

福 Rehabilitation Gazette

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

January 1992 Vol. 32, Number 1

More than ten years have elapsed since Larry Schneider wrote to the *Rehabilitation Gazette/79* (Vol. XXII) — *Those Passing Years: I* — asking readers to “submit names of doctors they might know who can easily relate medical problems to polio problems.” In *Rehabilitation Gazette/80* (Vol. XXIII) in *Those Passing Years: II*, Larry reported that “most writers seem to have made an excellent, but quite difficult, adjustment to polio ... they would like to know and exchange ideas with other polios.” This issue features *Those Passing Years: III*. 4

福 We asked Alice Mailhot to report her thoughts ten years after *Age and the Old Polio; Do the Virtuous Fade First?* (*Rehabilitation Gazette/80* (Vol. XXIII)). She responded with *Ethics and the Old Polio; Will We Survive the '90s?* 1

福 Hugh Gregory Gallagher, advocate and author, shares his thoughts about polio and *Coming to Terms*. 6

福 Susan Ray expresses concern about the *High Cost of Things Medical*. 5

In addition, we have included *Resources, Resources, Resources*.

Ethics and the Old Polio; Will We Survive the '90s?

Alice Mailhot

Well, here we are, most of us, a decade or so older and somewhat wiser.

So, how are we doing?

A few hard-heads are still busily tearing themselves limb from limb — dislocating their own joints, overworking their own muscles, pinching, stressing, poisoning their own nerves.

But most of us have realized that, however flawed, our bodies are resources to be conserved, not enemies to be destroyed. We are enjoying the world of mechanical advantage and electronic control, enjoying our middle-aged ease, serene in the knowledge that we are not lazy, but prudent.

How does it look for the future?

I have good news and bad news: WE ARE NO LONGER OUR OWN WORST ENEMIES. And it is no longer our virtues we have to fear. The “ethics” of others may do us in.

“How much health care are we obligated to provide to the elderly, the terminally ill, or the chronically ill?” asked Leonard Fleck, a medical ethicist at Michigan State University. “These are good things to do, but they are generally very expensive, and as a society we really have to decide which of these things we ought to be investing in.” (*Ann Arbor News*, May 6, 1990)

“Can something be done politically both to lower the cost of

caring for the expensive 10% (people with major health problems) and to take that cost off the shoulders of the relatively healthy 90%?” (*New York Times*, July 21, 1991) Who else is there to pay for it? Or are people with major health problems to simply disappear?

Would an “ethicist” approve your life?

“As technology’s ability to keep people alive continues to grow (as does its expense), the question of which person will be of greatest value to society will be applied in making medical decisions, according to John Kiner, a professor of medical ethics at the University of Kentucky.” (“Choosing Whom We Keep Alive: Should Life-or-Death Decisions Rest on a Patient’s ‘Social Value’?” *Issue Scan*, 1991)

There’s plenty more, but you have surely caught the gist of it. We have gone from wealth-for-the-wealthy in the '80s to health-for-the-healthy in the '90s.

You will see it in health care plans.

The impact of “ethics” is and will continue to be most visible in health care plans, which the “ethicists” propose funding out of money that would otherwise go to paying for medical care for people with serious medical problems; the elderly, the disabled, the chronically ill. If you do not spend money on really

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Ethics and the Old Polio

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sick people, you have more money to spend on people who are not so sick.

The Oregon Plan is a famous example of this sort of thinking at work. (Write to me for a summary of the priority list. But be warned; you will not like it.)

Yes. It is true that we have health care "rationing" now in the sense that some people have no coverage and others have grossly inadequate coverage. We need to solve that problem.

Unfortunately, many of the people who cannot get medically necessary health care now will not get it under the new, "ethical," rationing either, and for the same reasons: cost. If your long-term prognosis is expensive, the new rationers do not want you any more than the insurance companies do.

These issues are fairly easy to deal with. Read what is happening in your state and at the federal level. Scream bloody murder if it does not look right. Tell people. Get political.

You will see it in hospital admissions and care.

Maybe you will see it. It is a lot less visible here. You could

die before you realize what hit you.

Increasing numbers of doctors and nurses are being swayed by "ethical" considerations in deciding on hospital admissions and medical treatment. The patient-practitioner bond (and responsibility) is being supplanted by gatekeeping obligations, choices based on "social good."

We are in trouble.

We are disabled: medical costs for disabled people are four times the norm. We are getting older. Older means more medical expense. Worse yet, more and more of us are retiring, becoming "unproductive," an increasingly dangerous condition to be in.

Needing "life support" can doom you.

A respirator is a "life support." If you are on "life support," people who cannot get away with shooting you may get away with killing you by not letting you use one.

If you cannot breathe on your own, should you be alive?

Our breathing difficulties increasingly lead us to need

respirators. If you go into a hospital, can you get one? It is easier for a hospital to refuse to put you into a respirator than to get you out or to turn it off.

If you cannot eat and drink like normal people, if you get food and water through a tube — or some other "artificial" means — you are on life support. People who probably could not get away with refusing you food and drink if you could chew and swallow, may get away with starving or dehydrating you if you cannot.

Can you state your redeeming "social value"?

Are you prepared with a succinct and compelling statement of your social value, your social function, your current contribution to productivity?

Are you prepared to let a medical gatekeeper know quickly and decisively just how valuable you are and why you should be allowed to have medical care, why you should be allowed to live? ("I want to" does not count. "My relatives will sue" is a last resort; it could backfire.)

Do you have a patient advocate?

Is your advocate prepared to represent your interests? You had better have an advocate.

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

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Written by and for individuals with a disability, Rehabilitation Gazette (formerly Toomey j Gazette) has been published since 1958. Its aim is to reach, to inform, and to dignify individuals with disabilities throughout the world.

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Special thanks to: Joseph B. Leone

PUBLISHER:
Gazette International Networking Institute
(G.I.N.I.)
5100 Oakland Avenue, #206
Saint Louis, Missouri 63110 U.S.A.
314/534-0475

ANNUAL SUBSCRIPTION:
U.S.A.: Individual Consumer \$12;
Health Professional, Affiliated Individual,
Organization, Institution \$20
CANADA/MEXICO & OVERSEAS (Surface):
Individual Consumer \$14; Health
Professional, Affiliated Individual,
Organization, Institution \$22
OVERSEAS (Air): Individual Consumer \$16;
Health Professional, Affiliated Individual,
Organization, Institution \$24

January 1992
Volume 32, Number 1

ISSUED IN JANUARY AND JUNE

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Gazette International Networking
Institute 5100 Oakland Avenue, #206
Saint Louis, Missouri 63110 U.S.A.

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ISSN 0361-4166

What if you are unconscious or in great pain? The further you are from being young and able-bodied (and white, and male, and prosperous, etc.) the more it is going to take to get good medical care.

In brief, your judge (gatekeeper) needs to know that other people value your life. And if some of them are also powerful and possibly (but not certainly) litigious, do not be shy about letting people know.

Is your underwear clean?

Our mothers were right. People who show up dirty or ragged are treated dirty and ragged. The less inherent social value we have, the more we need to look valuable.

Are we done for?

Ultimately, yes, of course. Prematurely? Quite likely.

Shall we fight them for it?

I plan to.

Who is "them"?

That is a tough one. We know who some of "them" are. We do not know who all of "them" are. Some of "them" are undoubtedly treating some of "us."

We know that ethicists are influencing medical professionals as vigorously as they can, especially young professionals in the course of training. We know that young professionals are being trained to "discuss" their "ethical" views persuasively.

(We know also that not all ethicists propose the demise of the medically expensive as the first step in solving health care problems.)

We know that our tax dollars support the very people who question the value of our lives or declare that they have none. As far as I know, opposing views are not being widely and vigorously promoted. (At least not in the publications I read.) As far as I know tax dollars are not

available to those of us who would like to develop and promulgate the notion that society cannot afford "ethicists."

Well, and who are we not to go quietly?

Are we not the people who messed over our own bodies following rehab experts' orders? Are we different now? When the PhDs say "die," will we ask, "how soon?"

A lot of us are people who once bought some bad advice.

We are also people who have beaten the percentages against the disabled and found work

and hung in there. As a group, we have been more successful than people with disabilities in general. We have raised families, and participated in human affairs, and functioned as responsible members of our society.

We have another battle now.

I hope we can be responsible one more time. I hope we all know now that experts are not always right; that sometimes we have to look out for ourselves.

See you in ten years?



Alice Mailhot

"I'm still working for the State of Michigan. I would like to retire and do other things and will as soon as I can afford it and have worked out a strategy for defending an 'unproductive' existence against medical gatekeepers.

"Of course, the state economy being what it is, I could be laid off shortly and be forced to retire before I can afford it.

"Thanks to the following, I am still physically functioning:

GADGETS: I have a power chair, van with lift and power everything. Pulling a manual chair into a two-door car was messing up my neck and shoulder. As soon as I stopped doing that, the pain and stiffness stopped. (Unfortunately, these gadgets are expensive.)

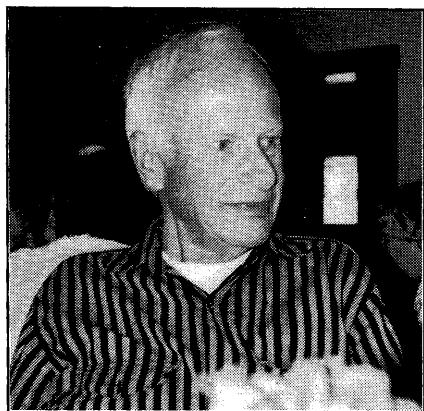
QUICK, RELIABLE REPAIR SERVICE: Both chair and van equipment repairs are available within five miles of where I work and live. Most repairs are complete the same or next day.

PUBLIC TRANSPORTATION: I use door-to-door bus service when it is too cold to drive my power chair or to scrape the windows on my van. Line buses are generally accessible and sometimes more convenient than door-to-door, which require at least a day's advance scheduling.

CONVENIENT APARTMENT: I live in a barrier-free apartment less than four blocks from work. It is kitchen to desk in 10 minutes by chair, a little more by bus. (Before I moved to Lansing, I was driving a 65-mile round trip to work.)

NEW OFFICE BUILDING: The 90% barrier-free new building has press-plate powered door openers on most of the doors that need them and completely accessible toilet stalls with doors that shut. (Killer protrusions under washstands, however,

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Those Passing Years III: 1992

Larry Schneider

SEVENTY!! I never expected to reach that age after contracting polio fifty-one years ago. It left me a quad, unable to lift either arm and partial use of my left hand.

Two years were spent in job searching before I was fortunate to begin working, mostly on the telephone, for a large company. I stayed there for 25 years, when post-polio syndrome forced me to retire. (I recently heard that one of the "problems" in my original job place was that I had to use a straw for drinking.)

I had post-polio syndrome previously explained to me as premature aging, however, medical journals indicate that there are additional factors involved.

In my case, it has been developing for over 20 years so that I can no longer stand or even wear shoes (I wear sandals). In spite of expert rehabilitation I have never been able to dress myself or go to the bathroom alone, so I constantly am on the lookout for new devices and ideas which will both assist me and the man who helps me.

Among these is a wide and easy-to-operate hospital bed to make it easier for me to be lifted from my chair. I now also use a commode wheelchair, a jet water device for cleaning my teeth, and a new shaped urinal which is more practical and easier for me. I also now need a daily laxative, and am still experimenting to find the best. I have found out that what helps one person is not suitable for another.

Several years ago I found a phone that automatically turns on after the second ring which has saved me missing many calls. (Unfortunately, the com-

pany is apparently now out of business.) After it became difficult for me to operate the dials on my bedside radio a search found an inexpensive one at a drugstore with tuning dials. So there are usually solutions.

An example of how we can be subject to change occurred a few months ago when I suddenly was unable to use my left thumb in the same manner as I had been doing since I had a muscle transplant in 1942. A few days later my fingernails were cut, and my thumb was "normal" again — apparently the slight extra weight had made the difference.

I presume that we will continue to grow weaker as we age and added to the prospects of serious illness — cancer, stroke, etc. — thoughts of euthanasia must occur from time to time, but the Hemlock Society advises that this is not the solution for quads, since we must have assistance and that would put "the helper" in trouble.

Let's smile onwards and upwards through the coming years — remembering there are usually solutions.

Alice Mailhot

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having nearly ripped my kneecaps off a couple of times. I approach with extreme caution.)

"The only way living could be easier would be if I had a butler. I take care of my own shopping and apartment and almost all other chores, paying a relative to grease the van equipment and, infrequently, to wash windows.

"The occasional muscle pains I have seldom last more than three or four days and can be considerably alleviated with Aspercreme and/or aspirin.

Generally, it is impossible to predict which muscle I will hear from next. It is like having a whimsical enemy throwing voodoo darts at my image.

"Although I wipe out occasionally, most of the time I feel fairly good.

"Now that I have the time and energy, I have been able to get involved in activities other than working, commuting, and doing chores. I am on the board of directors of the State Handicapped Association of Public Employees, interim president of our newly reactivated Lansing Area Chapter of the National Association of the Physically

Handicapped, member of the local post-polio group, and participant in a local Toastmasters group. I am enrolled in a night course at the local community college which begins mid-September.

"And I work on health care issues. I would like to hear from readers about this, especially about groups that monitor health care and/or the impact of "ethics" on it, especially groups (or individuals) who have been effective in maintaining our right to health care."

Alice Mailhot, 601 S. Butler, Apt. 4, Lansing MI 48915.

The High Cost of Things Medical

Susan Ray

After I had respiratory polio in 1952, the March of Dimes must have spent thousands of dollars on my equipment and care — a debt we have tried to repay to a small extent by helping to promote the organization and by making our own donations. The March of Dimes continued to provide me a couple of positive-pressure ventilators until I became eligible for Medicare disability coverage in 1986.

Early on my father began building most of my equipment, as he still does, which allows me to have equipment customized to my needs. It also has allowed us to be more independent of both private and government help than many families. We are also fortunate in that my father's group insurance plan covers me. My two ventilators are rented for me by Medicare and insurance funds.

We had always been concerned about the high cost of medical equipment, but since the beginning of our present leasing situation we are more keenly concerned! So the question keeps nagging me: is there anything that I and other people with disabilities can do to reduce the costs of our equipment?

HELP ME ANALYZE THE PROBLEM.

The overall issues of providing health care today are more complex than I can or even want to deal with in this article. Just within the field of medical equipment for us, the diversity of needs is probably greater than I realize. I am grateful to those who have worked to gain the government assistance programs from which I now benefit. I rejoice at all the new equipment and at the number of

companies trying to meet our needs.

But can we continue to rely on the government and others to help pay for more items of increasing sophistication without our questioning the prices? My concern is the high cost of almost everything medical — which makes us more dependent on financial help, and which may ultimately collapse our nation's ability to provide health care.

We need to know what factors contribute to equipment costs and in what proportion. I suppose that the factors include at least the following:

1. The specialized nature of such equipment.
2. The relatively small number of each item made.
3. The high quality standards that must be maintained.
4. The increasingly "hi-tech" features included.
5. The costs of maintenance and customer-service systems.
6. The rising costs of liability insurance.
7. The paperwork of dealing with government-assistance programs.

We need facts, of course, not just suppositions. A study of the factors involved in equipment costs should be made. How could we get such a study done? And by whom?

HELP ME FIND SOLUTIONS.

We who use medical equipment are in a unique position to see how factors such as those above might be changed for our benefit. While factors 2 and 3 cannot and should not be changed, our consideration of the others might be useful.

For instance, in regards to

factors 1 and 4, those among us and our daily associates who have mechanical/electronic aptitude often know how to build workable items that are relatively simple using fairly common materials and standardized parts.

As for factors 4, 5, and 6, we, the users, ought to help evaluate what risk protections are needed (such as alarms on ventilators), what customer services are worthwhile, and what systems for maintenance might work more economically. While we all want to be able to benefit from new technologies, we should help analyze which "hi-tech" features are beneficial and which are unnecessary complexities.

As for factor 7, government systems need to develop more realistic guidelines for aiding people with permanent disabilities. No doubt most medical equipment is used by people with temporary disabilities or by elderly people. But trying to fit our needs into guidelines designed for them is unfair to us and to those who supply our equipment. In the government-assistance game, our needs should be adequately met, equipment suppliers should receive fair payment, and taxpayers should be assured that payments are not excessive.

Let me share a personal example of what I think our role should be in this three-sided game. For a few years, Medicare and our insurance paid monthly rent on a humidifier for me — an amount that almost equaled its purchase price each year. Then Medicare decided, rightly I think, that such small items should be purchased for the client instead of rented. So Medicare paid the purchase price of a new humidifier for one that was at least five years old. When we finally discovered what was going on, for no one

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Thoughts from Hugh Gregory Gallagher ...

Hugh Gregory Gallagher, most known to polio survivors as the author of *FDR's Splendid Deception* (Dodd, Meade Co., 1985), was the luncheon speaker at the October, 1991 Polio Consumer Forum, Arlington, VA, sponsored by the American Academy of Physical Medicine and Rehabilitation, The Polio Society, and the National Rehabilitation Hospital. His remarks follow.

HUGH GREGORY GALLAGHER:

For whatever reason — and there are many theories — polio in the United States has always been a special sort of disease. Polio survivors, or polios as I call us, have always been independent, innovative, and assertive kind of people.

Over the years we have contributed greatly to the development of physical medicine and modern rehabilitation. Over a generation ago, polios at Warm Springs designed orthotic equipment, developed therapies still in use and pioneered function training. We are the forefathers of the disability rights movement. At Warm Springs in the 1920s and '30s polios invented independent living. "Hell, that's what we were doing," said an old timer, "We just didn't have a name for it."

When I was back in Warm Springs, researching my Roosevelt book, I talked with old Dr. Raper. He was then in his 80s and just as outspoken and feisty as he was in his 50s. "Tell me," he said, "Tell me, have you ever known a polio to be on welfare? Have you? Tell me." Well he was right. American polios have been remarkably self-reliant.

They have a remarkable record of achievement. Wheelchair using polios have included a vice president of United Airlines, a deputy director of CIA, a United States Senator, a Wagnerian soprano at the Metropolitan, a top twenty's pop singer, and Calvin Coolidge's Assistant Secretary of Commerce. My favorite wheelchair user was a bank robber described as

"armed and dangerous." And, of course, there was a certain President of the United States.

It is my theory that the eighteenth century English poet Alexander Pope was also a polio. He had a polio-like disease in his infancy and he grew up with weakened, very spindly leg muscles. Exceedingly vain, he would wear several pairs of stockings to make his calves look fuller. Dame Edith Sitwell, in what must be one of the stranger biographies of our time, claims that Pope wrote his verse in couplets because he lacked the strength to write in longer verse forms.

Be that as it may, polios are also distinctive in their demeanor. I have noticed in gatherings of polio a bonhomie and a vitality that is distinctive and most appealing. It is fun to be around polios.

Once I was back in Warm Springs for a checkup, in the 1960s, when the Foundation has begun to take in rehabilitation patients with diseases and conditions other than polio. I asked Emelie Simha, my old French teacher and herself a polio, what the new people were like. "My dear," she said, "they are not our sort at all!" So I guess we polios are snobs, too.

WARNING

DISCLAIMER AND ADVISORY

Mother always warned me about generalizations. "There you go again!" she would say. "You're generalizing!" I confess. Much of what I say today is generalization. It is based on experience, observation, impression. It speaks of the intangible

and the immeasurable. It may not be all true — valid in some cases, not in others — but there is truth to it and important truth, too.

Well, I don't know about you, but I am getting old. I sleep more, I do less, I hurt more. I now have an electric wheelchair — it is like riding around your bedroom in a little dodgem car. I whammed the bathroom door off its hinges, not once but twice.



This knowledge of ours, painfully learned, gives a unique perspective on aging. It brings us benefits and serious responsibilities.



All this is true but I do not believe the quality of my life has been diminished. Rabbi Ben Ezra said famously, "Grow old along with me! The best is yet to be; the rest of life, for which the first was lived." I wouldn't go *that far*, perhaps, but it is not all that bad.

It seems to me that polios have a certain advantage over the non-disabled when it comes to this aging business. Polios know things the non-disabled do not. Polios have, perhaps, a certain wisdom.

Many of us polios have looked death in the eye. We have known what it is to lose control, to be helpless, to suffer pain, to be terrified. And yet after all, as

William Faulkner put it, not merely to endure but to prevail.

We have known these things for all the many years since — as they used to put it back in Warm Springs — “We were struck down by the dread disease.” And of course for some of us, post-polio syndrome provides a refresher course. This knowledge of ours, painfully learned, gives a unique perspective on aging. It brings us benefits and serious responsibilities.

The benefits are of two types. The first accrues from already knowing how to live with limited mobility, limited energy, and chronic pain. We do not confuse the quality of our life with the quality of our tennis game. Happiness is not dependent upon range of activities nor is meaningful defined by trophies, titles, or things. A meaningful life may be hampered by — but it is not defined by — pain or disability.

The second benefit comes from a familiarity with death. We know death; it is not so much an enemy as it is to non-disabled people. Death is the end, but that is all it is. We know, better than most, that we need not panic over our own mortality. As we get older, as post-polio syndrome sneaks upon us, we are reminded again — and forcefully — how fragile a thing is well-being. Our understanding of the ever presence of death means that we do not defer living. If there is beauty and meaning, love and happiness, it is here, now, and nowhere else. More than most, we live in the now.

It is, as I see it, our responsibility to share this specialized knowledge of ours with non-disabled friends and family as they confront the reality that — as the Prayer Book has it — “In the midst of life we are in death.”

America's religion today is something different: it worships

youth and fitness. Eat your oat bran, avoid fat, work out on Nautilus, visit your plastic surgeon, and you will always be young, always be healthy, always invulnerable to disease, infirmity, and death — especially in California. The miracles of modern medicine, glowingly reported in the media, promise a life that is permanent and impervious to wear — like Ronald Reagan's.

When disease and death do come — as inevitably they do — they now come as a surprise. It is then that the non-disabled turn to us. It is then our turn to help them as they have helped us with our disability in the physical world.

Susan Sontag has written, “Everyone who is born holds dual citizenship in the kingdom of the well and the kingdom of the sick.” As Virgil was Dante's guide to the Underworld so, too, can we polios be guide to our families and friends as they pass through the kingdom of the sick.

This summer a close friend died of AIDS. He was young and went before his time. I understood with a profound understanding the anguish he was experiencing. He knew I understood and that I stood with him and this gave him, I think, comfort.

When my mother was dying of a brain tumor she had several months of pain, bowel and urinary problems, and physical helplessness. I was with her. “How come you can go such much faster in your wheelchair than I can go in mine?” she asked. “More practice,” I said. We were together.

And that was nice. Nice in an important way. In the hurly burly of our age it is not easy nor it is common for a person to understand the pain and fear of others and to reach out to them. Yet now, it seems to me, we polios find ourselves in a position to do just this. This is our gift, if we will use it. By so doing, we help others and we enrich and make more meaningful our own lives.



Gallagher's most recent book is *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich*, published in 1990 by

Henry Holt & Co. The book was hailed by the American Library Association Booklist as “A valuable contribution to the history of Germany ... as well as to the literature on the struggle for the rights of the disabled.”

Coming to Terms is a video documentary combining history and biography, telling the story of Hugh Gregory Gallagher who became disabled by paralytic polio in 1921 at the age of 19 and whose personal odyssey led him to confront stereotypes of the disabled and the public image of his childhood hero, adult role model, and fellow polio, President Franklin D. Roosevelt. The 56-minute film is distributed nationally by The Cinema Guild, (212/246-5522).

The High Cost of Things Medical

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had notified us, I told our equipment suppliers that they should either refund some of the money to Medicare, our insurance company, or exchange our old unit for a new one. They sent a new unit. We should be able to pay for any maintenance.

If, together, we could find more and other ways to serve our equipment needs more effectively and less expensively, then how would we get our ideas adopted?

HELP ME WORK FOR CHANGE.

I was interested to hear a television reporter say that, in looking for budget cuts, our state legislators would probably not cut programs for the "handicapped because of their well-organized political clout"! But economic changes are harder to achieve than political ones. So how could we go about trying to get lower equipment prices? Let me throw out some ideas and see what you think of them.

First, we ought to consider ourselves as consumers looking for the features we want and for the best prices. I feel the choices we would make in our best interests would also serve the interests of the taxpayers which includes many of us. Manufacturers and dealers, as well as the government, need to think of us as consumers in a free market.

Second, if a study showed that substantial price reductions are possible, we could push for them using the tools of other consumer movements — public awareness campaigns, selective buying, even protests.

However, I think a great alternative would be for equipment manufacturers and dealers to have user-advisors to help evaluate products and services and to be watchdogs of costs.

Third, I have contemplated a users' co-op to buy at manufacturers' prices. Hopefully, it would have enough buying power to ask for changes the member/customers might need.

Finally, there is one nebulous but important thing that we consumers with disabilities could definitely do: We could

begin to change the way everyone thinks about the cost of medical equipment. It seems to me that for medical equipment, like military hardware, price has been no object. The general attitude has been that these items are so special and so vital that they have to be exempt from mundane concerns such as cost. We are the best people to challenge this attitude while safeguarding our access to the equipment we must have.

I would like to know if you, the readers, share my views. I would appreciate your giving me your reactions to the following questions: Should we be concerned about the cost of our equipment even though someone else is paying the bill? Do you think a study of the factors contributing to equipment cost should be made? If so, who should do it? What do you think could or should be done to try to lower equipment prices?

Send your thoughts to:
Susan Ray, c/o G.I.N.I.,
5100 Oakland Avenue, #206,
St. Louis, MO 63110.

Grants for Farmers with Disabilities

The Cooperative Extension Service, of the U.S. Department of Agriculture, has joined with the National Easter Seal Society and other groups to establish education and assistance programs for farmers with disabilities in 10 states.

The states are Iowa, Illinois, Indiana, Louisiana, New York, Vermont, and Wisconsin. Idaho, Montana, and Wyoming are sponsoring a joint project.

The grants range from \$80,000 to \$115,000. Using a proposal review process, the Cooperative Extension Service selected

projects that will increase awareness of farm families who have members with disabilities of services available, increase their understanding of supported technology, accomplish home and worksite modifications, and establish networks of volunteers to assist families.

For more information, write to:
The Cooperative Extension Service, U.S. Department of Agriculture, Washington, DC 20250.

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We welcome items or articles for the

Rehabilitation Gazette.

Please send them to:

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PLEASE NOTE:

If you are moving, send both your old and new addresses to us because the post office will no longer forward your *Rehabilitation Gazette*.

Social Security Searches for Children with Disabilities

Social Security continues an effort to locate children with disabilities who may be eligible for benefits by enlarging the scope of its ongoing extensive initiative to locate children who may be eligible for retroactive Supplemental Security Income (SSI) disability benefits under the new rules for deter-

mining disability in children. The new rules result from the Supreme Court decision in *Sullivan v. Zebley*. Specifically, the Agency is trying to find children who either did not respond to a notice mailed in July 1991 or whose notice was returned to SSA as undeliverable.

Children potentially eligible for the retroactive benefits include those whose disability claims were denied for medical reasons or whose benefits were stopped between January 1980 and February 1990, even if they now are older than age 18. The message from Social Security is: If you did not receive a notice but think you or your child may be eligible, check with any Social Security office for information about what action you need to take to request a review.

Social Security Encourages Individuals to Develop Plans to Achieve Self-Support

The Social Security Administration (SSA) has added a new dimension to its programs for people with disabilities. The Agency is encouraging them to develop a PASS (Plan for Achieving Self-Support) an action that could have double significance.

If you are receiving Supplemental Security Income (SSI), a PASS may permit you to receive an increase in your monthly SSI payment. And, the PASS itself can be a stepping stone on the road to returning to or beginning work. If you are not currently eligible for SSI, a PASS may mean you will be able to qualify for SSI payments.

How It Works ...

Under an approved PASS, you can set aside income and/or resources to help reach a work goal. For example, money can be set aside to start a business, go to school, purchase work-related equipment, or get training for a job. The plan must include a feasible work goal, a specific financial plan, and a limited timeframe for achieving the goal. (A plan should not last longer than three years; but, it may last up to four years if it involves school or training.) The

plan must provide for a clearly identifiable accounting of the funds that are set aside.

Exclusions under Plan ...

The funds and/or resources (such as property or equipment) set aside specifically for the PASS work goal are not counted in determining either eligibility for SSI or the payment amount. Under SSI rules, if your countable resources exceed \$2,000 (\$3,000 for a couple) you are not eligible for SSI. But with a plan, such resources may not exceed the applicable limit and you may, therefore, qualify for SSI benefits.

To determine an SSI payment reduction, the amount of monthly countable income is subtracted from the Federal benefit rate (in 1991, \$407 a month for an individual and \$610 for a couple) and any applicable federally administered optional State supplemental payments. Income set aside under an approved PASS is not deducted from the maximum SSI payment. Thus, having a plan may entitle you to higher SSI payments than would be possible without a PASS. However, the payment cannot

exceed the maximum State SSI benefit.

Some people who receive only Social Security disability benefits, and who would not otherwise be eligible for SSI, may qualify for SSI payments by setting aside income and resources under a PASS.

It's easy to set up a PASS.

Any Social Security office can provide information and help you. A vocational counselor, social worker, employer, friends, or relative also can suggest a PASS or help you develop one.

Once the plan is developed, submit it to Social Security, where it will be reviewed and you'll be advised if any changes are needed. A PASS *must* be approved by Social Security for you to be able to take advantage of these provisions.

For more information about a PASS or about any of the incentives to help people with disabilities work, call Social Security. When you call the new 800/SSA-1213, we can help by setting up an appointment with a nearby field office representative.

RESOURCES, RESOURCES, RESOURCES

AGING

American Society on Aging, 833 Market St., Suite 512, San Francisco, CA 94103 USA, publishes a bimonthly newsletter, *Aging Today*, available for \$7.50 — members; \$25.00 — non-members.

CATALOGS

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

Massachusetts Association for the Blind, Store for Independent Living, 200 Ivy Street, Brookline, MA 02146 USA (617/738-5110) publishes a catalog which is available for \$3.

A catalog of innovative products dedicated to people with vision loss available from **Ann Morris Enterprises, Inc.**, 26 Horse-shoe Lane, Levittown, NY 11756 USA (516/796-4938). This catalog is available free in large print, audio cassette, and IBM and Apple format disk. Braille edition is \$8.00.

Contact **Technical Aids & Systems for the Handicapped Inc.** (tash Inc.), 91 Station Street, Unit 1, Ajax, Ontario, L1S 3H2 CANADA (416/686-4129) for a 1992 catalogue.

To receive a copy of the **Workplace Accommodations Catalog**, which lists computer products to accommodate employees with disabilities, contact: ComputAbility Corp., 40000 Grand River, Suite 109, Novi, MI 48375 USA (800/433-8872).

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

To order **The Illustrated Directory of Handicapped Products**, send \$12.95 to IDHP, 3600 W. Timber Ct. Lawrence KS 66049 USA (913/749-1453).

Accessories to Daily Living is a catalog from Lumex/Swedish Rehab, 100 Spence St., Bay Shore, NY 11706 USA (800/645-5272).

For Fred Sammon's catalog **Enrichments**, contact P.O. Box 32, Brookfield, IL 60513 USA (800/323-5547).

For North Coast Medical, Inc.'s catalog, **After Therapy**, contact 540 Salmar Ave., Campbell, CA 95008 USA (800/821-9318).

For the **Ableware Catalog** (72-page full color), call (201/628-7600) or fax your request to (201/305-0841).

Products to assist the disabled sportsman, J.L. Pachner Ltd., 13 Via di Nola, Laguna Niguel, CA 92677 USA (714/363-9831).

Free adaptive recreation equipment catalog available from **Access to Recreation, Inc.**, 2509 E Thousand Oaks Blvd., Suite 430, Thousand Oaks, CA 91362 USA (800/634-4351).

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

Laurel Designs, 5 Laurel Ave., Belvedere, CA 94920 USA (415/435-1891).

1991-92 Accent on Living Buyer's Guide, P.O. Box 700, Bloomington, IL 61702 USA. \$12.00 plus \$1.25 shipping.

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

Adaptations: Hardware Solutions for an Independent Life-Style, 1758 Empire Central, Dallas, TX 75235 USA (800/688-1758).

For a free **Medical Line Warehouse** catalog which contains patient aids and self-help devices, call 800/247-2256 or, in Florida, 813/924-2058.

For a free **Bruce Medical Supply** catalog which contains self-help devices, write 411 Waverly Oaks Rd., P.O. Box 9166, Waltham, MA 02254 USA, or call 800/225-8446.

Sky Walker is a combination catalog/newsletter whose purpose is to inform individuals with a disability of the therapeutic value of "being outside, looking at the sky, and controlling a kite." Contact: Sky Walker, 101 Mud Creek Lane, Ronan, MT 59864 USA (406/676-5135).

To obtain a free copy of the **ECRI Winter 1992 Catalog**, contact ECRI, 5200 Butler Pike, Plymouth Meeting, PA 19462 USA (215/825-6000). ECRI is a leading independent evaluator of health care technology which keeps the healthcare community informed about the risks and benefits of medical devices, trends in healthcare standards and regulations, and environmental and occupational health and safety issues.

COMPUTER-RELATED

The **American Association for the Advancement of Science**, 1333 H Street NW, Washington, DC 20005 USA (202/326-6440) is slated to begin in April, 1992, the **Online Journal of Current Clinical Trials**. It will publish new studies within 24 hours of their peer-reviewed acceptance. The \$110.00 annual subscription includes unlimited online access to research findings. Subscribers will access the Journal with an IBM or compatible personal computer equipped with Windows 3.0 software, a modem, and two megabytes of RAM.

DELPHI, a leading provider of online services, offers the **Handicap Forum**. The

Forum provides access to an expanding database of articles discussing issues for people with disabilities. Accessible by any computer and modem, DELPHI offers continuously updated news, financial information, travel and shopping databases, and access to many public domain software libraries. Individuals interested in participating in the Handicap Forum should call DELPHI Member Services at (800/544-4005). There are two membership plans available.

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

CLASS Adaptive Technology has produced a series of programs designed for the Apple Macintosh to assist the special needs learner in the classroom and in clinical studies. Most packages priced at \$50.00 each. Contact CLASS, 16 Haverhill St., Andover, MA 01810 USA (508/475-2492).

Direct Link is a newsletter from the Center for Computer Assistance to the Disabled (C-CAD). Contact R.E.A.C.H./C-CAD, 617 Seventh Avenue, Fort Worth, TX 76104 USA. \$5/year. C-CAD's Computer User Group meets every Super Saturday at Infomart. Contact C-CAD for details.

DIRECTORIES

The **1992 Post-Polio Directory** will be available soon to survivors (\$3.00), others (\$6.00). International orders please add \$2.00. Contact: G.I.N.I., 5100 Oakland Avenue, #206, St. Louis, MO 63110 USA (314/534-0475). Please specify 1992.

The Self-Help Group Directory 1991-1992, became available September, 1991. Send \$20.00 to: NJ Self-Help Clearinghouse, attention: Directory, Saint Clares-Riverside Medical Center, Denville, NJ 07834 USA.

The Directory of Independent Living Programs will be available soon for \$8.50 from IRLU, 2323 South Shepherd, Suite 1000, Houston, TX 77019 USA (713/520-0232). Please specify 1992.

Listing of organizations working with persons with disabilities in developing countries (second edition) by Robert Rosenfeld is available in print for \$15, or on 3.5 or 5.25 disc at \$15 a copy in Paradox, Q & A, D-Base II, III, or IV, DIF-Files, and ASC II. Contact: The Hesperian Foundation, P.O. Box 1592, Palo Alto, CA 94302 USA.

Heath Resource Center publishes a **Resource Directory** which disseminates information about disability issues in post secondary education. Single copy of Heath publications is free. Contact: Heath, 1 Dupont Circle, Suite 800, Washington, DC 20036-1193 (800/544-3284).

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

Directory of Accessible Van Rentals, Disability Book Shop, P.O. Box 129, Vancouver, WA 98666 USA (800/637-2256). \$5 postpaid.

The Complete Directory for People with Disabilities (ISBN# 0-939300-09-05) contains over 6000 entries in 17 chapters. This 600 page book was researched and published by Grey House Publishing, Pocket Knife Square, PO Box 1866, Lakeville CT 06039 USA. A 15-day review copy of this \$69.95 directory is available by calling 800/562-3129.

DISABILITY-SPECIFIC RESOURCES

The American Amputee Foundation, P.O. Box 250218, Little Rock, AR 72225 USA (501/666-9540 and 501/666-2523). National resource directory available with membership of \$25. Directory available to non-member consumers for \$12, and to non-member professionals for \$25.

The Amyotrophic Lateral Sclerosis Association, 21021 Ventura Blvd., Suite 321, Woodland Hills, CA 91364 USA (818/340-7500).

The Arachnoiditis Information and Support Network was formed in 1991. Send a business size SASE to the network, P.O. Box 1166, Ballwin, MO 63022 USA to receive a free copy of the first newsletter. Interested individuals may also call Carol Ahearn, 314/394-5741, or David Parker, 201/239-8870.

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

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

Several free brochures (child arthritis, rheumatoid arthritis, osteoarthritis, fibromyalgia, coping with fatigue, Help Your Doctor, Help Yourself) are available from your local Arthritis Foundation Chapter or call toll-free the **Arthritis Foundation Information Line** at (800/283-7800) or write Arthritis Foundation, National Office, 1314 String St., N.W., Atlanta, GA 30309 USA.

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

A National Support Group for Arthrogryposis Multiplex Congenita, PO Box 5192, Sonora, CA 95370 USA. Publishes **AVENUES** twice a year. \$7.50 donation requested.

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

The American Council of the Blind will award sixteen scholarships to outstanding blind students in 1992. All legally blind persons admitted to academic, vocational, technical and professional training programs at the post-secondary level for the 1992/93 school year are encouraged to apply. Applications are available from the ABC National Office, Attention: Veronica Braun, 1155 15th St., N.W., Suite 720, Washington DC 20005 USA (202/467-5081).

The RP (retinitis pigmentosa) Foundation Fighting Blindness, 1401 Mt. Royal Ave., Baltimore, MD 21217 USA (1/800/683-5555).

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

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

United Cerebral Palsy Associations, Governmental Activities Office, 1522 "K" St., NW, Suite 1112, Washington, DC 20005 USA (202/842-1266) publishes *Word from Washington*.

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

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

U.S.A. Fibrositis Association, Riverside Hospital North Medical Building, 3545 Olentangy River Rd., Suite 8, Columbus OH 43214 (614/262-8020).

The Fibromyalgia Association of Texas, Inc., 5650 Forest Lane, Dallas, TX 75230 USA, publishes a 40-page booklet on the basics of fibromyalgia. \$8.95 post-paid. US funds only.

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

Charcot-Marie-Tooth (known as Peroneal Muscular Atrophy or Hereditary Motor Sensory Neuropathy) Association, Crozer Mills Enterprise Center, 600 Upland Avenue, Upland, PA 19015 USA (215/499-7486). Services include newsletter, VCR rental, support group list, and a 16-page information booklet about CMT, entitled **CMT FACT**, is available for \$3 from CMT and has been distributed to 16,000 public libraries in the US. The Medical Advisory Board of the CMT Association is interested studying the effects of physical trauma upon the CMT

individual. Interested parties should contact Karol Hitt at the above address.

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

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

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

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

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

Epilepsy Foundation of America, National Headquarters, 4351 Garden City Drive, Landover, MD 20785 (301/459-3700).

Huntington's Disease Society of America, Inc., 140 West 22nd Street, 6th Floor, New York, NY 10011-2420 USA (212/242-1968). For a list of written and audio/visual materials call the toll free HD information line (800/345-HDSA). **Carling for Persons with Huntington's Disease** may be obtained at a cost of \$15 per copy plus \$3 shipping and handling.

National Multiple Sclerosis Society-toll-free information line (800/624-8236).

Multiple Sclerosis Society of Canada, 250 Bloor St. E., Suite 820, Toronto, Ontario M4W 3P9 CANADA.

Muscular Dystrophy Association, National Headquarters, 3561 East Sunrise Dr., Tucson, AZ 85718 USA (602/529-2000).

Society for Muscular Dystrophy Information International, P.O. Box 479, Bridgewater, Nova Scotia, B4V 2X6 CANADA. Quarterly newsletter available with an annual donation.

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

Osteogenesis Imperfecta Foundation, Inc., P.O. Box 24776, Tampa, FL 33623-4776 USA. Basic membership is \$15.

International Polio Network, 5100 Oakland Ave., #206, St. Louis, MO 63110 USA (314/534-0475) publishes **Pollo Network News**. \$12 consumers, \$20 others.

Short Stature Foundation, Inc., 17200 Jamboree Blvd., Suite J, Irving, CA 92714

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Resources

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USA has established a new 800 number telephone helpline. Call 800/24DWARF.

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

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

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

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

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

EDUCATION

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

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

EMPLOYMENT

The **Job Accommodation Network** is an international information network and consulting resource to enable qualified workers with disabilities to be hired or retained. It brings together information from many sources about practical ways of making accommodations for employees and applicants with disabilities. As a service of The President's Committee on Employment of People with Disabilities, JAN is available via a toll-free number (800/JAN-7234 in the U.S.; 800/JAN-CANA in Canada and 800/DIAL-JAN for computer/modem). For written information about JAN, write West Virginia University, Job Accommodation Network, P.O. Box 6123, Morgantown, WV 26506-6123 USA.

The Workplace Workbook: An Illustrated Guide to Job Accommodation and Assistive

Technology by James Mueller is available from RESNA Press, Department 4813, Washington, D.C. 20061-4813 USA (202/857-1199). 109 pages, including over 40 detailed illustrations and instructions, \$32.

Breaking New Ground (A newsletter for farmers with physical disabilities). Breaking New Ground Resource Center, 1146 Department of Agricultural Engineering, Purdue University, West Lafayette, IN 47907-1146 USA.

An Employer's Guide to Eldercare, the first of three publications provides up-to-date information for corporations interested in exploring options for employees with eldercare responsibilities. Copies of the Guide are available for \$18 from the Washington Business Group on Health, 777 N. Capitol St., N.E., Washington, DC 20002 (202/408-9320)

INTERNATIONAL

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

Interchange: a publication of the International Exchange of Experts and Information in Rehabilitation (IEEIR), a project funded by the National Institute of Disability and Rehabilitation Research to the World Rehabilitation Fund, Inc. The purpose of the IEEIR is to provide opportunities for the U.S. disability community to become more aware of developments in Asia, the Pacific, and Africa through fellowships awarded to U.S. disability specialists, through publications prepared by foreign experts, and through conferences and meetings. This newsletter is another way of sharing information about the IEEIR. For more about the Project, write or call IEEIR c/o Institute on Disability, 6 Hood House, University of New Hampshire, Durham, NH 03824 USA (603/862-4767).

World Institute On Disability (WID), 510 16th Street, Oakland, CA 94612 USA (415/763-4100). WID is a public policy center that is run by persons with disabilities and was established to combat "handicappism." Their goal is to use research, public education, training and model program development as means to create a more accessible and supportive society for all people.

International Center for the Disabled, 340 E. 24th St., New York, NY 10010 USA (212/679-0100) now has copies of the ICD Survey III "A Report Card on Special Education" for \$15.00 plus \$2.00 postage and handling. Copies of the first two national surveys are also in stock "Bringing Disabled Americans Into The Mainstream" and "Employing Disabled

Americans." They may be obtained from ICD at \$10.00 per report, plus \$2.00 for postage and handling.

NATIONAL RESOURCES

Independent Living Research Utilization (ILRU), 2323 South Shepherd, Suite 1000, Houston, TX 77019 USA (713/520-0232; 520-5136 TDD).

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

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

National Rehabilitation Association, 1910 Association Dr., #205, Reston, VA 22091-1502 USA. Membership information available.

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

The President's Committee on Employment of People with Disabilities, 1331 F Street, N.W., Suite 636, Washington, D.C. 20004-1107 USA (202/376-6200 Voice and 202/736-6205 TDD). **Tips and Trends** is the complimentary publication of the Committee.

NISH: creating employment opportunities for people with severe disabilities, 2235 Cedar Lane, Vienna, VA 22182-5200 USA (703/560-6800 Voice and 703/560-6512 TDD). Incorporated in 1974, NISH creates employment for people with severe disabilities under Public Law 92-28, the Javits-Wagner-O'Day Act. It does this by helping Work Centers identify and perform contracts to manufacture products or perform services for the government, thereby providing jobs for individuals whose disabilities have prevented them from finding employment in the competitive marketplace.

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

National Council on Disability (NCD), 800 Independence Avenue, S.W., Suite 814, Washington, D.C. 20591 USA (202/267-3846 voice and 202/267-3232 TDD). **Focus** is available free-of-charge. The National Council on Disability is an independent federal agency of 15 members appointed by the President and confirmed by the Senate. The NCD reviews all federal laws, programs, and policies affecting Americans with disabilities. The National Council has developed **ADA Watch**. It gathers information related to the

implementation and impact of the ADA and disseminates it. The ADA Watch will operate a multi-line, toll-free 800 number which is not yet functional, however, people with disabilities are the eyes and ears of ADA Watch, so if you have any information about effective ADA implementation initiatives which are underway, or in the planning stages, or about areas where you anticipate disregard for the law, we urge you to pass them along via the mail. Write to ADA Watch, National Council on Disability c/o Robert T. Kramer and Associates, Inc., 705 Melvin Ave., Suite 201, Annapolis, MD 21401 USA

National Rural Health Association (NRHA), 301 E. Armour Blvd., Suite 420, Kansas City, MO 64111 USA (816/756-3140). NRHA is a national, non-profit membership organization whose primary mission is to improve the health and health care of rural Americans.

National Association of the Physically Handicapped, Inc., 4230 Emerick St., Saginaw, MI 48603 USA (517/792-4672). Membership of \$10.00 includes a national newsletter. An organization with membership consisting of individuals with all types of disabilities.

PERIODICALS

Rehabilitation Digest is published quarterly by The Canadian Rehabilitation Council, 45 Sheppard Ave., E, Suite 801, Toronto, Ontario M2N 5W9 CANADA (416/250-7490). Domestic \$19.00; outside Canada \$22.00.

International Journal of Rehabilitation Research, editor Paul Cornes, is a quarterly, peer reviewed interdisciplinary forum for the publication of research into disability and handicap experience by people of all ages in both developed and developing societies. Sample copy and rate request should be sent to (USA/Canada) Journals Promotion Dept., Chapman & Hall, 29th West 35th St., New York, NY 10001-2291 USA; (Rest of World) Journals Promotion Dept., Chapman & Hall, 2-6 Boundary Row, London SE1 8HN United Kingdom.

KALEIDOSCOPE: International Magazine of Literature, Fine Arts and Disability, 326 Locust Street, Akron, OH 44302-1876 USA (216/762-9755 and 216/379-3349 TDD). Bi-annual: \$9.00 individual; \$12.00 institutional. Add \$5.00 for Canadian and \$8.00 for international. Upcoming issue will focus on "Disability and the Family" with an editorial deadline of March 1, 1992.

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

Different Times, an independent disability rights advocacy newspaper, 2600 N.E. 125th, No. 4, Seattle, WA 98125 USA. 14 issues, \$20.00.

The Disability Rag, Box 145, Louisville, KY

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

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

In The Mainstream, 1030 15th St., NW, Suite 1010, Washington, DC 20005 USA (202/898-1400). Subscription, \$20.

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

Mainstream, a magazine for the able-disabled, P.O. Box 370598, San Diego, CA 92137-0598 USA, published monthly except in January and June, \$16.98/1 year; \$32/2 years.

Disability Now, published by The Spastic Society, 12 Park Crescent, London W1N 4EQ ENGLAND. Monthly, 10 pounds.

Spinal Network Extra, P.O. Box 4162, Boulder, CO 80306 USA. Subscription \$15.

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

Independent Living, published by the Independent Living Center, New South Wales, P.O. Box 706, Ryde, NSW 2112 Australia. Subscription \$A22, \$A34 all other countries airmail.

Fibromyalgia Network is a quarterly newsletter developed to news about fibromyalgia/fibrositis. A one-year subscription is \$12. A complimentary copy is available on request. For more information, contact Fibromyalgia Network, 7001 School House Lane, Bakersfield, CA 93309.

PUBLICATIONS

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

Continence with Biofeedback by Susan Trunnell provides a comprehensive literary review and discussion of the medical problems and therapy essential to the management of organic fecal incontinence. Available from Advantage Publications, P.O. Box 489, Carmichael, CA 95609 USA (916/944-7454) for \$24.95.

How to be a Friend to the Handicapped, a handbook and guide by Leslie D. Park, educates non-disabled people by providing concrete information and ideas as to how people with disabilities can be assisted. Available from Life Services for the Handicapped, Inc., 352 Park Ave. S., Suite 703, New York, NY 10010 USA (212/420-1500) for \$13.95.

Disability in America: Toward a National Agenda for Prevention was written by The Institute of Medicine at the request of The Centers for Disease Control and The National Council on Disability. The report focuses on preventing conditions that

potentially lead to disability, preventing the occurrence of secondary conditions in persons with disabilities, and minimizing the effect of such conditions on productivity and quality of life. Copies are available National Academy Press, 2101 Constitution Ave., N.W., Washington, DC 20055 USA for \$29.95 plus \$3.00 shipping and handling.

Perspectives on Disability — Text and Readings, Mark Nagler, PhD, editor. A 666-page resource for understanding disability. For more information, contact Health Market Research, 851 Moana Court, Palo Alto, CA 94306 (415/948-1960). Cloth, \$75.00; paperback, \$60.00. Shipping US and Canada add 10%; other countries add 20%.

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

Out of the Corner of My Eye: Living with Vision Loss in Later Life by Nicolette Pernod Ringgold offers practical advice about adjusting to blindness and to encourage other elderly persons to seek services which enable them to stay active. Available on audio cassette as well as large print for \$14.95 plus \$3.00 shipping and handling from The American Foundation for the Blind, 15 West 16th St., New York, NY 10011 USA (212/620-2155).

Picking up the Pieces by Barbara Hansen is a resource to help people deal with difficult situations. The book focuses on the grieving process and what role active participation plays in the world of grief. For more information call 800/677-2800.

Pride Against Prejudice by Jenny Morris. Drawing on her own and others experiences of disability, she confronts the nature of the prejudice against people with disabilities. Available from The Women's Press, 34 Great Sutton St., London EC1V 0DX England.

Self-Help: Concept and Application is a 336-page book written by 46 contributors and editors. The Charles Press, P.O. Box 15715, Philadelphia, PA 19103 USA (215/925-3995). Paperback only, \$21.95.

Reaching Out to All People with Disabilities: A Guide for Consumer and Provider Organizations. The Guide highlights ways to reach people with disabilities who may vary in age, geographical location, or cultural background. The Guide begins with the essentials for an outreach plan. Then it describes the information needs and sources of different target audiences. The next section discusses varied outreach strategies ranging from no cost strategies to corporation-sponsored strategies. To help special populations fit into your organization, follow the tips for educating current members and facilitating assimilation of potential members. The final section briefly outlines ways to work with

Resources

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other organizations in collaborative outreach. Contact National Clearinghouse on Rehabilitation Training Materials, Oklahoma State University, 816 W. 6th St., Stillwater, OK 74078-0435 USA (405/624-7650). Available for a nominal fee.

RARE OR GENETIC DISEASES

National Organization for Rare Diseases (NORD) is a non-profit voluntary health organization dedicated to the prevention, control, and cure of rare "orphan diseases." Reprints of disease articles from NORD's Rare Disease Database are available for \$2.50 per copy. Contact: NORD Literature, P.O. Box 8923, New Fairfield, CT 06812 USA. NORD Services may be accessed on your personal computer by typing "GO NORD" at any prompt on the CompuServe Information System.

RIGHTS

Council for Disability Rights (CDR), 208 S. LaSalle, Suite 1330, Chicago, IL 60604 USA (312/444-9484). Membership of \$10 includes a monthly newsletter.

The National Disability Action Center, 1101 15th St., N.W., Suite 1215, Washington, D.C. 20005 USA (202/775-9231 voice/TDD). Organization dedicated to protecting the civil rights of people with disabilities.

ADAPT — American Disabled for Attendant Programs Today (formerly American Disabled for Accessible Public Transit), 12 Broadway, Denver, CO 80203 USA (303/733-9324 voice/TDD).

The Legal Aid Society of San Francisco, Employment Law Center, 1663 Mission St., Suite 400, San Francisco, CA 94103 USA (415/864-8848) publishes *Access to Employment*.

Committee for the Rights of the Disabled, 2487 W. Washington Blvd., Los Angeles, CA 90018 USA (213/731-8591) is a membership organization concerned about the rights of people with disabilities.

SHOES

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

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

SOCIAL SECURITY

Personal service available from the **Social Security Administration** from 7 a.m. to 7 p.m. each business day. Call (800/SSA-1213 or 800/772-1213).

Disability Workbook for Social Security Applicants: Managing Your Application for Social Security Disability Insurance Benefits (1990) by Douglas M. Smith, Attorney at Law is now available for \$14.95 plus \$3.95 shipping from Physicians' Disability Services, 1460 Ritchie Highway, Arnold, MD 21012 USA (301/974-1111). The booklet contains the appropriate information along with worksheets to assist in documenting and organizing a claim.

SPORTS AND RECREATION

United States Association for Blind Athletes, 33 N. Institute, Colorado Springs, CO 80903 USA (719/630-0422).

National Wheelchair Basketball Association, 110 Seaton Building, University of Kentucky, Lexington, KY 40506 USA (606/257-1623).

North American Riding for the Handicapped Association, Inc., P.O. Box 33150, Denver, CO 80233 USA (303/452-1212).

International Wheelchair Tennis Federation, 940 Calle Amanecer, Suite B, San Clemente, CA 92672 USA (714/361/6811).

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

Handicapped Scuba Association, 116 W. El Portal, Suite 104, San Clemente, CA 92672 USA (714/498-6128).

Wheelchair Athletics of the USA, 1475 West Gray, #161, Houston, TX 77019 USA (713/522-9769).

National Wheelchair Athletic Association, 3595 East Fountain Blvd., Suite L-10, Colorado Springs, CO 80910 USA (719/574-1150)

The 52 Association for the Handicapped, Inc., Washington Capital Division, 1813 24th St., South, Arlington VA 22202 USA (703/892-1985). Non-profit organization dedicated to providing people with disabilities sports and recreation opportunities.

Wilderness Inquiry, 1313 5th St., SE, Box 84, Minneapolis, MN 55414 USA (612/379-3858 or 800/728-0719), offers winter wilderness activities for all without regard to ability. Contact them for the 1992 winter adventure schedule.

TECHNOLOGY

Technical Aid to the Disabled Journal is the official journal of Technical Aid to the Disabled (TAD), 227 Morrison Road, (P.O. Box 108), Ryde, NSW 2112 AUSTRALIA (02 809 7670). TAD is a voluntary

organization dedicated to designing and making aids for people with disabilities when such aids are unavailable commercially. \$10 in Australia; \$30 Aus for overseas airmail.

Technical Aids & Systems for the Handicapped Inc., 91 Station St., Unit 1, Ajax, Ontario, CANADA L1S 3H2 (416/686-4129).

Technology to Assist Persons with Disabilities is a national information system which provides free information about resources in your state. Call (1/800/922-9234 Ext. 301) or in South Carolina (1/800/922-1107).

TRAVEL

Mobility International USA, P.O. Box 3551, Eugene, OR 97403 USA (503/343-1284) promotes and facilitates international exchange and recreational travel experiences for people with disabilities. Membership: \$20/year individual; \$25/year non-profit organization. Contact MIUSA for a listing of videos depicting groups of young travellers with disabilities.

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

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

For information on travel services for people with disabilities contact the **Society for the Advancement of Travel for the Handicapped**, 347 Fifth Ave., Suite 610, New York, NY 10016 USA (212/447-7284), and the **Travel Information Service of the Moss Rehabilitation Hospital**, 1200 W. Tabor Rd., Philadelphia, PA 19491 USA (215/456-9600).

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

New Directions for People with Disabilities, Inc., 5276 Hollister Ave., #207, Santa Barbara, CA 93111 USA (805/967-2841) is a non-profit public benefit corporation which provides leisure and educational travel programs for individuals or groups.

Travelin' Talk, P.O. Box 3534, Clarksville, TN 37043-3534 USA (615/552-6670) is an information network providing assistance to travelers with a disability.

Travelin' Talk and CMT International (1 Springbank Dr., St. Catharines, Ontario, Canada L2S 2K1) are selling "**Ability Alert**" 4x5 cards that show the international symbol of accessibility surrounded by attention-grabbing red flames and is filled out by guests with disabilities and

handed to the clerks to remind them of the assistance they might need in event of fire or other emergency. On the card are spaces for the guest's name, room number, dates of stay, and assistance they might need because of their disability such as inability to use stairs, hear emergency sirens, or see flashing alarms. Send \$6.00 in the currency of either USA or Canada to purchase 12 cards. No phone orders.

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

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

Travel for the Disabled by Helen Hecker. The Disability Bookshop, P.O. Box 129, Vancouver, WA 98666-0129 USA, or (800/637-2256). \$19.95 plus \$2.00 shipping.

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

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

Access America, a free quarterly newsletter published by the U.S. Architectural and Transportation Barriers Compliance Board (ATBCB), 1111 18th Street, N.W., Suite 501, Washington, D.C. 20036-3894 USA (800/USA-ABLE voice and TDD), provides information about the ATBCB and its activities. This is the same address used to file a complaint about building or facility access. The ATBCB also offers answers to questions relating to the Americans with Disabilities Act by calling the above 800 number.

VENTILATORS

International Ventilator Users Network publishes *I.V.U.N. News*, 5100 Oakland Ave., #206, St. Louis, MO 63110 USA (314/534-0475). \$8 for consumers, \$20 for others. If you are a ventilator user who has not filled out the I.V.U.N. Survey, please contact the above address.

To receive a copy of the **Ventilation Assisted Children's Center (VACC) Camp Program Guide**, contact: Cathy Klein, VACC Program Coordinator, Miami Children's Hospital, Division of Pulmonology, 3200 S.W. 60th Court, Suite 203, Miami, FL 33155 USA (305/662-VACC).

Pediatric Users Network, Jan Nelson, Aequitron Medical, 14800 28th Avenue North, Minneapolis, MN 55447 (800/824-7203).

YOUTH, FAMILIES, AND DISABILITY

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

National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, D.C. 20013 USA (800/999-5599). **Transition Summary** published September, 1991, features "options after high school for youths with disabilities." Single copies are free. Call for a complete publication list.

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

7910 Woodmont Avenue, Suite 460
Bethesda, MD 20814
(301) 657-8401
1-800-366-2223 (CCCF) free
FAX (301) 718-2686

The Beach Center on Families and Disability, a federally funded research and training center in the United States with an exclusive focus on families whose members have disabilities. For more information contact: Beach Center on Families and Disability, Bureau of Child Research, 4138, KS 66045 USA (913/864-7600).

Portland State University, **Research and Training Center On Family Support and Children's Mental Health**, P.O. Box 751, Portland OR 97207-0751 USA (503/725-4040). Call for a list of publications.

Joni and Friends, P.O. Box 3333, Agoura Hills, CA 91301 USA (818/707/5664) a non-profit organization that seeks to accelerate Christian ministry within the disability community, is sponsoring three family retreats for families with a member with a disability. For more information contact the above address.

To receive "**Hearing Alert!**" and "**Is My Baby's Hearing Normal?**" send a stamped addressed envelope SASE to Baby's Hearing, American Academy of Otolaryngology — Head and Neck Surgery, 1 Prince St., Alexandria, VA 22314 USA (800/255-4817).

To receive a free copy of a 24-page, full colored booklet designed for young children with disabilities to teach them to care for their mouth and teeth entitled "**Ronald McDonald Camp Fun-to-Brush**," write Ronald McDonald Camp Fun-to-Brush, University of Mississippi Medical Center, School of Dentistry, 2500 N. State St., Jackson MS 39216 USA.

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

payable to DIA-WWUDU.

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

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

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

VIDEOS

The Library Video Network in conjunction with the American Library Association has produced "**People First: Serving and Employing People with Disabilities**." The videotape outlines common-sense basics for serving people with disabilities. Cost of the videotape is \$130.00 and running time is 38 minutes. For more information, please call the Library Video Network (301/887-1373).

What of Tomorrow? is a video about two people with cerebral palsy who are shown leading independent lives. This 28-minute video costs \$39.95. Contact Sun Coast Media, Inc., 11801-6 28th St. N., St. Petersburg, FL USA 33716 (800/899-1008).

Wierded Out and Blown Away is a documentary which questions the general public's attitudes toward physical disability and challenges our perception of the disabled as somehow either weaker or more courageous than the non-disabled. It offers an insider's view on the subject in that its director, Sharon Greytak, uses a wheelchair. The film interweaves interviews with five young career people who have disabilities. The film does not try to generate sympathy, or to create heroes and heroines triumphing over their conditions, but instead simply tries to show the common ground shared by both disabled and non-disabled people. For further information or a complete catalog, write The Cinema Guild, 1697 Broadway, New York, NY 10019 USA (212/246-5522). Rental \$70.00; purchase video \$395.00.

Nobody Is Burning Wheelchairs is a 15-minute tape which explains the ADA's provision for equal access to employment, transportation, and telecommunications. For more information about this \$35.00 video, contact The National Easter Seal Society, 70 E. Lake St., Chicago, IL 60601 USA (312/726-6200)

Coming to Terms is a documentary combining history and biography, telling the story of Hugh Gregory Gallagher whose personal odyssey led him to confront stereotypes of the disabled. The 56-minute film is distributed nationally by The Cinema Guild, 1697 Broadway, New York, NY 10019 USA (212/246-5522). For sale, \$350. Rental, \$95.



Our label form is being changed to include the month your subscription is due.

American with Disabilities Act Fact Sheet

As the originator of the Americans with Disabilities Act of 1990 (P.L. 101-336), the National Council on Disability provides this edited version of the ADA Fact Sheet.

Employment

Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.

Employers can ask about one's ability to perform a job, but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities.

Employers will need to provide "reasonable accommodation" to individuals with disabilities. This includes steps such as job restructuring and modification of equipment.

Employers do not need to provide accommodations that impose an "undue hardship" on business operations.

Who needs to comply:

- All employers with 25 or more employees must comply, effective July 26, 1992.
- All employers with 15-24 employees must comply, effective July 26, 1994.

Transportation

New public transit buses ordered after August 26, 1990, must be accessible to individuals with disabilities.

Transit authorities must provide comparable para-transit or other special transportation services to individuals with disabilities who cannot use fixed route bus service, unless an undue burden would result.

Existing rail systems must have one accessible car per train by July 26, 1995.

New rail cars ordered after August 26, 1990, must be accessible.

New bus and train stations must be accessible.

Key stations in rapid, light, and commuter rail

systems must be made accessible by July 26, 1993, with extensions up to 20 years for commuter rail (30 years for rapid and light rail).

All existing Amtrak stations must be accessible by July 26, 2010.

Public Accommodations

Private entities such as restaurants, hotels, and retail stores may not discriminate against individuals with disabilities, effective January 26, 1992.

Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.

Physical barriers in existing facilities must be removed, if removal is readily achievable. If not, alternative methods of providing the services must be offered, if they are readily achievable.

All new construction and alterations of facilities must be accessible.

State and Local Governments

State and local governments may not discriminate against qualified individuals with disabilities.

All government facilities, services, and communications must be accessible consistent with the requirements of Section 504 of the Rehabilitation Act of 1973.

Telecommunications

Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices, effective July 26, 1993.