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### ABSTRACT

Eight articles address issues and programs in international rehabilitation. The issue is introduced by a message from the Assistant Secretary of the United States Department of Education for the Office of Special Education and Rehabilitation Services, Robert R. Davila. Next, "A History of International Rehabilitation" (Nora Ellen Groce) reports on a recently completed history. Martha Lentz Walker, in "Rehabilitation Service Delivery to Individuals with Disabilities: A Question of Cultural Competence," stresses the necessity for professionals to see rayond the boundaries of their own cultural interpretations. "Learning and Sharing Around the World" (H. Rutherford Turnbull et al.) looks at family services in other countries and in the United States. Paul R. Ackerman then reports on a rehabilitation project in India conducted by the National Institute on Disability and Rehabilitation Research. Next, "The United Nations and People with Disabilities", by Jeanne H. Nathanson, reviews programs supported by that agency. Barbara Duncan examines "The Role of Rehabilitation International in the United Nations Decade of Disabled Persons." Finally, the International Exchange of Experts and Information in Rehabilitation is described in "An International Project that Provides Opportunities to Learn about Policies, Programs, and Practices in Other Countries" by Diane E. Woods. (DB)

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# A MESSAGE FROM THE ASSISTANT SECRETARY

The past two years have been an exciting and eventful period for people with disabilities in the United States. Americans with disabilities enjoy more opportunities than ever before. In education, in employment, in social and cultural life. choices are now open to people with disabilities that would have been unimaginable just a few years ago. Limited opportunities have been expanded and more and more Americans who are disabled can now receive appropriate training and preparation to pursue careers in fields long considered impractical or impossible for them. Our skills contribute to the American economy, our expertise increases the knowledge base, and our talents enhance the quality of life for all Americans. We are at last beginning to realize the true meaning of social integration.

The empowerment movement in the United States and advocacy efforts by people with disabilities and by their friends and advocates who are not disabled, has led to the enactment of some of the strongest civil rig...s laws in the world. President George Bush is at the forefront of the revolution to open up opportunities to Americans with disabilities. Since he was elected president, George Bush has reached out to the disability community as no other president before him.

Indeed, one of his first actions as president was to name a number of people with disabilities to positions of influence and responsibility in the federal government.

Only a few months ago, President Bush and Secretary of Education Lamar Alexander made a commitment to revitalize education in the United States. Called AMERICA 2000, the plan challenges everyone in the nation to dedicate themselves to improving our schools and communities. For the disability community, President Bush and Secretary Alexander's promise to reform education gives us a chance to bring the empowerment movement into the classroom. The goal of AMERICA 2000 is empowerment, to give every child and adult, including children and adults who have disabilities, the knowledge and skills they need to compete in the world economy.

President Bush followed through on his commitment to individuals with disabilities when he signed the Americans with Disabilities Act just over one year ago. The ADA is the bill of rights for people with disabilities. It is the most far-reaching civil rights legislation to benefit individuals with disabilities ever

enacted. The ADA is the result of the greatest collaborative effort ever undertaken by all sectors of the disability community. With its passage, the United States has declared that all individuals with



# THE EMPOWERMENT OF PEOPLE WITH DISABILITIES IN THE UNITED STATES

disabilities are entitled to full inclusion in virtually every part of American society. Under the Act, private businesses and public agencies must make sure that individuals with disabilities can participate on the same basis as their nondisabled peers. With AMERICA 2000 and the ADA. President Bush and Secretary Alexander have given us, in the disability community, the tools we need to maximize our participation in American life and to realize our full potential.

Over the next few years, the ADA will reach almost every American who is disabled. In employment, in transportation services, in government services at all levels, the ADA calls for an end to discrimination and the beginning of accommodation. The ADA signals an era of change. Truly, we are entering the age of empowerment for individuals with disabilities. Recognition that each person who is disabled can make a contribution to our richly diverse nation has been slow, but the changes are irreversible. We are getting close to the day when individuals will not be judged by their disabilities. They will be judged solely by their abilities and skills. But every piece of legislation, every increment of social change, is due to the hard work and perseverance of people with disabilities and their advocates.

Every achievement we see today was a battle won by the empowerment movement.

The leadership role the American government plays today would not have happened without the dedicated efforts of thousands of people with disabilities. Working with one another and with their elected officials, people with disabilities helped to make empowerment a reality in the United States. The American achievements are just the beginning. Worldwide, people with disabilities are joining together to demand the right to full participation in their communities and the equally important right to contribute to their nation's economic well being. We need to continue to share our knowledge and strategies and our successes, and we need to learn! m our failures. Changes in America should benefit people with disabilities everywhere, just as changes in other countries should benefit Americans with disabilities. Those of us who are active in the international disability community are the ambassadors of change. People with disabilities all over the world must join the empowerment movement and help

make equal opportunity and independence a reality for all people with disabilities. We have an immense responsibility to create a better world for those who will follow us.

Excerpted from remarks made at the

World Federation of the Deaf Tokyo, Japan



TATERNATIONAL REHABITETATION

VOLUME IV NUMBER 2 FALL 1991

# Lamar Alexander

Secretary

United States Department of Education

# Robert R. Davila

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# A HISTORY OF INTERNATIONAL REHABILITATION

AN AMERICAN PERSPECTIVE



IN 1921, KENT STATE UNIVERSITY SOPHOMORE, ELAINE KERSHAW, TRIES OUT THE FIRST VACUUM



### Introduction

For nearly a century, American experts and advocates, institutions, and programs have made major contributions to the disability field worldwide.

In 1989, with funding from the National Institute on Disability and Rehabilitation Research (NIDRR), a collaborative research venture was undertaken by Rehabilitation International, the World Rehabilitation Fund, and the World Institute on Disability to research the history of American international rehabilitation efforts. The purpose of the history is to document the origins of the international disability field and to better define and direct goals for future efforts in this field

This recently completed history was compiled using a combination of methodologies. Existing published and unpublished sources were thoroughly reviewed. However, it became evident that much information had never been written down. Fortunately, a number of individuals now in their seventies, eighties, and nineties, who were involved in estab-

Nora Ellen Groce, Ph.D

Yale University and Newington Children's Hospital.



lishing and overseeing some of the most important programs and research, have continued to be very active in the field. As part of this study, twenty-one of these "founding members" were asked to provide extensive oral histories on the field of international rehabilitation and its roots in the United States. These oral histories were supplemented by a round-table conference in Washington. D.C. in January 1990, which brought together eighteen of these rehabilitation historians for an open discussion of programs, policies, and ideas relating to the history of the international rehabilitation movement.

# THE STUDY

Providing a historical overview of international rehabilitation efforts proved to be a fascinating endeavor. Until about thirty years ago, the word "rehabilitation" was used only in context to physical disabilities. "Rehabilitation." as it is defined today, is a term often used simultaneously with the broader issues of rights for citizens with disabilities including the right to appropriate medical care, a free appropriate public education, protection under the law, and social and economic

equality. As such, it is a field that is both cross-disciplinary and cross-disability in nature. Therefore, the history to be traced is not one, but a number of distinct histories. Nor could such a history be undertaken simply by discussing international efforts, for many of the American individuals and groups that were to make contributions internationally, first had a long and often involved history in the United States. The history of international rehabilitation in the United States proved to be a history of the growth and gradual intertwining of a number of very distinct fields.

# THE HISTORY

From the outset, American rehabilitation has had a strong international perspective. By the late 18th century, the new European views on disability, particularly deafness and blindness, were beginning to excite interest in the United States. A steady stream of American professionals and advocates visited European schools and institutions, bringing back ideas, and often, teachers as well. At the same time, active advocacy groups, particularly in the deaf and blind commu-

nities began to establish international ties of their own that would remain strong for decades. At first these early exchanges were primarily one-sided with American efforts mirroring the latest developments in Europe. However, the United States began to define some areas of interest distinct from those of Europe. By the mid-19th century, Americans were taking an active part in the development and dissemination of research. The establishment in 1864 of the first college for deaf students, now Gallaudet University, created a flurry of attention in European circles.

Issues related to physical disability began to emerge at the end of the Civil War as medical and surgical care of wounded veterans became a major concern to a whole generation of survivors. American surgeons increasingly wrote and lectured to their European colleagues on surgical innovations. However, well into the 1920s in both Europe and the United States, hospitals kept paraplegic patients lying on beds covered with sawdust as a convenience for caretakers who recommended this as an approach to bowel and bladder care.

In the years following World War I. the United States began to play a more prominent international role. In 1920. Congress passed the Vocational Rehabilitation Act that established the Office of Vocational Rehabilitation within the federal government. Originally established as a program only for those who had become physically disabled while in the work place, this would be the first such Office within the federal government to allow a focus on disability. The ways in which other countries addressed issues of disability in medical, educational, and legislative terms became an area for further government inquiry. Although the name of the Office of Vocational Rehabilitation and its affiliation within the government would change regularly over the decades, it would continue to contain a core group of committed professionals who would form the hub of an important network on disabil-

At the same time, the Institute for the Crippled and Disabled in New York.

established in 1917, provided a central focus for research and rehabilitation on physical disability within the United States. Of equal significance, what is today Rehabilitation International, was established in 1922 in Elyria, Ohio. While it would remain a very small organization for many years, it is one of the earliest organizations completely international from the outset. Although initially concentrating only on children with physical disabilities, it soon expanded to be both cross-disciplinary and cross-disability in nature. Throughout the 1930s. its World Congresses, meetings, and networking efforts proved to be an important forum for international contacts.

The rapid progress made within the disability field from the turn of the century through the 1920s was sharply curtailed as the Great Depression eroded available funds. Disability issues were placed at the bottom of a long list of special concerns. Within the United States, voluntary agencies closed. trained personnel went elsewhere, and monies for travel and programs disappeared. Programs in special education. for example, were so sharply reduced that not until the 1950s did the numbers of children served again equal the numbers served in the 1920s. International work was even more severely affected as finances and rising tensions in Europe made exchanges and travel increasingly difficult. Not all activity ceased. Rehabilitation International continued to hold World Congresses through the 1930s and still drew a large number of attendees from dozens of countries.

The start of World War II, however, brought the international disability field to a standstill. Rehabilitation International was kept alive only through the vision and forethought of Bell Greve, a remarkable woman from Ohio. Greve moved the entire organization to file cabinets in her office, and for almost a decade, ran it using her own time, energy, and savings.

While private efforts during World War II were substantially reduced, the war itself was a watershed period in terms of the future of international rehabilita-

tion efforts. American medical advances, particularly the development of antibiotics and improvements in prosthetics and orthotics, meant longer and healthier lives for many people with disabilities, and enabled the United States to assume a leading role in research. A new generation of medical and administrative leaders were introduced to rehabilitation issues through the armed forces and government service; and a new generation of disability advocates, many injured in the war, took up the cause of equal rights and employment for people with disabilities.

At the close of the war, interest in rehabilitation programs was renewed. Public interest in helping returning disabled veterans spawned a number of studies by Congress and private groups. This interest led to the realization that there were tremendous numbers of disabled American civilians for whom no programs existed. In response, President Truman established the President's Committee on the Employment of the Physically Handicapped. Although the President's Committee would not include other disability groups for almost two decades, its regular meetings quickly began to bring together individuals from a number of different disability groups.

The increased interest in disability issues and rehabilitation in the years following World War II established the United States as the center of new rehabilitation initiatives. Europe, to whom American disability advocates had turned for so long, was in economic and social shambles. The new nations of the developing world, long ignored in international exchanges, were redefining national priorities, and programs and legislation for individuals with disabilities formed part of this redefinition.

International work was undertaken by both the federal government and by nongovernmental agencies. The Marshall Plan and Fulbright scholarship program allowed a number of experts in various disability fields to study in the United States. By far the most influential international program in the federal government during these years

was located in the Office of Vocational Rehabilitation. There, in the 1950s, under the direction of Mary Switzer, an incredible network of funding for research and direct services was begun. Through a combination of administrative ability, compassion, and vision, Mary Switzer was to serve as a leader in the disability field, both nationally and internationally, for the next two decades.

Mary Switzer, with the help of several very able administrators, began to allocate funds to support international training and education exchanges. Switzer's most successful international venture was the passage of P.L. 480, which funded a generation of international disability programs. The bill allowed the allocation of "counterpart funds," monies generated through the sale of American grown grains to foreign governments: monies designated specifically for rehabilitation-related projects. From the early 1960s on, P.L. 480 funded the establishment of significant projects in fourteen developing countries. Many of these projects formed the basis for future self-sustaining national programs.

Nongovernmental groups were also active throughout this period. At the close of World War II, Rehabilitation International was revived with a small endowment enabling it to hire permanent staff. Its base of activity was moved to New York with the intention that it would develop close links with the newly established United Nations. Several years later, the World Rehabilitation Fund, an offshoot of Rehabilitation International, was established to focus on international issues that were primarily medical in nature.

During the decades of 1950s and 1960s, research efforts in the United States played a prominent role in the international disability field. American training programs and the funds to support them brought professionals from all parts of the world to the United States for training. Mary Switzer, always supportive of disability issues, made international rehabilitation an integral part of federal policy. And for



the first time, advocates for children with mental retardation in campaigning for improved educational opportunities, joined the disability community. Research funded by the Department of Health. Education, and Welfare, now the U.S. Department of Education, brought revolutionary insights into the potential growth and development of very young children with mental retardation.

# CHANGING FOCUS

The 1970s ushered in an era of tremendous change within the disability community. The rise of the disability rights movement brought with it major innovations, including a strong cross-disability unity and major legal redefinitions of disability. The disability rights movement itself was international in scope. New organizations, such as Disabled People International. were formed by disability activists to provide people with disabilities an international forum to present their own ideas and concerns. The World Institute on Disability was founded to provide a policy oriented international organization to pursue research and analysis from the disability perspective.

# THE PRESENT AND FUTURE

A review of the history of international rehabilitation in the United States and an analysis of current trends in the field, produced recommendations that, as part of this study, relate to three key areas.

The first area is the need for increased international cooperation on disability issues. This need for increased cooperation should originate at a national level with renewed resolve to the rehabilitation field and to disability programs. Many industrialized nations have mechanisms to involve their education, labor, social security, health, veterans, and foreign ministries in support of international disability outreach efforts. Such a collaborative approach should be considered for the United States.

The second area focuses on better training of personnel to carry out international programs. Currently, few channels exist in the United States to train young professionals for careers in the international disability fields. Unlike the field of public health in which international health is now a recognized subdiscipline or the field of economics

in which international development has become an acknowledged specialty, people training in the various medical. public policy, and advocacy roles that deal with disability in the United States receive no training that would enable them to work outside the American system. Training must be improved not only for American students but also for foreign professionals and advocates who come to the United States. These individuals often find

their educations geared to specifically American concerns and priorities, with many programs rarely addressing the real issues that they will face when they return home.

Finally, more cooperation is needed between American based groups and their counterparts in other nations. A number of United Nations agencies, as well as development agencies in many industrialized countries, are currently initiating an increased number of disability programs and projects. The United States should be a collaborative member of such initiatives. As the United States moves into the 21st century, it is time to reaffirm our ongoing commitment to disability issues world wide. People with disabilities must be involved in all aspects of such initiatives, not simply as recipients, but as decision makers and planners.

With a century of rehabilitation experience, a sopnisticated medical system, and an eloquent and active body of disability advocacy groups and individuals, the United States has much to share. And we, as a nation, also have much to learn. International programs must be initiated in a spirit of cooperation, with respect and consideration for differing approaches, beliefs, and concerns.



# REHABILITATION SERVICE DELIVERY TO INDIVIDUALS WITH DISABILITIES

# A QUESTION OF CULTURAL COMPETENCE

Cultural competence may be defined as the ability of individuals to see beyond the boundaries of their own cultural interpretations; to be able to maintain objectivity when faced with individuals from cultures different from their own; and to be able to interpret and understand the behaviors and intentions of people from other cultures nonjudgementally and without bias. Evidence of the presence of, or lack of.

Martha Lentz Walker, Ed.D. Kent State University

cultural competence among rehabilitation professionals lies within a vast body of research conducted over the past twenty years, research directed toward the development of appropriate services for rehabilitation clients (Watson, A., 1988.) Within the rehabilitation service delivery process, both the service delivery professional and the client may be bound by their own cultural assumptions.

# HIDDEN ASSUMPTIONS

If the professional providing rehabilitation services is a member of a culture different from that of his/her client, unquestioned assumptions may





cloud the manner in which the most appropriate service delivery is offered. Traveling outside the United States reveals assumptions that underline the values and the communication style known as "American." An international experience gives the traveler a clear view of his/her own culture and the unexamined assumptions that may lead to misunderstanding or miscommunication.

For those providers of rehabilitation services who have not traveled to other countries and experienced other cultures, many of their assumptions will unknowingly remain biased. As a substitute for direct experience, helpful frameworks have been offered to increase the knowledge and skills needed by professionals who serve minority and multinational members who have disabilities (LaFromboise and Dixon, 1981; Sue

and Zane, 1987; Portland State Research and Training Center, 1988; Ponterotto and Benesch, 1988).

The goal of cross-cultural training is the same, whether the purpose is sound professional practice or adjustment to foreign culture when traveling: constructive reactions to cultural differences. While the reduction of discomfort, confusion, and anxiety in the presence of persons from different cultures is desirable for travelers, it is essential for rehabilitation service delivery professionals. Cross-cultural training specialists teach students to distinguish among description, interpretation, and evaluation (Althen, 1988). Evaluation is based on one's own cultural standards, and while judgments may lead to misunderstandings in a foreign country, they may lead to unwarranted and unfair conclusions in the helping process that takes place between client and rehabilitation service provider.

### DIVERSITY

Jake Whitecrow, the late leader of native American health outreach, stressed that we all share basic needs; we differ in the way in which we go about meeting these needs (Whitecrow, 1989). Problems, Jake Whitecrow believed, occurred when any group insists on an interpretation of reality that is based on the perceived reality of his/her own culture.

Members of the majority culture in the United States resemble one another in these assumptions: that each individual is separate, responsible for decisions and destinies; that people can control their environments and their futures: that organization and efficiency are virtues (Althen, 1988). If a professional, who is also a member of the majority culture, understands that these are only assumptions, not truths, then judgment can be culture fair.

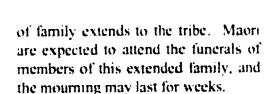
If professionals understand that differences in assumptions are the basis of pluralism, the way of the majority will not be the standard by which rehabilitation services are applied. With this understanding, American minority and multinational cultures are respected, while a sense of the American community is preserved. Recent research in Colorado on the satisfaction of Mexican Americans with rehabilitation services (Smart, 1990) revealed that most clients considered themselves to be bicultural and were satisfied with services they received. The sensitivity of the data gatherer (she was bilingual and bicultural) and the availability of the instruments in both English and Spanish enabled respondents to describe their acceptance of disability in culturally relevant terms.

With an understanding of assumptions (those we carry with us and those we encounter), the professional will be aware of possible differences in the definitions of work, health, help, and family that cultural diversity creates.

New Zealand, for example has grappled with the problem of "ailing in an alien world" by including the Maori perspective on health in the government's health system. A study of New Zealand's attempt to be culturally responsive to the Maori world view dramatizes American assumptions. For Maori, health is not the absence of disease or infirmity, but spiritual, mental, family, and physical harmony (Durie, 1986.) The Westernized assumption that accurate diagnosis and current medical procedures constitute good treatment does not satisfy the Maori need for hospitals to nurture total well being, which is impossible without the presence of family and the tohunga (spiritual healer.) The contrast of assumptions as different as American and Maori makes the importance of cultural & understanding clear.

# Model for the Helping Process

The professional wishing to be helpful to a rehabilitation client who is a member of a minority or multinational group must have prior knowledge of the culture from which the client comes. Being aware of one's definition of family and its boundaries can also be a lesson learned from New Zealand. In New Zealand, the concept



In rehabilitation planning, an approach to understanding the role of cultural diversity in the helping process might include the following questions asked by the rehabilitation professional in advance of meeting with members of minority or multinational populations who are disabled.

- Does a person from this culture typically have difficulty dealing with ambiguity? Should I provide more structure (and advice) than I normally do?
- Can I expect someone from this culture to express feelings openly?
   If not, am I prepared to "lead" the discussion?
- Is language a barrier? If so, am 1 prepared to interpret nonverbal



# FIGURE 1: CULTURAL TEMPLATE

# CULTURAL ASSUMPTION - IMPLICATIONS FOR WORK

Family Boundaries - Life crises, attendance at funerals, births, etc.

Quality of Life - Independence or interdependence.

Importance of Social Status - Response to supervision.

Importance of Religion - Work schedules, community support.

Meaning of Work - Wages, manhood?

Dislike to work alone or with strangers.

Meaning of Education - Major benefit of job? Best done by elders?

Decision making Style - Group or individual? Authoritarian or permissive?

Belief in Change - Individual control or fatalistic?

Response to New Situations - Aggressive or shy?

Work Routines - Main meal at midday?

Clothing congruent with health and safety needs?

cues carefully, and with assistance?

- What are the prevailing attitudes of this culture toward persons with disabilities? Will that attitude affect family involvement?
- What client assessment(s) is available that has culture-specific norms?
- Have I any preconceived notions about vocations for "this culture?"
- What is the usual help-seeking attitude of this culture? Are there traditional family or ethnic group associations which have already been tapped?
- Is age an important factor in this culture? Are there traditions of authority I must respect?
- Is status a factor in this culture? Are there titles (mine or his/hers) that prescribe roles for decision making?
- What attitudes toward work might I expect from someone of this culture?
- How might this person feel about particular types of jobs?

How does this client feel about family obligations, working alone or in a group, work hours, the work environment, travel to work?

This model was constructed from research conducted by rehabilitation researchers during the last decade (Pape, Walker, and Quinn, 1983; Edgeley and McDonald, 1984; Chan, Lam, Wong, Leung, 1988; Leung, and Sakata, 1988). The questions cannot be properly answered if the professional is uneducated regarding the cultures of the minority or multinational group. The model can be helpful in revealing how little a rehabilitation service provider understands a culture different from his/her own.

# CULTURAL TEMPLATE AND WORK

The world view of a member of a minority or multinational group who has a disability becomes important for rehabilitation planning. The information learned about the culture provides the professional with a structure to understand the individual. Perhaps the client

has adopted the assumptions of the majority culture, but a check-list of concerns relating work to culture allows the professional to ask important questions.

Figure 1 lists cultural factors (assumptions) having implications for work. An illustration of the most abstract factor, "quality of life." is the insistence by South Pacific Islanders on caring for a family member who has a disability. The rehabilitation hospitals diligently promote independence, only to find that upon discharge, the family assumes its cultural role as caretaker. A goal of independence is much more consistent with the American way than with the Samoan way.

In preparing a rehabilitation plan, the cultural template has the additional value of facilitating understanding and preventing inappropriate job placements.

# Dynamics of Difference

While understanding of a client's culture is important, it is not always sufficient in rehabilitation service provision. The interaction of a professional with a client from a different

The first task
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culture calls for the development of additional interpersonal skills. Two basic processes have been identified that enhance cross-cultural interactions: credibility and gift-giving (Sue and Zane, 1987.) In other words, the professional must be viewed by the client as trustworthy, and the client must believe something of value was received in the interaction.

LaFromboise and Dixon (1981) investigated behavioral cues that communicate trustworthiness. Eye contact similar to that of the client, erect posture of the service provider, reference to time only in the final minutes of the session, and an aura of confidence in and respect for the client conveyed tructworthiness. The first task of the professional is to gain credibility in the eyes of a culturally different client.

Sue and Zane (1987) have established three areas of interpersonal dynamics in which cultural issues are important. In conceptualizing the problem, selecting means for resolving a problem, and determining goals, the professional and client should have congruent understandings.

If an initial level of trust is established, the professional should search for some meaningful, immediate gain that the client will perceive. Frequently, the rehabilitation counselor explains interventions, but does not provide immediate benefits. Rehabilitation counselors have noted the use of simple "gifts," for example, allowing the use of the telephone by clients who may not have access to a telephone at home. Sue and Zane (1987) mention additional "gifts," such as anxiety reduction (through sharing thoughts and feelings and remarking that many individuals have encountered similar experiences); cognitive clarity resulting from goal setting and assisting the client to make sense of a seemingly chaotic life situation.

Further research is needed to study the construction of credibility and hope (through "gift-giving"). Some authors (Westwood and Ishiyama, 1990) describe the communication process as the validation of the clients' inner world of experience. When a client feels confident that he or she has been understood, a gift is given and trust is formed.

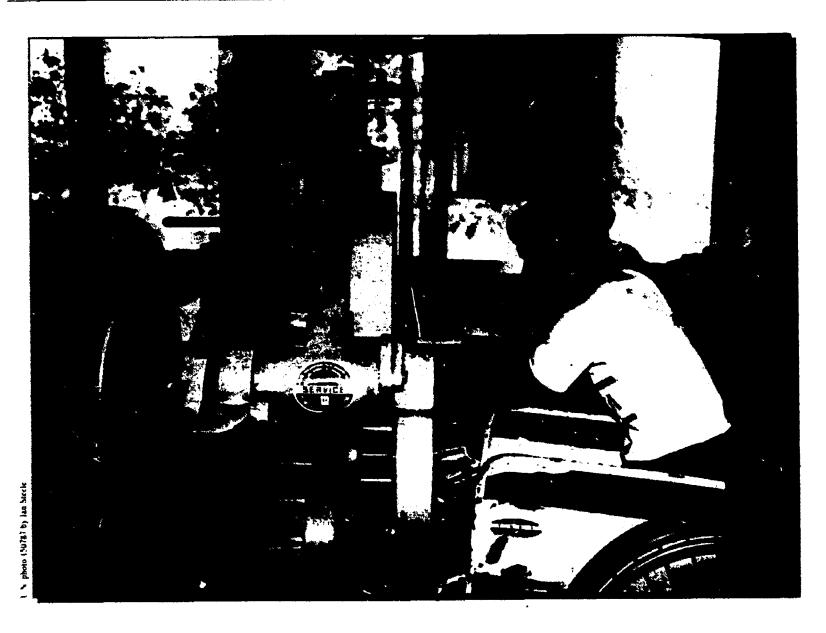
The technology of interaction analysis, which has been improved greatly within the past five years, allows researchers to study the communication process between a client from a minority or multinational culture and a service delivery professional from a majority culture. Videotaped interaction sequences can be closely studied for thaviors identified as trust-building. Cultural competence will be further defined through this analysis process, improving the cross cultural training of rehabilitation professionals. Research is underway at Kent State University, applying computer-assisted observation analyses to decision making moments in the rehabilitation process.

### Conclusion

The goal of providing appropriate rehabilitation services to minority or multinational persons with disabilities will become even more important as

the demography of disability in the 1990s is known. Research and training of the past two decades provides us with terms such as "cultural competence" (Portland State Research and Training Center, 1988.) Rehabilitation professionals must ask themselves if they are culturally competent, discovering hidden assumptions, and developing the necessary skills enabling them to be effective in cross-cultural helping situations. A model approach to understanding cultural diversity, a cultural template relating work to the culture of the individual client, and good interpersonal communication skills may release the rehabilitation professional from the bonds of his/her own culture and improve service delivery to minorities and multinationals who are disabled.

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# LEARNING AND SHARING AROUND THE WORLD



# DIFFERENCES AND SIMILARITIES

When we think about families in other parts of the world who have members with disabilities, it is easy to focus onhow they differ from families in the United States. Some differences are obvious and usually not all that important, such as differences in color of skin or differences in language. Some differences are obvious and important, such as the economic conditions of families or their ability to access good health care services. Other differences are sometimes less obvious but still important, such as difference in values and cultural traditions.

Yet along with those differences there are deep similarities among families around the world. Around the world, families share a desire to provide a home that can nurture all family members, and to foster the mental, physical, and emotional development of their children. Around the world, families suffer and are anguished when one of their members suffers. Around the world family members rejoice in each other's achievements.

H. Rutherford Turnbull, III, Ll.M. Ann P. Turnbull, Ed.D. Gary Brunk

BEACH CENTER ON FAMILIES AND DISABILITIES
UNIVERSITY OF KANSAS

The existence of differences and similarities provides a framework for the development of the International Program of the Beach Center on Families and Disabilities at the University of Kansas. Similarities across families around the world can be the basis for the establishment of relationships built on an appreciation of those fundamental values and commonalities. When approached with respect, differences can be the basis for learning from each other and for mutual assistance.

# FAMILY SUPPORTS

Because of the similarities that exist among families, it would not be surprising to find that there are similarities in the ways that different countries offer support to families with children who have disabilities. A recent study (Gartner, Lipsky and Turnbull, 1991) of family supports in Australia, Canada, Israel, Japan, Kenya, Sweden, the United Kingdom, the United States, and Uruguay found that, although there are significant differences among those countries, there are also significant common trends:

 A growing sense that persons with disabilities can and should live in the community and not in institutional settings. OSERS NEWS 18 PRIST



- The growth of national legislation to provide increased services to persons with disabilities, especially children.
- The development of rights-based guarantees, both to persons with disabilities and to their families, of participation in decisions affecting them.
- The belief that the environment, physical and social, is the key factor that determines the extent to which an individual's impairment becomes a disability.
- A recognition that the family, in both the attitudes it has and the support it receives, is the central social institution affecting the life of the child with disabilities.
- Increasing development of organizations among persons with disabilities, parents of children with disabilities, and other community and professional groups.

The point concerning families and supports for families with a member who has disabilities is that to provide support appropriately requires cultural understanding of both the meaning of disability and the nature and roles of families and ways in which they can be supported.

While the industrialized and wealthy countries provide a wider range of formal services, this does not always result in better support for families. Indeed, in many countries, Canada for example, there is an effort to move away from formal service provision to greater use of informal systems and natural environments. However, in less wealthy countries. Kenya for example, there are increasing efforts to develop government provided services. Another area of contrasting development is the extent to which services for people with disabilities are organized separately from the general social service system. Sweden is at least a partial resolution to this dichotomy of service delivery, with the primary design involving the incorporation of services to persons with disabilities as part of the "regular" services to various population groups.

One must guard against simply generalizing from those nine countries to the rest of the world. Yet, in those countries there is a growing body of experiential knowledge that encourages those trends. Knowledge from one country could be useful to another country. For example, the first item on the list of trends is the growth of the belief that persons with disabilities can and should live in the community. Quite obviously. living in the community will have very different meanings in different countries. However, as that belief grows. more individuals, families, and government and non-government organizations are experimenting with ways to implement community living, and there is a parallel growth in the knowledge of ways to promote living in the community.

# Basic Social Welfare Provisions and Financial Assistance

Among the nine countries there is a considerable range in basic social welfare arrangements, from the rich array of public sector provisions in Sweden to Kenya's limited resources, from the United States' reliance on employmentbased benefits to Canada's increasing preference for "natural" networks. The type and amount of assistance provided is widely different in the nine countries. Only Sweden provides support to all families with a child with a disability. Common tendencies across the nine countries include: (1) a trend toward access to common or general services: (2) growing fiscal constraints amidst expansion of service programs: (3) increased development of communitybased program designs; and (4) a growing recognition of the need to support the family with a child with a disability.

# Providing Information to Families

In each of the nine countries, the formal systems that provide information about disability exist primarily through the systems of prenatal care



and general hospitals. Overall, where these are extensive and well-developed, considerable information is available to parents regarding their child's particular condition. The extent to which government bodies provide information to families varies among the nine countries. Only to a limited extent in any of the countries is the information sensitive to the needs of differing cultural groups.

### EDUCATION

In each of the nine countries, there is a universal system of publicly supported education within which educational services for children with disabilities is provided. Both the overall systems and the services for students with disabling conditions vary as to the ages of children served and the level of government that is responsible. For the family of a child with disabilities, education is many things. First, it provides the child with the means to live a productive life. Also, education is an aspect of participating ir society. In terms of the effect of the child's education on the family, when the child attends school, especially with age cohorts, the family is viewed less as "special." Additionally, as with all families, the child's time in school frees family members from care responsibilities.

# RESPITE CARE FOR THE CHILD WITH DISABILITIES

The question here is whether taking a break from responsibility for meeting the needs of a child with a disability (respite care) is an opportunity for the nondisabled family members to take a break for earing for the member who is disabled or an opportunity for the child with a disability to benefit from a different environment and to be with other people. In six of the nine countries (Australia, Canada, Japan, Sweden, the United Kingdom, and the United States). there are government supported respite activities. Successful respite services are offered in diverse ways. In all of the countries studied there appears to be

agreement that respite services, formal or informal, are essential for families. The broad issues of respite care include: the purposes for which respite is to be provided; whether respite provisions are provided from the perspective of the family or of the child; the relationship of respite to other services the family may require: and the integration of respite care into the larger sphere of the family's life. The needs of the child with a disability and those of other family members, while they may overlap, are not identical. The growing attention to connecting respite services to informal support services, that is, allowing families to identify friends and relatives to be engaged as respite providers, is an important development.

# EMOTIONAL SUPPORT

Too often, just as the child with ai. impairment becomes the impairment, so too is the family labeled. With this label comes a set of assumptions about capacity, or more usually incapacity. Diversity among the nine countries in providing emotional support to families with a child who is disabled ranges across not only the services provided. but also the definition and purpose of services. The need for emotional support should be seen within the context of meeting the full range of the family's needs. The extent to which there is a need for emotional support is a function of the interaction between the burdens placed on the family and the resources provided both to ease the burdens and to support the family.

Family support systems have been developed in many countries as a result of the recognition that the consequences of disability affect both the individual with disabilities and the family members. Within the context of this understanding, the issue becomes the nature of the support to be provided, affected by the characteristics of the family and its dynamics as well as by the individual who is disabled. Stress is most often not a factor of psychological dysfunction but, rather, the absence of sympathetic social or economic systems.

Although the definition of "family support" varies widely among the nine countries, it is the recognition that a family offers stability, consistency, and close relationships that cannot be duplicated by institutional service systems.

The need for flexibility in services grows from the reality that no two families, with or without children with disabilities, are alike. Considerable variation exists within families; moreover, families' needs evolve and change over time. To be effective, support services must be consistent with the culturally based preferences of individual families.

# CULTURAL DIVERSITY IN THE UNITED STATES

In the United States providers and policymakers also have specific reasons for wanting to know more about the how other countries are dealing with issues related to families and disabilities. Those reasons are based on the increasing cultural pluralism of our society.

The United States has always been a nation where a significant proportion of its inhabitants were immigrants. For a long time the bulk of the migration came from European countries. In the last couple of decades, new groups of immigrants have been coming from Asia and Central and South America. Those new immigrants join an already strongly multicultural community of American Indians, African Americans, Asian Americans, and European Americans and contribute to making our country perhaps the most culturally pluralistic nation in the world. Such an abundance of cultures has implications for many different aspect of our society and for issues related to families and disabilities. There are a number of significant issues that must be dealt with in any effort to improve the effectiveness of services to minority students with disabilities. Key among them is the need to increase the cultural sensitivity of professionals who work with students and their families.



In light of the need for cultural sensitivity, one benefit of learning from the experience of cultures outside the U.S. is the potential application of their modes of service delivery.

Hispanics, for example, are the fastest growing cultural group in the U.S. As we develop services for Hispanic families who have children with disabilities, it would seem very valuable to have a better understanding of services currently in existence in Central or South America. While those services may not readily be adapted to conditions in the U.S., they may have important clues to the kinds of services that do or do not work.

# BENEFITS TO THE "MAINSTREAM" CLLTURE

There are lessons to be learned from other cultures that have broad applications. There is in the U.S. are-emergence of policy that emphasizes the value of the family. There is more recognition that psychic compensations, not just financial benefits, are important ingredients of employment satisfiction. And, particularly relevant to the lives of people with disabilities and their families, there are insistent, persistent, and largely successful attempts to structure national, state, and local policy that emphasizes interpersonal relationships among people with and without disabilities and that also assures that home-based and commu-

nity-based care, not institutional-based care, will be the policy of the national and state governments.

Thus, as the new ethic of interpersonal commitment takes hold and as policy either reflects or enables that ethic to be realized, it seems important to understand how the Latin American family. which is so family-centered, has been able to do naturally what federal and state policy seems to encourage Anglo families to undertalle as new behavior, namely, to use informal family-based supports to maintain the person with a disability at home and in the community. In effect, a deeper understanding of families who have members with disabilities in other cultures can inform and strengthen how we develop policy here in the U.S.

# THE INTERNATIONAL PROJECT AT THE BEACH CENTER ON FAMILIES AND DISABILITIES

The international program at the Beach Center is part of a greater international effort at the University of Kansas. Although the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, the U.S. Department of Education, funds the Beach Center's research and training center activities, the International Program is funded only by endowment. A portion of

the proceeds of the endowment are used to fund an award in honor of Dr. Eloisa G.E. de Lorenzo. The Eloisa de Lorenzo Award recognizes Dr. de Lorenzo's outstanding contributions on behalf of persons with disabilities and their families in the American countries. The award is presented every other year to individuals or organizations who have demonstrated excellence in the provision of services, training, or research on behalf of families who have members with disabilities.

# OTHER AREAS OF COOPERATION IN LATIN AMERICA

The Eloisa de Lorenzo Award is consistent with the belief that there is much that practitioners both in the U.S. and around the world can learn from exemplary work being done elsewhere. The Beach Center is currently pursuing other cooperative activities in Latin America, During 1991-1992, the Center is working with the Organization of American States' InterAmerican Children's Institute (IACI) in developing a comprehensive plan with a strong disability focus for the Children's Institute. That plan will help define future work with the IACI, and will include exchanges of practitioners and researchers, joint training sessions, and translations of disability-related documents.

Given its focus on families with members who are disabled, the Beach Center is currently pursuing relationships with government and non-government organizations in the American countries, especially family organizations, and in encouraging communication and sharing among those organizations.

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# NIDRR'S INDIA PROJECT

One of the lesser known facts about the National Institute on Disability and Rehabilitation Research (NIDRR) is that it has an international research program. NIDRR's legislation encourages active outreach to other countries with similar rehabilitation concerns. NIDRR cooperates in jointly-funded programs with India and Yugoslavia and has also taken part in several projects with the USSR in cooperation with the Department of State and other international agencies. NIDRR also conducts a worldwide program for the exchange of experts and information on rehabilitation.

The legislation which authorizes NIDRR tells the whole story. The Rehabilitation Act of 1973 and Amendments (Sec 204 (b)(5)), state that NIDRR should:

research, demonstration, and training for the purpose of developing new knowledge and methods in the rehabilitation of individuals with [disabilities] in the United States, cooperating with and assisting in developing and sharing information found useful in other nations in the rehabilitation of the individuals with [disabilities] and initiating a program to exchange experts and technical assistance in the field of rehabilitation of [disabled] individuals with other nations as a means of increasing the levels of skill of rehabilitation personnel."

"Conduct...a program for international rehabilitation

Paul R. Ackerman, Ph.D.

NATIONAL INSTITUTE ON
DISABILITY AND REHABILITATION RESEARCH (NIDRR)
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
UNITED STATES DEPARTMENT OF EDUCATION

Following the mandate of this statute, NIDRR developed several ongoing relationships with researchers in other countries. The largest of its efforts at the present time is with the Ministry of Welfare (MOW) of the Government of India (GOI). After a period of fifteen years of funding individual grants for discreet rehabilitation projects. NIDRR and the GOI decided that a unified course of action was needed to make global change in the pattern of services to Indians with disabilities. The scope of the program needed to be vast because there are 800 million persons in India, approximately-50 million of which have disabilities. Only the Indian government was large enough to attempt such a project and had the resources available to experiment with the research and development of models that could offer hope to India's disabled populations. The U.S. provided the expertise to assist India with the research and development of these mod-

In 1984, the project to affect this change was launched by three government staffs: the GOI, NIDRR, and the U.S. Embassy. The project is titled the "District Rehabilitation Centre (DRC) Scheme." In India, as in many other countries, a scheme is a

formal written plan. The DRC Scheme is a systematic plan for the provision of rehabilitation services to all persons with disabilities in Indian rural villages that are located in specific medical districts. At the core of this plan is an advocate or "angewaddy," a local villager trained to become the facilitator of rehabilitation to any person who has a disability.

village rehabilitation The angewaddy is employed by the GOI and performs a variety of functions to educate villagers in matters of the practical prevention of disabilities. It is also the responsibility of the "angewaddy" to identify those persons whose disabilities can be treated: to work with families and neighbors of rural residents who are disabled: to integrate the individual who is disabled into the family and community; to refer the Indian with disabilities for further treatment or rehabilitation; to work with schools to integrate children with disabilities; and to help the village blacksmith, carpenter, and cobbler fashion aids and appliances as well as repair the prosthetic devices of those persons who have physical disabilities.

The village rehabilitation angewaddy is trained by the multidisciplinary personnel of the Rehabilitation Research and Training Centers (RRTCs) and the local district hospital. He/she is paid by the Central Coordinating Unit and is provided with information through the National Information Center. Additionally, the angewaddy is supported by the research of the Rehabilitation Engineering Center (REC), and his/her work efforts are supplemented by the efforts of the job development components of the DRC Scheme. All of these components have received rupees from the U.S./India fund through the DRC Scheme project of NIDRR and the GOI.

# DRC FUNDING

The DRC Scheme grant is monitored by NIDRR and administered through the U.S. Embassy in New Delhi. The funds for the project are indigenous; that is, they come from the U.S./India

Fund of rupees, paid for U.S. grain in the 1970s but held in India at the U.S. Embassy for such cooperative research programs. A proposal is written by the MOW/GOI, and then reviewed by NIDRR. After negotiations and additional clearance from the Indian Government, the proposal is accepted. All authorizations adjustments are then made NIDRR through recommendations to the U.S. Embassy which administers the paperwork for the grant. Included in NIDRR responsibilities to the project are on-site monitoring and provision of consultations and technical assistance from the U.S. rehabilitation and special education community.



### SITE VISITS

Site visits and consultations from NIDRR and U.S. consultants to the India Project are unlike any type of domestic monitoring experiences. The trip is arduous-twenty hours of flying, and a ten and onehalf hour time difference. Visits to the local DRCs may take a full day and many kilometers of some of the most harrowing driving experiences in the world. U.S. visitors will often become involved in government recentions. meetings with highly placed government officials, and diplomatic situations.

Shortly after his appointment as assistant secretary of the Office of Special Education and Rehabilitative Services. Dr. Robert Davila received an invitation from the Indian

Government to inaugurate the job development component of the program. He accepted the invitation to show his support of the project and to further assist the Government of India in planning for programs of rehabilitation for Indians who are deaf. His site visit occurred in March of 1990 and accomplished far ...ore than its original goals. The appearance of a highly placed U.S. government official with a disability created more awareness to the general Indian public of the possibility of equality for people with disabilities than any speech given by a politician. Furthermore, Dr. Davila brought to the Indian Government the most up-to-date perspectives on rehabilitation program planning and policy implementation. One government official stated of Dr. Davila "that India will have made progress in rehabilitating its citizens with disabilities only when it, too, is represented by a gifted and productive individual like Robert Davila--regard-



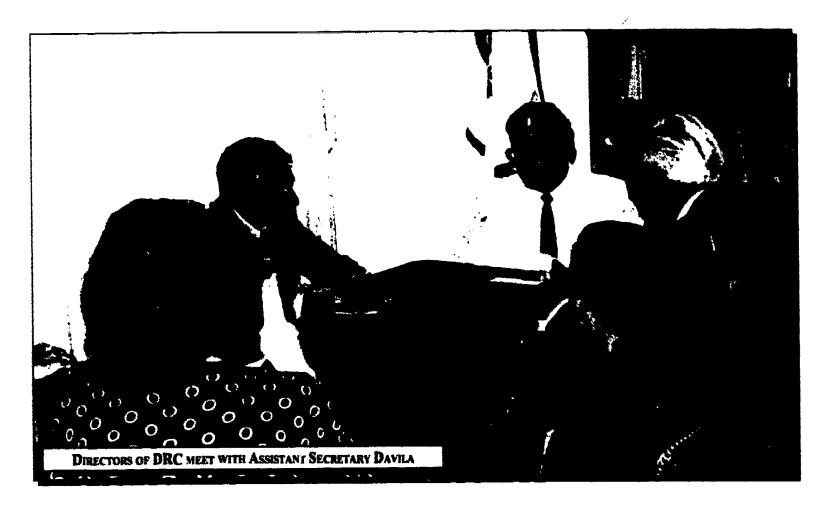
less of any disabling condition." Dr. Davila's objectives were realized when he visited the smaller centers, urban and rural. He taught the children. He signed to the clients. He advised the leaders. He was described by Embassy personnel as being the most visible example of the American ideal that the rehabilitation community in india had experienced.

# THE GROWTH OF THE DRC SCHEME

The DRC Scheme project has grown in two phases. In Phase 1, 1984 to 1989, the MOW and NIDRR systematically developed a series of village-based model programs that trained rehabilitation angewaddys in prevention, assessment, counseling, treatment, referral, and follow-up actions for assisting all ages, sexes, and types of disabling conditions found in rural set-

tings. The angewaddys utilized village craftpersons and artisans to help with architectural modifications and orthoses and prostheses. Additionally, they also began to integrate children with disabilities into the village's small school programs. These models offered the first public rehabilitation program for India's 700 million rural inhabitants.

At the end of Phase I, the program was evaluated by an independent Indian Although they found agency. management problems and unmet training needs, they also found that many villagers with disabilities were getting rehabilitation and special education services for the first time in their lives. Whole villages were integrating residents with disabilities into their communities. Schools were changing to adapt to the needs of children who needed special help. Referrals were being treated more effectively at district hospitals. O S E R S N E W S I N P R I N T



Eventually, the management problems were alleviated through administrative changes and additional training plans were developed.

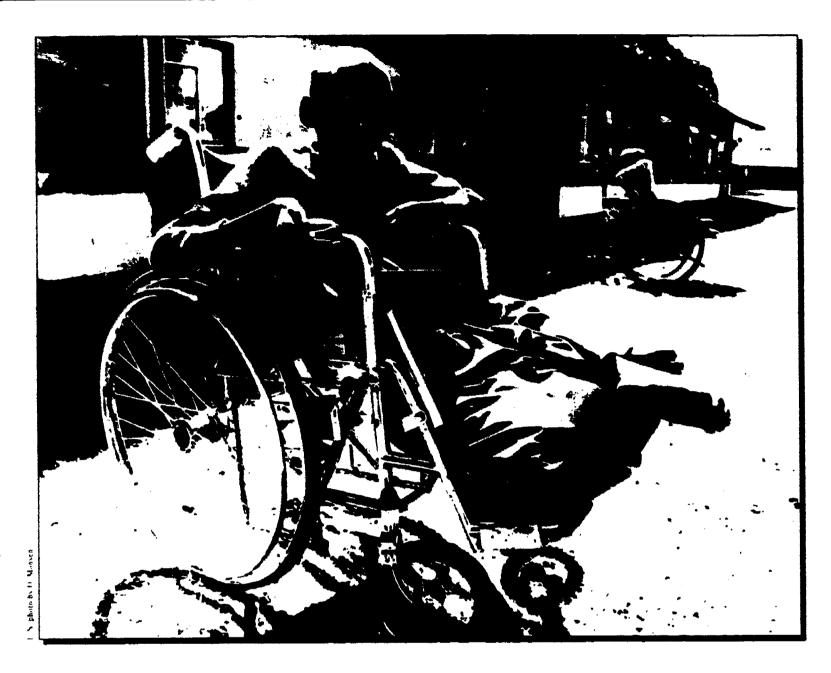
The Indian Government adopted the DRC concept in the most realistic way possible--by including the DRC program in its plans for government sponsorship. Now the Indian Government expects to replicate those first ten models from the four original districts to 100 districts within four years. serving almost one-fourth of India's rural residents. The U.S. Embassy in New Delhi has called it one of the most successful cases of research diffusion in its repertoire of 400 research projects. The DRC program has been so successful that its growth is assured through its inclusion into India's next Five Year Plan for economic and social growth and development.

Currently, the project is in its second year of Phase II. This phase contains the components that continue to support the models and the concept behind the models. Thus, the grant to the MOW/GOI contains the following elements: (1) a small central adminis-

trative and coordinating unit located in New Delhi that is responsible to the Ministry of Welfare and to NIDRR: (2) four Rehabilitation Research and Training Centers (RRTCs), located in the four quadrants of India. whose multi-disciplinary staff affect all the training of village workers and district medical personnel in rehabilitation and the modification of rehabilitative practices for rural areas: (3) a computerized documentation and information center, also located in New Delhi. to provide information on available rural resources, funding possibilities, treatment centers, training and job placement resources, and rehabilitation aids: (4) a rehabilitation technology center that will help develop India's technological capacity to meet rehabilitation needs through the funding of development and design of assistive technology aids; and (5) job development centers that research and test the possibilities of job accommodation, training, evaluation, and placement of Indians with disabilities. In 1991, the budget for these projects exceeded 20 million rupees (over \$1 million)

NIDRR director William Graves, acting upon a request by the government of India, requested the U.S. rehabilitation research community to volunteer in a consulting capacity to the Government of India. To date, over 175 dedicated rehabilitation and special education personnel have volunteered. Dr. Graves and eight volunteer consultants will be site visiting the India project in October 1991 to provide the requested specialized technical assistance to the Indian RRTCs. Within the next year, two Fulbright Scholars in rehabilitation and special education will also donate several months of time to the training of personnel. Other requests for U.S. assistance to India are being developed for the next three years of Phase II.

Qualified individuals who are interested in volunteering to participate in the DRC Scheme may call Dr. Paul Ackerman, Director of International and Interagency Activities (NIDRR), at 202/732-1115. The benefits in terms of data exchange for participants is obvious. The opportunity to benefit in terms of personal and professional growth is unparalleled.



# THE UNITED NATIONS

# AND PEOPLE WITH DISABILITIES

# Introduction

Implicit within the Charter of the United Nations are primary values. These values include the reaffirmation of the

principles of peace, the faith in human rights and fundamental freedoms, the dignity and worth of each person, and the promotion of social justice. The United Nations has a long history of commitment to assisting the world's disabled community. In 1971, the

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General Assembly adopted the "Declaration on the Rights of Mentally Retarded Persons." This Declaration states that people with mental impairments have the same rights as other citizens to proper medical care, economic security, rehabilitation, and job training, as well as the right to live in the community and in a family situation rather than in an institutional environment.

The Assembly further declared that there must be legal safeguards to enforce the rights of people with mental impairments where these rights may have been restricted or denied.

In 1975, the General Assembly adopted the "Declaration on the Rights of Disabled Persons," which proclaims that people with disabilities have the same civil and political rights as other citizens. This Declaration provides for equal treatment and services that would develop to the maximum the capabilities of persons with disabilities, while has-Aening their social integration or reintegration into society.

In a further statement of concern. the General Assembly, in 1976, proclaimed 1981 as the "International Year of Disabled Persons" and called for a plan of action at the national, regional, and international levels, with an emphasis on equalization of opportunities. rehabilitation, and the prevention of disabilities. The theme and purpose of the Year were "full participation and equality," defined as the right of persons with disabilities to participate to the fullest possible extent in the life and development of their societies; to enjoy living conditions equal to those of other citizens; and to have an equal share in improved conditions resulting from socio-economic development.

Other objectives of the Year included increasing public awareness, understanding, and acceptance of persons who are disabled and encouraging persons with disabilities to form organizations through which they could effectively express their views and call for action to improve their situations. The image of persons with disabilities depends on social attitudes, which may be the greatest barrier to the realization of their goals of full participation and equal-

# WORLD PROGRAMME **OF ACTION CONCERNING** DISABLED PERSONS

A major outcome of the 1981 International Year of Disabled Persons was the creation, in December 1982, of the World Programme of Action Concerning Disabled Persons. The World Programme of Action is a global strategy to prevent disability, to enhance rehabilitation, and to provide for the full participation of persons with disabilities in society and in the economy. It explicitly recognizes the right of all human beings to equality of opportunities, in effect extending the concept of human rights. The World Programme is a declaration of principles and guidelines for national, regional, and international action. Its three chapters include an analysis of principles, concepts, and definitions relating to disabilities; an overview of the world situation regarding persons with disabilities; and recommendations for action at the national. regional, and international levels. "Equalization of opportunities" is the underlying theme of the World Programme and its guiding philosophy for the achievement of full participation of persons with disabilities in all aspects of social and economic life. An important principle is that issues concerning persons with disabilities should be treated not in isolation but within the context of the services that are offered to the entire population. In order to promote effective measures for the prevention of disability, the rehabilitation of people with disabilities, and the realization of the goal of "full participation" of persons with disabilities in all areas of society. these concepts need to apply with the same scope and with the same urgency to all countries, regardless of their level of development.





To achieve the goals of "full participation and equality." rehabilitation measures aimed solely at the individual who is disabled are not sufficient. Experience shows that it is largely the environment that determines the efferman impairment or a disability on a person's daily life. A person is handicapped when he or she is denied the opportunities that are necessary for the fundamental elements of living. These elements include family life, education, employment, housing, financial and personal security. participation in social and political groups, religious activity, access to public facilities, and freedom of movement.

All over the world, persons with disabilities have started to unite in organizations as advocates in order to influence decision makers in government and in all sectors of society. The role of these advocacy organizations focuses on providing a voice for

individuals with disabilities, enabling them to identify specific needs, to express views on priorities, to evaluate existing services, and to advocate for change and for public awareness. As a vehicle for self development, these advocacy organizations provide the opportunity to develop skills in the negotiation process and in organizational abilities, to gain from mutual support, and to engage in information sharing.

# The United Nations Decade of Disabled Persons (1983-1992)

In order to provide an initial time frame during which governments and organizations could implement the recommended activities of the World Programme of Action, the UN General Assembly proclaimed the period 1983 to 1992 as the United Nations Decade of Disabled Persons. The major

achievement of the Decade has been an expansion of knowledge and an increase in awareness of the problems of individuals with disabilities worldwide. In countries where the will and commitment is strong, governments. service agencies, business and industry, and other organizations have worked with the disabled community to institute changes. With this united effort. significant progress has been made. In some areas, progress has been limited. and in many of the developing areas. the situation facing people with disabilities has remained largely unchanged.

# DISABILITY AND THE DEVELOPING COUNTRIES

The problems of people with disabilities in developing countries merit special attention. As many as 80 percent of all persons with disabilities

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live in isolated rural areas in the developing countries. In some of these countries, the percentage of the disabled population is estimated to be as high as 20 percent and, thus, if families and relatives are included, 50 percent of the population could be adversely affected by disability. The problem is made more complex by the fact that, for the most part, persons with disabilities are also usually extremely poor. They often live in areas where medical and other related services are scarce, or even totally absent and where disabilities are not and cannot be detected in time. In many countries, resources are not sufficient to detect and prevent disability and to meet the need for the rehabilitation and supportive services of the population with disabilities. Also, the disability problem is further compounded by the population explosion. There is, therefore, an urgent need, as the first priority, to help such countries to develop demographic policies to prevent an increase in the population with disabilities and to rehabilitate and provide services to those who are already disabled.

Much disability could be prevented through measures taken against malnutrition, environmental pollution. poor hygiene, inadequate pre-natal and post-natal care, water-borne diseases. and accidents of all types. Through a worldwide expansion of immunization programs, the international community could make a major breakthrough against disabilities caused by poliomyelitis, tetanus, whoopingcough, and diphtheria, and to a lesser extent tuberculosis. The most important measures for prevention of impairment are: avoidance of war; improvement of the educational, economic, and social status of the least privileged groups; identification of types of impairment and their causes within defined geographical areas: introduction of specific intervention measures through nutritional practices. improvement of health services; early detection and diagnosis: proper health care instruction; family planning; legislation and regulations; and the fostering of better informed and strengthened families and communities.

The transfer of resources and technology from developed to developing nations could vastly improve economic conditions in the developing countries, particularly in rural areas, providing new employment opportunities for persons with disabilities and needed resources to support measures for prevention, rehabilitation, and the equalization of opportunities. The transfer of appropriate technology could lead to the development of industries specializing in the mass production of devices and aids for dealing with the effects of physical, mental, or sensory impairments.

The United Nations encourages multilateral assistance as well as bilateral aid to developing countries for disability-related work and coordinates such activities by bringing worthwhile project proposals to the attention of donor countries. The Voluntary Fund for the UN Decade of Disabled Persons provides support to governments and organizations for catalytic and innovative projects to promote the implementation of the World Programme of Action. Priority is given to project proposals from least developed countries.

# THE YEAR 2000 AND BEYOND: A SOCIETY FOR ALL

As a major activity to mark the end of the Decade, the General Assembly is considering the proposal of a meeting of experts for a world conference. The purpose of the conference would be to adopt a long-term strategy with the theme "A society for all by the year 2010." The World Programme of Action provides an essential instrument for the continued progress of people with disabilities. It serves as a guiding philosophy for action now and in the years ahead. The mid-term analysis of progress achieved and obstacles encountered during the Decade has clearly indicated, however, the need for the formulation of priorities. identification of crucial areas of concentration as well as elaboration of appropriate measures and provision of specific guidelines for new efforts. A long-term strategy would then comprise a new set of practical objectives designed both to secure and to strengthen progress already achieved and also to speed up advancement of people with disabilities in all aspects of political. social, cultural, and economic life. The theme of such a long-term strategy would be "A Society for All." The long-term strategy would consist of four parts: an introduction; global trends and perspectives that affect the advancement of people with disabilities; national strategies and their implementation; and regional and international strategies.

For additional information and a list of publications, please contact:

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Editor's Note:
Portions of this article were taken in part from the referenced publications.





THE ROLE OF

# REHABILITATION INTERNATIONAL

# IN THE UNITED NATIONS DECADE OF DISABLED PERSONS

### BACKGROUND

The United Nations Decade of Disabled Persons (1983-1992) has the broad purpose of translating into reality the ideals and aspirations that emerged during the International Year of Disabled Persons in 1981—to ensure full participation and equality in society for all disabled persons.

The use of Years and Decades is a central information and awareness tool of the United Nations to promote universal progress in its common social agenda among its member governments.

Barbara Duncan
Assistant Secretary General
Rehabilitation International

The headquarters for coordination and implementation for the UN Decade is provided by the Center for Social Development and Humanitarian Affairs, UN Vienna International Center, Austria. The Vienna International Center is responsible for UN activities in most social issues, including aging, women, drugs, and people with disabilities. To promote the Decade throughout the world, the Vienna International Center carries

out a multitude of activities, including: Experts Meetings on specialized topics such as women and disability in the 1990s, newsletters, technical assistance projects, and coordination of disability



related actions of the UN agencies, such as UNICEF, the World Health Organization, the International Labor Organization, the UN High Commissioner for Refugees, and UNESCO.

In addition, a film, "Breaking Barriers," and a series of public awareness and technical publications have been issued by the UN to support implementation of the goals of the Decade.

# ROLE OF REHABILITATION INTERNATIONAL

Rehabilitation International (RI), founded in 1922, is the oldest non-government international organization in the disability field. Since the early 1950s, it has

enjoyed a close consultative status with the United Nations and many of its specialized agencies. Consultative status, held by hundreds of international non-government organizations (NGOs) working in social and scientific fields, essentially means that the NGO works with the UN to implement its goals and programs. On a practical day-today basis consultative status implies several types of action: the NGO utilizes its network to promote knowledge of UN programs and activities; the NGO may offer technical advice and assistance on program implementation; and the NGO may work in concert with similar NGOs to advocate that the UN initiate new projects and programs or update its philosophy and outlook on existing programs.

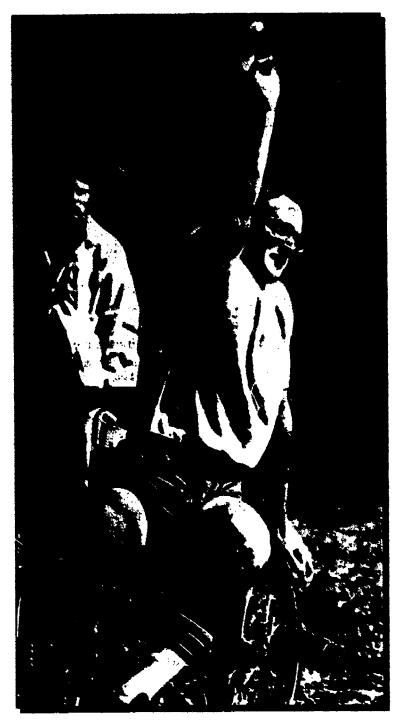
# REHABILITATION INTERNATIONAL AND THE DECADE OF DISABLED PERSONS

Rehabilitation International has the largest international network in the disability field, having 145 member organizations in eighty-three nations. In addition, through provision of the Secretariat for the International Council on Disability, it collaborates directly with more than fifty other international organizations working in the disability field.

Beginning with the International Year of Disabled Persons and continuing throughout the Decade, RI has utilized its many periodicals, conferences, and other outreach mechanisms to publicize the goals and purposes of the Decade.

RI periodicals include the International Rehabilitation Review, the International Journal of Rehabilitation Research, One In Ten (a specialized newsletter on childhood disability in developing countries), and Rehabilitacion (a Spanish language periodical covering disability developments in Latin America, Spain, and Portugal).

In each of these periodicals regular reports on the Decade have appeared. Perhaps one of the best known of these reports was a 1990 feature in the International Rehabilitation Review, entitled "The UN Decade of Disabled Persons: Can It Be Saved, Should It Be Replaced?" This comprehensive discussion featured experts from throughout the world with strong opinions about the weakness of the Decade program and concrete suggestions on how to place it on a more practical footing before its close. In general, the opinions proffered were unanimous in their assessment that the UN had not sufficiently backed the UN Decade with funds, personnel, and other resources to enable it to achieve its goals. Recognizing that this was a problem inherent to most international public education programs, the authors stressed the need for the Decade and other similar programs to have a more grounded set of achievable objectives.



RI DECADE PROJECTS

In support of the Decade, RI has undertaken two different types of projects throughout this period: technical assistance and educational programs.

Funded by the UN voluntary fund for the Decade of Disabled Persons and he Arab Gulf Fund, three technical information projects are underway. Three information kits reporting on worldwide progress in three concrete areas are being prepared for publication prior to the completion of the Decade. They are: an information kit on trends

disability prevention: manual on peer support techniques carried out by persons with disabilities involved independent living programs (in collaboration with the World Institute Disability); and a worldwide status report community-based rehabilitation activities.

The two main educational activities of Rehabilitation International which have received the imprimatur of the United Nations Decade are: the third International Abilympics. which took place in Hong Kong in August 1991; and the seventeenth World Rehabilitation Congress, to take place in Kenya in September 1992.

Abilympics is a series of events designed to illustrate to employers and to the general public the employment skills of people with disabilities. The 1991 event featured skills competitions, a conference on technology and employment, a technology exhibition, and a Guiness Book of World Records event.

The seventeenth World Congress of Rehabilitation International, under the patronage of the President of Kenya. is RI's first global event in Africa. It is being planned to attract maximum attention to the situation of disabled people in developing countries. par-

ticularly geared to the needs of African countries and will produce strategies for the coming decade. It has been accepted by the UN as the premiere event to culminate the Decade in the African region.

# COLLABORATIVE PROJECTS

In addition to the above projects being carried out by RI, the organization is also working closely with other international agencies in their Decade projects. Among current efforts are: contributions to a United Nations information kit on women and disability and active participation in the UN Global Project for the UN Decade. The Global Project, under UN auspices, is working to launch a worldwide fund-raising and consciousness-raising campaign to create wider support for disability projects. particularly in developing countries. The Global Project is particularly interested to involve U.S. disability groups in its efforts and can be contacted as follows: Rachel Hurst, Global Project, Room 109, 11 Belgrave Road, London, SW1V IRB. England: telephone 71-834-0477; fax 71-821-9539.

# THE UN DECADE AND THE UNITED STATES

Primarily, the United Nations works in each country through its member governments. In the case of the United States, two groups in particular have been active supporters and centers of information about the UN Decade of Disabled Persons They are the National Organization on Disability, Washington, D.C., which initiated a world committee for the UN Decade; and the National Council on Disability, Washington, D.C. which represented the United States at several UN meetings on the Decade.

For copies of the International Rehabilitation Review reports on the UN Decade or for other RI publications. contact: Rehabilitation International, 25 East 21 Street, New York, New York, 10010, telephone 212/420-1500, fax 212/505-0871.



# AN INTERNATIONAL PROJECT THAT PROVIDES OPPORTUNITIES TO LEARN

ABOUT POLICIES, PROGRAMS, AND PRACTICES IN OTHER COUNTRIES

### Introduction

Since 1978, the World Rehabilitation Fund in New York City has been funded to carry out the International Exchange of Experts and Information in Rehabilitation (IEEIR) through grants from the National Institute on Disability and Rehabilitation Research (NIDRR) and its predecessors. The idea is to "import" and make available to the U.S. disability community knowledge

Diane E. Woods
International Exchange of
Experts and Information
In Rehabilitation

about disability issues and exemplary programs in other countries. The methods by which the aims of the program have been carried out are (1) through the awarding of short-term fellowships to U.S. disability specialists to study

overseas; (2) through publishing monographs prepared by foreign and U.S. experts; and (3) through the convening of seminars, meetings, and symposia related to selected monographs or fellowship topics.

Initially, the World Rehabilitation Fund responded to a Request for Proposals (RFP) developed out of legislation appearing in the Developmental Disabilities Amendments of 1978 to the Rehabilitation Act of 1973.

The World Rehabilitation Fund received funding for two international projects. One project was based on the effectiveness of "first-hand purposeful experiences," i.e. stud, visits; the other project considered the viability of brief, state of the art, targeted topical monographs, as methods for dissemination and utilization of ideas from other countries, with the "utilization" conference used as a method to increase interest in certain topic areas written about in the monograph.

After the first three years, the two projects, the International Exchange of Experts in Rehabilitation (fellowships) and the International Exchange of Infermation in Rehabilitation (monographs), were combined into one program, iestead of three-month fellowships offered to fifteen "experts" per year, the project was able to offer ten three- to six-week fellowships per year. Instead of being able to hold all-expenses-paid utilization conferences on three out of the five monographs published each year, the utilization component had to be altered in a way that encouraged piggybacking with national conferences and co-sylvasoring conferences and meetings \ 1 other interested organizations.

Basic changes which have been made over the course of the project include:

- In 1981 the project expanded to include any country in the world (the first three years of the project focused only on the U.K., Sweden, Japan, and Australia);
- In 1987 NIDRR funded another similar project and asked the World Rehabilitation Fund/IEEIR to handle exchanges with Asia and the Pacific and Africa, while the World Institute on Disability handles exchanges with Europe, Canada, and Latin America.
- In 1990 the project changed venue: the University of New Hampshire (UNH) is the new site.
   (The World Rehabilitation Fund subcontracts the grant to UNH and the project is now affiliated with



the Institute on Disability, a University Affiliated Program.)

# PRIMARY OBJECTIVES AND PROJECT THEME

The primary objectives of the current project funded by the National Institute on Disability and Rehabilitation Research (NIDRR) from September 1990 through September 1993 are:

To create a collegial, active network of U.S. and foreign researchers on issues and subjects which are key to the disability/rehabilitation community;

- To greatly increase the amount, quality, and impact of information and data flowing between these groups:
- To effect a closer collaboration among researchers and leaders in this field who have disabilities and those who do not; and
- To identify and "import" the best foreign innovations in disability/ rehabilitation research and practice and to augment the identification and "export" of the best from the United States.

Activities that support these objectives include the following:

- The project provides opportunities through fellowships for experts on disability issues in the U.S. in areas of their expertise to study exemplary programs, pracnices, policies, and research in other countries, and to make use of and disseminate that knowledge in the U.S.
- The project prepares written monographs about programs, practices, policies, and research abroad
- The project provides opportunities for U.S. and overseas experts to increase the potential for utilization and dissemination of new ideas and to develop a more extensive transnational network.

The general theme of this project is "Lifespan Habilitative and Rehabilitation Policies, Practices, Programs and Research." Using resources here in the U.S. and linking with resources abroad a range of topic areas that are receiving priority consideration and funding here in the U.S. include:

- · Services to infants and toddlers:
- Issues related to aging with a disability or becoming disabled late in life;
- Special needs at times of life transitions;
- New funding patterns and financing of services for persons with disabilities including developing standards for certifying new kinds of care givers such as case managers;
- The relationship of life-span needs to living independently in the community;
- Delivery of services to underserved populations such as those living in rural and isolated areas, victims of disasters, and refugee populations;
- New technologies and appropriate access to technology throughout the life span;
- Psychiatric and psychosocial rehabilitation of persons with chronic mental illness, including

- the need for better cooperation among providers of services; and
- New employment schemes especially for young adults and aging citizens.

# PEOPLE WITH DISABILITIES IN SOCIETY: "TRADITIONAL" VIEWS OF DISABILITY

Because the IEEIR is no longer handling exchanges with Europe and Canada where exemplary programs and practices abound, we have to be able to hone in on learning experiences which are available in the "developing" world. To this end another concurrent theme has emerged which can best be stated generally as "People with Disabilities in Society: Traditional Views of Disability."

Ideas that are currently being explored include how traditional societies cope with change, to what extent people with disabilities are included into the society, and what happens when the traditional role in the culture of the person with disability changes. This gives IEEIR the opportunity to examine the effects of western disability advocacy approaches and concerns on traditional societies.

Another topic area which builds on advocacy and consumer concerns, is that of trends relevant to persons with psychiatric disabilities. In cooperation with other groups such as the Boston Center for Psychiatric Rehabilitation, it is expected that the IEEIR will explore the changing role of the person with mental illness in society.

In January and Fabruary 1991 forty contacts in Asia and Fabruary 1991 forty the following questions in anticipation of developing potential fellowship sites, as well as gathering written material for a monograph which addresses the People with Disabilities in Society theme:

 In what way are people with disabilities viewed in your society, and how is that changing or not changing?

- In what ways have the availability of programs and services been improved (or not)?
- What is the role of "professional standards and practices" in your country?
- What roles do the family, school, church, and other community organizations play in enabling people with disabilities to participate in society?
- How has your country responded to needs of family members and used them as resources in the rehabilitation process?
- How have people with disabilities themselves influenced change? Can you identify leaders of a "disability rights" movement in your country?
- Do you feel that U.S. disability rights advocates should be working with people with disabilities in your country to help them become more aware of their place in society? What suggestions might you have in this regard?

There is a growing interest on the part of U.S. disability advocacy groups to assist people with disabilities in emerging countries to recognize their own rights and values in society. However, cross-cultural education often does not adequately take into consideration values, mores, and attitudes towards individuals with disabilities in other countries.

# Some Examples of Lessons Already Learned FROM ABROAD

Richard Tyler, who has been involved in cochlear implant work on adults for over eight years, visited several of the children's cochlear implant centers in Australia. During the visit. Tyler not only learned about their program, observed children with implants, visited schools for the deaf, and talked to parents, but actually interacted with clinicians to design new tests for children with hearing impairments. Upon returning to the U.S., many of the de-

tails of the Australian children's cochlear implant program have been incorporated into a similar program at the University of Iowa.

Judy Kugelmass investigated the impact of having a child with a mental disability on the lives of fourteen families in Bandung, Indonesia. Through in-depth interviews and participant observation in the homes, schools, and communities of these families, she discovered a system of caring that provided children with environments that maximized their functioning while providing support to their families.

Tom Kay spent five weeks in New Zealand and Australia studying treatment of persons with traumatic brain injury. The early intervention approach of his hosts to minor head injury and the style of working early on with post-concussion patients has been extremely helpful in guiding Kay's research in minor head injury within the Research and Training Center on Head Trauma and Stroke at New York University Medical Center.

The purpose of **Douglas Biklen's** study visit was to observe, learn, and

report on facilitated communication. As a result of the visit to the DEAL Communication Centre. in Melbourne, Australia, Biklen was able to draw the following conclusions: 1) Rosemary Crossley's use of facilitated communication has enabled people with autism and other developmental disabilities to demonstrate unexpected literacy skills; 2) The methods that constitute facilitated communication will likely force revisions in how we think about autism as well as other disabilities.

Hearings on HR4267 and S933, respectively the House and Senate versions of the Television Decoder Circuitry Act of 1990, were held May 2 (House) and June 20 (Senate). The two bills are among the most important outcomes from the World Rehabilitation Fund fellowship-study visit to Japan and Korea by Frank G. Bowe, Professor. Hofstra University. Bowe made his September 1989 visit to the Far East at the request of Senator Tom Harkin (D-IA). who indicated he would likely introduce legislation if Japanese and Korean television manufacturers indicated support, or at least non-opposition, for such lawmaking. Bowe asked the Far East manufacturers, who make more than 90 percent of all televisions sold in the United States, if they would agree to incorporate closed-captioning computer chips into their TV set designs. The firms indicated they would not oppose any such effort by the United States as long as sufficient lead time were allowed. Senator Harkin's bill set October 1992 as the deadline, a date the Japanese and Korean firms found acceptable.

These are but a few recent examples of how some study-visits have incluenced research and practice and provided general enrichment here in the U.S.

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# A MESSAGE FROM THE EDITOR

The editor and staff of OSERS News In Print wish to apoligize for the production and printing errors that occurred in our Summer 1991 issue. These errors are minor and do not affect the content or presentation of the issue. We hope that you will continue to enjoy OSERS News In Print, and we will endeavor to be error free in the future.

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