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by and for Persons with a Disability

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What Really Limits Us? — Elevating Everyone's Expectations

"What Really Limits Us? — Elevating Everyone's Expectations" was one topic of discussion during the Fifth International Polio & Independent Living Conference held in Saint Louis, Missouri, May 31-June 4, 1989.

Richard Goodwin, the Executive Director of IMPACT, an independent living center in Alton, Illinois, presented the following paper entitled "Disability as a Social Role." *Max Starkloff, Speed Davis, Cyndi Jones, Jim deJong, Carol Rowse, and August Rüggeberg* then reacted to his premise.

Disability as a Social Role

The history of people with a disability in America has never been studied or written about in any methodical, comprehensive fashion. There have been writings published regarding specific disabilities in history and specific approaches such as people with a disability in literature, but no comprehensive writing regarding what it means to become disabled in America has ever been published.

It is difficult to extrapolate what actually limits people with disabilities given the dearth of an historical perspective. However, the independent living movement has focused on disability as a role in society and how the expectations associated with that role are terribly restrictive, patronizing, and essentially offer little hope of living a full and productive life.

A social role, defined simply, is a grouping of expectations. Any role that you can think of, whether son, mother, doctor, friend, or second baseman, consists of numerous expectations. The disability role is fraught with restrictive, negative expect-

tations which lead a person to believe that life must be miserable and extremely limiting. Some of the expectations associated with the disability role include the following:

- you are sick
- you need to be taken care of and should not live alone
- you cannot work
- it is in your best interest to exclude you from your age and community peers in the educational process
- you do not have an inalienable human right to fully participate in your community
- you will be perpetually depressed about your lot in life
- your travel needs will be vastly different from the general public
- you are asexual

These expectations are reinforced by American policies and laws which provide vast amounts of funding to support us in the dependent, low status, separated, un-American, archaic, patronizing disability role. The disability role is, of course, an ascribed role that we do not choose to enter. However, society makes it very

difficult to break out of the disability role because often the power of American law requires that we be limited in our options. Those who do manage to rise above the disability role are thought to be brave and heroic, when in reality they are simply seeking to live a normal American life in the face of discriminatory, restrictive policies and laws.

The disability role is the logical extension of the archaic notions and prejudices which Americans have come to accept as facts regarding people with

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disabilities. Most Americans never interact with persons with a disability on a peer level and are not even likely to be in the mere co-presence of persons with a disability due to the fact that historically persons with a disability have been kept out of the mainstream of American life. Even today it remains the exception for a child with a severe disability to be educated with his or her age and community peers. No wonder Americans carry with them archaic notions regarding what it means to have a disability.

Our laws, regulations, and policies essentially preclude face to face interaction between disabled and non-disabled children, and yesterday's children are today's legislators, personnel directors, teachers, and bureaucrats. It is important to highlight the fact that those of us who become disabled and those of us who become parents of children with a disability are fraught with the archaic notions we have tacitly accepted as fact. There is nothing more important than educating persons with disabilities and their parents that a disability can be effectively managed, and that people must raise their

expectations as to what it is possible to accomplish as a person with a disability. Accepting society's ascribed disability role is equivalent to compliance with a life of limited options, depression, exclusion, and isolation.

People with disabilities achieve less, earn less money, have less education, more poverty, less health care, less transportation options, enjoy social/recreational activities less, are less politically active, and receive prejudicial treatment routinely. The disability role, when perpetuated at the community level, results in restrictive policies and laws which limit fully integrated community participation of people with disabilities in every social context and every type of disability is affected, whether physical, mental, or sensory. Additionally, when disability happens to an individual, acceptance of the disability role as your lot in life correlates with low achievement, low self-esteem, and inability to manage and cope with life with a disability.

Promoting full community participation of people with disabilities is an issue involving social, political, social/psychological, moral, economic, and legal issues. Strategies for

social inclusion of people with disabilities must effectively influence a broad spectrum of societal entities.

DICK GOODWIN: After a spinal cord injury in 1967, people expected certain things of me — I was sick, I needed to be taken care of and the other "expectations" mentioned above. It's important to note that if people buy into all of these negative, restrictive expectations, they sentence themselves to a life of living up to the expectations.

One need not accept that as life. Centers for independent living attempt to raise people's expectations, so they don't accept society's projected social role.

I think that everybody on the panel would agree that one can live a full and productive life, whether one is in a chair, deaf, or blind. But society's perceptions and what society projects is that people with disabilities belong outside of the mainstream.

In the Saint Louis area, we have the Special School District — a school district set up to deal with disability. The expectation is that if you are a child with a disability, it's not in your best interest to be educated with your peers but in your best

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interest to be taken out of that environment and put into an environment of people who are "like you." This is just one policy that tends to perpetuate the disability role and the expectation that we are to be excluded, limited in our choices, and not a part of the mainstream of society.

I'm going to ask members of the panel to respond to or add any perspective that they think is important in terms of what limits people with a disability.

MAX STARKLOFF, President, Paraquad, Inc., Saint Louis, Missouri: I agree with the paper that Dick has written. What we need to look at is the solutions. There are so many issues to deal with that sometimes they are very fragmented. We need to bring this all into focus. We need to expand awareness to the level of the community and then start to organize at the grass-roots level.

We need to make people aware that they're being discriminated against. Most people with disabilities don't realize it. I think the apathy, or maybe it's despair, people have felt is a result of believing that their way of life is the only way they can live. We've got to make people realize that that is not true and even make them angry — angry enough to speak out.

I don't think we're organized well enough to get people to speak out to their representatives in government and to the other power people in their communities. I think that if we were organized in our communities to start speaking out in large numbers, congressional leaders would start listening to us. The only reason they haven't listened is that they haven't realized that we are a large voting block. Until we speak out, nobody is going to realize that.

We also need to develop "brain trusts or think tanks" where leaders of this movement can start to address all of the issues in an organized way. We need to develop papers that can be distributed to our congressional leaders in a way that they start to listen to us. We also need to realize that there are large numbers of people who support our positions.

We have to be very careful not to fall back on economics. Economics was never an issue until the Reagan administration, and then, all of a sudden, we started addressing all of our problems in an economic way. We don't really know what the economics of the movement is. When we start to talk about economics, we lose the civil rights aspect. We lose the idea of equality, forget about human rights, or what is the "right thing to do." We need to put leaders' minds together along with grass-roots organizations and start to study the problem more effectively. Then we can start to address the issues that Dick very succinctly stated in his paper.

SPEED DAVIS, Assistant Director, Massachusetts Office on Handicapped Affairs, Boston, Massachusetts: I read Dick's paper, said "He's right," and then put it down. Later in thinking about the approach I would take, I thought about other groups in the United States. The United States is a melting pot where wave after wave of different people arrived on our shores and somehow, for the most part, have been able to work their way into society. I wondered what was similar and what was different between those groups and the collection of people who have disabilities in the United States.

I can see one very fundamental difference — we're asking society to operate on a different basis.

When the Irish Americans or African Americans stood up and said, "I want to be counted," they were not asking society to change the way it did business. All they were doing was asking society to change who they did business with. They were saying, "I want to be part of your system but you don't need to change the system."

We, as individuals with a disability, are saying, "We need to change the system. We need to change how we design buildings. We need to change how we build buses. We need to change the role of the employer in supporting employees. We need reasonable accommodation, which means, 'I am going to hire you because you have the skill to do the job. I also understand you need a little bit of help and I'm going to do that for you.'" We are fundamentally asking for a very different baseline in society.

Max Starkloff spoke about economics and he is exactly right. Society has been saving money for decades because they haven't been doing the "right thing." We are finally in a position where we can say, "We're not going to take it anymore. We want a new baseline."

The Fair Housing Amendment which was passed at the federal level last summer took a giant step in that direction. Beginning in 1991, all housing available for occupancy after that date has to be adaptable housing. It will open up major segments of the housing market for us. It's going to do more than just make my place accessible, it's going to make the homes of my friends and my neighbors accessible. It's going to assist me to become a more social person. Instead of having everybody over to my place for a party, we

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can go to somebody else's place. I can make a conscious decision that they throw a better party or that I don't want to clean up afterwards!

To get this new baseline, we can't just ask for it. We've got to be in a position to demand it.

Several months ago there was an attempt to organize a nationwide series of rallies about a court decision on accessible transportation. The turnout was pitiful. Nobody showed up in some cities. In other cities, 10 or 12 people showed up. In Boston we had the premier crowd in the country — over 100 people. We need hundreds of people if not thousands of people at any rally. We need to be on the TV screens every day. We need to be on the front pages of the newspapers.

In Massachusetts, our transit company built a new commuter rail station but did not put in accessible features. A complaint was filed and the station has been sitting empty for six months. Nobody is allowed to use the station until we are allowed to use it. That's the kind of decision, that's the kind of line we need to draw. We are part of society and until the whole of society recognizes us, we need to say, "No, you can't do it until we can."

CYNDI JONES, Publisher & Editor, *MAINSTREAM*, San Diego, California: I'm going to talk on a personal level because I believe that's where change happens. It happens between the person I'm talking to and me. In his paper Dick says, "The disability role is, of course, an ascribed role that we do not chose to enter." I disagree. I believe that each and everyone of us chooses that role on a daily, minute-by-minute basis.



Cyndi Jones, *Mainstream*

We allow ourselves to accept that role and have that role foisted upon us rather than putting it back to the giver. I think we are our own worst enemy because we allow it to happen.

We buy into second-class citizenship every time we accept what I call "pity percs" — handouts, freebies, half-price tickets, discounts, reduced bus fares in lieu of fully accessible transportation. Will we sell off accessible transportation for a half-price ticket? Half-priced tickets aren't good enough when we can't get on the bus. What about reduced price movie tickets in lieu of an accessible theater where you can sit where you choose? Every time we accept small pieces of charity, we buy into discounted citizenship, or maybe more simply stated, "just being discounted." Another way to think of it is being "invalids or invalid."

I know well-meaning people who offer me things, and it's hard to say, "No, thank you." At a recent wedding reception, we parked in valet parking and the attendant wouldn't take my money. I seemed ungrateful because I wanted to pay for

service I am rendered. If I accept his offer and then stop and think what I'm paying for that freebie — a slice of my dignity and your dignity — I'm obligated to say, "No, thank you, I'll pay." As long as we allow our dignity to be eroded slice by slice, we will be denied our dignity.

We have to stop selling ourselves short and cheap. We buy into reduced expectations that society has for persons with a disability. How many of you work? How many of you are the first to come to your office and the last to leave, the first to volunteer to do extra work to prove that you are able to do the job above and beyond expectations? We try to live up to our own expectations because we don't want to live down to others' expectations. As long as we are trying to prove that we're acceptable people, we've bought into believing that we're not.

There's a point at which we have to start living and believing that we are equal with everyone else. In a video a few years ago, there was a song called "Tell Them I'm a Mermaid" by Nancy Becker Kennedy. The song states, "Don't you wish that you could be disabled? Don't you think that everybody should? With everybody thinking you're not able, you'll never be expected to be good."

Do we really believe that we're not worthy enough to command basic common dignity such as bathroom doors that close? I believe that somewhere deep down in our souls we feel individually, and perhaps corporately, unworthy. We've bought into the disability role as society expects. We've bought into the societal value of people with disabilities as being less than non-disabled individuals.

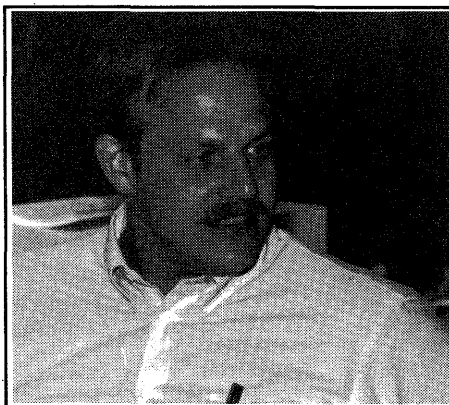
Also deep down in our souls, some of us feel that we are worthy individuals and deserve to be respected as a person. But some of those other people with a disability drool, fall down, or talk funny. Do we feel they deserve as much dignity and respect as the rest of us?

Until there's an individual and corporate consciousness that believes we all have a right to dignity and respect as do all other people, we're not going to get it.

I think we need to begin by believing in ourselves and in each other. I've long been an advocate for doing something for the other guy first. Maybe that's because my own energy levels are low, and if I take care of my own needs first, I don't have enough energy to give a helping hand.

How often are people with a disability the recipients of help but not the givers of help? I think we need to change that role also. If we can put a halt to the low expectations we have of ourselves and each other, I think we can break the barriers that limit each one of us. We need to believe in ourselves and each other because nobody else out there in society believes in us. We need to set high expectations for ourselves because the outside world is not going to set high expectations for us. We need to hold each other accountable because nobody else holds us accountable. We need to think larger than ourselves. We need to think corporately. How does my individual act of taking a charity handout in a parking lot of a hotel affect us? Sometimes we think we don't have the money and I admit we are 65% unemployed, but if we refuse to be treated as second-class citizens, we will make headway in becoming treated equally in this society. Just say "No!"

JIM deJONG, Executive Director, Coalition of Citizens with Disabilities, Springfield, Illinois: The paper pointed out some excellent points and near the end it addresses our laws and regulations and policies which essentially preclude face to face interaction between disabled and non-disabled children. Yesterday's children are today's legislators, personnel directors, teachers, and bureaucrats.



Jim de Jong, Coalition of Citizens with Disabilities in Illinois

I think that we, as people with disabilities, parents, family members, and professionals have done just about everything in the world to divide ourselves. Divided groups can be conquered, and we are most certainly conquered at this point. It is my belief that today's laws are a direct reflection of the past advocacy efforts, and those efforts have been fragmented. Spinal cord injury groups went to Washington or their state capitols and got what they needed. The developmentally disabled community went to Washington and got what they needed. What people forgot to do was to tie the programs together. So now what we have is a fragmented approach to dealing with individuals with disabilities. We are all overworked, the barriers before us are massive, and the funding is not adequate. Instead of uniting our approach to our capitols, we

turn on one another. We fight other groups within our own disability community.

I am close to saying, "I doubt there is a community." What I see is a very fragmented, distrustful group that has got to learn to grow up. We need to recognize that there are prejudices in the world, that the world is inaccessible to us, and not turn against one another but unite. At least one in ten people in this country has a disability. It seems to me that if family members, people with disabilities, and the dedicated professionals would work together, we could name our legislation, we could obtain adequate funding for our programs, and elect a president of our choice. Only 52% of eligible Americans went to the polls in 1988. Let's take advantage of their apathy and unite. Let's get together in think tanks and clearly lay out our national agenda that will include comprehensive training for grassroots groups. We need to cause change in each community and then come together for the collective impact on state and federal governments.

A futurist has stated that 97% of the scientists ever born in the world are still alive today. The amount of change we will realize in the world in the next decade will exceed what we have already experienced in our lifetime. We cannot plan to integrate a static society that will no longer be the same in the future.

We must realize what the future holds. We have seen the creation of a video encyclopedia that will allow children to sit in their homes and learn more than you or I ever learned going to great universities. We must realize the impact this will have upon the education system and plan accordingly. We must integrate systems while
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realizing that the systems are fluid, not static, and direct our efforts with the future in mind.

To understand how to get power, let us break down the word "POWER." The first letter "P" is for pride. We need pride in ourselves, we need pride in our movement.

We need "O"utreach. One disability group cannot advance at the expense of another. We must continually reach out to other groups. We need to support professionals who came into the field for a good reason but are tired and bogged down with the paperwork. They need a revitalization, and we must reach out to all who are in our field.

"W" is for wisdom. We must be wise about the system we wish to integrate. What will that system look like in five years? What will society look like? We must understand our political system and the basic concepts of democracy.

"E" is for the endless energy that we all need. As has been said, we need to reach out to other groups because as we come together we don't divide the pie, the pie expands and is bigger for everyone. We must have that constant energy because we must always look at where the line of prejudice is drawn against one group. Tomorrow that line could be drawn on the other side of your group.

The "R" comes from respect. We must learn to trust one another and recognize that each of us as individuals and as organizations has a part to play in integrating our society. We must respect one another and realize that each person is doing their bit. Some are integrating the local church club, some are integrating the

country club, and some are fighting to get on a bus. Whatever the individual effort is, it assists the collective integrative activity.

When you change society it takes all of the players. If we unite, the disability community will have power and not only will be able to name its laws, but I believe be able to elect legislators that will represent a comprehensive viewpoint in Washington and in state capitols.

CAROL ROWSE, Pukerua Bay, Wellington, New Zealand: I feel as though I'm separated from the political issues of the United States but still have something to say about disability roles and how each of us who considers ourselves disabled fits into the world community. Cyndi Jones started her speech with almost my first sentence. I don't know whether it has something to do with the women's movement or not! Perhaps women have more experience in fighting for the ways in their world.

Dick's paper did say that the disability role is an ascribed role and that we do not choose to enter it. I think that many of us do choose to enter it, even if it's only in a limited way. In New Zealand we have an umbrella organization called the Disabled Persons' Assembly which includes the Crippled Children's Society, the ill, the arthritic, and others. On behalf of that association, I recently visited a group who call themselves the Tararua Disabled Organization. They have a van which was paid for by public money. Recently the community and Disabled Persons' Assembly decided that it would be in the interest of the total community to establish a "Maxi Taxi" system which would transport the elderly,

people with disabilities, or anybody else who needed a special ride.

I went to the meeting thinking this group of people would be really keen to see a district-wide system that provided adequate transport. But I didn't find that. I found a group of people who complained about their disabilities, who said they needed all sorts of other things, and who saw the total scheme as being unwanted. They had a van they didn't want to share. They were expecting me to be sympathetic because I had the right job title, and I came away feeling really bad because I wasn't at all sympathetic. I was actually cross! From that experience and the fact that they were not willing to share with people whose range of difficulties was greater than their own, I felt that they had accepted the role that society gave them.

In October, Disabled Persons' Assembly ran an employment week. We suggested to this small district that people with disabilities should enroll themselves with the employment service if they would like to work. As long as no one is asking for work, the facilities are not going to be there. No one in the district of 170,000 people who was not already working registered or asked if they would be able to work. Those who had organized the week found it disappointing because people who were disabled were not really looking to be treated as ordinary people.

In New Zealand, we have recently introduced mainstreaming into secondary schools. I interviewed numbers of parents who said their child couldn't walk to school, and they would not teach them how to walk to school because they had to cross a railway line or main road. The law in New Zealand is that anybody may

attend school until their 19th birthday and a person with a disability may have an extension of one year. Some people ask for two and three extensions. They want their children to attend school until they're 22 or 23. If you stay in school too long, you are going to have to unlearn many things to be a grown-up.

I feel this ties in with what Cyndi Jones said. We ask for these privileges instead of taking the consequences that everybody else has to take. I found endless people who felt that older pupils with a disability shouldn't have their behavior altered because this is how they had always behaved.

My approach to the issue is that one has to try not to accept the role of a person with a disability, whatever the handicap, and at the same time expect to live an ordinary life. A real life has its ups and downs, its horrible moments, and its good moments. Many of the attitudes that turn people into "disabled people" come from what they are taught at home.

It's a little off the point, but I once had a client whose husband had been an alcoholic and he became cured. The wife came back to see me and complained bitterly about her life. She'd actually lost her whole life because her whole life had been telling everybody how dreadful he was and how hard life was for her. I think we have to be very careful that family members don't use our disabilities as their reason for an existence. My belief is that we are best able to contribute to the community and to society at large when we are ourselves complete individuals.

AUGUST RÜGGERBERG,
Zornheim, West Germany:

Dear friends, talking at what I might call Gini Laurie's confer-

ence has always been an honor for me. Being asked to comment on Dick Goodwin's paper requires also that I be intellectually honest and speak from my heart. First, I am blind and don't see you due to genetic conditions and not due to the fact that you expect me to behave as a blind person. The fact that some of you don't hear me will not be cured by my expectations that you all listen carefully.

Second, sometimes I am really sad that I cannot see the beloved faces of my girlfriend or of my children, or I am angry that I cannot easily find the right person among the bulk of people at a conference like this. Some people conceive of overcoming disability by having an optimal organization of attendants and assistants. I have such an organization, being able to get a person to read to me with ten minutes to two hours notice. And yet, I still feel sad sometimes for not being able to see, and this part of my disability remains. It is independent of all your expectations about me as a blind person.

Third, some aspects of the American view of disability suffer from what I would like to call an unintegrated bi-polar over-exaggeration of an extremely physical view on the one hand and an extremely role-type view on the other hand. Being honest with ourselves, disability is more than a mere bundle of social role expediencies of the so-called "non-disabled" people. Nor is it true that peer counselors can only be good if their lesion is at the same height of their spinal cord as the one of their client.

Stressing these respective one-tailed views of disability can be useful as ideological background for certain demands or policies or for the solution of practical problems. It can be

useful to come closer to what I may call external autonomy or independence. However, there remains our internal autonomy, our capability to cope with the rest which inevitably remains even under optimal conditions of personal care and assistance, technical aids, and a well-educated and well-informed society of the future.

My feeling is that society as a whole and many people who are suffering with a disability lack the capability of creating a good relationship with their suffering, their limits, their sickness, and perhaps their deaths. Discovering positive experiences, insights, and ideas which all relate to the so-called "dark side" in our lives or to view these problems as interesting, sometimes even fulfilling tasks, may help us cope with inner isolation and inner dependence. They may create some inner autonomy.

Don't misinterpret me as one of those experts saying, "First, lady, you have to accept your disability!" I don't mean that. I don't know of a better example of this kind of inner autonomy than our beloved Gini Laurie. She is showing this kind of inner autonomy and independence in the face of sorrow and suffering and therapy, giving strength and courage to herself and to us.

Let me end by explaining why I give you these philosophical conjectures now. I get the impression that in the American disability and independent living movement, disability is over-exaggerated as a "speciality." Disability is not yet broadly conceived of as only one form of weakness or suffering among many, many other forms of isolating, discriminating, weakening, and limiting conditions of life. Stressing one's own problems has often meant

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to underestimate the problems of other people and does lead to a sort of self-isolation. Suffering exists in the lives of all people. This notion shows a way of integration and partnership between people with disability and non-disabled people which is more than mere adaptation to the standards of a pseudo-healthy society.

I feel that coping with disability, sickness, weakness and death, living on a smaller scale, and reacquiring a form of modesty will be major tasks in the years coming up. The value of life is greatly endangered by modern biotechnology which proclaims the perfect individ-

ual. Genetic screening promises, or better threatens, to prevent any babies with a disability. Abortion regulations may become stricter again, but aborting fetuses showing a disability will be treated with what liberality?

Making an end to one's life is presently being propagated as a personal right or almost as a human rights issue. Soon it may be that people 60 years or older may be recommended to get themselves their gratis poison from the drug store. Parents wanting a baby may be required to have a genetic license guaranteeing the high quality of offsprings. People like me, being blind for genetic reasons, may be forbidden within

20 years.

All these visions, which could become reality faster than we all think, require a broad coalition between the disability movement and the broadening movement against biotechnology and genetic engineering. What we really need is a nationwide or international anti-eugenic coalition. I bring this to your attention because the bonds between the disability movement and the ecological movement against genetic engineering in the United States and in Europe are not strong enough. My wish is that I have raised your expectations to these problems so they may become a major issue of future conferences.

QUESTION: *I don't see anything wrong with getting anything half-priced or free. Organizations give out free samples. Would you return them?*

CAROL ROWSE: As long as they're offered to everyone, I don't care. But if they're singling me out because I have a disability, then I think that it's inappropriate. I think that companies offer free samples for a lot of reasons and as long as it's across the board, I think that it is appropriate.

CYNDI JONES: Nothing is free. I would rather live in a society that gave me an equal opportunity to participate economically in what's going on so that I have the wherewithal to buy the product because I could afford to buy it. What's going on is that people are buying us off! It's much easier for them to give a half-priced ticket to a movie theater than it is to make that theater accessible. I'd rather they took the hard way and let me negotiate with them on prices on the same basis as everyone else does.

QUESTION: *Would you comment briefly on the Illinois Coalition of Citizens with Disabilities and what effect it has had on state legislation and the perception of legislatures on the role of persons with disabilities in society? Any suggestions as to what steps to take to bring disability groups together for the common good?*

JIM deJONG: The Coalition came together, in part, because of the

request of legislators. Many of us were going to the legislature. Finally, they said to us, "Would you get your act together? You folks come in and the next day another group comes in and says the opposite." Representatives were saying, "Thank goodness, someone is asking for unity because you all are speaking in a hundred different directions and to be honest, I'm not going to take your issues anymore because I'm damned if I do and I'm damned if I don't."

To build a coalition, one of the first things we need to realize is that not all parents are the enemy, nor are all professionals the enemy. There are very good and dedicated family members and professionals involved in this field and we need to expand our base. I think that we need to utilize all the energies and all the connections. We have become experts at finding our differences; we've got to learn to concentrate on our commonalities.

MAX STARKLOFF: I think the Independent Living Centers (ILC) can play a valuable role by holding public hearings at the local, state, and regional level to get responses from individuals with a disability about what the problems are. For example, in Missouri we have a problem with the personal assistance legislation. Right now we have money to fund 48 individuals throughout the state. Through public

hearings and the ILCs, we can bring together people who speak to these issues. If we start to do that nationwide, we can bring together grassroots groups and work together for common good.

QUESTION: *Your disability role sounds more like the crippled or handicapped role. Given that semantics influences people's thoughts and attitudes, what does the group of people with physical disabilities wish to be called? Would it not be wise to avoid using "disability role" as Goodwin has done?*

DICK GOODWIN: I think that I am very sensitive to language and have written about language perpetuating the myths about people with disabilities. When we're referred to as victims and sufferers and patients, it conjures up an image in people's minds, and I think that we definitely need to avoid those kinds of images. Within the independent living movement, we think of ourselves as persons with disabilities and try to emphasize the person aspect. Many times our language is lazy and rather than saying ten words, we say two words. There certainly is not an attempt to stereotype or characterize people with disabilities in any negative way by using "disability role."

JIM deJONG: There's another implication in the question. Every person (continued on next page)

Americans with Disabilities Act Becomes Law

Little notice was taken when, during the early part of the Reagan era, Congress, at the behest of then-Senator Lowell Weicker (R-CT), as Chairman of the Senate Subcommittee on the Handicapped, detached the little-known, minuscule National Council on the Handicapped from the Department of Health and Human Services and gave it independent status. Now known as the National Council on Disability, the agency consisted of a board of Reagan appointees, including Justin Dart, now Chairman of the President's Committee on Employment of People with Disabilities, and a small staff.

Congress charged the Council with investigating the state of disabled Americans and make recommendations to improve their lot. Forums around the country led to the same conclusions: It is barriers and discrimination, rather than the inherent physical or mental characteristics of persons with disabilities themselves, which are to blame for the staggering unemployment and isolation of these



Photo: Yeager

citizens, the country's largest minority. (The Louis Harris survey of disabled Americans in 1987, commissioned by the Council confirmed earlier findings that two-thirds of Americans with disabilities are not employed.)

The chief recommendation that the National Council on the Handicapped made to Congress and the President was the passage of a broad equal opportunity law covering employment,

housing (which was removed from the legislation due to the passage of the Fair Housing Act of 1988), transportation, public accommodations, public services and communications.

The draft legislation was introduced in the House and Senate in the fall of 1988 and got nowhere. Most lawmakers found the measure too seeping and anti-business. But then congressional committee aides worked with members of the disability and civil rights communities to refashion the bill. Quietly but firmly, a movement was growing.

The Americans with Disabilities Act (ADA) of 1989 was reintroduced, after a number of key modifications, in the spring of that year. With one more major compromise — the removal of punitive and compensatory damages from the remedies allowable under the employment section of the bill — the Bush Administration endorsed the ADA, and it easily passed (78-9) in the Senate in August 1989.

In the House however, with four separate committees (as opposed to the Senate's one) (continued on page 10)

What Really Limits Us? (continued from page 8)

plays multiple roles in life — father, student, disabled person, voter. As long as we continue to define and present ourselves primarily as persons with disabilities, society is going to react to us in that way. As individuals we need to learn how to redefine ourselves so that the disability is one aspect or one of the roles that we play, and that our primary role is as a citizen taking part in a local society. When we get to that point ourselves, it makes it easier for us to carry our message. People who are giving us freebies and half-priced tickets will then see us as people who work for a living instead of people who don't work for a living. They'll see us as equals instead of unequals. We are people, we do lots of things, we vote Republican, we vote Democrat, we mow the lawn, and we also have a disability.

RESOURCES:

National Council on Independent Living (NCIL), 2539 Telegraph Avenue, Berkeley, CA 94704 USA.

Independent Living Research Utilization (ILRU), 3400 Bissonnet, Suite 101, Houston, TX 77005 USA.

MAINSTREAM, Magazine of the Able-Disabled, is edited by polio survivor Cyndi Jones. MAINSTREAM's articles focus on how to make life a little easier so there is energy left after the daily essentials are done. By providing extensive information all year long MAINSTREAM saves a lot of foot work, phone calls, and miles of frustrations. Sample copies are available on request. To subscribe to 10 issues send \$16.98 to MAINSTREAM, P.O. Box 370598, San Diego, CA 92137 USA. IF YOU WOULD LIKE \$3.00 FROM YOUR PAID SUBSCRIPTION TO BE DONATED TO THE GINI LAURIE ENDOWMENT, WRITE GINI LAURIE ENDOWMENT ON THE ENVELOPE AND CHECK.

Coalition of Citizens with Disabilities in Illinois, 1 West Old Capitol Plaza, #412, Springfield, IL 62701 USA (217/522-7016).

Americans with Disabilities Act Becomes Law

(continued from page 9)

scrutinizing the broad measure, the going was much more deliberate. But one by one, with a number of clarifying amendments along the way, the Americans with Disabilities Act was marked-up and approved by the Education and Labor Committee (35-0; November 1989), the Energy and Commerce Committee (40-3; March 1990), the Public Works and Transportation Committee (35-5; April, 1990); and the Judiciary Committee (32-3; May 1990).

Before reaching the House floor, the Rules Committee had to decide which, if any, of over 45 proposed amendments to the ADA (many of which had been rejected in subcommittee and/or full committee mark-up sessions), would be allowed to be debated before the final vote. The committee, deciding along party lines, allowed just eight....

After a preliminary vote to override the Rules Committee failed on the House floor, the legislators spent the better part of two days debating the amendments and the ADA in general.*

In late May 1990, the House of Representatives cast their decisive vote of 403-20 in favor of ADA.

A select Senate-House Conference Committee was established to work out differences in the two versions. A major question was how to deal with the House amendment offered by Jim Chapman (D-TX), which proposed that employers may transfer food handling employees with "infectious or communicable diseases" to other jobs. The amendment was seen by many as counter to the intent of the legislation.

In late June, the House/Senate Conference Committee settled on its version of the ADA. The Chapman amendment was vetoed and replaced by the Hatch amendment which calls for the Secretary of Health and Human Services to post a yearly list of those diseases which are communicable by food handling.

The House passed the final version 377-28 in mid-July with the Senate approving a day later by a 91-6 vote. In a White House ceremony, President George Bush signed the landmark civil rights legislation on July 26, 1990.

The legislation makes it illegal to discriminate against people with disabilities in employment in the private sector, services provided by state and local governments, public and private transportation, public accommodations, and telecommunications. The law defines an individual with a disability as anyone with a mental or physical impairment limiting "some major life function." It also includes sanctions for those who discriminate in hiring. Victims of employment discrimination may seek back pay, reinstatement, and attorneys' fees. Businesses with fewer than 15 employees are exempt from the hiring provisions.

Regulations will give the law its teeth and that process will be designated to several agencies: Department of Justice, Equal Employment Opportunity Commission, Department of Transportation, and the Federal Communications Commission. The bill contains five titles, each with differing effective dates and each with regulations to propose.

RESOURCES:

* Used with permission from *In the Mainstream*, 1030 15th Street, NW, Suite 1010 Washington, D.C. 20005. In the *Mainstream* is available for \$20 a year.

Moving Toward Equity: A Kaleidoscopic Journey

Mary Jane Owen, M.S.W.,
Director, Disability Focus, Inc.**

A July 14, 1990 headline tells the world: SENATE APPROVES DISABILITY RIGHTS BILL: BUSH EXPECTED TO SIGN LAND-MARK LEGISLATION. Hardly a routine legislative decision. It took hard work and thoughtful efforts focused on doing what was necessary, so we could start doing what is right!

REVOLVING IMPRESSIONS OF THE STRUGGLE

An amazing victory for millions of Americans; won by countless people working in their home communities; coming to Washington, educating Congress, demanding their civil rights be guaranteed.

Merging flashes in a kaleidoscope of newly gained power and will: Friday the thirteenth brings a morning of good fortune. Senator Tom Harkin speaks silently in sign for his deaf brother and with spoken words of hope. Senator Orrin Hatch, fighting tears, remembers the powerful strength of a relative who survived polio to sleep each night in an iron lung. Senator Ted Kennedy traces personal ties to disability through his sister, Rosemary, and his son, young Ted. Each recognition ignites memories of blighted dreams but fuels future hopes.

Flashes of memory blend images of past and present: May 22 meant celebrating House action long months after the Senate version passed in September 1989. The same chairs in rows in Statuary Hall; the overflowing crowd watching the

debate on TV monitors; finding space in the "handicapped" gallery; the intimacy of those lucky enough to fit into its narrow space; the interpreter signing to deaf advocates; the rotation of young kids in wheelchairs into a spot by the door so someday they can tell their kids they'd been a part of their own history; then the sudden burst of tears, cheers, hugs, and kisses of pure joy upon final passage; the jubilant rush down marble halls past statues of solemn heroes of the past to heap laughing greetings upon the heroes of this latest victory;



Mary Jane Owen,
Disability Focus, Inc.

calling friends in town and far away to share the unifying news: ADA has passed!

Honoring efforts both great and not so great, but each equally essential to create momentum toward eventual equity; the flickering images of all the rallies and marches; the Day of Solidarity merging all the best into one grand memory; its sun drenched route between the White House and the Capitol; a long, thin line of people moving forward to make demands of their public servants; the chants of "What Do You Want? - ADA; When Do You Want It? -

NOW"; the traffic held up at each corner, drivers puzzled; the cheers from lunch hour sidewalk observers, happy for a change of scene and the diversity in the street; the blind woman in pumps and business suit strolling by the motorized wheelchair used by a mother from Texas with ADAPT on her shirt; the passionate speeches; the hot sun; the "crawl up" the Capitol steps; not even the WASHINGTON POST's judgment of "pathetic" dims the flair and passion which drove that effort further up the path toward equity.

As thousands gathered on a perfect summer day, President Bush calls for a sledgehammer to break down the wall of prejudice; assures the business community that America's know how knows how; fried chicken and rock music on the Ellipse; a Senate reception honoring everyone for this biggest day in the Civil Rights struggle.

All who joined the movement's past milestones on the road to equity hold shimmering dreams of what ADA can mean; a new future lies ahead; expanding employment, transportation, public accommodations, communications options all await our testing. Glancing back at past victories and the route already behind, we resolve to move always forward, anxious to reach the goal which brought us to this point: EQUITY!

RESOURCES:

** The stated mission of *Disability Focus, Inc.*, a non-profit organization, is "to provide a disability perspective to all levels of social policy and decision making." The organization seeks to provide a vision of the possibilities for individuals with a disability. For more information contact, *Disability Focus, Inc.*, 1155 15th Street, N.W., Suite 720, Washington, D.C. 20005 USA (202/483-8582).

Is There Life After Spinal Fusions ... or Cold Pea Soup?

Mary Jane Tesch

As I sit wincing in pain and holding my breath to keep from toppling over, the words of a poem come to mind,

"there are times when life is thick and slow and it hurts and every morning is not a new day but a swollen extension of yesterday."

Is this some cruel existential joke? I was quite used to being severely disabled. Since infancy, I've dealt with "Werdnig-Hoffmann's Syndrome," a type of severe spinal muscular atrophy (SMA) which attacks the same motor neuron cells as does polio and usually ends an individual's life before two years. I never crawled, stood, or walked. The medical profession had little to offer (not expecting me to live), so I grew into adulthood with a severe scoliosis, pelvic obliquity, and bilateral hip and knee contractures, among other deformities.

Looking like the Hunchback of Notre Dame and being totally dependent on others for my physical care did not keep me from being healthy and happy! I was able to obtain a graduate education and enjoyed an active professional career in rehabilitation counseling ... that is, until my first surgery.

In 1974, at age 30, I did what my medical colleagues deemed essential and underwent an anterior spinal fusion. The carpentry was a huge success (curvature corrected from 138 degrees to 74 degrees), but my respiratory capacity fell from 60% pre-op to 35% post-op, and I could no longer sit without a painful lumbo-sacral support.

(continued on page 12)

Is There Life After Spinal Fusions?

(continued from page 11)

Three years later brought a posterior fusion in an effort to prevent further respiratory loss, stabilize my balance, and hopefully toss the corset.

Unfortunately, I proved to be one of those patients who do NOT "follow the book." The results of the fusions were the exact opposite of the goals intended. No longer could I breathe easily, use my arms, or control my head or torso. Chronic allergies, intense heartburn, and pain from a Hoke-type corset became daily companions. An irritated sciatic nerve made (and still does) even lying in bed uncomfortable. *Though I looked cosmetically more attractive, for the first time I knew what being disabled truly meant!*

Little did I realize that though an orthotic corset was now needed both to assist breathing and to hold my body together, finding one I could tolerate would prove futile. I'll not recite the litany of attempts over the years to secure a proper fit. Suffice it to say that the experience has been devastating and most humbling. Numerous contacts across the country have led to some scary conclusions:

1) Most physicians fail to realize that a spinal fusion for persons with severe neuromuscular disabilities and severe scoliosis means substantial loss in respiratory vital capacity. When the curvature is corrected, the torso naturally becomes elongated (I gained four inches), and the diaphragm falls, further embarrassing an already impaired respiratory function. To this day I still have orthopedic surgeons who ask me why I wear a corset which is a good question since I'm totally fused from C-6 to the sacrum. The answer is simple. It is necessary to support the diaphragm and facilitate

breathing. (Also, since osteoporosis is usually present, the skeletal structure is fragile and cannot bear the weight from the added height and rigidity of the spine.)

2) Today's "state-of-the-art" lumbo-sacral orthotics consist of plastic body jackets that have NO corrective features. They conform to the body "as is" rather than move the figure to a position of balance. They are hard, painful, and not tolerated by persons with severe neu-



Mary Jane Tesch

romuscular disease. My closet became so crowded I resorted to sending them back.

3) True custom corset designing is a dead profession. One orthotist told me it was not "cost effective" to employ someone with these skills. They take too long to make and there is no call for them anymore. I wonder what are all the old polio survivors doing as their corsets wear out?

Survival these past ten years has depended upon an old abdominal support that my mother and I found in a retail store and altered to fit my needs. Each day my mother struggles for an hour to get it on and place me

in my chair. As I cannot find a replacement, the reality of being bedridden is fast approaching!

*"...and I wonder if it is real
for each day dies
with a desperate sigh
at the thought of
tomorrow
each day is swimming in
cold
pea
soup
and I get tired."*

The quest has left me physically exhausted. Yet, I am determined to find some semblance of comfort, and I wonder just what others like me are doing to stay vertical? I have not found that creative genius who enjoys a challenge and is willing to work "with me," not "on me." Maybe someone else has? In any case, I would like to hear from you. Perhaps we can pool our knowledge and create new ways to crawl out of the pea soup.

RESOURCES:

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

Families of Spinal Muscular Atrophy, P.O. Box 1465, Highland Park, IL 60035 (708/432-5551). Contact them for a confidential questionnaire to assist Indiana University School of Medicine as it compiles the SMA Roster.

Mary Jane Tesch,
S31 W30469 Sunset Drive,
Waukesha, WI 53188 USA.

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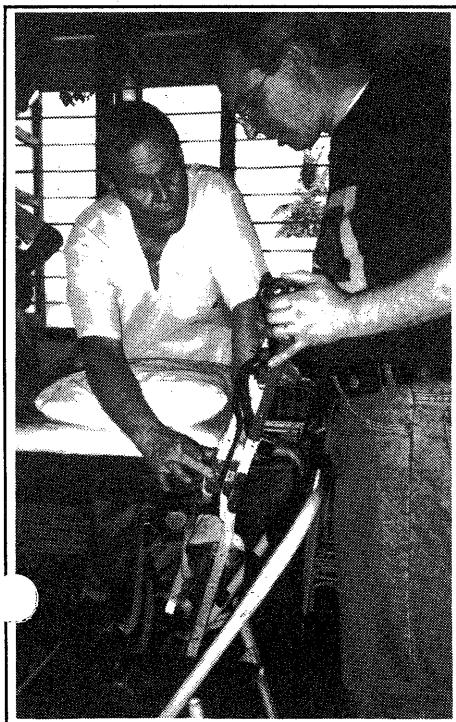


FRIENDS AROUND THE WORLD

Polio Eradication and Rehabilitation in India*

Sunny Roller

A team of health care professionals visited India from January 25-February 14, 1990. Frederick M. Maynard, M.D., an Associate Professor of Physical Medicine and Rehabilitation at the University of Michigan Medical School, led the group sponsored by Michigan's Rotary District 638 and Rotary International's Special Projects Program. Team members included: Celest Van Wert, PT; Hans Schaepper, CO; and Sunny Roller, Coordinator of the Post-Polio Research and Training Program. An orthopedic surgeon originally from India and past president of Rotary District 638, Mav



Dr. Maynard (left) and Hans Schaepper (right) evaluate a typical brace.

Sanghvi, M.D., was instrumental in organizing the trip.

An estimated 12 million polio survivors are living in India today with 80,000-100,000 new cases per year. The team evaluated over 50 children with polio paralysis, lectured at the Trivandrum Medical College, visited several homes for children with polio, and participated in India's Polio Eradication and Rehabilitation conference.

The national conference, sponsored by the Home for Handicapped (Polio) Children in Trivandrum, Kerala, was attended by 100 professionals who participate in polio eradication and rehabilitation programs in India.

After two days of professional presentations and discussions, a third day of deliberations resulted in a series of recommendations for action to promote polio rehabilitation and eradication.

The Indian subcontinent may account for 40% of current worldwide new cases of polio. Approximately half of the new cases occur in children less than one year of age and 95% in children under age five. Dr. Maynard comments, "The problems of polio rehabilitation are those of providing continuing rehabilitation services to children who are growing and developing with significant paralytic involvement of leg muscles." This problem is most evident in poor, rural areas and is compounded by inadequate transportation and limited rehabilitation services.

Polio eradication was the second topic of concern. Discus-

sions at the conference and a later review of the medical literature revealed that eradication of polio in developing tropical countries may not be successful by using the same vaccination techniques that have proved to be successful in developed temperate nations. Dr. Maynard reports, "There are significant differences in the epidemiology of new cases of poliomyelitis in tropical developing countries. Many of the problems relate to the type of vaccine, vaccination procedures, and to the practical issues of administering vaccine to large rural populations of people." The conference concluded that there are 10 major problems preventing effective polio eradication in India. These have been outlined in a report to the leaders of Rotary International's PolioPlus Program. Write to Sunny Roller, Coordinator, Post-Polio Research and Training Program, University of MI Hospitals, N12A09 300 N. Ingalls Bldg., Ann Arbor, Michigan, 48109 USA for a copy of this report.

* Excerpted from *Polio Network News* (Vol. 6, No. 2) published by G.I.N.I., 4502 Maryland Avenue, Saint Louis, MO 63108 USA.

"I am still involved as a consultant on disability concerns. I am particularly interested in empowerment of persons with disabilities in Asia and the Pacific through community-based rehabilitation (CBR) and formation of self-help organizations. I will visit Bangkok to facilitate discussions on the creation of a fund for persons with a disability and will serve
(continued on page 14)

Friends Around the World

(continued from page 13)

as a consultant to a leadership training seminar in Suva, Fiji, organized by the Asia-Pacific Regional Council of Disabled Peoples' International.

"Human Care Association, the first independent living center in Japan, is directed by my husband, Shoji Nakanishi. He is organizing a leadership training tour for independent living to Houston, Texas and Saint Louis, Missouri from August 28 to September 8, 1990.

"The group, including 24 severely disabled persons and their attendants, will visit ILRU (Independent Living Research Utilization) in Houston where independent living center philosophy, characteristics, and management techniques will be discussed. Houston Center for Independent Living (HCIL) will present sessions on peer counseling and skills training.

"While in Saint Louis, Parquad, Inc., will provide training sessions related to public relations, fund raising, board development, advocacy, attendant care, and the whole range of center services.

"Shoji will lead the group and Ms. Akiko Saito and I will serve as interpreters."

Yukiko Oka,
Consultant of Disability Concerns
200-17 Suwa-machi
Hachioji 193, Japan

"Our vacation in the Canary Islands was interesting from a handicapped point of view. Playa del Americanos, a city in South Tenerife, had two hotels for wheelchair users. One was built by the Swedish government and the other was a private German hotel with ALL the trimmings including electric wheelchairs for rent. The town

北京市儿童福利院

June 17 1990

4502 Maryland Avenue
St Louis Missouri 63108 U. S. A.

Dear Mr Jack

I am glad to receive a " Rehabilitation Gazette "from you.
Thank you very much ! I am reading in the " Rehabilitation Gazette "I think of Mrs Laurie, I will be long of memory her.

In May 1990, Beijing 20 middle school ' s students give me a present a English typewrite. I can ' t use it by my hands. I type it by my mouth, I am writeing letter to you now. Though my write is not good, I have done my best.



Sincerely yours.

Zhang Li

Zhang Li

Zhang Li, Beijing, China

itself had miles of beach promenade and shopping malls with ramps everywhere. I never saw so many wheelchairs in my life. The weather is in the 80's all year around. You can't swim in the ocean because the beaches are rough lava, but each hotel has beautiful pools."

Juliana Sawyer Stolle
Kaninchenbergweg.63
2400 Lubeck
West Germany

"I do hope you will keep me informed of the next polio conference. I could not attend the previous one because at that time I had a car accident and was flat on my back for nearly two months."

Zohra Rajah
15, Avenue Farquhar Quatre
Bornes
Mauritius

"I should be very happy if in the next *Rehabilitation Gazette*, you could tell your readers about a new book available in French. Georges Cornuty has described his experiences with disability in *La Rage De Vivre Contre La Mort Aux Trousses*. It is available for 40 French francs from Georges Cornuty, 73200 Allondaz, France. He is also seeking someone who would be interested in filming his story."

Mlle Solveig Kihlgren
1 square de la Bresse
75016 - Paris
France

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Potpourri



Independence Day: Designing Computer Solutions for Individuals with Disability

by Peter Green, Brown University, and Alan J. Brightman, Apple Computer, Inc., was written in a case-study format so the book does not give solutions, but focuses on the process people must use to find solutions for themselves. The book is available from DLM, One DLM Park, Allen Texas 75002 USA for \$17.95.

Vocational Rehabilitation Services to Persons with H.I.V. (AIDS)

is available from Research & Training Center, Publications, Dept. AB, University of Wisconsin-Stout, Menomonie, WI 54751 USA (715/332-1380) for \$17.95.

Colleges That Enable,

subtitled, "A Guide to Support Services Offered to Physically Disabled Students on 40 U.S. Campuses," was authored by Jason Tweed, who is affected by Werdnig-Hoffmann Disease, and his mother. To order send \$10.95 plus \$3.50 to Park Avenue Press, 401 Park Avenue, Oil City, PA 16301 USA (814/676-5777).

Career Perspectives: Interviews With Blind and Visually Impaired Professionals

is available in large print, braille, and cassette for \$11.95 plus \$3.00 from the American Foundation for the Blind (AFB), 15 West 16th Street, New York, NY 10011 USA (212/620-2028). AFB also offers **Dimensions**, a vital resource for individuals concerned with visually impaired persons with multiple disabilities, for \$12.95 plus \$3.00.

To subscribe to **Spinal Network Extra**, a resource maga-

zine for the wheelchair community, send \$15 (outside USA add \$6) to Spinal Network, P.O. Box 4162, Boulder, CO 80306 USA.

Mainstream, Inc., P.O. Box 65183, Washington, DC 20005-5183 (Attn: ADA-AID) has compiled a packet of information on three fundamental issues employers will have to address once the ADA goes into effect. To purchase "**Making Reasonable Accommodations**," "**Architectural Accessibility**," and "**Interacting with Applicants and Employees with Disabilities**" send \$20 to the above address.

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

Single copies of **DU-IT 1990 Catalog**, which includes several new or improved products, are available free from: Barbara Heinrichs, DU-IT Control Systems Group, Inc., 8765 TR 513, Shreve, OH 55676 USA (216/567-2906).

For people with serious or chronic illness, **ECaP (Exceptional Cancer Patients, Inc.)**, founded by Dr. Bernie Siegel offers a free catalogue of books and tapes including self-help items. Send a SASE to: ECaP, 1302 Chapel Street, New Haven, CT 06511 USA.

The Mariott Foundation for People with Disabilities was established to foster employment of youth with disabilities by developing internships in area businesses. For more information contact: Robin Murphy of Porter/Novelli for the Mariott Foundation 201/342-7000.

Life Services for the Handicapped, Inc. is a non-profit organization that offers individuals with a disability and their families assistance in planning for the future. A Discretionary Trust and Life Service Program makes it possible for parents and relatives to leave money to individuals with a disability without losing public entitlement. The organization offers an alternative to individual family plans and works through existing community organizations in carrying out the program. Contact: Leslie D. Park, Life Services for the Handicapped, Inc., 25 E. 21st Street, New York, New York 10010 (212/420-1500).

For more information about the new organization called United Federation of Chronic Fatigue Syndrome/Chronic Fatigue and Immune Dysfunction Syndrome/Chronic Epstein-Barr Virus Organization, Inc. (CFS/CFIDS/CEBV), contact the **United Federation of CFS/CFIDS/CEBV**, 2141 W. Fairlane Avenue, Milwaukee, WI 53209 USA.

Microsystems Software, Inc. (MSI) have agreements to distribute their HandiWARE Software Products in Canada, France and the Benelux countries. They also have a new release of **HandiWORD**, a memory-resident facility which provides statistically-weighted word prediction, abbreviation expansion, and macro capability for individuals with limited keyboard ability. It includes local language dictionaries in French, German, Italian, and Spanish and provides translation between English and these local languages. Contact: MSI, 600 Worcester Road, Framingham MA 01701 USA (508/626-8511).

A seminar and workshop on accessibility legislation (and *(continued on page 16)*)



Potpourri (continued from page 15)

design solutions) in Central and Eastern Europe will be held in Budapest, Hungary, September 1991. For more information, including **Call for Papers**, contact: CIB W84 Secretariat, Department of Building Function Analysis, The Royal Institute of Technology, 100 44 Stockholm, Sweden (Fax 46-8-790 85 39).

An **Invitation for Proposals** was issued by the Chronic Disease and Disability section of the Western Social Science Association for presentations in the area of disability studies. (December 1, 1990 deadline.) Contact: Gary Kiger, Department of Sociology, Utah State University, Logan, UT 84322-0730.

Research Grants for projects that impact the treatment and management of disabilities are available from the National Easter Seal Society's Easter Seal Research Foundation (ESRF). Grant applications must be received on or before December 15, 1990. Contact: Norman D. Grunewald, Vice President, ESRF, 70 East Lake Street, Chicago, IL 60601 USA.

The **New Address** of Respironics Inc. is 1001 Murry Ridge Drive, Murrysville, PA 15669-8550 USA (412/733-0200 or 800/638-8208).

MOVING?

After this issue, *Rehabilitation Gazette* will no longer be forwarded. Please notify us of your old and new addresses when you move.

**Upcoming
Events**

Post-Polio Conference, Holiday Inn, Billings, Montana, USA, September 15-16, 1990. Contact: Shirley Tankink, Easter Seal Society of Idaho, Montana, and Wyoming, 4400 Central Avenue, Great Falls, MT 59405 USA (406/761-3680).

Abilities Expo '90, Cervantes Convention Center, Saint Louis, Missouri, USA, October 5-7, 1990. For more information about a show of products and services for individuals with a disability, seniors, professionals, educators, and dealers, contact RCW Productions, Inc., 1106 2nd Street, Suite 118, Encinitas, CA 92024 USA (619/944-1122).

National Disability Employment Awareness Month - October 1990. Contact: President's Committee on the Employment of People with Disabilities, 111 20th Street, NW, Suite 636, Washington, DC 20036-3470 USA.

New Jersey Conference on the Late Effects of Polio, Somerset Marriott Hotel, Somerset, NJ, October 13, 1990. Contact: Jean Brogdon, Box 537, Martinsville, NJ 08836 USA.

"Hiring Minorities with Disabilities," the first of a series of conferences sponsored by The Dole Foundation will be held in Chicago on October 23, 1990. Contact: Jeanne Argoff, Director of Grants Programs, The Dole Foundation, 1819 H Street, NW, Suite 850, Washington, DC 20006 USA (202/457-0318).

The Americans with Disabilities Act of 1990: New Access to the Workplace, October 25-26, 1990. This conference, held at the Hyatt Regency Bethesda, MD, is the 1990 Mainstream Annual Conference. Contact: Mainstream, Inc.,

P.O. Box 65183, Washington, D.C. 20035 USA.

The First Czechoslovak Medical Conference on Post-Polio Syndrome, November 13-16, 1990. Contact: Mrs. M. Fidlerova, UV SI v CsR - OSR I, Karlinske nam. 12, 186 03 Prague 8, Czechoslovakia, Europe.

Bay Area Post-Polio Conference III-Perspectives for the '90s, Hyatt Regency Oakland, February 1-2, 1991. Contact: Renah Shnaider, 350 Vernon, Apt. 101, Oakland, CA 94610 USA.

Japan/USA Conference of Persons with Disabilities, Saint Louis, Missouri, October 1991. Contact: Colleen Starkloff, Director of Education & Training, Paraquad, Inc., 4475 Castleman, Saint Louis, Missouri 63110 USA.

G.I.N.I. SUBSCRIPTIONS

This issue of *Rehabilitation Gazette* is late. Thanks to several people, we now have a functioning computer program to record subscriptions and to run mailing labels.

A new combined brochure, order form, and renewal notice is used for all Gazette International Networking Institute (G.I.N.I.) publications (*Polio Network News*, *I.V.U.N. News*, and *Rehabilitation Gazette*). Notices for future issues of *Rehabilitation Gazette* will be sent this month. Please notify us if you have any questions about your subscription.

G.I.N.I. would like to thank the many people who have been supportive during this year of transition. We believe our worldwide networking is vital to you as an individual with a disability as well as to disability-related organizations, health professionals, and families and friends.

We invite you to join the network by asking your questions, sharing your answers, and financially supporting our efforts.

Gazette International Networking Institute (G.I.N.I.) is a 501(c)3 and any donation is tax-deductible. Please mail your contributions to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 USA. Our subscription rates are listed on page 2.