

PERSONAL ASSISTANCE SERVICES (PAS)

“PERSONAL CARE is one of the first areas of human activity in which an individual learns to become independent, yet it is still one of the last areas in which a severely, physically disabled individual can become independent. To be dependent in the care of one's own body is to renounce much of one's personal autonomy. To manage one's own personal care is to reclaim one's sense of self-worth.”

Chapter 9, Attendant Care, by Gerben DeJong and Teg Wenker in *Independent Living for Physically Disabled People* by Nancy M. Crewe and Irving Kenneth Zola, 1983.

PERSONAL ASSISTANCE is broadly defined as assistance from another person with activities of daily living to compensate for a functional limitation. It includes a wide range of services that have historically come under other rubric such as attendant care, home health services, home care, chore services, and homemaker services, as well as services of readers and interpreters. Independent Living Research Utilization (ILRU).

Personal Assistance Services: Critical Questions
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LEADERS OF THE INDEPENDENT LIVING MOVEMENT stress the option of complete consumer control over needs determination, selection, and management of persons providing assistance and payment for services provided. It should be noted, however, that many people requiring personal assistance in one form or another do not want and/or are incapable of assuming complete control over service delivery.

Voices of Experience by Max Starkloff, Leah Welch, Alma Krekus, and Jenny A. Reed. ... page 7

THE CONCEPT OF INDEPENDENCE has been interpreted by most in the independent living movement with a conservative, not a civil rights, perspective. They have taken this concept of independence to mean that people with disabilities have to do everything themselves. This view of independence runs into major problems when you recognize the reality of disabled people's lives. Support services are a necessary part of our lives. American Disabled for Attendant Programs Today (ADAPT).

A Civil Rights or Interdependent Perspective on Attendant Services by Bob Kafka. ... page 13

CURRENTLY, 1.5 MILLION PEOPLE REMAIN IN NURSING HOMES, and 300,000 remain in facilities for people with retardation.

The number of persons with disabilities who need assistance with some day-to-day needs is estimated to be 7.7 million, or 3.3% of the total population in the U.S. The large majority (81%) of persons needing assistance live with relatives or a spouse, and 79% receive volunteer help only. The reality is that the vast majority of persons with severe disabilities have no contact with formal programs.

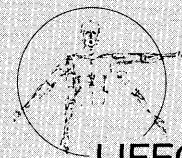
Not Just a Statistic
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GAZETTE
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(G.I.N.I.)

Rehabilitation
Gazette 福

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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Like most people, my life is very busy, often hectic. Working at the office and at home, attending meetings and appointments, running errands, shopping, spending time with family and friends, frequently create something short of a scheduling nightmare. Unlike most of the individuals with whom I have contact, however, my daily activities and accomplishments are not simply the result of my own stamina and desires, but to a great degree the effect of the willing assistance and support of my personal attendant and friend, Christy. I could easily state that Christy is important to my well-being, but it would be a terrible understatement. Instead, I think a brief description of what she does for me during a typical day would reflect more accurately the vital role she plays in my life.

For the most part, my day begins when Christy walks through my bedroom door. Living at home with my parents, who provide a large portion of my personal care (especially through the evening and night), enables me to limit the amount of services I need from a personal attendant. This is an extremely important benefit, since my salary is not sufficient to purchase full care around the clock.

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Due to the severity of my physical limitations, I rely on her to do almost all that is necessary to get me from my bed to my wheelchair and out the door. It is, however, more than merely a matter of dressing and toileting. Having since childhood viewed mornings as only slightly more appealing than a dental appointment, Christy is often faced with an attitude which can range from a crabby toddler (at best) to a Ms. Hyde (as in Dr. Jekyll's alternate personality). In addition to the morning's physical routine then, she helps open my mind to a new day by talking about the weather, what she heard on the radio during the drive to my house, the events of the day ahead of us, or the various things happening in our lives.

If it is not one of "those" mornings (you know, when the body moves slowly from insufficient rest, the mind is distracted with more pressing concerns than what shirt to wear under which sweater, or that a desired item of clothing still has a hint of last week's chili lunch on it), Christy and I will be on the way to the office or a meeting within 45 minutes of her arrival at my home. (Her familiarity with my routine, needs and tastes, which has developed over the year and a half we have known each other, helps ensure the speed necessary to keep on schedule.) With Christy at the wheel of my van I am free to plan my day, prepare for the various obligations lying ahead of me, or take advantage of a few last minutes of peace listening to the radio and chatting with my friend. Time in the van is a type of buffer between the daily activities in my life. Spending such times alone, without the interplay with Christy, seems alien, even though I realize many people do so every day.

If my first destination of the day is my office, Christy's role quickly expands from that of a personal attendant to include the usual tasks performed by a secretary. (As part of my job offer, she was hired

as support staff to the office for the time I am there, a positive arrangement for all concerned — a much needed personal aide to me; an efficient worker for my employer, and a variety of duties for her when I am working on my own.) Throughout the day, Christy hands me materials, takes dictation, answers the telephone, makes photocopies, runs errands, delivers messages, files papers, and does a myriad of uncounted activities while also attending to my personal needs. (No, she is not interested in finding a new position. Are you, Christy?)

Meetings and seminars fill anywhere from a third to half of my time each week. Depending on my particular role at such functions (which can range from leading the event to merely being a member of the audience), Christy's degree of involvement can change quite dramatically as we go from one activity to the next. As my level of participation increases, so do her duties. When I chair a meeting to help present a workshop, Christy can be as busy as a congressional aide — retrieving files, dispersing information, managing materials, taking minutes, attending to my personal needs, and acting as a liaison between myself and others when I am busy. The rapport we have developed, and her ability to anticipate my requests before they are made, virtually eliminates the negative effects of my disability.

Not all my activities away from the office, however, are so demanding of Christy's assistance. Frequently, she can relax and simply observe the meeting or seminar, and may take a moment or two for herself. Her presence, though, is still needed to occasionally move materials and physically adjust my position in my wheelchair. Perhaps surprising to many people, these less "active" periods during any given day can often be the more difficult times for Christy, especially when the subject matter is of little interest or the format is

dull. Few people are spared those painfully boring events, where eternity exists in each minute and excitement seems to lie in the thought of watching dirt crack. As the personal attendant to an attorney, Christy has had far more than her fair share of such functions. Fortunately, however, she has the endurance of a "saint-to-be."

On a typical day (one where there are no night meetings or a particular item of work with a pressing deadline) Christy and I will return to my home about 10 hours after she first arrived in the morning. At its shortest, it is a long day for her. What Christy does for me during a day, however, often goes beyond the usual day just described. Like other individuals, my life is more than work. Time

away from work is spent going to doctor appointments, running errands, shopping for myself and others, doing personal projects (straightening my room, putting photographs into albums or doing equally newsmaking tasks) and occasionally, if I am lucky or deserving of a small reward, going to a movie or concert or visiting a friend.

Although there is much I can do for myself, with little or no assistance from others, I am dependent on the care and support of family, friends, and especially Christy, in order to do what so many others take for granted. For the many others in situations similar to mine, however, a personal attendant provides more than physical assistance. Companionship, with

its comfort and supports, is of equal importance to what Christy does for my physical well-being. I have been exceptionally fortunate in having someone enter my life who, not only has the special temperament necessary to care for the many needs of a person with a severe disability, but also with whom I can work professionally and from whom I receive friendship, encouragement, and the humor essential for self-work and self-esteem. More than what Christy does *for* me, I value what she enables *me* to do for *myself*. My job and many other activities outside my home, which add depth to my life, are possible because of Christy, my personal attendant and friend. ■

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Having lived as a ventilator dependent quadriplegic for the past 38 years, I attribute much of my success as a capable person, managing a full, independent and productive life, to the availability of personal assistance services. Personal assistance services, which were formerly known as Home Care Services, encompasses my personal care (toileting, bathing, and personal hygiene), household chores (laundry, house-keeping, marketing, and meal preparation), and financial management (paying bills, balancing my checking account, and other bank related activities).

My requirement for personal assistance was a result of polio. When I became disabled, housing and other support services for significantly disabled people were generally unavailable except in long-term rehabilitation facilities like the one in which I lived for more than 20 years. I was exposed to the institution's staff at all levels and soon became aware that if I were ever to return to an independent lifestyle in the community I

would need the services of a skillful, capable, organized, and patient attendant.

My gradual indoctrination to independent living occurred in the 1960s and 1970s before there was formal independent skills training. I had to learn the need for independent initiative, for creativity, and the importance of controlling my life despite the institution's sheltered and paternalistic environment.

Since my discharge from the institution in 1976 to my home, I have gone much beyond the institution's definition of life as a disabled person, to a new definition which encompasses an independent lifestyle, with the support of a personal assistant. As a program participant and vice president of Concepts of Independence, Inc., a consumer-directed personal assistance program in New York City, I am responsible for the employment, training, scheduling, and supervision of my personal assistants. The acceptance of these responsibilities has given me

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greater flexibility in defining my own life, following the principle that we are what we do.

I want to give you some sense of a "typical day" in my life beginning when the alarm wakes me at 5:00 a.m. After toileting I take my bath at about 6:00 a.m. and have breakfast about 30 minutes later. With the radio playing in the background, I select my wardrobe, usually with some input from my assistant, am dressed and am made ready to transfer to my power chair by about 7:30 a.m. Although there are a multitude of adjustments and refinements required before I am ready to meet the day, 8:30 a.m. finds me comfortably seated, my Pneumobelt, the breathing device I use while seated, properly engaged, my shave and shampoo accomplished. I will next place a few early morning phone calls, pay some bills, and leave instructions regarding laundry and meal preparation.

If I have planned a day out, as is frequently the case, the transporter will meet me between 9:00 a.m. and 9:30 a.m. for a day of meetings at the office, teaching, or keeping medical appointments. On those days, when I am outside my home, my assistant will help me overcome obstacles, manipulate papers, facilitate changes in my attire, or corrections to my position, assist with lunch, and other aspects of my personal care.

Returning home at 4:00 p.m., I continue my telephone calls and review my mail. The dinner I planned would be prepared and served by the assistant by 7:00 p.m. and is eaten with the assistant and a friend or two. After dinner, the assistant cleans the kitchen and respects my privacy, affording me the opportunity to engage in some private conversation with my friends. Sharing with friends affords me the opportunity to socialize, maintain relationships, and generally gives me a pleasant break in my hectic schedule.

Obviously, friends are not always present at dinner, and the social interaction between my personal assistant and myself is important. My relationship with the assistant is intelligently structured so as to include both sensitivity to our needs and a sense of mutual respect.



*Ira E.
Holland*

Later that evening, before returning to my bed, my assistant prepares the Puritan Bennett ventilator, mouth piece, lipseal, and other components required for non-invasive positive pressure ventilation. After my assistant prepares my ventilatory support system, I may review my day's activities and prepare an outline for the following day. My assistant will update my calendar, address some last minute letters, perform a passive range of motion exercise, turning me on my side for a period of time for relaxation and comfort and finally readies me for a night's sleep.

The services provided by my personal assistant have enabled me to complete a full and fulfilling day. I have been able to live my life as I would wish to and not as an institution directs. I have been productive and functional, made my own decisions, and had the opportunity to meet with and speak with other people, either in the course of my work or social interaction. I am reminded of the essential

importance of the personal assistant in virtually every aspect of what has been accomplished today.

Living in New York City and taking advantage of the Concepts Medicaid-funded client-directed program, affords me personal assistance services that are quite

comprehensive. Problems which are commonly associated with home care programs which rely upon expensive nursing professionals, are that they cost in excess of \$30 per hour* in comparison to \$9.38 per hour for the assistant services I receive. My personal care assistants provide me with round-the-clock coverage seven days a week.

As has been shown repeatedly*, the cost effectiveness of these services is another compelling reason for the utilization of personal assistance services. In this era of cuts and shrinking budgets, the advantages of personal assistance certainly make a lot more sense than hospitals or related institutions.

The singular advantage is that the coverage permits me to live my life in a manner that allows both the flexibility and the dignity of making my own decisions and appointments with a schedule that allows for my individuality. ■

*CHEST, January 1992

Some Critical Questions

BY MARGARET A. NOSEK, Ph.D.

Personal assistance services (PAS) can make the difference between living successfully or succumbing to disability. Although several states have made strides toward making these services available to those who need them it remains one of the most frustrating problems faced by persons with severe physical disabilities in this country. A national policy that would establish a personal assistance services system could relieve much of this crisis, yet it is an issue fraught with controversy. Lawmakers argue it would demand large financial resources; advocates claim the money already exists but is being misdirected to institutions. Administrators want medical supervision for accountability; advocates demand the option of complete control over the service.

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This article presents various sides of several critical questions in the PAS debate.

WHO SHOULD PROVIDE PERSONAL ASSISTANCE?

There are four ways people with disabilities meet their need for personal assistance: family, paid in-home provider, congregate living, and institutions. These options can be judged in terms of cost, opportunity for consumer control, and quality of life for the individual.

By far, the most commonly used option is assistance from family. Parents, spouse, children, or other relatives help as an extension of a natural and socially expected role. Census studies cite that from 79% to 81% of people who need personal assistance receive unpaid assistance only. Even if a family is functional under normal circumstances, the introduction of a need for extensive physical assistance may cause mixing of roles and strain relationships to a breaking point. It is also not safe to assume that family will always provide the best assistance. Children with disabilities are often denied the right to seek independence as they mature because there is no feasible option for personal assistance beyond family.

Paid in-home providers may be used to supplement family or may be relied upon exclusively. This option is regarded by the independent living movement as the most preferable and the most conducive to independence. Congregate living, with two or more consumers sharing the same assistants, has the advantage of administrative efficiency, but compromises consumer control.

Institutions are generally regarded as the most expensive, restrictive, and least desirable option. For persons who lack family resources for assistance and have no other option for survival, nursing homes or other institutional settings are their only alternative in our present society.

WHAT SERVICES SHOULD BE INCLUDED?

Informal arrangements for receiving assistance, especially within the family, are rarely controversial in terms of what services should be included. Needs may range from the full spectrum of personal tasks, including bowel and bladder programs and taking medications, to homemaking tasks, to assisting with mobility and communication.

When public funding is used, or when services are purchased from an agency, each task is scrutinized to determine who is best qualified to perform it, how long it takes, and how much it should cost. Most home health care providers have very strict rules about who can perform tasks that are judged to be medical and often will not allow assistance with household tasks, even meal preparation. Much of the debate on this problem centers on the distinction between a medical need requiring a health service and an activity of daily living requiring a social service.

HOW MUCH ASSISTANCE SHOULD BE PROVIDED AND WHO IS ENTITLED?

One method for controlling the costs of PAS is to place strict limits on how much assistance can be provided. Most states set the limit for personal assistance at 30 to 40 hours per week. Control of costs is also exerted by limiting allowable tasks. For persons with very extensive needs, the cost argument favors institutionalization, while the benefit argument (in terms of quality of life) obviously does not. The solution lies not in limiting services to unreasonable extremes or forcing institutionalization, but in basing cost analyses on the entire spectrum of need and setting reasonable limits on how much of that need will be met with public funds.

Another controversy in the issue of how much assistance

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should be provided is who estimates need and priority. Advocates claim the right to control the needs assessment process, criticizing current methods as arbitrary and claiming that only they understand the complexities of their lives. However, such a practice would allow potentially unlimited demands on the system. Administrators defer to the expertise of medical professionals. Once again, the question of "how much" is currently moot, since availability of funding and restrictions on its use are the determinants. In an ideal system, amount of service would be determined by functional and financial need. Advocates are currently discussing a mechanism that could identify an individual's level of need, with funding priority given to the highest level of need.

WHO SHOULD PAY?

The choice of options for receiving personal assistance depends more strongly on the availability of funds than a conscious decision about which funds should be used. Most often, when family provides the assistance, no out-of-pocket expenses are involved. However, there are many indirect costs, such as lost wages by persons who forego employment to assist a disabled family member. Most individuals with disabilities who work and live on their own must bear the full burden of paying for PAS expenses, which can consume large portions of their salaries.

Primary public sources of funding for personal assistance for working-age, but generally unemployed, persons with disabilities are Medicaid, Title XX (Social Services Block Grants), and Veterans benefits, with a much smaller but growing amount becoming available from special state programs and state/federal rehabilitation agencies. Most of these funding resources have strict eligibility requirements, primarily based on income and assets. Until recently, individuals receiving

Supplemental Security Income and Medicaid benefits lost funding for personal assistance services if they earned even minimal salaries. With the adoption into law of Section 1619 of the Social Security Act in 1982, such individuals can now work and earn a limited amount of money while retaining Medicaid-funded personal assistance benefits.

Researchers and advocates have offered many suggestions for revising current funding structures for personal assistance services. Before any of these can be implemented, however, lawmakers must affirm that society bears the responsibility, at least in part, of assisting individuals with their disability-related expenses as an entitlement or even a civil right. Some recent moves by Congress reflect the belief that employers also share some of the responsibility for providing personal assistance to their employees. The Americans with Disabilities Act, passed in 1990, requires that employers provide reasonable accommodations to the known disabilities of their employees, including personal assistance during work hours.

Fragmenting resources for PAS is ill-advised. Individuals without family resources could easily end up having their personal assistance at home in the early morning paid for by Medicaid, their assistance at work paid for by their employer, and their assistance at night paid for out of their own pockets, with no assistance available at all if they were sick or wanted to take vacation time. If any one of those resources dried up or was subject to cutbacks, the individual would be unable to function. If a combination of resources are used, they should be flexible and coordinated.

THE NEED FOR ORGANIZED ADVOCACY

Solutions to the PAS dilemma have been proposed. In its 1986 report to Congress, *Toward Independence*, the National Council on



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Disability presented 14 criteria for a national system for providing personal assistance services. This system would offer services without regard to age or disability type; instead, services would be based on functional need. There would be opportunity for optimum self-direction, such as offering hire/fire authority to the consumer, an advocate, or agency, as the consumer prefers. Persons at all income and asset levels would be eligible for services with cost sharing as appropriate, with no disincentive for employment. Assistance would be available for a full range of tasks, at all times of the day or night, on a respite or emergency basis, and wherever it is needed. There would be outreach and training for consumers on managing personal assistants. Administrators and staff would be trained in the concepts of independent living. Agencies would recruit personal assistants and offer reasonable wages and benefits. Consumers would participate in administering and developing policy for these services.

The World Institute on Disability developed a draft of a bill for a uniform national system for the delivery of personal assistance services called the Personal Assistance for Independent Living Act. Each state would designate an agency to administer and coordinate the program according to a state plan developed with substantial consumer involvement, based on the criteria listed above.

The recommendations have been well considered and docu-

mented, yet the response of lawmakers has been lukewarm at best. Living examples of programs that operate using many of these recommendations have been used to illustrate the feasibility of a national PAS program, yet the people with power to institute such a program do not appear to have considered them. There are large, well-funded, and vocal consumer organizations and coalitions taking on the issue of health care reform, but even they are not well-informed about consumer controlled, community-based PAS. There is a critical need for disability groups to educate not only lawmakers, but just as importantly, advocacy organizations.

A national personal assistance program would have the potential to make a significant improvement in the independence, health, and productivity of persons with severe physical disabilities, and eventually yield enormous cost savings for society. Creating such a program will require converting traditional services based on a medical model to services based on an independent living model that offers options and the power of choice and control to consumers. As sophisticated medical technology continues to save and prolong lives and as our population continues to age, it becomes more and more evident that personal assistance is a solution, not a problem, and the time is now to establish a national personal assistance services program. ■

This article is an excerpt from Dr. Nosek's "Personal Assistance Services: The Hub of the Policy Wheel for Community Integration of People with Severe Physical Disabilities" that will appear soon in the *Policy Studies Journal*.

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Disabled and Despondent

BY MAX J. STARKLOFF

I am angry. I am angry and frustrated, and I have thought more about suicide the past month than I ever have before. I am angry because a lot of people with severe disabilities like mine contemplate suicide. And the main reason most of them have a death wish is that they are not getting the support they need to carry on full, productive lives.

It just should not be happening. The problem is that government-provided support systems more often fail people with disabilities than benefit them. And that is pushing a lot of people with disabilities to suicidal despair. They are simply fed up with having to deal with the frustration and isolation caused by inappropriate or inconsistent services.

I am not one of those people. I am one of the lucky ones. I have always had a very supportive family and network of friends and others who have helped me meet the needs of my disability for more than 33 years now. But I am angry that others, like a man I know in St. Louis who has been disabled for 23 years, desire suicide over life because he did not have the kind of social network I have. And he and others like him are willing to choose death because their "safety net" — the government-sponsored support systems they rely on to live — are both underfunded and inappropriate. Some people, and even some state courts, agree with the "better dead than disabled" attitude, regardless of whether a person has a terminal illness.

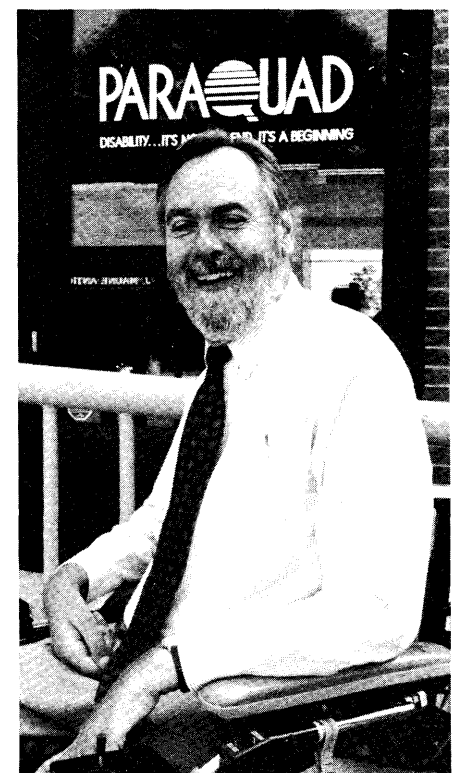
But just because the choice for death is legal in a few places and some people think it is rational, still does not make it right. All those court decisions and so-called enlightened attitudes demonstrate

a chilling reality: our society's devaluation of individuals who have disabilities.

Think about it. Whether you have a disability or not, would not you be a little unsettled by a legal system that judges a life with a disability as hopeless and worthless? The problem is that people perceive the lives of those with disabilities as unbearable. Instead of helping people live quality lives by ordering the provision of various options, the courts prefer actively to help people die. And instead of increasing funding for key support programs that help people with disabilities live full, independent and productive lives, Missouri and other states prefer to fund costly support systems that segregate disabled individuals from society in institutional isolation.

We in the independent living movement are committed to the pursuit of "life options" for people with disabilities — because we are committed to fighting for an individual's right to self-determination and an equal opportunity to live.

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The Personal Care Assistance program allows a person with a disability the chance to hire attendants to assist with their basic needs. But the program relies only on modest state funding. What's more, those funds only support 100 people in Missouri. There are 3,000 who would qualify for services. That's 3,000 people waiting in Missouri nursing homes or other situations because they need physical assistance, not for health reasons.

Just given the staggering costs related to nursing home care, increasing funding for the Personal Care Assistance program makes sound economic sense. The Bush administration estimates that America spends more than \$200 billion annually to keep people dependent. In Missouri and elsewhere nationwide, that amounts to about \$50,000 a person each year. But personal assistance services can serve as many as five people for the same amount and provide people with disabilities the opportunity to live independent and productive lives. Why pump hundreds of thousands of taxpayer dollars into institutionalized care when all a disabled individual needs is the money to hire his own attendant and get on with life? Nationwide estimates show the lack of appro-

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priate funding for such independent living alternatives as attendant services costs the country \$100 billion a year in lost productivity and economic contributions from those denied the option to live and work independently.

But more than economics is at stake. Support for attendant services is just the morally right decision to make. The program must be expanded and funded at a substantially higher level if it is to free thousands of disabled individuals living in state-subsidized institutional care.

The Personal Care Assistance program must also be reformed. Minimal attendant pay causes high turnover rates among often poorly qualified attendants. The rapid turnover results in frequent stretches of unreliable and inconsistent care — and a sense of helplessness and frustration among disabled persons. Thus, the suicidal despair of people with disabilities like my friend here in St. Louis who are faced with inadequate and under-funded attendant services makes a very clear statement about how their government-sponsored support system has failed.

And it should not be happening.

We need a higher funding level for the Personal Care Assistance program that will also help provide a more competitive pay scale for attendants beyond the minimum wage and better trained and qualified attendants.

My friend, and others like him around the country, have chosen to live — for now. But they are vulnerable and precariously perched between life and death, with government-sponsored support systems the only choice.

Missouri can show through more funding for the Personal Care Assistance program and Centers for Independent Living — that it is committed to providing well-supported life options to citizens protected by the Americans with Disabilities Act to live with dignity and purpose. ■



Lessons Learned

BY LEAH WELCH

Minnesota has had personal assistance service (PAS) since 1977. In the beginning, personal care assistants (PCA) were hired, supervised, and fired directly by the recipient of the service and were considered to be independent contractors. The state paid the wages directly to the PCA. The supervisory nurse was directly recruited, hired and/or fired by the recipient also. The supervisory nurse submitted the assessed hours to the state and supervised the care on an ongoing basis. This service was limited only to adults with physical disabilities who could direct their own care.

Generally speaking, the system worked well and there were very few abuses. As the service grew so did the administrative work by the state but with no corresponding increase in staff. Questions or concerns were directed to the state Department of Human Services (DHS). The service continued to grow, the calls increased, and so did the distress of the DHS staff. They became concerned about liability and in 1988 implemented a requirement that all PCAs must

be processed through a middle man (a provider agency). The provider agency was required to have a contract with DHS and show financial ability to maintain a cash flow.

At the same time, the services expanded to include all segments of the disabled population as required by the Federal Health Care Finance Administration (HCFA). This included children, as well as adults with developmental disabilities, mental illness, brain injury, and physical disabilities.

The service as it was originally implemented gave people a good deal of control over their ability to live independently. From 1977 until 1988, Independence Crossroads was the only agency recruiting PCAs in the state, and we still recruit, screen, and refer applicants to clients and provide information/referral, advocacy, counseling, and public education regarding personal assistance services (PAS).

Today in the state of Minnesota, 3,000 people are on this program with over 100 PCA provider agencies. Individuals who are financially eligible for medical assistance have the opportunity to live independently in their own homes.

In an attempt to cut costs, the state initiates new rules and regulations on an annual basis. This is done under the guise that there are many "cheaters" using the service,

and money will be saved if they are caught. The state sees more rules as the answer.

This has created more paperwork for the Department, put them more behind in their day-to-day operations, instituted more appeals by the recipients, made more paperwork for the provider agency, and increased the cost of operating the provider agency and DHS. All this has not only increased costs to the state, but the individual with a disability loses more control over his/her life. In general, the service in Minnesota is becoming more and more a medical model and a huge bureaucracy, and less and less an independent living model (see Figure 1. Adapted from The Independent Living Model of Personal Assistance in National Long-Term-Care Policy by Gerben DeJong, Andrew I. Batavia, and Louise Bouscaren McKnew in *Generations, Journal of the American Society on Aging*, Winter, 1992.)

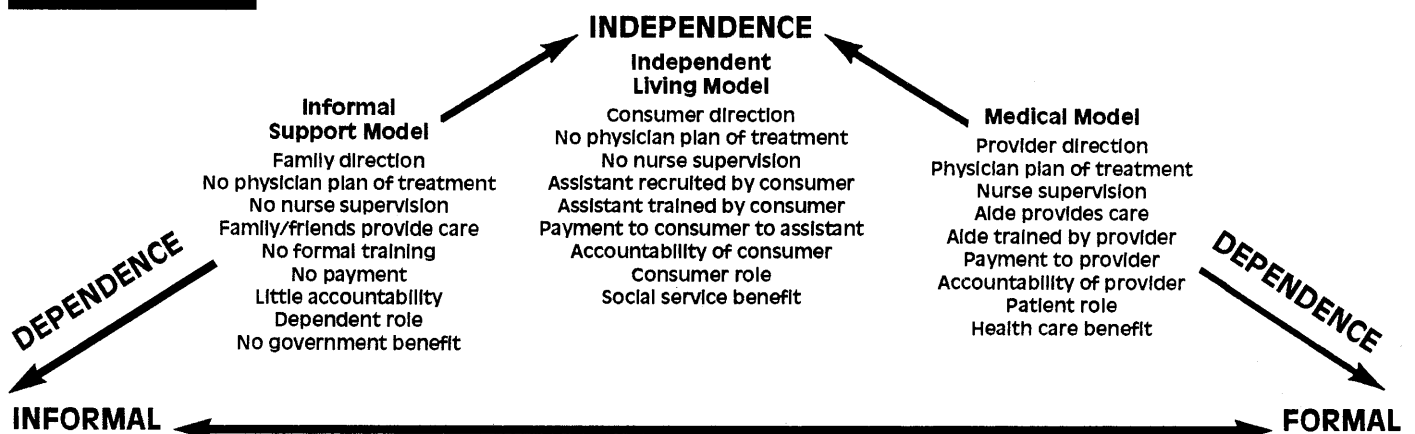
DHS and advocates of the disabled community need the opportunity to work together to develop the *necessary* rules and regulations with a common goal of quality service. DHS operates on the theory that in order to save money, they need to decrease hours provided. The disabled advocates for the service have consistently argued that quality service cannot be provided with decreased hours. It is "us"

Leah Welch uses a wheelchair and ventilator as a result of polio in 1949. She is founder and director of Independence Crossroads, Inc., 1073 10th Avenue SE, Minneapolis, MN 55414 USA (612/378-0027), a non-profit independent living center, funded by Hennepin County. She is the founder and Chairperson of Independence Crossroads-PCA (IC-PCA), a non-profit provider for personal care assistant services. Her daughter, Donna Robb, is Director of IC-PCA. Leah has been a long time advocate for people with disabilities and has received numerous awards for her contributions, including the national Victory award in 1991.

versus "them." The priority of the state is to cut costs by whatever means. Advocates have recommended the state look at the decrease in institutional costs with the implementation of PAS and compare those costs with the cost of the personal assistance service. So far, our attempts have been in vain.

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FIGURE 1.



Perhaps a different approach entirely to providing independent living services to people with disabilities is needed. In the 1980s, Hennepin County used a direct grant approach to provide personal assistance services to the individual with a disability. At that time, people received a flat grant from the county for their housing and food expenses. An additional amount was added for the personal assistant. This worked out well.

If we opted for a direct grant approach, rather than after-the-fact reimbursement, the care required would be provided without an invasion of privacy, and without the recipient losing control. This kind of approach would necessitate a different funding source than Medicaid and would require some mechanism to collect worker's compensation, unemployment, and taxes. Along with this, there should be provisions for the necessary recruitment, advocacy, and information and referral necessary to assist the individuals to maintain themselves in an independent living situation, a service many independent living centers are now providing and for which they are well qualified.

The direct grant approach does require someone willing and able to take on this responsibility. There are others who could not or would not choose to use this kind of approach. The ideal situation would be two options. The one with a direct grant approach, where the recipient does all the recruiting, training, etc., or the approach that would allow the recipient to go through a provider where the recruiting, screening, and hiring, is offered by others. ■

Attendants and Attitude

BY ALMA KREKUS

In my experience as the Attendant Care Coordinator at Services for Independent Living, Inc. (SIL), an independent living center in Cleveland, Ohio, one problem is the rapid turnover of attendants. Why? I think the answer is very complex, but a major factor is attitude. I am referring to the attitude of the individual *needing* PAS.

Some people with disabilities (and some without) seem to think that "everybody owes them," and that attitude is taken into the relationship with an attendant, whether they are hired privately or through a nursing agency. Nobody is going to work for long when they are treated rudely or shouted at; consequently, the attendant quits or requests another assignment. In many cases, attendants are not paid for time they have worked if they quit.

Many people believe that because a nursing agency is receiving state and/or federal funds to provide PAS, they cannot refuse services to a consumer. This is not so in Ohio, and those who are rude and unnecessarily uncooperative are having problems in finding an agency or attendant.

On the other hand, of course, some attendants think that anyone who has a disability is not capable of knowing what assistance they require. I correct that mistaken impression and inform prospective attendants that anyone who might hire them through SIL probably lives on a fixed income and cannot pay more than \$5 per hour.

Consumers need to understand their role as an employer and should not take the responsibility lightly. It is most important that consumers inform their caregivers firmly, but politely, of their needs.

When looking for an attendant, list all the duties the attendant must do and explain them in detail at the interview. For example, bowel routine should be discussed because everyone's routine is different. It is important to discuss payment because attendants also have bills to pay and need to know how much and when they will be paid. If employer taxes are to be paid, tell the attendant that their Social Security/Medicare contribution will be deducted before payment. Proper records must be kept with names of employees, dates of employment, their Social Security numbers, and the deduction amount.



Currently, it is extremely difficult for anyone to acquire information about services that they are eligible for under state/federal programs. As the Attendant Care Coordinator, I assist consumers in accessing those programs. In Ohio, home-based PAS can be provided by Medicaid, Waiver programs, Medicare, and the Personal Care Assistance (PCA) Program*. I believe many people are struggling from day to day making the best of a bad situation simply because they are unaware that they may be eligible for state/federal services.

For those consumers who are not eligible for state/federal services which generally include those who are working, or those whose spouse is working, I refer them to the attendants who are listed with the agency, or to those local nursing agencies who do not charge exorbitant prices.

In either case, I discuss with consumers how to find attendants, write ads, keep payroll records, file employer taxes, and most importantly, how to direct the attendant. Consumers need to recognize that they can control the situation and direct their PAS as they want, by following these guidelines:

- ◆ Do interview as many applicants as possible.
- ◆ Don't hire sight unseen.
- ◆ Do check into previous work-related references.
- ◆ Don't accept friends as references; they always say good things.
- ◆ Do write a list of duties expected to be done, including how and when.
- ◆ Don't expect the attendant to know what you are thinking.
- ◆ Do discuss wages and how and when the attendant will be paid.
- ◆ Don't forget to include deductions for Social Security, etc.
- ◆ Do treat your attendant as you would like to be treated.
- ◆ Don't have an attitude.

A universal problem is the lack of good, reliable attendants. Even the nursing agencies, who pay more than the average consumer can afford, are unable to find enough dependable people. I have tried high schools, colleges, churches, state agencies, and even though I get a good response to my inquiries, the end result is always disappointing. From 30 responses, five will keep their appointment for an interview, and when checking their references, I may only receive a decent reference for one person.

Many consumers prefer to have a best friend relationship with their

Alma Krekus was born in England and moved to Cleveland from London in 1967 with her American husband and 3 month-old son. A year later she injured her spinal cord in a freak accident which left her a paraplegic. She has worked with Services for Independent Living, Inc., 25100 Euclid Avenue, Suite 105, Cleveland, OH 44117-2663 USA (216/731-1529), since 1982, first as a peer counselor, then as a member of the Board of Trustees and, since 1986, as the attendant care coordinator. Alma recognizes that in her job she deals with only the problems of PAS and knows that her comments are some what negative.

attendant rather than a working relationship. In this situation, it is the consumer's responsibility to make sure that everything needed to be done has been done.

The number of people needing PAS is increasing daily and good reliable attendants are extremely hard to find. Now is time for everyone to become an advocate to bring about a national PAS program. The elections are over, and legislators must be reminded of our needs and their promises to us. ■

*The PCA Program is a state-funded program administered by the Ohio Rehabilitation Services Commission (ORSC). The Program pays \$4.75 per hour up to 35 hours a week and is consumer controlled. For more details call Heidi Radde, PCA Program Specialist at ORSC, 614/438-1270 or me at 216/731-1529.

Addressing the Unmet Needs of Kansas Citizens with Disabilities

BY JENNY A. REED

Personal Care Assistant Network is a program of the Coalition for Independence, a not-for-profit organization that works to meet the unmet needs of persons with disabilities who live in the greater Kansas City area. The Coalition functions within seven counties on both sides of the Missouri-Kansas state line and works with any person, any age, with an disability. It is a consumer-based organization and seeks to assist a consumer in preserving the level of independence that they choose. As of October, 1992, it has assisted over 175 persons in their search for reliable, affordable home-based personal assistive services.

The Personal Care Assistant Network assists people with disabilities as well as elderly persons in securing appropriate, affordable personal care. The system allows each consumer to maintain control over hiring, training, scheduling, and firing.

How did the network begin?

The idea for this community service resulted from meetings held in July, 1988. A group of people committed to enhancing the lives and expanding options for persons with disabilities met to answer the question, "What is the major unmet need of the disabled community?"

The conclusive answer: the lack of personal care assistants (PCAs) available for long or short term use by the growing number of persons

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with disabilities choosing an independent lifestyle.

The PCA Network was born, becoming operational that December. Coalition For Independence then took form because a new organization was needed to tie all the agencies serving people with disabilities together.

How do people use the PCA Network?

Consumers are provided the names and information about personal care assistants who are able to meet their expressed needs. The PCAs are then interviewed by the potential user and hired with an agreement that certain services will be provided at specified times and days at a mutually agreed upon cost per hour.

PCA services are available on a regular basis, or a one time only basis, or as respite care to relieve a family caregiver. The Coalition does not charge the consumer for providing the information about the PCAs.

What kind of care?

The Network has a bank of PCAs who are able to assist a consumer with daily living activities from bathing, dressing, grooming, personal hygiene, transferring to and from a wheelchair, eating to house-keeping, meal preparation and laundry. PCAs set their own hourly charges. Many PCAs are Certified Nurse Aids (CNAs).

What does the PCA Network do?

The Services coordinator screens applicants, assists in training or interviewing, if necessary, and monitors the relationships to maximize their quality and effectiveness.

Contact is maintained with both parties throughout the length of the relationship to assess the success, mediate if necessary, and help in any way possible. We do not duplicate the services offered by any other social service agency.

Who uses PCA Network?

A mother, forced to give up her \$24,000 job to care for her daughter now quadriplegic from a car accident, asked for help to return to work.

A 93-year-old person who is blind wanted occasional assistance with cooking and cleaning.

Wife needed care for husband with Parkinson's disease while she worked.

Husband needed woman to care for wife who has Alzheimer's disease.

Man with MS sought aid to attend daughter's wedding.

Young man, quadriplegic from a gunshot injury, needed aide to maintain his daily routine.

Who can participate?

Individuals living in Cass, Jackson, Platte, Clay (Missouri), or Johnson, Leavenworth, and Wyandotte County in Kansas are eligible.

Does the program have a weakness?

One weakness is the fact that most of our consumers pay this expense out-of-pocket. Even though our care services are inexpensive by "nursing service" standards, \$6.50 to \$8.50 per hour, it is still unaffordable for many who need personal assistant services. We are recognized as care providers for the Kansas home-based care services, and provide care through the Missouri Bureau of AIDS Prevention. However, we are not as yet, Medicare/Medicaid providers.

What are the strengths of the program?

PCA Network was the idea and dream of Paul Levy. His vision of this one-of-a-kind, affordable, consumer based program is its major strength. An additional asset is the personal care assistants themselves who meet monthly to hear speakers from various organizations, like the Parkinson's Disease Foundation, to discuss issues such as advanced directives, and to just socialize.

For more information about Coalition for Independence and the PCA Network contact:

Paul H. Levy, 9805 Pennsylvania, Kansas City, MO 64114 (816/942-1100) or Jenny A. Reed, 106 East 31 Terrace, Kansas City, MO 64111 (816/753-0999). ■

The discussion of Personal Assistance Services (PAS) will continue in the June issue. World Institute on Disability states, "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." Simi Litvak and Judy Heumann from WID will contribute *Where Do We Go From Here, and How Do We Get There?* Articles will include opinions and thoughts from individuals raising families, those who are blind, those with developmental disabilities, and those who are deaf. Individuals or

groups wishing to contribute their point of view to the discussion of PAS should contact Joan Headley at 314/534-0475.

Additional copies of this issue of the *Rehabilitation Gazette*, Vol. 33, No. 1, are available for \$6 postpaid. Contact G.I.N.I. for bulk rates. To also receive the upcoming June, 1993 issue (Vol. 33, No. 2) send \$12, the normal subscription rate.

A Civil Rights or Inter-dependence Perspective on Attendant Services

BY BOB KAFKA

The evolution of the disability rights/independent living movement can be characterized in many different ways depending on, who you are, and how you interpret the original philosophical foundation that began the movement.

The rhetoric surrounding the independent living movement would lead you to believe that it has developed as other civil rights movements. However, just the opposite seems to be true. The concept of independence has been interpreted by most in the independent living movement with a conservative, not a civil rights, perspective. They have taken this concept of independence to mean that people with disabilities have to do everything themselves. This is somewhat analogous to vocational rehabilitation concepts where disabled people will be trained to be independent, get jobs, and live happily ever after. An integral corollary of this perspective is that government programs have an inherent paternalistic, dependency fostering component that we must, at all costs, stay away from. The welfare analogy is frequently used pejoratively as a righteous argument for why we must stay away from government programs.

This view of independence runs into major problems when you recognize the reality of disabled people's lives. Support services are a necessary part of our lives: the attendant to get us out of bed or help us manage our checkbook;

the interpreter who makes communication with deaf people possible; the mobility instructor who assists the blind person to access his/her environment.

Philosophical concepts have had little effect on the support service *needs* of disabled people. Training does not provide these support services and it certainly does not provide the means to pay for them. Employment as a means to pay for support services is an admirable goal, but with an almost 70% unemployment rate for people with disabilities, there needs to be some other funding sources available to pay for essential support services while disabled people are being trained and/or competing for jobs.

An alternate view of independence is the "civil rights or interdependence" perspective, as represented by the American Disabled for Attendant Programs Today — ADAPT.

ADAPT is not a traditional organization. It has no president, board of directors, or executive director. It is a national network of committed disability activists who are committed to one issue — the development of a national attendant services policy in this country.

ADAPT began in 1982, growing out of a Denver-based home health agency called The Atlantis Community. The Atlantis Community began in 1975 to provide attendant service to young disabled people who had sued the nursing home industry for their right to community-based attendant services. Atlantis now receives both Title XIX (Medicaid) and Title VII (independent living) funding.

ADAPT originally worked on the issue of accessible public transportation. ADAPT then stood for American Disabled for Accessible Public Transit. Its strategy of using non-violent civil disobedience as an ongoing tactic to bring about a national mandate for lifts on every public transit vehicle was unique in the disability rights movement.

ADAPT also is unique in using basic, community organizing techniques to organize people with disabilities. Using Saul Alinsky organizing methods to bring about change was common in the poverty and civil rights communities, but it had not been a commonly used strategy by disability rights advocates until ADAPT appeared on the scene.

The passage of the Americans with Disabilities Act, which included all of ADAPT's accessible public transportation demands, vindicated the strategies and tactics of the group.

ADAPT, utilizing a similar strategy, has now moved on to the issue of the 90's — attendant services.

ADAPT's position focuses in on the nursing home portion of the Medicaid funding stream and the American Health Care Association, the nursing home lobby group that influences that funding. Currently, about \$60 billion are spent in the USA on nursing homes every year. \$30 billion comes out of the pockets of the general public, and about \$30 billion is funded by Medicaid.

ADAPT's position is simple. ADAPT asks for no new funding for attendant services. ADAPT wants 25% of the current Medicaid funding for nursing homes, approximately \$7.5 billion, redirected to fund a national attendant services program.

This national attendant services program should be dependable and available in the location of our choice, based on the functional needs of the individual regardless of age and available 24 hours a day, seven days a week, with provisions for backup and emergency services. ADAPT's position also calls for maximum control of the service by the person with a disability and should have a cost sharing component.

For many of the ADAPT activists, the move to the issue of attendant services is an opportunity to change a system that has

Continued on page 14

treated them badly. This system incarcerated them in Medicaid-funded nursing homes and in state institutions because community-based attendant services were not available because of lack of funds. Emotion and anger can be felt whenever ADAPT activists get together on this issue.

Another aspect of the ADAPT strategy has been the focus on Secretary of Health and Human Services, Louis Sullivan. Sullivan is the current symbol of the government's position on attendant services. Every state is mandated to have a nursing home program. However, there is no such mandate for attendant services. ADAPT has challenged Secretary Sullivan and will challenge the newly appointed HHS Secretary, Donna Shalala, to take a position for a national attendant services program.

The ADAPT strategy is to make the delivery of attendant services a civil rights issue. It is to build a

grassroots network in each state that will take action and put pressure on the state health care associations and will send a clear message to state legislators and bureaucrats that disabled people will settle for nothing less than a fully-funded and consumer-controlled attendant services program.

How does the ADAPT strategy fit into the disability community's growing cross-disability call for personal assistance services? One can only surmise. ADAPT's style of using non-violent civil disobedience as a tactic, which frequently ends up with disabled people going to jail, has still not gained wide acceptance in the traditional disability rights community (though it is growing). There is the same ambivalence towards ADAPT now, as there was when ADAPT was fighting for accessible public transit.

ADAPT is used to going it alone and will keep focused on the issue

rather than the internal politics of the disability community. As the pressure builds toward a national policy for attendant services, ADAPT will be an active participant.

"Free Our People," the ADAPT slogan, is gaining wider and wider acceptance by the people who use attendants. People with disabilities are getting angry. They know that without the energy of ADAPT, thousands of disabled people who need community-based attendant services will be needlessly incarcerated in nursing homes and other similar institutions. We ask them to join us in this civil rights struggle for an institution-free America.

For more information contact:
ADAPT, 12 Broadway,
Denver, CO 80203 USA
(303/733-9324, FAX 303/733-6211)

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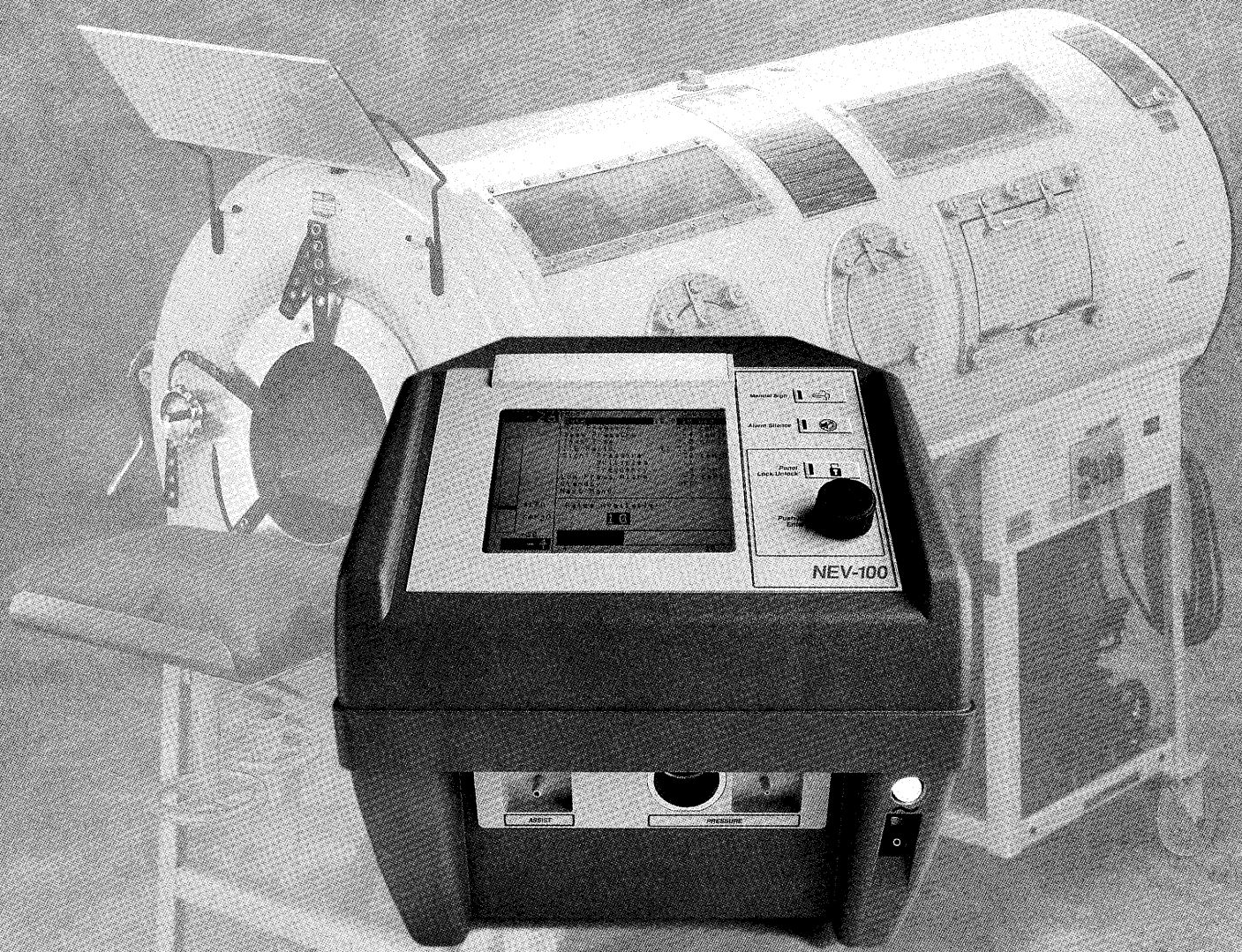
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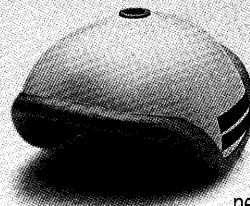


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The new, updated 4th edition of *The Self-Help Source Book: Finding and Forming Mutual Aid Self-Help Groups* (ISBN: 0-9634322-0-6, paperback, 224 pages), is a valuable resource for all networkers. In addition to listing contacts and descriptions for over 700 national self-help groups, it offers suggestions on how to find, create, and operate a group. International Polio Network's self-help philosophy is featured on page 191. Order from: American Self-Help Clearinghouse, Attn: Source Book, St. Claires-Riverside Medical Center, Denville, NJ 07834. US, Canada and Mexico \$10 first class postage; \$9 book rate postage; \$14 overseas air-mail; \$10 overseas surface.

Directory of Independent Living Programs, 1993, is available from ILRU, 2323 S. Shepherd, Suite 1000, Houston, TX 77019 (713/520-0232, — 5136 TDD). Printed edition costs \$10; on computer disk \$10; on mailing labels \$15.

International Polio Network's Post-Polio Directory — 1993 will be available March 1st. Please send any additions to G.I.N.I. immediately. To order send \$3 (consumers) or \$6

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Other G.I.N.I. publications include: the quarterly *Polio Network News*, available for \$12 (consumers) or \$20 (others); the bi-annual *I.V.U.N. News* for \$8 (consumers) or \$20 (others); *Directory of Sources for Ventilation Face Masks* for \$2.50; *Ventilators and Muscular Dystrophy* for \$6. For international rates, contact G.I.N.I.

Phantom of the Night, by T. Scott Johnson, M.D. and Jerry Halberstadt, offers information on recognizing and understanding sleep apnea syndrome (SAS) including a detailed overview of normal sleep and breathing, how sleep is tested, and current treatment. For more information contact: New Technology Publishing, Inc., POB 9183, c/o Mail Boxes, Etc., 955 Massachusetts Ave., Cambridge, MA 02139. \$20 plus \$4 S&H.

Just like everyone else, a collaborative effort on the part of many World Institute on Disability staff, is a 16-page oversize format publication intended to provide perspective and information about the independent living movement and the Americans with Disabilities Act. The booklet provides facts and statistics and explores where we are today, where we've been, and how things have changed. To order, send \$5.00 to World Institute on Disability, 510 16th Street, Suite 100, Oakland, CA 94612.

Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness (ISBN 0-393-03408-9) by psychologists Paul J. Donaghue, PhD and Mary E. Siegel, PhD, describes

what people with invisible chronic illnesses face and offers them the means to cope. Published by W. W. Norton & Co., \$22.95 USA; \$27.99 Canada.

When The Worst That Can Happen Already Has: Conquering Life's Most Difficult Times (ISBN 1-56289-985-8) by Dennis Wholey, combines personal stories with practical advice and messages of hope. Published by Hyperion, \$19.95 USA; \$24.95 Canada. ■

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