

# 福 Rehabilitation Gazette

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

June 1992 Vol. 32, Number 2

## Requests for Articles and Personal Experiences Related to Personal Assistance Services (PAS)

The high costs of things medical is no better exemplified than in the cost of institutionalization vs living independently at home.

In *The Ventilator-Assisted Individual: Cost Analysis of Institutionalization vs Rehabilitation and In-Home Management* by John R. Bach, M.D., et al (*Chest*/101/1/January, 1992), the authors stated, "The conversion to and/or maintenance on 24-h nontracheostomy ventilatory support permitted discharge to the community by allowing the VAI to be attended by trained but uncredentialed home care attendants, thus avoiding prohibitively expensive in-home nursing for tracheostomy care. This created a savings to the public of 77 percent or \$176,137 per year per client." The key is home care attendants or personal assistance services.

福 Rehabilitation Gazette invites organizations to share a summary of their goals, their work, and how others can join their effort regarding PAS; invites international representatives to share their views on PAS; invites individuals to submit their views and opinions based on personal experiences. Deadline for submission is November 10, 1992. For more information, contact G.I.N.I.

## The High Cost of Things Medical, II

### Update from Susan Ray

"In response to my article, *The High Cost of Things Medical* (January, 1992, *Rehabilitation Gazette*, Vol. 32, No. 1), Geoffrey Waters, Senior Vice President of LIFECARE, has offered to help me conduct the type of study I proposed on medical equipment costs. How long the study may take and how far I can take it, I do not know. I will be reporting our findings to the readers of the *Gazette* and welcome further comments." Susan Ray, 3110 Cavu, Georgetown, TX 78628 USA.

### Other Comments in Response to Susan's Article

"I agree that we, as consumers, should do *something*, but I'm also pessimistic. The problems seems so large that it seems a waste of time."

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"One way to lower some prices is to loosen requirements to allow payment to non-professionals. I've gotten good, cheap accelerator extensions and wheelchair repairs from local people who are handy and enjoyed being inventive. There are still some creative tinkerers around."

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"In terms of lowering total cost of medical equipment, we might do more in the way of passing it along to other people who need it. My first power chair was given to me by someone who had other chairs. I used it at work for a couple of years. When I got a new one — respectable-looking with no maintenance batteries and tires — I loaned the old one to someone else. Are there groups who facilitate this? The *Gazette* could publish a list. Perhaps, we could will our equipment to that group. I'm sure our executors would really appreciate it."

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"I've heard that equipment is much cheaper in other countries. Is that true? Could we press for duty and tax free imports?"

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The High Cost of Things Medical, II presents an overview as to why medical costs are so high and information from some groups which are addressing the problem. Not all aspects are covered. Missing are the pros and cons of HMOs; managed care; self-referral of patients by physicians who own labs and clinics; and physician advertising. Comments on these issues are welcomed.

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## The High Cost of Things Medical, II

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### Facts, Figures, and Viewpoints from The Robert Wood Johnson Foundation (RWJF)

Assuring access to basic health care is one of RWJF grant-making goals. *ADVANCES*, a newsletter from the Foundation, is published quarterly and contains reports from grant recipients. For information on receiving this publication, contact Communications Office of RWJF, P.O. Box 2316, Princeton, New Jersey 08543-2316 USA (609/452-8701).

The following four reports were excerpted from *Challenges in Healthcare: A Chartbook Perspective 1991* also published by the Robert Wood Johnson Foundation.

### Health Expenditures Here and Abroad

Health care expenditures in the U.S. are higher than those of any other nation, by any measure. In 1988, U.S. per capita health care expenditures were \$2,140 — \$546 higher than in Canada, the country with the second-highest per capita rate. In that same year, 11.3 percent of the U.S. Gross Domestic Product (GDP) went toward health care, compared to the proportion of GDP spent by Canada, Sweden, the United Kingdom, and the Federal Republic of Germany, which ranged from 5.9 to 9.0 percent.

U.S. spending on health care increased more rapidly between 1980 and 1988 than did spend-

ing in other countries mentioned. In the 1980s, faced with growing economic pressures, these countries imposed restraints on health care costs, and the proportion of their GDP spent on health care remained relatively stable, with Sweden's proportion actually declining in 1988. By contrast, the United States — which faced much the same economic situation — imposed more moderate restraints, and the proportion of GDP spent on health care increased a full two percentage points, from 9.3 percent in 1980 to 11.3 percent in 1988.

Several explanations have been suggested for the disparities in health expenditures between the United States and other wealthy

industrialized nations. One oft-cited reason is that, in other countries, governments tend to regulate health care expenditures more closely. In Sweden, for example, county councils with broad powers own and operate hospitals, determine how many patients a physician will care for and levy taxes to pay for health services. Even in countries where hospitals and physicians are in the private sector, governments impose controls on budgets, fees, and capital expansion.

A second explanation is that public financing of health care plays a smaller role in the United States than in most other countries. Public programs account for just over 40 percent of all U.S. health care expenditures, whereas public sources pay for more than three-fourths of health care in other industrialized countries, on average. While a predominantly private system may be thought to be linked to higher health care costs, that is not inevitable, as shown by the experience of West Germany.

A third explanation for higher U.S. health expenditures may be the high cost of administering our current system: Even an old estimate — based on 1987 data — suggests that some 24 percent of the total U.S. health budget was spent for such things as

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

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billing, recordkeeping, claims processing, and marketing, an administrative burden that has not decreased with time. These costs are passed on to consumers in higher prices for health service.

### Health Expenditures in Context

In the United States we spend more on health care than we do on either education or national defense. In 1988, six percent of the Gross Domestic Product was spent on national defense and 6.5 percent on education, while more than 11 percent was spent on health care. Although this is more than other nations spend on health, the question of how much of the GDP should be spent on health care is a value judgment.

Because the health care sector continues to consume an increasing proportion of the GDP, some economists worry that in the future the high cost of care will be met at the expense of other goods and services. In 1970, the United States spent just eight percent of the GDP on national defense, even though we were in the middle of the Vietnam war; we spent 7.5 percent on education then, even though the baby boom generation was mostly in school; and we spent 7.4 percent on health care. In the two decades since, *the proportion of GDP spent for education and national defense has decreased, while the proportion for health care has increased 50 percent* — even after adjusting for economy-wide inflation and even though a great many Americans still receive inadequate care.

One reason for increased health expenditures is *the aging population*. Another is *the proliferation of sophisticated medical technology*, which gives us the capacity to prolong the lives of very sick patients — at a tremendous cost.

Demonstrating the interrelationship between health care spending and social values, some analysts warn that Americans may be forced to make hard choices about who receives costly services if we truly wish to contain spiraling health care costs. Other experts say that increased efficiency and system reforms may produce enough savings to enable us to forestall explicit rationing of health care. Still others maintain that we are not spending enough on health services for Americans.

### Why Health Costs Grow

Personal health expenditures in the U.S. increased 10 percent — from \$434 to \$478 billion — between 1987 and 1988, a period when economy-wide inflation, as measured by the Consumer Price Index, was only 4.4 percent. What accounted for this large increase in the health sector?

The increases are attributed to four factors — *economy-wide price inflation, additional medical inflation, population increase, and intensity of care*.

Economy-wide price inflation affects the price of all consumer goods. Inflation is measured by standard indexes, which also monitor the prices of medical services. The difference between annual price increases in medical services and economy-wide price increases is termed additional medical inflation. Between 1987 and 1988, the rate of additional medical inflation was 2.3 percent.

The population increase factor takes into account population growth — the greater number of people who are buying health care services and thus raising the personal health expenditures total from one year to the next.

Intensity of care is a residual category, which estimates the effects of the aging of the popu-

lation and the use of expensive technology, for example, as well as per-person increases in the number of office visits, tests, and other services.

Additional medical inflation was more important in the price increases that occurred in 1988 than in 1968 or 1978. In fact, additional medical inflation, responsible for 24 percent of the annual increase between 1987 and 1988, cost the United States \$10 billion in that year alone.

One reason for growing health costs is that *the health services market does not operate like conventional free markets*. In conventional markets, consumers select goods and services — food, home repairs, clothing — based on price and a personal assessment of their necessity and value. These assessments help regulate prices. In the health services market, *consumers do not exert the same influence on prices, largely because they do not pay for services directly*. Also, *consumers don't believe they have the knowledge to judge for themselves the necessity, quality, or price of the health care services they are purchasing*. As a result, they rely heavily on health care providers — physicians, in particular — to make "buying decisions" for them.

### Disability and Health Insurance

Despite the diversity of problems and ages, the health insurance status of people with disabilities can be discussed as if they were a cohesive group. Some 62 percent of the work-disabled population has private insurance; yet, this coverage may be inadequate, because *it typically contains numerous exclusionary clauses and limitations*. Because of the vulnerable state of health of people with disabilities, their potential heavy use of health care services and their low employment rates, private

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insurers are reluctant to cover them, and many have no private health insurance at all.

Do existing public-sponsored health programs provide a strong enough safety net? The answer is no. A greater proportion of people in this *age group with disabilities (almost 17 percent) report no health insurance*, compared to people without disabilities (14 percent).

Medicare and Medicaid cover only about 30 percent of working-age people with disabilities. People who have worked a set amount of time before becoming disabled are eligible for Medicare under the Social Security Disability Insurance Program; however, they must wait two years to qualify for this coverage. To qualify for Medicaid, disabled people must meet state eligibility requirements. Many have *too much household income to be eligible, even though they are near poverty and have high disability-related medical expenses.*

### Other Facts, Figures, and Viewpoints

**Health Care Solutions for America**, a non-profit policy study organization in Washington, released a study which says that almost 30 percent of the 35 million people without health insurance would buy it with their own money if they could deduct the full cost on their income tax returns.

Current tax policy allows corporations to deduct the entire cost of health insurance for their employees, while individuals purchasing their own insurance are not allowed any deduction at all. The study concluded that because of federal and state income taxes and Social Security

taxes, "a middle class family buying insurance may need to earn an additional \$8,200 to have enough net income to purchase a policy which costs a corporation \$4,000 to provide."



**C. Everett Koop, M.D.**, was interviewed by **William Allen**, *St. Louis Post-Dispatch* science writer. During the interview, Dr. Koop's comments focused on the U.S. health care crisis and parts are excerpted below.

**Q:** What are the forces behind the health care crisis?

**A:** The forces behind it are those things that have forced the cost of medicine upward. One highlight is *high-tech medicine and the desire on the part of every hospital in the country to have everything available* in order that in the competitive health care market — which is not freely competitive — they can at least make a profit or not turn in a red figure.

A second highlight is the *increasing wages for health care workers and physicians.*

Another issue is the *cost of surgical materiel.* We have become a disposable society. We suddenly are presented with a whole world of plastics in hospital that you didn't ask for. You have your own plastic bed pan, your own plastic spittoon, toothbrush, soap dish, plastic tubes, plastic needles, plastic everythings. And because they are disposable, our society thinks they must be cheap. They are extraordinarily expensive.

**Q:** You stated that each of us must make a personal sacrifice — a short term loss, in order to win the game. What kinds of sacrifices are you talking about?

**A:** *Cut the administrative load.* Blue Cross-Blue Shield of Massachusetts employs more paper pushers than the entire country of Canada. You can touch

administrative things without touching the patient.

*Change the tort system for malpractice claims.* Skip the courts and go to mandatory binding arbitration. I don't say that just because I'm a physician and I'm trying to protect doctors. I'm very concerned about a Harvard study that found that out of every 12 people injured in a medical/surgical encounter, 11 of them found the legal system so intimidating that they never got any redress.

Costs (under an arbitration system) would go down by stopping the practice of defensive medicine. If you come in and I don't think you need a test for your "blood rhubarb" level, I'm going to get one anyway, because three years from now your lawyer may ask me why I didn't get it.

**Q:** You said the health care marketplace is not "freely competitive." What do you mean?

**A:** There are no natural forces such as competition for price, quality and service. If there are two gas stations on the street corner in your town, there will eventually be a gas war and eventually the price of gas will go down. But *if you put two orthopedic surgeons on those corners, the price of replacing a hip will go up and up and up.* That's because each will say, "I've got to do it better. I've got to get a 'this.' I've got to get a 'that'." There is nothing to say that physicians can't do that.

**Q:** What are some other reasons for the high cost of health care?

**A:** One is the *unbelievable debt the average medical student graduates with.* If he goes to a state school, it's \$40,000-\$70,000. But if he goes to a private school, it's \$150,000-\$175,000. To pay that off, he

shifts to orthopedics, or cardiovascular surgery, or plastic surgery, and as a result, we have too many high-priced specialists in the suburbs and not enough doctors in rural America or the city ghettos.

**Q:** What's the solution?

**A:** Pay for the education of doctors. We're the only civilized nation in the world that doesn't do that, except possibly South Africa. It's the only way you can get a handle on manpower.

**Q:** What is the role of health insurance companies in solving the crisis?

**A:** We have got to convince insurance companies that in the future, they have to go back to the notion of the past, and that is that sick people and well people got together and got insurance so that when people get sick, they'd be covered. Currently, insurance companies go into the community, and they pick out of it those people who are high risk and would cost them money, and *they end up by just insuring the healthy.* That's crazy. It's also unfair and unconscionable.

### U.S. and Canadian Physicians' Views on Health Care

As the United States eyes the Canadian health system model, researchers have criss-crossed the border to compare the views of physicians in both countries. Attitudes of physicians in residency training are of special interest, because these doctors have not yet become established in a practice style and because they will help shape the future of medical care.

This survey comprised 542 Canadian residents and 1,745 U.S. residents and sought to determine levels of professional satisfaction, satisfaction with income, and opinions on access,

quality of care, national health insurance, and government control.

*Residents overwhelmingly preferred their own country's predominant system* — 87% of U.S. resident supported private, fee-for-service health care, and 85% of Canadian residents supported government-funded national health insurance. However, the survey indicates *less opposition to national health insurance among future U.S. physicians* than previously thought. Only 17% strongly opposed it; 10% strongly supported it; and 42% expressed some support.

#### OTHER FINDINGS:

Professional satisfaction was about equally high among U.S. and Canadian resident physicians (76% and 79% were very satisfied).

U.S. residents were more likely to perceive a serious access problem in their own country than were Canadian residents (75% compared with 18%); yet, residents universally agreed on the ethical obligation to provide care to everyone — regardless of social circumstances.

*U.S. residents were more likely to believe there are too many controls on the medical profession*, while Canadian residents were somewhat more likely to believe government interference has hurt quality of care.

Significantly fewer Canadian residents approved of extra billing if government fees were too low (41% versus 58%).

In this survey, U.S. residents in internal and family medicine share the commonly held view that the incomes of primary care physicians (their own) are too low and the incomes of surgical specialists too high. Medical residents planning subspecialty practices were more likely to think medical subspecialists' incomes are fair, but agreed that surgeons' income

are too high. In Canada, where income differences among specialists are less marked, residents were likely to believe that primary care salaries are too low or other groups' salaries too high.

*A common criticism of the Canadian system* — when the possibility of national health insurance for this country is raised — is that patients often must wait months for elective surgery. Another group of researchers examined in depth the reasons for a "queue" for cardiac surgery in British Columbia from 1986 to 1990.

They found that the length of the queue varied significantly among surgeons, *with three of the province's 14 cardiac surgeons accounting for two-thirds of the waiting list.* Because operating room slots are allocated only partly based on the length of the individual surgeon's waiting list, some long waits may be due to lack of coordinated referral.

Also significant was a temporary shortage of key support staff. In 1989, the waiting list doubled (from 400 to nearly 800 patients) following work slowdowns by nurses and a worsening shortage of perfusion technologists. Once these personnel problems were addressed, the hospitals couldn't gear up to take care of the backlog of waiting patients, despite the availability of additional funds and surgeons. The constrained services supply in Canada simply makes the system slow to respond to changing conditions.

Hayward RA, Kravitz RL and Shapiro MF. The U.S. and Canadian Health Care Systems: View of Resident Physicians, *Annals of Internal Medicine* 115 (August 15): 308-314, 1991.

Katz SJ, Mizgala HF and Welch HG. British Columbia Sends Patients to Seattle for Coronary Artery Surgery. *Journal of the American Medical Association* 266 (August 28): 1108-1111, 1991.

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Dr. Katz was a Robert Wood Johnson Clinical Scholar at the time of this study.

Reprinted from *ADVANCES*, the national newsletter of The Robert Wood Johnson Foundation.

## Physicians for a National Health Program

Physicians for a National Health Program (PNHP) was conceived at a summer conference in Boston in 1986 on "Caring for the Poor," where a small group of physicians became convinced that the situation was critical and would worsen without systemic reform. Its current membership of 4,000 physicians across the country maintains that health care reform is not only necessary, it is possible.

PNHP's original proposal for health care reform was published in January, 1989 in *The New England Journal of Medicine* (A National Health Program for the United States: A Physician's Proposal, David U. Himmelstein, MD, Steffie Wollhandler, MD, MPH, et al, January 12, 1989, Vol. 320, No. 2, pp. 102-108).

Since physicians are most effectively persuaded by well-researched data, the PNHP presents its program and viewpoints in peer reviewed scientific journals and makes its arguments on that information and analysis. Additional papers published in *The Journal of the American Medical Association* include *Liberal Benefits, Conservative Spending: The Physicians for a National Health Plan Proposal*, Kevin Grumbach, MD, et al, May 15, 1991, Vol. 265, No. 19, pp. 2549-2554; *Caring for the Uninsured and Underinsured; A National Long Term Care Program for the United States*, Charlotte

Harrington, RN, PhD, et al, December 4, 1991, Vol. 266, No. 21, pp. 3023-3029.

PNHP is currently developing proposals in the areas of occupational health, mental health, and medical education. They believe that physicians have an important role to play — to educate the public and policy makers about the fundamental flaws of the present system, to clarify the effects of those flaws on the health of patients, and to encourage fundamental policy changes.

For a summary of PNHP's proposed national health program, or membership information (available to non-physicians as well) contact PNHP, 332 S. Michigan Ave., Suite 500, Chicago, IL 60604 USA (312/554-0382, FAX 312/554-0383).

## DRIVE (Disability Rights In Voter Empowerment)

DRIVE, a project of the **Boston Center for Independent Living**, 95 Berkeley, Suite 206, Boston, MA 02116 USA (617/338-6665) has asked the presidential candidates for their positions on disability issues. Contact **Amy Hasbrouck** for position papers by President Bush and Governor Clinton. They are presently preparing a paper on Ross Perot's position.

## House Republicans' Health Care Reform Package

Action Now Health Care Reform Act for 1992 was unveiled earlier this month. If you are interested in the House Republicans' position on health care reform, contact Missi Pessier, 202/225-0600 or write to Robert H. Michel (IL) or Newt Gingrich (GA), Leaders' Task Force on Health, U.S. House of Representatives, Washington DC 20515.

## Word from Washington

Senior policy analyst, **Bob Griss**, of United Cerebral Palsy Associations, Inc. (UCPA), has intensively studied and written on health care reform particularly as it relates to disability. For more information contact UCPA, 1522 K St. NW, Suite 1112, Washington, DC 20005 USA (800/USA-5UCP or 202/842-1266 and ask for information on their publication, *Word from Washington*.)

## Disabled But Able to Vote

4215 12th St., NE, Washington, DC 20017 USA (202/832-6564)

This organization is actively working for passage of the **National Voters Registration Act** (S 250) which was approved by the Senate on May 20, 1992. The House is expected to act on the measure in the next two weeks. President George Bush may veto the measure, but the White House has issued no veto threat.

About 70,000,000 Americans eligible to vote are not registered. Under the bill (1) the 90% of the voting population with drivers' licenses would automatically be registered to vote when they applied for or renewed their licenses (27 States now allow this). (2) States would be required to allow voters to register by mail (27 States allow this). (3) States would be barred from removing names from registrations rolls just because people did not vote in recent elections.

States that allow voters to register on the same day as an election (ME and MN) would be exempt.

For more information contact **Jim Dickson**, Executive Director, Disabled AND Able to Vote at the above address.



## Thoughts from Munhie, Jill, and Aimee

Aimee and Jill first row left;  
Munhie, second row,  
second from right.

**My name is Munhie So** and I came from South Korea. I attend Forest Park Community College in St. Louis, MO, and I plan to transfer soon to the University of Missouri in Columbia. I am an open-minded person who likes to be helpful. I like to go out and have fun with my friends. I am also an outgoing person who is spontaneous.

**My name is Jill Ostermeyer.** I am 15 years old. I go to Francis Howell North High School in St. Louis, MO. I am caring and self confident. I have one sister, one brother, two cats, and one dog.

**My name is Aimee Weatherford.** I am 14 years old. I am very sociable. I don't hide my feelings from others. I don't let things get in my way. In some ways I'm very independent. I don't let others put me down. I don't let people say I can't do this. I don't let people talk behind my back when they're talking about my disability, and when they get angry because I have the same rights they do. Sometimes I get very upset if people don't tell me how they feel about me. I don't let people underestimate me. I tell them what I can and can't do.

### What Is It Like to Be a Teenager in the 90's?

**Munhie:** Being a teenager in the 90's is very frustrating and difficult because of so much peer pressure, drugs, violence, and high expectations from parents coupled with the lack of supervision of parents due to both of them working. It is hard at this stage because you feel confused, ignored, and stranded. Teenagers, especially with disabilities, have a tendency to be left out of a whole lot of activities. Maybe many of us have not experienced major controversial episodes related to our disability, but we still can feel confused, ignored, lonely, ashamed, and angry.

**Jill:** Being a teenager in the 90's is both frustrating and rewarding. The frustrating part about it is, there is pressure put on us that we know isn't right. The rewarding part about being a teenager is you get more freedom to go places like shopping, skating rink, etc.

**Aimee:** I think it's very hard to be a teenager in the 90's, because there is so much you have to deal with. I've had to deal with some teenagers who think that teenagers in wheelchairs can't get jobs, can't think for themselves, and can't do for themselves.

I had a really hard time getting on a ride at Six Flags. This one person wouldn't let me get on,

but the rest of the people there knew I could. I have to fight with a lot of teenagers because they don't invite me to parties. However, a lot have accepted me the way I am. Dealing with adolescence has been a different experience for me. I've had to deal with peer pressure when kids ask others questions *about* me instead *of* me. A lot of times in my teenage life people ask my parents things instead of me.

### Do You Have a Message to Share with Those Close to You?

**Munhie:** A message to my classmates with or without disabilities is that we need to be better aware of each other. People are people, and we all have a heart and feelings, so we should all work as a whole.

**Jill:** A message I would like to send to my siblings is that just because I'm in a wheelchair doesn't mean that they can get away with anything.

**Aimee:** I have a message for my classmates. I'd like to try to thank them for being so supportive and so patient with me sometimes. I'd like to thank my friends for including me in almost everything they do. I

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## Thoughts from Munhie, Jill, and Aimee

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especially like going out with them to the mall and skating rink.

### Do You Have a Message for the World?

**Munhie:** I would like to tell the whole world that a disability is not going to stop me from getting an education, a job, and a social life just like other people without disabilities. I have the potential to make it happen.

People like us get discriminated against just like people of different races. We all need to educate, communicate, and share opinions and ideas to better ourselves. I ask the world not to leave us out empty in the open field.

**Jill:** I would like to tell the world that just because I'm in a wheelchair doesn't mean I'm different. I have many friends. I have a boyfriend that loves and appreciates me. I do what any normal teen does.

**Aimee:** I would like to tell the whole world that just because someone is in a wheelchair does not mean they don't have a mind of their own, and do not know what they want. I would also like to add that some people think just because you're disabled, you can't have a personal relationship. I would not want a sexual relationship until I am married, but I still feel I can have a boyfriend.

### What has the integrated youth program at Paraquad taught you?

**Munhie:** The youth program at Paraquad is a program designed for youths with disabilities to have fun with a group as well as learn about themselves, others, and needs in the society. We do

career planning as well as field trips to enhance our abilities.

**Jill:** I feel the youth group has taught me to be more confident with myself, and it has taught me to fight for what I believe in as a disabled youth. It also has taught all of us about our rights. The Paraquad youth group has fun activities. Some examples are sailing trips and canoe trips.

**Aimee:** The youth group at Paraquad has taught me that



4475 Castleman, St. Louis, MO 63110 USA (314/776-4475, TDD 314/776-4415) is one of over 300 independent living centers in the U.S. which offers services for people with disabilities.

**Paraquad's Youth and Family Program** began in the mid-80's to address the fact that many of the adults they were serving had been disabled at birth or at an early age. They lacked the confidence, knowledge, and skills necessary to achieve their potential. Common sense dictated that these individuals and their families needs assistance at an earlier time.

The Program provides an opportunity for youths with and without disabilities to participate in a variety of social/learning opportunities. All of the activities encourage the participants to test their personal limits and explore their many abilities. Activities range from five-day canoe trips, to meeting with State legislators to discuss policy development, to exploring career opportunities. Developing independent living skills is a part of both individual consultation and group activity. Each individual has an opportunity to be a part of a team to develop a strong sense of self,

you can do things on your own without people telling you can't do this or that. We do a lot of interesting things. We've gone canoeing down the Current River here in Missouri. We've gone sailing on Lake Carlyle. We work on getting things accessible for people with physical and mental disabilities — like fighting the St. Louis Zoo to have the right to ride on the train. We've gone Christmas shopping on our own.

and to discover his or his capabilities and those of their peers.

Contact **Juli O'Leary**, Youth and Family Coordinator at the above address for more information about the Youth Program.

**福 Rehabilitation Gazette** invites other teens to respond to the remarks of Munhie, Aimee, and Jill, or to express their own thoughts for publication.

**The Southern California Post-Polio Network (SCPPN) and UCLA** are presenting the conference **"Utilizing Local Talent"** on November 21 & 22, 1992.

Health care professionals will discuss symptoms, treatments, research and types of assistance available to post-polio survivors.

For registration information, please contact Glenn Ham-Rosebrock or Diane Legbandt at 310/862-7674 or Carol Mutchnik at 818/957-4160, or write SCPPN, 9041 Imperial Highway, Suite L, Downey CA 90242 USA.

The conference will be held at the Long Beach Airport Marriott Hotel, 4700 Airport Plaza Dr., Long Beach, CA 90804 USA (310/425-5210). Contact the hotel directly for room registration and mention the SCPPN for a special conference rate. A Friday night reception will be held to welcome conference registrants.



## Selected Resources

**The Department of 4-H Youth and Breaking New Ground Resource Center** at Purdue University have developed a leader's guide for use by 4-H professionals and volunteers as they work to involve more youth with disabilities in the 4-H program. The leader's guide contains sections on: laws pertaining to mainstreaming; definitions of mainstreaming and the types of disabilities; suggestions for involving youth with disabilities in 4-H projects and activities; and recruiting youth with disabilities into the 4-H program. The leader's guide, although written for 4-H professionals and volunteers, contains information which could be used by anyone wishing to involve youth in their programming.

In addition to the leader's guide, two brochures have been developed. One brochure is designed for 4-H professionals and volunteers and the other is oriented towards the parents of youth with disabilities.

For additional information contact **Roger Tormoehlen**, Extension Specialist, 4-H Youth, AGAD Building, Purdue University, West Lafayette, IN 47907 USA (317/494-8429).

**Good Intentions, Mistaken Assumptions** is a video aimed at making classroom teachers more sensitive to students with disabilities who have been mainstreamed into their classes. In it, nine adults with a wide range of disabilities share memories of schooldays and of the teachers who made an impact on their lives. The researchers found that most children are not allowed to have free access because of mistaken assumptions. It also deals with issues related to the American With Disabilities Act. Available through Veriation Films. Cost is \$95 plus \$5 shipping and handling. Write 2800 Emerson Ave., Palo Alto, CA 94306 USA.

**Natural Ties** is a program aimed at integrating students with disabilities into college organizations, including fraternities and sororities. For more information contact Patrick H. Hughes, Jr., Executive Director, Natural Ties, Sigma Alpha Epsilon National Headquarters, P.O. Box 1856, Evanston, IL 60204 (708/475-1856, ext. 225).

**National Information Center for Children and Youths with Disabilities (NICHCY)** publishes *News Digest* three times a year. Vol. 1, No. 2, 1991 featured *Related Services for School-aged Children with Disabilities*. Vol. 1, No. 3, 1992, features *Sexuality Education for Children and Youth with Disabilities*. The approximately 24-page publication contains excellent information, complete with references and resources. Individual subscriptions in the U.S. are free. NICHCY disseminates other materials and can respond to individual inquiries. For further information and assistance, or to receive a NICHCY Publications List, contact NICHCY, P.O. Box 1492, Washington, DC 20013 or call 800/999-5599; 703/893-6061 in the DC area; 703/893-8614 TDD.

**The Self-Help Sourcebook, Finding and Forming Mutual Aid Self-Help Groups.** This paperback book is the most complete, updated, nationwide listing of self-help networks. Self-help clearinghouses are listed by state. Compiled and edited by Edward Madara and Abigail Meese. Available through the American Self-Help Clearinghouse, Saint Clares-Riverside Medical Center, Denville, NJ 07834; 201/625-7101; \$10.

**The Exceptional Parent Annual Directory of National Organizations.** This yearly publication of *Exceptional Parent* magazine lists the parent-to-parent training centers in each state and the varied support available for all pediatric disabilities. Edited by Maxwell Schleifer. *Exceptional Parent*, 1170 Commonwealth Ave., Third Floor, Boston, MA 02134; \$5.

**The Parent Resource Directory.** This paperback book contains a national list of parents who are available to talk with other parents who have a child with a similar disability. Association for the Care of Children's Health, 7910 Woodmont Ave., Suite 300, Bethesda, MD 10814; 301/654-6549; \$5.

**Introduction-to-Your-Child Booklet Series.** A set of 28 booklets discusses cause, treatment, and parental support for childhood conditions. The question-and-answer format tells parents what they want to know in an easy-to-read style. Helpful illustrations are included and the booklets are revised as significant developments occur. The booklets are 5-1/2 X 8-1/2 and average 17 pages in length. The entire set of 28 is \$24.61 including shipping; 2 sets are \$46.47; and 3 sets are \$69.51 (in WA add 8.2% tax). Individual titles are available. Professionals may request a copy of an individual title without charge. Write Medic Publishing Co., P.O. Box 89, Redmond, WA 98073 or call 206/881-2882, FAX 206/867-8939 to order or for a list of titles.

**HEATH** is a national clearinghouse on post-secondary education for persons with disabilities located at One Dupont Circle, Suite 800, Washington, DC 20036 USA. Over the last several years, the **HEATH Resource Center** has been collecting information published by various statewide systems of higher education. For more information about higher education for individuals with disabilities in your state contact HEATH Resource Center. HEATH has also compiled a list of **Summer Pre-College Programs for Students with Learning Disabilities**. Programs vary in length, from a week to a month. Many are on the east coast and have a tuition. Call or write for a free copy.

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## RESOURCES, RESOURCES, RESOURCES, continued

### CATALOGS

**Self Care Catalog**, 5850 Shellmound Ave., Emeryville, CA 94662-0813 (800/345-3371).

**The Disability Bookshop Catalog**, Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666-0129 USA (call 800/637-2256 US & Canada to order a catalog which is \$2.00 or a catalog on two audio cassettes which is \$6.00).

### COMPUTER RELATED

**Personal Computers for Persons with Disabilities, an Analysis, with Directories of Vendors and Organizations**, by William Roth, professor at the State University of New York at Albany who established the Center for Computing and Disability in 1984. The 224-page paperback book (ISBN 0-89950-698-4) is available for \$31.95 postpaid from McMillan and Company, Inc., Box 611, Jefferson, NC 28640 USA (919/246-4460).

### DIRECTORIES

**Telability Media Guide**, Charles E. Winston, publisher, P.O. Box 1488, Columbia, MO 65205-1488 (314/445-7656) is the nation's first statewide survey of mass media, print, and electronics for persons with disabilities (Missouri only). The publication may not be sold. Single and multiple copies are free to all who request it. It is also available on tape.

**The 1992 Directory of Canadian Rehabilitation Services** listing public and private resources, province by province, is available for \$22.95 plus \$3.00 postage and handling, from **Canada Rehabilitation Council for the Disabled**, 45 Shepard Ave. E., Suite 801, Toronto, Ontario M2N 5W9 Canada (416/250-7490).

**National Healthlines Directory** (which is registered), is a guide to 800 and local telephone numbers of the major United States organizations that provide direct telephone responses to questions on health topics. May be purchased for \$15.00 plus \$2.75 for postage and handling from Information Resources Press, Suite 500, 1110 N. Glebe Rd., Arlington, VA 22201 USA (703/558-8270).

### DISABILITY SPECIFIC RESOURCES

**Deaf American** is now published once a year. The 1992 monograph, **Viewpoints on Deafness** (Vol. 42), was published this Spring. Contact: **National Association of the Deaf**, 814 Thayer Ave., Silver Spring, MD 20910-4500 USA (301/586-1791 TDD).

**The 1992 National Technical Institute for the Deaf Resources Catalog: A Clearinghouse of Education Materials** contains

resources for those interested in learning more about deafness, obtaining educational products for deaf people, or are professionals working with deaf people. To request a catalog call 716/475-6853 (voice/TDD) or write RIT/NTID, Division of Public Affairs, Lyndon Baines Johnson Building, P.O. Box 9887, Rochester, NY 14623-0887 USA.

**Stay Well!** is an extensive manual for a health promotion program for polio survivors presented by **Polio Network, Inc. serving Michigan**. The contents of the manual were created by a national team of post-polio specialists to be user-friendly for community organizers who will initiate the program and for the professional facilitators who will make it happen. It includes step-by-step guidelines on how to start and organize a program, program curriculum guidelines, and extensive information on the late effects of polio. Designed to help participants alleviate, manage, and prevent a variety of secondary conditions that are associated with the late effects of polio, this potential wellness program presents three important strategies for staying well: (1) sound nutrition (2) individualized exercise (3) lifestyle enhancement techniques — including stress management. Send \$35.00 to Polio Network, Inc., 2877 S. Ennis, Ithaca, MI 48847 USA.

**Families of Spinal Muscular Atrophy**, P.O. Box 1465, Highland Park, IL 60035 USA (708/432-5551).

### EDUCATION

**Global Perspectives on Disability** is a curriculum designed for use by instructors at the secondary and higher education levels and in international programs, who wish to explore international disability issues. The entire five lesson curriculum is thorough, specific, and could be an entire course at the secondary or college level. The five lessons include: Disability Awareness; Rights of Persons with Disabilities; International Participation in Education Exchange Programs by Persons with Disabilities; International Perspectives on Disability; International Perspectives on Disabled Women.

**Global Perspectives on Disability: A Curriculum** is available from Mobility International USA, P.O. Box 3551, Eugene, OR 97403, USA. Cost is \$40.00 which includes postage and handling.

**Services for Independent Living, Inc.**, 2511 Euclid Ave., Suite 105, Cleveland, OH 44117-2663 USA (216/731-1529, FAX 731-3083) has available five publications designed to teach independent living skills to people with disabilities, and to provide disability awareness activities for people who are non-disabled. 1. **Focus on Ability** geared towards students grades six

through 12 (\$16.00). 2. **Just Like You and Me** for upper elementary (\$15.00). 3. **With Feeling** for college level professionals who are/will be working with parents of newly-diagnosed children with disabilities (\$15.00). 4. **Moccasins of Disability** for college level students in education, nursing, rehabilitation, or other health and social services (\$15.00). 5. **Discover the World of Independent Living** for educators, independent living staff, and others wishing to serve youths with disabilities (\$15.00). For more information contact: Diane Shaddock at the above.

### EMPLOYMENT

The **Job Accommodation Network ADA** Info Service's number is 800/ADA-WORK.

### EQUIPMENT

**Knobbles** are soft, thermal plastic sleeves that form a cushiony, ridged grip and increase traction on any slippery doorknob surface. They are installed by soaking in hot water and stretching over the front of the doorknob. Knobbles are available in brown or white at \$15.00 per dozen; 144 for \$82.00. Contact: 800/346-KNOB (5662) or 7235 S. Steele Circle, Littleton, CO 80122-1940 USA.

**Accessibility Stick** was devised as an accessibility survey tool that will allow beginning or experienced surveyors to make quick and accurate measurements of accessibility. Its design is based on key access measurements of the American National Standards Institute (ANSI). Each of these key measurements have been incorporated into the recently released regulations on ADA Accessibility Guidelines. The Accessibility Stick is constructed from highest grade pine or mahogany. Instructions for access measurements, and a 32 inch ruler are silk screened on each stick. Two coats of satin varnish are added. The Accessibility Stick is offered at \$19.95 (plus \$3.50 shipping and handling). Discounts are available for bulk orders of 10 or more. Allow two to four weeks for shipping. Glen W. White, Pres., Access, Inc., 2608 Bond Pl., Lawrence, KS 66049 USA (913/841-0321).

American Phone Products, Inc., 5192 Bolsa Ave., Suite 5, Huntington Beach, CA 92649 USA (714/897-0808) specializes in telecommunication products. The company's current line includes elevator phones, college campus emergency phones, phones for the motion impaired, and for the hearing impaired. **Alert Plus**, one of their new products, is an electronic notification device which alerts hearing impaired guests to door knocking, the sound of a smoke detector, alarm clock, and telephone ringing. Designed for hotels it uses a strobe light, a bed shaker, and a loud buzzer simultaneously.

Quartet Technology Inc., 7565 Tiptoe Lane, Cupertino, CA 95014 (408/253-1971) has introduced a voice-activated environmental control unit called **Simplicity Series 6**. The unit controls up to 16 lights and appliances, an electric bed, door opener, page turner, telephone, television, VCR, and cable box. It also controls IBM (and compatible) PC/AT of PS/2 personal computer systems. When controlling a personal computer it acts like a keyboard under voice control. The Series 6 trains to the user's voice in less than five minutes and has a one hour battery backup.

Prentke Romich Company, 1022 Heyl Rd., Wooster, OH 44691 (USA 800/262-1948, Canada 800/253-1989, International 1/216/262-8031) has released two new software programs. (1) **WiViK (Windows Visual Keyboard)**, developed by the Hugh MacMillan Rehabilitation Centre, allows equivalent keyboard entry into all applications within the Windows 3.0 environment. It features extensive customization capabilities including overall dimensions, number of keys, key size and shape, key spacing, key label, keystrokes, fonts, and colors. Eighteen international keyboards are provided along with a range of sample macro keyboards. Macro keyboards may be created with any arrangement of keys desired. Up to 800 keystrokes may be programmed behind any key. Up to 50 pages of keys may be defined with each page linking to another through key buttons that may be placed anywhere on a page. (2) **ScreenDoors**, developed by Madenta Communications, Inc., is designed to work in the Macintosh environment. The first predicts the word currently being typed. When the first letter is typed, words that begin with that letter are presented. These words are based on the frequency of use. If the desired word appears, just select it with the cursor and ScreenDoors finishes typing it automatically. If the word does not appear, type the next letter and words are displayed which begin with those first two letters. This continues until the word is completed. The second type predicts the most likely "next word" to follow. This helps speed text input by an estimated 40-60%. These dictionaries can be created easily and quickly by importing text files on specific topics. ScreenDoors is available for \$350.

Franklin Electronic Publishers, Inc. has made available **Language Master 600SE Special Edition** — the world's first hand-held fully-speaking electronic dictionary, thesaurus, spelling correct, and English language resource exclusively designed for individuals who are blind, or who have visual and speech impairments, learning disabilities, and dyslexia. The Language Master pronounces out loud every letter as it is typed, allows the user to increase and decrease the speed of spoken speech, has raised location dots, and allows up to 26 messages to be entered, stored, and spoken at any time. It weighs 11 ounces, measures 5-1/2 by 5 by 1 inches, and comes complete with a cassette

and print instruction manual, headphones for private listening, 4AA batteries, an AC adapter, and a carrying case. It sells for approximately \$500. For more information write or call Franklin Electronic Publishers, Inc., 122 Burs Rd., Mt. Holly, NJ 08060 USA (609/261/4800, FAX 609/261-1631).

## NATIONAL RESOURCES

**NARIC (National Rehabilitation Information Center)** provides information on a wide range of disability related topics and has taken over **ABLEDATA**, the database which contains more than 17,000 products for people with disabilities. Call 800/346-2742 or 800/34-NARIC.

**National Easter Seal Society**, 70 East Lake St., Chicago, IL 60601 USA (312/726-6200).

## PERIODICALS

**Accent on Living**, P.O. Box 700, Bloomington, IL 61702 USA, is published quarterly. One year, \$10.00; two years, \$17.50; three years, \$25.00. Add \$1.50 extra per year for Canada, Mexico, and foreign. Inquire about foreign airmail rates.

**American Journal of Art Therapy**, Vermont Colleges, Norwich University, Montpelier, VT 05602 USA, is published four times a year. U.S. subscribers, \$27.00; foreign, \$32.00; institutional subscribers, \$48.00.

**KALEIDOSCOPE: International Magazine of Literature, Fine Arts, and Disability** is seeking work — fiction, non-fiction, poetry, and visual art — that explores the experiences of disability during the years of formal education, at various age levels, activities workshops or classes, vocational programs, and the like. This issue also plans to examine various literary and artistic media that will help all people more fully understand the experience of disability. We are requesting material offering different points of view from the individual with a disability, relatives, friends, and educators. The deadline for submissions to the "Disability and Education" issue is August 1, 1992. Send all inquiries to: Darshan Perusek, PhD, KALEIDOSCOPE, 326 Locust St., Akron, OH 44302-1876.

**American Rehabilitation**, the official publication of the Rehabilitation Services Administration (RSA), is published four times a year. Paid subscriptions are accepted. \$5.00 domestic; \$6.25 foreign. Correspondence concerning subscriptions should be mailed to Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402 USA.

**Moving Forward**, the national newspaper for people with disabilities, P.O. Box 3553, Torrance, CA 90510-3553 USA (310/320-8793), is published every month. \$10.00 for one year; \$18.00 for two years. Foreign subscriptions, \$36.00 for one year.

**Direct Connect** is a quarterly publication for DIRECT LINK for the DISABLED, Inc., a non-profit organization which gives help

and hope to people with disability related needs. A \$10.00 donation is requested to cover the cost of the newsletter. Contact DIRECT LINK, P.O. Box 1036, Solvang, CA 93464 (805/688-1603) USA.

## PUBLICATIONS

**Accent On Living Buyer's Guide** (1992-1993 edition) is available for \$13.25, postpaid, from: Accent On Living, P.O. Box 700, Bloomington, IL 61702 USA.

**Effets a Long Terme de la Poliomyelite** (the French translation of Gazette International Networking Institute's Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors) is available (for 90F) from: Bon de Commande, a Envoyer a L'Association des Paralyses de France Service Information, 17, boulevard August Blanqui, 75013 Paris, France.

Patient-Doctor Communication was the topic of a Margaret E. Backman, PhD project while visiting New Zealand, Australia, the Republic of Fiji, and the Cook Islands. Interviews and discussions focused on research, techniques, and programs that have the potential for improving communications between physicians and patients/consumers. To order **Strategies for Enhancing Communication and Interaction Between Physicians and Persons with Physical Disabilities**, send \$3.00 to International Exchange of Experts and Information in Rehabilitation (IEEIR) Room 6, Hood House, University of New Hampshire, Durham, NH 03824 USA.

**Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled** by Ken Kroll and Erica Levy Klein was recently published by Random House, Inc. 201 E. 50th St., New York, NY 10022. The book is written with the insight of experience — that of a disabled husband and a non-disabled wife. Self-Help/Sex & Health; 10 black-and-white illustrations; 6x9; 256 pages; A Harmony Book (517-375329); \$22.50 hardcover, Canada: \$30.00 hardcover.

For your free copy of **That All May Worship**, contact National Organization of Disability (NOD), 910 16th St., N.W., Suite 600, Washington, DC 20006 USA (202/293-5960, 202/293-5868 TDD, 202/293-7999 FAX).

Employers who focus on the Americans with Disabilities Act may be missing the bigger issue: that a well-run disability management program goes far beyond ADA regulations. It also gets disabled employees back to work more quickly, thus increasing productivity and reducing health care costs and disability benefits. **Disability Management: A Complete System to Reduce Costs, Increase Productivity, Meet Employee Needs, and Ensure Legal Compliance**, by Shelia H. Akabas, Lauren B. Gates and Donald E. Galvin (AMACOM Books, 135 W 50 St., New York, NY 10020 USA), \$49.95, Hardcover, 288 pages.

(continued on page 12)

## Resources

(continued from page 11)

## RIGHTS

The **Legal Rights of Persons with Epilepsy** (1992 edition) is now available from Materials Service Center, Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785 USA (301/577-0100) for \$14.95 plus a shipping and handling fee.

**Access America**, a free quarterly newsletter published by the U.S. Architectural and Transportation Barriers Compliance Board (ATBCB), 1331 F St., N.W., Suite 1000, Washington, DC 20004-1111 USA (800/USA-ABLE voice and TDD), provides information about the ATBCB and its activities. This is the same address used to file a complaint about building or facility access. The ATBCB also offers answers to questions relating to the Americans with Disabilities Act by call the above 800 number.

The Physicians' Disability Services, Inc. (PDS) has updated **Social Security Disability Assessment: Inseparable from Patient Care**. Written by disability lawyer Douglas Smith, the 13-page booklet equips doctors who prepare reports for Social Security disability benefit applications to respond to the agency's unique requirements for evaluating functional loss. A copy may be purchased by sending a check or money order for \$2.95 to the publisher: PDS, P.O. Box 827, Arnold, MD 21012. The booklet will be sent postage paid, first class mail.

## SUBSTANCE ABUSE

Copies of the 29-page report, **Final Report: Case Studies Project — An Investigation of Alcohol and Drug Problem and Recovery Among Five Persons with Disability**, is available for \$4.00 from John deMiranda, Principal Investigator, 2165 Bunker Hill Dr., San Mateo, CA 94402 USA.

**Graedon's Guide to Drug & Alcohol Interactions** is available by sending \$2.00 with a long (No. 10) SASE to Graedon's People's Pharmacy, No. A-8, P.O. Box 52027, Durham, NC 27717 USA.

## TAPES

The entire **Bible** on 48 audio cassette tapes, narrated by Alexander Scourby, can be purchased for only \$16.95 plus \$4.00 for shipping and handling from Vision Marketing, Box 850, Hemet, CA 92546 USA.

## TECHNOLOGY

**Tetra Development Society**, Plaza of Nations, Box 27, 770 Pacific Blvd., S., Vancouver, BC V6B 5E7 Canada (604/688-6464) is a volunteer group that pairs engineers with people with disabilities to resolve engineering problems of life in a wheelchair.

## TRAVEL

The **Handcapped Driver's Mobility Guide** aids drivers with disabilities in finding equipment and locating services to improve their mobility. Contact your local American Automobile Association (AAA).

**Directory of Accessible Van Rentals**, send \$5.00 for postage and handling to the Disability Bookshop, P.O. Box 129, Vancouver, WA 98666-0129 USA (800/637-2256).

**Directory of Travel Agencies for the Disabled**, send \$19.95 plus \$2.00 for shipping to the Disability Bookshop, P.O. Box 129, Vancouver, WA 98666 USA (800/637-2256).

**Wheelchair Vagabond**, send \$9.95 for softcover, \$14.95 for hardcover, plus \$2.00 for shipping to the Disability Bookshop, P.O. Box 129, Vancouver, WA 98666 USA (800/637-2256).

**Mini Tour of Alaska**, by Leanore Smith-Miller, is a book for persons desiring more information about Alaska or as a resource book on Alaska for Social Studies teachers. The six regions of Alaska are presented. Transportation is listed for persons with a disability visiting Anchorage. "From an Alaskan Kitchen" is an added bonus of 55 recipes ranging from Clam Gulch Chowder to Rhubarb Custard Pie. One dollar from each book will go to Alaska-Horizons Unlimited, a nonprofit organization whose mission is to develop architectural accessibility as well as wilderness accessibility in Alaska for residents as well as tourists. Mini Tour of Alaska costs \$8.95 plus \$1.75 postage and handling and can be ordered from J. Miller International, 3605 Arctic, Suite 2701, Anchorage, AK 99503 USA.

**Easy Access to National Parks: The Sierra Club Guide for People with Disabilities**, also useful for seniors and families with young children, by Wendy Roth and Michael Tompane. Divided into three sections, **Easy Access to National Parks** includes: Introductory Chapters on the essentials of preparing park journeys for people with disabilities; "Best Visit Chapters" detailing in prose 18 national parks chosen by the authors as exceptional for their accessibility, regional significance, and natural scenic beauty; and "At a Glance Directories," focusing on accessibility in 50 greater national parks. Available at bookstores or by direct mail from: Sierra Club Store Orders, 730 Polk St., San Francisco, CA 94109 USA. (Prepaid orders only. Enclose \$16.00, plus \$3.00 for postage and handling. California residents include applicable sales tax.)

A new travel guide lists accessible accommodation throughout Wales UK, and also gives information on travel, accessible restaurants and toilets, local services, and sports facilities. It can be obtained from the **Wales Council for the Disabled**, Lys Ifor, Crescent Road, Caerphilly CF8 1XL Wales UK. Price £2.50 (including postage and packing.) There is now available a new edition of the **Disabled Person's Guide to York UK**. The Guide costs £2 per copy

and is available from York Access Group, Acomb House, 23 Front Street, York YO2 3BS UK.

**California Parks Access: A Complete Guide to the State and National Parks for Visitors of Limited Ability** (ISBN 0-9630758-3-7), by Linda and Allen Mitchell. Cougar Pass Publishing Co., P.O. Box 463060, Escondido, CA 92046 USA (800/735-3806). \$19.95.

**Wheeler's Accessible Van Rental, Inc.**, 6614 W. Sweetwater Ave., Glendale, AZ 85304 USA (800/456-1371), and **Wheelchair Getaways, Inc.**, 24251 Tahoe Ct., Laguna Niguel, CA 92656 USA (800/659-1972, 714/831-1972) are national companies that rent vans (daily, weekly, or monthly) specially converted for wheelchair users.

## VENTILATORS

**Aequitron Medical, Inc.** now has three new 800 numbers. Customer service: 800/497-4968, Technical service: 800/497-3787, and General information: 800/497-4979.

**Breathing Support Options: A Consumer Perspective**, prepared by Maureen Colgan, research development co-ordinator. This 43-page booklet, complete with a glossary and resources, assists potential ventilator users in exploring the many options available. It is composed of two parts: Part I, The Process: Decisions in the Use of Breathing Support Equipment, and Part II, The Opinion: Breathing Support Equipment from a Consumer Perspective. Copies of Breathing Support Options are available at a cost of \$10.00 postpaid to organizations or individuals who can afford it. Free copies will be made available to individuals exploring their own breathing needs. Contact: Maureen Colgan, Independent Living Resource Centre, 201-294 Portage Ave., Winnipeg, Manitoba R3C 0B9, Canada (204/947-0194/TDD).

## VIDEOS

**Tracks of Winter**, a guide to responsible snowmobiling, was produced by the International Association of Snowmobile Administrators, and is available for \$12.95 from Outdoor Empire Publishing, P.O. Box C-19000, 511 Eastlake Ave. E., Seattle, WA 98109 USA (206/624-3845).

**Providing Public Transportation to Everyone**, is a 15-minute video explaining why accessible transportation is not just a concern for people with disabilities. It also describes the ADA provision as well as federal tax relief program available to public and private transportation providers who make changes. Send a check or money order for \$35.00 to National Easter Seal Society, Administrative Services Dept., 70 E. Lake St., Chicago, IL 60601 USA.

**And, remember ...**

We have a new address and telephone number: 5100 Oakland Ave., #206, St. Louis, MO 63110 USA (314/534-0475). We can receive incoming FAXes at 314/645-8454. Our office hours are 9:00 to 5:00, CDT.



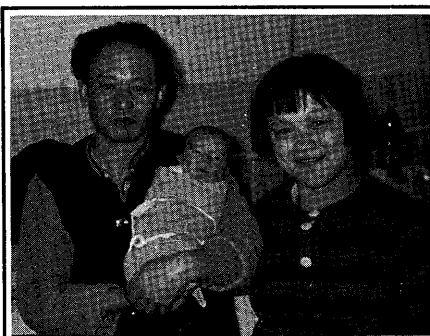
# FRIENDS AROUND THE WORLD

**LaVonne Schoneman**, 16734 8th NE, Seattle, WA 98155 USA, writes: "An exciting thing happened last year. An independent film producer, Mardig Sheridan of Mardig & Company, contacted me after reading the preface in #2 *How to Cope, More Practical Tips for Polio Survivors*. The preface, entitled *The Girl in the Yellow Dress*, is a short story telling about my first encounter with polio in 1949 which was prior to my contracting it in 1955. He was impelled to make a dramatic and educational ten-minute film from this story. He rallied the Seattle film community into donating time, talent, and equipment to this project. The small town of Glenoma, WA where the original incident happened, also gave freely of its time and resources."

**Mardig Sheridan**, 3817 29th Ave. W., Seattle, WA 98199 USA (206/283-4252) whose sole goal is to distribute *The Girl in the Yellow Dress* as widely as possible, will make it available on all formats of video tape. He requests that you pay the cost of the cassette plus postage. When ordering please specify which format you want. Mr. Sheridan states, "the short film contains many messages and would be an excellent piece to view to promote group discussion." He is particularly interested in any feedback from individuals after viewing the film. The information would be very useful to him in securing funding, so he can produce the film on release print which can be projected on a big screen.

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"I am very happy to inform readers of the *Rehabilitation Gazette* and the friends I met at the 1989 G.I.N.I. conference that I was married January 12, 1991 to Li Jid Xu, and left the Beijing Children's Welfare. We have a five-month-old son, Li Shdo Chen. We are very happy. Our only problem is that we take in limited money and to buy a house is utterly impractical." **Zhang Li**, No. 7 Zhu Fang Dong Zhuang. Qing He. Hai Dian Beijing, China.



Zhang Li, her husband and son

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"**League of Rights of Wheelchair Users in Czechoslovakia** is a specialized organization which was founded after the democratic changes in Czechoslovakia in 1989 and strives for complete rehabilitation of wheelchair users, their independent living, and the abolishment of any discrimination.

"The League consists of two independent chambers: Czech Chamber with the centre in Prague and Slovak Chamber with the centre in Bratislava. The founder of our League is Ing. Oldrich Pechar.

"Special seminars and courses are organized for members. The League also publishes a maga-

zine, *VOZICKAR*. League members can be individuals or organizations. The League is financed through grants, gifts of sponsors, and voluntary contributions from members.

"Our League is seeking cooperation with international disability organizations. Our participation in foreign and international seminars, which are useful for wheelchair users, is still limited because of the economic situation here. We welcome any foreign publication which contains information helpful to our members and would be pleased to send our *VOZICKAR* with an English summary in exchange." **Dr. Alois Wokoun**, Chabarovicka 1333, 182 00 Prague 8, Czechoslovakia.

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"We are setting up a Los Angeles chapter of the **Live At Home Foundation**, a California non-profit foundation set up to serve severely disabled persons who are trying to live as independently as possible. We would like to network with other organizations who already exist with the same goals." **Renee Provitt**, Live At Home Foundation, Los Angeles Chapter, c/o 9430 Popanga Canyon Blvd., Suite 106, Chatsworth, CA 91311 USA.

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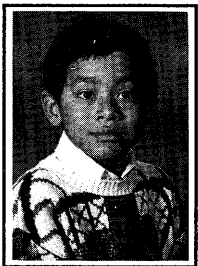
"I wanted your readers to know about the unique store called **Yes I Can**, which my husband Bob and I opened this year. **Yes I Can** is a store dedicated to finding products to help everyone enjoy life more completely. We have shopped the houseware, gift, and hardware mar-

## Friends Around the World

(continued from page 13)

kets to find products from all over the world. Our store is unique in that the products are displayed under one roof in a realistic, homelike setting. You can browse through a bedroom, bathroom, living room, dining room, and kitchen and try the products to see if they would be of benefit. We are located at 35-325 Date Palm Dr., Suite 131, Cathedral City, CA 92234. We are open Monday through Friday, 9:00 to 5:00, Saturday, 9:00 to 1:00, or by appointment. We recently installed an 800 number (800/FON-ICAN). My 35 years of having to cope with the limitations caused by polio, and my desire to assist others in living a full life, is the reason why we opened this store. It is a dream come true."

**Lois Jackman.**



Ricky Velliquette

"Our son had polio when he was very young. We are in the process of creat-

ing a library of information which he will find useful as he grows older, and we would welcome your suggestions. We are particularly looking to buy a copy of **A History of Poliomyelitis** by John R. Paul, MD. The copyright is 1971 by Yale University. The ISBN number is 0-300-01324-8." **Richard and Judith Velliquette, 5755 Old Farm Circle East, Colorado Springs, CO 80917 USA.**

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"I am looking for more information about Desmoid tumors. My daughter has had two removed from behind her knee and two from her foot. They recurred.

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This time the doctors amputated her leg mid-thigh. Can anyone help"? **Joan Glenn, RR 1, Box 146, Versailles, IL 62378 USA.**

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"I have a strong background in residential construction and in remodeling kitchens and baths. My firsthand experience of aiding my wife during a bout with cancer has opened my eyes to a need for more adequate accessible housing. I would be willing to talk to individuals in my area." **D. J. Yoder, 946 E. 300 South, Marion, IN 46953 USA (317/998-7160).**

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"I am interested in connecting with anyone who has information on Hopkins Syndrome. My seven-year-old son has had this disease since he was four and a half. It is caused by a virus and the course of the illness is almost identical to polio." **Kerry Chama, 3010 Barge, Yakima, WA 98902 USA.**

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"Our daughter, Kimberly, is now trached and we would like to donate an adult iron lung and the machinery which operates a custom chest shell. Interested individuals should contact us." **Nancy C. Pearsall, 11177 East Maple Ave., Davison, MI 48423 USA.**

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"I have started a program called 'Adopt A Friend' at St. Gregory Catholic School in St. Nazianz, Wisconsin. Third, fourth, and sixth graders have adopted adults with disabilities and communicate with them by writing poetry. This program is done in conjunction with another entitled 'Creating Wellness Through Poetry.'" **Stephen Mickey, 224 W. Main St., Box 172, St. Nazianz, WI 54332 USA.**



Matthew Stone and friend

**"Congenital Central Hypoventilation Syndrome (CCHS) a.k.a. Ondine's Curse** is a rare condition characterized by respiratory depression during sleep. Some children hypoventilate during awake periods as well. All children with this disorder require ventilator support, either by mechanical ventilation or diaphragmatic pacemakers.

"A major frustration is the lack of information on CCHS and the vast differences in treatment protocols. I rely on others to bring to light any new or alternative ideas regarding the management of CCHS. I hope we can have a national conference and bring together all parties concerned. If anyone would like to talk, share ideas, frustrations, etc. Write or call **Nancy Stone and Matthew, 4260 Melbourne Rd., Indianapolis, IN 46208 (317/299-0801).**

"A national network of families coping with CCHS has been established and a newsletter is published, profiling individual families, sharing new medical information, and just generally supporting each other. A national directory is also available." **Mary Vanderlaan, 71 Maple St., Oneonta, NY 13820 (607/432-8882).**

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(continued on page 15)

# Potpourri

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**Women in Citizen Advocacy: Stories of 28 Shapers of Public Policy** by Georgia Mattison and Sandra Storey is now available from your local bookstore.

Former Peace Corps volunteers Sandra Storey, publisher of the *Jamaica Plain Gazette*, and Georgia Mattison, public affairs director of the Visiting Nurses Association of Massachusetts co-authored *Women in Citizen Advocacy: Stories of 28 Shapers of Public Policy*.

The book examines the role of advocates through interviews with 28 women, most of whom are associated with non-profit organizations, who lead efforts for change across the country.

The late Gini Laurie, founder of *Gazette International Networking Institute*, is included as one of the women, who, "Unlike politicians, advocates direct attention more to causes than characters. In many instances, they have become the voice of the people."

## Friends Around the World

(continued from page 13)

"Would you please share with your readers information about Hastings Place Villa, Duncans, Jamaica. It was designed to be handicapped accessible and is located in Silver Sands Estates, a resort consisting of about 70 villas. Interested persons can obtain more information about availability, cost, and amenities." **Norman or Sue Johnson**, P.O. Box 378, Rutherford, NJ 07070-0378 or, on evenings and weekends, phone 201/933-1504.

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The 288-page book (ISBN 0-89950-700-X) is available for \$29.95 from your local bookstore or McFarland & Company, Inc., Box 611, Jefferson, NC 28640 USA.

## QUIMBY is short for Qualified Medicare Beneficiary (QMB).

It can provide help for low-income Medicare beneficiaries and what they pay for Medicare coverage.

In the QMB program, State governments help low-income Medicare beneficiaries by paying the Medicare medical insurance premium of \$31.80 a month. This means each beneficiary can save at least \$381.00 a year. And, the State may also pay the Medicare deductible and coinsurance amounts, so the savings could be much higher.

To qualify, your yearly income can't be more than \$6,810 for one person or \$9,190 for a

couple. Your other resources must be limited, too.

Your State can decide if you can get help from the program. Contact your State or local welfare or social service agency to apply.

**Social Security Update** contains figures on earnings limits, work credits, wage bases, etc. or up-to-date information for 1992 about the "built-in" changes.

Up to 100 copies of the factsheet can be ordered through the Public Information Distribution Center at 410/965-0945; FAX 410/965-0696; or written requests may be sent to the following address: Social Security Administration, Office of Public Affairs, Public Information Distribution Center, P.O. Box 17743, 6401 Security Blvd., Baltimore, MD 21235. Please specify that you are order SSA Publication Number 05-10003.

## The Surveillance Challenge: Final Stages of Eradication of Poliomyelitis in the Americas

Current levels of surveillance have contributed to substantial reductions in morbidity and mortality due to poliomyelitis in the Americas. Despite the success of the poliomyelitis eradication initiative, it has become critical that surveillance be intensified so that the absence of wild poliovirus circulation can be verified with confidence in countries not reporting confirmed cases of poliomyelitis. Cases of acute flaccid paralysis continue to be classified as compatible with poliomyelitis, because investigations of such patients do not provide suffi-

"I have a question that perhaps you can answer for me. Do you know of any polio survivors who are on Medicare disability and also have a Medicare supplement? I am 64 years old and cannot get the supplement for people over 65. I have inquired all over the country. I know of one company that does offer this, but I did not meet their 'standards.' I am desperate. As you know, Medicare alone is not good." **Leonore Hodgson**, 37 Bearpaw, 38-B, Irvine, CA 92714.

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(continued on page 16)



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

## Americans with Disabilities Act Training and Implementation Network

**ADA Network** is a project which will provide authoritative, in-depth ADA training to 400 people with disabilities in the United States. ADA Network is a project of the **Disability Rights Education and Defense Fund (DREDF)**, a national law and policy center dedicated to furthering the rights of people with disabilities and **Independent Living Research Utilization (ILRU)**, a national center for information, research, and technical assistance for independent living. The network will link the participants to ADA specialists, update them on the latest ADA developments, and provide follow-up technical assistance to assist them in coordinating ADA projects in their local communities. The project is funded by a contract with the **Equal Employment Opportunity Commission**

**(EEOC), and the Department of Justice (DOJ).**

The 400 persons selected will participate in a five-day, Phase 1 Training Program which will be conducted in five different cities — Houston (training in July; application deadline May 20), District of Columbia (training in August; application deadline June 15), St. Louis (training in September; application deadline July 15), San Francisco (training in October; application deadline August 15), and Denver (training in November; deadline September 15). These 400 participants must conduct ADA training projects with at least 50 people with disabilities, and at least 30 employers or other covered entities in their communities.

One hundred individuals who demonstrate strong interest and

training ability, and who implement effective local projects, will be selected to participate in a more advanced, six-day Phase 2 Training Program.

There will be no registration fees for selected applicants. All training materials and programs as well as technical assistance and follow-up services will be provided without charge. However, applicants and their sponsoring organizations will be responsible for all travel, lodging, and meal expenses while attending either Phase 1 or Phase 2 training programs.

For more detailed information and an application contact: **Alan Meyer**, Project Coordinator, ADA Network, ILRU, 2323 S. Shepherd, Suite 1000, Houston, TX 77019 USA (713/520-0232, 520-5136 TDD, 520-5785 FAX).

### Potpourri *(continued from page 13)*

cient information to rule out wild poliovirus as the cause of paralysis. At this stage of the eradication initiative, the presence of compatible cases in some countries in Latin America indicates a failure of the surveillance system. The greatest challenge for the eradication initiative may be correcting the remaining deficiencies of the existing surveillance system that hinder efforts to verify that wild

poliovirus is no longer being transmitted in the Americas.

SOURCE: *Morbidity and Mortality Weekly Report*, April 10, 1992, Vol. 41, No. 14.

The American Association for the Advancement of Science (AAAS) has published a **Barrier Free in Brief** series which includes four booklets — **Workshops and Conferences for Scientists and Engineers; Laboratories and Classrooms in Science and Engineering; Access in**

**Word and Deed; and Access to Science Literacy.** Contact Beth Goodrich, AAAS, 1333 H St., N.W., Washington, DC 20005 (202/326-6630).

We welcome items or articles for the **Rehabilitation Gazette.**

Please send them to:  
Gazette International Networking  
Institute (G.I.N.I.),  
Attn: Joan Headley,  
5100 Oakland Ave., #206,  
St. Louis, MO 63110 U.S.A.