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The National Newsletter for Independent Living

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Dear Colleagues,

We have been holding up this issue of ILRU INSIGHTS in order to bring you information as up-to-date as possible on three important stories that promised to break during the summer. And break they have. One concerns the JM Foundation's announcement of its 1990 Search for Excellence program which includes independent living centers as a category for the first time. Another involves the just-concluded meeting of the Robert Wood Johnson Foundation national advisory committee to select independent living centers to advance to the next stage of its independent living project. The third and most momentous is the signing of ADA--which is the lead story.

ADA SIGNING

As all of you know, the Americans with Disabilities Act (ADA) was signed into law by President Bush on July 26. As you also know, the signing was a major event, taking place on the White House South Lawn and attended by over 3,000 supporters of the disability movement--said to be the largest audience ever to attend a White House bill-signing ceremony. It was also observed by countless others as it was televised live on the CNN cable network and replayed on news clips on national and local news throughout the day.

On the podium with President Bush, Mrs. Bush, and Vice-president Quayle were four guests of honor: Justin Dart, chair of the President's Committee on Employment of People with Disabilities; Evan Kemp, chair of the Equal Employment Opportunity Commission; Sandra Parrino, chair of the National Council on Disability; and the Reverend Harold Wilke, long-time disability movement supporter. Following a stirring speech by the President, which was interrupted several times by applause from the appreciative audience, the bill was signed. Mr. Bush used four different pens for the signing, and gave one to each of the four honored guests on the podium with him.

Immediately after the signing ceremony, the 3,000-plus people in the audience attended a celebratory picnic which was held on the Ellipse--grounds located between the White House and the Washington Monument. And, that

evening, a Congressional reception was held to honor members of Congress and individuals in the disability movement who supported ADA, and over 1,000 individuals attended.

The news clip we saw most frequently in Houston was of the President interrupting his signing to hand the first pen to Justin Dart. It was a very special moment--unforgettable and a fitting cap to a remarkable two-year effort to have this law passed which would secure civil rights for persons with disabilities. It seems fitting to take a moment to acknowledge the beginnings of ADA. As you recall, back in 1988 ADA took form under then-National Council on Disability executive director Lex Frieden, and it was given momentum by Justin Dart as chair of the Congressional Task Force on Rights and Empowerment of Americans with Disabilities. The foresight and leadership they displayed at the inception of ADA as well as throughout the lengthy process to see it become law contributed significantly to the success we celebrate this day.

BEHIND THE SCENES OF THE ADA SIGNING

This was without question one of the landmark occasions of the disability movement, and by all accounts it was splendidly carried out from beginning to ending. A number of people in the disability movement worked incredibly hard in the very short period of time available to make the signing and all the surrounding events to be as grand as the occasion demanded.

We are able to bring you a behind-the-scenes view of activities surrounding the signing ceremony because our colleague, Peg Nosek, was in D.C. the week before the event, attending a meeting of the American Congress of Rehabilitation Medicine. Word came down on Wednesday the 18th that the signing was set for the 26th, and Peg immediately contacted Justin Dart to volunteer to stay over and assist him with preparations.

According to Peg, the main activities that had to be done by the White House prior to the 26th were to compile a list of individuals to attend the signing ceremony and to mail invitations to them. The White House requested prominent supporters of ADA to submit names for the list. Those contacted included senate and congressional representatives who had been instrumental in the passage of ADA, Justin, and the Consortium for Citizens with Disabilities (which represents over 80 cross-disability organizations). Peg says that there was also a list submitted of people in independent living, presumably all center directors. From all the names submitted, the White House compiled a list of 3,500 individuals. According to Peg, the White House considered this list to be final by Monday afternoon, the 23rd, and no additional names were accepted except on the specific request of a senator or representative.

Apparently invitations went out immediately, because one of Peg's duties was to cover ADA-related telephone calls. She says that the calls fell into two basic categories. One involved people who received more than one invitation and wished to give the extra to someone else. This was not possible because only those with their names on the White House list would be admitted. The second involved people who were not invited and wanted to be. Up until Monday the 23rd, these names were submitted to the White House, but after then, people were told to contact their Congressional representatives. (If we as a movement have learned anything from this experience with ADA it is all the different ways

we need to work with our representatives, and how to get over being shy about asking them to do things on our behalf.)

There was a mild and amusing flap over whether or not attendants would be admitted to the signing ceremony. Peg fielded many calls on this. For, if you can believe it, a number of creative people saw this as a means of gaining admittance for their wives, husbands, parents, children, and other significant others whose names could not be added to the White House list. It was decided that if someone clearly needed an attendant, the attendant would not be sent away. Peg got a call from an associate of ours in a neighboring state who is a long-time movement person who wanted his 83 year old mother listed as his attendant, but acknowledged that they would probably both need attendants of their own. Not long after this call, it was decided that no more than one attendant per person would be allowed. Following the law that for all rules there are exceptions, Peg received a call from a woman in a hospital with a broken hip who said that she would need to be accompanied by two attendants, because it would take two to push her in a stretcher, and she did not want to miss this event no matter what. Sure enough, she came straight from the hospital, stretcher, two attendants, and all.

For the picnic, Sharon Mistler, executive director of the ENDependence Center of Northern Virginia in Arlington, took lead responsibility for making logistical arrangements--and as you can imagine when planning for 3,000 guests, they were awesome. For those of you with an interest in material things, the picnic cuisine featured fried chicken, salad, and soft drinks, the exact equivalents of which you can obtain at any nearby fast-food chain restaurant. There was also a cake which was decorated with pictures of the President and Representative Hoyer and Senator Harkin.

The Congressional reception, which took place on Thursday evening from 4 to 7 p.m., was organized primarily by Pat Wright and Liz Savage of the Consortium. The reception was held at the Hart Senate Office Building and attended by over 1,000 people. Unfortunately, many of those attending the signing ceremony, including our associates from Houston, had to miss this event in order to make return trips home. One thing they missed was a decidedly more upscale cuisine--lobster and shrimp donated by Red Lobster as well as salad donated by McDonald's. There was also another spectacular cake. This one was decorated with "ADA" and a picture of Mr. Bush. The cakes at both the picnic and the reception were prepared and donated by the Heidelberg Pastry Shop in Arlington.

One of Peg's assignments for both the reception and the picnic was to contact Capitol Hill heavyweights to ask them to speak at both events. The response was great, with over 30 members of Congress and Administration officials speaking at both events. Speakers from the Senate were Bob Dole, Tom Harkin, Orrin Hatch, James Jeffords, Ted Kennedy, John McCain, and Paul Simon. Representatives included Steve Bartlett, Jack Brooks, Hamilton Fish, Steny Hoyer, Norman Mineta, Major Owens, and former representative Tony Coelho. Representing the Administration were Vice-president Quayle, Attorney General Dick Thornburgh, and White House staffer George Covington. Speakers addressing the importance of this day from the perspective of the disability movement included Justin Dart, Evan Kemp, Pat Wright, Sharon Mistler, as well as Ralph Neas of the Leadership Conference on Civil Rights, Marilyn Golden of DREDF, Janet Dorsey, assistant post master of the Senate, and Ted Kennedy, Jr.

Both the picnic and the reception were privately sponsored and made possible through funds generously donated by the Dole Foundation, the Paralyzed Veterans of America, McDonald's, Tony Coelho, and Justin and Yoshiko Dart.

When we asked our colleagues who attended the signing ceremony about their impressions of the event, we were told that there was a great sense of excitement and awe over the importance of the occasion. Peg was struck by the extreme cordiality of the White House staff. As one entered (having gone through metal detectors), staff greeted each individual with a hearty "Welcome to the White House." On entering, people were handed a flier with a synopsis of ADA, another flier that was a factsheet on ADA, still another flier with invitations to the picnic and reception, small American flags, and boutonnieres. During the signing ceremony, as the temperature crept steadily upward, ice tea, lemonade, and ice water were passed out to people in the audience.

People came from all across the nation to be at the signing ceremony. We have heard only a few of what must be many wonderful stories. The woman who came on the stretcher. The person from South Dakota who drove all night to arrive just in time for the signing. The people at ADAPT headquarters in Denver who pooled their funds to send not the top-level administrators but a person who represented much that the movement is trying to achieve--a man who formerly lived several years in a nursing home and now is married and living independently in the community. The former director of a center who gave his hard-earned frequent flier credits to a consumer long involved in movement activities so that she could fly herself and her attendant to D.C. A person who obtained contributions from movement people in different communities all over one state in the southwest to purchase airline tickets for a married couple extremely active in ADAPT who could not afford the airfare. A couple prominent in the disability movement covered the expenses for the woman to attend the signing ceremony whom President Bush mentioned in his speech as being unable to go into the theater in her hometown.

What was the mood of the people who traveled from all over the country to attend this extraordinary event? Exhilaration and pride and great happiness. There was apparently an acute awareness by many people in attendance--and many of us back home--that, for the movement, this was the event of the century. Peg told us that Justin had some 1,000 buttons made which said, "Independence Day One, July 26, 1990." It is certainly a day that few of us will ever forget.

ADA REGULATIONS

The feds are wasting no time in developing regulations for ADA. In the August 1 issue of the Federal Register (on page 31192), there appears a call for comments. The request is for interested parties to submit ideas, comments, or concerns which should be considered in the course of framing the regulations. Among other things, the regulations will address what is meant by the terms, "disability," "reasonable accommodation," and "undue hardship." Send comments by August 31 to Frances M. Hart, Executive Officer, Executive Secretariat, Equal Employment Opportunity Commission, 1881 "L" Street N.W., Washington, D.C. 20507. The announcement says that there will be additional opportunity for comment following the "notice of proposed rulemaking."

SEARCH FOR THE MOST EXCELLENT ILC

The JM Foundation's fifth annual Search for Excellence in programs for people with disabilities will for the first time include independent living centers as a category. The Search for Excellence program is a national competition to recognize the most outstanding program in the country in a given category, based primarily on impact on the lives of people it serves. Independent living is one of three categories in which searches will be conducted in 1990.

The winning center will be presented with \$20,000 and an award designed specifically for the 1990 Search. In addition, it and the other centers that are finalists will be honored at a reception in Washington, D.C., along with winners and finalists in the three other categories. The three other categories for the 1990 Search include community-based work services (supported employment), community-based employability development, and facility-based employability development.

Eligibility criteria: Independent living centers that have been in operation at least one year, provide multiple services, serve people with a variety of disabling conditions, and have policy boards composed of at least 51 percent of persons with disabilities. Centers of all types, sizes, and locations are encouraged to participate. A number of leading figures in the independent living movement were involved in developing the application process, including Marca Bristo, Lex Frieden, Peg Nosek, June Kailes, Brenda Premo, Judy Heumann, Michael Winters, Sam Dardick, Jim Budde, Joe Klier, and Charlie Carr.

Application materials were sent in mid-July. Completed applications must be submitted by August 24. One of the sets of mailing labels being used is our Directory of Independent Living Programs, so most of you should receive an application set automatically. If you do not, however, or if you have questions about the Search, contact Gary Prazak at Walker and Associates in Minneapolis, (612) 870-4420.

RWJ FOUNDATION ILC PROJECT UPDATE

We just received this statement from staff of the Robert Wood Johnson Foundation:

"Another step has just been taken in the selection of community agencies to be awarded planning grants under the Robert Wood Johnson Foundation's program to improve service systems for people with disabilities. On August 9, the program's national advisory committee members met to identify centers that they believe have the best potential for improving independent living opportunities for people with disabilities. They based their decisions on comprehensive reviews of centers' proposals and one-day site visits at each center under consideration.

"According to Lex Frieden, who is the RWJ program director, the committee's decisions were very difficult due to the overall excellence of the proposals and the impressive showings made by centers during the site visits.

"The committee's recommendations will be forwarded to the Foundation's staff for review, and from there to the board of trustees. At their October

meeting, the trustees will make final grant award decisions. Funded projects will begin November 1."

We have learned that it is not the practice of the RWJ Foundation to make public at this stage the names of programs still under consideration for funding.

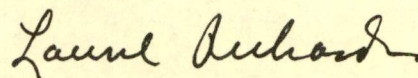
BONUS INSERT NUMBER ONE

Readers on this issue of ILRU INSIGHTS are provided with two captivating inserts. The first is the second set of updates to our 1990 edition of the ILRU Directory of Independent Living Programs. A copy of the 1990 Directory, which contains nearly 400 entries, can be obtained from us (at the address given below) for \$8.50. A copy of the first set of updates, also approximately six pages, are available on request.

BONUS INSERT NUMBER TWO

The second insert lists some of the publications available from ILRU which make for fascinating reading, especially in late summer/early fall. Topics examined include advocacy and how centers can more effectively fulfill their mission in this area, how state voc rehab agencies are using their Title VII, Part A funds, areas in which centers are vulnerable to legal liability, insurance coverage to protect centers against liability lawsuits, and so on. All are priced with your meager pocketbook in mind.

Cordially,



Laurel Richards for the
ILRU INSIGHTS Editors

ILRU INSIGHTS Editors: Laurel Richards, Laurie Gerken, Peg Nosek, and Quentin Smith. Production: Rose Shepard, Shirley Herzog, and Dawn Heinsohn.

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The editors welcome any comments on articles, suggestions for future articles, and recommendations for making this newsletter more responsive to the needs of persons involved in the field of independent living.

ILRU INSIGHTS is a publication of the ILRU Research and Training Center on Independent Living at TIRR; 3400 Bissonnet, Suite 101; Houston, TX 77005; 713-666-6244, 666-0643 (TDD).

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REPUBLICAN DISABILITY REPORT

President Bush signs landmark legislation for disabled rights

With the sweep of a pen, President Bush knocked down long-standing walls of discrimination as he signed into law the Americans with Disabilities Act (ADA) — the civil rights act for the disabled.

The President signed the act July 26, at a White House ceremony attended by senior government leaders and disabled citizens who had worked to create and pass the bill.

The President said that with the signing of the landmark legislation, "every man, woman and child with a

disability can now pass through once-closed doors into a bright new era of equality, independence and freedom."

The goal of the ADA is simple: Provide equal employment opportunities and access to public services for individuals with disabilities.



Joyce C. Natchayan/The White House

President Bush signs ADA bill at White House. With him are, clockwise from left: Evan Kemp, Chairman, Equal Employment Opportunities Commission; Rev. Harold Wilkie; Sandy Parrino, Chairperson, National Council on Disability; and Justin Dart, Jr., Chairman, President's Committee on Employment of People with Disabilities.

Under the act, an employer must provide any disabled individual equal opportunity

in employment. The act also specifies that all disabled individuals must have full and equal access to goods, services, facilities, privileges, advantages, and accommodations available to all Americans.

ADA will provide equal employment opportunities and access to public services for those with disabilities.

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A message from the chairman

As chairman of the Republican National Committee, I can tell you that our party's commitment to the disabled is real and immediate.

There must be no barriers to having the minds and creative powers of disabled citizens involved in our policies and in our campaigns. That's President Bush's directive.

And the President's words are matched by his leadership in deeds. President Bush recently signed the Americans with Disabilities Act (ADA), of which he has been a strong supporter. It could be said that if Abraham Lincoln was the great emancipator for Black Americans, then George Bush is the great emancipator for Americans with Disabilities. For Americans with disabilities, this is their Civil Rights bill.

ADA will work to eliminate attitudinal, architectural, and communications barriers in employment, transportation, public accommodations, public services and telecommunications. Greater access, greater opportunity, fuller lives— these are the goals of the ADA, President Bush and our Party.

The GOP understands what the disabled have experienced: Discrimina-

tion can be rooted in things other than color or creed. The disabled know that it isn't only the human heart that can discriminate — but the physical world, with doors too narrow, transportation that cannot be taken, and buildings without access.



Lee Atwater

Today, two-thirds of all disabled Americans between the ages of 16 and 64 are not working. The overwhelming majority of these citizens want to work. The psychological costs are great for disabled citizens who cannot work because of imposed physical barriers or discrimination. Being disabled should not mean being disengaged from American society. We must bring the disabled into mainstream society — where they belong.

The Bush Administration's commitment to tearing down the walls of discrimination is powerful, and we are committed to broadening opportunities for all Americans.

Republicans are proud of this Administration's powerful commitment to ending discrimination and broadening opportunity for more Americans. Together we will achieve our goals.

Bush tells Committee:

Disabled belong in mainstream America

Calling the Americans with Disabilities Act (ADA) one of the country's most important pieces of legislation ever, President Bush stated that it is time — past time — that people with disabilities are included in the mainstream of American life.

opportunities to millions of Americans with disabilities."

President Bush praised Justin Dart, Jr., chairman of the President's Committee on Employment of People with Disabilities, as a great humanitarian and one of the strongest advocates for equal rights and equal opportunity for all Americans.

Addressing the President's Committee Meeting on Employment of People with Disabilities, President Bush said, "The ADA will form the foundation for policies and programs that can create opportunities for Americans with disabilities to find and hold jobs, and to enjoy the income and satisfaction that productive participation in society brings to us all. No longer can we allow ignorance or prejudice to deny



Susan Biddle/The White House

Bush signs landmark disabled rights bill

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The act was originally drafted and presented to Congress by President Reagan's Council on Disability. After two years of hard work the ADA evolved and was passed overwhelmingly by the U.S. Senate last fall and the U.S. House this spring.

"As a person with a disability, I take great pride in contributing to the enactment of legislation which will go a long way toward eliminating the attitudinal barriers that have plagued us for generations,"

said Republican leader Bob Dole, a key backer of the bill.

ADA's passage also will have a direct benefit for the economy. The ADA will promote independence, allowing disabled individuals to enter mainstream America. The result will be more disabled people working, increased earnings, less dependence on the Social Security system, increased spending on consumer goods and increased tax revenues.

Vice President visits San Diego disabled center

Vice President Dan Quayle, right, talks with Raymond Zannella, Assistant Director for Business Enterprises for the San Diego-based Community Service Center for the Disabled. Quayle visited the center with Sen. Pete Wilson, second from right, to view the work done by the organization and to meet with its staff to discuss disability issues and the administration's strong commitment to the rights of the disabled.



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REPUBLICAN DISABILITY REPORT

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 310 First Street, S.E.
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Lee Atwater
 Chairman

Jeanie Austin
 Co-Chairman

Republican National Committee
 310 First Street, S.E.
 Washington, D.C. 20003



THE AMERICANS WITH DISABILITIES ACT OF 1990

OCTOBER 1990

SPECIAL REPORT

On July 26, 1990, President Bush signed into law The Americans With Disabilities Act of 1990 ("ADA"), which he called "the world's first comprehensive declaration of equality for people with disabilities." The sweeping impact of this legislation is evident from the law's finding that some 43 million Americans (approximately one of every six United States residents) have one or more physical or mental disabilities "and this number is increasing as the population as a whole is growing older."

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- IV. PUBLIC ACCOMMODATIONS AND SERVICES OPERATED BY PRIVATE COMPANIES
- V. TELECOMMUNICATIONS

The ADA prohibits discrimination against disabled individuals and requires accommodations to disabilities in employment, public services, transportation and telecommunications. It also requires non-discriminatory provision of services and accommodations by private entities.

This is a summary of the major provisions of the Act; it is not exhaustive and should not be considered legal advice. We also caution that regulations will be promulgated by the federal agencies charged with enforcement of the Act; these regulations will have the force of law.

It should also be noted that while some of the provisions of the ADA will not take effect for over a year, many requirements of the Act are already applicable under federal or state laws currently in effect. For example, at least 45 states and the District of Columbia have laws prohibiting discrimination in employment on the basis of disability, and the Rehabilitation Act of 1973 bars handicap discrimination and requires affirmative action by federal contractors and aid recipients. Similarly, the Fair Housing Act prohibits discrimination on the basis of handicap in the sale or rental of housing.



I. DISABILITY

The ADA uses the same broad definition of "disability" used to define "handicap" in the Rehabilitation Act of 1973. Different terminology is used in the ADA because many persons with disabilities and the organizations representing them object to the use of the terms "handicapped person" and "the handicapped." An individual is disabled if he or she has (1) a physical or mental impairment that "substantially limits one or more of the major life activities" of the individual; (2) "a record of such impairment," or (3) "is regarded as having such an impairment."

Physical or Mental Impairment

Any physiological, mental, or psychological disorder or condition which substantially limits such "major life activities" as walking, learning, caring for oneself, performing manual tasks, seeing, hearing, breathing or working is a qualifying condition. Examples range from conditions requiring wheelchairs to impairments such as cancer, heart disease, epilepsy, diabetes, learning disorders, psychoses, mental retardation, alcoholism, and infection with the human immunodeficiency virus.

The breadth of the ADA's definition of disability is implicit in the narrow range of the statutory exclusions from the definition. The only specific exclusions are transvestism, transsexualism, homosexuality, bisexuality, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, other sexual behavior disorders, compulsive gambling, kleptomania, pyromania, and psychoactive substance use disorders resulting from *current* use of drugs.

Record of Impairment

Individuals who have no current impairment, such as persons who have recovered from cancer, are also considered disabled for the purposes of the Act. Persons who have been misclassified as having an impairment, such as

persons erroneously classified as mentally retarded, are also covered.

Regarded as Having an Impairment

A person who is not and has never been impaired is covered if the individual is treated by a covered entity as if he or she had an impairment which substantially limits a major life activity.

Examples include severe burn victims, who are sometimes discriminated against because of their appearance, and persons who have no current back impairment but who are rejected by an employer on the basis of an x-ray which reveals an anomaly.

FACTS ABOUT DISABLED AMERICANS

67% of individuals between the ages of 16 and 64 who have disabilities are not working

67% of non-working disabled persons say they would like to have a job

50% of adults with disabilities have household incomes of \$15,000 or less

40% of adults with disabilities have less than a high school education

80% of company managers surveyed in a Harris Poll said disabled people often encounter job discrimination

Source: Report of Senate Committee on Labor and Human Resources

II. EMPLOYMENT

Coverage and Effective Date

The employment title of the ADA takes effect July 26, 1992, for employers with 25 or more employees; two years later, coverage extends to employers with 15 or more employees. Tax-exempt bona fide private clubs are not covered by the Act. State and local governments are covered. The Equal Employment Opportunity Commission (EEOC) is required to issue regulations under the Act at least a year before it becomes effective. These regulations will be substantive in nature.

Discrimination Prohibited

The ADA prohibits discrimination against any "qualified individual with a disability" in any term and condition of employment, including job application procedures, hiring, training, compensation, advancement and discharge. This general ban on discrimination does not require employers to give preference to persons with disabilities. It is supplemented, however, by several provisions which require employers to take positive steps to provide disabled individuals with employment opportunities.

Employment Decisions Must be Based on the "Essential Functions" of a Job

A "qualified individual with a disability" is "an individual with a disability who, *with or without reasonable accommodation*, can perform the *essential functions* of the employment position that such individual holds or desires." It is discriminatory to disqualify an applicant or employee from a particular position because he or she cannot perform a task which bears only a marginal relationship to a particular job. An example provided in the legislative history suggests that it would be discriminatory for an employer to require ability to drive for a job which does not regularly require driving because the employer believes that someone who drives is likely to be on time or may be available to do an occasional errand.

Consideration shall be given to the employer's judgment as to what functions of the job are essential. If the employer has prepared a written job description before advertising or interviewing applicants for a job, the job description shall be "considered" as evidence of the essential functions of the job. While the employer's judgment is to be given weight, it is not dispositive.

"Reasonable Accommodation" Required

It is discriminatory for an employer to refuse to make "reasonable accommodation" to a known physical or mental limitation of an otherwise qualified applicant or employee unless the accommodation would impose an "undue hardship" on the operation of the employer's business. "Reasonable accommodation" may include making existing facilities used by employees readily accessible to and usable by individuals with disabilities, job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities. The decision as to what reasonable accommodation is appropriate must be determined on the facts of a particular case.

"Undue hardship" means an action requiring "significant difficulty or expense" when considered in light of the following factors: the nature and cost of the necessary accommodation; the overall financial resources and size of both the covered entity and the facility involved; and the fiscal and other impact of the accommodation.

The type of operation or operations of the employer, including the composition and structure of the workforce, geographic separateness and administrative relationships are also relevant to the issue of undue hardship. Obviously, this inquiry is highly fact-intensive.



Discriminatory Contractual Arrangements Prohibited

The Act prohibits an employer from participating in a contractual or other arrangement or relationship that has the effect of subjecting that employer's applicants or employees to discrimination. This includes a relationship with an employment or referral agency, labor union, an organization providing fringe benefits to an employee or an organization providing training programs.

This provision prevents employers from doing indirectly through contractual arrangements that which they may not do directly. Thus, for example, a company which contracts with an outside agency to perform training of its employees is liable if the training company does not make reasonable accommodation to the needs of the employer's disabled employees. Similarly, if an employer contracted with a hotel for an employee conference, it would have an affirmative duty to ensure accessibility of the facility to its disabled employees.

Discriminatory Impact

Employers are prohibited from utilizing standards, criteria or methods of administration that have the *effect* of discrimination on the basis of disability or that perpetuate the discrimination of others who are subject to common administrative control.

They are also prohibited from using qualification standards, employment tests or other selection criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities unless the tests or other selection criteria used by the employer are shown to be job-related for the position in question and are consistent with business necessity. They must also select and administer tests concerning employment in the "most effective manner" to ensure that when such tests are administered to job applicants or employees with disabilities that impair sensory, manual or speaking skills, such test results accurately reflect the job skills or aptitude of such applicant or employee rather than reflecting the impaired

sensory, manual or speaking skills, except where such skills are what the tests purport to measure.

Discrimination Based on Association

The ADA prohibits excluding or otherwise denying equal jobs or benefits to a qualified individual "because of the known disability of an individual with whom the qualified individual is known to have a relationship or association." This provision prohibits, for example, refusing to hire an applicant because his or her spouse has a disability which will cause the applicant to be absent frequently. The "reasonable accommodation" requirement does not apply to non-disabled persons, however. Thus, an employer need not waive a neutral attendance requirement because a non-disabled person is frequently absent to care for a disabled relative or friend.

Retaliation Prohibited

The Act also contains a provision prohibiting retaliation against persons who oppose practices made unlawful under the Act or who file charges or participate in any manner in an investigation or other proceeding under the Act. Further, it is unlawful to coerce, intimidate, threaten, or interfere with any individual in the exercise or enjoyment of any right under the Act, or because he or she encouraged or aided another in the exercise or enjoyment of a right.

Medical Examinations and Inquiries

The ADA severely limits an employer's lawful use of medical screening. Except as specifically permitted by the Act, employers may not conduct medical examinations or inquiries.

It is discriminatory for an employer to ask a job applicant if he or she is disabled. The employer may ask, however, if the applicant can perform job-related functions. For example, an applicant for a job which includes typing could be asked if he or she can type, but could not be asked if he or she has a visual impairment. However, the legislative history of the Act sug-

gests that employers who are engaging in affirmative action or remedial action to correct past discrimination may ask disabled applicants to identify themselves, but cannot require responses to such inquiries.

No applicant for employment may be subjected to a medical examination until after an offer of employment has been extended. The employer may condition the offer of employment on the results of a physical examination if (1) all entering employees are subjected to the examination regardless of disability; (2) the results of the examination are not used to discriminate on the basis of disability; and (3) information obtained regarding the medical condition or history is collected and maintained in separate forms and in separate medical files and is treated as a confidential medical record.

The Act prohibits medical examinations and inquiries of an employee as to whether the employee has a disability or the nature or severity of a disability unless it is shown to be job-related and consistent with business necessity. The Act permits voluntary medical examinations, in-

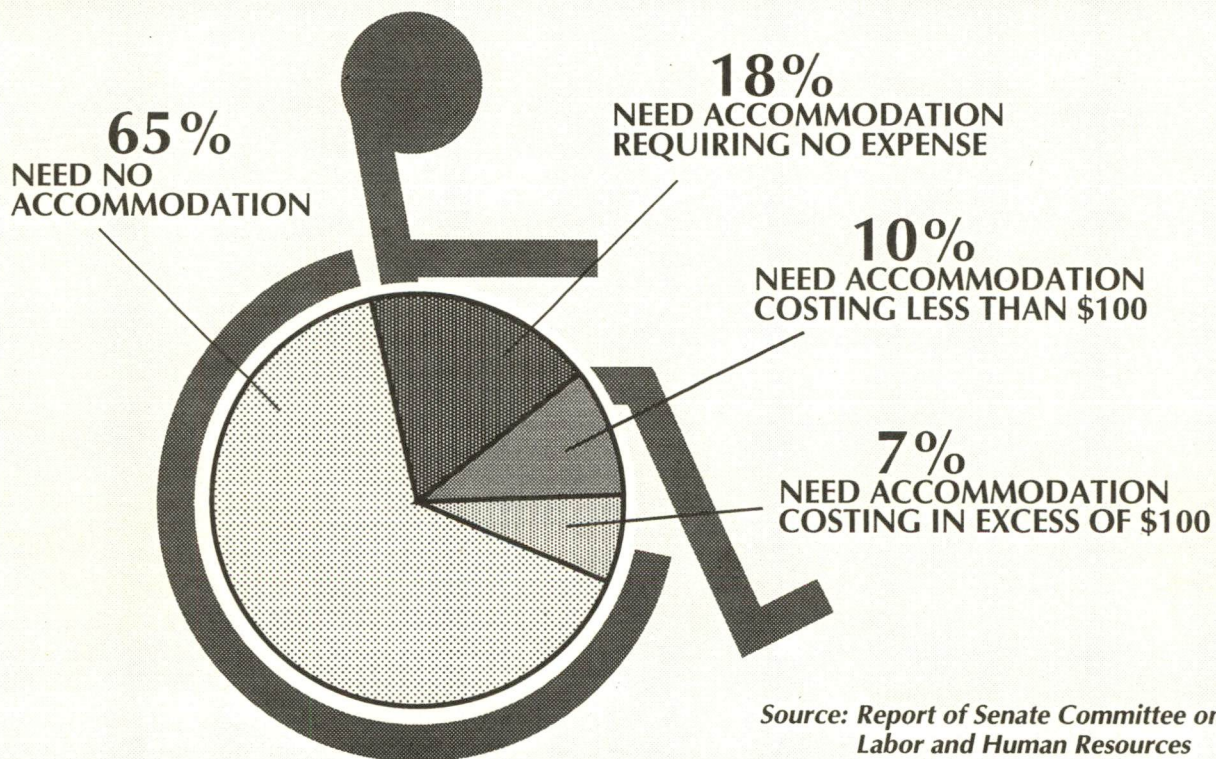
cluding voluntary medical histories which are part of an employee health program, and permits an employer to make inquiries into the ability of an employee to perform job-related functions. The information obtained from such permissible inquiries must be kept confidential.

Drug and Alcohol Abuse

An employee or applicant who is a current illegal user of controlled substances is not protected by the Act if the employer makes an adverse decision on that basis. However, an individual who has successfully completed a supervised drug rehabilitation program and is no longer illegally using drugs, who is participating in a supervised rehabilitation program and is no longer using drugs, or who is erroneously regarded as being an illegal user of drugs is a qualified individual with a disability. The Act does not prohibit an employer from adopting or administering reasonable policies or procedures, including drug testing, designed to ensure that rehabilitated drug users are no longer illegally using drugs.

continues

ESTIMATED COST OF EMPLOYING DISABLED WORKERS



Employers may (1) lawfully prohibit the use of alcohol or the illegal use of drugs in the workplace; (2) require that employees not be under the influence of alcohol or illegal drugs at the workplace; (3) require employees to behave in conformity with the requirements of the Drug-Free Workplace Act of 1988; and (4) hold an employee who illegally uses drugs or who is an alcoholic to the same qualification standards for employment or job performance and behavior that it holds other employees, even if any unsatisfactory performance or behavior is related to the use of alcohol or drugs. The employer may also require employees in "sensitive positions" as defined by the Department of Transportation Regulations, the Department of Defense drug-free workplace regulations, and the Nuclear Regulatory Commission regulations, to comply with the standards established by such regulations. A test to determine the illegal use of drugs is not considered a medical examination for the purposes of the Act.

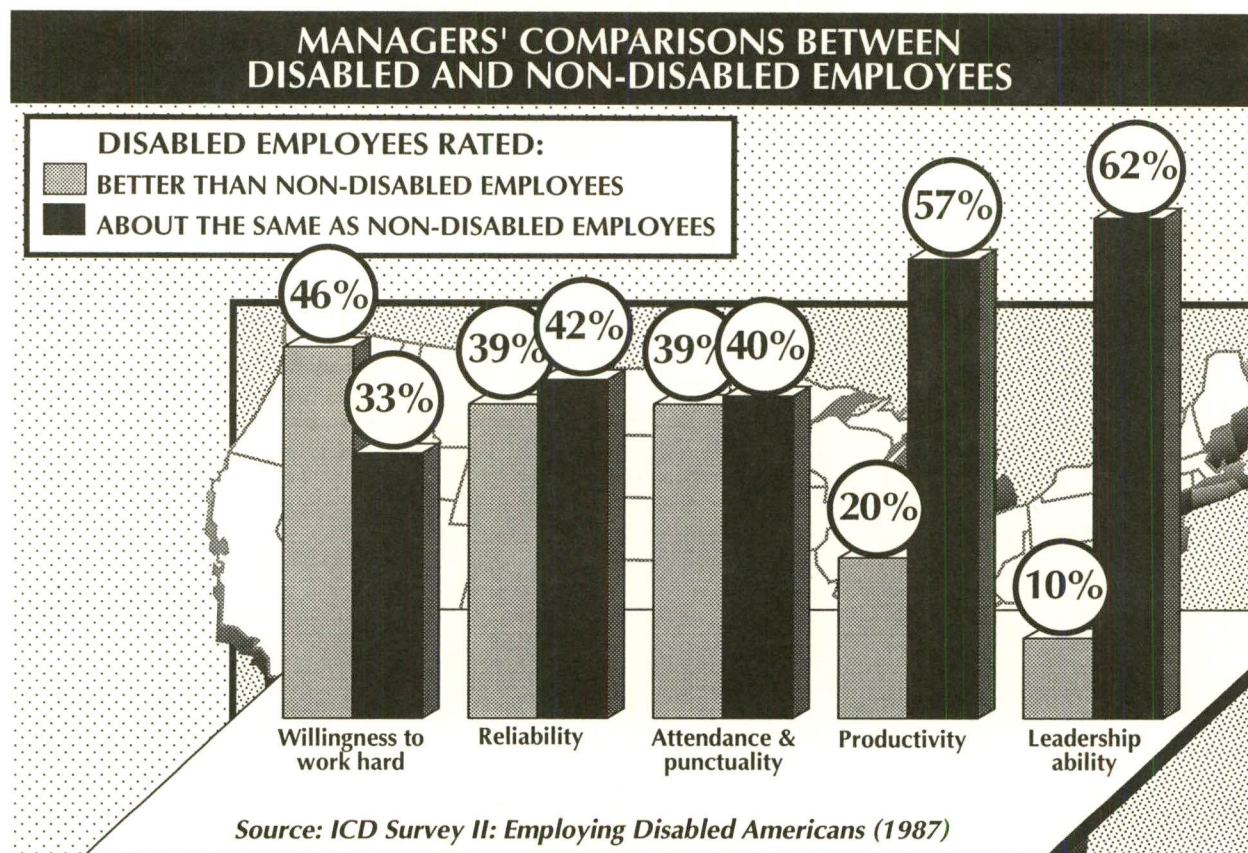
The ADA contains a provision amending the Rehabilitation Act of 1973 to provide that current users of illegal drugs are not protected by that Act. It also amends the Rehabilitation Act to

provide that an employee whose current use of alcohol prevents the individual from performing the duties of the job in question or who poses a direct threat to property or the safety of others is not protected by the Rehabilitation Act.

Benefit Plans

The ADA does not prohibit insurers and benefit plan administrators from classifying risks; nor does it prohibit an employer from establishing and administering a bona fide benefit plan, provided that the plan is not a "subterfuge to evade the purposes of the Act." The "subterfuge" proviso is identical to a provision of the Age Discrimination in Employment Act which has been interpreted to mean that the terms of the plan may be observed unless they are used to discriminate in some non-benefit aspect of the employment relationship, such as hiring or discharge.

The legislative history of the Act indicates that Congress did not intend to prohibit plans or policies from excluding pre-existing conditions from coverage. It did intend, how-



ever, to prohibit an employer from refusing to hire an individual because his or her disability is not covered by the employer's plan, or because hiring the individual would increase the employer's insurance costs.

Notices

Every employer, employment agency, labor organization, or joint labor-management committee covered under the Act will be required to post notices to applicants in a manner similar to those prescribed by the Civil Rights Act of 1964.

Enforcement

The employment title of ADA uses the enforcement scheme of and provides the same remedies as Title VII of the Civil Rights Act of 1964. It will be enforced by the EEOC and the Attorney General. Any persons alleging discrimination on the basis of disability in violation of the Act may file private lawsuits.

Effect on Other Laws

The ADA does not repeal the Rehabilitation Act. The Office of Federal Contract Compliance Programs (OFCCP) and other agencies which enforce the Rehabilitation Act are to coordinate with the EEOC to avoid duplication of efforts and to prevent imposition of inconsistent or conflicting standards. State laws which provide greater or equal rights to disabled individuals are not preempted, nor are laws which regulate smoking.

III. GOVERNMENT SERVICES

Coverage and Effective Date

Title II of the ADA, which covers discrimination in the provision of public services, applies to state and local governments and their instrumentalities and agencies, to Amtrak and to commuter rail authorities. Certain provisions

relating to transportation (*infra*) are currently in effect; the remaining provisions become effective January 26, 1992. The Attorney General and Secretary of Transportation are to issue implementing regulations on or before July 26, 1991.

Discrimination Prohibited

Public entities may not exclude or discriminate against a qualified individual with a disability in the provision of services, programs, or activities. A person is a qualified individual with a disability if, with or without reasonable modification to rules, policies, and practices, the removal of architectural, communication, and transportation barriers, or the provision of auxiliary aids and services (such as readers and interpreters), the individual meets the essential eligibility requirements for the service, program, or activity.

Public Transportation

Effective immediately, any bus, rail car, or other vehicle which a public entity purchases or leases for use in a fixed route transportation system must be accessible to persons with disabilities, including persons in wheelchairs. When used equipment is leased or purchased, a good faith effort to purchase accessible vehicles must be demonstrated. No vehicle may be remanufactured in such a way as to extend its useful life for five years or more unless it is made accessible to the maximum extent feasible.

All fixed route systems except those limited to commuter bus service must develop a plan to supplement their system with paratransit or other special transportation services to provide disabled individuals a level of service comparable to that provided the general public. This includes, to the extent practicable, response time. If the public entity demonstrates that provision of equal services would cause an "undue financial burden," the Secretary of Transportation may diminish the requirements solely to the extent necessary to remove the burden.

Demand-responsive public transportation systems must also lease or purchase only acces-

continues

sible vehicles unless the system, when viewed in its entirety, provides equal levels of service to disabled and non-disabled persons.

New public transportation facilities must be accessible to persons with disabilities, including those who use wheelchairs. When alterations are made to existing facilities, they must be made accessible to the maximum extent feasible.

Rail systems must have at least one car per train accessible to disabled persons as soon as practicable, but no later than five years from the date of the enactment of the ADA. Key commuter rail stations and rapid transit or light rail stations must be made accessible within three years except where "extraordinarily expensive structural changes" are necessary.

IV. PUBLIC ACCOMMODATIONS AND SERVICES OPERATED BY PRIVATE COMPANIES

Coverage and Effective Date

Title III of the ADA covers private companies and persons. Three broad categories are covered: (1) "public accommodations" (see box on page 9); (2) "commercial facilities," defined as nonresidential facilities whose operations will affect commerce; and (3) private transportation companies. Private clubs, religious organizations, and entities controlled by religious organizations, including places of worship, are not covered. With the exceptions noted below, the title takes effect January 26, 1992. The Attorney General and the Secretary of Transportation are to issue regulations no later than July 26, 1991.

Discrimination in the Provision of Services and Accommodations

The ADA prohibits discrimination by owners, operators, lessors and lessees of public accommodations against disabled individuals in their enjoyment of "goods, services, facilities,

privileges, advantages or accommodations." Providing only unequal benefits or participation is prohibited. Disabled individuals must be accorded the opportunity to join "in the most integrated setting appropriate to the needs of the individual"; separate benefits are proscribed unless provision in that manner is necessary to provide equal benefits.

Private companies and persons offering public accommodations are specifically prohibited from using unnecessary eligibility criteria which screen out disabled individuals and failing to make reasonable modifications to policies and procedures to allow benefits to or participation by the disabled (unless the modification would "fundamentally alter" the nature of the benefits or participation). In addition, the Act prohibits discrimination against individuals or entities because of their association or relationship with a disabled individual.

Provision of Auxiliary Aids and Services

Public accommodations must provide auxiliary aids and services to disabled persons where they would otherwise be excluded or segregated unless provision would "fundamentally alter" the nature of the service, product or facility being offered or provision would place an "undue burden" on the provider. These aids and services include interpreters, readers, taped texts, the acquisition or modification of equipment and "other similar services and actions." The same factors used in the determination of "undue hardship" in the employment context (see p. 3) will be used to determine whether provision of auxiliary aids and services would impose an "undue burden."

Removal of Barriers

Architectural barriers and communication barriers which are structural in nature and transportation barriers in existing vehicles used to transport individuals must be removed where removal is "readily achievable." An action is "readily achievable" if it is "easily accomplishable and able to be carried out without much difficulty or expense." Changes which may be readily achievable include installation of grab bars,

The following privately owned or operated entities are "public accommodations" for purposes of the ADA:

Retail sales and rental establishments, such as grocery stores, bakeries, clothing stores, hardware stores, and shopping centers

Service establishments, such as banks, hospitals, laundromats, dry cleaners, barber shops, beauty shops, travel services, shoe repair services, funeral parlors, gas stations, offices of lawyers, accountants, and health care providers, pharmacies, and insurance offices

Hotels, motels, inns, and other places of lodging

Restaurants, bars, and other food and drink establishments

Schools, colleges and universities, and other places of education

Theatres, motion picture houses, concert halls, and other places of exhibition or entertainment

Auditoriums, convention centers, lecture halls, and other public gathering places

Terminals, depots, and other stations used for public transportation

Museums, libraries, galleries, and other places of public display or collection

Parks, zoos, amusement parks, and other places of recreation

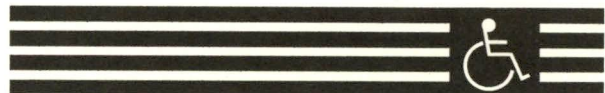
Day care centers, senior citizen centers, homeless shelters, food banks, adoption agencies, and other social service centers

Health spas, gymnasiums, bowling alleys, golf courses, and other places of exercise and recreation

simple ramping of a few steps, lowering of telephones, installation of raised letter and braille markings on elevator control buttons, addition of flashing fire alarm lights, and rearrangement of furniture or display shelves. The Act provides that retrofitting of vehicles with wheelchair lifts is not required.

Where barrier removal is not readily achievable, services or accommodations must be provided to disabled persons through alternative

methods if those methods are readily achievable. Examples in the legislative history include coming to the door of an inaccessible building to receive or return dry cleaning, providing assistance to retrieve items from an inaccessible location, and rotating movies between an inaccessible second floor theatre and an accessible first floor theatre.



Direct Threat to Health or Safety

The Act does not require provision of services or accommodations to individuals who pose a direct threat of significant risk to the health and safety of others which cannot be eliminated by modification of policies or by auxiliary aids and services. Similarly, persons may be denied services or accommodations because of their current illegal use of drugs.

Examinations and Courses

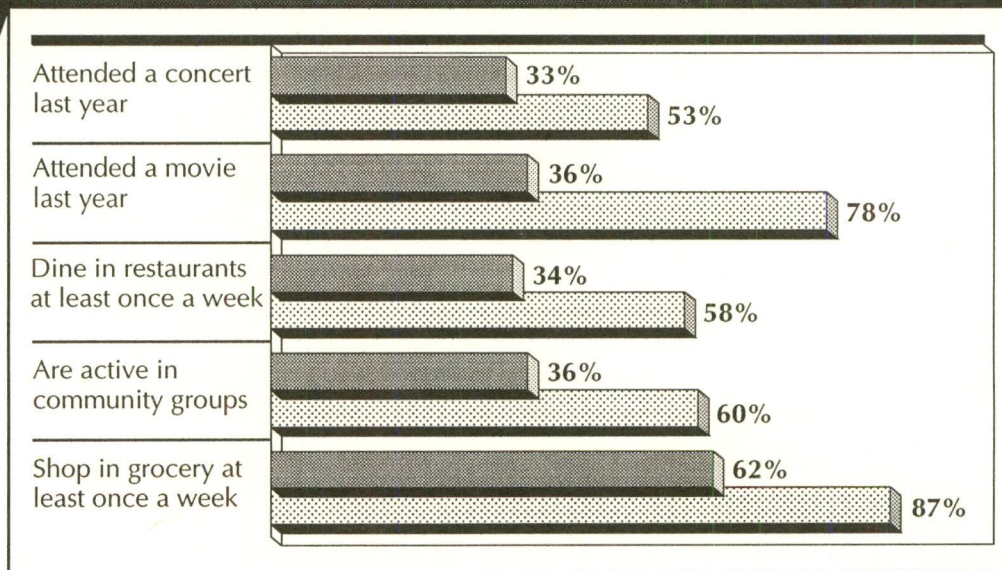
All examinations and courses relating to applications, licensing, certification or credentialing for secondary or post-secondary education, trade, or professional purposes must be offered in a place and manner accessible to disabled individuals, or alternative accessible arrangements must be made for disabled persons.

New Construction, Alterations to Existing Structures

Any public accommodations or commercial facility constructed for first occupancy after January 25, 1993, must be readily accessible to and usable by individuals with disabilities. An exception exists if the entity can demonstrate that it is "structurally impracticable" to meet accessibility standards to be set forth in regulations by the Attorney General.

When alterations are made to a facility that could affect its "usability," the alterations must be made in a manner which, to the maximum extent feasible, provides access to persons with disabilities, including those using wheelchairs. If the area altered contains a "primary function" of the facility, the path of travel to the area and the restrooms, telephones, and drinking fountains serving the altered area must be usable by

THE EFFECTS OF DISABILITY ON PERSONAL LIFE A COMPARISON OF DISABLED ADULTS AND ALL OTHERS



■ Disabled Adults
■ All Others

Source: ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream (1986)

persons with disabilities, unless the costs of achieving this accessibility are disproportionate to the overall costs and scope of the alterations. The Attorney General is to issue regulations affecting these determinations.

The Act does not require elevators to be installed in buildings of less than three stories or which have less than 3,000 square feet per story unless the building is a shopping center or mall or an office of a health care provider. The Attorney General may designate other categories of buildings which require installation of elevators.

Private Transportation Companies

Private entities which provide public transportation have requirements imposed on them similar to those imposed on public entities, including an immediate ban on purchases of certain new vehicles which are not wheelchair-accessible. Special provisions apply to over-the-road bus companies.

Enforcement and Penalties

Title III adopts the enforcement scheme used in the public accommodations title of the Civil Rights Act of 1964. Individuals may file private suits if they believe they have been discriminated against or if they believe that they are "about to be subjected to discrimination" by the construction of inaccessible facilities. The Justice Department is required to investigate alleged violations and to conduct compliance reviews. It may institute civil actions challenging patterns or practices of disability discrimination or discrimination raising "an issue of general public importance." Violators of the Act may be ordered to modify challenged practices or structures, to pay the aggrieved person monetary

damages specified by the Court, and to pay civil penalties of up to \$100,000.

V. TELECOMMUNICATIONS

Coverage and Effective Date

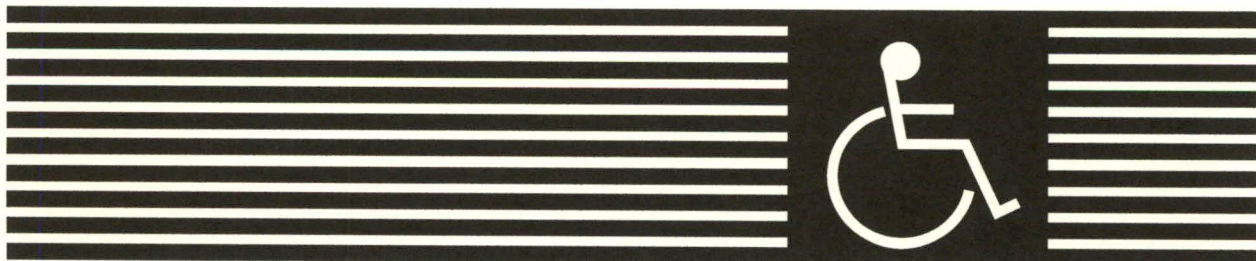
Title IV of ADA amends the Communications Act of 1934 to require that telephone companies provide telecommunications relay services within three years which permit persons with hearing or speech impairments to communicate with hearing individuals by means of Telecommunications Devices for the Deaf (TDDs). The Federal Communications Commission is to promulgate regulations to accomplish this objective by July 26, 1991.

Requirements

TDDs use a device equipped with a message display (screen or printer) to send typed messages through the telephone networks. Relay services, which currently exist in less than half of the states, provide third party operators who establish the connection between TDD users and hearing persons and act as an interface, reading TDD messages by voice and typing voice responses for receipt by TDD. The Act requires that relay services be available 24 hours a day at rates no greater than those charged for functionally equivalent voice communications.

CONCLUSION

Given the inherent ambiguity of many of the provisions of the Act, the regulations issued by the various agencies will be of critical importance. Affected entities should participate in the rule-making process to urge the development of clear, workable standards.



Houston
1301 McKinney, Suite 5100
Houston, Texas 77010
(713) 651-5151

Austin
600 Congress Avenue, Suite 2400
Austin, Texas 78701
(512) 474-5201

Dallas
220 Ross Avenue, Suite 2800
Dallas, Texas 75201
(214) 855-8000

San Antonio
300 Convent Street , Suite 2200
San Antonio, Texas 78205
(512) 224-5575

Washington
Market Square
801 Pennsylvania Avenue, N. W.
Washington, D.C. 20004
(202) 662-0200

New York
345 Park Avenue
New York, New York 10154
(212) 486-9500

Los Angeles
Sixth Floor, Broadway Plaza
700 South Flower Street
Los Angeles, California 90017
(213) 626-5241

London
2 St. James's Place
London SW1A 1NP
(0114471) 629-1207

Hong Kong
1301 Bond Centre, East Tower
Queensway, Central
Hong Kong
(852) 801-5100

Zurich
Bahnhofstrasse 22
Postfach 4174
8022 Zurich, Switzerland
(011411) 211-2597

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DEF'RIO 95 Attracts 3000 to Brazil to Discuss Disability Policy Issues

by Rosangela Berman-Bieler, President of Def' Rio and IDEAS 1996 Research Fellow in Cultural Adaptations of Independent Living and CBR



The Opening Ceremony of Def' Rio 1996

As a major event in Latin America last year, various national and international organizations, with the support of governmental and private institutions, joined together for DEF'RIO 95. This series of International Meetings of People with Disabilities took place in Rio de Janeiro, November 23 to 26. The general theme of the event was "Full Participation is a Right and a Responsibility of Everyone".

During four days numerous seminars, symposia, workshops and meetings of specialists and activists took place, mobilizing around 3000 participants from 20 countries from all over the world. Also featured was a large exhibition of equipment and technology.

Special events of Def' Rio were: the 2nd Latin-American Meeting of Rehabilitation International, 2nd Ibero-American Symposium on Independent Living, the 2nd Ibero-American Meeting on Women with Disabilities, the 4th Ibero-American Meeting of Alternatives in Rehabilitation and the 2nd Latin-American Meeting of the Deaf. These events gave to DEF'RIO 95 an international dimension,

while other specific activities had a national or local approach, bringing together people who had never had the opportunity to work together and exchange experiences before.

Associated Events

As part of the program, publication premieres were held for many books of disabled writers, as well as the translation into Portuguese of "Disabled Village Children" with the presence of the author, David Werner, from Health Wrights-USA. There were workshops and discussions on equipment and appropriate technology, featuring the participation of experts in the field such as Ralf Hotchkiss, from Wheeled Mobility Center, USA, and representatives of Handicap International-France, among others.

As a follow-up to DEF'RIO 95, from November 27 to 29, the Ministry of Justice of the Brazilian Government (National Coordination for Integration of People with Disabilities-CORDE) organized a "Technical Roundtable to discuss and develop a Bra-

zilian Model of Community Based Rehabilitation", involving 30 disability experts and advocates.

The secretariat of the Organizing Committee of DEF'RIO 95 was the Center for Independent Living of Rio de Janeiro - CVIRJ. It coordinated a group of 20 national and international contributing institutions for and of disabled people, most cross disabilities.



Two IDEAS collaborators at Def' Rio: Lex Frieden of ILRU and Rosangela Berman-Bieler

Independent Living in Latin America

One of the most important events of DEF'RIO 95 was the 2nd Ibero-American Symposium on Independent Living. The first one, held as a part of DEF'RIO 92, involved international advocates as Judy Heumann (USA) and Rachel Hurst (UK). This 2nd Symposium brought together leaders of the Brazilian Centers for Independent Living and some international fellows from the United States and Sweden. They discussed with a large audience, representing the Latin America Region and Spain, about philosophy, models and characteristics of the IL Movement and how to adapt it to developing countries.

The Independent Living Movement in Latin America began in the late 1980's, sparked by the foundation of the first Center for Independent Living in Brazil (the Centro de Vida Independente do Rio de Janeiro-CVIRJ) in December, 1988. Introducing many new concepts to the region, a group of disabled advocates representing various grassroots movements, started to spread a new model of organization, adapting the philosophy and the services of the "first world CIL's" to the reality of their country. Now Brazil has eight CIL's in different regions of the country, demonstrating the rapid growth and deeply-rooted acceptance of the IL philosophy and the necessity of those services for the disabled community.

Symposium Highlights

During the 2nd Symposium on Independent Living, many different subjects were presented and discussed with the large audience composed mainly, but not only, of disabled people. Families and professionals also demonstrated serious interest in the concepts and services that are being offered by the Centers in Brazil and they were welcomed to the debates.

To stimulate the exchange of experience and information, the organizers invited some important figures from the international movement, such as Kathy Martinez and Suzanne Reier, from the World Institute on Disability (California, USA), and Lex Frieden, from the Institute for Rehabilitation and Research (Houston, USA) who could expound on their experiences related to the empowerment of people with disabilities. During DEF'RIO, they also had the opportunity to present the IDEAS Project and run a parallel meeting on international cooperation, that drew on the practical experiences of 35 persons from different countries and organizations.

Most of the panels of the 2nd IL Symposium were coordinated and presented by the leaders of the Brazilian CIL's, involving issues such as housing, civil rights, equipment, peer-counseling, training and employment, accessibility, transportation, personal assistance and information services.

Founding a CIL

Another important aspect of the meeting was the presentation of leadership training and information resources about how to start and manage a CIL, including fundraising, organic structure, definition of services and decision-making.

At the end of the meeting, the Brazilian centers met to discuss the by-laws of the new of the National Federation of Independent Living Centers of Brazil which will be formalized during 1996.

In Brazil, the IL Movement is growing very fast in terms of respect and credibility. Many other groups of people with disabilities and institutions are starting to adapt their organizations to its approach that, at this point certainly represents the avant-garde in the social field internationally.

After the Symposium, many participants from the Latin-American countries contacted the leaders of the Brazilian CIL's to request support information for the possible foundation of centers in their countries.

CBR as a New Trend for Brazil

At the end of DEF'RIO 95, as an associated event, the Brazilian government agency, CORDE (National Coordination for the Integration of Persons with Disabilities) held a three day intensive technical meeting on Community Based Rehabilitation. The objective was to discuss and develop a Brazilian model of CBR to be implemented in the poorest areas of the country, where rehabilitation cannot reach the local population.

The meeting was a significant collaboration of international experts including Dra. Alicia Amate (Former PAHO Rehabilitation Coordinator) from Argentina, Ana Maria Frappola (Director of the Inter-American Institute of the Child-Uruguay), Marie Chuberre, Severine Dumas and other members of the CBR programs of Handicap International in France, Mozambique, Nicaragua, Ecuador and Brazil and David Werner and Ralf Hotchkiss from USA, and Brazilian disability leaders and representatives of various organizations and governmental offices.

CORDE is the governmental office for the disability sphere and operates within the Ministry of Justice of Brazil, one of the primary sponsors of DEF'RIO 95. Based on the document developed at that meeting, CORDE will launch the Brazilian Program of CBR, involving other organizations such as UNDP and local institutions.

The document was very progressive, taking into consideration the empowerment and the on-going participation and orientation of disabled people in the process of their rehabilitation, including Independent Living concepts as the basic principles to guide the program.



DEF' RIO 95 Conclusions

The main objective of DEF' RIO 95—to offer a social-cultural and political forum where people with disabilities, professionals, families, community and authorities could work together on disability strategies and perspectives was clearly achieved. For the first time in the region, a large number of institutions of and for disabled people, NGO's or governmental offices, private companies and individuals shared the same "vibrations", believing that the way to make the future better for everybody is to fight and to build together a society for all, with the full participation of all, with solidarity.

The local press provided major visibility to the meeting and many important authorities—such as the Ministry of Health, and Members of the Parliament—visited the conferences and delivered supportive statements for the main ideas put forward by DEF'RIO 95.

The local and international organizations that promoted and sponsored DEF'RIO 95 decided to continue working together and have already begun to organize DEF'RIO 98, to evaluate their progress and to initiate new strategies for the year 2000 and beyond.

During 1996 Ms. Berman-Bieler will work with WID and RI to develop a comprehensive regional report on IL and CBR in the Latin American region, with special focus on Brazil.

Third World Voices at the 18th International Congress on Education of the Deaf (ICED)

Representatives of 72 countries attended the 18th International Congress on the Education of the Deaf held in Tel Aviv, July 1995. The Congress was held under the auspices of the Tel Aviv University School of Education, the Hearing Impairment Program, with the cooperation of the Association of the Deaf in Israel, Society for Deaf Children and SHEMA for Education and Rehabilitation of Hearing Impaired Children and Youth.

In the following is a brief summary of the part dealing with the Third World from the trip report of Katherine D. Seelman, Director of the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, who participated in the Congress.

Participants from Third World Countries voiced concerns which the developed world needs to hear and pay attention to. A member of a religious order working at the Holy Land Institute for the Deaf in Jordan contrasted the emphasis the West puts on high level training and performance within the sphere of special education and rehabilitation compared to the emphasis in other parts of the world on people - "on excellent teachers/interpreters but without university training". He argued that the West was at risk of losing rich resources because these people do things differently in community-oriented education and transfer of values and behavior. In the West he contended people have "created" handicaps through special education and

rehabilitation. He argued that research must benefit not only universities, but children, families, and community. He questioned the Western concept of time which is quantified and contrasted it with the Eastern concept, which he saw as "qualified" i.e., What have you done with your time?

A representative from Zimbabwe presenting on children with special needs, especially children with many disabilities, noted that most of these children were in the Third World where Western models of intervention were often inappropriate. She stressed the need to develop curricula which are "culture sensitive." According to the speaker, parents in Zimbabwe need to be much more involved with their disabled children and not resort to the solution of dumping children into institutions because of financial constraints. Regrettably, husbands often leave wives because they blame their wives for the child with a disability; superstition is widely used as a basis for explanation. Disabled children are doubly at risk for violence and abuse. Zimbabwe needs legislation, a disability awareness campaign and community-based rehabilitation, in her estimation.

Third World representatives raised issues around justice of resource allocation because of the concentration of individuals with disabilities in their countries. They talked about cultural relevance and questioned the applicability of Western values as the basis for design of services and technology.

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Season For Giving Thanks

TEXAS MEDICAL CENTER

NEWS

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Lex Frieden: "Champion for People with Disabilities"

by ROGER WIDMEYER
Texas Medical Center News

Lex Frieden is on a conference call. He is all business. Assembled via the telephone lines, the group is discussing a draft of a report. Add a sentence here, Frieden says. Strengthen the introduction. He adds some sentences to the conclusion.

Frieden and his colleagues are drafting a report to be delivered to President Clinton on Nov. 15 regarding a national policy of employment for disabled people.

Lex Frieden, 49, has been active in legislation affecting disabled people for more than 20 years. He has been almost completely paralyzed for 31 years.

Frieden has just returned from Washington D.C., where he received the 1998 Henry B. Betts Award, an honor given to one person each year who has made contributions toward improving the quality of life for people with disabilities. The award carries a \$50,000 non-restricted cash award with it. In nominating Lex Frieden for the award, former President George Bush wrote, "Throughout his life, Lex has been a champion for people with disabilities."

As the major architect of the Americans With Disabilities Act - passed in 1990 - Frieden may know more about the difficulties a person with disabilities faces than anyone else in America.

"There have been several important laws," says Frieden. "The Rehabilitation Act of 1973 was very important, and it's been amended and improved since then. The 1975 Education for Handicapped Children Act was critical because it meant that kids with disabilities would receive their education in 'normal' schools, integrated with the rest of their peers."



Mac Brodie and Lex Frieden - a mutually beneficial partnership.

In 1967, Lex Frieden was an honor student looking forward to his first year of college at Oklahoma State University. But his dreams of college were shattered, just as his neck was, in an auto accident; he was a passenger in the car.

His father visited rehabilitation facilities in New York, Chicago, Los Angeles and Houston. "He said there was no choice, really: TIRR was the place for me," says Frieden. "Dr. Ed Carter was my doctor. He's still here." Following rehabilitation, Lex applied to a university in Oklahoma, an architecturally modern group of buildings. He was denied admission because of his wheelchair.

"I couldn't believe it," he recalls. "I had a 4.0 grade point, excellent test scores and recommendations. I spent several weeks in shock."

"It darn sure had an impact on the way I looked at life."

At another school, the University of Tulsa, the dean had a simple solution. "He said they would simply hold the classes I wanted to take in a new building which was accessible. No big deal. But it gave me the idea of 'reasonable accommodation,' a concept which we have incorporated into the Americans With Disabilities Act."

Back in Houston in 1972 to pursue a master's degree in social psychology at the University of Houston, Lex met Mac Brodie, a Vietnam veteran who had suffered a severe brain injury. "He was living in a halfway house but he was also volunteering at the assisted living dormitory in which I was living," says Frieden. "This was a dorm actually begun by a bunch of former TIRR patients who were now going to school, and Dr. Spencer encouraged us to hire assistants and arrange our own transportation."

"Anyway, Mac and I started a partnership - and friendship - that has benefited us both."

Mac lives with the Friedens - Lex, his wife, Joyce, and their grandson Trey. Joyce is paraplegic because of disease which struck her brain and spinal cord. Mac helps Lex with physical tasks, and Lex helps Mac compensate for deficits in his memory and ability to reason.

"We have 20 years of data that indicates 99 percent of people with disabilities would greatly prefer community living to institutional care," says Frieden. "No surprise there. What is surprising is that we continue to pour millions of dollars into nursing homes and institutions - when community living is cheaper and certainly provides a more independent feeling to that person." Frieden describes a model of assisted living that is a kind of hybrid nursing home. The assisted living quarters are outfitted with adaptive devices, and a caregiver comes in two or three times a day for meals and to help with dressing. "We don't need physicians and nurses to help us pull up our pants," he says.

Frieden, now a senior vice president at TIRR and mastermind of TIRR's grants program, is also the founder and director of TIRR's Independent Living Research Utilization

Program, a national center of research and training about independent living. "It is one of my missions to spread the word about independent living," he says.

Frieden was asked to come to Washington in 1984 to serve as executive director of the National Council on Disability, a 16-member board appointed by the President. "The council had been given an ultimatum by Congress: produce a report with meaningful recommendations, or pack your bags," says Frieden. Under his leadership, the council produced "Toward Independence," a landmark document which for the first time clearly articulated the needs of disabled people. "It was really hard work, partly due to the political environment in Washington, but we did produce some reports that were respected." The reports that came out of Frieden's four-year term as director of the National Council on Disability have influenced international standards on civil rights for people with disabilities and helped generate new policies at the Centers for Disease Control and Prevention (CDC) and the U.S. Department of Education.

Most importantly, Frieden's work produced the original draft of the Americans With Disabilities Act, the most important piece of legislation affecting people with disabilities. Essentially, the ADA is a civil rights law, guaranteeing people with disabilities rights to access, employment, and all the opportunities every American has.

"Look, a whole lot of people come out of rehabilitation programs," says Frieden, "but they are lost once they finish because the community they are going to lacks a support system for them. That's why I work so hard to focus public policy on two fronts: ensuring an opportunity to work and an opportunity to live independently. There are still too many employers who look at a disabled person and simply fail to see the qualifications of that person. In 1990, when the ADA was passed, 68 percent of people with disabilities were unemployed. Today, 68 percent are still unemployed. And there are still too many people who spend a lot of time and energy convincing the government that they are indeed disabled so they can collect benefits - and they come to see themselves as dependent.

"We - our community and our society - have to do better."

*from the
President*



Congratulations to Lex Frieden who received the 1998 Henry B. Betts Award on Oct. 29 at the Library of Congress in Washington D.C. The Betts Award is given to one individual each year who has worked towards improving the quality of life for persons with disabilities.

Lex is certainly worthy of this award. For over 25 years, he has worked tirelessly in a campaign to make all the opportunities afforded most Americans also available to persons with disabilities.

In the early 1970s, in Houston, Lex - with the encouragement of TIRR's founder, Dr. William A. Spencer - began articulating the philosophy of independent living for persons with disabilities. "It's so simple," Lex says of the cornerstone definition of independent living that is now used in legislation and academics: "Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing every day activities."

Lex and his colleagues in Houston created "New Options," a model of transitional living where people with disabilities gained "hands on" experience for their essential daily skills of independent living.

Lex Frieden took this concept to Washington D.C. in 1984 where he became director of the National Council on Disability and, during the next four years, produced important studies about disability on America - including "Toward Independence," the document which became the blueprint for the Americans With Disabilities Act (ADA), one of our finest pieces of civil rights legislation. Lex worked brilliantly with Congress during the process of getting this act passed. Until the ADA was passed in 1990, it was legal for employers to discriminate against people with disabilities.

Since 1990, there has been a shift in attitude and in thinking about people with disabilities. That is very rewarding.

As a member of the United Nations Panel of Experts on the Standard Rules for Disability, Lex now has a voice that will be heard 'round the world. In too many countries, people who become disabled are simply expected to go home and stay there.

We thank Lex Frieden and his many colleagues who have allowed so many people to gain a sense of belonging and empowerment. We all benefit when everyone is given an opportunity to participate in working and learning.

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e-Mail: tmc-info@tmc.edu

URL: http://www.tmc.edu/tmcnews/11_15_98/page_01.html (Modified: Nov-18-1998)

Dr Richard E. Wainerdi is president of the Texas Medical Center and publisher editor of the Texas Medical Center News.

TIRR

MIDWEEK

THE INSTITUTE FOR REHABILITATION AND RESEARCH • TIRR FOUNDATION • TIRR LIFE BRIDGE • TIRR REHABILITATION CENTERS • TIRR SYSTEMS

Customer Corner

Customer service occurs around the elevators: waiting for people to exit the elevators before entering; letting patients and family enter the elevators first, and letting the elevators close and proceed instead of having the occupants stop the doors and reopen them. You can catch next one or take the staff service elevators!!

A Change in the OJI Process

When there is an OJI/exposure, please page **Betty Clark, Employee Health Nurse, @ 833-5426** and she will return your call and provide directions for treatment/drug screen. If treatment is refused, we will still send the employee to UT for drug screen. If Betty is unavailable by beeper or does not return the call within 15 minutes, call UT Health Services- 500-3267 and ask for the on-call MD/NP. They will provide directions for treatment. Send the completed OJI packet to Human Resources **ASAP**. We have to process the OJI with our worker's compensation insurance company within 24 hrs of the occurrence.

If you have questions about this or need for Betty to provide an inservice on OJI's, to your area/department, please call 797-5263.

TIRR's Vision

"Your ONLY Choice for Rehabilitation"

TIRR's Mission

To serve our community and customers by providing:

- Service to our customers
- The highest quality rehabilitation at competitive prices
- Geographically accessible services
- Various levels of care matched to patients' needs
- Charity care and community services within our resources
- Opportunities for research breakthroughs
- The highest quality staff

TIRR Brain Injury Program Day Hospital Moves to SNF

Jean Herzog, BIP Administrator

As of November 9, TIRR Brain Injury Program (BIP) patients attending day hospital have their own room on the SNF unit. Because they are technically outpatients, there is no conflict in having a room designated in that area for them. They are still admitted to the Brain Injury Program, participate in the Program groups, and are seen by the BIP staff. **Estella Conde, LVN** with the BIP nursing staff on PCU-3, is providing the nursing supervision for the patients. BIP day hospital patients who require beds will still be admitted to PCU-6 or PCU-3. By moving these folks to their own area, the day hospital room on PCU-6 can better accommodate the children in the Pedi. program.

The extension for the BIP day hospital room is 7333. Thanks to everyone at TIRR and TIRR LifeBridge who helped to make this a smooth transition.

Lex Frieden Honored With Reception Hosted by TIRR, Baylor and Texas Medical Center

More than 200 attended the November 12 afternoon reception at TIRR honoring TIRR senior vice president Lex Frieden upon his return from Washington where he received the Henry B. Betts Award. That so many attended on a rainy afternoon and lingered past the 3 p.m. conclusion of the festivities speaks well of Lex and his many friends in this community.

A similar large turnout was reported for the Oct. 29 Washington ceremony, held at the Library of Congress. The event was well attended, and the estimated 180 there was more than had ever been present for a Betts ceremony before.

Funded by Prince Charitable Trusts, the Betts Award is named for Dr. Henry B. Betts, former CEO and Medical Director of the Rehabilitation Institute of Chicago. The purpose of the Henry B. Betts Award is to change attitudes toward people living with disabilities and to reward individuals who have powerfully affected that change.

Louisa Adelung, president of TIRR, conducted the TIRR November 12 program. Participating with remarks about their association with Lex Frieden were Martin Grabojs, MD, executive vice president for medical policy, TIRR and chairman, Department of PM&R, Baylor College of

Medicine, and Dr. Richard Wainerdi, president, CEO and COO, Texas Medical Center. H. Joan Ehrlich, district director of the Equal Employment Opportunity Commission, presented Lex with a commendation from her office and Al Calloway, representing Mayor Lee Brown, spoke of his work as senior assistant to the mayor for the city and proclaimed it Lex Frieden Day in Houston.

Others on hand for the reception, held in the dining room at TIRR, included U.S. Congress member Sheila Jackson Lee, Dr. William Spencer, founder of TIRR, Charles Beall, President and CEO of TIRR Systems, Willard Walbridge, who once headed KTRK-TV (Channel 13), and trustees of the John S. Dunn Research Foundation.

Also on hand were TIRR trustees Jerry Johnston Andrew, Paul Frison and William Lehner, and trustees of TIRR Foundation Muffin Clark, Tom Conner and his wife Anne, and Debbie Jones.

Displayed were congratulatory letters Lex Frieden has received, including those from President Bill Clinton, Vice President Al Gore, Texas Governor George W. Bush, Oklahoma Governor Frank Keating, Houston Mayor Lee Brown, and members of the Texas Congressional delegation.

Lex ended his special day with his usual good humor, saying "I will be glad when all of this is over so I won't have to wear a tie so often."



Lex Frieden is shown with two of his favorite people, his 7-year-old grandson Trey and TIRR's Dr. William Spencer.

And Another Thing...

Sampling of The Breakfast Exchange Issues/Responses from the October Meeting

Are there going to be merit increases this year?

Response: We are considering this right now and will make a decision prior to the next pay period.

Are we going to get bonuses this year and, if so, will the same amount of taxes be taken out this year?

Response: We won't make a decision about bonuses until the end of the year, based on our activity and performance. TIRR doesn't get to decide the amount of taxes to be withheld. The Internal Revenue Service determines the amount to withhold, based on how many dependents each employee claims.

How is the direct deposit working?

Response: For the first payroll with our new Meditech computer system, no direct deposits were made. For the second payroll that was just issued, direct deposits were done. All deposits except Nations Bank were successful. Nations Bank had problems unrelated to our computer change.

Why do the recruitment ads include a graphic that does not reflect what we do? When did our logo change?

Response: The logo hasn't changed. Human Resources will discontinue use of the additional graphic which had been suggested by the ad company.

Can we have Day Care on site?

Response: We have studied this benefit many times. The problem is the lack of volume. Having this very expensive service for just a few children (past employee surveys indicate a maximum of 6-7 children would be enrolled) is just not feasible.

*Why aren't TIRR therapists invited to attend the seminars
TIRR Rehabilitation Centers sponsors?*

Response (from Bob Dalecki of TRC):

We will have a spinal mobilization course coming up in November and a McConnel Taping course early next year. The courses are open to all but the class sizes are limited by the instructors to 12 therapists. Our priority was to get all TRC therapists updated in these new spinal techniques first, since it is a critical core competency needed to practice in an outpatient clinic. For this reason, priority was given to TRC therapists, then other therapists in the system.

We will have the same course again in February or March and will make sure the information is available to those who could not attend either because of their personal schedules or because of the class size set by the instructor.

Please know that we want these events to be open to all TIRR therapists and will provide repeated opportunities, if necessary, to satisfy our internal needs (all TIRR therapists) before opening registration to outside therapists.

The November course is the first in a series of ongoing continuing education opportunities that TRC will offer.

The Breakfast Exchange is a monthly meeting held by Louisa Adelung, TIRR President, with a randomly invited group of TIRR employees. October's attendance: **Lamairlas Carmona, BI/CVA Program, Stacy Foster, Physical Therapy, Mary Hall, PCU-6, Diane Johnson, Admissions, Celine Matthews, SCI/Amputee, Amy Myers, Occupational Therapy, Anita Patton-McHaney, BI/CVA Program, Arvind Surati, Medical Records, Edward Thompson, Radiology.**

Up For Grabs

TIRR Occupational Therapy has a large, dark desk up-for-grabs in OT. Please contact Peggy Sherman at 797-5954.

Music Therapy: upright piano. It is located in the Recreation Room (E-109) and must be moved by Friday evening November 20. Come try it out – it plays and should be considered a "handyman's dream". The first person to contact Cindy Bukauskas by email or phone (797-5936) gets it and will be responsible for moving it.

Accolades & Acknowledgments

Diane Atkins, OTR, Amputee Program Coordinator, presented "Measuring Outcomes of Upper Extremity Prosthetic Use—What is Currently Practiced?" at an Amputee Rehabilitation Outcomes Measurement Symposium at the American Academy of Physical Medicine and Rehabilitation (AAPM&R) annual meeting in Seattle WA, Nov. 6.

Lourdes Cuellar, Director of Pharmacy, TIRR Pharmacy, has been reappointed by Governor Bush to serve another term on the Family Practice Residency Advisory Board. Congratulations Lourdes!

Terri Haight, LifeBridge Therapy, attended Harvard Medical School's Continuing Education Conference on "Neurology Behavior" in Boston, MS, Nov. 2-3. Terri also attended the Rehabilitation Technology Conference in Pasadena, TX, Nov. 10.

Terri Hudler-Hull, Division of Education, conducted Think First and Think First for Kids to four (4) schools with a total attendance of 1165 people during October.

Angella Sanders, Ph.D. and Walter High, Ph.D., Brain Injury Research Center (BIRC), attended the American Congress of Rehabilitation Medicine Conference and presented a poster titled "Factor Analysis of the Community Integration Questionnaire Revisited" in Seattle, WA, Nov. 8-11.

Little Bits

December Blood Drive...Tuesday, December 15, 10am to 5:30pm. Sign Up Day, Monday, December 14.

Birthdays Across TIRR Systems

November 18 – November 24

Nov. 18	Karen Oakley, TIRR Medical Records
Nov. 20	Laurel Richards, ILRU
Nov. 20	Delton Justice, TRC-Atkinson
Nov. 20	Richard Garber, TIRR OT
Nov. 20	Shana Kueck, TRC-Matagorda
Nov. 21	Cindy Lucia, TIRR Foundation
Nov. 21	Theresa Calderon, TRC-Central
Nov. 21	Debra Gray, TRC-Mid County
Nov. 21	Deborah Robblee, TIRR PT
Nov. 21	Julie Davis, TIRR OT
Nov. 22	Theresea Burros, PCU-6
Nov. 22	Jennifer Macmillan, Marketing
Nov. 23	Carol Gilliam, Dietary
Nov. 23	Betsy Triplin, Marketing
Nov. 23	Ty Benard, Communication
Nov. 24	Faye Nichols, LifeBridge Long Term
Nov. 24	Kailli Liu, PCU-5

Microsoft Outlook Tip of the Week: Looking for a Name?

There may be times when you don't remember how to spell a person first and/or last name. Let Microsoft Outlook help with its **Find** feature. Here's how:

1. Open Microsoft **Outlook**
2. Point to click on **Tools**
3. Point and click on **Address Book**
4. Point and click on **Tools**
5. Click on **Find**
6. A **Find** window appears where you can look for people's names out of the **Global Address Book** by first name, last name, and more. Great!!

That's Life

*The world of reality has it
limits; the world of
imagination is boundless.*

- Jean-Jacques Rousseau

How to Write Good

-  Don't be redundant; don't use more words than necessary; it's highly superfluous.
-  Go around the barn at high noon to avoid colloquialisms.
-  Who needs rhetorical questions?
-  One-word sentences? Eliminate.

In-Services To Attend

Mandt Training

2-Day Mandt Training

DATE: Mon.-Tues. Nov. 23-24
TIME: 8am - 4:30pm
LOCATION: Conference Room 2A

Mandt Recertification Training

DATE: Fri., Dec. 4
TIME: 12Noon – 4:pm
LOCATION: Private Dining Room A/B

DATE: Tues. Dec. 15
TIME: 12Noon – 4pm
LOCATION: Conference Room 2A

Microsoft Computer Classes

-  **Registration:** You may either register by Mail Messaging Rennie Swift or calling 713/797-5247.
-  **NEW: Electronic Training Registration**
You can now register yourself for any of the training posted in **Global Training**. **Global Training** is located in the software Microsoft Outlook in **Folder List: Public Folders/All Public Folders/Global Training**.

With Electronic Registration, you have two registration options. Remember, make sure you have confirmed with your manager before participating training.

Option One

-  Send a **New Mail Message** to Rennie Swift with your name and class information. (Example: Rennie Swift, Mandt Recertification, Dec. 15, 12N-4pm)

Option Two

- ✓ Double-Click on the class **Post-It** you wish to attend.
- ✓ Click on the **Reply** Button (Third row down from top, person's head with purple arrow pointing to the left). This will open a **Message Window** to Rennie Swift. You can add additional comments if you wish.
- ✓ Click **Send** when you are ready.
- ✓ **Location Note:** Computer Training Rooms 1/2, 3, and 4 are located on the second floor of the Clinic Building. Conference Room 2C is located in the Dunn Tower, second floor.
- ✓ A listing of the **course contents** can be found at:
Microsoft Outlook: Public Folders/All Public Folders/Global Training/Training Information.

Your MidWeek Team

Contributors:

Editor:

Graphics/Printing:

Everyone Working at TIRR

Rennie Swift (797-5247)

Bruce French (797-5974)

Submissions to the TIRR MidWeek are due by Noon the Monday before each Wednesday's issue. Submissions may be sent to Rennie Swift, Human Resources (O-101), PhoneMail at 797-5247, or FAX at 797-5245, and e-mail!

Date	Time	Location	Topic
11/19	12:30-4:30pm	Nursing Classroom	Advanced Outlook
12/09	12:30-4:30pm	Conference Room 2C	Word: Vol. 1
12/10	8-12N	Conference Room 2C	Word: Vol. 3
12/10	12:30-4:30pm	Conference Room 2C	Basic Outlook
12/11	8-11am	Conference Room 2C	Windows NT
12/11	12:30-4:30pm	Conference Room 2C	Word: Vol. 1
12/14	12:30-4:30pm	Conference Room 2C	Basic Outlook
12/17	8-12N	Conference Room 2C	Advanced Outlook
12/17	12:30-4:30pm	Conference Room 2C	Advanced Outlook
12/18	8-12N	Conference Room 2C	Word: Vol. 3
12/18	12:30-4:30pm	Conference Room 2C	Basic Outlook
12/21	12:30-4:30pm	Conference Room 2C	Word: Vol. 1
12/28	12:30-4:30pm	Computer Training Room 3	Advanced Outlook
12/29	12:30-4:30pm	Computer Training Room 3	Word: Vol. 2
12/30	12:30-4:30pm	Computer Training Room 3	Word: Vol. 3

Baylor College of Medicine Computer User Support Services (USS)

The Baylor College of Medicine Computer User Support Services is offering the following computer classes:

Course	Date	Time	Hours	Cost
Access 97 – Advanced	11/19	8:30am-4:30pm	7	\$96
Word 97 – Large Reports	11/24	8am-12N	3.5	\$61
Word 97 – Mailing Lists, Tables, Forms & Macros	11/25	8:30am-4:30pm	7	\$96

Classes meet at Digital Consulting and Software Services (DCSS), located in the Nations Bank Building at 1020 Holcombe at S. main, 15th Floor. Call 281/243-2460 to register and call USS at 713/798-8737 for more information.

TIRR MIDWEEK

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Out Of Office

Renita Alexander, PCU-3, Out: Until Mon., Dec. 21. Coverage: Ann Nichols, Nurse Manager (797-7360; pager 919-3717) day shift unit issues; Marilyn Lockett, Assistant Nurse Manager (797-7665; pager 919-6380) evening shift unit issues.

Colleen Black, Medical Records, Out: Wed., Nov. 18 (after 2pm) through Fri., Nov. 20. Coverage: TIRR: Karen Kanaway (799-7071). TIRR LifeBridge: Terri Neal (799-6984).

Karen A. Hart, PhD, Out: Wed., Nov. 18 (after 2pm) through Fri., Nov. 20. Coverage: Marj. Gordon, (797-5944).

Carlos Ortiz, Interim Coordinator, Respiratory Care, Out: Sat., Nov. 21 through Sun., Nov. 29. Department Issues: Jackie Brogdon (797-7211). Admin. Issues: Donna Stultz (797-7663).

Physicians Call Schedule

November, 1998

DATE	FIRST CALL	ADMIN. CALL
Wednesday, 11/18	Dr. Guerrero	Dr. Salmeron
Thursday, 11/19	Dr. Afong	Dr. Lai
Friday, 11/20	Dr. Lord	Dr. Salmeron
Saturday, 11/21	Dr. Nguyen	Dr. Salmeron
Sunday, 11/22	Dr. Guerrero	Dr. Salmeron
Monday, 11/23	Dr. House	Dr. Lai
Tuesday, 11/24	Dr. Mahajan	Dr. Salmeron
Wednesday, 11/25	Dr. Nguyen	Dr. Zidek

Residents – November, 1998

Resident	Service	
Anthony Afong, MD	(Parsons)	713/891-5681
Pio Guerrero, MD	(Donovan)	713/833-9880
Glen House, MD	(Ivanhoe)	713/833-8460
Edward Lord, MD	(Valena)	713/833-9391
Gagan Mahajan, MD	(Francisco)	713/833-8289
Benjamin Nguyen, MD	(Zidek)	713/833-7456

Plastic Surgery or Baclofen Pump Issues

Contact: Lalita Thompson RN at ext. 5741 pager (713) 833-9293.

TIRR Case Management Issues

Please contact the new **Manager of Case Management, Mary Ann Beachler**, 797-7463 and beginning Dec. 1, 797-7568. Thank you.

rehabilitation gazette

Independent Living: The Role of Gini Laurie

Joan L. Headley, Executive Director

Gazette International Networking Institute, Saint Louis, Missouri

It has been written that there are two grandmothers of the independent living movement. One was Mary Switzer, the Director of the Office of Vocational Rehabilitation from the 1950s to the late 1970s. During her tenure and within a 15-year period, dollars for vocational rehabilitation increased 40-fold. An amendment in 1965 included tuition and attendant care for persons with severe disabilities. Mary Switzer demonstrated to Congress the financial rewards of turning adults with disabilities into "productive" citizens and "taxpayers."

According to Gini Laurie, the other grandmother of the independent living movement, Mary Switzer's role was vital because vocational rehabilitation monies developed an educated leadership — which was essential to the independent living movement.

Why is Gini Laurie considered one of the grandmothers of the independent living movement? Who was she and why did she get involved with disability?

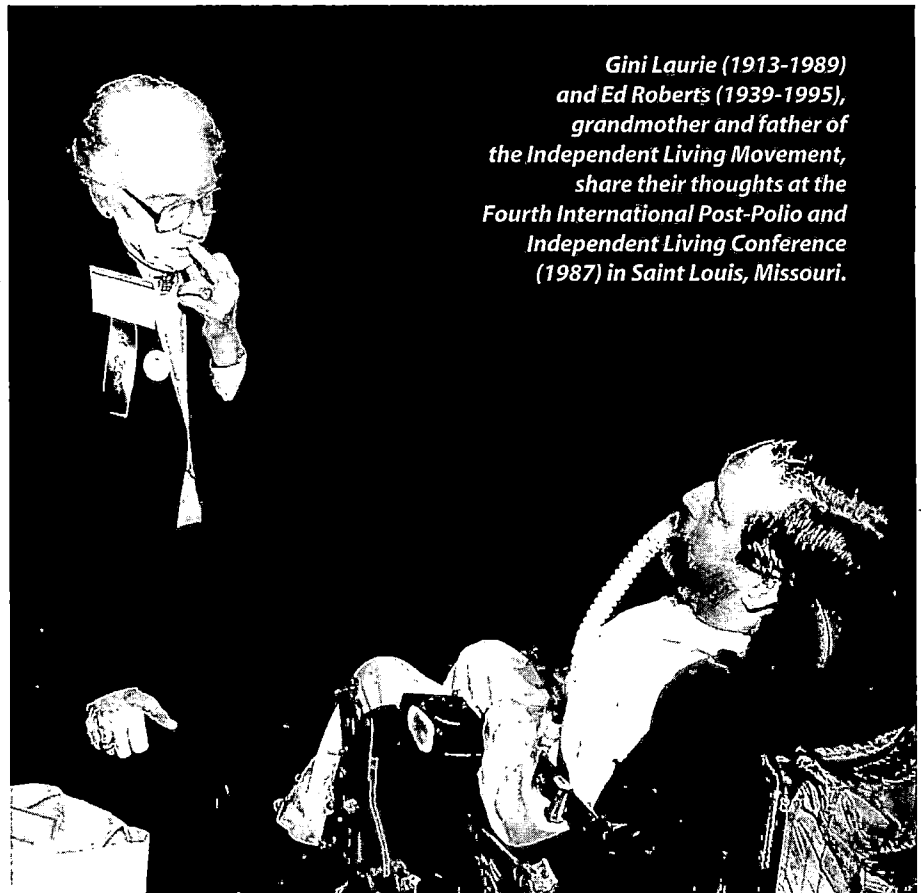
She revealed a very personal reason, October 1988, at the dedication of the new St. John's Rehabilitation Hospital in St. Louis.

"My father was a surgeon and on staff at the old Euclid Avenue St. John's [Hospital]. In 1912, the year before I was born, four siblings were struck by polio:

a 12-year-old sister was mildly disabled, a 6-year-old brother very severely disabled, and two sisters, aged 3 and 9, died within days at St. John's. In their memory, my mother painted a mural on the ceiling of the St. John's chapel depicting them as angels.

at one of the 15 polio respiratory centers operating in the late 1950s.

The centers, where individuals with severe polio in need of rocking beds and iron lungs were sent, provided superb medical and psychological rehabilitation but, until 1953, most of the permanent respirator users seemed doomed to remain in the hospital for the rest of their lives.



Gini Laurie (1913-1989)
and Ed Roberts (1939-1995),
grandmother and father of
the Independent Living Movement,
share their thoughts at the
Fourth International Post-Polio and
Independent Living Conference
(1987) in Saint Louis, Missouri.

"Sixteen years later, I watched my significantly disabled brother die of pneumonia and underventilation at St. John's. His funeral mass was in the chapel, underneath the mural of our sisters."

Because of her family experience, it was only natural for Gini Laurie to become a Red Cross volunteer

In order to save money by avoiding lifelong hospitalization at the high daily rate of \$37, Rancho Los Amigos Respiratory Center for Poliomyelitis in Downey, California, pioneered a system of home care that cost only \$10 per day and polio survivors were sent

PRESENTED AT THE
1997 REGION V INDEPENDENT
LIVING CONFERENCE,
OAK BROOK, ILLINOIS, OCTOBER 1997

home with their iron lungs and chest cuirasses.

Meanwhile, Gini Laurie volunteered at the Toomey Pavilion Respiratory Center in Cleveland, Ohio, and kept up with her old polio pals who had gone home.

Reflecting in her later years, Gini commented that it was "apparent they [polio survivors] had two vital needs ... people and information. They wanted to keep [up] with each other ... and wanted to share information about their lives and equipment."

Gini and her husband, Joe, started to meet those needs by building a heated pool with a lift at their home, where they held annual reunions of the alumni of the respiratory center.

In 1958, the same year, they started publishing *Toomey j Gazette*, featuring news of how polio survivors managed at home.

By 1959, the vaccines had stopped polio, the public stopped giving to the March of Dimes, and the March of Dimes stopped paying for attendants and closed the respiratory centers.

The sudden loss of attendant payments caused panic. There was no Social Security Disability, no Medicare, no Medicaid, no vocational rehabilitation for people with severe disabilities. There was only welfare or help from churches or family. Fortunately, polio survivors who had gone home from the centers had worked with attendants for a few years, and had worked out some systems of community support. However, they also needed the psychological support of other survivors.

That is where the *Toomey j Gazette* (later to become the *Rehabilitation Gazette*) came in.

Gini led a letter-writing campaign in 1959, alerting survivors in every state to write to their congressmen urging national attendant care legislation. The national campaign was unsuccessful, but it called Washington's attention to the problems of people with severe disabilities.

However, the California campaign was successful due to the efforts of the respiratory polio survivors, and state legislation established attendant care (in her words) "that later cleared the path for the independent living movement — for attendant care is the linchpin of independence."

The 1959 campaign for national attendant care demonstrated and solidified Gini's belief in networking — the power of connecting people with people and the power of information.

"Networking links people who share common needs or common goals. Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all, it is a method by which people get things done."

The following excerpts from the GINI archives demonstrate her persistence, her acceptance of people as they were, and her constant connecting.

Gini featured Ed Roberts in the Spring 1965 *Toomey j Gazette*, after receiving a clipping from *Parade Magazine* (April 5, 1964) with an article entitled "This Student Majors in Courage." The accompanying photo caption read, "Helped by brother Ron, polio victim Ed Roberts goes to classes."

Later she received this postcard from Ed Roberts. "Editor ... I am sorry you did not come to me to update the article. This article taken from *Parade Magazine* was not only inaccurate in many

instances but also poorly written. I am sorry to say that you have compounded the errors ..."

Gini responded August 3, 1965. "Dear Ed, Mea culpa, mea culpa, mea maxima culpa ..." and explained why she had not consulted him. "I shall be most grateful if you will tell the story of your teaching career, living at and attending university. It is vitally important, not only to the young would-be college students but to the vocational rehab departments who will be financing their studies ... Meanwhile, could you help with some information as to your present living arrangements at the Cowell Hospital? A very brilliant young respo in Germany is fighting to find a university in the U.S. which he can attend."

She sent Ed another note dated August 12, 1965. "Dear Ed ... My friend, Adolph of Germany, has sent the enclosed letter to me to forward to you. Do hope you are the magic button for him. I am so interested in helping him attain his pinnacles. Cheerio, Gini."

On September 9, 1970, Ed Roberts, in a postcard, made the following announcement. "I have begun [a] consultation business for anyone needing help with problems of cripples. Thus far I have consulted with Health, Education and Welfare in Washington, DC, about programs for cripples in higher education. Helped secure \$80,000 grant for University of California at Berkeley program run by cripples for the education of cripples. I brought John Hessler in as director. He is doing a magnificent job. Would you like to hear more? I believe no other consulting firm like this in country!"

He shared his philosophy with her in a 1970 letter. "I am tired of well-meaning non-cripples, with

their stereotypes of what I can and cannot do, directing my life and my future. I want cripples to direct their own programs and to be able to train other cripples to direct new programs. This is the start of something big ... **CRIPPLE POWER.**"

Another clipping from the archives dated January 31, 1971 documents a shift in thinking. "Judy Heumann grew up being called crippled, but today calls herself 'disabled and discriminated-against.' She feels that the word 'crippled' suggests that a person is not physically whole. ... 'If militancy means asking for something that is yours, then we're militant,' said Judy, president of the group. 'We're just tired of remaining silent just because we're scared of losing the little we have.'"

In 1988, Gini Laurie, at the Center for Independent Living in Springfield, Illinois, reviewed the independent living movement. "Independent living did not just happen. Two quads in Berkeley in the early 1970s did not wave their mouthsticks and say, 'Let there be IL centers.'"

"The independent living movement was not isolated. It was very much a part of its time and a reflection of its time." She further mentioned some of the influences on its evolution.

"The movement was influenced by the awakening of the importance of the individual; of the worldwide awakening to the rights of individuals and minorities. The independent living movement paralleled and was patterned after the black and women movements.

"It was influenced by the fact that there were many more healthy and long-lived disabled and elderly because of medical advances, such as penicillin. There were many more healthy, long-lived,

and severely disabled veterans who survived Korea and Vietnam [wars] due to better evacuation and treatment learned during WWII. The movement was also influenced and preceded by other organizations: Canadian Paraplegic Association, Paralyzed Veterans Association, The National Paralysis Foundation, [and] American Coalition of Citizens with Disabilities (ACCD)."

"The ACCD was very important ... because, for the first time, people who were blind, deaf, and physically disabled worked together for their mutual benefit. It brought together people with disabilities from east, west, midwest, and south. I was a token non-disabled member of the coalition."

Gini continued to publish the *Rehabilitation Gazette* until her death in 1989. She had added *Polio Network News* for polio survivors who were experiencing what has come to be known as the late effects of polio, and *IVUN News* for ventilator users. She spent fifty years of her life supplying people with disabilities with information and knowledge and connecting people with people.

Gini many times ended her presentations with caveats.

"I prefer to think of the movement as an interdependent living movement rather than an independent living movement."

"The [phone] calls usually start by asking for the name of a nursing home that will take people on ventilators. I react violently to the suggestion and remind them that they do not need nursing. They need a pair of hands that they can direct. They do not need to be buried alive in a nursing home. They need to continue to live their lives as they choose."

"Beware of bringing the hospital home; beware of making the cost of using a ventilator astronomical. Society will choose the more economical alternative — no ventilator."

"Beware of the edifice complex; people don't need buildings; they need improved systems."

"Beware of UBI, universal bureaucratic idiocy — be careful you don't become what you were originally created to fight against."

"Reach out to the aging population. ILCs should practice what they preach; hire [people over 70] as peer counselors; put older people on [their] boards."

"Respect each other; the elderly may feel same about young's lack of understanding that disabled feel about non-disabled's lack of understanding."

"We can't let divisiveness happen. We must all work together ... visual impairments, hearing impairments, physically disabled, mentally retarded, mentally ill, the elderly."

"We're a power if we work, think, and play together ... and only if we do."

rehabilitation gazette

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Gazette International Networking Institute (GINI)

4207 Lindell Boulevard, #110
Saint Louis, Missouri (MO)
63108-2915 USA

314/534-0475 ■ 314/534-5070 fax
Relay MO: 800/735-2966 TDD, 2466 V
gini_intl@msn.com

Editor: Joan L. Headley
Special thanks to ...

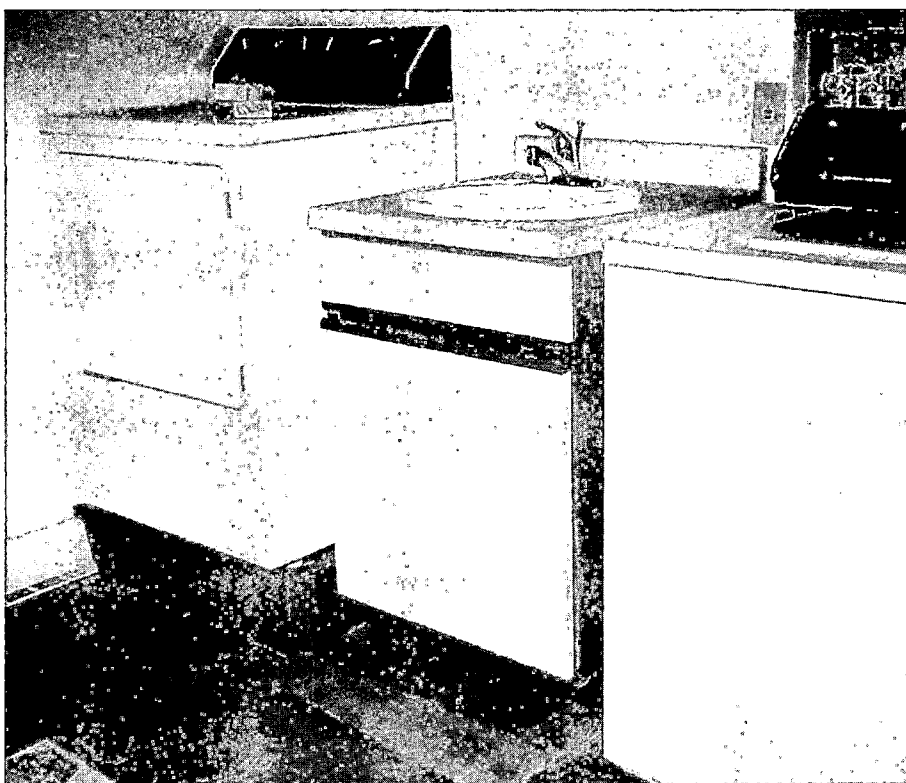
Justine N. Craig, Jessie Easton, MD,
and Sheryl R. Prater

An Accessible Lake Home



It started as a dream of a rustic small shelter with the only real requirements that I be able to get in and out easily and that there be plumbing. I had bought the lot with 100 feet of shoreline some years before, and with retirement it seemed the right time to build. So, I found an accessible house plan that I liked.

I had heard that the state vocational/technical schools would build houses to order, to be moved to the customer's lot. In the fall of 1995, I contacted the school in Watertown, South Dakota, 20 miles from the lake, and asked about building. I talked to the man in charge, Dale Howlett, and set up a charge account at the UBC lumber yard.



*Jessie Easton, MD
Sioux Falls, South Dakota*

David Gill at UBC looked at my plan and determined the house was too wide to go down the road.

He modified it to travel, as a two-bedroom, two-bath house with a large kitchen and living room and a laundry room that also served as the way out to the garage. He found subcontractors to do the concrete and electrical work, plumbing, and gutters, and for the foundation, garage, deck, and ramps, he recommended "Scooter" Jacobson, an independent contractor.

I was in charge of permits, carpet, and appliances, and had to choose lighting fixtures, wall surfaces, paint colors, as well as the kitchen and bathroom cupboards and plumbing fixtures.

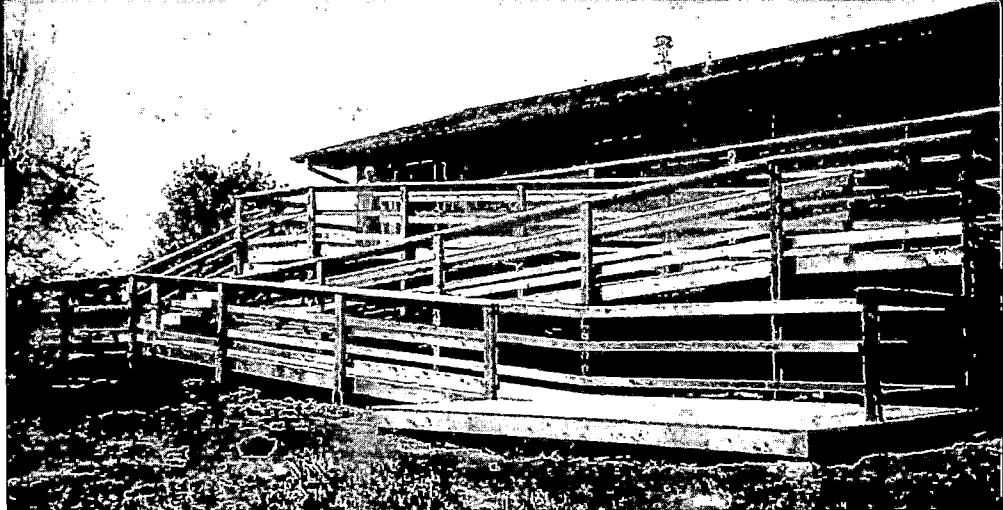
The house was built during the winter on a concrete pad at the school. A gas heater was installed as soon as the walls were up and the roof on. As the work progressed, I would get phone calls asking whether I wanted the walls textured or plain. I would ask what the students needed to learn and then would agree that "textured would be just fine." I missed seeing the painful times Dave told me about as the students struggled. I understood that sometimes I would be charged for extra wood or material when there was a difficult task to be learned. I understood it better when I had a chance to watch some of the finishing work being done, as one lad took four tries to get a piece of molding to fit over a door.

All the materials I chose were commercially available in our area. The house has a four-foot wide hall and three-foot wide doors. The doors have handles

instead of knobs. The carpet is a short-loop, firm, commercial type with a firm pad under it. The "big" bathroom, laundry room, and kitchen have non-slip vinyl floor covering.

In the bathrooms, the sinks have lower than usual counters (27-28") and are open underneath, with a medicine cabinet/light fixture combination set low enough for a seated person.

The guest bath has a tub with shower and grab bars as needed. The bigger bath has a shower that came with a low threshold, a seat,



In the kitchen, a bottom-freezer refrigerator has shelves that pull out. The upper part has a deep door for storing frequently used items, and shelves that are adjustable to accommodate different needs.

space (6") at the bottom. The cupboard doors have no knobs and open with a groove on the bottom or top. If pulls were to be put on, a plain round or oval knob would be easier to grip than some of the fancier small handles.

The garage is larger than usual (24' x 26'), with a ramp from the laundry room door to the floor. It has two doors, eight feet high. One is nine feet wide and the other is ten feet wide to accommodate a van.

There are electric openers for the doors, operated by switches at the back door and by a remote control in the car. (The one remote operates both doors at once, so it is necessary to have them both in the right position when leaving.)

On the lake side, there is a deck the length of the house, with a ramp to the shore level, and a flight of 6" steps for the impatient people. A second set of steps (5.5") leads off the other end of the deck so it is not necessary to go through the house. There is a smaller piece of deck at the bottom of the ramp, with a short ramp to the ground.

On the street side, a concrete ramp leads to the driveway. As the landscaping was considered, a graded ramp was put on the slope, to be seeded with grass and eventually graced with a rock garden. A set of steps beside the end of the wooden ramp, made of railway ties, allows quicker access to



and a bar at the back. The students added grab bars at the sides. The grab bars at the toilets, which can have risers added, are standard height.

The closets have low bars (30") and adjustable shelves. One closet is a large walk-in to provide room for storage in a house without basement or attic. I chose the washer and dryer by going around the store checking which ones I could reach the bottom and back of easily. The dryer, which opens to the front, was installed on a raised platform to make it more accessible.

The cook-top has an open space beneath and is electric, with the switches along the right side. It is level with the counter (28") so I can slide heavy pots rather than lift them. The sink is also open underneath and lower (26") than the counter for sitting to wash the dishes. There is also a dishwasher beside the sink, at standard height, to hide the sink from the living room.

The wall oven, placed in the lower cupboards has a side-opening door for easier access. The counter is lower than standard (28") and there is a deeper kick

CONTINUED ON PAGE 6

the shore. My plan is to have most of the land in native-type grass and have it cut a few times a year.

There is rural water and a septic tank and drain field. Some day there may be a proper sewer system. The furnace burns propane, and the water heater is electric. I use a cellular phone, however, regular telephone service is available.

There are a few things I would do differently, now that it is done and has been lived in. The bathroom doors open in, as most do. If they opened out, the smaller bath would be more accessible and the larger would have space for a hamper or chair. The door on the oven and the dryer should open the other way. The cook-top switches should be in front. I would opt for three bedrooms to accommodate a greater assortment of guests.

As it is, my next project is the addition of a screened sleeping porch on the north side of the house, with sliding glass to keep the wind out when needed and roll-down screens for privacy. That will come someday ...

I acted, with David Gill's help, as my own general contractor. It

would have been easier to have a contractor to do the organizing and supervising at greater cost.

I am particularly grateful to Scooter, who did the deck, ramp, and garage, and most of the picky little details at the end, putting up window shades and grab bars and shower curtains, making a wood box, and tidying up the yard.

My rustic cabin turned out to be a second home. I look forward to using it and then turning it over for others to use when I no longer need it. It has taught a class of technical students about adapted housing, and has been shown to

a lady with multiple sclerosis for whom Habitat for Humanity built a home. I have had members of the polio support group for a Saturday picnic, and they got some ideas for their own places. The mover who brought the furniture walked around saying, "Oh, my!" and I learned later that he remodeled his house for a recently injured family member. Overall, it has been a great adventure. I have learned, and so have others, that commercially available items can be found to provide a house that works for people with and without disabilities at a fairly reasonable cost.



I am a 66-year-old semi-retired physiatrist, who grew up in Alberta, Canada, where my parents bought a lake cabin (truly rustic, no plumbing) when I was about nine. I had polio at age seven, for which the doctor advised swimming. No pools were available, so I went swimming at the lake, and learned to use a saw and ax and make a fire and boat.

After medical school and a career in physical medicine and rehabilitation, including a clinic for polio survivors and work with children with multiple handicaps, I am now ready to go swimming and row a boat again. The ax will not be used to chop firewood for cooking, but will be used for a fun fire in my new fireplace.

Forty Years of GINI

In 1958, Gini Laurie became editor of *Toomeyville Jr. Gazette*, the mimeographed newsletter for Toomey Pavilion, Cleveland, Ohio, a respiratory center for poliomyelitis patients.

1959 Incorporated as the International Iron Lung Polio Assistance, Inc.

1964 Changed name to Iron Lung Polios and Multiplegics, Inc.

1970 Renamed Rehabilitation Gazette, Inc.

1971 Moved from Chagrin Falls, Ohio, to St. Louis, Missouri.

1979 Published letter by polio survivor regarding new problems.

1981 Coordinated first GINI conference, Chicago, Illinois — "Whatever Happened to the Polio Patient?"; changed name to Gazette International Networking Institute, Inc.

1984 Published *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* edited by Laurie, Maynard, Fischer, and Raymond.

1985 Formed the International Polio Network.

1987 Organized the International Ventilator Users Network.

1989 Established The Gini Laurie Endowment.

1995 Created The GINI Research Fund.

Attendant Services Debate **MiCASA (H.R. 2020)**

The House of Representatives will consider legislation (H.R. 2020) during the 1998 legislative session that was introduced by House Speaker Newt Gingrich (R-GA) June 24, 1997 at the counsel of Americans with Disabilities for Attendant Programs Today (ADAPT). Designed to amend Title XIX of the Social Security Act, the bill will redirect longterm funding, currently restricted to institutional use, to a consumer-controlled system. The bill is pending in the House Committee on Commerce and has bipartisanship support from 23 members of Congress.

Known as MiCASA, Gingrich introduced H.R. 2020 under the formal title, Medicaid Community Attendant Services Act. As its title suggests, this bill would create Qualified Community-Based Attendant Services, allowing only individuals eligible for Nursing Facility Services (NFC) or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) a choice of institutional services, community-based services, or attendant services.

Today, two million Americans who live in nursing homes may be eligible to take advantage of the MiCASA amendment to make the transition from nursing facilities into a home setting. The emphasis of the current system on institutional care and the resulting cost of such care are the main targets of this legislation. Currently, the United States spends 80% of Medicaid's long-term funding on nursing home care. The cost control measures proposed by H.R. 2020 would enable two people with disabilities to receive funding for adequate in-home or community-based care for every one person currently receiving

the same care in a nursing home. The bill limits spending to what is currently spent on NFC or ICF-MR services.

The debate has several hurdles to overcome before the bill can be voted into law. The largest would be what Gingrich referred to as "significant cost implications." The Congressional Budget Office (CBO) released a letter to Gingrich that projects spending for this new service at \$10-20 billion and calls the spending cap "difficult to apply." At ADAPT's insistence, the CBO has agreed to reevaluate their findings using other medical models. The Office of Management and Budget (OMB) will also release its report on cost projections of H.R. 2020 to the President this session.

Other hurdles in the debate include similar bills before Congress. The Senate will be considering similar legislation (S. 879) introduced by Senator Russell Feingold (D-WI). Although there are significant differences between the language of the two bills, they hold similar goals: to allow people with disabilities to choose how services such as help with dressing, bathing, eating, toileting, and ventilator care are to be provided. Feingold is from Wisconsin, one of the few states which currently offers community-based and attendant services.

Concerning the upcoming debate over both bills, Mark Johnson, ADAPT, said, "We hope this won't become a contest [between S. 879 and H.R. 2020]. Let's get hearings, let's testify, let's draft language that makes both bills better ..."

H.R. 2020 is scheduled for hearings in the Commerce Committee's subcommittee on Health and Environment, headed by Representative Michael Bilirakis (R-FL), by the end of March 1998. To be involved in the debate, contact him at the House Committee

on Commerce, 2125 Rayburn House Office Building, Washington, DC 20515, Commerce@mail.house.gov, or 202/225-2927.

MiCASA is the first step towards future and expanded national attendant care legislation. Debate and discussion will continue in both the House and Senate in the upcoming year. To contact legislative leaders who will be involved in this debate, contact the Senate web site at www.senate.gov/, connect with the House of Representatives web site at www.house.gov/, or call the Capitol switchboard at 202/224-3121. Written correspondence regarding MiCASA can also be sent by addressing letters to the Honorable (representative's name), US House of Representatives, Washington, DC 20515, or to the Honorable (senator's name), US Senate, Washington, DC 20510.

If you have further questions, please contact Justine Craig, gin_i_intl@msn.com, 314/534-0475, 314/534-5070 fax.

GINI expresses its appreciation for the contributions received in memory of friends and family ...

Alan Brewington
Hubert Edson
Leland J. Longhofer
Dorothy McGraw
Art Madsen
Susan Dorothy Pohland Mahan
Thomas S. Marshall, Jr.

GINI acknowledges a \$10,000 bequest from Robert J. Kinney to The GINI Research Fund.

New Publications

The ABC-CLIO Companion to The Disability Rights Movement by Fred Pelka; ABC-CLIO, P.O. Box 1911, Santa Barbara, California 93116-1911, 805/968-1911 or 800/368-6868, 805/685-9685 fax, sales@abc-clio.com; ISBN #0-87436-834-0; 1997; 422 pp.; \$60.00.

This encyclopedia is the latest work in ABC-CLIO Companions to Key Issues in American History & Life Series. It contains nearly 500 entries arranged alphabetically exploring prominent figures, historic events, programs, disability laws and issues, and key concepts. The book is cross-referenced, illustrated, indexed by subject, and contains a detailed chronology.

1998-99 Accent Buyer's Guide, 11th edition; *Accent on Living Magazine*, P.O. Box 700, Bloomington, Illinois 61702, 800/787-8444 or Acntlvlg@aol.com; January 1998; spiral bound; \$15.00 plus \$3.25 shipping.

The Self-Help Sourcebook: Your Guide to Community and Online Support Groups, 6th edition, compiled and edited by Barbara J. White and Edward J. Madara; American Self-Help Clearinghouse, Northwest Covenant Medical Center, 25 Pocono Road, Denville, New Jersey 07834-2995, 973/625-9565, 973/625-9053 TTY, 973/625-8848 fax, www.cmhc.com/selfhelp/; ISBN #0-9634322-7-3; 1998; 348 pp.; index; \$12.00 postpaid.

In addition to providing free help to anyone interested in starting a needed new mutual help support network, the American Self-Help Clearinghouse publishes this excellent resource. It has information on how to find or help form a group, develop an online support network, as well as the latest research studies. The resource lists over 800 national and model groups.

New from GINI

IVUN Resource Directory 1997/1998, compiled by IVUN News editor Judith Raymond Fischer, is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

Future GINI Publications

Post-Polio Directory 1998 will be available March 1. Entries from 1997 are being confirmed. Other post-polio clinics, health professionals, or support groups committed to addressing post-polio issues should contact GINI to be included. The cost of *Post-Polio Directory 1998* (after March 1) is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors edited by Gini Laurie, Frederick M. Maynard, MD, D. Armin Fischer, MD, and Judy Raymond (1984) will be updated during 1998 thanks to a grant from the March of Dimes Birth Defects Foundation.

Gazette International Networking Institute (GINI)

celebrating 40 years as ... a source of information ... a network of people

GINI also publishes ...

Polio Network News — for survivors of polio, families, friends, and health professionals who treat them. After March 1, the subscription rates for this 12-page quarterly will be \$20 USA; \$25 Canada, Mexico, and overseas surface; \$30 overseas air (US funds only).

Post-Polio Directory

IVUN News — for users of home mechanical ventilation, families, friends, and health professionals who treat them. After March 1, the subscription rates for the new 8-page quarterly will be \$17 USA; \$22 Canada, Mexico, and overseas surface; \$27 overseas air (US funds only).

IVUN Resource Directory

rehabilitation gazette

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