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Coping with Disability and Aging:

Adversity and Adaptability

by Willa T. Schuster

Universalizing personal experience is difficult, if not impossible. I recount my own experiences in adapting to major life changes not with any sense of superiority, but rather in the modest hope that others facing similar losses and changes might take some small comfort in knowing that others who have endured similar difficulties have coped successfully.

Somehow I knew that my failure to extinguish the 40 candles on my birthday cake signaled momentous changes ahead. Indeed, the insidious onset of respiratory failure and other post-polio sequelae symptoms coupled with the sudden illnesses and death of both my parents, my primary caretakers, all within an 18-month time frame, culminated in a life upheaval that required immediate acceptance, positive action, and necessary adjustments on both physical and emotional levels.

In retrospect, the emotional groundwork and sense of preparedness for coping with adversity are probably established during a time when life is going well. My parents, family, and friends all contributed to my own sense of preparedness with their acceptance of me as a total person following my initial polio onset in 1955 when I was 15. A ventilator-dependent quadriplegic, I returned home after a year's hospitalization and was accepted as a functioning, contributing member of my family and community.

Our family's life together was happy, secure, and rich in experience. I graduated from high school and college, started my own business, and participated in extensive volunteer work. After my three siblings left home to make their own way in the world, my parents and I lived together, traveled together, and maintained close ties with our growing family.

Throughout these years, however, the realization lurked subliminally that at some point my parents would no longer be able to care for me. Most of us who are totally dependent upon others for physical care would probably admit to similar insecurities at the threatened loss of primary caretakers, be they parents or others.

The acceptance of life without these special people actually begins long before the eventuality occurs. One is unable and unwilling to make definite plans to meet a vague future need, but in letting an awareness of future uncertainty filter through one's mind, one develops a facility for coping. What results is the security of knowing one can handle a major problem if faced with it.

Fortunately, the challenge of adversity can become a catalyst for positive action, and as the fabric of our family's long-standing routine and comfortable living situation began to unravel in a sustained period of crisis, the process of adjustment and adaptability began almost unconsciously.

When my father and I both landed in the hospital, our upheaval was truly underway. Efforts to stabilize my breathing difficulty, mental confusion, and fatigue were successful with my return, after 24 years, to nocturnal ventilatory assistance via a rocking bed. My physical and mental vitality were renewed, and so, as a family, we focused our efforts on providing care, comfort, and support for my father, whose death within two months precipitated immediate adjustments in the daily routine.

With minimal outside help, my mother shouldered the major portion of my care, and together we reorganized our routine to compensate for the help my father had regularly provided. The emotional adjustments at this juncture were manifold, but out of the normal grieving process came a renewed understanding and acceptance of life's transitory nature, and a realization that there is an intrinsic positivity in all of life's experiences. The awareness that my mother was now terminally ill heightened the need for emotional stability and flexibility. It was no time to be unresponsive to new ideas.

The first priority now became one of providing care and support for my mother, who elected, with our family's encouragement, to remain at
home as an alternative to dying in a hospital. We made a firm family commitment to care for her at home in keeping with the hospice philosophy that dying, like living, should be a shared experience. Our sharing of life’s ultimate experience, giving care, solace, comfort, and reassurance when we could, was our last gift of love to our parents. Their last gift to us was an acceptance of death as a normal aspect of life, better understood, less feared and abhorrent.

With both parents gone, I knew immediately that the period of adjustment and adaptation would have to swing into full gear if I was going to maintain any semblance of my customary routine. Clearly, either I picked up the pieces and took control or the situation would control me. Opting for the former, I made a personal commitment to strive immediately and resolutely for self-control, self-reliance, and self-sufficiency. My responsibilities included myself, my surroundings, and my living situation, so I set about reorganizing my life and my own home with outside help.

At once I felt elevated to new levels of maturity and adulthood. The modification of established routines with new ways of achieving similar goals required flexibility, patience, self-control, and decision-making at every turn. Somewhat dubious about my capabilities, I began with an evaluation of my immediate and long-range needs, determining that my present needs consisted primarily of helpers to cover daytime and nighttime hours not already covered by a schedule of family dinners, work, and volunteer activities.

Totally unaccustomed to hiring practices, I drew upon my experience in volunteer work and business and began my search for interesting people with whom I would enjoy spending some time. And did fortune smile on me! Reasoning that anyone who did not pale at the idea of hands-on physical care including washing, dressing, lifting, and bedpans was worthy of consideration, I accepted three willing candidates and we still remain close friends four years later.

Nighttime hours are often difficult ones to staff. Compatibility is essential when choosing someone to be with during the evening hours of relaxation when work is completed and fatigue sets in. Filling in the unstaffed daytime hours of my week was somewhat akin to fitting together the pieces of an intricate jigsaw puzzle, the resultant whole being a tapestry of helpers, family, and friends.

Having decided early on that spending an inordinate portion of the week with the same person held a strong potential for stress and boredom on both sides, I elected to have several part-time helpers. A variety of helpers also reduces the risk of being stranded with no help in the event of illness or other emergency. Back-up help is essential.

My helpers are truly the key to my independent living situation. Opening my life to strangers and trusting my well-being and my home to them has been easier than I ever anticipated. Any reti-
cience or worry on my part was totally unfounded. Indeed, the diversity of their lives, their interests, and their generosity enrich my life daily.

My helpers are my friends, seen less as employees and more as members of my extended family. They are part of the network of family and friends who compose the support system that makes it possible for me to function as a contributing member of society.

The success of my adjustment to self-dependency lies in the mutual trust, respect, and responsibility my helpers and I have for each other. We are all members of a team whose objective is to keep the household functioning smoothly.

My helpers all know that they have my complete trust and I in turn try to factor their individual likes, dislikes, abilities, and preferences into the equation of my needs. In the interests of a balanced checkbook, a clean house, thriving plants, happy pets, and pleased palates, it works best to tailor the tasks to the abilities and interests of the helpers available. Some are adept with a blow dryer or good at dog bathing; others flinch at financial statements but shine at dinner preparation or gardening.

With the helper/companion structure firmly in place, it remained for me to organize the household affairs into some semblance of order. After 40 years of living with two vital, energetic parents who handled the mundane necessities of our home, I was now responsible for activities that I had so easily taken for granted: grocery shopping, preparing three meals a day, yard work, financial affairs, and car and home maintenance.

We purchased a van with a lift—a educational experience in itself. In yet another investment in modern technology, I obtained an innovative overhead lift designed and built by a friend to get me in and out of my rocking bed with the help of just one person.

The process of adjusting to an independent living situation is an ongoing one demanding regular reassessment of my needs and how to meet them. The van and the bedroom lift are two examples of resourceful solutions to such needs. After careful evaluation, we reached the difficult decision to sell our family home of 42 years. This determination meant my buying, renovating, and moving into a smaller house, equipped for my needs, in a different neighborhood—a positive move to be sure, but a demanding one in terms of time, energy, and emotion.

In retrospect, I think I can honestly say that with the complete and willing support of family and friends, I never seriously doubted that I could make it on my own. It has taken time, planning, and hard work, but the positive aspects of the change from dependence to self-dependence far outweigh any negative factors.

Perhaps the hardest adjustment was the transition from a relatively private life to a living situation that is a proverbial “open book”—long on trust and short on private space and time. My home has a perpetually revolving door always open to a diversity of individuals who are part of my life and whose friendship and support more than compensate for my lack of privacy. The change in my living situation has also meant a reduction in the time I spend in volunteer activities—as my responsibilities to myself and my home increase, less time remains for outside interests.

Overall, the changes of the past three years have been a challenge and a growing experience. They have given me the opportunity to explore new areas of learning on all levels, cerebral and emotional, and have stretched me as a person.

Having used the past to build toward the future in a sustained process of assimilation, adjustment, and adaptation, it has been precisely this use of the skills, strengths, and knowledge of past experiences that has made it possible for me to meet the challenges of the present.

Life will continue to give me upheavals, and I in turn will continue to apply my strengths in meeting them. Out of it all comes the realization that independence is really the “connectedness” of the people in our lives, and that coping with adversity is a united effort. Together we shall continue to explore “the astonishment of living.”

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“JANimals” to the Rescue

by Jan Ruehling

My struggle to continue to stay in my home began in 1977 when my mother, who for 20 years had assumed most of my care, had a serious heart attack, which ultimately caused her death in 1982. My stepfather, who had assumed increasing amounts of financial responsibility for me, suddenly passed away from lung cancer in 1984.

It was a scary, harrowing time, but I was determined not to put my home up for sale and go into a nursing home, as so many had suggested, or move into an apartment, another often-voiced suggestion! I couldn’t rent an apartment as cheaply as my monthly mortgage payment, and space for my equipment would be a problem. I use a rocking bed six to seven hours daily, and alternately between my chest respirator, IPPV, and frog breathing for the other 17 hours. My wheelchair carries a respirator platform plus battery, so it is never folded; I also have an extra battery and charger. A specially built desk accommodates my electric typewriter. I was determined to stay and make it on my own.

Instinct told me that I would be the best person to find a solution to my financial dilemma. While racking my brain for ways to earn money, my miniature dachshund, Gus, ran into my room, carrying a piece of fresh asparagus my sister had dropped while cooking. I love playing with words and phrases, and immediately I made the connection between “Gus” and “asparagus.” “aasparAGUS” — an original character was born! Next came his girlfriend, “aasparAGUSTA,” and their hippie-friend, “Poofdog.” I pictured how each would look in my mind — all I needed was to find someone to draw my “JANimals.”

A young artist from my church, Kathy, offered her services, and between my describing and her sketching, they came to life. A newspaper article followed, detailing my plight and my creative approach to solving it. Through suggestions of new friends whom I met as a result of the article, I began having my “JANimals” screen-printed on T-shirts, realizing that I had to have something tangible on the market if “JANimals” was to get its paws off the ground. They’ve been selling slowly for over a year now.

With the advice and guidance of another new friend who owns a women’s clothing store and also sells the shirts for me, I’ve begun designing and selling wooden jewelry, featuring elephants and dogs. We take the products to different fairs and festivals, and I’m constantly thinking of new characters and designs. Friends sell the shirts and jewelry for me, and every bit we make goes to pay nurses and bills and buy more supplies. I hope to get a large toy and/or novelty company interested in licensing my copyright and paying me on a royalty basis.

My dependable and loyal nurses have stuck with me, despite the fact that I have been unable to give them the raises they clearly deserve. My overnight ladies accept the flat rate I am able to pay, since they know how hard I’m trying to make it on my own.

For us disabled individuals who are determined to live independently outside of institutions, I feel the ultimate answer is a “National Home Attendant Care Program.”

Last year, through diligent lobbying of the legislature, a pilot Home Attendant Care Program was passed in Mississippi, and I was overwhelmed to have been one of the 35 chosen to receive this financial help. It is funded for one year only, but we are determined not to let it end there.

Coping with the psychological devastation I experienced after losing both parents so close together remains a daily challenge. I silently talk to myself and handle it within myself. Some days it works better than others, but it does work. What I’ve learned, having been more or less sheltered for
Joyce and Carole are polio survivors, and as social workers and psychotherapists, they have led therapy groups for polio survivors and their families on the psychological stress of polio's late effects. They have designed Living With It, a program of psychological services for adults with a disability.

Facing Disability
by Carole Carsey, M.S.W. and Joyce Ann Tepley, M.S.W.

The new physical problems developing for polio survivors require new coping skills. Those with a visible disability have coped well for many years. For other survivors who were left with little visible signs, the emotional stresses, fears, and angers which have lain dormant since the initial illness have resurfaced.

Polio survivors believed that once one had reached a stable level of functioning, one would remain there until old age. Many now feel cheated and outraged at having that long-held belief shattered.

To understand the current psychological stresses, one must understand how polio survivors coped with the acute phase of the disease.

Denial was especially useful when one had positive expectations of getting well. The amount of recovery varied with each individual. For some, complete recovery did not occur. As months went by, this became apparent and denial changed to minimizing.

Minimizing reduced the overwhelming fears for the future. It is a healthy way to cope since it allows people to set aside fears in favor of believing that life can be meaningful and that "normal" activities can still be engaged in.

Over-compensating was another strategy. If physically weak, one can gain psychological control with the belief that if one tries hard enough one can get well. This belief was encouraged in many ways by family, friends, and the rehabilitation team. This coping strategy served polio survivors well, contributing to their assertiveness and bringing them to the highest possible level of functioning.

Polio survivors who left the hospital with less than complete recovery had to cope with feelings of being different and being less worthy. To cope, one tried to prove otherwise and to live as "normal" a life as possible, with high expectations for doing well in school, work, and family life. For many, the fear of not being as good as others was taken as a challenge which pushed them to become over-achievers. For those who were severely disabled, this type of coping gave them the skills needed to live competitively in this world.

The old coping strategies of denial, minimizing, and over-compensating cannot be used with the late effects in the same way they were used many years before because the person's physical condition requires a different approach. One needs to pay attention to the fatigue or pain level as a signal that it is time to rest.

Thirty years ago, therapists taught polio survivors to push to gain more strength. Now this would be detrimental. Conserving strength is more important. Polio survivors who have been successful in their endeavors have pushed themselves physically. They have not "given in" to their physical limits. It is a major change in one's thinking to be easy on oneself and not push beyond one's limits. It is only natural to feel deep sadness
at having to give up activities one has enjoyed and change a self-concept built around achievement.

When one’s physical limitations increase, however slight or severe they have been, one grapples with the identity issue of being disabled. Being disabled presents negative images in our culture. Rather than taking on these negative images, persons with polio created images of themselves as healthy, self-sufficient, productive, contributing members of society.

Many disabled individuals do not see themselves as disabled. They refer to other people with disabilities as “those handicapped people.” They do not identify with them as a group.

There are positive gains from seeing oneself as disabled. The greatest gain is that it allows one to be pleased and impressed with what one has and can accomplish.

Another gain is that one allows oneself to have disabled friends and associates. Sharing feelings about how hard it is and even complaining with other “post-polios” or disabled persons is an unlearning of our initial lesson to be strong and cheerful. The gains of support and self-understanding that come from this sharing become more important than the self-sufficiency that isolated us from each other in the past.

One who is experiencing polio’s late effects should try to adopt a new attitude of making life easier. Activities can be continued with more technical assistance, such as using a wheelchair and walking less, using a power chair instead of a push chair, sleeping with night ventilation, or wearing a brace again after 30 years without one. The decision to obtain a handicapped parking sticker can be difficult, but not having to walk as far saves energy for other things. This decision involves declaring a new identity of being disabled to ourselves, our families, our friends, and the public.

Support groups can provide an emotional environment in which to experience with the support of others the painful feelings that accompany physical loss. It can be a relief to let the pain out instead of holding it inside. The psychic energy which had been used to hold back the pain can be used creatively to find new solutions.

The rigidity of denial can be replaced by a negotiation process. The pride of not using a respirator can be traded for feeling rested in the morning and being able to continue working.

The push to compensate through overachievement must also be given up. The physical gains from not pushing ourselves are more important. As polio survivors reflect on what they have achieved, they do not have to push themselves, because they no longer have anything to prove. They have done so well that they made it look easy. They can be proud of the initial process of coping and the achievements it brought. Past success proves that polio survivors can cope again.

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British Polio Survivor
by A.P. Smith

This is my second affair with a ventilator. The first started in 1939 when I was a school student of 18. At that time, I was a solitary case of polio making vital use of one of the first iron lungs in the United Kingdom.

In retrospect, what I remember is the adjustment to breathing on my own again after the security of weeks in a ventilator — the trauma, the stress, and the feeling of panic. Adjustment to muscle weakness and muscle failure is gradual, dogged, and fed by hope.

That first recovery from polio left weakness in my legs, arm, and breathing function, but enough performance to allow me a full-time teaching career after graduation from university. It was also enough to permit a complete range of activities, a full family and professional life, and enough stamina to cope with those demands. A four-wheel drive vehicle underwrote my mobility.

The late effects of polio made their appearance progressively some 30 years later, requiring first a stick, then wheeled walking aid and lifting chairs. The response to increasing fatigue and knee joint pain was to step up my determination
and to see it as no more than a natural aging process. There was no one around to tell me otherwise.

Then, after 43 years, it was back to a ventilator again. The crunch came in 1982, at age 61, with the classic symptoms of respiratory insufficiency, which were perfectly recognizable as such under that heading in *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* (available from G.L.I.N.). Hospitalization dealt with the immediate crisis, with subsequent therapy by those experienced in post-polio respiratory problems.

I was now using a negative pressure ventilator. A tracheostomy followed because my windpipe had to have a bypass to stand the extra strain.

Ventilators can be lived with and loved. Tracheostomies are a love-hate affair. The positive pressure ventilator that initially goes with it takes away speech and denies independence. After 10 days, I was well enough to try to breathe on my own again. At first, panic, then confidence returned until it was minutes, then hours, before I gave in and was reconnected. Finally, I got my set of silver tubes, nighttime bypass, daytime speaker. I was human again, coughing, maybe, but no longer frustrated by being unable to speak.

Six weeks after it all began, I went home. My wife, for 40 years my companion and helpmate, was now my paramedic, attendant, physiotherapist, etcetera. Nighttime meant being put into the ventilator bag (poncho), and zipped up for an airtight seal. My wife had to learn to sleep next to a pulsing, wheezing pump and a coughing husband in need of a urinal bottle at least once during the night. Morning, 10 hours later, the tasks went into reverse.

Three months after coming home, I went back to work, more or less fulltime. Even though I daily arrived late, colleagues continued to recognize me for myself, not what I seemed, and to keep a discreet eye to see that I came to no harm. Students likewise showed their care, often poignantly.

Finally, I retired. Later adjustments came with and after retirement from full-time work and the city to part-time activity and the country. A made-to-measure cuirass has restored my nighttime independence. Three years later, I can look back calmly and forward to a future with mobility and opportunity.

Polio in a way made it all possible — it gave life a sharp focus and introduced a wife who believes all things are possible and some even desirable. Having to cope gives insight into the problems of others and an understanding of how to lend a hand. Our recent related discovery of the *Handbook* has brought relief, confirmation, and the urge and opportunity to spread the message among survivor friends and local professionals.

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**Living With Adult Children**
by Olivert "Bubbles" Vinson

My husband, Chalmers, and I were missionaries in China in the 1940s. In 1954, several years after our return to the States, I became paralyzed from polio. Because of loving help and encouragement from Chalmers and our two sons, we lived with what seemed like insurmountable problems and frustrations, but nevertheless with success.

My husband's poor health was our constant concern, but over the next 25 years or more I made steady progress, strengthening the little muscle I had and learning to take care of many of my personal needs. Often my family's "You can do it! We know you can!" gave me that extra spurt of energy I needed.

When, in 1980, my husband's health became such that he could no longer practice medicine, even on a limited basis, we knew we had to rethink our living patterns. Our son, Dan was already practicing medicine in Banner Elk, North Carolina. He, his wife Linda, Chalmers, and I agreed that Chalmers and I should no longer continue to live alone.

Dan and Linda were building a home at the time. The plans already included a small apartment that was part of the house, yet entirely private. I thought the apartment would be a great vacation home, but I did not think it wise for three generations to live together all the time.
My philosophy was that if we lived together we would look forward to the times we could get away from each other, whereas if we had homes in different places we would thoroughly enjoy getting together. My son’s response to this was, “What alternative do you suggest, Mom?” I had none. We all realized that the idea had to work, so we planned the apartment to meet our specific needs and then tailored it to fit what we could afford.

There are two rooms, a living room with a small kitchen area, and a bedroom plus the bathroom. The living room opens onto a deck that Dan himself built for us. From it and the large living room windows, we see our wonderful mountains, uniquely beautiful each season of the year. We furnished the apartment with a combination of old family pieces and carved Chinese furniture. On the walls we hung Chinese watercolors. We put into the apartment things with which we lived comfortably — things that made it a home.

Chalmers and I enjoyed our home for a short while before he died in 1982.

Dan remembers almost nothing that happened before I had polio. He grew up a loving, caring son and now gives sustained, concerned care to many people. Linda, with whom I spend more time, becomes more precious all the time. It falls to her lot to dress me and undress me regularly; it is Linda who gets me into the shower for a “real bath.” I don’t quite trust helpers who know me less well and are less capable, so at times I settle for bed baths. I have a woman to help me twice a week, and once a week I have professionals do basic cleaning in the entire house.

I could complain about the errands I need to do but cannot for lack of someone to take me. Linda could complain sorely about having to take me places. How many young women do you know who really want their mother-in-law living with them? We each realize that no one is perfect. Our appreciation of and affection and respect for each other make our living together workable and good.

The door into the hall leading to Dan and Linda’s home is always open. To Amy and Matt, my grandchildren, the apartment is an extension of their house. Amy is eight years old. She dresses and undresses me several times a week and does other things, too, like helping me check my bank statement. She is the delight of her teachers because she is so sensitive to the problems and feel-

ings of her fellow students. Six-year-old Matthew helps, too. He sometimes gets out my clothes or makes my bed on the weekend. Both children are knowledgeable wheelchair attendants.

Vacations are sometimes taken together. One summer we all went to the beach together. A year ago, I went with a friend to Israel and Europe. While I was gone, Dan, Linda, Amy, and Matt went on their own vacation. Once, they went camping and someone came in each day to help me.

Not all retired people, whether disabled or not, can live with their adult children. When you consider it, ask yourself these questions:

• Will the home meet my physical needs?
• Are the financial arrangements clear and satisfactory to all who are involved?
• Do I really like my child and his or her spouse?
• Do I like my child’s in-laws?
• Do my children and I have the same values?
• Am I flexible enough to move to a new area, far away from old friends, and put down new roots?
• Can we arrange our housing to provide privacy for each generation?
• Do I like my grandchildren?
• Are each of you unselfish, loving, and caring or at least consistently trying to have these qualities?

Every night, Dan, Linda, Amy, Matt, and I have prayers together. Our love of God and His love for us make us reach out to each other. Often I hear, “Thank you, God, for putting us all together in a family.” I breathe a prayer, “Thank you, God, for allowing me to be a member of this family.”

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Independence Through Foot-Controlled Driving

by Diane Rice Smith

"Is there something you've always wanted to do, but couldn't because of your disability?" I didn't have to think about an answer. I immediately said, "Yes, to drive a car." The question was asked by a new friend at dinner in the Sheraton St. Louis Hotel during the 1983 GLIN conference for polio survivors. Little did I know then that that question and answer were about to change my life.

I had polio at age 10 and spent 15 months in hospitals, including several months at Warm Springs in 1950. My residual involvement was flail arms, poor right hand, fair left hand, no quad in right leg (necessitating a long leg brace), and scoliosis. I developed good balance and walked without crutches. I accepted early on that I would not be able to drive a car. But the fantasies and longing to do so never left.

After one year at Southern Illinois University, I dropped out to get married in 1959. My husband, also an "upside-down polio" but with breathing problems, too, couldn't drive either, so we hired someone to drive us or depended on family. After 14 years of marriage, my husband died. I couldn't afford a driver then, so my feeling of dependency increased as I relied more than ever on family and friends for transportation. How I wished I could drive!

The day following the dinner conversation at the conference, I was introduced to Norma Depoyan who had similar arm involvement and drove with foot controls. She told me she drove in Los Angeles freeway traffic and anywhere else she wanted to go. Observing her upper arm and hand involvement, I began to think that maybe I could do it, too. Norma was confident and said, "You'll drive yourself to the next polio conference in two years."

After thinking it over for a week, I decided to share the new information with family and friends. A very protective dad was instantly against it and insisted there was no way I could safely drive. A few friends were very supportive and urged me to "go for it." Others listened politely, but I sensed a "you've gotta be kidding" attitude.

With determination spurred on by negativism, I phoned Cameron Enns in Fresno, California to inquire about foot steering. Cameron, another "upside-down polio," developed a foot-operated steering mechanism back in the '50s when he wanted to drive. He questioned me at length on the phone several times and I sent him a recent muscle test. He was optimistic from the beginning and assured me the problems I might have because of the leg brace could be worked out. He suggested I try the adaptations he made for Valerie Parrish, yet another "upside-down polio," in a nearby town.

At this point it was time for the big decision—should I buy a $10,000 + car, pay to have it adapted, and have no guarantee I would be able to drive, or should I forget the whole thing and wonder all my life if I could have done it? I went for it, and decided on an Olds Cutlass Ciera, console shift, four-way power seat, power windows and locks.

Meanwhile, Cameron and I were negotiating how and where the adaptation would be done. He offered to come to Illinois if I paid expenses for him and his brother who works with him. My savings were dwindling fast with all these extras, but I had to do it.

My car arrived in October. It was exciting, but also scary. It's not my nature to worry, so I took it a day at a time and had a positive feeling about the outcome. "So what if it doesn't work—I'll sell the car, take my loss, and I will have tried." I also thought, "It probably will work,"—but I wasn't...
prepared yet for those kinds of thoughts of
credible. The two most rewarding aspects of driving
are at last being able to help others in a tangible
were except for 45 minutes of frog
breathing. With the assistance of two home
attendants, I have lived in my own apartment in
Manhattan for the past 10 years.
I started with the early respirators of the '50s
and '60s — the reliable old black Bantam, the big
green Huxley, the loud but powerful Monaghan,
and the Aih Thompson. I lived for a short time
with an Emerson rocking bed, and for 20 years
hung on to my trusty chestpiece with adhesive
tape holding it together.
As my life changed, the Bantam was replaced,
yet I still found that the 17 amp per hour battery
drain limited my activities and kept me running
from outlet to outlet.
I realized I could not continue to look for "a
place to plug-in," and that the constant concern

Adapting to Ventilator Changes
by Ira Holland

I am quadriplegic and use a power chair that is
breath-controlled. I am completely ventilator-
dependent due to polio at the age of 15 in 1955, and
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have no free time except for 45 minutes of frog
breathing. With the assistance of two home
attendants, I have lived in my own apartment in
Manhattan for the past 10 years.
I started with the early respirators of the '50s
and '60s — the reliable old black Bantam, the big
green Huxley, the loud but powerful Monaghan,
and the Aih Thompson. I lived for a short time
with an Emerson rocking bed, and for 20 years
hung on to my trusty chestpiece with adhesive
tape holding it together.
As my life changed, the Bantam was replaced,
yet I still found that the 17 amp per hour battery
drain limited my activities and kept me running
from outlet to outlet.
I realized I could not continue to look for "a
place to plug-in," and that the constant concern
with brushes and blue lights had to give way to current ventilator technology. I changed over with some reluctance to the M25. It took a few weeks to become accustomed to the variations in cycle, and I am only sorry I did not make the change sooner. The M25 has been replaced by the M25B, which is a pressure volume ventilator offering more flexibility in selecting a breathing pattern comparable to

I reluctantly returned to my turtle shell. Three months later, headaches and a real concern about dying from a simple lack of air drove me to try the lipseal again. This time, it was fitted with four velcro straps, two closing above my ears and two below and around my neck.

I purchased a small intercom from Radio Shack and placed one unit on the bed next to me and the other one in the bedroom where my home attendant slept. We connected the lipseal to a Puritan Bennett Maxivent and made sleeping more comfortable by using a humidifier. I slept as I had not slept in many years, and awoke refreshed and rested.

The Maxivent proved to be a simple and rugged piece of equipment. In four years with the same unit, I travelled to Montreal, Cape Cod, Vermont, and upstate New York with no mechanical problems, and have only replaced two pilot lights since November 1981.

The lipseal is available from Puritan Bennett with velcro straps, and for those of you who are still struggling to hang onto that old rocking bed or taped-up chestpiece, give it up and try the lipseal.

I want to emphasize that the old problems of living for so many years with ventilators can today be made easier, if one is willing to understand that giving up the ventilators of yesterday may be in one's best interest. We are all very much creatures of habit — perhaps more so because of our dependence on life-sustaining equipment that we have lived with for so many years. Change for anyone is difficult, but when change involves an area as sensitive as our breathing, we are naturally reluctant, if not apprehensive, to try anything new. The most difficult part of changing to new equipment or new modes of ventilation is the decision itself. Once the decision is made, the next step of adjusting comes quickly.

Address: Ira Holland, 540-A Main St., #B432, Roosevelt Island, NY 10044.

"The most difficult part of changing to new equipment or new modes of ventilation is the decision itself." Ira Holland, Vice-President, Concepts of Independence, Inc., a home care organization in Manhattan serving self-directed disabled individuals.

"I go through the entire day without plugging-in, since the M25B uses only 5 amps per hour. Battery time is increased threefold. The M25B's internal battery can provide an extra half-hour running time if my chair battery runs down and I'm not near an outlet.

Sleeping began to be more and more difficult. My vital capacity as measured in the pulmonary laboratory kept declining. Finally, when I was well below 300 cc, I asked about alternatives. The lipseal was suggested, but after a few days of trying it, I felt that I might die with it strapped to my face and no way to call for help."
Coping with Disability and Aging:
MUSCULAR DYSTROPHY & ALS

Independence Through Mobile Arm Supports
by Ireta Stone

In my early 20s I was finally diagnosed as having muscular dystrophy. At 25, I needed the aid of a Huxley respirator at night, using a cutlass. Now I also need a PVA during the day. I use mouth positive, securing the hose/mouthpiece to my chair with a "gooseneck" (flexible metal rod), which is easily reached when I need it by slightly turning my head. I've been trying to learn GPB (frog breathing). When I'm sitting up in my chair, I wear a lightweight body brace to support my weak back.

I have always lived with my parents, with a great deal of support and help from my sister and her family. For the past few years, I have used attendant services from the In-Home Support Service, a California program.

In October 1983, I was fitted for mobile arm supports at Rancho Los Amigos Medical Center by Occupational Therapist Denice Greathouse. She had evaluated my arm muscles and found enough shoulder strength to move and control the mobile arms.

The Orthotics Department at Rancho then made up my present mobile arm supports. They are designed to support the wrist, forearm, and shoulder (almost like floating), and have an adjustable "holder" by the thumb for pen, pencil, spoon, etc. This arm connects to two horizontal 10- and 12-inch metal rods, which insert into a bracket on the side of my wheelchair. Ball bearings at the pivot points allow easy movement with minimum effort.

With these "miracle arms" I can now type, draw, write, feed myself, turn pages, and even play an electronic musical keyboard. Without them, I am completely helpless.

I use a rubber-tipped stick with my left mobile arm for typing, turning pages, and playing the musical keyboard. For eating, I use a swivel spoon or "spork," with a six-inch "riser" attachment, which holds my arm in a higher position. My writing and drawing is done with both arms together, a pen through both holders for steadiness.

For most of my reading I use a Touch Turner (electric page turner).

In occupational therapy, I was introduced to a patient who created crossword puzzles entirely by typewriter. After trying this idea unsuccessfully I switched to "doodling," using the symbols, letters, and numbers, which led me to typing pictures. I have designed my own Christmas cards, and stationery which is both a challenge and a satisfying achievement.

Address: Ireta Stone, 5448 W. 118th Place, Inglewood, CA 90304.

Living Independently at 81
by Fay Daniels

I am 81 years old. I was born in Arta, Greece, migrated to America and to New York City in 1909. I've lived in Manhattan and the Bronx, never married, and led a full and productive life.

I have facioscapulohumeral, one of the muscular dystrophies, with an open tracheostomy and respiratory insufficiency since 1971. I use a motorized wheelchair, which is fully equipped with a portable respirator, batteries, and charger. Although I cannot stand or do daily routine things for myself, I can use my hands to feed myself, to write using a lap board, and to use an electric typewriter.
I started working in 1919 and was employed in various offices until 1947, when I resigned my last executive position in order to take a year off to do whatever I wished — traveling, sightseeing, etc.

In March of 1948, I decided it was time to earn instead of spend, so I took a job, naming my own terms — to come and go at will and get paid only for what I produced. I did this until bad health took over. After several fractures from falls, and major surgery, my working days ended in 1967.

When my physical condition worsened, I was admitted to Goldwater Memorial Hospital, Roosevelt Island, New York, where I spent ten days in an iron lung before a tracheostomy was performed. For three months, I was bedridden and didn't care if I lived or died.

When I realized I was going to live, I made a decision — despite using a wheelchair, plugging into a respirator, and having an open trach, I still had to be the Fay Daniels I had been before total disability.

In 1979, I decided that I wanted to re-enter the mainstream of life. It took over a year to find a suitable apartment in the area I wanted, but, in 1981, at age 77, I moved into my own apartment. Thanks to Medicare and Medicaid, I have attendants whom I interview and hire myself, equipment and medical supplies, and good medical care. I have returned to the mainstream of life even though I need others to take care of my every need.

Currently, I'm involved with several organizations for people with disabilities, am a member of the Goldwater Memorial Hospital Community Board, and am part of the Advisory Council for General Social Services in my district.

Having lived to this ripe old age, most of my old friends have died, but I have met new friends since my disability. My family is scattered throughout the United States and I don't seem them often.

I like having company, good conversation, and good food. I enjoy most sports, music, and plays, and when I go out, I carry a portable battery/electric-powered suction machine.

Having been an active person who lived most of my life as an independent individual, it has not been easy to depend upon attendants for every need. I try to make each day productive in some way.

Address: Fay Daniels, 135 West 23rd St., Apt. 407, New York, NY 10011.

Is a Nursing Home for You?

by Victor Young

In 1983, at the age of 70, I was diagnosed as having amyotrophic lateral sclerosis (ALS) also known as Lou Gehrig's disease. I had recently lost my wife to cancer, and had no close family nearby.

I held on to my precious home and all the prized possessions acquired over a lifetime for a year. In the meantime, I pondered the inevitable — where would I go? Who would take care of me? I knew that the walker, wheelchair, and other aids would not solve my problems forever, since with ALS, some gradual physical decline can occur.

I moved to a nice four-room apartment and kept most of the furniture. I had my car, my freedom, my friends, and I ate out often. I needed a little help each morning to assist me in bathing and dressing, and a cleaning lady occasionally, but I was quite happy with the arrangement.
I left this neat little nest, because I was sensible. I fell down too many times, and the cordless phone was not always within reach. A call to the man with keys to my apartment was not always answered. I couldn’t crawl anymore. Sometimes I wore myself out calling for help.

When fear is a frequent companion, it's time for a change. When a strong wind scares you to death, you freeze up. I once sat in my car for over an hour waiting for a neighbor to help me on the short walk from the car to the front door.

I chose to move from the apartment to a nursing home. It was difficult to even consider the environment of a nursing home, but I tried to weigh the advantages against the environment.

Most homes are modern buildings with level entrances, handrails, wide hallways, and elevators. I can now move from my parking space to my room without a step or a curb in the way. I can easily and safely use my wheelchair and walker.

The other residents represent about half of the people in the environment. Nurses, aides, housekeepers, medical technicians, waitresses and cooks, janitors, etc., abound daily.

Baths are provided every other day with attendants nearby for assistance and safety. There is no scolding for accidents, and so no need for embarrassment or apology. Aides assist with dressing as necessary, since residents are encouraged to do what they can.

It is important that your physician also accept the nursing home. He or she must be willing to answer telephone inquiries, make house calls, furnish reports after periodic examinations, and specify changes in treatment and medicines.

When you are in a good nursing home, you have greatly improved your safety, health, and happiness. I know I made the right choice for me.

ALS in the Netherlands
by Henk Wiedemeijer

In the summer of 1983, my only brother died of cancer, and I was diagnosed as having ALS (amyotrophic lateral sclerosis or Lou Gehrig’s disease). I am age 57, married, and have a family of five.

For 35 years, I was an executive in the surgical instrument business. When I had to use a wheelchair, I lost my job. Now as a use of leisure, I make art prints and oil paintings, and have built an original music box.

To live with an incurable disease isn’t different in other parts of the world. It is important that I and my family cope mentally. Every morning I inventory, do my own mental training and a few exercises.

I have learned to use what I still can use, to accept what I can’t, and to believe in what I can do with the rest. I enjoy life and am happy and thankful for the soft glimmer of the future. I have trained my mind to control my emotions — it is my best weapon in my fight against ALS.

Address: Victor Young, Christian Old Peoples Home, 800 Chambers Rd., Ferguson, MO 63135.

Social Security Disability Benefits

What You Should Know About Your Social Security Disability Case

by Robert Crowe

How Do I Prove I Am Disabled?

Social Security's Special Definition of Disability — Social Security has its own specific definition of disability. Other agencies' decisions (like the VA, state welfare agencies, or Workers' Compensation) are disregarded by Social Security. In the case of DIB, SSI, and DAC claims (categories of disability benefits which are covered in the following sections), you must prove that you cannot do any substantial gainful work activity because of one or more physical or mental medical problems which are backed up with clear-cut medical proof. This serious disability must last for at least twelve continuous months, or else be expected to result in death. You can file a claim before you have been disabled for twelve months, but you must be able to prove that your disability is certain to last that long, in order to qualify. In the case of DWB claims (a special benefit for disabled widows and widowers), Social Security has a stricter meaning of disability. You must be unable to do any gainful work whatsoever.

The Importance of Medical Proof — You must have hard medical evidence of some physical and/or mental problem, or combination of problems, which keeps you from working. This is why it is so important to be under regular medical care at all times throughout your claim. Medical evidence from a doctor, hospital, or clinic is the main way that Social Security has to measure how severe your condition is. No matter how sick or hurt you say you are, Social Security is not allowed to pay you benefits without a clear medical explanation of why you are disabled.

Other Things Social Security Considers — If you have applied for disability insurance benefits on your own work record, SSI benefits, or disabled adult child benefits, Social Security will also look at your age, education, and past work experience, including any skills you may have learned at your past jobs for the last fifteen years. Some people think that Social Security will find them disabled if they can't go back to their old job. This is not always true. Social Security will look at your duties at your old jobs, to see if you learned any skills which you might be able to use in another, easier kind of job, and then decide whether you can physically or mentally do that kind of work. The younger and more educated you are, the easier they think it will be for you to adjust to a new job. For this reason, it is harder for younger people to get disability (although it is certainly not impossible), and easier for older people to qualify.

Social Security is not allowed to consider whether you would be hired by someone, or the fact that you have not been hired when you applied for a job. All they can consider is whether jobs exist somewhere in the U.S. for a person of your age, education, and work experience, and with your medical conditions. If there are jobs that you can possibly do, you will be found not disabled. On the other hand, you do not have to be in a wheelchair or a nursing home to get benefits; you just have to be unable to work. To put it another way, Social Security will pay you if there is a medical reason why you cannot do any job for which you might qualify. Whether you can actually get a job does not count.

What Kind of Benefits Am I Eligible for?

There are several kinds of disability benefits for which a person can be eligible. Depending on the facts, you may only be entitled to one of these benefits, or you may be entitled to more than one. Each has its own requirements which must be met.

Disability Insurance Benefits (DIB) — You are only eligible for these benefits if you have paid a certain amount of Social Security tax over a period of time, enough to have disability insurance coverage in force. In general, you must have paid some tax in 20 calendar quarters out of a 40 calendar quarter period before your total disability began. In other words, you must have worked and paid Social Security tax for about five out of the last ten years before you became totally disabled. You must prove that you became disabled while your coverage was in force, or you are not entitled to benefits, no matter how serious your medical condition is now. If your DIB claim is approved, the
monthly payment you will receive is set by your income during your working career. There is no minimum rate, and the maximum a person can receive at this time is about $800 per month. There is a cost-of-living raise in the monthly payment at the start of most years. In many cases, your dependents will also get benefits in addition to your own.

Supplemental Security Income (SSI) — SSI can be paid whether or not a person has paid in enough Social Security tax to get disability insurance benefits. You must be disabled under the same rules as for disability insurance, or be blind, or be over 65. You must also have very little income or property; because this is a welfare-type benefit. Social Security looks at all other income and property in the household you live in, not just your own, and also the value of any support (like free room and board) you may get from others, to determine whether you are financially eligible for SSI. Social Security does this in addition to deciding if you are disabled. Also, children 18 or younger with a severe disability can get a monthly benefit if their family income is low enough. There are special rules for children’s SSI cases, and in order to be eligible, the child must fit these requirements exactly.

Disabled Widow/Widower Benefits (DWB) — The disability rules are different and tougher for this benefit than either DIB or SSI. A person must have one or more conditions which fit in, or are just as severe as, a list of very disabling problems which Social Security has set out in their rules. It is hard to meet this test, even with a serious illness (although it is certainly not impossible). In order to qualify, you must be between the ages of 50 and 60, and have been married for a minimum amount of time to the person who was covered under Social Security at the time of his or her death. Also, you must have proof that your disability was severe enough to meet these rules within seven years of your spouse’s death, with some exceptions for those already receiving other kinds of Social Security benefits. If you are awarded DWB benefits, your monthly rate is determined by your deceased spouse’s income and Social Security tax payments. Your monthly rate will be reduced for every month you collect benefits before you reach age 60. This is because a survivor’s pension can usually be paid at the age of 60, regardless of any disability.

Disabled Adult Child Benefits (DAC) — In order to be eligible, you must be a child of a person already receiving Disability Insurance Benefits or Retirement Benefits, or who died while covered for Social Security. You must be at least 19 years old, and you must prove your total disability began anytime before the month you turned age 22, and is continuing. The monthly rate if you are awarded benefits is based on a percentage of your parent’s rate. Therefore, it is different in each particular case.

What Are The Steps in Applying for Disability Benefits?

All disability claims begin by filing an application with Social Security. This can be done by either calling Social Security, or visiting any one of their local offices. You do not need legal help to file a claim.

Initial Determination — Disability Determinations, a state office working with Social Security, does the initial disability review. They will order copies of your doctor, clinic, or hospital records, and sometimes send you to see a doctor for an examination at their expense. If you miss this examination scheduled by Social Security, they may deny your claim. While you cannot request that Social Security send you to a particular doctor, you do have the right to object to the doctor they choose, and ask for someone else. A decision is then made based on Social Security’s own guidelines. In most cases, a person is turned down at his first step, and this includes many people with serious disabilities. If you think Social Security is wrong, you have the right to request a reconsideration of your claim. This must be done within 60 days after you receive the written notice of your denial. You should not give up if you are denied at this step — be sure you appeal on time!

Reconsideration — A different person from Disability Determinations will re-examine your file and update the medical evidence on your case. Once again, this can be done by either calling or visiting any Social Security office. In some cases, Social Security will schedule a face-to-face conference with a hearing examiner, who is a non-lawyer working with Disability Determinations. Your attendance at this conference is optional, unless
you have been receiving benefits in the past and Social Security wants to examine your continuing eligibility. Often, this “mini-hearing” will not help your chances of winning, and you might want to talk to a lawyer before deciding whether to go to it. The decision at reconsideration is generally the same as that at the initial determination stage, and most people are denied again. Following this denial, a person has 60 days to request a hearing with an administrative law judge. This is done by filing a Request for Hearing form by either calling or visiting any Social Security office, or having a lawyer do it for you. Once again, no one should give up at this point — everyone with a serious case should go on to at least the next step.

The Administrative Hearing — This is by far a person’s best chance to get Social Security benefits. The administrative law judge is an experienced lawyer who listens to your testimony and evaluates the medical evidence. He or she makes an entirely new decision, paying no attention to your earlier denials. The hearing is very informal and quite different from what you would expect in a courtroom. Other people, including your personal doctor, can be present to testify at your hearing, although medical reports and records are usually enough. After your hearing, you will get a written decision in the mail, either granting or denying you benefits. Most people are represented by a lawyer at a hearing, although it is not required.

In most cases, there is no lawyer at the hearing opposing the claimant and representing Social Security. However, an experimental program is underway at the time of this writing in the Los Angeles—Pasadena area, Baltimore; Columbia (South Carolina), and Kingsport (Tennessee), in which a government representative appears to oppose the claimant in cases where the claimant is represented. This experiment has been widely criticized by lawyers specializing in Social Security and in Congress. Indeed, the program has been dropped after a one year trial in the St. Louis County, Missouri, office. We do not know at this time whether the program will be expanded or withdrawn altogether.

Appeals Council — If you lose at the hearing, there is one last level of appeal inside Social Security itself, known as the Appeals Council. Like all other Social Security appeals, you must file for this within 60 days of the date of the judge’s decision. Your file, any new medical evidence, or any written argument you want to send, are considered. Another decision is sent to you by mail, but unfortunately very few cases are approved by the Appeals Council. However, appealing to the Appeals Council is a requirement if you want to have your case reviewed in United States District Court (see next section).

Federal Court Review — Within 60 days after you receive the Appeals Council written decision, a formal law suit can be filed with the United States District Court for your area, seeking review of Social Security’s final decision. The District Court is only permitted to review your medical evidence and a written transcript of the hearing. No further evidence can be received. Your lawyer and the government’s lawyer file legal briefs arguing each side, and the District Court issues another written decision. You never appear in court in person — this is all done on paper. Your chances of winning can be fairly good if your case is strong. In general, the federal court can do one of three things: the judge can reverse Social Security’s decision outright and order them to pay you benefits; the judge can affirm or agree with Social Security’s decision denying you benefits; or your case can be remanded, or sent back to Social Security for a new hearing.

In order to have your case reversed or sent back to Social Security, you must show that there was no “substantial evidence” for Social Security’s decision, or that the government committed a serious legal mistake in deciding your case.

If I Am Approved, How Long Will I Get Benefits?
If your disability benefits are approved, you will be paid as long as you still qualify. Social Security will stop your checks if certain things happen. The most common reasons for stopping your benefits are: your medical condition improves to the point that you are able to work again; you actually go back to work and make over a certain amount of money; or (for people on SSI only) the income or property of your household goes over the limit allowed by SSI. Sometimes Social Security cuts off

(continued on page 23)
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 recognized 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 1985, 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 1983, 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 to all interested persons 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 ventilation. 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, glossary of terms, pharyngeal 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 movement since the early 1970s.

The lives of disabled individuals as role models are chronicled in the pages of the Gazette and parallel the evolution 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.

Gazette International Networking Institute
4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475
Back issues of Rehabilitation Gazette $8 each.

Polio Information

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors.
Edited by Gini Laurie, Frederick Maynard, M.D., D. Armin Fischer, M.D., and Judith Raymond.
48 pages, 6" × 9".
References. Resources. Glossary.
$6 in U.S. and Canada. $8 overseas.

The Handbook is a compilation of information and the experiences of physicians and survivors who participated in Rehabilitation Gazette's two international post-polio conferences and Warm Springs' research symposium. Topics include aging and weakness, arthritis, depression, diet, exercise, fatigue, frog breathing, muscle weakness, overuse weakness, pain, respiratory insufficiency, sleep apnea, tracheostomy, vaccines, and ventilators.

Proceedings of Rehabilitation Gazette's Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability, May 6-8, 1983, St. Louis, Missouri.
Edited by Gini Laurie and Judith Raymond.
$16 in U.S. and Canada. $18 overseas.

Comprehensive source of information on the late effects of poliomyelitis for physicians and other health care professionals, and polio survivors. The Proceedings supplements the information in the Handbook. Topics cover worldwide immunization, post-polio research, health maintenance, ventilatory equipment, long-term ventilator users, attendants, independent living.

Proceedings of Rehabilitation Gazette's Third International Post-Polio and Independent Living Conference, May 10-12, 1985, St. Louis, Missouri.
Edited by Gini Laurie and Judith Raymond.
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$16 in U.S. and Canada. $18 overseas.

New information since the 1983 conference on the late effects of polio for physicians and other health care professionals, and polio survivors.

Topics covered include the role of exercise, the management of pain, need for respiratory support, psychological adaptations to changing respiratory support, post-polio research, polio immunization programs, ventilator-assisted living for spinal cord injured, muscular dystrophy, etc., the independent living movement worldwide, and attendant care programs.

Polio Network News.
Edited by Gini Laurie and Judith Raymond.
Quarterly bulletins. Available through membership in the International Polio Network. (See membership form on next page.) Treatment and research, support groups and clinics, post-polio issues.

Post-Polio Directory.
Compiled by Judith Raymond. Annual with quarterly supplements. Available through membership in the International Polio Network. (See membership form on next page.) Directory of physicians, clinics, support groups, and resource persons worldwide.

ORDER FORM

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

Make checks or money orders in U.S. dollars payable to G.I.N.I.
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Publications

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☐ YES, I would like more information on G.I.N.I.'s 4th International Polio and Independent Living Conference, June 4-7, 1987, at the Sheraton St. Louis Hotel.

Gazette International Networking Institute (G.I.N.I.)
Membership benefits include:
- Rehabilitation Gazette subscription, two issues per year
- G.I.N.I.'s information service and library
- Discounts on G.I.N.I.'s conferences and membership events
$25 per year for individuals
$35 per year for institutions
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International Polio Network (I.P.N.)
Membership benefits include:
- Polio Network News subscription, quarterly
- Polio Directory, annual with quarterly supplements
- Networking with polio survivors and health professionals
$5 per year for polio survivors
$15 per year for health professionals
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International Ventilator Users Network (I.V.U.N.)
Membership benefits include:
- I.V.U.N. newsletter, bi-annual
- Networking with ventilator users and health professionals
$5 per year for ventilator users
$15 per year for health professionals
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G.I.N.I.'s 4th International Polio and Independent Living Conference
June 4-7, 1987
Sheraton St. Louis Hotel
Ted Kennedy, Jr. and James Roosevelt
Congressional Site Hearing on Home Support Services chaired by Missouri Representative Richard Gephardt

REHABILITATION GAZETTE.
benefits unfairly, just as they do not always approve people who are truly disabled when they first apply. If you do not agree with Social Security’s reasons for stopping your checks, you have full rights to appeal, including a hearing with an administrative law judge.

Just like when a person first files for benefits, there are strict time limits to file appeals if the government tries to cut you off. In addition, the legal and medical questions involved in stopping your benefits can actually be more complicated than when you first apply for benefits. If Social Security sends you a letter telling you that they are stopping your checks, it is a good idea to talk to a lawyer right away.

What About Having a Lawyer on a Social Security Case?
What A Lawyer Does For You — No one is required to have a lawyer represent them on a Social Security case, but most people do have a lawyer at least by the time of the hearing before the administrative law judge. The government’s own figures show that people who have a lawyer are more likely to win. A lawyer who is familiar with Social Security cases will know all the details of how to appeal. He or she should be skilled in sizing up your disability and counseling you on how the law applies to your condition. Your lawyer should know how to decide what medical proof is needed for your case, and how to get it. He or she will prepare you before your hearing, so you can explain your disability to the judge in the strongest way possible. Your lawyer should also be able to explain all of the government’s decisions, and help you with any problems that come up about your payments if you are approved.

When to Call a Lawyer — You do not need a lawyer to file a claim — just visit or call any local Social Security office. Our firm is happy to talk to you on the phone, without charge, before you file if you have any questions about whether you are eligible. Some people file the first appeal on their own if they are denied, but a lawyer can begin to help you at this point. If you are denied a second time (what Social Security calls a “reconsideration”), it is a good idea to see a lawyer as soon as you can. The third step is the hearing with an administrative law judge — that is the time you need a lawyer the most, and when the lawyer can do you the most good. If you do not have a lawyer at the hearing and the judge turns you down, it is sometimes too late for a lawyer to fix the problems in your case. However, if you are in this situation, you should still call a lawyer to get advice on appealing again or filing on a new claim.

How Do Lawyers Charge on Social Security Cases? — On most, but not all, Social Security cases, lawyers charge what is called a “contingent fee.” This means that the lawyer’s fee is a percentage (usually 25%) of any back pay the government owes you by the time you finally win the case, and if you do not get benefits the lawyer does not charge you anything. No retainer fee is required, but you may be asked to make a deposit for the cost of getting medical reports and records used as proof. These expenses are your responsibility.

There are some kinds of Social Security problems where you may need a lawyer, but you will not be due any back pay if you win. A lawyer cannot take this kind of case on a percentage — there is nothing to figure a percentage on. The lawyer may want to charge by the hour (whether you win or lose), or you may make some other arrangement. Fees should be clearly set out before you decide to hire a particular lawyer.

All lawyer fees are regulated by Social Security. Your attorney must file a written application with Social Security at the end of the case, and the final amount of the fee is then set by the government. In some cases, Social Security will hold out the 25% of your back pay, and send your lawyer a check for the fee they approve. In other cases, you will have to pay the lawyer yourself. Be sure to ask your lawyer how his or her fee will be paid in your particular case.

How do I Find a Lawyer Specializing in Social Security Cases? — The National Organization of Social Security Claimants Representatives (NOSSCR) is a nationwide group of lawyers specializing in disability cases. NOSSCR provides a free referral service and will locate a lawyer for you. Call toll free 1-800-431-2804, between 9 a.m. and 5 p.m., EST, Monday through Friday.

Address: Robert Crowe, Crowe & Shanahan, 915 Olive St., Suite 1001C, St. Louis, MO 63101
314-231-6660.

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Travel Warnings for Ventilator Users


Several announcements have appeared in the Rehabilitation Gazette in recent years suggesting that if you are in England or Europe with a respirator and need help, you should contact Phipps Unit at the South Western Hospital in London or me personally, and everything will be taken care of. While we are pleased to do what we can to help, we only have a limited amount of American equipment and naturally have to put the needs of our own patients first.

However, an increasing number of enterprising American visitors are arriving unannounced, expecting immediate respirator service, replacement, delivery to their hotel, airport, or even dispatch by air freight to their chosen continental destination. Some have even asked us to arrange suitable accommodations for them. The following episodes illustrate the lack of knowledge and advance planning.

Episode A. At 6 p.m. on a Sunday evening, a huge American motorhome drove into the hospital grounds. A man dangled a 110-volt 60-cycle electrical lead out of the window, with an American plug on it, and asked for a "hook-up"—he wished to spend the night in the hospital grounds! Nobody present had even seen an American motor home before. The "hook-up" principle for motor homes doesn't exist in this country. The plug didn't fit, which was just as well—if we had connected him up to our 240-volt 50-cycle mains, the Emerson iron lung inside would have blown up, together with its occupant.

It transpired that the equipage had driven off a ship at Southampton, found that camp sites with American hook-ups didn't exist, and had driven to us. We managed. A technician was called in to fix up a transformer, the vehicle moved away from the ambulance access route, and stayed with us for two days.

Angry letters came to me from the hospital administration saying the hospital wasn't a camp site, the vehicle was blocking fire engine access, was the patient admitted and could a bill be sent? The tank occupant went off happily, but though the episode was interesting, there was a cost in goodwill.

Episode B. An American lady and her husband in transit to India arrived at Heathrow Airport. She had been treated for polio at a well-known American centre and supplied with four or five 110-volt 60-cycle Monaghan 170C respirators and some 12-volt car batteries. The batteries were flat on arrival and she was brought to hospital in an emergency ambulance. She had been told that she should not use any alternative respirator.

All our modified 240-volt 50-cycle Monagahns were in use, and late at night I had to visit one of our patients at home and borrow her spare machine while our technicians carried out modifications. She spent a week in the hospital. Why didn't the American hospital send her off without checking mains voltage in England or India?

Episode C. A lady from California telephoned Phipps from her hotel in London where she was spending a few days on her way to Paris. She had come equipped with two Thompson Bantam respirators, two Life Products LP3s, and two transformers for continental voltage (220-volt to 110-volt). On our 240-volt mains, the transformers blew their fuses. One Bantam had broken.

Fortunately, a Senior Ward Sister who had dealt with this sort of problem before was on duty and knew what to do. Next morning, with her husband and on their off-duty time, they both traveled to the lady's hotel with a modified 240-volt Thompson M25, which we fortunately had available as a spare. Our Ward Sister spent two hours showing her how to use this strange machine, explaining that the Thompson Bantam was obsolete and the M25 would do as well. The lady took it to Paris for her holiday, and all was well.

Geoffrey Spencer is an anaesthetist. He is Consultant-in-Charge at St. Thomas' Hospital in London.
Genuine medical emergencies affecting visitors in the UK are treated without charge under the National Health Service. The Service, however, is not concerned with helping people to take holidays. At Phipps, we will try to help as a favor without charge, though a voluntary donation towards ward funds does promote goodwill.

The nurses, technicians, and I have so far been able to cope and provide temporary stopgap help by working on our own time, at our own personal expense. We have no way of charging for these services as they are usually non-medical. We have also been lucky — so far — in that we have happened to have something suitable available at the crucial moment. Sooner or later, though, we are bound to be caught short and somebody will have to be admitted to the hospital at great expense and disruption to their holiday.

Living independently is great, but setting off into the blue, assuming that somebody will cope with respirator needs, is living dangerously.

Dr. Spencer's Points to Remember

Respirators.

There are very few American respirators anywhere in Europe. Phipps is about the only place with any at all. Most European countries manufacture their own respirators, which are quite different from any Americans are used to and would probably require a week in the hospital to learn to accept.

Despite the Common Market, there is very little medical contact between European countries. Scandinavia is a notable exception, though most respirator users there have tracheostomies. Very few, if any, hospitals in Europe will even consider lending a respirator, and there is no commercial respirator rental in the UK, like LIFECARe in the USA.

In general, negative breathing respirators are much less widely used in Europe than America. They are virtually unknown in continental countries other than France.

Apartment from English respirators, Phipps has 25 Monaghan 170C respirators, 13 Thompson Maxivents, four Thompson M25s, and three Bennett AP5s. All these are adapted for English voltage, but most are in regular use by our patients. Sometimes we can lend one for a short period, if we know in advance.

We are always short of respirators because American machines here are much more expensive for us than their English equivalents. Repair and service for American respirators is almost non-existent here. Our technicians do most of it themselves and some of the machines, particularly the Monaghan 170Cs, are less reliable than they should be.

There are no Emerson iron lungs in this country. We prefer our own made by Cape Warwick, but they are quite unfamiliar to most Americans.

Electrical Voltage.

50-cycle AC mains are standard throughout Europe, though voltage varies from 210 to 240 in different countries. If one brings a voltage transformer, remember that it won't correct the cycle rate. Therefore, an American 110-volt 60-cycle machine, operating via a transformer, will run safely, but at 5/6ths of its normal power and speed, so all the settings and rates will need adjustment. If the machine is normally used at its full power, it will have less when operated here and may be insufficient.

Electrical Plugs and Sockets.

Virtually every European country has different-sized electrical plugs and sockets. If one travels about, one must plan to buy local plugs on arrival and fit them to one's own leads, so bring necessary tools.
Batteries.
Liquid-filled batteries are strictly illegal in aircraft cabins and certainly never permitted in the baggage hold. However, an increasing number of airlines are now prepared to accept batteries with special non-spill caps or seals in cabins as a favor to the disabled. This practice is much less common on European airlines than it seems to be on American domestic routes, so don't count on batteries being allowed abroad. The airlines have the right to refuse. Aircraft electrical power sockets of suitable voltage are rarely available in flight. Most airplane electricity is 400-cycle AC, which needs a special motor in your respirator. Non-spill gel filled batteries are coming into use, but they are expensive and, so far, of a capacity usually insufficient to power a respirator throughout a trans-Atlantic flight.

Bringing American Equipment.
It is always better to bring one's own if possible. Provided total baggage is reasonable in quantity, most airlines will carry respirators without setting their weight against one's baggage allowance. Despite this, we have had two visitors who left respirators behind at their departure point in America when threatened with excess baggage charges. Fortunately, when they arrived respiratorless, we were able to provide. This was just luck as we had no forewarning — do not count on it or assume that we will always be able to help.

Address: Geoffrey Spencer, O.B.E., M.B., B.S., F.F.A.R.C.S., Phipps Respiratory Unit, St. Thomas' Hospital, South Western Hospital, London SW9 9NU, England.

Airline Travel
by Ed Roberts

Airline travel should be a routine, simple procedure, but for a person with a disability it can be an exercise in frustration unless you plan ahead and are assertive.

When making reservations, provide the travel agent with information about your disability, equipment, method of travel, and attendants, which the agent can pass on to the airline. (Call the airline a few days before departure to make sure they received the information.)

Obtain a copy of Incapacitated Passengers Air Travel Guide (available from International Air

World traveler Ed Roberts, disabled by polio in 1953, is Co-Director of World Institute on Disability, Berkeley, California.
Transport Association, 2000 Peel St., Montreal, Quebec H3A 2R4 for US4). The Guide "classifies" disabilities so the airline will know what special services are required, conditions under which medical clearance are required, and equipment regulations. It is wise to carry the Guide with you to prevent airline personnel from creating new regulations on the spot.

Plan ahead how you will transfer from your wheelchair to the airline seat. The wheelchairs the airlines provide are narrow, and falling off can be a hazard for persons with little muscle control below the neck. (My attendant carries me onto the plane from the jetway, but some of the airlines object to this.)

Airlines are hard on wheelchairs. Some people take a push wheelchair as a spare, others replace their power chairs every few years due to airline mishandling. If a wheelchair is damaged in baggage, the airline is responsible. Be prepared for what to do if you arrive and your wheelchair does not.

Always know if you can get off the airplane when it lands. Most major airports have jetways, ramps, or lifts, but you never know when stairs will appear.

If you use a ventilator, you need to be especially careful about the type of equipment you are planning to take with you. Be sure to take dry or gel cell batteries in sufficient number to run your power chair and ventilator for at least 24 hours after you arrive. (I take six batteries — four for the power chair and two to run the ventilator on the plane.)

The travel process is in your hands. You must take charge. Never accept an alternative you consider dangerous to your personal well-being. Be assertive.

Address: Ed Roberts, 6031 Chabot Rd., Oakland, CA 94618.

An Accessible Alaska Cruise
by John Hessler

On September 8, 1985, my wife, Jean, and I boarded the Fairsky in San Francisco to begin a cruise to Alaska. It turned out to be one of the most interesting, carefree, restful vacations we have ever had. The cruise lasted 12 days, covered 3,500 miles, visited several Alaskan and Canadian ports, and took us through vast stretches of wilderness, including Glacier Bay and the Inside Passage.

The Fairsky, a Sitmar Company ship, reminded me of the luxury liners of past decades when sailing was the poshest way to travel. Varied wood, polished brass, and sumptuous carpets all evoked a life of quality and richness.

There are six accessible state rooms with 32" wide entry doors, roll-in showers, and ample room to maneuver. When docked, the Fairsky is entered or exited via ramps. In San Francisco, the ramps were smooth and level with the ship's floor and city pier. In Juneau, Alaska, and Vancouver, British Columbia, the ramps were bumpy, and each end had at least one and sometimes two steps. The crew spoke Portuguese, but they understood the mechanics of lifting and moving a wheelchair with someone in it, so in Juneau and Vancouver it took only a little more effort to get on and off the ship.

In port, the Fairsky either drops anchor in the bay or inlet or docks at the city's piers. When at anchor, the ship slowly drifts with the currents and tides so that sitting in one place on deck eventually gives close to a 360° view — a very pleasant way to sight-see. At anchor, tender boats are used to transport passengers to the docks. It is not easy to use these boats if you use a wheelchair, but it can be done.

Much simpler, if less adventurous, is when the ship ties up at the dock. Juneau and Victoria, B.C., are very accessible with many curb cuts. Juneau's downtown is located a mere two blocks from port, and its museum another four blocks or so. Victoria's parliament, museum, and famed John Hessler, C5-6 quad since a diving accident in 1957, roomed with Ed Roberts in Berkeley during their college days. A co-founder of the Berkeley Center for Independent Living (CIL), John is now Chief, Operations and Capital Projects for the California Department of Health Services.
Empress Hotel are farther (about a mile from where the Fairsky docked), but Jean and I found it an easy walk.

The Fairsky has a crew of 550. Of these, a room steward, a waiter, and their assistants are on call or stationed by your table to help you in any way they can. Our steward, Novo, seemed never more than 30 seconds from our room. The first thing I had him do was put an additional mattress under the regular one so that my bed was at wheelchair seat level. (It would have been a good idea to have requested this ahead of time through the travel agent.) Novo cheerfully responded, as he did the next 12 days, whenever Jean and I asked him to help transfer me via a sliding board from bed into the wheelchair, or when we had slept in and opted for breakfast in our room.

Moving around the ship was quite easy. Whichever way we went from our room there were three roomy elevators waiting at the end of the hall. The outside control buttons were easy to reach, but the inside ones took some effort.

The Promenade deck features a showroom big enough for 750 people, three lounges, three bars (two with live music), a pizza parlor, a casino, a swimming pool, and a wide, wooden open promenade that went one-third of the distance from the bow of the Fairsky around the stern and back. To walk that distance five times was to walk a mile. The swimming pool was the only inaccessible place on the Promenade deck.

I liked the Lido deck the best. It, too, had an outdoor promenade, but large, paneled glass shielded much of it from the chilly North Pacific wind. Without such protection, even my parka did not keep me warm for long. On this deck one could have a large, hot breakfast and look at glaciers or watch whales and still be warm while icy winds blew. For some reason, this deck was abandoned after lunch. I could sit undisturbed for hours as the ship slowly moved on the Inside Passage, floating amongst forests and giant snow-capped mountains.

Another surprise was how much I enjoyed the company of other passengers. Before the trip, I had planned to do a lot of sightseeing and reading. I did plenty of the former, but I never opened even one of the books I brought. While viewing the natural wonders from the Promenade and Lido decks, I kept meeting the most interesting people.

Some were other wheelchair users, so I am profiling them here to show how accessible the Fairsky cruise and tours are and to give an idea of the variety of activities that people with disabilities participated in.

Helen Jones is an English instructor in the disabled students program at DeAnza Community College near San Francisco. She also works as a travel agent for the Anglo-California Travel Agency. The Alaskan cruise had several side tours associated with it, from simple walks around town with a guide to helicopter flights onto glaciers. Naturally, Helen flew to these giant packs of ice. Since there wasn’t room on the bird for her wheelchair, she borrowed a parka from the pilot and sat on the frozen snow. She reported that on the glacier tour,
Cindy Turner and Char, her sister, had walked to the Juneau Museum as had Jean and I. We were descending the long spiral ramp from the top floor when we saw them and they asked what to do about the wheel falling off Cindy's chair. I had a wrench in my book bag and we quickly tightened the axle bolt.

Pat Gruppe and her sister, Ellen, flew in from Florida for the cruise. Pat, disabled by polio, was able to walk with Canadian crutches until about five years ago when she began using a power chair to conserve energy. However, to avoid airline hassles that all of us have experienced, Pat brought only her push chair. (To me, having one power and one push chair enabled us to most fully enjoy the freedoms and independence available on the cruise.)

In Juneau, they took a tour bus up to Mendenhall Glacier. The tour folks lifted Pat and put her in the front seat of the bus. In Ketchikan, they took a walking tour that included a fish hatchery and Old Town, and a nature cruise that included the harbor and wild life areas. In Sitka, along with Ed and Bob, they boarded an accessible bus (with lift) and toured the city, which is famous for its Russian heritage, and its Orthodox Church.

Jean and I learned about the FairSky and its September 1985 Alaskan cruise in the early fall of as well as on the other tours that required lifting, everyone was willing to help.

Ed Levine and his friend, Bob, got off at almost every port, even if they had to go from ship to shore on one of the tender boats. They are better than life boats, but if one is in a chair, there is very little room on the tender boat, and that room is in the cabin that everyone must pass through to enter or exit. No one whom I asked tried it in a power chair.

Ed and Bob, like Helen, also took an amphibious plane ride in Ketchikan, and, in Juneau, they took a helicopter ride to Mendenhall Glacier. Since the seats were not full, Ed was allowed to take his wheelchair.

1984. We contacted our travel agent, Helen Jones, and were lucky to get the last accessible room. They had been booked that fast a year in advance. Anglo-California Travel required a payment of 20% of the ticket price to hold the reservation.

A few weeks before the departure date we received a packet that contained a questionnaire, tickets, visitor boarding passes (for the debarkation party), and insurance forms.

The questionnaire asked if someone would like first or second seating for meals, and gave the times for each. We chose second seating, which got us breakfast in the dining room at a civilized hour. If I had known how easy it was to get breakfast in the room, or that it could be had on the Lido deck, I would have opted for first seating.

The insurance forms in the packet allow one to insure baggage, health, and cost of tickets. Insurance on the cost of tickets probably makes more sense psychologically than financially, and is only a five percent surcharge on the ticket price.
The packet also contained advice on what
clothes to bring, how much money to bring and
in what form (on board one can charge a certain
amount and pay at the end of the voyage, but don't
wait until the last moment to pay as the queue is
longer than the Alaskan pipeline), when and how
much to tip, what shopping one can do on the ship,
and Customs duties on items bought in Canada.

Warm clothes and something rain resistant
are a must. We had only one day of rain, but those
who weren't prepared had to forego a visit to Sitka
or get soaked. On formal evenings, people wore
formal attire. One probably won't get thrown out
of the dining room if one doesn't, but one will feel
very much out of place.

The food is everything it's reputed to be (deli-
cious and in endless supply) and comes as part
of the package. Drinks do not, nor anything else
bought on board or in port.

Tips are a personal matter. We gave more be-
cause the service was always excellent. Besides, I
didn't want the Fairsky waiters and stewards to re-
member the last disabled person they served as
a cheapskate and/or ingratitude.

A few additional things one might bring in-
clude a camera, binoculars, and any medication
or personal equipment needed. There are profes-
sional photographers on board whose pictures
can be purchased during the cruise, and a gallery
where pictures taken the day before can be
viewed.

The usefulness of binoculars might come as
a surprise. After all, on deck one is 100 to 150 feet
above the water and the air is so clear one can see
for miles. That's the problem — there is so much
in between. Johns Hopkins Glacier appeared to be
within our reach, but it was over two miles away.
When we looked through our binoculars, we could
see dozens of harbor seals resting on the low level
icebergs between us and the glacier. Those ice-
bergs had appeared deserted to the unaided eye.

There are a doctor and other medical person-
nel on board, equipped to handle the usual ship-
board emergencies — seasickness, indigestion,
heart problems, etc. The treatment cost may
be high.

It is important to have a way of fixing or sub-
stituting essential equipment. The mechanics on
the Fairsky will fix what they can. One should ask
oneself what a competent individual unfamiliar
with a transistor box or respirator, should reason-
ably be expected to repair. Bring an extra of what
cannot be fixed or substituted.

Above all, leave your cares, worries, and
problems behind.

Address: John Hessler, 1042 9th Ave., Sacramento,
CA 95818.

Travel Miscellany

Apartment Exchange

"We will trade our accessible two-bedroom apart-
ment in Berkeley for an accessible place to stay in
New York City for one month this summer."
Herb Haver 415-548-5523 or Paul Trudeau
415-548-9389.

England

Access to the Underground, a guide for elderly
and disabled persons, charts the complete route
between street level and platforms at all tube
stations in London. Includes information on
lavatories, buses, and telephones. Available for
70p (within the United Kingdom) from London
Regional Transport, Unit for Disabled Passengers,
55 Broadway, London SW1H 0BD, England.

Travelling with British Rail: A Guide for Disabled
People. Available for £2.00 (£2.80 for posting
within the United Kingdom) from RADAR,
Expo 86

The Complete Resource Guide for the Disabled to Expo 86 by Helen Hecker. Available for $3.50 plus $1.00 shipping from Twin Peaks Press, P.O. Box 8097, Portland, OR 97207.

Guides

AA Travellers’ Guide for the Disabled, 1986, provides information on the accessibility of over 400 hotels, B & Bs, inns, etc., throughout the British Isles. Free to members, $2.25 to non-members from Automobile Association, Fanum House, Basingstoke, Hampshire RG21 2EA, England. (American Automobile Association has a reciprocal agreement with the AA. AAA membership cards will be honored in the UK, as will AA cards in the U.S.)


Japan

“I would like to correspond in braille or on tape. I am a graduate of a university in the U.S. and I speak English fluently . . . I am interested in music, literature, independent living, and the education of disabled persons at all levels. I am a teacher of English to college students . . . If any Gazette readers come to Kyoto, I shall welcome them and show them the sights of our city.” Hiroko Okamura, 1 Sanko Mansion, 15 Morimaecho Mibu, Nakagyoku, Kyoto 604, Japan.

Handi-Tours, a voluntary organization for travel by disabled persons in Japan is directed by Naoyuki Ishizaka. Ishizaka, quadriplegic due to muscular dystrophy, publishes Handi-Tours Inform (in Japanese), a monthly newsletter. Ishizaka, who speaks English, will be happy to advise disabled travelers planning a trip to Japan. Write Naoyuki Ishizaka, Jishshudai, Futsu, Chiba 299-16, Japan.

Magazines

Itinerary, still the best magazine for travelers with physical disabilities, is published bimonthly for an annual subscription of $7 (89 per year to Canada, $12 per year outside North America). Write Itinerary, P.O. Box 1084, Bayonne, NJ 07002.

LTD Travel is a new travel newsletter for able and disabled individuals edited by Mariam Allen-Brownson and Mary F. Smith. Subscriptions are $15 for four issues per year in U.S. and Canada, $20 per year overseas. Write LTD Travel, 116 Harbor Seal Court, San Mateo, CA 94404.

Vaccinations


Vaccination Certificate Requirements and Health Advice for International Travel, 1986 by World Health Organization, Geneva. 81 pages. $7.25 including postage from WHO Publications Center USA, 49 Sheridan Ave., Albany, NY 12210.

Van Rentals

Disabled individuals can rent vans from Vanmaster which are air-conditioned and equipped with wheelchair lifts. There are 13 locations across the U.S. For rates and locations, call 1-800-VAN RENT, or write Vanmaster, Inc., 16 Andrews Dr., W. Paterson, NJ 07424.
Aging A.M.C.

"For 60 years I have been an ambulatory quad because of arthrogryposis multiplex congenita (A.M.C.). I'm adding chapters to my unique autobiography by mouth-typing on my word processor...I'm slowing down because of aging. The 'good muscles' have had excessive lifetime use...I dread dependency as aging increases but I maintain emotional balance because I keep involved with life," Viola Henne, 2206 N.E. 88th Street, Vancouver, Washington 98665.

Pen Friends

"I had polio at the age of nine months...I have never thought of myself as disabled. I use a wheelchair. I hold a full-time job and I am involved with many meetings connected with my job and my church...I have many pen friends in the US and would like more foreign friends — especially in Australia and New Zealand. My hobbies, besides my pen and ink or tape recorder friends, are ham radio, crafts, reading and photography."
Helen O. Babier, P.O. Box 5, Dryden, Maine 04223.

"I am an above-knee amputee and have a friend, Linda, who is quadriplegic, both as a result of motor accidents. I am 30 years of age and Linda is 25. We are both very keen to correspond with other disabled people of our age group in the U.S.A." Lionel Davidson, P.O. Box 1640, Attasville, 1465, Boksburg, Transvaal, South Africa.

Czechoslovakia News

"As your 'International Adviser,' I enclose a photograph of the fifth annual Grand Prix Para Brno which took place in September 1985. There were representatives in wheelchairs from both German states, Poland, England, Yugoslavia, and Czechoslovakia...Also, in September, Rick Hansen, the Canadian who is wheeling around the world, was hailed here...In July was published the rule that limits architectural barriers in buildings, on communications, sidewalks and enables disabled persons to reach handles of windows, apparatuses in telephone boxes, mailboxes, etc."
Dr. Alja Wokoun, Chabanovicu 1333, 182 00, Praha 8, Czechoslovakia.

Pen Friends

"I have post-polio, also a spinal cord injury at T14, and I found out I have M.S. also...My hobby is writing pen pals and I have built over 110 model ships with plank on frame...I am a young 45 years, unable to work. I'm not married anymore, as my wife left me while I was in the hospital."
Eugene Clyde, 3148 N.E. 82 Street, Seattle, Washington 98115.

"I'm a very friendly, articulate, kind, young quadriplegic amputee who writes pen in mouth and wishes to meet everyone, any age, any place. I'm interested in anything positive, all types of sports and recreation." Barry Blanchette, 529½, South 71st Avenue West, Duluth, Minnesota 55811.

"We are an organization interested in improving life for senior citizens, the disabled, and other special population groups. Our vehicle is outdoor education, adventure, and travel...Our new program is a U.S./Chinese disabled persons exchange and pen-pal correspondence." Ron Bass, Wilderness Wish, 9121 S. Van Ness, Inglewood, California 90303.

"For nearly two years, I am in a wheelchair with limited contact with other people. Through your magazine, I want to correspond with some of your readers. Although I do not know English, I hope to learn to speak it." Gloria Ramirez, AA 1991 Armenia, Quindio, Colombia.
Good news!
"I finally married in October, 1985 at age 48. My wife, Karen, is a T-4 para, age 30. We were married at the Union Presbyterian Church. We are the parents of a charming daughter, Ciara... Karen was hurt in an auto accident when she was 17. She returned to high school and graduated from college... We met in 1983 when I happened by and offered to get her wheelchair from the back of her car... Some people would call this serendipity. In fact, we believe it was the will of God... Karen works as a medical secretary and I am a financial consultant at the Merrill Lynch Brooklyn office." Pete Linberg, 8124 Ridge Boulevard, Brooklyn, New York 11209.

G.I.N.I.'S
Fourth International Polio
and Independent Living
Conference
June 4-7, 1987
Sheraton Hotel
St. Louis, Missouri, U.S.A.

People with disabilities, physicians and health care professionals, and government officials from around the world are cordially invited to participate in G.I.N.I.'s Fourth International Polio & Independent Living Conference.

The purpose of the conference is to exchange information worldwide; to encourage poliomyelitis prevention, treatment, and research; and to promote independent living and community-based home support services.

If you live outside the United States and are seeking funds to attend, visit or write the United States Embassy in your country. Ask for suggestions of public and private sources of funding to contact for assistance with conference and travel expenses that include a study and information exchange tour before or after the conference. G.I.N.I. will gladly help with advice and suggestions. Send copies of your correspondence to G.I.N.I., 4502 Maryland Avenue, St. Louis, Missouri 63108, U.S.A.

Zaire Workshop Requests Help
"Dans le soucis primordial de donner des activités productives et professionnelles aux handicapés pour leur permettre de gagner dignement leur vie. Nous venons de mettre à exécution les projets des coopératives, de coordonner et couture aussi faire de l'atelier de la céramique une unité de production. Cependant ces activités nécessitent absolument de crédit enfin de les rendre opérationnelle, ou une assistance matérielle: 10 Machines à Coudre, de tissus à Confection, des Fil, 2 Moteurs à meule électriques, cuir et outillage de la Courdonière, 300 kgs d'Émaux pour la Céramique." Lwambwa Tshay K., Président de la Ligue pour l'Intégration Sociale des Handicapés et Invalides Physiques, B.P. 1908; Lubumbashi, République du Zaire.

Far right: Lwambwa Tshay Katafie in the ceramic workshop in Zaire.
Telephone Pioneers of America

Telephone Pioneers of America, a nonprofit community service organization in the U.S. and Canada, is made up of active and retired employees of telephone companies and AT&T. They provide a wide range of services and give both time and money for community service.

One such Pioneer is Al Scala of Columbus, Ohio, who developed these adaptations. Scala retired from AT&T after 32 years of service. His electronic background combined with machine and woodshop experience has been helpful in designing aids for disabled individuals. The plans for the devices and adaptations pictured here are available free from G.N.I., 4502 Maryland Ave., St. Louis, MO 63108 with a self-addressed stamped #10 envelope or write Al Scala at 1166 Ironwood Dr., Columbus, OH 43229.

Goose neck phone holder.

Cantilever phone holder.

Off hook unit for phone.
Respirators/Ventilators

Bear Medical Systems, Inc. has published a "Patient Instruction Manual" for ventilator users and their families. The manual covers the anatomy of breathing, the need for mechanical ventilation, tracheostomy and tracheostomy tubes, suctioning, infection, communication, living at home, and coping. The manual was designed to accompany Bear Medical’s New BEAR 33 Volume Ventilator. For information on ordering the manual, write Bear Medical Systems, Inc., 2085 Rustin Ave., Riverside, CA 92507 or call 1-800-331-BEAR.

Cape Warwick's new portable version of the iron lung is designed to provide nighttime breathing aid in the home. The lung will be marketed and serviced in the U.S. by Bear Medical. For specifications, write Cape Warwick Ltd., Birmingham Rd., Warwick CV34 4TX England.

Porta-Lung, developed by WS. Weingarten of Colorado, is now being marketed by LIFECARE. Porta-Lung is a non-invasive negative pressure ventilator which Weingarten claims is equal to the iron lung in providing ventilatory aid, but is 1/6 the weight, 1/3 the size, less expensive than the lung, and easier to use. The Thompson Maxivent or Monaghan 170-C are recommended for use with the Porta-Lung. Write LIFECARE, 5505 Central Ave., Boulder, CO 80301 or WS. Weingarten, 401 E. 80th Ave., Denver, CO 80229.

The Passy-Muir Tracheostomy Speaking Valve or “talking trach” allows a person with a tracheostomy to speak normally.

The adaptation fits most universal hub trach tubes, including pediatric sizes, and can be applied with a simple twist.

David Muir, a young man with muscular dystrophy who is quadriplegic and who developed the speaking valve, and Dr. Victor Passy, who has done research on the valve, claim several advantages including more natural breathing, decrease in nasal and oral secretions, improved sense of smell, improved hygiene, and less infection. Write Passy & Passy, Inc., 4321 Campus Dr., Suite 273, Irvine, CA 92715.

Communication

British Telecom's Action for Disabled Customers programme has produced an excellent Guide to Equipment and Services for Disabled Customers, 1985. The Guide is a clear and handy catalog of different equipment and services for persons with impaired hearing or vision, speech difficulties, or impaired mobility and dexterity. Write Action for Disabled Customers, Room B5049, British Telecom Center, 81 Newgate St., London EC1A 7AJ, England.

EZRA, a single switch environmental control system, designed by Ken Yankelevitz.

Easy Remote Access (EZRA), a single-switch environmental control system, allows disabled persons to control a television, radio, lights, appliances, and a call buzzer to alert an attendant. EZRA was designed by Ken Yankelevitz, a McDonnell Douglas aerospace engineer, for the United Cerebral Palsy Association of Los Angeles. EZRA includes a color television, AM/FM radio, computer operated scanning program, X-10 controller, and wireless operating switch. EZRA costs approximately $999. Write KY Enterprises, 3039 E. 2nd St., Long Beach, CA 90803.
High tech. Low worry.

One look tells you how user-friendly the new BEAR 33 Home Care Ventilator is...

No intimidating lights, dials and knobs. It’s clean and simple, with a completely sealed, splash-proof digital touch panel. So it’s easier to use, understand and maintain.

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Introducing the BEAR® 33 Home Care Ventilator. It does more...simply.
Adoption
Special Needs Adoption portfolio provides details on adoptive efforts for 33,000 disabled children who are school age, legally free, and waiting for a permanent, adoptive home. Write Dept. of Health and Human Services, Office of Human Development Services, P.O. Box 1182, Washington, D.C. 20013.

Amputees

Sislin for lower extremity amputees is a cosmetic cover for artificial legs available from Hosmer Dorrance Corp. The silicone leg skin cover closely resembles natural skin in both texture and appearance. It is elastic and supple, durable, resistant to tearing and staining, easy to clean, and does not absorb moisture. Write Hosmer Dorrance Corp., 561 Division St., Campbell, CA 95008.

Sports and Recreation for Those with Lower Limb Amputation or Impairment by Bernice Kegel, P.T. is an excellent publication from the Veterans Administration Rehabilitation R&D Service. It is Clinical Supplement No. 1 to the Journal of Rehabilitation Research and Development, Office of Technology Transfer (1531D), Veterans Administration Medical Center, 50 Irving St., NW, Washington, D.C. 20422.

Artists
Disabled Artists' Network enables professional artists with disabilities to act as a self-help bulletin board. Write Sanda Aronson, P.O. Box 20781, New York, NY 10025.

Body Awareness Training
Shake-A-Leg is a nonprofit organization providing a second phase rehabilitation program for persons with spinal cord or related injuries. Shake-A-Leg's Body Awareness Training Program is aimed at enhancing physical efficiency and spasticity control and increasing range of motion. A six-week program combines physical and aquatics therapy, psychological and nutritional counseling, personal exercise planning, Rolling, Feldenkrais, massage, and group activities. Write Shake-A-Leg, P.O. Box 1002, Newport, RI 02840.

Cerebral Palsy
Rachael, Being Five is a 28-minute case study documentary following the life of a five-year-old child with cerebral palsy for a one-year period. Another video about Rachael includes interviews with her parents, educators, and health professionals. The video programs are free of charge to regional and national groups. Write Video Services, Dept. of Physical Therapy, School of Medicine, 32 S. Greene St., Baltimore, MD 21201.

Children
Homeward Bound: Resources for Living at Home with a Chronically Ill Child by the Ventilator Assisted Care Program, Children's Hospital, New Orleans. 77 pages. 1986. $4.00 from Kathryn Kirkhart, Ph.D., Project Coordinator, VACP, Children's Hospital, 200 Henry Clay Ave., New Orleans, LA 70118. Written especially as a resource for Lousiana families, this directory is an excellent guide on the needs of the families and the necessary home support services for any family in any state.


The More We Do Together Adapting the environment for children with disabilities by the Nordic Committee on Disability in cooperation with the World Rehabilitation Fund. 84 pages. 1985. $5 from World Rehabilitation Fund, 400 E. 34th, New York, NY 10016.

Computers
Basic Computer Knowledge for Nonprofits: Everything You Need to Know Made Easy, by the National Center and the TAIF Group, presents a business-like approach to managing nonprofits and help in assessing what type of computerization might be suitable for a given agency. 825.00 from The National Center, III N. 19th St., Suite 500, Arlington, VA 22209.


Coping with Illness
... On With Living, Inc., (OWL), is a nonprofit organization with a video tape library of conversations with people who have faced chronic or life-threatening illness and developed techniques for coping. OWL video tapes provide additional insight for health care professionals and family members, as well as others with serious illness. Write Bob Schillenger, 319 E. Main St., Medford, OR 97501.
Employment
Project MATCH is a new clearinghouse linking employers in the New York City metropolitan area with recent college graduates who have physical, emotional, or learning disabilities. Located within a 50-mile radius of the city in the New York-New Jersey-Connecticut area, over 80 colleges and universities have formed a consortium to assure that disabled graduates enter the workforce as readily as their non-disabled counterparts. Write Project MATCH, Long Island University, University Plaza, Brooklyn, NY 11201.

Health Information
Toll-Free Numbers for Health Information is available free from National Health Information Clearinghouse, P.O. Box 1133, Washington, D.C. 20013. Call 1-800-336-4797.

Incontinence
Kylie Incontinent Draw Sheet is designed to keep incontinent persons dry and comfortable for long periods without disposable underpads, absorbent cotton pads and catheters. The Kylie reduces odor and the risk of bed sores. It is a washable, double-layered fabric that preserves a dry surface against the skin. Write Robert Duke, Kiwi Brands, Inc., Route 662 N., Douglasville, PA 19518.

The Simon Foundation publishes a quarterly newsletter called The Informer available for $8 per year to members. It also published Managing Incontinence: A Guide to Living with the Loss of Bladder Control, a hardcover 150-page book for $12.95. Write The Simon Foundation, P.O. Box 815, Wilmette, IL 60091.

Nancy Aunapu, who is paraplegic (T12), has taught herself female intermittent self-catheterization, and welcomes inquiries about her technique. Write Nancy at 2131 Joy Ridge Rd., Occidental, CA 95465.

Independent Living Aids
Control Data Corporation has initiated a Disability Services Division to help persons who are disabled increase their independence. A Catalog of Products and Services lists assistive equipment, special computer courses, training programs, evaluation equipment, and seminars and workshops. Write Disability Services Division, Control Data Corp., 7600 France Ave. South, Minneapolis, MN 55435 or call 1-800-828-8001.


Rural Rehabilitation Technologies Database is a catalog of innovation, inventions, and ideas to benefit disabled persons living in rural settings. Both commercial products and do-it-yourself aids and techniques are included. Developed by the Engineering Experiment Station and the Medical Center Rehabilitation Hospital in Grand Forks, North Dakota, the catalog is available free while quantities last from ICRR Headquarters, Box 8103, University Station, Grand Forks, ND 58202.

Enhanced Consumerism within Commercial Rehabilitation Product Markets: A Goal for Independent Living provides program ideas for organizations dedicated to supporting disabled individuals as consumers of rehabilitation equipment. A sample of programs are examined for the strategies used to assist consumers in product financing, information finding, training, maintenance/repair, and used equipment exchange. For a copy, write Electronic Industries Foundation/Rehabilitation Engineering Center, 1801 Pennsylvania Ave., NW, Suite 700, Washington, DC. 20006.

Medicare
Information on Medicare and Health Insurance for Older People is a clear and concise booklet on Medicare, supplemental Medicare coverage, hospice care, nursing homes, and home health services, etc. A useful checklist for Medicare gaps is included. Available to members of American Association of Retired Persons (AARP), 1909 K St., NW, Washington, D.C. 20006.

Radio
The American Radio Relay League (ARRL) is an organization devoted to promoting the advancement of amateur radio. For a copy of the ARRL Program for the Disabled, write Katherine Heyenger, WB8TDA, Coordinator, ARRL Program for the Disabled, ARRL, Newington, CT 06111.

RESNA
Rehabilitation Engineering Society of North America (RESNA) is changing its name to the Association for the Advancement of Rehabilitation Technology (AART). However, the RESNA logo will be used for the next two years. RESNA's address is still 1101 Connecticut Ave., NW, Suite 700, Washington, D.C. 20036.
Rights

Toward Independence, the special report to the President and Congress from the National Council on the Handicapped is an assessment of federal laws and programs affecting persons with disabilities. The report details current priorities in federal programs and analyzes those programs in specific areas. For information write National Council on the Handicapped, 800 Independence Ave., SW, Suite 814, Washington, D.C. 20591.

Trusts

One of the projects of AMICUS, a non-profit organization providing services to people with disabilities, is designing a special trust program to enable persons on public assistance to inherit property from family members without the unnecessary loss of their monetary, medical, and services benefits. Contact Paulette Caswell, AMICUS, PO Box 481015, Los Angeles, CA 90048.

Urinals

RESTOP, a disposable urinal for men and women, is a quart-size plastic bag attached to an oval funnel. An absorbent polymer packet solidifies urine and eliminates odor. After use, the bag can be thrown away or the polymer gel flushed down the toilet and the urinal washed for reuse. The kit comes in a small package that fits in a purse or pocket. It can be used while standing, lying down, or sitting. Available from local medical supply dealers or Star Pioneer Products, Inc., 2691 Dow Ave., Suite D, Tustin, CA 92680. Thanks to Leroy deBoom of St. Louis Park, MN for this tip.

Ventilator Parts, Wanted

Old Huxleys and parts are needed by Iris Faria, 15787 Vassar Ave., San Lorenzo, CA 94580.

Lewis Guneraman, M.D. has two old Emerson chest respirator pumps (CRV models) he is no longer using. Others who use this model might benefit from having some spare parts for their pumps. Write Guneraman, 28 Unger Lane, Pittsburgh, PA 15217.

Betty Spires, polio survivor, needs a small generator for emergency use. Contact Betty at 451 E. 300 North, Provo, UT 84601.

Ventilator Users


Wheelchairs


The Beachmaster, an aquatic wheelchair with four-inch-wide wheels, rolls over sand. The chair features a non-corrosive stainless steel frame, seat and seatback of marine grade canvas, and removable teak armrests. Approximately $1,000 each, the chairs are handcrafted by Jim Rice, Beachwheels, Inc., Building 101, Naples Airport, Naples, FL 33942.

Writers' Guide

A Readers/Writers' Guide to Disability Studies lists popular publications in the field. Copies are available for $10 from Professor Joseph L. Baird, Kent State University, Kent, OH 44242.

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Gini Laurie in China and Japan

Gini Laurie was one of several experts in rehabilitation from the United States, England, Australia, Canada, and Hong Kong invited to participate in the First International Conference on Rehabilitation of the Handicapped in the People's Republic of China. The conference was held at the Great Wall Sheraton Hotel in Beijing in January 1986.

Over 800 Chinese health professionals attended the conference, hosted by the China Welfare Fund for the Handicapped, a national social welfare organization, established in 1984 by Deng Pufang, son of China's leader, Deng Xiaoping. Deng Pufang, who is paraplegic, is Director-in-Chief of the organization.

Among the other U.S. representatives were Ted Kennedy, Jr.; John Kemp, National Easter Seal Society; Sandra Parrino, National Council on the Handicapped; Henry Betts, M.D., Rehabilitation Institute of Chicago; and Marilyn Hennessy, The Retirement Research Foundation.

After Beijing, Laurie met in Tokyo with disabled Japanese leaders including Dr. Masao Nagai, Director, Department of Psychiatry, the National Rehabilitation Centre. For the last 10 years, Nagai, who is quadriplegic, has directed the translation of the Rehabilitation Gazette into Japanese. Nagai arranged Laurie's visits to independent living centers in Tokyo and Kyoto where she lectured on the history and philosophy of the American independent living movement.

Laurie's trip was made possible by the generosity of the Sheraton St. Louis Hotel, Japan Air Lines (St. Louis), and the International School of the Sacred Heart in Tokyo.
Zhang Li, disabled since birth, is a talented writer who uses a mouthstick. She lives in the Children's Welfare Home in Beijing.

Dr. Masao Nagai, Director, Department of Psychiatry, National Rehabilitation Centre, in Tokyo, with Gini Laurie in the Hotel Otani. Dr. Nagai directs the translation of the Rehabilitation Gazette into Japanese.

Gini Laurie with Elta Yashiro, paraplegic, a Senator in the Japanese Diet.

Conference participant. Note the pull handles which operate the wheelchair.
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