

Meeting in St. Louis

The Sixth International Post-Polio and Independent Living Conference was convened June 16-19, 1994 at the St. Louis Marriott Pavilion Hotel in downtown St. Louis. The gathering attracted 400 participants from 13 countries, 42 states, and seven provinces. This meeting was the first since the death of the network's founder Gini Laurie in 1989, however the goal of the conference was the same — providing opportunities for interaction between professionals and the individuals they treat in their practices and analyze in their research.

The conference once again offered an opportunity for people with disabilities to learn from each other and to share their "I've been there" expertise with professionals.

Many of the sessions were audio and video taped and are available from St. Louis Audio Visual. *See pages 13-14.*

The conference presentations will also be transcribed and published in future G.I.N.I. publications — *Rehabilitation Gazette* (see next column), *Polio Network News*, *I.V.U.N. News*.

For G.I.N.I. conference photos and reflections ... *See pages 10-11.*



SIXTH INTERNATIONAL POST-POLIO AND INDEPENDENT LIVING CONFERENCE, JUNE 16-19, 1994

Challenges Facing Individuals with Disabilities

William R. Green, EdD, polio survivor and retired special education teacher, moderated the Saturday morning session, Challenges Facing Individuals with Disabilities, and introduced the presentations by stating, "An individual has dignity only to the extent that one has reasonable control over the significant aspects of one's mode of living. Some degree of dignity is lost when the inclination to direct one's lifestyle is threatened or jeopardized."

DIANE WOODS, Project Director, IEEIR (International Exchange of Experts and Information in Rehabilitation), University of New Hampshire, Institute Disability/Heidelberg Harris, 125 Technology Dr., Durham, NH 03824-3595 (603/862-0551).

To open my remarks I would like to reference two current international publications. The first, published by the World Blind Union is called *World Blind*. A major global concern was expressed on the cover of the last issue. The quotation goes like this, "For peace's sake one should spare no effort to understand the arguments of one's adversary, and one must be willing to renounce part of one's position if that is to help in reaching a meeting point with the other."

That quote certainly puts into perspective the largest global challenge that we face in terms of disability — the national conflicts and other aggressive activities which provide the backdrop for hundreds of thousands of people becoming disabled annually. The problem is

perhaps more global and more pervasive than we want to think about or can possibly handle.

A clear and formidable challenge to all of us is the fact that in 46 areas of the world, including Bosnia and Somalia, one price of war is physical and emotional disability.

Other less horrendous challenges are expressed in the contents of another international publication called *CBR News* [Community Based Rehabilitation (see box on page 2)] published by AHRTAG (Appropriate Health Resources and Technologies Action Group, One London Bridge St., London SE1 9SG, United Kingdom).

The contents of the most recent issue express some of the concerns in other parts of the world including disability and literacy, and changing attitudes toward leprosy.

People in Africa and India are beginning to use videos for training. However, we cannot transfer our technology to all parts of the world. For example, on a recent trip to India I was in a village where the polio

vaccine was delivered but there was not adequate refrigeration.*

It is my belief that North Americans need to become more interested in and aware of the differences and similarities of other nations and other cultures. It makes us more open if we are interested in the way other people live. It gives us more information to work in our own countries where there is a very diverse population.

Rehabilitation professionals and disability advocates need to stand back from their own cultural biases and assumptions. They need to learn about other cultures and then accommodate when meeting the needs of people with disabilities and their families from various cultures.

The organization for which I work, International Exchange of Experts and Information in Rehabilitation (IEEIR), has been able to fund short-term study visits to other countries through grants from the National Institute of Disability and Rehabilitation Research (NIDRR). The fellowships allow an individual an opportunity to understand and collaborate with individuals in other cultures.

Recent topics of these field studies represent some of the cutting-edge concerns. (Contact IEEIR for a listing of the monographs.)

If the United States as a nation is to have a renewed national commitment to disability internationally, it must insure that graduates of our universities in disability-related fields are knowledgeable about concerns related to disability in all parts of the world.

Most universities have many students from other cultures in

*To preserve the potency of the oral polio vaccine, the temperature must be constantly maintained at a cool temperature. This is commonly referred to as the cold chain.

attendance and they are excellent resources. However, the international students studying here in disability-related areas have to be offered ways to help interpret the courses into their own cultural language to solve their own culture's problems. Additionally, American students interested in working abroad need the appropriate training and skills to work with other cultures.

We can really no longer afford to work in a cultural vacuum. We need a willingness to be open to the interest and needs of other cultures in order to enrich our own culture as well as to help others.



Abdul Rahman Sahak, a triple amputee as a result of war in Afghanistan, founded Afghan Disabled Society (ADS) to promote and protect the human rights of over one million Afghans with disabilities, many of whom are refugees in Pakistan. ADS is com-

mitted to independent living, economic independence, full participation, equalization of opportunities, and empowerment of people with disabilities.

Currently, Afghanistan is restructuring politically and economically. This is an excellent opportunity for individuals with disabilities to ensure their human rights. Now is the appropriate time to offer legislation protecting the rights of disabled persons in Afghanistan's social, economic, cultural, and political affairs.

ADS is interested in receiving information relating to disability and the empowerment of individuals with disabilities, including audio visual and printed materials regarding ways to protect rights; provide funding for technical, administrative, and leadership training; provide opportunities for disabled Afghans to study abroad. Contact: Abdul Rahman Sahak, ADS, House #1, Canal Bank Road, Khalil Town, Near (B.I.S.E.) Board, U.P.O. Box 1463, Peshawar, NWFP-Pakistan. ADS has branch offices in Khost City and Qandahar City, Afghanistan. ■

The International Centre for the Advancement of Community Based Rehabilitation (ICACBR) is an organization committed to advancing the concept and practice of Community Based Rehabilitation (CBR) in partnership with persons with disabilities and their communities around the world.

PRINCIPLES OF CBR The term CBR is now in international use with several different meanings. There is, at this time, no single conclusive definition of CBR, and ICACBR does not advocate one approach in particular. There is, however, consensus on its general principles and components.

CBR ATTEMPTS TO:

- ❖ change community attitudes and behaviours towards disability;
- ❖ empower persons with disabilities, enabling them to function in the community as long as possible;
- ❖ assist in the change from users of services to participants in health programs;
- ❖ establish partnerships in the development and implementation of programs;
- ❖ translate appropriate clinical knowledge to self-help skills;
- ❖ increase level of knowledge of contact people; and
- ❖ develop appropriate rehabilitation services.

ICACBR is developing a list of available CBR materials such as publications lists; slides; video tapes; teaching or training materials. Contact: ICACBR, Queen's University, Kingston, Ontario K7L 3N6 Canada (613/545-6881, FAX 613/545-6882).

LORI HINDERER, Ability 2000, 2417 Wallis Ave., St. Louis, MO 63114 (314/429-3386). Ability 2000 is dedicated to fostering independence through consulting, speaking, writing, and traveling. Lori maintains a computer-based reference service offering a wide range of resources to people with disabilities. Lori uses a ventilator (Aequitron LP-6) full time via a tracheostomy.

I was asked to touch upon my personal perspective as someone with a progressive disease and as someone with a disability.

Currently, there are 49 million people with disabilities in America all with varying degrees of disabilities and all with very diverse needs. However, while the ideals of the independent living movement encompass all people with disabilities, it is important to recognize that agendas may differ among those with different disabilities. One such group consists of those with progressive, often life-threatening diseases such as cancer, AIDS, or certain forms of neuromuscular disorders. Diseases, for example, often impose emotional as well as physical changes, many times limiting one's focus to fighting for one's life. Therefore, understanding the implications of the difference between having a disability and having a progressive disease is essential.

It's no surprise, in fact, that a hierarchy among people with disabilities exists. Several authors have pointed this out, suggesting that among physically disabled people those with more static disabilities tend to enjoy a more favored status. On the other hand, those with more progressive disabilities tend to experience a lesser status and indeed a more stigmatized one.

By virtue of having a neuromuscular disease (muscular dystrophy) since birth, I share the disability rights agenda and fully support inclusion of all individuals with disabilities into all aspects of daily life. But,

even if I lived in the most enlightened society — a society that offered complete universal access, personal assistance services, and total inclusion — I still would have a disease that continues to destroy a little more of my muscles every day.

Although my life is very rewarding and meaningful, the worse that could happen (and one of my greatest fears) is that it may be snuffed out by a disease that is very real, and there is nothing I can do to stop it or explain it away. For example, I was once able to walk, fully utilize my arms, feed myself, and even breathe without the aid of a ventilator. Accepting these changes, and also recognizing that my disease helps define me, is critical and helps me integrate as fully as I am able into the mainstream of society. For, on the other hand, denying disease denies people with chronic illnesses a central and core aspect of their identity and experience.

Accepting reality also means embracing hope. Within our century we have witnessed the miracles of medicine virtually eliminating many once fatal diseases. Therefore, it is inevitable that people with progressive diseases hold out hope for treatments or cures. In my particular situation, such a cure does not mean skipping through the fields with the wind whirling by, but rather stabilizing the progression of my disease.

Recognizing one's disease as the cause of one's disability, however, does not also make one a lesser member of the disability community. For in addi-

tion to sharing in the struggle against physical barriers and institutionalized discrimination, one must also balance this right against constant physical and emotional changes imposed by the disease.

For example, I remember well a conversation with a young man who had Duchenne muscular dystrophy asking me questions about what it would be like if he needed a ventilator. In the same breath, he explained that while it may keep him alive and productive, he didn't see how he was going to receive the increased level of personal assistance needed to consider such a choice.

I also knew a friend suddenly faced with cancer who soon became very debilitated as a result. In less than six months, she needed full time assistance, a wheelchair, and copious medications to control her pain. Often we talked about similarities we now shared, and as I talked about the need for more curb cuts along the street we lived on, it occurred to me that although she cared sincerely about a ramp, her current fight needed to be on surviving.

These experiences and others have helped me recognize how valid everyone's individual circumstances is within the whole of the disability community. In fact, paradoxical as it sounds, our inherent differences should not separate us but instead make us more unified in our understanding and accommodations of ALL people with disabilities whatever the cause and whatever the consequence.

I appreciate sharing my particular point of reference with you, and am proud to consider myself an integral part of a community that is helping people transform the way disability is defined. ■

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MAX STARKLOFF, president of Paraquad, Inc., 5100 Oakland Ave., #100, St. Louis, MO 63110 (314/534-5100).

We are talking about challenges facing people with disabilities, and I want to talk about what independent living centers (ILCs) need to address over the next several years.

The independent living movement itself has seen dramatic growth over the last ten or fifteen years and has developed into a solid network. That network has played an effective role in advocating and passing the Americans With Disabilities Act as well as advocating and working for legislation in state and local communities.

As independent living centers become more sophisticated and involve more people, we need more effective and organized outreach to people with disabilities who are not being served. Many are alone and isolated.

Professionals at rehabilitation centers who work with people who have traumatic disabilities, such as head or spinal cord injuries, say that people with disabilities in poverty are literally dropping off the face of the earth. Nobody has contact with them after leaving acute rehabilitation, until something major goes wrong, and they are hospitalized.

Independent living centers can work many ways to address this problem. We need to look at the issue of urban violence and the impact it has on disability. Rehabilitation centers and independent living centers are hearing more and more from people who have become permanently disabled through gunfire and gang violence. This is happening to 14 through 16 year olds with limited education and limited access to services. Our experience in the St. Louis area is

that they are usually African-American males. These individuals' self-esteem was low before they became disabled, and now that they are disabled it is difficult to work with them in rehabilitation. On the other hand, they are usually very intelligent and creative, or they would not have gotten as far as they have in doing illegal activities.

Centers could help turn their lives around, but we need to be realistic about the problem and address it in a better way. For example, a lady at an ILC said to a guy who was trafficking violence before he became a quadriplegic, "We can send you on to college." He responded, "Why should I do that when I am making \$1,000 a week selling drugs."

I am not suggesting a white male like me can go into an African-American community and help a black male deal with his disability. I have no way of understanding what that individual has to face. But we can involve people with good experience in those areas and send them. One of our board members at Paraquad is black and a paraplegic from a gun shot by a gang member's brother. After rehabilitation, he went to college, received his degree, and is now working at the University of Missouri in the criminal justice department interviewing gang members and leaders trying to understand them better.

He does not know any black male who has become disabled that was not injured by anything other than violence itself, and he finds that disabled gang members go back to what they were doing before. It is a very serious problem being pushed aside and being ignored.

Another concern is that the amount of abuse towards kids with disabilities is dramatically increasing. On the news you

quite often hear about abuse towards children. When a disabled kid is abused it is pushed aside. Maybe it is because we have institutions to place people, and we falsely believe the problem has been addressed.

We are seeing a lot of abuse toward disabled people by their personal assistants. As we establish personal assistance programs, we need to make sure that we have a way of requiring that we have the most qualified people available as personal assistants.

These are all issues that independent living centers can deal with, because I think the ILC

"...we need more effective and organized outreach to people with disabilities who are not being served."

approach is very realistic and practical. Also, we are people with disabilities. We are individuals who because of our own personal experiences can share through peer support.

Also, independent living centers need to establish relationships with universities to do research about disability. We need to provide data and information for distribution to the public.

All of us understand, especially we who are disabled, that the biggest obstacles are the attitudes which lead to discrimination. More information is needed about disability; to understand what disability really is and what it really means; to understand that those of us who are so-called "making it" in the community are not heroes but just normal people; to understand that a lot of other

people, if they had some of the same advantages the rest of us had, would make it as well.



QUESTION: *I am a researcher. Can you be more specific about particular areas of research you see as high priorities for an independent living center?*

MAX STARKLOFF: We need to research urban violence. What is happening to people; where are they going once they get out of rehab; why are disability organizations not keeping in contact with them? Is the problem related to financial aid or the inability of hospitals to follow up? Why do hospitals have problems communicating with community-based organizations like independent living centers? What are the neighborhoods doing to better understand disability? Police officers will tell you how often they are arresting people in wheelchairs on the corner with drugs. We need to know how to help people with disabilities become involved in disability issues such as making the community accessible politically and architecturally.

We need to find out what is happening with families in which individuals have disabilities. We have a program in St. Louis during the holiday season called the "100 Neediest Cases." It picks 100 situations in the community and highlights them in the paper to collect money for food, etc. I have been following it every year and at least 40% of the cases are related directly to disability. Nobody pays much attention to that fact. Nobody wants to resolve the problem; they just feed the money to it.

QUESTION: *What are the best methods for making rehabilitation programs culturally relevant to people with disability?*

MAX STARKLOFF: The job is being done piecemeal right now. ILCs need to hire people who under-

stand other cultures. We need staff who understands the language, understands what it means to live in poverty, and what it means to have gotten into gang member situations in the first place and why some want to stay. I have heard a few people explain that once they become disabled their quality of life improved. They now have access to financial support and a place to live. It would be good if they better understood that there is a disability movement that can have an impact on their lives. They do not necessarily have to get involved in the movement or become full-time advocates, but they should realize that there are opportunities out there for them and become advocates for themselves.

QUESTION: *What can be done to get more African-Americans actively involved in support groups or disability organizations?*

COMMENT: I am from Tennessee and am concerned. I am a minority at this conference. African-American have disabilities, and I am wondering why is it that they don't feel like a support group

can help them? It has helped me. I am concerned that blacks do not feel a part of or do not take an active part in various groups. I guess if I can do anything to change this, I would like to do it.

COMMENT: A study is taking place right now is trying to encourage or modify the curriculum of graduate programs that train rehabilitation professionals to encourage African-Americans to join in and become part of the system. Part of the answer is getting professionals who are African-Americans and using them as peer counselors.

COMMENT: When starting new programs remember to involve people you want to serve. Recently when starting a new program all of the directors were white males, and they wondered why no one else got involved. I work with a gentleman who says it has got to work from both ends. Sometimes we develop only "you-come-to-us" structures. We need to develop "go" structures where one of the person's peers goes into the community. It needs to be a two-way street. ■

DUANE GRUIS, independent living specialist, Paraquad, Inc., 5100 Oakland Ave., #100, St. Louis, Missouri 63110 (314/534-5100).

At Paraquad, my job is to monitor the state personal assistance services program (PAS) for the St. Louis region which covers eight counties including St. Louis City and St. Louis County. The program is set up to assist people with physical disabilities to maintain independence in the community.

Missouri's attendant program is unique in that people are able to maintain employment and still receive state funded ser-

vices. This means that a person on the program could use an attendant to drive them to and from work and assist them at work. A single person with a disability can make up \$17,400 adjusted gross income and still be eligible for the program. The income level increases as the family size increases.

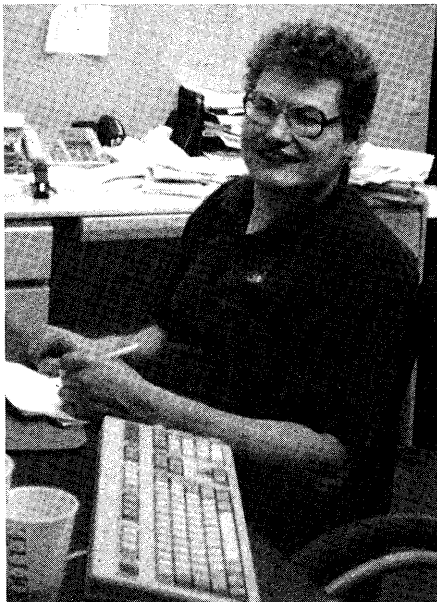
The program is consumer controlled. That means the person with the disability hires his or her own attendant and manages the attendant. Paraquad is under contract with the state of Missouri to assist participants on the program to learn to hire, manage, and train their atten-

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dants. This is done through quarterly training and individual and peer counseling.

Paraquad keeps a registry of those interested in being hired as attendants. It is the responsibility of the person receiving the service to do the screening and hiring.

Persons are able to receive services after their name has



Duane Gruis

come up on the waiting list. At that time the Missouri Division of Vocational Rehabilitation authorizes Paraquad to do an evaluation with regard to the number of hours that a person will need in order to maintain independence. The evaluation is done with a team of professionals which includes an independent living specialist, a registered nurse, an occupational therapist or physical therapist, and a vocation rehabilitation counselor. This team evaluates the total number of hours needed to do personal care and support services using an evaluation tool developed by the state.

Once the evaluation is completed, the person with the disability may start the program as soon as an attendant is found.

There are regulations for attendants. All attendants must be over age 18 and be able to physically handle all of the tasks that are requested. The attendant cannot be an immediate family member. He or she must be able to maintain confidentially and be able to handle emergency type situations.

There are currently 140 people in the State of Missouri on the program. Each of the independent living centers monitor a portion of the state. It is estimated that there are approximately 3,000 people with disabilities who could use attendant services in Missouri, so there is a waiting list. Currently in the St. Louis region there are 43 positions available and evaluations are being done on people who have been on the waiting list for four years. St. Louis is the largest region with the greatest population, so that tells you how underfunded the program is.

Since the waiting list is so long it is a major obstacle for persons with disabilities who want to be independent.

At the present time Missouri is looking into a Medicaid waiver program which would add Federal dollars to the program. If the waiver program goes through as planned in October of this year, the program size could increase by 50% across the state. This could mean an additional 50 to 70 persons served this fiscal year. If there is anyone who would like to get additional information on the program, or get on the waiting list, contact me at Paraquad at 534-5100. Even though there is

*ILRU — Research and Training Center on Independent Living, 2323 S. Shepherd, Suite 1000, Houston, TX 77013 (713/520-0232, 713/520-5136 TTY) compiles and publishes a directory of independent living centers.

a waiting list it is the first step to getting the services you may need. If you need to get on other attendant programs in other states, and most states have programs of some type, contact an independent living center in your state.*

It is important that all of us become involved in advocacy organizations for people with disabilities. This is especially true on the national level because there is such a debate about health care. It is important that people with disabilities stay active in advocating for long-term health care that includes personal assistance services as part of the national program. ■

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CHUCK GRAHAM, Missouri Coordinator, Region VII, Great Plains Disability and Business Technical Assistance Center, 4816 Santana Circle, Columbia, MO 65203 (314/882-3600, 1-800/949-4232, 314/884-4925 FAX).

Our official federal name is the Great Plains Disability and Business Technical Assistance Center which is why we usually call it the ADA Program. We serve the states of Missouri, Kansas, and Iowa. Each one of you has a Disability and Business Technical Assistance Center in your region. All nine centers have a common 800 number — 800-949-4232. It is 4ADA, but I quit using that when a friend who is blind asked, "What is ADA on my phone?"

Our technical assistance centers exist to provide information about the Americans with Disabilities Act (ADA) to anybody who is affected by it. We work with business, government, and any individual who has a question. We send out materials on the ADA; employment; accessibility standards. We give advice and assistance and answer questions.

We are not an enforcement agency. Do not turn in the local pizza parlor to us if they do not have a ramp.

Let me clear up three misconceptions about the ADA. First, it has been said that ADA is the lawyers employment bill — a rumor started by the Bar Association. They hope to make money every time we have a problem and go to litigation. There are different forms of advocacy we can use instead of turning to the court system. It may be as simple as writing a letter or talking to a manager of a hotel, for instance.

Secondly, the ADA is not going to drive small companies out of business. There is concern expressed in some communities that ADA is going to bankrupt

small business. The law allows that if there is undue hardship to comply, or it is not feasible, businesses may not have to meet all of the requirements.

The third misconception, and the most pervasive, is that the ADA is going to fix everything for people with disabilities. The ADA is a great piece of legislation, but it is not going to solve all the problems we have as people with disabilities.

Many areas are not covered by the ADA. For example, I am going to South Dakota tonight, and the plane does not have to be accessible. Also private single homes can still legally be built with smaller bathroom doors than the rest of the doors in a

house. So when visiting people the bathroom may still be inaccessible. We moved the out-house inside and never made it any bigger. My observation is that people like larger accessible restrooms because every time I go to use one somebody else is in it!

A massive education effort about the ADA is needed. If people do not know about the ADA, they can not know about their rights, and they can not advocate for their rights because they have no idea they have rights.

I experienced that situation after I was injured in high school. The principal put in ramps because he knew he had to. If I had known my rights, there would have been a lift on

the stage for graduation and accessible transportation.

I have been fortunate to visit schools and talk with children. There are obvious differences between schools. In one school I visited seven classes of second to fifth graders. All grades had certain attitudes about disabilities, and they all asked different questions. But two questions came from all grades. First, all the boys were fascinated with my pain threshold, and the fact that my legs could not feel pain. The boys would start a violence competition. "If I stuck you with a pin, you wouldn't feel it?" "If I stabbed you with scissors, wouldn't you feel it?" They kept one upping in violence.

One girl in every class would say, "Do you have a girlfriend who takes care of you?" She always assumed, first of all, that all people with disabilities do

"Each one of you has a Disability and Business Technical Assistance Center in your region. All nine centers have a common 800 number — 800/949-4232."

need care and, second of all, if we need care we should get a girlfriend or a boyfriend to provide it instead of having personal assistants. These attitudes are already established by the second grade.

My experience was different when I talked to a kindergarten class in which an autistic boy named Sam was a student. When I asked the kids if they knew anyone with a disability they all raised their hands because in kindergarten they know there are not any stupid answers or questions. It is in kindergarten where you learn everything. One would tell me about an aunt who has a walker. Another would describe an

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uncle with a hearing aid. Not one child mentioned Sam. He was "just Sam" to them at this point. He had not been labeled as a person with a disability. He was their friend Sam.

The challenge is to create a society where the people next to me are "just" Duane and Chuck and Sandy and Max. To accomplish this, we have to start very early in our schools.

However, education and awareness are not enough. We need to be involved in advocacy. People ask about the ADA and its enforcement. If one is worried about it not being enforced, look in the mirror. We with disabilities are the ADA police. The ADA was written as a complaint driven law. There are no inspectors looking for violations.

What is happening in enforcement on a federal level is shocking.* Under the employment provisions of the ADA, the EEOC (Equal Employment Opportunity Commission) has filed 15 lawsuits in the last two years. For Title II (public services) the Department of Justice has filed a total of six lawsuits for the entire United States of America. For Title III, places of public accommodation like this hotel, the Department of Justice has filed a total of eight lawsuits. That is a total of 29 lawsuits in two years. Do you think that there have only been 29 cases of discrimination on the basis of disability in the last two years in the United States?

We have been very good at creating legislation as persons with disabilities, but we have to make sure there is enough staff

*For a status report update on enforcing the ADA from the Department of Justice, in standard print or alternative format, call 800/514-0301 (V) or 514-0383 (TDD).

at these organizations to enforce them. The Department of Justice right now under Title III (public accommodations) has 900 complaints which have not been opened because they do not have the staff.

We need to develop disability rights coalitions to get all people with disabilities together. We need to look at cross disability issues and include people without disabilities in the effort, because they can also be excellent advocates.

We have to get involved in our communities and advocacy organizations, sticking up for ourselves. If we do not do anything, this conference will be the same type of conference 20 years from now.



QUESTION: *Is there anything we as a community can do to make airplanes themselves more accessible? Do you think there will be a day when we can roll our wheelchairs on the plane, stay in them and lock down?*

CHUCK GRAHAM: Air travel is covered under the Air Carriers Access Act of 1988 which gives us a right to fly, but it does not give us a right to make sure the plane is accessible. There are still huge problems. Some of them could be solved just through changes in policy. People with disabilities have to pre-board and be the last one off, but are the only ones who can not use the bathroom! I think that is kind of backwards.

How to File Complaints

Title I

Complaints about violations of title I (employment) by units of State and local government or by private employers should be filed with the Equal Employment Opportunity Commission. Call 1-800/669-4000 for the field office in your area.

Title II

Complaints about violations of title II by units of State and local government should be filed with:

U.S. Department of Justice
Civil Rights Division
Coordination and Review Section
Post Office Box 66118
Washington, D.C. 20035-6118
202/307-2222 (Voice)
202/307-2678 (TDD)

Title III

Complaints about violations of title III by public accommodations and commercial facilities should be filed with:

U.S. Department of Justice
Civil Rights Division
Public Access Section
Post Office Box 66738
Washington, D.C. 20035-6738

I would like to see people with disabilities make an effort to encourage a company like McDonnell Douglas to make accessible planes.

QUESTION: *You have painted a bleak picture about the EEOC and Department of Justice filing complaints on behalf of people with disabilities. I think it is imperative to point out that people have the ability to sue under the ADA. I wonder if you know how many of those types of suits have been filed, what some of the results have been, and if they are ever going to lift the \$300,000 cap?*

CHUCK GRAHAM: You are correct in saying we do have a private right of action under ADA. One of the difficulties of the ADA under Title I (employment) is that you have to file with EEOC and give them 180 days to act before one can initiate the right to sue. If you have been fired, that is six months out of work. I'd like to see the law changed to allow for immediate chance for action.

There have been some bills proposed to lift the \$300,000 settlement cap. The Civil Rights Act of 1991 allows caps for some discrimination and not others. The Act is saying that some forms of discrimination are worth more money than others and that, ironically, is discriminating.

There is no way to document private suits. One of the problems with private suits is finding attorneys to take the cases. There is a 70% unemployment rate in the disability community. We can't afford attorneys. A lot of attorneys are not interested in ADA cases because they cannot put in the year or two without being paid. Finding counsel is very difficult, and one, as advocates, we need to take a look at.

I would like to clarify one point; federal agencies are not covered by ADA. State and local governments are covered under

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Fourth Anniversary of the Americans with Disabilities Act



Justin Dart (with hat) and Judy Heumann (far right), Saturday dinner speaker for the Sixth International Post-Polio and Independent Conference, with President Clinton.

On July 26th, four years after the ADA was passed, the final phase of the employment title went into effect, requiring businesses that employ 15 or more workers to comply. Businesses that employ 25 or more have been covered since July, 1992.

Nearly 3,000 people joined President Clinton in commemorating the fourth anniversary of the Americans with Disabilities Act at the White House in July. In his comments President Clinton stated, "We are at a moment in history when our values — what we believe is morally right — and our interests — what is clearly good for us in a tangible material way — are one. We do not have a person to waste, and that is why we are here today to rededicate ourselves to an America where every man, woman, and child can reach the fullest of their God-given potential.

"Like every civil rights law in our history, the Americans with Disabilities Act is just that. It's about potential; it is not a handout.

"I have had the honor of appointing 44 outstanding people with disabilities to important jobs in our government including Judy Heumann, who is here with me today, as the Assistant Secretary for the Office of Special Education. She had to fight for her first job as a teacher. She's fought for disability rights for her entire life. Now she's fighting for the future of every child in America. I say that to make this point. We have not appointed a single, solitary person because of their disability. They have all been appointed because of their ability to serve the American people."

Also attending the commemoration was Justin Dart, former Commissioner of Rehabilitation

continued on page 12



G.I.N.I. Conference Photos

International friends attended from Australia, Canada, Denmark, France, Germany, Israel, New Zealand, Norway, Panama, Sweden, Switzerland, and Taiwan.



*Neil
Cashman,
MD,
Montreal
Neurological
Institute,
Montreal,
Canada*

Many presenters were individuals with disabilities contributing their professional expertise filtered through personal experience.



*Dorothy Woods Smith,
RN, PhD, University
Southern Maine
School of Nursing,
Portland, ME*

Panelists included friends and advocates for home mechanical ventilation.



*Edward A.
Oppenheimer, MD,
Southern California
Permanente
Medical Group, Los
Angeles, CA*

Long-time friends of G.I.N.I. and the polio community participated once again.



*Jacquelin Perry, MD,
Rancho Los Amigos
Medical Center,
Downey, CA*

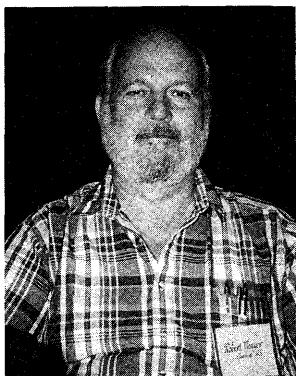
New experts were invited to share their perspective.



*John R. Fisk, MD,
Southern Illinois
University School
of Medicine,
Springfield, IL*

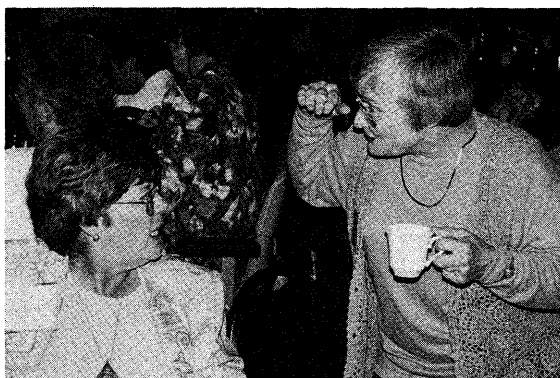
Networking ...

*Nancy Caverly, OTR,
Bland, MO and
Joan Headley,
St. Louis, MO*



*Robert Thayer,
Clinton, MS*

*Ann Morris,
Springfield,
MO (left)
and Jessie
Easton, MD,
Sioux
Falls, SD*



*Mary Westbrook, PhD,
Chatwood, Australia*

*Sandra Grant,
Cleveland, OH
and Gertrud
Weiss,
Rosenheim,
Germany*



Reflections

"It surprises me how much I still don't know about polio and non-invasive ventilation. I honestly feel that I could not have learned as much about these topics in the classroom. No doubt I will be a better respiratory therapist for having attended the conference." Emily Herndon, MO

"The open interaction of professionals was a big plus that brought a feeling of family to the occasion. Thanks for taking my suggestions to heart in covering topics I felt needed to be addressed." Lynn Martinka, AZ

"It was very pleasant meeting with patients I have seen in the past as well as learning from my colleagues in the field of post-polio research and therapy." Irwin Siegel, MD, IL

"The number of people who attended was impressive, but more important was the quality of the program and how efficiently it was run." Max Starkloff, MO

"The program with all the contributors (including some unusual therapy methods) constituted a valuable overview of activities, expertise, scientific knowledge, and trends in the post-polio field. Experience of many years has shown me that life can still be enriched even in view of growing problems. The friends I have made at each G.I.N.I. conference since my first in 1983 have contributed very much to this attitude." Gertrud Weiss, Germany

"One of the challenges of my job is to make sure all polio, post-polio, and disability issues are discussed. (To do that, I have to be very careful not to allow my own personal experience regarding polio to become a form of censorship.) The 40-year history of G.I.N.I. is steeped in challenging stereotypical thinking. The sixth conference, as all other G.I.N.I. conferences, served as a catalyst to energize the post-polio and disability community." Joan L. Headley, MO

ADA under Title II (public services). Federal agencies are covered under Section 504 of the Rehabilitation Act. They have to provide accommodations. Not all of them are up to speed in understanding the needs of people with disabilities, however.

QUESTION: *Nobody has brought up handicapped parking. Is there anything in print on the number of parking spaces or size? I have been to shopping centers where there is one handicapped space.*

CHUCK GRAHAM: ADA guidelines spell out exactly how it is supposed to be striped and a percentage. It starts at 4% for the first 100. Once over 1,000 spaces it is 2%. One space has to be van accessible, the first. After that the spaces are eight foot with a five-foot access. One in every eight has to be van accessible.

QUESTION: *Who can we go to see this is taken care of?*

CHUCK GRAHAM: First of all, go to the landlord who operates that parking lot. I think that is the first form of advocacy. Show the guidelines and see if they will change it. There is a 50% tax credit for their facilities to help them afford it. Other forms of advocacy could include a petition drive or filing a complaint with the Department of Justice or filing an ADA lawsuit to make them fix it.

QUESTION: *I know of a bank building with a handicapped sticker in the window, but you cannot open the doors.*

CHUCK GRAHAM: Unfortunately, there is nothing illegal about putting an accessible sign on something that is not accessible. Morally it is wrong, but legally it is not. ■

Services Administration and Chair of the President's Committee on Employment of People with Disabilities during the Reagan-Bush Administrations. A long-time advocate for persons with disabilities, Justin was a major force behind the passage of the Americans with Disabilities Act and consistently embraces the independent living philosophy. He is now concentrating his efforts on health care reform, making sure that the issues of people with disabilities are not ignored.

Health care reform was discussed at the Sixth International Post-Polio and Independent Living Conference, and resulted in the following resolution:

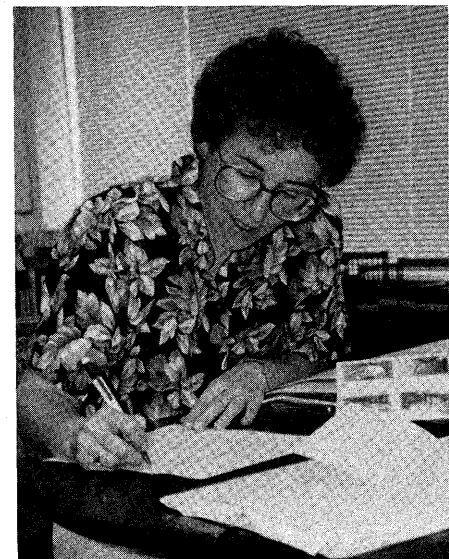
"We, (the undersigned participants in the Sixth International Post-Polio & Independent Living Conference, June 16-19, 1994), appeal to our legislators that U.S. health care reform legislation

guarantee there be universal coverage for quality health care that is accessible and available to all citizens including those with disabilities. This care must include durable medical equipment, personal attendant services and long term care coverage. We believe that the only way to guarantee the inclusion of the above services is to specify them as part of a comprehensive benefit package which is part of health care reform legislation." The resolution was signed by many of the participants. No one knows what the final action, or inaction, of congress may be. Members of congress are being bombarded with orchestrated messages. Congress needs to hear from us. The *Gazette* encourages persons with disabilities, regardless of political affiliation, to be involved and to speak for themselves during this debate. ■

Resource Center in Israel

Joyce Olshan, OTR, a native St. Louisan, visited the G.I.N.I. office in July to collect information for her employer MILBAT. MILBAT (The Israel Center for Technology and Accessibility) is the country's largest information and product display center for individuals with disabilities. The staff consists of occupational therapists, a speech therapist, and dozens of volunteers who help adapt the equipment to the individual's needs. The extensive information library receives books, videos, and magazines from organizations and centers throughout the world. The display rooms exhibit everything from can openers to computers.

MILBAT, a non-profit organization, receives more than 600 inquiries a month. Visitors are requested to make a donation, and while most people do, services are not denied to those who cannot afford to pay. Private



Joyce Olshan in G.I.N.I. office

donations and funding from Israeli ministries have enabled the center to continue its efforts. For more information, contact: MILBAT, Shoshana Goldberg-Mayer, OTR, Director, Tel Hashomer, Ramat Gan 52621 Israel (03-5357812 within Israel or 03-5303739). ■



Sixth International Post-Polio & Independent Living Conference

June 16th - 19th, 1994 • St. Louis Marriott Pavilion Hotel

AUDIO & VIDEO TAPES ORDER FORM

| | Audio Cassette | VHS 1/2" Video |
|---|----------------|----------------|
| TAPE #1 G.I.N.I. Then & Now Post-Polio Syndrome 101: Acute Polio & Post-Polio Theories Date: 6-16-94 Time: 9:30—11:30 a.m. | _____ | _____ |
| TAPE #2 Status of Polio in World Today Defining Post-Polio Problems Incidence & Prevalence of Post-Polio Date: 6-16-94 Time: 1:30—3:00 p.m. | _____ | _____ |
| TAPE #3 Coordinating Post-Polio Treatment The Battle with Bracing Date: 6-16-94 Time: 3:30—5:00 p.m. | _____ | _____ |
| TAPE #4 Post-Polio Corrective Surgery Recovery from Orthopedic Injury Date: 6-17-94 Time: 8:30—9:45 a.m. | _____ | _____ |
| TAPE #5 Facing Surgery When Breathing is a Problem New Breathing Problems & New Swallowing Problems in Aging Polio Survivors Date: 6-17-94 Time: 10:15—11:30 a.m. | _____ | _____ |
| TAPE #6 Finding Your Personal Threshold Determining Prescribed Activity Date: 6-17-94 Time: 1:30—3:00 p.m. | _____ | _____ |
| TAPE #7 Choosing Correct Equipment Adapting to Using Adaptive Equipment Date: 6-17-94 Time: 3:30—5:00 p.m. | _____ | _____ |
| TAPE #8 Living with Disability: Perspectives Date: 6-17-94 Time: 1:30—3:00 p.m. | _____ | _____ |
| TAPE #9 Living with Disability: What Works Date: 6-17-94 Time: 3:30—5:00 p.m. | _____ | _____ |
| TAPE #10 Improving Cough & Decreasing Infection Changing Equipment as Diagnosis Change Date: 6-17-94 Time: 1:30—3:00 p.m. | _____ | _____ |

| | Audio Cassette | VHS 1/2" Video |
|--|----------------|----------------|
| TAPE #11 Diaphragmatic Pacer Living at Home: Overcoming Obstacles Date: 6-17-94 Time: 3:30—5:00 p.m. | _____ | _____ |
| TAPE #12 Challenges Facing Individuals with Disabilities Date: 6-18-94 Time: 9:00—10:00 a.m. and 10:00—11:30 a.m. | _____ | _____ |
| TAPE #13 Face Mask Show & Tell Date: 6-18-94 Time: 9:00—10:00 a.m. and 10:30—11:30 a.m. | _____ | _____ |
| TAPE #14 Post-Polio Research: What's Being Done & What Needs to Be Done Date: 6-18-94 Time: 1:30—3:00 p.m. | _____ | _____ |
| TAPE #15 Health Care Reform Date: 6-18-94 Time: 3:30—5:00 p.m. | _____ | _____ |

Information for Ordering Conference Tapes

Please indicate which tape you would like by putting an X on the proper line to the right of each tape title. The cost of each audio tape (1-1/2 hours or less) is \$6 plus 5.725% tax; each video cassette tape is \$12 plus 5.725% tax. Please add \$3.50 for postage and handling. Fill in the address of the person who is to receive the tapes below.

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G.I.N.I. Conference Attendees Introduced to Real-Time Writing

The Saturday morning session, "Challenges Facing Individuals with Disabilities," of the Sixth International Post-Polio and Independent Living Conference was presented in real-time. Real-time writing is new technology which allows people who are deaf or with hearing loss an opportunity to immediately read the presentations of speakers.

Kimberly A. Pflieger, the real-time writer at the G.I.N.I. confer-



Kimberly Pflieger with equipment for real-time writing.

ence, describes the system. "As I listen, I type into the steno machine which is cabled to a laptop computer. The laptop computer has my own personal 63,000 word dictionary that I have compiled and add to continually. (That is why I ask for names and subjects beforehand.) The dictionary contains the steno outline and the English word equivalent. The laptop translates the steno into English and produces the transcript onto the laptop screen, or in the case of your conference, onto a large overhead screen."

Real-time writing requires typing skills between 200-225 words per minute on a steno machine, a well-rounded knowledge of many subjects, good grammar skills, and the ability to key in every word verbatim.

Kimberly is a freelance court reporter and does closed captioning in the metropolitan St. Louis area. In addition, she is a part-time teacher at St. Louis Community College-Meramec where she graduated with an associates degree in court and conference reporting.

Meramec's Real-Time Translation Project was designed by Judy Larson and was funded, in part, by a \$20,000 grant from the Southwestern Bell Foundation. Today Meramec's court-reporting students accompany deaf and other students with disabilities to select classes and record the lectures verbatim using shorthand stenograph machines hooked into a computer system that simultaneously translates the symbols onto a television monitor or the student's laptop computer. Transcripts of the classes are also available within 24 hours.

The project at St. Louis Community College-Meramec has been copied by 75 other colleges and universities including Harvard, Stanford, and Michigan State. Many job opportunities are available in the field with the passage of the Americans with Disabilities Act. Television stations, business, and industry will be able to meet some of the requirements of ADA, by using this system of real-time writing and closed captioning. ■

*For more information, contact:
Kimberly A. Pflieger, CSR
34 President Drive
O'Fallon, MO 63366
(314/926-8858).*

MOVING?

Please send both your old and new addresses to:

G.I.N.I.

5100 Oakland Ave., #206
St. Louis, MO 63110-1406 USA

Resources Needed for Polio Film

Adam Csillag, a polio survivor from Budapest, Hungary, has teamed up with English-born Nick Thorpe, a correspondent of the London Observer newspaper based in Budapest, to film a documentary entitled "Polio — The Last Word." The purpose of the film is to document the discovery of the virus, development of the vaccine, rehabilitation of those affected, and the continuing push for complete eradication.

The crew has already filmed in the Sudan when a cease fire was declared so children could be vaccinated, and across the border in the refugee-camps of North-West Kenya where many Sudanese, Ethiopians, and Ugandans have fled to escape the troubles in their own countries. In Hungary, Dr. Domokos Boda, the gentleman largely responsible for Hungary being the first country in the world making polio vaccination mandatory, was interviewed.

The crew also plans to film in Russia, Denmark, Pakistan, India, Geneva, Switzerland, the headquarters of the World Health Organization, and the United States.

As with any project of this magnitude, resources both financial and technical, are needed when the crew is on site. For more information, or to provide assistance, contact: Csillag & Adam Film, B.T. 1118, Budapest, Regos koz 5 (361 173 5273).

Csillag and Thorpe hope to complete the project well before April, 1995, the 40th anniversary of the announcement from Ann Arbor, Michigan, that the Salk vaccine trials had determined the vaccine effective and safe. ■

Rehabilitation Gazette welcomes your essays or reminiscences regarding the upcoming 40th anniversary of the Salk vaccine. Please submit to our office by December 15, 1994.

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



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Potpourri

Supplemental Insurance

Consumer Reports, September, 1994, highlighted the problem people with disabilities under age 65 have in purchasing supplemental insurance. Few insurance companies offer policies to people with disabilities under age 65 because most states do not require them to do so. Depending of where you live, individuals may have no choice of plans, may pay premiums much higher than those paid by people over 65, must meet medical requirements before they can buy, and some companies won't issue a policy to individuals with specific diagnoses. *Consumer Reports* recommends contacting your state insurance department to learn state rules.

The following is a list of insurers that told *Consumer Reports* that they do sell to people with disabilities in many states: Aid Association for Lutherans (800/225-5225, Ext. 5913), AFLAC (800/992-3522), Banker's Life and Casualty (800/621-3724), some Blue Cross and Blue Shield plans, Pyramid Life (913/722-1110), or United American (214/328-2841). *Consumer Reports* noted that offerings and prices vary considerably. They recommend that buyers should comparison shop.

N.O.D./Harris Survey available.

The National Organization on Disability (N.O.D.), in January, 1994, commissioned Louis Harris and Associates to conduct a nationwide survey of people with

disabilities. Two publications are now available. The complete 175-page report for \$95, or a 32-page summary of highlights for \$30. Both include shipping and handling. Call 800/240-4520 to order, or for more information, contact N.O.D., 910 16th St., N.W., Washington, DC 20006 (202/293-5960 / TDD 202/293-5968).

Resources on Spinal Cord Injury

The Institute for Rehabilitation and Research (TIIR) has revised and updated its national data base of resources on spinal cord injury. It currently contains over 500 videos, pamphlets, booklets, and manuals addressing 12 major subject areas relating to spinal cord injury — such as bowel and bladder management, recreational activities, sexuality, employment, etc. Information on one or two subject areas is free of charge. To purchase all major subject areas, send a check for \$50 payable to Baylor College of Medicine to Linda Herson, Division of Education, TIIR, 1333 Moursund, Houston, TX 77030 (713/797-5945).

Toy Guide available at Toys"R"Us

Toys"R"Us and the National Parent Network on Disabilities (NPND) have created a shopping guide containing toys which meet the standards set by the U.S. Consumer Products Safety Commission and have been tested by children with disabilities. The 22-page guide available at Toys"R"Us stores identifies appropriate

toys for children with disabilities by coding with a "skill building symbol" such as auditory, language, tactile, fine motor, self esteem, etc. The guide is a joint effort by Toys"R"Us and the National Parent Network on Disabilities, 1600 Prince St., #115, Alexandria, VA 22314 (703/684-6763). ■

Calendar

American Academy of Physical Medicine and Rehabilitation - AAPM&R's Consumer Forum, "Commonalties of Aging with a Disability Across the Life Span," Anaheim Hilton, Anaheim CA, October 8, 1994. Contact: Karen Donovan, MSW, 1100 Glendon Ave., #1634, Los Angeles, CA 90024 (310/208-3348).

Let's Get Real: Strategies That Work for Diverse Learners, Webster University, St. Louis, MO, October 24-25, 1994. Contact: The Institute for Inclusive Education, Nora Carr, 1460 Craig Rd., St. Louis, MO 63146 (314/872-8282).

International Symposium and Exhibition on Orthopedic and Paralysis Sequelae Rehabilitation, Beijing, China, October 16-20, 1995. Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China.

Abilities Expo — 1995
March 10-12, Florida State Fair Expo Park, Tampa, Florida
April 21-23, Anaheim Convention Center, Anaheim, California
June 16-18, Raritan Center Expo Hall, Edison, New Jersey. For more information, call 203/256-4700.