

PERSONAL ASSISTANCE SERVICES (PAS)

"The task at hand is to identify an effective method for redirecting existing funds from medically oriented personal assistance services to independence oriented personal assistance services. Concomitant with this task is the need for developing a new system or for modifying existing systems to make available formal personal assistance services to the broadest possible segment of the population in need at a reasonable cost to individual consumers and the public. Whether or not these changes can be enacted is directly related to the availability of good qualitative as well as quantitative research, communication between service providers and organized advocates, and the will of Congress."

Personal Assistance Services:
A Review of Literature and Analysis of Policy Implications,
by Margaret A. Nosek, PhD, 1991.

Personal assistance is typically viewed as a service to assist people who have physical disability with such daily activities as going to the bathroom or eating. Most people with mental retardation do not see this as applying to their lives, unless they also happen to have a physical disability.

**Personal Assistance Services and
People with Mental Retardation,
by Julie Ann Racino ... page 2**

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Who decides what is appropriate? Here there should be no differences. The individual with the disability should make the decision.

**PAS for People Who are Blind or Visually Impaired,
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The goal is to create a national personal assistance services program that serves all those who need it regardless of age, disability, and income. The program needs to involve choice of service models to accommodate people with various capacities and desires for self-management.

**Where Do We Go From Here and How Do We Get There?
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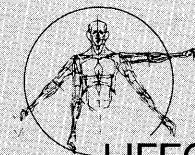
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Rehabilitation Gazette 福

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with a disability,
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Its aim is to reach, to
inform, and to dignify
individuals with
disabilities throughout
the world.*

*Special Information
for Ventilator
Users ... Page 11.*

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PERSONAL ASSISTANCE SERVICES AND PEOPLE WITH MENTAL RETARDATION

BY JULIE ANN RACINO

"Everybody in this world today needs support of one kind or another. People need support to go ahead and do things whether this support comes from a good friend, parents, a social worker, or guardian. There is no person so independent that they don't need anybody. We all need support, but with that support people don't want someone coming in and taking over their lives."

MICHAEL J. KENNEDY, 1990

Views of personal assistance in the field of mental retardation.

People with mental retardation are often excluded from the generic personal assistance system in their state. Instead, they are referred to the specialized mental retardation/developmental disabilities system. People associated with these systems across the U.S., whether individuals with disabilities, family members, direct service staff, or administrators, often share one or more of the following views regarding personal assistance:

First, until recently, many people simply had not heard the term personal assistance. Similar types of support services may be described in different language (e.g., follow-along staff, come-in staff) and are often agency-controlled. Even state and local administrators in the field of mental retardation may know relatively little about the generic personal

Michael Kennedy, who lived over 15 years of his life in institutions, explains that all of us need support, which may at times, come in the form of paid services. This essay draws on the author's experiences in over 25 states in the U.S. on how support services might be organized to better assist people with mental retardation in their efforts to lead fulfilling community lives. It affirms the perspective that all adults, no matter how severe their disability, can live in typical homes in the community, if adequate support services, such as personal assistance, are available.

assistance system in their states.

Second, personal assistance is typically viewed as a service to assist people who have physical disabilities with such daily activities as going to the bathroom or eating. Most people with mental retardation do not see this as applying to their lives, unless they also happen to have a physical disability.

Third, the term personal care is used in some states in the field of developmental disabilities to refer to a funding stream that supports group homes (i.e., agency facilities) and traditional foster care (i.e., where a person with a disability resides in the home of another), thus bearing little resemblance to personal assistance as a user defined and determined service.

Aspects of personal assistance of relevance for people with mental retardation.

If they were perceived as needing intensive support services, people with mental retardation have been traditionally confined to a life in agency facilities. Often they are also often viewed as not being able to speak for themselves. Instead representatives, who usually hold different perspectives, speak for them. (This is part of my own discomfort in writing this essay.)

With the international growth in the self-advocacy movement, including the 1991 election of a national (U.S.) self-advocacy steering committee, and a movement toward supporting people to live in their own homes, things are beginning to change. This discussion centers around at least six important opportunities.

USER DEFINITION AND DETERMINATION OF SERVICES.

Personal assistance services are typically user defined and determined. In contrast, most service for people with mental retardation assume that the agency or others know best. In fact, a review of the literature on choice, indicates that people with cognitive disabilities are usually presumed to be incompetent to make their own decisions. If making value decisions in conflict with prevailing norms, they are in particular jeopardy of social control.

THE PERSON WITH A DISABILITY AS EXPERT.

Users of personal assistance have strongly held that training should be done by the person with a disability, with the underlying premise that each person is unique. In the field of developmental disabilities, there has been a movement toward competency based training, irrespective of the individual. But, people with mental retardation are not regularly involved in group-based training, and resistance continues in some circles, to people participating in their own service planning meetings.

PERSONAL DETERMINATION AND FAMILY EMPOWERMENT.

Family empowerment has rightfully become recognized, and family support programs are now available in virtually every state. These programs, however, are typically constructed from the parental point of view (i.e., relief of the "burden" of caring), and seldom take into account the fact that the wishes of parents and their children do not always coincide.

Minimally, discussion about personal assistance for children needs to occur, instead of thinking about the service as simply respite for caregivers.

"INFORMAL" AND PAID SERVICES.

In the field of developmental disabilities, there is a growing interest in the crucial roles that friends, neighbors, co-workers, and other community members can play in the lives of people with disabilities. While there are many positive aspects of this rediscovered interest in relationships, agencies are often deciding for people with disabilities how and when formal services can be replaced by informal relationships. Most people with disabilities want the *option* of informal services in place of having paid services. Most want the right to be able to *choose* whether to involve family, friends, or others in personal assistance services.

PERSONAL ASSISTANCE AND DECISION-MAKING SUPPORT.

Personal assistance designs have not always taken into account the needs of people with mental retardation for support with decision making. Greater discussion is necessary about the role of allies and supporters and how assistive decision making can occur, while still retaining the people first orientation of the independent living movement. It is essential to set up flexible personal assistance systems that include choices to manage one's own personal assistance; to share responsibilities with an agency or other person selected by the person with a disability; and/or to have another individual or organization perform all these functions.

PERSONAL ASSISTANCE AND INCOME SUPPORTS.

Instead of using the need for support as a rationale to force worker or agency control, cash subsidies or basic income support offer an important opportunity to rethink the current systems of case management and payeeships that typi-

cally allow for little input by people with disabilities.

What are some fears of professionals and advocates in the field of developmental disabilities?

THE FIGHT OVER WHO KNOWS WHAT IS BEST FOR PEOPLE WITH MENTAL RETARDATION.

Though this is not usually publicly acknowledged, one of the deepest fears is that people with mental retardation will not have an equal voice in any coalition with groups such as people with physical disabilities. In other words, people in the developmental disabilities field view themselves in a better position to listen to, support, and encourage people with mental retardation to come into their own. (Regretfully, this ends up at times, taking another form of protectionism.) However, these fears are not totally invalid. People with mental retardation have often been on the bottom of a disability "pecking order," and the wording of the Americans with Disabilities Act (ADA) itself indicates their marginality in the movement.

INTERACTION OF PEOPLE WITH MENTAL RETARDATION INTO AN INADEQUATE SERVICE SYSTEM.

Personal assistance systems have been tenuously constructed in most places, with many problems besetting stability, flexibility, security, and quality. People involved in the field of developmental disabilities generally do not wish to simply see people with mental retardation participate in such inadequate systems. Unfortunately, as yet they do not view it as their role to help with the changes that would be necessary to improve the current system. Advocates who are working to expand the role of the ILCs will find that effort not adequate to address the challenges. Systems aspects, such as having a city emergency backup aide service, are not even known as options among developmental disability agencies, who

instead are currently moving toward developing their own specialized systems.

RIGHTS VERSUS MUTUALITY.

One important area of concern in the field of developmental disabilities is that rights cannot and will not insure that people will have a good quality of life. As one ally described, "people are dying with their rights on." This is an area of mutual concern with people in the independent living movement, yet meaningful discussions about the kind of society we are hoping to achieve (e.g., a power reversal or a more mutual way of coming together) and the relationship between self-determination and mutuality, are seldom taking place.

Where can we go from here?

Increased discussions are necessary for fundamental change at the local level as well as a political victory in creating a civil right to personal assistance. To further pursue these efforts, we can work together to:

- Create more opportunities for exchange of ideas between all groups concerned with PAS.
- Overcome the language barriers between different groups by describing better what is meant by terms such as independence.
- Organize around common issues such as the nursing practices acts which have been problematic in several states for people to live in their own homes.

Personal assistance offers one visible opportunity for people to come together to create changes in ourselves, our families, our service systems, and our societies that can lead to better community lives for all of us. ■

This article is based in part on an article that appeared in *Disability Studies Quarterly*, 12(1), 81-86, Winter 1992. Correspondence should be directed to Julie Ann Racino, Community and Policy Studies, 2103 S. Geddes Street, Syracuse, NY, 13207 USA (315/422-2296).

Having grown up in the '50s and '60s, long before the existence of concepts such as PAS or attendant care, living independently meant self-reliance. My parents, backed by a small, but unrelenting, army of rehab professionals pushed, prodded, and persevered so that when I grew up I would be able to feed, bathe, and dress myself without needing any assistance — no matter how long it took. Sure, I might always need someone to cut my nails, or prepare food and do the laundry, but they held the belief (and passed it on to me) that there would always be someone around to help.

What does my personal history of PAS have to do with child care and disability? Everything! For me, PAS became a central issue in my decision to take on the awesome responsibility of raising a child. I had spent a good portion of my 36 years becoming self-sufficient. A child would force me into a certain level of dependency on a system (PAS) still in its infancy.

Of course, the decision of raising a child was not mine alone to make. My husband, Neil, and I had always wanted a child as part of our family. Neil's cerebral palsy is very similar to mine; we were both brought up on the same self-reliance-means-independence philosophy. Yet, the PAS issue did not concern him in the same way that it concerned me. He focused more on the financial considerations. Neil, a full-time (computer) systems architect at Wells Fargo Bank supported us, a two-wheel-chair family. What would have been an ample salary for a non-

disabled couple had to be stretched to cover our disability-related expenses. The amount of money we spent on attendant care per week — a total of seven hours of meal preparation, housekeeping, and assorted odds and ends — would (we figured out) almost triple. I, on the other hand, worried about getting used to dealing with the habits and idiosyncrasies of a virtual stranger coming into my home to take care of my baby.

Neil and I knew we would be treading on uncharted territory. The first question facing us after we made the decision to adopt involved what kind of assistance we were looking for at a price we could afford. While we knew disabled people who used attendants and non-disabled people who used au pairs, we had never come across attendants who did baby care or au pairs who had been personal assistants. We needed a cross between the two, and struggled in those early years to clarify and define our own expectations.

In becoming a mother of a three-month-old, I discovered there were many issues I had to be concerned with that I had not anticipated. I did not have the preparation time most mothers-to-be have because the adoption came around rather quickly (but that is another article). I assumed I would need help with the baby's physical care, but I was not sure how much. Indeed, there was no way of knowing until David came home.

We had, of course, done some planning ahead. Years before, we razed our dilapidated garage and built a studio apartment in its place. We would offer room, board, and a salary for a part-time housekeeper/child care attendant — which is how we advertised the position.

It was apparent from the onset that there were two major periods of the day when I need the most help — morning and late afternoon/early evening. David, thank-

fully, was a late riser (and, to my chagrin as we approach first grade, still is), which allowed our attendant to arrive at the decent hour of nine o'clock to feed, bathe, and dress him. She would prepare his formula bottles for the rest of the day, with one or two extra (just in case), throw in a load of everyday baby laundry, and do light cleaning. When she returned in the late afternoon, she would prepare and serve dinner, clean up, and get David ready for bed.

I did not realize, however, the issues that would not be so apparent until David came home, such as the stresses of being a new mother, the long stretch of time between morning and afternoon help, and the changes in a baby's needs that occur as a baby grows. As I look back on those first years, with experience now on my side, I would offer disabled parents who need assistance the following suggestions.

◆ *Look for a PAS with knowledge of specifically taking care of babies*, i.e., experience with younger siblings, babysitting. Our first attendant had taken care of children, but had no idea what to do with babies: sterilizing bottles was as new to her as it was to me.

◆ *Discuss flexibility with your PAS*. Needs change and in a short period of time, David went from eating a convenient two meals a day (breakfast and dinner) to an inconvenient three meals a day (lunch). As he grew older and needed less physical care, I could cut down on attendant hours. Illness and transportation needs were additional concerns I had to consider, making sure that my attendant could be available in emergencies.

◆ *Ask for a commitment*. During the early years we hired a new attendant at an average of every four to six months. After our second live-in attendant felt "the need to move on," I decided it would be less stressful and more cost-effective to rent out the little studio and

Denise Sherer Jacobson, MA, is a writer and mother of six-year-old David. She has just completed the soon-to-be published book, *The Question of David*, about the Jacobson's experiences in starting their family.

PAS FOR PEOPLE WHO ARE BLIND OR VISUALLY IMPAIRED

BY ALAN DINSMORE, GOVERNMENTAL RELATIONS,
AMERICAN FOUNDATION FOR THE BLIND

hire separate attendants for the morning and afternoon. The arrangement worked better for us. Still, since the turnover for PAS is high, I felt as though I was always in a state of change. Consistency is also very important to a child in terms of security and, when he gets older, discipline. While I understand the difficulties in the nature of the PAS system, I think it is important to seriously discuss a length of commitment and consider it when hiring.

♦ *Be aware of your needs as a parent.* I remember the first year of motherhood being very physically, emotionally, and psychologically demanding and exhausting. I felt that I should be with David even when my attendant was around. After all, my attendant was only supposed to be my "hands," and what if my child bonded better with her than with me because she met many of his needs. Once a routine is established it is okay and necessary to take a break. You will need one.

♦ *Finally, get to know people in your neighborhood, especially the ones with kids old enough to baby sit.* On weekend mornings, we hired neighborhood teenagers to help us with David. It helped us become better acquainted with our community. It was economical, and it helped us, as new parents, add to our support network. ■

Moving?

Please send both your old and new addresses to:

**Gazette International
Networking Institute**
5100 Oakland Avenue, # 206
St. Louis, MO 63110-1406 USA.

Rehabilitation Gazette will not be forwarded by your post office.

People who are blind or visually impaired may need personal assistance services too. For some people those are fighting words. Both consumers and professionals in our field have worked long and hard to overcome the stereotype of the blind person as a helpless figure. Make no mistake, most people who are blind or visually impaired are independent and do not always need outside assistance to live full, productive lives. It is also a mistake to think that all people who need personal assistance services need help in every aspect of their lives. The whole point of these services is that they provide assistance in carrying out a task or activity which the individual with a disability could do for him/herself, but for the existence of a disability.

The key to effective personal assistance services for persons who are blind or visually impaired is to insure that such services are appropriate to the individual's needs whatever those needs might be. Assistance may be needed only on an occasional or sporadic basis, or may be an ongoing requirement. For example, an older person who is blind with severe arthritis may desire assistance in bathing, dressing, or self-injecting medication. By contrast, a young visually impaired person, perhaps a professional individual, may require reading assistance to stay abreast of the latest developments in his/her field, or may need help in shopping for clothes, coordinating a wardrobe, or performing other tasks where sight would be convenient or helpful. Another individual may need assistance on a one time only basis, e.g., transportation to visit an ill aunt who resides in a rural area not served by public transportation.

A person who is deaf-blind may need help in effective communication such as a conference with a bank officer about a loan or a consultation with a surgeon about a needed hospital procedure. Most people who are blind and who do not have additional disabilities function independently, and may require only minimal services. Even for these individuals, temporary illness or incapacity may affect a person's mobility skills in such a way as to require a sighted guide when traveling. Reading services may also be required either on a temporary or permanent part-time basis.

Who decides what is appropriate? Here there should be no differences. The individual with the disability should make the decision. In order for this to work all individuals who need such services should receive training in acquiring and improving their skills in scheduling, training, supervising, compensating, evaluating, disciplining, and discharging personal assistance workers. A person who is blind should receive this training in the mode of communication which is most appropriate and materials should be provided in an accessible format. People who are blind and who may use such services, like other individuals with disabilities, may not always need the full range of such training, and they should not be required to take such training as a basis for receiving such services. However, all people with disabilities should receive information, in accessible formats, about their rights as a recipient of such services and about appeals processes in the event of non-compliance with agreed upon personal assistance plans.

For people who are blind and who also have cognitive or com-

Continued on page 6

munications impairments, it may be appropriate for a legally appointed representative advocate, or parent to be informed of and provided such training upon request. In these circumstances, it should always be clear that the role of these individuals is to elicit and advocate for the views, choices, and preferences of the individual who is blind.

A person who is blind may, depending on the circumstances, need an array of personal assistance services. These services

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should include, but not be limited to, assistance in activities of daily living, household services, communications, use of assistive communications technology, and mobility services. It is absolutely necessary that such service be designed as part of an individual service plan developed in a similar process to that called for by the Rehabilitation Act's individualized written rehabilitation program.

Both the states and the federal government must develop a training package for personal assistance workers to insure that these individuals understand their role, rights, and responsibilities along with the roles, rights, and responsibilities of personal assistance users. All of these materials should be in an accessible format and such workers should receive at least basic training in the modes

of communication used by people who are blind and deaf-blind.

Finally, and this is very important, states and the federal government need to develop quality assurance standards. Abuse, neglect, and exploitation of individuals with disabilities cannot be tolerated. It is important to recognize that not all individuals with disabilities, including people who are blind, have the same capacity to recognize such problems and deal with them. Every individual needs to have the assurance that management of personal assistance services will not so overwhelm them that they are unable to undertake the activities which these services are supposed to support. ■

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WHERE DO WE GO FROM HERE AND HOW DO WE GET THERE?

BY SIMI LITVAK AND JUDY HEUMANN

The World Institute on Disability (WID) is a public policy organization founded by some of the original leaders of the independent living movement. We provide training, public education, research, and advocacy on disability policy from the point of view and perspective of people with significant disabilities.

WID's president, vice president, and many others on the staff are users of Personal Assistance Services (PAS). We have, therefore, experienced firsthand the problems of not having a national PAS policy: insufficient hours, lack of emergency services, and paying a significant part of our salaries for PAS. Because of our personal experience with PAS, WID has gotten very involved and has been working with many different groups around the country to get this

issue on the national and state agendas. These past few years a primary research focus at WID has been the types of PAS around the country, who needs it, and what PAS users think constitutes a good PAS program.

In 1988, WID developed a PAS policy statement and took it to the Consortium for Citizens with Disabilities (CCD) for review and endorsement. CCD, in Washington, D.C., is a coalition of more than 50 disability-related groups. CCD had a primary role in the lobbying effort for the ADA and worked on WID's model PAS legislation re-shaping it into a draft position paper. (1) The position paper represents the substance of a "flagship" bill for which sponsors are being sought.

The CCD position paper is also being used as a standard for lan-

guage that can be inserted in any disability related legislation that is proposed in order to educate Congress on the importance of PAS and to build the constituency for PAS. Most recently, the position paper served as a resource for the bill re-authorizing the Rehabilitation Act in 1992.

Two major issues that are far from settled are whether nursing homes are desirable and the degree of control PAS users want over services. There are those in the aging arena who would prefer "long-term care" reform for older people as separate from the efforts of the independent living movement. The CCD position paper was an important resource at a summit meeting in Washington, D.C., in 1992 between CCD and American Association of Retired Persons (AARP) to criticize the "long-term

care" proposal being developed by AARP, the largest organization in the country representing older people.

CCD and WID are developing a grass roots movement to advocate for a national PAS policy. American Disabled for Attendant Programs Today (ADAPT) is also forging a nationwide force demonstrating for reallocation of Medicaid funds from nursing homes and institutions into PAS.

The goal is to create a national personal assistance services program that serves all those who need it regardless of age, disability, and income. The program needs to involve choice of service models to accommodate people with various capacities and desires for self-management (see Figure 1). There needs to be a range of models from those that allow the PAS user to be in total control to those in which an agency provides all or some of the service management functions (see Figure 2).

The choices of models (see Figure 3) may be mandated by the federal program, but the models that individual states chose to make available may vary depending upon the programs that already

Figure 1. Levels of Consumer or Family Management Relative to Size of Consumer Population

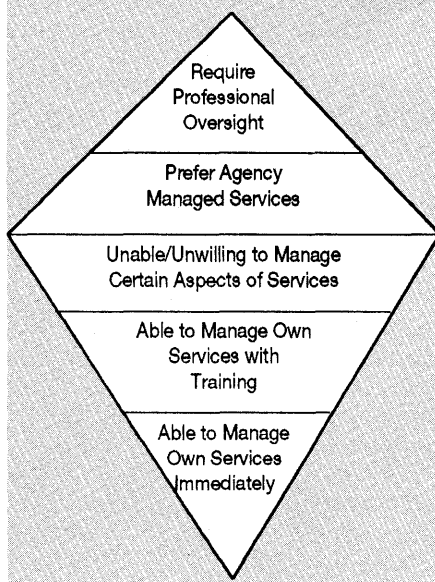


Figure 2. Management Services

- RECRUITMENT
- SCREENING
- INTERVIEWING
- HIRING
- TRAINING OF ATTENDANTS
- TRAINING OF FAMILY
- TRAINING OF CONSUMERS
- SUPERVISION
- PAYMENT
- TERMINATION
- CASE MANAGEMENT
- CONFLICT RESOLUTION/MEDIATION
- SELF ADVOCACY
- QUALITY MONITORING

exist and the power of the advocacy effort from consumers as well as provider agency lobbyists.

The financing of such a PAS system will be one of the major areas

ference in Little Rock, December, 1992, Clinton is aware that Medicaid mandates nursing home and institutional placement and makes optional "community-based, consumer driven services." This is a major accomplishment for which all the organizations which have been working so hard on this issue deserve much credit. The precise mandate of a Task Force on Personal Assistance has not been set, but it will certainly look for ways to reverse Medicaid's institutional bias.

In the meantime, it is imperative that users of PAS become knowledgeable about the PAS "non-system" in their particular state. In the fall of 1991, WID host-

Figure 3. Models of Publicly Funded Personal Assistance Services

Models of consumer and state responsibility	State sends funds directly to consumer	State monitors utilization of funds/ consumer manages funds and service	State administers program/ consumer manages service	State administers program/ consumer manages some aspects of service	State administers program/ agency manages service and funds
Program variations within models	SSI supplements for PAS	Vouchers	Independent provider hired by consumer/ consumer is employer for purposes of employee withholding	Independent provider model/ community agency provides assistance on an as needed basis	Private agency receives government contract or fees for providing services, employing PAS and monitoring the service
	VA Aide and attendant allowance	Individualized funding	Independent provider hired by consumer/ state or intermediary is employer for purposes of withholding and other worker liability benefits		

of debate. There are many possibilities which range from the ADAPT demand to reallocate institutional funds to new taxation. (2)

President Clinton has promised to form a Task Force on Personal Assistance Services. Judging from his remarks at the economic con-

ference a symposium for PAS users nationwide. One of the outcomes of the conference was a resolution (see page 9). We encourage you to review the resolution, take it to various groups, including post-polio support groups. Hold discussions

continued on page 8

about why there is a need for PAS and create an advocacy agenda about this issue. Organize tasks forces made up of consumers, state and local program administrators, disability advocates, and attendants to begin the process of state-by-state reform. Use the resolution as a report card to evaluate the quality of existing services and to make recommendations for improvement. Be forewarned! In this time of fiscal crisis, the absence of a strong state level PAS consumer voice gives legislators an opportunity to gut programs in order to deal with state budget deficits. In addition, write letters to the editor of your local newspapers and link up with WID and other organizations. And — most important — send your letters of endorsement of the PAS Resolution to WID.

Discussing one's personal needs such as feeding, toileting, and dressing is difficult for many

people mainly because our society does not support discussion of how many times we go to the bathroom, what we do if we cannot use the bathroom when we want, etc. However, without such frank discussion, the nature of our concerns may never be understood.

We must make legislators and the community as a whole understand that effective PAS, controlled by the user, results in greater self-esteem, integration into the community, and keeping people out of institutions. For people who have significant disabilities, the ADA will not become a reality until PAS is part of national policy. You have the power to make that happen.

(1) The Consortium for Citizens with Disabilities' Task Force on Personal Assistance services. (1992, May). Recommended Federal Policy Directions on Personal Assistance Services for Americans with Disabilities. Copies available from World Institute on Disability,

510 16th Street, Oakland, CA 94612 for \$2.00.

(2) Litvak, S. (1992). Financing personal assistance services: Federal and state legislative and revenue-enhancing options. *Journal of Disability Policy Studies*. 3(1). ■

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Judy Heumann, who had polio and uses PAS, was a vice president of WID from 1983 until her recent appointment by President Clinton to the position of Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS), Department of Education.

POTPOURRI

Imprinting Our Image: An International Anthology by Women with Disabilities, edited by Diane Driedger and Susan Gray, is a collection of writings from women from 17 countries relating their personal experiences in their fight to be equal members of their communities. To purchase, send \$12.95 Canadian plus \$1.50 for shipping to Gynery Books, P.O. Box 2023, Charlottetown, Prince Edward Island, C1A 7N7 Canada.

International Sani-Fem Company is the manufacturer and marketer for four different products — disposable Freshette TM, regular Freshette TM, the Complete System, and the Medical Freshette TM — all designed to assist women when no toilet is available, when standing or transferring is difficult or impossible, and for females in bed. For more information call International Sani-Fem information line, 310/928-3435 or write the company, P.O. Box 4117, Downey, CA 90241.

Abilities Expo Midwest is scheduled for August 6-8, 1993 at O'Hare Expo Center, Chicago, IL, and **Abilities Expo Florida** will be at Orlando Expo Center on January 14-16, 1994, Orlando, FL. For further information contact Rod Ellis, Expocon Management Associates, Inc., Seven Cambridge Dr., P.O. Box 1019, Trumbull, CT 06611, or call 203/374-1411 Ext. 105.

Caregiving Packet: To order a single free copy of Caregiving Packet, distributed by the National Institute on Aging (NIA), call 800/222-2225, or write NIA, 9000 Rockville Pike, Bethesda, MD 20892.

Can You Help?

Roy was born in Montego Bay, Jamaica in 1975 and contracted poliomyelitis in 1981. After a year of the acute phase of the illness he came to this country for intensive rehabilitation at Newington Children's Hospital. Roy is a quadriplegic requiring nighttime ventilation.

In 1983 he was adopted by Carl and Rachel Wheeler Rossow, who founded Alpha & Omega, Inc. in 1974 for the purpose of providing an alternative to institutionalization for children with disabilities. Alpha & Omega, Inc. is a not-for-profit, charitable organization 501(c)(3) which owns the Alpha & Omega residence where Roy, his adopted parents, and 19 siblings (14 of whom are severely disabled) live. Alpha & Omega, Inc. was the umbrella under which the Rossow family could exist, expand, and reach out to other families with children with disabilities through counseling, respite care, and technical assistance.

Roy graduated from high school this Spring and would like to attend college in the Fall to study computer graphics. Roy and his parents would like to hear from anyone who has suggestions for sources of funding to finance his college education.

For more information from Roy, contact him at Alpha & Omega, 15-1/2 Lanz Lane, Ellington, CT 06029 (203/872-0345). ■

Resolution on Personal Assistance Services

RESOLUTION

WE, PEOPLE WITH DISABILITIES AND OUR ALLIES, have come together from across the United States and around the world from September 29 — October 1, 1991 in Oakland, California at the symposium entitled EMPOWERMENT STRATEGIES FOR THE DEVELOPMENT OF A PERSONAL ASSISTANCE SERVICES SYSTEM.

This conference has focused on personal assistance services as an essential factor in independent living, which itself encompasses the whole area of human activities, including but not limited to housing, transportation, community access, education, employment, economic security, family life and interpersonal relationships of choice, leisure, and political influence.

Recognizing our unique expertise derived from our experience, we are taking the initiative in the development of policies that directly affect all people with disabilities.

People with disabilities are entitled to be enabled to achieve the highest possible level of personal functioning and independence through appropriate education, health care, social services and assistive technology, including, as necessary, the assistance of other people.

We firmly uphold our basic human and civil rights to full and equal participation in society as called for in the Americans with Disabilities Act and the United Nations Universal Declaration of Human Rights.

We consider independent living and the availability of support services to be critical to the exercise of our full human and civil rights, responsibilities, and privileges.

To this end, we condemn forced segregation and institutionalization as direct violations of our human rights. Government policy and funding should not perpetuate the forced segregation, isolation, or institutionalization of people with disabilities of any age. The Americans with Disabilities Act was passed into law to promote the equalization of opportunity. The passage of comprehensive federal personal assistance legislation is essential to realizing the historic promise of the Act.

The recommendations of the United Nations World Programme of Action (s 115) specifically state that "Member states should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in so doing should ensure that persons with a disability have the opportunity to develop and manage these services for themselves."

In support of the international movement of disabled people in Disabled Peoples' International, which has a special commitment to setting up a network of initiatives for personal assistance services as part of the implementation of the equalization of opportunities, we call on governments and policy makers to assure greater and more equitable access to personal assistance services based on the following principles:

1. Personal assistance services are a human and civil right. These services shall serve people of all ages, from infancy throughout a person's lifetime, when the person's functional limitation(s) shall necessitate the services. This right is irrespective of disability, personal health, income, marital and family status, and without discrimination on the basis of race, national origin, cultural background, religion, gender, sexual preference, or geography.

2. All people with disabilities (and their self-designated or legal representatives if applicable) shall be informed about their rights and options related to personal assistance services in accessible format, and appropriate languages. All levels of personal assistance services should respect the privacy and confidentiality of the user.

3. Personal assistance users shall be able to choose from a variety of personal assistance services models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all people regardless of their ability to give legally informed consent or their need for support in decision making or communication.

4. Services shall enable the users to exercise their rights and to participate in every aspect of sociocultural life including, but not limited to home, school, work, cultural and spiritual activities, leisure, travel, and political life. These services shall enable disabled people, without penalty, if they so choose, to establish a personal, family and community life and fulfill all the responsibilities associated with those aspects of life.

5. No individual shall be forced into or kept in an institutionalized setting because of lack of resources, high cost, substandard, or non-existent services or the refusal and/or denial of any or all services.

6. These services must be available for up to seven days a week, for as many as needed during the 24-hour period of the day, on long-term, short-term and emergency basis. These services shall include, but are not limited to assistance with personal bodily functions; communicative, household, mobility, work, emotional, cognitive, personal, and financial affairs; community participation; parenting; leisure, and other related needs. The user's point of view must be paramount in the design and delivery of services. Users must be able to choose or refuse services.

7. Government funding shall be an individual entitlement independent of marital status and shall not be a disincentive to employment.

8. Government funding must include competitive wages (based on consumer

cost experience within the private sector) and employment benefits for assistants and related administrative and management expenses.

9. Payments to the user shall not be treated as disposable, taxable income and shall not make the user ineligible for other statutory benefits or services.

10. Sufficient governmental funding shall be made available to ensure adequate support, outreach, recruitment, counseling, and training for the user and the assistant. Government efforts shall ensure that a pool of qualified, competent assistants shall be available for users to access through a variety of personal assistance services models, including, but not limited to, individual providers and full service agencies.

11. The user should be free to select and/or hire as personal assistants whomever she/he chooses, including family members.

12. Children needing personal assistance services shall be offered such services as part of their right to inclusive education as well. Such education and personal assistance services shall include age-appropriate opportunity to learn to use and control personal assistance services effectively.

13. There shall be a uniform appeals procedure which is independent of funders, providers, and assessors that is affected in an expeditious manner and allows the applicant/user to receive advocacy services and legal counsel at the expense of the statutory authority.

14. In furtherance of all of the above, users must be formally and decisively involved and represented at all levels of policy making through ongoing communication and outreach in planning, implementation, design and development of personal assistance services.

Rehabilitation and disability-related organizations, as well as individuals, are encouraged to formally adopt and endorse this Resolution. Send your letters of endorsement to the World Institute on Disability at 510 16th St., Suite 100, Oakland, CA 94612-1502. Voice and TDD 510/763-4100, FAX 510/763-4109. ■

COMMENTS ON TODAY'S SYSTEM

Jim Gassen uses a ventilator as a result of Duchenne Muscular Dystrophy. He writes from Illinois, "The Medicaid Home Services program is administered by the Department of Rehabilitation Services (DORS). Its purpose is to avoid the restrictions and costs of institutionalization. However, there is a DORS regulation which states that a personal assistant (PA) can only provide services in the home. The PA cannot be paid by Medicaid for doctor visits. I could keep doctor appointments in my wheelchair by using a paratransit service if my PA was 'allowed' to accompany me. The alternative is an ambulance trip, or perhaps hospitalization for a simple checkup, at the expense of Medicaid.

"Another problem arises when I am hospitalized. The hours are deducted from the PA's check. My experience is that the PA, which is hard to find, quits and then a search for a new one begins. During this process I will be in the hospital at over \$1,000 a day, or in a nursing home appropriate for ventilator users at over \$250 a day. Medicaid will pay those bills. It would cost under \$50 a day to keep my PA."

Mark Geisler has Becker Muscular Dystrophy and uses a ventilator 24 hours a day. He lives

independently in an annex to his parents' home and uses personal care attendants (PCA). He writes, "The Deputy Commissioner for Medical Services has interpreted Massachusetts regulations regarding personal care attendants. He explains that personal care attendants provide unskilled care, which can be performed by anyone able to understand and carry out directions and, therefore, can be provided by a parent, legal guardian, or voluntary caregiver. Additionally, the regulations require that all services paid by Medicaid be medically necessary, (defined as having a demonstrable clinical benefit and is the most cost effective alternative available). The most cost effective alternative is the assistance of parents, legal guardians, or voluntary caregivers. If I have to depend on anyone other than my PCAs for my daily care needs, I will eventually end up in an institutional setting, which is certainly not cost effective."

Polio survivor Ira Holland is a 24-hour a day ventilator user. He writes, "After almost two years of working with the New York legislature, a law was passed which permits the expansion of the role of paraprofessionals working for individuals with a disability in a home care program. (New York State

Law, Paragraph A of Subdivision 1 of Section 698 of Education Law, as amended by Chapter 795 of 1992). Prior to the law, unlicensed attendants were not permitted to engage in any invasive procedures. Through the efforts of consumers and health professionals who are advocates for home mechanical ventilation, suctioning and other ancillary procedures are now permitted by attendants, as long as two requirements are met: the attendant has been trained by a professional and has demonstrated ability to do suctioning, etc., and the attendant must be working with a self-directing client. Individuals receiving such assistance do sign a waiver of liability for the attendant and for groups providing those attendants.

Polio survivor Money Luckett who uses a ventilator writes, "I would like to connect with polio survivors who have had to leave their homes. I have been living with friends, and out of my disappearing savings I pay over \$500 a week to attendants. As far as I have been able to discover I do not qualify for assistance. What are other post-polio respiratory dependent quads doing?" ■

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INCARE: MODEL PAS IN IRELAND

Center for Independent Living (CIL) in Dublin recognized that the choices of living alternatives for those with significant physical disabilities were: you can be cared for by your family, or you can move into institutional care. Last summer they launched a model personal assistance program called INCARE. Fifteen people with significant physical disabilities will be instructed in all areas of personal assistance man-

agement, from interviewing, hiring, and training of PAS to become advocates for themselves and role models for others. Simultaneously, 35 non-disabled individuals will be trained to act as personal assistants for these 15.

At the end of the first two years, CIL will hold an international conference on the theme of independent living for people with significant disabilities. The project's goal is to persuade the Government to

fund a personal assistance program. If it works, the CIL which has no interest in becoming a service provider itself, will hand INCARE over to existing organizations as it looks for other ways to carry out its role as a catalyst in creating options for independent living.

For more information about INCARE contact Martin Naughton, CIL, Carmichael House, Brunswick St., Dublin 7 Ireland (01 730 986). ■

BACKGROUND

What is a ventilator?

"Mechanical ventilators are used to compensate for deficiencies in normal breathing by aiding, or augmenting, spontaneous breathing, or by completely regulating a prescribed breathing pattern for a patient who cannot breathe without assistance." (Health Devices, ECRI, 1992.)

Negative Pressure Ventilation:

The iron lung ventilates by enclosing the whole body, except for the head, in a chamber. Negative pressure is created in the chamber causing air to flow into the lungs. Chest cuirasses operate on the same principal. Instead of the whole body being placed in a chamber, a cuirass is placed over the chest and upper abdomen. The cuirass is then connected by hose to a negative pressure ventilator (Monaghan 170-C, Huxley, or Thompson Maxi-Vent, NEV-100). The rocking bed ventilates by tilting. The bed moves in an arc of about 20 degrees, alternating head down with feet down. The abdominal contents then drop, causing inspiration and move upward (head down), causing expiration. Other negative pressure ventilator options are the Pulmo-Wrap and NUMO suit.

Positive Pressure Ventilation:

The pneumobelt or exsufflation belt system includes an inflatable bladder, supporting abdominal corsets, and hose. The bladder is placed over the abdomen with a corset holding it in place. Positive pressure is pumped into the bladder which then inflates, causing the abdominal contents to displace upward producing exhalation. (The individual must be sitting upright for inhalation to occur.) The hose of the pneumobelt is attached to a positive pressure ventilator.

Today, positive pressure ventilators are used in critical and home care.

In the hospital intensive care unit, most ventilators are the size of a four-drawer chest. The tube connecting the ventilator to the individual's windpipe (trachea) is inserted through the nose or mouth and into the windpipe. An individual venti-

lated this way is said to be intubated. This is an invasive procedure.

In home mechanical ventilation, individuals may utilize negative pressure ventilation, positive pressure ventilation, or both. The type of ventilation and how many ventilators are needed is dependent on the diagnoses. The type and how many can also affect the quality of life and the independence of the ventilator user. Positive pressure ventilators used in the home setting are small (approximately 13" x 10" x 13") and portable and function somewhat like a reverse vacuum cleaner being turned on and off. The air passes through flexible tubing connected to the user via a tracheostomy — an opening in the neck, which is an invasive procedure, or via the nose or mouth with a face mask.

Who uses a ventilator at home?

Individuals with the following diagnoses may use a ventilator full or part time at home: polio, post-polio, muscular dystrophy, spinal muscular atrophy, amyotrophic lateral sclerosis (ALS), spinal cord injury, kyphoscoliosis, congenital central hypoventilation syndrome (CCHS), central aveolar hypoventilation syndrome, sleep apneas, and chronic obstructive pulmonary diseases (COPD) such as cystic fibrosis, emphysema, bronchitis. This is only a partial listing.

Portable volume ventilators

for home use are available with varying degrees of sophistication. The ventilator delivers room or oxygen-enriched air, which can be humidified and/or heated. Most portable ventilators use an accumulator which collects oxygen and mixes it with air (LP-6, LP-6 PLUS, LP-10, Bear 33, PLV-100, Companion 2801). The LIFECARE PLV-102 delivers oxygen through an internal proportioning valve eliminating the need for an accumulator.

Ventilation Modes: Ventilators may deliver breaths at chosen intervals i.e., using the Control mode (Bear 33, PVV, PLV-100, PLV-102, and Companion 2801), or they may deliver breaths whenever an individual's effort to breathe is not ade-

quate, i.e., the Assist mode (PLV-100, PLV-102, Companion 2801).

Some ventilators combine both Assist/Control modes (LP-6, LP-6 PLUS, LP-10, PLV-100, PLV-102, Companion 2801, and Bear 33) providing assistive breath when inspiratory effort rises above pre-set levels and providing mandatory breath when breath falls below the pre-set rate.

SIMV (Synchronized Intermittent Mandatory Ventilation) mode synchronizes the mandatory breath with the individual's inspiratory effort (LP-6, LP-6 PLUS, LP-10, Bear 33, PLV-100, PLV-102, Companion 2801).

Ventilator Cycling: Portable ventilators use various methods of cycling from inspiration into exhalation.

Volume-cycled ventilators cycle into exhalation when a pre-set volume has been delivered (LP-6, LP-6 PLUS, LP-10, PVV, PLV-100, PLV-102, Companion 2801).

Time-cycled ventilators cycle into exhalation after a pre-set time. A variant of volume- or time-cycled ventilation is volume- or time-cycled pressure-limited ventilation (LP-6, LP-10, PVV, PLV-100, PLV-102, Companion 2801). Because exhalation is passive, more time is required to clear air from the lungs, therefore expiratory times are set longer than inspiratory times.

What major companies manufacture portable volume ventilators?

LP-6, LP-6 PLUS, LP-10, Aequitron Medical, Inc., 14800 28th Ave. N, Minneapolis, MN 55447-4834, 800/497-4979.

Bear 33, Bear Medical Systems Inc., 2085 Rustin Ave., Riverside, CA 92507-2437, 800/232-7633.

PVV, PLV-100, PLV-102, LIFE-International Inc., 655 Aspen Ridge Dr., Lafayette, CO 800/669-9234.

Companion 2801, Puritan-Bennett Corp., Portable Ventilator Div., 4865 Sterling Dr., Boulder, CO 80301, 800/248-0890.

Who pays for ventilators?

Ventilators can be purchased by individuals, charitable organiza-

Continued on page 12

tions, and insurance companies, or leased by the aforementioned. Some individuals receive their ventilators through Medicare/Medicaid.

◆ **ISSUE 1**

HCFA, the Health Care Financing Administration, an agency of the Department of Health and Human Services, directs the Medicare and Medicaid programs — overseeing what these programs will and will not cover. HCFA has been reviewing and making changes in the whole Medicare system. They have already reduced the number of benefit codes for ventilators to only two — one code for positive pressure ventilators and one for negative pressure ventilators.

The simplified and logical codes could cause problems for multiple ventilator users who previously were utilizing three ventilators for three different purposes (i.e., someone who uses an exsufflation belt during the day, an iron lung at night, and a PLV-100 when breathing is difficult). Multiple ventilator users are in danger of being disallowed because they, on paper, are billing Medicare three times under two codes, or twice under one code, etc. (Long-time readers of the *Gazette* will remember that HCFA attempted to disallow payment for multiple ventilators in 1984. Consumer protests convinced them to rescind that policy.)

HCFA also has reduced their carriers (the insurance companies, also called DMERCS — Durable Medical Equipment Regional Carriers) to only four, dividing all states into four regions. (We have names and addresses, if you want them.) How could this streamlining of paperwork cause a problem? No one can guess what will be the new carriers' policy on providing multiple ventilators.

LIFECARE, a manufacturer of ventilators, and the company with the contract with the March of Dimes to provide ventilators to the post-polio population, contacted the four new insurance carriers, asking how they would deal with the

multiple ventilator issue. The answer was that they were establishing a national policy to be published for comment on May 1, 1993. LIFECARE submitted a position paper prior to May 1. About a week after May 1st, it was learned that Medicare had issued medical policy on approximately the top 100 or most-used codes. Since ventilator use is not that prevalent, no policy was issued. So, for the moment, the status quo, or "local control," is in effect. However, since the "local control" is now the new carriers, LIFECARE has asked for a clarification from each and should receive word after July 1. As of this date, HCFA has confirmed that there is no current plan to create a national policy for ventilators. Only one of the four carriers responded to the request for policy, and that carrier plainly states that a backup ventilator will not be provided.

What should we do?

G.I.N.I. will monitor the situation and will alert its readers and friends about the need for any direct action. In the meantime, you may wish to contact your representative or senator to express your view on the topic of the availability of multiple ventilators, and how a change in policy would affect your day-to-day life. Remember, many individuals, possibly your legislators, think of people on ventilators as being hospitalized and/or comatose, and they would not choose to be on a ventilator. They, of course, have really not had to choose. A letter or phone call would help educate them about life in the community on a portable ventilator.

Your legislators may be reached by calling the Capitol switchboard, 202/224-3121, or by writing to them at the U.S. Senate, Washington, DC 20510, or the U.S. House of Representatives, Washington, DC 20515.

HCFA's decisions appear to be motivated by cutting costs. Long-time users of ventilators know that a change in the policy to allow payment for multiple ventilators could ultimately result in the institutionalization of some, which we all know is more costly. In fact, the additional cost to our health care system is

documented to be nearly *one billion dollars!*

Therefore, you or your legislators may also wish to contact individuals at HCFA, explaining to them how the change in policy would affect your life. Your letters or phone calls should be directed to Carol Walton, Director, Bureau of Program Operations, Health Care Financing Administration, Room 300 Meadows East Bldg., 6325 Security Blvd., Baltimore, MD 21207, or Bob Wren, Director, Office of Coverage and Eligibility Policy, Bureau of Policy Development, Health Care Financing Administration, Meadows East Bldg., 6325 Security Blvd., Baltimore, MD 21207. The phone number for HCFA is 202/690-6726.

SAMPLE SUGGESTED MEDICAL POLICY AVAILABLE

A proposed policy on ventilators, defined "as a device that assists or replaces the normal function of the respiratory system of moving air into the lungs" and "incorporate a respiratory rate control," has been prepared by representatives of the health professional organizations and manufacturers. This policy is being circulated as suggested medical policy regarding ventilators. G.I.N.I. has a copy of the medical policy and will be glad to send it to its readers. The phrase pertaining to multiple ventilators reads, "Additional ventilators are payable if 1) the patient has ≤ 4 hours of ventilator-free time (spontaneous, unassisted ventilation) per 24 hours, or 2) where additional ventilators avoid the necessity for more invasive ventilation or improved medical care and/or provide a therapeutic necessity."

While following the multiple ventilator issue, we learned that HCFA did release medical policy for the BiPAP Systems.

BACKGROUND

What are mask CPAP and BiPAP® Systems?

CPAP stands for Continuous Positive Airway Pressure. A machine maintains continuous positive pressure (higher than the surrounding atmospheric pressure) in the upper airway. Air flows from the machine through a hose to a face mask at a speed of about 20 to 60 liters per

minute. The amount of flow is based on providing air to match your breathing pattern while always keeping the prescribed positive pressure in the circuit, even when you are exhaling. So, the flow is actually changing constantly as you breath. This pressurized air acts as a "pneumatic splint" to keep the airway open during inhalation and exhalation preventing the airway from collapsing. CPAP was first used in 1981 to treat obstructive sleep apnea. (Sleep apnea — interruption in breathing during sleep.)

The BiPAP System (Bi-Level Positive Airway Pressure), which is a pressure support ventilator, can provide two different pressure levels — one for inhalation and one for exhalation. For example, instead of a constant pressure as with CPAP, with a BiPAP System a person receives a lesser pressure on exhalation than on inhalation. BiPAP can also provide a timed respiratory rate. If a person's breathing stops for longer than a pre-determined interval, the device will deliver the set level of pressure and, in effect, give the person a pressure support breath.

The BiPAP S model (S for spontaneous) senses the user's inspiratory and expiratory efforts and changes pressures to keep the airway open and support breathing based on the users' breathing pattern. This model is currently filed under "Intermittent Assist Device with Continuous Positive Airway Pressure Device" in HCFA codes.

The BiPAP S/T (S/T for spontaneous/times) can be set at a minimum breathing rate, and if the user's rate goes below the minimum, it will deliver a breath. It can also be set in the timed mode at a fixed rate and a fixed inspiratory time. This model is filed under "Therapeutic Ventilator" in the current HCFA codes. (The therapeutic ventilator is included in the aforementioned sample suggested medical policy.)

BiPap Systems and CPAP machines are considered assist devices and are not intended to provide the total ventilatory requirements of an individual, and must

not be used for life support ventilation. Generally, users wear these systems during sleep, with some daytime use to help with shortness of breath or fatigue.

Who uses CPAP?

Individuals with obstructive sleep apnea syndrome (OSAS).

Who uses BiPAP S?

Individuals with OSAS who cannot wear CPAP, or who would benefit from assisted ventilation and do not need a ventilator rate control based on their clinical evaluation and physician's judgment.

Who uses BiPAP S/T?

Individuals who would benefit from assisted ventilation and whose clinical evaluation indicates that a minimum respiratory rate setting should be prescribed. This model has commonly been prescribed for patients with a range of neuromuscular and musculoskeletal disorders.

Who manufactures CPAP, BiPAP S and BiPAP S/T?

Respironics, Inc., 1001 Murry Ridge Dr., Murrysville, PA 15668-8550, 800/345-6443.

◆ ISSUE 2

The BiPAP Systems were placed under the general CPAP category in the new DMERC medical policy. In the proposed policy, to be effective October 1, 1993, the codes that apply to the BiPAP S and BiPAP S/T have been listed under CPAP as an alternative to CPAP. Medical professionals suggest that intermittent assist device with CPAP (applies to BiPAP S System) and the therapeutic ventilator suitable for 12 hours or less per day (applies to BiPAP S/T System) should have their own separate medical policies and not be listed under CPAP. The major reason being that they are alternatives to either surgical intervention or volume ventilation, but not alternatives to CPAP.

The HCFA draft policy also indicates that a claim must include records showing that an individual has not responded to other pul-

monary respiratory therapy, and that those therapies have failed to stop the progression of disease. The policy also requires sleep latency testing (the time required to fall asleep once lights are turned out), and a polysomnogram (recording of many types of information about a sleeping person). Most individuals using BiPAP Systems today would not meet this criteria, because requiring these tests is contrary to standard medical practice.

What should we do?

In a call or letter to legislators or HCFA (see addresses above), question the DMERC medical policy regarding CPAP (HCPCS codes E0451, E0453, E0601). Explain that you use an intermittent assist device with continuous positive airway pressure, or a therapeutic ventilator, and that their recommended additional testing of a polysomnogram and multiple sleep latency test, as well as responding to other pulmonary therapy including CPAP, are not needed and would unnecessarily increase the cost of your treatment.

G.I.N.I. also has copies of Respironics' recommended wording for this issue.

SURVEY

I.V.U.N. holds a request from individuals in academia wanting to direct mail a survey to ventilator users. If you do not want to receive specific and screened direct mail as a result of your I.V.U.N. affiliation, please notify us.

In 1991, I.V.U.N. requested readers to fill out a survey which we used for collecting your thoughts and opinions. If you have not completed the I.V.U.N. survey, please contact our office.

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The Legator

Our founder, **GINI LAURIE** (1913-1989) worked tirelessly for individuals with disabilities, developing a network of people bonded by some basic principles.

"The greatest of the resources are the polio survivors themselves."

NOVEMBER, 1985.

"Positive attitudes cannot be legislated. They are the personal responsibility of each one of us, whether disabled or non-disabled. Each of us must strive to see, to feel, and to understand each other's humanity, and to appreciate each other's value and uniqueness as a human being."

NOVEMBER, 1986.

"The 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."

JUNE, 1987

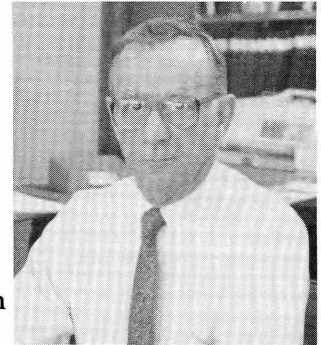
"I cannot say enough about the superb physicians who have worked with us. We have created a new medical degree for these dedicated and caring physicians; it is R.D. — Real Doctor."

NOVEMBER, 1988

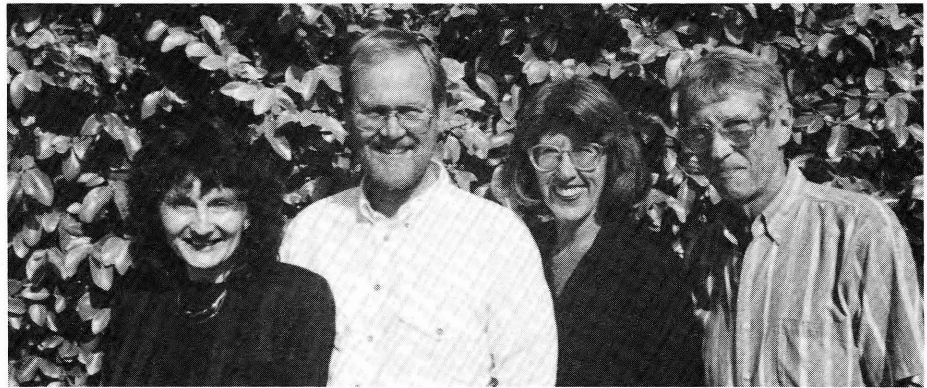
Carrying on the Legacy



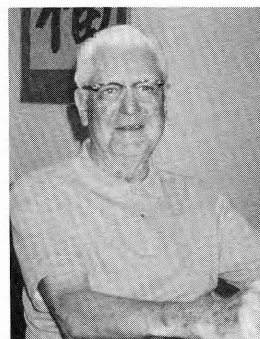
JOAN HEADLEY: Executive director of G.I.N.I. since 1987, and editor of *Rehabilitation Gazette* and *Polio Network News*. Joan is a polio survivor.



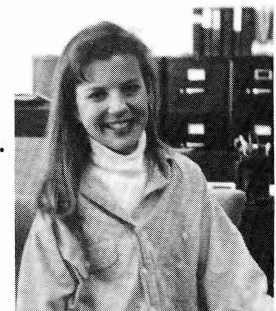
JOE LEONE: A former long-time volunteer, Joe joined G.I.N.I. in an administrative capacity in 1991.



JUDITH FISCHER: Former executive director of G.I.N.I., now editor of *I.V.U.N. News*. Judy, third from left, is pictured with Dr. Frederick Maynard and Dr. Armin Fischer with whom she and Gini Laurie co-edited the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. Also pictured is Joan Headley.



DICK DEVERELL: Dick has been G.I.N.I.'s regular Monday morning volunteer for many years.

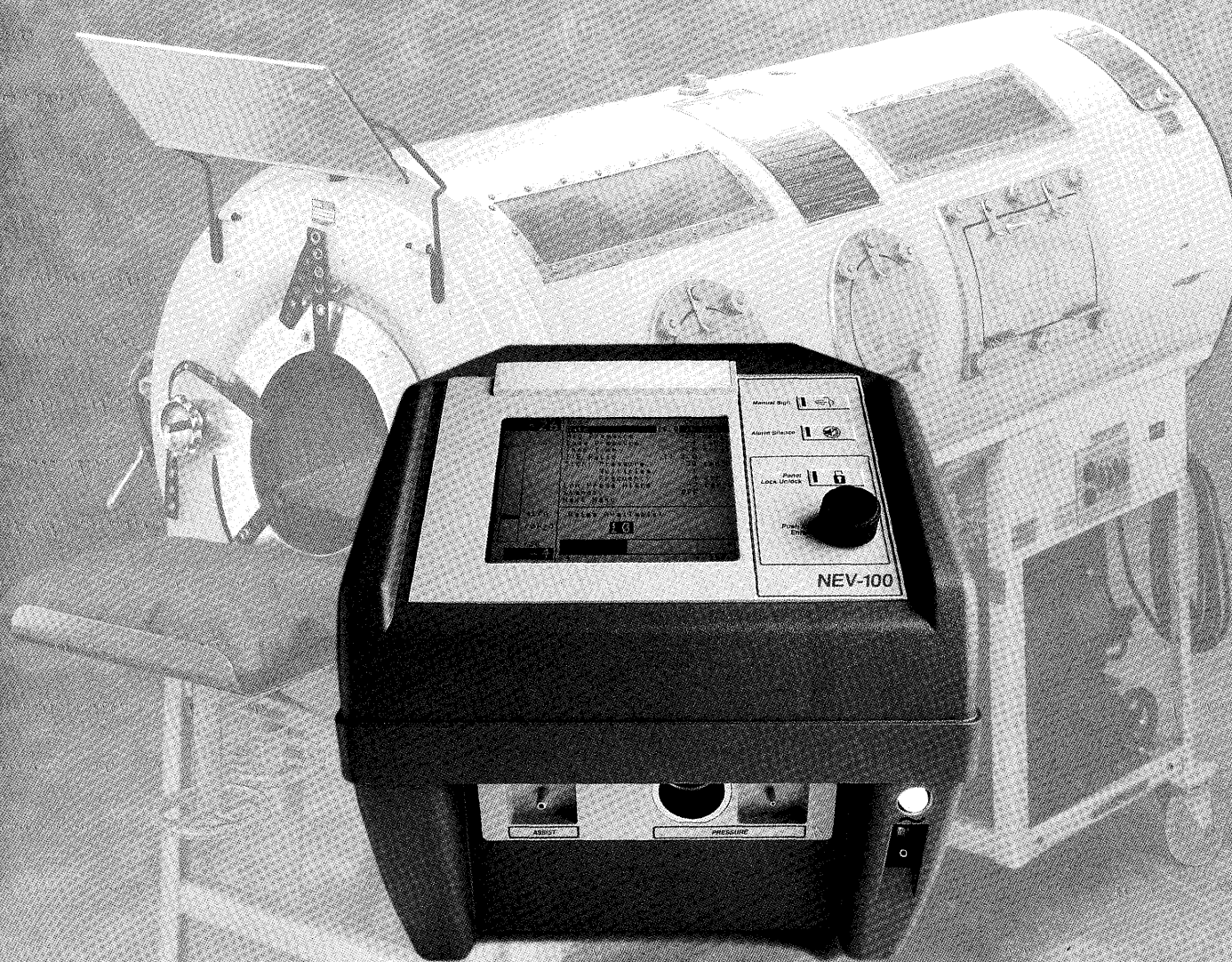


AMY KAMP: Designed G.I.N.I.'s Conference logo. Amy is a ventilator user who graduated from Webster University and now has an assistantship at Indiana University.



Join us for the **Sixth International Post-Polio and Independent Living Conference**, June 16-19, 1994, St. Louis Marriott Pavilion.

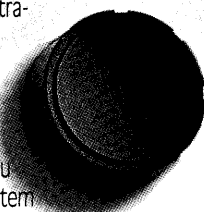
Watch for details and registration information in future publications of G.I.N.I.



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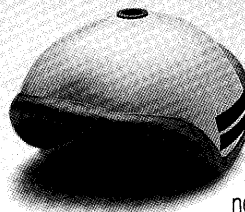


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POTPOURRI

Health Care Reform Readings:

Contact The National Council on Disability, 800 Independence Ave., SW, Suite 808, Washington, DC 20591 (202/267-3846) for a copy of *Sharing the Risks and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health Related Services*.

Contact Bob Griss, United Cerebral Palsy Associations, 1522 K St., N.W., Suite 1112, Washington, DC 20005 (202/842-1266) for *Principles for Health Care Reform from a Disability Perspective*, a position paper prepared by the Consortium for Citizens with Disabilities Health Task Force.

Contact Richard Daggett, Polio Survivors' Association, 12720 La Reina Ave., Downey, CA 90242 (310/862-4508) for a copy of *Report on Home-Based Long-Term Care*.

Contact *In The Mainstream*, a bi-monthly newsletter of Mainstream, Inc., 3 Bethesda Metro Center, Suite 830, Bethesda, MD, 20814, for a complimentary copy of Vol. 18, No. 3, May/June, 1993 which contains an article by Dr. Frank Bowe entitled "Doing Our Part: SSI, Medicaid, and People with Disabilities." The annual subscription rate is \$60.

Health Care Reform Useful

Names and Addresses: Task Force on National Health Care Reform, Hillary Rodham Clinton, The White House, 1600 Pennsylvania Ave., Washington, DC 20500; The Hon. (), U.S. Senate, Washington, DC 20510, and The Hon. (), U.S. House of Representatives, Washington, DC 20515; Donna Shalala, Secretary of Health and Human Services, 200 Independence Ave., SW,

Washington, DC 20201. (HCFA, the Health Care Financing Administration, is an agency of the Department of Health and Human Services and directs the Medicare and Medicaid programs — overseeing what these programs will and will not cover).

Study of Sexuality Issues: After doing in-depth interviews with 31 women who have a variety of physical disabilities and cover the spectrum of ages, races, and life situations, Margaret A. Nosek, PhD, Associate Professor, Baylor College of Medicine, and her staff found all but two of the women interviewed reporting horrifying abuse. The team of researchers, all women, most with disabilities, is nearing completion of the first phase of a three-year study funded by the National Institutes of Health.

The study will enter its second phase this summer with a national survey of 1200 women, 600 with physical disabilities and 600 of their non-disabled, female friends. Survey items will be based on the broad range of issues that arose during the interviews. Being sexually active or having a sexual partner is not required to be eligible for the study. Women interested in participating may call 713/520-0232, or write to Margaret A. Nosek, PhD, Baylor College of Medicine/ILRU, 2323 South Shepherd, Suite 1000, Houston, TX 77019.

International Exchange of Experts and Information in Rehabilitation (IEEIR) has recently published monograph #53, *Traditional and Changing View of Disability in Developing Society*. For information about this monograph and other IEEIR publications, contact Diane Woods, IEEIR, c/o

Institute on Disability, 125 Technology Dr., Heidelberg-Harris Bldg., Durham, NH 03824-3577 (603/862-0551, FAX 0555).

It's Okay! is an international consumer-written newsletter on sexuality, sex, self-esteem, and disability. Editor/Publisher Linda Crabtree, a disabled person with Charcot-Marie-Tooth, is looking for good stories, letters, and ideas. The eight-page quarterly is available from Phoenix Counsel, Inc., One Springbank Dr., St. Catharines, Ontario L2S, 2K1, Canada. The annual subscription rate is \$23.95 Canadian. Add \$2 for postage if you live outside Canada. ■

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