Understanding Depression
Helping with Grief.
Avocations. Vocations.
Housing/Independent Living.
Housing and Home Services for the Disabled

Guidelines and Experiences in Independent Living

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Understanding Depression—Helping With Grief

by John L. Quigley, Jr.

Those of us who know about physical disability know that depression is a very real and sometimes the most vexing problem associated with the loss of body function. Many of us have known the experience we call “depression” in our own lives, having lived through it at least once in a profound way, and perhaps also in more ordinary times when it is a little less difficult to manage. Others of us have seen “depression” in our patients and have tried, with varying degrees of success, to be helpful. Frequently, however, those of us who have a disability and those of us who practice the related professions don’t understand enough of the dynamics of what is happening in “depression” to be able to help others or ourselves. Perhaps an article outlining the basics about “depression” can give us a working knowledge of those dynamics and enable us to deal with “depression” more helpfully.

First of all, let us distinguish three dynamic processes which are frequently considered to be the same thing, but are not. The first is the grief process. Grieving is the process which everyone inevitably goes through after any significant loss—the death of one we love or the loss of body function. In grieving the whole personality tries to adjust to a radically altered course of life, coming to grips with its threats, with old and new fears, with who one now is in the absence of a significant part of one’s former self, and with what effect the loss will have on all our relationships. We will look at the grief process in some detail below.

The second idea to be distinguished from the others is the concept of reactive depression. These words suggest the familiar process of being “down,” perhaps angry, hopeless, and intensely preoccupied with an upsetting event. The important idea is that in this kind of depression these feelings are associated more or less directly with the specific event, sometimes one involving great loss. In other words, this condition has all of the characteristics of what we usually call “depression” but it has a focus. Reactive depression is an important part of the grief process, as we shall see, and it is the kind of depression we are usually referring to when we talk about depression following a disabling loss. This depression can also occur in lighter forms at the time of an anniversary of an injury, or can be seen in the feelings that come on when one is vacationing in a place that arouses memories of activities which were enjoyable before a disabling disease or injury and are now no longer possible. Most people will experience this depression occasionally and, even when it is severe, will be able to work it through—sometimes with help from others—and get on with the business of living.

But there is another kind of depression which, while it may be triggered or made worse by a recent specific event, is more generalized and pervasive in the personality. It is much more difficult to work through. Depression in this sense is an entire system that some people fall into for managing the conflicts of everyday life. A depressed person of this kind believes that he is a bad and worthless person, fit only to be hated and rejected. Most of the resources of this kind of personality are immobilized by a very inward, angry process of self destruction. Now, this kind of depression also characterizes some people after a great loss. When a person who is prone to this kind of depression sustains a loss, the usual reactive depression associated with the loss loses its focus and the grieving process dead-ends in the more generalized depression. This depression feeds on itself. It is a way of managing unconsciously conflicts which predate the loss. The injury and loss seem to fit the system, but the real issues are more primitive and much less accessible for the process of working through. In short, this self-perpetuating kind of depression serves needs other than those appropriate to real loss and...
thus it is much more difficult to relieve.

What, then, is going on in each of these processes? What can be helpful or hurtful in response to people exhibiting these characteristics? And what can we do to help ourselves when we get depressed?

**What Happens in Grief.** Any great loss, and particularly the loss of body function, threatens a person in the most basic way. It is not so simple as the loss of limbs or enervation, it is the loss of part of our selves as we have understood ourselves. A self is the unique synthesis of the inner drives and needs of an individual with the relationships and experiences that have surrounded that individual as he has developed. To have any part of the fabric torn away is to have a part of what we know as our selves torn away, too. A great loss is accompanied by very deep anxiety. Regardless of the age of the onset of disability, we have spent our whole lives to that point organizing and developing our own individual selves. In the earliest years of life we have had to learn to manage the fear that we will be abandoned helpless by those around us who are most important to maintaining life itself. We have had to learn when to take initiative, utilizing our bodies and all our capacities to the full, and also how to manage the doubt we have about ourselves. We have had to learn to relate as individual persons to others and to conquer the fears associated with those relationships. In short, we have had to negotiate life’s problems at every stage of life, using all of our available resources, including most especially our bodies, and we are the pattern we weave out of these struggles. The loss of body function, the most basic of our capacities upon which we have built our personalities, arouses anew, and with the same primitive sense of panic, all of the deep anxiety associated with those early fears and struggles. The loss of body function threatens the destruction of the whole self. It portends the ultimate threat to life which is death, and nothing less.

The memories of the specific fears in our lives and how we handled them are long since pushed out of consciousness, but the anxiety associated with them remains. That anxiety is what engulfs a person who has sustained a great loss; a great loss arouses the fear of being helpless and in life-threatening danger again. This anxiety triggers all of the emotionally protective devices (defenses) available to the individual to shield him from pain. The defenses protect in two ways. They seek to protect us from the awful memory of those early fears of abandonment and destruction we all carry with us, and also to protect us against the terrible pain of having to deal with the real, immediate trauma and its consequences which are just too much to handle all at once. This is what is happening in the early phase of the grief process. Very basic defenses are rigidly constructed—such as denial (It’s only a temporary disability. It will all improve in time.), projection (Don’t worry about me. I’m going to be all right.), and others.

In addition to rather rigid defenses there is also a shrinking of psychic awareness, away from all of the many and complicated aspects of living, and a focusing in on an intense preoccupation with one’s self, one’s immediate needs and the most elementary aspects of one’s immediate experience. This can be seen when individuals, just after a loss, complain about seemingly trivial things: hospital food, noise, etc. There is also withdrawal in this phase of grieving, the better to regroup one’s forces for the struggle ahead. It is a time of withdrawal from people, and even from the many remaining emotional resources still available within the personality. Most of one’s strengths and abilities are forgotten and the new inabilities are accentuated. The point is that the denial, the shrinking of awareness, the withdrawal and the preoccupation with past, now lost, capacities—all of these maneuvers of the mind are entirely necessary. They tend to arouse anxiety in others not experiencing the loss and the grief because they seem “unrealistic.” Or more honestly, others intuitively understand the anxiety which has triggered these responses in the grief-stricken person and would like it all to go away. But fighting these defenses in the name of helping will only impede the grief process.

**The Reactive Depression.** When the early defenses are in place and time and reality begin to erode their effectiveness, a person begins to move into the reactive depression that is the most significant part of the grief process. We often speak of sinking into depression and that is exactly right. If a person is finally to adjust to the reality of a great loss he must gradually relinquish the controls or defenses that hold the line against the pain of acceptance. He must then slide backwards (or regress) to points where he can allow himself consciously, and with all of the associated emotions, to experience and accept bit by bit the impact of the loss on his life. It is a process of giving up and feeling the awful facts. A person in this process will give way to remembering recent events prior to the loss in a wistful effort to bring back the former happy state of things, there may be fantasies of conversations or events that might have been, and there will be verbalization of the loss. Gradually the pain can surface and can be confronted in itself.

Moreover, and perhaps most important, it is in this regression that a person can experience and express the anger, indeed the rage, that is every person’s response to the anxiety associated with threats to oneself. The unsympathetic observer may become very annoyed at what he perceives as childish or even infantile behavior. Though this attitude totally lacks empathic understanding, the perception is essentially correct. A person working through grief of this magnitude needs to renegotiate so many of life’s issues
over again, that he must regress emotionally through all the feelings associated with those issues and must reprocess the most basic, primitive emotional experiences. That means becoming childlike. It means expressing basic frustration, and fierce, impulsive anger. If those feelings cannot be expressed and reintegrated they will be directed inward and will become the substance of a hard-core, guilt-ridden depression.

Acceptance. As a person is able to experience the real loss he has suffered, which is at first covered up by the generalized anxiety he experiences, he also begins to be able to see that his personality or self does not depend totally on what has been lost and that he may be able to master even a greatly altered life. Acceptance is this acknowledgment and mastery of the facts without a lot of anxious distortion. It is the psychic decision to live with the realities, the deeply ambivalent feelings, the ambiguities, one's great dependence on body function but also one's psychic independence from it. Acceptance is grounded in knowing the pain and the anger because they have been directly experienced in expression, and also knowing that one is big enough to live with these powerful emotions as they really are and have plenty of one's self left over. When one gets beyond that awful knot of diffuse anxiety and can in time begin to acknowledge the more primary feelings associated with a loss, more and more energy will become available for the work of reconstituting one's life.

Reconstitution. The final phase of the grief process is reconstituting oneself based on reality. The possibilities for reconstituting the self are, of course, as varied as there are people going through the experience. In all cases, however, the process is one of replacing the capacities which have been lost with new ones, or greatly enhancing old ones. Old relationships must be renegotiated based on new realities; some will be given up and new ones will be formed. It is a gradual process of redefining the self through new interactions with others based on things as they now are. As this process takes place the grieving person is gradually able to widen his field of awareness and eventually can resume living his life.

The Other Depression. It all sounds so simple when written out like this in sequential fashion. But not everybody has the capacity to work through the grief process to a full resumption of living. Successful grieving requires enough inner confidence to let one face the facts and acknowledge the feelings, to hold things together through the reactive depression. Anger and frustration, the wish to be cared for, the feeling of helplessness, the wish to die—none of these are feelings we like to acknowledge. Normally we would like to avoid them. So something must be available in us to let us work them through without losing our sense of balance in the process. For some who don't have this capacity life is lost when body function is lost. We say that such a person does not have a very well-differentiated self, or lacks a strong enough ego. Such a person doesn't have much of an idea of his own uniqueness and worth. He doesn't have a foothold in an on-going self which is invulnerable to outside attack. This person gets depressed and stays depressed. There are several important explanations of how and why this occurs which are too tedious to discuss here. What is really important to understand is that there is a difference between being depressed yet being able to work it through by gradually accepting more and more of a real loss, and being stuck in a depressed dead-end. There are things we can do to help with the reactive depression which is a part of grieving as described above, but there is not much the untrained person can do to help lift the dead-end kind of depression.

Well, what then can we do to help a person grieve successfully, to work through the reactive depression which will permit acceptance of the loss and reconstitution of one's self? What should we do about dead-end depression? And what can we ourselves do when we get down?

Helping with Grief Work. Certainly the beginning of helpfulness is to know the difference between grief and depression. If we understand the process of grieving we will not be so likely to get in the way, for example, by becoming annoyed at the many childish, hostile, aggressive, or passive withdrawn expressions which are necessary steps in the process. Some professional people, with institutional concerns foremost in mind, inadvertently make a difficult struggle just that much harder by demanding certain levels of social behavior and adherence to schedule, expecting steady progress, and not permitting necessary regressions. They show little empathy, let alone support, for the struggle of the individual within. A reactive depression following a significant loss is nothing to be alarmed about and it is nothing to try to force a person out of.

If one wants to help another through grief, it would be wise to let the process take its course without any attempt to force it or speed it up. The early defensive maneuvers, such as denial, which clearly seek to shut out others and reality, are necessary and appropriate. Any attempt to knock them down or cut through them before a person is ready to give them up will only force a redoubling of the defense and retard the process. Help comes through a genuine, steady, accepting relationship. Such a relationship is possible only if the helping individual can see past the outward defensive behaviors of the grieving person and can perceive and relate to the basically good and unique self within. Such a relationship implicitly communicates affirmation of the larger self. It says, 'you are someone...
other than the lost body parts and function, different from the anger, from the annoying behavior, and also from any particular style of life you followed before." When a grieving person is ready and when he feels this kind of empathic support he may then begin to confront the real loss and his very personal feelings about it. He may then be able to work through the depression to the extent of his capacity, until he has achieved a newly integrated self. This kind of empathic relationship is essential, but it isn't easy. Think of the feelings aroused in you as someone you want to help directs his anger and frustration at you personally. You want to get away or retaliate. Understanding what is happening can help you respond more helpfully.

In addition to understanding the process and being available for an accepting relationship, there are some direct ways to be of help during the grieving process. It is not very difficult for a sensitive person to tell when another is facing into the real loss and expressing the real feelings associated with it. This will often seem to be the period of deepest depression, but it will have a quality of authenticity about it that will earmark it from anxious resistance to accepting the loss. This is a time when direct help can be given and it can take several forms. One might try to help the grieving person look objectively at just how much has been lost and how much remains useful.

As a person authentically faces his loss he is ready to give up the sense of total loss he has been wrestling with and may be ready to regroup the resources he retains. These remaining resources, which are often not so obvious to the grieving person, are more clear to another. Emphasizing them is supportive and can begin to point the way toward reconstitution. It can also be helpful at this point to encourage the grieving one to look at old relationships which have been maintained and have changed, as well as new ones formed since the loss, so that he can see for himself that he is in fact still a very significant person, capable of genuine human interaction and capable of having a positive effect on the people around him. If these interventions are offered prematurely (as they often are because they seem to be so obvious) they will fall on deaf ears. Offered too soon, they will seem superficial or even harshly challenging. But offered as a person is gaining control over his real feelings and the real loss, such observations can be helpful and reinforcing.

HELP FOR DEPRESSION. Though professional help with deep grief would be helpful and even advisable, when a stagnant depression is encountered, it should definitely be treated professionally. As I have said, it is different from the reactive depression we have looked at above in that there doesn't seem to be any active struggle taking place. There is very little expression. A seriously depressed person cannot easily respond to an empathic relationship. It is not always easy to distinguish these two kinds of depression as I have done in an overly simple way here. So as an additional rule of thumb I generally think it makes good sense to consider the depression of the first two years after loss of body function to be a part of the grief process and to treat it accordingly. If depression continues to immobilize a person after that point or if the reactive depression seems to be completely overwhelming, it is probably best then to consider getting professional assistance.

HELPING OURSELVES. And what about helping ourselves when we get down? It's been twelve years since my injury and I still have times of depression. I still grieve my loss. I have learned that I cannot make my depressed feelings go away when they occur through any effort of discipline or will. I compound the problem when I try. So I encourage myself, to the limits of my capacity, to sink into those feelings and to let them become as vivid and real and hurting as they will. I try to sharpen those feelings and make them as poignant as possible. I am reasonably confident that they are not the whole story about me and that the sadness and hurt will not ultimately overwhelm me. If there are any realistic ways I can improve my situation by removing a consistently upsetting stimulus or improving a way of accomplishing something, I do it (e.g., repairing a wheelchair that's been getting me down through procrastination). Most of all I try to acknowledge my wishes, even the deeper ones, regardless of whether I can ever fulfill them, and I try to accept the frustration that goes along with this as the actual frustration which is a part of real life.

During this sort of depression I invest myself even more than usual for a time in a trustworthy relationship. One can almost always find a good friend, a minister, a counselor, or best of all one's spouse, with whom one can let go of some of the control. The point is that it is helpful to seek out a relationship of this kind actively, rather than to withdraw further into one's self. In such a relationship I can afford to be vulnerable and weak and upset, and I don't need to spend a lot of my emotional energy "keeping myself together." In that relationship I can usually express more of what troubles me than I can to myself, by myself. When I do these things I find I begin to rally. I feel renewed and can move ahead more on my own.

In Conclusion. As I said at the outset, most of us are aware of depression as a significant problem in the aftermath of a disabling loss. We understand some of its process. But it is remarkable to me how often in good rehabilitation facilities, in able and well-intending families, and in presumably helpful groups of physically disabled, the inner struggles and growth of persons trying to adjust to great loss are
Avocations

Club Work and Hobbies

by Jim Wallace

In October, 1937, I was born in Saskatoon, Saskatchewan, Canada, with the condition of arthrogryposis multiplex congenita. The doctors warned my parents that I would be severely handicapped. Naturally, mother and dad were very disappointed but they decided to make the best of things by raising me as normally as possible.

Childhood days were happy. I can remember sitting on the floor for hours playing with my building blocks and other toys. When I couldn't do what I wanted with my right hand, which was the best one, I would lean over and use my mouth. I became very good at playing marbles with my tongue instead of fingers.

I had no trouble attending public and high schools. I enjoyed school, especially associating with the able-bodied students. The young people were fantastic in helping me around the schools. In high school I had to travel from classroom to classroom so I had a desk built that would fasten to the wheelchair. The kids would throw their brief cases and books on my desk and away we would charge down the halls or the guys would grab the chair and hoist me up or down the stairs.

The trend seems these days to put handicapped children in special schools. This is good as far as making it easier physically but I feel they miss a lot if they can’t associate with the able-bodied students. Of course, the ideal thing is to have the special class integrated with a normal school.

For several reasons, such as transportation, further education didn't make itself possible after high school here in the Vancouver, B.C., area. I took bookkeeping

Jim Wallace, "I type with a mouthstick and use surgical forceps to insert the paper. The square of cardboard behind the typewriter keeps paper from falling over. . . . Note levers on knobs of my 'ham' radio so I can manipulate them with my mouthstick."
Many disabled have thought about or actually tried writing or broadcasting as a means of expression and a way of making money. Some who have tried writing columns have succeeded in having them published or broadcast. They have become effective, helpful voices in their communities and beyond, and some have gained a regular income. The subjects of this article, however, are agreed that monetary reward is the least of the benefits of column writing. The biggest are being heard and being helpful.

Terry Brickley’s column, “HANDICAPsules”, shares the experiences of the disabled (and some able-bodied) in the problems of daily living and their solutions. It has been published weekly for three years in five California newspapers. As proof of Brickley’s success, the column has recently been bought by a syndicate, which will increase its readership immensely. Syndication is every columnist’s dream.

Brickley is 42 years old, married, and a former model engineer who was professionally unaware of the problems faced by people in wheelchairs or on crutches trying to enter the buildings he helped design. His own confinement to a wheelchair as a result of multiple sclerosis gave him a whole new view of things.

As a construction engineer he became aware of the extremely hard and challenging work involved in building buildings that were as safe and accessible to disabled people as possible.

Terry Brickley: “A construction engineer can actually build a building. But I can write about the problems that a disabled person faces trying to enter it.”

Terry is now a freelance writer; he has written a book, Handicap Bolt, and is working on another. He is an editor of the local paper and a former president of the local disabled sports club for adult athletes.

The unit in the column is bought by and loaned to me from the Kinsmen Club Rehabilitation Foundation. They also service it.

Address: Jim Wallace, 4195 Napier Street, Burnaby, British Columbia, Canada, V5C 3G5.

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the "handicapped subpopulation." "Synthesis" is a 15-minute program that has been written and broadcast by Farr every Sunday night since May, 1974. It includes interviews with resource people, news items of particular relevance, and other features which provide useful information. Like Brickley, Farr spends two hours a week in preparation. On the advisability of others starting such programs, Farr said, "Do it. It needs to be done. Patience, persistence, and perseverance are required. Qualifications vary from station to station. I had some radio experience and am personally disabled."

Farr's broadcasting experience was as promotion manager for a radio-TV station in Hawaii where he and his wife lived while she got her master's degree in social work. They went there a year after Farr graduated from college and discovered he had MS. He is now working on his PhD dissertation at Stanford University. His subject is how people with disabilities get helpful information related to living with a disability. A position as Enabler at De Anza Community College provides his main source of income. Farr is looking toward television to do a "Synthesis" type program. He said, "'Synthesis' was the first radio program of its type, but I hope there will be many more. I will be glad to help anyone who wants to get such a program started."

Columns are not always slanted to the disabled. Larry Schaefer, who is confined to a wheelchair and largely unable to speak as a result of encephalitis, writes a photography column. "A few years after I became disabled I wrote a short article on how I made personalized greeting cards for all occasions with a Polaroid Land Camera and movie titling set, and I sent it to the columnist who then wrote the camera column in the Gary, Indiana Post-Tribune. She liked the article and printed it under my by-line as a guest columnist. For a number of years she encouraged me to write articles on various photo subjects, all of which she printed under my by-line. When she decided to retire, she persuaded the management of the Post-Tribune to let me write the column permanently. For the last five years I have been writing a weekly column for the Sunday section. The Post-Tribune is the largest daily newspaper in northwest Indiana."

Schaefer's intended career before his illness was photojournalism. After he became disabled he took courses in magazine writing, short story writing, philosophy, and psychology. He also has a diploma from the International Correspondence School in commercial art. Over 100 of his cartoons and pen-and-ink drawings have appeared as illustrations with his column.

"Any disabled person who has a special hobby or interest about which he can write knowledgeably is sure to find that writing a newspaper column is a satisfying way to earn some extra money. Community recognition from the column could lead into new areas of activity and usefulness.

"I would advise anyone interested in writing a column to write about four samples and make an appointment to discuss them with the managing editor of your local newspaper. (Weeklies are usually more receptive to new columns than dailies.) It might even be a good idea to offer to let him print the first four columns free of charge so that he could determine reader reaction. Even if he decides against continuing with the column, you will have the clippings to show future prospects that your work has appeared in print."

Still another type of column is written by Geri Cogan of New Jersey. It is a chatty, humorous view of particular news events or life in general. This column is printed once a month, or whenever Cogan gets it done, in the Pascack Valley Community Life, a weekly newspaper.

Cogan began writing when she found at age fifty that she had multiple sclerosis. Although she had done various types of writing during a lifetime of theater work, she brushed up with a creative writing course. At one time she had been a press agent, a theatrical agent, and personal secretary to Helen Hayes for three years and to Gladys Swarthout for twenty-five years.

She advises new writers to "take a good journalism course, in school, correspondence, or adult education." She lists qualifications as "the need to write, sticktoitiveness, perfect spelling, grammar, composition, imagination; know how to search out ideas."

A shining star among journalists who are disabled is Bill Kiser of Winston-Salem, North Carolina. He was awarded the President's Trophy as 1976 Handicapped American of the Year. Along with Dick Farr, he was one of the pioneers in broadcasting a program especially for the disabled. Of his work Kiser said, "I have five papers carrying my weekly column, The Handicapped Mailbag. For the last two years I have been writing a weekly radio program. I do this program for the North Carolina Department of Human Resources, and it is carried on 20 stations throughout the state. As you might imagine, the program takes up a major part of my effort and provides me with my main source of income."

Kiser has cerebral palsy and was once, after unsuccessful brain surgery, considered hopelessly disabled. He was in a nursing home for eight years until friends, a rehabilitation counselor, and a physical therapist encouraged and helped him to leave. His news service was organized in 1974 through the sale of stock to friends. Now he lives alone in an apartment adapted to his needs and goes back and forth to his office across the street in his electric wheelchair.

"As to whether handicapped people should write columns or not, it is very difficult to make any money
Iin this work, although it is very rewarding. The only way anyone can make a living on columns is to sell them to a syndicate, which I have never been able to do.”

Kiser received most of his formal education from his mother, who was a teacher, and passed a high school equivalency test. He has since audited 50 hours of courses at Furman University.

Vocations

Vocations and Disability

by Fr. Patrick Lewis, C.S.Sp.

June, 1959, was a red-letter day for the disabled. On the 10th day of that month, the first paraplegic in the Catholic Church’s history was ordained to the priesthood. Fr. Leo Close sustained a severed spinal cord in a mountain fall while on pilgrimage to Fatima; he is now director of religious education in the diocese of Dunedin in New Zealand.

In the subsequent years, other severely disabled seminarians were ordained to the Catholic priesthood: the present writer in December, 1964, Fr. Bob Ronald, S.J., in early 1965, and Fr. Bill Atkinson, O.S.A., a quadriplegic, in 1974. In each case, a special dispensation from Canon Law was obtained.

In every instance, these men were already seminarians when they joined the ranks of the disabled. However, the fact of their ordination has raised the hopes of other severely disabled persons who feel the desire for the religious or priestly life, and has raised a question of admitting them to the preparatory seminary programs. Except for some religious orders specifically founded for the disabled, entry into the generality of seminaries and religious orders is a difficult, if not impossible matter, for those with severe physical disabilities.

In examining why this is so, it may be well to consider briefly the Catholic theology of vocation.

If we are to conceptualize vocation as a “calling” or “invitation,” then all men are called, everyone has a vocation—“it is the will of God that all men be saved and come to the knowledge of the truth.” There are others, however, who feel called to a more direct or immediate following of Christ and his teaching. So men and women have drawn together into groups and have organized their lives to serve their fellow man and to facilitate a less hindered becoming of the ideals Christ set before us. These groups are the Religious Orders in the Church.

The Church itself has an organizational aspect—an aspect which demands the fulfilling of many roles and functions. The Catholic Priesthood is one of those functions, one which has as its essence an intermediary role, a role of service, a role of “being for others.”

Those who contemplate entering the religious or priestly life will need to examine for themselves whether they have the abilities to fulfill the basic requirements of the life they desire. This, too, will be the basis of the assessment made of them by the institute or seminary they want to enter. (The process here is not greatly different from the selection process for any vocation and some will be automatically excluded; e.g., a blind man will not be accepted for pilot training.) For the religious life, the criteria will be different from those pertaining to the priestly life.

For the religious life, the basic questions will be:

- Is this person physically capable of living the essential aspects of this institute’s way of life?
- What reasons has the individual for wishing to join this institute? In all cases, one has to be aware that motivation is mixed but one seeks to
avoid the person who wishes merely to escape the responsibilities of life or is hoping for a secure shelter.

- Is the congregation willing to assume the health care of this individual?
- The bugbear for all the physically disabled: has the institute suitable facilities free of architectural barriers which enable the candidate to fulfill the demands of this role?

As regards the priestly life, the main questions will center around whether this person can fulfill a role for others. Can he administer the sacraments, preach (in words or writing), and be of service to his fellow man? It was due to the public nature of the office of priesthood that the Canon Law of the Church laid down that a disability or disfigurement that would cause _admiratio populi_ would be an impediment to ordination. _Admiratio populi_ is a grave feeling of distraction and/or discomfort on the part of the congregation. That some forms of disability or disfigurement could cause such a reaction can be admitted. On the other hand, this formulation of the law has both the disadvantage and advantage of reflecting the attitudes and assumptions of society at a particular time, and of accommodating changes of attitude over a period of time.

It has been rightly said that the Church's prophetic role should preclude it from being the slave of public opinion. Law of itself does not have the charisma of prophecy, it deals with present facts. Church Law, however, as distinct from any other codified law, has an inbuilt provision for dispensation from nearly all of its provisions—a true recognition of the complexities of human situations. Such a provision used by charismatic men in the recognition that "God chooses the weak to confound the strong" has been, and will continue to be, the avenue by which social attitudes are changed and the severely disabled officially enter a life of service to God and their fellow man.

Ordained After a Delay of 23 Years

by Rev. Charles Kram

The most unforgettable event of my life occurred on December 5, 1975 when, at the age of 46, I was ordained to the priesthood after spending half my life as a quadriplegic.

I had contracted respiratory polio in 1952 when I was one year short of ordination and, under Church Law, had been judged ineligible to continue. I was already a subdeacon at the time and had taken a vow of celibacy and the obligation of the daily recital of the official prayers of the Church.

After rehabilitation, I returned home to my parents on a farm near Shiner, Texas. I spent as much time as I could in my wheelchair and rested on a rocking bed. I kept in touch with the outside world by way of amateur radio. I held on to my commitment to the Church and devoted a good deal of time to prayer and meditation.

Over the years numerous efforts were made to secure permission from Rome for my ordination, but the answer was always the same—no. But in recent years the trend within the Church has been toward greater freedom and greater emphasis on love and pastoral needs than on inflexible law. Thus my bishop, Archbishop Francis J. Furey, Archbishop of San Antonio, was finally able to clear the way for my ordination.

The steps were to first ordain me a deacon and then a priest. My ordination to the diaconate took place here at home on the evening of December 4. The archbishop ordained me a deacon during Mass by the ancient rite of laying on of hands and a prayer of consecration. My mother, age 83, who is now a resident in a local nursing home, came home for the occasion. Also present, of course, was my father who, at the age of 89, is still my faithful attendant.

The next day friends and relatives loaded me into a van borrowed from a saddle factory. When our caravan arrived at our parish church, the school band was playing outside. At 2 o'clock three bishops and some 100 priests, who had come from near and far, marched down the aisle, led by a group of white-gowned little flower girls who scattered petals in their path. Then came my parents and finally I, followed by the archbishop.

As with the ordination to the diaconate, the ordination to the priesthood also takes place during Mass. The bishops and priests filed by one at a time and laid their hands on my head. After the laying on of

Archbishop Furey of San Antonio laying on hands at the ordination of Father Charles Kram, respiratory polio quadriplegic.
hands a chalice and a paten were placed on the lap-board of my wheelchair and the bishops and priests and I proceeded to concelebrate the ordination Mass.

At the end of Mass came the blessing. My first priestly blessing was for the archbishop who knelt before my wheelchair. I was the 98th priest he had ordained. After Mass I was wheeled to the center of the church to be with the crowd of well wishers until it was time to proceed to the nearby parish gym where a turkey dinner was waiting.

In spite of all the congratulations and praises I received that day, I went to bed that night knowing that was the same one. I was the priestly kind of services. I was waiting. I was the one who knelt before the first ordination. After Mass I was wheeled to the center of the church to be with the crowd of well wishers until it was time to proceed to the nearby parish gym where a turkey dinner was waiting.

Address: Father Charles Kram, Route 1, Box 96, Shiner, Texas 77984

A Profoundly Deaf Seminarian

by Thomas J. Coughlin

The idea of a profoundly deaf person studying for the Roman Catholic priesthood is a novel thing, at least for now. Yet one does not really need ears in order to be able to learn. Communication need not be strictly aural or oral; rather, it should be comprehensive, that is, communication can be achieved in various mediums such as sign-language, visual arts, drama, and a few others.

We deaf people have been using sign-language as our major learning tool. We use sign-language to interact with other deaf persons. But what about a deaf person who happens to live in a total hearing environment? It is a completely different situation, and indeed, a difficult and painful one, too.

Since I am the only deaf seminarian in the Department of Theology at the Catholic University of America in Washington, DC and one of the only two deaf seminarians in the USA, I do find it somewhat difficult and frustrating to be in a total hearing environment. I have studied at Catholic University for almost four years now and have already earned my MA degree in theology. Very often, during the course of my studies, I have encountered loneliness, depressions, frustrations, and several other unpleasant situations. These difficulties have stemmed mainly from the communication breakdown. I have made every effort to communicate with others, but I cannot bear the stress of lip-reading at all times. I find it to be exhausting. There are times when I simply quit and withdraw into my world of loneliness and solitude. When I experienced hardships, very often, my aspiration to become a priest would become shaky.

The whole thing has now changed. I am very fortunate to have a priest-friend who showed me that one can find meaning in hardships and struggles. It is a matter of personal decision. One can easily sit back and wallow in one’s sufferings. The handicap of deafness is truly a cruel one only if you allow it to be. Our physical handicaps can derive their beauty and meaning when we try to understand them not as a curse or a punishment, but rather as a challenging gift from our God.

Address: Tom Coughlin, Trinity House, 949 Gor- such Avenue, Baltimore, Maryland 21218.

ED: Because of space limitation, it has been necessary to shorten the articles of Father Lewis, Father Kram, and Tom Coughlin. If any one of the articles is of particular interest to a disabled reader, we shall photocopy the original.

Three Religious Communities

The Congregation of the Sisters of Jesus Crucified was founded in Paris in 1930. The first American house, Regina Mundi Priory in Devon, Pennsylvania, was founded in 1955. St. John’s Priory was established in England in 1959, and St. Paul’s Priory in Newport, Rhode Island, in 1962. There are now houses in Japan, Holland, West Germany, and five houses in France.

The sisters live a monastic, contemplative life in the tradition of St. Benedict. Candidates must be between the ages of 20 and 35 and must have a wholesome attitude toward health and be emotionally and psychologically balanced. Candidates need not be dis-
First of all, we have Sister Eleanor Imelda, OP, who
volunteer her time to help CSVA
members of the community. Many of them also
modeled their lives and actions on the example of
disabled adults and young people
who are active participants in the community.
I have come to consider a number of disabled
Through the Catholic Union of the Sick in
America,

by Anna Marie Sopko

Religious

Disabled Pipers and

Deserted Villagers

in New Jersey

Avenue Overlook, Kentucky 40321

Mary Elmore, F.R.F.A., associate director of
community affairs and information from 1969 to
1979, also helped people who were disabled.

The Ollies of Spain just come up with a
refuge for disabled adults.

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refuge for disabled adults.
30 years he has been telephone operator, receptionist, editor, author, promoter of the Marianist Apostolate in socioeconomics affairs, and lecturer to the novices of the Society of Mary. He now shares his time and counseling with our groups of blind members in CUSA, corresponding via Braille and tapes. His address is Marianist Novitiate, 4435 E. Patterson Road, Dayton, Ohio 45430.

The Visitation nuns occasionally accept an applicant who is handicapped, but this is done on an individual basis.

Address: Anna Marie Sopko, 176 West 8th Street, Bayonne, New Jersey 07002.

More Disabled Priests and Religious
Rev. Robert J. Ronald, SJ, has been wheelchaired by polio since he was a seminarian. He works more than full time as a missionary and certified rehabilitation counselor. He is a psycho-social and vocational rehabilitation consultant for the Rehabilitation Medicine Department, Veterans General Hospital, in Taipei as well as the founder of Operation De-Handicap, an association to meet the disabled needs. Father Ronald and another Jesuit, Father Shevlin De La Roza, spent nearly all of the year 1975 touring the United States in order to raise funds for the expansion of the association. His address is Ho Ping West Road, Section 2, Lane 98, No 6, Taipei 107, Taiwan, Republic of China.

Father Brian Doran, a young deaf priest, was recently appointed to head the Archdiocese of Los Angeles’ pastoral ministry to some 40,000 disabled persons. Father Doran, who was ordained in 1971, has his office equipped with a teletype phone system. The address of the Archdiocese of Los Angeles is 1531 West 9th Street, Los Angeles, California 90015.

Another young man who is deaf is just beginning his seminary training in the Society of Jesus (Jesuits); his address is Joe Bruce, 188 Beacon Street, Chestnut Hill, Massachusetts 02167.

Brother Patrick Martin, director of the Office for the Handicapped in the Diocese of Connecticut, is legally blind.

ED: The next issue will include the experiences of disabled individuals who have fulfilled their vocations within religions other than the Roman Catholic. We hope our readers will help us reach ministers who are disabled. We would also like information on churches that have been made accessible.

Teaching The Blind To Type
by Daniel J. Tomasek

The typewriter keyboard is Man’s most common interface with communications in the business community and with the world’s growing treasury of computer-born information. Until recently, blindness has been the most formidable disability to be overcome in the learning of the keyboard. For those afflicted with disabilities not involving sight (even aphasia—see Rehabilitation Gazette for ’75, page 46) an arsenal of keyboard training and operating aids is available, but the neophyte blind typist faces a complexity of forty-five or more keys arranged in a pattern intended to impede the performance of all typists.

A backward glance at the history of keyboard designs unravels the riddle of why even computer scientists must converse with their electronic creations from a keyboard layout which could most certainly be improved by an illiterate child dictating keyboard locations at random. In 1873, the Remington Arms Company marketed the first workable typewriter. The designer, C. L. Sholes, found that the gravity-return action of the keys was slower than the finger movements of typists striving for the then inconceivable speed “equal to handwriting.” He decided to slow down the operators to match the performance of the sluggish machine, and produced one of the most con-founded arrangements of keys possible. Sholes’ 19th century “success” plagues high school typing classes and data wizards today in the form of the familiar “QWERTY” (read the third line of your typewriter) keyboard.

A 20th century solution to the anti-learning, anti-speed design was offered by a disciple of that human-efficiency genius, Frank (Cheaper by the Dozen) Gilbreth. A busy stenographer’s fingers travel up to twenty miles a day on a QWERTY keyboard, and Dr. August Dvorak designed a simplified keyboard which reduced that digital journey to one mile for the same workday—the implications of Dvorak’s design for sighted individuals with upper-extremity limitations are obvious. Forty-four years after his development (in 1975), production line manufacture of the “DSK” was begun by Smith-Corona, but as any typist will

Daniel Tomasek, supervisor for Teletype Corporation in Little Rock, Arkansas, returned to college after a “20-year sabatical” and earned his MS in rehabilitation counseling at the University of Central Arkansas in 1976. He plans to work on the Bell System’s Affirmative Action Program for disabled individuals.
 testify, the cumbersome QWERTY is King—even when it compounds the handicaps of its users. The Bell System, world leader in communications, has introduced the DSK at its Western Electric Training Center in a trial-training program, and initial results have been favorable.

Why has a deliberate crippling of skills been endorsed with the manufacture of almost every typing device made in this century? Dvorak said, “One typewriter company president told me he would fight to the death over the prospect of having one typewriter do the work of two,” and he added that business colleges were not pleased by the prospect of teaching typing in nine weeks rather than nine months.

If keyboard design for sighted persons is 100 years behind available technology, the situation for blind typist-trainees has (until recently) lingered in the Iron Age. Although braille-writing accessories have long been available for a broad variety of keyboard devices (see the American Foundation for the Blind International Catalog), the fragile link between the thoughts of the blind typist and her sighted reader has been dependent upon her ability to memorize the intricacies of the keyboard and relate the unseen print and format to their braille counterparts. A blind typist without a braille reproduction device or a print-to-touch converter such as the OPTACON lost the dignity of independence to a sighted proofreader.

Until very recently, the blind candidate for clerical work has been frustrated by the double whammy of keyboard communications: (1) most schools for the blind train typists through sighted teacher-monitors who provide a running, spoken narrative of the student’s efforts, and (2) the learning-and-achievement-busting QWERTY keyboard is in universal use. Of course, the schools are right in their approach. Blind typists will work and compete in a sighted world and avoidance of special training equipment has been imperative.

Today, the media by which the blind learn and use keyboard devices are about to take “one giant step” into the space age. Researchers at the University of British Columbia at Vancouver, Canada, have produced three prototype “talking” typewriters. To the psychologist, the typewriter that instantly “tells” the blind typist which key has been struck represents a profound improvement over the one-to-one, sighted-to-blind teaching technique now used with rare exception. Knowledge of response is a factor known to be critical in fast learning. Generally speaking, the learning of any skill is dependent upon how quickly the results of each effort are made known to the trainee. SPELLEX, the title of the typewriter “talking” attachment, echoes each letter instantaneously as it is printed on an IBM Selectric typewriter. Strike the letter K and the hand-size box next to the typewriter says “kay.” The sounds are specially “compressed” to assure that the audible feedback keeps pace with even a skilled typist. Although the scientists responsible for SPELLEX are using the retarding QWERTY keyboard on their successful prototypes, the conversion of an IBM Selectric to the superior DSK arrangement can be accomplished by any clerical worker in a few minutes at a cost of less than one hundred dollars. The blind typing students’ double whammy is about to be exorcised.

Another bicentennial boon in training aids is the talking calculator, SPEECH PLUS, put into production this February by Tele-Sensory Systems of Palo Alto, California. Its operation is to small calculators what SPELLEX is to typewriters. Now then, if they’ll hook up the typewriter to a computer-dictionary so we can forget about spelling errors, tie the calculator into a metric conversion system, then surely, someone will come up with a way to make the piano keyboard block out sour notes, and then...

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Dvorak, A., There is a better keyboard. National Business Education Quarterly. December '43.
A Compendium of Employment Experiences of 21 More Quadriplegics

The 1975 issue of Rehabilitation Gazette featured the employment experiences of 101 quadriplegics. The response was so enthusiastic that we plan to continue the compendium in every issue. So that the series may be coordinated, the same system of categorizing occupations is being used.

Our quad readers are asked to continue to share their experiences. Just dash off a quick summary, recounting your educational and employment experiences, adding whatever thoughts you think would be helpful to other quads, their parents, and their counselors.

Artists

CARICATURIST. (Quad because of multiple sclerosis.) Enrique Mate, Biarritz 2085, 1916 Buenos Aires, Argentina. "I was born in 1915. After I finished my military service, I worked at general office work. In 1940 I became an important bank official. Previous to my marriage in 1942, I began to feel discomfort in my right foot and arm. In 1943 the neurologist diagnosed my illness as multiple sclerosis. I continued working, using my left hand and not abandoning my vocation as a caricaturist. As MS advanced inexorably, I was pensioned off as disabled in 1950.

"We now had three sons and there began a difficult period for me to adapt to complete immobility. In the necessity of helping the children with their homework, I learned to write with the pencil held fast in my mouth. With the help of friends I obtained work to be done in my home as a proof-reader. A minister of the English Evangelical Church arranged for me to contribute my spare time to reading textbooks to blind students. Almost at the same time my ex-banking companions found a place for me as a caricaturist in their club magazine.

"Soon afterwards the Argentine publishers of the International Association of Painters Without Hands (Vaduz-Lichtenstein) invited me to join the Association on a scholarship. That was in 1960. Since then I have dedicated my life and my strength to painting. The Association, of which I am now a lifetime mem-

Steve Maples, C6-7 quad, medical social worker.
ber, has provided me with sufficient means to maintain my home with dignity and without economic pressures."

WATERCOLORIST. (C-4 quad since an auto accident in 1960.) Stanley L. Obritski, Jr., 75 Augusta Street, Irvington, New Jersey 07111. "After spending three years at the Kessler Institute for Rehabilitation in West Orange, New Jersey, I went home to live with my parents. After a long struggle trying to find a suitable vocation I finally found painting. I studied via mail with the Famous Artists School in Westport, Connecticut, on a scholarship and I attend class once a week at The Yard School of Art in Montclair, New Jersey, on a scholarship. My mother takes me there and picks me up.

"I paint watercolors by holding the brush in my mouth and since September 1975 I have been a student member of the International Association of Mouth and Foot Painting Artists based in Lichtenstein. The Association pays me a monthly stipend of 900 Swiss francs for which they have the right to reproduce my work on greeting and note cards, calendars etc. I submit my work periodically to them for evaluation and hope someday that it will be good enough to earn me a full membership. If this happens my stipend will double and be guaranteed for life. This will help make my future secure and allow me to purchase my own home which will have a permanent studio and art gallery connected.

"I have won several prizes since I started painting and my work is in private collections in seven states and in the Netherlands.

"My hobbies are chess and amateur radio. I play chess over the board, via mail in sanctioned tournaments in the U.S.A. and internationally, and over the radio with my friends up and down the Eastern seaboard on the 40 meter band."

Health Careers

SPEECH PATHOLOGIST, DEPARTMENT DIRECTOR, REHABILITATION HOSPITAL. (C-5 quad since an auto accident in 1964 while in college.) Grant W. Jones, MS, 828 Clifton Drive, NE, Warren, Ohio 44484. Grant received his BA in speech forensics in 1969 from Linfield College (very inaccessible). After marrying that summer, he began working toward an MS in speech pathology at Oregon College of Education. He graduated summa cum laude and was honored with a "Citation for Commendable Achievement" from the Oregon Governor’s Committee on Employment of the Handicapped. After working on the staff at Hillside Hospital in Warren, Ohio, for a year he passed his exam for the Certificate of Clinical Competence given by the American Speech and Hearing Association in 1972. In 1975 he was made Director of Speech Pathology. He is an active member of the Ohio Governor’s Subcommittee for Barrier-Free Architecture and was instrumental in establishing a county chapter. He is listed in Outstanding Young Men of America. He and his wife, Jay, recently adopted a 2-year-old girl.

CLINICAL PSYCHOLOGIST. (Polio quad since 1955 at age 11.) Caryl Halper Smith, PhD, 7610 Westwind Lane, Houston, Texas 77071. Tutored at home through junior and senior high schools, Caryl attended Brooklyn College and graduated with a Woodrow Wilson Fellowship to attend graduate school. "Stanford University accepted my application for graduate work in psychology, offered me a place to live and the opportunity to work with a great man, Dr. William Dement, a famous researcher on problems of sleep and dreaming. (Volume XIII, pages 24-26). . . . I received my doctorate in psychology in 1973. For the next three years, I worked as Assistant Professor of Psychology at a university in Chicago. I am married to a psychiatrist and we have a year-old daughter. We have most recently moved to Houston, Texas, where I will continue full-time employment combining my research and clinical interests in psychology. I expect eventually to develop a private clinical practice as well."

CHILD PSYCHIATRIST. (Polio quad since 1950.) Dr. Ross Williams, 2 Frances Street, Randwick 2031, New South Wales, Australia. "I was disabled by polio while in a country general practice. After three years of rehabilitation and through the help of a good many friends and colleagues, I found my way into child psychiatry. . . . Back in the early 1950’s, I had a good deal to do with establishing a rehabilitation society in Sydney. . . . My own life these days is divided between mornings spent in the Department of Child & Family Psychiatry at the Royal Alexandra Hospital for Children in Camperdown, Sydney, and a certain amount of work in private practice in the afternoons at my own home. I have found that the most important special aid which people like us need comes through the interest and help of family and friends in which respect I have been extremely fortunate."

COMMUNITY RELATIONS, HOSPITAL. (Polio quad since 1962, at age 18.) Ismael R. Chavez, 183 Sherman Avenue, New Haven, Connecticut 06511. "I am a Cuban, I leave my country in 1960 with my family to live in Venezuela. There the polio struck me. After 1 1/2 years in the hospital and rehab center in Caracas we move to San Juan, Puerto Rico. In 1964 we move to New Haven, Connecticut. I attended Candler College, Southern Connecticut State College, and I have my BS from La Salle University. My first job was at Community Progress, Inc., the anti-poverty agency in the city; my work was as a community and employment counselor.

"In 1968 I was hired as a community relations officer at Yale-New Haven Hospital. My duties are pa-
tient advocate, patient relations, and translations for the Spanish patients. I work an average of 8-10 hours a day, 5 to 7 days a week. I am also active in several hospital committees.

"My main interest is to abolish the architectural barriers. As chairman of the New Haven County A.B. Committee, I do a lot of traveling, meetings, speeches, in the city and state. . . . I live with my parents and my dog. My brother and two great friends are the drivers of my van for work, meetings, and vacations. . . . We must all get involved. We must go out and demand and try. But we must be involved."

Knowledge and Information Industry
LEGAL RESEARCHER. (Cerebral palseid quad.) Mick Joyce, Midwest Information Center for Equality of the Handicapped, CA 106, Southwest State University, Marshall, Minnesota 56258. "My parents were told that I was ‘very retarded’ and should be ‘put away’ in an institution. Fortunately, they and my three older sisters didn’t believe it. I attended a special class in the public schools until the fifth grade when I enrolled at the Crippled Children’s Hospital and Home in Sioux Falls, South Dakota, and stayed there until I finished high school. After trying college correspondence courses, I came to Southwest State. I majored in creative writing and social science. During college I began gathering information on laws relating to the handicapped. After graduation I obtained a Northwest Area Foundation grant to compile and catalog federal and state (Minnesota and the surrounding states) laws and court cases, to publish a guidebook in early 1977, and to establish a center here at SSU to provide information relating to the civil rights of the handicapped individual."

Law and the Ministry
ATTORNEY/ASSISTANT PROFESSOR, (Incomplete quadriplegic since 1963.) Jack Achtenberg: "I received my AB from the University of California Berkeley, JD from Loyola Law School in 1969, LLM from Berkeley, MA from UCLA, and I am presently a candidate for my JSD from Berkeley. My special field of interest is in the rights of the physically and developmentally disabled. I have lectured and written extensively on the subject. I am president of the A. Milton Miller Memorial Foundation, Western Center on Law and the Handicapped. I am assistant professor and chairman of the contracts department at the University of San Fernando Valley College of Law. I recently received a commission from the American Civil Liberties Union to produce a ‘rights handbook’ for the disabled . . . The physically disabled are presently second-class citizens. They are rebelling against the restraint imposed upon them by society . . . The ‘Crip Lib Movement’ is now expanding from the halls of legislature to the steps of the courthouse . . . Persons with long-term disabilities are not asking to be taken care of. They are asking for their rights to be a part of the mainstream of society. This is not a medical question or a psychological question but rather a question of effective enforcement of civil rights. These rights must be enforced not simply because the integration of the disabled is good social policy but because the laws of the various states and the Constitution of the United States require that they be enforced."

ED: We are deeply grieved by Jack's untimely death in mid-september 1976 when he was killed by a hit and run driver near his home. Ironically, he was riding in his wheelchair in the street because the sidewalks are not accessible.

Rehabilitation Careers
SOCIAL WORKER, (C-5 quad since 1967 at age 21.) Dick Goodwin, 4402 McPherson, St. Louis, Missouri 63108, "My life as a quad began to take direction in 1969 when I started school at Southern Illinois University at Edwardsville (a model campus in terms of accessibility). I finished my BA in 1973 and went right into graduate school in sociology with the help of a teaching assistantship. I finished my graduate classes in 1975 and I am now finishing my thesis. In March of 1976, with the help of the ‘Queen of the Crips,’ Gini Laurie, I began working at Goodwill Industries of St. Louis as a social worker. This meant either moving to St. Louis or driving over 60 miles round trip every day; I moved. With the help of friends I found an apartment close to work, and then I ran ads to find two attendants. I had a good number of responses. The arrangements that I offered was that I would pay the total rent and the basic telephone bill in exchange for the assistance I needed, and we would split the food bill. Beyond the personal assistance, their responsibilities are cooking and keeping the apartment relatively clean. All is well."

EMPLOYMENT COUNSELOR, (Polio quad since 1959.) Lynne Recagno Graebner, 2086 Kellogg Way, Rancho Cordova, California 95670. "I was disabled at 16 and finished high school by tutor and limited attendance. While at Sacramento State College, I lived in the dormitory with the help of student attendants. After 6 years, I earned an MA degree in psychology. Since 1968 I have been an Employment Counselor in the California State Employment Development Department in Sacramento. I use sliding arm supports and hand braces to write, type, and operate my motorized wheelchair. I work at a specially designed electric turntable desk top and use a push button dial telephone with a headset. I take the bus to work. Sacramento Regional Transit has a CAREFUL COACH with a lift for wheelchair passengers at the regular fare. I have a Chevvyvan with a lift for private use and field work. Counseling people with job related problems
and conducting job search groups is challenging work. My husband, my 4-year-old daughter, and my job all make up a very rewarding life.”

MEDICAL SOCIAL WORKER. (C6-7 quad since 1966, when in the eleventh grade.) Steve Maples, 125 South 57th Street, Birmingham, Alabama 35212. “I have an Associate Degree in radio and television broadcasting from Jefferson State Junior College and a BS degree in social welfare from the University of Alabama. I am also a member of the consumer advisory board for the South East region of Rehabilitation Services Administration.

“My wife, Jane, is a teacher for the John Simpson Cerebral Palsy Center in Birmingham. Jane and I and our two dogs enjoy getting out in the woods camping or just picnicking with friends. We also enjoy traveling. My main hobby is photography and photofinishing. I have my own darkroom in my house and do all of my processing.

“I work for Spain Rehabilitation Center in Birmingham. I work with spinal cord injured people in personal counseling, group therapy, and sexual counseling, along with other duties of a social worker.”

COUNSELOR. (Quad because of dermatomyositis.) Victoria Conley, 2230 Marquette, Alton, Illinois 62002. “I’ve been working for nine months at Specialized Services, Inc., a workshop for the disabled. At 26 I received my Masters in human services and am now a counselor. My disability, dermatomyositis, a bone and muscle disorder, keeps me in a chair, but has not hindered my ability to work or to drive a specially equipped van. My advice to anyone is to believe you have the same rights as any human being and therefore have the same responsibility to fulfill those rights.”

Sales, Home-Based

OWNER, BROKERAGE FIRM. (Respiratory polio quad since age 19, when a freshman in college.) Thomas W. Rogers, 1001-25th Avenue Court, Moline, Illinois 61265. “My first productive activity was a mail order business which never rose beyond the launching pad. . . . I took a course in income tax from the local college and read financial publications extensively. While helping friends with their income tax returns I was offered a job by a nationwide underwriter of mutual funds on a commission basis. Business grew slowly. After six lean years, I expanded into a wider range of investment securities and opened up an office at home. I managed to clear the regulatory agencies and pass all the necessary tests to establish my brokerage firm in 1966.

“With the help of three part-time secretaries, we have managed to stay afloat and survive the vicissitudes of the market. The securities business is a telephone business and involves the dissemination, interpretation, and evaluation of information. It is a fascinating, fast-moving business which crowds my day. During the morning, I am on the phone or doing required reading. Actual office hours are from 1 to 10 pm when I am up and in the wheelchair.”

OWNER, GIFT SHOP. (Respiratory polio quad since 1952.) Jean Ryan, 484 Country School Road, Dundee, Illinois 60118. “I was fortunate to own the little country school building from which I graduated. Six years after polio, the Country School Gift Shop was opened as an outlet for items made by the disabled. It is adjacent to my home and under my direction, attended by ladies who also care for me. For the past eight years, friends have come twice a week to bathe me, wash my hair, etc.

“I have a 1974 seventeen foot Handivan with a ramp especially built by a neighbor and driven by my children and friends. Our three children are grown and my husband and I were divorced in 1974.

“I continue to use my cuirass, pneumo belt, or positive pressure machine. My arms are completely paralyzed, but I provide for myself and regulate my own life with daily outside help. Very much of this help is the T.L.C. of devoted friends.”

Sales, Office-Based

STOCK BROKER. (C4-5 quad since 1946, while in high school.) Robert H. Winner, 110 Riverside Drive, New York 10024. “While I was floundering for three or four years after graduation from college, a friend suggested the securities field. In 1957, after a year of personal study and observing the market from the sidelines, I spent six months as an observer in a small brokerage firm, then took the exam for Registered Representative. It was very slow in the beginning (broken by too frequent illness) but by the mid 1960’s I was quite successful and have suffered the much publicized woes of the industry since 1969. . . . It was easy to build in the 50’s and 60’s, but there are fewer opportunities now and in today’s job market a quad would need some accounts to start with.”

Services, Home-Based

BOOKKEEPING AND TAX SERVICE. (C4-5 quad since a diving accident in 1957.) Larry Cunningham, 4822 East Olive, Fresno, California 93727. “I started my bookkeeping and tax service in 1957 after taking correspondence courses. My mother is a bookkeeper and did a lot of the work in the first couple of years. . . . It took several years to become independent, I lacked experience and did not promote business as rapidly as I could have. In other words, with what I know now I could have done better sooner. . . . Now my business is doing well. I have two employees—a full-time bookkeeper and a secretary. I do most of the interviewing and personal contact with the clients. We use a computer service for the bookkeeping and
the income tax returns. We also have a typing and a notary service. . . . I didn't expect to do as well as I'm doing now.

Letter-writing for Small Businessmen. (C5-6 quad since 1956.) John M. Williams, 5843 Vandale, Wichita, Kansas 67217. "The experiences of others in the Gazette built a fire under me to go back to college in 1964 at the age of 31. . . . After many failures at home business, I've developed a letter-writing business for small businessmen. I'm paid a commission from the sales generated from these letters. As an old quad, I'll urge you to keep at it. Never give in to the 'NO's' that you get every place. Don't quit and be satisfied to watch TV until you die."

Teachers

Professor, College. (Polio quad since 1950.) James A. Graaskamp, Ph.D., 202 Breese Terrace, Madison, Wisconsin 53705. Education, post-disability: AB, Rollins College; MBA, Marquette University, and PhD in urban land economics, University of Wisconsin. "I am presently chairman, real estate and urban land economics. I carry a full range of faculty duties and travel extensively. I operate independently as a teacher and a business man (real estate) with the aid of three students who live in my home, a cleaning lady for most household chores, and three student secretaries." Jim's hobby is deep sea fishing. He uses an electric reel which he operates with a mouthstick.

Teacher, Junior College. (Polio quad since childhood.) Ellen Fay Peak, 625 26th Avenue NW, Birmingham, Alabama 35215. "Like other polio quads, I have found 'making it' enormously hard—not only for me but for those who have had to help me and to watch me do it. But looking back, I realize that I am successful by most anyone's standards: After years of only hit-or-miss tutoring, I earned my BA Phi Beta Kappa; I earned my MA while working as an editorial assistant with a national magazine; I then taught French, Spanish, and English in a public high school; and I now teach English, including creative writing, at Jefferson State Junior College. Along the way, I have enjoyed using my amateur radio operator's license (W4PXO); have had a number of my own pieces published; have served as faculty advisor for the campus student newspaper and literary magazine; have co-authored with a colleague Supermarket Merchandising and Management, a major textbook about the food industry, that Prentice-Hall Publishers is now advertising on campuses across the country; and have enjoyed the home and automobile that my mother and I share as a result of my career. Although I have constantly in mind how narrow is the edge between my life and one of stringing beads, I seldom ever think now about my first Rehab 'counselor' who advised me to accept the fact that stringing beads was about the best I could hope to do."

Teacher, High School. (C5-6 quad since 1971.) Matthew J. Green, 1221 Tahiti Drive, Crestwood, Missouri 63126. Injured in the spring, Matt was able to return to his teaching position in September of the same year, on a part-time basis. "I was determined to get back to work as soon as possible and with the help of many good friends I was able to resume my career quickly."

Matt is now teaching full-time in a public high school. He drives to work in a specially equipped van. Since his injury, he completed his MS ED, was appointed chairman of the Foreign Language Department at his school, and served two years as the chief negotiator and spokesman for the local teachers association. He is currently working on his MAT degree.

Writers

Editor, Newspaper (Quad because of a lifelong neurological disableness.) C. J. Lampos, Achievement, 925 Northeast 122nd Street, North Miami, Florida 33161. A student of Byzantine culture who speaks three languages, Connie is the doyen of editorial writers who are disabled. "They call me the grandfather of today's generation of militants. . . . My life's work has been fighting discrimination." His rebellious but constructive spirit pervades the monthly newspaper, Achievement, which he founded nine years ago to fight for the rights of the disabled. The 16 page tabloid is now an effective voice of the disabled with a nationwide circulation of 16,000.

Profile

John H. Parker—Attorney at Law

"There were times when I wanted to quit. I would think of the five steps I had to be pulled up and just want to stay home," remembers John Parker of his years at law school. He continued to be pulled up the steps each day, however, and now makes a living as a lawyer with a general practice.

John had finished his undergraduate study at Denison University a month before the diving accident that
made him a C-5 quad. The choice of a graduate school was challenging for John because it meant deciding between two ways of life. The University of Illinois Law School was wheelchair accessible and the law school near his Ohio home was not. "I could either stay in my own social atmosphere and have the support of family and friends but a hard time with the law school near my time I made was a sophomore at Wayne State. Carol continued to work as an occupational therapist for four or five years after their marriage until John was through school and earning enough to be their sole support. Over the next years they adopted two babies. Their boy is now ten years old and their girl is seven. John feels there are few differences between a father who is disabled and one who is able-bodied. He has to use words instead of actions to discipline and there are a few more worries and missed balls when he throws a baseball with his son.

John's law office is in his home. He thinks case research is the most difficult part of his work. Then he "closes all the doors, shuts off the phone, and starts to search out the facts."

John is assisted with his morning care by his wife. His experiences with attendants have been largely unpleasant with the exception of his long-time weekend helper. Agencies he has found to be of little help, leading him to the conclusion that hospitals are the best places to find attendants. If a person needing an attendant does not make regular visits to a hospital for therapy or checkups, John suggests talking to a rehabilitation counselor for referrals of possible attendants.

For about ten years John served as a councilman in his community. Active in many of the decisions and policymaking that shaped the growth of his city, he strongly feels that everyone should serve a couple of years in public office. "You will learn what is involved in decisions, how they are made, by whom, and how much they cost. It's a real education." While still quietly active in community affairs, John has determined that his law practice deserved more time and, therefore, decided to leave local politics to others.

One of the less public and publicized ways that John now helps others is counseling families with spinal injury members. He waits for six or eight months until the doctors know whether the disability is permanent or not, and then contacts the family. He offers to share his experience and information with them so they will realize there is still hope for a full life and learn some of the ways to attain it. "I wish someone had done it for my family," says John. "I was an only child and my parents were worried sick. They were in the dark about my prospects for a normal life and didn't know where to turn for help. Luckily, they chose the right place to send me, the Institute for Physical Medicine and Rehabilitation in New York City. There I saw many other young people in wheelchairs and many who had been in them for several years. I began to think that maybe life wasn't hopeless after all. It's much easier to solve problems when you can compare with others in the same condition. It took me a while to get my head back on and I want to help hasten that process for others.

"If it were possible, everyone should go to law school for a couple of years, whether they want to be a lawyer or not. It unlocks a lot of doors, teaches you the way our society works, and grants a lot of opportunities. Just two years would do it."

John is a member of the Exchange Club, the Junior Chamber of Commerce, two fraternities, and the Cleveland and Ohio Bar Associations.

Address: John H. Parker, 31500 Lake Road, Bay Village, Ohio 44140.


Schneider, Katherine, Department of Psychology, University of Arkansas at Little Rock. Personal telephone conversation of December 8, 1975 and other conversations. Dr. Schneider is a psychologist, a typist, and she is blind.
Tomasek, D. J. Assessment of audible feedback keyboard in training of blind typists. Research proposal submitted to Dr. T. Smith, University of Central Arkansas, 1975.
Sports and Recreation

Tennis

_A Therapeutic Sport for All Levels of Disability_

Jack Kenney, an outstanding tennis player and a talented and gifted teacher, has been operating his well-known Tamarack Tennis Camp in New Hampshire for many years. During recent winters he has been volunteering his teaching talents, working with disabled and retarded children and young adults. He has traveled all over the New England area at his own expense, demonstrating to recreational and physical therapists the benefits to the disabled when tennis is included in the regular exercises.

He has worked out ingenious methods of teaching, such as using fleece balls or balloons or holding a tennis ball by Velcro to a string suspended over the lap of a person in a wheelchair who can tap it with a forefinger or mouthstick. He has mimeographed step-by-step lists of exercises and games that cover every type of tennis that can be played singly or in groups, starting with the lowest-ability groups and working through to whatever level an individual can reach.

One of the first rehabilitation centers to use his tennis teaching methods is the Crotched Mountain Center, a comprehensive rehabilitation center located at Greenfield, New Hampshire. After several years of experience it is very enthusiastic about the benefits of his tennis program to its disabled children and adults. William W. Roots, director, Public Affairs, at Crotched Mountain Center responded enthusiastically to the Gazette's inquiry about Jack's program there. The following are excerpts from a recent letter from Mr. Roots:

"Jack is a devoted gentleman who goes about his work expecting no accolade for the long hours he devotes."

"Here at Crotched Mountain, as at many other facilities geared to physical restorative care for the handicapped, few and far between are the situations where any youngster actually looks forward to an exercise period, but through the efforts of Jack Kenney, assisted by our own physical education staff, tennis has become an exercise period which is anticipated with joy rather than dreaded as a routine."

"Nearly every one of the 170 school aged handicapped children at Crotched Mountain participates in one manner or another in the tennis program established by Jack Kenney."

"Most important is the degree of improvement we have noticed in numerous cases with respect to greater body utilization and range of motion experi-
can be substituted in the rehabilitation process for a
definite, firm and positive success experience and a
successful experience is exactly what has come from
the tennis program here at Crotched Mountain."
Jack's success with teaching tennis to the disabled
and the retarded has made him a "crusader" and he
will welcome inquiries from therapists and share his
mimeographed exercises. He is also interested in
knowing of the experiences of others with tennis as
a therapeutic exercise.
Address: Jack Kenney, Tamarack Tennis Camp,
Franconia, New Hampshire 03580. Phone: 603-823-
5656.

Skiing by a T12-L1 Para
by David Lendle

Skiing was a big surprise to me! It all started when
a girl I met at the hospital in Rochester who is a T12-
L1 para was talking about a guy who teaches handi-
capped skiing. Before I knew what was happening
she called a friend of hers who works at his ski resort
and everything snowballed so I was at the resort in
Colorado four days later.
The instructor's name is Ed Lucks, a really amazing
person. He's been teaching handicapped for quite a
few years. He invented the outriggers, which are
Canadian crutches with small skis attached.

I was skiing down the smallest hill the first day and
went half way up the mountain the last. What a fan-
tastic feeling! Ed and one other person, sometimes
his wife, would ski each on a side with a pole between
for me to hang on to. This was to get me used to the
skis and help me until I found my balance position.
The balance was the biggest problem, but Ed had all
kinds of ideas. We had the front of the skis clamped
together and a rope around my ankles. This kept me
in a perfect parallel position. I graduated off the pole
the third day, highest in my class. I then used their
thumbs to give me the little balance still needed. I
also used a small brace on my left leg (the stronger
one) to keep it straighter. We would try the outriggers
intermittently, but I hadn't got the balance down well
enough.
All this time we were working on the smallest hill
(Fanny Hill—well named, believe me!). The last day,
Ed asked if I wanted to go up half way. Wow! He sure
didn't have to ask twice. So up we went and up and
up the mountain. It was really a breathtaking look at
the scenery. We took all the intermediate slopes. We
fell about three times and almost hit a tree once, but
otherwise had a safe run down.

Sounds like a fairy tale, right? Would you believe
it was all free! Everything except my flight and the
lodging with my friends was picked up by the Aspen
Ski Corporation.

Address: David Lendle, RFD 3, New Auburn, Wis-
consin 54757.

Books

Please Know Me As I Am
by Donna McGwinn

Eleven suggestions for sensitizing children to the
feelings of those with special needs are described. For
instance, to better understand those who cannot see,
certain children were blindfolded and paired off with
others who were not. Each of the pair performed cer-
tain activities together and then both shared their feel-
ings with each other and the class.
These experiments are imaginative, positive, effec-
tive and well described in this book. Appendixes in-
clude the names and addresses of resource agencies,
an annotated bibliography of books for children
through the eighth grade which reinforce learning and
understanding of those with special needs, and list-
ings of pamphlets and audio-visual aids.

Trapped

By Betty Banister, Western Producer Prairie Books,
446-478 Second Avenue, North Saskatoon, Sas-
katchewan, Canada. 1975. Paperback. This story is
told in 100 pages and a somewhat staccato style that intensifies the emotion and flow of action. The author's effectiveness in recounting the first days and weeks after getting polio could be felt by this reader in shivers of remembrance. Even the avoidance of looking at and coping with one's most personal problems, an avoidance we all experience at some time or another, is described. In this case the problem is the uncertain, declining state of the author's marriage.

Betty Banister was a young wife and mother whose life was radically changed by disability. In time she worked her way out of the iron lung and still spends much of her time in a chest respirator and rocking bed. Limited finances prevented her from leaving the hospital where she has lived since the onset of polio in 1953. What this confinement did to Betty and her family affirms the wisdom of present practices of helping the disabled leave hospitals and other institutions and establish normal lives.

Betty discusses her selfishness during the early years of her disability and the depression that kept her from wanting to do anything except lie in bed. With the help of her family and hospital staff she began to take more interest in herself and life, attaining acceptance of her limitations and recognition of the many joys still possible.

Uplift

What People Themselves Can Do. By the United States Jaycees Foundation. Olympus Publishing Company, 9327 East Ninth Street South, Salt Lake City, Utah 84105. 1974. This is a super book. It contains 458 pages of stories about disadvantaged people who have helped themselves and others to improve their lives. The foreword is by M. Carl Holman, president of the National Urban Coalition. He states, "For the first time, people involved in successful self-help efforts are sharing their experiences on a large scale to encourage others to follow in their footsteps and to help others to avoid their mistakes."

Areas covered are economic development, education, employment opportunity, housing, social services, health services, offender rehabilitation and community organization. There are from 10-15 stories in each section. They are short, from 4-6 pages, and easily read capsules about people organizing to fix up their homes, provide community health services, work themselves back into society after illness or imprisonment, channel redirected energy into acceptable, profitable actions, and help themselves when society has given up on them. A people-packed, helpful, inspiring compilation.

Light a Candle with Multiple Sclerosis

By Herbert Cochran, 513 9th Avenue, Coralville, Iowa 52241. 1975. "If every man lights a candle, a million lights shall glow, and there shall be no darkness," is a Chinese saying by which Cochran tries to live. His autobiography is full of facts about his life, philosophical musings, business advice, family pictures, and some information on multiple sclerosis, a disease which he has had since 1936. The book is self-edited, printed, and distributed.

Silent Victory

By Carmen McBride, Nelson-Hall Co., 325 West Jackson Boulevard, Chicago, Illinois 60606. 1969. $5.95. For those who have had or whose loved ones have had aphasia, there is no encouragement or help quite as meaningful as that given by someone who has been through a similar experience. This is the reason Ben and Carmen McBride decided to write a book. When Ben had a stroke and a resulting loss of speech in 1956, there were few other than very technical books to refer to for help.

Carmen finally wrote the book by herself. In the six years between the onset of Ben's stroke and his death either there had been no opportunity or he had not enough energy to help her. It is a personal story full of information about interpersonal daily living for and with the aphasic, and one of the most tender, moving love stories I have ever read. Ben and Carmen knew each other from childhood, were married almost 50 years, and when Carmen states that their communication reached its deepest level after Ben's stroke, the reader knows this couple had the epitome of closeness. Whether or not your life has been touched directly or indirectly by aphasia, this is a beautiful story.

The many ways a person can assist a loved one to readjust to life without speech are woven into the story. There is also an appendix with hundreds of words and the different spellings Ben made of them.

So Your Child Has Cerebral Palsy

By Gil S. Joel, University of New Mexico Press, Albuquerque, New Mexico. 1975. No mere review can do justice to the excellence of this primer for parents of cerebral palsied children. It is equally pertinent to all children with or without disability. A master of easily read, succinct prose, Joel packs all of his best advice into 53 pages. His knowledge came from four decades of living with a severe form of CP and his acquaintance with many others with the same disorder.

Joel touches on all phases of development from birth to adulthood, employment, marriage, and parenthood. His main lessons spin off from his beliefs that the duty of parents is to make themselves unnecessary and life is to be enjoyed. In his list of priorities for CP's, No. 1 is, "He must have a deep and abiding faith in his own value as a person and be fully aware of his own sexuality." He writes of the lifelong need for physical contact and affection and how regularly the disabled are deprived of them. Stroking and cuddling should be part of their introduction to life and the expectation of its continuance in marriage part of their adolescence and maturity.
New Light of Hope

By Bill Kiser, Keats Publishing Co., 212 Elm Street, New Canaan, Connecticut 06840. 1974. $7.95. Bill Kiser has experienced all the frustration, rejection, humiliation and sense of worthlessness that are part of having cerebral palsy. His autobiography deals frankly and personally with the problems and people he has encountered. He anticipates that “will probably infuriate seventy-five per cent of the people who have worked with me,” and he may well be right for it is an angry book.

Kiser’s anger finds positive outlets, however, such as this fine book with which thousands of people will be able to identify and the amazing improvement in physical and emotional control that many proclaimed impossible. Relentless struggle characterizes much of his life, but he also has many spectacular successes that prove his belief that “there is in each of us a history and destiny which need not be determined solely by our condition.”

A Home Is Not a Home

By G. Janet Tulloch, Seabury Press, 815 Second Avenue, New York, New York 10017. 1975. $6.95. The subtitle of this book is “life within a nursing home.” It is autobiographical fiction by a woman in her mid-forties who is disabled by cerebral palsy. Tulloch has lived in a nursing home for ten years and her perception, sensitivity, and excellent writing combine into a vivid, inclusive portrait of daily life in an institution populated mainly by the aged and ill. The foreword is written by Senator Charles H. Percy of Illinois, who calls this a “disturbing book.”

Exploitation of patients and possessions, staff and volunteers’ inability or unwillingness to relate to patients as people, the atmosphere of impending and living death—no aspect of nursing home living is left out. Although the author adjusts well to this environment and continues to live an active life outside and produce a book inside, the reader may wonder why an alternative living arrangement was not chosen by the author/main character. The reasoning appears to be that the alternatives “... involved the same degree of dependency on a different group of people.” A deeper reason might be found in the closing sentence, where the main character reflects on the several-times-emptied wine glass of the senile mother of friends left after a Christmas gathering, “After all, Granny’s cup did belong to them all.”

The aging process is our common denouement and Tulloch shows that each deals with it in a different way, some miserably, some triumphantly.

Putting the Ill At Ease

By Evelyn Wilde Mayerson, Ed.D., Harper & Row, Publishers, Inc., 2350 Virginia Avenue, Hagerstown, Maryland 21740. 1975. $9.95. Although written for medical personnel, this book can be read with benefit and enjoyment by anyone. It focuses on communication between the physician and patient, describing the patient’s feelings in different states of illness or incapacities and how the physician can read and respond, both verbally and non-verbally, to those feelings for optimal effect. As most of us or our loved ones have been “patients” at one time or another, we learn a lot about ourselves and all human beings.

Mayerson, who is associate professor of psychiatry at Temple University School of Medicine, writes of the art of medicine, “the compassionate part of the patient-physician contract.” The sources of quotes to introduce her chapters range from T. S. Eliot to Shakespeare, a wide array analogous to the wide scope of Mayerson’s human understanding. I found the chapter on the elderly patient particularly moving and helpful.

It might be a good idea for readers to give this book to their family physicians for Christmas. That way it would be a gift to ourselves too.

Friends Around the World


Ich bin 39 Jahre alt, habe ein Auto und führe meinen Haushalt alleine.

Ich beantworte sofort jeder Brief in Englischer Sprache und würde mich über viele interessenten freuen.” Rosemarie Hessler, D 6000 Frankfurt/M-50, Jasperstrasse 87, West Germany.

“I am a youth professing The Christian Faith. I am also a handicap having both my lower limbs affected with poliomyelitis right from the age of 3, at present I am aged 23. Last year I completed my studies, I have passed the BA (Hons) and LLB exams and am now employed in a local private firm for a meager salary. . . . In order to overcome the public transport difficulty I have been forced to purchase a 3-wheeler cab and I have taken a loan and am paying an exorbitant interest of 16½% to the local bank. In the light of the afore, I earnestly pray if any association of han-
"I have a magic, electric and electronic typewriter from England." Vera Stadler, Budapest 23, 9 F 14, Hungary.

disabled could assist me financially in whatever small measure as a sympathetic gesture towards a genuine and deserving cause." William S. Rebello, 146/Malbat, Margao 40361, Goa, India.

"I was diagnosed as having Severe Poliomyelitis Scoliosis with collapsing spine in 1957 when I was two years old. I stayed in a Rehabilitation Center for two years and now I'm living with my parents and sister. I attended classes in school through junior high school. I have been taking English courses and studying painting, I paint pictures and porcelain pieces and sell them at home. I collect stamps and postcards. I enjoy music, reading and going to the movies. I have a Volkswagen bus but I need someone to drive for me. I would like a motorized wheelchair but the Brazilian factories don't make them and to import one is very expensive. . . . I can't find words to tell you how good the Rehabilitation Gazette is. You can find everything that can interest you in it. I would like to translate the articles that can be adapted to Brazil into Portuguese and be its representative here for I have been working to help disabled people in Brazil." Marisa do Nascimento Paro, Rua João Ramalho, 145, apto 102, Perdizes - 05008 - São Paulo - São Paulo - Brazil.

"In December 1975 I went to Hungary to visit my girl friend with whom I have been corresponding for three years. She has a 15 year old son. On January 20 we were married in Budapest. . . . A Gazette friend, Vera Stadler, had an important role in our marriage. When my attendant had to return to Houston on January 15th, I had to find someone to help for an additional week so the wedding could take place in Budapest instead of in Houston at a later date. I went to visit Vera, Geza, and others at Baba Ut and when Vera found what my problem was she went to work and found a young man who works there part-time to help me out. Vera and others deserve all the credit for making my visit and especially our getting married in Budapest possible." Phil Clarke, 2550 North Loop West, Suite 101, Houston, Texas 77018.

"The situation here has changed so much in the last few years. Inflation caused many of the residences for the disabled to close; now everyone is preoccupied with the new dollar/peso ratio. . . . I have rented a larger house. I have good aides and can take a few disabled men or women as residents. Ken's residence for men, La Morada, is still going strong. . . . Asociación de Lisiados de Jalisco, A.C., a young group with a spirit of independence, is growing. They print a newsletter and they have just raffled off a car. With the proceeds they bought a 6-wheel-chair-passenger van to transport their wheelchair members to and from work. . . . Padre Gallego from Spain is in Mexico City trying to establish the Fraternidad Catolica De Enfermos in Mexico." Eileen Van Albert, Apdo 5-208, Guadalajara, Jalisco, Mexico.

"I have multiple sclerosis. I would like to read more of the personal articles by MS patients that were in the '75 issue of the Gazette. Dick Farr's article was gratifying. I said to myself, I'm not alone. I chuckled upon reading Selma Sack's article. How about implementing a pen pal program for MS patients?" William Ferrer, 350 Prospect, Mamaroneck, New York 10543.

The GAZETTE's new international correspondent, Marisa do Nascimento Paro of Brazil, is planning to translate the GAZETTE into Portuguese.
I want to write to men 35 to 45 years of age in the USA and foreign countries. I can speak Romanian, but I can only read and write in English. I am 35 years old, 5'2" tall, and weigh 110 pounds. I like to be outside in the fresh air and sun. Some of my interests are writing letters, watching TV, and bowling. I have the adult type of muscular dystrophy and I am dependent on a wheelchair. I had ostomy surgery for urine and would like to hear from readers about how to attach the stoma ring.” Betty Jean Teth, 111 Third Avenue, Roebling, New Jersey 08554.

I would like to find more people to correspond with, especially others similar to myself (born without arms or legs but wear artificial limbs). I now have an Associate Degree in mental health. While I look for a job, I am painting and writing. I wrote a short story that was published in Exceptional Parents magazine.” Terry Haffner, 4600 Dor arrow Drive, Fort Wayne, Indiana 46825.

I became 100% disabled overnight in January 1974 due to a complex nerve and muscle problem, coupled with Parkinson’s and diabetes. . . . I am 53 years of age and have been an avid camper for many years. Thru the 1974 Rehabilitation Gazette and a camping magazine I located a club for handicapped campers, the Handicapped Travel Club, Inc. It is an utterly fantastic organization. The friendship, good will, and assistance are the greatest. It has brought new meaning to my life, especially in the field of outdoor recreation and camping therapy, by overcoming problems while traveling. I am now Illinois director of this national club and I urge other disabled to join the HTC! Hugh J. (Fritz) Saynor, Sr., PO Box 47, Genoa, Illinois 60135.

“I would like to correspond with others who have cerebral palsy, both men and women. I walk on crutches, I am 22 years old. I work at NASA Johnson Space Center in Houston. My interests are reading, music of all kinds, embroidery, and anything I can do to help the handicapped.” Connie M. Moore, 308 West Allendale, Pasadena, Texas 77502.

“I would like to introduce our organization, Handicapped Aid Program (HAP), which was formed in 1972 to help disabled persons in the hobby of shortwave listening (SWL). HAP provides the following free services for its disabled members: equipment loans, membership in a SWL club, a HAP pal to assist, and taped bulletins for blind members. Many shortwave listeners progress into amateur radio and others into citizens band. I shall be glad to answer questions.” Lawrence I. Cotarin, 8041 North Hamlin, Skokie Illinois 60076.

The September 1976 issue of England’s Spinal Injuries Association Newsletter has the following item: “There is an offer of a free service for disabled people from International Correspondence Service, PO Box 10, Matlock, Derbyshire, England.”

“I’m a teacher now. My life is quite normal though my right leg is paralyzed. I would like to ask if anyone knows of some new gadgets in the U.S.A. I mean an electronic or electric prosthesis which works on the muscles of the leg.” Danillo LisclandrI, Via Corridoni 22, Milano, Italy.

“Several years ago I had a suprapubic cystostomy. Finally, I learned to keep a silicone-Elastomer-coated catheter in for almost a year and stay free of infection. I have a way of cleaning out the urine every week or ten days. I never irrigate the bladder. My urologist sanctioned what I have been doing to keep the catheter clean. . . . If anyone has questions I'll try to answer them. . . . I have had multiple sclerosis for 30 years.” Rev. Homer L. Harris, 5091 Clayridge Drive, Apt. 215, St. Louis, Missouri 63129.

“If anyone knows of used electric wheelchairs or electric hospital beds, I would appreciate their being channeled my way. I am a paraplegic of long standing (sitting).” R. E. Patterson, 2309 Langford Avenue, Modesto, California 95350.

“Friendship’s Door is a pen pal club in which disabled persons can either write letters or tape cassettes to one another. If you are interested, please write.” Maxine Gabe, 2671 Emory Drive East, Apt. L, West Palm Beach, Florida 33406.

“I’m the president of the Florida Chapter of FACA, Inc. (Freidreich’s Ataxia Group in America, Inc.) I would like to locate members for my Florida chapter. Someday (soon we believe) there will be a ‘breakthrough.’ Love, hope, and research will conquer.” R. G. Bird, 17715 Gulf Boulevard, #712, Madeira Beach, Florida 33708.

“My patient and friend Bruce Hopkins (75 Gazette, page 35) is now married to girl in picture and is living at his own home all the time.” Philip Wrightson, 18 Crocus Place, Remnara, Auckland 5, New Zealand.
Housing and Home Services
by Gini Laurie

A bountiful thanks to all the Gazette readers around the world who helped with the book, Housing and Home Services for the Disabled. Your personal experiences with independent living and attendants, your adaptations to your homes, your homemaking techniques, your specialized equipment, and your information on worldwide housing projects and experiments give the book a special quality.

Putting the book together over the last three years has been exciting, enlightening, and a tremendous amount of work. It has also been a joy to work with the perceptive and exacting editors of the Medical Department of Harper & Row, Publishers. (To order a copy, see the details on the page inside the front cover.)

My continuing reaction to these experiences of independent living and to these housing projects around the world is one of pride in the accomplishments of the individuals who are disabled, of the involved organizations, and of the parents of individuals who are mentally retarded. Universally, governments have not initiated housing for the disabled. It has been initiated and accomplished by individuals and voluntary organizations by fighting for support from governments and by donations from the general public.

Supplemental References. The book, Housing and Home Services for the Disabled, includes extensive references to literature related to housing and independent living around the world. Following are a few additional references to supplement those in the book. Most of them became available after the book had been finalized. There also some pertinent references in the "Architectural Barriers" and "Independent Living" sections of "Potpourri" in this issue. Future issues of the Gazette will continue to add material so that, in effect, they will function as a supplement to the book.

Disabilities and Housing Needs. By Anders Gustavii, 1975. Basic information on the special needs in the homes of certain categories of disability, such as allergy, cystic fibrosis, epilepsy, hemophilia, impaired sight or hearing, extremely short stature, etc. $3.50 from ICTA Information Centre, Fack, S-161 25 Bromma 1, Sweden.

Freedom of Choice. Housing Needs of Handicapped Individuals. Report to the President and to the Congress by the Architectural and Transportation Barriers Compliance Board. Reprinted August 1976. This very informative publication is free from the Architectural and Transportation Compliance Board, Washington, DC 20201.


Home is A Good Place. A national perspective of community residential facilities for developmentally disabled persons. By Gail O'Connor, PhD. 1976. $4.95 from American Association of Mental Deficiency, 5201 Connecticut Avenue, NW, Washington, DC 20015.


The Housing and Community Development Act of 1974: Impact on Persons with Disabilities. The Consortium Concerned With the Developmentally Disabled Task Force on Housing issued this report. The report covers HUD's failures to develop a program for severely and multiply disabled persons. The identified obstacles are caused by the lack of a national housing policy related to persons who are disabled, training needs, appropriateness of housing, long range financing, long range service support, and zoning. The report also discusses special problems encountered in implementing the Community Development Program and the Section 8 subsidy program. Copies of the report are available from National Association for Retarded Citizens, United Cerebral Palsy Associations, and the National Easter Seal Society for Crippled Children and Adults.


Learning to Live Independently. The examples of individuals in the book reflect the gradual evolution from segregation toward the goals of a normal freedom of choice of lifestyles within the community and a normal transition within the limits of each individual’s potential and personality. Some of them learned the techniques and skills of independent living through trial and error, many learned through service organizations of the disabled such as the Center for Independent Living, and others learned through various combinations of groups of disabled individuals in apartments or houses.

Among the apartment projects within the community detailed in the book is that of the Glass Mountain Inn, Inc. (GMI). This experiment evolved from one person’s dream of a segregated facility to a group of individuals who live in apartments and share attendants. The group in the original apartments is now full and GMI is faced with the problem of expanding at the present location or in small units elsewhere in the community.

In the August, 1976 issue of GMI’s publication, Feedback Journal, the editor, Alice B. Kendall, summarizes the members’ dilemma, the value of their five years of experience, and the importance of learning how to live independently.

Possibilities of HUD’s 202 Housing. Alice Kendall’s article, which is reprinted in full, is important for all who are considering any kind of housing. It is particularly timely because of the recent expansion of funding of 202 housing for the elderly and disabled. This could result in too much segregated housing for the disabled; it should result in transitional housing that would be a way of learning to live independently and to exercise freedom of choice—including the choice to live in segregated housing. Nonprofit groups that are working with HUD on 202 housing should try to prevent all the housing from becoming a “cast in bronze” one-time solution without a choice and to make 202 housing projects function primarily as transitional centers for learning to live independently elsewhere in the community.

How Big is Too Big

by Alice B. Kendall

The GMI living experiment on Del Monte Drive has been alive and growing for about five years. It obviously provides a viable and valuable experience for those handicapped people who are able to live independently with the help of an attendant. Many of the original settlers on Del Monte still live happily within the group. There are also a number who have moved away, to be replaced by newcomers. Some have left because they could not make the adjustment from home or hospital, or because they required more physical care than an attendant could provide. Others have departed because they felt that group living stifled their individuality and inhibited their freedom. These have succeeded in finding their own apartments elsewhere in the community.

Experience shows us that independent living contributes substantially to the physical, emotional, and spiritual well-being of those who are able to take the leap and make the adjustment. It is also evident that the young adult can survive this change of environment much more readily than those who have been too long set in their ways and waited upon hand and foot.

In the beginning, the grouping of apartments is helpful. This makes possible the sharing of attendants (to allow for time off), and the opportunity to share experiences and learn from one another. However, after an individual has made the initial adjustment, he should be able to leave the group, set out on his own initiative, and make his own way without group support. He should be ready and able to live in his own apartment, wherever he may choose in the community. It might be advisable to limit group apartments to clusters of three or four. These could serve as starting points or way-stations toward further independence, rather than the end-point.

We say this because when a large group lives in a close-knit unit, subtle changes may occur within the
individual member. Over a period of time, a group order, group mind, group lifestyle may readily develop. Interdependence tends to promote a false sense of security, wherein the individual may be swallowed up in the group. He may, little by little, surrender his ideas, his independence, for fear of losing his place in his secure social unit. Disagreements may lead to formation of cliques and the establishment of a pecking order. Finally, rules and regulations must be formulated to insure an orderly existence. Who then will determine the rules? It may be the clique or the head of the pecking order who will decide what is best for all.

But such decisions should be made via the democratic process, with all members of the group participating. These are the problem situations which may arise when a group becomes too big.

We believe that group living should be a way-station en route to greater independence, not an end unto itself. We feel that such way-stations should be limited in size, for the well-being of all concerned. We hope that the handicapped who adopt the independent lifestyle will move out individually into the community as soon as they feel able. We know that when this happens, the community will more readily accept the handicapped in its midst.

Bureaucratic Disincentives

by Beverly Beber

Probably the most important turning point in my life occurred during the summer of 1974, when I was accepted as a resident at Creative Living, an 18-unit apartment complex for severely disabled people who work and/or attend school. That turning point was the bridge between 19 years of education and that which I am working to become: a competent social worker, an outstanding artist and musician and the author of poems and a book.

In 1949, I had polio at 12 and am paralyzed with the exception of my hands, wrists and biceps. In 1955 I graduated from public high school and in 1961 I got my A.B. degree in psychology from Wilmington College, a Quaker liberal arts college in Wilmington, Ohio.

It is interesting that the Ohio Bureau of Vocational Rehabilitation did not accept me as a client until I was a junior in college because I was "too disabled." My last two years, they paid about $200-$300 annually toward my tuition and nothing for room, board, attendants, books, equipment or any of the things that they provide assistance for today. It was like educating two people for my parents and both sets of grandparents who provided financial help for me and my roommate-attendents.

In 1969, I got my masters degree in social work from the University of Missouri. Accessible buildings and cut-away curbs were a welcome change!

Since the fall of 1974, I have been living at Creative Living in Columbus at Creative Living. All residents employ their own attendants, usually university students, who provide morning and evening care. There is always a staff assistant on call at CL to provide assistance for residents when attendants are not with them.

Since I've been living here, I have been employed as a social worker with the Cancer Rehabilitation Project at the O.S.U. medical complex. The project is research-oriented and its purpose is to provide counseling and rehab services for cancer patients and their families. I'm employed part-time because I am also a severe diabetic and have many health problems from this. My diabetes often tends to be more limiting than my polio disability because I am extremely susceptible to infections and sores that don't heal very well. I almost lost my job last year because of a pressure sore that kept me down for six weeks. This has been a much better year. I am very happy with my job.

My greatest problem is my financial needs versus bureaucracy! My part-time salary is commensurate with my medical expenses: about $400 a month for prescriptions, doctor bills, attendants and other disability-related expenses. For almost 3 years, I have gotten SSI ($137 monthly) which pays for part of my attendant costs and Medicaid (health card issued by the state) that pays for most of my prescriptions, doctor bills and supplies. My paycheck covers my rent, food, phone, and the remainder of my living and medical costs. Without my SSI and Medicaid, my medical expenses would be more than my income each month.

Last fall, the state took away my Medicaid card. After two state hearings in which I thoroughly explained my disabilities and extraordinary expenses, the final decision of the state, made entirely on the basis of my gross income, was that I could NOT have Medicaid.

In May, 1976, my lawyer took the case to the Franklin County Common Pleas Court. They upheld the decision of the state and charged me $100 for court costs (they wanted $250, but my lawyer talked them out of it). The judge refused to see me in the courtroom and said, "I know what she is going to say, so there's no need to waste time listening to her." He also said to my lawyer, "If she can afford a lawyer, I'm not concerned about her." The lawyer explained that he is donating his services.

In August 1976, I received notice from Social Security that my SSI payments were being stopped. "The Bureau of Vocational Rehabilitation informed us that you were no longer receiving their services. Therefore all of your income as of August 1976, must be counted against your supplemental security income payment. With an income of over $500 a month you were ineligible for supplemental security benefits... As long as your income is more than the legal limit, no checks can be sent to you."
My lawyer is planning to continue to appeal these decisions and to have a reconsideration at the state level. This could take years! I was very disappointed that the National Association of Law and the Handicapped could not help me. I’ve only been able to locate two people in similar situations: a para, sued in the amount of SSI payments she received while working. Her transportation was so expensive that she couldn’t afford to work without financial help. She finally quit her job and regained the benefits and now $50 a month will be taken out of her SSI check until her debt is paid. The other is a quad who paints with a mouthsticker and has to “barter” her paintings for art supplies because the welfare department won’t let her earn money.

I’m apparently a “test case” and am willing to use my situation and skills to set a precedent, so that quads who aren’t able to earn $800-$1000 a month can live with independence and decency. I’ll need all the help I can get from people in similar situations, organizations, agencies and anyone else who is able to provide me with information and suggestions.

The sad thing is that the State of Ohio would not hesitate to spend $600-$1000 a month of taxpayers’ money to send me to a nursing home for the rest of my life, should I be willing to go. Yet fully capable people are penalized for working and being productive!

Address: Beverly Baer, Apt. 3, 445 West 8th Avenue, Columbus, Ohio 43201

Home Health Care

by Helen Wallen

Though disabled for other reasons, wearing a long leg brace with pelvis band, and using canes, I held a responsible position as executive secretary in one of the largest corporations in New York City. At home in the evening of a workday—September 20, 1967, to be precise—I had a bad fall, breaking my right shoulder and cutting the brachial plexus. After a period of hospitalization and considerable therapy under the Expanded Blue Cross Plan carried by my company, the doctors wanted to transfer me to St. Barnabas. However, knowing there was a provision for short-term Home Care in my company’s policy and always hoping to continue to live independently and to return to productive work in my company, I opted to return to my apartment where I live alone.

The Home Care services of the hospital were called to take over, but to shorten a long story, I particularly would like to mention the most important phase which made the project of independent living feasible—it was the dedicated work of the occupational therapist. The OT called on me while I was still in the hospital and we discussed some of the problems. She then visited my apartment to see what was immediately required to make the transfer home possible and, together with my sister who lived out of town, they rented and put into place the necessary equipment and rearranged the apartment to make it as wheelchair accessible as possible. However, neither the bathroom nor the kitchen was usable for me and major construction work had to be designed and completed.

After my transfer home, the OT came every day to teach me how to dress myself and do all the other activities of daily living. She arranged for an overhead sling and made a hand splint to give me as much use of my arm as possible. Meanwhile, we had to plan the reconstruction work and through the efforts of the OT arrangements were made with the Institute of Rehab Medicine to come and work out the architectural plan for the kitchen while we worked with the construction people to make the changes in the bathroom.

Meanwhile, the Visiting Nurse came by in a couple of weeks; she took my temperature and tried to get me to sign up for Medicaid. When I said that I knew I was not eligible for welfare and that my particular need was for physical and occupational therapy, I learned to my sorrow some three months later that the nurse just closed the book on my case after her visit, which automatically cancelled all my Home Care after her visit and made me liable for the rental of all equipment, the therapists’ continued services, as well as the expenses I knew I was facing with the reconstruction costs and the purchase of needed permanent equipment. Certainly none of what I required was available within a couple of weeks’ time. How fragile is the best of ideas when bureaucratic redtape gets involved in the picture!

Therefore, I would like to reemphasize the great need for qualified occupational therapists in the Home Care picture for the period of time required to solve the problems involved, with access to the backup equipment the therapists need to accomplish the job.

This used a great portion of my lifetime savings and there are most probably thousands of others like me who have a continuing cost problem and who are not poor enough for welfare but are not really covered under Medicare for much of their real needs because they represent a chronic population. What then is the future Home Care situation to be for these people who are trying to live as independently as possible?

Coordinating Attendant Care

by Etta Marie Gill

I have gone into the health care field because I have been a respiratory polio quad since I was a small child and I know the problems at first hand. I am now working on my Master’s thesis. My degree will be in health administration, with specialization in long-term care.
In the last year I have developed and administered a questionnaire to study the problems of severely disabled individuals, both in and out of nursing homes. The questionnaire demonstrated that it was the lack of a source of attendants that was denying most disabled persons their independence. As a result, I have joined a consulting service, Synergy, and have worked with several local groups to coordinate attendant care.

The San Fernando Valley Office of the Easter Seal Society asked me to write a proposal for a referral service to meet the need for a source of attendants. The grant was accepted and in June, 1976, we began the service with one full-time person in the office to answer the phone and disabled volunteers to interview prospective assistants and to do follow-up. Those whose rating scores add up to only “fair” or “poor” are screened out. At least two names are given to the disabled individual for at-home interviews. The first month we had 163 requests for jobs, did over 50 interviews, and referred 13 to the prospective disabled employers.

The service saves individuals the cost of ads and the emotional drain of interviewing. It is particularly valuable to the disabled in long-term care facilities where it is difficult to manage the logistics of an ad and interviewing and to overcome the reluctance of people to go into an institution to be interviewed. The existence of a pool of attendants removes the fear of being left stranded if an aide should leave suddenly.

The referral office coordinates the recruitment, interviewing, and referral of prospective employees to the disabled employer. At this point, the disabled employer takes over and makes all the employment agreements.

Synergy is working with the Pacoima Memorial Hospital to develop a Creative Coping Center. The creative coping approach is directed to working with the individuals affected to create ways of helping them to help themselves in all the varied problems and aspects of disability. The approach involves the patients themselves, both individually and in self-help groups, and ranges from biofeedback to patient education.

Address: 8540 Marklein, Sepulvada, California 91343.

Planned Cheshire Homes in the U.S.

The problem of housing for the disabled was spotlighted by a forum on May 10 organized by Lady Ramsbotham at the British Embassy. Entitled, “The Role of the Disabled in Society,” the forum was chaired by William P. McCahill. Group Captain Leonard Cheshire, a World War II hero and founder of the Cheshire Homes, described his experiences with 150 residences for the disabled around the world.

The forum, which was followed by a dinner for about seventy persons, was attended by disabled individuals, architects, government officials from the Department of Health, Education, and Welfare, the Department of Housing and Urban Development, and voluntary agencies providing services to the disabled.

As a result of the forum, a steering committee was formed of which Lady Ramsbotham is Hon. Chairperson. Lady Ramsbotham is directly concerned with the problems of the disabled because her daughter is a quad as the result of an auto accident. The committee is working with local groups to create a pilot project in Washington, DC or in Morris County, New Jersey. Efforts to organize a Cheshire Home in New Jersey have been frustrated for several years because the plans for a familylike home do not fit into any established pattern for facilities providing care. For information, write to Cheshire Home, Inc., Red Cross Building, One Madison Avenue, Madison, New Jersey 07940.

Preparing Quads for Independent Living

by Arthur Heger

I am a mechanical engineer, a C3, 5 quad, employed by the Rehabilitation Engineering Center of Rancho Los Amigos Hospital to work in a new program called Project Threshold. The purpose of this program is to provide a homelike experience to severely disabled patients prior to being discharged, and to allow them to try alternatives of equipment and adaptive furniture before purchasing. My work in the project includes some counseling and the recommendation or design of special equipment, if unavailable on the market.

Our program has a model home next to the Spinal Cord Injury Ward. I have my office there, so equipped that I do all my work with no assistance at all. I have a desk with two revolving tables that I turn with my mouthstick. This way I have easy access to a typewriter, dictating machine, etc., on the right revolving table and reference material, like dictionaries and files, on the left table. I also have a portable desk that I "park" or "pick up" by myself, and a simple device with which I can handle any number of books placed standing on a single long shelf against the wall. All of this equipment, which I designed as part of the program, enables me to be 100% independent at work.

Aware of the tremendous need for a personalized engineering service to solve the independent living and working potentials of high level quads outside the hospital, my brother and I have just started a company called "Extensions for Independence." He is now working on orders for revolving-table desks similar to mine and a bed that rocks, turns like a Stryker, and stands up.
The Transportation Problem

The Red River Valley Handicaps Club has had extraordinary success in solving the problems of both housing and transportation. Founded in 1955 by Ruth Erickson, this pioneering group was the catalyst for the special disability public housing project, New Horizon Manor, which was opened in July, 1972.

After 20 years of frustration because of a lack of transportation, the club set its sights on gathering 2 million points from coupons found with Betty Crocker products. Finally, after 18 months of concentrated effort, the group gathered enough coupons to realize $8,539.86 from General Mills.

Donations furnished the balance and they bought a van with a raised roof and a CB radio. The state vocational office funded a hydraulic lift. Bookkeeping and scheduling are done by volunteers; the drivers are funded by grants and city funds. Scheduling must be done a day in advance, except in emergencies. Use of the van is limited to club members and residents of the Manor.

Comprehensive Needs Study of Individuals With the Most Severe Handicaps

Section 130 of the Rehabilitation Act of 1973 directed the Secretary of HEW to conduct a Comprehensive Needs Study of the most severely disabled persons. The one million dollar contract to carry out the study was won by the Urban Institute of Washington, D.C.

In June, 1975, the Urban Institute submitted the following three documents to HEW:

• Final Report of the Comprehensive Needs Study of Individuals with the Most Severe Handicaps. The 854-page report may be viewed at any one of HEW's 10 regional offices. It is being printed for sale through the Government Printing Office.

• Summary Report of the Comprehensive Needs Study of Individuals with the Most Severe Handicaps. This 58-page report is not being reprinted.

• Executive Summary of the Comprehensive Needs Study of Individuals with the Most Severe Handicaps. This 41-page summary is available, without charge, from Public Affairs Staff, Room 1427, Mary E. Switzer Building, 330 C Street, SW, Washington, DC 20201.

The study addresses a few key questions: Who are the most severely disabled individuals? How many are there? What is their situation? What are their needs and how are they being met?

The study surveyed: 869 persons who were not accepted for vocational rehabilitation (VR) services or whose cases were closed because of severity of disability; a little over 300 patients of 10 Comprehensive Medical Rehabilitation Centers (CMRC) who had not applied for vocational rehabilitation; and 1,300 responses from vocational rehabilitation counselors, workshops, and professional organizations and individuals.

Definitions: “The residual limitation resulting from a congenital defect, disease, or injury is an impairment. A person with an impairment, then, may or may not have a disability, an inability to perform some key life functions. When the disability interacts with the environment to impose impediments to the individual's goals for travel or work, for example, the individual has a handicap: that is, there are severely handicapping environments as well as impairments.

"An impairment can only be alleviated or remediated through devices or medical care. A disability can be remediated through training, or devices, or medical care. A handicapping condition, on the other hand, can be remediated through changes in the environment, or training of the individual, or both.

"Different persons react differently to a given impairment. Thus, similar impairments may result in different disabling or handicapping conditions. Some persons are more disabled or handicapped by a given level of impairment than others for reasons other than the impairment itself, such as motivation, age, education, family, and environmental or attitudinal barriers."

The study concludes that the RSA definition of the severely disabled furthers the practice of "labeling," although there is only a minimal relationship between diagnostic labels and severity.

A method which focuses on measuring functional limitations appears to have the greatest number of advantages since it is reliable, valid, and relatively easy to administer.
### Estimated U.S. Disabled Population in 1975

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<td>Total 10,067,000</td>
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### Comparisons of the Two Groups Studied

(A) VR Group—889 turned down or closed by vocational rehabilitation because of severity:
- 12% of people rejected were working or had worked within a year.
- 31% under 45.
- Only 11% were severely or totally dependent.
- 68% had some type of equipment, such as wheelchairs, canes, or dentures.
- Youngest age group seems to have the greatest need for services.
- Age plays a crucial role in the impact of a disabling condition.
- Education generally makes it easier to overcome a disabling condition.

“The implication of this finding is that two people with the same set of characteristics who apply for services would have different likelihood of admittance to the program depending upon the financial allotment to the state program.”

“Based on the findings of this survey, it would appear that many of this group of disabled are in need of services, and that many want to work and appear capable of working but are sitting at home, often quite isolated socially. Others who are less physically able are often even more neglected, in part due to conditions which could be changed with more careful planning for the needs of the disabled. The service and equipment needs identified are within the known ability of VR (vocational rehabilitation) to deliver.”

(B) CMRC sample—a little over 300 patients of 10 Comprehensive Medical Rehabilitation Centers:
- The CMRC sample included three times as many individuals under 30 years of age as well as almost three times as many individuals over 60 years of age.
- Almost one third of the group was severely or totally dependent.
- The major physical needs exceeded those of the VR sample and included rehabilitation therapy, attendant care, and equipment.

(C) Both groups:
- More than 50% are older than 50.
- Population are largely male, married, white, and living with their families.
- “Both groups needed similar kinds of services in order to facilitate their return to work, although the CMRC population had a higher need for medi- cal and home care services than the VR population.”

### Problem Areas for the Disabled

- **Architectural Barriers.** Local governments have made very limited efforts to eliminate barriers in public housing and facilities. . . . Public Law 90-480 appears to be weakly enforced. . . . 16% of the sample had difficulty living in or getting in or out of their homes because of architectural barriers. The major reason the barriers were not removed related to the costs of the changes.
- **Transportation.** Transportation services were second only to vocational placement in perceived need. . . . Most of the transportation needs of the sample were taken care of by friends and relatives. . . . Almost one-third of the VR sample go outside once a week or less. . . .

To meet the complex needs, a wide range of solutions must be explored and evaluated. Among the options are paratransit, retrofitting existing programs, tax subsidies for excess transportation costs to the disabled, and reform of existing public systems.
- **Employment.** Unemployment of the disabled is affected by inadequate aggregate demand, capital disincentives, employer discrimination, and lack of full employment in the economy. . . . The options for enhancing employment include "affirmative action, public sector employment, public service work programs, sheltered workshops, wage subsidies, employment quotas, and projects with industry."
- **Social Interaction.** Many severely disabled are socially isolated, have poor self-concept, and are prevented from participating in social activities by attitudinal, architectural, and transportation barriers.
- **Mental Retardation.** Retardation is the primary disability in almost one eighth of all rehabilitations. However, the severely disabled retarded are a minority.
- **Blind and Visually Impaired.** The aging blind constitute a majority of all blind. To attain the status of self-care they need a variety of rehabilitation services, which include home teaching, mobility services, and supportive services.
- **Mentally Ill.** They have a high probability of being accepted into vocational rehabilitation if they get to applicant status but they also have a high probability of ending up not successfully rehabilitated. In 1972 5.5% of all clients rehabilitated were mentally ill.
- **The Deaf.** One-third of all deaf people have other disabilities besides deafness. Prevalence of deafness is more than three times as high in persons aged 65 and over than in all age groups combined. The average income of the employed deaf is far below the national average.
PROVISION OF SERVICES

- The number of rehabilitation facilities should be increased and support added to existing facilities.
- A subsidy program to both workshops and individuals in a workshop setting should be considered.
- Devices for the disabled should be developed, manufactured, and disseminated. Consumer involvement should be included.
- Disincentives should be removed so that the severely disabled could work without significant penalties in lost medical benefits, income supplements, and other programs.

FINANCIAL OPTIONS. Whatever combination of state, federal, or local financing is used, programs can be funded from more than one source. Procedures should be developed by which the rehabilitation agency could pay vendors for needed services through a revolving fund. Vocational rehabilitation would then be reimbursed from the programs which finance the services such as Medicaid.

HEALTH COVERAGE. The study suggests further investigation of the costs of separating health care coverage from income maintenance, extension of health coverage to all severely disabled persons regardless of employment or income (but with reasonable cost-sharing provisions), and extended scope of services covered to include ongoing needs for equipment maintenance and replacement, attendant care, interpreters for the deaf, readers for the blind, etc.

As a minimal proposal the study suggested that Congress eliminate the rule requiring 2 years of receipt of Disability Insurance Benefits before persons are eligible for Medicare coverage.

COORDINATION OF HEW PROGRAMS. If Congress seriously expects coordination of HEW programs then it will itself have to make major efforts to reconcile differing legislative purposes and to mandate more authority to the Office of Handicapped Individuals in order to gain the full cooperation and participation of the various agencies.

CONSUMER INVOLVEMENT. Rehabilitation must make greater use of the growing number of consumer-run organizations and the growing awareness and advocacy of many of the individuals to establish a more effective program, especially in the area of services.

INDEPENDENT LIVING PROGRAM. The most crucial decision area is in regard to development of an independent living program. If the Congress and Administration feel that the self-care, homemaking outcome is as important as job placement then services would be expanded to those with severe disabilities without vocational objectives. This service program could be run by a non-public agency, a consumer-run self-help organization such as the Center for Independent Living in Berkeley, California, or by the vocational rehabilitation agency.

If any initiative is to be mounted in new areas, the study proposes that it be in the rehabilitation of persons in nursing homes and related long-term care facilities. While many persons in these institutions need some level of care and supervision, there are some who could be rehabilitated to their homes or more congenial community settings if they got some rehabilitation services. Movement to these settings could reduce outlays in Medicaid and Medicare for these individuals and offset costs of rehabilitation services.

SUMMING UP. Many disabled individuals need services, want to work, and are able to work, but they are neglected by vocational rehabilitation. Yet, the service and equipment needs identified by the study could be delivered by vocational rehabilitation.

The study estimates that only 2% of the $22 billion the government spends each year on severely disabled persons goes for rehabilitation. The rest is spent on maintenance programs.

"The Veterans Administration programs, while special expressions of appreciation for military sacrifices, nonetheless so far outstrip how we treat the nonveteran that the comparisons are embarrassing when looked at solely from the perspective of human need. Much technical knowledge exists to allow the severely disabled to realize their potential. Design of a goal oriented program and significant financial commitment is required. This commitment must be undertaken if the promise of providing comprehensive services is to be fulfilled."
Self-Help Organizations

- We should share the things we learn with others so that everyone doesn't have to invent everything every time.
- I would like to correspond with others who have paralysis of the respiratory muscles.
- I hope to contact others with syringomyelia and form an organization.
- The pleasure I have derived from corresponding with other M.S. patients has prompted me to form a club.

The excerpts above are taken from letters in the Friends Around the World section of the Rehabilitation Gazette. They express the universal human need to share common experiences. For those who are severely disabled, this sharing may also include the specialized techniques of managing disability that make it less handicapping.

When the diagnosis is a rare and relatively unknown disability, there is a need not only to share but to inform the medical profession and the general public as well as to raise funds for research into the cause and cure.

The following listing of specific disability organizations includes only those that are created and run by disabled individuals with similar disabilities. It does not include professional organizations that are for the disabled. Most of them were started by one disabled individual with a great deal of determination and a need to share. The story of the evolution of the Stroke Clubs of America is typical of these self-help organizations.

The founder and president, Ellis Williamson, a Monsanto Co. employee, suffered a stroke in 1964. Following a depressing period when he could neither read nor write, he met with several others who had had similar experiences. At the suggestion of Dr. John Derrick, they formed a club to help others who had had strokes.

Ellis now devotes an enormous amount of energy and time to organizing stroke clubs. All the club officers and committee members must be stroke victims. The free newsletter, International Stroke Club Bulletin, includes pen pals, helpful hints, reading lists, and questions and answers.

In 1973, the Galveston Stroke Club became part of the American Heart Association. As the movement toward forming stroke clubs has spread around the United States, Canada, Mexico, and England, other organizations, such as The Easter Seal Society and Salvation Army, rehabilitation centers, and hospitals have started stroke clubs.

Ellis, a certified public accountant, married and fathered three sons after recovery from his stroke. He exemplifies the main purpose of the clubs, which is to show that they can overcome handicaps and go on to lead profitable lives. "A doctor can tell a patient he understands," says Ellis, "but the patient doesn't really believe him. We stroke victims have been there. We know what it is like, and we know how to help."


Amputee Service Association, 520 North Michigan, Suite 1504, Chicago, Illinois 60611.

Amyotrophic Lateral Sclerosis Society of America, 11520 San Vicente Boulevard, Suite 206, Los Angeles, California 90049. H. Eames Bishop, president. (The chairman of the board, Robert G. Dicus, described in detail his experiences with ALS in the 1973 issue of the Rehabilitation Gazette.) Incorporated as a non-profit organization in November, 1975, by ALS-involved families, ALSSOA has a goal of raising 2½ million dollars a year for research. It is estimated that there are between 10,000 and 20,000 living ALS patients. All ALS patients are given charter membership in ALSSOA whether or not they can afford the $25 membership contribution.

Amyotrophic Lateral Sclerosis Foundation, Inc., 2840 Adams Avenue, San Diego, California 92116. K. F. Vanier, president. This organization, started in May, 1973, has no connection with ALSSOA, though both are working to raise money to fund research.
There are chapters in San Diego, Los Angeles, San Francisco, Hawaii, Tennessee, and Illinois.

**Arthrogryposis Association, Inc.**, 2210 Utah Street, Carson City, Nevada 89701. Myrtle Hogan, president. Arthrogryposis multiplex congenita causes generalized contractures of the joints of the arms and legs. The Association was incorporated in 1972 to share experiences and to foster research into its causes. Viola Hamby, who is a talented artist with a mouth-held brush, edits its quarterly newsletter.

**Australian Paraplegic & Quadriplegic Council**, P.O. Box 2, South Hurstville, New South Wales 2221, Australia.

**Biofeedback, Etc.**, 412 Woodward Boulevard, Pasadena, California 91107. Sue Owen, a paraplegic, wrote of her experiences with biofeedback in the 1974 issue of the *Rehabilitation Gazette*. Subsequently, she has been in contact with many others who are trying biofeedback and various methods of controlling movement and pain. She has started a delightfully informative newsletter, *The Bumblebee*, for about 250 readers who are mostly disabled by spinal cord injury but also by strokes, polio, MS, or transverse myelitis. She will welcome readers who wish to share any kind of physical progress. The cost per issue of the quarterly is 50¢.

**Brittle Bone Society of Scotland**, 63 Bryon Crescent, Dundee, Scotland DD3 6SS. Mrs. Margaret Grant, secretary.

**Canadian Paraplegic Association**, 520 Sutherland Drive, Toronto, Ontario M4G 3V9, Canada. Membership and subscription to its quarterly, *The Clipper*, are $2/year. The CPA is concerned with every phase of rehabilitation of the spinal cord injured, from the initial trauma through home adaptations, employment, and lifelong adjustment.

**Cancer Patients Anonymous**, 48 Cedar Valley Lane, Huntington, New York 11743.

**Committee to Combat Huntington’s Disease**, 250 West 57 Street, New York, New York 10019. After the death of her husband, Woody Guthrie, the famous folk singer, Marjorie organized the Committee to reach other families with HD and to promote research into cure and treatment. Informative pamphlets and a newsletter are available without charge. In 1975, the International Huntington’s Association was formed to represent groups in the United States, Canada, and Great Britain.

**Developmentally Disabled, Polling Magazine**, 122 East 23rd Street, New York, New York 10010, is the advocate of the DD consumer movement. Edited by Daniel A. Poling II, it includes sections relating to cerebral palsy, epilepsy, and mental retardation. Published quarterly, it is available without charge.

**Friedreich’s Ataxia Group**, Bolsover House, 5/6 Clipstone Street, London W. 1. England. Founded in 1964 by Mr. and Mrs. Heard of Dawlish, Devon, who published a newsletter of aids and reports on fundraising, the organization now has a London office and a professional publication.

**Friedreich’s Ataxia Group in America**, Inc., P.O. Box 11116, Oakland, California 14611. Raymond S. McCarthy, president. Founded in 1970, the organization has grown to more than 1000 members and several dozen chapters. Working along with the National Friedreich’s Ataxia Foundation, the organization is cooperating with researchers and raising funds to increase FA research. A newsletter reports individual and chapter activities, encouraging correspondence between members around the country.

**International Association of Laryngectomees**, 219 East 42nd Street, New York, New York 10017. The IAL is made up of several hundred “Lost Chord” or “New Voice” clubs.

**Little People of America, Inc.**, Box 126, Owatonna, Minnesota 55060. Billy Barty, TV and movie personality, formed LPA in 1957. With a motto of “Think Big,” the organization is now a nationwide, voluntary organization with a dozen districts, local chapters, and an annual national convention. The annual dues are $7.50 per person, $10 per family, and $5 for teens or children. The national newsletter, LPA NEWS, is published 10 times a year. The Member’s Handbook contains ideas and suggestions on every phase of living, from gadgets to clothes and employment. LPA has established a foundation to encourage research and to assist agencies in the placement of Little People for adoption.

**Lupus Foundation of America, Inc.**, 11675 Holly Springs Drive, St. Louis, Missouri 63141. Roger K. Sturdevant, president. Systemic lupus erythematosus (SLE) is variously labeled a collagen-vascular, immune complex, or connective tissue disorder. Its prevalence is estimated at two or three per 100,000. Roger, who has been disabled by SLE for more than 10 years, founded a national organization of SLE’s and their families that now has 86 chapters in the United States, as well as in Canada and Puerto Rico. Its national newsletter explains medical facts in simple, nonmedical terms. Members call on the newly disabled and help each other by sharing knowledge and experience. Booklets and pamphlets are available without charge.
NATIONAL ASSOCIATION OF THE DEAF, 814 Thayer Avenue, Silver Spring, Maryland 20910. Frederick C. Schreiber, executive secretary. Founded in 1880, the association serves as a clearing house for information relating to deafness. A free list of publications is available.

NATIONAL ASSOCIATION OF COUNCILS OF STUTTERERS, Speech and Hearing Clinic, Catholic University of America, Washington, DC 20064. Michael Hartford, president. Formed in 1974, the Association is directing its efforts toward the promotion of new self-help groups and research.

NATIONAL DISABLED LAW OFFICERS ASSOCIATION, Inc., 75 New Street, Nutley, New Jersey 07110. Peter A. Frazza, president. Peter was injured in 1963 when a stolen auto crashed into his patrol car. The accident caused permanent loss of equilibrium and he was retired. Since then he has founded and organized NDLOA for the estimated 5000 disabled law officers in the country. The aim of the organization is to further their employment and to effect legislation to provide more and better benefits. The organization has helped a number of individual members to get service-connected pensions and to retain their jobs. Operating without dues, the organization offers an information service which includes sharing the names and addresses of other disabled lawmen.

NATIONAL FEDERATION OF THE BLIND, 218 Randolph Hotel Building, Des Moines, Iowa 50309.

NATIONAL PARAPLEGIA FOUNDATION, 333 North Michigan Avenue, Chicago, Illinois 60601. Don A. Olson, Ph.D., president. Founded in 1948 by the Paralyzed Veterans of America, the NPF is concerned with both research for a cure and the continuing care and total environment of those disabled by spinal cord injuries. There are 63 chapters in 27 states. Its informative bimonthly publication, Paraplegia Life, is $4/year or free to members. A comprehensive list of publications relating to spinal cord injury is available.

OUR WAY, 4303 Bradley Lane, Chevy Chase, Maryland 20015. Nancy L. Mauzy, president. A non-profit group concerned with the problems of disabled in general and specifically with those who may be single-handed.

OSTEOGENESIS IMPERFECTA FOUNDATION, Inc., 1231 May Court, Burlington, North Carolina 27215. C. C. McNeely, Jr., president. The OIF is concerned with the genetic defect known as “brittle bones.” Chartered in Georgia in August 1970, its purpose is to fund research and to exchange information between OI patients and their families. Active membership dues are $10/year. Its quarterly publication, Breakthrough, contains sections on pen pals, successful careers, equipment information, book reviews, and information on its nationwide chapters.

PARALYZED VETERANS OF AMERICA, 7315 Wisconsin Avenue, Suite 301-W, Washington, DC 20014. The PVA is dedicated to the removal of environmental barriers to benefit wheelchair veterans and civilians and to the assistance of veterans in obtaining benefits and legislation. Its excellent monthly journal, Paraplegia News, is in its 30th year of publication. The subscription is $4/year or free to chapters and members.

POSSUM USERS ASSOCIATION, 25 Worlds End Lane, Weston Turville, Aylesbury Buckinghamshire HP2255, England. The members and readers of its quarterly, Possability, are quadriplegic and dependent upon the remote control device known as POSSUM.

RESPONAUT, 62 Priory Road, Newbury, Berkshire, England. Margaret Haines, treasurer, will send free copies of the quarterly publication, Responaut. The editor and writers are quadriplegics dependent upon respirators or other gadgets because of respiratory polio or other disabilities.

SPINA BIFIDA ASSOCIATION OF AMERICA, 104 Festone Avenue, New Castle, Delaware 19720. Editors of the organization’s newsletter, The Pipeline: Sandra Helton, 9 Mountain Avenue, Montville, New Jersey 07045.

SPINAL INJURIES ASSOCIATION, 24 Nutfield Place, London W1H 6AN, England. The membership cost of £1 includes the newsletter which is sent to its 1200 members. 

STROKE CLUBS OF AMERICA, 805 12th Street, Galveston, Texas 77550. Ellis Williamson, president.

TOTALLY DISABLED HELPERS ASSOCIATION, 217 Hullett Street, No. 3, Long Beach, California 90805. Celeste Thompson, president. In 1974, a group of former Rancho Los Amigos Hospital poliomyelitis quads led by Richard M. Carman formed TDHA to solve their transportation and attendant problems by attacking the problems together. They have achieved a Living Maintenance Supplement from revenue-sharing funds of Los Angeles County of $100/month for those of their group who need 7-day a week live-in care. In addition, they have acquired the use of a Rancho van whose scheduling they arrange. They are working for a $200/month supplement and a van of their own. One of the members runs an informal attendant referral service. The group has organized an auxiliary, Volunteer Project for In-Home Services. A newsletter keeps members informed of the latest regulations, changes in benefits, and fund-raising and lobbying activities.
United Ostomy Association, Inc., 1111 Wilshire Boulevard, Los Angeles, California 90017. Since it was founded in 1962, the organization has grown to include 18,000 members. Its purpose is to disseminate information to persons who have lost the normal function of their bowel or bladder necessitating colostomy, ileostomy, or urinary diversion surgery. It publishes care and management manuals and Ostomy Quarterly.

In addition to the above listing of national organizations, that were originally created to share the problems of a common disability and then evolved to rights-seeking, there is a burgeoning number of local organizations being formed by individuals of all disabilities to achieve equal rights by eliminating the barriers that impede normal living within the community.

We would like to publish an extensive listing in the next issue of the Gazette. If you would like to have your organization listed, please send us the details. We would also like to be on your mailing list to receive your newsletter and to be kept up to date on your achievements.

The White House Conference

The White House Conference on Handicapped Individuals will be held May 23-29, 1977 at the Sheraton-Park Hotel in Washington, DC. The Conference will be officially attended by 672 delegates who were selected at the State Conferences which were held in the fall of 1976. The delegate proportions are 90% disabled individuals, 25% parents or guardians of disabled individuals, and 25% nondisabled individuals.

The timing of the Conference is auspicious for the growing movement among disabled individuals to organize themselves to attain effective enforcement of civil rights. Planning and working on the State Conferences broadened participation in the movement by disabled as well as nondisabled individuals and fomented a spirit of determination to continue to work together, not only to make the 1977 Conference produce tangible results, but to make the results lasting through legislation, such as a Disabled Americans Act similar to the Older Americans Act.

The following excerpts from the speeches and writings of the executive director of the Conference, Jack F. Smith, who is wheelchair-bound by polio, effect the determination. "The White House Conference will have a profound effect on this nation's mentally and physically handicapped Americans. . . . The White House Conference will make recommendations for public policy to the Congress and the President which will move the handicapped of this country into the mainstream of greater dignity, independence, and full participation in community life.

"The disabled of this country are becoming not only more vocal as individuals and organizations, but also much more visible. We are becoming sophisticated as spokespersons and advocates. There is a pressing need for involvement in all policy-making efforts that impact on the disabled. . . . We're beginning to understand that litigation techniques are available, and that litigation is a reasonable avenue that is often necessary. . . . The disabled of this country are saying, 'Separate but equal is not equal.'

"One of the great benefits of this conference will be a whole new generation of disabled leaders who will understand something of the process and how to influence change. Some positive avenues to bring about change are to register, vote, and work along with other disabled persons on behalf of political candidates.

"Clearly, in the area of civil rights, the handicapped should not be denied access to training, education, or employment because of the handicap.

"Disincentives to work must be eliminated and employers either be given incentives or be required to modify jobs to employ the handicapped and provide upward mobility.

"In the area of housing, the handicapped want more options.

"Information dissemination, both in terms of benefits available and in terms of educating the general public and those individuals who influence employment and the tearing down of both the physical and attitudinal barriers must become more sophisticated.

"There's a wave of change taking place in this country and the disabled are the generating force behind this wave.

"We, as individuals, must be willing to tear down the programs that are not delivering and support those that are delivering. We need new mechanisms to evaluate existing programs and to provide new initiatives. It's an awesome opportunity. The White House Conference is required by law to develop an implementation plan; that is, to develop a plan that will insure that the Conference recommendations are followed up and executed. This has never been done before, and it sets this White House Conference apart from others.

"The Conference cannot possibly solve all problems of the mentally and physically handicapped. We will solve the major ones. . . . Cooperation—not competition—that's the key."
American Coalition of Citizens with Disabilities

In many states the spirit of cooperation that was generated by the State Conferences resulted in the forming of task forces as a preliminary to joining the American Coalition of Citizens with Disabilities (ACCD) as a state coalition.

ACCD, which was established in 1974, was described in detail in the 1974 issue of the Gazette (pages 19-20). Since then its membership has grown steadily and it has become increasingly effective as a champion of civil rights for the disabled.

Among the national and regional organizations of the disabled that are active members are: American Council of the Blind, National Association of the Deaf, National Association of the Physically Handicapped, National Paraplegia Foundation, Paralyzed Veterans of America, Teletypewriters of the Deaf, Florida Coalition of Handicapped Organizations, Massachusetts Council of Organizations of the Handicapped, and New York's Congress of People with Disabilities. Among the associate members are the National Association for Retarded Citizens and the National Rehabilitation Association.

Member organizations retain complete autonomy. ACCD functions as a catalyst for unity in pursuing solutions to the problems that confront all members of the nation's disabled population. With one "token" exception—the Gazette's editor—all of the officers and board members are disabled. The 1976 officers and members are as follows:

Officers. President, Eunice Fiorito, Director, Mayor's Office for the Handicapped. First Vice-President, Charles C. Estes, National Association of the Deaf. Second Vice-President, Dr. Frederick Fay, Director of Research, Tufts-New England Medical Center. Secretary, Judy Heumann, Associate Director, Center for Independent Living, Treasurer, Louis T. Rigdon II, Planning Specialist, White House Conference on Handicapped Individuals.

Board Members. Cheryl Davis, Environmental/Service Needs Specialist, Massachusetts Department of Community Affairs, Gini Laurie, Editor/Publisher, Rehabilitation Gazette. Jack Martin, Coordinator, Disabled Student Services, U of Washington. Terrence O'Rourke, Director, Communicative Skills Program, National Association of the Deaf. Roger Petersen, Services for the Handicapped. Reese Robraln, American Council of the Blind. Phyllis Rubenfeld, Hunter College. Richard Santos, Former Executive Director, Center for Independent Living. David Williamson, Staff Assistant, Programs for the Elderly and Handicapped, HUD.

ACCD has been awarded a $59,000 grant from HEW's Rehabilitation Services Administration to conduct a feasibility study and to develop a national model of cross-disability cooperation and communication. The RSA grant has allowed ACCD to hire its first full-time staff person, Dr. Frank Bowe, who will serve as project director and conduct the feasibility study. Dr. Bowe, who is deaf, is a graduate of Gallaudet College and holds a PhD in clinical psychology from New York University. He has been a rehabilitation specialist with the RSA and a training specialist at New York University.

To join ACCD, request an application from Terrence O'Rourke, Chairman, Membership Committee, American Coalition of Citizens with Disabilities, Inc., Room 817, 1346 Connecticut Avenue, NW, Washington, DC 20036. Phone: (202) 785-4265. Annual membership dues are as follows: Organizations of the disabled: $100 national; $50 state organizations or coalitions; $25 local. Organizations for the disabled: $100 associate. Individual membership, disabled or nondisabled, $5.

ACCD Philosophy

by Roger D. Petersen

ED: This draft philosophy statement was presented at the November 1976 meeting of the Board of Directors by Roger D. Petersen, Philosophy Committee Chairperson. If Gazette readers wish to share their thoughts with ACCD, send them to Roger at 1229 Columbia Road, NW, Washington, DC 20009. Since he is blind, it would be helpful if the comments were on cassette or in braille.

The American Coalition of Citizens with Disabilities has been in existence long enough that it has taken a number of stands on particular issues affecting people with disabilities. Through resolutions of the Delegate Council and actions of the Board of Directors as well as congressional testimony and comments on administrative regulations, we have taken positions on such subjects as special education, health care, rehabilitation, civil rights, transportation, income maintenance, and environmental barriers.

As we proceed in this manner, it is becoming apparent that there is a general philosophy underlying these various positions and that making this philosophy explicit would be useful in the development of future positions. Thus this statement is an attempt to enunciate this underlying philosophy of the American Coalition of Citizens with Disabilities.

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Definition of Disability. An important first step in
this undertaking is to define the population which
ACCD represents and thus to which our philosophy
refers. This definition should include the people to
whom the name ACCD refers and exclude all others.
Furthermore, it should show how the disabled population
is similar to and different from other groups such as
ethnic minorities and women.

A disability is a physiologically or psychologically
describable characteristic which impairs or is generally
taken to impair a person’s general functioning, and
which thereby places that person in a socially defined
negatively valued minority group. The two aspects of
disability, the impairment and the social stigma, vary
in their relative importance in different disabilities; but
they are both always present. Thus, as will be detailed
later, disabled people have in common with other
minorities the stigmatized status, but there are impor-
tant differences owing to the different origins of the
stigmata.

The Disabled as a Minority Group. In many ways,
disabled people occupy a place in society which is
equivalent to that of racial and ethnic minority groups
and women. (Although they are not numerically a
minority, women are to be included in the term
“minority group” as used in this paper.) We (people
with disabilities) are looked upon by society as a
homogeneous group, all having the same needs and
abilities. We are segregated into ghettos in terms of
education, housing, recreation, employment, and trans-
portation. We are faced by discrimination and other
indigencies every time we venture into the world of the
non-disabled.

There are, however, ways in which we are unique
among minority groups. By definition, we have im-
pairments of function for which society must make
accommodations; thus our barriers are physical as well
as social and economic. Disabilities are usually congen-
tal or adventitious rather than hereditary; thus one
may be physically disabled whereas one cannot become
black, and a disabled infant is not born into a disabled
subculture.

The Nature of Equality. It is very likely that all of us
in ACCD would agree that we are striving for equality
for people with disabilities. It is perhaps well here to
examine what we mean by equality in the light of the
foregoing analysis of the nature of disability. In a gen-
eral way, we mean a fair or equal chance to participate
in all aspects of society. We refer to the human rights:
life, the means to sustain life, medical care, etc.; lib-
erty, autonomy, self determination; and the pursuit of
happiness, self actualization, education, opportunity
to function at the highest level of which one is capable.
We would further include integration in the concept of
equality. Viewed in these terms, the achievement of
equality will require a two-pronged approach. On the
one hand, we must operate on society to remove bar-
rriers, physical and social. On the other hand, we must
provide the disabled person with the means of com-
pensating for the limitations imposed by the disability
and for the barriers which cannot be removed in the
foreseeable future. It should be noted that there is in-
evitably some arbitrariness as to where the line is
drawn between barrier removal and compensation,
and the balance between the two will vary with time
and circumstances.

Barrier Removal. As noted above, our barriers are
social and physical. We must chip away at the social
barrier through antidiscrimination legislation, public
awareness campaigns, litigation, and all the standard
legal, political, and social methods used by other
minorities. The goal is that there should be no law,
regulation, policy, or individual whim to keep a per-
son from doing anything which he/she is otherwise
qualified to do because he/she has a disability.

Some of the same methods as well as a good deal of
research and implementation are necessary to remove
the physical barriers. The goal of this endeavor is to
make all facets of society accessible to people with dis-
abilities. This means not only that there should be no
architectural barriers for people with motor limitations
but also that all information required for full participa-
tion must be available in forms accessible to more than
one sensory modality. Some aspects of this broadly
defined accessibility are not as yet technically possible,
but the goal should nevertheless be kept in mind.

Compensation. The gigantic constellation of services
and financial benefits for the disabled are provided by
way of compensating him/her for the limitations which
the disability entails and for the socially disadvantaged
status which he/she occupies. Disabled people can be
trained to overcome their limitations to one degree or
another through special rehabilitation training. De-
vices can be provided which improve mobility, sen-
sory acuity, ability to communicate, etc. Wherever
training and devices do not suffice, personal services
can be purchased; e.g., to read inkprint to blind
people, to interpret to deaf people, and to assist se-
verely motor-impaired disabled people with their
physical needs.

Our main concern about these modes of compensa-
tion is their adequacy and appropriateness. The chief
problem related to adequacy is to develop a means for
determining need for such services which takes into
account the individual differences among disabled
people and at the same time avoids the abuses of the
means test used in welfare. The appropriateness of
compensatory aid has to do with the relevancy to the
particular person and the disability which he/she has.
Compensation should be specifically aimed at a par-
ticular deficit, like payment for attendant care, and not
just general charity, like free concert tickets.
Equipment

The Gazette does not accept any advertising. The gadgets and devices presented here were gleaned by the editors from readers’ letters and other sources. They are presented as ideas for the readers to pursue on their own by sending for brochures and latest prices.

The Gazette does not specifically endorse any product nor accept responsibility for any approximate price listed.

COMMUNICATIONS

Prenkte Romich Company has developed three new aids for the non-vocal—those who cannot talk, write, or use a typewriter: Message Selector can be used by children who cannot read but who can select pictures. Alphabet Message Scanner permits the use of words, pictures, or Bliss symbols. Strip Printer combines the lighted message with automatic printing on a strip of pressure-sensitive paper. Address: RD 2, Box 191, Shreve, Ohio 44676.

The Medical Engineering Section of the National Research Council of Canada has worked with cerebral palsy children to develop communication aids. They include Commandi (a scanning grid and typewriter) and Occur (a light-operated typewriter) as well as bio-feedback devices, electronic games, and a page turner for pocket books. Address: CRCD Engineering Advisory Committee, Bldg. M-50, Room 167, National Research Council of Canada, Ottawa, Ontario K1A OR8.

An excellent catalog of communication aids and environmental controls is available from Gregg C. Vanderheiden, The Trace Research and Development Center for the Severely Communicatively Impaired, 922 ERB, 1500 Johnson Drive, University of Wisconsin, Madison, Wisconsin 53706.

Toby Churchill Limited has created the “Lightwriter” for people unable to speak. When the typewriter-like keyboard is punched, up to 32 characters may be made to appear on a luminous display. The phrases move like a news-strip across the display. There is a buzzer to attract attention and a way to correct errors. For information, write to Toby Churchill at 20 Panton Street, Cambridge CB2 1HP, England.

Communication Aids for the Brain Damaged Adult. By Lillian Cohen. The booklet is intended as a guide for professionals. Suggestions are given for constructing types of aids. $2 from Sister Kenny Institute, Chicago Avenue at 27th Street, Minneapolis, Minnesota 55407.

REMOTE CONTROLS

Switch-O-Matic. Herbert S. Merrill, an electronics design engineer, who has been a respiratory polio quad since 1953, has spent years perfecting an environmental control system for other quadriplegics.

The system can be operated from a single micro-switch attached to a piece of Velcro pinned to sheets or clothing by breath, by voice, or by a tiny portable radio transmitter unit. It can be operated by a severely disabled person from a hospital bed, an iron lung, a rocking bed, or a wheelchair. An ambulatory person can operate it with portable wireless control.

The basic system consists of an input control module, a scanning module, and one or more output control modules. Through its modular building block design it can easily be changed and expanded to 20 appliances as needs evolve. It can operate TV, radio, alarm, stereo, typewriter, doors, lights, tape recorder, camera, speaker, telephone, intercom, page turner, and citizens band radio.

A descriptive brochure is available from Down East Electronics Mfg. Co., 44 Bucknam Road, Falmouth, Maine 04105.

TOSC-2. Mr. R. Cairns, a traumatic quadriplegic, developed the first TOSC unit for his own use. Prosthetic Services, Health and Welfare Canada, is co-ordinating and funding further development of this and other technical aids. More than 40 TOSC-1 instruments are in daily use in Canada.

The unit is 17½’ wide, 5½’ high, and 11’ deep and weighs 25 pounds. The system allows severely disabled individuals to use a call buzzer, work a two-way intercom, unlock the front door, receive or make telephone calls, switch the radio on and off, operate a TV set, or a tape recorder, and turn lights on or off. Additional control switches can be used for appliances such as a page turner, an electric bed, or a typing aid.

Details and prices available from Prosthetic Services, Department of National Health and Welfare, % Sunnybrook Medical Centre, 2075 Bayview Avenue, Toronto, Ontario M4N 1C5, Canada. Phone 416-486-3568.

English Consultant/Assessor. An expert is available to English disabled: Roger M. Jefcoat, Willowbrooke, Swanbourne Road, Mursley, Buckinghamshire MK17 OJA, England. His experience has been extensive in working with individuals in their homes to adapt the POSSUM electronic control aids to each person’s particular need. (For details of POSSUM, see pages 54-55 of the 1971 Gazette.)

Electronics Center. The Prenkte Romich Company has continued to develop electronic control devices in addition to its Automatic Dialing Telephones. The Environmental Control unit can control a TV, lamp, radio, nurse call, electric bed, microfilm reader, tape recorder, and other electrical devices. It may be
operated by breath or by a touch of the hand, tongue, or lip.
Wheelchair controls are designed
to operate by chin, shoulder, breath,
or joystick. The DU-IT wheelchair
controls include the operation of
accessories such as horn or
headlight, tape recorder, power
recline, or splint.
Catalog available from Prentke
Romich Company, Electronics
Center, R.D. 2, Box 191, Shreve,
Ohio 44676. (Phone: 216-567-2906.)

Rehabilitation Engineering Project
is a service program of the Bio-medical
Engineering Center, T-NEMC, Box
1014, 171 Harrison Avenue, Boston,
Massachusetts 02111. Address
inquiries to Earl Gaddis, project
director.

Harvard-M.I.T. Rehabilitation
Engineering Center. Projects and
Activities: February 1, 1973 to April 30,
1974. Free from REC Executive
Officer, Room 3-435, MIT, 77
Massachusetts Avenue, Cambridge,
Massachusetts 02139.

Voice-Controlled Computer. SCOPE
Electronics, Inc., 1860 Michael
Faraday Drive, Reston, Virginia
22090, has developed a voice-
controlled computer terminal that can
be operated over telephone lines.
The VDETS 1000 converts spoken
words or short phrases to machine
readable code. It has been operated
successfully by quads at Woodrow
Wilson Rehabilitation Center.

Australian Automatic Arm Appliance
has been developed by Mr. George
Clarke, senior splintmaker at the
Royal Adelaide Hospital in Adelaide,
South Australia. The device uses CO2
to power an artificial muscle to close
the fingers so that quads can write.
The device is triggered by twitching
the shoulders to open or close a
valve. The appliance, tailored for
each individual, weighs about 250
grams (about 8 oz.) and costs about
$A170. Further details available from
Australian Information Service, PO
Box 12, Canberra A.C.T. 2600,
Australia.

Jack Quigley, C5-6 quad, drives his Step
Van on extended camping trips.

TRANSPORTATION by Joe Laurie
We quote from Paraplegia News, May,
1976: "During the past few years
there has been a big boom in the
purchasing of specially equipped
vans with various types of lift
systems, adaptive devices, and
driving controls . . . From time to
time PVA receives complaints about
certain vans which are not living up
to expectation . . . Write your PVA
research director at the National
Office, 7315 Wisconsin Avenue,
Washington, DC 20014."

Lift with care! The lift on a van is
designed for one purpose only: to
raise or lower a person in a
wheelchair. It is not to be used to
hoist furniture or refrigerators or
pipes; it is not a plaything for the
kiddies. A long life has been built
into it. Use it carefully—have it
serviced too. It can be removed and
installed in a newer vehicle.

HP Bus Corporation of North
Billerica, Massachusetts 01862
(617-729-8983). They modified a
Volkswagen Microbus by lowering
the floor of the seating compartment
behind the driver a distance of 6" and
fashioning a simple ramp from a
steel plate which is hinged to the
floor on the inside near the sliding
exit/entrance door panel. After the
door has been opened, the ramp can
be flipped out onto the street or the
curb and the wheelchair person
can roll out on the very gentle slope.
The VW van can be equipped with
air conditioning, and should prove
a handy vehicle for local getting about.
Write or call for brochure.

Two St. Louis quads, influenced by
the 1975 Gazette article on Step Vans,
found that the almost 6 foot high
"standing room" well suited their
needs, as both are big men, and they
didn't have to "duck" when getting
in.

Max Starkloff's GMC Step Van's
aluminum body is unpainted, and
gleams like a plane's fuselage. He
arranged for a sliding door to be
located on the passenger side, and
the rear door was not used. Double
D Industries installed the lift and
door-openers; large windows
were placed in the sides to the rear,
and a sofa there makes a fine place
for passengers to view the
countryside as Colleen drives Max
around on his various missions of
Farquad.

Jack Quigley's aluminum van had
been painted white; large windows
on each side, with curtains for
privacy, convey an aura of a "house-
boat." The Double D lift is in the rear
entrance door and when lowered
provides a tongue for entrance.
The steering column was made
adjustable, and with the driver seat
removed, Jack can drive right from
his electric wheelchair, after locking
the hold-downs and putting on the
seat belt. Two bunks were built along
the sides, and each has commodious
storage space. He took wife Nancy
on quite a cruise this summer,
retracing the Oregon trail westward
-6500 miles of living and camping
in their "yacht" proved its
"seaworthiness" . . . and now it
carries him off to his daily counseling
work.

WHEELCHAIRS

Wheelchair Loader by Rhonda Galper
In 1972 and 1973 I introduced and
instructed a remedial art program at
the Glenrose Hospital, Edmonton.
This involvement in rehabilitation
medicine led me into an engineering
project as consultant with Chrysler
Canada Ltd. It involved the

Joe Laurie has been volunteering as editor and major-domo of the Gazette since he retired several years ago.
Rhonda Galper of Alberta, Canada, and the wheelchair loader which she developed with Chrysler, Ltd. Rhonda, a paraplegic, is one of Alberta's leading artists.

development of an automatic wheelchair loader which is adaptable to most two-door auto models, both compact and larger size.
The loader consists of a motor driven hoist mounted behind the right front passenger seat, a lever type switch which can be mounted anywhere, and an extension hook. The user first transfers to the passenger seat, then folds the chair, swings out the boom, and secures the chair to the hoist cable by a hook. After transferring to the driver's seat, the user operates the switch that raises the chair. The chair is pivoted into the car behind the passenger seat with the extension hook and then lowered to the floor of the car by reverse activation of the switch. The passenger seat is driven rearward by its electric seat mechanism. To unload, the procedure is reversed.

Chrysler Canada Ltd. has no plans to patent or produce the loader. It offers the design and technical advice to anyone who wishes to produce it or develop it further.

Additional details available from Rhonda Galper, #1210-11307-99 Avenue, Edmonton, Alberta, Canada T5K 0H2 or Stan McDowall, P. Eng., Manager, Product Quality Engineering, Chrysler Canada Ltd., Chrysler Center, Windsor, Ontario, Canada N9A 4H6.

ROHO Cushion by Colleen Starkloff
My husband, Max, has been a C4-5 quad for 17 years as a result of an automobile accident. When he first heard about the ROHO cushion he was living in a nursing home and had been in bed with a decubitus ulcer for several weeks. He was unable to adequately carry on his work and was becoming irritable, depressed, and bored. His doctor told him that he had heard of another cushion on the market that a quad had told him about. (ROHO, P.O. Box 658, Belleville, Illinois 62222.) He said that since Max had tried everything else he might as well try this one, but warned him that regardless of what he sat on he would still have to lean from side to side every 15 minutes to relieve pressure because he had no "padding" to sit on.

Max had tried foam, orthopedic seats, and air-filled and gel-filled cushions. None of them worked sufficiently. He was unable to get through a year without spending a minimum of two weeks in bed, especially in the summer months when his skin perspired a little, making breakdowns more threatening. No matter what he did the skin over the ischial tuberosities became more sensitive to pressure and more prone to breakdown. He began going to bed at 7 PM every evening and still his skin was bright red even though he leaned over every 15 minutes. The doctor had warned him that surgery might be necessary if the situation did not improve. We were dating at that time and were very reticent about staying out late because we were afraid to push our luck.

So, Max bought a ROHO balloon cushion. He started sitting on it for 15 minutes, 30 minutes, 45, etc. and built his time up to many hours. The cushion is composed of 72 balloons affixed to a flat base. We tied down one balloon under each ischial and inflated the cushion so that the ischials were suspended ½ inch from the base of the cushion. (According to instructions, tying down the balloons is not necessary but can be done to achieve zero pressure.) He healed in four months! Four months of getting up at 8 AM and working 8-10 hours a day.

It seems strange to say that a cushion has changed one's life-style, but this one has. Max got the balloon cushion almost two years ago and he has not had a bedsore since that one I mentioned above. His skin looks fantastic. He no longer leans from side to side and is not plagued by the awful feeling that "the ischials might be catching pressure," although he checks his skin every night. We have been married for over a year now and the balloon cushion has affected me, too. Max is up at 8 AM and we both follow a busy schedule all day. The only reason he goes to bed now is to sleep or... Our activities are no longer restricted by his skin tolerance. Our life style would be seriously hampered without a balloon cushion.

The cushion has provided Max with excellent stability. He can move freely on it without that "sitting on a basketball" feeling. Being air inflated makes it lightweight and easy to handle. I clean it by tossing it in the tub and using a mild soap and the shower on it.

Several of our friends now use the cushion and have as much success with it as we have, or more. We present two because they do puncture occasionally and Max can use one while the other is being
Gas-Powered Wheelchair. "Four years ago I had my chair built for only $300. A local metalsmith built it from a rough sketch and high school boys did the finishing. I used all new materials but it could be made with parts salvaged from junk yards, wornout lawn mowers, and surplus companies. My chair is very stable. I had a friend ride it up and down sidewalks on a 30° slope on a bank

and it did not even come close to turning over. I am a C5-6 quad and I’ve ridden it everywhere a person can walk. It can do anything in woods, pasture, or plowed field except jump a ditch. I cannot understand why some company has not built this type of chair." Richard A. Simons, Route 2, Box 83, Calhoun City, Mississippi 38916.

Steven Motor Chair Co. This company, which has been making motorized wheelchairs since 1948, carries parts for all its chairs. Formerly in Kansas City, Missouri, it has moved to 120 North Gunter, Siloam Springs, Arkansas 72761.

Mint-Amigo. The newest addition to the AMIGO line features interchangeable parts so it can fit little people or growing children. Brochure from Amigo, Inc., 6693 Dixie Highway, Bridgeport, Michigan 48722.

REACTORS’ IDEAS


Floor and Carpet Sweeper. "The Hoky is such a lightweight sweeper that it is easy to use from a wheelchair. It works on carpet or bare floor, has a long and flexible handle, and is built so low that it will get under most things. Brochures from Hukuba-Cowdery Corp., 718 W. 77½ Street, Minneapolis, Minnesota 55423." Jean Stange, 11655 South Maplewood, Chicago, Illinois 60655.

Bowling Ball Holder-Ring. "My holder keeps the ball over your lap while you wheel up to the foul line. It is like having a third hand! You can attach it to most wheelchairs. To order, send me $9.99 (plus $1 to the West coast)." George H. Snyder, 5809 N. E. 21 Avenue, Fort Lauderdale, Florida 33308.

E-Z Reacher. "This lightweight device can be used by library staff members of short stature or by wheelchair patrons and senior citizens. It is 30° long, made of aluminum. Available from Physical Aids Mfg. Co., 4848 (Suite F), Ronson Court, San Diego, California 92111." Jody Raymond, Twinsburg Public Library, Twinsburg, Ohio 44087.

Canadian Home Elevator. No major structural changes to the home are required to install this one-man elevator which can travel from one to a three floor rise. Brochure from Bruce A. Robertson, 59 Highheave Avenue, Scarborough, Ontario M1N 2H4, Canada.

Bladder Pacemakers for Paralyzed Bladders. Within a five-year period, about 200 persons have had a pacemaker surgically implanted in a subcutaneous pocket in the left abdomen, with electrodes attached to the bladder. Voiding is accomplished by pushing a button on a pocket-size transmitter. Write: Mentor Corporation (Biomedical Systems), 3104 West Lake Street, Minneapolis, Minnesota 55416.

English Female Urinals. A new device will soon be made by J. G. Franklin & Sons, PO Box 11, High Wycombe, Bucks., HP12 3TD, England. Address inquiries to Mr. C. Gadsen, Product Manager.

The Fall 1976 catalog of Suburbia, Finch Building, 366 Wacouta, St. Paul, Minnesota 55101, has a number of items that would be useful to our readers: Travel Adapter/Converter Kit (pg. 4); Easy-Read Stand adjusts tilt and height (pg. 6); Light Dimmer can be operated by a fingertip (pg. 28); Whistle Switch turns on TV, lights or any appliance with a hand-held transmitter (pg. 38).

Go-Lift. "We are very pleased with our new Go-Lift as it is sturdy, compact, and light. Also, it is adjustable to any vehicle door. Brochures from Holeck Engineering Co., 9255 Cliney Avenue, Downey, California 90240." Sr. Beverley Marie, Waterloo and Fairfield Roads, Devon, Pennsylvania 19333.

Big Numbers for Touch Tone Phones. Self-adhering device widens the touch area for mouthsticks or wandering fingers and enlarges the numbers for poor sight. Page 70 of Fall ’76 catalog from Joan Cook, 851 Eller Drive, Ft. Lauderdale, Florida 33316.

Long-handed Lotion Applicator. "Try either a piece of plexiglass with a rounded end or a hemostat with a piece of cotton or gauze." Robert E. Hilt, 1182 Warren Road, Lakewood, Ohio 44107.

Dressing Aid. With this pair of aids, one can be flat on a bed or upright in a chair and dress without bending hips or knees. With one in each hand, one can put on shoes, stockings, slippers, underpants, party hose, or trousers. They may also be used by arthritics with a limited finger grip. Brochures from Lyle O. Otto, Hospital Appliances, 2801 Texas Avenue South, St. Louis Park, Minnesota 55426.

Hydroponic gardening: "A firm here in Pasadena sells a kit for around $35. Plants can be grown indoors using no dirt if a window with a southern exposure is available." Learning Laboratory: "We have designed a course to help counselors be more effective in serving the severely disabled. We give the course about once a month for 12 of our counselors from all over the state. We have 'trained' over 200. It has been very successful."
Mobility Evaluation for Driving for Severely Disabled Persons. "This is also a hit. We equip the cars or vans with custom devices that our rehab, engineer makes for the individual. We are getting quite a few persons so severely disabled that they would be turned down by most evaluation centers." A. I. Garris, California Department of Rehabilitation, 214, 7601 East Imperial Highway, Downey, California 90242.

One Arm Fishing Gear. "After I had a stroke in 1962 I worked hard to devise ways of fishing again, using techniques such as manipulating the line through my front teeth. Now there are some commercially made devices for the one armed angler: a rod holding harness and a left-handed spin-cast reel. For prices and a brochure, write to: The Garcia Corporation, 329 Alfred Avenue, Teaneck, New Jersey 07666. Virgil Ward made a TV film of me trout fishing which was shown in 185 cities last spring and summer." Norton S. Sanders, 701 Westgate Avenue, University City, Missouri 63130.

For Sale: New Dodge Van with Lift. "76 Royal Sportman, blue and white, Double D lift, automatic doors, side entrance, radial tires, motorized captain's swivel seat, fiber glass top, extended doors, a/c, radio, 318-V8, torque flight transmission, lock downs. Only 3 weeks old! Call 314-436-3600 or write Bernie Estrin, 440 Mansion House Center—TWA, St. Louis, Missouri 63102.

The Mandi-Stick. "The activities of the highest level quads (C-1 and C-2) have been very limited because they cannot move their necks or hold a mouthstick firmly.

"For these quads, we have designed the Mandi-Stick, a new concept in mouthsticks using the one part of the body that they can move in all directions: the mandible (lower jaw). We had the device attached to the mandible by means of a deep impression of the teeth made in acrylic securely placed on the underneath side of a flat horseshoe-shaped mouthpiece. To secure the device, a chin harness is used. "Now C-1 quads who were not expected to do much by themselves can do math, write long hand, draw, paint, type, and turn pages.

"Requests for detailed information on the Mandi-Stick are welcome. Write to Arthur Heyer, Neuromuscular Engineering, 500 Hut, Rancho Los Amigos Hospital, 7601 East Imperial Highway, Downey, California 90242."

NUTRITION

Self-Help to Health. "My ignorance of the laws of good health contributed to my falling victim to polio in 1951. For the past 10 years or so I have been concentrating on the study of modern nutrition-vitamin-mineral therapy with the aim of building maximum optimum health. I have over 70 recent books in my library on self-help to health by nutrition as chronicled by world famous biochemists and metabolic nutritionists. They could be a great help to other disabled in avoiding respiratory ills, etc., by learning about proper diet and the whys and wherefores.

"Here are brief reviews of the 10 that I consider of most value. I shall be happy to send a mimeographed copy of the entire list to any Gazette reader who sends me a request with a self-addressed, stamped envelope: Mrs. Ruth Anne Black, 2431 Benjamin Drive, Mountain View, California 94043."

- Psycho-Diethetics by Dr. E. Cheraskin & Dr. W. M. Ringsdorf, Jr., with Arline Brecher (Stein & Day Pub., New York, 1974) 228 pp., $7.95. "It's not what's eating you, it's what you're eating." Food is the key to emotional health, but you don't have to suffer from emotional distress to benefit from this book which provides an optimal diet to correct or prevent metabolic distortions that can create emotional ailments.

- Megaminerals For Your Nerves by Dr. H. L. Newbold (Peter Wyden Pub., New York, 1975) 360 pp., $11.95. How nutrition affects the nervous system, how food allergies and nutritional addictions can shatter your nerves, how vitamins help control your nerves, how minerals help to control your nerves.

- Nutrition Against Disease by Roger J. Williams (Putnam Pub. Corp., New York, 1971) 319 pp., $7.50. Internationally respected biochemist believes we already have enough knowledge to mount an effective campaign of nutritional prevention against a wide variety of deadly diseases.

- Sweet and Dangerous by Dr. John Yudkin (Peter Wyden, Inc., Pub., New York, 1972) Bantam Books, $1.95. We have become a nation of sugar addicts without realizing it—learn what this white poison can do to your health.

- The Healing Factor—Vitamin C Against Disease by Irwin Stone. (Paperback, $1.95.) Forty years of research have convinced this world famous biochemist that vitamin C is a vital healing factor against a wide spectrum of diseases, including the common cold, heart disease, mental illness, and cancer.

- Nutrition and Your Mind by George Watson, Ph. D. (Paperback, $1.95.) How you may treat and avoid emotional problems through proper diet. Dr. Watson, a research psychobiologist, maintains that much erratic human behavior has no psychological meaning or reason at all, but is the result of an improperly nourished brain.

- Confessions of a Sneaky Organic Cook (or How To Make Your Family Healthy When They're Not Looking) by Jane Kinderlehner (Rodale Press, Inc., Emmaus, Pennsylvania, 1971) 245 pp., $6.95. How to prepare vitamin-rich, mineral-full meals. Hundreds of tested recipes, as well as information on relationships between vitamins and minerals and your health.

- Vitamin E for Ailing and Healthy Hearts by Dr. Wilfrid E. Shute & Harold J. Taub. (Paperback, $1.65, Pyramid Books, New York) How vitamin E may help prevent some types of heart disease and control others. Based on more than 25 years of successful treatment of over 30,000 cardiac patients.

- Let's Eat Right To Keep Fit by Adelle Davis (Signet Book #5329, $1.75, 1972) A nutrition classic by a pioneer nutritionist.

- Let's Get Well by Adelle Davis (Signet Book #5347, $1.95) Almost an encyclopedia of information about common diseases and illnesses and how to assist medical treatment with good nutrition and vitamin therapy.
Potpourri

by Gini Laurie

Justice William O. Douglas:
Our society has an obligation to provide the handicapped with the means to enjoy their basic civil rights: the right to vote, the right to gainful employment, the right to equal educational opportunities, and freedom of movement.

Legislation eliminating environmental barriers for the physically disabled has improved the accessibility of transportation systems and federally financed buildings, thereby increasing the mobility of the handicapped. With increased mobility, disabled people have the opportunity to become active participants in the world around them.

Attitudinal barriers are more difficult to eradicate. Therefore, we need massive re-education programs, particularly for potential employers, to stress the contributions handicapped persons can offer to business and communities.

Affirmative Action

The official Section 503 regulations were published on April 16, 1976. For a copy, send 75¢ to Superintendent of Documents, Public Documents Department, USGPO, Washington, DC 20402, requesting Federal Register Vol. 41, No. 75.

"Call for Compliance," a hotline service, provides information on the new regulations governing Section 503. The nonprofit organization, Mainstream, Inc., answers questions from contractors and individuals. Call: 202-833-1139.

The West Virginia Research and Training Center, West Virginia U., 509 Allen Hall, Morgantown, West Virginia 26506, has received a training grant from RSA/DHEW to develop a model Affirmative Action plan for businesses and to train rehabilitation agencies.

Architectural Barriers
Access '76: A Blueprint for Action. A summary of methods for modifying or removing actual barriers in Boston's historical and cultural sites. Access to Boston '76. Under the aegis of the Easter Seal Society a group of community agencies compiled this excellent guide to historical and cultural sites and support facilities. Both of these useful publications are available from Easter Seal Society, 14 Somerset Street, Boston, Massachusetts 02108.

People are asking about . . . displaying the symbol of access. A succinct guide to using the symbol that is available from the President's Committee on Employment of the Handicapped, Washington, DC 20210.

Accessible Hotels and Meeting Places. Dr. Andrew S. Adams, U.S. Commissioner of Rehabilitation Services, took a very positive step by issuing the following policy at the National Paraplegia Foundation (NPF) Convention in August, 1976, at St. Petersburg, Florida: "For the conduct of meetings, conferences and business, it is expected that all grantees and contractors awarded funds by the Rehabilitation Services Administration will use facilities that are architecturally accessible . . ."

The last two conventions of the NPF have had an impact on the accessibility of the two hotels used: NPF's publication, Paraplegia Life, listed the adaptations made by Ft. Worth's Hotel Sheraton in 1975. Kirby Payne, manager of the St. Petersburg Hilton, summarized the experiences of his hotel with the 1976 convention. Following are excerpts from Mr. Payne's memo, titled Preparing for and Profiting from Doing Business with the Disabled:

"Once you get your hotel physically and emotionally adjusted to paraplegics, they are easier to work with than most, and also profitable . . . We did not expect the group to out-drink most other conventions, but they did, which gave us an unexpected boost in beverage revenue . . . . The lounge was lively with people dancing (in wheelchairs, no less), singing, clapping, and really relaxing . . . . Meeting rooms were easier to set—not as many chairs were needed . . . . All buffets and cash bars were set up so that people in wheelchairs could reach them . . . . During peak period of registration, we moved our portable key rack and room registration over to the convention registration . . . . Quite a few chairs were taken out of the lounge and dining rooms, and furniture rearranged. Some traffic patterns were changed also . . . . Our elevators were timed properly for large crowds so three wheelchairs were no more of a problem than 15 able-bodied convention goers . . . . Several partitions and doors were taken out of each public restroom; wire stringers and shower curtains were installed. We shall probably install accessible stalls at a later date . . . . Maids were instructed not to move items of furniture moved by the guests and to leave personal articles where the guests left them rather than tidying up the room . . . . The local NPF Chapter assisted us in making our pool accessible with lifts. (This type of equipment should be installed and tested well before the group's arrival) . . . . It was a very enjoyable and profitable week."

Additional information available from Kirby Payne, Manager, St. Petersburg Hilton, 333 First Street South, St. Petersburg, Florida 33701 and the National Paraplegia Foundation, 333 North Michigan Avenue, Chicago, Illinois 60601.


Urban Wheelchair Use, A Human Factors Analysis. A research project report by a group of students at the Illinois Institute of Technology. 21 pages. $2. These three helpful publications are available from Access Chicago, Rehabilitation Institute of Chicago, 345 East Superior Street, Chicago, Illinois 60611.

Funding Guide for the Removal of Environmental Barriers. This concise guide is free from Architectural and Transportation Barriers Compliance Board, 330 C Street, SW, Washington, DC 20201.

Removing Architectural Barriers. Illustrated Handbook of the 1973 New Mexico Uniform Building Code. Division of Vocational Rehabilitation, New Mexico Department of Education. P.O. Box 1830, Santa Fe, New Mexico 87503.


Accessibility signs. “Our NPF chapter now sells a complete line of both the signs and the decals of the international symbol of wheelchair accessibility.” Free brochure from Ellen D. Daly, Greater Milwaukee Area Chapter, National Paraplegia Foundation, 3575 North Oakland Avenue, Milwaukee, Wisconsin 53211.

Barrier Free Environments, Inc., a design firm headed by a paraplegic, Ronald L. Mace, AIA, specializes in design for people with disabilities and offers technical assistance, consulting services, and educational and training materials on design for the disabled. Its two recent publications are required reading for everyone concerned with accessibility and are $2 each from Barrier Free Environments, Inc., P.O. Box 53446, Fayetteville, North Carolina 28305:


Design of Bathroom Fixtures and Controls for the Able-Bodied and the Disabled. The Division of Architecture and Environmental Design of the College of Architecture and Urban Studies at Virginia Polytechnic Institute and State University, Blacksburg, Virginia 24061, has received a two-year research grant from HEW to design and test bathroom fixtures. For further information, contact Professor Pascal M. Malassigne.

Access to America: a 300-page compendium of federal and state legislation that covers codes, statutes, and laws pertaining to curb cuts, polling places, license plates, and the elimination of transportation and architectural barriers. $15 from Michigan Center for a Barrier Free Environment, 6522 Brush Street, Detroit, Michigan 48202.

Environmental barriers consultant. Cheryl A. Davis, a paraplegic, is employed as an environmental/service needs specialist by the Massachusetts Department of Community Affairs and as a consultant on the environmental needs of the handicapped by Camelot Research, Inc. She has had practical experience in service planning and barrier-free design. “I am especially interested in providing assistance to federal contractors and educational institutions in their development of affirmative action programs, with special attention to offering cost-effective means of eliminating environmental barriers.”

Address: 80 West Dedham Street, Apartment 1212, Boston, Massachusetts 02118.

Arts

Arts and the Handicapped. An Issue of Access. A Report from Education Facilities Laboratories and the National Endowment for the Arts. 78 pages. Order from EFL, 850 Third Avenue, New York, New York 10022. $4. This charming publication is an excellent guide for all types of disability to accessible theaters, museums, colleges, special schools, community service centers, etc.

Kenny International Art Show by Disabled Artists is held annually in the late summer and early fall. Entrance requirements available from Mrs. Maggie Ruff, Chairman, % Sister Kenney Institute, 1800 Chicago Avenue, Minneapolis, Minnesota 55404.

Materials on Creative Arts (Arts, Crafts, Dance, Drama and Music) for Persons with Handicapping Conditions. An analysis of program and research literature, resource persons, and related associations. 104 pages. $3.50 from AAHPER Publications-Sales, 1201 16th St., N.W., Washington, DC 20036.

We’re pleased that you are interested in making the arts accessible to everyone. Free pamphlet listing resource organizations and materials available from: ARTS, Box 2040, Grand Central Station, New York, New York 10017.

Art Therapy In Theory and Practice. By Elinor Ulman and Penny Dachinger. This fascinating collection of articles from The American Journal of Art Therapy, originally entitled The Bulletin of Art Therapy, traces the development of this form of therapy over the past 30 years. The 488-page book includes information on existing programs, as well as the development of new techniques. Published in January, 1976, the book is available from Schocken Books, 200 Madison Avenue, New York, New York 10016. Price: $15.

Attendants

The Federal Minimum Wage became applicable to household workers in 1974. As of January 1, 1977, household workers are entitled to a minimum wage of $2.30 per hour. The National Committee of Household Employment (NCHE) includes the following in its code of standards for household workers:

Sick leave: Employees should receive at least one day of paid sick
leave a year for each day per week worked.

Vacations: Full-time workers should receive two weeks of paid vacation for one year of service. Part-time employees should receive at least two days of paid vacation a year for each day per week worked. For longer service there should be an increase in paid vacation time.

Holidays: Live-in workers should receive a minimum of eight legal holidays with pay per year. Full-time live-out employees should receive the equivalent of six legal holidays with pay a year. A day worker should receive at least one legal holiday a year.

Attitudinal Barriers/Publicity
English TV Programme for Disabled. LINK, the first continuous nationwide series for disabled people, deals with all disabled people—physical and mental, old and young, deaf and blind. Aimed at raising awareness, it is divided into two sections—an information section dealing with aids, income, and services and a discussion section reassessing traditional attitudes toward disability. ATV House, 17 Great Cumberland Place, London W1A 1AG.

Course for Able-bodied Students on the problems and assets of the disabled person was sponsored by Project Outreach and Disabled Student Services, 2211 Michigan Union, University of Michigan, Ann Arbor, Michigan 48109.

Publicity Tips, a series of guides to media coverage for small organizations. Free from President's Committee on Employment of the Handicapped, Washington, DC 20210

Weekly Radio Program—The Disabled—Rights and Wrongs. Hosted by Bob Moss, founder of Paralyzed Veterans of America and the National Paraplegia Foundation, the program is heard on Wednesdays at 3:30 PM over WNYE-FM, NY. 91.5. The program is available to other stations on request. It is being carried by WNDU in South Bend, Indiana, and WLRN-FM in Miami, Florida. Bob Moss, 56 Carriage Lane, Roslyn Heights, New York 11577.

The Gray Panthers, an activist group of 7000 old and young striving to break the barriers of ageism. The group shares many problems with the disabled, particularly in the areas of housing and transportation, and members have joined with disabled groups in many areas. 52 includes membership and a newsletter, The Network.

Blind
A monthly braille information service for blind psychologists and their employers is free to blind persons in the UK, USA, and Canada. The pilot plan of braille abstracts is offered in cooperation with the American Psychiatric Association and Warwick Research Unit for the Blind, University of Warwick, Coventry CV4, England.

Toll-free information service. The National Blindness Information Center, Suite 212, 1346 Connecticut Avenue, NW, Washington, DC 20036, will answer questions by phone (800-424-9770) or by letter. Callers will be put in touch with local agencies or receive general information.

Free braille calendars, cassettes of Catholic periodicals, and taped books are available to any person who is blind or partially sighted in U.S. and Canada through the Xavier Society for the Blind in New York. Write: Sight, Catholic Golden Age, Scranton Life Building, Scranton, Pennsylvania 18503.

Banking for the blind. The American National Bank, 6639 S. Kingshighway, St. Louis, Missouri 63109, offers services for the visually handicapped that include a check-writing guide and braille statements.

Device to enable blind persons to use electronic calculators and other business machines. Brother Gabriel Kane of Manhattan College, Manhattan College Parkway, Riverdale, Bronx, New York 10471, has devised "a tactile numeric display device" and a companion "translator." The blind person can thus sense a specific digit. The final result is a series of digits with a readout in electrified braille.

Cats and Dogs
Catnip Mice. Every Christmas the cats of the Gazette receive a present of irresistible catnip mice from Dr. Donald W. Hey, a wheelchaired veterinarian. Our cats recommend the catnip enthusiastically! 4 for $1 from RR3, Box 450, Webster, Massachusetts 01570.

Handi-Dogs. An obedience class for the dogs of disabled and elderly persons teaches useful skills such as picking up dropped objects, barking on command and fetching a newspaper. Natalie Carlton, Handi-Dogs, 5332 East Rosewood, Tucson, Arizona 85711.

Hearing-Ear Dogs. Using the techniques for training seeing-eye dogs, a non-profit group is training hearing-ear dogs to bark in response to a ringing telephone, a doorbell, an oven timer, a crying baby, or whatever a deaf individual wants. Douglas E. Wachs, Public Relations Department, 3M Company, P.O. Box 33600, St. Paul, Minnesota 55133.

Children

Clothing
Convenience Clothing and Closures. An attractive and useful booklet filled with ideas for using zippers and Velcro to make dressing easier for everyone. Free from Talon Educational Service, 1777 Boston Post Road, Milford, Connecticut 06460.

A trio of ladies have formed a business to make clothing for the wheelchaired and incontinent. The basic styles are wrap skirts with Velcro closings and pants with drop seats. Brochure from PTL Designs, P.O. Box 364, Stillwater, Oklahoma 74074.


Rehabilitation Gazette
Deaf
The September 1976 issue of Performance, free publication of The President's Committee on Employment of the Handicapped, Washington, DC 20210, has several items of special interest to those who are deaf. The PCEH now has a TTY number: (202) 653-5337.

MCM (Manual Communications Module), weighs only 3 lbs. and is completely portable. Information from: Micon Industries, 252 Oak Street, Oakland, California 94607.

Congressman Tom Harkin (D-Iowa) is vitally interested in the rights of the deaf since he has a brother who is deaf. He urges the deaf to be assertive and to write to their Congressmen and Senators and express their needs. Congressman Harkin's address: U.S. House of Representatives, 514 Cannon House Office Building, Washington, DC 20515.

Education
First Ponder, Then Dare. Illustrated brochure of 14 accessible colleges and universities. 1975. Free from The President's Committee on Employment of the Handicapped, Washington, DC 20210.

Correspondence Course in Judaism. A free catalog lists 13 courses and a fascinating list of relevant books. About 600 persons in 36 states and abroad are taking courses. Each of the students is assigned an individual instructor in Jewish studies at various colleges. Write: The Academy for Jewish Studies Without Walls, 165 East 56 Street, New York, New York 10022.

College in a Hospital. Texas Jaycee Campus of Victoria College offers college classes on the grounds of the Texas Rehabilitation Hospital. About 30 hospital residents are working toward associate of arts degrees. Attendante care, room, board, and therapy are provided. Details from the college, Box 58, Gonzales, Texas 78629.

Employment

Be Informed on Finding a Job. Hints on opportunities, want ads, applications, and interviews. $15 from New Readers Press, Box 131, Syracuse, New York 13210.

Out of Work. Information on unemployment insurance, welfare, unions, veterans' benefits, voc. rehab., and job training. $15 from New Readers Press, Box 131, Syracuse, New York 13210.

The Industry-Labor Council of the White House Conference on Handicapped Individuals has named the well-known expert on handicapped persons, William P. McCaffery, as executive director. Bill was executive secretary of the President's Committee on Employment of the Handicapped from 1947 to 1973. The co-chairman of the Council are John R. Opel, president of IBM, and George Meaney, president of AFL-CIO. For information about the Council's plans for the four regional meetings of management and labor, write to: 1111 20th Street, NW, Room 636, Washington, DC 20036.

The Response lists hundreds of organizations in the U.S. and around the world that are seeking volunteer lay persons to work with Catholic missionary priests and religious. Most missions furnish room and board and pay $50 or so a month. The booklet is $2 from International Liaison, 39 Lackawanna Place, Bloomfield, New Jersey 07003.

Films
I Am Not What You See. 16 mm color; 27:50 minutes. An interview with Sound Diamond of Philadelphia, who is quadriplegic because of cerebral palsy. Now a practicing psychologist, working on her PhD, she tells of her struggles and of her internal feeling, "I am not a disabled person. I am not what you see visually. I am a woman." Available from CBC Educational Films, P.O. Box 500, Terminal 'A', Toronto, Ontario M5W 1E6, Canada.

Walk Ashile In My Shoes. 16 mm color; 27:05 minutes. The film, produced for the Transportation Development Agency, underlines the problems faced by the disabled because of transportation systems, inaccessible buildings, and public attitudes. Available from The National Film Board, Box 6100, Montreal, Quebec H3C 3B5, Canada.


Water Free. A film on swimming for the disabled, presented by the Association of Swimming Therapy, illustrates progressive teaching stages and activities. For rent or for sale from: Town and Country Productions, Ltd., 21 Cheyne Row, Chelsea, London SW3, England.

General

Help: The Useful Almanac, 1976-77. A 410-page guide to buying wisely and living economically. The variety of information ranges from how to qualify for food stamps to how to reduce electric bills and how to avoid high-cost funerals. $4.95 paperback from Consumer News, Inc., 813 National Press Building, Washington, DC 20045.

Free Mail Privileges. According to Anteas, March 1976, you may be able to send and receive specified types of material without charge. (Handwritten letters are not mailable free of charge.) In addition to the blind, other disabilities which prevent normal reading such as paralysis or lack of coordination or confinement to iron lungs or other mechanical devices are included in the free mailing privileges.

Certification of disability, such as CP, MS, MD, polio, SCI, etc. must be
obtained from a professional authority. Apply to your local office for information on Part 138 of the Post Office Manual. Additional information from: General Manager, Domestic Mail Classification Division, Office of Mail Classification, United States Postal Service, Washington, DC 20260. (Let us know your experiences; we’ll pass them on to others in the next issue. We hope to see many “Free Matter for the Blind and Handicapped” stamped on envelopes instead of postage stamps.)

Excerpts from the article, Images, Words, & Identity, by Eric A. Gentile and Judy K. Taylor, Handicapper Programs, W 409 Library Building, M.S.U., East Lansing, Michigan 48824. “Identity is quite often shaped by the language we use. . . To build positive identities in relation to persons experiencing handicaps we must begin to positize the American Language. . . . Today, ‘dis’ as a prefix has a totally negative meaning. ‘Disability’ is defined as: ‘inability; lack of ability; a legal disqualification or incapacity.’ On the other hand, the modern definition of ‘handicapper’ has a positive meaning. A modern ‘handicapper’ is one who determines the direction for and extent of his/her own potential and destiny regardless of physical characteristics. One who does not accept the arbitrary or inactive role in life usually associated with certain physical characteristics.”

Free copies of the full article complete with graphics are available on request from the authors and they welcome reader reactions.

How to Get the Computer to . . . . (For those who don’t know the first thing about computers). By Arthur S. Tabachneck. Free from Research and Training Center, West Virginia Rehabilitation Center, Institute, West Virginia 25512.

The National Center for Disease Control warns that a massive outbreak of polio could occur unless about 5 million children are vaccinated. Both middle class and ghetto children are among those not immunized.

A Survey of the Severely Disabled in Iowa. Client and Counselor Perceptions of Vocational Deterrents and Rehabilitation Needs. May-June 1975. This study of 650 disabled individuals was supported by an Innovation and Expansion Grant from HEW. Available from Easter Seal Society for Crippled Children & Adults of Iowa, Inc., P.O. Box 4002, Des Moines, Iowa 50333.

The annual Sickroom Service seminars in October in Milwaukee attract about 700 medical professionals from across the country. The workshops and exhibits cover the entire range of health care. Write to Joy Lewis, 2534 S. Kinnickinnic Avenue, Milwaukee, Wisconsin 53207.

A Fund Raising Primer. Guide to writing proposals. Bibliography on funding sources and direct mail solicitation. $3.40 from Together, Inc., Human Resources Consultants, P.O. Box 52528, Tulsa, Oklahoma 74152.

How to Provide for Their Future. Suggestions for Parents Concerned with Providing Lifetime Protection for a Retarded Son or Daughter. This informative pamphlet is useful to all disabled. It includes SSI, Medicaid, Medicare, etc. Available from National Association for Retarded Citizens, 2709 Avenue E East, P.O. Box 6109, Arlington, Texas 76011.

Sexism and the Disabled Woman. Do disabled women constitute a “double-disadvantaged” minority? What is the impact of sexism in our society on the options and opportunities of the disabled woman? To what extent do cultural and religious factors delineate her role in society? Bette Knapp, a political scientist specializing in international affairs and a quad resulting from juvenile rheumatoid arthritis, is engaged in preliminary research on this issue. She would like to hear from anyone interested in the subject, as well as from disabled women who would be interested in forming a worldwide network to explore the issue and to exchange information. Write: R. E. Knapp, chairperson, MAINSTREAM, 560 Riverside Drive, Apt 9G, New York, New York 10027.

Independent Living
U.S. Department of Agriculture. For information on programs designed to help learn domestic skills and live independently, contact: (1) County Extension Agent; (2) Home Economics, State Land-Grant University; (3) Extension Service Liaison-Handicapped, USDA, Washington, DC 20250.


The Institute for Consumer Ergonomics, University of Technology, Loughborough, Leicestershire LE11 3TU, England, has been commissioned by the Department of Health and Social Security to evaluate eating, drinking, and personal hygiene aids. For further information, contact Margaret Robinson, Research Associate.

How I Live With ALS. By Robert G. Dicic. Free from Amyotrophic Lateral Sclerosis Society of America, 12011 San Vicente Boulevard, Los Angeles, California 90049.


Illinois “Hotline for Handicapped Citizens.” Individuals with problems may call collect: 312-793-5000. The service is sponsored by the Governor’s Committee on the Handicapped.

MS Home Care Course has been developed in conjunction with the American National Red Cross. Information on the course, which is geared to training relatives and friends, is available from local MS chapters.

Aids to the Handicapped. Booklet on homemaking and grooming. 35¢ from Extension Publications, 318

REHABILITATION GAZETTE
Ricks Hall, North Carolina State University at Raleigh, North Carolina 27607.

View of Life. A booklet written by a talented young writer, Henry Henscheid, who is wheelchair-bound. 25¢ from Easter Seal Society for Children with Crippled Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois 60612.

The best bargain in self-help booklets for every type of disability is only $1.25 for 124 pages from the Arthritis Foundation, 1212 Avenue of the Americas, New York, New York 10036. Every phase of living is covered. The hundreds of aids included are relatively inexpensive and easily available. Request the booklet, Self-Help Manual for Arthritis Patients.

On Your Own. This very helpful newsletter has made its 1975 copies into a booklet for $1 from Office of Independent Study, Division of Continuing Education, P.O. Box 2967, The University of Alabama, University, Alabama 35486.

Dr. John Knowles, president of the Rockefeller Foundation, says "... the next major advance in the health of the American people will result only from that which the individual is willing to do for himself."

Information Services

Call for Action (CFA) offers confidential telephone assistance in 42 cities. Staffed by 2500 volunteers, CFA assisted 300,000 in 1975 via the radio and television stations that participate in the program. Calls for assistance are not broadcast. CFA volunteers record the information, which is kept confidential, and refer the caller to the proper agency. Two weeks later, CFA makes a follow-up call for a progress check. Volunteers usually work Monday through Friday, from 11 a.m. to 1 p.m.

CFA volunteers have directories of public and private agencies and organizations which furnish information on legal services, pensions, workmen's compensation, utility shut-offs, and various forms of bureaucratic red tape and programmatic failures.

In addition to suggesting that the information services would be helpful to readers we think that organizations of the disabled should notify their local CFA of their availability to assist other disabled with problems.

Watch for Call for Action ad by one of your stations. Otherwise, call them all and see which one has the service.

International


Survey of Institutions for the Handicapped in India. Edited by Mrs. Kamala V. Nimkar under the auspices of the Indian Society for Rehabilitation of the Handicapped. 1975. A comprehensive and well organized compilation of information on 589 institutions by states in the categories of mentally retarded, orthopedically handicapped, deaf, and blind associations. $1 or Rs. 5— from N.R.T., The Amerind, 15th Road, Khar, Bombay 400 052, India.


Proceedings of the European Conference on Integration of the Severely Disabled into the Community, which met in September 1974 in Portugal, are available for $5 from the Assistant Secretary General of the European Conference, Center for Medical Rehabilitation, Alcoita-Estoril, Portugal.

Mobility International. For the past four years The Central Bureau for Educational Visits and Exchanges, 44 Baker Street, London W1M 2HJ, England, has been developing programs to give opportunities to young disabled. More than 80 projects have been developed through its committees, Disabled International Visits and Exchanges (DIVE) and the Committee for Hearing Impaired Visits and Exchanges (CHIVE). For details, subscribe to the Bureau's publication, Intercon at £1.

Home-to-Home Exchanges. Mrs. Kay Duncaife, a member of DIVE, is building a register of families who will host a young disabled visitor. Details: Kay Duncaife, New Forest Continental Youth Centre, Corner Cottage, Hangersley, Ringwood, Hampshire, England.


Director/gerente: J. Hugo Monroy P. Circulacion: 1,000 ejemplares. (ED: Congratulations, ALJAC, on the excellence of your newsletter and best wishes for the continued growth of your organization!)

Germany has a quota system that requires an employer to have a minimum of 8% of his employed classified as disabled or pay a fine. The fines are used for vocational rehabilitation and sheltered workshops.

New Dimensions in Rehabilitation. Planned for release in 1977, this book will include a selection of papers presented during the 13th World Congress. In English; 420 pages. Prepublication price, $15. Order from: Israel Society for Rehabilitation of the Disabled, 10 Ibn Gvirol Street, Tel Aviv, Israel.

Legal Rights

A Handbook on the Legal Rights of Handicapped People. This excellent summary covers the fundamental rights of disabled individuals in the District of Columbia, Maryland, and Virginia. All states should have similar handbooks! Available from The President's Committee on Employment of the Handicapped, Washington, DC 20210.

Rights Handbook of Ohio's Physically Handicapped. $2 from Ohio Easter Seal Society, P.O. Box 6728, Columbus, Ohio 43209.

Consumer Rights for Disabled Citizens. A comprehensive outline of the problems of citizens with disabilities in the market place, and with transportation, SSI, Medicare, housing, etc. The appendix includes sources of service. $2 from Department of Consumer Affairs.
City of New York, 50 Lafayette Street, New York, New York 10013.


“Crips” Unite to Enforce Symbolic Laws: Legal Aid for the Disabled: An Overview. By Jack Achtenberg. An excellent summary of significant information regarding the disabled, the article maps out the areas in which lawsuits seem most appropriate. The article appeared in Vol. 4, No. 2, Fall 1975 of the University of San Fernando Valley Law Review. The issue may be purchased for $6 from: Law Review, U of San Fernando Valley, 8353 Sepulveda Boulevard, Sepulveda, California 91343.

Legislation
Advocates for the Handicapped, 77 West Washington, Chicago, Illinois 60602. This group of 22 volunteer lawyers and law students is concentrating on legal action against all types of discrimination. They are particularly interested in precedent-setting issues. A major goal is to develop a log of court decisions concerning the disabled for the use of all lawyers. The board is a mixture of disabled and nondisabled and professionals and nonprofessionals that meets monthly.

A report on the effectiveness of the Architectural Barriers Act of 1968 (P.L. 90-480) has been published by the House Public Works and Transportation Committee. Copies are available from The President’s Committee on Employment of the Handicapped, Washington, DC 20210.

Guidebook to state and federal legislation and court cases pertaining to the physically handicapped will be published in early 1977 by Mick Joyce, Midwest Information Center for Equality of the Handicapped, CA 106, Southwest State University, Marshall, Minnesota 56258.


Congress and Health. A guide to the legislative process and the major health committees. $2.50.

Congressional Staff Aides for Health Legislation. Directory of the health-oriented staff members of senators and congressmen. $1.25.


The three publications are available from National Health Council, 1730 Broadway, New York, New York 10019.


Tax Exemption Legislation for 501(c)(3) organizations which permits lobbying up to 20% of annual expenditures was passed in September, 1976, as part of the Tax Reform Act, HR 10612. Copies of HR Report No. 94-1210 are available through your member of the U.S. House of Representatives.

HR 6691 “Attendant care bill” would amend the Social Security Act Title XX to provide that employable persons unable to care for their personal needs could be eligible for home health aide services. Introduced in May, 1975, it was sent to the Committee on Interstate & Foreign Commerce.

Recreation

One-Arm Dove Hunt Association, Box 582, Olney, Texas 76734. Designed for arm or hand amputees, the annual hunt is held in September. In addition to the dove hunt, the day’s activities include a dove dinner and Texas-type events.

The Architectural and Transportation Barriers Compliance Board held a national hearing on recreation in Boston in October, 1976. The information will be used to formulate recommendations for meeting the recreation needs of the disabled. To request a copy of the hearing, write to the Board at Washington, DC 20201.

$10,000 design competition to develop a playground where disabled and nondisabled children can play together was announced by the co-sponsors, Eastern RVA and New York City Parks Department and the City Planning Commission in the fall of 1976.

Sport for the Disabled. By Sir Ludwig Guttmann. A comprehensive guide. This was mentioned in the Newsletter of the Spinal Injuries Association, 21 Cedar Close, Patchway, Bristol BS12 5HD, England. We have not received any further information. We would like to have the price, etc.

Sex

Sex Education for the Developmentally Disabled. By H. L. Fischer, University Park Press, Chamber of Commerce Building, Baltimore, Maryland 21202. $4.75. A guide to help parents, teachers, and professionals explain concepts of sexual development.


Entitled to Love. The Sexual and Emotional Needs of the Handicapped. By Wendy Greengross, a London GP, marriage counselor, journalist, and
broadcasters. 128 pages. Paperback only. £1.95 and 21p packing ( $4.25).
Published in April 1976 by Malaby Press (J. M. Dent) in association with National Fund for Research into Crippling Diseases, Vincent House, 1a Springfield Road, Horsham, Sussex, England.

Spinal Cord Injury

So You're Paralyzed. Guide for paras, guides, and their families is available from Spinal Injuries Association, 24 Nutford Place, London W1H 6AN, England. £1.30 to members, £2.30 to nonmembers. (About $2.60 and $4.60).

Responsibility for Decubiti. The Newsletter of the Spinal Injuries Association in England reports in its July 1976 issue that pressure sores are not a normal part of paralysis.

"... Their prevention has been established beyond doubt in the case of Mrs. Bliss v. Lewisham Group Hospital Management Committee. Any person developing sores in hospital should consider legal action against those responsible for bad nursing care."

New England Resource Directory 1976. This 146-page guide to programs and services for SCI is free from The Spinal Injury Foundation, 369 Elliot Street, Newton Upper Falls, Massachusetts 02164. Another recent publication, Standards and Criteria of Care, is also available.

California Regional Spinal Cord Injury Care System Home Care Manual. This is a splendid guide to self-care and to the teaching of other people to take care of one's needs. Available from Health Services Coordinator, 751 South Bascom Avenue, San Jose, California 95128.

Nursing Care of the Spinal Injured. Edited by Susan Purdy, RN, and Alan Dahart, RN. Comprehensive overview of care of both acute and chronic SCI's. $5 from National Paraplegia Foundation, 333 North Michigan Avenue, Chicago, Illinois 60601.


A National Spinal Cord Injury Data Research Center has been established at Good Samaritan Hospital in Phoenix, Arizona. The 10 regional spinal cord centers funded by RSA will feed data on status before injury, cause of injury, treatment, and rehabilitation. All centers and hospitals treating SCI will be invited to participate.

Investigation of Methods Suitable to Village Conditions for the Rehabilitation of Paraplegics and Quadriplegics. By Dr. Mary Verghees, formerly of C.M.C. Hospital in Vellore. Presently of Malankara Mission Hospital, Kolencherry P.O., Ernakulam Dt., Kerala, South India.

The National Paraplegia Foundation, L. W. Freeman Chapter, with the assistance of the Ostomy Association, presented a Visitiation Training Seminar in October, 1976, in Indianapolis, Indiana. The professionals represented on the program were: an attorney who handles malpractice cases, a former executive director of Goodwill Industries, a professor of anatomy, a physiatrist, a social worker, a professor of neurology, a nurse, a physical therapist, an occupational therapist, a rehabilitation counselor, the visitation chairman of a county agency, and the Director of Chaplain Services at Indiana University Medical Center.

As a result of the seminar, the following visitation recommendations have been implemented: (1) visitations will be made only by members who have completed a training program and have been certified; (2) each visit will be recorded and kept on file for follow-up; and (3) additional training through bi-weekly sessions in role playing using psychological techniques of paraphrasing will be required.

The all-day seminar was professionally recorded with financial assistance from the Lilly Endowment, Inc. These tapes will be transcribed and will be available to National Paraplegia Foundation chapter members at cost and to others for a nominal fee.

Contact: James K. Paulley, 1808 North Moreland, Indianapolis, Indiana 46222.

Psychological, Sexual, Social and Vocational Aspects of Spinal Cord Injury: A Selected Bibliography. Nearly 700 references are included. $2.95 from Gary T. Athelstan, PhD, Project Director, University of Minnesota, Department of Physical Medicine and Rehabilitation, Medical School, 860 Mayo Memorial Building, Box 297, Minneapolis, Minnesota 55455. Its usefulness is not limited to the spinal cord injured. An up-dated supplement will be available.

Selective Index of the Paraplegia News from July 1946 through December 1975. The 32-page index is available for $1.50 from PN Index, 935 Coastline Drive, Seal Beach, California 90740. Paraplegia News is of value to all disabled, as well as to paraplegics and quadriplegics. Published monthly, the yearly subscription rate is $4. A good buy!

Another publication that is a good buy for all disabled is the quarterly, Accent on Living. $3.50 from P.O. Box 700, Gillum Road & High Drive, Bloomington, Illinois 61701.

And still another is Achievement, a great bargain at $2 a year for this Lampsonian monthly from 925 N.E. 122nd Street, North Miami, Florida 33161.

Housing Alternatives for Individuals with Spinal Cord Injury. By Fred Fay, PhD. Limited copies of the paper are available for $2 from Fred at Box 337, 171 Harrison Avenue, Boston, Massachusetts 02111.

Practical Management of Spinal Injuries. By Alan G. Hardy, FRCS, and Reginald Elson, FRCS. For the medical profession, not the average disabled individual. £3.95. Churchill Livingstone, Medical Division of Longman Group Limited, 23 Ravelston Terrace, Edinburgh EH4 3TL, Scotland.

Spina bifida papers by Betty Pieper are available for $2 a set from Joyce Graves, 112 Hudson Street, South Glens Falls, New York 12801. The dozen papers include the following topics: Advocacy, shunts, urological care, skin care, sexuality, bowel management, financial aid, lobbying, and right to treatment.

Biofeedback In Neuromuscular Re-Education—History, Uses, Procedures. By Owen, Tomim, and Taylor. An introductory book written for both professional and lay persons who are interested in the applications of biofeedback methods to muscle re-education. A practical guide to the various applications of biofeedback techniques, $5.50 ($4.50 to disabled). Biofeedback Research Institute, 6325 Wilshire Boulevard, Los Angeles, California 90048.

Statement of Needs

Statistics

Transportation, Public


The details of a program to train bus operators to recognize the special needs of disabled and elderly passengers are available from Moss Rehabilitation Hospital, 12th Street & Tabor Road, Philadelphia, Pennsylvania 19141.

Organizations of disabled file suit to force accessible mass transit. On June 17, 1976 twelve organizations of the disabled and seven individuals filed suit against the Department of Transportation and the Urban Mass Transportation Administration to force the federal government to require that all buses used in mass transit be accessible to the disabled and elderly, including those in wheelchairs.


The combined membership of these organizations totals more than 5½ million people.

The cost of the lawsuit is partially supported by a grant to the Public Interest Law Center by The Max and Anna Levinson Foundation.

Siggi Shapiro, president of DIA of Pennsylvania, summarizes the feelings of the disabled and elderly, "Twenty years ago court action made it possible for blacks to sit anywhere in a bus—we want a court decision which will allow us to get on the bus."

On October 19, 1976 the California Department of Rehabilitation filed an action to join in the suit. The motion would authorize the State Department of Rehabilitation to appear in the action as Amicus Curiae. California's motion points up the fact that there are 3½ million chronically disabled in the state, of which about 750,000 are presently unable to use public transit.

MARTA Elderly and Handicapped Program. Summary of the Metropolitan Atlanta Rapid Transit Authority (MARTA) program is available free from MARTA, 1300 Equitable Building, 100 Peachtree Street, NW, Atlanta, Georgia 30303.

Equal Access to Public Transportation.
This handbook was compiled by the Public Interest Law Center in Philadelphia. It analyzes the law's application to equal access and deals with ways of implementing the right through advocacy, litigation, legislation, and rule making. Available free from The President's Committee on Employment of the Handicapped, Washington, DC 20210.

The Taxi Project: Realistic Solutions.
This 160-page book describes the taxis of the future which were exhibited at the Museum of Modern Art in mid-1976. $8.45 from Customer Sales Service, Museum of Modern Art, 11 West 53rd Street, New York, New York 10019. Some of the taxis include features to make them easily accessible to the elderly and the wheelchair.

Travel
Rocking Bed Travel Problems. "My husband and I enjoy travelling but trying to sleep in a chest respirator takes all the fun out of a vacation. I checked on using a rocking bed in a hospital but you have to enter the hospital just like a patient and pay regular room rates. What about 'home-swapping with someone that uses a rocking bed?'" Mrs. Betty Mielke, 115 Bischoff Street, Fond du Lac, Wisconsin 54935.

Using Iron Lungs in Great Britain's Hospitals. "I holidayed in England and Scotland with my sister, sleeping in hospitals in both countries and using their respirators. Everybody was most kind and helpful and I was quite a novelty to most of the staff who'd never seen an iron lung in use before." Ethna O'Dowd, Ward Seven, Cherry Orchard Hospital, Dublin 10, Eire.
English Students' Study Tour of Rome. England's Open University, which has over 1200 disabled students, arranged a study tour of Rome. Ten of the 21 tour members (ages ranging from 25 to 70) were wheelchair-bound, polio, multiple sclerosis, cerebral palsy, and an assortment of other disabilities. The details are delightfully told in a 144-page book edited by Rachel Bleackley. All royalties go to a trust set up to help future study tours. The tour organizer, Valerie Saunders, stresses: "We are a group of individuals, not just numbers in pages of bland statistics." Order from Educational Explorers Ltd., 40 Silver Street, Reading, Berkshire RG1 2SU, England. £1.65. Available in U.S. from Educational Solutions, Inc., 80 Fifth Avenue, New York, New York 10011.

List of Accessible Mexican Hotels. Seasoned traveler Barbara Carter, who is wheelchair-bound by polio, will share a mimeographed list of "sort-of-accessible hotels in picturesque Mexican towns." All hotels/motels listed are AAA-rated Good or Very Good. Send a stamped, self-addressed envelope to Barbara Carter, 1051 White Oak Avenue, Granada Hills, California 91344.

ACCESS WASHINGTON. A guide to Metropolitan Washington for the Physically Disabled is available free from Information Center for Handicapped Individuals, 1619 M Street, N.W., Washington, DC 20036.


International Bibliography of Guides. Free from Rehabilitation International Information Service, 6 Stiftung Rehabilitation, 6900 Heidelberg 1, P.O. Box 101409, West Germany.

Hotel guide for Handicapped. In both English and Danish this very attractive and informative booklet is available for U.S. $4 from Society and Home for Disabled, 34 Esplanaden, DK-1263, Copenhagen K, Denmark.

Nationwide tours on accessible buses will begin operation in January, 1977. Judd Jacobson, a quad, has been granted an Interstate Commerce Commission tour broker's license. Details from Judd, Flying Wheels Tours, 143 Bridge Street, Box 383, Owatonna, Minnesota 55060. He can design a motorcoach tour for any group of 15 persons anywhere in the U.S. or individuals can be dovetailed into planned tours.

On-campus vacations at colleges and universities range from $2 to $13 a night, usually $7, with meals at college prices and many on-campus activities free. Further information may be found in Guide to Low-Cost Vacations and Lodgings on College Campuses. One edition covers international accommodations, the other U.S. and Canada. Either may be ordered from: CMG Publications, P.O. Box 630, Princeton, New Jersey 08540 ($3.75). Another book, Where to Stay in the U.S.A. from 50 cents to $9 a Night, by the Council on International Educational Exchange is available at local bookstores.


Guide to Public Toilets in Scotland Accessible to People in Wheelchairs. This loo guide lists 114 toilets in 80 cities, towns, and villages. 25p (50c) from Scottish Council on Disability, 18/19 Claremont Crescent, Edinburgh EH7 4QD, Scotland.

TWA, 605 Third Avenue, New York, New York 10016, has published a brochure, "Consumer Information About Air Travel for the Handicapped."

Highway Rest Areas for Handicapped Travelers. More than 400 accessible rest stops in the U.S. are listed in this free booklet. Write: The President's Committee on Employment of the Handicapped, Washington, DC 20210.

Easy Wheelin' in Minnesota. Of the many guides to accessibility in the U.S. and abroad, this one has special personality. It was compiled by a quad, Robert R. Peters, One Timberglade Road, Bloomington, Minnesota 55437. It is available from Education Services Department, The Minneapolis Star, Minneapolis Tribune, 425 Portland Avenue, Minneapolis, Minnesota 55408.

Dialysis Worldwide for the Traveling Patient. Free pamphlet lists the facilities which have dialysis facilities. Write Leo Smerling, National Association of Patients on Hemodialysis and Transplantation, 505 Northern Boulevard, Great Neck, New York 11201.

Disabled Drivers. A report on the problems in about 25 countries. $2.50 from ICTA Information Centre, Fack S-161 25, Bromma 1, Sweden.

If you're in the Philadelphia area and want to enjoy a completely accessible nature center and trail, head for the Schuylkill Valley Nature Center at 520 East Willow Grove Avenue, Wyndmoor, Pennsylvania 19118. Its director, Dana W. Tobin, will welcome you warmly to the center and the trail. The 10’ wide, hard-surfaced trail has a built-in self-guided tour with tape-recorded messages on cartridges.

France has a new organization to help disabled travelers: Association pour le transport et le tourisme des malades et des handicapés (ATTMH), 19-21 rue Bertrand-de-Goth, 33000 Bordeaux.

Vacationlands New York State. Supplement for Handicapped and Senior Citizens. I. Section on Hudson Valley. The first accessibility guide of eleven sections of New York State.
U.S. Periodicals and Newsletters for the Disabled

Periodicals By The Disabled

Accent on Living. P.O. Box 700, Gillum Road & High Drive, Bloomington, Illinois 61701. Quarterly. National. $3 year.


Handy-Cap Horizons. 3250 E. Loretta Dr., Indianapolis, Indiana 46227. Quarterly. International travel. $3 year disabled; $6 year nondisabled.


New World. California Association for the Physically Handicapped, Inc., P.O. Box 229, Northridge, California 91324. Monthly. $5 year.


Paraplegia News. 935 Coastline Drive, Seal Beach, California 90740. Monthly. National. $4 year.

Rehabilitation Gazette. 4502 Maryland Avenue, St. Louis, Missouri 63108. Yearly. International. $3 disabled; $5 nondisabled.


Free Newsletters by Disability Groups

Amyotrophic Lateral Sclerosis Foundation, Inc., 2840 Adams Avenue, San Diego, California 92116. Quarterly. $1 year.

Arthrogryposis Association, 106 Herkimer Street, North Bellmore, New York 11710. Quarterly. $5 year.

Committee to Combat Huntington's Disease, 250 West 57th Street, New York, New York 10019. Quarterly. $5 year.

Friedreich's Ataxia Group in America, Inc. Box 11116, Oakland, California 94611. Quarterly. $5 year.

Little People of America, Inc., 1010 Hilltop Drive, E-1, Grapevine, Texas 76051. Monthly. $5 year.

Spina Bifida Association of America, 104 Fostome Avenue, New Castle, Delaware 19720. Quarterly. $5 year.

Stoke Clubs of America, 805-12th Street, Galveston, Texas 77550. Bimonthly. $5 year.

Free Periodicals for the Disabled

On Your Own. Division of Continuing Education, University of Alabama, P.O. Box 2967, University, Alabama 35486. Monthly. $5 year.


Amicas. National Center for Law and the Handicapped, Inc., 125 North Eddy Street, South Bend, Indiana 46617. Bimonthly. $5 year.

Free U.S. Government Newsletters


Programs for the Handicapped. Office for Handicapped Individuals, Washington, DC 20201. Quarterly. $5 year.

The President's Committee on Employment of the Handicapped, Washington, DC 20201: Performance, Feedback, Newsletter Committee on Recreation & Leisure, and Legislative Memo.
Canadian Quads in Hawaii

An Hawaiian holiday in March, 1976, for 14 severely disabled individuals from Aberhart Hospital in Edmonton, Alberta, was dreamed of and promoted by a respiratory polio quad, Gary McPherson. He began to plan in the summer of 1975, generating a tremendous amount of enthusiasm amongst the other patients. The whole thing seemed to catch fire. A sum of over $18,000 was raised in various ways, most of it by donations. The donations included $6000 from the Edmonton Civic Employees and other generous gifts from individuals and service clubs such as Rotary, Kiwanis, Legion, and Knights of Columbus. This meant that each disabled person was able to go for a very modest cost.

The Aberhart Hospital lent its wholehearted support to the project. According to Pierre Gariety, executive director of the Alberta Division, Canadian Paraplegic Association, "The fact that the patients had their own staff going over with them helped a good number of them to decide to go. Some of them had not been out of the hospital at all for a considerable period of time." The staff on the trip included a doctor, a respiratory therapist, two nurses, two certified nursing aides, one aide, five orderlies, and an electrician. Although the hospital paid their regular salaries, the staff members paid their own travel and other expenses for the trip. The staff helped feed and wash the patients, as well as lift wheelchairs up and downstairs. Each staff member had two or three days off during the two weeks in Hawaii.

The flight posed special problems to the airline, Wardair, since the group, most of them disabled by polio, included six who required respirators during the six to seven hour flight. This meant extensive mechanical changes to the plane’s power supply, borrowing special equipment, and some rule-bending by airport authorities. Wardair borrowed three power converters from Boeing in Seattle and oxygen from the University Hospital.

"Wardair was more than cooperative," says Gary. "They couldn’t do enough; there was no hesitation. When there was a problem, they didn’t say no but said they would look into it—and they did. If they said they were going to do something they did it. They also gave us practically a whole section in the no-smoking area to ourselves so those who could not sit up could lie down. A Wardair engineer traveled with us in case there would be difficulties."

After they arrived in Hawaii they used an excellent privately owned wheelchair cab service. As a group, they used the cab service four times; individual members used it frequently for shopping and sight-seeing trips.

Although their hotel, the Sheraton Waikiki, had accessible facilities for wheelchairs, it was necessary to remove several of the doors to make room for respiratory equipment. The group spent time relaxing by the hotel pool. Besides taking in the sun, they also took in some of the night life. They went on an island tour and visited the Polynesian Cultural Center, Sea Life Park, and the state capitol. Several people went on the Pearl Harbor midnight cruise while several others took in the island supper cruise.

The trip had a noticeable therapeutic effect on the disabled. People who use oxygen used less in Hawaii. Skin problems were lessened. They were more active, more outgoing, more optimistic there and they continued to be more active when they returned. Dr. James Archibald, resident in pulmonary care, who accompanied the group, attributed their improvement to their mental outlook and high spirits during the trip. "I think one of the best things about the trip was it showed the patients that such trips are possible."

For more details, write to Gary McPherson, Room 7127, Aberhart Hospital, Edmonton, Alberta T6G 2J3, Canada.
Hitch-Hiking Through Europe in a Wheelchair
by Solveig Kihlgren

Why is hitching only for able-bodied people? Why are youth hostels built with staircases? Last year I decided to discover Normandy in my wheelchair, getting around by hitch-hiking. After touring Normandy and visiting a friend in the lovely old town of Fecamp, I decided to cross to England and visit more friends by hitch-hiking.

My friends in London actually live far away from Central London so I had to go by train to Victoria. With the help of the friendly employees of British rails I managed a nice long staircase in the railway station. I often went around London by tube and I always found the employees of London transports ready to help me—unlike the employees of Paris transports who do not want to give me a hand.

I spent three wonderful weeks in London. I discovered plenty of things and plenty of nice people too. Thus I discovered the small Orthodox monastery in northern London, the Russian churches in Kentington, and a wonderful organ concert at Westminster Abbey. When I was at one museum I made a terrible mistake in the special bathroom for the disabled. Instead of pulling the chain, I pulled the alarm—and the guard came quickly. As I was leaving another museum I found I had a flat tire and the security drove me home so my friends could fix it.

In England it is easy to hitch. You wait for five minutes and somebody picks you up. But when I came back through northern France it was hopeless. No one would stop.

This year I was supposed to go to Sweden—still and always hitch-hiking. I started my journey in Marseille. A nice lorry driver put me off in a small village near Geneva. By chance, some very nice nuns there put me up at their old folk’s home. Then I went to Geneva to a Russian church with beautiful bells and that weekend celebrated the feast of all the Russian saints. Orthodox liturgy is heaven on earth.

Afterwards I went to the tunnel of Mont Blanc and found a lorry driver who put me off in Metz near the Luxembourg border. Then some friends in Belgium came and picked me up. After a visit, they put me on the road to Antwerp. After many hours I found a Dutch lorry driver. The Dutch people are like English people—very kind and very helpful. I found another Dutch driver who invited me to come and stay with his family in a small town on the German border. I had a marvelous time there with them and their friends.

Next a French family took me up to Hamburg. I do not like Germany. They thought I was crazy to be hitch-hiking. But I met some Red Cross people in Germany and they were nice. They were also very kind to me in Denmark. The custom people thought my travelling funny and they put me up for a night at a holiday camp for disabled children.

It is impossible to hitch-hike in Sweden. So my journey had a bad end. Never mind. It was a wonderful experience to discover Europe from a wheelchair. “Normal” people who think that my way of travelling is crazy do not know how happy you can be in your wheelchair.

Address: 1 Square de la Bresse, 75016 - Paris, France.

A TRIP TO MONTANA
by Dr. Duncan A. Holbert

In the spring of 1972 my mother gave me a brand-new 16 foot International Step-Van and enough cash to build a recreational vehicle out of it. The basic problem was to make room for an Emerson Tank respirator, all of the respirator gear, a kitchen unit, a miniature furnace, air conditioner, a toilet, general storage space for food, clothing etc and finally seating and bunk capacity for two other people. Jammed into odd corners was a 4000 watt Kohler generator plus a B & S 2500 watt backup generator, a radio telephone, oxygen tanks and two auxiliary breathing devices.

Dr. Duncan A. Holbert, the GAZETTE’s medical consultant, has been a respiratory polio quadriplegic since 1949. His breathing aids are an iron lung and a rocking bed. Before polio, he was an internist. After polio, he returned to medical school for refresher courses in allergy and dermatology.
two hours later, a steady raw rain was falling and continued to fall as we made the long climb up the seaward side of the Sierras. The summit around Lake Tahoe was hidden by great drifts of rain-full clouds and hard sheets of rain streamed over the windshield. In the mud by the roadside we could see ahead of us the soaked figure of a young man thumbing for a ride. We slowed to a stop beside him—slid open the door and he hopped in beside me. Slipping out of his dripping coat he leaned over and started to say something, but instead, he sneezed a great big juicy sneeze right in my face!

Mike Hill, my good friend and driver, pulled him back out of the way and I could hear stern voices in the rear of the van. Well, it turned out that he had a bad cold and so we reluctantly drove on for a couple of miles until we reached Truckee where we let him out. The rain had stopped and there were places to get in and dry out, but it was too late for me, and two days later I came down with the most awful respiratory infection I had ever experienced. Of that, more later.

Donner Pass, named after the ill-fated Donner Party who lost their lives there in the 1850’s, reaches somewhat over 7000 feet before it begins to descend on the Nevada side. I usually carry my relative pressure in the Emerson Tank at 16-CM of water. This was very comfortable up to about 6000 feet. Then I began to notice that I had to work a little on my own to get enough air. It’s times like this when I get little plaguing thoughts like “I hope the hell we don’t get a flat tire” or “When the devil did we get gas last?”

7000 feet quickly gave way to 6000 feet then 5000 feet etc. As dusk slowly hid the mountains and left the crashing storm behind we rolled into the biggest little city in the world—Reno, Nevada! I really don’t know why, but none of us seemed to feel like stopping and trying our luck at the gambling tables. We asked Peg, my wife, who was following us in her car, if she wanted to try her luck, but she said, “No, let’s go on.” The rest of us cheerfully agreed and so we quickly left the sparkling lights of the casinos and struck out over the barren Nevada desert on route 80 E.

Overhead the stars were incredibly bright and clear in the black sky; the night air was warm and we hummed along toward Lovelock nearly 100 miles further on. Remembering the limitless, unpeopled spaces that make up most of the state of Nevada, again I had little cold shivers thinking about what might happen if we threw a rod or some secret essential system failed out there 50 or 60 miles away from anybody. However, I had a Thompson auxiliary breathing unit, Ambu bag, an oxygen tank and at least 50 gallons of gasoline for the generators. The lockers were full of food and we had 20 gallons of water plus fruit juices so I felt relatively secure. We also had a long-range radio-telephone communication set with which we could contact our Congressmen, if we had to! And I might as well give credit—the International Van performed flawlessly over 4000 miles of desert and mountain roads. She started without a cough every morning, cold or hot, and never failed us once even under the worst kind of conditions!

We stayed that night at a KOA camp in Lovelock, Nevada, way out in the sheep country. The stock cars rumbled and slammed all night, busily loading sheep and cattle. Sleep was short—the cold dawn filtered through the cottonwood trees and in no time Peg had the bacon and eggs sizzling on the butane stove. All the next long day and part of the day after we pushed on straight east. Luckily the days and nights were pleasantly cool.

Late that evening Wells appeared and we turned sharply north onto highway 95. Next day was endless plains, low rolling hills and gradually climbing higher on the way into Idaho. The countryside became more prosperous with mile-wide pastures, cultivated fields and livestock looking slick and well-fed. Twin Falls was an attractive small city in the midst of these purely agricultural surroundings. One of the most unusual features was the Snake River which lay along the eastern part of the city. Over eons of time this great river had cut its way vertically through at least 400 feet of solid volcanic rock and now lay in a narrow gorge far below us on its way south to its many forks. On the east side of the Snake River the terrain changed unbelievably—green watered fields gave way to barren volcanic craters. On either side the ground looked scorched and burned. There was practically nothing growing and we realized we were entering the Craters of the Moon!

For several hours we ground over the steep hard mountains and then descended to the edge of an enormous flat desert area without any sign of habitation or living thing. At the northern apex of this vast barren desert we rolled into the little all-nuclear town of Avco. Signs everywhere bragged about the “first nuclear city” powered by all atomic energy. I think we all felt a little sick and a little sorry, as though these luckless villagers had been abandoned in this distant desolation where some day perhaps, scientists will examine what happens when science abandons morality and we realize too late that Pandora’s Box should never have been opened.

Beyond Avco we entered the real wilderness, following the course of the beautiful Salmon River. Grass once more appeared, flanking the mountains that rose abruptly from the river and the gorge, perhaps 8000 to 10,000 feet, hidden by the clouds. These magnificent peaks were the last homes of the rocky mountain goats and sheep. In the lower forested valleys were still elk and black bear. The flavor of the old West and of the mountain men lay faintly in the evening air, but the not uncommon portable aluminum modular home on jack-up wheels suggested
certainly that the old ways were long gone and the ugliness of civilization was finally forever encroaching on the quiet, hidden, green, and lovely mountains and the sparkling waters.

On Lost Horse Pass we wound our way down through stands of trees so dense that late afternoon suddenly became evening and we felt lost in the land of Chief Joseph and Nez Perce. We could imagine them, struggling and starving, driven this way into Canada. At the bottom of the Pass, we once again skirted along the banks of the Salmon River and beyond it the Sapphire Range. An hour or two of daylight remained and we realized that our immediate destination, Hamilton, Montana, was less than 30 miles away.

The Bitterroot Valley and the forest-covered ranges fading in the evening light seemed to me like the last of the Frontier. This grandeur was the same as it was in the days of the Fur Trade when it drew James Ohio Pattie and his comrades to the rendezvous and the beaver streams. Hamilton is a small town so we found our friends easily and drove up just at supper time. Mike backed the van over the curb and up the front walk to the porch. My ramp spanned the few feet across the porch and we rolled right into the front room. Peg and I and the boys had a great supper of antelope shoulder, frontier biscuits, and home-canned fruit.

Ruth Brandborg, to whom half the credit goes, is a continual surprise. After years as an administrator in the Peninsula schools, here we found her equally at home among blueberry pies, mugs of cowboy coffee, and shelf after shelf of jellies, preserves, and canned fruit which she and Brandy had processed together. Our long-suffering host, Brandy, is in his middle eighties, a tall, rawboned ex-forester who is still fighting the good fight for the diminishing forests for this last corner of original wilderness. The big lumber interests are stripping the mountain sides, the rains and snow wash away the soil and nothing will regrow. It is a sad story that is going on now and the bounty of nature that belongs to all of us is being turned into millions of dollars profit to individuals and outfitters who have the right connections.

The next morning we awoke early to the smell of frying bacon and freshly-caught mountain trout—none smaller than two pounds. In spite of the temptations, I sadly realized that my nose was stopped up and my throat was raw and sore. In my mind's eye I could see again the drenched little hitchhiker and I cursed him royally for the worst cold I'd ever had. We had oxygen tanks bubbling, vaporizers steaming up the room, nurses twenty-four hours a day, and all the other equipment for intensive care. Our poor friends were almost squeezed out of their house—like the story of the camel and his master's tent!

Days were not so bad, and I enjoyed visiting with some of the research scientists from the Public Health Laboratories which have given Hamilton international renown. It was there that the cause of Rocky Mountain Spotted Fever was discovered. There are over 300 highly trained specialists in the laboratories, working on exotic diseases from all over the world.

By Friday of that week the flow of lung secretions had thinned out and I was able to get two to three hours of sleep at night. My son, Tom, who is a physician, flew in from California with some suction equipment and we loaded up, gave grateful thanks to our long-suffering friends, cried a little, said a silent prayer, and took off! That evening, amid a Wagnerian thunderstorm we turned west over the Lolo Pass, through more forests and rushing rivers—the Sweetwater into the Snake and finally to the broad slack water of the Columbia beyond the Nez Perce Reservation where Idaho meets the eastern border of Oregon.

On the road again at daybreak, we passed through the barren deserts of eastern Oregon and then through the verdant greenery from central Oregon on into Portland—probably the loveliest part of the trip. Portland suddenly emerged from the scenery streaming by and we stopped there long enough for a good big breakfast at lunch time. So far we were averaging 60 miles per hour, 10 miles per gallon of gas and a stop every 30 minutes for the troops to jam their arms through the portholes to help me cough up another hunk or two of lung! The whole performance began to seem so completely ridiculous that we began to laugh and clown like a bunch of idiots!

By late that afternoon all of Oregon was behind us plus Grants Pass and the northern segment of the Redwood Highway. The dreary KOA camp in Eureka was like a friendly beacon—Santa Cruz and home was now less than a day away and, with my hacking and my poor helpers climbing around in the cold dark, sleep was impossible. As the grey foggy dawn crept in over the edge of the beach we dabbed a little cold water over our faces and headed for the nearest sign of hot coffee and breakfast. The rest of the day was just eating up the road!

The great old Redwoods and finally the hills and vineyards of Sonoma County were all familiar as I had grown up in this country. By noontime the Golden Gate bridge slid by under us and the familiar fog separated long enough to reveal the fishing boats far beneath, hurrying home on the early afternoon tide. I think that we were all completely numb from the lack of rest and decent food, and we saw nothing and heard nothing but the faithful hum of the engines.

In an hour and a half we scraped into the driveway of the parking lot with the dogs barking a welcome. It was two weeks later and 4000 miles of some of the most spectacular and lovely parts of this great country of ours.
Glossopharyngeal breathing (GPB) is commonly known as “frog breathing” because of the similarity between this method of breathing and that employed by amphibians. Basically, the mechanism of GPB is the same as that of a pump: the tongue and the throat act as a piston, and the mouth, the soft palate, and the larynx act as valves. There results an expansion of the lungs as air is pumped into them.

GPB has been used inadvertently for centuries by swimmers to fill their lungs with reserve air just before diving and by individuals with breathing difficulties. During the polio epidemics of the fifties some of the patients accidentally taught themselves to use GPB. When physiological studies proved its value, GPB was taught in respiratory centers around the world.

The best GPB teachers were other polio patients. Most people learned quickly by imitation or from word cues. GPB has been used extensively for more than twenty years by respiratory polio quads to produce adequate respiratory ventilation without the use of mechanical equipment—a sort of self-operated respirator. Some use it only while being transferred from one type of respirator to another; others use it during their waking hours when not using a respirator; and some use it for regular chest stretching and coughing.

In the fifties, Rancho Los Amigos Hospital was the leading proponent of GPB for respiratory polio patients. According to the book, Quadruplegia After Spinal Cord Injury: A Treatment Guide for Physical Therapists, written by staff members of the physical therapy department at Rancho, they are now using it with equal success with traumatic quads: “Glossopharyngeal breathing (GPB) is taught to patients with lesions at C4 and C5 and these patients are encouraged to use it routinely for chest expansion and cough force. Patients with lower lesions are taught GPB to provide a more effective cough force if, after orientation to the advantages of GPB, they express a desire to learn.”

For high-level quads and others with respiratory problems, who could benefit from learning GPB, here are some of the more successful word cues of respiratory polio quads:

“Take a large breath and hold it while practicing the stroke. Be sure to pull back the tongue far down the throat on each stroke.”

“After five years of trying I thought I would never learn to frog breathe. Then, once when ‘goofing off’ I imitated, in an exaggerated way, my friends I had seen doing it. Suddenly, I found myself laughing very loud laughs—I was frogging too!”

“Don’t get the air in your stomach. You have to close off your larynx. Don’t move your Adam’s apple, then you are swallowing. Leave your throat alone. Work with your tongue. The air goes down automatically.’”

“I close the back of my throat, just as one does when he pretends to have a cold in the nose.”

“We used a hand bellows, the type used to pump up an air mattress. With this I was able to get the feel of air in my throat and enough pressure to close my larynx against.”

“Try to scratch an itch on the back of your throat with your tongue so that you almost gag (SKIP the roof of your mouth).”

“Try to make believe you are blowing up a balloon, then follow through with the motion of dropping the throat muscles.”

“On my imaginary straw I take a big swig of a yummy, thick, chocolate milkshake.”

“I learned by continuously ducking my Adam’s apple until I obtained a steady rhythm of taking in air.”

“You have a big orange hanging in front of your mouth. Reach out with your lips and get it in your mouth, then move it around and then swallow it.”

“As you gulp, hold your breath. It closes off the throat and keeps the air from escaping. Once you learn to do it the holding of your breath doesn’t seem to come to mind.”

“For a long time I have been trying to put down in words a simple way to explain GP breathing. Some of you may like to try the following: Put a straw in your mouth, then suck on it, using your mouth and tongue only to make the suction. Then after each time you draw in air, put the end of your tongue over the end of the straw to keep the air from escaping. Also, I’ve found that the front part or the tip of your tongue plays little part in GP breathing because I am able to hold my tongue between my teeth and, with my mouth closed, pump in air through my nose. This is a more advanced method, but it might give someone the clue.”

“Anybody who has tried to learn ‘Frog Breathing’ will know that the main idea is to take a mouthful of air, seal it against your palate with your tongue and swallow it. I find that the more mouthfuls you take and the faster you take them, the better the lungful of
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“Frog breathing’ can be learned by practicing the
following sequential steps: Inflate your lungs, normally,
to your maximum inhale and hold your breath;
close internal nasal passages; with mouth slightly
open, pull tongue and larynx down to bring air into
your mouth; close your mouth, think inhale, and press
your tongue upward to compress the air trapped in
your mouth. Air will pass into your lungs. Hold it! and
repeat the last two steps several times before exhal-
ing.”

“Four suggestions: (1) If difficulty is experienced in
closing the nasal passages, this can be learned by plac-
ing a mirror and light in a position which allows you to
observe the movement of the soft palate at the back of
the roof of your mouth. Experiment with moving your
soft palate up and down. You can feel your nose be-
come blocked when your palate is pressed upward,
constricting the passage leading from the back of your
throat into your nose. After you learn to ‘frog’ this
becomes automatic. (2) It is not necessary to inhale
normally before you ‘frog’ (Step 1, above). But, while
you are learning, the first breaths you obtain will prob-
ably be of low volume, and if your lungs are filled to
their accustomed amount before you ‘frog,’ you are
more apt to notice the increase in pressure. (3) You will
discover that by pushing your lower jaw forward in
the mouth-open phase, and drawing it back in the
mouth-closed phase, a greater volume of air will be
inhaled. (4) Contrary to appearance, this is not swal-
lowing air! If you swallow while holding air under
pressure in your mouth, you will obtain a bloated
stomach rather than inflated lungs.”

“If you have the problem of losing air through the
nasal passages, it is usually due to incoordination. Try
the following method of closing the nose: First, with
the nose clip on, practice GPB until it is performed
easily. Second, if you have a quiet stroke, change it to
a very loud and noisy one. Retain your tongue roll, but
say ‘up’ at the same time you pull the tongue back. It
will be a guttural sound. At first this may be difficult.
Some persons say they can’t do it, but have always
succeeded in the end. Keep this up until you can make
a loud sound while stroking and still take in air. Next,
practice cutting each stroke off in a staccato manner.
Caution: Make sure you are filling your chest with air
easily on each step before trying to proceed to the next
one.

“Repeat the loud stroke and practice chopping it off
until you can do it with ease and are obtaining enough
air on each stroke to fill up readily. This may require
from one to three weeks. Be sure you are putting effort
into the stroke. Work at it as if you meant business.
When this has been accomplished you may take off the
nose clip and there should be no leaking. You can test
with a mirror or feather.”

“Try to open the mouth, close it, and force the air back with your tongue several
times in quick succession . . . You can’t just open and
close your mouth and expect to start frog-breathing.
You have to put some force into it and get the tongue
in the habit of working in conjunction with the open-
ing and closing of your mouth.”

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Staff volunteers, "Quadland" neighbors, Board Members of the St. Louis Chapter of the National Paraplegia Foundation, and out-of-town guests at 4502 Maryland Avenue, the Laurie's home and the Rehabilitation Gazette office.

Nandini Nimbkar Rajvanshi
Roger M. Jefcoate
Jill Kinmont Boothe

Out-of-town guests, at parties and sightseeing

Vivian Naylor
Gini and Eunice Fiorito

Nandini Nimbkar Rajvanshi, granddaughter of Mrs. Kamala V. Nimbkar, of India
Roger M. Jefcoate, electronic expert, from England
Jill Kinmont Boothe, former ski champion, from California

Vivian Naylor, Churchill Fellow, from England
Gini and Eunice Fiorito, president, American Council of the Blind of New York State
Guests at a luncheon in honour of Lady Ramsbotham, wife of the British Ambassador to the United States and mother of a quad.

Colleen Starkloff, Frank Block, and Lady Ramsbotham

Willie Bjorkman, associate editor, and Nancy Quigley

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