate.

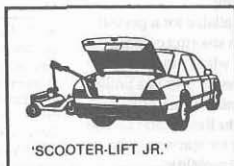
福

Scott MacDonald, C5-6 quadriplegic, is program director of Impact, Inc., an independent living center in Alton, Illinois. Scott drives a Ford Econoline 150 van. Greg Sacks is with United Medical Mart, van conversion specialists in St. Louis, Missouri.

Address: Impact, P.O. Box 338, Alton, IL 62002.
United Medical Mart, 1-800-367-7123.

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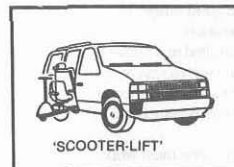
'PICK-UP LIFTER'



'WHEELCHAIR LIFTER'



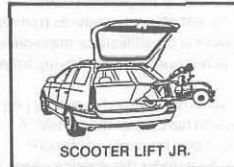
'SCOOTER-LIFT SR.'



'SCOOTER-LIFT'



'SCOOTER-LIFT SR.'



SCOOTER LIFT JR.



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Electric Drawing Board

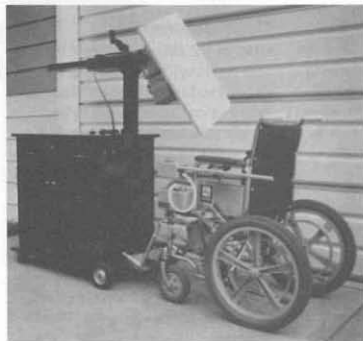
Jack Harvey, a retired engineer from Manton, Michigan, designed and built an electric drawing board for an artist friend who is quadriplegic.

The drawing board (18" x 24") can be controlled from a wheelchair and allows rotation of the drawing board 360 degrees, both clockwise and counterclockwise. It adjusts vertically and horizontally, and forward and backward, enabling a person whose legs are in a horizontal position to work comfortably.

The motor that moves the work surface is a television antenna rotator from K-Mart, mounted in a box on the front of the base cabinet. A 10-foot cable connects the control box and the wheelchair.

The base cabinet (optional) acts as a counterbalance for the motor and drawing board, and as a storage unit with 1 or more shelves.

Harvey built the machine for about \$300 (including the base cabinet). Complete blue prints and instructions are available free of charge by writing Jack Harvey, 8728 Arnold Rd., Rt. 3, Manton, MI 49663.



Electric easel with cabinet base

Jack Harvey © 10-31-86

Leg Bag Emptier

Designed by Richard Dagostino, quadriplegic for 13 years, the electric leg bag emptier is an inexpensive, light-weight, battery-powered valve mounted

on the open end of a leg bag. The valve operates on 12- or 24-volt wheelchair batteries. A simple wheelchair mounted switch operates the valve, made of stainless steel.

The cost of a standard switch is \$156, the cost with standard switch, battery, and charger is \$306, and the cost of standard switch operated by mouth is \$216. Write R.D. Equipment, 12 Herring Run Rd., Harwich, MA 02645, 617/432-3948.

Camera Mount

Weighing less than 4 pounds, the BODYPOD enables an individual with limited mobility to be a photographer. The BODYPOD has all the advantages of any tripod and is more convenient than a tripod because it is adjustable on the photographer's body with a vinyl belt, elastic straps, and Velcro fasteners. One-handed film loading and unloading are possible. BODYPOD uses sturdy light-weight anodized aluminum tubing and fittings. BODYPOD is available in small, medium, and large sizes. The cost is \$49.95 plus \$6.00 shipping and handling from Vic Crowley, 329 Fifth St., Madras, OR 97741, 503/475-2730.

Computers

The National Special Education Alliance (NSEA), a new alliance spearheaded by Apple Computer, Inc., ties together a core group of organizations dedicated to providing personal computer technology to persons with disabilities in their communities. One such group joining NSEA is Technical Aids and Assistance for the Disabled (TAAD) Center in Chicago.

TAAD provides printed information on hardware and software, hands-on use of computer systems, and help in obtaining loans of adapted microcomputers. TAAD is a project of the Committee on Personal Computers and the Handicapped (COPH-2).

For information, write or call Margaret Pfrommer, TAAD Center, 1950 W Roosevelt Rd., Chicago, IL 60608, 312/421-3373.

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Amputees

"Prosthetic and Worksite Modifications for Farmers with Upper Extremity Amputations" is a technical report from *Breaking New Ground*, a newsletter for farmers with disabilities available from the Department of Agricultural Engineering, Purdue University, West Lafayette, IN 47907. Common problems and solutions are discussed and illustrated with photographs and drawings, in addition to a list of resources.

Architectural Barriers

Section 502 of the Rehabilitation Act of 1973 created the Architectural and Transportation Barriers Compliance Board (ATBCB) to enforce the Architectural Barriers Act of 1968. The act requires certain buildings and facilities designed, constructed, altered, or leased with federal funds after accessibility standards were issued (in 1969) to be accessible and usable by persons with disabilities.

Written complaints about facilities covered by the act should include the following:

- 1) Your name, address, daytime telephone number, and congressional district. (Confidential.)
- 2) Brief description of barrier-related problem.
- 3) Name and address of building where barrier is located.
- 4) Name and telephone number of agency/office occupying building.
- 5) Name and telephone number of agency/person responsible for building.
- 6) Name of building owner.
- 7) Name of federal agency occupying building or providing funds for its lease, alteration, or construction.
- 8) To your knowledge, has the building been altered since 1969?
- 9) Your suggestions for solving the problem.
- 10) Your actions taken to date.

If a complaint was filed with the agency involved or with another state or federal agency, submit name of agency or person handling the complaint, telephone number, date filed, status of complaint, and your signature and date. (The Board will process the complaint even though filed with another agency.)

Send information to: Compliance Specialist, ATBCB, 330 C St., NW, Room 1010, Switzer Building, Washington, DC 20202.

Attitudes

Guidelines for Reporting and Writing about People with Disabilities, second edition, 1987, is available from Media Project, Research and Training Center on Independent Living, BCR/311 Haworth, University of Kansas, Lawrence, KS 66045. Positive terms and examples of portrayals of people with disabilities useful for everyone.

Disability Law

American Bar Association's (ABA) Commission on the Mentally Disabled offers readers of *Mental and Physical Disability Law Reporter* a variety of specialized research and information services. Write ABA, 1800 M St., NW, Suite 200, Washington, DC 20036.

Education

College Freshmen with Disabilities Preparing for Employment reports that the percentage of college freshmen with disabilities attending college has tripled in the past seven years. The Higher Education and Training for people with Handicaps (HEATH) Resource Center for the American Council on Education published the report in March 1987 and copies are available from HEATH, One Dupont Circle, Suite 800, Washington, DC 20036.

Ethics

The Physician and the Hopelessly Ill Patient: Legal, Medical, and Ethical Guidelines by the Society for the Right to Die, 92 pages, 1985. Distinguished physicians recommend medically and ethically appropriate levels of care. Right-to-die issues and a state-by-state summary of the laws. Available for \$5 from the Society, 250 W. 57th St., New York, NY 10107.

Exercise

Awareness Through Movement: Health Exercises for Personal Growth by Moshe Feldenkrais, 173 pages, Harper & Row, 1972. The Feldenkrais method is growing in popularity with polio survivors who are still ambulatory and health professionals working with polio survivors and others with limited mobility. Both the philosophy and the exercises are described. Available through local libraries and bookstores.

Health Information

OHIC or the Office of Disease Prevention and Health Promotion in the Public Health Department's Health Information Center wants to help people with health questions find organizations with answers. Both professionals and the general public can use OHIC by calling 1-800-336-4797. OHIC's objectives are to identify health information resources; to channel requests for information to these resources; and to develop publications providing information on health-related topics of widespread interest.

Home Health Care

The Home Health Care Solution: A Complete Consumer Guide by Janet Zhun Nassif, 1985, Harper & Row, \$9.95 paperbound. Index. An excellent, informative guide to living with the home health care alternative. Includes

checklists, costs, and addresses of organizations. Recommended.

Housing

Barrier Free Environments, Inc., of Raleigh, North Carolina, has received a 3-year research and demonstration grant from NIDRR for a project called "Less Restrictive Housing Environments: Examples, Methods, Designs, and Guidelines for Improving New and Existing Housing." Emphasis of the project is on the development and dissemination of practical information to solve the problems of suitable housing for persons with disabilities.

Anyone who has successfully designed, built, or modified any type of housing is invited to participate in the project. Write Less Restrictive Housing, Barrier Free Environments, P.O. Box 30634, Raleigh, NC 27622.

Meetings, Barrier Free

The Planner's Guide to Barrier Free Meetings by Barrier Free Environments, Inc., of North Carolina and Harold Russell Associates, Inc. of Massachusetts, c1980, offers excellent advice on making meetings accessible to all participants. Chapters include accessible meeting site evaluation, meeting room layout to accommodate wheelchairs, hotel room layout for bed and bath, and lists of equipment sources and services. Available for \$14.95 postpaid from Harold Russell Associates, Inc., 8 Winchester Place, Suite 304, Winchester, MA 01890.

Parking

A Case Study of Effective Consumer Action on Handicapped Parking Violations by Yolanda Suarez de Balcazar and Stephen Fawcett describes the action of a consumer group who worked with the business community and the city government to improve accessibility. Copies of the case study

and *Consumer Guide: Taking Action on the Problem of Handicapped Parking* (\$6) by the same authors are available from the Research and Training Center on Independent Living, The University of Kansas, Lawrence, KS 66045.

Personal Care Assistance

Concepts of Independence, Inc. has developed an interviewing alternative for people who do not wish to interview prospective attendants in their homes. Interviewers may use a room in the Concepts office in which to conduct the interview, and, if requested, a staff person from Concepts will also be present. Write Concepts of Independence, Inc., 853 Broadway, Suite 1404, New York, NY 10003.

Poetry

Joseph Baird and Deborah Workman, coeditors of *Toward Solomon's Mountain: The Experience of Disability in Poetry*, are planning an anthology of short prose as a companion volume and are seeking original manuscripts dealing with the theme of disability. All types of prose — except the excessively sentimental or superficially religious — will be considered. Please submit manuscripts to Joseph Baird, English Department, Kent State University, Kent, OH 44242 or Deborah Workman, Kent State University, Trumbull Campus, 4314 Mahoning Ave., N.W., Warren, OH 44483.

Recreation/Sports

The International Directory of Recreation-Oriented Assistive Device Sources edited by John Nesbitt, EdD, 298 pages with illustrations and photographs, 1986. Available for \$29.95 postpaid from Lifeboat Press, P.O. Box 11782, Marina Del Rey, CA 90295.

Resources

Resource Directory of Scientists and Engineers with Disabilities is the second edition published by the American Association for the Advancement of Science (AAAS). Listings are referenced by scientific specialty, disability, geographic location, and gender. \$13 postpaid from AAAS, 1333 H St., N.W., Washington, DC 20005.

The Sourcebook of Patient Education Materials for Physical Medicine and Rehabilitation compiled by Sandra Koch, MD, 741 pages, softcover, 1986. First edition of a standard reference book for professionals, as well as persons with disabilities, documenting at a national level all available educational material whether self-help group, agency, company, etc. Available for \$17.95 postpaid from The Center for Disability and Rehabilitation, Comanche County Memorial Hospital, P.O. Box 129, Lawton, OK 73502.

Shoes

The Clawson Rocker shoe provides a "rocker" effect, as a result of its design, that allows a person improved mobility with less fatigue. Polio survivors are finding that the shoes enable them to walk upright for considerable distances without pain and fatigue. Write or call Caroline Clawson, New Freedom, Inc., P.O. Box 472, Rexburg, ID 83440, 1-800-252-9766.

The One Shoe Crew is a new service that matches shoe sizes with potential shoe partners. Persons who register send in their names, addresses, phone numbers, and shoe sizes. When a match is found, a \$10 minimum fee is charged for the first two names (\$5 for each additional name requested) of potential shoe partners. The responsibility for agreeing to share shoes and expenses rests with the partners. Write or call Georgia Hehr, RN, 86 Clavela Ave., Sacramento, CA 95828, 916/682-7655.

The National Odd Shoe Exchange is back in business in Phoenix. Jeanne Sallman, director, charges a fee of \$32.50 for adults (anyone over the age of 62 is only charged \$22.50) to join the exchange. Members are asked to give the exchange a year to fill their needs. The fee is returned if the exchange is unsuccessful. Contact the exchange at P.O. Box 56845, Phoenix, AZ 85079, 602/246-8725.

Spinal Cord Injury

Spinal Cord Injury: A Guide for Patient and Family by Lynn Phillips, Mark Ozer, Peter Axelson, and Howard Chizek, 1987, Raven Press, \$12.95 (paperbound) or \$25.95 (cloth).

Index. An excellent, basic guide to living with a spinal cord injury for persons with new disabilities. Each chapter contains suggested readings, and abundant appendices list addresses of treatment centers, R & T centers, organizations, publications, etc. Recommended.

Tax Reform, 1986

Provisions of the Tax Reform Act of 1986 affecting people with disabilities and their employers:

- 1) Medical expenses must exceed 7.5% of taxpayer's adjusted gross income in order to be deducted.
- 2) Certain capital expenditures made to a personal residence to accommodate a person with disability, such as entrance ramps or widening of doorways for wheelchairs, are deemed medical expenses that can be deducted.
- 3) Tax-sheltered annuities maximum annual contribution is \$9,500 for employees of tax-exempt organizations.
- 4) Adoption expenses' current deduction of \$1,500 for adoption of children with disabilities has been repealed. Title IV-E of the Social Security Act provides assistance.

5) Blind or elderly taxpayer's exemption is replaced by an additional standard deduction of \$750 for single taxpayers and \$600 for each married taxpayer on joint return. Taxpayers both elderly and blind can claim deduction of \$1,500 for single, or \$1,200 for each married taxpayer on joint return.

6) Attendant care can be deducted as well as other services necessary to enable an employee with a disability to work.

7) Charitable donations for non-itemizers has been eliminated. Itemizers can continue to deduct.

Wheelchairs

Independence Through Mobility:

A Guide to the Manufacture of the ATT-Hotchkiss Wheelchair by Ralf Hotchkiss, 154 pages. 1985. Softcover available for \$15 from Appropriate Technology International, 1331 H St., NW, Suite 1200, Washington, DC 20005. Instructions for making the ATT-Hotchkiss Torbellino wheelchair, which is 10 pounds lighter, yet strong enough to maneuver over rugged terrain. Wheelchairs can be manufactured locally by small groups of skilled mechanics with access to thinwall steel tubing and simple welding equipment.

Compax, a new adult wheelchair weighing only 23 pounds, is compact, folding to the size of a small golf bag. The steel reinforced aluminum frame has full 8-inch wheels suitable for indoor or outdoor terrain. Three models are available, ranging in price from \$500 to 650. Write Convoid Products, Inc., P.O. Box 2731, Palos Verdes, CA 90274.

A bumper-mounted wheelchair carrier, the Barkel carrier, slides easily onto a bumper plate that can be mounted on almost any bumper or trailer hitch. To load, the chair is backed into the carrier, the safety strap is fastened, and the carrier handle is pulled backward to rotate the carrier into a locked travel position. To release the carrier, the locking latch handle is released to allow the carrier to lower to street level. (Black vinyl weatherproof covers are included.) For more information, write Doyal French, Handi-Cap Aids of Oklahoma, Inc., 7701 N. Broadway, Suite A-1, Oklahoma City, OK 73116, 405/842-0511.

Access, International introduces a new wheelchair narrower that is easy to install and fits most collapsible chairs. It can be moved to other chairs as well. Cost is \$149.95 plus \$4 shipping from Access, International, 200 N. Robertson Bl., #332, Beverly Hills, CA 90211, 213/276-9560.



福 G.I.N.I.'s Fourth International Polio and Independent Living Conference, June 4-7, 1987



Robert Crowe, G. Jackson Burney, Susan Suter, and Hank Graden during panel on Social Security disability benefits and vocational rehabilitation

Gazette International Networking Institute's Fourth International Polio & Independent Living Conference, held June 4-7, 1987 at the Sheraton St. Louis Hotel, attracted 747 registrants from 18 countries and all across the United States.

The audience — polio survivors, physicians, health care professionals, equipment dealers, and other persons with disabilities — filled the hotel ballroom. More than half of the speakers and the participants were wheelchair users, and many used portable ventilators.

"The excitement and spirit of the conference attendees was almost palpable," says Conference Coordinator Gini Laurie. "The mutual respect between the physicians and health professionals on the panels and the audience was another conference highlight."

Conference sessions covered the latest treatment and research findings on muscle weakness, pain, fatigue, sleep and breathing problems, exercise, nutrition, bracing, and seating. Polio experts included Jacquelin Perry, MD; Augusta Alba, MD; Ernest Johnson, MD; Rubin Feldman, MD; Frederick Maynard, MD; Richard Owen, MD; Neil Cashman, MD; D. Armin Fischer, MD; Lauro Halstead, MD; David Wiechers, MD; and Geoffrey Spencer, OBE. "I felt that the medical information portion of the conference was extremely well presented and very up-to-date scientifically," said Dr. David Wiechers of Columbus, Ohio.

Polio survivors on each panel presented personal perspectives on the late effects of polio. A special session on face masks for night ventilation was packed with polio survivors demonstrating masks they had designed themselves.

The psychological aspects of disability and the problems of coping with the late effects of polio many years after the acute stage were discussed in several panels and workshops on coping relationships with family members, friends, and attendants. Stress management was another important topic providing valuable information.

"It will take some time for me to absorb all the information, experiences, and feelings of your marvelous conference. And the inspiration of being with so many who have not let their disabilities prevent them from living active, loving, joyous lives is beyond description," stated Charlene Bozarth, Chair of the Michigan Polio Network.

Cultural attitudes towards disability around the world provided an international forum for leaders of disability groups from the following countries: Australia, Austria, Brazil, Canada, China, Denmark, El Salvador, England, West Germany, Japan, Mauritius, Netherlands, New Zealand, South Africa, Sweden, Taiwan, U.S.A., and Zaire.

The conference celebrated the 10th anniversary of the implementation of Section 504 of the Rehabilitation Act of 1973 — the bill of rights for persons with disabilities. Ted Kennedy, Jr. was among the keynote speakers at the conference banquet, as well as Justin Dart, Jr., Commissioner of the Rehabilitation Services Administration, and Eunice Fiorito and Judy Heumann, both activists in the disability rights movement.

Plans are being made for G.I.N.I.'s Fifth International Polio and Independent Living Conference, scheduled for May 31-June 4, 1989. *Proceedings* of the 1987 conference will be published in 1988, and can be ordered now for \$16 postpaid from G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

福 G.I.N.I.'s Fourth International Polio and Independent Living Conference, June 4-7, 1987



Gini Laurie, Tamara Tretyakova Levin, Mark, and Simon Levin. Tamara, a Russian polio survivor, was granted an exit visa from U.S.S.R. after 8 years thanks to the efforts of International Polio Network.



Marcus Allen, PhD, French translator for Luwmbwa Tshany of Zaire



Lauro Halstead, MD, National Rehabilitation Hospital, Washington, DC



Anne Isberg of Denmark with Tom Partin of Michigan



◀ *Justin Dart, Jr., Commissioner of Rehabilitation Services Administration; Karen Foss, KSDK-TV anchorwoman and mistress of ceremonies for conference banquet; and Ed Roberts, World Institute on Disability*



Gordon and Jean Packer of Canada dancing at Saturday night disco



▲▲ *Hugh Newton-John, MD, of Australia and Ed and Mary Ann Hamilton of Colorado during face mask workshop*



▶ *Eileen Giron, El Salvador*





*Liu Zhirui, MD, and Li Qi-Hong, MD,
Beijing, Peoples' Republic of China*



*Irving Zola, PhD, Brandeis University,
Massachusetts*



Ted Kennedy, Jr. with Japanese delegation



*Judy Heumann, World Institute
on Disability, California*



*Geurt Heykamp of Holland with
Kent Kloeping, EdD, of Arizona*



*Phyllis Rubinfeld, EdD, Hunter College,
New York*



*Janet Dean of Michigan dancing with
Tom Partin at Saturday night disco*



*Uwe Frehse of West Germany with
Susan Armbricht of Ohio*



*David Wiechers, MD,
Ohio*



◀ *Adolf Ratzka, PhD,
of Sweden with
Jack Genskow, PhD,
of Illinois*



▶ *Robert O'Reilly,
Rev. Robert Ronald, SJ,
of Taiwan, and
Joan O'Reilly,
conference registration
coordinator*

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

Reaching, informing, and dignifying people with disabilities throughout the world.



Origin

Rehabilitation Gazette, an international journal for independent living by people with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences.

The *Gazette* grew from a local newsletter to a renowned international journal and evolved to include other physical disabilities and the aging of all disabled persons.

In 1983, The *Gazette* celebrated its 25th year as a journal and information service, and was reorganized to expand its services. The new organization was named Gazette International Networking Institute (G.I.N.I.).

G.I.N.I. is incorporated as a non-profit [501 (c) (3)] organization. Donations are tax-deductible.

Publications

Published since 1958, *Rehabilitation Gazette* embodies and reflects the imaginative, practical, down-to-earth life experiences of its disabled readers.

It is a form of peer counseling and therapy by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. Personal experiences in the *Gazette's* articles motivate other readers to live full and independent lives.

The *Gazette* is an invaluable tool for creative rehabilitation, providing health care professionals with additional insight into the interests and needs of people with disabilities. Readers include doctors, nurses, therapists, social workers, rehabilitation counselors, government officials, educators, and the relatives and friends of persons with disabilities.

The *Gazette* reaches 30,000–50,000 readers in 87 countries with translations in five languages. It is read by people who are disabled with ALS, amputation, arthritis, cerebral palsy, head injury, multiple sclerosis, muscular dystrophy, polio, spinal cord injury, and stroke.

In 1986, G.I.N.I. began publishing two issues of the *Gazette* per year and offered membership in the G.I.N.I. organization. Membership benefits include a subscription to *Rehabilitation Gazette*, G.I.N.I.'s information service and library, and discounts on G.I.N.I. conferences and membership events.

Other G.I.N.I. publications include the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* and the proceedings of G.I.N.I.'s polio and independent living conferences. Order forms are available from G.I.N.I.

Polio Network

G.I.N.I. has maintained a worldwide polio network since 1958. Consequently, when an increasing number of polio survivors began to report new symptoms of pain, fatigue, weakness, and breathing difficulties, G.I.N.I. took the lead in organizing the first coordinated look at the problems with its 1981 polio conference.

G.I.N.I.'s subsequent biennial polio conferences continue to educate physicians, promote research, and provide information and psychological support to polio survivors.

In 1985, G.I.N.I. formally established the International Polio Network (IPN) to link polio survivors and to encourage the formation of post-polio support groups.

G.I.N.I. publishes the *Polio Network News*, a quarterly bulletin for IPN members and coordinates and maintains the national and international directory of post-polio support groups, clinics, and physicians.

IPN membership forms are available from G.I.N.I.

Ventilator Users Network

Polio survivors who started using home mechanical ventilation in the 1950s formed the nucleus of G.I.N.I.'s International Ventilator Users Network (IVUN).

IVUN links ventilator users with each other and with medical personnel interested in home mechanical ventila-

tion. These ventilator users include infants, children, and adults disabled by neuromuscular diseases or injuries affecting the respiratory system.

IVUN's members receive a biannual newsletter featuring ventilator equipment and adaptations, glossopharyngeal breathing techniques, psychosocial aspects of long-term ventilator use, sleep disorders, organizations concerned with ventilator users, travel, etc.

Membership forms are available from G.I.N.I.

Information Service and Networking

G.I.N.I. is a primary source of specialized information on do-it-yourself equipment, independent living, polio, spinal cord injury, and ventilators.

The library, with materials amassed over 35 years, is a special collection of books, periodicals, monographs and reports, pamphlets, clippings, and case histories.

Using the library's unique resources, G.I.N.I. answers questions on disability-related subjects, such as architectural and attitudinal barriers, civil rights, housing adaptations, wheelchairs, vans and lifts, etc. Questions about coping with disability are answered by referrals among G.I.N.I.'s international people network.

The information service is available only to G.I.N.I. members.

Independent Living

Gini Laurie is well known as the historian of the independent living movement. She has watched and encouraged the growth of the independent living centers since the early 1970s.

The lives of disabled individuals as role models are chronicled in the pages of the *Gazette* and parallel the involvement of the independent living movement.

G.I.N.I. provides information on all aspects of independent living including attendants, education, employment, equipment, family life, sex, sports, and travel.