Resource Kit for Independent Living

TOOLS FOR POWER

Disabled Peoples' International
Independent Living Committee
April 1992

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Editor's preface

The "Resource Kit for Independent Living 1992" is a first attempt. Its purpose is to illustrate some of the possibilities such a kit can offer and to show the direction in which it can develop.

The resources presented here represent a very limited and biased sample of all the materials that exist. Limited, because we had very little time and money in the production; biased, because we are not aware of all groups/organizations, and finally, only a small percentage of those asked to respond supplied us with information.

The Independent Living Movement and its ideology exist in many more countries than are represented here. For this issue we received hardly any material from outside North America and the United Kingdom. In the future, we hope to have resources to be able to translate and edit texts from and into other languages.

The aim of the "Resource Kit" is threefold:

- to empower disabled individuals and organizations of disabled persons by providing them with easily accessible information on Independent Living philosophy and approach, model projects, and sources of technical assistance in organizing grass-root initiatives,
- to serve as a handbook for professionals working in such areas as community planning, social policy and services, rehabilitation, and vocational training,
- to aid NGO's in their disability work and to inform potential sponsors about the innovative approach that Independent Living entails for the equalization of opportunities for persons with disabilities.

Present plans are to update and publish a new issue of the "Resource Kit for Independent Living" every third year. We hope that there will be more and more people with disabilities from a growing number of countries joining the Independent Living network, that we will start new projects, expand into new areas, produce more documents and find new and better tools to empower ourselves.

In this sense we hope that any edition of the "Resource Kit on Independent Living" will be outdated as soon it is printed.

April 1992

for the Independent Living Committee of Disabled Peoples' International

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This is a reprint of an old article in "Psychology today", for a flavor of the original CIL, Center for Independent Living.

Declaring independence in Berkeley

by Sonny Kleinfield

At the Center for Independent Living in Berkeley, California, one encounters the revolution in microcosm. From a crowded storefront, disabled people of all kinds agitate in the community for better jobs and housing. They also apply their talents to finding ways to help one another.

They make revolutions in Berkeley. This is where the Free Speech Movement and the People's Park struggles found their momentum. The hotbed of liberal fervor. In more recent years, something new and positive has been happening here. People with disabilities were clanking into town and living independent lives. The reason for all the action, I was told almost reverently, was the Center for Independent Living.

The center crouched low on Telegraph Avenue. It had the look of a lawn-furniture store from the outside, an unlovely affair with walls splashed with white paint, wedged between Pancho Villa Mexican restaurant and a small parking lot. With a staff of 120 people, half of them disabled, the center now serves about 5,000 clients on an irregular basis. Every conceivable degree of disability is handled, from the elderly who have mild mobility problems and need to be bused, to the totally paralyzed.

I walked inside. There was an imploded look to the place. Some individuals in wheelchairs jostled along the hallways. Several people at the reception desk were hugging phones and talking animatedly. The white hallway walls were scuffed from wheelchairs whacking against them. They resembled retaining walls at auto racetracks, dirtied from cars slewing out of control. From an open office I heard a young woman, progressively going blind, tearfully unloading her problems to a counselor. I checked out some of the many notes thumbtacked to cork bulletin boards in the corridor. One read: "Disabled man seeks companion for headtripping, studying together, Scrabbles, etc. Ray". Another: "For sale, one chrome wheelchair. Used for three months. $100. Call Peter." Another: "For sale. 1977 Dodge van. Built to drive from a wheelchair. Low mileage. Like new. Price: $10,000. Call Mike." Another: "Self-defense course. Become familiar with your own areas of strengths and weaknesses and how to apply these to self-defense techniques. The course will concentrate on using canes, crutches, and wheelchairs as tools in self-protection. Starting March 6." If you were disabled and needed help, this seemed to be the place to come.

The mover and shaker behind the center was an outspoken and vigilant man named Ed Roberts. In 1962, Roberts, a postpolio quadriplegic, became one of the first severely disabled students to attend the University of California at Berkeley. Not only was Roberts using a wheelchair, but he also needed to spend most of his time inside an iron lung. He was put up at the Cowell Hospital on campus. Within a couple of years Cowell became a haven for a dozen seriously disabled students in what had turned into a formal program, the Cowell Residence Program. The patients, however, found the hospital custodial in nature. They rarely ventured off campus into the community, the main reason being that the community was architecturally inaccessible to them. A unity developed, with a dim sense of purpose. They began to entertain the selfish, ambitious hope that they could get out of the hospital and live like non-disabled folks.

They decided to whip up some alternative to the Cowell arrangement. With funds from the federal Office of Education, they created a Physically Disabled Students' Program in 1970. lt was a sharp departure from past practice in medical and rehabilitation fields. The notion was to assume a hostile approach to society's limitations and to set up services directed at getting people with disabilities to live independent lives. The philosophy of the nine founding members was: these who best know the needs of persons with disabilities are the disabled themselves; comprehensive programs are urgently needed to meet those needs; disabled people must get out and get into the community.

As the founders began to sculpt and implement programs, they found the disabled student population steadily swelling at Berkeley; more and more of these students began to move from Cowell into the community. Requests for help rose at an astonishing rate. Rarely were pleas turned away, even when they came from nonstudents. By the spring of 1971, the amount of time devoted to community people began to impinge seriously on the program's ability to meet the needs of students. Thus was hatched the idea of a separate Center for Independent Living to serve everybody.

The particulars were hammered out for more than a year. The group was officially formed in April of 1972. A roach-infested two-bedroom apartment was found with haste on, appropriately enough, Haste Street. The organization had one nagging problem: no money. Dollars were dug out of personal pockets, some benefit poker games were arranged, but not until July of 1972 was the financial squeeze settled. The Rehabilitation Services Administration produced a grant for $50,000, enough to tide them over while other funds were secured.

Jerry Wolf, who use a walker to hobble about because of the effects of multiple sclerosis, coordinates the housing department. He was my first stop. The purpose of Wolf's department is to act as a listing agency of accessible housing for persons with disabilities and an advocacy group to prod landlords into making their housing accessible. The formidable hurdles it faces were in black and white on a tattered map of Berkeley tacked to the wall behind Wolf's desk. Shaded-in portions represented accessible housing. That meant six or fewer steps to get in. Most of the town's perhaps 90 percent was unshaded. One reason was that a ramp to surmount just six steps could cost as much as $1,000.

"The general vacancy rate in Berkeley is just 1 percent," Wolf said to me. "Finding wheelchair-accessible places cuts the supply down quite a lot. Anyway, rents are usually too high. They've gone up a good deal lately, so that a two-bedroom is $200 or up. Finding a studio under 150 bucks is a feat of magic. We keep lists of people looking and try to arrange roommates. That's the only way some of these people can afford to put a roof over their heads." Wolf pointed out that although persons with disabilities can apply for housing subsidies, they're tough to get and insufficient as yet to keep pace with demand.

Around 100 requests a month were streaming into the department, far too many to fill. "One of the problems we have is that Berkeley is being advertised as a Utopia for disabled people," Wolf said. "But not enough housing is a available. People are literally flocking here from all over the country. They are landing at the airport and calling us up. About once a month someone pulls up outside in a taxi with all his belongings and says, 'Here I am.' One person showed up with an assistant and we had to put him in a hotel. His assistant left and he started asking bellhops to empty his leg bag. The hotel kicked him out. We finally found him a place with another assistant. People commonly show up with no money. One guy hitchhiked here with his wheelchair."

Wolf shook his head. "The truth is, we're placing about eight to 10 people a month, though sometimes I'm surprised that we place anyone at all." I wondered how successful Wolf had been in convincing landlords to make the modifications that would render more dwellings accessible to persons who have a disability. "Mixed success," he said. "A lot of landlords are reluctant to do anything because they think ramps look ugly. Then again, every so often we get a call from a landlord who wants to rent to disabled people. He likes them because the turnover tends to be low. One of the big problems is that no one provides money for modifications. We try charitable organizations and private benefactors. We do get money sometimes, but not much. lt's a case of twisting arms." New housing, under law, is required to set aside a certain number of apartments accessible to persons with disabilities. However, the law is useless if no housing is going

up. Berkeley hasn't seen any since 1972. Land is expensive; nobody is buying.

I walked outside and meandered through the parking lot to a cluster of garages. This was where the van modification and wheelchair-repair departments were housed. At the far end of the garages was a shop where wheelchairs were fixed. "We can fix 'most anything the same day," one of the men in the shop said. "You go to many places and they'll take weeks. Here, if we take any length of time, we have chairs to loan out so these people don't lose their mobility." Eight repairmen work in the shop, three of whom ride chairs themselves. The shop does about $10,000 worth of repair work a month. Wheelchair frames break constantly. "We do a whole lot of welding work," one of the men said. "A regular user may be in almost every week for repairs. These chairs are made terribly."

In a small room off the chair shop toiled Vance Grippi, design engineer. Since late in 1975, he has been working to build the perfect wheelchair, a superchair. If he has his way, extant wheelchair manufacturers can go into the lawnmower business. His chair will be the best. Taped on the wall was a gigantic artist's rendition of it. "You know, nobody has given a thought to the mobility of disabled people ," Grippi said, playing with a pencil. "Nobody cares about building a better chair. Well, I care. We talked to a lot of disabled people and most of them were unhappy with what they were riding. The speed, the range, the reliability, the flexibility. They really had no voice in what they needed. 'Here's a wheelchair,' they were told; 'take it or leave it.' Wheelchairs, understand, are their legs. We started with a clean sheet of paper."

He pointed out some of the features of the superchair. lt will have a cast frame that will be much sturdier. State-of-the-art technology will be incorporated. Grippi has designed an electric system that he claims will be much more reliable than conventional system. "Most chairs will go four or five miles an hour and 10 or 12 miles before the battery needs charging," he said. "Ours will go six miles an hour and 30 miles without charging. We've got a totally solid-state system, rather than a relay system."

The chair will be adjustable to handle any size person. With a traditional chair, you have to pull the armrests out of the sockets and toss them on the floor to transfer out of the seat. In Grippi's chair, the rests will pivot downward electronically. The wheels are sturdier. And the chair is being constructed out of standard equipment that you can get anywhere. For instance, it uses Schwinn bicycle tires and an ordinary automobile battery. Everest and Jennings has its own tires and batteries. The model is expected to be out sometime in late 1980.

That night I ate dinner with Phil Draper and Judy Heumann - executive director and associate director, respectively, of the center. Both are quadriplegics. The Chinese restaurant was a tiny, dimly lit place. A half-dozen young people were crammed into the small room, their leathery faces and rumpled clothes blending with the dun-colored walls. Because of its proximity to the center, the restaurant often was patronized by disabled people, and so fellow diners paid us no particular mind. Draper used a fork that was strapped to his wrist with an Ace bandage. But he could shovel food down pretty fast. The wheelchair doesn't disguise Draper's owlish, rabinical bent. He speaks, not with soapbox intensity, but softly, with an almost mournful tone.

I asked Draper and Heumann how they spent their time. "The administration of CIL devotes most of its time to looking for money," Draper said unhappily. "It's a hard sell. It shouldn't have to be that way. We're not eating the money. This is a damned good cause. You find me a better one." The center was operating on a yearly budget of approximately $1.2 million, money extracted from about 25 different sources. "We have tapped every conceivable source," Draper said. "One of the biggest problems is that we have no permanent source for funding. So it's soft money. Most places fund for a year and that's

it. Social-service programs have a high mortality rate."

I asked them how the movement was going. "One thing that's very important," Draper said, "is the collectiveness, people working together. That's how they got their strength. Activism is found in only a few places in this country. We need more involvement. Too many disabled people are still sitting in their attics and reading old comic books. They've got to start shouting." Heumann is a petite woman with a positive, earnest manner. She is 30. She was once arrested on an airplane for refusing to get off after she and her wheelchair had been cleared to fly. She went to court and won.

"I think the movement lies in the hands of disabled individuals," she said. "I am concerned that not enough people understand the Independent Living program. One of the reasons I think CIL is so successful is because it's run by disabled people. Our clients have hope when they see other disabled people managing their own lives. I don't know that the government is pleased that disabled people run these programs. Disabled people need to be much more militant about this. I think the next few years are going to be critical in the development of the movement. In a sense, the movement is just beginning."

Are more demonstrations needed? "More involvement," Draper said. "Just more involvement." Heumann was crisp and downright. "We need more demonstrations. We still have many scores to settle." The center's Law Resource Center is housed in a shopworn building across the street from the main building, and the next morning, I went there to talk to the program's director. Mismatched desks and chairs and bookshelves were spaced around the room. The floor was much scuffed up; track marks from wheelchairs were plainly visible. Old Congressional Records and Federal Registers were piled high on the floor. Coffee was percolating in a percolator. A spider plant was hanging in the window.

The director of the law center, Bob Funk, is a lawyer, one of two in the department. We sat and talked in a small airless room. "Our goal here is to be a backup to a lot of community groups," Funk said. "We're agitating to get disabled folks to be more assertive. To have them know they can raise hell."

A good deal of what the office does is to explain the laws and rights of disabled people. It will also file suits and negotiate settlements. Funk said three suits were in court at the moment, and six were about to be filed. Three previous suits had already run their course, all successful for the center. He said he was trying to help about 160 clients at the moment, the vast majority of them complaining about discrimination of one form of another. Funk rattled off some recent cases. Three local restaurants wouldn't serve customers riding wheelchairs. A waiter at one of them flatly said, "We don't serve wheelchairs." The second restaurant said it would serve the person if he sat in an isolated walkway that joined the place to a coffee shop. The third place refused service because it said the person was too disturbing a presence. He was in a wheelchair folding out like a bed. "He would be disturbing," Funk said. "But that's tough. That's the law."

Complaints were reaching the center about auto-insurance firms charging disabled people 30 to 50 percent higher rates than non-disabled people, though documentation makes clear they aren't greater risks. Funk said a class-action suit was being readied against one immense insurance firm. "We are clearly in the right in almost every case we get," Funk said. "They're blatant cases of discrimination. Not even subtle discrimination. They haven't a chance in court. Discrimination is such a traditional thing in this country that these people don't even realize they're discriminating. We can't possibly lose most of these cases. In fact, we're forced into court a lot more often than we should be."

Funk laughed at the thought of how ridiculously simple most of the cases were. "What's

likely to happen is that, at first, all of the cases will be blatant. Then, they'll get subtler and subtler. People will get more sophisticated in their discrimination. Restaurants will refuse to serve a disabled person, but say the reason is that he's rowdy or doesn't have a tie on. The disability won't even be mentioned. This happened with the civil rights movement, and took 20 years to run its course. The same will happen with disabled people."

Anna Steiner is a beautiful woman with raised eyebrows and poignant circles of pure white skin around her eyes. Her only disability is a bad case of arthritis. She's in her 30s and has an infirmity most people don't get until their 60s. She heads the center's job-development program, which faces the awesome task of trying to get jobs for disabled people. "Basically, we're a placement service," Steiner said to me. "Somebody has to come in here with some education, skills, abilities that could be translated into jobs. We've had lawyers. We've had a person who was a missionary. We've had a talented artist. We're mostly working with physically disabled persons, but we're expanding into the mentally disabled ."

The program has a caseload of 125 clients, Steiner said. Since the program began in the fall of 1975, the placement rate has hovered around 40 percent, she said, though it had of late nudged up to 60 percent. She spoke of some unusual cases. A blind janitor had been placed in a nearby town. "This was one of the cases where I said, no way, there's just no way for this one." The man told Steiner that he had experience scrubbing his father's laundromat. He was totally blind in one eye and legally blind in the other. How would he clean a room? He said he would scout out the premises in advance until he knew the area by memory. How would he tell what was dirty and what was clean? He said he would assume everything was dirty and clean it all. Steiner said that a man with muscular dystrophy got a job doing drafting for the Navy. The only necessary concession was a lower drafting table.

"We work a lot with employers, too," Steiner said. "Basically, we try to advocate for disabled people in general. We don't go in and say, "Hey, you're really stupid to have the kind of attitude you have.' We're subtler than that. We generally work with personnel people, who are sympathetic, because they don't have to work with disabled people. We'll do whatever is needed to help the employers. We'll check out the work environment to see what modifications are necessary. We'll help draft affirmative-action plans. We're getting a lot more interest from employers worried about the law."

Tanya Temporal, a counselor in the research and demonstration project, sat on top of a desk on the first floor, beneath the blind-services department. She was finishing a staff meeting. Temporal counsels severely disabled people. The project she is a part of hopes to prove that peer counseling works better than any other kind. Her short frame and lean, cheerful face belongs in California; her hair, wild and electric, looks fine in Berkeley. She's in her early 20s, and prematurely gray. Her conversation is a stream of information, a Niagara of words that, even so, somehow seems laconic. She smiles quickly and steadily.

"One of the main things we do is emotional counseling," she told me. "Getting people to deal with their disability and to accept it. We have five part-time counselors, and each one handles about 10 clients. We have a caseload, altogether, of about 80 clients." She talked about her most difficult case at the moment: a 23-year-old girl with severe cerebral palsy who was living in an institution. Her speech is extremely difficult to understand.

"I'm dealing with her on an emotional level," Tanya said. "I'm not telling her. I'm allowing her to discover. A lot of time we role-play. 'Okay, here we are in your apartment. I know you like to bowl. Let's go over how you'll set up a bowling appointment. Who are you going to call?' I've got to get her to demand to go out and do

things, not wait around for others to ask. She hasn't really accepted her disability. She views it as a burden that God has placed on her. She believes that by God's magic power she'll recover some day. She's very religious. I try not to discourage that belief altogether. I try to tell her, okay, for today you're not going to get better. What can we do today?"

Tanya studied human development in college. For 13 years, she has had rheumatoid arthritis. She has no idea why she got it. She has no pain, but has trouble walking and holding things. She occasionally resorts to a wheelchair. "I have accepted my disability," she said. "I can't say I don't get angry when I drop something on the floor and can't pick it up. But I don't let anger overtake me. I'm not going to paint the picture of the Super Crip. Some people make it out that they're the Super Crip and it's wonderful to be disabled. But you can still be a whole person, still be a happy person."

I went next to another hive to chat with Lon Kuntze. He, too, is in his early 20s, a big, broad-shouldered man with frizzy hair and a beard. Deaf since birth, he runs the deaf-services program. He nodded hello when I came by. Lynette Taylor, the center's staff interpreter, was to assist in our interview, though she was preoccupied with some phone calls. Kuntze suggested we begin by writing questions and answers on a legal pad.

"The biggest problem for deaf people," he wrote, "is, of course, communications. Deaf people are the only disabled group that can't regularly use the phone." The only way deaf people can talk, Kuntze explained, is by use of what are known as TTYs. Basically old teletypewriters that, by use of a jack, can be hooked to a phone line, they clack out in written form what conversation is to be exchanged. They aren't cheap and they aren't readily available, so even if a deaf person could get hold of one, he couldn't call very many people. Some federal offices have installed them, as has the phone company at a few of its service centers. One of the troubles is that it's an agonizingly slow way to talk, yet anyone talking over a TTY pays standard phone rates. A popular deaf person can run up staggering bills.

Lynette finished with her calls, and came over to interpret. Her mother was deaf, so she picked up sign language early on. Kuntze was relieved; he was getting a writing cramp. "Deafness is a disability on the communications level, whereas other disabilities are on a physical level," Kuntze said. "Deaf persons can't deal with people who don't know sign language. The best remedy for the communications problem is interpreters. The biggest trouble is there aren't enough interpreters, and there's no money for interpreters. They cost up to $10 an hour. Most of them get $7.50. Court work costs $15. The money, from their standpoint, is terribly low. It should be equal to foreign-language interpreters, who get $15 to $35 an hour. That's why more interpreters haven't been attracted to the field. Deaf interpreters simply don't get a decent wage."

My last visit was with the community affairs department. Its aim is to address community issues and to inspire demonstrations when it senses the need. I spoke with Kitty Cone, who has muscular dystrophy, and with Hale Zukas, whose cerebral palsy is so severe that he has but limited use of his hands and can barely utter intelligible speech. When he gets bogged down, he spells out his thoughts with a brisk tapping of the pointer. The back of his wheelchair sports a button reading: "ACCESS AMERICA."

Of late, the department had been working at mobility and architectural issues. Thumbtacked on the wall were two immense maps, one of Berkeley and one of Oakland. Black dots were inked in where ramps or curb cuts had been made. Berkeley looked pretty good, but Oakland had a long way to go before it could be called an accessible city. "We are working quite a bit on transportation issues," Kitty said. Hale began to struggle, wanting to say something. I couldn't understand his grunting. Saliva drooled down his beard and onto his clothes. Kitty had to interpret. "Hale says, 'Boy, do we work on

transportation. We're suing everybody in the world.'"

Paramount to all severely disabled people is the issue of getting around. For long distances, matters have improved since the Federal Aviation Administration ruled in May of 1977 that airlines can't deny seats to disabled individuals. It had ben common practice for the airlines to boot disabled people off planes, contending that they might hamper evacuation procedures should there be an emergency. Now, all airline personnel are required to be properly schooled in ways of assisting disabled people. Several cruise ships have started to take wheelchair travelers. The first ocean liner so designed, the Queen Elizabeth II, boasts nine staterooms that were made for disabled passengers. Thirteen elevators are on the ship. Some of Amtrak's trains can accommodate wheelchair riders in certain bedrooms, and these trains offer accessible bathrooms. Stations are being built barrier-free. Hertz and Avis have hand-control cars at some of their locations, and the newer highway rest areas accommodate disabled people. For lodging, Holiday Inns is making one in every 100 rooms accessible to the disabled population.

Local travel, though, is something else again. Wheelchair users can't very well hop into taxis. Subways, with the exception of the San Francisco, Washington, and Atlanta lines, aren't available to the severely disabled. And no available evidence suggests they ever will be. Elevators would be needed, and the cost is prohibitive. Public busses aren't much better, since their floors are around 35 inches above street level. A protracted battle, involving a spate of suits by disabled groups, resulted in an order in May of 1977, from Transportation Secretary Brock Adams, requiring that busses with 22-inch floors-called Transbusses-be produced by 1979. Twenty-two inches is about as low as busses can be made without having them scrape the ground when climbing hills or going over bumps. The busses would also have to include ramps that would shoot out from underneath to allow wheel-chair riders and mobility-hampered individuals to come aboard.

Disabled people, however, aren't exactly ablaze with enthusiasm over the Transbusses. For one thing, the low-floor busses won't start rolling down city streets until 1981 or 1982, and a complete transition will take a good deal longer. The old busses must first wear out. What's more, how are disabled people going to get from their homes and offices to the nearest bus stops?

The center was in the midst of a suit against AC Transit, the biggest bus line in the Berkeley area, for failing to order accessible busses, as required by a California law, as well as by the federal order. AC owns a fleet of about 800 busses. As I talked with Kitty and Hale, a big AC bus rumbled past. "Let us ride your bus," Kitty shouted out the window. Hale laughed loudly and nodded his head in agreement.

Another transportation issue had to do with BART (Bay Area Rapid Transit). One of the three accessible subway systems in the country, BART was planning to automate a lot of its stations by withdrawing agents and monitoring stations through closed-circuit TV. The disabled people were aghast at the prospect. They sometimes needed help to pay their fares, and if someone has an epileptic seizure or a blind person falls on the tracks, no agent would be available to assist. The main issue is safety, though, since disabled people fear that muggings and rapes would climb at an alarming rate. So Kitty and Hale were orchestrating protests to pressure BART into abandoning the idea. Pickets and rallies were being planned. "We don't want to badmouth BART, because they are accessible to us," Kitty said. "But this just isn't going to happen. No automation. Automation is for the birds."

Kitty then related a horrifying story that illustrated the inequities in the benefits system for people with disabilities. A 27-year-old woman named Lynn Tompson who had muscular dystrophy lived with an assistant in Los Angeles. Most of her medical expenses were

being picked up by Supplemental Security Income Payments. In general, Social Security laws define a disabled person as someone who can't engage in "substantial gainful activity." Such activity, according to these laws, is any enterprise generating an average income of $200 a month over a nine-month stretch. That means, in effect, that someone who can't budge a muscle below his chin, but who holds a job paying a mere $200 a month, isn't disabled in the eyes of the law, and thus isn't eligible for the SSI program or for Medicaid and other benefits. It's a rotten system, disabled people agree.

Without paying staggering premiums, severely disabled people can't get conventional medical coverage. The architects of the welfare laws plainly never imagined that severely disabled people might earn a salary. Under current laws, they would have to either make a pretty scant income and get benefits to help out, or else earn a fairly hefty salary.

Lynn Tompson wasn't happy sitting in her apartment and rotting away. So she started working as a dispatcher. Eventually, she worked her way up to an income of $500 a month, hardly enough to meet all her bills by itself, but she was gaining some freedom. Social security people stopped in one day to check up on her and discovered her extra income. She hadn't reported it to them. Her payments were immediately cut off. What's more, she was notified that she owed $10,000 in back payments that had been made to her. The only way she could live would be to go to a nursing home. Instead, in February of 1977, she committed suicide. She left a note saying that her death could be blamed on Social Security.

One of the cruel ironies of the case was the fact that, unbeknownst to Lynn, California had recently passed a measure allowing disabled people to draw medical coverage, as well as funds to pay for personal assistance, while they're working. The law established a graduated scale so that, beyond a certain income, a person chips in part of his expenses and the state furnishes the rest. Disability groups are trying to persuade other states to follow that precedent. "The tragedy of this story," Kitty said, "is that Lynn Tompsons can be found all over the country. California has done something to rectify the benefits problem, but what are other states doing? Disabled people must scream at their legislators to start moving, because the laws are sending us to psychological deaths."

Early the next morning, I caught a plane out of San Francisco, leaving the center behind. Beyond doubt, I had returned to the "real" world. I checked carefully the passengers aboard my crowded United Airlines flight. Not o one was disabled.

Source: Psychology today

Power to the people

by April D'Aubin

Power to the people! A popular slogan - but how do you get from rhetoric to reality? In Canada people with disabilities are giving power to themselves - personal empowerment - through their activities in Independent Living centers (ILCs). Canadian ILCs are self-help,

non-profit, community-based organizations established and operated by disabled people to assist themselves and others with disabilities gain and maintain control over their lives. To legitimately carry the ILC name an organization must establish constitutionally that people with disabilities make up at least 51 percent of the center's board of directors.

Personal empowerment, which stands as the main goal of Canada's ILCs, is promoted through IL core programming: information and referral, peer counseling, individual advocacy, service development capacity.

IL programming rests on the belief that access to knowledge and information empowers individuals so that they can exert control over their personal lives. For example, a disabled person who knows how to appeal the decision of her welfare worker is in a far stronger position than one who believes her worker's decision is final. If contacted by a disabled person experiencing a welfare problem, the ILC's Information and Referral program would provide the consumer with information on appeal procedures and the Advocacy Program, if requested, would assist the person make the necessary appeal. Through the peer support program, which specializes in the area of mutual support activity, somebody who has a disability can share her experience with others who have been in a similar situation. This provides disabled people with an opportunity to share their experiences with others in the community who can benefit from them.

Canadian ILCs engage in personal, as opposed to class action, advocacy assisting individuals get around the old bureaucratic run-around. A center's advocacy coordinator works with a disabled person to assist them cut through bureaucratic red tape and reach a desired conclusion identified by the disabled individual. The advocacy coordinator involves the disabled person every step of the way, as the program's goal is for the individual to learn to advocate on their own behalf. Centers seek to enhance disabled peoples' skills as self-advocates.

Class action advocacy, which involves such activities such as pushing government for changes in programs and legislation, remains the preserve of the advocacy organizations of disabled persons, affiliated with COPOH (Coalition of Provincial Organizations of the Handicapped), Canada's DPI member. In Canada these organizations are referred to as consumer groups. These organizations also monitor those who provide services affecting disabled persons. Consumer groups have refrained from becoming involved in service provision, because it is felt that an effective monitoring organization cannot also provide services.

Despite this separation of roles, consumer groups have always maintained a keen interest in Independent Living. In fact, COPOH introduced the Independent Living concept to Canada in 1980 when it invited Gerben DeJong, an influential American Independent Living theorist, to speak at its Defining the Parameters of Rehabilitation Conference. Since that time both COPOH and its member organizations have been enthusiastic promoters of the Independent Living philosophy.

Canadian ILCs have banded together to form the Canadian Association of Independent Living Centers (CAILC). Established in 1986, CAILC's membership currently consists of the nine established ILCs operating in Canada. The Association's primary goal, as stated in its By-Laws, is to promote and coordinate the development of Independent Living centers and services throughout Canada. It has as its objectives: establishing standards, networking and information sharing, promoting IL, developing and clarifying IL definitions, promoting IL research, supporting the self-help movement of disabled persons, supporting staff training, and liaising with ILCs in other countries.

To facilitate the advancement of Independent Living, Canadians with disabilities have

adopted a national definition of an Independent Living center. The Canadian definition states, "Independent living centers: promote and enable the progressive process of citizens with disabilities taking responsibility for the development and management of personal and community resources. Centers, while reflecting each community's unique character will be: consumer controlled, cross disability, community based, nonprofit, promoters of integration and full participation. Essential program components are: information and referral, peer support, individual advocacy, service development capacity, e.g. via research and planning, demonstration programs, service delivery and coordination, service networking, consumer monitoring (including such services as: housing assistance, personal assistance, transportation, vacation relief, technical aid loans)." This definition has been adopted by centers, themselves, and by COPOH.

The future looks bright for ILCs in Canada. Recognizing the importance of ILC's new brand of service delivery, the federal Department of Health and Welfare has begun to fund centers' operations. This recognition by the federal government stands as an important milestone for the IL movement in Canada. Centers have been seeking similar recognition at the provincial and community level. Centers have been promoting the idea that ILC essential operational funding (i.e. rent, salaries, equipment, supplies, etc.) should be met according to the following formula: one third community support, one third provincial government support, one third federal government support. Foundations, income generating projects, donations, contracts, etc. are additional sources of revenue.

Many challenges still face ILCs, but centers are prepared to meet these. In the very near future Canadian ILCs will be dealing with the development of evaluation procedures, staff training programs, income generating projects, and the like. To address these concerns, Canadians in the Independent Living Movement are beginning to reach out to those involved in IL in other countries. It is felt that by networking internationally IL will be strengthened both here at home and around the world. Canadian centers look forward to learning through DPI's work different IL approaches that have been tested elsewhere.

Source: COPOH, 926-294 Portage Ave, Winnipeg Man R3C 0B9, Canada.

Divisions in the disability community

by David Pfeiffer

Within the community of disabled persons in this country there is a division between those concerned with civil rights and those concerned with service delivery. On the one hand, there is the Independent Living Movement which is a necessary fact of life for disabled persons in this country today, whether or not they require the services of an Independent Living center. There is also the Disability Rights Movement which is a necessary for disabled persons in this country today, whether or not they face civil rights violations. Although there is an overlapping membership, persons who identify with the Independent Living Movement are concerned with the provision of services to disabled individuals in order to make them truly independent. They say that without transportation, income, housing, and other necessities, disabled persons cannot be in a position to work for civil rights. Persons who identify with the Disability Rights Movement say that services will never be consistently and adequately provided until the civil rights battle is fought and won. The differences can be illustrated by an example. If a disabled person has

a job, but no transportation to that job, a person in the Independent Living Movement would assist him/her to obtain some means of transportation to work. A person in the Disability Rights Movement would assist him/her to undertake political and legal action to make local transportation accessible and available because the disabled person, as a matter of law, has the right to use it as other persons in the community can use it. The Independent Living Movement people would talk about reduced fares, paratransit, and negotiation. The Disability Rights Movement people would talk about lobbying, demonstrations, and law suits. The recent disputes between ADAPT and some local Independent Living centers reflect this divergent perspective on the problem of transportation.

It is an interesting side note that many claim that California was the origin of both the demand for services and the fight for civil rights. They lump both together under the name of the Independent Living Movement. Others claim that Massachusetts was the origin of both the demand for services and the fight for civil rights. They lump both together under the name of the Disability Rights Movement. Persons in Illinois, Florida, Texas and almost every other state make a similar claim. Opponents to the various claims say that Californians were concerned about civil rights only as an afterthought, while in Massachusetts services were viewed only as a means to obtain activists. Illinois is criticized for not being controlled by disabled persons. Florida is criticized for being concerned only with physical disability, thereby leaving out half of the disability community. Texas is shrugged off as a newcomer. This writer was born in Texas and lived there until 1964. I can state unequivocally that by 1948, as a teenager, I was working for both services and civil rights. However, I was a voice crying in the wilderness and did not encounter any organized activity until moving to Boston in 1970. Nevertheless, the final resolution of this question on the origin of the Movement(s) I will leave to some historian. My point is that the divisions are not recent and are not inconsequential.

This split is also seen in the Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE). Many members of AHSSPPE come from a student personnel orientation and express the position that the association and its journal (Journal of Post-Secondary Education and Disability) should focus on the delivery of services to disabled post-secondary students. The field, as they understand it, encompasses concerns such as the administration of an office for the delivery of these services, attitudes of faculty and administrators toward disabled students, technical details of how persons with various disabilities can be accommodated in different courses, questions of admission and retention, data about specific disabilities with implications within the post-secondary context, and related matters. On the other hand, AHSSPPE was one of the earliest professional associations that welcomed papers which went beyond this range of topics at its national meetings. In part, it was because many (including members coming from a student personnel orientation) perceived their job in terms of the civil rights of disabled post-secondary students. It was also because a large number of AHSSPPE members taught on a regular basis. Many of them guest lectured in courses, many taught as adjuncts, and many (including this writer and the editor of the DSQ) had regular faculty appointments. Nevertheless, the division between providers and advocates can be seen in the topics listed in the annual AHSSPPE meeting programs, but it is diminishing.

This FOCUS began with a discussion of division as a split. However, there is another meaning of division which is very important. Division can also mean a part of something. The "divisions" of which I write can be seen as parts of the overall whole. There is no necessary conflict between those mostly concerned with civil rights. Both activities must occur at the same time: individual and systemic advocacy for services and civil rights and there will not be people to fight for civil rights without the provided services. We must work cooperatively to achieve the goal of an open society composed of truly independent

and interdependent people.

The challenge of middle age for the Independent Living Movement

by Gerben DeJong

Ten years ago, the U.S. Congress passed the 1978 amendments to the Rehabilitation Act. These Amendments included Title VII, a new grant program for Independent Living centers. Title VII was hailed as a victory for the Independent Living Movement. Today, there are approximately 200 Independent Living centers, many of which had their beginnings in the Title VII program. But with the passage of the 1978 Amendments, the Independent Living (IL) movement crossed a threshold and entered a new stage in its life cycle as a social movement.

Social movements, like the rest of us, go through life cycles. Knowing where we are in our life cycle can significantly enhance our understanding of who we are, where we have come from, and where we might be going. In an analogous way, the IL movement has gone through various developmental stages. The 10th anniversary of the 1978 Amendments offers a propitious occasion on which to reflect on Independent Living as a social movement.

In the early stages of our own development, we seek to establish our identity as individuals with distinct interests, commitments, and needs. We seek to communicate to the rest of the world who we are. We tend to be self-absorbed with our own identity. Later, as we become more secure about ourselves, we also have an enhanced capacity to reach out to others and help meet their needs through friendships, marital relationships, business relationships, and through participation in the larger life of the community. More secure in the knowledge of ourselves, we make selected accommodations with the larger society and its institutions. We do not necessarily "sell out," but we tend to have a deeper understanding of the tensions between our individual values and the values of the institutions in which we are involved.

I would like to suggest that this scenario is not unlike some of the developmental issues faced by the IL movement. At present there are two major developmental issues for the IL movement that can be better understood in the context of "life cycle theory."

The first issue is the tension between the movement´s "grass rootsy" origins and the movement´s willingness to take on providers status. It is the old advocacy versus provider status issue. The 1978 Amendments, in a sense, conferred official legitimacy on the movement by offering provider status for IL centers - the main service delivery vehicle of the IL movement. The real significance of the 1978 Amendments is that they signified a shift in movement history away from the in-the-streets advocacy to the nurturing of institutional structures committed to movement goals.

The second issue is the movement´s ability to broaden its base to incorporate persons

with disabilities whose disabilities are different from those of the movement´s original adherents. The early leadership of the movement was largely drawn from the ranks of those with disabilities such as spinal cord injury, post-polio, cerebral palsy, and a few others. This problem has been particularly acute in regard to the ability of the movement to assimilate persons who have a diminished capacity for self-direction such as persons who have mental retardation or brain injury.

The issue of provider status

A social movement cannot sustain itself by being in the streets indefinitely. Eventually, the ideals and values of the movement are assimilated by others and achieve sufficient social legitimacy to by incorporated in legislation and in various societal institutions. At that stage, the identity and legitimacy of the movement is no longer the focal issue. Instead, attention can be turned to how the movement can sustain itself financially and institutionally.

The 1978 Amendments offered IL Centers a funding source that allowed IL Centers to become more financially viable despite the very limited availability of Title VII funds. IL centers, like other provider groups, have organized themselves into a national organization known as the National Council on Independent Living (NCIL) which has also become the IL movement´s focal organization. Instead of marching and wheeling in the streets, NCIL´s membership ply the halls of Congress and various governmental organizations. Instead of demonstrating at the gates of the White House, members are giving cocktail parties on Capitol Hill. The IL movement has come of age. ¨

However, the basic conflict between advocacy and provider status has not been resolved. Nowhere is this issue more apparent than in the hotly contested issue of whether IL centers should be accredited by an external accrediting body such as the Commission on Accreditation of Rehabilitation Facilities, an accrediting body developed within the framework of the movement, or in some other group. The fundamental issue, I believe, is not whether IL centers should be accredited but rather the extent to which movement organizations are willing to take on the additional trappings of provider status in the hopes of achieving greater organizational legitimacy while coping with all the baggage that comes with being a service provider.

There are enormous economic advantages in acquiring provider status. External accreditation legitimizes IL centers as service delivery organizations in the eyes of funding sources. Procvider-based financing also pays the salaries of movement leaders and offers resources for travel that enable movement leaders to participate in movement activities.

The down side is also apparent. Being beholden to certain funding sources does tend to blunt the sharpness of one, advocacy. The old adage still applies: It is difficult to bite the hand that feeds you. However, movement ideas and ideals must be operationalized institutionally if they are to survive the convictions of the movement´s original leaders and adherents. Institutions offer a framework in which human energy can be harnessed (and compensated) in the pursuit of specific movement goals. I am not advocating accreditation, but if social movements are to be mainstreamed into American life, they cannot just be viewed as fringe elements. They must become part of the system - on their own terms, of course.

Persons with disabilities want to be included in the mainstream of American life. However, at the risk of some generalization, I am not sure that leaders within the IL movement are prepared to see movement organizations such as IL centers fully mainstreamed into the fabric of America´s health and human services system for fear that the movement´s cutting edge will be blunted. Thus, at midlife, the movement remains

torn as to the nature of its accommodation within various social institutions.

The issue of incorporating new groups

The other issue for the IL movement is its ability to fully assimilate persons whose disabilities have compromised their capacity for self-direction. Some observers speak of the movement´s original spinal cord injury bias or the movement´s bias toward disabled persons who are young and fit.

At the outset of the movement in the early 1970s, persons with physical disabilities wanted to be viewed as competent, self-directed, and capable of managing their own lives. The participation of persons, whose capacity for self-direction had been compromised, threatened that image of competence.

Many IL programs deserve credit for reaching out to groups who earlier had been overlooked as partners in the IL movement. However, the broadening of the IL movement in recent years comes as much from overlooked groups seeking the help of IL programs. Nowhere is this more evident than among persons with brain injury and their advocates who have looked to IL programs for support. The brain injury community has become increasingly organized and has challenged many of the assumptions of the IL movement such as the IL movement´s traditional aversion to transitional living programs.

As the movement becomes more secure about its own identity, it will assimilate disability groups from outside its original group of adherents. The people with persons who are less self-directed is that their participation in IL programs is often attended by the not-too-distant and heavy hand of professional paternalism or by anxious parents who have continued/resumed their parenting role in the lives of their adult children. Such participation is viewed as an affront to the very principles on which the IL movement was founded.

Mid-life crisis?

The IL movement is now about 17 years old depending on how one chooses to date the movement. As far as social movements are concerned, the IL movement is well into middle age. Some might argue the IL movement is in late adolescence or young adulthood, depending on the issue at hand. In any case, issues that remain unresolved in the early stages of a movement´s life cycle are sure to resurface as the movement ages and matures. The assumption of provider status and the broadening of its constituency challenge the very assumptions and identity of the IL movement and its place in American social and political life.

The stage theory of life-cycle approach to understanding the IL movement - and its closely related movement, the disability rights movement - can also be misleading. The theory assumes that the IL movement has affected all disability groups uniformly. A more accurate assessment is that specific disability groups are at various stages of development in terms of their own identity and role in American life. We have only to witness the recent uprisings of students with hearing impairments at Gallaudet University in Washington, D.C. to remind us that all disability groups have not benefited equally in the quest for full equality and full participation in American life.

I am not prepared to describe the IL movement as having a mid-life crisis but I do believe that a life-cycle understanding of social movements can give us a better understanding of the issues and tensions within the IL movement.

**History of the
Independent Living Movement**

Resources

The following resources are published by the Independent Living Ressearch Utilization Program, Houston:

Tate, Denise and Linda Chadderdon, eds. International Perspectives about Independent Living. 1983. University Center for International Rehabilitation Publications. Available from ILRU.

Summarizes presentations and discussions at a one-day conference held to view Independent Living issues in the U.S., discusses related programs and practices abroad, and makes recommendations for future directions in the U.S.

Tate, Denise and Linda Chadderdon, eds. Independent Living: An Overview of Efforts in Five Countries. 1982. University Center for International Rehabilitation Publications. Available from ILRU.

Rehabilitation and special education professionals from five countries--Costa Rica, Denmark, the Federal Republic of Germany, Japan, and Yugoslavia--describe their services for people with disabilities, including the development of Independent Living programs The volume concludes with summaries and comparisons of the basic aspects of each country.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Crewe, Nancy M. & Harkins, Arthur,"The Future of Independent Living", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Zola, Irving Kenneth,"Toward Independent Living: Goals and Dilemmas", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983

**Independent Living:
Ideology & definitions**

Possibilities of Independent Living of persons with disabilities in Africa

by Felix Silwimba

This is a very important subject requiring deep thought and analysis. It requires a multi-disciplinary approach taking into consideration the fact that little has been written about people with disabilities in Africa. Therefore, reference material has to be drawn from the general textbooks of social sciences and principles of community health on the epidemiology of diseases. One approach will be to take an historical analysis broken down into three parts.

- pre-colonial era
- colonial era
- independence era

In the pre-colonial era life could be described as being war-like. It was survival of the fittest. Tribal wars were common place and wild animals also poised another big danger. In this period, there were very few disabilities because the traumatized or severely ill person eventually met with early death as medical services were not available. The only disabled persons where those with hand, earlobe amputations or those who had their eyes plucked out as a form of punishment for wrongdoings. Therefore, persons with disabilities were highly ostracized. Visual impairment of other causes may have occurred but it is not mentioned very much in most of the folklore. Congenital conditions such as club foot, missing limbs or part of a limb is made mention of in folklore. Mostly they are described in humanistic terms. There is one strong example in the Bemba history in which a chief's sister gave birth to their only baby boy who had no hand. The chieftainess reacted by surrendering the care of the boy to her sister for it was held that the chiefs children have to be perfect. The paradox is that this same baby later turned out to be one of the best chiefs of his tribe. Therefore, we can say that even at this time some disabilities were accepted nicely.

Colonialization brought with it ceasefires between waring tribes. Peace and stability gradually became a reality. Strong men were required to go and look for jobs in the mines. Medical services and the hygiene of the communities gradually started to improve. This meant that a severely traumatized person or one suffering from a chronic disease, i.e. tuberculosis, had a chance to survive. Consequently, conditions which may have caused death now lead to disablement. The two world wars also left disabled individuals.

Missionaries capitalizing on their previous experience in Europe started to care for people with disabilities to the relief of the afflicted families. This benefitted the missionaries most since it enabled them to convert many resistant persons to their religious convictions. Since that time the care of a disabled man has been left in most part to missionary societies.

The struggle for independence brought with it new forms of disabilities as a result of clashes between the nationalist movements and colonial government forces. This is not so significant in Zambian society. However, in recently independent nations it is of utmost importance. In the Zambian situation after independence many changes took place; there was a marked improvement in providing services to the community. The hygiene of the community improved and infant mortality fell and the poliomyelitis paradox set in, which today accounts for over half of the physically disabled youths and adults in Zambia and most developing nations.

In traditional society, a disabled man is considered as a sick man which implies that he has to be provided for by the other family members and the extended family. It is strongly believed that letting a disabled family member suffer is offending ancestral spirits. Should he/she die unhappily, a spell will be cast on that family. Consequently, they tend to hold disabled persons with reverence. They tend to over-emphasize the disability, thus allowing individuals who have a disability little opportunity to explore the environment. Naturally, our people tend to derive pleasure in giving to disabled people rather than receiving from them.

Some factors associated with independence in contemporary society

The majority of the population in developing nations live in rural areas. The lifestyle in these places require physical strength to grow enough food and to support a family. Thus, the deaf and mentally disabled can lead a better life than the physically and visually disabled. In my experience most deaf persons lead independent lives in their communities and are considered hard workers in manual work. They marry and raise a family. I know of a few blind men who are good charcoal burners and farm workers and have married. However, for the physically disabled even with provision of technical aids, life is still hard in rural areas.

Living in urban areas depends more on being brainy than brawny. This is the ideal place for physically disabled persons because their survival depends on intelligence, creativity and ability to organize people. In town, there are many ways to raise money without much physical effort even if one is not well educated.

Factors associated with individual independence

The outcome of the disabled person's desire and ability to be independent depends on various factors most of which can be overcome. Some of these are parental influence, age at onset of disability, type of disability, educational status of the individual and environmental barriers.

In considering parental attitudes, I take an ideal situation where homes for children with disabilities are well provided for. It can be stated that poor parents, for obvious reasons, would be willing to surrender their disabled child to such homes. Conservative parents, because they want to give special care, may also surrender their child to the so-called experts. However, liberal parents, mostly with college education, are mostly unwilling to surrender their child. In most instances they would rather keep the child themselves and treat him/her like anyone else. Liberal parents build a mind of seriousness, critical analysis and desire to succeed in a disabled child who,being well adjusted and disciplined, may eventually become the envy of society. Generally, liberal parents are not authoritative and do not offer everything on a silver platter. They allow the disabled child to explore his own environment and set up his/her own standards and learn to live with his/her limitations in a respectful independent manner.

The age at onset of the disability is of special relevance for independence tendencies of a

person. People disabled from early childhood in general terms tend to be well adjusted and can be rated high on the independence score. They have had enough time to explore the environment and thus adjusted to the limited resources. This is of significance to Africa because most of the disabilities are a result of childhood infections.

Individuals disabled in adulthood find it hard to adjust, for obvious reasons. They are firstly in a state of social shock because they do not know what to do. Some lose employment and their families denounce them. They have just suddenly lost all the virtues of being non-disabled. Some go into a state of depression upon realizing they are now objects of charity and pity. They used to be providers and now they are being provided for. In case of ladies, they loose their beauty. The significance of this group is that our societies are defined in masculine terms; the ideal being an athletic body. Disabled men are generally considered as inferior and less potent. Therefore, this group shows high divorce rates, cry for dependency and become a liability to society. This is the group which requires concerted efforts at rehabilitation to help them re-learn. They are largely responsible for the negative things attributed to disabled people.

The best way and most rewarding thing to do for a disabled person is to give him/her every educational opportunity possible with higher educational qualification and training provided for by reputable institutions. The disabled person can get a well-paying job and be able to have a family and the effects of the disability cease to be recognized. It is overwhelming to note how suddenly everyone starts giving you respect and admiration. Women with disabilities when provided with good education, are able to lead better, respectful lives and possibly marry men of good education and understanding. In fact, disabled women need to be educated most because they are a target of sexual abuse. A poorly educated woman having children is a hurdle to be borne by society. Low standard of education is associated with poor understanding of events, fear to speak one's mind, to stand up for one's rights, leads to withdrawal and menial jobs. Such that negative effects of disability become pronounced. A vicious cycle sets in. The person slowly falls into poverty eventually into learned helplessness because all efforts at survival seem to be exhausted in a non-supporting environment. In this society, the talents of disabled people in art, music and other forms of entertainment are not being exploited because our society is still obsessed with the ideals of 'normal' or 'standard'.

By environmental factors, I mean those factors outside the disabled person's convictions as regard dependency. I take this opportunity to state that perhaps based on humanitarian and moral obligations society conceived of the idea of charitable organizations. Consequently, this duty fell under the auspices of missionary societies who in carrying out the services gathered disabled children, organized for sponsorship and provided needed technical aids and skills. Unfortunately, this kind of aid was limited to a certain age group. After disabled persons left this center, it has been noted, they face problems in adjusting to the hardships of real social life. Being provided for blocks social maturity. In contemporary Africa, Zambia in particular, charitable organizations must review their approach to aiding disabled people. They should take us as full human beings with all the needs of mature adults.

An average African is highly superstitious and easily falls prey to mysticism so that to them disability is a mystery. They take persons with disabilities as people with special powers or as an occult challenge to the afflicted family. Therefore, providing for disabled persons is deemed as appeasing the ancestors. Currently, I am noting that most disabled persons established in their own communities take up leadership or arbitrator roles in community issues. Some have engaged in creative jobs like carving, shaping handles for farming tools, become herbalists and tailors (mainly mending). However, due to the poor purchasing power of the communities, these jobs do not earn enough money for one to live independently. Thus they are mostly exploited. It is only for the joy of contributing

something to society that they keep on.

The physical barriers of significance in Africa are the long distances one has to walk to get to schools and shopping centers, and a poor public transport system which does not take into consideration the needs of people with disabilities. Therefore, technical aids have to be quite durable. Wheelchairs are provided by donor agencies. However, they are not very well adapted to our rough roads and long distances, since they are not made locally. Bicycles which can be of benefit to a single amputee or a person with with one paralyzed limb, are not regarded as orthopaedic aids. It is very expensive to get one.

Lower limb prostheses and calipers should be designed to enable the user to walk for long distances on rough surfaces and sometimes slippery wet ground in the rainy season. The appliances that are available, especially calipers, are heavy and uncosmetic, unattractive and frightening to persons who have not seen one before. It is a normal human quality to look for attractiveness and acceptability of an object by others. Today's technologies have the capability to make light-weight, durable, all-weather appliances from metal and plastic. They can be made cheaply and fast. Presently these appliances are provided to very few, selected, better placed disabled persons. Provision of hearing aids, special walking canes or seeing-eye dogs should also be considered.

Architectural barriers seem to be far from being eliminated. In our cities it is risky for persons who have a disability to move about because there are no special paths for wheelchairs and bicycles. Pedestrian crossings are few. Where traffic lights exist they are unreliable. Careless driving is common. In general most of our drivers are not cautious of the pedestrian needs.

Busses and minibusses for public use are not provided with rails for holding on to when getting on or off. There is no legislation for reservation of certain seats for people with disabilities such that if a disabled individual finds all the seats occupied the he/she has to stand. It is difficult to request a comfortably seated person to leave a seat for a stranger. In most cases the busses are over-crowded and uncomfortable.

Let's now consider the concept of prejudice and see how it relates to contemporary African Society. A prejudice can be defined as a previously formed judgement applied to some person, object or situation usually in a hostile manner without considering facts. Prejudices are learnt through contact with the object of prejudice or contact with others who have the prejudice, the latter is the most important. The former may even help eliminate prejudices.

Prejudices tend to persist and get stronger when contact between the prejudiced and his objects of prejudice is remote. Prejudices tend to gratify individual needs and alter memory and perception. That is, in the social hierarchy the prejudiced person feels superior. That is to say a bigot non-disabled man of low economic status may console himself by thinking he is superior to an economically advantaged person who has a disability.

Prejudices can also be considered as a form of displaced aggression channelled towards a weak group that can not retaliate. A lustful non-disabled man who fails to grab a beautiful lady from an economically well-placed and understanding disabled man may develop hate against the disabled community.

When a person is prejudiced, his perception and memory alter that he only sees what he wants to see or what he believes he is going to see. He may be able to remember only the bad side of events concerning his target group. Probably because of their difficulties in understanding their own prejudices, many when reporting to a person in a superior

position alter the statement to exonerate themselves and label persons with disabilities as people who lack understanding. This kind of experience is well known to those of us who take every opportunity to stand up for our rights.

Prejudices at their worst lead to social handicap in which the inferior group is prevented from adequate schooling, library facilities, housing and social amenities. The result is poor education, mediocre skills and high unemployment amongst the group, thus making the prejudice true. For instance, the belief that all persons with disabilities live in poverty and unemployment might lead to the provision of substandard training in the name of charity. Thus the training results in lowly educated and semi-skilled personnel who cannot compete for jobs on the open labour market. Therefore, this kind of behavior leads to a vicious cycle where the effects of prejudice help to maintain the prejudice by providing an observable basis for it. This point is of special importance to Africa where many charitable organizations are claiming to be providing for persons who have a disability.

The bad social ressult of prejudice is that it leads to segregation of the two groups, the oppressor and the oppressed. However, in the case of persons with and without disabilities, physical segregation is not possible because disabled children are born from non-disabled parents. The outcome of a marriage between two disabled partners is often an non-disabled off-spring. Despite this, some form of social does segregation exist. This is seen by the actions of most disabled persons especially men when they succeed in getting a good education, a well-paying job or a prosperous business. They tend to marry several beautiful women or rather divorce non-disabled women one after another.

In contemporary Africa, some of the things perpetuating such prejudices are the methods used by charitable organizations providing for persons with disabilities. They provide basic substandard training in crafts such as typing, tailoring, carpentry and metal work and agriculture. Mostly the instructors themselves are lowly qualified such that the disabled graduates are not confident and competent enough to enter for remunerative jobs on the open labor market.

The continued existence of special schools accommodating exclusively students with disabilities is blocking contact between the prejudiced and the object of prejudice. These schools must change into integrated ones. This should be effected at all levels of the educational system from nursery to vocational rehabilitation centers. This kind of arrangement allows for self-exploration as well as re-evaluation of oneself. In this regard both parties start understanding each other. Since we are considering Independent Living of persons with disabilities, it is natural that we realize that it is the concepts of help, charity, sympathy and pity that limit our independence. Therefore, I now analyze what help is.

Help, aid, charity, sympathy, pity -- all these terms are used to express one thing: concern over the suffering of fellow man. However, they are concepts that should be applied continuously when dealing with persons with disabilities because our needs as human beings are intact despite the shape of our body parts or the or the loss of some function. Therefore, we have our own feelings about being helped. Common knowledge shows that help can have the following effects:

Accelerate progress

With respect to physical disability the most obvious is when such help is directed towards making mobility easy. For example, giving a bicycle to a person who uses crutches and can ride one, will do him good because the bicycle will not only ease his mobility problem but will also help exercise the weak limb. Consequently, some degree of development and restitution of function is allowed.

Retard progress

Take the example of a child with cerebral palsy who needs a long to time to dress. Out of pity the poor mother/attendant dresses this child. In this case the child won't know how to dress on his/her own. In long run he or she will remain dependent on other people and cannot develop skills fully. Whereas if he/she was given a chance to dress by himself/herself, he/she would learn the technique and eventually be independent.

Status symbol

This implies that the person giving out help is superior and the recipient is inferior or a second-class citizen. This feeling is strongest among disabled males because our society emphasizes maleness. Thus disabled men being human feel the need to express their worth as men who can do things and be counted on. Also, women with disabilities who get a good education express a need for independence and free expression.

A sixteen year old boy had the following experience when he attempted go assist a person with a physical disability. The boy saw this man buy 10 kg of sugar, so he reasoned that this man with own weak limb would not manage. Consequently, he went close to him and politely asked whether he could assist. To the surprise of the young boy the man refused and lifted up his own sugar and laboriously carried it. The implication is that the man looked at the offer as a challenge of his manliness, especially if the opposite sex was present. Thus he demonstrated that he has strength and can do things independently. The young sympathizer was right in his willingness to help as it is a sign of being a good boy. However, he lacked judgement and timing. If he had allowed this man to carry the load several meters away and then made his move, I am sure he would have been most welcome.

Therefore, help sometimes may be unnecessary or even annoy the recipient, especially if the donor shows signs and symptoms of self-aggrandizement or is himself considered of low credibility. It should also be realized that persons with disabilities also would like to give out just as well as they receive, because help is a two-way process. That is a social relationship in which if you are ready to give then be ready to receive. This is a very important point to be taken care of whenever help is attempted.

Sexuality

Sexual relationships for persons with disabilities are often left out in discussions of the disabled persons' problems. The teachings and actions of society require that disabled persons repress their sexual desires. Sex is a natural innate need present since early childhood. It is the force through which we express our inner feelings, love and establish affectionate relationships. It is a means by which families previously unknown to each other are united. Above all its ultimate purpose is to procreate.

The relevance of appreciating the sexuality of persons with disabilities in analyzing Independent Living of the disabled is that for the proper satisfaction of sex, marriage is the answer, but then it is only an economically independent person who is expected to marry and possibly procreate. Thus when the concept of sexuality is thrown aside in planning rehabilitation of the disabled, emphasis is on teaching only the most elementary skills by which somebody who has a disability cannot become economically independent. Therefore, these persons remain a liability to society, are consequently excluded from the basic human need of expressing and feeling love.

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Independent Living:
Ideology & definitions

The Disability Rights Movement: its development in South Africa

by Kathy Jagoe

The cripple

Disabled people had for centuries been viewed as poor helpless cripples, blind beggars, dumb idiots standing on street corners with contorted outstretched hands groping, and spluttering for the small offerings their pitiable image could entice out of guilt-ridden passersby. They were outcasts, denied the recognition of human beings, denied at every point the rights of participation in their society. Generally they were either cast out of families or hidden behind closed curtains and doors for fear they would bring shame upon and ostracizing the entire family.

Charity/welfare

From this, a new phase developed - the emergence of the charity/welfare organizations. At this point society's individual guilty consciences came together into organizations which took on the responsibility of "looking after" these indigents, these helpless cripples. It is at this point that the idea of institutions developed to house, "educate" and "employ" these misfits in society. While there is no doubt that a place which offers food, beds, some sort of activity and safety to people who have never had any, is a great advancement, they were nevertheless "dumping grounds" which served to get and keep the problem out of sight. The only reminder society had of their existence was now the more respectable, acceptable member of society "begging" on street corners on their behalf. The tacit agreement: give us money and we'll look after them for you and keep the burden on society in manageable confined institutions. The "able bodied" now became custodians, caretakers of those too horrid, too frightening, too burdensome to

contemplate.

Intervention of medicine/professionals

Throughout the centuries wars, poverty and lack of sanitation have not only killed but also maimed people. By the Second World War, medicine was sophisticated enough to keep many of those injured alive, and in some cases, set up rigorous rehabilitation programmes to build on the remaining strengths of these newly disabled people and teach them new, compensatory skills. The responsibility for the lives of disabled people was now being shared by welfare workers, doctors and nurses. Slowly, as specialization developed, other professionals, such as occupational therapists, physiotherapists, psychologists and social workers were added to the group who assumed responsibility for the lives of disabled people. Obviously, persons with disabilities owe a great deal to this team of non-disabled professionals and charity workers. Firstly, for keeping them alive; secondly, for teaching them new skills; and thirdly, for obtaining a certain amount of institutional security. And grateful we are. However, not all that has been done, in the name of caring, has been of benefit to disabled people - or the broader society. Medical and custodial care was mostly seen as short term, as certainly many physically disabled people did not live very long. Blind people seemed to "cope", other disabilities like deafness and epilepsy were invisible enough not to cause concern; and mentally disabled people were easily hidden in institutions. However, two major developments have changed this pattern irrevocably: 1. The advancement of medical technology and 2. The increase of violence.

The late sixties saw a whole generation of post-polio, young adults who had, through the advance of medical technology in the late forties and fifties, been saved from dying. At the same time people returned from wars in the sixties - notably Vietnam and the Israeli Six Day War - with severe injuries often resulting in permanent disability. These were young adults who, all around them, watched the swelling liberation movements of people of color, students, women and gay people. People who were fighting for their rights as equal citizens in society. Their cry for consumer rights, self-help, demedicalization, de-institutionalization, equal accessibility to education, employment and public facilities were all issues that, had particular relevance to people with disabilities who had mostly been excluded from the society in which they belonged.

Stereotyping

There exist many stereotypes which have boxed disabled people into neat rather sub-human categories. These stereotypes define people with disabilities as passive, weak, helpless, unable to make decisions or take responsibility for themselves, overly sensitive, asexual etc. The saddest thing about stereotypes is that they have the potential to develop into self-fulfilling prophesies.

The flip side of all negative stereotypes is equally destructive and unrealistic. For very often those people who break out of the box, are then seen as brave, amazing, having superhuman qualities such as a 6th sense. These people are put on pedestals as "examples" to be waved around like toy flags - "supercrips". They are equally unrealistic - and dangerous - as they deny the essential humanity, vulnerability, range of emotions and responses with which we credit average human beings.Most stereotypes emerge from a combination of a personal projection of tragedy and ignorance. How often does one not hear both ends of the continuum in one reaction to a person with a disability: "Oh shame, how dreadful, I couldn't cope in her situation." This reaction distances the able bodied person from someone with a disability, often with an inherent assumption that they can't be "one of us".

As soon as someone is seen as other than "one of us", different standards can then apply.

This parallel is clearly seen in the racial stereotypes in this country. Once white people have classified people of color as "different from us" such attitudes and standards easily arise, for e.g.. it doesn't matter that black people are facing a winter living under plastic sheets or in corrugated iron shanties as "they don't feel the cold like we do ." We conveniently sweep aside the fact that 20 or more Black people will be sharing a tiny house which would acceptably house l or 2 white people excusing it as "part of their tribal pattern." On and on until we have laid all the blame on the individual and taken the responsibility away from ourselves and the broader society. People with disabilities, like people of color, women and gay people have begun to say "hang on, those are your projections, your assumptions, your definitions of our inferiority and that these projections are convenient to maintain the power balance firmly on your side."

Coming of age

The late 60's and 70's saw a "coming of age" of people with disabilities across USA, UK, Europe and Scandinavia. Disabled people not only began to unite, but to identify areas in which they were discriminated against and oppressed. They also began to understand the methods of their oppressors. Oppression was often unconscious in the heads of the oppressors, or excused as "being for their own good" - and runs along very similar lines to patronizing colonialism. Once recognizing their oppression disabled people began identifying with other oppressed groups and from them learnt strategies with which to fight it.

It must be pointed out that while we have come a long way, we still have not completely shaken off the view of disabled people as being pitiable outsiders, recipients of welfare and patients in the medical system. Each phase has left its stamp and embedded influences.

There are a number of common characteristics of the medical and the welfare phases. There is the belief that the professional is the "expert", the controller of knowledge and has the power to direct the situation. The disabled person is regarded as the client or patient, an inferior member of the "team" - if a member at all. The latter is considered a passive recipient of whatever service. Not only are disabled people deemed incapable of making decisions about our own lives, but the hierarchical relationship itself perpetuates passivity, ignorance and inhibits participation in every aspect of our lives.

Characteristic of this phase is that the "problem." is perceived to be within the individual and that therefore the focus of expert attention is on changing the individual to fit into society. This phase, in its extreme, does not question the status quo of society. Segregation into special institutions, separate (and often unequal) facilities - such as transport, sheltered workshops, schools and homes are not questioned, but rather the individual is shaped to fit into this divided, Apartheid-like society. The society is satisfied it has now matured enough to provide such facilities, and professionals are unquestionably taught to prepare disabled people for this life.

Disabled people began to realize that the preparation to live a " life apart" was not just an individual matter but common to almost all people with disabilities. They began to recognize that oppression was similar regardless of the disability. And that their strength lay in a united force against a society which discriminated against them because they dared challenge the myth of the "normal healthy body." In fact their challenge has become more conscious and more concerted than this: For equal opportunity and full participation in society.

The liberation movement

In the 70's and 80's people with disabilities around the world have gotten together to identify issues and strategies. One of the most clear cut foundations of the next phase, the liberation movement, is the identification of the difference in the terminology between disability and handicap. (Different countries have slightly different terminology, but the distinction is the same).

Disability refers to what is inherent in the individual and to a large degree unchangeable and static. Handicap refers to the restrictions experienced in society.

These are dynamic barriers which prevent integration. They are most obvious in attitudes, education, environments, transport, employment, relationships and the media and also in the availability of equipment, medical services, information, housing, personal assistance et al. Disabled people internationally are effectively coming together and challenging society, those in authority and professions in the related health care fields:

- To recognize that disability is not our major barrier to living fulfilling lives.
- That the barriers outside us, including the attitude towards disability are where our oppression lies.
- That we too are "experts" in the field of disability. And what is needed is a democratizing of knowledge.
- That we can identify needs, make decisions and evaluate services.
- That we no longer accept the inferior, passive role of the recipient.
- That if they are to work in the field of disability the only relationship acceptable to disabled people is that of equal partners.

This undoubtedly demands a great deal of change in the relationship between professionals and people with disabilities, changes which have engendered enormous feelings of inadequacy and discomfort in able bodied professionals.

The parallels are easily identifiable in those cries from many white liberals in this country, who equally have staked a claim on: ways of relating, where they live, are educated, work and play holding other standards for those they see as "different". Statements like "but they'll be happier to be with people of their own kind," "they will be protected and have facilities geared especially to them in separate institutions" are constantly heard. Some people have begun to recognize the hollowness and political connotations of such statements when describing racial issues. Few have seen how in the disability field they are also serving the needs of the dominant group - under the insidious cloak of supposed "caring".

The South African Disability Rights Movement (DRM)

The development

In 1981 we saw the foundations of the South African Disability Rights Movement/Independent Living Movement (DRM/ILM) being laid. It was designated by the United Nations as International Year of Disabled Persons (IYDP). While the South African Government chose not to recognize this year, individual communities in South Africa formed coordinating committees to work on disability issues. The composition of these groups varied in different areas, but a striking aspect of some was that disabled people were represented and were sometimes even in the majority - taking leadership roles.

We had learnt an important lesson in watching the international scene a year previously. Disabled people from around the world demanded a 50/50 partnership of the professional/welfare dominated organization Rehabilitation International (RI), or, a total

split. They were not granted the equal partnership - professionals were still threatened by having to take their patients/clients opinions seriously - so disabled people broke away and formed their own organization - Disabled Peoples' International (DPI).

Gaining strength

Welfare, in splitting us off into different disabilities - supposedly to deal more effectively with specific problems - had in fact weakened us by denying our common barriers. We grew, excitedly, to realize that, regardless of whether we were blind or used a wheelchair, our strongest handicap was society's view of us, that because we were different from the so-called norm, we were inferior. Our only way of effectively challenging this and changing our destiny was a united front. This was one of our most dynamic and energizing experiences in South Africa at that time.

Through the next few years self-help groups emerged around the country. These sometimes emerged as a result of ineffective professional services, sometimes because stereotypes were simply non existent and only occasionally with the blessing and encouragement of professionals. By 1984 we had formed a national organization, Disabled People South Africa (DPSA). This is primarily a coalition of self-help groups, but also a way of linking up individual people with disabilities.

The composition of DPSA is strictly across disabilities, races and ages. lt remains outside of party-politics, and has at any one time included a range of attitudes from anti-white attitudes to very conservative whites. It is interesting to observe that in national conventions it is for some people the first time they have sat next to and communicated - as equals - with both people of a different race and a different disability. Like the DRM worldwide, DPSA is challenging the barriers which prevent us from participating on an equal basis in a society. This includes a challenge to welfare and health-care professionals. In other countries much of the challenge has been reinforced with legislation. This anti-discrimination legislation is based on the recognition of human rights.

A question which obviously confronts the DRM in South Africa is how do we legally confront discrimination against us as disabled people in a country which does not recognize the equal rights of all people. How do you fight for an improvement in the very inadequate disability grants - which for whites is over R200 per month, when for coloreds and Asians it is half of that; and for black people it is half again. And this, for anyone who has an income, will immediately lose.

We have additional problems in South Africa: extreme overcrowding of black hospitals, insufficient training in basic nursing techniques related to long term disabilities, the inappropriateness of knowledge and experience of White therapists taught in "white" medical schools working in "black" hospitals, and the environment of the majority of black people. For example, of what use is it to learn to transfer sidewards from a wheelchair to an accessible toilet if you only have a corrugated iron privy in the back yard into which you can't get a wheelchair. But how many white therapists have intimate knowledge of that community? We are separated, by color, from the time we are born, yet they are supposed to teach their "patients" useful skills. Nothing is untouched by Apartheid.

The most widely accepted requirements to keep a spinal cord injured (SCI) person alive is the combination of knowledge, a high level of sanitation, the right equipment and the motivation to live. How do we expect black SCI people to cope when most of the medical staff don't speak their language, have too many people to treat so time for careful interpretation is often non-existent -and we then return the person (even if we have given them a state-provided wheelchair and cushion) to an environment too small for a

wheelchair to manoeuvre in and in which one tap is shared by a whole street with no prospect of employment. Many SCI people recognize that re-employment will rely on education qualifications that are higher than those of others and a tendency towards managerial and sedentary work. The majority of black SCI people have little education and were often manual laborers.

Sanitation/poverty

The medical profession has long recognized that many diseases are directly related to poor sanitation, overcrowding, undernourishment and compounded by inadequate education. Many of these diseases result in long term disability, viz polio, TB, tracoma and leprosy, rheumatic heart disease and meningitis. It is acknowledged by many that these types of disability are far more prevalent in 3rd World countries. While some, like polio, have been almost stamped out in developed countries like USA, UK and Scandinavia.

It has to be pointed out that while we don't find a high incidence of the disabilities related to poverty in "white" South Africa, they are still extremely prevalent in "black" South Africa. For instance, there were 150 known cases of polio in Letaba, Gazankula in 1982, with more recent outbreaks in Alexander and the Transkei this year - the two former being rural homelands, the latter, Alexander, an urban " location" - both used as dumping grounds to keep "black" people out of "white" South Africa and "white" Johannesburg respectively.

Violence

A further aspect of our South African society is the prevalence of violence in "black" communities. At "normal" non-unrest times we look at the difference in causes of injury in "white" compared with "black" communities. The majority of "white" people will sustain injuries in motor vehicle accidents or sport. In people of other colors the major cause is violence: stabbing and gun shot - many of these by "trigger happy" police.

How then does this picture change in an unrest situation? From 1976 onwards, we have been fed the cold, frightening figures of those detained, killed and those known to be injured. Seldom have we publicly been made aware that, of those injured, some will be disabled for the rest of their lives. From the '76 Soweto riots we know that children lost limbs from bones being shattered or bullets going septic. Others were paralyzed through being shot in the back while running away.

In the last few years, increasingly we know of people being spinal injured (even with bullets going through as high up as the neck), blinded by birdshot, brain injured from bullets through the skull and even now suffering permanent hearing loss through torture. To what do we have to return these people? Overcrowding, bad sanitation, appalling roads, few community resources, little education, less employment. While professional-patient relationships still leave a great deal to be desired, the problems are far greater than this, they are within the structure of the political system. There are individuals who are health care professionals who are enormously caring, and who have begun to recognize the value of working with those of us in the DRM. But they alone cannot solve the problems, we need a concomitant change in the political structure.

An often asked question in South Africa is how politicized are people disabled by violence - even "domestic" violence. Politicized they are, that there is little doubt. But around what issues will they devote their energies? First and foremost, it seems disability issues. This is not a cop-out of broader political issues but must be seen in a realistic context. If Apartheid has said black people can't get onto "white" busses, live in "white" suburbs, get "white" jobs and are limited in relationships, disability has meant they can

get on no busses, lose almost all prospects of employment and often lose houses and families and, as long as health care and sanitation is inadequate, they will continually be dogged by health problems. They will also now live with a constant mobility, media, education, relationships, housing and transport handicap because of their disability. In order to get back into the "normal" struggle of black life, they first have to break down disability related discrimination.

Conclusion

All over the world traditional welfare and health professionals alone have been totally unable to substantially diminish handicaps faced by people with disabilities. It is only when disabled people themselves have taken responsibility into their own hands that we have seen a noticeable change. The particular handicaps the majority of disabled people in South Africa face are inextricably linked with Apartheid. Therefore in challenging and dismantling these handicaps we also need to do the same to Apartheid. However there is no point in waiting for post-Apartheid society, we need to change attitudes and break down barriers now both for the existing disabled people, but also for all those who will become disabled.

Source: Disabled People South Africa, P.O.Box 662, 5256 Gonuble, Republic of South Africa

Independent Living and Our Organizations

Presentation at the conference "Our Common World" organized by Disability Rights Advocates Hungary in Siofok, Hungary, May 9-11, 1997

Dr. Adolf D. Ratzka
Institute on Independent Living, Stockholm, Sweden

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves. To this end we need to support and learn from each other, organize ourselves and work for political changes that lead to legal protection of our human and civil rights.

Statistics show that disabled people have less education than the rest of the population, have worse housing, are more often unemployed; fewer of us get married and have children. We have been told that we are different and that our lives are worthless. In many countries babies with disabilities are not even given the chance to live, they are killed before they are born.

One of the most important causes of our second class citizenship is the way society looks at persons with disabilities. There is a tendency to label people who are different as "sick". Sick people do not have to work and are exempted from the normal duties of life. As long as we are considered sick by the general public, there will be little understanding, for example, why we need to use regular public transportation, why we demand real jobs and not just therapy.

If we let other people treat us as if we were sick persons, we should not be surprised, if they try to protect us and in the process control and limit our lives. If we consider ourselves sick and in constant need of a "cure", it will be difficult for us to accept our disability as a normal part of life and to carry on with our lives.

The medical model of disability sees the problem in the individual. I cannot use public transportation in most countries. Is it because I had polio some 30 years ago or is it because the busses are constructed without consideration for the needs of all users, including people like me who use electric wheelchairs? As long as society believes that the problem lies within me, there will be no accessible busses.

The medical model uses diagnostic labels which tend to divide disabled people into many different groups. Diagnoses make us feel different when, in fact, we share many of the same problems. In the Independent Living philosophy it does not matter for what reasons we have a disability. What matters is the recognition that all people regardless of type or extent of their disability can learn to take on more responsibility, to make more decisions concerning their lives and to contribute more to their families and the community.

Rehabilitation is an intervention that is limited in time and scope. We need to have access to the best medical and rehabilitation services including assistive devices. But real life starts after rehabilitation, only then we find out whether society is ready to accept us. Unfortunately, most often we find that society needs to be rehabilitated more than we do.

Many of us are shut away in institutions. There, it is claimed, we can be better "cared for". With this argument we are put into special kindergartens, special schools, special workshops, special housing and special transportation. Special schools or special workshops make us feel different and prepare us poorly for the competition in the real world. Our movement is fighting to shut down institutions and to force our way into the mainstream of society.

In many countries there are charity organizations, headed by non-disabled individuals, which raise funds by depicting us as helpless, pitiful and miserable beings. Often these organizations speak out on behalf of disabled people and advise governments on disability policy. Disabled people themselves are seldom asked about what they need.

How can we improve our situation? How can we empower ourselves?

We must break the monopoly of non-disabled professionals who speak on behalf of us, define our problems and suggest solutions to our needs. We must build effective organizations that represent the views of disabled people themselves. Governments have to recognize our organizations as partners in shaping disability policy.

Disabled people have to utilize the political process and run for office. In most countries, about 10% of the population have a disability. The world would look different, if in each country 10% of the politicians had a disability.

By the same statistics, with only 10% of the population we are a minority. In a democratic system we cannot expect to get legal reforms and support systems approved by parliament unless we are able to convince other voters. We need political allies, we need to build up alliances among the various organizations of persons with disabilities. We also need to look for allies among the non-disabled. There are many non-disabled persons who support our fight for equal opportunities, for human and civil rights. And we have to reach out and convince more people of our just cause. But one thing has to be made very clear: We are the experts. Disabled people have to run, represent and control their own organizations. We have to be at the forefront of this struggle. Non-disabled people can support us from behind.

In fighting for our rights we can be more effective when we help each other in changing our attitudes towards ourselves. To see yourself as a profoundly ordinary person is difficult when you have always been told that you are different, that you can not do this and can not do that. In this struggle we need to talk with somebody we can identify with, with people who are in a similar situation. We call it peer support. Peer support means to share the fruits of one's experience.

In a number of countries, disabled people are helping each other in Independent Living Centers by sharing information, advice, legal aid and peer support and by organizing the disability community. The people who work in Centers for Independent Living are themselves disabled and know what they are talking about from first-hand experience. The centers work for changes in the communitiy, such as improved access in housing and transportation. In several countries, Centers for Independent Living receive regular government funding, because it is recognized that disabled people are the best experts on matters concerning disability.

Any society that claims to be a democracy and respects human rights has to extend these rights to all its citizens. In order to guarantee our rights there has to be proper legislation including monitoring, periodic revisions and effective sanctions. The organizations of disabled people have to be decisively involved in all these stages. Legislation must protect us from discrimination in all areas of public and private life. The United States have set an example with its Americans with Disabilities Act that was highly influenced by the Independent Living philosophy. Such legislation is now in place or is being worked on in a growing number of countries. But we disabled people must realize that no piece of legislation by itself will automatically guarantee our equal rights unless each of us in his or her everyday life actively claims and uses these rights.

Throughout history there has been the attitude that disability is a catastrophe for the individual and the family, that we depend on the mercy or solidarity of other members of society, that we can not contribute, that we are a burden. This brainwashing has distracted us from the realization that disability is a political problem, a question of unequal distribution of power, not a medical or technical problem.

Because we have been told we cannot do much for ourselves, we have relied on other people to fight for our cause.
Because we have been ashamed of our disability, we have stayed in the background.

We are the last minority to fight for our rights and we will not go away. Even with the most sophisticated prevention, early detection and rehabilitation services there will always be people with disabilities and we have to build our societies in such a way that everybody

can live in them with dignity and self-respect. And we have to start now.

An American definition of Independent Living

What is Independent Living?

Essentially, it is living just like everyone else - having opportunities to make decisions that affect one's life, able to pursue activities of one's own choosing - limited only in the same ways that one's nondisabled neighbors are limited.

Independent living should not be defined in terms of living on one's own, being employed in a job fitting one's capabilities and interests, or having an active social life. These are aspects of living independently. Independent living has to do with self-determination. It is having the right and the opportunity to pursue a course of action. And, it is having the freedom to fail - and to learn from one's failures, just as nondisabled people do.

There are, of course, individuals who have certain mental impairments which may affect their abilities to make complicated decisions or pursue complex activities. For these individuals, Independent Living means having every opportunity to be as self-sufficient as possible.

Independent living. It isn't easy, and it can be risky. But millions of people with disabilities rate it higher than a life of dependency and narrow opportunities and unfulfilled expectations.

Independent Living centers

Fortunately, people with disabilities don't have to do it all on their own. The purpose of this brochure is to describe a kind of service organization which is designed specifically to assist people with disabilities who themselves have been successful in establishing independent lives. These people have both training and the personal experience to know exactly what is needed to live independently. And, they have deep commitment to assisting other disabled people in becoming more independent.
Services of Independent Living centers

Centers offer a wide variety of services. Four are essential to efforts of people with disabilities to live independently, including:

- Information and referral: Centers maintain comprehensive information files on availability in their communities of accessible housing; transportation; employment opportunities; rosters of persons available to serve as personal assistants, interpreters for hearing impaired people, or readers for visually impaired people; and many other services.

- Independent living skills training: Centers provide training courses to help people with disabilities gain skills that would enable them to live more independently; courses may include using various public transportation systems, managing a personal budget, dealing with intensive and discriminatory behavior by members of the general public, and many other subjects.

- Peer counseling: Centers offer a service in which a person with a disability can work with other persons who have disabilities and who are living independently in the community. The objective is to explore options and to solve problems that sometimes occur for people with disabilities, for example, making adjustments to a newly acquired disability, experiencing changes in living arrangements, or learning to use community services more effectively.

- Advocacy: Centers provide two kinds of advocacy: 1) consumer advocacy, which involves center staff working with persons with disabilities to obtain necessary support services from other agencies in the community and 2) community advocacy, which involves center staff, board members, and volunteers initiating activities to make changes in the community that make it easier for all persons with disabilities to live more independently.

- Other services: Centers also offer a number of other services, generally depending on specific needs of their consumers and lack of availability elsewhere in the community. Among the most frequently provided services are community education and other public education services, equipment repair, recreational activities, and home modifications.

How Independent Living centers differ from other service organizations

There are many different types of organizations which serve people with disabilities - state vocational rehabilitation agencies, group homes, rehabilitation hospitals, sheltered workshops, nursing homes, senior centers, home health care agencies and so forth. These organizations provide valuable services and are important links in the network of services that help people with disabilities maintain independent lifestyles.

What makes Independent Living centers very different from these other organizations is that centers have substantial involvement of people with disabilities making policy decisions and delivering services. Why this emphasis on control by people with disabilities? The basic idea behind Independent Living is that the ones who know best what services people with disabilities need in order to live independently are disabled people themselves.

A final word on Independent Living

Changes that make life more satisfying don't occur overnight. But, for people who are willing to work toward greater independence, Independent Living centers can help put the pieces together.

Source:
ILRU at Texas Institute for Rehabilitation,
2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Independent Living:
Ideology & definitions

Resources

By the time this kit is ready for distribution, the BBC Education Service will have produced a series of 5 one-hour television programs on disability under the catchy title "Labelled Disabled". One of these programs will be on Independent Living featuring many of the persons, projects and locations that you find here. The BBC will also produce a publication accompanying the television programs. For details write to BBC Education Service, Villiers House The Broadway, Ealing W5 2PA, United Kingdom.

Berrol S, "Independent Living Programs: The Role of the Able-Bodied Professional", Arch Phys Med Rehabil, 60:456-457, 1979.

The Independent Living Program movement was created by the disabled community. It has established a broad coalition of diverse disabilities functioning to provide services on a broader scale than has been traditionally offered by the rehabilitation community. The effectiveness and the strength of the movement lies in consumer control. The non-disabled professional can provide expertise, balance and a vital link with established rehabilitation programs. The integrity of the Independent Living program movement can only be maintained and developed if these basic concepts are respected.

Nosek, Peg, Yayoi Narita, Yoshiko Dart. A Philosophical Foundation for the Independent Living & Disability Rights Movement. Occasional Paper No. 1. Houston: ILRU Program, 1982.

This monograph presents a personal reflection on the nature of Independent Living. It includes a blend of philosophical concepts form many cultures and critical lessons from personal experiences. The views are also shaped by discussions the authors held with leaders of the Independent Living Movement.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

DeJong, Gerben, "Defining and Implementing the Independent Living Concept", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Personal accounts

What is your personal definition of Independent Living?

It is the ability to live independently and productively in the community and to live with the same freedom of choice as a non-disabled person. So it's not that you are living on your own but that you control where you live and have the same range of choices as a non-disabled person. (Jill Weiss)

Independent living means the ability to examine alternatives and make informed decisions and direct one's own life. This ability requires the availability of information, financial resources and peer group support systems. Independent living is a dynamic process, it can never be static. A person's physical, emotional and social environment and subsequent needs are continually changing and evolving. The struggle for Independent Living and personal determination is something each disabled person must approach in their own way. However, as disabled persons we have common problems and concerns and we must continue to work together to eliminate artificial barriers to our full and equal participation in society. (Michael Huck)

Independent living really is an idea, a concept, a thought process. You apply this thought process to your lifestyle. I would think that even if a person were in prison and the only choice that they could make would be whether they would eat their food when they first got it, or eat it an hour later, they would still be practicing Independent Living. (Elizabeth Semkiw)

I feel Independent Living is living independently without the dependency created by an institution.
(Doreen Demas)

Is your current lifestyle an example of Independent Living?

I have not the same choices as a non-disabled person but over the years I have developed a system and options. So I have close to the same range of choices but that's only because I have my own money. If I were simply dependent on what society has to offer, I would not be productive. It's very clear to me that what I am able to do in terms of the work I do in the BC Coalition of the Disabled and in other organizations is a function of the aids I have acquired. If I didn't have them when I needed them, I couldn't make my contribution to society.

Having control over my own workers is very important. I have arranged things so I select my own worker now. That has made a big difference in my life. As long as I was getting homemakers from the government agency that took an enormous amount of time each week. You have to really work to ensure that the homemakers do the work that you need done. I used to establish a close personal relationship with the person so they would have motivation.

Now that I pick my own people they feel responsible to me. Legally they are the agency's employee but they and I know that they are my employees. It takes a lot less of my time and energy this way. It also makes an enormous difference that I have money to pay for extra hours. I'm able to say, this is what I want. If there are things that I want done that are outside the government's guidelines, I pay for it with my own money. (Jill Weiss)

I control my finances, activities, schedule, routine the things that most people control. I have as much control as a person can have. Let's face it, nobody can have perfect control. Control is a key factor. Any aspect of living in which one chooses the management and organization such as medical supports, banking or buying groceries, is an avenue of exercising control. (Elizabeth Semkiw)

Well I feel it is and it is not. My lifestyle is an example of Independent Living as I took responsibility for myself and made the decisions concerning my living arrangements. When I was living with my parents, I chose to move out. Then later on I chose to move back home with my parents. In both living situations I took responsibility for ensuring that my personal care needs were met.

My current living arrangement is not an example of Independent Living because I have not attained the living situation which I desire, or which is complementary to my lifestyle and future goals. This is due to a lack of support services in the community where I live. (Connie Oxelgren)

I would say I'm very independent. I have my own responsibilities, I take full responsibility for my family. I've lived the same as if I were not disabled, up to the point where my disability precludes what I want to do due to architectural barriers or something like that.

I don't feel in the area where I live, which is a rural community, that Independent Living is possible without the backup of a family. There are a lot of people who would say that this is not Independent Living but to me it is. I feel I'm very independent! I'm a mom. It's my house, I'm responsible for it. I manage the cheque book! The car is in my name, I drive it. What I'm saying is that my life is no different than it would be if I wasn't disabled. The only difference is the architectural barriers that say to me, you can't go there, there's no way you can get in. (Myrna Ells)

What obstacles did you have to surmount in order to achieve your current lifestyle?

Well, I think probably the biggest obstacles to disabled people is economic freedom. I think that if you have money, you can do a whole lot more than a disabled person on a pension. I have been on a pension and know what it is like to be on a limited income. The reason I own a home is because I'm married to someone who makes a reasonable income and at one point I was working too, so we were able to buy a home. When we were buying a house we were treated exactly the same as any other consumer buying a house. If a person has a limited income often they have to live in subsidized housing which sometimes provides personal assistance. A lot of times that is ok and you can control the hours but sometimes you can't and you have to be there for the convenience of the service provider. What I like about my life is that I don't have too much of that. (Pat Israel)

Two things, the severity of my disability and what is even more important, the perception of the position that my disability will play in my life. I need a lot of support services. If a person unexpectedly came into my situation, as from an able bodied situation, they might say, "Well, I can't possibly live alone!" However because it came up gradually, I've been able to adjust my perceptions and organization of supports and say, yes, I can do it. The disability is not what's most important. What's most important is your psychological ability to say despite my disability I can do it. To control. (Elizabeth Semkiw)

When I was young I went to a segregated school for blind children - an institution. Before I went there I'm not sure if I realized that I didn't see very well. So all of a sudden I was forced into a totally different situation. You also have to remember that I was taken away from my own cultural setting - the native culture. So it was a big shock for me. I did a lot of observing. I had never been around a blind person in my life before. I didn't speak English either.

At Brantford we didn't get much exposure to the outside community. We were allowed to go out every so often, but it was always in a segregated way. So you don't learn to interact socially with other people. You are used to being with your... I shouldn't say your own kind, but that's how it was. Then you come out and reality hits and you go through this identity crisis. I have come across other people who went to Brantford and who had the

same experience.

I was lucky because I didn't do all my schooling at Brantford. I went when I was six and I stayed there until I was twelve. After I left Brantford I had to interact socially with my own peers in public school. It wasn't easy. All of a sudden I realized that in some ways I felt really different, that I wasn't like everybody else. I think I went all through school with that attitude - that feeling of inferiority.

So I think for a while I put all my efforts into being normal. Until one day I realized, normality was accepting myself for what I was. Once I broke out of that I found things so much easier. I've learned how to feel comfortable around people.

The biggest obstacle for me was my attitude. For a while I thought I'd never be independent the way I wanted to be. Then I realized that everybody relies on somebody for something. You have to take the attitude that given the right situation, the right approach, you can function like everybody else. That's a start towards other things. (Doreen Demas)

In 1983 I moved out of my parents house, and into my own rental accommodation. Before making the move, the first and most important obstacle I had to surmount was myself. I needed to have the self-confidence that I could live more independently than in a nursing home. This transformation occurred in an interesting way. In 1981 the Saskatchewan Voice of the Handicapped began a series of Independent Living projects. I gained a lot of support from the peer counseling project. Project staff believed I could move into a more Independent Living situation even when I did not. That was important. Looking back, I view that project as a catalyst towards my becoming more independent.

As far as other obstacles I had to surmount, they tended to be skills I had not developed. On the job I quickly gained knowledge about screening and interview techniques, scheduling attendants and general attendant management.

Some people may encounter funding an attendant a problem. I did not. I simply approached my social assistance worker and explained my personal care needs, the amount of time I required assistance, and the projected total cost. Within a couple of weeks the funding was approved. (Connie Oxelgren)

The biggest obstacle was the realization that my life circumstances changed all of a sudden to being a person with a disability. I made an effort to learn the system. What made me able to live an independent lifestyle in the community was that I treated my disability as a job. I think at this point in time the major obstacles to greater independence or any improvement in my lifestyle are basically financial. (Glenn Cave)

What governmental and community changes do you believe are required to facilitate Independent Living efforts?

There needs to be self-help counseling right away for a newly disabled person. Secondly there needs to be adequate services for someone who has just become disabled: homemaker care, transportation, financial support, etc. I know for myself, I made my disability worse by continuing to work but there was no alternative.

Adequate services in the proper amounts have to be conveniently available. It is already enough to deal with a disability and then to have to deal with the complicated and terribly disorganized service delivery system is to add insult to injury that is already deep enough.

Services all should be under the individual's own control and designed to facilitate independence. For example, it is insane for homemakers to be allowed only to make meals and change beds. They should be allowed to file papers, help with transportation, do all those things that are necessary for a person to be productive. The disabled person should be in control. There is absolutely no reason why a disabled person shouldn't be choosing their own worker. All the necessary supports should be available, then disabled people could go out into the community and succeed or fail on their own merits. (Jill Weiss)

The availability of appropriate housing and support services are tied closely together. In Edmonton a small number of housing facilities for disabled persons have homemaker and personal care services associated with them. This has restricted the range of housing options available to us. Universally available support services would allow us the opportunity to choose housing on the same basis as families without a non-disabled member. (Michael Huck)

I think government should just give disabled persons who need attendants a cheque. Let them hire and fire and train their own attendants. I think that this would make a big difference to any person who needs any kind of personal assistance. I think disabled people would be able to move out of institutions a lot quicker and wouldn't have to stay in them as long if they could get good personal assistance with people they could rely on. I think they should be the ones to train them because they are the experts.

I think we should be like England where there are a lot more in-home services. They have found that the seniors and the disabled can stay home a lot more if there is an appropriate amount of services. I hate to see people going to nursing homes or institutions that could stay out another 10 or 15 years. Each city or small town has to have appropriate amount of services. I think consumers have to have direct input into them and have control. Having the appropriate services will lead to a disabled person having a much better life and doing other things like getting a job or volunteering at a job or whatever. I think the government should recognize Independent Living as a right and the public should recognize it as a right. There should be more publicity aimed at that. I think that now people see it as a privilege.

With respect to community changes I have a complaint to make about the women's movement and women's services that are offered. I find that they're not offered to disabled women, mainly because of inaccessibility. I would like to use women's services because as a feminist, I feel more comfortable with the women who are providing these services. I call and get frustrated because they're inaccessible. We need to remember disabled women are mothers and need access to child care services. They often can't get their kids into a nursery school because it has two or three steps. These services are part and parcel of the world we live in but nobody ever thinks that a disabled woman might need an accessible child care center or something like that. I think we have to think more broadly in terms of services for disabled people. Every service, that any person would use, should be accessible to us. (Pat Israel)

Community needs to change its perspective and to accept that support services are a right not a charity. Government must provide funds to the disabled so they can achieve the change in perspective. Government must also make its own services accessible to all. (Henry Vlug)

They're going to have to smarten up! Two things are going to have to happen. Firstly, they're going to have to listen, to really listen to what disabled people have to say. Secondly, they have to recognize that when you control your life and make your decisions, you also incorporate a risk and that is part of life. No matter how disabled a

person is, they choose to take a certain risk because it gives them certain freedoms. It is their choice and it is not anybody else's right to interfere with that choice. Very often a risk is taken again, for freedom, trading one thing off for the other. That has to be recognized by the community. That it is a disabled person's right. (Elizabeth Semkiw)

If I were building an ideal support service system, I think I would develop a program that was very much individualized. Where the individual would come in and they would tell you exactly what their needs were. If they said ok, I need x amount of nursing services or personal assistance services, I need x amount for homemaking, then that need would be assessed and if it was justifiable, (I think you always have to be accountable) then have the monies flow directly to the individual. I'm a firm believer that the individual knows best what their needs are and the best way how to meet them. I think it best if the dollars went directly to the person and they themselves were able to go out and purchase their own services. Three things I think would happen, 1. I think the thing would be more cost effective, 2. better meet the person's needs and 3. it would give them the control that I talked about earlier when I defined Independent Living. You'd soon see a lot of these service providers falling into line. No longer would they be just developing services because the government gives them the bucks. Either they'd be meeting people's needs or they wouldn't be in business. I think the concept of the dollars following the individual is a really good one. (Rick Laird)

What recommendations do you have for other disabled citizens?

Society has to be changed. You can't do it yourself. There is no way. There is no way out except with everyone else. Unless you are really rich and you have a lot of money. The way to make things better for oneself as an individual is to pull and struggle with other disabled persons. You have to keep fighting like a tiger. (Jill Weiss)

I think my one recommendation is to be extremely assertive, sometimes aggressive, because if a social worker says to you that you can't have something and you know you need it, go above that worker's head, go to the top, go to the media. Use what's out there to get what you need. Feel that you're an equal person to everyone else.

Peer support is important. I think in terms of peer support, I can tell a young disabled person a lot of things that no non-disabled social worker could tell them. They might listen to me a lot more and maybe learn things that they would never know. for example, I met a woman who had just become a quadriplegic by MS and the one thing that she was worried about was that she couldn't turn herself in bed at night. I said, "well, why don't you get satin sheets?" Satin sheets for a disabled person are wonderful! You can actually turn yourself on a bed much easier and much quicker. Now, no nurse, no rehab worker had ever told her this and I think they had never thought of it. There are so many little things like this. (Pat Israel)

Make the best of what is available now. It isn't enough but it's there. But don't be satisfied with what is available. Fight for what we are entitled to. We may never get it all, but by fighting we will get more. (Henry Vlug)

I recommend that they really decide if Independent Living is for them, if they want it, that's what it boils down to. Just because everybody else is doing it, they don't have to if they really don't feel that they want to take that risk, they don't want the control, they don't want the decision making. That is their choice too. They should feel free to say "Well, I'd rather be in a situation where this is decided for me and I don't have to worry about it." That is their prerogative. If they want to go into a situation where they have to take a great deal of risk for a great deal of freedom, that is also their choice. They should really sit

down and match one against the other. They should write down what they want to gain and what they are willing to lose. They can figure it out from there.

I also emphasize the gradual accepting and organizing more help for yourself because very often, physical conditions for everyone vary from month to month and year to year. Some years you are in really good shape and you don't need a lot of help end the next year you need a lot of help for six months. If you do need more help for a while, don't have a mindset that that's how it's going to stay. Think positively that you can grow out of it, out of the situation that you are in. People have gone from nursing homes to independent lifestyles. It's not that you are in one particular situation and have to stay in it, but adjust with your physical disabilities. If it's time for your body to get more help then get more help.

When we don't gradually increase the help we need, and struggle from an unrealistic sense of independence, then we often fall into crisis situations and there we really lose all control by ending up in a hospital etc. We then have to struggle to get back up where we were.

I would hope that there would be more push. That the advantages of Independent Living both in terms of cost and people should be got across to the powers that be. (Elizabeth Semkiw)

One has to want to be independent. When that's established, everything else will come. Most things are not impossible. Attitude is a very big thing. You're not special because you are disabled. Nobody's responsible for you except yourself. So it's up to you to make your way. Be assertive but not aggressive. (Doreen Demas)

Well, one of the things that is key is that you have to seek out and educate yourself to what resources are available and make best use of what is available. Lots of times what we have to do is piecemeal programs. One program generally doesn't cover it all. You have to look around and try to put together as much service as you can. There are an awful lot of generic services that are available that we don't use. They do cost and sometimes you might have to put out money for them. For example, I know that some of the regular food stores have programs where they deliver groceries. Getting groceries could be a problem for one person. Instead of going to the government and saying will you hire someone to deliver these things, you could pay two bucks, or whatever it is, to have those groceries delivered by the store. There are a lot of services in the community that sometimes are pretty reasonable. You have to make good use of those.

I think disabled people should put some energies into developing their own personal support network. It is really tough to go from a very controlled environment like an institution to full blown Independent Living. You are all of a sudden put in the position of having to make every decision for yourself. It's a real learning process. Not having a well developed personal support network can be disastrous.

Employment is also important so a person should systematically approach trying to get some employment through retraining or schooling. Once you have marketable skills, you can have a good income. There are costs that are associated with Independent Living. It's just easier that if when you need something you can go out and buy it. With public assistance every dollar is accounted for. (Rick Laird)

Source: Defining the Parameters of Independent Living, COPOH, 926-294 Portage Ave., Winnipeg, Man R3C 0B9, Canada

What is your personal definition of Independent Living?

Interview with Mr. Javed Hassan, Pakistan

To me Independent Living means just what it says -- living independently. It means being able to take care of yourself without being dependent on another human being. One may depend on gadgets like computers; remote control units; motorized wheelchairs; specially equipped homes; baths; toilets and automobiles, but as long as he/she does not ask the other person for help while eating, changing clothes, taking a bath, going to the toilet, travelling to and entering the work place, one is independent .

I do not want to give the impression that in order to live independently one should live alone. One can be married or live with his/her parents but if he/she is independent in the activities mentioned above, one is independent. Being dependent on personal assistants for dressing, toileting, etc., is not independent living as I look at it.

Independent living carries the meaning of self-help. We should not confuse it with attendant care or personal assistance which negates independence and limits one's freedom. Even if you pay for the personal services you need, the fact remains that you are dependent on someone else's time and energy. And if that someone does not show up on time, you cannot do the next thing and you are helpless until he or she comes to help you out.

Is your present lifestyle an example of Independent Living?

To some extent and in certain departments I am independent. I meet most of my personal needs myself. But, like many other disabled people of my region, I am handicapped by the lack of transport and the absence of an accessible environment and in this respect I am not independent.

If I have to travel to a foreign country, I go alone. That's because I can manage myself. And as long as I can manage myself, I shall keep travelling alone. My disability is progressive and I am not sure how long my present state lasts but until it does, I am independent and I am happy.

What obstacles did you have to surmount in order to achieve your current life style?

Independence really is a state of mind. One has to want to be independent; so whatever obstacles or inhibitions one has, exist in the mind. To begin with, I shall say that I am fortunate enough to be able to take care of myself given architecturally safe conditions and then all I have to do is gather courage to do the things I want to do.

When I first went abroad to attend a conference of disabled people, my parents were not sure about my ability to handle myself. But I was confident that Australia was much more safe (accessible) than Pakistan and hence I wouldn't face difficulties. So I went alone. This first trip gave me the confidence needed and now I don't hesitate to go anywhere all alone. I do face certain problems of access in my home but they can all be solved if I put in more time, effort and money.

What governmental and community changes do you believe are required to facilitate Independent Living efforts?

In the Asian sub-continent there is no concept of social security to the disabled. It seems to me that our governments do not realize that disabled people also need economic security. We cannot always remain as financial burdens on our parents, brothers and sisters. We have to have our own income and since most of us are unemployed, we should get some form of allowance like SSI. Economic security is essential. IL allowance for personal assistants is also needed by some but it is a dream wish that may never come true in this part of the world.

Independent living does not mean Independent Living in the home only - it also means being independent where ever you are, at the work place, in the bazaar or at school. Outside the home, the Government 's responsibility lies in providing accessible and safe surroundings. Without architecturally accessible offices, banks, post offices, schools and universities, libraries, museums, community centres, shopping stores etc. our independence is incomplete.

What recommendations do you have for other disabled citizens?

To live a dignified life, you've got to be independent as much as possible, take risks and have control over the forces and factors that concern you. Be responsible for what you do or do not do. Keep striving, keep fighting and keep demanding. Assert yourself; never take a back seat. Don't be discouraged if somebody says "no"; keep banging and knocking until you make a dent.

Economic security is a must for any degree of independence. Without it you cannot choose what you want; you can't go where you like; you can't hire the help you need and you won't have any self respect . So try to find some employment, some paying job or, if that's not possible, set up your own business. Self employment is best for most of us. You can work when are up to it and stop work when you want to. You are master of your time. By having your own job and mastery over time you'll be in greater control .

Address: Mr. Javed Hassan, Association of Physically Disabled Persons, House 2, Street 40, F-7/1, Islamabad, Pakistan

Commentary

Not all of us will feel comfortable with Javed's emphasis on physical independence. We asked Phil Mason from the Hampshire Centre for Independent Living, United Kingdom to respond. Phil controls his electric wheelchair with his clean-shaven chin and uses personal assistance for many everyday life tasks.

Dear Mr. Hassan,

I found your article interesting and I admire all that you have achieved in your life. However we differ on our understanding of Independent Living. I believe that people are inter-dependent. We rely on the work of others in virtually every aspect of our lives. For example: food is grown by farmers; paper is made in pulp mills; the typewriter is made in a factory, etc.

What is important is the degree of control that we exercise in our lives. That is to say, we buy the food we want, we choose the paper that we prefer and use the typewriter that we have chosen, etc. This follows in our lives as disabled people. Independence is being able to control what we do, how we do it and when. Independent living is to do with the degree of control that one exercises, not what I can or cannot physically do for myself. I do not grow my own food. I do not feel obliged to have made this paper before I am

prepared to use it. I do not mind using a postman to deliver my letters. Etc. In the same way I do not see that my use of personal assistants in any way diminishes my independence - as long as I control the assistants.

Whilst appreciating your every endeavour to retain the physical ability to do for yourself the things that you require in your every day life I do not see this as being a satisfactory definition of independence.

Philip Mason,
Hampshire Centre for Independent Living,
4 Plantation Way, Whitehill, Bordon, Hants GU 359 HD, United Kingdom

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Personal accounts

Resources

Zola, Irving Kenneth (ed.), Ordinary Lives, Apple-Wood Books, Inc., Cambridge-Watertown, 1982.

From Irving Zola's introduction:

"Of course, most people are born into the world of the non-disabled. We only become disabled or learn we are physically different later. We are socialized into the same world as everyone else, with many of the same expectations as well as prejudices. Thus having a disability or disease, or living with someone who has, does not automatically qualify us either to be an expert witness or a writer. For this anthology, I have chosen authors who, while writing about disease and disability, are also writing about the human condition. The sources of my selections are diverse and include autobiographies, essays, novels, short stories, and poetry. I hope that whatever else they are, these are good stories -ones that make you laugh, or cry, or think about what you've read."

Zola, Irving Kenneth, Missing Pieces: A Chronicle of Living with a Disability, Temple University Press, Philadelphia, 1982.

From Irving Zola's introduction:

"I am by professional training both a social observer and a psychological counselor. Yet for over two decades I have succeeded in hiding a piece of myself from my own view. Given the obviousness of my physical handicap this has taken some doing."

This book is about Irv's encounter with Het Dorp, the 'pioneering' horizontal ghetto for disabled people in the Netherlands, and his own disability.

Advocacy

Disability issues: organizing community support

As a disabled person or as somebody close to a disabled person, you are aware of the problems that disabled people face daily. Living in a small town, you probably experience these problems to a greater extent than disabled people in large cities. There are few if any service agencies located in your community. There is little or no public transportation available to you. If you are in a wheelchair, there are few curb cuts or ramps in local business and public buildings. If you are blind, nobody uses braille. If you are deaf, there are no interpreters. Perhaps your local school representatives say that the school cannot accommodate students who have disabilities. In other words, you are segregated by the environment.

These problems are not only your own personal problems, but they are problems for today's and tomorrow's disabled people, too. Since they are the problems of a group, their final solutions are best sought by a group. If one person attempts to resolve these problems, he or she is often viewed as a person with a personal problem. When a group addresses these problems, however, the problems are viewed as "community issues", deserving of the attention and action of the community.

There is also support in numbers. Group members support each other, while "going it alone" can be frightening. In addition, solutions to the difficult problems facing disabled people require problem solvers with varying levels of skills, information, and contacts. Only a group can provide all that is needed.

Recruiting your support

The first step in developing a group is selecting an "issue"; that is, a problem that affects disabled people as a whole. An issue attracts many people with the same needs and interests. An example may be reducing physical barriers to all disabled people whether they have visual, hearing, or mobility impairments. The first issue you pick should be one that would be fairly easy to accomplish; people are more likely to try to tackle difficult problems after they have experienced some success. Research the facts about your issue by contacting such organizations as the Disability Rights and Education Defense Fund, 2212 Sixth St, Berkeley, CA 94710, United States, or your nearest Independent Living program (your state vocational rehabilitation agency should have this program address). Then organize your thoughts and opinions.

The next step is to plan your first meeting carefully. Some important points to remember are:

> Site and time selection
> Be sure you select a site that is barrier free and a time which is convenient to most people. If you have blind or deaf participants, try to make arrangements for readers and interpreters.

> Invite people with different disabilities - Don't work against each other.

> Advertise
> Try to let as many people as possible know about the issue and the meeting. This can be done through word-of-mouth, church bulletins, newsletters, community organizations, clubs, hospitals, community calendars, or the local paper and radio stations.

The meeting's agenda

Allow an opportunity for participants to respond to your opinions on the issue, to feel like active members of the discussion. Allow time for the group to decide on the time, place, and agenda of the next meeting.

Organize your group early

It is important that your group make some decisions on how it is going to operate as soon as possible. Obviously, your first meeting or two will be devoted to clarifying your issue to all members of the group, gathering the members' opinions, and getting members to commit themselves to resolving the issue. Once you have the understanding and commitment, it is time to make all the various members into a unified, thinking, working group.

The members need to elect officers or leaders of the group. Every group needs leaders to ensure that all members are working together, to keep members informed of each other's activities, as well as to speak on behalf of the group when it is time to act. Since the group is working on disability issues, it is important that disabled people are seen in roles of leadership in your group.

Finally, the group needs to decide on its goals. What is the final result the group wants from its efforts? Having that goal, the group can decide on the steps needed to reach that goal and the members who will work on each step. This kind of planning is sometimes difficult for a group to begin. You may want to ask somebody from an established organization to help with this initial planning. But remember, the final goal and plan to reach that goal must be what the group as a whole wants. Only then will all the members dedicate their time and effort to resolving the issue.

Taking action

Once the group knows what it wants, it is time to take the agreed-upon steps to reach the goal. It is time to make the community aware of the group's issue and the solutions. Whether the appropriate place to voice your issue is at a public hearing or at a meeting with community leaders, there are two points to remember:

- Be prepared-Before you go to your public hearing, make sure the whole group agrees on the major points it is going to make. Do not contradict each other. However, the group should not look like a copy of its leader. Each member should prepare various examples of the group's points.

- Go public-Before the hearing or meeting, each member of the group should tell as many people as possible of the group's issue, solutions, and upcoming meeting. Get them to support you, if possible, by sending letters of support or other obvious means such as signing petitions. If possible, contact the media-write a letter to the local paper, see if you can talk about the issue on the radio. Make your issue a community issue.

Finally, after each step is taken, the group should discuss its results. What did we accomplish, if anything? What should we have done differently? What should we do next?

In conclusion

There are many existing rights and services for disabled people that you may not know about. Moreover, just because you learn about them does not mean they will automatically protect and serve you. These rights and services must be insisted upon by

the people they are supposed to benefit or they may never be practiced. An organized group of committed people is the best avenue to attain and ensure the rights of disabled people. When disabled people become active in the community, it benefits the entire community. So, help yourself. Help the community. Get organized.

Source: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Advocay

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Excerpts from

Preserving disability civil rights:
a step-by-step guide to taking action

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This is the manual you have always wanted to consult. Have a look at the table of contents to whet your appetite:

> Fundraising, putting on an event, writing proposals, talking to lenders and donors, media/public relations, press release, letters to the editor, bringing television to your event, getting an interview in the media, politicking the politicians, community organizing, starting a small group,
>
> creating coalitions, educating the community, and much more.

Media public relations

If people are going too support your causes, they must know you exist. The quickest and most effective way to advertise your cause is by using the media. Could you imagine the manufacturer of a new product putting it out on the market without publicity? For the sake of editorial clarity, we are separating a discussion of media and its uses from the section in this manual on community outreach. In the real world, no such distinction can be made. If a supporter of your cause appears on television, they are going into people's living rooms. It's different than if s/he were there in the flesh, but media is community outreach, and in the modern world of satellites that outreach is global.
The press release.
The purpose is:

- to announce an upcoming event and invite the press to cover it.
- to issue a statement or take a stand on a news development or issue
- to provide background information or to supplement late-breaking news.

Form of a press release. Neatness counts. Editors and reporters are bombarded with press releases, and a simple method of elimination is to discard those that are sloppy and unprofessional. No typos, no misspellings or crossouts.

Content. Every young reporter is taught that in preparing their story they must

include the five w's: who, what, where, when, why. You must also include then in your press release.

The lead paragraph, your first, should answer as many of the five w's as possible without sounding awkward. If you don't answer at least two of the five, your press release will most likely end up in the trashbasket. All five w's have to be answered by the end of the second paragraph.

Make your most important points and write in a quotable way. Your lead should convince the editors to cover your story. You must hook them in.

Press releases can be longer than one typed double-spaced page, but follow the inverted pyramid rule of diminishing importance. Give all your important information, especially what is newsy and quotable, on the first page. Keep it lively. Succeeding pages should be used for background detail.

If you refer to individuals in your press release, give their titles, and how to get in touch with them if you want the media to get in touch with them.

Your closing paragraph should be a succinct statement of the meaning and purposes of your cause.

Timing

Press releases should neither be mailed too early nor too late. If you send it in too early, it will be forgotten, and if you send it in too late, the results are obvious. Releases should arrive three to five days before an event.
Follow-up phone calls

Two days before the event, call the person to whom you sent the press release. Update your press release, adding any new information that would be of interest. Don't browbeat reporters or editors; give them the impression you have a solid story which will make good copy. Call again the morning of the event, but be very brief.

To whom do you send press releases? Find out who has been covering similar stories in the past. Send them a press release. Work at developing a friendly first-name relationship with this individual. Never send a release to more than one person at the same newspaper.

Some cities have media guides, often published by the local public relations association, that tell you what publications exist and who are the editors, reporters and feature writers. You can get information about this guide by calling a local public relations association or a local public relations firm.

Television

More people learn about the world through watching television than reading newspapers. What television likes to show. 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 humor, 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 non-English speaking 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.

Street theater (agitprop)

Street theater which is performed in advocacy of your cause is great fun. Fun for the performers and the onlookers. It's a free show. Street plays are brief, 3-5 minutes, involving anywhere from one to six people or a few more. Dialogue is simple and brief; sometimes it is shouted. Costumes are colorful, faces can be painted and most of the message is conveyed through movement, facial expressions, mime and various exaggerated forms. The best street theater makes one point. You do not need a professional playwright or performers. Any group of people who like to have a good time can get together and develop a street play.

Street plays present good opportunities to give out leaflets, sell buttons, distribute bumperstickers and raise money. Take along someone just for fundraising.

Legislative access--politicking

Very few politicians would risk having the reputation of being rude and mean to disabled citizens. Use that to your advantage.Read the Paper. A good way to find out what politicians are doing on the city, county, state and federal level, is by reading the newspapers, including features, columns, editorials and letters to the editor. Find out what battles are going on in the various legislatures, what issues are being debated, what bills

are being presented, what amendments are being offered. What is being said on the floors of assemblies, and in the cloakrooms? What individual seems most likely to be sympathetic to your cause?

You will find the press coverage insufficient. Use your personal ties--and you should develop these--with reporters and editors to fill in the gaps. Learn to trade information with them.

Know your representatives

When planning an approach to an elected official, learn something about them. Read the press, the weekly magazines, obtain from their office any public position papers they have issued on relevant material, consult the relevant congressional and legislative records. Know their voting record and the legislation they have sponsored or actively opposed. Go to the library, consult the various "Who's Who" volumes for any reference to your official. If you are doing your research in depth, check the tax and property records of the city s/he lives in.

Need: Go to an elected official when you want support for your cause, when you want them to back or oppose something, or when you need personal aid in dealing with a government agency. But don't go too often or you will eventually be dismissed as a nuisance.

Timing: If you want an official to take a public position on an issue, either by speaking, voting or writing a letter, approach them at a time that is relevant. If you write a letter six months before the matter is coming up, your letter will be filed and forgotten. Pick a time in which the official you are contacting is likely to be thinking about what is on your mind, e.g., a time when s/he is determining how to vote on a pending piece of legislation, or when an issue has become a matter of public debate.

Gaining access - introducing yourself and your group

In order to meet an elected official:

- Call their office and ask to speak to the administrative aide in charge of appointments. Explain who you are and why you want to meet the official. State what you are going to ask the official to do. If you are disabled, say so.
- It will take a few days for contact to be made with the administrative aide in charge of appointments.
- The administrative aide may set up a meeting between you and a staff member rather than between you and the official. Don't be put off, officials are totally dependent on their staff, and if you recruit a staff member to your cause, you have done a good day's work.
- You may be told that an appointment is unnecessary, that your request should be put in the form of a letter and given due consideration. Make your own judgement as to whether this is true. If it is not, then keep insisting on a face-to-face meeting.
- Connections help. They are not indispensable but they make things easier. Do you know any officials personally, or any staff people? Do you know anybody who knows politicians personally or is related to them--a contributor, a sympathetic reporter, a member of the clergy, a campaign worker? Have you written any letters to politicians and received answers? If you have already established contacts, take advantage of them. A friend or supporter could make the initial call and help set up the interview. You may be given a little more time and attention.

Politicking the politicians

Writing letters. The easiest, cheapest, and one of the most effective ways to communicate with public officials is by letter. You write to a politician when you want to obtain or send them information on legislation and issues, to make requests, to ask for personal help, to extend invitations, to express gratitude or criticism. Your letter must be:

- Timely. Is the matter you are raising relevant to the official at the time you are raising it?
- Precise. An official may receive between 100 and 1,000 letters in a week. If your letter is not clear, it will have no effect.
- Factual. Your letter should include all relevant facts, and yet be to the point.
- Specific. If you are writing about a particular bill, include the name of the bill and the bill number.
- Clear. Present the official with a clear and concise argument either for or against a proposed action.

If you have ever met the public official you can personalize your letter, saying Dear Joe or Dear Betty. A personalized letter will get special attention in the office.

Don't send a pre-printed or form letter that hundreds of other people are going to copy and send to the same official. An obviously orchestrated campaign is not attractive. Orchestrate your campaign with subtlety. Don't use cliches.

Don't write about your problem. Write about what you want the official to do about your problem. Here is a successful example:

> I have a disabled child. Here is a problem I am having (state it), and this is what I suggest you do (make a specific suggestion). I don't know anything about writing laws, but I do know that this is one way to solve this problem.

Face to face. When you meet with an official or a staff member, be very prepared. You are meeting busy people, individuals who think fast and are impressed by those who do likewise. When you talk with an official, you should:

- Ask them to do something. Don't just tell them you have a problem. Suggest a creative solution and seek to enlist their support.
- Be concise. You may only have a ten or fifteen minute interview. Don't read from prepared statements. You can consult notes, but be extemporaneous. Be prepared to answer questions. Think through in advance what the official or staff member may ask you. Don't get angry. Don't be intimidated. Don't be condescending. Be humorous when it is appropriate.
- Bring along documentation, fact sheets surveys, newspaper clippings, petitions, photographs, whatever you think will back up your case. Leave these with the official for further study.
- Be patient if the official does not show up for the appointment. (This may happen, since unexpected hearings are always being called and emergencies developing.) You may be given a staff member instead. If so treat the meeting with the same seriousness you would have accorded the official.
- Be neatly dressed.
- Be flexible. An official may be prepared to go only part of the way with you. They will always be balancing various demands. If partial support is all you get, don't be argumentative. Thank the official for what s/he is willing to do and state that you hope they will be able to do more in the future. Politics is the art of

compromise and the possible.
- Be alert. Politicians are smooth at public relations. They may smile a lot, give you "stokes", in an effort to co-opt you without really doing anything on your behalf. Develop strategies for not being taken in and yet not being rude. Be persistent. It is not what officials say but what they do that counts.
- Follow up your face-to-face interview with a friendly letter, thanking the official for their time and support, if they have offered it. If no immediate support was offered, reiterate that you hope support will be given in the future.

Source: Disability Rights and Education Defense Fund, Preserving disability civil rights: a step-by-step guide to taking action .

Address: Disability Rights and Education Defense Fund, 2212 Sixth St, Berkeley, CA 94710, United States

References:

Brager, George and Specht, Harry. Community Organizing. New York: Columbia University Press, 1969.

Caulkins, Phil. Building Coalitions. Raleigh, North Carolina: Barrier Free Environment, 1981. (Watergarden Highway 70 West, Raleigh, North Carolina 27622).

Coover, Virginia; Deacon, Ellis; Esser, Charles; Moore, Christopher. Resource Manual for a Living Revolution. Philidelphia: New Society Press, 1978.

Foundation for Community Organization. Handbook for Community Organization. Durham, North Carolina: Foundation for Community Organization, 1969.

Midwest Academy. Organizing Handbook. Chicago: Midwest Academy (600 W. Fullerton Avenue, Chicago, Illinois 60614).

Advocacy

Resources

Shields, Craig V., Strategies: A Practical Guide for Dealing with Professional and Human Service Systems, Human Services Press, Richmond Hill, Ontario, 1987.

Although the book's emphasis is on assisting parents of exceptional children to deal with professionals and special service systems, this handbook is valuable for all of us who find themselves fighting social service bureaucracies.

From the table of contents: Developing the right attitude; Understanding professionals; Knowing "The System"; How to begin; How to select professionals or agencies; How to deal with professionals.

Address: Craig V. Shields, c/o Human Services Press, P.O. Box 421, Richmond Hills,

ONT L4C 4Y8, Canada

Economic and Social Commission for Asia and the Pacific, Handbook on Community Awareness Programs Concerning Disability, United Nations, New York, 1989.

Varela, Rita A., "Organizing Disabled People for Political Action", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Varela, Rita A.,"Changing Social Attitudes and Legislation Regarding Physically Disabled", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

The following resources are published by the Independent Living Ressearch Utilization Program, Houston:

Bell, Guy, Laurel Richards, and Laurie Gerken. Your Disabled Child´s Right to a Free Education. ILRU Field Work No.2. Houston: ILRU Program, 1985.

This is the second of a set of three brochures developed for ILRU´s National Technical Assistance Project for Rural Independent Living. It summarizes federal provisions regarding disabled children´s rights to a free and appropriate education, and it includes a list of support organizations and publications.

Dalrymple, John and Laurel Richards. "Independent Living and Policy Changes: Reflections on a Decade's Progress". Issues in Independent Living No. 5. Houston: ILRU Program, 1983.

This monograph is a study of the extent to which progress has been made in nationwide implementation of Independent Living-related policies over the past ten years. Areas assessed include entitlement to rehabilitation services, transportation, housing, employment opportunities, and elimination of architectural and communications barriers.

The Inclusion of the Handicapped Person in Community Life: A Program for Action Now. Houston: The Institute for Rehabilitation and Research, 1980.

This document presents a plan to improve the quality of life for people with disabilities by identifying problems and steps that should be taken to resolve them. The plan was developed at an international conference held in Houston in April 1980 Contributing to the plan were representatives of organizations of people with disabilities, sociologists, economists, architects, industrial designers, physicians, lawyers, legislators, and human service providers from around the world.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

The following resources are published by the Research and Training Center on Independent Living, University of Kansas:

Seekins, T, Balcazar, F, & Fawcett, S B (1986). Consumer involvement in advocacy organizations, Volumes I-IV. Lawrence: RTC/IL, University of Kansas.

Four-volume manual covers broad range of consumer advocacy strategies and includes lessons, exercises, and answer keys. Volume I introduces consumer involvement and describes different advocacy strategies. Includes monitoring events, legal responsibilities,

consumer etiquette, identifying information sources, reporting issues. Volume II describes how group discussion leaders can chair effective meetings. Includes topics on forming an issue agenda, opening meetings, leading discussions, etc. Also provides instructions for group secretary. Volume III presents the Project Planning Guide, an index listing a sequence of 35 possible actions for each type of advocacy issue and goal. Index allows consumer groups to consider full range of legitimate responses for a variety of goals. Volume IV provides guidelines for proctors, peers, or instructors on how to train group members and teach advocacy skills. Covers preparing additional materials, questioning trainees on content of materials, evaluating trainee performance, and using positive reinforcement.

Seekins, T, Balcazar, F, & Fawcett, S B (in press). "Promoting effective consumer involvement through training in constructive advocacy." American Rehabilitation.

Article reports the development of a consumer involvement training program that has resulted in increased leadership and constructive advocacy in a field test with a consumer advisory committee.

Staff (1986). "Advocacy: IL cornerstone." Independent Living Forum, 4 (1). RTC/IL

Focuses on IL advocacy strategies, including protection and advocacy systems for persons with disabilities, self-advocacy, disability rights. Other issues include handicapped parking, voting, communication skills, and advocacy groups and impact of disability rights on federal law.

Seekins, T, & Fawcett, S B (1984). Guide to writing letters to the editor. Lawrence: RTC/IL, University of Kansas.

Designed to help consumers prepare effective letters to editor that may place an issue on the public agenda, educate the public, change attitudes, or convey gratitude.

Seekins, T, & Fawcett, S B (1984). Guide to writing letters to public officials. Lawrence: RTC/IL, University of Kansas.

Designed to help consumers prepare well-written, effective personal letters to influence public officials.

Elkins, S R, Jones, M L, & Ulicny, G R (1987). The media watch campaign manual. (Research edition). Lawrence: RTC/IL, University of Kansas.

Offers different strategies for promoting acceptable media features, focusing on appropriate terminology and portrayal of people with disabilities. Explains procedures for monitoring articles and TV programs and teaches how to write appropriate feedback letters and make effective phone calls.

Address: RTC/IL, 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States.

Personal Assistance:

Towards an operational definition

Persons with extensive disabilities need assistance by other people in their everyday lives with such activities as getting bathed and dressed or going to the toilet; with shopping, preparing meals, cleaning or doing the laundry; with such responsibilities within the family as doing the practical tasks involved in raising small children or assisting one's aging parents. Assistants help the user at work, about town and on travel. They assist in communicating or in structuring the day, as the case might be. In brief, assistants help with those activities which the user would have done by himself or herself, had it not been for a physical, sensory, mental or intellectual disability.

Just as other persons with less extensive disabilities can compensate their functional limitations by using assistive devices, assistance - if properly organized - can enable us to become fully-functioning citizens. Doing everything by oneself is not always the most efficient way of achieving one´s goals. What counts is to get things done according to one´s own needs and wishes.

People who are dependent on others for the most basic needs of life face prejudices. For instance, somebody who is physically dependent on other persons may also be considered emotionally and intellectually dependent. Somebody who cannot pull up his or her pants like a small child, may be treated as a small child in other respects as well. The result is often over-protection and custodial care where other people make the decisions.

It is no surprise then that the Independent Living philosophy is most easily grasped by people who are dependent on assistance in their every-day lives. This is also the reason why the Independent Living Movement emphasizes the importance of the quality of assistance for users who want to achieve maximum independence. In order to provide an operational definition for quality, the Independent Living Movement coined and defined the term "personal assistance":

"Personal" assistance means that users exercise the maximum control over how services are organised and custom-design their services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the individual user decides

- who is to work,
- with which tasks,
- at which times,
- where and how.

Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, "personal assistance", means that the user is the boss.

It is recognized that users with learning or mental disabilities will need support from third persons with these functions.

Personal assistance enables users to take their rightful place in family, at work and society with all the rights and duties that the general population takes for granted. With personal assistance persons with extensive disabilities need no longer be a burden on their families. Parents, husbands or wives do not need to stay at home and sacrifice their careers. Personal assistance users not only manage on their own, they can also take their share of

household and child-rearing. With personal assistance we can attend school and educate ourselves, enter the labour market and become tax-payers. When we fall in love, our partners need not fear that they are about to sign up for a life-long 24 hour job.

Most existing services cannot be called "personal" assistance because they are tied to given physical locations, such as institutions, and not to the individual who needs the service. Thus, the user has to follow the service rather than the other way around. In this way, many disabled persons spend their lives away from their families in institutions, since assistance is provided only in the institution but not in the community.

Most community-based services do not provide "personal" assistance either, because the individual user is not in the position to recruit assistants and has to accept assistance from available staff. Inherent in these solutions is their hierarchical structure with the user at the bottom and the user' s dependency on the decisions and rules made by other people. Also, whenever several users share the same staff, freedom of movement and choices are severely limited.

Other limitations exist when assistants do not have proper employment contracts and wages. Under these circumstances users can neither demand quality work, attention and reliability nor can they feel fully in charge.

Adolf D. Ratzka

April 1997

What is personal assistance ?

Everybody uses assistance. Nowadays, we all are dependent on each other. Nobody can perform all the tasks necessary to sustain his life-style. So, people instead of fixing their own car take it to a mechanic. Most people do not know enough about cars or do not have the time. By utilizing somebody else's knowledge and resources we can compensate our lack of ability or lack of time. People like to specialize in doing what they are good at. Most other things they delegate to somebody else. In this way one can be more efficient in the sense that one gets more done.
"Personal assistance" then means that we compensate our disabilities by delegating tasks to other persons. These tasks involve activities which we cannot carry out ourselves or which we are not good at. We delegate in order to have the time and energy to specialize in those activities which we can perform well. "Personal" connotes that the assistance has to be customized to my individual needs. "Personal" also means that the user decides what activities are to be delegated, to whom and when and how the tasks are to be carried out. I think in a world of personal computers and personal telephones the term "personal assistance" is quite descriptive.

What are the alternatives to "personal assistance"? In English, the terms "attendants", "personal care attendants", "carer", "home help", etc are used. Most of these words contain the word "care". To me this word carries the connotation of taking care of somebody who cannot take care of himself or herself. The relationship between "carer" and "caree" implied by this term is not one of voluntary association for mutual gain, it does not clearly state that the "caree" is the one who decides what has to be done. The term "home helper" indicates that "help" is to support activities only in one's home as opposed to a lot of other places such as at work, on the bus, at a friends' house, on trips,

etc. I am sure that in most languages we will find similar expressions which imply that we are helpless, somewhat stupid persons who, like small children, cannot look after themselves and need supervision.

If we want to design services which get us closer to the goal of equal opportunities, we have to find expressions for such services which portray us as responsible and capable citizens who are in command of their lives and not as passive objects. Language both influences and reveals attitudes including our own attitudes towards ourselves.

In what forms has assistance been available so far?

Family as assistance provider

In most countries the most common form is the family. Reliance on the family may work for some time but the limitations - even under the best of circumstances - are given. Family members get older, they are risking their health in assisting us. Children often have to take too much responsibility too early in their lives. Adults cannot pursue their career and feel locked in. The results are relationships of mutual dependence, sacrifice and guilt. Where guilt is often mistaken for love.

Facing the alternative which in many countries is institutional placement of the disabled family member most families hold out as long as they can - often without any outside assistance - burdened by immense physical, financial and emotional strain.

Volunteers

In some places families get help from volunteers. The virtues of volunteerism are most often praised by conservative politicians whose motives are to cut taxes for the benefit of their voters. Obviously, users of assistance from volunteers cannot demand the same competent, punctual, and courteous work from volunteers as they might from assistants who are paid competitive wages. But in most instances users who utilize volunteers do not have that choice.

Stationary institutions

The alternative that most of us in Europe have is to live in some sort of institution. Institutions are administrative entities and as such are governed by the necessities of administering buildings, workers and inmates within the boundaries given by budget, labor unions, and state regulatory agencies. These constraints are expressed in a multitude of rules which cannot be adapted to the needs of each individual. Otherwise there would be chaos. As a result, a certain order has to be maintained to guarantee the smooth functioning of the whole. The individual's challenge, then, is to adapt himself or herself to the existing order both physically and psychologically without losing one's integrity as a human being. That is very difficult. One of the survival strategies is to develop a pleasing personality with which you can achieve privileges at the expense of other inmates who are not as adaptable.

The general results of institutional living are known as "hospitalism", that is loss of social skills, foregone life opportunities, and stunted human growth. The problem we are facing in helping people who have been staying in institutions is that they often have lost their self-confidence and are frightened by the prospect of leaving their secure confinement.

A definition of an institution

Perhaps it is appropriate at this point to attempt a definition of an institution. I suggest that

we face an institution if

- there is no other alternative,
- we cannot choose who is to assist us,
- the user has to adapt his needs to the needs of the whole scheme,
- there are written and unwritten rules regulating the assistance, rules over which the user has no control,
- the assistance is limited to certain hours, activities, locations (for example, you have to live in certain houses as opposed to living anywhere),
- the staff providing assistance is shared by several persons,
- there is a hierarchy with the user at the bottom of the pyramid.

If we accept this list of institutional characteristics, then most forms of assistance fall under this category.

Mobile, ambulatory institutions

Take community-based public services. In most of these schemes a caseworker at the municipal social service department or at some charity organization assesses your needs and sends workers into your home. Tasks and hours are well defined. Hiring, training and scheduling of the workers is done by the supervisor. These services constitute a tremendous advantage over institutional placement. But you as the user are not in control, you share assistants whom you cannot choose or train yourself. As a result, you are made dependent on other persons' judgement and have to limit your life. You might even limit the use of this type of service to the absolute minimum, because the quality is so low.

Sometimes community-based services are run by organizations of disabled people. If they use the same organizational solutions, the quality of their services will not be much better.

False independence

Those of us who need assistance are used to restricted lives. For one, most of us have been exposed to the present rehabilitation philosophy which wants us to do as much for ourselves as we possibly can and even more. "Push your limits, try harder. Exercise, exercise. Don't get lazy, use your manual wheelchair, not your power chair! "

Our first goal, according to rehabilitation professionals, is to be independent and manage with a minimum of technical aids. Personal assistance should only be used as a very last resort, since it is considered a recognition of failure on the part of the professionals and ourselves. Or have any of us been taught by a rehabilitation specialist how to delegate tasks to other people? Many of us have accepted these professional priorities. Their purpose in life seems to get out of bed by themselves, get washed and dressed by themselves, to cook and clean. Never mind that it takes the whole morning. Never mind that they get so worn out that they have to rest the other half of the day to recover enough strength for going to bed. They may not have a job, they may not be able to do much outside the home, they may not have time and energy to get involved in disability politics and fight for equal rights. But they are proud of being independent.

This narrow definition of independence is reinforced by society around us. "Good boy, look how hard he is trying!" Politicians and administrators like to see us try hard, since they save money on us this way. Personal assistance is expensive. But what a narrow definition of costs this is! What about the time and energy we could use for other achievements, if we allowed ourselves to use personal assistance!

Medical evidence in recent years shows that many of us overexert their remaining muscles, nerve cells and ligaments. As a result they wear themselves out before their time. Too much exercise may cause irreparable damage. The harder we try, the faster we waste ourselves.

The brainwashing that many of us receive in rehabilitation distracts us often effectively from painful comparisons with other people, our non-disabled friends, relatives and neighbors. How often do we allow ourselves to compare our lives with theirs? It can be painful to admit to oneself that we too would like to have a good job, a nice home and a family. But for many of us these things will be out of reach forever, if we do not have the possibility of delegating practical tasks to personal assistants. Ultimately, it is a question of self-respect. If we respect ourselves as persons of equal value, then we expect and demand the same lifestyle that others take for granted. Then, we will also want to use personal assistance as one of the tools to achieve these goals.

I would like to use an analogy. An entrepreneur or administrator will realize that he or she alone can get done only so much. By employing other persons the entrepreneur can delegate work and in this way increase the total output. Would it be wise for a factory owner to try to do everything all by himself? Most likely such a person would either die of exhaustion or be out of business pretty fast. If entrepreneurs and administrators are not ashamed to utilize manpower to achieve their goals why should we hesitate to do the same?

Adolf Ratzka

1992

Personal assistance

Employing your own personal assistant

So, you've been awarded funding from the Independent Living Fund to employ your own care staff. How do you go about it?

GAD's Center for Independent Living can help.

We have already assisted nearly a dozen people in the employment of their own personal assistants. This really does put you, the disabled person in control. You can decide who to employ, which hours they should work and what they should do. But control brings with it responsibilities and this is where GAD can help. We can help with:

- Advertising/recruitment
- Interviews/selection
- Contracts of employment
- PAYE and National Insurance

Don't let this put you off. There is plenty of support to be had, both from GAD staff and from disabled people who are already employing their own staff and know the ropes.

Even PAYE and National Insurance aren't half as difficult as you think they will be - there is a Simplified Deduction Scheme and we have found the local Tax and National Insurance offices really helpful. Of course, if you only employ personal assistants on a part-time basis and they earn less than £42.99 you won't have to bother about tax or national insurance.

We won't pretend that finding personal assistants is easy - these days there are more openings for young people and the job can be demanding. Generally the pay is not high and there is certainly no career structure. Disabled people across the country are encountering the same problems. Recently Hampshire CIL, who have done so much of the pioneering work in this area and who have produced two excellent source books, held a seminar for disabled people employing their own assistants. GAD representatives who attended found it extremely useful - we were all able to share ideas about recruitment, funding, emergency cover etc.

Hampshire are in the throes of setting up an employment agency and hope to recruit personal assistants from as far afield as Australia and America (so far the further GAD has gone has been Liverpool!) Often there are young people wanting the opportunity to experience life in England, working for 6 - 12 months. GAD hope to work closely with Hampshire CIL, and other organizations of disabled people, in this area.

Source:
GAD, "Strength In Unity",
GAD Newsletter Summer 1989

Developing assistants management skills

With little or no previous experience the disabled person seeking to live independently suddenly finds her/himself thrust into the role of employer. Not surprisingly the effective management skills essential to coping with the day-to-day matter of relating to her/his personal assistant are sometimes absent or under-developed.

The relationship between a disabled person and her/his personal assistants has a lot to do with simple human chemistry - but it isn't enough to leave it at that. Disabled people must adopt a responsible approach to the working relationship. It is not good enough to leave things to chance, or 'flying by the seat of one's pants'. The need for care and the control of care lie at the very heart of a disabled person's existence and we must do what we can to ensure success in our chosen lifestyle. This means that we need to be sensitive to the needs of personal assistants, both 'new' and long-standing personal assistants, and be constructive in the way we enable them to function.
Some common complaints among personal assistants are:

The lack of a specific job description - leading to unequal expectations. Personal assistant understanding that you need one thing and you believing that you are to receive something else. (Adjectives such as 'less' and 'more' are often appropriate here.)

The disabled person's inability to provide effective objective feed-back on performance.

Personal assistants want and need something more than general 'complaints', 'bad temper', 'euphoric gratitude', or an (apparently) 'indifferent silence'. Caring is a job and all humans require ongoing job satisfaction, which only the employer (the disabled person) can provide.

Of course many disabled people have developed their own ways of dealing with these issues and it is not the purpose of this chapter to imply that the following is the only acceptable procedure. Rather it is to draw attention to a most important subject and to provide some ideas when considering it. Independent living advocates need to propose procedures that enable a disabled person to train and manage attendants more effectively. For this purpose we suggest the use of performance check lists.

Performance check lists

These are compiled by the disabled person and outline specific job descriptions. Each check list details the steps in a given work routine and can include information how often routines are performed, the materials needed and set-up procedures.
Drawing up check lists:

- List the areas where care is essential, such as: bathing, dressing, bowel and bladder care, meal preparation, housekeeping, passive- movements, transfers, wheelchair maintenance etc.
- For each area develop a check list by listing exactly what duties the personal assistant has to perform. This can be compiled from memory or have notes taken during the chore, or make a tape recording while the routine is being performed. It is important that the check list contains each duty to be performed.
- It is very important that each check list reflects YOUR own requirements! You can have check lists for bathing routines, house cleaning tasks, etc.

The check lists provide:

Instructions to personal assistant, useful in interviewing and training.

Help the disabled person to monitor, evaluate and provide feedback to personal assistant on her/his performance. A prompt for occasions when the disabled person is not present.

After training, the check lists can be used for continued supervision by providing a means of periodically re-evaluating performance and so stimulate feedback, thereby encouraging consistent performance by the personal assistant.

Using a check list to train a 'new' personal assistant:

Remember, each list gives a 'new' personal assistant a clear idea of what is to be done, when it is done, and in what order. This is an invaluable training aid.

Make sure the 'new' personal assistant understands each item on the check list. One way of doing this is for the 'new' personal assistant following through the list while an 'old' personal assistant does the job described. Or, the disabled person can explain each item as she/he and the 'new' personal assistant go through the list together.

Don't start on-the-job training until 'new' personal assistant understands the routine on the list.
During training the check list could be clearly displayed enabling a ready prompt for 'new' personal assistant.

Remember: the check list only outlines WHAT is to be done, the disabled person still needs to supply detailed instructions during training to ensure that the 'new' personal assistant knows HOW things are to be done.

Using a check list to provide feedback opportunities:

Immediately after a care routine is finished the disabled person and the 'new' personal assistant review the check list together, the disabled person commenting on each item as to the performance of the personal assistant. Feedback sessions ensure that the 'new' personal assistant receives positive feedback for correct performances and specific instructions to correct areas that need improvement.

Positive feedback: If an item is satisfactorily accomplished then say so and describe why, thus providing positive feedback. E.g. hair brushing "Correct - you really got to all parts, just as I like it."

Negative feedback: If an item is unsatisfactorily accomplished and needs improvement, then say so and explain why, giving specific details on how to correct the problem. E.g. hair brushing "Not correct - you missed my hair in front and behind my ears."

Ongoing feedback: For reasons of job satisfaction it is very important that the personal assistant receives regular, constructive feedback, both positive and corrective, even after the initial training period. Check lists should be used on a continuing basis, even if only intermittently, by way of ensuring ongoing positive feedback and also providing a forum for ironing out small difficulties before they become big problems.

To conclude

You may find all these suggestions frighteningly formal and perhaps contrary to your understanding of a disabled person/personal assistant relationship. You may even think that these suggestions are positively threatening, or damaging to a disabled person/personal assistant relationship. This is not the intention. The purpose is to provide a structure that can enhance communications between the disabled person and her/his personal assistant, encourage the very best from each other, and so promote job satisfaction on the part of the personal assistant. It is up to you whether you use this check list system or not, or maybe even devise your own.

The essential human chemistry: your tone, your attitude, respect, the way you interact, how you 'gel', etc., remain ingredients that only the two of you, as people, can deal with. If you don't 'get on' with each other, then a structure may enable you to survive, but it won't resolve the basic 'chemistry'.

Conclusions

- Remember you are in an employer/employee situation - a business world. Don't ignore the value of developing management skills that can lead to positive benefits in the quality of your life.
- The traditional medical model of nursing care assumes the training of the personal assistant. However, in the course of a lifetime a disabled person might employ well over 50 personal assistants. Common sense indicates that it is cheaper to systematically train one person, the disabled person, in her/his specific routine rather than 50 personal assistants.
- Not all people will want or have the necessary skills to train personal assistants without any structured input. This is where more focus needs to be put into training and enabling the development of such skills, preferably through people

who have direct experience in Independent Living, or through CILs who
sometimes can offer advice and training.

Source:
Source Book Towards Independent Living,
Care Support Ideas, HCIL (Hampshire Center for Independent Living)

Address: Philip Mason, 100753.1164@compuserve.com
Hampshire Centre for Independent Living,
4 Plantation Way, Whitehill, Bordon, Hants GU 359 HD, United Kingdom

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Personal assistance

Concepts for Independence, Inc.:
a unique approach to personal assistance

by Sandra Schnur and Ira Holland

Concepts of Independence, Inc. offers an opportunity for self-directing persons with
disabilities to maximize their goals of living independently. If such an alternative were not
available, these same people would be forced to receive services from an agency that does
not consider their needs and strengths, only their physical limitations. As representatives
from Concepts have said,"...without Concepts, one controlling health care institution
would be exchanged for another." This statement reflects the reaction to conventional
home health care systems that require passivity on the part of service recipients and a
willingness to accept agency mandates. An agency can send any available personal care
attendant with little concern for the working relationship.

In several states, the local department of social services has elected to fund personal care
services for elderly and disabled persons. This is done in New York with Medicaid
monies for persons with minimal income, who are elderly or disabled, and who are
authorized to receive personal care services. The Human Resources Administration is the
administering agency for Medicaid and home attendant personal care services in New
York City.

Because of the threat of agency intervention and domination (i.e., workers who have an
allegiance to the hiring agency, not to the consumer), a core group of severely disabled
persons held a protest demonstration in 1977 outside the chambers of the New York City
Board of Estimate which approves City contracts. People in motorized wheelchairs, most
of whom had to have their ventilators plugged into corridor outlets, sat waiting to talk
with Board of Estimate members.

The demonstration led to many meetings with City and State representatives, which took
place over a two-year period. In 1979, this same core group of severely disabled persons
developed and presented an alternative mode of service delivery to City and State
representatives. The alternative is Concepts of Independence, Inc., New York City's only
client-maintained plan. Its services are available throughout New York City's five
boroughs; currently, Concepts offers a system of recruitment assistance which helps to

augment the member's own program of locating appropriate candidates for home care employment. In order to become a Concepts member, a person must be Medicaid eligible, authorized to receive personal care services, and be deemed self-directing by the Human Resources Administration (based upon a completion of a lengthy questionnaire).

Concepts members are varied in age and lifestyle as is the general population, but all Concepts members have disabilities of varying significance. All Concepts members receive varying allotments of personal care attendant hours based on the recommendation of a team that includes a physician, nurse, medical social worker, and a Human Resources Administration caseworker.

Concepts is a fiscal intermediary that receives Medicaid monies to administer personal assistants payroll and benefits package. Upon hiring a personal assistant, it is the member's responsibility to enroll the person, to fill out and submit weekly time sheets.

Concepts is unique in that it requires members (consumers) to interact directly on a one-to-one basis with their personal assistants. Members of Concepts receive and distribute payment directly to the personal assistants, thus reinforcing the belief that the personal assistants are the employees of the consumer, not the agency. Concepts requires members to choose their own lifestyles. For Concepts members, this means assuming responsibility for recruiting, hiring, training, supervising, paying, dismissing and developing a cadre of backup personal assistants.

Currently, Concepts offers a system of recruitment assistance which helps to augment the member's own program of locating appropriate candidates for home care employment. In addition, Concepts Board of Directors has written Living Independently: A Consumer's Guide About Personal Care Attendants. This publication offers advice on such topics as how to recruit help, developing emergency backup resources, how to interview, supervising your employee, lifestyle choices, evaluating your employee, and terminating your employee.

The ability to determine one's lifestyle as well as how, when, and with whom this will be accomplished has resulted in greater self-esteem and satisfaction for each Concept member.

Address:
Concepts of Independence,
120 Wall Street Suite 1010, New York, NY 10005, United States,
Fax 1-212-293 3040.

Personal assistance

A comparison of some of the characteristics of two models of personal assistance services

Independent Living model of personal assistance services

- No medical supervision required

- User manages own assistants, including hiring, training, paying and firing
- User is a partner in determining the number of hours and types of services
- Provides for a broad range of personal, homemaker, cognitive and communication services as needed
- User direction
- Serves people of al ages and disabilities
- Social service benefit

Medical model of Home Health Services

- Physician plan of treatment/nurse supervision
- Agency hires, trains, pays and fires workers
- User has limited role to play in assessment and plan development
- Narrower range of services provided
- Services available to user according to hours set be agency
- Agency direction
- Serves people with acute conditions
- Health care benefit

Source:
World Institute on Disability,
510 16th St, Oakland, CA 94612, United States.

Personal assistance

Resources

DeJong, Gerben & Wenker, Ted, "Attendant Care", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Degener, Theresia, Independent Living and Personal Assistance Programs for Disabled Persons: A Comparison of Social Welfare Legislation between the United States, Sweden, and West Germany, LL.M: Thesis, University of California, Berkeley, School of Law, 1989.

Address: Theresia Degener, Münsterer Str. 1, 6000 Frankfurt, Federal Republic of Germany.

The PAST Chronicles is published 10 times a year by Personal Assistance Services Today. The Chronicles is a newsletter devoted to personal assistance issues in Virginia, USA.

Address: PAST, 8403 Thames St, Springfield, VA 22151, USA.

S. Roberts & N. Sydow, Consumer Guide to Attendant Care, Access To Independence, Inc., 1981.

Suffolk, Valerie, Challenge of Demanding Personal Autonomy, University of Manchester, 1986.

Ratzka, Adolf D., Independent Living and attendant care in Sweden: A consumer perspective, World Rehabilitation Fund, New York, Monograph No. 34

The following resources are published by the World Institute on Disability, Oakland.

The Personal Assistance for Independent Living Act of 1989: A Draft Bill prepared by the World Institute on Disability, February 1989

"In order to develop model legislation in the area of personal assistance services we asked ourselves what an adequate, equitable Independent Living oriented system could look like. First, it would be available throughout the country. It would serve people of all ages and disabilities. It would be flexible and provide for varying degrees of user self-reliance. People who are totally capable of managing their own assistance and wish to do so would be accommodated. Those who need training to be able to manage their own assistance would receive training. Those unable to learn all the management tasks or unwilling to take them on would be able to receive assistance management services such as recruiting assistance, training assistance, case management or self-advocacy assistance. Those individuals requiring more professional assistance because of mental or intellectual disabilities would also be served. An adequate system would promote independence in the way it was designed. It would be affordable to disabled people and their families through a sliding fee scale for those earning above an income level from which disability related expenses are deducted. The program would offer quality service delivery and would respect the rights of people with disabilities. Finally, it would guarantee providers decent wages and benefits."

Attendant Services Network Newsletter, published quarterly.

Attending to America: Personal Assistance for Independent Living, WID

This publication reports on results of its recent national survey of publicly-funded attendant services programs. Findings show that even though there is no state in the U.S. recognizes attendant services as a major need. While $1.6 billion was spent on publicly-funded attendant service programs in 1984-85, research indicates the money could have been more effectively spent, resulting in higher quality services for a greater number of people. Services funded with Medicaid dollars had a strong orientation to the medical model, a factor that increases costs. Currently, more than 3.8 million disabled and elderly people in the U.S. require assistance in performing the personal, mobility and household tasks necessary for Independent Living in society. However, only 25% of them receive any help from government-funded programs. The rest rely on the volunteer assistance of family and friends, paying for the service out-of-pocket when they can afford to, or live in institutions. While most states now provide some publicly-funded personal assistance, these programs are typically inadequate. Most of them foster user dependency rather than independence, are poorly distributed geographically, and offer widely varying service packages. A major inadequacy of existing programs is their restrictive eligibility requirements: 59% of the programs do not serve certain ages, 44% exclude certain disabling conditions, 50% do not serve people with income above the poverty level, and 42% do not provide the full range of services required by users. Only Massachusetts and Minnesota serve as much as 50% of their populations in need, while six states (Arizona, Mississippi, North Carolina, North Dakota, Utah and Vermont) leave more than 95% of their people in need unserved. Nationally, the largest population of people needing but not receiving services is the elderly, an estimated 1.2 million.

Reporting on this national situation, the 170-page "Attending to America" and its 30-page "Executive Summary" discuss the history and current status of personal assistance in the U.S. and examine program goals, structure, funding and encouragement of users´ self-direction--a principal concern in the Independent Living Movement. The Report also discusses a major concern of the disabled community--that most publicly funded programs discourage user self-direction. Only 6% of the programs allow users to be part of the decision-making process regarding which services are needed and how they are provided. 50% of the programs do not allow disabled people to hire their own providers, and only 10% are supportive of users´ desire to be retained during employment.

WID has received a three-year grant from the National Institute on Disability and Rehabilitation Research (NIDRR) to research the cost and effectiveness of attendant services. Subcontractor Monroe Berkowitz of Rutgers University´s Bureau of Economic Research will join WID to analyze needs for and benefits, costs, and scope of attendant services as related to different delivery models and disability groups.

Address: World Institute on Disability, 510 16th St, Oakland, CA 94612, United States.

The following resources are published by the Independent Living Ressearch Utilization Program, Houston:

Board, Mary Ann, Jean A. Cole, Lex Frieden, and Jane C. Sperry. Independent Living with Attendant Care. 3 Vols. Houston: The Institute for Rehabilitation and Research, 1980.

A set of three booklets providing common sense approaches to personal assistance is now available from the ILRU. Unlike many manuals on personal assistance which describe tasks to be performed, Independent Living with Attendant Care focuses on how disabled persons and personal assistants can develop effective working relationships. Each booklets has its focus: the individual with a physical disability, the personal assistant, and the parents of disabled children. Among the topics discussed are locating a personal assistant, wording an advertisement, interviewing applicants, establishing satisfactory working arrangements, terminating an attendant, and developing back-up plans. For the assistant the themes are looking for employment, wording a "position-wanted" advertisement, clarifying key issues during and interview, and working out a satisfactory relationship. Also, overviews of the concepts of disability and Independent Living are given. The booklet directed to parents discusses recognizing implications the Independent Living Movement may have for disabled children, teaching children who have disabilities to be responsible, utilizing support systems, and identifying when to use personal assistants. Independent Living with Attendant Care is also intended to be useful to persons working in Independent Living centers, state agencies, and other rehabilitation facilities who wish to counsel severely disabled persons and their families about living independently with personal assistance.

Independent Living with Attendant Care: Personal Assistance for People with Disabilities: An Annotated Bibliography by Margaret Nosek, Ph.D., Carol Potter, M.S., Huong Quan, Ph.D., Yilin Zhu, M.S., ILRU, 1988.

Presents information about books, articles, and audiovisual materials covering a wide range of topics related to personal assistance. With descriptive summaries of over 150 entries, this reference guide will assist consumers, Independent Living specialists, and rehabilitation counselors in locating information about specific personal assistance options. Researchers, policymakers, advocates, and service providers will find the bibliography useful for reviewing the broad spectrum of personal assistance service

systems and planning for the refinement and expansion of personal assistance services nationwide.

"Personal Assistance: Attendant Services", by Margaret A. Nosek, Ph.D., in Toward Independence: An Assessment of Federal Laws & Programs Affecting Persons with Disabilities - with Legislative Recommendations: Appendix. National Council on the Handicapped, ILRU, 1986.

A chapter from the Council's report to Congress presenting definitions and information on need and costs, funding sources, and issues surrounding delivery of attendant services program based on input from leaders in the field at a national conference sponsored by the Council, as well as the Council's recommendations to Congress.

Toward a National Policy on Attendant Care: The Dutch Backdrop. Conference report prepared by Margaret A. Nosek, Ph.D. for the World Rehabilitation Fund, 1985.

Contained in this conference report are summaries of presentations on personal assistance from an international perspective given by Gerben DeJong, Gini Laurie, and Adolf Ratzka. The summary of discussions among participants covers the assistance continuum, need and demand, eligibility, delivery of services, funding, and strategies for establishing a national attendant services system.

Bustin' Loose to Independence: Through Personal Attendant Services by Margaret A. Nosek, Ph.D., ILRU, 1988.

This four hour audiotape series and training package contains information on how persons with spinal cord injury and others with severe disabilities can gain independence by using attendant services. Self-assessment check lists, resource lists, and a course outline make up the accompanying written supplement. The audiotapes and written supplement are combined in a convenient ring binder/tape storage package. And additional audiotape and guide sheet for parents and service providers orients them to concepts, techniques, and issues related to living independently with attendant services.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

The following resources are published by the Research and Training Center on Independent Living, University of Kansas:

Ulicny, G R, Adler, A B, Kennedy, S E, & Jones, M L (1988). A step-by-step guide to training and managing personal attendants. Lawrence: RTC/IL, University of Kansas.

Materials describe a consumer-directed model for training and managing personal attendants. The package consists of two manuals-one for consumers and one for ILC staff, and a training videotape.

Staff & Guest Authors (1984). "Disabled employers can increase their attendant management skills." Independent Living Forum, 2 (3).

Focuses on personal assistance and management skills and includes generic checklists, interview with consumer who used personal assistance model, legislative updates, book reviews, and article on aftereffects of head injury.

Ulicny, G, Adler, A B, & Jones, M L (1988). "Consumer-directed attendant management." American Rehabilitation, 14 (3).

Presents results of studies evaluating the effectiveness of the consumer-directed attendant training and management procedures.

Ulicny, G, & Jones, M L (1985). "Enhancing attendant management skills of persons with disabilities." American Rehabilitation, 11 (2).

Presents a model using performance checklists to enable disabled persons to train and manage their attendants more effectively.

Ulicny, G R, & Jones, M L (1987). "Consumer management of attendant services." NARIC Rehabilitation Research Review. Washington, DC: National Rehabilitation Center. Also available from NARIC, 4407 8th St., Washington, DD, 20017.

Analyzes review of attendant services focusing on research related to consumer-directed models. Results support consumer-directed model but suggest importance of long-term, large-scale demonstration projects.

Ulicny, G R, White, G W, Bradford, B, & Roste, C (in press). "Consumer exploitation by attendants: How often does it happen, what can be done about it?" Rehabilitation Counseling Bulletin.

Paper presents results of a survey designed to evaluate the magnitude of exploitation of consumers by personal attendants and to examine what consumers can do to decrease the likelihood of exploitation.

Address: RTC/IL, 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States.

Peer support

Peer counseling: an overview

Introduction

The counseling room is crowded. It is obviously not designed for two people in wheelchairs. One of the individuals in the wheelchair is a counselor, the other individual is the client. The client is in the process of telling how embarrassed he was the first time he went to the beach. The conversation went something like this:

> Client: "I suddenly hated all the manhandling - being lowered into the water by someone else with everyone on the beach looking on. All of my plumbing (catheter and leg bag) were exposed. I became acutely aware that I did not have the body beautiful that you see on T.V."

> Counsellor: "Yeah, there are big bodies, little bodies, straight bodies, and not so straight bodies. With us the old locker room concerns about penis size and breast size become very insignificant."

We both laughed and proceeded to compare notes on experiences we have had as persons with disabilities. Many sessions followed where we talked about and experimented with various coping mechanisms we used, to deal with everyday problems.

Robert was my first client and from that very initial experience I realized how important it was for a person with a disability to have the experience of meeting and talking with another person with a disability. I also realized the uniqueness of my own experiences and how valuable it was to me to share those experiences. This is what peer counseling is all about. The peer counselor is that individual who has attained disability related experiences, knowledge, and coping skills, to assist others with their disability related experiences. The goal of peer counseling is directed toward enabling the individual to meet personal needs in order to more fully function and take control of his life, in his home, community and employment.

Independent Living model

In order to understand peer counseling fully, one should look at it in the context of the Independent Living model. This model is a concept or an expression of people's desires to be in control of their own lives. This model can be understood more fully when compared to the rehabilitation model. The rehabilitation model, to put things very simply, states that if changes or adjustments are to be made they happen within the client. The client is expected to internalize, to see his/her weakness, his/her shortcomings, make changes within him/herself, and most of all learn to be accepting of his/her disabilities. The counselor working within the Independent Living model would look at the problems from outside the client - that is looking at the environment and helping the client determine what in the environment needs to be changed in order for the client to function more fully.

Advantages

Peer counseling has many advantages to the client, the counselor and the community. The client is given the opportunity to model after someone whom s/he has reached out to. S/he is given the opportunity to develop coping skills that presumably work because they work with the peer counselor s/he is relating to. S/he can learn to advocate on his/her own behalf. His/her feelings of self-worth can be enhanced because s/he has a counselor who truly understands.

The peer counselor gains in feelings of self-worth for s/he has the opportunity to share a valuable and worthwhile experience. This in turn can motivate the counselor to reach out to others and to perfect his/her skills. For many peer counsellors this position can be a vehicle for career development.

The community, of course, is helped to form a positive image of the disabled. More important, the service to persons with disabilities is improved allowing these persons to take up a more meaningful role in the community. The development of peer counsellors would appear to be the grassroots answer to a growing technology, allowing people to grow closer together rather than apart.

Personal characteristics

It should be pointed out that not all individuals can be peer counsellors. The good counselor is a person who can show empathy toward other people's problems, be able to listen, communicate, be direct, sincere, be able to share personal experiences, be trusting, and have knowledge and skill that would be helpful. The counselor should have a broad range of good personal characteristics.

In addition to the above a peer counselor must have a 'rights bearing' attitude. This involves an understanding and acceptance of the fact that people with disabilities have the same rights and responsibilities as all other individuals. That is, they have the right to make contracts, hold a drivers license, make a will, marry, adopt or bear children, hold and convey property, equal educational rights, equal employment opportunity, and an opportunity to vote and participate in political affairs. This suggests that the peer counselor must have a fair knowledge about many issues relative to disabilities.

Ethics

It is important for the peer counselor to know the philosophy and policies of the place s/he is working. It is highly important that the counselor know his/her abilities and limitations. It is important to know when and when not to act. This issue of confidentiality is important. The counselor must know the difference between being a support person and being a 'protector' or 'rescuer'. It has to be recognized that persons with disabilities have a right to make their own decisions and to live with the consequences of that decision.
Models of peer counseling
There are various models of peer counseling being used. The kind or kinds of models used depends on the needs of the community and the expertise of the peer counselor. There are four approaches which are most common.

The generalist approach

Almost every program has one person amongst them who can work as the 'generalist' in the program. Often this person is placed at the 'intake' level or is the first person to come in contact with the person seeking help. It is the responsibility of this type of counselor to feel out the nature of the problem, to determine who could best work with this individual and determine how long the involvement would be. Usually, the generalist works for a very short time with the individual and then refers to someone who is more specialized in what the person needs.

Instructional counselor

This approach basically involves the teaching of skills. This type of counselor is often called peer educator or peer tutor. The main objective of this type of counseling is to help individuals make that transition from being totally dependent to being as independent as possible by giving training in the areas that the individual seems to be lacking, e.g. social skills, attendant management, financial management, functional needs, academic skills, etc.

Outreach

This type of work involves going out to people to make known to them what the Independent Living philosophy is. This type of counselor is meeting with people who often do not have the ability to reach out. In some ways they have become too accepting of their situation and do not realize there are other ways.

Advocacy

The main function of this type of counselor is to help people work their way through systems so that they can get what is rightfully theirs. This can be looked upon as more a teaching role - what is the nature of the system, how does one work through the hierarchies to get what one wants. There may be a need to teach letter writing, communication skills, telephone skills, etc.

History

Peer counseling is a term being heard with greater frequency, particularly throughout the various Independent Living centers in North America. Although to some it seems like a new concept, the concept has been in existence for many years and proven to be very worthwhile. Such organizations as the Alcoholics Anonymous, the Canadian Paraplegic Association, the Canadian Association of Children with Learning Disabilities, parent groups that form to help improve and get involved with school systems, the Cerebral Palsy Association, etc., the list could be very long. All the organizations have demonstrated that consumer based organizations can deliver important kinds of service. They all use peer support and peer counseling as a feature of their service. They all operate on the premise that:

- the peer counselor provides a role model,
- the peer counselor can serve as a link between the person seeking help and the service provider,
- the peer counselor can draw on a wide range of unique experiences which cannot be observed by anyone else.

Program planning

The peer counseling movement is a response to a number of different factors in our society. Recognizing this and recognizing the potential that peer counseling has for improving service steps should be taken to finance, administer and develop such programs. Initial issues which have to be addressed in setting up a program such as this are:

- do the counsellors need professional training or not,
- how formal should a peer counseling program be,
- should peer counsellors be paid or should they be willing to offer their area of expertise on a volunteer basis.

There are legal concerns, as well, that have to be addressed:

- what is the liability of the organization using peer counsellors,
- what supervisory mechanisms need to be in place in order to use peer counsellors,
- how can the client's rights to confidentiality be guaranteed when the peer counsellors do not belong to a licensed body whose responsibility it is to monitor this.

Conclusion

Peer counseling is a developing concept that should not be looked upon as a panacea for alleviating personal problems in others. However, evidence of the benefits of peer counseling can be seen in many programs and it should be evaluated as an area of great potential.

Source:
Patricia Sisco,
COPOH,
926-294 Portage Ave, Winnipeg Man R3C 0B9, Canada

Peer counseling programs: observations from the field

The ILRU Newsletter featured a series of articles on operating peer counseling programs. The following excerpt is taken from their third article.

"These articles are synthesized from discussions among mid-level managers in Independent Living centers. They occurred during our two management training programs focusing on supervising peer counseling programs. These training program were attended by 24 program managers. These individuals came from small centers and large ones, from urban and rural settings, and from all parts of the country. Their approaches to peer counseling service delivery were very different, ranging from all volunteer counselors to all professional counselors to qualified non-professional counselors, from use of the group session format to the one-on-one format to a mix of both.

Despite their differences in approaches and settings, the 24 participants had many things in common--the difficult things: insufficient community resources, perceived lack of consumer progress, peer counselor discouragement and burnout, a sense of disconnection within the center, consumer apathy or passivity, and overwhelming paperwork demand among others. Ways that centers are addressing these problems to operating peer counseling program were presented in the two previous instalments of this series. In this third instalment, the proper balance between service delivery and advocacy will be addressed. It should be noted that all of the comments belong to the training participants, as captured in our notes.

Regarding the importance of systems (also known as community) advocacy in Independent Living centers, Lex Frieden told training participants that advocacy is what people in Independent Living centers are doing that traditional service providers cannot do. He added that it is advocacy that tells us what services are needed. At these two training sessions, a frequently expressed concern was that because of the high demands of delivering services--including having more requests for services than can be met to completing endless paperwork--systems advocacy, which focuses on changing the community, does not receive the attention it should.

One long-time center administrator wondered if centers nationwide were becoming complacent--and putting too much emphasis on service delivery and much too little on advocacy. This led to a discussion of the proper time split between services and advocacy. When asked to estimate the percentage of time spent at their centers on services and on advocacy, most of these mid-level managers said 80 percent services, 20 percent advocacy. Some put advocacy a little bit higher. When asked what the ideal spit should be, the managers' consensus was 60 percent to 40 percent in advocacy's favor. Some would like to see it 80 percent advocacy to 20 percent service delivery.

Being middle managers and therefore essentially task-oriented and practical, they wondered how such a swing in center emphasis could be implemented, for it would mean limiting services. How, they asked--and no one had a ready answer--could that position

be sold to the board, center consumers, and the community?

Some centers have found ways to help their service delivery staff keep a focus on advocacy's significance. In a western center, the staff meets every three months to review activities being done by center personnel to change the system. This was instituted in response to management's need to remind staff of the center's 'roots' and to stress the importance of advocacy. In a midwestern center, staff are assigned both service delivery and advocacy responsibilities. It is believed that this dual responsibility provides essential perspective: through service delivery activities, staff learn about problems and can then develop (or try to) ways to address the problems.

One program manager raised the issue of centers' responsibility to help consumers become self-advocates. He expressed the concern that consumers' needs have been met just enough to keep them quiet and uninvolved--and with no anger to motivate action for change. He believes that staff should help them realize that they have a right to be angry (e.g., "Why should I have to vote from my car window? Why can't I enter the voting precinct and cast my ballot like everyone else?") and then help them channel that anger into positive action. In this discussion, another experienced counselor said that in such cases, the center needs to provide consumers with assertiveness training because of the difficulty associated with confronting and working with anger.

We will close this piece on the proper role of advocacy in centers with a comment by Lex Frieden when asked about the threat to funding if a center does 'too much advocacy'. His response was, "Who decides how and why we get the money? This is why we need to get people on since rehabilitation agency boards and why we need to influence legislation. It is our responsibility to make changes."

Source:
ILRU Insights, The National Newsletter for Independent Living,
Vol.7 No.5&6, Sept.-Dec. 1989.

Address:
ILRU at Texas Institute for Rehabilitation,
2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Peer support

Resources

Ater, E. Carolyn; Baugh, C.W.; Elias, Jeffery. "A Peer Advisory Consumer Program for the Elderly." The Personnel and Guidance Journal 58. (October 1979): 106-109.

Back, Kurt W. and Taylor, Rebecca C.. "Self-Help Groups: Tool or Symbol?" Journal of Applied Behavioural Science. 12 (July-August-September 1976): 295-309.

Borck, L E, & Fawcett, S B (1982). Learning counseling and problem-solving skills. NY: The Haworth Press. Order from: Haworth Press, 28 East 22 St., New York, NY,

United States.

Borman, Leonard. "Self-Help and the Professional." Social Policy. 7 (September-October 1976): 46-47.

Institute on Rehabilitation Issues (1981). Peer counseling as a rehabilitation resource. Hot Springs: Arkansas Rehabilitation Research & Training Center.

Saxton, Marsha, "Peer Counseling" in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

World Institute on Disability, Peer Counseling Manual, (forthcoming)
Address: 510 16th St, Oakland, CA 94612, United States.

Zola, I. K. (1979). "Helping one another: A speculative history of the self-help movement". Archives of Physical Medicine and Rehabilitation. 60 (10).

The following resources are published by the Independent Living Ressearch Utilization Program, Houston:

Barker, Linda Toms, Maya Altman, and Andrea Youngdahl. "Dimensions in Peer Counseling: Observations from the National Evaluation of Independent Living Centers". Issues in Independent Living No. 7. Houston: ILRU Program, 1987.

Delivery of Peer Counseling Services in IL Centers. This study involved reviews of literature on peer counseling, examinations of data from the evaluation related to peer counseling, and follow-up interviews with selected centers which participated in the national evaluations.

The Definition of "Peer": Consumer Perspectives and Significance in the Delivery of Counseling Service.

The project focuses on perceptions of counselor credibility. The research question asks which factors account for the great variance in ratings of counselor credibility: disability status of the counselor, whether or not the counselor is professionally trained, and whether or not the content of the interaction is disability related.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

The following resources are published by the Research and Training Center on Independent Living, University of Kansas:

Moses, H, Borell, K, & Siler, A (1982). Issues in developing peer counseling programs. Lawrence: RTC/IL, University of Kansas.

Report developed for rehabilitation and IL personnel includes sections on evaluation of peer counseling, models, functions, benefits, implementation strategies, administration, and information on programs.

Pittman, J L, & Mathews, R M (1984). "Peer counseling: Four exemplary programs." American Rehabilitation, 10 (4).

Case study approach used to identify critical components of four peer counseling

programs: Boston Self-Help Center, Independence Center of N. Virginia, Ann Arbor Center for IL, and Paraquad, Inc., St. Louis.

Roessler, R T (1982). Role of IL Counselor. Stillwater, OK: National Clearinghouse on Rehabilitation Training.

Discusses critical role of Independent Living counselor in IL programs. Addresses advocacy, counseling, and case management skills.

Address: RTC/IL, 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States.

Disability, women and love

It is the most natural thing in the world for a human being to love someone. It springs from the most basic human instinct of all - preservation of the species. However, for me being physically disabled, loving someone was always fraught with great fear and pain. Nevertheless, I couldn't deny my natural emotions and have loved many men since I was young. It took me a long time to learn to express my own feelings and live naturally without fear and also to have confidence in being loved myself. Now I have been in love with my boyfriend for nearly three years and realize, if you don't love yourself you can't love anybody else.

When I think about my past life, I realize I was treated negatively from the moment I was born; "What a pity!", "How can she be happy with that body?", "You should never have been born.". As I grew up I completely lost my self-confidence and couldn't love myself at all. When I was twenty years old I became involved with a group of disabled people who were trying to live independent lives. The ten years following I struggled to work through the deep sexual problems I had accumulated through the lack of recognition of myself as a sexual being while growing up. Almost all people with disabilities are confronted with this problem. Many of us develop personality scars because of never having been acknowledged as a true man or woman. We therefore build up great illusions in our minds about marriage and male and female roles.

My disability

I was born with a bone malfunction which was characterized by stunted growth and bone fragility. It is a very rare condition and so far, neither cure nor treatment has been discovered. I have had more than twenty bone fractures and subsequent operations. I spent one fifth of my life in bed wearing a plaster cast up to my chest, during my primary school period. I find it difficult to describe the harshness, both in words and actions, of the doctors who treated me during this time. These awful experiences have left their mark on me.

I'm now involved in "co-counselling", a form of peer counseling and therapy which attempts to clear blocked emotions through reliving stress situations and releasing the blocked energy. I am an ardent believer in this method and active in disseminating it throughout Japan. After such a session, problems come into clearer focus. When I relive

past experiences in these sessions, I am astonished by how much I must have suffered when I was young. I have never felt comfortable about my body. On the contrary, it was always the cause of pain and suffering and because of it I was pitied, denied and despised most of the time. I never received compliments. Despite all the complexes I had to cope with, on reaching puberty and entering adolescence I discovered my own potential for sexual relationships. I then entered into relationships not because I loved but because of my need to be accepted. During this time I never felt any satisfaction in love, but I accepted that this was the only path open to me.

Relationship with my first boyfriend

The relationship with my first boyfriend (if I can call him that) started on shaky ground, neither of us daring to communicate verbally with the other. It was not so important for me to attract him mentally, but I always felt great anxiety about my tiny misshapen body being physically attractive to him. It was so important for me to feel accepted by him. We therefore spent a lot of time together exploring eroticism. It was a typical male/female relationship, the woman as sexual object, the man judging her by her appearances. The time I spent with this boyfriend reflected such habits and was very painful to me. I was afraid to ask him to use contraception and of telling him I didn't feel any satisfaction from our relations. The need for my body to be accepted was so intense, it distorted this impulsive young act imagining it to be love.

Recently I read a report about prostitution. It detailed how many girls involved in prostitution had no financial need for doing so, but that they had been sexually abused as children. I think there is a lot of truth in this. Harsh experience paves the way for a woman to allow herself to be treated as a soulless sexual object. When I reflect on my first relationship it saddens me how I was treated merely as an object and that I couldn't assert myself as the woman I am. Out of my many painful memories, there is one story of abuse by medical personnel that I would like to share now.

Behind closed doors

Before starting primary school, I had to have an X-ray examination. A radiologist asked my mother to wait for me outside the room. That was unusual. He then told me to lie down on the cold X-ray machine. He took my underwear off with such authority that I didn't dare protest. That was also unusual. I felt great fear and anxiety. Then he abused me sexually using a metal stick, all the while whistling and looking as if he were enjoying himself. I could neither scream nor tell mother afterwards about the dreadful violence. This affair left me deeply scarred.

This is one great danger we disabled women have to face. On one hand we are denied and insulted as women but on the other hand we can easily be raped. I really wish to point out to people with disabilities that we must not allow ourselves to be discouraged by such hard situations. There is no limitation on our ability to love. We can even perhaps achieve a better, deeper and more honest kind of communication through our disabiliyt and learn to live our lives to the fullest. But in the meantime we are very dependent on the sensitivity and humaneness of medical personnel. To enable us to develop more positively we really need medical personnel who are self-confident and mature. I sincerely hope for more of this type in the future.

About my marriage

After I split up with my young lover, I lived together with a disabled man for nearly six years. This relationship was the first step in learning to love myself. However I didn't ever consider marrying him, because I didn't believe that marriage would improve the low

status we had in society. But on the other hand I believed in my own mind that if, I married an able-bodied man, this would be my passport into normal society and would lessen the discrimination against me.

In 1983, after I finished my six month course of study in the United States, I told myself, "This life I only live once, so I should live it how I want to." At that time I had a strong desire for marriage and soon after started to live with an able-bodied man. My life with the disabled man finished with his kind words, "You must live as you think best." Later I realized how different living together and marriage really are, and his parting message came to mind.

The proposed marriage with the able-bodied man was opposed violently by his parents and our relationship ended after eight months or so. Now I'm glad that they opposed the marriage. However at that time I was so surprised, disgusted, angry and sad. I began to realize how distorted the current marriage system was with its discrimination and lack of humaneness. Traditionally in Japan, being a good wife required obedience to the husband's family. The love and hope of the couple came second. The capacity to bear children was the woman's greatest asset. I didn't fulfill any of these expectations so I was completely rejected by my fiancé's family. If the marriage system depends on the notion that a man and a woman have to have fixed roles in society, it is extremely difficult for us disabled people to be part of that system.

Even if we had been able to be married without opposition, we would soon have realized that we couldn't have a balanced relationship because of the social inequality of the sexes. For eight months I took on the role of proper housewife and was treated as his wife by all people except for his family. Before we decided to marry, he looked after his guests by himself and I was able to keep up my old habits. However, after deciding to marry, I felt that I was responsible for the care of his guests and should therefore change my lifestyle. Even being called by his name seemed to me to be destroying the sense of my own identity.

Through all these experiences I realize that I am discriminated not only for my disability but also for my being of the female sex. In Japan, we believe that marriage is a passport to join society. However, my desire for marriage has completely disappeared since I became aware of how much our society is based on sex discrimination. Of course, I wouldn't question anyone's attempt to create a balanced relationship for themselves through living together, but as a means of recovering from my pains, it is very comfortable for me to meet my boyfriend just three or four times a week. It took me a long time to come to the realization that only we two can decide how to love each other. Now we are trying with love and trust to live what we have learned.

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Various disability groups

Independent Living for various disability groups

The history of Independent Living as a specific process whereby disabled persons are enabled to be more self-directing and participating to an integrated manner in the community, shows very clearly that it is a process tried, tested, and proved for persons with severe mobility and visual impairments as evidenced by the literature in both the U.S.A. and Canada. The personal assistance service so closely associated with Independent Living in the United States is a service particularly required by persons with mobility disabilities. As indicated in the Zukas history of CIL in California, a deliberate decision in 1972 brought persons with visual disabilities into the Independent Living process where they have remained ever since, using Independent Living services particularly suited to their needs such as reader referral services.

Since the deaf and hearing impaired community is also desirous of living in as much as possible a self-directing, integrated manner in society and has a membership which is quite capable of achieving this, it would seem they too should benefit from involvement in the specific processes we have called Independent Living. That they have not done so to this time may be explained in part by communication difficulties between this group and others, the fact of their own American sign language culture, and a history which did not include recent institutionalization to the same degree as is the case for blind and mobility disabled persons. Another factor which would bear consideration is that for most profoundly deaf persons in the American Sign Language (ASL) culture, integration does not mean integration of the individual in society at large but rather, integration of their community into the community of communities which makes up our society. It seems reasonable to think that sign language interpreter referral services, Independent Living skill training, and various other adaptations of Independent Living services would be of great benefit to hearing impaired and deaf individuals.

In the area of psychiatric and intellectual disabilities, some more profound difficulties may occur in an attempt to modify Independent Living concepts and services for use by these groups. For example, the central concept of self direction/self-determination, may present some difficulty for some intellectually disadvantaged persons and for some psychiatrically disabled persons. Still, there may be great benefit to be gained by researching the application of Independent Living concepts and processes to these disability categories.

A person with an intellectual disadvantage, for example, might benefit from some staff assistance, just as a mobility disabled person does by way of a personal care attendant, or the deaf individual does by way of a sign language interpreter. Intellectually disadvantaged persons might benefit from services of someone whom he/she trusted to simplify complex matters and analyze these for reasonable options for the intellectually disadvantaged person to choose from. The Community Services Model in British Columbia also offers an interesting parallel to the personal assistance program in California, (often associated with Independent Living}, inasmuch as it makes governmental moneys available to the disabled individual's family or guardian in much the same way as California makes moneys available to the disabled individual for the purchase of personal assistance services. In the Community Service Model of British Columbia, the family or guardian of the intellectually disadvantaged person is then able to purchase services including the services of a broker who assists the intellectually disadvantaged person with day-to-day living decisions.

Valuable research could also be done with psychiatrically disabled persons in order to determine whether Independent Living concepts and processes could be applied to this group. These disabled persons have a long and tragic history of institutionalization as do persons with intellectual disadvantages. Drug discoveries of the past two decades have led to massive de-institutionalization for psychiatrically disabled persons. Unfortunately, the

side effects of these drugs and other treatments are debilitating themselves. The result has been some very unsatisfactory re-institutionalization in boarding houses where they are neither integrated and participating in the community nor truly self-directing in that, for the most part, very few options are available to them. It seems reasonable to think that some form of assistance to compensate for some of the side effects of the drugs these individuals must use could improve the variety and quality of options available to them, and perhaps allow them to live in a more integrated manner in the community. Peer counseling and support would almost surely be of some help to psychiatrically disabled persons. At this point, however, the idea of Independent Living applications to psychiatrically disabled persons is, in the main, somewhat speculative and would require some very fundamental research to determine the feasibility of such applications.

It is important to understand that Independent Living as a specific process of benefit to disabled persons has largely been limited to persons with mobility and visual disabilities. This is not a fatal flaw by any means, rather it is a mark of its versatility as a technique for ameliorating the conditions of disabled persons, and advancing their status in the important ways it does, that it is applicable to persons with various physical disabilities. Many other concepts are applicable only to more limited sub-categories of disabled persons. Complete and absolute versatility should not be required or expected of Independent Living. At the same time, it is important that some research be initiated into the application of Independent Living processes for persons with intellectual and psychiatric disabilities.

Source:
Independent Living Resource Center,
207-294 Portage Avenue, Winnipeg, Man. R3C 0B9, Canada.

A brief history of brokerage

by Craig V. Shields

According to one source, brokerage is an innovative demand-based approach to service delivery, which has its roots "in the growth of consumerism and the advent of constitutional rights". The term first came into usage in the late 1970's to refer to an approach being developed by a group of West Coast Canadian families "who believe that their severely disabled children should have the right to plan their own lives, and be given the opportunity and appropriate resources to do so".

The evolution of service brokerage as a concept began in early 1976 in Vancouver, British Columbia. A number of parents, whose sons and daughters had been institutionalized because of severe developmental handicaps, came together to share their frustrations about the current service system. Their interests at this stage were twofold: some parents were primarily interested in improving existing institutional services, while others were more interested in developing community alternatives to institutional placement. It was this latter interest that provided the stimulus for what would become service brokerage.

As these parents continued to meet, adding to their number as they went along, they

began to identify a number of things that they felt needed to happen in order for their disabled children to successfully return to the community. A major concern was funding. Government dollars were flowed to agencies rather than individuals, limiting the responsiveness and accountability of service providers to consumers, and making it next to impossible to obtain services based on an individual's unique needs. Thus, "the notion of individualized funding emerged from a dream the parents had that funds could be aggregated and used flexibly to benefit each child, as his or her needs changed and grew".

Another major concern was the feeling of exhaustion that parents shared as a result of their efforts to find out about the system: how it worked, what services were available, their eligibility criteria, how to apply for them and so on. The parents realized they would need a resource to help them "sort out the patchwork of social services and obtain what was needed". And yet they did not want this resource to simply "take over", they wanted the right to be involved in planning decision-making, and they wanted the right to veto any plan that they felt to be inappropriate.

These different elements - individualized funding, a systems resource, and consumer involvement - became the core of a concept the parents began to refer to as 'service brokerage'. In the fall of 1976, the group developed a proposal for implementation of this concept which they submitted to William Vander Zalm, then Minister of Human Resources. The Minister's response was to agree to divert to the new program some funding that normally would have covered the costs associated with institutionalization. The parents then needed an organizational entity to receive funds and to help make cost-efficient decisions about what services to purchase. In 1978, therefore, they incorporated as a not-for-profit corporation under the name 'Community Living Society'.

In that same year, 1978, the first ten children were brought out of institutions into the new program, and service brokerage became a reality. The original concept has continued to evolve as experience has required. It also has been adopted and adapted, sometimes with significant variations, in other settings such as Calgary and Edmonton. While it is probably fair to say that there is no single, uniform approach to service brokerage, the different models are linked by a common commitment to a set of values emphasizing the worth and dignity of individuals with handicaps and their right to live in the community.

Source:
Service Brokerage For Persons With Disabilities In The Province Of Ontario, Prepared for Services For Disabled Persons Branch, M.C.S.S. by Craig Shields, Human Services Consultants, March 28 1988

Address:
Craig V. Shields, c/o Human Services Press,
P.O. Box 421, Richmond Hills, ONT L4C 4Y8, Canada

Disability and aging

Independent Living Movement:
organizing for an active, disabled old age

by Judith E. Heumann

Controlled by disabled elders and younger people, the movement promotes Independent Living through education and advocacy.

The Independent Living Movement is becoming more actively involved with the community of elders. For the past few decades, persons with various types of disabilities have been organizing the Independent Living Movements to gain control over their lives. This movement, which began to pick up steam in the late 60's, is represented by people who have various physical disabilities - people who are blind, deaf and hard of hearing; people with invisible disabilities such as epilepsy, cancer, heart disease, back problems; people who are mentally retarded and mentally disabled; people of all races and ages. Like other movements, the Independent Living Movement works to protect the rights of its constituency. And like such groups as the Grey Panthers, one of the ways this has been achieved is through the creation of organizations that are significantly controlled by the affected constituency. The organizations are called Centers for Independent Living. The first program was started in Berkeley in 1972; since then more than 150 programs have been developed in the United States and throughout the world.

These centers for Independent Living are committed to the development of a social system in which all people with disabilities have the opportunity to lead productive, meaningful lives as integrated and valued members of their communities. One of the reasons why these programs are successful is that many of the staff providing services are disabled people themselves. They developed the programs to prove to themselves and to others that people with the severest of disabilities can live independently, integrated into the community. Advocacy and a peer approach are integral to the philosophy of this movement. The workers in these programs seriously want to reach out and work with people who are in institutions, and they want to prevent other from entering institutions' doors. The reasons are simple: personal experience or having visited too many friends in these facilities have made us want to provide the tools to allow people to make it in the community with appropriate supports.

There are twenty-two Independent Living centers in California. Their statistics for the quarter ending September, 1983 show that 27% of their clients were 61 or older. This may be a conservative estimate. Elderly people with disabilities have very similar needs to younger disabled people. Some of the most commonly used services are attendant referral, housing placement and transportation services. There are large numbers of other elderly disabled people who could benefit greatly from services delivered by Independent Living centers. The cause of many elderly disabled people not using these programs is attributable, we believe, to lack of knowledge of the programs, and/or discomfort elderly disabled people may have about being categorized with younger disabled people.

As many of us who have been disabled for many years begin to acknowledge that we too will become old, we have started to look at the elders in our communities. We have begun to join such groups as the Grey Panthers and have sought to actively participate in the discussions concerning long term planning. We see that the prejudicial attitudes that non-disabled people have historically held towards disabled people take a large toll on older people as they acquire disabilities and lose some functional capabilities. As the younger, non-disabled become the older disabled, they become increasingly isolated from friends because of transportation problems, architectural barriers and prejudice. We see they are plagued by an attitude which has taught them to think that to be disabled is a tragedy. Younger people fail to recognize that the likelihood of their becoming disabled is significant and that they must be adequately prepared. So we see a community of elders today who fear disability because they believe it means an end to their lives as

independent people.

The World Institute on Disability's objectives are to work with appropriate organizations to:

- Enable people who are elderly and disabled, and those who are elderly and might well become disabled, to see that their lives are not over.
- Conduct workshops rum by younger and older disabled individuals where people can discuss their concerns about being disabled and learn how to do such things as hire and work with attendants, use accessible public transit, order para-transit systems and articulate their true concerns and desires to the medical profession, other health professionals and family members.
- Conduct workshops where people can have hands-on experience with technical aides such as speaker phones, communication devices, push and motorized wheelchairs, closed captioned TV units, ramps, electric beds, inexpensive modifications to kitchens and bathroom, etc.
- Ensure that elderly disabled individuals are actually involved in the development of programs and are workers in the projects.
- Conduct media campaigns to educate the younger population to the positive realities of ageing and disability.
- Assess current public policy to determine where weaknesses currently exist, to make recommendations and to help convince people that it is in their best interest to prepare for the future by working for change.
- Review policies in other countries as they pertain to disabled and elderly disabled individuals and, where appropriate, work towards adoption of these policies.

The Independent Living Movement has begun to positively affect the lives of many disabled people. Our vision is one that leads people to see a future that they previously have denied - life as active, disabled elders.

Source:
Generations, Summer 1984.

Intellectual disabilities

The changing role of the People First advisor

by Charles Curtis

People First is a self-advocacy organization operated by and for people with mental (intellectual) handicaps, with help from nonvoting non-disabled advisors. People First has been in existence for about a decade. Curtis describes "good" advisors as being:

- interested in the welfare of mentally handicapped people;
- respectful of individual differences;
- understanding of special needs;
- personable and open-minded;

- available when needed; and
- committed to self-advocacy.

Their jobs, at the local level, are to help members develop group-process, decision making, and self-advocacy skills; train officers for their positions; facilitate liaison with other community groups; and help with public relations. People First philosophy envisages a time when local chapters can function without full-time advisors, using only temporary help as needed.

Advisors are often drawn from agency/institution staffs, especially for new chapters, and this causes concern. Professionals who hold traditional views of intellectually limited consumers may be overly active in their diligence to protect and their reluctance to allow risk taking. This can hinder individual member and chapter development. Also, conflicts of interest arise when advisors must help People First groups pursue grievances against their employers. Such conflicts can only be avoided when members are able to handle such grievance actions without advisors' help.

According to Curtis, only where the advisors meet the criteria listed and will provide leadership without taking control, do chapters grow in membership and competence.

Curtis, Charles. "The Changing Role of the People First Advisor", American Rehabilitation, April 1984.

Source:
Rehab Brief. Vol. VIII, No. 5 May 1985. National Institute of Handicapped Research. Office of Special Education and Rehabilitation Services, Department of Education, Washington, D.C. 20202.

**Women,
various disabilities,
aging with disabilities**

Resources

Genskow, J.K ."Independent Living Programs and services for Older persons with Disabilities",The Journal of Rehabilitation. Vol. 54, No. 4, October/November/December 1988.

Assessment of the role of Independent Living programs (ILPs) in providing services to older persons with disabilities. A national sample of 200 ILPs are surveyed and include members and percentages for elderly clients, services offered, age at occurrences of disability, and plans for services to this population. Low response rate (30% return with 25% usable) and partial response on some items challenge representativeness. Appears that at least 80% of ILPs do serve elderly and that some serve relatively high numbers of them. More research needed to define differences between responses to disability at various times of life. Orthopedic disabilities appear most often served, and emotional least

often, regardless of age at onset. Authors suggest need for more services to help older ILP consumers who are living in either their own homes or with relatives or friends continue to live independently. Appears to be considerable interest on part of ILPs toward working with older persons with disabilities. Needed additional resources identified as better and appropriate housing, transportation, home helpers, community awareness including marketing of IL philosophy and needs of elderly persons with disabilities. Possibility of overlapping services which are offered through existing programs for the elderly.

Genskow, J.R. Independent Living and the Elderly Disabled in Denmark. Sangamon State University, IL. World Rehabilitation Fund, Inc. International Exchange of Experts and Information in Rehabilitation, 1986.

A World Rehabilitation Fund Fellowship Report on services and programs for the elderly disabled in Denmark. Without benefit of abstract, table of contents, or index, this report attempts to chronicle the author's study trip to Denmark to collect data on the disabled elderly which the author believes will be useful for a variety of U.S. audiences. The author chiefly sought to learn how the Independent Living model, which arose from community work with younger persons, was working when applied to an elderly, disabled population. Essentially, the author interviewed both the elderly themselves as well as care givers at their "living sites" and places of work. He also collected national statistics. Among the many findings to emerge from this report are: the Danes believe that since taxes are so high, the government should take over care for those in need; as in other places, the Danish population is growing older; there are many programs intended to encourage elderly Danes to stay at home; the Danes are in part reversing their traditional Socialist model of the state caring for the needy by encouraging individual initiative; Independent Living is seen as the most desirable life style for the elderly disabled; Decision-making power lies with local communities rather than the state; and home health service is provided to encourage staying at home.

Address: Prof. Jack R. Genskow, Sangamon State University, Human Development Counselling, Springfield, Ill 62708, United States.

J. Ryan & F. Thomas, The Politics of Mental Handicap, 1984.

The following resources are published by the Independent Living Ressearch Utilization Program, Houston:

Sigelman, Carol and Jerry Parham. "Independent Living and Mental Retardation: The Role of the Independent Living Program". Issues in Independent Living No. 4. Houston: ILRU Program, 1981.

For persons with limited familiarity with the field of intellectual disabilities, the authors provide a brief history of the movement and describe the present mental retardation service network, giving particular emphasis to services that pertain to Independent Living. To assist administrators of Independent Living centers to determine how they may serve persons with retardation, the authors discuss ways that relevant service agencies, centers, and consumer organizations can collaborate to establish a division of labor that will result in a coherent network of alternatives.

Petal, Marla. "Independent Living and Deafness: Incorporating Deaf Clients into the Independent Living Network". Issues in Independent Living Vol. 1. Houston: ILRU Program, 1980.

This monograph addresses the need for Independent Living centers to include people with

hearing impairments among their service constituency. It includes an annotated checklist of services that the author has identified as minimal requirements for Independent Living on the part of a person with deafness. It concludes with profiles of five programs (not Independent Living centers) which provide Independent Living services to this population.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

The following resources are published by the Research and Training Center on Independent Living, University of Kansas:

Jones, M L; & Ulicny, G R (1986). "IL perspective: Applications to services for adults with developmental disabilities." In J A Summers (Ed.), The right to grow: An introduction to adults with developmental disabilities. Baltimore: Paul H Brookes. Reproduced with permission. Copyright 1986 by Paul H Brookes.

Discusses principle of normalization and how it can enhance Independent Living for persons with developmental disabilities.

Ward, M, Summer, C, Victor, J, Swirsky, J, Brennan, D, & Summerville, J (1986). Toward transition: Model approaches to IL services for disabled youth. Lawrence: RTC/IL, University of Kansas.

Four organizations: CIL, Berkeley; HAIL, Denver; Human Resource Center, Albertson, NY; Services for IL, Euclid, OH; and the U.S. Dept. of Education, Office of Special Ed. and Rehab. Services, describe their programs to facilitate a more successful transition from school to community life for young people with disabilities.

Turnbull, A P, Summers, J A, & Brotherson, M J (1984). Working with families with disabled members: A family systems approach. Lawrence: RTC/IL, University of Kansas.

Outlines a family systems approach to serving disabled persons and their families. Emphasis is on interaction, life cycle changes, and coping with stress.

Brotherson, M J (1984). "Families and independent living: An interview with Colleen Starkloff." Independent Living Forum, 2 (2).

Interview with Starkloff describing her work with families at Paraquad, St. Louis begins an issue devoted to families with disabled members.

Brotherson, M J, Turnbull, A P, Summers, J A, & Turnbull, H R (1986). "Fathers of disabled children." In Robinson and Barrett, (Eds.), Fatherhood. Baltimore: University Park Press.

Uses a system approach to review various reactions of fathers from different family structures to their disabled children.

Scott, S (1981). "Family systems". Lawrence: RTC/IL, University of Kansas. Presentation for Conference on Independence, University of Kansas.

Discusses family decision making with focus on independence for mentally disabled persons.

Brooks, D (1982). "Independent living and women with disabilities". Lawrence: RTC/IL, University of Kansas.

Discusses unique concerns and complex choices disabled women face.

Address: RTC/IL, 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States

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The greatest problem experienced by most disabled people anywhere is poverty. This article shows one example of a possible line of action, the employment scheme of the Self Help Association of Paraplegics, SHAP in Soweto, Republic of South Africa.

Self Help Association of Paraplegics, SHAP, Republic of South Africa

The background

SHAP was launched in 1981 by a group of unemployed Soweto paraplegics who reasoned that a gainfully employed disabled person would be in a stronger position to help him/herself in all areas of life. They decided to operate a factory employing only disabled people, doing work on a subcontract basis for industry.

They found that it you knew where to go, sponsors were relatively available for building, equipment and vehicles (in that order), and to a lessor extent, for cash. The secret of their fund raising success was their self help nature, their self-supporting potential, the imaginative but inexpensive presentation of their case, and their sound administration - the latter allaying fears of misuse of funds. Their building was completed in 1983. It incorporated 600 sq.m. of potential production space, offices, ablutions and not enough storage.

Developing self sufficiency

During the months of waiting for the completion of their building, they had spent their time in assessing, motivating and selecting their initial workforce of 30 paraplegics, and a reserve pool of 30 workers. By the time the building was completed, workers were so motivated to secure employment that they worked for six months for only their daily transport and a simple midday meal - as personal contribution to the project.

With a highly motivated but unskilled workforce only simple packaging and assembly contracts were sought initially. Later SHAP found that companies were at times prepared to assist with training, if it meant that companies could 'contract out' an aspect of their production/service which was a headache to their own production process - at a reasonable cost and assured of quality.

SHAP has found markets for its products and services in the traditionally conservative mining industry, in medium sized South African companies, small businessmen as well as from multi-national corporations eager to become involved with developing Black business.

Whatever the supplying company's original motives for contracting with SHAP, the relationship must remain financially attractive to both parties and quality of service must obviously be maintained at all times.

SHAP today

The SHAP Factory employs 130 disabled people doing packaging and assembly work, manufacture of protective clothing and other sewing products, and repairing sophisticated mechanical and electronic devices, such as cameras and calculators. All administrative and supervisory positions are held by disabled people. Today SHAP only seeks funding from the community for capital projects and in support of its always partially self funded service programs.

SHAP's success has been widely publicized. SHAP leaders have been approached by disabled people from all over the country for advice on how they too might organize themselves to undertake a similar self help venture. There are now approximately 30 such emergent groups around the country seeking to emulate the SHAP example.

The experiences of SHAP are:

1 . Self help groups, made up of the people experiencing the problems, are in a unique position to identify desirable and effective courses of action to counter the effects of disability.
2. Self-help groups are attractive to trusts, large companies (including foreign corporations), foreign embassies/governments, churches.
3. Self help employment schemes, due to their typically low overhead costs (as a result of donated capital) can compete for a wide range of sub-contracted work from industry.
4. Self help employment schemes are capable of alleviating the poverty of disabled people in the townships in a relatively short time and with achievable capital expenditure.
5. The Self Help Factory differs from traditional concepts such as sheltered workshops, since they are run by disabled people , with all staff, including any able-bodied skilled people, responsible to an executive committee of disabled people.

Principles of Self-Help Factories

CONTROL/OWNERSHIP
Control of the project is vested in the management committee which is made up of a majority of disabled people elected by the members of the self help organization, all of whom are themselves disabled people. There are no shareholders and any profits derived from the factory's activity are put back into the business or used to fund service programmes in the interests of the members e.g. transport, education, health, recreation, etc. The project is therefore owned by the constituted Association rather than the members, although the members typically develop a strong 'sense of ownership'.

STAFFING
The factory is staffed by disabled people whose continued participation in the project is determined only by their ability to produce. The concept does not preclude the need for sheltered/protective workshops-the latter would address the needs of those who cannot compete successfully for work in either the open labour market or the Self Help Factory. Ideally the project would include all types of disability. Senior management staff will be disabled people, although able-bodied staff with particular skills may be employed. They too will be responsible to the management committee of disabled people.

MARKETING
The Self Help Factory sells its products and services on the open market dealing with all

levels of industry and State contracts. Potential buyers may be more sympathetic or prejudiced against the project's ability to produce. Sometimes they may also attempt to exploit the project by wishing to pay less than the market rate. Products and services selected will typically be labour intensive.

FUNDING/VIABILITY
The Association registers as a Fund Raising Organization. As such it is able to raise "venture capital" necessary for starting up the factory. The Self Help Factory aims to be economically independent (excluding the recovery of initial start-up capital and ongoing fund raising for the purchase of capital items such as equipment, vehicles, and building extensions) and to pay viable wages and salaries. Depending on initial start-up funds, it may only pay viable wages and salaries once its business has developed to a point where these can be afforded. The disabled workers may be prepared to work for less in order to build up the project in the expectation of more viable incomes later-in the same way that shareholders in a new venture do not expect to derive significant returns immediately.

In practice, it is unlikely that a Self Help Factory would achieve 100% comparative levels of productivity to other factories although their performance should not fall below about 75%. Their relative inefficiency may be attributed to inexperience in competitive business standards and methods, and simply the fact that the disabilities of the employees may limit their overall production. The net effect of this will be that base-line costs will be higher than their competitors but this would be offset by lower profit expectations and the fact that capital items would be community sponsored if their fund raising is successful. This relatively lower productivity also provides the justification for ongoing community support.

From an article by
Mike duToit, DPSA
in Rehabilitation in S.A., Dec 1989

Address:
314 Oxford Street
5201 East London, Rep South Africa

Manufacturing assistive devices in developing countries

Independence through Mobility by Ralf Hotchkiss is a book about the nuts and bolts of starting a shop and producing the Hotchkiss manual wheelchair with a minimum of equipment, materials, skills and capital in Third World countries.

Disabled people in the Third World are fighting to become actively involved in their communities, more mobile, and economically independent. To accomplish this, they need wheelchairs that are strong enough to withstand the stresses of maneuvering over rugged terrain, yet light and compact enough to be agile and easily portable. These wheelchairs must be affordable and designed to be repaired locally.

With four year's support from Appropriate Technology International and the assistance of wheelchair builders in over 20 countries, Ralf Hotchkiss has designed a sturdy wheelchair that is ten pounds lighter than similarly featured commercial models. It can be manufactured locally by small groups of skilled mechanics in areas with access to thinwall steel tubing and simple welding equipment. It costs approximately $80 (U.S.) for materials plus the cost, with overhead, of less than a week's work by a skilled mechanic.

This book contains detailed instructions for making the ATI-Hotchkiss Torbellino wheelchair, plus detailed information on the establishment and operation of the successful small businesses which have manufactured and sold the Torbellino wheelchair.

From the table of contents: starting a small business; tools and shop facilities; jigs; designing each chair to fit; taking care of the chair; wheelchair design challenges.

Introduction to Independence through Mobility:

Disabled people throughout the world, together with their families and friends, are beginning to change the ways that they live, work, and participate in their communities. Refusing to be defined by the attitude that they are a burden on society and no longer willing to remain hidden from others, disabled people are fighting to become actively integrated into schools, regular jobs, places to live, and public life. The know from experience that they can do many things well; they know that being successful does not have to be the exception for disabled people. They intend to live with independence and dignity, and are rapidly overcoming the obstacles that stand in their way.

Just as a blacksmith needs high quality tools to do a specific job, disabled people need the highest quality equipment to assist them in actively pursuing their goals. People whose mobility needs are not met by crutches or canes need wheelchairs that will enable them to be as mobile, productive, and independent as possible.

In the industrial world, the increasing demand from disabled people for mobility and independence has resulted in a revolution in wheelchair design. Lighter and faster chairs made of space-age materials are being introduced every year. These new wheelchairs designs are allowing U.S. wheelchair riders to compete in events such as the Boston Marathon (where the wheelchair racers make better time than the runners), to get to classes and jobs on time, and to move more easily, thus saving their energy for other tasks.

Unfortunately, the high cost of lightweight wheelchairs has put them out of reach of most of the Third World's disabled people. Those who can afford the high price of imported chairs often find that the chairs are not built to withstand the stresses of dirt roads, farm fields, curb climbing, and pocked pavement. When mechanical failures occur, it is often impossible to obtain replacement parts.

Poorer disabled people have either gone without a wheelchair or have used locally manufactured models that are often heavy, confining, and lacking in many of the necessary features of state of the art chairs.

Third World wheelchair riders need wheelchairs that can fold to fit in crowded living quarters or in the aisle of a bus. Many need wheelchairs with folding footrests that allow the rider to pull in close to beds and tables, and armrests that do not impede lateral transfer. These wheelchairs should have good traction, stability, and should be light and agile enough for the rider to travel over rough ground. Wheelchairs built for riders in the Third World should be strong enough to withstand rough handling (as they are tossed on and off the roof of a bus). When parts not least, these wheelchairs must be affordable.

Fancy wheelchairs are of no use if no one can afford to purchase them.

Working over the past four years with the support of Appropriate Technology International, and with the assistance of wheelchair builders in over 20 countries, we have designed the ATI-Hotchkiss wheelchair, the Torbellino (the chair was first named Torbellino, or whirlwind, in Peru). This wheelchair is ten pounds lighter than commercial wheelchairs with similar features, yet it is strong enough to stand up to heavy use. It can be manufactured locally and could be sold in many countries for less than one third of the cost of a comparable import.

Most wheelchairs are designed to be mass produced using highly expensive press forming equipment. Since capital and materials are severely limited in many Third World countries while resourceful labor is abundant, conventional manufacturing techniques are inappropriate. The Torbellino wheelchair has been designed to be built by small groups of mechanics using inexpensive handtools in areas where workers have access to thin wall steel tubing and gas welding. A high level of skill i required to build these chairs successfully; a high level of investment is not.

E. F. Schumacher in his book Small Is Beautiful said: "Any third-rate engineer or researcher can increase complexity; but it takes a certain flair of real insight to make things simple again." Our wheelchair design is a collection of such insights gained worldwide from some of the best wheelchair builders, many of whom are also wheelchair users. We have tapped into a rapidly growing network of small-scale wheelchair makers who are developing, producing, and selling full featured wheelchairs at highly competitive prices.

This manual has been written to make this technology generally available. It includes step by step descriptions of how to build the ATI-Hotchkiss wheelchair, guidelines for starting a small manufacturing business, detailed lists of the tools, parts, and other equipment you will need to begin production, as well as many photographs and diagrams which we hope will communicate when words fail us.

Even as this book goes to press, new ideas are being developed to improve the design of the chair and the methods for production. This diagram is our most recent design. We hope that you will use the ideas in this manual, improve upon them, and send us drawings and explanations of your good ideas. In this way you can join in the efforts of many others throughout the world who, by successfully manufacturing low cost wheelchairs, are enabling members of their communities to live more independent, productive, and dignified lives.

Ralf Hotchkiss

Cooperating organizations:

> Transcentury Foundation, Washington, D.C.
> Combined Disabilities Association, Kingston, Jamaica
> * Foundation for Advanced Education (FES) and Program for Small Enterprises (DESAP), Cali, Colombia
> * United States Peace Corps, Paraguay
> Goodwill International, Washington, D.C.
> Asociación de Rehabilitación Integral, Costa Rica
> Ciudad de los Niños, Cartago, Costa Rica
> Partners of the Americas, Washington, D.C.
> Federación Nacional de Impedidos del Peru, Lima
> Appropriate Health Resources and Technologies Action Group, Ltd., London,

England
* Fundación Hondereña de Rehabilitación y Integración de Limitados Fisicos, Tegucigalpa, Honduras
* Centro de Rehabilitación Vocacional, Guatemala City, Guatemala
* Comite Regional de Rehabilitación, Medellin, Colombia
* RESCU, P.O. Box 66044 KOPJE, Harare, Zimbabwe
* Fundación Pro-Rehabilitación del Minusvalido, Bogota, Colombia
* Program for Assisting small Enterprises (PROAPE), Dominican Republic
* Servicio Evanglico Peruano de Acción Social, Lima, Peru
* Organizacion de Revolucionarios Discapacitados, ORD, Managua, Nicaragua

* These organizations operate wheelchair shops using ATI-Hotchkiss innovations

Source:
Independence through Mobility: A Guide to the Manufacture of the ATI-Hotchkiss Wheelchair
by Ralf Hotchkiss, 6505 Farallon, Oakland, CA 94611 United States

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Turning a service into an income generating project

In some countries the field of disability is tightly controlled by professionals who work in rehabilitation, produce and distribute assistive devices or provide such services as personal assistance and paratransit. Often the services we get are insufficient in quantity and quality, carry institutional traits and make us more dependent. These services and especially their administration eat up a lot of resources. At the same time many of us are unemployed and lack training opportunities. What we need to do then is to use our creativity in finding ways to re-channel some of the money that is spent on behalf of us by other people. Start a business, perhaps in form of a cooperative, and take over those services when you are convinced that you can do a better job. The advantages are better quality services, income for our organizations, jobs and training for our own people. All this at no additional cost to the taxpayer. The following article is about how one Independent Living group has gone about it.

Personal assistance, like no other service, illustrates the key elements of Independent Living. People who need personal assistance have always been made dependent on others for the most basic needs of life such as eating or using the toilet. Given this physical dependency the conclusion was close at hand to consider us as dependent on others also emotionally and intellectually. If you cannot pull up your pants like a small child, you may be treated like a small child in other areas as well. It is no surprise then that the Independent Living philosophy is most easily grasped by people who need personal assistance.

In the Swedish Independent Living Movement we believe in self-representation and self-determination. We are the experts, nobody speaks for us but us. In our personal assistance user cooperatives only individuals who use personal assistance are allowed as members and board members. Staff positions are primarily reserved for people with disabilities, preferably, personal assistance users. In a society where, according to recent

government statistics, 70% of us are unemployed we must reserve the job and training opportunities in our organizations for ourselves.

In Sweden there are presently 8 personal assistance user cooperatives, the first and largest being STIL, the Stockholm Cooperative for Independent Living. STIL is the first alternative to the assistance services which local governments are legally obliged to provide to old and disabled citizens. The cooperative's purpose is to enable its members to improve the quality of their personal assistance by being employers of their assistants and to train and support members in their employer role.

Each member has his or her personal assistance need assessed by the local government. The need is expressed in a certain number of hours of services a week. For persons who wish to arrange the services themselves through membership in STIL the cooperative charges the local government a certain price per hour of services. Multiplying the number of hours a member has been granted by the current price per hour determines the size of the individual member's budget from which he or she pays assistants' wages and administrative costs.

The cooperative is the legal employer of our assistants. The presently 160 members have a total of 800 assistants together. But we do not share assistants. Each coop member is responsible for recruiting, training, scheduling and supervising his or her own personal assistants. We do not live together in one house, in the same apartment building or even the same city. Each of us lives in his own apartment or house with or without family. We are spread out over the whole county and consider our individual housing situation as completely unrelated to our need of personal assistance.

By establishing personal assistance cooperatives the Swedish Independent Living movement pursues three goals:

- to enable service users to take control and responsibility over their own lives,
- to create training and employment for persons who have been considered unemployable because they need personal assistance at work,
- to use these self-help schemes for income generation for the movement.

STIL is now an established business with an annual turnover of over $14 million. According to our experience so far, there is definitely a place for this type of venture in the movement. The potential disadvantages are that running a business takes a lot of energy and time which the organization otherwise would be able to devote to political work. Also, when a disability organization becomes a service provider, the goal of providing quality services and the goal of generating a surplus may not always be compatible. The potential goal conflict will depend on the degree of choice and control exercised by the individual user of the services. In the case of STIL the high degree of individual responsibility over one's services minimizes the effect of the coop on the quality of the services. Also, dissatisfied members have the option of leaving and starting another coop along their own lines.

Among the many advantages of our scheme are the changes that members have undergone. There is a strong sense of pride and accomplishment. Instead of limiting ourselves to complaining about the poor quality of the public services, we demonstrated for ourselves and the general public that disabled people are capable of taking their affairs in their own hands. The demonstration of the viability of our vision and our capabilities has gained us respect among politicians and civil servants. We generate good will in the community and contribute to an improved image of disabled people. Representatives of STIL are now considered experts and are invited to speak on cooperatives and how to improve the quality of public services. In this way we have improved our possibilities of

bringing about change.

Running our own business provides members of STIL with an exposure to managerial training which many of us would have never had given the high unemployment among disabled people. This experience is valuable also for other work in our movement.

Instead of turning to government and private corporations for grants to finance our movement, we try to generate our own funds by achieving a surplus in our business activities. We use part of our administrative resources for spreading the Independent Living approach in the country, for membership development, courses and seminars and international work through ENIL, the European Network on Independent Living and the DPI Independent Living Committee.

Resources

International Labor Organization, Cooperatives for the Disabled: Organization and Development, ILO, Geneva, 1978.

Harper, Malcolm and Momm, Willi, Self-Employment for Disabled People: Experiences from Africa and Asia, ILO, Geneva, 1989.

The authors of this book - one a small enterprise development specialist and the other a rehabilitation professional - have come together to see what disabled people can achieve as entrepreneurs and to examine the potential of self-employment as an option for those who want to and are able to earn their own living. The book is the outcome of a survey of 53 businesses run by disabled people in several Asian and African countries. At its core are 16 case studies showing in detail how the disabled entrepreneurs succeeded in self-employment, and highlighting the problems they faced.

Community Based Rehabilitation News, International Newsletter from Appropriate Health Resources & Technologies Action Group Ltd.

Examples of topics from recent issues: Alternative limbmaking, the Logmobile (a self-propelled cart), tricycles from India, How to make cutting-shears for sheet metal, handgrips made from easily available materials for writing utensils or tools. In the July 1989 issue David Werner, a disabled community organizer and rehabilitation expert, author of Where there is no doctor and Disabled Village Children among others, describes several innovative examples of Third World projects run by disabled people themselves producing rehabilitation services and assistive devices as income generating projects. He writes:

"While many exciting and innovative things are happening in programs for disabled persons in developing countries, my general impression is that there are only a very few programs in which disabled persons themselves play a leading role. In most of the programs I visited, whether government, religious or private, disabled persons tend to become the objects rather than subjects. Disabled persons are acted upon and not the actors in the process. Too often emphasis is on 'normalizing' the disabled persons into an unfair social order rather than on organizing disabled people in a struggle for a fairer more

just society."

"The Organization of Disabled Revolutionaries, ORD, in Nicaragua, is a group of mostly spinal cord injured young persons who came together over a common need: wheelchairs. With the increase of disabled persons resulting from the war against the Somoza dictatorship (and more recently against the Contras), the lack of a wheelchair factory in Nicaragua, and the difficulties of importing wheelchairs due to the United States embargo, the shortage was severe. Two disabled North Americans, Ralf Hotchkiss and Bruce Curtis, helped ORD set up a small wheelchair factory to design and produce low-cost high-quality, for use on rough terrain, wheelchairs. Now the so-called 'whirlwind' steel tube wheelchair is being produced by small collectives of disabled workers in various countries of Latin America, the Caribbean, and Asia. ORD has also branched out into different fields and is beginning to organize disabled people throughout Nicaragua."

"The Center for Rehabilitation of the paralyzed (CRP) in Bangladesh. In the CRP severely disabled persons, mostly from spinal cord injury and severe polio, play key roles in leadership, administration, designing, teaching, income generation and other activities of the program. Working from wheelchairs and gurneys, the disabled workers make a wide variety of rehabilitation aids and hospital equipment."

"Programs and equipment for disabled persons in developing countries often suffer from the imposition of Western medical and rehabilitation.

Address: AHRTAG, 1 London Bridge Street, London SE1 9SG, United Kingdom

The project that David Werner himself helped start is PROJIMO in western Mexico. PROJIMO can be described as an alternative rural villager run rehabilitation program. Some of its most important functions is income generation and training for persons with disabilities. The PROJIMO team consists of former 'clients' who after having received assistive devices and treatment themselves stayed on to learn various marketable skills such as brace and limb making, wheelchair manufacturing and repair, welding, physical therapy and peer counseling. During the years that PROJIMO has been in existence many of these workers have left the village to settle in other places of Mexico where they set up similar projects and activities. Thus, persons who under most other circumstances would have been doomed to a life as beggars have not only become proud professionals who can support themselves and their families through their work; they are also spreading their skills and role models among disabled persons and their families in other communities.

For more information on PROJIMO and David Werner's work see

Project PROJIMO, A villager-run rehabilitation program for disabled children in Western Mexico, The Hesperian Foundation, 1983.

Newsletter From the Sierra Nevada, an occasional newsletter.

Address: The Hesperian Foundation, Box 1692, Palo Alto, California 94302, USA.

For other appropriate assistive devices and their production in developing countries see

Lagerwall, Tomas, Appropriate Aids and Equipment for Disabled People in Africa: Ways and Means for Local Production in the Third World, ICTA, Stockholm, 1989.

Lagerwall, Tomas, Appropriate Technical Aids for Disabled People: Ways and Means for Local Production in the Third World, ICTA, Stockholm, 1989. Address: Handicap Institute, Box 510, 162 15 Vällingby, Sweden.

Housing adaptation

Toward a barrier-free home

An environment that is barrier free is a vital aspect to independence; it can substantially increase the options for establishing your own routine of daily living and working activity. There are many ways to change a seemingly inaccessible environment into a barrier-free living situation. The changes that you decide to make will depend on the following:

- Personal financial resources
- Applicable building codes
- Availability of a qualified, experienced carpenter
- Approval from your landlord if you rent or lease
- Your own ideas and creativity

While a dream house with all the features of accessibility may not at present be affordable, there are a number of changes that can be made for reasonable costs. A professional carpenter can make structural modifications that you need. However, a large number of modifications can be made by persons who are skillful with their hands. Whether you use a professional or a weekend carpenter, it is important that you make sure that the person knows exactly what modifications are to be done before beginning the work.

Another preliminary task involves checking to see if adding a room, moving a wall, or making other structural changes at your location requires a building permit.

If you are renting or leasing, you are required to get written permission from your landlord to make structural changes. Your landlord may be willing to share or pay for the cost of modifications.

Features of accessibility

Doorways

A width of 30 inches is required for manual and power wheelchairs. In the United States doors come in standard widths of 28, 30, 32, 34, and 36 inches. Doors with odd widths or larger than 36 inches are considered custom doors and have to be specially ordered. A 28-inch door can be made accessible by installing wrap-around hinges since they allow the door to open past the frame. These hinges are available at hardware supply stores.

Door handles with lever action can be installed in place of doorknobs.
Sliding doors save space but are considerably more expensive than standard doors.
Folding doors save swing space but take up valuable space in the doorway when folded.

Electricity

Relocating light switches and plug sockets will run approximately $30-45 each. Improperly installed electrical wiring can be dangerous, so a qualified electrician should be used to install or reroute the electrical wiring. The electrician should be given the exact locations for switches, plugs, and appliances.

Ramps

Ramps should be 36 to 38 inches wide with a slope of no more than 15 degrees or one foot of length for every inch in height. Wooden ramps exposed to weather should be constructed with treated lumber and marine-grade plywood. Rails at a height of 30 to 32 inches are recommended. A non-skid texturizer should be added to exterior paint on the ramp surface. The supports or legs for the ramp should be cemented 12 to 18 inches into the ground if the ramp exceeds a length of 10 feet. A deck or porch of 4-1/2 x 4-1/2 feet is recommended for exterior entry ways to allow for a 360-degree turning radius for a wheelchair. Similar platforms are needed at the end of a ramp and for ramps that change directions. The same dimensions apply for concrete ramps as for wooden ramps. Reinforcement steel rods are recommended for ramps that are longer than 8 feet.

Bathrooms

Roll-in showers generally require 16 to 20 square feet (4x4 feet or 4x5 feet) floor space. A sloped entrance and proper drainage are critical to prevent seepage into the floor or foundation. The installation and relocation of shower controls and drain can be done by a plumber. Lever action controls fro faucets are available at hardware stores. Also, curtains are easier to operate than doors on showers. Vanity cabinets can be removed from underneath the sink to allow for more mobility inside the bathroom.

Hot water pipes should be insulated to prevent burns or other injuries.
Lever action faucets for the sink are available.
Mirrors should be installed so that they can be used both by people standing and by people seated in wheelchairs. Adjustable mirrors may also be installed.
The seat of the commode needs to be 17 to 19 inches from the floor. There are brackets available to raise the seat or a plumber can raise the entire commode to the desired height. Grab-bars for steadying can be installed on sturdy walls next to the toilet and in the shower approximately 33 to 36 inches from the floor and of sufficient length to meet your needs.

Bedrooms

Closet doors which are 32 inches wide with a maximum threshold height of 1/2 inch are recommended.

Clothing rods may be lowered and adjustable shelves may be installed to make the contents of closets more accessible.

The room should have a 5-foot diameter turning space.

Location of temperature control switches is important. Switches for air conditioning units, fans, heaters, and thermostats all need to be 33 to 36 inches from the floor. Windows that open with ease by using a lever or a weighted pulley system located at a comfortable height for the user can be installed and modifications can be made to accommodate the user.

Kitchens

A width of 5 feet is required between counters for turning space.
Stoves that are level with the counter make the transfer of pots and pans easier. It is safer to have temperature controls on the front of the stove and staggered burner plates. Ovens that open to the side can be approached more closely for the removal of hot items. Also, ovens that are placed either below or above the counter should have controls and racks within reach.
An open area underneath the sink can be made by removing the cabinet. The area at minimum should be a height of 27 inches, a width of 30 inches, and depth of 19 inches. Switches for lights and garbage disposal can be placed on the front of the counter or cabinets.
Cabinet doors can be replaced with curtains. Cabinets and shelves need a toe space of 9 inches high and 4 to 5 inches deep. Carousel shelves and shelves on smooth rollers can be useful for reaching objects stored on the back part of the shelf. Small carousel shelves are also handy to use inside the refrigerator for storing small items.

Communications

Specific information about telephones such as speaker phones, pushbutton dials, self-dialing phones for frequently used numbers, and volume-control receivers is available from your telephone company. Teletypewriters (TTYs, TDDs) are available for people who are hearing impaired.
Citizen-band radios are useful back-up systems for communication in cases when the power goes off.
Flashing lights can be installed to indicate to a hearing impaired person that someone is at the door or that the phone is ringing.

Mobility

Hard surfaces are best for wheelchairs since surfaces such as loose gravel and shag carpets, to say nothing of loose earth, make travel difficult. For people who are visually impaired, rope trails with spaces for cross traffic can be helpful in bad weather or when crossing large open spaces, such as fields. Different textures of soil, grass, gravel, and corner-marking stones can also be used to mark paths without rails for people who are visually impaired.

Steep grades and uneven ground can be leveled in frequently traveled areas. Proper drainage is necessary to prevent mud and erosion. Conversions and modifications can be made on trucks, tractors, and other farm machinery to allow for greater use of the vehicles. For more information on adapting farm machinery, contact Bill Field, Breaking New Ground Project, Purdue University, Lafayette, IN 47907. Other types of travel machines can be modified too, including snowmobiles, 3-wheel motor bikes, bicycles, etc.

In conclusion

When considering ways to make your home more accessible, the best of all tools and designs is a well coordinated amount of common sense and a generous use of your creativity.

For more information about modifications, contact:

Accessibility Guidelines for Multi-family Housing, Regional Rehabilitation Continuing

Education Program
P.O. Box 1358
Hot Springs, AR 71901
Breaking New Ground Project
Purdue University
Lafayette, IN 47907, United States

National Clearinghouse for Rehabilitation Training Materials
115 Old USDA Building
Oklahoma State University
Stillwater, OK 74074, United States

Barrier-Free Environments, Inc.
Ron Mace
P.O. Box 30634
Raleigh, NC 276722, United States

Source:
ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Housing adaptation

Resources

The following organizations may provide architectural accessibility information and printed materials related to architectural design standards and specifications.

Abledata, Newington Children's Hospital, 181 East Cedar Street, Newington, CT. 06111, United States.

American National Standards Institute (ANSI), 1430 Broadway, New York, NY. 10018, United States.

Architectural and Transportation Barriers Compliance Board, 1111 18th St., N.W., Washington, DC. 20202, United States.

Center for Accessible Housing, Research and Training Center, Box 8613, North Carolina State University, Raleigh, NC. 27695.8613, United States.

National Organization on Disability, 2100 Pennsylvania Avenue, NW, Suite 234, Washington, DC. 20037, United States.

National Rehabilitation Information Center (NARIC), 8455 Colesville Road, Suite 935, Silver Spring, MD. 20910-3319, United States.

Paralyzed Veterans of America, 801 18th Street, NW, Washington, DC. 20006, United

States.

Rehabilitation Engineering Center on Modifications to Worksites & Educational Settings, CP Research Foundation of Kansas, Inc., 2021 North Old Manor, Box 8217, Wichita, KS. 67208, United States.

Rehabilitation Training Center on Community Living, University of Minnesota, 101 Pattee Hall, 150 Pillsbury Drive, SE., Minneapolis, MN. 55455, United States.

CIB W84 "Building Non-Handicapping Environments" is an international NGO committed to universal barrier-free design. CIB W84 works for better awareness of the environmental needs of old and disabled persons, technical expertise on design solutions and access legislation. The following publications are available:

CIB Building Non-Handicapping Environments Newsletter

Urban Renewal and Accessibility for Old and Disabled Persons, Proceedings of the CIB W84 Expert Seminar in Prague 1987.

Accessibility Issues in Developing Countries, Proceedings of the CIB W84 Expert Seminar in Tokyo 1988.

Address: CIB W84 Secretariat, Department of Building Function Analysis, Royal Institute of Technology, 100 44 Stockholm, Sweden.

"A Barrier-Free House: Accommodating a Wheelchair Calls for Careful Planning Inside and Out", in Fine Homebuilding Magazine, No. 53, April/May 1989, pp. 67-71.

Both exterior and interior design are covered in this 5 page document which includes a copy of the floor plan and several photographs of selected features.

Adaptable Housing: Marketable Accessible Housing for Everyone. 1987.

This book advocates well designed housing that is usable by all populations and does not look any different than any other house.

Available from HUD USER, PO Box 6091, Rockville, Maryland 20850, United States.

American National Standard for Building Facilities: Providing Accessibility and Usability for Physically Handicapped People. Revised 1986.

These are the ANSI specifications for making buildings and facilities accessible to and usable by persons with disabilities. These are intended for use in new buildings, and renovations to older buildings except "historic" structures. Reference for this publication is under A117.1-1986 of the ANSI publications listing. Contact the American National Standards Institute at the address above.

Creation of the Barrier-Free Interior. 1988. Written by Patricia M. Johnson

This is an excellent publication which focuses on all areas of home accessibility. It also gives tips on accessible interior design. 148 page publication, well illustrated.

Available from A Positive Approach, Inc., 1600 Malone Street, Municipal Airport, Millville, NJ. 08332, United States.

"Designing a Barrier-Free Environment for Deaf and Hard of Hearing Persons" in Rehabilitation Digest, Vol. 20, No.1, Spring 1989, pp. 12-14.

This is a short narrative discussion of the need for and means of designing buildings and homes for sensory-impaired persons. This article has a Canadian perspective that gives design solutions for various problems.

Source: Request Program, Rehabilitation Engineering Center, National Rehabilitation Hospital, 102 Irving Street, NW., Washington, DC. 20010-2949, United States.

Daviels, T., Beasley, K. "Accessible Housing", in Paraplegia News: Vol. 43, No. 5, May 1989.

Narrative discussion of the status of accessible housing, building products and related regulations for aging and disabled citizens in the U.S. Developers are encouraged to offer basic plans with sufficient flexibility, allowing units to be modified at the time of purchase to meet the buyer's specific needs or allowing the owner to make future modifications, at reasonable cost, should the need rise. Other topics include: multifamily housing and assisted living; changes in residential construction and home products; and, accessible housing in the context of the community. Figures and a summary of the Fair Housing Amendments Act of 1988 included.

Sharp,David, Laurel Richards, Laurie Gerken, and Kathleen Hampton. Constructing a Barrier-free Home. ILRU Field Work No. 3. Houston: ILRU Program, 1985.

This is the third of a set of three brochures developed for ILRU´s National Technical Assistance Project for Rural Independent Living. In this concise format, authors provide information on modifying one´s home to make it more accessible. It includes basic accessibility requirements for key features such as doorways, kitchens, bathrooms, cabinets, and ramps.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Design with Care: A Guide to Adaptation of the Built Environment for Disabled Persons in Developing Regions, United Nations Center, Vienna 1981.

The aim of the guide is to facilitate the work of planners, architects, and designers, as well as others who are engaged in public and private building projects in developing regions. The guide refers primarily to public buildings at urban or village level. The guide also attempts to present simple solutions to frequently occurring practical problems, in order to make public buildings and the entire urban environment usable for various groups of disabled persons.

Available from: United Nations Center, CSDHA/United Nations, P.O.Box 500, 1400 Vienna, Austria

Housing and Home Services for the Disabled: Guidelines and Experiences in Independent Living, Laurie, Gini, editor. Harper and Row, 1977.

A world-wide assortment of housing experiments is presented. The aim is to enable government agencies, voluntary organizations, organizations of disabled persons and individuals to find either specific solutions to these problems or pertinent examples to use as models. Reference to legislative and housing projects designed for the elderly, developmentally disabled, and physically disabled are included.

Available from: Harper and Row Publishers, Inc., 2350 Virginia Avenue, Hagerstown, MD 21740, United States.

Lifchez, Raymond and Winslow, Barbara, Design for Independent Living: The Environment and Physically Disabled People, University of California Press, Berkeley and Los Angeles, 1979.

This book is as much on accessible architecture as it is on the community of disabled people living in Berkeley, California. It gives useful examples and hints on how to make your house or apartment more accessible. At the same time, it provides the reader with portraits and role models of disabled individuals by way of beautiful and very personal photos. Unlike most books on such subjects, Design for Independent Living depicts us as unique individuals.

Lifchez, Raymond, "Designing Supportive Physical Environments", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Lifchez, Raymond, "The Environment as a Support System for Independent Living." Archives of Physical Medicine and Rehabilitation. Vol. 60, No. 10, October 1979. American Academy of Physical Medicine and Rehabilitation, 30 N. Michigan Avenue, Chicago, Illinois 60602, United States.

This study evaluates the environment of physically disabled young adults living independently in Berkeley, California and its ability to accommodate their needs.

Harkness, Sarah P. and James N. Groom, Jr. Building without Barriers for the Disabled. New York: The Whitney Library of Design, 1976.

Resource Guide to Literature on Barrier-Free Environments. Washington, D.C.: Architectural and Transportation Compliance Board, January 1977.

Steinfeld, Ed (ed.) Access to the Built Environment: A Review of Literature, US Department of Housing and Urban Development, Washington, D.C., 1979.

Address: Prof. Ed Steinfeld, Adaptive Environments Laboratory, SUNY/Buffalo, 112 Hayes Hall, 3435 Main St., Buffalo, NY 14214, United States.

The following resources are published by the Research and Training Center on Independent Living, University of Kansas:

Mace, R L, Young, L C, & Telles, C (1980). Planner's guide to barrier free meetings. Raleigh, NC: Barrier Free Environment & Harold Russell Association, Waltham, MA.

Offers practical advice on how to include disabled people in general meeting-planning activities. Covers preplanning concerns, such as site selection, services, publicity; accessibility of meeting rooms and overnight rooms; locating resources for services and equipment.

Scott, B (1986). Book of renovations. Lawrence: RTC/IL, University of Kansas.

Beautiful illustrations depict most common problems and solutions to renovating existing buildings and facilities to make them accessible to and usable by people with physical disabilities.

Lifchez, R (1981). Architects and the movement for barrier-free design. Lawrence: RTC/IL, University of Kansas. Presentation for Conference on Independence, University of Kansas.

Discusses architect's noncommitment to barrier-free design. Accessibility laws examined as well as possibility of uniform accessible building codes.

Nelson, C F, Jones, M L, & Salkind, N J (1986). "Promoting wheelchair accessibility of private settings." Environmental and Behavior, 18 (1).

Documents barriers to access by wheelchair in a sample of 2,000 privately owned, public use settings in one midwestern city. Six intervention strategies evaluated to encourage getting managers to call or write for free technical assistance in making their setting more accessible.

Address: RTC/IL, 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States.

Penton, John, A Handbook on Housing for the Disabled, Center for Accessible Environments, London. Address: CAE, 35 Great Smith Street, London SW1P 3BJ, United Kingdom.

Research and Evaluation

ILRU Research & Training Center on Independent Living at TIRR

A five year grant to establish a research and training center on Independent Living has been awarded to The Institute for Rehabilitation and Research (TIRR) and will be operated by the ILRU (Independent Living Research Utilization) program located in Houston, Texas. Funded by the national Institute on Disability and Rehabilitation Research, U.S. Department of Education, the ILRU Research and Training Center on Independent Living at TIRR will develop and implement research, training, and technical assistance projects which focus on ways individuals with severe disabilities can live more independently in their communities. In the area of research, projects will be conducted on the meaning of independence to people with disabilities, techniques used to maintain independent lifestyles, and ways programs serving disabled people can better assist them in living as independently as possible.

A variety of training activities, including a bi-monthly newsletter, a technical report series, and a computerized bulletin board, will be used to disseminate information resulting from these research projects as well as information about model research and demonstration programs around the country.

Under the technical assistance wing of the center, methods will be developed through which individuals with expertise in different aspects of Independent Living can be accessed by Independent Living programs and other interested organizations.

Since its establishment in 1977, ILRU has served as a national center for information, training, and technical assistance in Independent Living. One of its first accomplishments was to develop a definition of Independent Living, which has since become widely accepted in the field. It also developed a system for categorizing different models of Independent Living programs, conducted one of the first national surveys of Independent Living programs, and has since maintained and annotated registry of programs in the country.

In addition, ILRU has taken a leading role in developing and disseminating information related to rural Independent Living activities and is widely recognized for its innovative management training programs for upper level administrators of Independent Living centers.

ILRU project staff serve Independent Living programs, state rehabilitation agencies, organizations of disabled individuals, federal and regional rehabilitation agencies, rehabilitation medical facilities and other service providers, disabled people and their family members, educational institutions, and other organizations active in the field, both nationally and internationally.

Major accomplishments

- Designated and funded by National Institute on Disability and Rehabilitation Research as a research and training center in Independent Living in 1985.
- Developed and conducted management training programs for directors and middle managers of Independent Living centers.
- Served as a rural Independent Living research utilization center.
- Directed the design of a comprehensive management training program using a simulation format for directors and administrative staff of Independent Living centers and other nonprofit service agencies.
- Developed a comprehensive set of definitions and a method for categorizing model of programs providing Independent Living services.
- Conducted comprehensive evaluations of Independent Living center networks operating in the United States.
- Sponsored major conferences of national scope, training persons from all over the country.
- Provided on-site technical assistance to Independent Living centers in 32 states and five foreign countries.
- Compiled a national directory of programs providing Independent Living services, which is updated regularly.
- Developed and maintained the ILRU National Database on Independent Living Programs, a computerized listing of data on 167 programs.
- Distributed books, pamphlets, posters, and videotapes related to Independent Living.
- Maintained an on-going agenda of research, publications, and conferences on attendant services, including publishing a current bibliography on attendant-related literature, and developing a method for assessing the adequacy of attendant services.

Tenets for research and training on Independent Living

In recent years there has been increasing recognition of contributions that severely disabled people can make and are making in their communities. This recognition is largely the result of the Independent Living Movement --a network composed principally of pioneering individuals with disabilities who broke from the confines of restrictive attitudes and traditional service for disabled persons and established a new focus on the

continuum of needs for Independent Living and the value of the disabled person as the Independent Living service provider. The Independent Living Research Utilization (ILRU) program, founded and staffed predominantly by severely disabled persons, was the first organization to respond to the Independent Living movement's need for research, training, and technical assistance. Since 1977, ILRU has contributed significantly to the spread and acceptance of the goals of the movement and has developed services to increase the level of sophistication of Independent Living centers.

The ILRU Research and Training Center on Independent Living at TIRR (The Institute for Rehabilitation and Research) focuses on making significant contributions to the body of scientific and practical knowledge about independence and Independent Living for persons with disabilities. Rather than restrict potential Center collaborators to individuals located in the Houston area, a deliberate effort has been made to involve some of the nation's most experienced researchers, trainers, and providers of services in the field of Independent Living. Some participate as senior Center consultants, some as advisors, and some as consultants on specific projects. Additionally, several members of the Center's staff are professionals with disabilities who have long-standing involvement in issues bearing on Independent Living including experience as founders, board members, and directors of Independent Living centers.

In these critical, formative years for the Independent Living Movement, a research and training center has the potential to play a powerful supportive role. The staff of ILRU and those who collaborate with them conduct the activities of the Center according to the following tenets:

Tenet 1: The Center should have persons with disabilities play substantial roles at all levels of operation.

Personal experience with disability is an invaluable and irreplaceable qualification for persons involved in research and training activities in this field. The ILRU Center staff includes six disabled persons (four of whom have severe, multiple disabilities) as research director, technical assistance director, research associates, research assistants, and administrative assistant. Other disabled persons are involved as senior Center consultants, project consultants, and advisors. All efforts are made to acquire the services of persons with a variety of disabilities as new positions become available.

Tenet 2: The Center should conduct research and offer training and technical assistance opportunities that lend support to state and local agencies and organizations in providing the best quality Independent Living services to disabled persons.

Providers of Independent Living services should be integrally involved in the conduct of all Center activities.

The Center's principal constituency is comprised of organizations which provide services to facilitate Independent Living for persons with disabilities. This includes Independent Living centers, state agencies which fund Independent Living centers, and other private and public organizations which sponsor Independent Living centers or provide Independent Living services directly. It should be noted that while many of the Center products and programs will focus on and be of interest to consumers, the Center, as a general rule, avoids offering services directly to consumers in favor of conducting activities designed to promote development of strong service delivery components at state and local levels.

Tenet 3: Research presents the cornerstone upon which training and technical

assistance programs are developed, leading to quality service provision.

Given the grassroots origins of the Independent Living Movement and the overwhelming individual needs which Independent Living centers attempt to meet, it is understandable that service delivery has traditionally been given a higher priority than research and training programs. We at ILRU believe, however, that before Independent Living services can reach a level of maximum impact and effectiveness for individuals and communities, training and technical assistance opportunities must be available and must be developed from sound basic and applied research. Scientific investigation into needs of disabled persons and into the most effective techniques and mechanisms for meeting these needs will allow for development of maximally effective training and technical assistance programs.

Tenet 4: The Center should conduct research and offer training programs that will have an impact on national policy.

Lasting change on a national scale in the many areas integral to Independent Living must be accompanied by changes in national policy. The Center strives to conduct quality research in order to provide reliable and valid information to authorities who make policy and who must translate it into feasible and equitable plans of action. An example of such an application is the National Policy for Persons with Disabilities developed by the National Council on the Handicapped which mentions independence as a criterion for all disability related services.

Tenet 5: The Center should use existing resources to the greatest extent possible.

As noted above, considerable pioneering work has been done to develop effective Independent Living services by both researchers and service providers. The Center should make concerted effort to identify and build on this work without duplication and should establish collaborations with individual researchers, programs directors, and Independent Living centers to maximize benefits accruing from available expertise and interest.

Independent Living Research Utilization

Address:
ILRU at Texas Institute for Rehabilitation,
2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Research & evaluation

Independent Living as a state of mind

by Gerben DeJong

This study should be viewed as a point of departure for future research on IL issues. One of its central arguments has been that Independent Living offers a perspective that is unique to the analysis of disability issues and outcomes. Until now, the field of disability

policy and research for physically impaired persons has been largely confined to the disabled person's limitations. The traditional emphasis on one-to-one clinical practice has tended to exclude disciplines from outside the rehabilitation professions. By broadening the problem of disability to include a wide variety of environmental variables, IL can open the field of disability policy and research to other disciplines - law, architecture, economics, and policy research.

It is persons with disabilities who must ultimately set the terms for research and debate on disability policy issues. At the core of all disability research and policy are certain assumptions about disability and its nature than can only be validated by persons with disabilities. Without this check, these basic assumptions may be adjusted, if not twisted, to suit professional self-interest, economic constraints, and pre-existing theoretical biases.

The IL movement is the clearest statement available about how disabled persons want to be viewed in American society - not as passive victims needing constant professional intervention, but as self-directed individuals seeking to remove environmental barriers that prevent their full participation in community life. Thus, Independent Living should be viewed not merely as a social movement, but also as a state of mind that should become deeply rooted in our basic understanding of disability issues.

Implications for research and evaluation

The outcome measures used in the study portray how long-term outcomes of significance to policymakers can be developed "from the group up" by incorporating the views of interested parties. Also noted is the importance of developing intermediate outcome measures that are sensitive to the immediate post-program impact of IL services.

Because the study was able to account for a significant portion of the variance in outcome, a research model grounded in IL theory can contribute significantly to the understanding of disability outcomes. Researches observed a need to extend the model to other disability groups. Moreover, there is a need to integrate psychological variables (not included in the Urban Institute survey) to help account for IL outcomes.

Source:
Gerben DeJong,
"The Influence of Environmental Barriers On Independent Living Outcomes",
REHAB BRIEF: Bringing Research into Effective Focus, Vol. IV, No. 5

Research & evaluation

The World Institute on Disability

The World Institute on Disability (WID) is a private, non-profit corporation focusing on major policy issues from the perspective of the disabled community. It was founded in 1983 by Judy Heumann, Joan Leon and Ed Roberts. It functions as a research center and as a resource for information, training, public education and technical assistance.

Programs

Personal assistance services

Some of the terms used to refer to the basic support services which many people with functional limitations require are: home care, attendant services, in-home supportive services, homemaker chore services, and long term care. No matter what terminology one uses, the issue is the same: the services are simply not available in a way that is appropriate and affordable to the majority of people who need them. As a result thousands of people make due without the services and in doing so experience unnecessary isolation, unemployment, deteriorating health and institutionalization.

Since its inception, WID has taken on personal assistance services as a priority and conducts a broad and extensive program of research, policy analysis, technical assistance and public education.

Personal assistance services research

WID has undertaken a number of research projects including:

- A 50-state survey of publicly-funded personal assistance services completed in 1987. A report and executive summary are available.
- An in-depth study of personal assistance services in California, Colorado, Connecticut, Massachusetts, and Missouri - completed Spring, 1988.
- A three-year comparative study of personal assistance service delivery systems. This study, funded by the National Institute on Rehabilitation and Disability Research, focuses on comparisons of cost, and advantages and disadvantages of different service delivery models.
- Collaboration on a national representative survey of the use of personal assistance services by persons with spinal cord injuries conducted by Monroe Berkowitz of the Bureau of Economic Research, Rutgers University, N.J.
- Continuing analysis of national data bases to determine the incidence of functional limitations requiring personal assistance in the U.S. and prevalence by age group.

Public education

- WID publishes a quarterly newsletter, Attendant Services Network, which focuses on issues and problems faced by persons who need personal assistance services. The newsletter reports on developments at the state and federal level and discusses major policy issues.
- Presentations at Conferences - WID reports on the latest developments in the field and our own research and public education efforts at major conferences and symposia around the country and internationally.

Technical assistance

WID has responded to more than 500 requests for information about personal assistance services from individuals, organizations, government agencies and elected representatives. It also has undertaken technical assistance contracts with a number of organizations including the National Council on the Handicapped, the Department of Rehabilitation of the State of Illinois, the University of Pennsylvania, the University of California, San Francisco and others.

Access to affordable health care

WID has received a grant from the National Institute on Disability and Rehabilitation Research to develop four policy bulletins on health insurance and disability issues from a consumer perspective. The bulletins will cover the following topics: (1) comparison of different approaches to health insurance in the U.S., (2) characteristics of persons with disabilities or chronic illness, (3) limitations of the existing systems for financing and delivery of health care to persons with disabilities or chronic illness, and (4) international comparisons of health care systems as they affect persons with disabilities or chronic illness.

International affairs

Disability is a worldwide phenomenon, and in spite of great cultural, political and economic differences there are also many communalities in the experiences of disabled people around the globe. WID has established itself as one of the world's foremost research, training, policy analysis, and resource centers representing the disabled community. One of its missions is to share the Independent Living philosophy around the world. Current activities include:

Research grants for information exchange

WID has embarked on a 3-year federally-funded program to advance cooperation and information exchange between U.S. and foreign disability researchers. Through this program WID and its sub-contractor, Rehabilitation International, issues small grant awards to U.S. experts in the disability/rehabilitation field to study innovative policies, practices and programs in other countries for the purpose of information dissemination within the U.S. disability community.

Training programs in Independent Living

WID designs individual training programs to help people with disabilities from around the world to meet the diverse needs of their own communities. Located in the San Francisco Bay Area of California, the cradle of the Independent Living Movement, WID offers foreign visitors a unique opportunity to visit many innovative programs fro the disabled including Independent Living Centers, technical aids centers, an increasingly accessible community environment and public transportation system, and many severely disabled persons living and working in the community. WID arranges both local and national programs, and to date has hosted and trained visitors from over 30 countries.

Information and referral services

WIDserves as an international resource center for the sharing and exchange of knowledge about disability issues between people of different countries and cultures. WID's international affairs department responds to requests from other countries for contacts in the disability field, bibliographies, articles, and other information in a large number of areas.

International technical assistance and consulting

WID has an experienced staff and consultants available for consultation with government agencies, organizations and individuals in many countries. International conferences, workshops and training sessions are tailored to specific needs for information about disability policy issues and services, but draw on the fundamental tenets of the Independent Living philosophy.

Aging and disability

Bay Area Aging and Disability Project

WID has been awarded matching grants for one year from the Koret Foundation and the Henry J. Kaiser Family Foundation to initiate a Bay Area Aging and Disability Project. The purpose of the program is to bring together leaders from the Bay Area aging and disabled communities so that they can learn from each other, share resources, build alliances and develop projects to address common problems. For this project, WID is collaborating with the American Society for Aging.

National Conference on Aging and Disability

WID and the Institute on Health and Aging, University of California, San Francisco, for the first time brought together leaders of the aging and disability fields to initiate a dialogue on the applicability of Independent Living concepts to the aging field. The conference was held at the Wingspread Conference Center in Racine, Wisconsin in September 1985. A Bay Area conference on similar lines was just held at Stanford University.

Training and disability

The Independent Living Movement of people with disabilities has played a major role in influencing public attitudes toward disability and promoting the civil rights of people with disabilities. WID is committed to a program of public education and training to further the work of the lives of more disabled people.

Current WID Activities in the area of training and public education:

Speaking engagements

Representatives of WID travel extensively as the guests of disability organizations, government and other agencies to provide lectures, workshops and consultation to disabled and non-disabled policy-makers, advocates, health professionals, academics, and program administrators on issues of disability and Independent Living.

PEW Charitable Trust Public Education Project

This three-year project supports WID's work to build bridges between the systems serving the elderly and the disabled. It enables WID to take the information, statistical data and analysis developed in the Attendant Services and Aging and Disability project areas and to package this information in ways which are most suitable for the audiences which need to be reached. It also makes it possible for WID to work closely with policymakers in education, government and health and social services on ways in which this information can be used to improve the services and opportunities available to disabled people of all ages.

AC Transit Training Project

WID has a contract to conduct disability awareness training for personnel at all levels at AC Transit, and to make recommendations directed at improving the quality of service to the disabled community. During the course of this project, WID conducted surveys of drivers and users with a variety of disabilities in order to ascertain the strengths and weaknesses of the service that AC Transit is currently providing.

Supported employment enterprises: businesses with a future

WID provides technical assistance to organizations nationwide interested in developing economically self-sufficient small businesses as transitional supported employment programs for people with developmental disabilities. The Kennedy Foundation has given WID a one year start up grant for this purpose. WID strongly supports the development of model projects which can be used and learned throughout the country.

Empowering disabled people within their religious denominations

Eighty disabled members of the California Episcopal Dioceses were mobilized and trained to work for integration of the disabled into the congregation and church life. Fifteen parishes agreed to develop projects. A film is being produced on the model project.

Publications and materials

Descriptive Analysis of the In-Home Supportive Services Program in California. Describes one of the most innovative programs in the country. Examines the history of the 25-year old program, how it operates, who it serves, and its problems.

Attending to America: Personal Assistance for Independent Living.
Explores state of attendant services, contains policy recommendations, action steps, directory of attendant service programs in the U.S. and a bibliography.

Ratzka, Adolf D., Independent Living and Attendant Care in Sweden: A Consumer Perspective, World Rehabilitation Fund, Monograph 34, New York, 1986.
A consumer-based analysis of the attendant services system in Sweden.

Report on National Attendant Care Symposium 1985. Proceedings from a national meeting sponsored by the National Council of the Handicapped.
Recommends changes in legislation.

Attendant Services, Paramedical Services, and Liability Issues.
Explores the issue of liability of providers of different skill levels performing personal service tasks.

Zukas, Hale, Summary of Federal Funding Sources for Attendant Care. Overview of the provisions for attendant services under Medicare, Social Service Block Grant, The Rehabilitation Act, and Title III of the Older American's Act.

Zukas, Hale, The Case for a National Attendant Care Program.
An analysis of the federal funds presently utilized to finance attendant services, their inadequacy to fill the need, and the need for a national entitlement program.

Attendant Service Programs that Encourage Employment of Disabled People.
Brief state-by-state description of programs encouraging employment, giving information on eligibility criteria, administrating agency, funding.

Ratings of Programs by Degree of Consumer Control.
Ratings of each programs' degree of consumer control based on the Handicapped's ten point criteria.

Attendant Services Network Newsletter. Personal Assistance For Independent Living.

Research & evaluation

Resources

The RTC/IL

The Research and Training Center on Independent Living (RTC/IL) was established in 1980 to help individuals with disabilities live more independent lives. The Center conducts in-depth research and training on current issues in the Independent Living field. Research and training staff from a variety of disciplines at the University of Kansas have joined together to help increase opportunities and choices available to persons with disabilities. The RTC/IL produces materials developed from preliminary studies, research reports, and training activities, such as presentations and seminars. Publication efforts are aimed at timely dissemination of information on topics such as legal and political issues, services for persons with disabilities, advocacy and consumer control, and community responsiveness. The RTC/IL offers a Catalogue of Publications free upon request which currently lists available publications.

Address: 4089 Dole Bldg./LSI,University of Kansas, Lawrence, KS 66045, United States

The ILRU (Independent Living Research Utilization) Research and Training Center on Independent Living has a number of projects under way central to issues in Independent Living: Operational Definition of Independence: The project is designed to develop an operational definition of independence that incorporates perceptions of control over one´s life, psychological factors, and behavioral or functional characteristics. Toward that end, an assessment instrument to quantify an individual´s independence in each of the above 3 domains was developed--the Personal Independence Profile or PIP. The PIP was first tested on 61 severely physically disabled subjects referred by an urban and a rural ILC. A demographic questionnaire was administered covering basic personal characteristics, activity patterns, use of attendant services, and health. Data collected is currently being analyzed for correlational relationships between PIP scores and personal demographic and behavioral characteristics. The next step will be to conduct validity tests of PIP by administering the PIP to 48 individuals of known characteristics referred by 4 ILCs in various parts of the country. Congruence between their score profiles and general assessments of independence given by the ILC staff will be determined.

Parameters of Independent Living: Their purpose is to maintain a database on the status of IL programs nationally and through analysis, identify trends in their development, the emergence of new problems and new solutions for the delivery of IL services, and changes in the characteristics of consumers of these services. The survey used in previous

ILRU studies was refined and mailed to each of the more than 300 programs listed in the ILRU Directory of Independent Living Programs. Information was solicited on populations served, services provided, characteristics of persons providing services, methods by which services are provided and programs administered, funding sources, and relationships between programs and their community. Profiles of each program responding to the survey are published in the ILRU Registry of Independent Living Centers.

The first examination of the data addressed questions of compliance with requirements for consumer control of IL centers. Results indicated that compliance levels with key requirements of Title VII, the IL provision of the 1978 Rehab Act, are quite low. Only 51% of programs receiving funds meet requirements for consumer involvement in direction, management, and service delivery. Complying programs were shown to offer significantly more services and serve significantly more persons than noncomplying programs.

Address: ILRU at Texas Institute for Rehabilitation, 2323 S. Shepherd, Suite 1000, Houston, TX 77019, United States.

Source: Disability Studies Quarterly, Summer 1988.

DeJong, Gerben, The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research, Tufts New England Medical Center, Boston, MA, 1979.

Evaluation of Independent Living Movement in relation to disability research and services; an in depth analysis of movement's constituency, origins, legislative history, and relationship to allied social movements (e.g., civil rights, consumerism, de-institutionalization).

DeJong, Gerben. Environmental Accessibility and Independent Living Outcomes: Directions for Disability Policy and Research. 1981. University Center for International Rehabilitation Publications. Available from ILRU.

Examines the role of environmental barriers as constraints to Independent Living and the policy issues incumbent on these findings.

Stoddard, Susan, "Evaluating Program Methods and Results", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Brooks, Nancy A.,"Using Field Research to Gain Subjective Insights", in Crewe, Nancy M. & Zola, Irving Kenneth, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

Disability Studies Quarterly. Editor Kenneth I. Zola, Dept of Sociology, Brandeis University, Waltham,MA 02254, United States.

This quarterly publication focuses on a different theme each issue. It features essays; book reviews; film critiques; call for papers; grant proposals, and manuscripts; and reports on current research in the field of disability studies.

Prof. Harlan Hahn,
Program in Disability and Society, University of Southern California,
Los Angeles, CA 90089-0044,, United States.

Disability, Handicap & Society

From the editorial of the first issue:

"In the past decade important changes have taken place of both attitudes to, and policy towards, disability and handicap. Alternative perspectives to the dominant medical model have provided a series of serious challenges to official or professional interpretations that have emphasized individual deficits or problems. An important contribution to this work has been made by disabled people themselves. Definitions of disability and handicap have been increasingly acknowledged to be relative to specific historical and cross-cultural factors. Custodial approaches have been seen to be inadequate an unacceptable, resulting in greater emphasis being placed on community care and integration.

Policy in many instances has been piecemeal, cosmetic and lacking carefully thought through guidelines. Where appropriate frameworks ar being developed, too often the money to implement subsequent programmes is not sufficient or even made available. Given the impact of economic recession, the task of ensuring that even the basic needs of these groups are met, is becoming an increasingly daunting task facing all societies.

It is against this global picture that this new international journal is being published, and we hope that its pages will reflect the debates and struggles that are taking place locally, nationally, and internationally around such issues as human rights, discrimination, definitions, policy and practices. The aim of Disability, Handicap & Society is to provide a forum where various issues and questions on disability and handicap can be highlighted and discussed.

We do not wish the journal to be viewed as a vehicle for merely representing professional perspectives. Thus, we want to encourage the consumers of services and people with disabilities to speak for themselves. We thus expect accounts to critically examine institutional and social relationships, to reveal power relationships and the reality of decision and policy making. We would particularly welcome case studies and analyses that seek to place debates within the context of the common social position of disadvantaged groups."

Evolution Power Tools. Specialising in accurate, reliable, powerful circular saws, mitre saws, chop saws & blades. Specialising in accurate, reliable, powerful circular saws, mitre saws, chop saws & blades. I have a few Evolution power tools now, they have never let me down, the quality really stands out. For me the saws are second to none, very reliable, easy to use, the blades speak for themselves. Evolution are really leading the way, no need to change blades because one does the lot.