



Rehabilitation Gazette

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by and for Persons with a Disability

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Arm in Arm with Strangers: Independent Living The Walt Whitman Way

By Karan McKibben

There is perhaps no experience so conducive to the development of a liberal mind as living on a 24-hour basis with a variety of strangers. My own experience in living with strangers began in earnest a decade and more ago, when I decided that as a ventilator-dependent, polio quad I could best establish an independent lifestyle by depending not on trusted family and friends but on strangers whose only recommendation was their expressed desire to fulfill the duties advertised in the local university newspaper. This experience convinced me that Walt Whitman was right and that a liberal mind was essential to my independence not only because it enabled me to develop cooperative relationships with an amazing variety of live-in attendants, but also because it encouraged me to develop and express my own individuality.

Thus, one year I found myself living with and depending upon an Austrian whose Germanic fantasies included a need to defend Hitler from his bad reputation; another year it was a homesick young woman whose brothers had kidnapped her from Thailand and who longed to return to her ailing grandparents; still another year it was a Chinese whose relatives had kidnapped her from Vietnam and who was struggling to understand Christianity and her American relatives. One of the most enduring relationships I established was with a born-again Christian rebelling against the Orange County culture of her parents. And one of

the latest relationships to evolve was with a rugged, American individualist who took pride in the nonconformity of her Mojave desert heritage.

With each of these young women the relationship was quite different and required a good measure of adaptability. The initial, formalized employer-employee relationship always quickly shifted into a more personal and symbiotic relationship. Undoubtedly the shift was a matter of survival because there were just the two of us to forestall what seemed like impending doom as dishwashers, respiratory equipment, and personal dreams tottered on the brink of self-destruction. With the Austrian, German food and after-dinner conversations over coffee were important in bonding us in cooperation; with the homesick young woman from Thailand, gentle guidance and a certain amount of mothering were required to make her strong enough to cope; with the Chinese, lots of busy-work and introduction to American culture helped to channel her optimistic energies. The born-again Christian required adequate time for prayer meetings, avoidance of any discussion of Darwinism, and the suppression of my latent mothering instincts. The Mojave desert individualist needed room for an expensive mountain bike and a large tool box along with respect for her nonconformist ways and unwavering self-reliance from me.

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Syringomyelia in Paraplegia*

By Bernard Williams, MD, ChM, FRCS

This article is based on questions and answers, asked by a recent patient. She had paraplegia at 15; the development of slight numbness in one arm at the age of 17, progressing to severe numbness by the age of 24, but still without weakness. Scans showed a syringomyelia cavity, or syrinx, attacking the inside of the spinal cord.

Q: WHY DO I HAVE IT?

Nobody knows. The complication occurs in between 2% and 5% of paraplegics, and it is not possible to identify the cause.

One of the interesting things is the morphology, or the shape of the cavity in the cord.

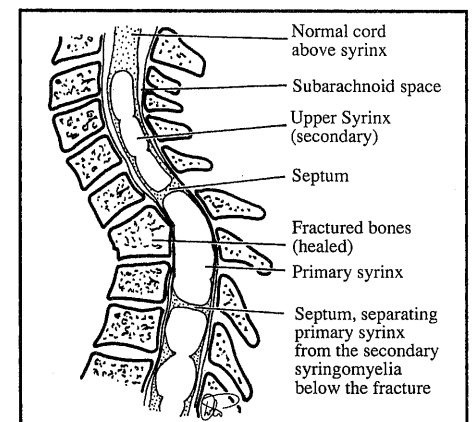


Diagram 1 — The typical appearances of post-traumatic syringomyelia. The diagram represents a vertical section down the middle of the back, front facing to the left. Thus the vertebral bodies are on the left and the laminae on the right. Not all cases have a primary syrinx.

There is one interesting kind where there is a distinct separate cyst opposite the site of the fracture, and this may have a firm

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Arm in Arm

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In adapting to these constantly changing relationships, I discovered that my self image began to expand and grow in confidence. Until the homesick young woman from Thailand moved in, I had never considered myself especially adapted to any kind of mother role. In the long after-dinner conversations with the sophisticated but misguided Austrian, I made the decision to try to express a Whitman-like liberalism in personal as well as political attitudes even though it was not easy to listen patiently to such repugnant views as Nazism and anti-Semitism. And with the need to respect the nonconformity of the Mojave desert individualist, I came to respect my own individuality.

Respect for one's own individuality is, of course, the very point of striving for an independent lifestyle. For a physically dependent person, however, respect for one's own individuality becomes also an essential survival skill. Indeed, in developing a working relationship with a live-in attendant, it is just as important not to give away one's own individuality as it is not to jeopardize one's physical well-being. The trick is to develop appropriate checks and balances between the interests of two individuals so that both can express their individuality as fully

as possible without infringing unduly upon the well-being of the other. In an apartment in California just as in the halls of the United States Congress, democracy is the key to independence.

Thus, in negotiating a schedule that enabled my attendants enough time for their prayer meetings, biology labs, and skiing trips, I sometimes had to remind myself and my attendants of my own interests and physical needs as inconvenient as they may have been. In making the household rules as flexible as possible, I tried to make it clear that I would not tolerate blatant violations of my own moral standards and quiet lifestyle. And in tolerating a variety of work habits that frequently placed household chores well below final exams and boyfriends in priority, I sometimes had to become authoritarian about cleaning the kitchen floor or taking out the garbage. The Austrian solved the problem in her unique way — by talking her mother into hiring us a maid.

As I learned in some difficult times, working out democratic relationships with live-in attendants is by no means easy. And what makes it particularly difficult is the unavoidable vulnerability inherent in being physically dependent on unrecommended strangers in order to get out of bed in the morning, to eat more than Domino's pizza for dinner, and even to breathe through the

night should the ventilator fail or become disconnected. Only a liberal's underlying faith in the fundamental decency of human nature allowed my mind to rest easily with the realization that my very life depended upon prudently trusting the strangers who came knocking at the door with newspaper ad in hand and unknown personalities lying behind eager smiles. The risks were obvious, but they could be managed as long as I did not allow xenophobia to narrow the options and to imprison me in intolerant attitudes toward self and others.

After all, strange and wonderful differences in food and dress, in cultural heritages, in work habits, in moral standards, in life histories, even in psychological responses to the way of the world are but the external manifestations of the basic humanity that all of us share. We are all human beings having the same basic needs for understanding and respect no matter what particular song may be used to express that humanity. In the past decade and more my home has been filled with music: the hard rock of the Chinese attendant, soft rock from the young woman from Thailand, country western from the American individualist, jazz from the Austrian, and classical from my stereo. When the balance was right, there was surprising harmony.

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Karan McKibben

In a very real way, establishing an independent lifestyle by depending physically upon live-in attendants is an exercise in living the liberal life. It is an exercise that involves practicing on a daily basis tolerance and acceptance of a wide range of individuality. It is also an exercise in developing a healthy respect for one's own individuality. As Walt Whitman would insist, respect for human individuality is imperative for any one's or any nation's independence, and as he would remind us also, this respect derives from a fundamental trust in the unique goodness of the human spirit no matter how it comes clothed. Thus, as I learned, living with a procession of attendants is living day-to-day the all-inclusive democracy that Whitman sings about when he celebrates in *The Leaves of Grass* the sacredness of the multiple individuals who comprise the human spirit.

Each singing what belongs to him or her and none else,

The day what belongs to the day — at night the party of young fellows, robust, friendly,

Singing with open mouths their strong melodious songs.

Personal Assistance Services

By Margaret Nosek, Ph.D.

Personal assistance services refer to the kind of help people with disabilities need to compensate for their functional limitations. If it takes an extraordinary amount of time or energy to do certain activities for yourself, such as getting out of bed, taking a bath or preparing a meal, then you need someone to help you do it. However, this creates a need for an entire service area. Although it has been assumed that families are able to provide this care, quite often family members are not available to assist or, if they are, the workload on them creates unnecessary strain.

According to a 1988 study conducted by the U.S. Census' Survey of Income and Program Participation, the number of persons with disabilities who need assistance with some day-to-day needs is estimated to be 7.7 million or 3.3% of the total population in the U.S. Those of working age (18-64) who need assistance number 3.16 million. The large majority (81%) of persons needing assistance live with relatives or a spouse, and 79% received volunteer help only. People who need this service generally have very low incomes or depend on family financial assistance. They often have no insurance, very little access to employment opportunities, and have a very serious problem in finding money to pay people to help them over and beyond what their family can provide.

TIRR's Independent Living Research Utilization (ILRU) program and the Baylor College of Medicine Research and Training Center on Spinal Cord Injury have been studying the most common arrangements for receiving personal assistance services. A study of 655 persons with spinal cord injury revealed that 50% of the sample was assisted by family exclusively, 31% by non-family exclusively, and 19% by a combination of

family and non-family.

Most agencies set up to assist in this problem have numerous restrictions. For example, the Department of Human Services offers attendant services, but you have to meet their income eligibility. Basically, if you work, you are not eligible. So you are caught in the bind where you can work and earn money, but you cannot earn enough money to pay for your assistant.

Action in Texas

The Texas Rehabilitation Commission has started a new program in San Antonio which provides funds for those who are employed to help pay for their attendants. There are efforts to expand this program to other parts of the state. The Coalition for Barrier Free Living (CBFL), through its Personal Assistance Task Force, co-chaired by **Nita Weil** (TIRR Hospital) and **Linda Pickle** (TIRR Systems), will be strongly advocating in the next session of the legislature for the state to increase funding for this personal assistance program. The aim is to turn present policy from supporting institutional services, such as nursing homes, toward funding more community-based services.

In the 1991 session of the legislature, CBFL will be advocating for additional funding for personal attendant services through the Department of Human Services and the Texas Rehabilitation Commission. The goal will be to make this a national policy, whereby the individual in need of a personal assistant will be eligible for financial assistance, via a sliding scale.

A demonstration project funded by the Department of Human Services in Beaumont, Texas, offers funds for personal atten-

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Action in Texas

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dants through a home health agency, Medicare. The service provides referrals for attendants who are not limited to day hours as well as an emergency backup pool. Funds may also come directly to the consumer who pays the attendant. The program is very responsive to the consumer needs and according to ILRU's research, consumers are very satisfied with the service. It may serve as a model program nationally.

If you are interested in learning more about the Personal Assistance Task Force of the Coalition for Barrier Free Living, contact **Nita Weil** at 713/797-5230 or **Linda Pickle** at 713/528-0504.

RESOURCES:

Personal Assistance Services for People with Disabilities: An Annotated Bibliography by Peg Nosek, Carol Potter, Huong Quan, and Yilin Zhu. Send \$5 to ILRU, 3400 Bissonnet Suite 101, Houston, TX 77005 USA.

Bustin' Loose to Independence: Through Personal Attendant Services by Margaret A. Nosek, Ph.D., 1988. A four-hour audiotape series and training package containing information on how persons with spinal cord injury and others with severe disabilities can gain independence by using attendant services. The audiotapes come with written supplemental material. Order from ILRU, 3400 Bissonnet, Suite 101, Houston, TX 77005, 713-666-6244. (Four-tape set for consumers, \$30; one-tape set for parents, \$10; one-tape set for service providers, \$10.)

ADAPT, formerly American Disabled for Accessible Public Transit, has changed its name and focus. Since the passage of the Americans with Disabilities Act, ADAPT has redefined its direction by focusing on attendant services programs for people with disabilities. The group, now known as **American Disabled for Attendant Programs Today (ADAPT)**, is headquartered in Denver, CO. For more information on their agenda and activities contact: National Adapt, 3005 West Gill Place, Denver, CO 80219 USA (303/936-1110).

World Institute on Disability (W.I.D.), 510 16th Street, Oakland, CA 94612 USA (415/763-4100), with the assistance of the National Council on Disability is drafting a bill called The Personal Assistance for Independent Living Act. To provide your input on this bill which will eventually be introduced in Congress, contact Simi Litvak at W.I.D.

Syringomyelia in Paraplegia (continued from page 1)

septum or wall across the cavity at the top, the bottom, or both, and there may be a syrinx cavity involving the spinal cord going upwards or downwards. I call this a secondary syrinx and the cyst opposite the fracture, I call the primary syrinx. This suggests that there has been a cavity formed by bleeding into the spinal cord at the site of injury. The body attempts to wall that off and may be partly successful. That is what these septa are. There is another kind which is rare and in which the spinal cord is entirely flattened opposite the fracture, but there is a separate syrinx either above, below, or both.

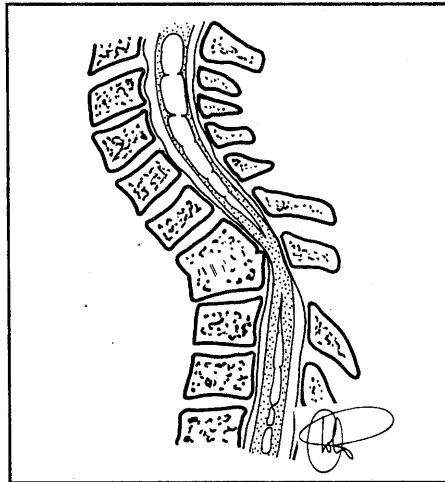


Diagram 2 — Less common findings in which the spinal canal is narrowed opposite the fracture, and the cord is scarred and constricted. There may be a cavity either above or below this, or, as in this case, both. Such cavities do not communicate.

Much the commonest kind, and this is what you have, is a big cyst going upwards and downwards from almost the top of the spinal cord to the bottom and present opposite the fracture. We cannot be certain if this started with a

hemorrhage unless we had good MRI scans taken at the time of your injury.

Q: DO I NEED AN OPERATION?

With a big syrinx, absence of reflexes, and severe sensory loss, I believe operation is advisable. Unfortunately, no-one can see into the future. If they could, surgeons would never do any operation which was going to produce complications. All we can say with certainty is that your spinal cord is distorted by cystic enlargement and that probably you will suffer more sensory loss and weakness in the upper limbs.

Q: WILL THIS COME ON SUDDENLY?

Again, it is impossible to answer. After a sudden event, such as a fall, patients sometimes deteriorate quickly. I have at least two patients who worsened after second accidents. In each of those cases, it is likely that had they had the operation before the second accident, they would not have suffered further deterioration.

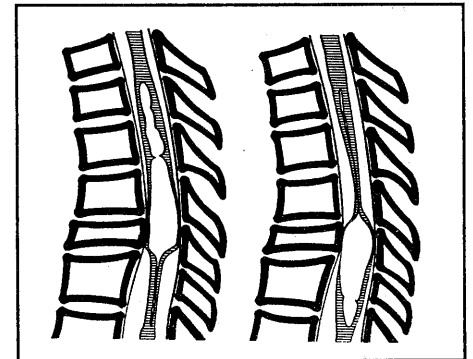


Diagram 3 — In the commonest variety of post-traumatic syringomyelias, there is a swelling of the cord, thinning of its wall, and free communication both upwards and downwards. Even in this case, there may be septa in the cavity which are either complete (above) or partial (below).

Q: WHAT SORT OF OPERATION CAN BE DONE?

The operation which I favour involves a long cut centered on the fracture. I take off the laminae, those are the bones which

Fall 1990 of *Spinal Network Extra* featured "Personal Care Services: Buyer Beware." A single copy is available for \$5 from Spinal Network, P.O. Box 4162, Boulder, CO 80306 USA.

The Disability Rag also featured the need for attendant services in its January/February 1991 issue. A copy is available for \$2.50 from The Disability Rag, Box 145, Louisville, KY 40201 USA.

arch over the back of the spinal cord, for a distance of 4 or 5 inches, which usually means five laminae. I then try and open up the subarachnoid fluid spaces outside the cord above and below, and then I put in a drainage tube and drain the fluid from the inside of the cord to the pleural cavity. I choose the side where there is less pain sensation, and if possible, I go below the level of sensory loss to lessen pain from the chest.

Q: HOW SOON WILL I BE UP AND ABOUT AFTER OPERATION?

It is difficult for a patient with paraplegia. You are dependent on your arms for everything, such as turning. Your back will be sore because half the cut has to be above the area of sensory loss. This means that the nursing staff will need to help with turns and so on. Bladder management may become temporarily more difficult and an indwelling catheter is necessary for a few days. Given reasonable progress, the arms can be used to pull you up the bed and to help you to turn after three or four days. You should be able to sit out after four or five days, and you should be able to resume transfer between six and nine days after surgery.

Q: WHAT HAPPENS IF THE TUBE BLOCKS UP?

It is expected that the tube will block up after only a few days because the spinal cord will collapse around it. The purpose of the operation is not chiefly to drain the fluid. The purpose is to stop the fluid from being driven into the inside of the syrinx. This is why a big cut and opening up of the subarachnoid spaces (spaces around the spinal cord) is recommended.

Q: HOW CAN YOU BE SURE IT WON'T REFILL?

If it collapses down, then it doesn't refill. What sometimes happens is that if a cavity is collapsed down, in your case it would be a cavity chiefly on the

right side of the cord, then another cavity may open up on the left side if it is still being fed by fluid from below. I have seen two such cases that have required re-operation.

Q: WHY CAN'T YOU PREVENT THIS ENTIRELY?

The easiest way to prevent it is to cut the cord across. Obviously, this has to be done below the level of the sensory loss, and it is only reasonable to do it when the patient is a complete paraplegic. The tube can then be put into the cord both firmly tied so as to prevent the fluid from entering. In combination with the drain, this is the most secure way of preventing further filling. People may have an emotional attitude towards division of the cord, even when the cord function is gone.

Syringomyelia, sometimes referred to as SM, is a spinal cord disorder in which fluid-filled cavities develop within the spinal cord. As the cavities expand, the spinal cord gradually is destroyed.

They hope that there is going to be some technique discovered to make cord tissue regenerate. If indeed such ever becomes possible, it seems likely that the first step in the operation would be to cut out the damaged section and join together the other parts of the cord. The development of such techniques in the immediate future, during the time in which your syringomyelia is likely to get worse, is certainly very remote. What I would like you to consider is to give me a cart blanche to do what I think is best at the time of the operation.

Q: IF THE DOCTOR KNEW I HAD THIS WHEN I WAS 17, WHY DIDN'T HE SEND ME TO YOU THEN?

I think that many non-surgeons are suspicious of surgery. By

nature, surgeons are, of course, enthusiasts and optimists.

I would like to think that I am self-critical enough to monitor my work and not to mislead my patients. The attitude among many doctors is that surgery should be reserved for people in whom the syrinx is obviously giving trouble. I don't doubt that your physician said to himself, "Well, this young girl has got only a minor sensory deficit — she hardly knows she's got it; she has no loss of motor power, and she has no serious pain — let's wait a little while and see what happens." This is not an unreasonable attitude.

Q: WOULDN'T IT HAVE BEEN BETTER IF SOMETHING HAD BEEN DONE THEN?

You may know the name of Rossier. He was a medical student who was made paraplegic by someone jumping on him off a diving board. He has subsequently become an eminent doctor in paraplegia. He has reviewed cases treated by surgery and has concluded that it is not advisable to treat small syrinxes. This sounds sensible, but if you think about it, everybody with a large syrinx had at some stage a small syrinx which later grew.

If we knew which patients were going to develop large syrinxes, a small operation, possibly without a drain, might be helpful in the early stages. Unfortunately, the matter is not completely understood.

Q: WHAT CAN I EXPECT AFTER THIS OPERATION?

The most important gain would be stopping progress of the syrinx symptoms. Unfortunately, nobody can promise a complication-free convalescence. There is little chance of respiratory complications, particularly if there have been no previous chest troubles. The wound is necessarily painful. The part of the arm which is numb may become slightly more painful as sensation returns.

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FRIENDS AROUND THE WORLD

"I want to tell you about the miracle of wearing a brace again after not wearing one from July 1948 to October 1990 — 42 years.

"When I was first told several years ago that I should go back into a leg brace my brain said, 'If it has to be — it has to be!' The rest of me said, 'Oh, NO! We're going backwards. We're going to fight it.' Well, I was 'good.' I had a brace made.

"However, this particular orthotist was one that believed that the longer you wear a brace, the more comfortable you will feel in it. He also thought that it would be "OK" once I was able to get it on. You see, in addition to my right leg having no power from the hip down, I had polio in my

right hand which left me with what is called "flat palm." To explain it simply, I cannot stretch with my fingers and I cannot grab items the way someone else can. That made it impossible for me to put on the brace. Needless to say, that brace did not work out.

"Two years later I went to another orthotist in Suffolk County. To his credit, this young man tried very hard. He made me three different braces. The first was a short brace that started mid-calf and went up mid-thigh. It was easy to get on but, due to my gait, it slid down as soon as I started walking. The next one was a slightly longer version extending higher to my hip. Unfortunately, it also slid around. The last one we tried was

a full-leg brace with a foot plate in the shoe. When the orthotist put it on and then put my shoe on, it was fine. HOWEVER, it was impossible for me to do it. So there went the fourth brace into the closet.

"Just about that time our support group was arranging with St. Charles Hospital in Port Jefferson, Long Island, NY, for seminars with different medical personnel each week. The week that we had the orthotists was very enlightening. The young men work with children who have birth defects, cerebral palsy, etc. They also make braces for kids that have no hands.

"They told that if I lost some weight, they would guarantee a brace that fit and that I would be

Syringomyelia

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I have several patients who didn't like this, and one or two who were not grateful. In all these cases, however, the abnormal sensation has become less troublesome and what improvement there was in sensation has been gratefully received. There is little chance of considerable improvement.

With regard to motor power, I have had two patients who have become worse after the syrinx was drained. In each of them, they already had some motor weakness, and I think that the spinal cord lost function after it was collapsed because the cord was already so badly damaged.

I think in both of them, the deterioration was inevitable within the next few months anyway. I certainly wouldn't want you to feel that the risk of motor power loss was a reason for you not to have this operation.

The later you leave it, the worse things are going to get and the greater the risk to motor power.

UPDATE ON THE SURGERY

Melanie had her operation with transection of the spinal cord and placement of a drain to the pleural cavity. She initially had a marked return of sensation to the chest and upper limb which was itchy, tingly, and unpleasant. The unpleasant sensations improved and left her with an overall gain in sensitivity. She then developed a late complication with severe headache due to the drain having partly come out. This is an unusual complication and was completely resolved by removal of the drain. The cavities both upwards and downwards remained pleasingly flattened on the MRI scans.

* Reprinted with additions from *SIA (Spinal Injuries Association) Newsletter, Newpoint House, 76 St. James's Lane, London N10 3DF, ENGLAND (081-444 2121).*

FURTHER READING:

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Williams B: Syringomyelia in Paraplegia. *Rehabilitation Gazette* (Vol. 28, No. 1) 2-4. 1987.

Anderson A: The Maintenance of Function of People with Syrinx. *Rehabilitation Gazette* (Vol. 28, No. 1) 5-7. 1987.

RESOURCES:

Bernard Williams, MD, ChM, FRCS, Consultant Neurosurgeon, The Midland Centre for Neurosurgery & Neurology, Holly Lane, Smethwick, Warley, West Midlands B67 7JX, ENGLAND (021-558 3232).

Ann's Neurological Trust Society (Self-Help Group), Miss Ann Conroy, Jocelyn Lodge, Keythorpe, Tugby, Leicester, ENGLAND (053 756 244).

American Syringomyelia Alliance Project Inc., P.O. Box 1586 Longview, TX 75606-1586 USA (214/759-2469).

National Organization for Rare Diseases (NORD), P.O. Box 8923, New Fairfield, CT 06812 USA offers reprints of disease articles from its Rare Disease Database for \$2.50 per copy. Contact: NORL Literature, NORD Services may be accessed on your personal computer by typing "GO NORD" at any prompt on the CompuServe Information System.

able to get it on by myself. Well, I lost the weight and one of the young men (**Martin Mandel-um**, 5225-21 Neconset Highway, Port Jefferson Station, NY 11776 USA) was true to his word. Marty cast me for a long leg brace. To get what he wanted, he sent the cast to Canada.

"The brace is unique in that it has two kinds of plastic. The bottom part, including the foot pad, is a firm plastic. This goes to mid-calf. The upper part, which goes around the thigh, is of a flexible plastic lined with soft leather. Instead of the metal bars up the sides with hinges on both sides and a locking device in the back, this one (as my knee locks itself) has a figure-eight-type thing on the outside of the leg. The brace is held on by a strap approximately 4" down from the knee, a 6" wide piece of elastic going around the thigh and "velcroing," and a third strap going from the 4" down from the knee on the outside around the back of the knee to meet 2" above the knee. And, it works!

"It was then discovered that, although my left leg has always been my strong one, the ankle joint was riddled with degenerative arthritis. My orthopedist, **Dr. Joseph Farrell**, said that a short ankle brace would be helpful in avoiding surgery and fusing the ankle. Marty came through again with a short (mid-calf), firm, plastic brace with two velcro straps going around.

"As much as I fought it previously, all I can say now is that this makes it easier for me to get around, and, hopefully, to allow me to continue getting around for a few more years.

"If anyone would like to talk to me about these braces, please contact me."

Barbara Goldstein
 Hedgerow Court, Commack, NY
 11725 USA (516/499-5477)

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"In 1954, at the age of eight, I had polio and was left with a slight paralysis of the right upper leg including muscle weakness and joint problems in the knee. For 33 years I managed with these problems quite well. Then I noticed an increasing muscle weakness in both arms and legs. Visits to my doctors did not clarify the reasons for this weakness. A new "polio" was excluded, of course, as polio is considered "out" in Germany. By accident my family doctor read an article on post-polio syndrome in a medical journal. This article also mentioned that there have been some research studies on former polio patients.

"During vacation in New Jersey in summer 1989, I contacted a local self-help group and a surgeon. After a thorough checkup this doctor concluded that my problems might be post-polio syndrome. Thanks to this local support group I heard about **Polio Network News**. I subscribed because I wanted to get into the matter myself.

"In **Polio Network News**, I read a report of a research program conducted by **Dr. Raymond Roos**, from the University of Chicago. Dr. Roos and his team examine the sprouts of motor nerve cells for anatomical abnormalities using a biopsy of the anconeus muscle. With electron microscopy, they are able to look at the actual terminal nerve sprouts, as well as the muscle itself and the neuromuscular junctions. [The neuromuscular junction is abnormal in the case of another neuromuscular disease (myasthenia gravis) that shows fatigue as a prime clinical symptom as does post-polio syndrome.]

"As this team was interested in recruiting patients for these tests, I contacted Dr. Roos. In March 1990, a biopsy study on the anconeus muscle of my right arm and EMG studies were done. The findings of these studies showed anatomical changes with ongoing denervations and electrical abnormalities correlating with

increased muscle fatigue when stressed. After these studies, I was told for the first time that I had had polio in all four extremities.

"My main problems at the moment are muscle weakness, muscle pain, muscle atrophy, and swelling in both arms and legs. I was advised to reorganize my daily life, e.g. to relax more often and not to work too much. Every day I do some physical exercise and once a week I go swimming. I also do some transcutaneous nerve stimulation. Dr. Roos also recommended that I use medication containing pyridostigmine. As a result of following all of these suggestions, I do not feel so tired anymore and feel quite well. [The Summer 1989, **Polio Network News** reported from a successful trial using pyridostigmine by **Dr. Daria A. Trojan**, Montreal, Canada.]

"The findings of these tests in Chicago have been very useful for me, my doctors in Germany, and for Dr. Roos and his team. All these checkups have been free of charge, and I was happy to get this done by experienced specialists such as Dr. Roos and **Dr. Maselli**. However, the present findings must be confirmed by additional biopsies and EMG studies. Therefore, it would be helpful if more survivors would participate. Interested readers should contact Dr. Raymond Roos, Dept. of Neurology, University of Chicago, Medical Center, 5841 South Maryland Avenue, Chicago, IL 60637 USA."

Renate Schindler
 Ortlehnerstr. 54, D-8269
 Burgkirchen, GERMANY

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"Do you have any information about motels and hotels in the USA that have "roll-in" showers and not just handicap rooms. I only know of three in San Diego. This prevents me from travelling now."

Larry Schneider
 811 N. Longfellow Avenue,
 Tucson, AZ 85711 USA

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Friends Around the World

(continued from page 7)

"The European Network on Independent Living met at "Het Timmerholt," Netherlands, 31 August — 3 September 1990. We developed long term goals and an action plan. Members of the Steering Committee include: **Marry van Dongen**, Moennond 27, 3334 CL Zwijndrecht, Netherlands; **Uwe Frehse**, Westendstrasse 93, 8000 Munchen 21, Germany; **Philip Mason**, 4 Plantation Way, Whitehill, BORDON, Hants. UK. GU35 9HD, England; **Adolf Ratzka**, Norrbackagatan 41, 11341 Stockholm, Sweden; **Bente Skansgard**, Norderhovgt. 15, 0314 Oslo 6, Norway. For more information contact any of the above."

Uwe Frehse
GERMANY

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"The Offinso District Branch of the Ghana Society of Physically Disabled was formed in 1988 as a non-governmental and non-profit organization aimed at assisting members with a disability to live independent lives. We have 345 individuals in Ghana West Africa in our Society, of which 200 are polio survivors. We have been able to set up two workshops for training individuals in sewing and leatherwork. We ask anyone interested in helping us to contact the following person."

J.A.K. Addai (Secretary)
Ghana Society of the
Physically Disabled
P.O. Box 135, Offinso, GHANA

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"The First Medical Conference on Post-Polio Syndrome in Czechoslovakia took place at the Recreation Centre of Czechoslovak Union of Disabled Persons at Hodonin near Kunstat on 13-15th November 1990.

"Fifty-one doctors beside a number of selected physiotherapists

took part with two German doctors, who participated thanks to your announcement of the Conference in the **Polio Network News**. Several papers were read. I acquainted the participants with Gini's life and G.I.N.I.'s publications. All papers will be published in *Czech Proceedings* next year, and I will send an English summary of medical opinions."

Dr. Ala Wokoun
Chabarovicka 1333,
182 00 Prague 8,
Czechoslovakia, EUROPE

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"I have written poems for many different occasions (birthday, wedding, thank you, etc.) and have printed them on parchment paper. They are suitable for mailing or for framing. Anyone who sends me a SASE envelope will receive a sample and the current prices."

Stephen P. Mickey
224 W. Main Street
St. Nazianz, WI 54232 USA

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"I am writing to you out of the growing concern in regards to the Social Security Administration's budget and staffing cutbacks which have been imposed on Disability Determination Services (D.D.S.) across the nation.

"Over the past four years there has been evidence of a serious breakdown in services to persons with disabilities due to these cutbacks. The Massachusetts D.D.S. Advisory Committee has witnessed backlogs and diminishing allowance rates in our state, and we hear of similar backlog in other states.

"The backlog of pending cases rose by over 94,000 during F.Y.'90 due to a higher than expected number of receipts per the level funding. The nation was left with 484,941 initial reconsideration and OHA cases pending at the end of F.Y.'90. This was a 24% increase over those pending at the end of F.Y.'89.

"Eighty percent of the states report that their pending cases are so high that it deters them from completing cases in a time manner. It is expected that these backlogs will occur again this fiscal year.

"This problem has been addressed before at Congressional Hearings where D.D.S. representatives testified on behalf of their own agency. And, we have been holding meetings with the Massachusetts Congressional Delegation members expressing our concerns.

"To date things are beginning to improve. We now have the support of **Social Security Administration Commissioner Gwendolyn King** and **Secretary of Health and Human Services Dr. Louis Sullivan**.

"Commissioner King responded to requests for more staff and money by asking for a contingency fund tap plus a supplemental appropriation and by pushing for an adequate F.Y.'92 budget. She has submitted her requests to Dr. Sullivan, who in turn asked for the funds from the Office of Management and Budget (OMB). Acting for the OMB, Richard Darman turned down Dr. Sullivan's request. However, it has been reported that Commissioner King and Secretary Sullivan are not accepting Darman's denial and plan to meet with President Bush to urge him to approve the funding.

"To secure the necessary funds, the voices of people with disabilities, their families, and friends need to be heard.

"Write or call your Congressman and Senators. Ask them to support an increase in the Social Security budget earmarked for D.D.S. in F.Y.'92."

Kathleen Simpson
Massachusetts D.D.S. Advisory
Commission, Chairperson

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RESOURCES RESOURCES RESOURCES

CATALOGS

Complete Closed Caption Video Catalogue describes over 1500 captioned movies. Send \$3.95 to: One Video Place, Closed Caption Department F, 405 Lowell Street, Wakefield, MA 01880 USA.

LS&S Group Inc., P.O. Box 673, Northbrook, IL 60065 USA, (800/468-4789 or 708/498-9777 in IL) publishes a catalog with products for the visually impaired.

Massachusetts Association for the Blind, Store for Independent Living, 200 Ivy Street, Brookline, MA 02146 USA (617/738-5110 or TDD 617/731-6444). Call for information about **Aids and Appliances Catalog** and new products.

Contact **Technical Aids & Systems for the Handicapped Inc.** (tash Inc.), 70 Gibson Drive, Unit 12, Markham, Ontario, L3R 4C2 CAN-ADA (416/475-2212) for a Catalogue Supplement with new 1991 prices.

DU-IT Controls Systems Group designs and manufactures aids for people with disabilities. To order their new catalog write to: Barb Heinrichs, DU-IT Control Systems, 8765 Township Road 513, Shreve, OH 44676 USA.

To order **The Illustrated Directory of Handicapped Products**, send \$12.95 to IDHP, 3600 W. Timber Ct., Lawrence KS 66049 USA.

To receive a copy of the **1991 Ableware Catalog** (72-page full color), call (201/628-7600) or fax your request to (201/305-0841).

Avenues (clothes, etc.), Everest & Jennings, 3233 East Mission Oaks Blvd., Camarillo, CA 93012 USA (800/848-2837).

1990-91 Accent on Living Buyer's Guide, P.O. Box 700, Bloomington, IL 61702 USA. \$10.95.

Solutions: Products that make life easier, P.O. Box 6878, Portland, OR 97228 USA (800/342-9988).

CHEMICAL DEPENDENCY

Congress on Chemical Dependency and Disability (CCDD) offers technical assistance, training, and advocacy information

throughout the country. Contact: CCDD, 34 Wild Horse Loop, Rancho Santa Margarita, CA 92688 USA.

Rehabilitation Institute of Chicago (RIC) conducted research for several years on alcohol and drug related problems with spinal cord injuries. For information about a demonstration treatment and recovery program, contact Allen Heinemann at RIC, 345 East Superior Street, Chicago, IL 60611 USA.

COMPUTER-RELATED

DELPHI, a leading provider of online services, announces the establishment of the **Handicap Forum**. The Forum provides access to an expanding database of articles discussing issues for people with disabilities. It also enables members worldwide to communicate via a public message forum, live conferences, and electronic mail. Accessible by any computer and modem, DELPHI offers continuously updated news, financial information, travel and shopping databases, and access to many public domain software libraries. For a limited time, individuals interested in participating in the Handicap Forum can join DELPHI for only \$9.95. For additional information, call DELPHI Member Services at (800/544-4005).

InfoTech Inc. and Levin-Koopman & Associates have developed the **Verbal Input Processor (VIP)** which is an IBM-compatible based system which allows you to use your voice as input. It has a vocabulary of 30,000 words and will respond to your voice. For more information, call InfoTech, Inc. (517/336-9434). The price of approximately \$15,000 includes software and a 386 standard bus computer.

S.E.R.I.E.S. Computer Network Bulletin Board provides information exchange on Independent Living and Adult Service. Call (503/346-3534) to register.

BrainTrain, 1915 Huguenot, Richmond, VA 23235 (804/794-4841) offers a free catalog of **Cognitive Rehabilitation Software**.

Direct Link is a newsletter from the Center for Computer Assistance to the Disabled (C-CAD). Contact R.E.A.C.H./C-CAD, 617 Seventh

Avenue, Fort Worth, TX 76104 USA. \$5/year. C-CAD's Computer User Group meets every Super Saturday at Infomart. Contact C-CAD for details.

DIRECTORIES

The **1991 Post-Polio Directory** will be available soon to survivors (\$2.00), health professionals (\$15), and institutions (\$25). Contact: G.I.N.I., 4502 Maryland Avenue, Saint Louis, MO 63108 USA (314/361-0475). Please specify 1991.

The **Directory of Independent Living Programs** will be available soon for \$8.50 from ILRU, 3400 Bissonnet, Suite 101, Houston, TX 77005 USA (713/666-6244). Please specify 1991.

For a free directory of messages and access codes for a **Senior Helpline** call (800/328-7576 or in Utah Valley, 801/378-7576) or write F-274 HFAC, BYU, Provo, UT 84602 USA. The system, developed by Brigham Young University's Gerontology Resource Center, offers free messages (lasting up to three minutes) which cover a variety of subjects for older individuals.

A **National Directory of Services for Women and Girls with Disabilities**, Educational Equity Concepts, Inc., 114 East 32nd Street, New York, NY 10016 USA (212/725-1803). \$12.

Annual Directory of Travel Agents Serving People with Disabilities. Twin Peaks Press, Box 129, Vancouver, WA 98666 USA (800/637-2256). \$19.95 plus \$2 shipping.

DISABILITY-SPECIFIC RESOURCES

Self Help Group for Arachnoiditis (Inflammation of the spinal lining) is a voluntary organization, who through correspondence, is endeavoring to collect information on the condition. Contact Lisa Rowe, Arachnoiditis Self Help Group, 14 Windsor Terrace, East Herrington, Sunderland, Tyne and Wear, SR3 3SF ENGLAND.

National Aphasia Association, P.O. Box 1887, Murray Hill Station, New York, NY 10156-0611 USA.

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RESOURCES

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Free brochures about nonsteroidal anti-inflammatory drugs (NSAIDs) and about corticosteroids, both used to reduce inflammation, is available from your local Arthritis Foundation Chapter or call the **Arthritis Foundation** Information toll-free at (800/283-7800).

The **Arthrogryposis Group** (a national support group), Diana Piercy, 1 The Oaks, Gillingham, Dorset SP8 4SW, ENGLAND (0747 822655).

The **American Foundation for the Blind (AFB)** operates a toll-free telephone hotline (800/232-5463) from 8:30 a.m. to 4:30 p.m. Eastern Standard or Eastern Daylight Time, Monday through Friday. New York Residents should use (212/620-2147).

March of Dimes Birth Defects Foundation, 1275 Mamaroneck Avenue, White Plains, NY 10605 USA (914/428-7100).

American Carpal Tunnel Syndrome Association, P.O. Box 6730, Saginaw, MI 48608 USA.

Cerebral Palsy Overseas (CPO), 6 Dukes Mews, London W1M 5RB ENGLAND (0 71 486 6996), offers information or advice regarding any aspect of cerebral palsy and provides direct contact with professionals involved in the field. The service is free unless the request is extensive.

National Chronic Fatigue Syndrome Advisory Council, Corresponding Office, 12106 E. 54th Terrace, Kansas City, MO 64133 USA (816/931-4777).

United Federation of CFS/CFIDS/CEBV Organizations, Inc., 2141 W. Fairlane Avenue, Milwaukee, WI 53209 USA (414/351-5837).

Charcot-Marie-Tooth (known as Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy) Association, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015 USA (215/499-7486). Services include newsletter, VCR rental, and support group list.

The Simon Foundation for Continence, P.O. Box 815, Wilmette, IL 60091 USA, publishes a quarterly newsletter, *The Informer*. Available with membership of \$15.

The NAD Broadcaster is published by the National Association of the Deaf 11 times annually. National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910 USA (301/587-1788 voice) (301/586-1791 TDD). \$10 per year.

National Down Syndrome Society, 666 Broadway, New York, NY 10012 USA (800/221-4602).

National Head Injury Foundation, Inc., 333 Turnpike Road, Southborough, MA 01772 USA (508/485-9950).

The National Survivor's Council (brain injury), 1700 Luna, Las Cruces, NM 88001 USA.

The Perspectives Network is an organization/publication established by a survivor (brain injury) for the purpose of opening a forum for survivors and professionals to discuss related issues. Contact: The Perspectives Network, 9919 Orangevale Drive, Spring, TX 77379-5103.

This Brain Has A Mouth, 61 Brighton Street, Rochester, NY 14607 USA. Various rates for professionals and survivors.

Traumatic Brain Injury and Vocational Rehabilitation edited by David W. Corthell, Ed.D. Publication Coordinator, Research and Training Center, Stout Vocational Rehabilitation Institute, School of Education and Human Services, University of Wisconsin-Stout, Menomonie, WI 54751 USA (715/232-1380).

Huntington's Disease Society of America, Inc., 140 West 22nd Street, 6th Floor, New York, NY 10011-2420 USA (212/242-1968).

Society for Muscular Dystrophy Information International, P.O. Box 479, Bridgewater, Nova Scotia, B4V 2X6 CANADA. Newsletter available.

Families of Spinal Muscular Atrophy of Louisiana, Inc., Interstate Bldg., Suite 110, 3616 South I-10 Service Road, Metairie, LA 70001 USA (504/834-5852).

Osteogenesis Imperfecta Foundation, Inc., P.O. Box 14807, Clearwater, FL 34629-4807 USA (813/855-7077). Basic membership is \$15.

Short Stature Foundation, Inc., 17200 Jamboree Blvd., Suite J, Irving, CA 92714 USA has established a new 800 number telephone helpline. Call 800 24DWARF.

National Spinal Cord Injury Association, 600 West Cummings Park, Suite 2000, Woburn, MA 01801 USA.

Spinal Injuries Association, 76 St. James's Lane, London N10 3DF ENGLAND (01-444 2121), is a self-help group controlled and run by spinal cord injured people themselves to assist those with similar disabilities to get back to an ordinary, everyday life following injury.

American Paralysis Association (APA), P.O. Box 187, Short Hills, NJ 07078 USA (800/526-3456).

National Stroke Association, 300 East Hampden Avenue, Suite 240, Englewood, CO 80110 USA (303/762-9922).

The Stroke Fact Book: Everything You Want and Need to Know About Stroke—from Prevention to Rehabilitation by Conn Foley, M.D. and H.F. Pizer, P.A.C. Courage Press, (800/553-6321). 5x7-256 pages, \$12.95.

For information on tinnitus, send a self-addressed stamped business-sized envelope to: **Tinnitus**, American Academy of Otolaryngology — Head and Neck Surgery, One Prince Street, Alexandria, VA 22314 USA.

EDUCATION

HEATH (Higher Education and Adult Training for People with Handicaps) Resource Center, One Dupont Circle, N.W., Suite 800, Washington, D.C. 20036-1193 USA (202/939-9320) is a national clearinghouse on postsecondary education for individuals with handicaps. *Information from HEATH* is published two times a year and is free.

Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE) is a national, nonprofit organization of persons from all 50 states, Canada, and other countries committed to promoting the full participation of individuals with disabilities in college life. Contact: AHSSPPE, P.O. Box 21192, Columbus, OH 43221 USA (614/488-4972) for membership fees and benefits.

EMPLOYMENT

The **Job Accommodation Network** (800/JAN-PCEH) provides information which enhances the ability of employers to provide reasonable and appropriate job accommodations for

qualified persons with a disability and increases job opportunities for persons with disabilities.

The Workplace Workbook: An Illustrated Guide to Job Accommodation and Assistive Technology by James Mueller is available from RESNA Press, Department 4813, Washington, D.C. 20061-4813 USA (202/857-1199). 109 pages, including over 40 detailed illustrations and instructions, \$32.

Return to Work by Design: Managing the Human and Financial Costs of Disability by Gene L. Dent is available from Martin-Dennison Press, 3633 Stone River Circle, Stockton, CA 95219-3146 USA. (209/478-3448). \$28 (includes shipping).

Breaking New Ground (A newsletter for farmers with physical disabilities). Breaking New Ground Resource Center, Department of Agricultural Engineering, Purdue University, West Lafayette, IN 47907 USA.

Write to Sell: How to Add Dollars to Your Income Writing Nonfiction Articles and Getting Them Published (185-pages) by Ruth Wucherer is available to Gazette readers for \$13.00 postpaid. Ruth also wrote **ravel Writing for Fun and Profit** (107-pages) is available to Gazette readers for \$10. Send your order and check to: Ruth Wucherer, 3370A S. 12th Street, Milwaukee, WI 53215 USA.

INTERNATIONAL

Rehabilitation International is a federation of 145 organizations in 82 countries conducting programs to assist people with disabilities and all who work for prevention, rehabilitation, and integration. **International Rehabilitation Review** is published three times a year, 12 pages per issue, costing \$30, including airmail postage. Exchanges are available to other disability publications. Contact: Barbara Duncan, Editor, 25 East 21st Street, New York, NY 10010 USA.

Ethical Issues in Disability and Rehabilitation, the report from the international conference held in Denver, Colorado, in 1989, is available from World Institute on Disability, 510 16th Street, Oakland, CA 94612 USA (415/763-4100 voice and TDD). 170-page softcover-\$10 in USA, \$20 in other countries.

World Institute on Disability (WID), 510 16th Street, Oakland, CA 94612 USA (415/763-4100). WID is a

public policy center that is run by persons with disabilities and was established to combat "handicapism." Their goal is to use research, public education, training and model program development as means to create a more accessible and supportive society for all people.

A Spanish version of "**Disabled Village Children — A Guide for Community Health Workers, Rehabilitation Workers, and Families**," by David Werner issued in 1987 is now available. The book is based on experiences from Projimo, a community-based rehabilitation program for disabled children and their families in western Mexico. The book is available from the Hesperian Foundation, P.O. Box 1692, Palo Alto, CA 94302 USA. \$15 postpaid (USA), \$13 postpaid (12 or more copies and low-income buyers), \$7 (1-11 copies for low-income citizens), \$6 (12 copies or more for low-income citizens).

NATIONAL RESOURCES

NARIC (National Rehabilitation Information Center) provides information on a wide-range of disability related topics. Call (800/346-2742). NARIC also sells mailing labels of extensive mailing lists.

ABLEDATA is a database which contains more than 16,000 commercially-available products from 2,000 manufacturers. Contact The Adaptive Equipment Center at Newington Children's Hospital, Newington, CT or call (800/344-5405). **ABLEDATA** is also accessible by computer users. Contact BRS Information Technologies by calling 800/345-4BRS.

National Rehabilitation Association, 633 South Washington Street, Alexandria, VA 22314 USA (703/836-0850 voice and 703/836-0852 TDD). Membership information available.

National Council on the Aging, 600 Maryland Avenue, S.W., West Wing 100, Washington, D.C. 20024 USA.

President's Committee on the Employment of People with Disabilities, 1111 20th Street, N.W., Suite 636, Washington, D.C. USA (202/653-5044 Voice and 202/653-5050 TDD). **Tips and Trends** is the complimentary publication of the Committee.

National Organization on Disability (NOD), 910 Sixteenth Street, N.W., Suite 600, Washington, D.C. 20006 USA. **Report** is a publication of NOD and available on request.

National Council on Disability (NCD), 800 Independence Avenue, S.W., Suite 814, Washington, D.C. 20591 USA (202/267-3846 voice and 202/267-3232 TDD). Focus is available free-of-charge. The National Council on Disability is an independent federal agency of 15 members appointed by the President and confirmed by the Senate. The NCD reviews all federal laws, programs, and policies affecting Americans with disabilities. It is the only federal agency with cross-cutting responsibility for disability policy.

Healthy People 2000: National Health Promotion and Disease Prevention Objectives (Summary Report), S/N 017-001-00473-1. Superintendent of Documents, Government Printing Office, Washington, D.C. 20402-9325 USA. \$9.00.

PERIODICALS

A Positive Approach, A National Christian Magazine for the Physically Challenged Person, 1600 Malone Street, Municipal Airport, Millville, NJ 08332 USA (609/825-4804). Quarterly — \$15.

The Disability Rag, Box 145, Louisville, KY 40201 USA. Six times a year — \$12.

Paraplegia News, 5201 North 19th Avenue, Suite 111, Phoenix, AZ 85015-2994. Yearly US subscription — \$12.

Independent Living (Health Care Magazine Serving Dealers, Rehabilitation Facilities, and Their Clients), 44 Broadway, Greenlawn, NY 11740 USA. Free.

Careers & the Handicapped, 44 Broadway, Greenlawn, NY 11740 USA. Twice a year — \$10.

RARE OR GENETIC DISEASES

National Organization for Rare Diseases (NORD) is a non-profit voluntary health organization dedicated to the prevention, control, and cure of rare "orphan diseases." Reprints of disease articles from NORD's Rare Disease Database are

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RESOURCES

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available for \$2.50 per copy. Contact: NORD Literature, P.O. Box 8923, New Fairfield, CT 06812 USA. NORD Services may be accessed on your personal computer by typing "GO NORD" at any prompt on the CompuServe Information System.

Alliance is a coalition of genetic support groups, concerned individuals, and involved professionals. Its mission is to strengthen collaboration and communication between consumers and providers for the benefit of all affected by genetic disorders. Contact: Alliance of Genetic Support Groups, 1001 22nd Street, N.W., Suite 800, Washington, DC 20037 USA (800/336-GENE).

RIGHTS

Council for Disability Rights (CDR), 203 S. LaSalle, Suite 1330, Chicago, IL 60604 USA (312/444-9484). Membership of \$10 includes a monthly newsletter.

The **National Disability Action Center**, 2021 L Street, N.W., Suite 800, Washington, D.C. 20036 USA. (202/467-5730 voice/TDD). Timothy M. Cook is director of this organization dedicated to protecting the civil rights of people with disabilities.

SHOES

One Shoe Crew, 86 Clavela Avenue, Sacramento, CA 95828 USA (916/364-7463). For a \$2.50 fee, the service registers individuals who want to find a shoe partner. There is a \$10 fee when a partner is found. Write or call early in the morning Pacific Standard Time.

National Odd Shoe Exchange, P.O. Box 56845, Phoenix, AZ 85079 USA (602/841-6691). Non-profit charitable agency that assists amputees and people with different size feet.

SOCIAL SECURITY

Personal service available from the **Social Security Administration** from 7 a.m. to 7 p.m. each business (800/2345-SSA.)

Disability Workbook for Social Security Applicants: Managing Your Application for Social Security Disability Insurance Benefits (1990) by Douglas M. Smith, Attorney at

Law is now available for \$14.95 plus \$3.95 shipping from **Physicians' Disability Services**, 1460 Ritchie Highway, Arnold, MD 21012 USA (301/974-1111). The booklet contains the appropriate information along with worksheets to assist in documenting and organizing a claim.

TECHNOLOGY

Extend Their Reach is a pamphlet focusing on electronic devices for individuals with disabilities, including companies that manufacture and sell products. Send a self-addressed business envelope (No. 10) with a 29-cent stamp to: Electronic Industries Association, Consumer Electronics Group-Communications Department, 2001 Pennsylvania Avenue, N.W., Washington, D.C. 20006-1813 USA (202/457-4919).

Technical Aid to the Disabled Journal is the official journal of Technical Aid to the Disabled (TAD), 227 Morrison Road, (P.O. Box 108), Ryde, NSW 2112 AUSTRALIA (02 809 7670). TAD is a voluntary organization dedicated to designing and making aids for people with disabilities when such aids are unavailable commercially.

Volunteers for Medical Engineering, Inc. (VMEI), c/o The Good Samaritan Hospital (3 East 329), 5601 Loch Raven Blvd., Baltimore, MD 21239 USA (301/532-4360). VMEI's mission is to provide practical, affordable solutions to physical limitations confronted by people with disabilities and the elderly.

TRAVEL

Mobility International USA, P.O. Box 3551, Eugene, OR 97403 USA (503/343-1284) is a national non-profit organization whose purpose is to promote and facilitate international exchange and recreational travel experiences for people with disabilities. Membership-\$20/year individual, \$25/year non-profit organization.

Wheelchair Travel, 1 Johnston Green, Guildford Surrey GU2 6XS, United Kingdom is a new service for travellers in the UK. Contact Trevor Pollitt at the above address or (44) 483-233640.

Travelin' Talk, P.O. Box 3534, Clarksville, TN 37043-3534 USA (615/552-6670) is an information

network providing assistance to travelers with a disability.

The Wheelchair Traveler 1990 edited by Douglass R. Annand. Douglass R. Annand, Ball Hill Road, Milford, NH 03055 USA. US \$20, Canadian \$22, postage included.

The World Wheelchair Traveller by The Automobile Association in conjunction with the Spinal Cord Injuries Association. Spinal Injuries Association, Newport House, 76 St James's Lane, Muswell Hill, London N10 1DU. 3.95 English pounds plus 50p postage.

You Want to Go Where? A Guide to China for Travelers with Disabilities and Anyone Interested in Disability Issues by Evelyn Anderton and Susan Sygall. Mobility International, USA, P.O. Box 3551, Eugene, OR 97403 USA. \$8.95 (\$7.95 for members) plus \$1.00 shipping.

Directory of Travel Agencies for the Disabled by Helen Hecker. Twin Peaks Press, Box 129, Vancouver, WA 98666 USA (206/694-2462).

World of Options for the 1990's: A Guide to International Educational Exchange, Community Service and Travel for Persons with Disabilities by Cindy Lewis and Susan Sygall. Mobility International, USA, P.O. Box 3551, Eugene, OR 97403 USA (503/343-1284). \$14.00 members or \$16.00 non-members.

Station Design Guide for Disabled Customers (Travelling by British Rail), British Railway Press Office, Euston House, 24 Everholt Street, London NW1 1D2, ENGLAND.

The Itinerary: The Magazine for Travelers with Physical Disabilities, P.O. Box 2012, Bayonne, NJ 07002-2012 USA (201/858-3400).

Access America, a free quarterly newsletter published by the **U.S. Architectural and Transportation Barriers Compliance Board (ATBCB)**, 1111 18th Street, N.W., Suite 501, Washington, D.C. 20036-3894 USA (1-800-USA-ABLE voice and TDD), provides information about the ATBCB and its activities. This is the same address used to file a complaint about building or facility access.

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YOUTH, FAMILIES, AND DISABILITY

The **National Center for Youth with Disabilities (NCYD)**, University of Minnesota, Box 721 UMHC, Harvard Street at East River Road, Minneapolis, MN 55455-9940 USA (800/333-6293). **Connections** is published quarterly. The organization also collects information for its National Resource Library.

National Information Center for Children and Youth with Handicaps (NICHCY), P.O. Box 1492, Washington, D.C. 20013 USA (800/999-5599).

Sick Kids Need Involved People (SKIP), 990 Second Avenue, 2nd Floor, New York, NY 10022 USA (212/421-9160).

The **Beach Center on Families and Disability**, a federally funded research and training center in the United States with an exclusive focus on families whose members have disabilities. For more information about a national conference in Lawrence, KS, June 27-30, 1991, entitled "Great Expectations for Life after High School," contact: Beach Center on Families and Disability, Bureau of Child Research, 4138, KS 66045 USA (913/864-7600).

Women with Disabilities United, P.O. Box 323, Stuyvesant Station, New York, NY 10009 USA. The group publishes a newsletter, is expanding its membership internationally, and is seeking to identify key women with disabilities around the world. Send \$10-\$25 for membership dues. Make checks payable to DIA-WWU.

A Guide to Pregnancy and Birth for Women with Disabilities by Judith Rogers and Molleen Matsumura. Demos Publishing Co., 156 5th Avenue, #1018, New York 10010 USA. \$24.95, plus \$3 shipping and handling.

Women, Development and Disability (1989, Second Edition) edited by Anne Gajerski-Cauley. Available free from Coalition of Provincial Organizations of the Handicapped (CO-POH), #926-294 Portage Avenue, Winnipeg, Manitoba R3C 0B9 CANADA (204/947-0303).

Families and Vocational Rehabilitation Working Together is available from Arkansas Research and Training Center in Vocational Rehabilitation, Publications Department, P.O. Box 1358, Hot Springs, AR 71902 USA (501/624-4411).

Living Well with Chronic Illness by Gayle Heiss, P.O. Box 210, Mendocino, CA 95460 USA. Send \$2.60.

For a free booklet, **How to Choose a Home Care Agency**, contact: The National Association for Home Care, 519 C Street, N.E., Washington, D.C. 20002 USA.

For a booklet, **Long-term Care: A Dollars and Sense Guide** (\$9), contact: United Seniors Health Cooperative, 1331 H Street, N.W., Suite 500, Washington, D.C. 20005 USA.

For a list of accredited **continuing-care communities**, send a self-addressed, stamped envelope to: Continuing-Care Accreditation Commission, 1129 20th Street, N.W., Suite 412, Washington, D.C. 20036 USA.

ETC.

Design Without Limits by Dolores Quinn and Renee Weiss Chase. Simplicity Pattern Co./Design Without Limits, Box 2102, Niles, MI 49120-8102 USA. \$14.70.

Shake-A-Leg, P.O. Box 1002, Newport, RI 02840 USA, (401/849-8898).

Foundation for Science and the Handicapped, Inc., 3817 W. Granville Avenue, Chicago, IL 60659 USA.

AirLifeLine, 1116 24th Street, Sacramento, CA 95816 USA (916/446-0995). Pilots all over the United States give unselfishly of their skills, time, fuel, and aircraft to fly medical missions.

Able to Garden — A Practical Guide for Disabled and Elderly Gardeners by the Society for Horticultural Therapy. Batford Books, 4 Bakers Mews, London W1M 1DD ENGLAND. 12.90 English pounds.

American Board of Professional Disability Consultants, 5119A Leesburg Pike Suite 226, Falls Church, VA 22041 USA.

Patient Information Guide for Neurology (Fourth Edition) is available for \$10 from American Academy of Neurology, 2221 University Avenue SE, Suite 335, Minneapolis, MN 55414 (612/623-8115).

What Is Life Services?

The primary concern of Life Services is the wellbeing of people with disabilities, especially those whose families can no longer care for them.

Life Services is set up to address the primary question asked by parents of individuals with disabilities, "What will happen when we are no longer able to care for our child?" Assisting families of the disabled to develop a plan for this inevitable time, and then helping to put such a plan into effect, is what Life Services is all about. A primary aim is to make sure that the full measure of private and governmental resources flow to the individual as long as he or she lives.

The objectives of Life Services are carried out in partnership with a wide variety of local voluntary organizations and religious groups, or directly through Life Services when there are no alternatives.

Life Services for the Handicapped, Inc. is approved as a not-for-profit corporation under New York State laws and the Internal Revenue Service. A Governing Board and an Advisory Council oversee the general management of the organization and provide continuity in carrying forward its objectives.

Tax deductible contributions from individuals, organizations, foundations, and businesses support the work, in addition to appropriate fees-for-service charged to governmental agencies, organizations, and individuals.

Write or call **Life Services** at 352 Park Avenue South, New York, NY 10010 (212/532-6740).

Potpourri



ADA INFORMATION

Understanding the ADA is a booklet published by the Eastern Paralyzed Veterans Association (EPVA) which provides a summary of the ADA. For a free copy, write to: EPVA, 75-20 Astoria Blvd., Jackson Heights, NY 11370 USA (1-800/444-0120).

The ADA is available in print from: Government Printing Office, Superintendent of Documents, Washington, DC 20402 USA. Request PL 101-336 in writing and enclose a check or money order for \$1.50 per copy, payable to The Superintendent of Documents.

The text of the ADA is available on the Enable electronic bulletin board for downloading. Phone via modem: 304/766-7842.

The text of the ADA is available on audiocassette from the Senate Disability Policy Office, Hart Senate Office Building SH 113, Washington, DC 20510.

The Department of Justice has ADA fact sheets available in print, Braille, large type and audiotape. Contact the Coordination and Review Section, Civil Rights Division, U.S. Department of Justice, Box 66118, Washington, DC 20035. Phone: 202-514-0301 (v) or 202/514-0381 or 383 (TDD). Electronic files on a bulletin board are available by modem at 202/514-6193.

INTERNATIONAL COUNCIL FOR BUILDING RESEARCH STUDIES AND DOCUMENTATION

A report has recently been published of the third International Export Seminar on Building Non-Handicapping Environments: Accessibility Issues in Developing Countries, held in Tokyo, September 1988.

The report prints papers presented by speakers at the seminar from a number of countries. However, much of the meeting was dominated by Japan's concern over its growing population of older people and problems they will have over access.

The reports discuss the need for proper planning to ensure that disabled people's requirements are met. This involves educating planners and architects who are often not as aware as they should be of first the needs of disabled people and secondly the simple solutions available when incorporated at the planning stage.

Two further seminars on building non-handicapping environments will be held in 1991. These will focus on legislation and design solutions. The first will be held in Budapest, Hungary, on September 2-4, 1991; the second in Harare, Zimbabwe, on October 1-3, 1991. The Montevideo, Uruguay seminar has been postponed until early 1991. Contact: **Adolf Ratzka** at CIB W84 Building Non-Handicapping Environments, Building Function Analysis, Royal Institute of Technology, S-100 44 Stockholm, Sweden.

EASTER SEAL SYSTEMS CREATES NEW NATIONAL LOAN PROGRAM

A national loan fund has been set up to assist persons with disabilities in purchasing computer-assisted and other technologies designed to provide them with the supports needed to become more independent.

Easter Seal Systems' Computer Assisted Technology Services (CATS) received a federal Demonstration and Innovation Projects Technology-Related Assistance grant for \$144,000 — awarded in

October 1990 under the provisions of the Disability Related Technology Assistance Act of 1988. Authorized to use \$85,000 to create a lending fund, Easter Seals has developed the first national loan program designed to enable persons with disabilities to buy computer-assistive technologies tailored to their individual needs.

Typically loans will range from \$1000 to \$3200 during the first year, to increase the number of applicants/participants of the program.

The initial loan period begins February 1, 1991 and ends September 1, 1991. Applicants should contact Sully JF Alvarado, Technology Related Loan Fund Officer, **Easter Seal Systems**, 5120 South Hyde Park Blvd., Chicago, IL 60615 USA, (312/667-8400 Voice and TDD) for information and loan-fund applications.

TEXTBOOK ON POST-POLIO SYNDROME

Post-Polio Syndrome, edited by **Theodore L. Munsat, M.D.**, with 15 contributing authors, is now available from Butterworth-Heinemann, 80 Montvale, Stoneham, MA 02180 USA (ISBN 0-409-90153-9) for \$44.95. Contributing authors include Donald W. Mulder; Robert H. Brown, Jr.; Lauro S. Halstead; Marinos Dalakas; John J. Kelly, Jr.; Neil R. Cashman; Ricardo A. Maselli; Robert L. Wollmann; Jack P. Antel; Richard Finkelman; Theodore L. Munsat; Patricia L. Andres; B. Thornell; C. Brussock; Gini Laurie; and Dorothy Woods Smith.

In the preface, Dr. Munsat states, "While we are still a long way from having a definitive etiology for post-polio syndrome, this text

provides our current knowledge and treatment for this disorder.

"It is my hope that physicians and therapists will find it a useful and enlightening resource when treating patients with post-polio problems."

NONINVASIVE VENTILATION VIDEO PRODUCED BY LIFECARE

Introduction to Noninvasive Ventilation interviews prominent medical professionals with noninvasive respiratory expertise to discuss the benefits and limitations of noninvasive techniques. It also demonstrates several effective alternatives to invasive ventilation through a unique blend of modern and early technology. The video is available through the 18 district offices and the international network of distributors. Contact **Jim Seeley, LIFECARE**, 655 Aspen Ridge Drive, Lafayette, CO 80026 USA (303/666-9234).

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VOTER REGISTRATION ACT OF 1991

The National Voter Registration Act of 1991 (§ 250), was recently introduced by **Senators Wendell Ford** (D-KY) and **Mark Hatfield** (R-OR). Last year a nearly identical bill, with strong bipartisan support, passed the House of Representatives by a vote of 289 to 132, but with the beginning of the new two-year Congressional calendar, the motor-voter bill begins another trip along the legislative pathway with Senate hearings scheduled for March 21 and April 10, 1991.

Jim Dickson, National Coordinator with Disabled But Able to Vote, a national advocacy network, is planning to make sure this simplified and more convenient voter registration legislation moves forward during the current session of Congress and that people with disabilities are in the forefront of that effort.

The proposed legislation provides that vocational rehabilitation offices and those providing related services shall offer voter registration to its clients at the point of intake. Disability advo-

cates are also recommending that the legislation allow such locations as rehabilitation and independent living facilities to offer voter registration. This law would encourage the disability community to become more involved in the political process.

But the change which earns this bill its catchy name of Motor-Voter Law is the connection it makes between driving and voting. Under the new law, unless a person declines in writing, an application for a driver's license is also an application for voter registration. Currently, between 80% to 90% of those citizens who are eligible to vote are drivers. And proponents of the bill suggest non-drivers will also be fully accommodated by the other simplified registration procedures.

Fact sheets, summaries and copies of the National Voter Registration Act are available from the **League of Women Voters of the United States**, 1730 M Street, N.W., Washington, D.C. 20036, 202/429-1965. Jim Dickson can be reached at their number or at 202/832-6564 or Disabled But Able To Vote, 4215 12th Street N.E., Washington, D.C.

ABOUT US ...

SUBSCRIPTIONS: By the time you receive this *Rehabilitation Gazette*, we will secured and installed a new computer program. Our goal is to provide, as one reader requested, "greater efficiency." We electronically transferred some data, and we re-entered other. Errors were likely. PLEASE CONTACT US IF YOU KNOW OF ANYONE WHO SHOULD HAVE RECEIVED THIS ISSUE BUT DID NOT.

CONFERENCE: We will not be sponsoring a G.I.N.I. Conference in the Spring of 1991. However, we are hopeful that a successful 1991 will allow us to plan another conference in the near future. Your comments and suggestions are welcome and we will keep you posted.

PUBLICATIONS: G.I.N.I. publishes the *Polio Network News*, which discusses all aspects of the late effects of polio, the *I.V.U.N. News*, which networks ventilator-users and health professionals committed to home mechanical ventilation, as well as the *Rehabilitation Gazette*.

The *Rehabilitation Gazette* is our cross-disability publication written by and for individuals with a disability. We consider it a forum for you, a person with a disability or a health professional working on the behalf of people with disabilities, to share "what works for me," to ask questions, and to speculate. We sincerely invite you to send your ideas, successes, and problems so we can expose them to the network.

Thank You!

Everyone connected with the G.I.N.I. organization appreciates your patience and continued support.



UPCOMING EVENTS

International Conference on Pulmonary Rehabilitation and Home Ventilation, Hyatt Regency Denver, Denver, CO USA, March 10-13, 1991. Contact: Adele Gelfand, Manager of Professional Education, National Jewish Center for Immunology and Respiratory Medicine, 1400 Jackson Street #M222, **Denver**, CO 80206 USA (303/398-1359).



Beyond the ICU III: Perspectives on Ventilation, Ramada Inn, **Toronto**, Ontario, Canada, April 19, 1991. Contact: Steve McPherson at 416/241-8882.



Ohio Polio Network Post-Polio Conference, Holiday Inn on the Lane, Columbus, OH USA, August 24, 1991. Contact: Betty Sugarman, Ohio Easter Seal Society, 2204 S. Hamilton Road, **Columbus**, OH 43232-0462 USA (614/868-9126).



Second Colorado Post-Polio Educational Conference, Westin, **Denver**, CO USA, September 13-14, 1991. Contact: Alison Kron (303/233-1666).



Independence 92, International Congress & Exposition on Disability, Vancouver Trade & Convention Centre, **British Columbia**, Canada, April 22-25, 1992. Contact: Independence 92, Suite 200, 1190 Melville Street, Vancouver, B.C. V6E 3W1 Canada (604/689-5084).



Fourth Annual Convention of the Society for Disability Studies, Hyatt Regency, **Oakland**, California, USA. June 26-29, 1991.

Themes for paper presentations will include research issues of policy, history, sexuality, law, culture, statistics, methods, politics, media, literature, gender, self-image, cross-cultural issues, family, and related topics.

The Society for Disability Studies (SDS) is a multidisciplinary organization dedicated to the development of an appreciation and understanding of disability-related theory and its application as well as an agenda for further research in this area. For membership information, contact Professor Irving Kenneth Zola, Department of Sociology, Brandeis University, Waltham, MA 02254-9110 (617/736-2644).

Registration material will be sent to Society members and non-member presenters on April 1. Other persons may contact Professor David Pfeiffer, Department of Public Management, Suffolk University, Boston, MA 02108.