

Independent Living Newsletter



Dear Reader,

looking for funding for our printing and mailing costs is time-consuming and has delayed this issue. We have high hopes that a major part of our funding needs will soon be covered.

Our mailing list is growing rapidly as readers pass around their copies and as requests for free subscriptions flow in. Make use of this increasing circulation; the Newsletter is your tool for sending and receiving information. The combined experience of our readership represents an immense databank on solutions to problems which persons with extensive disabilities experience.

Among the themes that we can take up in the next issues is personal assistance, that is help with the daily routines of living, such as getting up in the morning, doing household chores, getting around town or assistance at your work. I am looking for articles, notes, personal accounts and references to resources. Describe your situation and how you have solved your needs. Do not only send us sunshine stories; other persons' success stories can be encouraging but will be more useful, if they also contain realistic accounts of the trials and errors you have gone through and what still needs

to be done. Perhaps you and friends with similar needs have joined forces and work together for improvements. Your group might want to share experiences with others who are interested in the same work.

When you write us, please, indicate whether you have a disability. Your readers need to know from what personal perspective you speak. Enclose pictures of yourself, your organization and your work. I hope to hear from you!

Adolf Ratzka, editor

Interpretations

I would like to continue the discussion on Independent Living initiated by Jahved Hassan and Phillip Mason in previous issues of the Newsletter. I am a lawyer with cerebral palsy. I cannot walk, I use a wheelchair, generally propelling myself with my feet. I cannot write with a pen, but use an electric typewriter and two fingers.

My personal definition of Independent Living has varied over the years and will doubtlessly alter again as time passes. When I first left home to pursue studies and career in the city, I was fiercely independent and aspired to live in every way like my peers at work. I engaged a personal assistant whose job it was to do for me those things I was disabled from doing myself. I lived completely on my own for thirteen years.

The ravages of loneliness and inflation then compelled me to live with a family of friends. I had also come to realize that the quest for absolute independence is a Quixotic one. Firstly, no disabled person can be as independent as his non-disabled brother. It is a contradiction in terms. If he was, he would not be disabled. Secondly, it is doubtful whether any human being - disabled or not - can ever be truly independent.

If pressed, I think my present defini-

tion would be the mode of life which brings the greatest satisfaction in one's circumstances. This may not go far towards physical independence, but the peace of mind does much for independence of thought, which to my mind is of far greater importance. In order to minimize the negative feelings engendered by dependency, I suggest that disabled people should aim at living lives designed to create such respect among those with whom they come into contact that help will be willingly provided.

I endeavour to follow my own precepts and insofar as I do, my lifestyle is an example of independent living. Of course the goals are set high so I frequently fall short, in my own estimation, of generating sufficient respect. But people do respond to thoughtful treatment and with the help of many friends I gain enormous satisfaction from life.

I am not a militant, though I recognize that militancy has virtue in certain situations. I am an evolutionary rather than a revolutionary, though I recognize that there are times when evolution requires a judicious jolt to get us anywhere. In my experience more lasting solutions are built on understanding rather than abrasiveness. I believe strongly that equality with the non-disabled is a basic human right for the disabled, and I believe that such a right is

worth fighting for, where fighting is necessary and appropriate. But I do not believe that it is necessary and appropriate for people who are disabled to always be belligerent and forward, to be forever asserting him or herself against those who say no, to continually gnaw at the hand that feeds us. Loud and vexatious people seldom enjoy respect. Treat those who offer help with sincere gratitude even if you suspect their motives for helping may not be sincere. By all means, strive to make the most of life, but do not allow ambitions to be like a normal person become an obsession. To aspire to be considered equal to another person is a different thing from wanting to be a carbon copy. Accept what you are with dignity.

Mike Watson, 18 Tunsgate, Mount Pleasant, Harare, Zimbabwe.

Not all will agree with Mike's precepts, in particular, their practical implications for securing every-day personal assistance. What ways are there to get personal assistance other than creating respect in those around you? How can we keep our self-respect without funds to pay our workers? I hope other personal assistance users will respond.

Anti-discrimination

Europe-wide protests against discrimination

On May 5, 1992 disabled people from 17 European countries launched the first "Europe-Wide Protest Day for Equal Rights and against Discrimination" initiated by Disabled Peoples' International (European Region) and the European Network on Independent Living, ENIL. Many other organizations joined in a common effort to turn Europe Day 1992 into a strong disability rights day by means of demonstrations, blockades of inaccessible buildings and transportation systems, panel discussions with politicians, presentations about our demands, information booths and public relations campaigns in more than 100 cities throughout Europe.

Next year's activities are planned in the form of a Europe-wide Disability Awareness Week for Equal Rights and Against Discrimination of Disabled People May 3-9, 1993 with a common protest day on Europe Day May 5, 1993.

Coordinators: DPI-ECC and ENIL, att: Ottmar Miles-Paul & Uwe Frehse, Kurt-Schuhmacher-Str. 2, 3500 Kassel, Germany.

Discrimination watch cases in South Africa

Disabled people are not yet exploiting the legal services we render to the full under this program, partly because most of them are either institutionalized and are thus isolated from the outside world. I spent 12 years at a school for the blind and we were not even allowed to listen to the news on the radio, let alone news from the print media. People in the rural areas lack facilities of communication and it is difficult in that area as well to reach out to people.

Our unit has taken on the case of a Black school teacher who became a paraplegic after an accident and was retired from his duty by the government of Ciskei (one of the bantustans). The reason given was a legal provision that no seriously and chronically sick person can work for the Board. Our argument has been that this provision does not apply in this case. While the teacher is disabled, he is not sick. After his rehabilitation he enjoys good health compensating the loss of the use of his legs by using a wheelchair. After many months the government has now offered to our

advocate to settle out of court by taking him back to his former employment, subject to a medical examination, to assess whether he is still fit to continue working.

At the same time, the government has refused to recompense our client for the period that he was unemployed, starting from the time when he made himself available to assume duty. Therefore, we intend to proceed in court. If we win, our client might succeed in claiming an amount of approximately R15 000.

In a similar matter, involving the South African Department of Home Affairs, our client who uses a wheelchair as well, was instructed by the Director-General of that department, as his employer, to undergo medical examination to determine whether he is still fit to work. I intervened in the matter and insisted that a reason for the instruction be given. The department has not responded to me since.

We hope to soon bring a Supreme Court application for the declaration of the rights of a disabled client who successfully claimed an amount of R25 000 as a result of a car accident in 1975. This money was placed under a curator; at that time he was merely a child of 9 years. This money has now accumulated to R66 000 and our client has never enjoyed any benefits from it. We hope that the application will place him in direct control of all these, his moneys; he has had to suffer serious financial hardships despite the fact that he owns these moneys, simply because he was called a patient and therefore was placed under the care of a trustee.

Michael Masutha, Lawyers for Human Rights, Disability Rights Unit, PO Box 5156, Johannesburg 2000, Rep South Africa.

Impressions from Vancouver

One of the strongest lessons learned from other countries at Independence 92 that actually serves as a reminder to us in welfare countries was the importance of persons with disabilities (PWDs) to be organized, politically strong, and visible. The Social Change Strategies session, consisting of eight speakers in an international panel, repeatedly emphasized this point. Says Joshua Malinga of Zimbabwe, and the

Chairman of Disabled People International, "PWD organizations must have two arms -- political and noisy." Vilja Kuzmin of Estonia adds, "There are two levels of liberation: political and economical. We must work at the grassroots level. Changes are made there, not by politicians."

Malinga reminds us, "Throughout the world, disabled people face pitiful lives, street begging and complete rejection by all levels of society. Now, what is needed is action. We need legislation to protect and promote our interests."

The panel made it clear that PWDs still lack access to basic community services like education, housing, and transportation. Many PWDs are simply warehoused in institutions. Juan Enrique Morales of Chile tells us, "Institutions are mostly supported by charities from other countries. PWDs need to fight this."

Because Independence 92 marks the closure of the United Nations Decade of the Disabled (1982-1992), feelings were expressed that this event should be the catalyst to begin the process of change. As Malinga concluded, "Our meeting today is historic and we need to make historic decisions which will impact on the 500 million disabled people of the world. Our struggle has only begun, but in the words of Winston Churchill, 'We must never surrender, never, never, never'."

Karen G. Stone, Box 10655, Albuquerque, NM 87114, USA.



Handicapism = Colonialism

Here's the final installment of Hale Zukas' account of the origins of the Center for Independent Living Berkeley. He wrote the article in 1975. Since then the CIL and the whole movement has grown and changed.

CIL History cont'd

Over the years, the Cowell residents had evolved what might be called a philosophy of disability out of their collective experience. In the proposal for the PDSP, the guiding principles of this philosophy were clearly articulated for perhaps the first time. They were the following:

1. Those who know best the needs of disabled people and how to meet those needs are the disabled people themselves.
2. The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services.
3. Disabled people should be integrated fully into their community.

Most of those activities in the development of the PDSP were spinal cord injured people and they were naturally primarily concerned with the services that would meet their own needs. But there was also an awareness on the part of some of those involved that broadening the program to serve people with a wide range of disabilities, including the blind, could be beneficial to all concerned. In addition, it was hoped that establishing a working relationship between disability groups which had traditionally little to do with one another would lead to a coalition which could exert increased influence in the political arena. It was consequently decided that there would be blind representation on the PDSP staff.

Funded in July 1970, the PDSP began full operation two months later with a full- and part-time staff of nine, of whom five, including the director, had extensive disabilities or was blind. During its first year, the PDSP provided a clear demonstration of the validity of the premises on which it had been founded. Disabled students began moving from Cowell out in the community; the drop-out rate was almost nil compared to that among students at other institutions of higher learning; and there was a sharp reduction in medical problems. The effectiveness of different disability groups working together was also shown. Not only did the extent to which their problems and needs coincided become apparent, but

services originally tailored to the needs of orthopedically disabled were adapted to the needs of the blind. For example, the attendant referral service was expanded to also provide readers for the blind.

That the PDSP was providing needed services unavailable anywhere else was indicated by the steadily growing number of requests of assistance it received. At first, these requests came from students, but as word of its unique services spread through the surrounding community, more and more disabled non-students began to call upon the PDSP for help. The PDSP rarely, if ever, turned people away on the grounds that they were non-students. By the Spring of 1971, the time devoted to community people had begun to seriously affect the PDSP's ability to meet the needs of the students whom it was established to serve. Out of this dilemma arose the idea of establishing another program parallel to the PDSP to serve disabled and blind people in the surrounding community. Thus the seeds of the Center for Independent Living were planted.

At the instigation of the PDSP administration, a group of interested disabled people, including both students and non-students, met in May 1971 to begin discussing how to put together a community-based services program. Over the next year, this group put in many hours of hard work toward this end.

From the beginning there was a firm commitment not only to the three principles outlined above, but also to the principle that CIL would be an organization of and for all disability groups, more specifically, a coalition of the orthopedically disabled and the blind. These two groups had traditionally gone their separate ways, and in this pioneering attempt to work together, it was only to be expected that strains would occasionally develop in their relationship. By its very nature, a coalition is a gathering of groups with different interests which come together to pursue some larger objective. Making any true coalition work thus requires a conscious effort. Those involved in organizing the CIL made this effort; the resultant benefits accruing to

both the disabled and the blind have shown that it was eminently worthwhile.

For example, wheelchair curb ramps in Berkeley have been placed so the blind will continue to have the detectable curbs they need in order to know when they are about to cross a street.

It was after the idea of coalition between the disabled and the blind spread beyond CIL to groups active in the political arena, however, that it produced its biggest dividends. For the first time the disabled came to be recognized as a force to be reckoned with in the California legislature. Their efforts were in no small part responsible for the fact that SSI benefit levels in California are just about the highest in the country.

The groundwork laid by the PDSP was of inestimable value in defining the general approach and methodology the CIL would follow. The task entailed in establishing the CIL, however, differed in several important respects from that which faced the founders of the PDSP. For one thing, the populations to be served by the two programs were quite different. The disabled students at the University were a relatively small and homogeneous group, residing for the most part within a limited geographical area, and readily identifiable. The target population envisioned for the CIL, on the other hand, was considerably larger and very heterogeneous, spread over a comparatively large area, and in large part very hard to identify, let alone reach. Those involved in the development of CIL were well aware that they were not representative of the disabled community at large. They were thus very conscious of the need for community input into the design of services and, once those services were in operation, in their evaluation.

Secondly, obtaining funding for the CIL was more difficult than for the PDSP; other than the in-kind support provided by the PDSP, its only resources during this period were occasional contributions from some of those active in the organization, proceeds from a few benefit poker games, and a \$250 donation from the local Rotary Club.

In July 1972, three months after its incorporation, the CIL received a one-year \$50,000 grant from the federal Rehabilitation Services Administration to enable it to get on its feet organizationally and to do a systematic job of research and planning for a comprehensive community-based services program for the disabled and blind. During most of the grant period, the major emphasis of the CIL was on developing a proposal for such a program costing in its various forms from \$240,000 to \$400,000 per year. As the expiration of the grant drew near and prospects of new funding continued to prove fruitless, the CIL staff lowered its sights considerably, and the prime objective became not expansion but simple survival. In the last week of June 1973, the CIL was informed that a renewal of the planning grant, its last hope, would not be forthcoming. At this point the CIL was in serious danger of

going under. In an attempt to avert this eventuality, a few CIL staff members met with the University Vice-Chancellor to ask for his help. As a result, \$15,000 was made available through the University's Community Projects Office to keep the CIL afloat for another four months. In August the City of Berkeley allocated \$15,000 to the CIL to cover a year's overhead costs.

While it would have been desirable to obtain funding for the CIL in one comprehensive package, experience had thus shown that the only feasible strategy was to fund CIL on a piecemeal basis through an accumulation of relatively small grants. The CIL has continued to pursue such a funding strategy in the intervening period with considerable success, and several new programs have been established as funding has become available. The multiplicity of funding sources and

the accompanying rapid expansion makes it difficult to chart, except in very general terms, the direction CIL should take in its future development. One thing has not changed, however: the CIL's overall objective is still eminently well described by its name.

Hale Zukas, World Institute on Disability, 510 -16th Street, Oakland CA 94612, USA.



Income generation

Computers for training and work for people with and without disabilities

In 1981, representatives of our organization, the Association of Colombian Paraplegics, ASCOPAR, visited Japan Sun Industries in Beppu, Japan, where we saw some of the possibilities that technology offers to people with disabilities. Coming home we tried to adapt some of these ideas to Colombia which turned out to be not easy. While Colombia does have Law 82/88 which is based on the ILO agreement 159, there are no legal provisions in the form of "sticks and carrots" for enforcement. Another obstacle is the low level of formal education among our disabled population and the general assumption that modern technology is very expensive.

We started in 1986 with a feasibility study that identified a need for information about rehabilitation and disability issues. We also found among the disabled people who were interested in working for the project a high level of education in literature, graphic skills and foreign language capabilities. As a logical conclusion, we purchased two computers and started the production of educational material, our newsletter, *Ascopar-Servimos* and our journal, *Venciendo Barreras*.

The next step was the development of training activities not only in the use of computers but also in journalism, layout

and all other aspects of desktop publishing, printing and administration of such a commercial enterprise. In this we were able to get help from the National Training Services (SENA).

Most of our workers use wheelchairs and have severe transportation problems in the absence of accessible public transportation, since they have no cars. We also had problems learning how to use the computer equipment. For one, we found instruction manuals and dealer support to be insufficient. Also, some of our staff have limited use of their hands and can not use ordinary keyboards. With this we received help from the local university's Industrial Design department.

Today, thanks to the assistance of national sponsors and the Canadian Government, ASCOPAR owns the basic equipment for desktop publishing and printing. We now sell services and provide employment to members with extensive disabilities. Our members have not only received training and employment, our project has also instilled them with pride and self-confidence.

ASCOPAR, Apartado 89040, Santa Fe de Bogotá, DC 8, Colombia.

International Disability Development Organization

Major barriers faced by disabled persons are isolation, neglect, ignorance, poverty and unemployment. These barriers are of human making and as such can be thrown overboard. What is needed is international coordination of individual and organizational activities.

Disabled people in Nigeria have concluded that an international organization which will be known as International Disability Development Organization, IDDO, has to be founded. This organization when set up will enable individuals and disability organizations to have wider access to finance, information, trade and education. These are vital weapons in our struggle to remove our artificial barriers!

IDDO intends to operate a revolving loan program. The program will assist individual and organizational projects of disabled persons. It will reach applicants through organizations of and for disabled persons which are affiliated to IDDO. IDDO will also gather and distribute useful information as well as coordinate trade and education. We invite your comments and suggestions. We need experts in the field for our IDDO forming group.

Godian C. Amadi, IDDO, PO Box 3224, Qarki Abuja, Nigeria.

Personal account

"I am a woman with physical disability and with a very clear vision and consciousness. I belong to the special breed of Zimbabweans who are stopping at nothing but success." Ruth Tembachako

Education

I come from a family of six - four boys and two girls - and I am the third born. My family is a very loving joyful family. My parents did not send me to an institution. I was educated at so called "normal" schools. When I first went to Njerere Primary School in Mvuma, it was a great struggle for me to get into the school, because of my physical disability. The headmaster and teachers thought that I was not normal. I was finally accepted on a trial basis so they could assess my performance. It turned out that I was better than three quarters of the class, so they finally registered me at the end of the second term.

I went on to secondary school, but could not complete my education because the family had money problems. My father was a tailor, but he had to resign from his job because of ill health. I had nobody to turn to for help, until Father Staker, a Roman Catholic missionary, offered to sponsor me for a two-year course in domestic science at Driefontein Mission in 1976.

Job difficulties

I found it very difficult to get a job. So I did embroidery and crochet work to keep myself going. Sometimes I used to help my mother to sell fruit and clothing at Mvuma bus terminus. I really wanted to get a job so that I could lessen my mother's burden.

Employment at last

In September 1979 I was employed by Mushayavudzi Area Board as a pre-school supervisor. My salary was only \$10 a month, which was just a token really. My other two workmates gave up because they could not stand working for such a low salary. But I wanted to take bread home, so I did not give up. I believed that in order to reach Point C, I had first to start from Point A and move through Point B. I attended short courses aimed at community development whenever I could. I then started working with women's clubs and giving adult literacy lessons.

In 1983 I joined the Central Creche and Nursery School in Kwekwe where I worked as a nursery school teacher until 1986. I was determined to improve my education, so I joined evening classes at Amaveni Secondary School. That was a very tough time for me because I lost my father that year, and, out of my earnings, I had to help my brothers who were at secondary school, and also pay my own study fees.

When the nursery school changed hands and was taken over by a business woman I was forced to change my working hours from half day to full day. Other teachers who were White did not have to do this. It seemed like discrimination to me and I was not about to be treated like a doormat, so I quit.

I later joined Glen Forest Training Centre in August 1986 as a Skills Trainer, specializing in pre-school education. I managed to attend a workshop in Tanzania on Women in Development and Management Programs. I came back to Zimbabwe very inspired and immediately helped to incorporate Gender Issues into our training courses. This was a great achievement because it helped rural women to take on new things and participate in courses only done by men before, like carpentry, blacksmithing and building. My aim also was to initiate courses for men on Child Care, so they realize the importance of women's work in the home as well as in development.

The sky is the limit!

At the end of 1988 I got a scholarship from the National Council of Disabled Persons of Zimbabwe. What an opportunity for me! It was difficult to get a whole year study leave. Rather than lose the chance of a scholarship, I had to give up my job. I have recently graduated as a social worker.

I am an active member of the National Council of Disabled Persons of Zimbabwe Women's Group, where I am the national secretary. I believe that women with disabilities are double-discriminated against by the society we live in. Since Independence women have been given the same legal status as men, but disabled women have been left behind. We do not have sufficient access to education, employment, housing, transport, sports. In general, disabled, blind and deaf women are at the very bottom of the ladder, while our non-disabled sisters are already climbing up.

Research on problems faced by disabled women has been carried out quite a lot, but we are still ignored most of the time when it comes to policy making. I feel the Government should do something more positive about our problems. I also want to urge my disabled sisters not to isolate themselves. I feel it is high time we put

more energy into fighting for our rights as disabled women. Women's organisations should not leave us out, be it in clubs, co-operatives, church or political groups.

I am a member of the Women's Action Group executive committee, and I am determined to put disabled women on the

agenda. I believe that all women should fight for our liberation together. Disabled women have a role to play. Disability does not mean inability!

I became disabled when I was a baby of 9 months. This was caused by the disease TB of the bones, which affected my spine. I was in hospital for almost three years, moving from one hospital to another. When I finally went home to my family, I was so used to being in hospitals that I cried to leave the doctors and nurses because I thought that they were my parents!

I only managed to walk when I was four



years old. My parents were overjoyed and thought it was a miracle because they had lost hope that I would ever be able to walk or do home chores. They never dreamt that one day I would be employed and be able to lead my own life.

Disability is not a curse from God

My disability was only actually painful when I was very young. I don't even remember the pain now. These days I have normal health, just like anyone else. Often other people do not want to associate with a disabled person because they are embarrassed, or feel that if they touch them or hug them, they may hurt them. Others think that disability is a contagious disease, which of course, IT IS NOT! Many people think that disability is a sign of punishment from God, or a curse of some kind. All these wrong beliefs often lead to the exclusion of disabled people from ordinary social and cultural life. This is very sad and very oppressive for disabled women. All women's problems are the same, but

for disabled women they are doubled because they are discriminated against by both men and other women. Men often exploit us sexually: some are just curious and want to experiment without having any feelings of love. This can result in having a child by yourself, without any help from the father. When a disabled woman goes to the courts to try to claim maintenance, she is often harassed. Also disabled women do not know what steps to take to get their rights.

We don't want pity and charity

We are ordinary people just like everyone else, and of course we want to marry and have a loving partner and children. But in many cases disabled women meet with a lot of resistance from the in-laws. Especially the mothers who misguide their sons or threaten to commit suicide, if their sons marry a disabled woman. These are some of my own experiences. They are the same as most disabled women face, and most will agree with me that non-disabled people need to change

their attitudes towards disabled people.

Personally I don't want to be the object of pity or charity. I am proud of my disability, because it is not inability. I am a liberated woman since I joined the National Council of Disabled Persons of Zimbabwe in 1983.

Ruth Tembachako, N.C.D.P.Z., Box 3846, Harare, Zimbabwe.



Networking

One of the outcomes of the meeting of ENIL, the European Network on Independent Living, in Berlin, October, 7-10, 1992 is a list of criteria that must be met by all who use the term "Independent Living" in their work.

Definition of disability

A disability exists, if essential personal and social experiences are influenced by physical and mental limitations and their resulting discrimination.

Purpose of the criteria for work with Independent Living

1. To challenge the misleading applications of the English use of the term "Independent Living" and the native tongue translation of the term "Independent Living".

2. To provide a means of identifying organizations which are controlled by disabled people.

Criteria for use of the term "Independent Living"

Any organization, governmental or non-governmental including organizations for disabled persons, individuals and professionals who use the term "Independent Living" in their work have to comply with the following principles:

1. Solidarity

- a) To work actively for the development of full participation and equality for all persons with disabilities regardless of type or extent of disability, sex, age, residence, ethnic origin, sexuality or religion,
- b) to work so that people with disabilities can have the resources to live independently,
- c) to recognize Independent Living as a basic human right,
- d) to share or exchange information, advice, support and training in appropriate form, e.g. tape, braille, large print, free of charge for persons with disabilities or, where there is a charge, to ensure that people with disabilities have the resources to pay for these services,
- e) to cooperate with and support other organizations which belong to the international Independent Living network or who support the goals of the Independent Living movement.

2. Peer support

- a) to use peer support as the foremost educational tool for sharing information, experiences and insights in order to make people with disabilities conscious of the audio, visual and cultural, psychological, social, economic and political oppression and discrimination that they are exposed to,
- b) to make persons with disabilities aware of their possibilities to reach full participation and equality,
- c) to empower persons with disabilities by assisting them to acquire the skills to manage their social and physical environment with the goal of full participation and equality in their families and society.

3. De-institutionalization

- a) to oppose all types of institutions, stationary or mobile, especially designed for persons with disabilities. An institution is any public or private establishment, organization

or service which creates special segregated solutions for persons with disabilities in education, work, housing, transportation, personal assistance and all other areas of life, which by its nature limits disabled persons' possibilities to make their own decisions about their lives or reduces their opportunities to participate in society on equal terms.

- b) In particular, establishments, organizations or services may not use the term "Independent Living", if they promote or accept personal assistance services that require the user to live in special dwelling units or which deny or reduce the individual user's right to

full choice and control over his or her life by forcing the user to live by the routine of others.

4. Democracy and self-determination

Organizations may use the term "Independent Living" only, if all the following conditions are satisfied:

- a) if they are membership organizations based on democratic principles such as one person - one vote and
b) if full membership with voting rights is reserved for persons with disabilities only and

- c) if the organization as a practice favors disabled persons for positions within the organization for both paid staff and volunteers including the head of staff and
d) if the organization as a rule is represented in negotiations, meetings and the media by disabled persons.

Organizations who do not comply with these conditions but want to use the term "Independent Living" in their work have two years to comply with these conditions.

Resources

Are you planning to participate in the next Europe-wide protest day? Here's some advice on how to organize for such an action. The Disability Rights Education and Defense Fund prepared a manual on such issues as fundraising, putting on an event, writing a press release, setting up a press conference, letters to the editor, community organizing, creating coalitions and educating the community. Here are excerpts from the section on television.

Television news people would rather cover a fire than a press conference. Have you ever noticed how much of the six o'clock news is devoted to fires, explosions, oil spills and other natural and human-created catastrophes? All of these events have one thing in common: they are visually interesting. When you are planning an event and intending to invite the television cameras, ask yourself if the event will be exciting to look at, not simply to hear or read about.

Making it visual. If you are organizing a public hearing on the Justice Department's proposed guideline changes you might do the following:

- Organize it like a court room with judges, witnesses, questioners, lawyers. Television loves courtroom dramas.
- Think about selecting a provocative place for your hearing, possibly as near the Department of Justice as you can get.
- Have the "jury" in the hearing arrive together for dramatic impact, and announce each member separately with some lively bit of biography.
- If you have invited some key public officials to attend, and they have failed to show up, have a prominent empty chair with the person's name on it. Consider putting a stuffed mannequin in the chair, dressed as a clown.
- How should people be dressed?

Depending on what you have to say and your sense of humour, dress will vary,

but do not be drab. Do not wear white shirts for television cameras.

- Have your event come to a dramatic conclusion, let a "verdict" be passed and have interesting-looking people announce both the verdict and what will result from it. Let the TV people know in advance when the "verdict" will be announced. Bringing television to your event. The press release, the follow-up phone call, the Daybook should all be employed. Your media committee should cultivate relationships with television journalists, editors, public service time editors and station managers. Do not neglect other language television and radio, or the overseas media. The television press release should put a special emphasis on describing activities in an evocative and exciting way. Suggest that your event will present opportunities for lively television footage. Remember, you are competing with fires.

Preserving Disability Civil Rights: A Step-By-Step Guide to Taking Action, Disability Rights Education and Defense Fund, Inc, 2212 Sixth Street, Berkeley, CA 94710, USA.

Self-help manuals in Spanish

CEPRI's manual *Self-Care After Spinal Cord Injury* is now available. It is the only

manual of its kind available in Spanish. It costs U.S. \$10.00, plus \$2.00 additional postage. U.S and Canadian checks and money orders can be made out to CEPRI, and sent to CEPRI, NICA BOX 243, PO Box 52-7444, Miami, Florida 33152, USA. Our other manual *Sexuality After a Spinal Cord Injury* is available for the same price.

CEPRI, Apdo 5765, Managua, Nicaragua.

Accounts from personal assistance users needed

Those of us who have extensive disabilities need help in their daily lives for things which other people can do by themselves, such as getting dressed, go to the toilet or cook meals. The next issue will focus on personal assistance. We need articles and letters from readers in both developed and developing countries. We invite readers to describe their needs and how they are met. What are your alternatives to your family for personal assistance?

Disability leaders from developing countries - most often men with little need for personal assistance - when asked about personal assistance in their countries give the impression that personal assistance is not an issue in their countries. There, according to these leaders, the extended family serves as assistance provider or one can hire a domestic worker because wages are so low. Is this really true? I would like to hear from grassroots people, from women who need personal assistance, from people who have no family around them, from those who cannot afford to pay helpers.

The editor

Networking

Dear Editor,

I was very happy to receive the Independent Living Newsletter and found it most interesting. Even more, for me it was the first time to learn something about disabled people from other countries. I am a 26 year old Estonian. My hands are weak and I can write only with difficulty.

When I studied at the University my mother drove me to the lectures. Three years ago I graduated and work giving mathematics lessons at home to students.

The period that separates my nation from the time of darkness has been very short. The brutal communist invasion of Russia oppressed our country for 51 years and now when we have regained our independence there is still post-socialistic chaos everywhere. Around us we can see social misery, cold and hunger (due to the lack of fuel and food) - something which could be called a shabby life. But even greater is the crisis that we see in the sphere of spirit, of ethics and of humanity

The late bureaucratic regime of the soviets had a careless attitude towards people with disabilities. This attitude is changing only very slowly, since many ex-communists are in positions of power - even in our disability organizations. I want to contact people from other countries.

Jaak Võsa, Vilde Tee 70-3, Tallinn, Estonia.

Dear Editor,

Italy is a disabled country and I will fight to make it less disabled. Independent Living is an important discovery, but it was like I was waiting for it. Our most important cultural problem is to become visible, because non-disabled people do not know any disabled people. The most important tool for living in Italy is the mother, for me too! The other first barrier against Independent Living is the father, maybe because men have built the present kind of society. Independent Living comes to

change that way of life. Our achievement is useful to human growth, our issues are not new but this way to think and to see them is new.

I am interested in learning how other people solve their practical problems such as personal assistance. My first need is to get organized. I am 29 years old man with muscular dystrophy and a member of the ENIL, European Network on Independent Living, group in Florence.

Giorgio Casu, Viale Ariosto 687, 50019 Sesto Fiorentino, Italy

Dear Editor,

I read your publication recently and was very glad. My name is Asghar Shirzady. I fell ill in 1967 with polio. I am studying mechanics at the university. Not only can my disability not stop me, but also, I took the decision to continue my education seriously. I am 27 years old and have learned the use of machine tools and to repair electric appliances. I succeeded to pass the exams. I am very interested in being one of your members. Please send me more information about your organization's activity. I am looking forward to your answer very soon.

A. Shirzady, No. 1 Bist Metry Shobiry, 16 Amiry, 13518 Tehran, Iran.

League for Rights of Wheelchair Users in Czechoslovakia

The League for Rights of Wheelchair Users in Czechoslovakia founded after the democratic changes in Czechoslovakia in 1989 works for rehabilitation and independent living of wheelchair users and against discrimination. The League consists of the Czech Chapter in Prague and the

Slovak Chapter in Bratislava. Local organizations of wheelchair users send representatives to the Assembly which elects the Executive of each chapter.

The League informs its members through its magazine and its counselling office, arranges seminars and courses, and carries out other projects. Both individuals and groups can be members. The League's activities are financed by grants, sponsors and voluntary contributions.

Our League cooperates with international and foreign organizations. Due to our financial constraints we depend on invitations and travel grants from the hosts when participating in foreign events.

Dr. Alois Wokoun, League of Rights of Wheelchair Users, Chabarovická 1333, 182 00 Prague 8, Czechoslovakia.

Calendar

Seminar on personal assistance in Central Europe, Budapest, April 1993. The organizers are ENIL and Independent Living Hungary. Contact: Gabor Zalabai, Ady Endre ut. 65, 1221 Budapest, Hungary.

Seminar on user cooperatives in the provision of personal assistance planned for May 1993 in Stockholm. The organizers are ENIL and STIL, Stockholm Cooperative for Independent Living. The Seminar is intended for representatives of existing user cooperatives and for groups that are about to start user cooperatives as an application of the Independent Living philosophy. We will share experiences on such topics as membership development, financial control, organizational issues, staffing requirements, negotiating with public funders, peer support for personal assistance users. Working language English. Contact Adolf Ratzka at address below.



The Independent Living Newsletter is published twice a year by the Stockholm Cooperative for Independent Living, STIL, for the DPI Independent Living Committee and the European Network on Independent Living, ENIL.

Disabled Peoples' International is a cross-disability coalition of organizations of disabled people. The DPI network has over 90 national affiliates of which the majority are in the developing world. The philosophy of DPI is that disabled persons are citizens with equal rights, and hence should achieve full participation and equality with their fellow citizens in all societies.

This issue has been sponsored by STIL, the Stockholm Cooperative for Independent Living, Sweden and the World Institute on Disability, Oakland, California, USA.

All material in the Newsletter may be reprinted without previous permission provided full credit is given to the Newsletter including its complete address. We invite individuals and organizations who are interested in the Independent Living philosophy and approach to send articles, letters, suggestions and comments to Adolf Ratzka, Editor, Norrbackagatan 41, 113 41 Stockholm, Sweden, Fax 46-8-32 93 24.