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CIL [Center for Independent Living] State of the Art Conference '75

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Center for Independent Living, Inc.
2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

Lex Frieden
Texas Institute for Rehabilitation & Research
1333 Moursund Ave.
Houston, Texas 77025

Dear Lex,

It gives me great pleasure to send you the report on CIL's State of the Art Conference one year ago. Due to the limited budget, we have decided to distribute broadly only a selection of the papers prepared for the conference. Please note, however, that all of the papers are available from CIL.

I would also like to take this opportunity to thank you for participating in the conference. It is our hope that this was just the first of many opportunities for those deeply involved in the Independent Living Movement to meet and exchange ideas and information.

Best regards,

Sincerely,

Phil Draper

Phil Draper
Executive Director

PD/jl

Center for Independent Living, Inc.
2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

September 1976

Dear reader,

How do you capture the state of the art of a dynamic, growing movement occurring simultaneously throughout the nation? One answer is to hold a conference, invite the leaders and the doers and publish a report.

The first conference on the Independent Living Movement was held in October 1975 in Berkeley California, It was sponsored by CIL under a grant from RSA. Attached is a report on the conference. The report reflects the embryonic nature of the movement, the tremendous diversity of issues, problems and approaches and the dreams, efforts and accomplishments of those who have been an active part of it. More than anything else the report dramatizes the importance of close, continuing communication between centers of activity and the need for many more opportunities to meet and exchange information and ideas.

The role of CIL's conference was that of a catalyst — to bring together consumers and professionals from all parts of the country and to initiate a dialogue leading toward a common understanding of the issues and problems, and a consensus of approach. The conference also served as the impetus for the continued development of consumer-based organizations similiar to CIL that can effectively attack the societal barriers that prohibit the independence and productivity of people with severe disabilities.

It is hoped that future conferences will continue this process and will result in a State of the Art of the movement in its maturity.

Sincerely

Phil Draper

Philip Draper
Executive Director

REPORT
ON THE STATE
OF THE
ART CONFERENCE
CENTER FOR
INDEPENDENT LIVING

OCTOBER 21-23, 1975

Enclosed is a selection of the papers presented at the conference. If you would like to receive copies of the other papers prepared, please contact CIL, 2539 Telegraph Ave., Berkeley, California 94704. There is a charge of $1 per paper to cover handling and postage.

Participants	Papers
Jack Actenberg Professor at Law University of San Fernando Valley College of Law 8353 Sepulveda Blvd. Sepulveda, California 91343	Crips Lib - An Overview of Legal Issues
Ralph E. Baird Administrative Assistant Special Education Pupil Personnel Services Tacoma Public Schools Tacoma, Washington	Progressive Inclusion - An Approach to Mainstreaming
Monroe Berkowitz Professor of Economics Bureau of Economic Research Rutgers University 165 College Ave. New Brunswick, New Jersey 08903	Programs and Expenditures For The Severely Disabled
Sheldon Berrol, M.D. Chief, Head Injury Rehabilitation Unit Santa Clara Valley Medical Center 751 South Bascom San Jose, Calif.	Medical Aspects of Disability With a View to Independent Living (co-author Edna Brean)
Edna Brean, R.N. Medical Services and Training Center for Independent Living	(see above)
Frederick C. Collignon Berkeley Planning Associates 2320 Channing Way Berkeley, California	
Barbara Duncan Managing Editor International Rehabilitation Review 122 East 23rd St. New York, N.Y. 10010	Legislation, Research and Programs Concerning Housing for Handicapped People in Belgium, Canada, the Federal Republic of Germany, Finland, France, Hong Kong, the Netherlands, Norway and Sweden
Frederick A. Fay, Ph.D. Director of Research Tufts New England R&T Center 171 Harrison Ave. Boston, Ma. 02111	The Federal Outlook

Allen Ferguson, Jr.
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Independent Living Arrangements for Severely Physically Disabled Persons

Don Galloway
Project Director
Research and Demonstration Project
Center for Independent Living

Donald E. Galvin
Director, Vocational Rehabilitation
Service
Box 1016
Lansing, Michigan 48904

The Role of the State VR Agency

Frank D. Gentile
Vice President
Human Resources Center
Albertson, Long Island, N.Y. 11507

A Model Sheltered Workshop

Dominic Harveston
Manager, CIL-Center for Health
Studies Joint Degree Program
Center for Independent Living

Francis H. Lauder
Office for Handicapped Individuals
Marty Switzer Memorial Bldg.
Washington, D.C. 20201

Peter Leech, M.S.W.
Clinical Coordinator, Counseling
Center for Independent Living

An On-Site Training Program for Professionals Working with People Who Have Severe Disabilities

Joan Leon
Special Assistant
Center for Independent Living

Dr. Herbert H. Leibowitz
Research and Demonstration Specialist
Social and Rehabilitation Service
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San Francisco, California

Wallace Motloch, C.O.
Chief Orthotist,
Rehabilitation Engineering Center
Children's Hospital at Stanford
Palo Alto, California

Systems Approach and the Physically Unable

Jeff Moyer
Manager, Client Services
Center for Independent Living

Thomas C. O'Brien
1975 Chairman, Transportation
American Coalition of Citizens
With Disabilities
15 Wellesley Rd.
Danvers, Massachusetts 01923

Transportation For The Mobility Handicapped

Daniel A. Poling, II
Editor-in-Chief
Poling Magazine
122 East 23rd St.
New York, N.Y. 10010

The Three R's of Disabled Consumerism

Richard J. Randles
Federal Systems Division
IBM Corporation
Gaithersburg, Maryland

Private Industry and the Vocational Rehabilitation Process

Ed Roberts
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A New Kid in Town

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Center for Independent Living In New York - a Residential Center for the Elderly Blind

Neil Jacobson
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Sexuality and Independent Living Skills

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Legal Services by the Disabled for the Disabled

Hal Kirschbaum
Mgr. Development
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Kent Kloepping, Ed.D.
Special Services Office
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University of Arizona

The Disabled Students Programs in the College and University Setting

Joseph Kohn
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New Jersey State Commission f/t
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Independent Living and The State Agency For The Blind - The State of the Art

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Karen Topp
Rehabilitation Counselor
State Department of Rehabilitation
Oakland, California

Kathleen Ursin
Director of Education
The National Center for Law and the Handicapped, Inc.
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The Impact of Litigation on De-Institutionalization: A Movement Toward Independent Living for the Mentally Disabled

Carolyn L. Vash, Ph.D.
Chief Deputy Director
State Department of Rehabilitation
107 S. Broadway, Room 7106
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The Psychology of Disability

Dale Williamson
Office of Rehabilitation Services
50 Fulton Street
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Hale Zukas
Coordinator, Community Affairs
Center for Independent Living

History of CIL

THE PSYCHOLOGY OF DISABILITY

Carolyn L. Vash, Ph.D.

Introduction

I begin this paper with what may seem a strange and irrelevant confession. I believed in reincarnation until I was 16. I thought everyone did. I got straightened out one day when my mother, my attendant, and I were looking at a magazine cartoon which prompted my attendant to say, "Humph! Whoever drew that must believe in that-there re-incarnation." I said, "Doesn't everybody?" Mother said, "Carolyn, where did you get such an idea?" I said, "Gee, I don't know, am I wrong?" She assured me I was. I gave up the belief without a whimper. I did check with a couple of friends to see if they believed in it. They had never heard of it. I decided it was my mistake and put it away. That was in 1951.

In 1975 and the dawning of the Age of Aquarius, almost everyone in the West knows what it is and many believe. One of these is a friend of mine; a rehabilitation administrator who, in a quiet moment one day, began to question her own motivations for doing what she was doing. She subsequently resigned her job, cast off her material possessions, and took a trip to the far East. Her studies there and since led her to a strong belief in the principle of reincarnation.

An important element of this belief is that one chooses one's body, one's parents, one's total life situation for the purpose of working out karma. Thus, one chooses to live in a disabled condition for some reason relating to spiritual development. It is not a regrettable accident. My friend told me that one result of embracing this belief is that now when she meets a person who is mentally retarded or severely disabled she no longer experiences pangs of pity as she once did. She doesn't think of herself as fortunate (and therefore superior) to an unfortunate (and therefore inferior) person. She relates to him/her as a peer, a colleague, and finds herself asking, albeit quietly to herself, "Ho there, what are you working out this time? I wonder if you are at a higher level of development than I for having come to such a test."

I cannot say that I believe in reincarnation. A physician colleague of mine who does is convinced that I was born knowing the truth and, though I let myself be dissuaded, will continue to be influenced by it. I do know that since my friend shared her observation with me, my own perceptions, beliefs, opinions, attitudes and feelings about what it means to be disabled have changed. The issues I think are important, the programs I view as successful, the policy decisions I believe should be made reflect less a desire to correct inequities in the material world of bodies and economics, and more a desire to remove interferences in the spiritual - or karmic, if you will - development of people who have disabilities.

Although I am a psychologist by trade, this paper will draw far more from my own experience with disability than from scholarly and professional pursuits. The reason is simple; that's where I've learned the most. Every theory I read, every experience shared with me by a patient or friend, is tested in the laboratory of my own feelings, senses, intuitions and thoughts - and either becomes part of my world view or fades because it somehow doesn't fit. By illustration, I will attempt to lay out the issues which I regard as most crucial in the area labeled "the psychology of disability." Then, I will describe some efforts which are being made to deal with these issues. Finally, I will share with you some thoughts about what should be done to be more helpful to people struggling to reach whatever it is life holds for us all.

The Psychology of Disability - What It Does and Doesn't Mean:

Part of me is reluctant to even acknowledge the validity of the notion, "the psychology of disability," because it seems to have led to gross and unhelpful exaggerations of the psychological differences between folks with disabilities and folks without. That part of me would like to just tuck it away and say, look, human beings are human beings. Whatever differences we have in our physical bodies or sensory capacities or intellectual abilities or anything else, we are more alike than we are different. Let's focus on our commonalities because they, not our differences, constitute the preponderance of our humanhood. For example, disabled people are said to experience a sense of loss over the functional abilities an illness or injury destroyed. Other people experience a sense of loss over something they once had and is now gone. The *stimulus* is different, but the sense of loss, the fear that you can't survive or be happy without "it" are the same — as much as any two people can be said to experience the same emotion. The psychology of disability is really nothing different from the psychology of being human. When we understand the nature of the basic Stimulus-Organism-Response relationships which are the building blocks of scientific psychology, there will surely be no residual that has to be studied separately to understand why disabled folks behave as they do.

Obviously, this is a "political" response, not unlike the popular reaction against Dr. Jensen's investigations into ethnicity and intellect. It is an extremist view, and the only reason I include it here is to emphatically illustrate a point. The psychology of disability, in my opinion, is the study of how human organisms respond to a set of stimulus conditions which are associated with disability. It is the study of normative responses from (psychologically) normal organisms to unusual stimuli.

Some of these unusual stimuli are biological, such as being paralyzed. Some are environmental, such as inaccessible entrances. Some are social, such as having a saleslady ask your companion, not you, what size you wear. Some are economic, such as not being able to get a job. Some are obvious, such as a restroom door that you can't get through. Some are subtle, such as people not using the word "cripple" when you are around. Some are pleasant, such as being allowed to board an airplane first. Some are unpleasant, such as not being allowed to board at all. As I write, I realize I could fill pages with such examples, which in itself illustrates the unusual stimulus situation the person with a disability is in — a continual flow of perceptions and experiences which cannot be shared with and validated by the vast majority of people around one. Thus, isolation and the lack of a sense of shared ideas and feelings are added to the list of unusual stimulus conditions. And so it goes.

Viewed in this light, the psychology of disability looms large, important, and bifurcated as an applied science. One branch is a rather typical applied behavioral science — embodied in a group of professionals who attempt to apply the findings of research and clinical experience to help people with disabilities cope with, adapt to, adjust to these unusual stimuli. The other branch is embodied in an activist movement — a group of people who have determined that it is the world that needs "treatment" not just the person with the disability.

This is a relatively new development. It emerged slowly after World War II, when medical science found ways to save wounded soldiers who would return, significantly disabled, to a society that felt it owed them something. But, feeling you owe a debt and figuring out how to pay it are two different things, and little measurable progress was made toward including the disabled in society. The Watts

riots in 1965 pointed the way. Some Blacks in South Central Los Angeles engaged in crazy, self-destructive behavior for six days and somehow, one of the results of it was that Blacks all over the country, other racial minorities, women, people with disabilities, and multitudes of other groups who had accepted powerlessness and half-filled cups all of their lives began to scream. They all began to realize that society, even an indebted society, is not going to "fix" it for you. The guy with the problem has to come up with the solution. And they discovered the Constitution. Everybody had known all along that Blacks were regularly deprived of their constitutional rights, but whoever thought people with disabilities were? The "expectation explosion" began, and "consciousness raising" attempted to ensure that everyone's expectations were as high as they should be.

A very few years ago almost the total emphasis in rehabilitation was on modifying the 'patient' so he could fit into the world as it was. (S)he was modified by medicine, surgery, physical therapy, occupational therapy, psychotherapy, vocational counseling, social counseling, prosthetic and orthotic devices, education, training and much, much more. Family homes were remodeled, sometimes at public expense, but to expect all housing to be built 'accessible" would have been viewed as an idealistic delusion — about as likely as having a Black mayor in Los Angeles. "If a round peg doesn't fit in a square hole, you square the peg, you don't ream out the hole". We've come a long way. The "other half" of the psychology of disability has become the *politics* of disability — and that, in my opinion, is as it should be. It doesn't take Freud to figure out that it's not very good for a person, psychologically speaking, to be deprived of his constitutional rights. If the applied psychology of disability is to be a helpful discipline, it must tend to the business of changing such stimulus conditions as well as the individual and his responses.

Devaluation

Following close behind outright oppression in psychologically damaging consequences is devaluation; being regarded as a lesser being, inferior, not very capable, not very useful, possibly burdensome, unesthetic and, generally, "one-down." People with disabilities consistently experience devaluation in the eyes of the people who comprise the general society, as well as other disabled people. This is true regardless of the nature of the disability — whether it impairs physical, sensory, intellectual or emotional functioning. The phenomenon was illustrated beautifully at the Statewide Conference on Rehabilitation held in Sacramento, California in October of 1974. Dr. William Rader, psychiatrist, psychodramatist and public performer par excellence, began an arousing display of the tragic, even deadly, effects of communication misfires between "helper" and "helpee" with a simple routine. He addressed the group alternately standing and sitting in a wheelchair; all the while challenging them to deny that their perceptions of his competence fluctuated as he stood and sat, stood and sat. There was much discussion afterward and without exception, everyone I talked with, from able-bodied to very severely disabled, acknowledged that their views of his competence HAD changed, had alternated dizzyingly as he stood and sat, that he had appeared more competent, more credible, more worthy of attention when he stood. It was an emotionally draining experience for many. It was a confrontation of prejudice they had ignored or denied for a long time — and they were forced to look at it nose-to-nose and eyeball-to-eyeball. Why this impact from recognizing that all of us, able-bodied and disabled alike, devaluate people with disabilities? Why is it so frightening that we have to hide from it? The hypothetical observer from another planet would almost certainly see it for the universal phenomenon it is. Can it be changed? Probably not, unless it is first acknowledged and examined in every aspect.

The first line of inquiry is, "Is it biologically based?" Does the human species instinctively shun damaged organisms because their perpetuation could threaten the survival of the species? We are all familiar with the anthropological folklore that primitive tribes leave injured or aged members to die because efforts to save them would endanger larger numbers. Is it possible that biological mechanisms which once operated for species protection have not "caught up" with an affluent and technological society which has rendered them anachronistic? I acknowledge my own prejudice here. It is my firm conviction that such mechanisms, if, indeed, they are operative, are anachronistic. As a severely disabled person who is dependent upon both technology and the goodwill of other human beings to aid me, I cannot allow myself to believe otherwise.

The second line of inquiry is psycho-social, but in content it is similar. People tend to shun, be prejudiced against, devaluate individuals who are *different.* This is more true if the difference occurs at the low end of the distribution; that is, if the individual has less of something than most people have. But people who are too beautiful or too brilliant or too rich or even too kind come in for their share of suspicion and punishment as well. This phenomenon may also have biological substrates, since it appears to have been "learned" by almost every culture on earth. Can people learn to tolerate a wider range of differences? How?

The third line on inquiry is politico-economic. In an affluent, technological society, saving lives and improving the quality of life for those saved but left damaged is not going to threaten the survival of the species. It can, however, reduce the sum total of goods available for the rest. The disabled, and especially the severely disabled, are viewed as a group of "takers" who don't put much back into the system — the family system, the community system, the social system.

If we are taking only materialistic values into account, this may be a valid notion. If severely disabled people lack the inner resources or miss the strokes of fortune which lead them to a job which pays enough to support their high-cost needs, then the issue is not whether the public pays, but how. Should it be managed through a tax supported welfare system or should it be "subsidized" through an employer who, in turn, passes the cost on to the general public in increased prices for goods and services? In terms of the long-run impact on the purses of the people, there may not be much difference. In terms of the psychological well-being of the severely disabled people affected the difference may be very great.

If one looks beyond materialistic values to spiritual values, the issue becomes meaningless. If one has faith, or at least adopts the belief that the purpose of life is spiritual development rather than materialistic acquisition, then sharing of goods with those unable to produce their own is not inconsistent with "enlightened self-interest." The reason for this is an associated faith that we are all parts of the same universal spirit. Selfishness and unselfishness become paradoxically the same. Just as one must "selfishly" pursue one's own development (and sometimes deny those who urge prior consideration of their wishes) if one is to become a truly beneficial influence for others, so must one also "unselfishly" pursue the removal of hindrances to other individuals' development because to do otherwise is ultimately to impair one's own. There is no reason to believe that people with severe disabilities put less back into this system than anyone else.

The Summary of the Comprehensive Needs Report done by the Urban Institute makes a few references to psychological services. Those services most often

requested by respondents were: vocational services, transportation and physical therapy. The report does make the point that, "the person's view of himself is often diminished by his handicap." In other words, he devaluates himself. But psychological services were not among those services most sought after by the respondents.

Yet this is a psychologically educated age. We are all aware of the potential destructiveness, to self and others, of impaired or undeveloped self-esteem. We understand that many psychiatric disorders are largely outgrowths of this. Newspaper accounts of individuals who commit "senseless crimes" relate histories of lack of self-respect and early efforts to prove that they "were somebody." Books like "I'm O.K., You're O.K. proliferate and sell millions of copies. We are this sophisticated, and yet the respondents didn't ask for help in dealing with their feelings of devaluation. And as we will see later, the providers typically offer only the most cursory efforts to help in this way. Why?

First, the sophistication is intellectual. When it comes down to "me", the expectations rush backwards a few decades and the individual is both inwardly and outwardly directed to handle this adjustment process him/herself. To need help is to be unacceptably weak, so the need is denied. The social sanctions against getting psychological — or, God forbid — psychiatric help interfere with asking even when the need is recognized.

Second, it is not easy to relate help provided in this area to savings of public dollars. Physical restoration can demonstrably reduce life-long medical costs which the public pays for. Vocational rehabilitation can reduce welfare cost and get some tax money coming into the system as well. If physical restoration and vocational rehabilitation can do that, who is going to worry about how the person feels about him/herself? Nobody else is very happy these days anyway.

Apart from any humanistic, quality-of-life concerns, it is very likely that sufficient attention to "soft data" of rehabilitation — such as the potential effects of psychological services — could further reduce medical, welfare and other related costs to a degree barely conceived of today. To evaluate such factors, we would gather data from the first moments post-onset through the entire course of the disability, which might last the rest of the individual's life.

People who feel badly about themselves generate needs which must be served. Unfortunately, those needs are often left unmet until after the person is in such deep psychological trouble that its effects are being felt by others as well.

Acceptance of Disability

In earlier days of the rehabilitation movement, there was a great deal of talk about the importance of "accepting one's disability." This sometimes meant the absence of the defense mechanism "denial." At other times it simply meant acknowledgement of one's loss without feeling rotten about it. Acceptance was good. However, in no case was the person supposed to *like* his disability. That would be a more serious neurosis than denial. Profits reaped were labeled "secondary gain" and secondary gain was a no-no. To benefit from the disability was considered unwholesome at best, immoral at worst. This required the person to know exactly where the line between acceptance and enjoyment lay, and to be eternally vigilant not to cross over. Acceptance was biting the bullet and smiling at the same time — and about equally easy.

About the time I entered the field of rehabilitation in 1958, it was becoming unfashionable to talk about accepting disability. The staff and the literature explained to anyone gauche enough to use such language that it did not make sense to expect a person to accept a disability; that the professionals of a prior era had laid a bum trip on disabled people. No one should be enjoined to accept something that means settling for second-rate hopes and goals. "Adapting to" and "coping with" became the preferred terminology.

Actually, it was this thinking that led in part to the advocacy revolution. Some realistic souls saw that you could counsel a disabled person until you were both blue in the face, but at the end of it, if (s)he couldn't get from point A to point B because there were stairs and no accessible buses in between, life was not going to be much fun because the world was not a very reasonable place to live. Thus, there was a switch of emphasis from modification of the person to modification of the world: removing the stairs and the discriminatory hiring practices instead of counseling him to stop liking upstairs restaurants and training him to do the few jobs he would be allowed to do.

I agreed with this until about 1967. At that time, I experienced divorce after a ten-year marriage and for the first time in my life was alone, independent, and scared stiff. I decided to invest a couple hundred dollars in ten psychotherapy sessions to see if I could get my head together. One of the first things the man said to me was, "The trouble with you is you haven't accepted your disability." "Oh brother," I thought, "I should never have come to a psychologist who hasn't had experience with disabled people. He doesn't know how inappropriate that remark is . . . even if it were true. I obviously have accepted my disability. I am working in a responsible position, making enough money to pay for my own attendant, am openly and unabashedly on the dating market and doing reasonably well. I have lots of friends, social and recreational activities. I paint, write poetry, and work 80 hours a week. How can he say I haven't accepted my disability? Paintings of anguish and poems with suicidal themes are what sell these days, and what's wrong with being dedicated? Actually, I'm in psychotherapy mainly for training purposes, since I'd like to have a small private practice some day," True, I wasn't exactly happy and couldn't figure out why. It took a few months to realize that one reason was, I hadn't accepted my disability.

When I did, it wasn't at all like the staff and the literature had envisioned it — settling for second-rate goals and dreams. It wasn't even de-fusing the disappointment that I would never again hear whistles when I walked, or dance, or ride in a horse show, or walk alone in the rain, or go to the bathroom by myself. It sure as hell wasn't the much touted process of discovering substitute gratifications for the ones I had lost.

It was more like those things not only didn't matter any more, they wouldn't have mattered even if I could still have done them. I didn't need to be able to do them — or to mourn their loss — in order to maintain some image of myself. I felt I understood the relinquishments that come with age. Joys of an earlier era are continuously "put away". Substitutions needn't be sought; new joys simply emerge, appropriate to the new era. I found myself no longer afraid of aging. Acceptance of disability was simply acceptance of myself — and there were parts of me that were harder to accept than my disability by far. I didn't have the language then, but from the personal studies I've done since, acceptance of disability was exactly the process the Western interpreters of Eastern mystics speak of as centering, ridding

oneself of Ego, and casting off attachments so they become, at most, preferences. The fact that a few of these attachments were ego-images and activities interfered with by disability was just one happenstance of a much larger process.

Summary of the Issues

Rather than attempt a comprehensive survey of psychological issues related to various aspects of disability — such as the effects of paralysis and/or sensory losses on the expression of sexuality, the effects of deafness on interpersonal relations, and other highly specific concerns that could not be covered exhaustively — I have decided to focus upon just those basic phenomena described in the foregoing: the processes of devaluation and acceptance. It may be too sweeping a statement, but I believe they constitute the underlying cause and inherent solution to most of the specific psychological issues which might be discussed. What are we doing and what can we do to reduce devaluation? What are we doing and what can we do to increase acceptance?

Current Practice

I will touch upon what is happening — or not happening — in five areas: 1) community hospitals; 2) rehabilitation hospitals or rehabilitation units in community hospitals; 3) the state-federal vocational rehabilitation agencies — including facilities from which they procure services; 4) independent living programs; and 5) the private sector of psychological clinics and practitioners. I will state my apologia now that what I know about is what my present and previous jobs have made me aware of. I have not had the opportunity to research and discover additional programs which may be going on.

Community Hospitals

A few community hospitals have limited psychological service programs; usually one or more staff or on-call psychologists, psychiatrists or social workers are available to talk with patients who want or appear to need such help.

Often it is for the dying patient or the patient who is a ward management problem. Hospitals which treat many patients with conditions thought to have considerable psychological overlay, such as low back problems, may have larger programs including both clinical and research components.

However, for the patient who is just plain scared because he senses that his brand-new catastrophic illness or injury is going to have some life-style jolting implications, I know of no programmatic efforts. The only ones I have heard discussed were by groups of severely disabled persons who proposed to go to hospitals on a volunteer basis to talk with newly injured patients. There is controversy here; whether and how hard to hit the person with the facts of a poor prognosis for eventual recovery — as the inexperienced patient would define it. Some say people need time to assimilate this reality; that to shove it down their throats when they are still systemically disturbed is not only unhelpful but cruel. Others insist that although it may be painful, it is not necessarily harmful; the earlier reality is faced, the earlier can the psychological as well as the physical repair processes begin. My instincts tell me there is no single answer. It could be helpful to some and harmful to others. Given a few years of experience working and just being with people who are in the acute stage of recovery from catastrophic illness or injury, I might be prepared to distinguish who is which. I certainly cannot now.

Rehabilitation Hospitals or Units

Most rehabilitation hospitals or units have at least a fledgling psychological service component and some have grown quite large, with a dozen or more psychologists on staff. One of the largest is the Psychology Department at Rancho Los Amigos Hospital. The problem is, despite its size, it isn't big enough. The majority of staff time goes into evaluation, leaving little time for treatment. It is not patients who want evaluations, it is other staff; for purposes of planning patients' rehabilitation programs or coping with day-to-day problems like "refusal to cooperate". The patients get only fragmentary help in a situation which most people — before it happens — are totally convinced they could not handle.

Psychologists from other rehabilitation hospitals report and lament the same experience. When I worked as a psychologist in a rehabilitation hospital it occurred to me that my role was to reduce staff anxiety. Somehow, having test data made us feel we had a better handle on something. If I gave a patient a WAIS and an MMPI and could say with assurance that he was normally smart and wasn't crazy; he was just a little upset over being paralyzed all of a sudden and suspected his wife had moved in with his best friend while he was in the hospital and he had never done any work except manual labor and didn't see how he could get her and the kids back unless he could support them and he probably couldn't satisfy her anyway so perhaps he was being selfish to want her back . . . the anxiety of the staff was relieved. But somehow no one ever said, "Wow! What a heavy trip! I'll do without my evaluations. You should spend your time just talking with people, seeing if you can guide them through this incredible trip, because it seems a lot more important!"

I squeezed in as much "just talking", counseling, psychotherapy — whatever you want to call it — as I could. We all did. But we never mutinied and said, "This is ridiculous! We're serving the wrong people. True, it's a heavy trip for them, too, going through this time after time. But the other guys need it worse. Let's re-order our priorities." We just went on assuming that our evaluations were so important they had to get done, and prayed for more staff.

I suspect the marginal status of practitioners of the psychotherapeutic arts has much to do with explaining this situation. One of the reasons for marginal status is low visibility of effort. One way to enhance status is to get visible. Test protocols and reports containing findings, predictions and recommendations are a visible product. Everyone can see that you're working. How do you prove you're a necessary member of the team if you just talk to people? Even the chaplain, with centuries of tradition behind him, is seldom regarded as crucial in this role.

A second reason for marginal status is low visibility of success criteria. Physicians have x-rays and blood tests to tell them and the world whether their efforts "worked". Physical therapists, lacking the physicians' hardware, at least have easy-to-describe behaviors like "puts on own pants - yes or no" to deal with. Many applied behavioral science fields are beginning to realize that if they are to survive, they will learn to play the game of "accountability" as well as everyone else. Every effort is being made to remove descriptions of therapy benefits from the abstract (e.g., improved insight) to concrete behavior (e.g., no longer beats wife). Unfortunately, the psychologists' status isn't helped by this as much as it might be.

The reason is that the benefits of his efforts are not expected at immediate or even intermediate range, but at long range — which further compounds the problem of

low visibility of success and is a third reason for the marginal status of the psychologist. If (s)he serves well as therapist, counselor, teacher, guide or guru, then the individual may be better prepared to deal with exigencies of his/her altered life weeks, months or years after (s)he has left the hospital. That is the hope and the intent. But the hospital staff, including the administrators who hold the purse strings, will never witness the "pay-off".

A fourth determiner of status is the extent to which a health profession deals in matters of survival versus "quality of life". When a psychologist correctly predicts, "If you put so-and-so in a full body cast, he'll cut his way out of it and leave the hospital," you can be sure they'll check with him/her the next few times they're considering using a full body cast. In that case, psychological factors have an impact on physical rehabilitation, the repair of his body — and that's close to a survival issue. When the same psychologist correctly predicts, "His wife really loves him but he's going to drive her away by continually testing her unless he gets some help," no one gets very alarmed. That only concerns his psyche, a quality of life issue. And if hospital staff acknowledge the need to deal with psychological problems before releasing the individual, they would not get Medi-Cal reimbursement for an extended stay.

It becomes fairly obvious why psychologists in rehabilitation hospitals do evaluations instead of treatment when there is not time for both. They have products which are immediate, visible — both as to effort and outcome — and are believed to impact issues closer to survival than quality of life. "You sure won't be any help to anybody if they close down your department." It's a matter of survival, and that's important.

State-Federal Vocational Rehabilitation Agencies

All of the VR agencies have psychological programs. There are certain basic functions, such as the certification of mental retardation, which are assigned to psychologists. Beyond these minima, the agencies vary. At the meetings of the Council of State Administrators of Vocational Rehabilitation (CSAVR) I always talk with two or three administrators about the subject. Only once have I found an administrator who was satisfied with the type, quantity and quality of psychological inputs (s)he was getting. Several of us who are disatisfied with our own programs, along with interested psychologists from the federal central office and the American Psychological Association, are proposing a nationwide workshop — which will include consumers — to develop alternate models for more effective psychological support systems for the VR agencies.

In most states, the emphasis is, again, on evaluation. There is very little case service funding priority for therapy; it is seen as prolonged, costly, and difficult-to-justify. Most administrators see a need for better mental health facilities in their states through experience with their clients, but are loath to provide such services with VR funds even when they appear essential to vocational goal attainment.

I believe that a significant proportion of "28 closures" (clients closed out not employed, agency failures) are a direct outgrowth of weakness in the psychological programming. The following observations led to that hypothesis. For three years I served as a member of the rehabilitation Appeals Board in California. This is a five-member body, appointed by the Governor, whose duty it is to review Departmental decisions which are being appealed by clients, former clients and client-applicants. The Board makes recommendations which can be construed as upholding the

decision of the Department or failing to do so. During the time I served on the Board, only once did it clearly fail to uphold the Department's decisions. Believing that no organization could err so seldom, we reviewed the cases we had heard to try to understand. We arrived at the following tentative conclusion: the specific decisions being appealed were usually correct decisions, but they came too late and often after a series of errors which they could not rectify. Thus, the client wasn't ready for the decision; (s)he'd been led to expect something different. In a few cases, a client probably should not have been judged 'feasible' at the outset without psychological or psychiatric concurrence. There were many cases in which we thought the counselor, ideally, should have recognized any number of red flags in the early case data to warn him/her: "There are psychodynamic factors involved here that may sabotage the rehabilitation plan" or, "This person needs a trained psychotherapist, don't get in over your head." There were other problems, too, but the prevalent precursor to an appeal appeared to be counselors' lack of psychodiagnostic acumen and follow-through skills coupled with inadequate resources for expert help.

As a result of this analysis I took the issue one step further. The supervisor of a VR branch office and I conducted an exhaustive case review of a year's total output of "28 closures" seeking to confirm or disconfirm these impressions. Out of 33 cases, we found four with no evidence of counselor error involved. These were recognized high risk cases in which the counselor had given his/her all, failed, and there was no fault to be found. The other 29 cases showed evidence of counselor error in one to four different areas; vocational (20 instances), psychological (16 instances), relationship (nine instances), and medical (three instances). Thus, the hypothesis was partially confirmed. Errors in the psychological area were not the most frequent, but they ran a close second with the third lagging far behind. Rehabilitation counselors cannot be expected to be expert practitioners in all of the many disciplines they are called upon to orchestrate on behalf of their clients. Nevertheless, it is clear that greater psychological expertise needs to be introduced into the system. As hinted above, California is beginning to make changes designed to respond to this need.

The California agency has a full-time vocational psychologist in each of its 26 district offices. Previously, that person's role was almost exclusively the administration and interpretation of vocational assessment instruments to guide counselor and client in the search for a suitable vocational goal. This was not a very fulfilling job, and it left significant unmet needs for the counselor. A new policy has been formulated. The functions of these psychologists have been expanded to include consultation with and training of counselors in the application of a wide range of psychological principles, knowledge, skills and techniques. Excess testing demands are to be contracted out to practititioners in the community so they will not, de facto, weaken the consultation and training program. The vocational psychologists still do not do therapy. Most are unlicensed and the time consumption would be too great. However, they are expected to know the community resources thoroughly so they can refer the client to the most competent treatment available for the types of problems he presents.

The VR agencies contract for work evaluation, work adjustment and related worker preparation services from private sector facilities such as workshops. Because psychologists are expensive and funds are always tight, almost none of these facilities include psychologists on staff. One exception is the Work Preparation Center at Rancho Los Amigos Hospital. Several clinical psychologists conduct and supervise

group and individual counseling/psychotherapy as well as rather sophisticated behavior modification programs centered upon work behavior. Two very different examples should illustrate the range of possibilities that this richness of psychological staffing can offer.

1) An experimental program was implemented for brain-injured men who were so affected by stimuli in the environment that they could barely sustain half minimum-wage production levels. A token economy was introduced and distracting stimuli were eliminated, step by step, until the environment was sufficiently distraction-free so that several of the men were able to work at minimum-wage productivity in the main shop.

2) A group counseling program for "singles" was offered jointly to workshop clients, who had a variety of physical and mental disabilities, and nearby Cerritos College students, who had no discernible disabilities. The hope was to get a few able-bodied students involved to mitigate the feelings of many clients that their "singles" problems were due to their disabilities. The response on the part of the students was so great that there had to be a limit on the number who could participate. Those students learned far more from the clients than the clients learned from them. They learned a little about tragedy, alot about coping, and the most about human commonalities. The disabled folks put a great deal back into that system.

Independent Living Programs

One of the most helpful approaches to appear on the psychological services scene is peer counseling — whether it relates to independent living needs of people with disabilities or being black, brown, yellow or red in a predominantly white society, or being a woman in "a man's world." Peer, rather than professional, counseling is being used in many places now, sometimes because of a lack of professional manpower, and increasingly often because it is the treatment of choice. Psychologically normal people adjusting to unusual situations often need tutorial more than therapeutic services — an experienced person to teach them how to traverse difficult terrain. Hot lines, group sharing, and a host of other peer counseling techniques are being used by self-help organizations of disabled people, including independent living programs, student groups, and organizations devoted primarily to social/recreational or political action goals.

The independent living programs are definitely not in the business of doing psychological evaluations. They are attempting to meet the needs for help, and largely through peer counseling. Some of the peers are actually highly trained, professional counselors from the spectrum of professional disciplines (e.g., psychology, social work, psychiatry, the ministry, marriage-family-child counseling, rehabilitation counseling). Others are crash-trained lay counselors. Still others do their counseling without benefit of any specific training. If the nature or extent of problems calls for it, the independent living programs provide referral services to professionals in the community.

The problem with peer counseling devolves upon selection and training as methods of assuring reasonable standards of competence. Not everyone, just because (s)he has experienced disability, is capable of being helpful to another. Some would-be helpers lack the qualities which are important in a helping relationship, such as the classics of warmth, genuineness and empathy. Others have developed un-

wholesome attitudes and responses to disability themselves and for this reason would not be helpful influences. Thus, even when peer counselors volunteer to work without pay they must still be screened and selected with care equivalent to that devoted to hiring salaried employees.

Similarly, it is a rare occurrence to find a natural counselor who is consistently effective with diverse people without benefit of training. Some kind of training must be provided for otherwise untrained peer counselors. Happily, there is much available to draw from. In the past decade, scores of excellent books and programs have come out detailing methods for preparing paraprofessional counselors to form helping relationships, or helping friendships, with people having many kinds of trouble. Some have so impressed me with their simplicity yet completeness of concept that I believe they would be good continuing education experiences for highly, and perhaps too theoretically, trained professionals.

The Private Sector of Psychological Clinics and Practitioners

There are very few practitioners, either in clinics or private practice who are aware of what we are here calling the psychology of disability. One of the reasons is economic. To date, not very many disabled people have been able to afford psychotherapy in the private sector. Thus, there was little demand to learn. Legislators and insurance carriers are beginning to manifest acknowledgement that these services should be covered by insurance, not out of pocket, so the demand may grow. With respect to traditional talking therapy, there may not be a crucial problem. If the therapist is good with people, (s)he should be good with a person who happens to have a disability.

However, some of the newer treatment approaches being used by psychotherapists are finally mending the mind-body split that has impeded both the medical and psychological healing arts for so long. Many of these cannot be used with disabled, especially severely disabled people, without thoughtful deliberation aimed at modifying the techniques. Some of these techniques are bioenergetics, body-awareness and sensory awakening techniques, aerobic and anaerobic exercises, and techniques drawn from ancient disciplines such as yoga, pressure-point therapy and the martial arts. Some, such as Rolfing may require medical advice as to contraindications before being used with people who have physical disabilities. Still others present no particular problems of application, such as biofeedback and a vast array of meditation techniques, but should simply be tried more systematically because they appear to offer remarkable opportunities for personal growth that are especially relevant to people with restricted mobility or sensory capacities.

Thoughts on the Future

I would like to see a pervasive shift in values; an attitudinal re-orientation both within the rehabilitation movement and without. The core of this change would be far more attention paid to the inner aspects of rehabilitation — the rehabilitation of the spirit, psyche or soul — and perhaps a little less to the outer aspects — the rehabilitation of the arms, legs and pocketbook.

Focusing on the rehabilitation hospital, I would like to see psychological services at the hub, and medical, social, and vocational out at the ends of the spokes where I think they belong. The body repairs and vocational re-establishment are important ancillaries to the real business of rehabilitation, which goes on in the head, heart

and gut, not the extremities. If the person knows (s)he's at least as okay as (s)he ever was and maybe a little bit better for having endured the test, (s)he'll make sure (s)he gets his/her body in the best shape possible — the better to carry on a life (s)he has reason to look forward to. If (s)he understands to the roots of his/her being that (s)he is only different today from what (s)he was yesterday, not less, (s)he'll make sure (s)he gets his/her pocketbook in the best shape possible for the same reason.

Professional rehabilitators are plagued by unmotivated, uncooperative patients and clients for one major reason. They are trying to build a rehabilitated fortress on the shifting sands of self-hatred. They don't reckon with it because they figure the self-hatred makes sense. There is only one group of people who can get the message across that it doesn't: people who have been through the experience and emerged on the other side unscathed and joyful — and feeling their joy would be less complete if any element of their experience were changed.

Focusing on the VR agencies, the needs for change are much the same. I am beginning to question whether *vocational* psychologists are needed at all. The rehabilitation counselor is, or should be, the vocational expert. Why do we need vocational experts for the vocational experts? The complementary skill and expertise needed is clinical acumen, non-vocational psychologists who can bring them something different from what they should already have. The VR agencies need to worry less about marshalling every resource to ensure '26's' and a little more about helping clients get their inner **** together — because if this happens, the 26's may very well take care of themselves.

With respect to the independent living programs, I have just one topic for comment. I have observed an area of potential danger for indigenous counselors. Having reached a certain level in our own development, and looking back with the proverbial magnifying retrospectoscope at pain and struggling that seem to have been needless, there emerges a desire to short circuit the process for others. In general principle, there is nothing wrong with that. But discriminations should be made as to when short-circuiting may relieve the person of needless suffering, and when it may cut necessary groundwork out from under a later stage of development. Maybe we had to go through it. Maybe they do, too. Training offered to peer counselors should include such considerations.

Services are available to disabled people who cannot use standard body techniques unless they are modified. Further, a disabled client or patient should not have to pay the same fee while a therapist experiments and tries to figure out how a technique can be adapted. More critical, both public and private insurance programs must pay. It will do no good for therapists to be waiting with modified treatment approaches if no one can afford to consume them.

Cutting across all, research must be done. I don't expect to be believed just because I say that taxpayers are paying in untold ways because society has not given credence to the importance of helping disabled people combat, conquer and transcend the devaluation that is forced upon them. The Rehabilitation Act could point the way it grows more sophisticated, realistic and sensible each time it is re-written and it guides the field. When it is next re-written it should mandate the needed research and, until the results are in, insist that the psychological substrates of vocational rehabilitation at least be attended to.

Finally, there are some things that need to be done in the 'other half' of the applied psychology of disability — advocacy to change certain destructive stimulus conditions. One of the foremost is to interfere with the way people with disabilities are represented in the fictional mass media, and not represented at all in advertisements of commercial products. The public's beliefs and feelings about groups of people with whom they have little contact is largely shaped by how they see them portrayed on the screen. When disabled people are typically portrayed as twisted or chronically depressed and unable to think about anything but their disabilities, it's no wonder salesladies ask our able-bodied companions what size we wear. How does a girl who uses a wheelchair grow up assuming, like other girls, that she will take care of a house someday when she never sees one of 'her group' waxing the floor or frying chicken? The answers you get when you make inquiries incite rage. "The people only want to see beautiful people!" "We can't use cripples, it would turn people off from our products!" I doubt it. A floor wax that could be successfully applied by someone using a wheelchair ought to sell like hotcakes. I think we have to get as assertive as the Blacks have in demanding that we be represented realistically in fiction and appear in commercials. We constitute at least as large a segment of the population.

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CIL HISTORY

Hale Zukas

The Center for Independent Living, Inc., came into existence as a formal entity in March 1972, but its origins extend considerably further back in time and place; on occasion fortuitous circumstance has also played a role.

The roots of CIL can be traced to the Cowell Residence Program at the University of California, Berkeley. In 1962, Ed Roberts, a post-polio respiratory quadriplegic, became one of the first severely disabled persons to be admitted to the University. Since he had to spend most of the time in an iron lung, it was decided that the only feasible living arrangement would be a room at the Student Health Service-Cowell Hospital on campus. By 1966, two traumatic quadriplegics had also moved into Cowell; three years later there were 12 severely disabled students in the Cowell Residence Program, which had by then been formally established and was being supported by the California Department of Rehabilitation.

In 1969, the atmosphere at Cowell was a peculiar combination of disparate elements. On one hand, the CRP provided a quite sheltered living situation; indeed, in its hospital location (albeit in a separate wing) it bore some resemblance to the custodial institutions to which disabled people are so often relegated. The residents of the Cowell Program, for the most part, confined their movements to the campus as there was considerable apprehension about traveling out into the community. In part this was because the electric wheelchairs then available were unreliable or had very limited range. Even if their chairs had been adequate to the task, however, the surrounding community was largely inaccessible to them. There were no curb ramps in Berkeley, for example, until a four-block section of the main shopping street south of campus was reconstructed in 1969-70; ramps were incorporated in this project at the urging of the Cowell residents.

This insularity also had its positive aspects, however. In the Cowell Program, residents were in close, continuing contact with other people having similar problems and concerns. A sense of unity and self-confidence gradually developed, largely as a result of the free flow of communication and sharing of experience. The residents' political consciousness grew as they became aware of the degree to which control over their lives had been taken over by medical and rehabilitation professionals. They thus came to realize that the concerns about self-determination raised by the black and student movements had considerable relevance to their own lives as disabled people. This consciousness-raising process was accelerated in 1969 when the rehabilitation counselor assigned to the Cowell Program tried, with the support of all but one of the professionals associated with the program, to have two of its residents evicted because she deemed their educational goals unfeasible and their life styles improper. United as never before, the Cowell residents defeated the counselor in this effort.

As time went on, the residents found the bureaucratic and *in loco parentis* restrictions under which they had to live at Cowell a source of increasing aggravation. Additionally, by 1969, some residents were nearing the end of their academic careers and consequently would have to leave Cowell. The need for some kind of alternative to the CRP was thus becoming more and more apparent. In order to address this need in a systematic manner, most of the Cowell residents in the Fall of 1969 organized their own class, called "Strategies of Independent Living," under the

University's group studies program. Initially the major emphasis of the class was on developing a proposal for a communal living arrangement which would be similar in some respects to the Cowell Program but which would be controlled by residents themselves and open to non-students as well as students. After a few weeks of work on the proposal, however, it became apparent that establishing and operating such a facility would be very costly and that funding would be extremely difficult to find.

In the meantime, Ed Roberts had learned of the Special Services program operating out of the federal Office of Education. Under this program various kinds of aid were available to disadvantaged students to enable them to successfully pursue college studies. In the establishing legislation Congress had expressed its intention that ten percent of the appropriation for the program be allocated to services for physically disabled students. It was reported that the Office of Education would be very receptive to a proposal for a program of services to disabled students on the Berkeley campus. Consequently, the students in the class put aside the establishment of a communal living arrangement and turned their attention to developing a program of supportive services which would enable severely disabled students to live independently and function more effectively as students.

Defining the services which should make up such a program was a relatively simple and straightforward process. The students drew on their own experience and figured out what services *they* would need in order to live independently in the community. They would need a pool of people available to help them in getting up, dressing, bowel and bladder care, preparing meals, and the many other activities of daily living that anyone leading an active life must perform. They would need fast, reliable wheelchair repair, for without a wheelchair in operating condition they were little better off than if they were bedridden. They would need assistance in obtaining the financial benefits and services to which they are entitled from other agencies, so they would have the resources needed to lead independent lives. Accordingly, an attendant referral service and provision for emergency attendant care, a wheelchair repair service, and an advocacy component were incorporated into the proposed program along with a component devoted to helping disabled students deal with University-related matters, such as pre-enrollment, getting classes moved to accessible locations, and making special arrangements for examinations when necessary.

The fact that the idea for a services program, on the one hand, came about largely for expedient reasons (namely, the exigencies of funding) and, on the other hand, was a logical outgrowth of the students' past experience might lead one to overlook its enormous significance for disabled people, not only in Berkeley but throughout the country. The approach envisioned in the proposed Physically Disabled Students' Program (PDSP) was a radical departure from past practice in the medical and rehabilitation fields. In contrast to the fragmentation which characterized the existing services, the PDSP would take a holistic, integrated approach by providing a comprehensive array of services in recognition of the fact that disabled people are likely to have a variety of needs, and functional independence will be hard to achieve unless *all* those needs are met. Self-evident though this may seem in hindsight, such an approach had, to our knowledge, never been tried before.

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

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

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

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

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

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

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

scious effort. Those involved in organizing the CIL made this effort; the resultant benefits accruing to both the disabled and blind have shown that it was eminently worthwhile.

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

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

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

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

In July 1972, three months after its incorporation, the CIL received a one-year $50,000 grant from the federal Rehabilitation Services Administration to enable it to get on its feet organizationally and to do a systematic job of research and planning for a comprehensive community-based services program for the disabled and blind. During most of the grant period, the major emphasis of the CIL was on developing a proposal for such a program costing, in its various forms, from $250,000 to $400,000 per year. As the expiration of the grant drew near and prospects of new funding continued to prove fruitless, the CIL staff lowered its sights considerably, and the prime objective became, not expansion, but simple survival. In the last week of June 1973, the CIL was informed that a renewal of the planning grant, its last hope, would not be forthcoming. At this point the CIL was in serious danger of going under. In an attempt to avert this eventuality, a few CIL staff members, along with Ed Roberts and John Hessler, Director of the PDSP, met with University Vice-Chancellor Robert Kerley to ask for his help. Through Kerley's personal intercession $15,000 was made available through the University's Community Projects Office to keep the CIL afloat for another four months. In August the City of Berkeley allocated $15,000 to the CIL to cover a year's overhead costs, principally rent and utilities. Even though these two grants by no means assured the CIL's future, there was a strong feeling among

the staff that there had been enough of planning and it was time to get down to the business at hand and start delivering direct services, without regard to what the future might hold. In September 1972, the CIL established its own attendant referral service, giving limited help with locating housing, and providing transportation with a donated Volkswagen van.

The University money stopped in mid-November 1973, and the CIL became essentially dormant. Understandably, demoralization among the staff was widespread. In late December, however, word was received with great rejoicing that the San Francisco Foundation had approved the CIL's application for $30,000. Regular operations were resumed with the start of the new year. In March 1974, the long search for a facility to replace the two-bedroom South campus apartment which had been the CIL's base of operations since August 1972, culminated in a move to a much larger and more centrally located quarters in the downtown area. At about the same time, the CIL was allocated approximately $35,000 on a six-month basis from Alameda County revenue-sharing funds. With the reasonable expectation that each of the current grants would be renewed, a relatively firm base of financial support had been established which assured that CIL would be able to maintain at least a modest level of activity over the next several years.

While it would have been desirable to obtain funding for the CIL in one comprehensive package, experience had thus shown that the only feasible strategy was to fund CIL on a piecemeal basis through an accumulation of relatively small grants. The CIL has continued to pursue such a funding strategy in the intervening period with considerable success, and several new programs have been established as funding has become available. The multiplicity of funding sources and the accompanying rapid expansion makes it difficult to chart, except in very general terms, the direction CIL should take in its future development. One thing has not changed, however: the CIL's overall objective is still eminently well described by its name.

CIL's service program is geared to increase the disabled person's potential for independence. The following is an outline of current CIL services and programs.

1. *Attendant referral counselors* interview, screen and place prospective attendants with disabled people who need help with such tasks as bathing, dressing, and housekeeping. Counselors also give advice on hiring, training, and firing attendants.

2. *Advocacy counselors* provide information to clients on how and where to apply for local, state and federal financial and medical aid programs. Counselors inform clients of regulations, benefits and rights under such programs. They also assist in fair hearings whenever necessary.

3. The *job development specialist* teaches job-seeking skills, maintains contacts with potential employers, and helps disabled and blind people find employment.

4. The *independent living skills counselor* evaluates a client's mobility, indoors and outside, examines the architectural layout of his home, and suggests special adaptive aids, equipment, and techniques which make daily living tasks easier. The counselor also evaluates the client's need for programs to increase muscle strength, joint mobility, etc.

5. *Peer counselors* combine professional counseling skills with personal experience gained from living with a disability. Counseling services currently offered include individual and family counseling, groups for mates and parents of disabled people, as well as consciousness-raising groups for the disabled themselves.

6. The *health maintenance program* stresses personal responsibility for body awareness and individual health. Through home visits and informal office sessions the program helps disabled people understand bowel, bladder, skin, and respiratory problems and treatments. Counselors suggest medical equipment, promote satisfactory communication between patients and medical professionals, and train prospective attendants and families in care techniques for the disabled.

7. The *housing department* keeps listings of accessible houses and apartments, helps disabled people find places to live, and is available for consultation regarding house modifications.

8. The *blind services department* conducts individual and group counseling, client advocacy, mobility instruction and recreational activities specifically for the blind and partially sighted.

9. CIL's demand-response *transportation service* is available to the aged, blind, and disabled of the East Bay. It provides cross-town mobility for any reason to people who have no access to public or private transportation. All vehicles are fully equipped with mobile radios, hydraulic lifts, and securement for wheelchairs. Service is available from 8:00 am to midnight, Monday through Friday, and the vans are available for charter on weekends.

10. CIL-s *wheelchair repair shop* is the largest in Northern California. It provides while-you-wait service for both manual and electric wheelchairs, 9:00 am to 5:00 pm weekdays and noon to 5:00 pm weekends. Emergency evening service is also available.

11. The *automotive and machine shop* mechanics conduct classes for staff and clients in vehicle maintenance and general machine shop practice as well as being responsible for servicing all CIL vehicles.

12. The *community affairs department* is attacking the physical, economic, and social problems of the disabled on the federal, state, and local levels. On the local level this has meant close cooperative work with city agencies leading to the installation of curb ramps and removal of architectural barriers.

13. The *communications department* publishes *The Independent,* a quarterly magazine with a national circulation. The relevance of *The Independent's* subject matter to the disabled everywhere is reflected by the increase in circulation from 1000 in the Bay Area to over 7000 nationally.

14. The *Research and Demonstration Project,* as one of six delivery system demonstration projects funded by the Rehabilitation Services Administration and coordinated with the National Comprehensive Needs Study of the Severely Disabled, is a demonstration of the advantages of a peer counseling approach to delivery of services to the severely disabled. The project works with a few, hard-to-serve clients providing CIL-type services on a small scale. Research staff carefully document procedures and results so that the project can produce guidelines and serve as a model for future disabled services agencies nationwide.

Training

1. The *Computer Training Project* trains people with severe disabilities in computer programming and places them in jobs with the help of an advisory committee of representatives from major corporations. The instructors, disabled themselves, and the CIL services staff work with the students to prepare them for the working world.

2. Through the California Department of Rehabilitation, CIL employs disabled and blind people as *On-the-Job Trainees* to learn skills ranging from wheelchair repair to peer counseling. Some trainees are guaranteed jobs at CIL after their training, and others go on to positions in business and government.

3. Using specially developed materials, CIL trains *rehabilitation counselors, police, and fire department personnel* to better understand disabled people. One part of the project is a five day course for rehabilitation counselors in which each counselor spends five days in a wheelchair or blindfolded.

4. CIL, in conjunction with the Center for Health Studies/Antioch College, offers *M.A. and B.A. degrees* in Health Services Administration and Psychology with emphasis on counseling and services for the disabled. This degree program is the only one in the United States focusing on the psychology of disability using the peer counseling approach as practiced at CIL.

Business Enterprise Program

Funding from private foundations and government makes it possible for CIL to provide services free-of-charge except for transportation (30¢ a ride) and wheelchair and van repair (paid by Medi-Cal, private insurance companies, or individuals). As a first step toward financial self-sufficiency, CIL has established a business enterprise program.

1. The wheelchair repair shop derives income from sale of parts and services and is currently self-supporting. The shop is a dealership for major brands of durable medical products, and its mail order department sells van tie-downs, Davis forks, and other equipment.

2. CIL's machine shop is in the business of making cars and vans accessible to the disabled by installing hand controls, lift gates, ramps, and tie-downs.

3. CIL is studying the state-of-the-art of wheelchair design in order to develop and eventually market a wheelchair with exceptional durability and performance.

4. The California Department of Rehabilitation contracts for CIL services such as mobility instruction and living skills counseling.

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THE ROLE OF THE STATE VR AGENCY

Donald E. Galvin

Introductory Statement

The state-federal vocational rehabilitation partnership is the oldest and most mature of all programs designed to make an impact upon dependence resulting from disability. Federal legislation concerned with rehabilitation had, since 1920, reflected a steadily-broadening concept. Beginning as a modest extension of vocational education, vocational rehabilitation agencies have gradually assumed responsibility for a greater array of services to a wider range and severity of disabling conditions.

The concern for expanding and improving services to the severely handicapped is a pervasive theme throughout the Rehabilitation Act of 1973 and the 1974 Amendments. Several specific references to the severely handicapped appear in Section 2, *The Declaration of Purpose.* For example, the Act reads, "The purpose of this Act is to provide a statutory basis for the RSA and to authorize programs to: (1) develop and implement comprehensive and continuing State Plans for meeting the current and future needs for providing vocational rehabilitation services to handicapped individuals and to provide such services for the benefit of such individuals, serving first those with the most severe handicaps so that they may prepare for and engage in gainful employment; (3) conduct a study to develop methods of providing rehabilitation services to meet the current and future needs of handicapped individuals for whom a vocational goal is not possible or feasible so that they may improve their ability to live with greater independence and self-sufficiency; (5) develop new and innovative methods of applying the most advanced medical technology, scientific advancement, and psychological and social knowledge to solve rehabilitation problems and develop new and innovative methods of providing rehabilitation services to handicapped individuals through research, special projects, and demonstrations; (11) evaluate existing approaches to architectural and transportation barriers confronting handicapped individuals, develop new such approaches, enforce statutory and regulatory standards and requirements regarding barrier free construction of public facilities and study and develop solutions to existing architectural and transportation barriers impending handicapped individuals."

Thus, with the passage of Public Law 92-112, the state-federal partnership has committed itself to expand and improve services to individuals with severe handicaps. State vocational rehabilitation agencies are now free from many of the legal barriers which have, in the past, discouraged counselors from accepting clients whose feasibility was questionable due to the severity of the handicap. The new freedom and the accompanying opportunity present a number of problems and challenges to vocational rehabilitation agencies. It will be necessary to plan for the provision of vocational rehabilitation services in the light of broad community needs and the ability of public and private vocational rehabilitation agencies to share common responsibilities. As important as this has been in the past, rehabilitation agencies now, and in the future, must be more effective in providing statewide and community leadership, in identifying the needs of the severely handicapped, and in providing effective services which result in enhanced independence and freedom for the severely handicapped.

I. Some Administrative Considerations

A. The State Plan

In keeping with the requirements of the Rehabilitation Act of 1973 and the 1974 Amendments, each state agency must include in its 1975 Program and Financial Plan to the Rehabilitation Service Administration a formal statement containing the plans, policies, and methods to be followed in carrying out the State Plan, including a description of the methods to be used to expand and improve services to handicapped individuals with the most severe handicaps. The Plan must also confirm that in the event that services cannot be provided to all who are in need of services, first consideration will be given to serving those with the most severe handicaps.

B. Program Planning

Rational planning and program development requires an estimate of the population in need, an appraisal of the variety of services required, the cost of such services, a determination of program effectiveness in achieving stated goals, the impact on related programs, and the identification of service delivery mechanisms which have proven most successful.

C. Program and Project Evaluation

The state agencies are required to initiate program and project evaluation to assess effectiveness in achieving the goals stated in the planning documents. State agencies are to assess population in need data as well as measure, analyze, and report the results of providing services to the disabled in general and to the severely handicapped in particular. States need to evaluate the effectiveness and efficiency of services in terms of benefits to clients and program costs.

D. Public Education

In 1968, the Report of the National Citizens Advisory Committee on Vocational Rehabilitation stated, "Public awareness of modern rehabilitation programs, and their capacity to deal effectively with the problems of disability, lags far behind technical advances in restoring disabled people to active lives . . . the average citizen knows so little of today's rehabilitation programs that he is completely unprepared when disability strikes him or his family." While some progress has been made in the last seven years, far too many citizens, in general the disabled and helping professionals, still lack the kind of information which will allow them to take advantage of the services which do exist.

This general lack of information and misunderstanding has many unfortunate consequences. The disabled too often must rely upon another agency to make contact with the state VR agency; often inappropriate referrals are made because the sending agent knows little about the state agency eligibility criteria, services priorities, and objectives. Job placement is hindered as most employers know little about rehabilitation or are misinformed about the skills and abilities of the disabled person.

It is an administrative responsibility to broadly enunciate the new policy statement in terms of priority to the severely handicapped through the media, interagency meetings, professional conferences, cooperative agreements, and publications. Public education can best be achieved through the coordinated efforts of public and private agencies, other service providers and consumers of services.

E. Legislative Relations

It is incumbent upon the state agency to develop a strategy which can convey realistic goals and objectives to legislative bodies. The state agencies need to arm themselves with data and evidence on cost and effectiveness in serving the severely disabled.

The state VR agency must also play a leadership role in effecting civil rights, employment, and Workmen's Compensation legislation which benefit the handicapped. The state agencies should also take a more aggressive and positive advocacy position in such areas as architectural barriers, availability and accessibility to housing, mass transportation systems, and recreational services.

F. Consumer Participation

A major theme in the vocational rehabilitation hearings before Congress involved consumer participation, i.e., the involvement of clients and client advocates in developing state agency policies, programs, and in the case service decisions which affect the lives of the handicapped. It is this concern which underlies the requirement in the new law for an individually-written rehabilitation program of service.

The renewed pride among the handicapped which has led them constructively and responsibly to seek and achieve a greater measure of their civil rights is a significant and promising development. This new self-reliance is reflected in the fight for and subsequent victories in some states in achieving barrier free design laws. Further, through the specific efforts of the handicapped, the whole question of civil rights for the handicapped is now before legislative bodies in several states.

In addition, through the efforts of the handicapped, there has been some "consciousness raising" among service providers, employers, public officials, and the general public. As an extension of their "self-declaration," we find handicapped persons participating much more with both public and voluntary agencies in devising those policies which will affect the lives of the handicapped. The handicapped are taking a healthy, participative role as consumers on various advisory councils, boards and commissions, and in providing testimony before legislative groups. Persons who at one time were served by rehabilitation agencies are becoming more evident as board members, policy-makers, consultants to, and staff of, the same rehabilitation agencies. The state VR agency can avail itself of the input and reaction of consumers, client advocate groups and service providers through including such representatives on advisory councils, boards and commissions, through public hearings dealing with issues of program policies and priorities, and through periodic review sessions between the VR administrative leadership and consumers on topical matters.

We should also note the more symbolic importance of the involvement of the client in the original development and all revisions of their rehabilitation plan of service. The written plan of service is to include the views of the client toward the plan and services received. In some states, the client or guardian will be asked to co-sign the plan of service. The new Act also provides for annual re-evaluations of those clients closed not rehabilitated, those not accepted because of severe handicap, and those closed in sheltered workshops and homebound programs. Client fair hearings and administrative reviews are also to be made available so as to deal with client dissatisfactions and resolve disputed issues.

G. Staff Professional Development

Much of what will appear later addresses itself to the need to enhance the quality of rehabilitation services through enriching the skills and knowledge of the rehabilitation counselor.

Unfortunately, many rehabilitation counselors are not prepared, by academic training, work experience, or personal interest to serve the severely handicapped. It is probably fair to say that a sizable proportion of those counselors hired by state VR agencies during the last decade have concentrated their efforts upon serving the mentally ill and those with behavioral disorders including alcoholics, drug abusers, and public offenders. These counselors have limited training or experience and, in some cases, lack the attitudinal make up to effectively serve the severely physically handicapped. There is clearly a need to "reorient" many counselors by way of extensive staff development.

Efforts should be made to convey medical information and the physical rehabilitation aspects of vocational rehabilitation; to place greater emphasis upon vocational evaluation techniques and the vocational implications of disabilities; to strengthen the role of the counselor as a vocational expert for the disabled; to conduct joint training with private health agencies, advocacy and consumer groups; and to develop formal training contracts with physical medicine and/or university affiliated medical centers for long-term and systematic training.

Attitudinal training of counselors which would help them to be more sensitive to the needs of the disabled and more relaxed and responsive in meeting their needs should not be overlooked.

A sound professional development program should also make use of modern media approaches to training and should emphasize a performance or competency based approach which will provide the rehabilitation counselor with the skills, knowledge and attitudes he or she will need to provide effective services to the severely handicapped. Some other components of a modern and comprehensive professional development program include the following:

1. A systematic approach to the determination of training needs.
2. A plan for continuing education within the larger framework of career development for all classes of employees within the agency.
3. A performance-based training evaluation system.

II. Some Service Delivery Considerations

Over the years, recipients and providers of service alike have commented upon long delays, duplication of effort and general inefficiency in the delivery of rehabilitation services. These concerns appear rather routinely in any evaluation of our human service delivery system. However, the prevalence of such dysfunction makes the consequences no more acceptable.

Our ambitions for the vocational rehabilitation service delivery system are indeed impressive. Ideally, we want to provide effective, comprehensive, and individualized services which are at the same time well coordinated, economical and expeditious — all within a responsible and accountable system which respects client rights and provides priority to those most in need.

Federal regulations and the principles of good professional practice dictate an individualized plan of service for each client; however, economies of scale are

deliberately sacrificed in such an approach for a conscious effort is made not to force a "group solution" upon individual clients. Complicating the problem is the fact that most services required by VR clients are not under the direct control of the state vocational rehabilitation agency. For example, the professional providers of diagnostic information, for the most part physicians and psychologists, are independent practitioners. While many such practitioners have extended special considerations to public and private agencies in an effort to accelerate the delivery of service, the fact remains these health care professionals are in limited supply and the demand for services often results in long waiting periods. Furthermore, the organizations and agencies providing evaluative, adjustment and training services, i.e., sheltered workshops, community colleges, trade schools and universities usually have waiting lists and/or periodic rather than continuous enrollment policies.

State VR agencies must extend even greater effort to identify and eliminate sources of delay, inefficiency, and neglect. Some suggestions follow.

A. Outreach and Referral Efforts

It would seem that the nature of the referrals to the state VR agencies and the service population are largely determined by the nature of the state agency's outreach efforts and referral development program. In essence, a supply/demand function may be in operation (as opposed to the more usual demand/supply function); that is, if the state VR agency places a counselor in a previously-unserved school or hospital, a caseload is soon generated. If a deaf specialist is placed in a district office, assuming that the individual is aggressive and resourceful, there will soon develop a caseload of unanticipated dimension. This phenomenon has repeated itself over and over whether the client be a disabled welfare recipient, a drug abuser, a public offender, or severely physically handicapped.

The "targets of opportunity" in terms of serving the more severely handicapped who seek greater independence include (but are not limited to) the following:

1. Social Security Programs
2. Physical Medicine Units of General Hospitals
3. University Hospital Physical Medicine Departments
4. State Mental Hospitals
5. Convalescent and Nursing Homes
6. Work Activity Centers
7. Health Organizations, i.e., Epilepsy, Heart, Cancer, Cerebral Palsy, Mental Retardation, etc.
8. Special Education Programs
9. State Schools for the Blind and Deaf
10. Special Purpose Medical Centers, i.e., Heart, Stroke, Neurology, Amputee Clinics, Burn Centers
11. Advocacy Groups Such as Organizations for Disabled Veterans, the Physically Handicapped, Deaf, and Mentally Retarded
12. Former Clients Who Were Unsuccessfully Served or Not Accepted for Service Due to Severity of Handicap
13. Former Clients Who Were Closed From Service in Sheltered or Homebound Employment.

In order to properly receive and serve the more severely handicapped, VR offices and rehabilitation facilities must be completely accessible. While this

might appear unnecessary to state, the fact is that many such offices and facilities present the same barriers which are so prevalent in the larger society.

B. Eligibility Determination

The language of the new law, while clearly maintaining the employment objective, also invites greater risk taking on the part of the state agency. The guidelines for the individual rehabilitation program direct that the counselor is to make the decision that the client is not eligible only after the evaluation of rehabilitation potential has demonstrated "beyond any reasonable doubt" that the individual is not capable of employment.

C. Evaluation of Rehabilitation Potential

The 1973 Rehabilitation Act and the 1974 Amendments introduce the following services. (1) Preliminary diagnostic studies to determine basic eligibility in all cases to include an appraisal of the current general health status of the individual. (2) A thorough diagnostic study which is provided as needed for the purpose of determining the nature and scope of the services needed by the individual. The thorough diagnostic study includes a comprehensive evaluation of pertinent medical, psychological, vocational, educational, and other related factors which bear on the individual's handicap to employment and rehabilitation needs. (3) Extended evaluation to determine rehabilitation potential. Such evaluation is provided when there exists a physical or mental disability which constitutes or results in a substantial handicap to employment but the counselor is unable to make immediate determination that vocational rehabilitation services will benefit the individual in terms of employability. Vocational rehabilitation services necessary for the determination of rehabilitation potential, including those provided within the thorough diagnostic study may be provided to a handicapped individual for a period not to exceed 18 months.

While there is growing development of pre-vocational and work adjustment services, there are insufficient resources in the face of the present and anticipated demand for such services. Individuals with severe disability complicated in many cases by problems of mobility and social isolation will require extended and comprehensive evaluation services.

The provision of thorough diagnostic studies and extended evaluation services can be expected to substantially increase the cost of services provided and will likely require considerably more time to complete. The state vocational rehabilitation agency will need to develop service arrangements, purchase of service agreements and cooperative projects which serve to utilize other funding mechanisms (Medicare, Workmen's Compensation, Social Security, Title XX) while accelerating the service delivery process. Hopefully, the experience gained through innovation and expansion grant projects in serving the severely handicapped, including RIDAC (Rehabilitation Initial Diagnostic and Assessment for Clients) projects, will provide living examples of comprehensive and expeditious service arrangements.

D. The Rehabilitation Counselor as a Vocational Expert for the Handicapped

The role of the vocational rehabilitation counselor has been the subject of debate for decades with painful lack of consensus. The troubled identity of the profession may in part be attributed to both this lack of consensus and the multiple expectations held by important "actors" in the field. That is,

counselor educators, counselor trainees, and employers have varying expectations as they contemplate the role of the rehabilitation counselor. Further, the nature of a rehabilitation counselor's work affiliation, i.e., state VR agency, private psychiatric hospital, ghetto drug center, physical medicine clinic, etc., materially affects the view the individual has of his/her "proper " role.

It should be understood that the comments in this paper are addressed only to the vocational rehabilitation counselor employed in the state VR agency. In sum, the author argues that the unique contributions of the VR agency counselor to the interdisciplinary social and health care system established to serve the handicapped is that of vocational counseling expert. In the galaxy of services/agencies which are available, in the array of physiatrists, psychologists, nurses, social workers, occupational therapists, physical therapists, and other specialities, it seems reasonable to assume that the VR counselor's individual professional talent — and the most significant contribution he or she makes to the team effort of rehabilitation — is their (1) vocational counseling expertise and (2) their ability to coordinate a wide range of community services which result in vocational success for their clients.

To the degree that the VR counselor neglects this very challenging role while emulating the role of one of the other team members, the counselor is engaged in duplication of effort while perpetuating ignorance and ineffectiveness in terms of providing professional vocational assistance to the handicapped. Too often, the VR counselor plays the role of "clinician," "psychotherapist," "social advocate," sometimes being sidetracked into areas where they are unqualified while neglecting the very special and thoroughly professional contribution that the vocational rehabilitation counselor can make in collaboration with other professionals.

To some degree, this phenomenon may reflect the professional preparation of the counselor in which great academic emphasis is placed upon diagnostic procedures, the implications of pathology, and generic therapeutic counseling with insufficient attention given to those competencies required if one is to assist in sound career planning with, and on behalf of, a physically handicapped person. The modern and effective VR counselor needs to have knowledge of job analysis, job restructuring, labor market information, the job economy, manpower programs, vocational education, and techniques for job placement of the disabled.

Both spontaneous criticisms and formal survey research have made it clear that what clients, family members, and referral agencies want and expect from the state VR agency is expert vocational assistance in choosing, preparing for, and finding a job which is rewarding and satisfying. Yet clients and cooperating agencies have perenially expressed dissatisfaction with our vocational services, specifically our job placement services. In the face of all this, we still find debates among staff as to whether or not job placement is a legitimate responsibility. We find the rationalization that "the truly rehabilitated" will find their own jobs accompanied by persistent requests that state agencies hire job placement specialists in the district offices who would relieve counselors of this "odious task."

After years of this debate, one has to wonder if we are not suffering a not so mild form of aversion neurosis. A simple approach-avoidance or negative vicious cycle may be in operation. State-of-the-art deficiencies and academic

neglect result in inadequate counselor preparation in the vocational area in general and job placement specifically. Possessing such deficiencies, feeling in some cases uncomfortable with what may be felt to be a subservient or subordinate role to employers (the beggar's role!), armed with all the handy rationalizations as to why others, i.e., the clients, specialists, aides and the Employment Service, should do placement, we should not be surprised that we aren't very effective. Perhaps our counseling staff is not as effective at job placement as they could be because the universities and state agencies haven't armed them with the skills necessary to do a successful job. We have provided few successful techniques or models, and in many cases, we have to overcome personality aversions to the task. Due to all these factors, the counselor experiences much failure and frustration. Constantly bombarded by such negative feedback, is it any wonder that counselors look to other areas to find satisfaction while implicitly asking clients to expose themselves to the frustration and disappointment of unsuccessful job seeking?

In short, both the university counselor education programs and the state agencies have a heavy responsiblity to provide the knowledge, skills and administrative support systems which will allow counselors to be effective in this critical aspect of their jobs. Not only will clients benefit directly but counselors will become more confident and satisfied with themselves as they experience the sense of true achievement which can come in helping a severely handicapped person attain success in work.

E. Job Placement Services

Due to the multiple roles played by the VR counselor, the broad Congressional mandate, the comprehensive nature of VR services, and the dimensions of client need, it is sometimes difficult to retain the primacy of the overriding program objective, i.e., placement of the handicapped into employment. Counselors, supervisors, and administrators in their concern with the service delivery process, the day-to-day activities of staff, the press of meetings, and paperwork, sometimes lose sight of the objective which gives meaning to all these activities and efforts.

There can be no doubt that the placement of handicapped persons, particularly the severely handicapped in these near depression times, is problematic. The client's residual limitations, frequent absence of substantial work skills and work experience, the counselor's lack of skills and techniques in job placement, employer fears and prejudices, architectural and transportation barriers, and a host of other factors complicate successful and permanent job placement. As a result, the disabled make up much of our country's "underemployed," those who are most vulnerable to economic adjustments. Evidence exists which suggest that many disabled persons are placed into jobs paying less than minimum wages, having few fringe benefits, and subject to periodic layoffs. Administrators within VR agencies must be sensitive to the number and proportion of clients who are "closed-rehabilitated" into sheltered employment, homebound work and as homemakers. Counselor professional standards, vigilant casework supervision, and administrative integrity should assure that such client outcomes represent appropriate, quality services consistent with client needs and functional capacities.

State VR agencies must seek assistance from, and cooperate with, universities, private consultants, insurance companies, employer associations,

labor unions, and others to better prepare their staff to fulfill their obligations as a vocational expert for the disabled. Specific training in vocational aptitude testing, work adjustment counseling, vocational evaluation techniques, labor market analysis, job engineering, manpower programs, etc., should be provided.

Casework supervisors should receive advanced training so that they might more effectively serve as vocational consultants to counselors. In reviewing casework, casework consultants must assure that clients have indeed received vocational counseling and guidance which is meaningful and relevant to their needs.

If counselors are to provide more effective job placement assistance, the state agency must reaffirm the importance of securing meaningful, well-paying employment for clients and must provide the counselor with a workable placement system. Some of the elements of a comprehensive placement system include:

1. The employment of employer relations and/or job development specialists in the state administrative offices.
2. A written plan from each district office specifying job placement objectives, relevant activities, inservice training needs, and consultation required to achieve improvement in all placement efforts.
3. The development of a client skill bank, job order bank, and major employer accounts in every district office.
4. The development and implementation in the district offices of comprehensive monitoring and evaluation procedures.
5. The utilization of Job Seeking Skills Clinics.
6. Provision of statewide inservice training and technical consultation as regards job placement.
7. Conducting local seminars throughout the state to inform employers of the services available to employers from the state VR agency, the rehabilitation provisions of Workmen's Compensation laws, affirmative action provisions in the new Rehabilitation Act, etc.
8. Special efforts to promote the hiring of the handicapped within all levels of government services.
9. Public education and advocacy in support and enforcement of Sections 503 and 504 of the VR Act of 1973.
10. The aggressive pursuit of legislation which fosters employment of the handicapped.

II. Continuing Concerns and Policy Issues

A. Program Integrity

Provision of services to more severely handicapped persons will make great demands upon all state vocational rehabilitation agencies. Counselors will be challenged as never before as they will be expected to serve many clients who formerly may have been considered ineligible for service due to the severity of their disability. Earlier, we commented upon the absolute necessity to enrich the counselor education programs and substantially augment career development efforts. More important, however, than these efforts to support counselors and assist them to acquire the skills they will require for effective performance of their duties is the absolute necessity that state and federal administrators and elected officials rethink the basic intent and objective of the public vocational rehabilitation program.

While the issue of quality of services, case closure standards, and preoccupation with single dimension, quantitative program measures have been recorded in countless journal articles, conference presentations, and program audit reviews, there is probably no more straightforward statement of the issue than that found in the 1968 publication "Report of the National Citizens Advisory Committee on Vocational Rehabilitation." Under a section entitled "The Counselor Dilemma," the committee comments most critically upon the prevalence of the so-called "numbers game." In the words of the original report . . .

> We were distressed to learn that the vocational rehabilitation counselor often finds himself in a condition of crisis today. Overwhelmed by large caseloads, pressures for 'closures,' excessive administrative chores and limited case service funds, the dedicated counselor is often forced to 'compromise his conscience,' his original concept of working closely with handicapped clients frustrated by the harsh realities of the job. Perhaps the most damaging force to the counselor's self-concept, and increasingly to the image of the entire vocational rehabilitation program, is the so-called 'numbers game.' The pressure, whether expressed or implied, to demonstrate substantial increases in the number of people rehabilitated is very real. The effect is to dispose the counselor to seek out the 'easy' case, the person who can be made employable with a minimum expenditure of agency time and money. As a result, the difficult case — the severely disabled, multiply handicapped person who most desperately needs help — is shunted aside as 'not feasible.' Quality of service is thus sacrificed for expediency. In sum, the 'numbers game' results in a perversion of both program objectives and counselor job satisfaction.

Testimony before Congress prior to the passage of the 1973 Rehabilitation Act, the oversight hearings of 1973, and state and Congressional audits during 1973-75 suggest that the situation is not materially altered from the evidence which resulted in this 1968 statement. Perhaps the explanation lies in the fact that state and federal administrators and legislators are faced with a dilemma in which the "success" of the program has historically been measured by the year-to-year "growth curve" of a single statistic, i.e., the number rehabilitated.

From the Congressional hearing room to the counselor's office located thousands of miles from Washington, D.C., the preoccupation has been "more rehabs." Counselors, supervisors, and administrators have become victims of the numbers game, the subtle trap which demeans and demoralizes. As a consequence of this singular and narrow definition of program "success," values, attitudes and behaviors were fostered which may now be subject to criticism. In the reporting of program accomplishments, no distinction was made between the severity of handicap and complicating conditions found among clients served, extent of services rendered, or outcome of service except whether the client was closed "rehabilitated" or not. For example, questions are now being raised in program audits and legislative reviews as to the appropriateness of clients admitted to the program, the quality of services provided, and claims of rehabilitation at closure. Reports of misbehavior, fraud, unjustified claims of success and lack of substantial services provided demand that we give most serious attention to the improvement of administrative practices, casework supervision, and the quality of services rendered.

In this age of accountability, we must guard against the temptation to become so quantitatively oriented and compelled to demonstrate our success that we accept less than the very best we can provide in making a qualitative difference in the lives of those we serve. Indeed, we must become more specific about what it is we do . . . the impact of rehabilitation services. We must work closely with program evaluators to devise better criteria so we can reasonably report client accomplishments — but we must never lose sight of, or forego, our professional obligations and standards. Perhaps this is the greatest challenge we face in the next few years . . . to improve quality of service, to be truly effective in what we do, and to report to the public in an understandable and valid manner in what ways the provision of rehabilitation service made a difference in the lives of those served.

B. "Serve First Those With The Most Severe Handicap" — Who Not To Serve?

An unsettling issue facing most state vocational rehabilitation agencies will likely be how to satisfy the requirement in the Act that services not be denied to anyone due to the nature of the disability while avoiding an excessive expenditure of case service and time resources upon those with more mild or moderate disabilities. More than one critic has observed that we must be vigilant in recognizing that our service model has a certain insidious element in which there is an advantage to providing services to those who may need it least — the high potential, college qualified, mildly disabled.

As noted above, case service reviews and program audits have revealed instances in which the services provided appeared incidental to the client's needs and case results. There have also been instances in which great imagination has been demonstrated in bringing into the system those whose rehabilitation would be rather straightforward, predictable, and safe. Research has also shown that often those most in need received the least in service (avoidance of a "poor" investment) while those with considerable advantages received the most expensive and lengthy services (invest in the winners).

Perhaps we need to be reminded of our first point of eligibility which states that the disability "must constitute or result in a substantial handicap to employment." State VR agencies may need to adopt a policy of referring the mildly disabled — those with a questionable vocational handicap — on to general programs and community services. Such clients would be declared not sufficiently disabled to qualify for state VR services but could and should be referred on to other programs and services. The state VR agency would perform a valuable information and referral service while avoiding substantial time and case service commitments. We would not be expending valuable resources intended for the unquestionably handicapped on those who have only an incidental claim upon these resources.

C. How Are We To Be Evaluated?

While the "numbers game" has clearly been abused, we are not suggesting that quantitative indicators are inherently malicious, unfair, or misrepresentative. We have an important responsibility to be accountable to the handicapped, the general public, and their elected representatives. Knowledge of the number of referrals to the agency, the number accepted for service, number of plans of service initiated, status at closure, percent of clients who are severely handicapped, and the percent who are public assistance

recipients is essential to the control and management of the program and is absolutely essential if one is to report the quantitative dimensions of program accomplishment.

While such data assists in an assessment of the workload and deals in part with questions of efficiency (time and costs), such data says little about program effectiveness; that is, the quality of impact of the program. Measures of effectiveness should reflect achievements or improvements in the functional abilities of clients and problems resolved in such areas as mobility, basic educational skills, work behavior, child care plans, transportation, housing, etc. We need to specify problems or barriers upon intake and document those reduced or removed through the provision of rehabilitation services.

These achievements should also be recorded and reported for all persons served — not only those closed rehabilitated. Hopefully, the counselor's concern with the requirements of "paperwork" including case documentation will be balanced by the recognition of the full range of benefits which clients achieve in the course of their rehabilitation. Additional closure statuses which reflect such accomplishments should eliminate the current "win/no win" dichotomy in which all clients depart from the service system as either "successes" or "failures."

Help may be on the way. The Rehabilitation Act calls for new program evaluation standards which will make it possible to assess to some degree the integrity of the state program on dimensions other than sheer numbers of successful closures per year. For too long, we have relied upon an emotional appeal and the ever-rising growth curve to justify our programs. Insufficient attention was given to such elemental questions as "How many disabled people are in each state? How many may be expected to benefit from rehabilitation services? In what specific, demonstrable ways has the client received benefits from his/her participation in the program? How lasting are the benefits? What happens to those deemed non-feasible or unsuccessful? In the absence of such basic information, administrators have often been forced to explain and justify the program on the basis of limited evidence.

D. Comprehensive Rehabilitation Services for Independent Living: A New Direction

A major social policy issue confronts Congress as they deliberate upon the basic intent and direction of the federal-state rehabilitation program. Essentially, the issue raises a question as to whether the program should restrict its orientation and intent to the vocational realm, with employment as the sole program objective, or be extended into comprehensive services leading to increased independence and enriched quality of life for the handicapped. This issue has been debated for at least 25 years. In 1954, RSA commissioner Mary Switzer campaigned vigorously, but unsuccessfully, for "Activities of Daily Living" services. On the other hand, as recently as 1973, former President Nixon vetoed the original version of the Rehabilitation Act arguing that the provision of Comprehensive Services (in terms of non-employment related services) in the original, Congressionally-approved bill, constituted "a distortion of the basic intent of the program." The compromised version of the Act included a modest sum of money for a nation-wide study of such services. As we contemplate new rehabilitation legislation during 1976 and 1977,

the results of the study will no doubt bring forth further debate on this essential and paramount issue. The final resolution of this question has the most profound implications as eligibility criteria, range of services provided, service delivery mechanisms, and basic program objectives will be directly affected.

Essentially, the question is . . . what is to become of those who are not accepted for service or are unsuccessful in their vocational pursuit? This question has plagued professionals in vocational rehabilitation, the disabled, and other agencies since the inception of the public vocational rehabilitation program in 1920. With recent growing concern, however, for the severely handicapped, there is renewed interest that public and private rehabilitation agencies accept extended responsibilities. In the Congressional hearings of 1972 and 1973, speaker after speaker expressed their concern for the welfare of those persons — particularly the severely disabled — who could not be accepted for services by the state VR agency because their disability was so severe as to preclude employment.

While many if not more of the severely handicapped can in fact achieve competitive, homebound, or sheltered employment, an appreciable number will be unable to (or should not) accept employment. Many of these people are confronted by mobility, social, and family needs. What is our society's responsibility to these people? The issue is compounded by many factors. Many VR administrators are understandably concerned that the public program may be assigned a new and additional responsibility with little or no increase in program resources. As a result, the vocationally-oriented service program may be diluted while staff and case service funds are redirected to comprehensive services. Some also worry that the present staff of state VR agencies do not possess the skills and knowledge that will be required and that inservice training time and resources which are needed to address other pressing concerns, i.e., job placement, meeting the special needs of the severely handicapped, etc., will, by necessity, now be directed to prepare staff to better provide comprehensive, non-vocational services. Some have argued that comprehensive services are traditionally and rightfully the responsibility of the voluntary agency sector and that these agencies should retain this responsibility although the state agency might serve to award program and staffing grants for the establishment and provision of comprehensive services.

Given recent Congressional interest in the program, the beginning of significant new directions in the 1973 Rehabilitation Act and Amendments, and the forthcoming deliberations in anticipation of new rehabilitation legislation, is it not an opportune time to consider substantial new directions? Perhaps this new law could stand as a Declaration of Independence from some of the restrictive provisions which have limited the state agency's full participation in serving persons with handicaps. Is it too radical to propose that all handicapped persons have a right to rehabilitation services regardless of age, disability, or feasibility for employment? That clients who are too disabled for sheltered, homebound, or competitive employment, those that should not work, and perhaps even those who do not want to work, are not thereby denied access to rehabilitation services.

Such a bold step would remove the "feasibility" prognostication and relieve the counselor of both the anguish felt upon denying service to a severely

handicapped person and the fear of the consequences of failure should the client not achieve rehabilitation some time in the distant future. Counselors would no longer be expected to project two, three, five years into the future and predict the effectiveness of the services to be rendered, the client's response to those services, labor market receptivity, etc. Following a simple establishment of disability and a need for service, the counselor would proceed to serve.

The present law stresses that ineligibility be established beyond a reasonable doubt and encourages risk taking, but stops short of defining rehabilitation services as a right. Adding new legitimate, specific, and verifiable client objectives, independent living for example, to the present employment objective would seem to be a logical extension and necessity as a result of the expansion of services to the more severely handicapped. The results of the present national study on comprehensive services to the severely handicapped may provide a vision of the future.

One of government's first efforts to treat and rehabilitate the disabled occurred in England in the 16th Century when that country, for reasons of economic necessity, established hospitals for merchant seamen. Soon after the American Revolution, Alexander Hamilton as Secretary of State established the same service in our own country. Since 1920, the public vocational rehabilitation program has been a curious mixture of humane concern and felt economic necessity. One might argue that the state-federal VR program has been primarily an economically-oriented program and to this day, in the more sophisticated terms of "cost-benefit" analysis, the essential justification for, and worth of, the program is viewed in light of its economic return on investment. Perhaps during our Bicentennial Celebrations it would be appropriate to ask ourselves whether our humanity as a nation has not matured beyond the marketplace mentality which seems to say that a handicapped person's entitlement to assistance from his/her government is in direct proportion to their contribution to the Gross National Product. The answer to such a question may ask much of us as a society; however, in the words of social historian Alfred North Whitehead, "Vigorous societies harbor a certain extravagance of objectives."

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PROGRESSIVE INCLUSION
An Approach to Mainstreaming

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Background

The operation of programs for handicapped children in the public school setting is a relatively new development in the history of education. Although today they are common, in most cases, these programs have been and continue to be isolated from programs for the majority of students, in philosophy if not always in physical location. This has been both because the staff in the so-called regular programs have felt inadequately prepared to deal with their special needs and because the staff instructing the handicapped have been concerned that the children's needs would not be properly met if the children were not instructed by staff with appropriate training.

The school boards and community in general often did not feel comfortable in having the "handicapped" near their children. Children, reflecting the attitudes of the adults around them, also felt uncomfortable and often made fun of the handicapped children in their neighborhood and at school, if they were at the same location. This behavior often led to sheltering children from the community in general; feelings of guilt on the parts of parents for having a handicapped child; and the development of separate private schools or institutional placements for the identified children. Many children with good academic skills often remained fairly segregated as adults. Their job opportunities were often limited by the relatively narrow scope of training available in the special schools and by preconceived ideas about the limitations of the handicapped held by the general public.

Another serious deterent to the development of appropriate educational programs for the handicapped has been the lack of research in earlier years into the best ways to sequence learning for children with specific handicaps. The excuse often given was that the small numbers involved did not warrant the expenditure of time and money required. Another way to say the same thing is that the pay-off is greater with the more capable child. These approaches are not sound, either from a fiscal or from a human resources point of view.

It does cost more money to educate the handicapped person who will be totally dependent on the public for his care. From a solely monetary point of view, it makes sense to educate the handicapped for independent living.

A far more important reason to provide the best education possible to the handicapped child is that of recognizing the worth of the individual and assisting him/her in maximum development for inclusion in all aspects of life.

Tacoma Study Group

It is with the latter idea in mind that the Tacoma Schools sixteen years ago established a study group to determine how a school district can best provide for the education of children with handicaps. From the beginning of the study it was regarded as imperative to affirm the right of all children to an appropriate education. The preamble to the Washington State Constitution reads:

"It is the paramount duty of the State to make ample provisions for the education of all children residing within its border without distinction or preference on account of race, color, caste or sex."

Hence, it was regarded as a legal as well as a moral duty for the State of Washington to be responsible for the education of all children. And the notion was rejected that it is possible to educate and strengthen the handicapped child apart from other children so that (s)he will be able to join general society at a later date.

Guidelines

The final report includes the following statements and guidelines for program development:

Since the exceptional child shares more attributes with other children than he retains uniquely, his education will have much in common with other education . . . As the exceptional child becomes the master of his exceptionality, his education plan should draw increasingly more on the general resources of public education.

The education of exceptional children should be an integral part of the total program of public education.

Programs for exceptional children should emphasize the similarities of exceptional children to other children. The needs of these exceptional children should be respected. It is important to understand the process of self-concept development in this regard. The child must be helped to see himself as having more in common with other children than he has unique attributes. The goal should involve continuous education of the exceptional child toward living in a general unrestricted society. Shared and unique services and facilities should be developed in harmony with this principle.

A reciprocal learning relationship exists between exceptional children and other children which can improve the quality of all education. Above all, each should have the benefit of learning to understand and respect the other. Implied here is an early beginning when children are relatively free from many learned negative feelings regarding self and others. In this way one is helped to become more human, living a more complete life because one understands, accepts and respects more fully than before.

The exceptional child should have the opportunity of attending school as close to home as possible. He should have the opportunity of being as close to other children as possible, in his neighborhood, school and community.

Decentralized provisions for exceptional children should be made in the public schools. As mentioned earlier, exceptional children need to live and learn with others; separate facilities make this difficult.

How can integration best be achieved?

How can handicapped children best be educated together with other children? If separate facilities in separate buildings are rejected, should handicapped children be mainstreamed completely so that they are in so-called regular classrooms with

other children? The study staff decided that the total inclusion approach may be impractical for many handicapped children as well as many staff members.

Under One Roof, Progressive Inclusion

We found workable and flexible alternatives in which facilities and programs are provided for handicapped children under the roof of the regular public schools. It was felt that if programs and facilities were arranged in this manner, it would be possible to include the handicapped child according to his/her own educational-plan. It would be possible to include handicapped children in programs with non-handicapped children on a progressive basis. Hence, we coined the term "progressive inclusion." Each child is included in regular programs to the fullest extent consistent with his or her physical or mental limitations, and an attempt is made to increase the level of inclusion of each child as he or she grows older. All children have some contact with the regular program.

Specific Program Aspects

Summary: Special services and facilities for blind, deaf, retarded, and physically disabled students are offered. People from ages 3 to 21 are served. Parents are encouraged to become very much involved. Each school has a multi-disciplinary support team of professionals who work together (and often with the parents and the child as well) to review each disabled child's progress and make decisions on inclusion. Individualized sequence learning is used so as to enable each child to discover and use his or her abilities and interests as fully as possible. Efforts are made to educate and involve the broader community.

At the elementary level, approximately 75% of the disabled children are based in a therapy program, located at one of two regular elementary schools, with its own rooms, teachers and support staff. This figure represents mainly the retarded and the severely multiply handicapped. These students spend the majority of their time in the therapy area, but also participate in regular programs on a routine basis. The therapy areas are used to offer occupational, physical and speech therapy, as well as other kinds of learning for the children who are based there. Academically capable students, including most spinal cord injured students, are based in the regular school program and use the therapy program according to their needs, e.g., for physical and speech therapy.

At the junior high level, at least 50% of disabled students are based in regular programs; in high school the figure is higher. Special services and learning areas are offered at the junior high and high school levels as well as at the elementary school level. There are pre-vocational and independent living skills programs for the retarded, including a kitchen and bathroom area for the latter program. For older disabled students, there are also programs to teach mobility in the community and career exploration with local employers. In addition, programs for non-disabled students designed to enable them to better communicate with disabled students are offered, for example a course in sign language at the high school level.

For blind students, most of whom participate in the regular programs, there are teachers of the blind and mobility specialists. Braille typing and all-braille materials are offered. Independent living skills are also taught, and there are special programs in the arts designed to foster body awareness and elimination of "blindism" (drama) and to expand one's sense of spatial relationships (sculpture).

For hearing impaired students, there is a "total communication program" in which only as much manual communication as necessary is used. The school district provides each hearing impaired student with a "binaural amplification" hearing aid to maximize residual hearing. At one elementary school, a special teacher of the hearing impaired and a regular teacher team teach a class.

Each school in the district has disabled children in attendance, many participating fully in the regular programs. Whenever a new program is added, e.g., when new state or federal funds become available for specific teaching uses, disabled students are included.

Rather than having a set curriculum for all disabled students, or even for all students with a particular disability, an individual learning plan is made for each student by a team of professionals and paraprofessionals. (See below). Emphasis is placed on task analysis and sequenced learning so that each student will be able to learn, starting from where (s)he is and progressing at his or her own rate. The general educational goals are the same for disabled students as for non-disabled students. The development of a positive self-image is one such goal. While all good educational programs have self-worth as one goal, the programs for handicapped have it as a priority goal to be achieved early in the life of the student.

The desire of the Tacoma Schools is to start the educational program as early in the child's life as is permissible by law and the resources available. This has generally been at approximately three years of age for the more disabled, for their needs to "catch up" require the greatest amount of time, and any delay makes only greater problems. The children with lesser handicaps are generally included at age five. We are currently working with parents and community agencies to begin working with children under three to assure more appropriate early intervention. Our desire is to increase this involvement in a planned intervention program. It is believed that the awareness of the public of programs for the handicapped and their acceptance will make it possible to identify children with problems earlier and bring support to the extended programs that we hope to institute.

An essential component of our program is that of identification. We rely heavily on the community for early identification. The medical community is a prime source of referral. Early childhood programs with increasingly better trained staff members are another major source of referral. Often a child and/or the family of a child served in the program is the best source of referral. Children with lesser handicaps usually are identified by the school staff.

This is done in a variety of ways. One way is general health screening. Another is screening by the communication disorder specialist for speech and language difficulties. The most common way is by the well-trained classroom teacher through planned observation of classroom and playground behavior. Suspected problems can then be referred to appropriate specialists for futher evaluation. Some of those commonly available in our district are nurses, occupational therapists, physical therapists, mobility trainers and psychologists (with philosophy of child study rather than simple test administration and interpretation).

Once identified the child has a program based on the specific information collected. The emphasis is always on what portion of this program can be carried on within the regular programming for children and what portion requires specialized help from support staff and teachers trained in specialized areas. If specialized help is

needed the goal is always to provide that as near his home as is feasible so that friendships developed at school can be extended in the time away from school.

Each school has a multi-disciplinary team, consisting of a psychologist, a social worker, a counselor, the principal, a teacher, and a special education coordinator who coordinates efforts to help each disabled student. Medical people, such as nurses and an orthopedist, also become involved in the team when they are needed. A conference is held twice per year for each disabled child, at which major decisions about what programs (s)he should participate in are made. Parents are involved in these conferences, as are older students. Since every student is involved to some extent in regular programs, there is a realistic basis for making decisions about his/her further inclusion in such programs.

Mutual respect for the skills of others is essential if a team effort on behalf of the identified child is to be successful. While it is essential to be aware of the special skills each discipline brings to the setting, there are areas of overlapping skills and a plan should be developed for the most efficient use of staff in meeting the needs of children.

Recruitment and Staff Development

Recruitment practices were changed so that every candidate for any position in our school district was told about our approach to educating handicapped children. The candidate was asked if this were something to which he could commit himself and something with which (s)he could feel fairly comfortable. In other words, we worked into our recruitment process a positive bias toward the school district position. Hopefully, if that were successful then we would strengthen staff acceptance and action regarding the acceptance of all children and the procedure of progressive inclusion. In addition, we encouraged principals to work with their staff members in explaining the concept and process. It did fall quite heavily on the shoulders of those staff members dealing more intensely with handicapped children to be missionaries of that action and to explain the concepts of inclusion and mainstreaming.

By cooperative agreement with various colleges and universities, as well as with other school districts, a program of in-service classes has been given in recent years to improve the skills of all staff members in serving children with learning problems. This is the key to quality instruction always, but it is particularly essential in a program of progressive inclusion. A variety of formats has been used to make learning opportunities available in a useful form for staff members. For those working on advance degrees, college credit programs have been developed in the community so the class is available during the school year. Professional credit and non-credit programs have also been developed using staff experts to teach. The instructional staff has come from all disciplines. Courses are developed primarily because of identified staff interest but some are developed to introduce new approaches to old problems or to strengthen skills in identified staff deficit areas.

Leadership pressure must be exerted continuously, in the sense that all staff members are expected to understand and to implement the adopted policy. Gentle but sustained pressure by the administrative staff has been a significant enabler of progressive inclusion.

Facilities

All new school buildings and additions to existing buildings within the school district have been made accessible to the disabled. In addition, many of the older buildings have been remodeled to be made accessible. No facilities addition or improvement is made without giving careful consideration to the problems of progressive inclusion.

Community Awareness

A positive self-image does need support. While many of the support activities come in the school setting, many of the activities for support are centered in shaping the community attitudes toward the disabled. This community attitude must be a positive one and in the Tacoma School District this has been developed by activities such as program budget building for handicapped students with citizens' involvement, recreational committees for the handicapped involving teachers, citizens, pupils and administrators. Similar activities have been conducted in the area of job identification, employment procedures, and work opportunity development. The staff participates in many activities designed to enhance the development of an independent living opportunity when the children complete their school training.

Another planned procedure which creates a community awareness is making sure that each community school has its share of the handicapped population. Of course this means more administrative problems for the schools, less efficient use of transportation, perhaps less efficient use of supervisory personnel, but it is our firm opinion that not only is this the humane thing to do, but that the positive attitudes developed by both the disabled pupil and the community will lead to a more fulfilled independent life style for the disabled.

In addition, literature and speaking engagements are used to create community awareness as is direct work with local voluntary and service organizations. For further information write to Tacoma Public Schools.

Conclusion

It should be obvious that the needs of the so-called handicapped are similar to the needs of all people. Any plan for programs must keep this in mind. It is more a matter of how, when and where we fulfill these needs that distinguishes programs for the disabled child from so-called regular programs. As indicated earlier, in our district the stress is on early intervention; attendance at a school as near the child's home as feasible; and as much participation in the regular classroom as acceptance and skills permit, but always with the support available to assure success in school and in the community.

We know that all children do not have the potential for totally independent living but each child should have the opportunity for as much independence as he can handle. It is to this goal our programs must be directed. It is our feeling that a philosophy of progressive inclusion best speaks to this issue.

People often ask if the payoff is worth the effort. As imperfect as our process is, the answer has to be a loud and emphatic yes. When children with various handicaps

mingle freely with their peer group, when many are able to handle their setbacks and some exceed our boldest expectations, we know that gains are being made.

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INDEPENDENT LIVING FOR INDIVIDUALS WITH "SEVERE DISABILITIES": THE FEDERAL OUTLOOK

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The title needs three brief explanations. First, the words "individuals" is underlined. While it is easy to lapse into the habit of labeling groups of citizens with the jargon of the day, *e.g.* "*the* severely disabled," we are talking about individuals. These *persons*, who happen to have functional limitations, are too frequently categorized and stereotyped, particularly by federal program planners. Second, the words "the severely disabled" are in quotes. Even when verbal shorthand seems to necessitate such terms, the reference is unclear. One can say, for example, there are 34 million handicapped in the U.S., 11 million of whom are "severely handicapped." But such statements are based on many assumptions about who is or isn't included. Of the eighty-five plus federal programs supposedly serving the target group(s) in question, practically none use the same definition of "the disabled," much less "the severely disabled." Third, the phrase "federal outlook" is equally ambiguous. Full participation in society by all citizens will require positive action by all three branches of government. Persons with disabilities must first get good laws through Congress, see that the laws are properly executed by the Administration, and, when necessary, appeal legal issues all the way to the Supreme Court. Only through effective citizen participation in the legislative, executive, and judicial arenas, will citizens with disabilities be able to secure their basic human, legal, and civil rights.

To adequately cover all federal legislation, programs, and legal rulings would require volumes. This paper will briefly a.) summarize the scope of the federal government's current role in serving severely handicapped individuals; b.) examine possibilities for consumer involvement in the Vocational Rehabilitation program; c.) make a brief statement on rehabilitation for independent living and finally; d.) make an action recommendation for the White House Conference.

I. Legislative Branch

In a summary of "Legislation Affecting the Handicapped: 94th Congress" from the National Paraplegia Foundation approximately 230 bills are listed. Subject areas include:

Architectural Barriers (11 bills)
Blind (28 bills)
Deaf and Hard of Hearing (7 bills)
Developmental Disabilities (4 bills)
Disabilities (5 bills)
Education (8 bills)
Employment (14 bills)
Handicapped Veterans (42 bills)
Huntington's Disease (5 bills)
Income Tax (22 bills)
Mental Retardation (5 bills)
Miscellaneous (9 bills)
Recreation (2 bills)
Social Security (36 bills)
Transportation (20 bills)
White House Conference on the Handicapped (1 bill)

These range from Senate Concurrent Resolution 11, "to assure to all citizens, including handicapped citizens, the right to live and work in a barrier-free environment," to Senate 662, "to amend the Urban Mass Transportation Act of 1964 to meet the needs of elderly and handicapped persons." Nearly every one of these bills would facilitate "independent living" (broadly defined) by persons with severe disabilities. Yet, if past Congressional performance is any indication, very few of the mass of bills that are now under consideration will become law.

II. Executive Branch

Looking at federally administered programs it is difficult to decide what to include. In its Interim Report to Congress (1975) the Office for Handicapped Individuals described the following programs:

Department of Health, Education, and Welfare

1. Public Health Service
   - National Institutes of Health
   - Alcohol, Drug Abuse, and Mental Health Administration
   - Health Services Administration
     - Bureau of Community Health Services
     - Indian Health Service
     - Bureau of Medical Services
2. U.S. Office of Education
   - Office of the Commissioner of Education
     - Bureau of Education for the Handicapped
     - Bureau of Occupational and Adult Education
3. Office of Human Development
   - Office of Child Development
   - Veterans Affairs Office
   - Volunteers Office
   - Architectural and Transportation Barriers Compliance Board
   - Administration on Aging
   - Office of Native American Programs
   - Rehabilitation Services Administration
     - Vocation Rehabilitation Program
     - Division of Developmental Disabilities

For this paper to be complete, each of these programs would have to be examined to determine the extent to which it helped or hindered independent living. And yet, from the number of persons now only surviving in various states of dependency it is clear that the Administration has a long way to go.

III. Judicial Branch

Several summaries exist regarding efforts by disabled citizens to use the courts to secure their full participation in society. John Homer in his 1974 article "Rights of the Handicapped" and Jack Achtenberg in his paper "Crips Lib: An Overview of Legal Issues" both document the increasing militancy and use of litigation to resolve problems relating to housing, transportation, education . . . and the many other areas where civil and legal rights have been denied. And yet, in the past, for lack of legal assistance, many issues have not reached the courts.

Citizen Role

In reviewing the three branches of government a three part question arises. To what extent are citizens with disabilities willing (1) to lobby for legislation to meet their needs for independent living, (2) to hold public program administrators accountable for effective execution of the laws, and (3) to use the courts when administrative efforts fail to assure basic rights? In other words, will there be full participation of all the governed in their government? This issue of "citizen participation" or "consumer involvement" seems basic to any analysis of the federal scene.

In recent years there has been a growing realization that if our government is to be truly "of, by, and for the people," then the people must make it happen. Ralph Nader, Common Cause, and the American Coalition of Citizens with Disabilities have become symbols of this growing movement. For handicapped individuals ACCD represents probably the greatest hope for meaningful change at the federal level. Only recently through ACCD have national organizations of the handicapped like the Paralyzed Veterans of America, the American Council of the Blind, the National Association of the Deaf, and the National Paraplegia Foundation begun to work together on common issues.

Last fall the proposed Rehabilitation Act of 1974 Amendments were in danger. ACCD member organizations literally wrote thousands of letters and made thousands of phone calls to help get Congress to override the Ford veto. Among other things the law established a consumer advisory council for the Architectural and Transportation Barriers Compliance Board, and mandated a White House Conference for Handicapped Individuals. Consumers have pushed for affirmative action in staffing the offices created by the Rehabilitation Act of 1973 as amended. When one looks around HEW's Office for Human Development in Washington the impact is clear: Hank Viscardi and Jack Smith, heading up the White House Conference for Handicapped Individuals, are both in wheelchairs. So are Andy Adams, Commissioner of Rehabilitation Services Administration, Jim Jeffers, Director of the Architectural and Transportation Barriers Compliance Board, and Bill Bean, Acting Director of the Office for Handicapped Individuals. Even here in California, Governor Brown responded to community involvement and had the wisdom to appoint Ed Roberts as new head of the state's vocational rehabilitation agency.

Consumer Involvement in the Federal-State Vocational Rehabilitation Program

Taking vocational rehabilitation as an example of a federal-state program, who and what are we talking about? Section 101(a) 18 of the Rehabilitation Act requires that the State agency will take into account, in connection with matters of general policy development arising in the administration of the State plan, the views of individuals and groups who are:

(a) recipients of vocational rehabilitation services, or as appropriate, their parents, guardians, or other representatives;
(b) providers of vocational rehabilitation services; and
(c) others active in the field of vocational rehabilitation.

What are some of the reasons for consumer involvement, as seen by the agency. The following list is from Chapter 25 of the Rehabilitation Services Manual. That

Chapter, "Policy Development Consultation," cites these advantages in involving "clients" and consumer organizations in policy formulation and administration:

- increased awareness of client needs;
- realistic insights as to how various aspects of the State vocational rehabilitation program are functioning and how they might be improved;
- establishment of better working relationships between the agency and clients, providers and other individuals and organizations active in rehabilitation in the State;
- better information sharing and clearer understanding of the State agency's mission, goals and objectives;
- increased and more effective advocacy for the State agency's programs and its program needs; and
- establishment of a mechanism to permit continuous external feedback from all segments of the population on current and proposed operations and plans.

To the consumer, increased involvement by his elected representative in the planning, delivery, and evaluation of rehabilitation services should, if properly implemented, result in increased relevance of rehabilitation to the real needs of persons with disabilities. But what does it mean for consumer involvement to be properly implemented? Again the RSA Manual offers some possibilities:

> Among the areas of program development and administration in which clients, their representative organizations, providers and other individuals and groups active in vocational rehabilitation should be assigned significant roles and in which they should work closely with the State Director and his representatives in presenting their views and recommendations are:
>
> 1. Program evaluations to identify strengths in services that would warrant further emphasis, gaps in services, and general and specific effectiveness and efficiency of operations including the formulation of methods and techniques for improving the delivery of vocational rehabilitation services.
> 2. Program planning and program development — the planning of future programs and the expansion of current programs to close gaps in service or to improve the effectiveness of the program or programs.
> 3. Assistance in developing legislative proposals and budgets for submittal to the State Legislature, both in their preparation and follow through in hearings before the State legislative committees.
> 4. Assessment of the physical accessibility to the handicapped of all offices and facilities operated, supported or used by the State agency and, as required, formulating plans for making them accessible or more accessible.
> 5. Assistance in studies and surveys being conducted by the State agency or its district and local offices, i.e., data gathering, client sampling, and follow-up.
> 6. The interpretation of State agency policies and program services to their constituencies and to the public at large.

7. Assistance in the State agency's in-service training and staff development programs to aid staff in achieving greater understanding of client problems and attitudes, providers' problems and in maintaining better working relationships with organizations representing clients, providers and other people engaged in vocational rehabilitation.
8. Assistance to the State agency in whatever role it may have in State and local activities leading up to the White House Conference on Handicapped Individuals, and assistance to the State agency in the implementation of recommendations, having State relevance, resulting from such activities and conferences.
9. Assistance to the State agency in tapping and securing full utilization of the resources of other public agencies and of private agencies in meeting the needs of the handicapped, particularly the severely disabled whose economic, adjustment, medical, housing and other needs may be the responsibility of these other agencies.
10. Assistance to the State agency in implementing the 1974 Amendments to the Rehabilitation Act, requiring that the State agency and facilities in receipt of assistance under Title I of the Rehabilitation Act "shall take affirmative action to employ and advance in employment qualified handicapped individuals covered under, and on the same terms and conditions as set forth in Section 503."
11. Assistance in the establishment of specialized facilities and programs to be operated by consumer and other groups through funding by the State agency, to meet the special needs of the severely disabled applicant or client such as peer counseling, centers for independent living, halfway houses and other transitional living arrangements, transportation and post-employment services.
12. Proposing research to deal with unresolved problems in vocational rehabilitation, and to help assess research proposals in terms of their applicability to the needs and priorities of a particular group of handicapped people or to handicapped people in general.

But legislation, regulations and guidelines are worthless unless the "target populations" keep the "implementers" honest. The RSA Manual declares that, with respect to consumer involvement "each state agency will need to: assess immediately the adequacy of its present practices in this area of activity; structure a program which in scope, degree and continuity of client, provider and other person participation meets the requirements of the Act and Regulations; describe this program, process or processes in writing; and make this written description available to the public."

The public, including organizations of the handicapped, must hold federal-state vocational rehabilitation accountable for the effective implementation of Section 101(a) 18 of the Rehabilitation Act of 1973, which led to the regulations in Chapter 25, as quoted previously. And if the executive branch proves inadequate, there are always the courts.

Consumer Involvement in Other Federal Programs

While VR was used to illustrate possible roles for consumers in relation to federal-

state programs, the principle of maximum meaningful participation applies equally to other federal programs. Whether the issue is civil rights legislation, transportation regulations (e.g. FFA, UMTA, or ICC) or special education litigation, Washington responds, to one degree or another, to political pressure. Individual citizens with disabilities, by joining local, state, or national organizations that in turn join the Coalition umbrella of ACCD, can have a voice in the decisions that affect their lives. The biggest challenge facing such organizations as they communicate and cooperate on the common problems is that of setting realistic priorities.

Many issues call for attention: architectural and communication barriers; national health insurance; and many others. One problem that is common to all persons with disabilities is discrimination. The impact of attitudinal barriers, be they in housing, transportation, education, recreation or employment, would all be minimized by strong, well-enforced civil rights legislation.

Rehabilitation for Independent Living

The following is quoted from an earlier briefing paper on the "Comprehensive Needs Study of Individuals with Most Severe Handicaps":

Background

As early as 1958, following the landmark Vocational Rehabilitation Amendments of 1954, legislation had been proposed to extend the benefits of rehabilitation to persons with the most severe handicaps, even when no vocational objective was obvious. It was argued that the Vocational Rehabilitation approach (an individual plan tailored to the needs of the specific individual, with case service funds for the purchase of needed services from qualified vendors when not directly provided) had much to offer for the most severely, non-vocational oriented, handicapped. Efforts to authorize the State-Federal program to offer such services (Independent Living Rehabilitation, if you will) resulted in bills passed by the 92nd and 93rd Congress. Both these bills were vetoed and override efforts failed.

These proposed pieces of legislation had two major thrusts. The first was authorization of a new formula grant program to provide services to individuals with the most severe handicaps (IMSH) *without* vocational objectives. The second was to move the vocational rehabilitation program in the direction of serving more severely disabled persons *with* vocational potential. Hearings conducted during the legislative process produced testimony to the effect that it was not certain just what was known about provision of services to these IMSH and that there was possible duplication of existing authorities which could provide the needed services. Thus, a compromise was reached by the Congress and the Administration as reflected in the provisions of Section 130 of the Rehabilitation Act of 1973 (P.L. 93-112). This compromise directed the Secretary of HEW to conduct a Comprehensive Needs Study of the most severely handicapped, reading as follows:

"Sec. 130 (a) The Secretary shall conduct a comprehensive study, including research and demonstration projects of the feasibility of methods designed (1) to prepare individuals with the most severe handicaps for entry into programs under this Act who would not otherwise be eligible to enter such programs due to the severity of their handicap, and (2) to assist individuals with the most severe handicaps who, due to the severity of their handicaps or other factors such as their age,

cannot reasonably be expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently or function normally within their family and community. Such study shall encompass the extent to which other programs administered by the Secretary do or might contribute to the objectives set forth in clauses (1) and (2) of the preceding sentence and the methods by which all such programs can be coordinated at Federal, State, and local levels with those carried out under this Act to the end that individuals with the most severe handicaps are assured of receiving the kinds of assistance necessary for them to achieve such objectives.

(b) The Secretary shall report the findings of the study, research, and demonstrations directed by subsection (a) of this section to the Congress and to the President together with such recommendations for legislative or other action as he may find desirable, not later than February 1, 1975."

The Rehabilitation Amendments of 1974 changed the report due date to June 30, 1975.

The authorization to carry out this Comprehensive Needs Study, (CNS), including demonstration projects, provides the opportunity for documentation of the needs of the severely disabled and of the place and role of rehabilitation in meeting those needs.

Among the issues to be addressed is the mixed feelings in vocational rehabilitation circles about moving in the direction of serving more of the severely handicapped both from a vocational orientation and of entering a new phase for the State-Federal program such as was anticipated on the proposed independent living rehabilitation provisions.

There are those who argue that the *vocational* rehabilitation job is not being done adequately due to a lack of sufficient resources and any new funds should be directed to these needs. Others argue that VR is not the place to put independent living at all - that is, that ILR is more the province of health or social services and *they* should be responsible for the IMSH population. Yet a majority of the State VR directors, (60%), responded to a National Rehabilitation Association survey in Aug. 1974 that independent living is appropriate for VR. This report is available from the NRA.

We should be aware of the strong position of congressional committees on the issue. The Senate report to the 1973 Amendments stated:

"The Committee points out that its intent is to enable as many individuals to make use of the basic vocational rehabilitation program as possible. Thus, in recognition of the fact that individual conditions are not static and that training can be progressive, the study should attempt to develop procedures, in addition to the individualized written rehabilitation program requirement in the bill, to ensure that a vocational goal is not discarded for an individual with a severe handicap unless it becomes absolutely clear that such a goal will never be possible."

"The Committee also continued to believe that many individuals now judged unable to achieve a vocational goal can lead full and productive lives, given the full promise of technology and knowledge currently available in this Nation. Furthermore, the Committee reiterates that the goal of independent living is a legitimate one for Federal recognition and support, and one which will benefit not only the individual but his family, and society. It, therefore, urges the Secretary to

explore all possible methods of providing community-based services, and stresses that such methods should include services to individuals who are currently homebound. The Committee urges the Secretary to act rapidly to set up and pursue this vital study."

The report issued by the House in conjunction with H.R. 8070 also stresses the nature of the compromise:

"In S. 7, the vetoed bill, the Committee established a comprehensive rehabilitation program for severely handicapped individuals who do not have readily identifiable vocational goals. The Committee established this program originally because of the recognition that there were many handicapped individuals throughout the nation who were not being served by the basic program because of the severity of their disabilities, and thus felt that to establish a special program for such individuals would help make them self-sufficient, independent and ultimately capable of receiving services under Title I (the basic program) of the Act. Title II was vigorously opposed by the Administration, which contended that such a title would detract from the original intentions of the Act. While the Committee disagreed with the Administration's position, in the spirit of accommodation it deleted the title and substituted for it a mandate that the Secretary conduct a special comprehensive study, including research and demonstration projects, to determine the feasibility of working with individuals who are so severely handicapped that they may not immediately be able to go to work."

(Authors note: The substance of this section was to have been based on the Comprehensive Needs Study. Since that study has not been released by HEW, this section has not been included.) One point is clear, however: in developing a program for independent living, properly funded, consumer run, self-help organizations can fill the present gaps in the disability service delivery system. For example, the Center for Independent Living in Berkeley, California is staffed almost entirely by people with severe disabilities. They set up and provide services themselves, since for many of the severely handicapped the services required are not in the domain of any given public agency — for example, instruction in home remodeling, assurance of equipment repair, or an inventory of experienced attendants.

White House Conference for Handicapped Individuals

The Rehabilitation Act Amendments of 1974 (Section 302) authorize the President to call a White House Conference On Handicapped Individuals to stimulate a national assessment of problems, and to develop recommendation for the solutions to such problems, facing individuals with handicaps. In authorizing this Conference the Congress found that:

> (1) the United States has achieved great and satisfying success in making possible a better quality of life for a large and increasing percentage of our population;
>
> (2) the benefits and fundamental rights of this society are often denied those individuals with mental and physical handicaps;
>
> (3) there are seven million children and at least twenty-eight million adults with mental or physical handicaps;
>
> (4) it is of critical importance to this Nation that equality of opportunity, equal access to all aspects of society and equal rights guaranteed by the

Constitution of the United States be provided to all individuals with handicaps;

(5) the primary responsibility for meeting the challenge and problems of individuals with handicaps has often fallen on the individual or his family;

(6) it is essential that recommendations be made to assure that all individuals with handicaps are able to live their lives independently and with dignity, and that the complete integration of all individuals with handicaps into normal community living, working, and service patterns be held as the final objective; and

(7) all levels of Government must necessarily share responsibility for developing opportunities for individuals with handicaps; and it is therefore the policy of the Congress that the Federal Government work jointly with the States and their citizens to develop recommendations and plans for action in solving the multifold problems facing individuals with handicaps.

The success or failure of the White House Conference itself will depend on the success or failure of the fifty State Conferences that precede. And the success of both depend in great part on the extent to which citizens with disabilities get involved. The most immediate action for individuals and organizations to take is to write their Governor, Senator and Representative and get involved in their State's Conference.

Summary

In the wake of Watergate, it has been said cynically that we have the best government that money can buy. As far as independent living for individuals with "severe disabilities," the federal government outlook will be as bright or as bleak as you and I make it. Ultimately, the existence or extent of any federal program for independent living will depend on the extent to which we convince the Congress, the Administration, and the Courts to make the appropriate decisions and provide the necessary resources.

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LEGISLATION, RESEARCH AND PROGRAMS CONCERNING HOUSING FOR HANDICAPPED PEOPLE IN BELGIUM, CANADA, THE FEDERAL REPUBLIC OF GERMANY, FINLAND, FRANCE, HONG KONG, THE NETHERLANDS, NORWAY AND SWEDEN.

Barbara Duncan

Introduction

Rehabilitation International considers the problems of housing for handicapped people one of its major concerns. In 1974, largely due to RI impetus, the United Nations held its first Experts Meeting on the implications of architectural design for disabled people. "Barrier Free Design," the official UN Report of that meeting, published by RI this year, strongly supports the investigation of varied and dignified solutions to accommodations for disabled people.

Much information in this paper is abstracted from that Report, which we have distributed worldwide to architects, laymen and people involved in rehabilitation. (The Report is available for $5.00 from Rehabilitation International, 122 East 23rd Street, New York, New York, 10010, USA.)

In 1976 Rehabilitation International plans to hold a European Seminar on the various experiments with supported living conditions. The seminar will be a forum for the exchange of experiences of many countries and will attempt to determine if any solutions can be universally recommended. From advance information, some of which is contained in the following paper, it can be assumed that research and experience will demonstrate that no one answer will suffice; that several alternatives should be available; that the disabled person must have options suited to his individual requirements and wishes. As can be seen from some of the following examples, the experiments meeting with the most success are based on these assumptions.

It should be kept in mind that all of the following examples of experiments with supported living arrangements take place within the established culture and social service structure of a particular country. It should not, therefore, be assumed that the solutions evolved by one country would be transferable to another.

> There is a risk to life or to limb in the participation of the handicapped in open society. While risks should not be foolishly ventured or needlessly imposed, the right to risk is basic to the right to participate in the hope of achievement of a rich and fulfilling life.
>
> Each society should so construct its facilities as to avoid needless risks to the whole population, the handicapped included, but not to segregate the handicapped under the

misguided impression that this is needed for them at the expense of their independence.

Handicapped people may elect to be closely associated one with another in special programs or in housing or other ways to achieve the benefits of special services. There is an inevitable compromise with the results of segregation that may derive from such activities and the impact of such segregation on maintaining social isolation and prejudice. The compromise should be examined carefully in each case.

UNITED NATIONS EXPERTS
MEETING ON
BARRIER FREE DESIGN

CONCLUSIONS OF THE FIRST UNITED NATIONS EXPERTS MEETING ON BARRIER FREE DESIGN, held June 4-8, 1974.

Housing

"The integration of handicapped persons within the population should be an identified goal in private as well as public housing. In order to promote integration it is highly desirable that disabled as well as non-disabled persons can pay visits to each other and have free choice of their own living unit.

"In order to permit people to pay each other a visit, new living units are recommended to be accessible. A living unit is considered to be accessible when a visitor in a wheelchair can enter at least into the living room.

"In order to promote free choice, new living units are recommended to be adaptable. It is noted that building codes in communities throughout the world, which provide a mechanism for encouraging the implementation for adaptable housing within the private sector.

"A living unit is considered to be adaptable, when it is accessible and can be modified with comparatively little cost in a way consistent with permanent living requirements of wheelchair users. If their requirements are met, the unit is fully livable to most of the other categories of disabled and aged persons as well.

"The group recognized the importance of the problem of housing requirements of severely disabled persons and suggested that attention should be given to the availability of fully adapted living units for wheelchair users, for individual as well as congregate living. For instance, units on ground floors and/or without barriers elsewhere in apartment buildings, construction of which has been subsidized by public funds, may be reserved for them.

"In order to ensure privacy and to diminish environmental stress in congregate housing, it was suggested that:

1. the living units should each have an independent entrance.
2. the complex should be situated in a residential area
3. the supporting facilities be made available also to other persons in the neighborhood."

BELGIUM

In Belgium, the National Housing Institute (Institut National du Logement), which is under the jurisdiction of the Ministry for Family and Housing Affairs, has conducted a study on the problems of housing for disabled persons. Federal grants are provided for the construction and adaptation (of furniture and fixtures) of private housing for disabled people.

The Parliament of Belgium passed on July 17, 1975 a law requiring that all future buildings and major alterations to existing structures include the design needs of the handicapped. The law further states that public buildings accessible to disabled people must display the International Symbol of Access. Negotiations as to what norms and criteria will be applied and further details of the legislation are taking place between the government and organizations dealing with disability.

CANADA

There has been extensive research in the field of housing for the handicapped in Canada in recent years, particularly by the Central Mortgage and Housing Corporation. As in many countries, there is a marked trend to investigate other than institutional accommodations.

Under Section 15 of the National Housing Act, financial assistance, loans and mortgage loans can be obtained for the establishment of residential group homes. The loans are extended to non-profit corporations or approved voluntary bodies and current projects include homes for children, mentally retarded people, the elderly and persons with cerebral palsy. Depending upon age and needs, a handicapped individual may select either a short-term home to serve as a halfway house between a hospital or rehabilitation center and a permanent home, or a long-term group home. At times, a short-time situation provides accommodations for individuals while architectural adaptations are being made to their own residences.

The Central Mortgage and Housing Corporation stated in 1974 that their work is based on the following premises: (1) Ambulatory persons with moderate disabilities should be afforded a wide range of choice in the type and quality of residential accommodation, (2) The moderately-disabled, including those confined to a wheelchair, should be free to choose where they live in the community . . . and their housing should allow a maximum degree of independence from personal assistance in performing everyday activities and (3) At least some of the severely handicapped now confined to institutions should have the opportunity to live in a non-institutional sheltered residential environment in their home communities. The Corporation further points out that the personal and emotional vulnerability of a disabled person requires that any public intervention or assistance must be carefully thought out. Respect for the individual should be a primary concern and this means that no stereotyped solutions should be considered. Research of the Corporation has led to the conclusion that all housing for handicapped persons should be well located with respect to a full range of community services and it has recommended that future Canadian projects emulate the Fokus experiment. (See SWEDEN)

Supplement No. 5 of the National Building Code, entitled "Building Standards for the Handicapped," is being revised and reconsidered by the Government in cooperation with major voluntary organizations involved in rehabilitation. The Canadian Rehabilitation Council for the Handicapped was appointed in 1974 to coordinate this work and other actions to eliminate architectural barriers. Supplement No. 5 is made law when adopted by municipal governments and the Canadian Council is assisting community groups towards this end. (The CRCD is an affiliate of Rehabilitation International and, as such, acts as a liaison between the national and worldwide activities in this field.)

FEDERAL REPUBLIC OF GERMANY

In the Federal Republic of Germany, within the framework of social assistance, disabled persons may be granted financial aid to improve their accommodations. An interministerial working group has been set up for the preparation of guidelines and recommendations for the gradual abolition of technical and structural obstacles in public and other buildings that make access for disabled persons unnecessarily difficult.

The Deutsche Normenausschuss in Berlin has issued standards for the construction of public buildings, public places and streets, as well as for apartments for the blind, severely visually-impaired and wheelchair users. As of January 1975, the standards for apartments had been officially passed and are being widely used as recommendations and applications concerning federal funding of buildings.

The University of Marburg has established housing units for severely disabled students. The units are integrated among those for able-bodied students and similar units are planned by several other universities.

On December 17, 1974 the Federal Minister for Labor and Social Affairs officially opened the construction of a model project in Bonn for housing disabled persons. The complex will be equipped with a social, cultural and sporting center for the entire community as an incentive and means for complete integration. This project is the first of several planned centers for cities throughout the Federal Republic.

FINLAND

In Finland, the latest amendment of the Care of Disabled Persons Act includes provisions for housing arrangements and for guidance of the family members of the disabled.

Building Statute 85a states that in construction of buildings containing premises to be used by the public, attention should be paid to the fact that these should also be accessible to persons whose physical or orientational ability is limited as a result of advanced age, physical injury or sickness.

The Board of Social Welfare in conjunction with the Association of the Disabled is conducting a research study on the needs of the severely disabled in the province of Kymi. The study covers disabled people between the ages of 16-60 who have considerable difficulties in activities of daily living, not including persons who are deaf, blind or mentally retarded. The goal is to investigate the severely handicapped persons' needs for rehabilitation, residential and transportation services. The method being employed is by

interview of the disabled person and his family. Material is treated statistically to assess regional and local needs, in order to estimate the total need for services nationwide.

FRANCE

In France, the Ministry of Equipment and Housing envisages the reservation of a certain percentage of adapted dwellings for the disabled on a priority basis within a special plan, known as "le secteur HLM." Legislation in 1974 requires public buildings to be constructed accessible to disabled people.

Studies have been undertaken to determine the comparative costs of building in accessibility at the planning stage versus adaptations made following completion of construction. The conclusions of an interministerial working group on Housing of the Physically Handicapped, published in May 1973, state that (1) adaptation for the use by the physically disabled of building approaches, building accesses and entrances involves no extra cost when these adaptations have been considered at the planning stage, (2) the addition of a lift to a lodging involves extra costs of up to 17.6% and (3) applying the minimum requirements of accessibility to the internal arrangement of the lodging involves a variable extra cost, depending upon the increase of the surfaces and the type of lodging.

Interest in experimenting with various solutions to the problems of housing handicapped people is evidenced in the following extracts from a paper by the French National Liaison Committee for Rehabilitation of the Handicapped:

"Rehabilitation of the disabled aims chiefly at a reinsertion into the community—a 'normal' environment. What is to be set up? Adapted dwellings . . . almshouses . . . homes and specialized hostels?

"There cannot be any definite reply since there is no standard solution: every disabled person is an individual case. The disability is not the sole governing factor—environment, position of the family, as well as psychological and intellectual factors must be taken into account. A range of solutions should therefore be developed.

"Like any other citizen, the disabled person should be able to move to another dwelling according to his family or vocational arrangements."

HONG KONG

An Ad Hoc Committee on Housing for Disabled People has been set up by the Joint Council for the Physically and Mentally Disabled of Hong Kong, Rehabilitation International affiliate organization. The Committee is in the process of collecting sample "case histories" of disabled persons in need of re-housing or adaptation assistance for the development of a position paper for submission to the Government. The Committee was established following many complaints about the low priority disabled people were being accorded by the Housing Authority.

The Joint Council has also taken action to ensure that current plans of the Hong Kong Government to construct an underground railway system include the needs of the disabled. Due to this, these needs are included in the transport survey of all factors to be considered in the planning process and the Council is following up this action in conjunction with other voluntary organizations.

NETHERLANDS

In the Netherlands, under the General (Exceptional) Medical Expenses Act and the Workers' Disability Insurance Act, grants can be given towards the adaptation of accommodation.

Het Dorp, which means "the village," is reported to be the first village in the world designed specially to provide for special housing and other needs of severely-handicapped individuals. Located in the town of Arnhem near the German border, it was opened during 1966 following the acquisition of funds resulting from a television telethon. The village, operated with the financial assistance of federal and local governments, currently houses some 400 disabled people from throughout the Netherlands. The founder of Het Dorp, Mr. A. Klapwijk, further describes the operation of the village:

> . . . Each home has been built to meet the specific requirements of its inhabitants. Some front doors, for instance, can be opened and closed by the radio impulse provided by a small transmitter which the inhabitants carry in their electric wheelchairs.
>
> For each row of ten houses, there is a covered street, so that mobility is guaranteed, even in bad weather. Nine homes in each block are inhabited by the handicapped. The tenth is for a non-uniformed trained helper. There is a community center for each block as well, where inhabitants can gather . . . some of the villagers are married; sometimes one, sometimes both members are handicapped. Couples live in double homes, converted from larger single houses.
>
> On each street in Het Dorp there are three blocks of ten homes. Since our land slopes downward towards the Rhine Valley, we built a single level at the highest point, two levels of homes further down and three levels at the bottom. Spacious lifts link all levels. Homes on the lowest level have gardens, upper level homes have balconies. Both indoor and outdoor streets and plazas have ordinary street names. . . . mail is brought to the doors as everywhere in Arnhem.
>
> Some inhabitants are employed outside the village, in Arnhem and reach their work by special transport. Most villagers, however, work in Het Dorp's sheltered workshops where their employment may be either clerical or hand labor. Het Dorp produces, for instance, toys, clothing and ceramics and it prints and binds braille books and tapes "talking books" for blind people. Inhabitants have priority for employment in Het Dorp's own shops.
>
> For cultural, social, recreational and religious activities, all of the community facilities of Arnhem are available.
>
> As Het Dorp began to be settled, we held elections for a "parliament" of Het Dorp which meets every six weeks to consult on current problems. (And I can tell you that our election contests took on an American color and liveliness which was certainly not in keeping with . . . other Dutch communities.) Every 30 inhabitants, or three groups of 10 homes, form a district and elect one representative to the Village Council. Two Council members are chosen by the Council to hold full membership on the Executive Board of the Het Dorp Foundation.

> The Foundation follows the following principles in selecting villagers for Het Dorp: (1) Het Dorp is open to the handicapped of all creeds, (2) HD is, in principle, intended for the handicapped of all ages. In reality, however, handicapped youths are usually still in stages of rehabilitation until their 18th or 20th year, and the handicapped older than 60 or 65 can preferably be placed in homes for the aged, (3) HD prefers to accept only the handicapped who have achieved maximum rehabilitation before arrival . . . (4) HD is not open to the mentally handicapped, since its community can in no way help them. With respect to this criteria, first consideration is not the intelligence quotient of the candidate, but rather his degree of social competence; whether he can provide a positive contribution to the community and profit himself from the association, (5) HD is not intended for those who are handicapped in the sensory organs only. However, the limited sight or hearing of the candidate is not, in general, a deciding factor so long as the other criteria for selection are fulfilled, (6) The seriousness of the handicap is not a deciding factor for admission . . . since both general and individual facilities are adapted and specifically designed . . . to achieve the most complete life possible . . .
>
> The Selection Committee consists of experts from Het Dorp itself (a rehabilitation doctor, public health expert, a social worker, a psychologist) but more largely of authorities who are acquainted with the special problems of the candidates.
>
> Het Dorp is adjacent—just across a secondary road—to the Johanna Stichting Foundation rehabilitation center. Villagers receive there the necessary medical and nearly all paramedical treatment, which is primarily physical therapy; x-ray, laboratory and dental departments of the center are also open to villagers.
>
> I am certain that all of you have noticed my enthusiasm for Het Dorp . . . I hope I have not given you the impression that we have created a kind of heaven on earth. We have not, thank goodness. It is a typically earthly community, with typically human shortcomings. Nor is Het Dorp meant to be a panacea, the only solution for the physically handicapped . . . it is intended to be a complement to the list of present possibilities—a complement which will make it possible to abandon obsolete living patterns.

Currently 70 percent of housing in Holland is government assisted as opposed to 20 percent in the United States, for example. The Ministry of Housing has reported that currently 2-1/2 percent of housing construction is adapted to the needs of disabled people.

The national standard for accessibility is now only a recommendation but, according to the Ministry of Housing, plans are underway to make it mandatory.

Adapted housing already in existence (some 1000 units in Southern Holland) includes the following alterations: In a group of townhouses, the separation wall between the two units at one end is removed, creating on the groundfloor a two or three bedroom one-level house, accessible to people in wheelchairs. The upper floors are then converted into two smaller homes, generally for retired couples. From the combined rental income from the three units (rather than 2) the builder reaps a larger return on his investment, so there is every incentive to proceed with a certain number of these modified units.

A factor leading to comparatively simple adaptations of kitchens and bathrooms in the Netherlands (as in Sweden) is the location of the fixtures. The plumbing and wiring are outside the walls, rather than imbedded in plaster, resulting in greater flexibility for change.

In the resort town of Zandvoort, there is also a complex exclusively for severely handicapped people. Housing approximately 200 people, the building is a star-shaped structure radiating out from a central circular lounging area, with each wing containing sleeping and dining quarters for the residents. The central area contains shops, restaurants and a bar.

In the Netherlands, use of the public railway system is made difficult for disabled people by the differences in levels of the doors to the railcars and the level of the approach platform to the train. There is also a gap of approximately 50 centimeters between the platform and the train. A portable ramp, developed by the Netherlands Society for Rehabilitation, member of Rehabilitation International, has proved successful in overcoming these differences and is in use at most major stations. Most of the railcar entrances have double doors blocked by a center bar. On each train, however, the center bars are eliminated at one entrance to give access to the wheelchair user. Dutch railways have a special telephone number enabling assistance to be given at most stations, if applied for 48 hours in advance. Free rail travel is provided for the escorts of handicapped people who cannot travel without assistance.

The Netherlands Society also directs the national activities of voluntary organizations in making the environment more accessible and utilizes the services of nearly 100 consultants, mainly handicapped people, to survey communities and to award the Symbol of Access to those meeting the criteria.

NORWAY

In Norway, pursuant to the National Insurance Act, loans and/or grants are available for the purchase of apartments and, in some cases, for the building of dwellings adapted to the needs of disabled people. A condition is that by means of improved living conditions or by relocation, the disabled individual may be ensured work which provides an income. The Norwegian State Housing Bank has special rules for dwelling support for the disabled, both in the building of new homes and in loans for the alteration of existing dwellings.

A proposal for new building regulations to benefit handicapped people has been introduced recently by the Norwegian Ministry of Local Government. According to the Norwegian Building Research Institute in Oslo, the proposal has been circulated for analysis to major firms and organizations dealing with planning and design and rehabilitation.

A current research project being conducted by the Norwegian Handicap Organization in cooperation with architects and planners is for the purpose of determining the costs of adapting existing dwellings and local facilities for use by the handicapped. The object is to establish the economic consequences of accessibility for society in general and to find if accessibility does "pay" for the handicapped individual.

Significantly, the underground railway system in Oslo is generally accessible to disabled people because the architectural planning principles utilized were sufficiently liberal to encompass the minimal requirements of barrier free design. Ramps of generous dimension, intended for the entire traveling public, are a feature of all station buildings. Large entrance doors to the cars, which easily accommodate wheelchairs, were planned to increase the efficiency of flow of all passengers. Interior space of cars is also liberal, which further facilitates wheelchair access on this subway system. Although the original plans for the subway in 1954 were completed without specific consideration of handicapped travelers, current plans to improve the system, including the addition of lifts within station buildings, are being made in consultation with Norwegian organizations for disabled people.

SWEDEN

In accordance with central recommendations from the Swedish association of local authorities, many municipal authorities provide a local authority housing allowance for handicapped persons. Other forms of support include the State housing grant for a disabled person to furnish and equip a dwelling, plus any excess costs for hydraulic or electric lifting devices. Apart from persons with severe orthopedic handicaps, certain persons with impaired vision and those with greatly reduced ability to use their arms are entitled to this grant.

The Swedish Government has assumed financial responsibility for the disabled; nearly 50 percent of the disabled population receive some sort of pension and technical aids required by handicapped individuals (some 450 items, including hearing aids and wheelchairs) are paid for by the state.

Municipalities have assumed responsibility for personal care, services (including some transportation) and various types of preventive measures. Municipalities draft building development plans and build suitably designed apartments for the handicapped. Ninety percent of all residential construction in Sweden is supported by state loans.

Standards for accessibility in Sweden were developed in 1964 and apply on a mandatory basis only to those buildings and residential structures built according to guidelines set by the National Housing Board. However, a movement is underway to make these norms mandatory in private construction also. Incidentally, a trend which will aid adaptation in private dwellings is a national movement towards the construction of single homes as opposed to high rise structures.

If a handicapped person is living in an older residence, the government will allow approximately $3500 to remodel the home; if an elevator is necessary, the grant will be higher. Each year, nearly 3000 dwellings are modified for disabled people. Local county housing boards decide on eligibility, in cooperation with rehabilitation counselors and physicians. Most recently, mentally retarded persons have also become eligible for these grants.

In order to facilitate housing alternatives for the disabled, the Swiss Federation for Integration of the Disabled into Economic Life has prepared directives on lodging construction. Recently, the Directorate of Federal Constructions adopted the directives for consideration in construction of all public buildings, as well as those subsidized by the Federation.

The Swedish Institute for the Handicapped is responsible for testing and evaluating all technical aids for the disabled population. The aids are then recommended to the National Board of Health and Welfare, which then approves them for grants. The testing also provides a basis for centralizing buying of aids and its decisions can influence manufacturers designs. The Institute also operates a telephone answering service for anyone wanting advice regarding aids. Also operating from the Institute is the International Center on Technical Aids, Housing and Transportation (ICTA), a standing commission of Rehabilitation International, and a center for the collection and dissemination of information on these subjects throughout the world.

Faltoversten is an inner city block of apartments sprinkled with units for the handicapped which allow for complete integration. It is built over a busy subway terminal, with a complete shopping center underground, accessible by elevator. A service unit is located in the terminal just off the elevator, connected to each apartment for handicapped people by alarm buzzers. Persons in wheelchairs can descend from their flats and go shopping, to a library, or to the "winter garden," which is glass enclosed and heated in the winter. The commercial, social and cultural services found in Faltovern are also used by residents of the urban vicinity. Fourteen apartments of the 536 in the complex are designed for handicapped individuals.

Undoubtedly, one of the most well known and emulated housing experiments for disabled people is Fokus. The following report is a summary of the proceedings of a seminar on the Fokus Society, held in 1972 in Canada:

> Social services in Sweden are highly advanced, and it is within the context of these services (and extremely high taxes) that the Fokus Society functions. County Councils fund local authorities, and the latter, in turn can provide many services to a variety of users. These services include home help, pensions, grants for renovating homes, technical aids, health support, transportation and assistance in obtaining employment. Dr. Sven Olaf Brattgard (founder of the Society) pointed out that although he is confined to a wheelchair, he is not considered severely disabled. In other words, his problems can be overcome by the normal provisions of state assistance.
>
> The group which Fokus caters to are the severely disabled, who would normally be confined to institutions. The Fokus program will shortly have housed 1,000 out of approximately 2,000 persons in Sweden falling into this category.
>
> In terms of new housing, the moderately disabled are well provided for. The Swedish Government guideline for all subsidized housing, "God Bostad," requires (1) flexibility in some unit designs to allow for conversion to suit a particular disabled user and (2) dwellings designed to allow wheelchair visitors.
>
> In Sweden, those suffering from various degrees of disability number about 10.4% of the population in the age group 0-66 years and 29% of those over 66. In Fokus units, 80% are wheelchair users, 52% need help for normal toilet and kitchen use, 20% need help in turning in bed and 25% come from nursing homes.
>
> There has been a large demand for family units—disabled users want to marry in almost the same proportion as the able-bodied population.

The following is a summary by the Fokus Society, describing the design of the apartments, the service component and the research element of its work:

One of the most important factors of successful rehabilitation is that the disabled person . . . has to have somewhere to live—a home. But the most suitable flat, well-planned and equipped is not enough. Equally important is the personal service he can get. Another important factor is his opportunity to make contact with others outside his home. Most of the money we spend on medical rehabilitation will be of little value if we forget our duty to bring disabled persons back to a social life.

The simplest way in which we can give the disabled complete safety is some type of institution. For some of the disabled, such an institution is necessary; from a social and psychological point of view, these institutions are very bad. If the disabled person is to be re-socialized, he has to take responsibility for his own life.

Planning for the disabled, especially the severely disabled, begins with the goal of integration. From this point of view, it is necessary to build flats for the severely disabled together with those for non-disabled in the same building. Such an integration of the flats forces the community to plan all blocks and their surroundings, all shops and offices with regard to the disabled. An integration of the flats will hasten the opening up of the whole community to the disabled.

Dwelling Units

For single persons, we have designed a type of flat which looks like an all-activity room. Only the bathroom is separated from the other part of the flat. The all activity room has an area of approximately 410 square feet. There are different functional areas in the room: one for preparing food, a dining area, a bed corner and a sofa group. But it must be borne in mind that all the fittings in this flat are free-standing units. Because of this flexibility, the tenant is able to redesign his flat according to his own desires. The idea of this is not only to permit the redesigning, but is also an attempt to introduce a home in which the tenant takes part in all that happens around him.

All the fittings are designed to offer tenants with some kind of disability the best possible opportunities. Most of the tenants are wheelchair users and are thus in a sitting position. Others use crutches and have to work in a standing position. All fittings in the kitchen and bathroom are therefore vertically adjustable. An easily operated console-track system makes it possible to adapt the height of work-benches, cupboards, stove and oven to what is best for the tenant.

The plan of the kitchen is based on a system of analysis and investigations in special laboratories, as well as in practical use. The place for food preparation is between the sink and the stove. Movable chests of drawers, preferably on wheels, offer the tenant an ever-present choice of where he wants his storage units.

The bathroom is planned after a series of investigations into how disabled persons move and act. With a special three-dimensional mirror-method, we have made an analysis of the functions of persons with different types of disability and with different technical aids. Both the hand-basin and the shower are placed in a console-track system.

Services

The service system is as important as the designing of the flats. Very often, all discussion of housing for the disabled is concentrated on the architectural level—very seldom do we discuss personal assistance. The disabled person who only needs an occasional helping hand is no problem; the situation is very different when day and night services are required.

From our investigations and practical experience of the problems of the severely disabled, we have found it necessary to create service units of not more than 12 to 15 flats. These flats are all integrated, but in such a way that it is possible for the personnel to serve the resident easily, for example, one flat on each floor. To avoid the tendency toward a total institution, we have arranged the service system as follows.

Every tenant who needs more than occasional help is given his own individual assistant who comes each day for one or more hours. The assistant takes care not only of the tenant, but also of his home. If the tenant needs, the assistant will wash clothes, clean the flat, prepare food and purchase what is needed. Assistance is also given as needed in daily living activities.

In addition to these individual assistants, the building has service attendants whose job it is to give all tenants a helping hand at any time of the day or night.

We have divided the service provided into these two groups for several reasons. Most importantly, the tenant likes to have his own individual assistant, someone who takes care of him in particular, who knows his habits and so on. It is thus unnecessary for the tenant to instruct all the attendants in detail. Another reason for having this organization is that the individual assistants come in from the outside and impart a special atmosphere. They are not regarded as servants—more as friends arriving with news.

Selecting the service personnel is a very important matter. They must not nurse in the ordinary hospital way, but must be very open-minded and careful of the tenant's privacy. It is very important that all service personnel should receive special training.

Special transportation arrangements can also be made to enable residents to enjoy cultural activities and holidays.

Development and Structure of the Fokus Society

The Fokus Society began in 1964. In 1965 we obtained a day on radio and television for a telethon which raised approximately 2 million dollars. With this money we have to date rented 280 flats in 14 cities throughout Sweden.

The Fokus Society never builds any houses or flats, but rents them from developers. The developers obtain from the Government a subsidy (maximum of around $3,000) for each flat completely adapted for a disabled person. If the costs for the flats and common rooms exceed this amount, the developers must cover the costs by rents. Therefore, the Fokus Society has to pay the "real" costs of the flat and common rooms except for the Government subsidy.

The rent for the flat includes garage as well as common rooms. The tenant himself must pay the rent, although if he has a low income, he will receive some subsidies from the authorities and the Fokus Society helps many of the tenants with their rents.

The cost per year for a tenant in a Fokus unit can be calculated from the experiences in the cities where the activity has been going on for at least two years. In the first year, there will be many extra costs which are not representative of the long-term normal expenditures.

As an example, we can examine the total costs per year for the Fokus tenant in seven cities in 1971. The mean total rent for the flats and the common rooms is about $1,300. The tenants themselves pay around 18%. The subsidies from the communities and Fokus total about $1,050 per year.

The mean total cost for the service staff, personal assistants as well as attendants in general, is $3,300 dollars per year, per tenant.

The total cost for housing and services is approximately $4,500 a year—less than half the cost of that in a modern nursing home or boarding school. The total cost per day is around $10 a day in a Fokus Unit.

The structure of the Fokus Society includes three groups of participants. The first consists of representatives of the community, the second comes from the organizations of the disabled themselves and the third comes from the foundations and societies working with and for the disabled.

The central board has the task of giving general directions for the work of the Society. In each city where Fokus is established, there is a local board. The members of these boards come from the local community, the tenants and the Fokus Society. Very close cooperation is thus maintained between Fokus and the community. At all stages the tenants or their representatives have an opportunity to make their voices heard.

Before establishing itself in a city, Fokus has discussions with the local authorities about the location of the unit, the opportunities for the tenants to obtain jobs and education. A very important item in the discussions is the transportation system for disabled in the city. In all cities where Fokus is established, the community has a special transportation system where the disabled with taxis or special buses can obtain transportation to and from work, school or other activities, including visiting the theater and friends.

Research

The Fokus Society has access to extensive research facilities. The Department of Handicap Research at the University of Goteborg is one. Special research teams can be assembled for specialized studies and paid for by the state. One example of the thoroughness of the research is a time and motion study of food preparation. A standard meal was prepared in a typical kitchen for the able-bodied and a Fokus kitchen. The meal in the "normal" kitchen required 152 wheelchair movements and 458 hand movements, compared with 12 and 158 respectively in the Fokus unit.

Employment

Although most of the tenants (80%) were pensioners and out of work when they obtained their flats, in the first 46 flats which have been in use now for more than three years, nearly 80% of the tenants are working or receiving education. For many, a job is a way to become closely integrated into society and to establish contact with others.

A selected international bibliography on barrier free design was published as an annex to the United Nations Report and is available from Rehabilitation International.

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A MODEL SHELTERED WORKSHOP

Frank D. Gentile

Today there are many sheltered workshops throughout the country. They represent a wide range of activities from remunerative work on a non-profit basis to a variety of services from evaluation to placement in competitive industry. There are work activity centers which require no minimum wage and serve the most severely disabled whose productive capacities may be inconsequential. Then, there are those shops which employ people and provide a wide variety of rehabilitation services for one type of competitive employment or another. This paper will deal mainly with those workshops which pay at least 50 percent of the minimum wage.

In 1968 the National Association of Sheltered Workshops and Homebound Programs (now the Association of Rehabilitation Facilities) defined sheltered workshops as follows:

> A sheltered workshop is a non-profit rehabilitation facility utilizing individual goals, wages, supportive services in a controlled work environment to help vocationally handicapped persons achieve or maintain their maximum potential as workers.

The best estimate today is that there are some 1700 workshops, many of which have two or more branches. Probably some 400 are general in nature serving a variety of disabilities and some 800 are work activity centers. The balance are specialized for the blind, the mentally retarded and mentally ill. With the exception of the blind, the average workshop has probably been operating for ten years.

Workshop Clients

The clients that are served by these shops represent a severely disabled population. Most clients are mentally retarded, mentally ill or blind. Many also have a secondary disability. It is safe to assume that most of the people who come to workshops for assistance have limited educational background and experience. In addition, they present workshops with such rehabilitation problems as transportation and assistance in activities of daily living.

Workshop Programs

Workshop programs fall into three main categories: rehabilitation, placement and work.

The area of rehabilitation covers personal adjustment training and activities of daily living. In personal adjustment training, clients are taught to deal with demands of personal and other relationships, and demands at work and in the general environment. In activities of daily living the severely disabled are taught to be independent in their daily self-care. This is especially true of the mentally retarded and the more severely physically disabled.

The second area is placement in competitive business and industry. This includes not only the actual placement of the individual at work but all the elements in the placement process, such as placement readiness training (e.g., job finding, interview techniques).

The third function of sheltered workshops is work which is remunerative and ranges from assessment on the job to long-term employment in the workshop at a minimum of 50 percent of the minimum wage or above the minimum wage.

Workshop Management

While a workshop provides programs for severely disabled clients, it must also be concerned with staffing, management, financial responsibility and contract procurement. In larger workshops there are basically two types of staff: the professional staff, which handles the rehabilitation aspects, and the management staff, which handles finance, business management and contract procurement. However, in smaller workshops with minimal staff, many of the people must assume multiple responsibilities, especially the workshop director. For the purposes of this paper we will attempt to describe the larger organization that has at least a minimal rehabilitation professional staff and management who must handle the day-to-day people and business activities.

In the area of management, two of the most important concerns in this country today are wages of clients and workshop finances. While it is difficult to get exact figures, we do know that the average wage is just above the minimum and that shops usually require outside sources of support. In addition, the individual also requires other sources of support, such as public benefits or their families. Some shops subsidize wages. Public benefits are available to the clients in a majority of the workshops. However, it is difficult to determine if these are sufficient to make workshop clients' incomes comparable to average wages in business and industries of the same size. In addition, the work sub-contracted to many shops is not comparable to business and industry.

Workshops receive income mostly from contracts, but, in addition, many receive income for services to clients from other agencies, and contributions. Contributions are generally the least of the three. The average workshop generally breaks even at the end of a fiscal year.

A Workshop Model

In order to more fully understand the role of the workshop and the severely disabled at work let us examine a model. This is a model not only of a demonstration work center but of a comprehensive rehabilitation center serving the needs of the severely disabled.

Human Resources Center

Human Resources Center, established in Albertson, Long Island, New York, is composed of three coordinated units: Human Resources School, Human Resources Research and Training Institute, and Abilities Inc.

Human Resources School is a private, non-profit educational institution chartered by the Board of Regents of the State of New York, offering a full academic curriculum to previously homebound disabled children from pre-school through senior high school. The school, in conjunction with the Research and Training Institute, conducts research in curriculum development, modifications of teaching equipment, physical plant design and

research in teaching techniques. The school also serves as a national center for teachers of the disabled at the pre-school, elementary and secondary level.

Human Resources Research and Training Institute is the non-profit component conducting research programs in medicine, bio-engineering and psychology relating to the disabled, aged and retarded. The Institute also conducts evaluation and training programs. In addition, a variety of innovative demonstration programs are conducted showing how the disabled can be productive.

Abilities Inc.

Abilities Inc, is the non-profit demonstration industrial and clerical work center. Abilities and Human Resources Center could serve as a model for any modern industrial and business complex. There are no stairs. Where there is grading, ramps are provided. No one can trip on a step and wheelchairs can move about unimpeded. Bathrooms, as well as water fountains and phone booths, are accessible.

In Abilities the workers are all disabled, retarded or aged. They work a full 40 hours each week to industrial standards. No pre-employment medical examination is given. The main requirement for employment is motivation—the will to work. The employee is interviewed, evaluated and trained, or hired on a three-month trial basis if he or she has had no work experience. The handicapped worker receives at least the minimum wage or a higher wage commensurate with experience. In addition, all the workers receive all benefits, including life insurance, medical, hospital, major medical and pension, at no extra cost to them.

The Abilities' engineering team evaluate both the job and the worker, and they modify the process by technical changes. Some of these modification have been adopted by local industry and have proven helpful to the non-disabled as well. These modifications have resulted in greater safety, increased production and less fatigue. In fact, the safety record at Abilities has been so good that it has a low insurance classification, qualifying it for a rate reduction of 30 percent.

Examples of job modification include such items as a raised working surface for a fused arthritic who can't sit; holding fixtures for individuals who have the use of only one hand; and bench machines lowered for those in wheelchairs, rather than being at a height designed for standing.

Originally set up in a converted garage in Hempstead, New York, Abilities Inc. now occupies 50,000 square feet of manufacturing space as part of the Human Resources Center complex. Abilities Inc. employs about 150 men and women, 99 percent sustaining a handicap of some kind. Despite this, they operate highly technical precision machinery, working from wheelchairs in many cases. Employees include those without full use of arms and legs, amputees, paraplegics, cardiacs, arrested tuberculosis, deaf mutes, retarded, etc. Every manager, foreman, production worker is totally qualified for his or her job. All are paid prevailing wages, and many support families. For the severely disabled, Abilities is a place where people are working productively and not soliciting business on the basis of a handout.

Abilities Inc.'s first work was in the aerospace industry. Under government contracts, it produced components for companies like Grumman, Sperry and Republic. The workers wired aircraft assemblies and put in circuit units. When the economic recession showed its

effects on business a few years ago, Abilities underwent a major reorganization in its attempts to diversify into other fields. As the aerospace market evaporated, management had to explore other possibilities, which led to production of computer parts for other manufacturers in the commercial field. The organization's own reservoir of potential management talent was tapped. Today managers from the handicapped workforce run the operation.

This was one of the most important aspects of Abilities Inc.'s development. In order for such a workshop as Abilities to survive it developed better management techniques and contract procurement procedures, as well as diversifying its work and enhancing its specialized areas.

Vocational Rehabilitation and Placement Programs

Another area of the Center which relates to Abilities' activities is the Research and Training Institute, which conducts a series of research, training and demonstration studies of the severely disabled in competitive work. The Center is a comprehensive vocational rehabilitation center with programs which include medical and psychological services, job modification, architectural barrier removal, evaluation, training, work adjustment, attitudinal seminars and placement.

One of the most important elements in a comprehensive workshop program for the disabled is good evaluation, training and employment demonstration where the severely disabled can succeed, and businessmen, professionals and others who are interested can see what can be done first-hand.

Work Evaluation

The evaluation phase should consist of a battery of evaluation work samples, skills and tests to determine potential. The series, where needed, should be adapted for the disabled. Standardized tests should only be administered where needed. More important are the informal and special instruments developed to measure the clients' progress during this phase.

The Pre-Vocational Evaluation program at Human Resources Center offers a pre-vocational evaluation to the severely disabled persons referred by the New York State Office of Vocational Rehabilitation and other organizations.

The program exposes the disabled to work and job samples in a wide range of skills areas. Included in the syllabus are small engine repair, gauges, meters, para-medical professions, drafting, and heating and air conditioning.

The program is also designed to provide private business and industry with a means of evaluating disabled employees for upward mobility potential, as well as to evaluate those employees who were recently disabled prior to returning to work.

A maximum of five clients is evaluated during the two-week program. Each disabled person is given the opportunity for vocational exploration through interest inventory testing, work and job sampling, and individual and group counseling. Once the academic competency level and areas of vocational interest are determined, the disabled individual and his counselor-

evaluator set up an individualized evaluation plan. This plan focuses on job and work samples utilizing the Singer, J.E.V.S. and MIND approaches which simulate actual on-the-job skills and physical requirements. The results of the pre-vocational evaluation indicate the training areas that would be most appropriate for the disabled person.

Upon completion of the program, a complete report with training and/or placement recommendations is sent to the state office of vocational rehabilitation or the appropriate organization to assist the counselor and client in developing a realistic vocational plan.

Vocational Training and Job Readiness Skills

Those who successfully complete evaluation should then enter a training phase. This should include work skill practice and social development skills such as working with others, work habits, grooming and safety and job readiness. Also during this time, counseling could be introduced for those who require it. It is also important to consider the use of audio-visual aids such as films and programmed instruction. Each client should be evaluated for any special devices required for successful placement.

While some of the disabled clients will have the basic education needed to perform the proposed jobs, many may require some form of remedial work in order to become qualified workers. Remedial classroom work in mathematics and reading, supplemented with individual study, should be planned. This aspect of the program will especially help those who were educationally disadvantaged.

Started in 1961, the Vocational Training Program at Human Resources Center serves the severely disabled, mentally retarded and aged. The disabled persons are referred to Human Resources Center by the New York State Office of Vocational Rehabilitation and other organizations.

The curriculum for the Industrial course consists of instruction in the use of hand tools, operation sheets and wiring diagrams, cable making, printed circuit board assembly, chassis wiring and mechanical assembly. In addition, soldering, component identification and color coding are included.

The Business Skills course includes filing, collating, typing, keypunch and office machine operation, as well as record keeping, payroll and inventory control procedures.

Preparation for employment is stressed in a number of job readiness programs: Group and individual counseling include role playing for job interviews, testing and personal grooming.

Sessions are also conducted in Job Seeking Skills.

Remedial assistance is available in Reading, Spelling, Grammar and Math if needed.

Adapted Driver Education

Many disabled clients have physical disabilities which are so severe that they cannot use public transportation; others live in areas where public transportation is not available. At Human Resources Center we have tried to solve this problem in the following way. Initially, the person is asked to provide his own means of transportation. If this is not possible, transportation during the evaluation and training phase is arranged through car pools,

private transportation on a reimbursement basis or the use of the Center's carryall bus adapted for wheelchairs. However, since one of our major goals is to help the disabled achieve independence, supportive transportation services are only utilized during the initial phases. Once the person has been placed on the job, he is encouraged to make more realistic transportation arrangements.

However, it is realized that adapted driver education is vitally important in the vocational placement of many handicapped individuals since mass transit systems do not offer a viable means of transporting the disabled to and from work. In order to help overcome this crucial problem and to aid the disabled to successfully enter the world of work, the Center offers a comprehensive driver education program.

Here, the severely disabled are first evaluated psychologically, physically and functionally in a driver simulator with adapted hand controls to fit individual needs. Following this, a modified curriculum is utilized in both computerized simulators and on the road in an adapted automobile. The laboratory is also being used to conduct a variety of research projects to advance the state of the art so that more severely disabled people can drive.

On-the-Job Training

The phase of On-the-Job Training may be conducted either at the workshop or in the actual business or industrial setting. Regardless of the setting, the individual should now be brought from a benign atmosphere to a competitive one since he will be expected to develop proficiency in all necessary job skills within the occupational classification.

This period requires a number of components important to successful placement. These include a length of time allotted to training for the particular job, supportive counseling for the client and employer, modification of equipment and facilities at the place of work, and extended periodic follow-up on the worker's progress.

Innovative Models in Placement

Concurrently with the components discussed above, Abilities provides information and attitude and sensitivity training for managers and first-line supervisors of companies interested in hiring the handicapped. Human Resources has found this to be a critical component. While those with negative attitudes may not become accepting, those who lack information or are uncertain may develop a more positive attitude as a result of seminars in a demonstration center such as Human Resources. This can demonstrate to the prospective employer the positive aspects of the disabled by seeing firsthand what can be done and how the disabled individual can lead a normal life.

Although the concepts of placement and employment are being discussed in other papers, placement is a primary and vital element of workshop activities. Described below are some of Human Resource Center's innovative placement programs.

Projects With Industry

Projects With Industry at Human Resources Center was designed for the severely physically disabled-disadvantaged client. Our primary goals were to obtain entry-level white-collar jobs in the business community and to expand the vocational opportunities for this population

in competitive commercial settings of major companies. In order to limit the Center's training programs to each company's on-the-job training program, the staff was required to work closely with a business advisory group so as to select and develop instructional materials and training equipment. The project was designed to place the trainee on the job as quickly as possible with evaluation and training limited to eleven weeks at the Center. Each industry assumed responsibility for training the individual in the specific job tasks.

Projects With Industry has placed approximately 254 severely disabled persons in competitive employment. Disabilities included are: paraplegia, quadriplegia, hemiplegia, cerebral palsy, cancer, blindness, deafness, heart disease, post-stroke condition and sickle cell anemia. Over 10 percent of the people have had to be placed in more than one job so that placements are in excess of 254. Salaries range from $5,000 to $10,000 annually. Examples of specific job titles include: microfilm technician, stock transfer clerk, accounting clerk, credit authorizer, file clerk, typist and teller.

Work Orientation for Severely Disabled College Students

The purpose of the Work Orientation Program is to provide the disabled college student with a realistic work experience related to his goal upon graduation and help in effective placement. The program also serves to help ease the transition from student to employee, and to better prepare the student to function as a productive, well-adjusted worker.

As part of the program each disabled student is offered a three- to five-day intensive workshop encompassing job-seeking skills, means of selecting an appropriate occupation, and methods to increase personal abilities in order to enhance employment opportunities.

Relevant part-time or summer employment is secured for those who complete the orientation. The participating employer pays one-half of the student's salary for 400 hours.

At the completion of the second year of the program, 70 severely disabled students had been employed in career-related summer and part-time positions. They were placed in libraries, universities, service agencies and industry.

Homebound Employment

Competitive work can also be found for those severely disabled who are homebound. Under a special innovative project the Center has developed jobs for the most severely disabled as Insurance Claims Adjustors for a major insurance company working at home. Successful placements have been made in a variety of telephone-based positions such as information operator for disaster calls; personalized answering service operator; dispatcher; and substitute teacher acquisition clerk for local school districts.

Affirmative Action

A recent development of particular importance to workshops is the Affirmative Action regulations requiring all companies having federal contracts in excess of $2,500 to develop and implement a satisfactory employment plan for the qualified handicapped person including elimination of architectural barriers to employment, personnel and training provisions and job modifications when necessary.

As a result, Human Resources Center developed seminars and an Advisory Service in order to help business and industry comply with these new regulations.

The Future

Workshops throughout the country must survive and grow in today's economy by developing and implementing a number of programs and practices.

One of the priorities is the development of better management and contract procurement procedures and policies. Workshops must begin considering the effective utilization of N.I.S.H. and the Wagner-O'Day Amendments in the procurement of contracts on a Federal, Regional and State basis. This might include such concepts as the organization of a consortium of workshops in an area to centralize strengths. Other developmental programs might also consider the use of business "consultants" in the manufacturing process and management techniques, as well as methods engineering for the more severely disabled in the actual sheltered work setting.

Another prime consideration in the actual work setting is the exploration of more diversified types of work and enhancing the current expertise of work skills available in the shop. This might include finding areas for better contracts and employment than currently being provided. For example, some shops could consider expanding from simple packaging to routine clerical tasks which might be available for sub-contract and entry level employment in local businesses. Another area of consideration could include upgrading the current level of work contracts in the shop from simple mechanical assembly to more complex mechanical assembly operations through job methodization and engineering.

In the area of vocational rehabilitation (i.e., placement), better and innovative placement techniques and programs should be given top priority, researched and developed for more effective placements. There are a number of models that have been developed across the country. These include group integrity placements, trial and short OJT placements, the training of placement specialists in the agency, and the development of jobs through increased and closer contacts with business and industry.

A second important consideration in placement is a more effective and vigorous implementation and use of the Affirmative Action sections of the Rehabilitation Act of 1973. This is an area where workshops and vocational rehabilitational facilities can be particularly helpful to the federal, educational and business communities. Expertise could be offered not only from a legal point of view, but as persuasive and educational techniques as well.

Finally and equally as important is the development and cultivation of closer relationships with the local, state, regional and federal vocational rehabilitation agencies (as well as other related organizations) in order to increase and enhance workshop activities. The proper maintenance of these relationships could lead to funding for expansion and innovation in placement process projects, professional and management staff development, more realistic training programs and an improved channel of information dissemination.

By not only recognizing the needs of the severely handicapped, but those of the employer and professional as well, and utilizing a realistic approach in placement, employment of the handicapped can work effectively. Each of the some 200,000 disabled people placed across the country each year have their own success story and have shown that vocational rehabilitation pays. It is the task of sheltered workshops and vocational rehabilitation centers to collaborate with business and industry and together prove the job can be done.

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INDEPENDENT LIVING ARRANGEMENTS FOR SEVERELY PHYSICALLY DISABLED PERSONS

Lex Frieden

Just as housing tops the needs list for the general population, so it does for severely physically disabled persons. The number of severely physically disabled (SPD) persons in the United States is not exactly known, but it is probably on the order of 200,000 (Fay, 1975). Several comprehensive surveys have been done to determine the housing needs of SPD persons, and they all reach the same conclusion: SPD persons are in need of specialized housing and few suitable solutions exist today (California, 1969; Fenton, 1972; Michel, 1972).

The problems of housing for SPD individuals should not be taken out of the broader context from which they come. Housing problems for SPD persons are special because such individuals have extraordinary needs. A severe physical disability, in the sense to which it is here referred, is a mobility or function impairment which requires a person to be significantly dependent on other people or devices to satisfy his basic life needs.

Housing generally refers to physical structures or dwellings, but when one speaks of housing in terms of severely handicapped persons, it must also refer to necessary life support systems. Life support systems provide services which must be incorporated in housing plans and implementation. To avoid associations with the traditional use of the word "housing," and to clearly indicate the broad nature of the problems involved in providing suitable living accommodations for SPD individuals, all references in this paper to housing in the broader context will be in terms of "living arrangements."

Almost everyone concerned agrees that SPD persons exist in significant numbers, and most authorities agree that many SPD people are forced to live in unsuitable accommodations. Disagreements begin to arise, however, when one tries to determine what sort of accommodations are suitable for SPD persons to live and prosper in. The thesis of this paper is that almost any living arrangement can be made suitable if the proper resources are available and if the SPD resident is given a part in the planning and management of the arrangement. A suitable living arrangement is an independent living arrangement.

Philosophical Concepts

Several basic philosophical concepts are critical to this position. Perhaps the most important of these is independence. The different between suitable and unsuitable living arrangements for SPD individuals may actually be the difference between independence and dependence.

Complete independence is not obtainable for anyone. It should be possible, though, for persons to choose what they will depend on and to readjust their dependency whenever they like. SPD persons will always be dependent on their social and physical environment to some degree. They may never be independent in terms of financial income, personal

physical care, or environmental barriers; but they should be able to choose what sort of wheelchair they buy, who takes care of them, and where they live.

To live independently one need not be physically independent. He must, however, have some control over his own life, and the extent to which he does influence his own destiny determines the degree of independence he maintains. A SPD person can involve himself in an environment free of physical and social barriers where reliable and sufficient attendant care is available. Under these circumstances, he can learn and work and live relatively independently. This is the epitome of an independent living arrangement (ILA). An ILA is a suitable living arrangement in which the SPD resident has an opportunity to manifest his independence by choosing his own course.

It should be noted that just because someone is given a choice, he may not necessarily make a decision. Some physically dependent persons who live in unsatisfactory nursing homes will not move to a more independent living arrangement even if they are given the opportunity. They should, nevertheless, be given the choice.

Everyone should be able to choose where he lives—in what section of town, in what sort of physical structure, and where in that dwelling he stays. The SPD person is restricted from making these choices now because very few housing structures are accessible to wheelchairs. Preference surveys of the sort which indicate that handicapped persons prefer to live together (Columbus & Fogel, 1971; see also Fishman, 1971) may be used to justify the construction of specially designed housing projects exclusively for SPD persons, or "ghettos" for the handicapped. These projects are fine for those persons who choose to live there, however they are unsatisfactory for those persons who must live there because they have no choice.

Another important concept which relates to independence and freedom of choice is individuality. The concept of individuality applies to living arrangements because it stresses the importance of planning not for a class of disabled person, but instead, for an individual person who may be disabled. Individuality should be manifested in the personalization of one's living space. Individuals should have the freedom to choose their own furnishings and decorations, regardless of where they live. Also, persons should not be restricted to their original selection and arrangement of furnishings. They should be free to rearrange their personal living space whenever and however they wish.

The individual's right to and need for privacy should also be considered by living arrangement planners. Provisions need to be made so that the SPD person will have a place to be alone whenever he desires, without feeling trapped or insecure.

Two basic theoretical approaches should be added to the concepts of independence and individuality to be used as guidelines by planners of ILA's for severely disabled persons. These are systems theory and developmental theory.

Generally, all considerations involving housing should be made from a systems viewpoint, with close attention given to the total environment. This is particularly important when SPD persons are concerned, for their needs are broader than those of the normal able-bodied population. For example, a SPD person who cannot drive his own car, yet who lives within rolling distance of his school or work, and other conveniences, may be just as independent

as an able-bodied person who drives his own car. In this case, environmental and systems considerations may have helped the mobility impaired individual compensate for his handicap by locating him in a community of nearby resources.

A systems approach to the problems of living arrangement design for severely disabled persons is also useful from another standpoint—that is, the organization of need-satisfying services. It is not sufficient to simply make available necessary services for the SPD person. These services must be provided in an organized fashion and this can only be done within a systems framework by someone who understands the needs of the individual and has the authority, resources, and competence to make the system work. In this way, the needs of the individual can be met in a coordinated manner consistent with his desires.

The developmental approach is an extremely useful one in the context of living arrangements for severely disabled persons. Disabilities are often developmental by nature. A person's physical condition may improve or become worse, slowly or suddenly. Attitudes may change in addition to physical abilities and these psychological variables may affect the living arrangement needs of individuals. In any case, living arrangements should be available to accommodate the severely disabled person during any stage of his life. Developmental considerations add emphasis to the need for a variety of solutions to the problem of arranging independent living opportunities for SPD persons.

The principle of normalization is closely related to the developmental approach. Normalization, in this case, is a transition by a SPD individual from an institutionalized sort of dependent living arrangement to a more independent community-based residence. Over half of the SPD individuals in a study reported by Stock and Cole (1975) moved from an institutionalized group living arrangement to a more independent setting. A SPD person may need to be institutionalized during some times of his life, but this fact does not justify keeping him institutionalized if he chooses to be more independent.

Physical Characteristics

Now, having reviewed the ideological bases of ILA's, let us look at some of the particular physical and social aspects. The physical characteristics of an ILA are very important for they may directly affect the degree of independence a resident can maintain. Many sorts of behavior are site dependent, and ecological studies have demonstrated that the degree of independent behavior by SPD individuals may vary as a function of changes in the physical environment (Willems, 1972; Willems and Campbell, 1975). A paraplegic who lives in a place where he has easy access to a bathroom will probably be considerably more independent than he would be otherwise. Likewise, the quadriplegic who can reach and operate the knobs on his wash basin may be more independent than one who cannot.

The SPD person will be able to realize and manifest his independence in a barrier-free environment. Many different physical barriers may prevent free access to the SPD person in a living arrangement. Among these are curbs, steps, narrow hallways and doorways, heavy doors, high counters and cabinets, small bathrooms and kitchens, low beds, low tables, and low toilet seats.

The best sort of barrier free environment is one which is adaptable. An adaptable design allows for individual differences and takes into consideration the developmental aspects of

disability as well as the transient nature of some individuals. A truly adaptable living space is one in which the walls are moveable, and in which the toilet seat, bathroom and kitchen fixtures, cabinets, shelves, and household appliances can be raised, lowered, and moved to meet the needs of any individual (see Brattgard, 1971).

Probably the most important consideration to be made in relation to the physical living space of the SPD person is location. It affects the extent to which an individual is dependent on transportation to reach location-bound goods and services. As pointed out earlier, living arrangement location may best be viewed from a systems approach, within the context of the total environment (LaPierre, 1974). Site planners should consider location with respect to an individual's occupation, as well as his service and convenience needs. Such needs might include medical centers, shopping centers, recreation centers, and transportation centers.

It is necessary to provide a suitable amount of personal and private space for every individual in an ILA. The amount of personal space one needs varies across individuals and time. Every person should have at least enough space for a bed, a desk, clothing, and personal articles.

In group residential settings, an extra room may be advantageously used as an operations center. Residents may use intercoms or other call systems to communicate with personnel in the center.

Many special considerations which lie beyond the scope of this paper may be given to the physical environment as it related to the SPD person. In addition to barrier free design, environmental control devices (i.e., remote controls, Possum, etc.) may be effectively utilized to make the mobility impaired individual more independent in his living arrangement. It should be realized that SPD persons may become dependent on a barrier free or mechanized environment to the extent that they cannot function outside that specially designed environment. In this case, independence in the broader sense may be sacrificed for a limited sort of physical independence.

Life Support System

The life support system is an integral part of any ILA. Probably the most critical service to be provided in a system of life support services for the physically limited is that of attendant care.

Attendants may be called upon to assist the SPD person in completing a variety of tasks. These tasks include daily living and personal hygiene activities. They may also include general housekeeping and maintenance activities. In some cases, attendants may be required to run errands or assist with transportation.

The foremost tasks to be done in making an attendant arrangement are selection and supervision. Attendant candidates may be located through a number of means. Employment agencies and school placement centers are usually the best sources of finding reliable employees since the individuals who are referred have been pre-screened. Newspaper advertisements get voluminous responses, but the chances of finding responsible attendants

through this route are not good.

Another potentially useful source for locating and screening attendants is a central registry. The Center for Independent Living in Berkeley has used this method effectively for several years and it should be tried elsewhere. Central registries may help coordinate life support systems across a number of ILA's, thereby allowing for better use of existing services.

Since almost anyone can learn the skills required to be a good attendant, the most important attendant selection criteria are those of attitude and dependability. The best bases from which to judge these characteristics are interviews. Information about attitudes may be obtained from discussions with the applicant, his friends, and former employers. Work histories and listed references may be useful in determining probable dependability.

After an attendant has been selected, it is standard to make a job agreement with him. He needs to understand the extent of his responsibility. A job description like the one in Table I may be useful in outlining expectations. The attendant should agree to give sufficient notice when he intends to quit. He should also agree to notify his employer as early as possible if he is not going to be able to work on any particular occasion.

It is prudent for the SPD person in need of daily assistance to always have a contingency arrangement worked out for use when the primary system fails. Satisfactory contingency arrangements are best made with family members or close friends.

Shared attendant services may be very efficient and cost-effective. ILA's involving small groups of four to eight are fairly easy to manage. With larger groups, attendant staffing and scheduling becomes complicated and administrative tasks multiply. Everyone in the group should assume a share of these responsibilities, whether they do so by hiring someone to manage the system or by dividing the work among themselves.

The key to good management of any successful ILA is organization. The SPD individual must plan and schedule activities ahead of time if he is to function independently in a living arrangement. Some persons may argue that extensive use of planning and scheduling makes an individual more dependent. In one sense, this is true. However, independence in the sense used here refers to managing one's own affairs. Plans and schedules are simply organizational tools which allow the SPD person to be more independent.

Table I
Attendant Job Description

The TIRR residential services program is a complete living arrangement designed to meet the basic needs of a group of handicapped young adults. The concept of independent living is supported by a system of assistive services provided by a staff of non-professional aides and attendants.

The duties and responsibilities of the aides and attendants are:

To assist in activities such as:

- showering
- dressing and undressing
- bowel and bladder programs
- transferring
- changing and caring for urinary devices
- emptying and cleaning leg bags and bed bags
- serving and setting up food trays

To provide assistance in the following housekeeping services in each individual room:
- laundry (wash, dry, fold)
- bed making
- straightening of personal articles in room

To accept responsibilities of general building maintenance by:
- emptying trash cans in orderly room and recreation room
- keeping tables in cafeteria clear of trash and trays
- keeping halls, recreation room, and orderly room clean and clear of trash
- keeping utility room clean

All established schedules such as shower schedule, laundry schedule, transportation schedule, get-up sheet, and evening activity sheet should be followed carefully and should not vary except in emergency situations.

All requests for assistance by the residents should be promptly considered and carried out without delay.

When not busy with resident assistance, all staff members should stay in the hall so that lights can be answered without delay.

Scheduling in group ILA's may be done ahead of time with sign-up sheets. These forms may be kept in a convenient place so that residents can write down when they wish to get up, go to bed, shower, or utilize transportation services. To avoid scheduling conflicts, service priorities should be predetermined when services are shared. Scheduling activities one day in advance seems to be sufficient in existing systems. This allows residents to make fairly spontaneous plans, and it gives the system manager the opportunity to adjust employee schedules to meet the demand.

Staff scheduling is a pertinent issue here. Improper staffing may lead to a number of problems. If too many attendants are on duty at any given time, unnecessary expenses are incurred and residents are tempted to depend on staff assistance with tasks they might otherwise do themselves. If too few attendants are on duty, residents may receive unsatisfactory care or become frustrated waiting on service.

To maintain maximum service efficiency, staffing patterns must be based on routine demand. Service demands vary, but individuals customarily develop predictable behavior patterns which make attendant scheduling easier. Peak demands occur regularly in the mornings when residents are getting up for work or school, and in the evenings when everyone is going to bed. Under normal conditions, staff needs can be predicted fairly accurately. Table II illustrates a method of determining how many attendants will be needed on duty during a particular part of the day.

After determining staff needs, an efficient routine staff schedule can be planned. Two primary staffing patterns and various combinations of these two have been operative with large groups. The first style is modelled after industrial staffing patterns where three eight-hour shifts follow each other consecutively throughout the day. This style works exceptionally well for groups of SPD persons who need constant or frequently unscheduled attendant care.

The other primary group staffing pattern is more efficient with smaller and less severely disabled groups. This style provides a personal aide for each resident every morning and evening to assist him with dressing, undressing, and bathing. In this arrangement the entire group shares a full time or live-in attendant for incidental and emergency care.

Attendant managers should always be aware of and take steps to accommodate special non-routine activities which may affect group needs (i.e., recreational events, holidays, etc.). Life support systems become overloaded when the demand for services exceeds the available supply. Since the demand for life support services cannot usually be stifled, the only solutions to system overload are to increase the number of attendants on duty or improve the proficiency of the existing staff.

Table II
Determining Staff Needs

		Amount of time over which dressing activities may be distributed.			
		1 hr.	2 hr.	3 hr.	4 hr.
Amount of time required to assist each resident in dressing.	30 min.	2	4	6	8
	1 hr.	1	2	3	4
		Number of residents cared for by one attendant.			

$$\frac{\text{TOTAL NUMBER OF RESIDENTS IN GROUP}}{\text{NUMBER OF RESIDENTS CARED FOR BY ONE ATTENDANT}} = \text{NUMBER OF ATTENDANTS NEEDED (round up)}$$

When staff shortages occur, standby attendants must be called upon. The best way to maintain an efficient routine system and still be able to accommodate system overloads quickly is to keep a long list of dependable standby attendants on call.

Administrative affairs of ILA's include the payment of bills and staff salaries. These functions should be handled expeditiously. Management duties in group ILA's may include resident selection and discipline. Resident selection is vital to the integrity of some groups. Applicants are screened by interview and questionnaire, and admitted on the basis of group-determined criteria. Group dynamics often dictate the use of authority to maintain order and stability. This authority logically falls to the management or leader figures in the group.

Transportation is sometimes considered a problem independently of living arrangements. However, the systems approach leads one to consider both problems in a broader related context. A SPD person may find an ILA which requires no more transportation than that of a wheelchair. If the SPD person has needs which must be satisfied outside of his immediate environment, then he must arrange for a more sophisticated means of transportation.

Depending upon the extent of his needs, he may be able to utilize public transportation, private jitney service, or his own private vehicle.

Groups may be able to provide themselves with transportation service by sharing vehicles and drivers. These arrangements are usually very efficient, but they require coordination much the same as group attendant management.

Food preparation is also a basic unit of the life support system in an ILA. Meals may be obtained at restaurants or cafeterias. Food may be brought in by attendants or friends. The SPD person may have someone assist him with meal preparation at home. Common dining facilities are popular and efficient with groups.

Many different physical structures and life support services may be combined to make an ILA. An ILA may exist in a nursing home, a family residence, a dormitory, a public housing project, a group home, or any other residential setting. Attendant work may be done by a visiting nurse, a nursing home aide, a neighbor, a student, a friend, a family member, or any other assistant. Transportation may be via a wheelchair, a public bus, a private automobile, or any other accessible vehicle. Food may be prepared in a cafeteria, a restaurant, a home, or any kitchen.

Examples

Several types of ILA have been created and tested by SPD persons. A variety of these exist in Houston today. Independent Lifestyles is located in a large accessible apartment complex. Each of the thirty residents is responsible for his own apartment. Physical assistance is provided by a staff of attendants who are supervised by a resident manager. Scheduling of physical activities is utilized extensively to avoid system inefficiencies. The nonprofit corporation which provides service to the residents owns a van and employs a driver. Transportation is provided on a first-come priority basis. Meal preparation is the responsibility of the resident, although attendants are generally available to assist in this task. Services are contracted on a monthly basis and charges vary depending on the amount of services needed. Monthly fees usually range from $500 to $600 including apartment rent. Some residents receive service subsidies from the state Division of Vocational Rehabilitation although most residents support themselves entirely. Independent Lifestyles has a Board of Directors made up of elected resident representatives who advise the resident manager on critical issues.

Spring Tree is a medium-sized apartment complex which has been remodelled to be wheelchair accessible. Twenty-four SPD persons live near each other in the complex and share attendants. An attendant manager schedules the twelve person staff. Routine care activities are scheduled by the residents. Attendants assist the residents with all aspects of their physical care. Transportation is provided by a charitable nonprofit corporation on a priority needs basis. This service is augmented by a private contractor who serves those residents who qualify for state subsidized transportation. Apartment rent in the complex is $165 per month. The State Department of Public Welfare pays $208 in staff salaries in behalf of each resident, all of whom qualify for Homemaker and Chore Services. Each resident contributes three dollars per month to a fund which is used for parties, gifts, and so forth. Spring Tree residents voluntarily assist the attendant manager with her duties and assume full responsibility for their own personal welfare.

Free Lives is a cluster of 11 SPD persons who live in the same wing of the 292-unit Independence Hall, a FHA 236 project for the handicapped and elderly. Each resident has his own apartment and subscribes to a cooperative attendant service. Routine physical care activities are scheduled by the residents, and the 12 person staff is managed by a chief attendant. Cafeteria service is available in the complex, although some residents prefer to use their own kitchens. Transportation is provided on a prescheduled basis by the apartment sponsors, Houston Goodwill. Service charges are based on mileage. Apartment rent ranges from $80-$151 per month, and attendant services are $260. Some residents' services are subsidized by the state Division of Vocational Rehabilitation and Goodwill. Free Lives has an elected grievance council and a resident administrator who interact with the attendant manager and the project management.

Cooperative Living, a more institutional group ILA, is housed in a hospital facility which it shares with the Texas Institute for Rehabilitation and Research. Twelve SPD persons live there in separate dormitory-style rooms. The residents manage and share their own attendant services. In addition to the cafeteria service available in the facility, some residents have refrigerators and hotplates and prepare food in their rooms. The residents also own and share a microwave oven. The groups owns a large van and they employ a driver. All transportation and routine attendant service is scheduled a day ahead of time on a first come basis. Monthly room fees are $110, attendant services range from $120-$220 per month, and transportation charges average about $60 per month. All service charges are based on the amount of service required. Residents receive subsidies from the local housing authority, the state Division of Vocational Rehabilitation, and Supplemental Security Income. Cooperative Living has a management council of four elected residents who divide and share the management responsibilities equally.

Several individuals in Houston have created innovative ILA's for themselves. One SPD person lives alone in a large apartment unit which has been made accessible. He depends on neighbors to come in and assist him each morning and evening. He drives himself but must depend on passers-by to help him load and unload his wheelchair. He pays his friends $2.50 per hour for their assistance and his monthly apartment rent is $185.

This writer, who is SPD, shares a house with two able-bodied individuals. One able-bodied person provides attendant assistance, while the other drives for the group. Since the attendant is brain damaged, the SPD person assists him with certain organizational functions. This cooperation results in a rewarding symbiotic relationship. Both disabled partners share expenses which amount to about $700 per month.

Comparisons

ILA's may be compared on two fundamental dimensions. These are dwelling type and life support service style. (See Figure I.) Dwelling types range from single family dwellings to dormitories. Life support service styles range from informal arrangements to highly organized programs. As illustrated in Figure I, those ILA's which involve large groups in multi-resident dwellings and employ many attendants in an organized program are more institutionalized than those ILA's which involve a single individual in a single family dwelling who depends on a neighbor to provide his care.

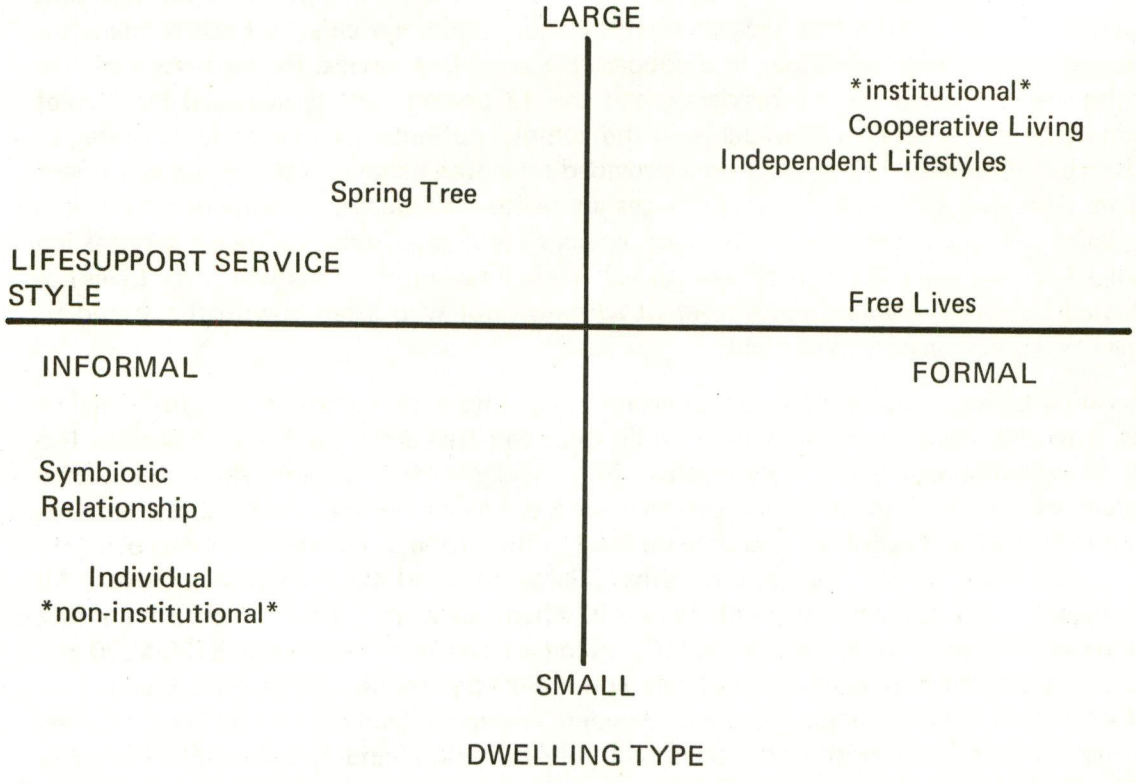

FIG. 1. A two-dimensional analysis of independent living arrangements.

General comparisons of ILA's may be done on the basis of cost-benefit analyses. Table III illustrates such a comparison. Costs of ILA's may be both material and non-material, while benefits are mostly non-material. Material costs of ILA's may be relatively low for those persons who live in multi-resident dwellings and share life support services. On the other hand, material costs may be relatively high for those persons who choose to live alone and hire a full-time personal attendant, or those who live in more institutionalized settings.

Non-material costs include frustration caused by waiting and compromising, insecurity caused by undependable attendant services, or uncertainty about arrangements, and boredom resulting from routinization and segregation. Some non-material costs, like frustration and boredom, may be higher in more institutionalized settings; while other non-material costs, like insecurity, may be higher in less institutionalized arrangements. Non-material benefits are high in any ILA. The independence one maintains in such an arrangement is invaluable.

Pragmatic Issues

Several pragmatic issues should be considered with respect to planning and implementing ILA's. Funding is always an important issue. Just as an ILA may be created by combining a physical facility with various life support system resources, so may the required funding be obtained from the combination of a variety of resources. In addition to what the individual may contribute himself, funds may be obtained from both public and private agencies. Federal, state, and private rehabilitation agencies, public welfare departments, Social Security offices, local housing authorities, community development offices, and charitable foundations should all be considered possible contributors to ILA's. Group ILA's which are subsidized or sponsored by established agencies are obviously more stable than those which are not.

Table III
A Cost-Benefit Comparison

	Material costs	(Possible) costs	Non-Material benefits
Independent Lifestyles	$550	frustration	independence
Spring Tree	$430	frustration	independence
Free Lives	$500	frustration	security independence
Cooperative Living	$400	boredom frustration	security independence
Individual	$550	insecurity	privacy independence
Symbiotic Relationship	$350	insecurity	integration independence

Note: Cost figures are approximate and do not include personal needs.

Accountability is also crucial. It is important for the SPD person to realize that if he depends on a third party to provide him with attendant service, he should hold that party accountable when the contracted service is unsatisfactory. It is his responsibility to communicate with his providers so that they will know when service is not satisfactory. Attendant care may be indispensable for SPD persons, but no specific attendant or service arrangement is indispensable. The ultimate accountability and responsibility for an ILA rests with the individual resident.

Social relationships are critical to the success of ILA's. The interpersonal relationship between a SPD person and his attendant is paramount. Good relationships are founded on consideration. These relationships may be balanced with friendship and kindness in addition to financial compensation. The relationship may become strained if the SPD person's physical needs are not well met. In this case, it may be beneficial for the SPD individual to be more assertive and authoritarian. The SPD person should never be afraid to seek a new attendant when one demands too much or gives too little.

Resident-to-resident relationships are vital in group ILA's. Residents must assume a more businesslike or formal attitude toward their living arrangement when services are shared. For the program to function smoothly, they must cooperate with each other and respect each other's needs. Schedules and rules must be followed closely by everyone to avoid imposing on other participants in the system.

Another important relationship exists between the SPD person in an ILA and his community. Persons who plan and live in ILA's should be considerate of public opinions and attitudes toward their arrangements. Good public relations can be maintained without sacrificing self-respect or personal values. SPD persons can be "good neighbors" by taking

part in community affairs and by respecting the viewpoints and privacy of others.

The concept of ILA's is based on a systems approach which presupposes an integrated society. In this society, SPD persons have a responsibility to maintain their independence and contribute to the general public welfare. Society has the responsibility of giving the SPD person the opportunity to create and maintain an ILA. New legislation providing for subsidized attendant care programs for SPD persons should be written and passed. Existing legislation which provides housing and transportation privileges for SPD individuals should be enforced. Innovative housing and social service legislation should be supported by higher funding levels. Finally, present third party welfare subsidies for SPD persons should be redirected to the disabled person himself.

It takes hard work to plan and organize all the necessary resources to make an ILA. ILA's must be maintained by financial support and good management. The main ingredients of an ILA are a physical structure, a life support system, and an SPD person who has the imagination and desire to be independent.

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TRANSPORTATION FOR THE MOBILITY HANDICAPPED

Thomas C. O'Brien

Introductory Statement

The characteristics of persons with physical handicaps, and those persons whose mobility, flexibility, and coordination are significantly reduced by aging, together with characteristics of the transportation system and process, make travel by the handicapped and elderly very difficult—often impossible. In a society where transportation is an integral link to all goods and services required for a full life, most handicapped and elderly persons have only limited access to jobs, medical services, shopping, recreation, and other community-based activities.

Despite this enormous need, the federal government, the transportation providers and equipment manufacturers have provided only token response to the near total lack of viable transportation alternatives for the handicapped and elderly.

Five years ago the U.S. Department of Transportation stated that it was national policy that the elderly and handicapped have the same right as other persons to utilize mass transportation. Today we are witnessing the implementation of the latest in a series of token responses to the "right to use" policy—off peak/half fare programs for the handicapped. A chart of relevant legislation appears on the following page.

Background

Sensitivity to the mobility problems of the elderly and handicapped has increased in the past few years. As recently as 1970 the chairperson of the jointly sponsored HEW/DOT conference on Transportation and Aging stated:

> this [conference] is the first systematic effort to accumulate a body of information on mobility . . .

Since the pioneering work on the mobility of the elderly, performed by Frances Carp in the late 60's, a significant effort has been developed towards analyzing the problems of handicapped and elderly. These studies have shown that the physical and, in some cases, psychological problems of the elderly and handicapped, together with the characteristics of the transportation system and the transportation process make it difficult, if not impossible, for most handicapped and elderly to use public transportation facilities.

Since the Biaggi Amendment, which also dictated that transit funds be utilized to finance transportation programs for the elderly and handicapped, there has been little done to address the problem of mobility. There have been studies but the results of most of these studies merely adorn the shelves of libraries and the results and recommendations are seldom implemented. The funding mechanism of the Biaggi Amendment was merely

optional and few states made any attempt to take advantage of the funding possibilities.

A later amendment to the UMTA act, the so-called Abzug amendment (Section 16 b 2) provides that grants and loans may be made to private, non-profit organizations to assist them in providing transportation services for the elderly and handicapped. This latest demonstration of a contrived impression of concern is the best example of false rhetoric. Many organizations of, by and for the handicapped have been created in recent years. Similarly, numerous Golden Age and Senior Citizen groups have been started and continue to exist on limited funding, at best. Yet, the 16 b 2 program requires these groups to pay for 20% of the capital costs of the program and 100% of the operating costs. There are no provisions for continuity.

The Federal Highway Act of 1973 offered a stronger statement regarding the elderly and handicapped:

> The Secretary of Transportation shall assure that projects receiving Federal Financial Assistance under . . . Section 147 of the Federal Highway Act of 1973 shall be planned and designed so that mass transportation facilities can effectively be used by elderly and handicapped persons who by reason of age, injury, illness, congenital malfunction or other permanent or temporary incapacity or disability are unable without special planning or design to utilize such facilities and services as effectively as persons not so affected.

This regulation affects only those projects funded by FHWA funds and not the majority of mass transit projects which are funded by UMTA.

The first law which contains a strong provision concerning transportation of the elderly and handicapped was the National Mass Transportation Assistance Act of 1974. Systems receiving assistance under Section 5 of this act (which provides operating assistance) are required to offer half fares to the elderly and handicapped during off-peak hours. At the same time that the Federal government is spending money on rehabilitation programs to put handicapped persons back to work, it institutes a program designed to save on transportation cost excluding the hours that most people travel to and from work.

However, Federal regulations are being proposed that may have the greatest impact on shaping transportation policy for the elderly and handicapped. The proposed UMTA regulations require that, effective October 1975, all transportation improvement programs and long range plans contain a definite plan for meeting the transportation needs of the elderly and handicapped.

Further, S 662, recently approved by the Senate Banking Committee, would require that new vehicles, station buildings, and other structures for any new or expanded rapid rail system meet accessibility standards. New buses would also be required to meet such standards "with such reasonable exceptions from accessibility standards as the Secretary may deem required by the nature of the vehicle, its proposed use, or the commercial availability of reliable equipment to facilitate accessibility." It is blatantly obvious that with such broad exceptions and the use of words such as "reasonable," there is little commitment to the policy statement that appeared in 1970.

Placing the blame totally on the Federal government is, however, not entirely fair. In 1961 the American National Standards Institute, Inc. (ANSI) published its "Specifications for Making Buildings and Facilities Accessible To and Usable By, the Physically Handicapped." The development of these standards, known as ANSI Standards 117.1, was sponsored by the President's Committee on Employment of the Handicapped and the National Easter Seal Society. These standards have been the underlying basis of most accessibility legislation and regulations for the handicapped which are currently law. I would like to point out the fact that the handicapped, as well as organizations of the handicapped, have failed to recognize the standard ANSI 117.1 as a useful tool to accomplish the task of insuring accessible facilities. Worse, is the fact that Public Law 90–480, passed in 1968, has been virtually ignored by the handicapped community as another tool, or in this case, a weapon to fight the unthinking or mindless builders and architects who continue to emulate the pyramids.

It is important to note that 90–480 is typical of numerous bills that are vague, contain no compliance and/or monitoring provisions and are as a result, permissive. Following 90–480 a series of other major barrier-free acts became law. One of the objectives of the Rehabilitation Act of 1973 (PL 92–112) was to make up for a lack of any strong enforcement mechanism in 90–480. Section 502 of the V.R. Act establishes an Architectural Barriers and Transportation Barriers Compliance Board. This board, the authority of which is enhanced by the amendments contained in P.L. 93–516 (passed in 1974), has the power to "conduct investigations, hold public hearings, and issue such orders as it deems necessary to ensure compliance" with the provisions of P.L. 90–480. The sincerity of the Federal government must be questioned again when one considers that it was mid-summer of 1975 before the new "Compliance Board" was staffed.

While the Federal policy towards transportation has been slowly evolving, a concerted effort to hasten action has been initiated by community groups in dozens of communities across the nation. Many legal actions have been filed and legislative actions taken in many states and ordinances and other acts at the local level.

The major battles are being planned now and we must utilize all the available resources. Most of all we need a unified position. Not necessarily a single viewpoint—but a well defined stand. The differences of opinion between the handicapped consumers must be presented as a mix of needed services and not the inability of those in need to agree on what they want or need. A recent editorial published in the American Public Transit Association Journal (August '75), entitled "Elderly and Handicapped: A Diversity of Opinion" states: "What we seem to be faced with is the lack of any real consensus as to what the requirements of the elderly and handicapped are . . ." Also, the editorial tries to undermine the similarity of problems faced by the elderly and handicapped by claiming that: "Clearly, in a great many cases, the transit needs of the elderly are not the same as the handicapped." An article in the May '75 issue of the Journal entitled "Mobility for the Elderly and the Handicapped: A Case for Choices," cites the difference between "MOBILITY" and "ACCESSIBILITY." In other words the transportation industry refers to the problem as the difference between "door to door" service, usually provided by van-type vehicles, and fixed-route service which traditionally provided by transit-style vehicles. Which is best? Both types? How much of each? What is the next step?

Before presenting possible solutions to this problem or, to be more precise, strategies and/or actions to be undertaken, it is important to note that there are three major questions which must be answered:

1. Who are the Transportation Handicapped?
2. Which of their transit needs are not being met?
3. How can those needs be satisfied?

The answers to these basic questions must be answered by the handicapped themselves. How often are programs designed for the disabled or, for that matter, any group with special needs, and the group in question is not part of the process by which the solutions or results are determined? A number of studies are aimed at getting answers to these and other questions but how effective are the results? Further research is being conducted on the national level to determine the numbers of persons affected—the type of disability and the transportation dysfunction. How meaningful the results will be is itself an unanswered question. However, I submit that demonstration projects that provide hardware and operational experiences are more meaningful and productive than surveys and questionnaires.

As early as December 1973 the National Technical Information Service, U.S. Department of Commerce, issued "A Bibliography with Abstracts" entitled Transportation for the Elderly or Physically Handicapped.

The emergence of the American Coalition of Citizens with Disabilities (ACCD) as a viable consumer organization is most encouraging. I am privileged to function as Chairman of the ACCD Transportation Committee and endorse the ACCD position which contends that full access to all public transportation is necessary. This position does not, of course, eliminate or even diminish the need for demand responsive or dial-a-ride systems to serve the handicapped when appropriate.

Two organizations have also recently emerged that will undoubtedly assist the handicapped and elderly achieve the goal of accessible public transportation: The Public Interest Law Center of Philadelphia (Pilcop, James J. Raggio, Atty., 1315 Walnut St. 16th Floor, Philadelphia, Penn. 19107) and The National Center for Law and the Handicapped, Inc. (Harvey A. Bender, Exec. Director, 1235 North Eddy, South Bend, Indiana 46617).

Three other resources for information are:

1. The National Center for a Barrier Free Environment
   Attn: Edward J. Leonard
   8401 Connecticut Ave.
   Washington, D.C. 20015

   President's Commission on the Handicapped
   Washington, D.C. 20210
   (202-653-5079)

2. Architectural and Transportation Barriers Compliance Board
   James Jeffers or Peter Lassen (202-245-1803)
   Room 1004
   Mary E. Switzer Building
   330 C Street, S.W.
   Washington, D.C. 20201

3. Office for Handicapped Individuals
   Frances Lauder (202-245-0449)

To coordinate with ACCD contact me, Thomas O'Brien, 15 Wellesley Rd., Danvers, Mass. 01923.

Conclusion

A single recommendation, I feel, is appropriate at the present time. Those with a mobility problem must establish a meaningful dialogue for the purpose of establishing a position on their transportation needs. The product of the discussions must include a strategy for implementing programs that will meet their needs.

Thomas C. O'Brien
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American Coalition of Citizens with Disabilities
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Major Funding Sources for Transportation Services For the Elderly & Handicapped

Level of Government Department and Statute Title	Specific Title Numbers If Relevant
I. Federal Sources	
A. Department of Health, Education and Welfare	
1. Older American's Act	III, IV, VII, IX
2. Public Health Service	III, XII
3. Social Security Act	VI, XIX, XX
4. Mental Retardation Facilities Construction Act	II
5. Vocation Rehabilitation Act	—
6. Higher Education Act	I
7. Library Service & Construction Act	I
B. Department of Transportation	
1. Urban Mass Transportation Act	Sections 3, 5, 6, 9, 16(b)(2)
2. Federal Aid Highway Act	Transfers from Interstate
C. Department of Labor: Comprehensive Employment & Training Act	III
D. Office of Economic Opportunity: Economic Opportunity Act	III, esp. Sect. 222
E. Veteran's Administration: Veteran's Health Care Expansion Act	I
F. ACTION: Domestic Volunteer Service Act	II
G. Revenue Sharing: State & Local Fiscal Assistance Act	—

MAJOR FUNDING SOURCES cont.

Level of Government	Specific Title Numbers
II. State and Local Sources (Illustrative Only)	
A. Special Taxes	—
B. Special Funds	—
C. Bond Issues	—
D. Tax Relief	—
E. Lottery	—
F. Transit Districts	—
III. Private Sources (Illustrative Only)	
A. Muscular Dystrophy	—
B. American Cancer Society	—
C. American Red Cross	—
D. United Cerebral Palsy	—
E. Easter Seal Society	—
F. Local Religious Groups	—

Source: Joseph S. Revis, Institute of Public Administration, *Transportation for Older Americans,* Final Report, Tables V-1, V-2, and V-3, April 1975.

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James J. Raggio, "Coalition Building and Direct Advocacy," The Public Interest Law Center of Philadelphia, 1315 Walnut St., Phila., Pa. 19107

Statement by Senator Harrison Williams, *Congressional Records,* Vol. 1.121, No. 19, Feb. 11, 1975, Washington, D.C.

Senator Harrison Williams, "Opening Statement," Hearings by Subcommittee on Housing and Urban Affairs on S.662, National Mass Transportation Assistance Act Amendments of 1975, June 17, 1975.

"Transportation for the Elderly or Physically Handicapped, A Bibliography with Abstracts," National Technical Information Service, U.S. Department of Commerce, Dec. 1973. COM-74-10887

"Consumer Leadership Conference," Massachusetts Council of Organizations of the Handicapped, Inc. in Collaboration with Tufts Rehabilitation Research and Training Center, April 1975; published by Cerebral Palsy Center of Metropolitan Boston, Newton, Mass.

Harold S. Remmes, "A Consumer's Guide to Organizing the Handicapped," Massachusetts Council of Organizations of the Handicapped, Inc. 41 Woodglen Rd., Hyde Park, Mass. 02136

Linda L. Mandel, "Transportation for the Handicapped—An Equal Opportunity to Travel, *Metropolitan Magazine,* May/June 1975.

Legislation

Public Law 90-480 Architectural Barriers Act of 1968

Public Law 91-453 Urban Mass Transportation Act of 1964;
Section 16 (Biaggi Amendment);
Section 16(b)(2) (Abzug Amendment)

Public Law 93-87 Federal Aid Highway Act of 1973

Public Law 92-112 Rehabilitation Act of 1973

Public Law 93-516

Public Law 93-503 National Transportation Assistance Act of 1974

Proposed UMTA Rule 609.11

Senate Bill 662

MEDICAL ASPECTS OF DISABILITY WITH A VIEW TO INDEPENDENT LIVING

Sheldon Berrol, M.D.
Edna Brean, R.N.

Introduction

Great strides are presently being made in the acute management of the severely disabled patient as a result of the development of regional centers for treatment of catastrophic illness. Unfortunately, the level of long term medical management has not as yet kept pace with this progress, due in no small part to the attitude of governmental and insurance organizations which are apparently only now on the verge of recognizing that adequate health maintenance can be equated with fiscal responsibility.

The team approach to the severely disabled involves not only the medical community and its recognized paramedical specialists, but also the rehabilitation counselor, the peer counselor, and when necessary the consumer advocate. The goal of this concerted effort should ultimately be independent living. In this context, independent living is more than living at home or in a sheltered workshop. It encompasses an active participation in the social process, being a head of household, and finding meaningful work which may or may not be remunerative. The role of health maintenance in this process revolves around freedom from egocentric body needs. This can only be achieved by indoctrinating sound principles of preventive health care in the daily routines of the disabled.

Our intent here is not to provide a detailed description of basic rehabilitation programs, but rather a brief overview of issues that interfere with the maintenance of an independent life style. We have essentially avoided surgical approaches to problems, except for a few selective instances. Some of our approaches may be controversial, but they represent the summation of successful experiences.

Routine Health Maintenance

The decrease in mortality rate among the severely neurologically disabled appears to parallel the adequate medical follow-up, the hallmark of which remains the annual physical exam. Most patients who live within reasonable geographic proximity of the rehabilitation center can generally have their evaluation performed as an outpatient. The patient who lives at some distance can usually have the full evaluation accomplished within two to three days.

A reasonably comprehensive evaluation should include intravenouspyelography (or a renal scan in the case of dye sensitivity) CBC, panel chemistries (which include a BUN), and serum creatinine. Pulmonary function studies should be included in quadriplegics, or when involvement of the thoracic musculature is present to any significant degree. In children with SCI, polio, myelomenigocele, muscular dystrophy, etc., evaluation of the spine for progressive scoliosis must be performed, and after capping of the iliac crests, on an elective basis. Urine cultures and sensitivities should be performed annually, but the method of obtaining the specimen should preferably be by Suprapubic Aspirate. If this cannot be accomplished, direct catheterization would be the next most reliable method. In no instance would obtaining a specimen from the indwelling catheter, or from a bad leg bag be

acceptable. If a change in residual capacity, or in bladder spasticity is suspected by history, a cystometrogram or air cystometry should be performed.

A full physical examination including a re-evaluation of neurologic function and disability must be performed, and establishment of potentially new rehabilitation goals considered annually.

Bladder

The most significant advance in the care of the urinary tract in patients with a neurogenic bladder has been the introduction of the intermittent catheterization program. If the patient has been fortunate enough to have had the program instituted early in the acute rehabilitation phase, then his urine may remain consistently sterile. Even if the injury or disease process has been longstanding, the success rate in preventing urinary tract complications is outstanding. An adequate evaluation of bladder function, i.e., the type of neurogenic bladder, must be done in order to properly determine the need for concomitant drug therapy. In the case of the small, spastic bladder, banthine is frequently of value in relaxation of the detrusor muscle of the bladder. In the flaccid bladder, bethanechol will increase bladder tone and produce more effective emptying.

The Crede procedure should be taught the patient with the Lower Motor Neuron bladder, and reflex stimulating procedures to the patient with an Upper Motor Neuron bladder. Careful attention should be directed to bladder residuals with a maximum of 20% for UMN bladders and 10% for LMN bladders.

Tidal drainage is mentioned as a procedure to be avoided.

In patients with high outflow resistance, a sphincterotomy is a simple procedure which usually results in elimination of the catheter. The male patient with an indwelling catheter is an anachronism at this point in time, with the exception of its temporary use in the case of ureteral reflux.

The female patient with her short urethra is, however, frequently treated by indwelling catheter. "Padding up" may be an acceptable technique for a small minority of women and is not without hazard to skin. The selective use of the artificial spincter in appropriate cases appears to be a major advance in bladder control.

Overdistention of the bladder must be avoided. Prophylactic antibiotic therapy appears to be an unwarranted approach in the avoidance of urinary tract infection. Recent studies suggest that the upper urinary tract is resistant to pseudomonas and, in the absence of symptoms, treatment on the basis of cultures alone is not necessary. Monitoring of pH of the urine should be taught to the patient and attendant, and appropriate acidification accomplished by dietary intake or supplemental ascorbic acid.

One must remain constantly alert to the possibility of bladder neoplasm, the incidence of which is significantly higher in the patient with the indwelling catheter.

Spasticity

The presence of spasticity is not an indication for its control. The patient with upper motor neuron spasticity should be adequately evaluated to determine if his functional capabilities could indeed be increased by proper utilization of spasticity.

Spasticity usually represents a loss of cortical inhibition, which may be modified by several modalities with varying success. In the physical therapy gym, local application of ice usually decreased spasticity long enough to range a joint, but results are rarely effective beyond two weeks. Acupuncture has achieved a degree of folk popularity, but clear-cut clinical trials in spasticity as yet are not available.

Conservative treatment remains the pharmacologic approach. Diazepam has for many years been the mainstay of drug control, but not without hazard. A frequent problem is the accompanying lethargy and altered reaction time by virtue of its central nervous system effects. It maintains a distinct addictive capability and may induce withdrawal seizure activity. Therefore any patient who has been on Diazepam, particularly in large doses, should be gradually tapered whenever the drug is withdrawn.

Dantrolene has been a major advance in drug control of spasticity in that the primary site of action is in the effector organ—the muscle fiber. It too must be carefully administered, with the dose slowly increased to maximum effect in order to minimize sedation and gastro-intestinal effects. Liver function studies must be closely monitored, for toxic effects are not uncommonly encountered.

The class of drugs generally considered "muscle relaxants" are essentially valueless in upper motor neuron spasticity.

Motor point blocks with phenol or alcohol can be most effective when spasticity can be isolated to a few major muscle groups.

Ablative surgical procedures for spasticity will not be considered here.

Contraception

The sexual revolution has created a new wave of societal mores and with it has evolved an awareness that the disabled are sexual beings. The psychological aspects of sexuality will not be discussed, but in considering medical management, concern must be expressed for effective birth control methods.

The severely disabled male may continue to use pre-morbid forms of birth control (if disability is due to injury) such as condoms (which may be an advantage if leakage of urine occurs) or continue to rely on his partner. The vasectomy is a simple and effective method of contraception that has gained a great deal of apparently well deserved attention and is applicable to most disabled men.

The woman appears to have greater problems. If the disability confines her to a wheelchair, then a sizable amount of venous stasis will occur in the lower extremities. If she does not have a regular routine of standing, be it a standing frame, braces, etc., then the incidence of

acute inflammation of veins of the leg may be increased if she uses oral contraceptive hormones. We know of no studies that take into consideration pre-existing venous stasis and its relation to thrombophlebitis when taking oral contraceptives. The IUD (intra-uterine device) may be preferable in selected cases of disabled women. A great deal of mythology has evolved regarding this device, and there have been some serious problems. There appears to be no greater danger of uterine perforation in disabled women. Indeed, such serious side effects are markedly decreased when insertion is accomplished by proficient physicians. The device may be expelled by the uterus and many women cannot use the device because of dysmenorrhea or menorrhagia. Where a monogamous relationship exists with a desire to avoid progeny, the male partner should consider vasectomy.

There is no one single method that is most desirable. The basic desirability and functional status of the individual must be considered in selecting an appropriate safe method of contraception.

Pregnancy

Some degree of controversy has existed in rehabilitation centers regarding the most appropriate site for delivery of the neurologically disordered woman. There is no question that adequate and comprehensive obstetrical care can be delivered in the general hospital setting, provided consideration of the special needs of the patient are met. Far too many of these women, whether SCI, polio, or myelomeningocele, are offered caesarian section rather than vaginal delivery because of unnecessary anxiety on the part of the obstetrician. The indications for surgical approaches are the same as for able bodied women.

A major concern must be in the prevention of pressure sores during delivery. The pain insensitive woman must not remain in the lithotomy position for periods longer than two hours. Indeed, she should not be brought to the obstetrical amphitheater until delivery is imminent in order to avoid prolonged and unnecessary pressures over boney prominences. Stirrup cuffs should also be sufficiently loose so as to avoid excessive pressure. A 2" foam pillow (or perferably gel) should be placed under the buttocks.

As with the able bodied woman, anesthesia should be held to a minimum, but the pain insensitive patient may be fortunate enough to be able to avoid any anesthetic.

Autonomic dysreflexia has occasionally been reported during delivery, and continual observation is essential. Close monitoring of bladder and bowel must be maintained.

If excessive spasticity is a problem, Diazepam may be administered I.V., keeping in mind its potential depressant effects on the fetus.

The mother and child should not be denied the pleasures and advantages inherent in breast feeding merely because of the mother's disability. Moreover, the convenience of breast feeding for the mother should not be underestimated when compared to the burdensome aspects of preparing sterile formula.

Pulmonary Problems

Sleeping problems are frequently encountered in patients with pulmonary insufficiency secondary to neuromuscular disorders. The administration of sedatives or soporifics

compounds the problem by further depressing respiration. Frequent evaluation of pulmonary function has been mentioned, but must be emphasized at this point. Significant abnormalities should signal the need for blood gas studies. All patients with decreased pulmonary function and their attendants, and family should be taught postural drainage, chest mobilization techniques and the essentials of good bronchial toilet. Breathing exercises should be taught at the rehabilitation center, and daily use encouraged by professionals involved in long-term management. Those patients who are high quadriplegics should learn glossopharyngeal breathing. In the presence of upper respiratory infections, antibiotics should be utilized when necessary, and all measures for reducing the viscosity of sputum should be encouraged early such as increasing fluid intake and the adequate use of expectorants. Steam inhalation is frequently of value. Antihistamines which may thicken secretions should be avoided in pulmonary problems.

Fractures

The osteoporosis which results from the loss of axial loading and resultant loss of stresses of muscle pull predispose the neurologically deprived patient to long bone fractures. An adequate maintenance program should reasonably include some method of obtaining an upright position to retard this process. The concept of weight bearing must be appreciated for its beneficial effect on calcium metabolism, urinary drainage, bowel function, prevention of bladder calculi, prevention of circulatory stasis, and maintenance of muscle tone.

Treatment of long bone fractures must be approached conservatively. Osteomyelitis is a major hazard to open repair. Bracing is generally not advisable in lesions above T-10. Mobilization should be delayed until adequate healing is demonstrated radiographically. If ambulation is not a factor, nonunion may be tolerated.

In fractures of the lower extremities, positioning should be maintained by pillow splints, and casts avoided. If a cast *must* be applied, then it should be bivalved to avoid excessive pressure, and carefully observed during the period of immobilization.

The possibility of spontaneous fracture must be kept in mind in patients with extensor spasticity.

Heterotopic ossification may occur as early as 1 month or as late as 12 months after injury. It is often confused with acute thrombophlebitis when it occurs unilaterally, and accurate differential diagnosis must be made to avoid incorrect treatment. It has not uncommonly been confused with sarcoma when evaluated by x-ray alone. Alkaline phosphatase elevations precede radiographic findings, and should always be determined serially when heterotopic ossification is suspected. When severe enough to cause limitation of function, correct timing for possible surgical intervention should be established using serial radio isotope uptake ratios. The presence of heterotopic ossification is not a contra-indication for passive range of motion, but an indication.

Autonomic Dysreflexia

The one true medical emergency in long-term management of the spinal cord injured patient is autonomic dysreflexia (hyperreflexia). It is found in patients with spinal cord lesions

above the level of the fifth thoracic vertebra. The stimulus may be a distended or spastic bladder, a stool impacted rectum or a locus of irritation in the skin. This stimulus initiates reflex activation of the sympathetic and parasympathetic nervous systems, which if not controlled, can precipitate a cerebral vascular accident and even death.

The patient complains of a pounding headache, nasal stuffiness, sweating of the face, and "goose bumps." He is excessively apprehensive, and demonstrates a bradycardia in the presence of a severe hypertension which may reach levels as high as 300/160.

The patient should immediately be placed in an upright position, to facilitate the pooling of blood by gravity in the lower extremities and abdomen. The bladder should be drained, and if the catheter is found to be plugged, it is irrigated gently with no more than 30 cc of solution. The rectum should be checked for a fecal mass. If present, a topical anesthetic ointment should be instilled to decrease the stimulus, and after symptoms have subsided, the feces removed. If the blood pressure does not decline immediately, parenteral drug therapy should be initiated, such as I.V. Diazepam, followed by a ganglionic blocking agent such as Regitine 5 mg. I.M. if the former is not rapidly effective.

Skin Care

The single most costly complication of the severely disabled remains the pressure sore. The tendency to legitimize this major effect of negligence by applying the title Decubitus Ulcer should be discouraged. The patient will be better served to acknowledge (as will the physician and nurse) that this is indeed a sore resulting from prolonged pressure.

The two major events contributing to its occurrence are prolonged pressure, and sheer forces that produce excessive friction. Prevention demands frequent relief of pressure, requiring turning every two hours while in bed. The patient must be indoctrinated with the importance of elevation in the wheelchair every 20 to 30 minutes. The skin may frequently be damaged by trauma from friction that occurs during transfers. The current availability of pre-washed jeans has apparently eliminated the firm abrasive seams that caused problems in the past. Bedsheets must be kept dry and free of wrinkles.

A host of predisposing factors facilitate the development of pressure sores and general measures for their correction should be instituted. The patient's perineal area must be kept dry and free from maceration. An adequate diet must be maintained, and in the presence of skin breakdown, the caloric intake should be increased above the normal levels, and maintained at about 3000 calories a day. Americans generally take vitamins in frighteningly excessive quantities, and the disabled are no exception, but the case for high doses (2-3 Gm. daily) of ascorbic acid appears to have been clearly established in the promotion of healing. The correction of anemia is a sine qua non in ulcer care.

Any reddened area occurring over a boney prominence that does not blanch with simple pressure must be considered a pressure sore, even without skin breakdown. The immediate care demands removal of all pressure, and the assumption of the prone position, alternating with side lying. Water beds have been much in vogue to reduce pressure. Strong consideration must be given however, to the loss of independent function incurred by the physically disabled on this soft bedding. Additionally, the plastic cover may contribute to undue maceration of skin and further compound the problem. The use of the partially

water-filled air mattress is a far less expensive and more portable means of pressure relief that enables the patient to utilize leverage for full bed independence. Additionally, the vertigo frequently encountered with water beds is eliminated.

Local care of the wound demands adequate aeration. This means the total avoidance of any occlusive medication such as antibiotic ointments, zinc oxide paste, and tincture of benzoin. The use of the latter as a skin toughener is totally without merit.

A simple but effective regime employs half strength hydrogen peroxide wash, followed by the application of povidone-iodine solution, every 4 hours. Deep ulcers frequently require packing with the latter.

The use of karaya powder alone or mixed with povidone-iodine has been of value in infected ulcers in some institutions, and the use of oral zinc therapy is felt to be of occasional value.

Patients must be motivated by the professionals to avoid the development of pressure sores, and it is our responsibility to insure that they are fully indoctrinated with these caveats.

Bowel Care

Although the principles of good bowel care and function are acquired and the client was laxative free before injury, (s)he often has difficulties in this area with the commonest complaint being slow response to suppository. Increased attention to bulk content of the diet is helpful with supplementary metamucil as needed. Enemas should be avoided and the use of glycerine or biscodyl suppositories followed by massage of the abdomen about 20 minutes later in a clockwise direction is beneficial. An attempt should be made to wean the patient from suppositories. Use of a commode chair is recommended to approximate the normal flexed or squatting position. The bowel program should take place at regular and specific hours (generally ½ to 1 hour after a meal to take advantage of the gastrocolic reflex), every other day or twice weekly. In an upper motor neuron disorder mere introduction of a gloved, well lubricated finger into the rectum with a circular motion may set off reflex bowel evacuation as well as reflex bladder emptying. Simple stretching of the anal sphincter can cause satisfactory peristaltic "rushes" with evacuation in some people.

In the rare instance when an enema becomes necessary, small amounts of fluid should be used, and the practice of securing the catheter in the rectum by means of an inflated foley bag should be condemned as intestinal rupture with subsequent serious complications is all too common, due to the inability of the intestine to expel the balloon in a peristaltic rush. In an enema, the catheter should only be inserted past the external sphincter and the fluid held no higher than 18 inches. Because of the need to maintain enema-free bowel balance, laxatives and enemas should not be ordered before IVPs and *only* before major surgery. Diarrhea caused by dietary indiscretions is usually self limiting within 4-6 hours. Useful in controlling diarrhea are lomotil, or bismuth and paregoric for 2 to 4 doses. Hemorrhoids can cause bouts of autonomic dysreflexion and should be looked for. Often they can be treated by anusol suppositories, careful attention to diet, and temporary discontinuance of digital evacuations. Relief of temporary constipation may be accomplished by increasing the dosage of stool softeners such as DSS (colace, surfak, softon, etc.) 1-4 capsules daily, Mondane 1-2 tables 4-8 hours before retiring, and metamucil, 1-2 tablespoons in fruit juice daily to provide needed bulk quickly. Attention to diet can frequently resolve most minor bowel problems.

Conclusion

The ongoing medical needs of the disabled in the period starting with discharge from the rehab facility and tapering off when full and competent involvement and participation in all life activities is reached can best be met by community based centers which offer diverse services in a non-medical setting. Those services which may be called "medical" are concerned with the prevention of illness and hospitalization together with enhancement of self-confidence, high competency in self-care technics, increase in energy levels, and continuing education in new and relevant medical advances. The model for this type of facility is the Center for Independent Living which, among other things, offers a diversity of necessary services in a warm and welcoming atmosphere. In the socialization process inherent in such a center, much can be dealt with at low-voltage levels which would otherwise be ignored or met with later as acute medical problems.

Health care teaching for the disabled should include categories of skin, bladder, bowel, respiratory, nutrition and obesity, spasticity, emergencies, monitoring vital signs, facts about supplies and equipment, communicable diseases including poison oak, VD, etc., using medical facilities and resources effectively, and costs and medical consumerism, among others. The professionals who work with peer health counselors should keep in mind the "seeding" effect and the need for propagation of this system in an expanding pattern for which the peer health counselors will be among the chief agents.

In addition to direct counseling and the establishment of peer health counselors, a system of teaching and training for non-professionals (attendant, aides, families, etc.) in home nursing skills and rehab principles should be instituted.

A third goal of such a comprehensive plan should be the establishment of "half-way" houses based on the Cowell Residence Program but not restricted to U.C. students or other "affinity" groupings. Such living systems offer maximum exposure to peer training and positive role models, plus low-key, steady professional input, and should have a specific time limit on periods of residency in order to have maximum beneficial impact.

Although experience is said to be the best teacher, it is certainly the most expensive and painful. The ability and opportunity to learn from others and to share one's own first-hand knowledge is surely as valuable and indeed, worth full inclusion in any on-going rehabilitation system. Among others, this concept provides one of the most sturdy underpinnings for the C.I.L.

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THE THREE R's OF DISABLED CONSUMERISM

Daniel A. Poling II

I. Preface

This paper is being written for a two-fold purpose. First, it is being written for a conference at the Center for Independent Living in Berkeley, California. This conference will be composed of a select group of professionals and consumers and will discuss the various problematic aspects of independent living which are confronted by severely disabled people.

Second, it is being written for the American Coalition of Citizens with Disabilities, Inc. ACCD is a brand new national organization which attempts to include consumers with all types of disabilities. It is experiencing growing pains and finds itself in need of developing both a basic code of ethics and a basic philosophy. It is hoped that this document will provide a foundation for this philosophical endeavor.

II. Introduction: My Philosophical Orientation

In order for you to know where I am coming from in this document, you must have some understanding of my basic philosophical orientation. I am a trained sociologist and, furthermore, a sociologist from the Functional School. Therefore, in order to understand me, you must understand something about Functional Sociology.

Functional Sociology views society as a gigantic system made up of many sub-components, sub-systems and sub-units. We believe that society is analogous to a human body or any other living organism. The smallest societal unit is the individual man, woman or child. For a society to be healthy, each sub-unit must contribute to the welfare of the whole. Hence, a pluralistic society, such as our own American Society, is one that is diverse, fluid and flexible. In return, a healthy society is capable of nurturing and developing the potential of its smallest unit; the individual man, woman and child. Thus, Functionalism implies a spiraling effect, either of growth or decline. In spiraling growth, all of the societal sub-units contribute to the whole; in turn, the whole society benefits its smallest sub-unit—namely, the individual. Conversely, in spiraling decline, the societal sub-units cease to contribute to the whole; resultantly, the whole is unable to continue to nurture the individual. Therefore, a society is analogous to a human body or any other organism; the whole is only as healthy as its smallest parts—namely, its individual cells. As, in the words of John Donne,

> Any man's death diminishes me, for I am
> involved in mankind . . .
> Any imposed restriction on one individual
> restricts each of us,
> for we are both singularly and collectively
> part of mankind.

I also believe in a modified version of Social Darwinism. I believe that both man and his society—our society—is evolving and not devolving. Within this evolution, there is a hydraulic process in which changes, improvements, or advances within one segment of society directly produce all cause, changes, improvements, or advances within another segment of society. Hence, the disabled minority was literally created by the continued advance of medical science. It has only been in existence 25 to 50 years. Because the disabled minority is brand new, it is like a precious gem which is still in the rough; it needs to be polished, refined and sophisticated.

In addition, even as all other human beings, the disabled individuals have the right to develop their potential to the maximum. However, before this can be achieved, not only must society recognize its responsibility to the disabled individual, but, also, the disabled individual must recognize his or her responsibility to society.

Finally, due to this sociological orientation, I am in disagreement with the phraseology, "The Art of Independent Living." In the first place, it is not as an art, but rather, it is a science—or, to be more precise, it is a behavioral science. True, an essential ingredient of both art and science is creative imagination; however, that is where the similarity stops. Every work of art is unique and cannot be reproduced, whereas, a science is governed by laws and therefore involved explanations, predictions, and ultimate control. Because science has the potential of controlling a situation, it also has the potential of reproducing the situation.

In the second place, even as a disabled person does not want to be forced into "dependent" living, so in reality he or she would not want to be forced into total "independent" living. For, complete independent living means total isolation and exclusion from society. All human beings—disabled or non-disabled—must function vis-a-vis society; no man is an island, no man can stand alone! In order for disabled people to live productive and fulfilled lives, they must integrate themselves into society in total. Therefore, in this paper I will be addressing the subject, the behavioral science of interdependent and integrated living of disabled individuals.

III. The Nomenclature and the Social Evolutionary Process

Language is one of the most effective ways for man to communicate. By studying specific words and the mental concepts that those words represent, we can gain insight into the entire evolutionary process that society is undergoing. For example, within the last hundred years, the black minority has undergone a tremendous transformation and upgrading. During this process, the words referring to a member of the black minority underwent corresponding changes. First, the word "slave"; then, it was "nigger"; next, it was "negro"; finally, the word has evolved to "a black human being."

We can trace the same type of social evolutionary process within the disabled minority by briefly noting the succession of words that have been used to denote its members. Probably, the first word to be used was "patient." "Patient" is a derivative of the latin, *passion,* and means "the suffering or the enduring of pain, trouble, or evil, with calmness and compusure." If one reflects upon this definition for a moment, one might stop to ask oneself how in hell can a human being endure pain, trouble, or evil, while remaining calm and composed. As I express in my book, *To Be Human is to Continually Strive to Better One's Lot in Life,* when one is continually striving, it is absolutely impossible for one to remain calm and composed. Consequently, there is a basic contradiction within this definition and the only way to resolve this contradiction is to literally de-humanize the patient. If a patient is void of all human feelings, then of course he can remain calm and composed—even in the face of pain, trouble, or being evil.

Clinton Hilliard, who has Cerebral Palsy and who is a specialist in speech pathology, best summed up this de-humanization in a description of his own birth:

> "It" was born, and I say "it" as "it" needed to be differentiated from the usual he or she that might have been born on March 16, 1927. "It" needs further differentiating as "it" was blue resulting from the then little known RH factor and "it's" skull was all distorted due to the use of forceps, both factors contributing to the resulting "it." The doctors being sure "it" would not survive since "it" could not swallow and hardly breathe at all, gave "it" little chance for survival. The parents were advised to ignore "it" and let "it" go back to "it's" maker and this they were advised as late as 11 years of age, only the methods of termination were changed with age.

The next term to come upon the evolutionary scene was "client." This is the term used by most providers of rehabilitation services. The word, "client," is a derivative of the Latin, *cliens,* meaning follower or one who leans on another for protection. In ancient Rome a client was a plebian under the patronage of a patrician, in this relation called a patron, who was bound, in return for certain services, to protect his client's life and interests. Obviously, this renders the disabled person an extremely dependent posture. The term possesses the danger of misleading both the disabled person and the service provider into thinking that the disabled person requires so much protection that he is incapable of making any decisions on his own.

The latest term to evolve is "consumer." "Consumer" is a derivative of the Latin, *consumare,* and means a person who buys goods or services for his own needs and not for resale. Referring to a person as a consumer automatically places that person vis-a-vis the producer or the provider. In general, consumerism is the effort to equalize the rights, access to information, and power of the buyer with those of the seller. "Consumer protection," says consumer advocate Bess Myerson, "is economic justice based on moral law."

Thus, by denoting a disabled person as a consumer ipso facto acknowledges that that individual possesses certain powers and specific rights. Yet, what do we mean when we place the adjective "disabled" in front of the noun "consumer"? What is a "disabled consumer"? In a report the Urban Institute defines "disability" in terms of functional limitations. Therefore, we may assume that a disabled consumer is a person who is seeking to purchase those goods and services that will improve his functioning within society.

We may further assume that, within the societal market place, a disabled consumer is no different from any other consumers. A disabled consumer must engage in competitive transactions. In any transaction there is a quid pro quo flow of social interaction. That is, just like any other consumer, the disabled person must give something in return. The things which a disabled person may offer in a social transaction, we may call "his or her responsibilities." The things which a disabled person may receive in a social transaction, we may call "his or her rights." Furthermore, a disabled person is free to use his or her creative imagination in negotiating or bargaining. That is, a disabled person can create new responsibilities in exchange for receiving new rights. This creative imagination of a disabled person we will call one's *repertoire.*

This document, then, is about the rights, the responsibilities and the repertoire of consumerism; or, in short, the 3 R's of disabled consumerism.

IV. The Rights of Disabled Consumerism

Before proceeding further, let us stop and define precisely what is meant by the word "right." The *Dictionary of American Politics* states that a right is a claim, entitlement, privilege, or prerogative which has been conferred upon a group or person by heredity, usage, or law. A legal right may be vindicated or protected in the courts.

Furthermore, the *Dictionary of Sociology* states that a right is that which any social unit, individual, or group, is entitled to expect from its environment in accordance with the norms of that society. Philosophically or ethically, the term is often used to apply to benefits or privileges which the individual or group feels that it ought to receive from society or from the world at large. Sociologically, rights have reality only as they are guaranteed and will be enforced by some social agent. All practical rights are socially conferred and socially guaranteed and have no existence beyond the extent to which they will be socially supported.

Basic human civil rights are shared by all individuals—disabled and non-disabled alike. What are these basic rights of any human being? Dr. Carl Rogers, the famous psychoanalyst, states, "the organism has one basic tendency and striving—to actualize, maintain, and enhance the experiencing organism."

The organism actualizes itself along the lines laid down by heredity. It becomes more differentiated, more expanded, more autonomous, and more socialized as it matures. This basic tendency of growth—to actualize and expand oneself—is seen to best advantage when an individual is observed over a long period of time. There is a forward movement in the life of every person; it is this ongoing tendency which is the only force that the therapist can really rely upon to effect an improvement in the client.

The right of each and every human being, then, is to have the privilege or the prerogative to grow, to mature, and to be fulfilled. It was with this growth motif in mind that Adler devolved the concept of the creative self. To Adler, the creative self is the first cause. It intervenes or mediates between stimuli and responses. The doctrine of the creative self asserts that men made their own personality out of the raw materials of heredity and environment.

> Heredity only endows him with certain abilities. Environment only gives him certain impressions. These abilities and impressions, and the manner in which he "experiences" them—that is to say, the interpretation he makes of these experiences—are the bricks which he uses in his own creative way in building up his attitude toward life. It is his individual way of using these bricks, or in other words his attitude toward life, which determines this relationship to the outside world.
>
> Lindzey Hall, *Theories of Personality*

Society has protected man's right to grow throughout its evolution. For example, the Declaration of Independence states:

> We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness . . .

Almost two hundred years later, this same basic principle was still being reiterated as the fundamental corner stone of our American Society! For, in 1960, the President's Commission on National Goals proclaimed:

> The status of the individual must remain our primary concern. All our institutions—political, social, and economic—must further enhance the dignity of the individual, promote the maximum development of his capabilities, stimulate their responsive exercise, and widen the range and effectiveness for individual choice.

This political line of reason also has solid support within the ranks of the behavioral scientists. For example, in 1965, the noted psychologist, John W. Gardner, in his book, *Self-Renewal,* posed this line of reasoning in these terms:

> As far as adults are concerned, it is not certain whether anything can be done to supply creativity that is not already present. But much can be done to release the potential that is there. It is the almost universal testimony of people who possess this trait that certain kinds of environments smother their creative impulses and other kinds permit the release of these impulses. The society interested in continuous renewal will strive to be a hospitable environment for the release of creativity.

Although the above quotations refer primarily to able-bodied individuals, this same right to grow and to mature belongs to the forty million disabled within this nation. On the 8th of October, 1973, at the International Conference on "Models of Service for the Multi-Handicapped Adult," Ms. Anna Maris Mulligan delivered a paper. Ms. Mulligan is a staff member of the Division of Social and Preventive Psychiatry, Nebraska Psychiatric Institute in Omaha. Ms. Mulligan stated:

> Normalization is the utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible. More simply put, we could say that the "Principles of Normalization" provide the handicapped individual with the means and opportunities for achieving a lifestyle that is as normal as possible.

Ms. Mulligan then went on to explain another precept which is interrelated to the concept of normalization. This precept is that of socially integrative opportunities. A socially

integrative opportunity is a situation within the community in which a severely handicapped adult has a chance, on a regular basis, to interact with non-handicapped adults. In fact, in many respects, this concept of Mulligan's is similar to Gardner's hospitable environment. According to Mulligan, it is society's responsibility to be a creative pioneer in generating these types of situations!

Therefore, in order for disabled people to enjoy the right of growth and maturity, they must be integrated into society. I used to do social work in the ghettos of Washington Heights and Harlem in New York City. In fund raising, one of my favorite quotes was that of the brilliant educator Max Lerner. Lerner once was asked to summarize in a single word the keystone of American development. He answered, "Access." Lerner went on to define what he meant by access. "By this, I mean access to economic opportunity, access to social mobility, access to geographic movement, access to political participation. Most important of all, perhaps, would be access to educational opportunity."

Lerner was speaking about social access. Social access is denied to all minorities before they become integrated into society. This is what I mean when I speak of the rights of disabled consumerism. I mean the right to live a relatively normal life in spite of one's disability. I mean the right to function as an equal of a non-disabled person. I mean the right to be creative and imaginative.

V. The Status and the Consequences of the Disabled being a Minority

However, before we can start demanding rights for the disabled, we must be sure that we know about whom we are precisely speaking. Fifty years ago there was no such thing as an aggregate of disabled individuals. Now that the social evolution has produced them, who are these individuals, and what type of group do they consider?

In her book, *The Sociology and Social Psychology of Disability and Rehabilitation,* Constantina Safilios-Rothschild discusses the question of whether or not the disabled minority can be legitimately considered a minority. There are certain similarities and certain dissimilarities between the collectivity of disabled people and other minorities. Each of these two categories will be examined below, and then conclusions will be drawn as to whether in fact this disabled collectivity does or does not constitute a minority.

Regarding the similarities:

This disabled collectivity is considered deviant, is segregated from the non-disabled, and occupies a *separate* and isolated social position within the general society. This segregation implies that the non-handicapped population segment considers the disabled collectivity as being inferior. Hence, segregation is the means by which the non-handicapped keep their social (and even territorial) distance from the disabled collectivity. This segregation is rationalized as being beneficial to the disabled. They are happier interacting with other handicapped individuals. The disabled tend to be evaluated according to their group characteristic rather than their individual attributes. This characteristic of group membership is "being disabled" and leads to ipso facto prejudice.

In regard to the dissimilarities:

There is no clear-cut dichotomy between disabled and non-disabled; in fact, almost every person is at least partially handicapped at one time of his life or another. The disabled minority does not constitute a homogeneous group itself. Its members are as varied in their attributes as are the members of its parent society. There are some subtle differences between discrimination between other minorities and the disabled. In the case of the disabled (as well as the old and women), discrimination is often camouflaged by protective legislation and is rationalized on the basis of biological and physiological limitations and weaknesses. The disabled collectivity does not self-perpetuate its own membership, nor does it perpetuate its own values and norms. Rather, its membership—as well as its values and norms—are determined by the general society.

Rothschild concludes (and I agree with her) that the general aggregate of disabled people can indeed be considered as a minority. Rothschild further states that the phenomenon of the disabled minority can be explained in terms of "the general series of deviance." "Rehabilitation," then, becomes an institution of social control, and sometimes it has a conflicting social role. On the one hand, it must help the disabled overcome those aspects of their condition that are considered deviant. On the other hand, however, it socializes the disabled to play the proper role of deviant.

There is a great deal of stigmatizing and stereotyping of disabled people by the non-disabled public. Because of this stereotyping and stigmatizing, a great amount of social distance is placed between these two societal segments. In fact, it is justified to state that, even as the black minority has been placed in urban ghettos, so the disabled minority have been placed in ghettos of ignorance and outright stupidity.

In its major research report, *Youth in the Ghetto* (1964), Haryou characterized the state of the Harlem Ghetto in the following manner:

> Ghettos in contemporary America may be defined primarily in terms of racial and color-determined restrictions on freedom of choice and freedom of movement. Ghettos are the consequence of the *imposition of external power* and *the institutionalization of powerlessness.* In this respect, they are in fact social, political, educational, and—above all—economic colonies. Those confined within the ghetto walls are subject people. They are the victims of greed, cruelty, insensitivity, guilt, and fear of their masters. The concrete indications of the powerless aspect of the American urban ghettos are to be found in deteriorated housing, overcrowdedness, infant mortality, and high disease rates. The psychological dimensions of the ghetto clearly related to, determined and reinforced by objective characteristics, involve patterns of general hostility, random aggressiveness, despair, apathy, a cursory grandiosity and posturing.

The critical two things regarding any ghetto or imprisoned minority are the imposition of power from without and the internalization of power from within. We are all familiar with the type of imposition of power from without regarding the disabled minority—that is, architectural barriers, job discrimination, and adequate housing, and so on. In other words, imposition of power from without is depriving the disabled minority of their human and civil rights. As serious as the problem of imposition of power is, I am even more concerned with the problem of the institutionalization of powerlessness from within.

By "the institutionalization of powerlessness from within," I mean that disabled people start to actually believe the stereotyping and stigmatizing of the general public. They place the self-fulfilling prophecy into operation. To be blunt, since they let themselves believe they are nothing but shit, they actually turn into a pile of shit. In other words, they themselves become their own worst enemy. The psychologist, G. W. Allport, describes a number of ego defenses which the disabled have developed. A few of these are:

Obsessive Concern: Hypersensitiveness
Denial of Membership: Rejecting their Disabled Status
Withdrawal and Passivity
Identification with Dominant Group:
Self-hatred & Feelings of Inferiority
Prejudice toward Own Group
Fighting Back: Militancy against Out-Group
Strengthening In-Group Ties:
Developing an *esprit de corps*
Enhance Striving towards the Norms
Symbolic Status Striving:
i.e., Compensation by Substitution
Self-Fulfilling Prophecy

VI. The Disabled Minority Needs An Active Advocate

At this stage of the evolutionary process within society, the disabled minority is in need of a leadership group that will be interposed between itself and the rest of society. Such a leadership group would function as an ombudsman, a referee, an advocate, or a mediator. This leadership group would attack both the imposition of power from without and the institutionalization of powerlessness from within. It would lobby on behalf of the disabled; for, consumerist Betty Furness points out the important function the government must play: "The consumer can't tell Detroit to build cars that get 20 miles to the gallon, but the government can. When consumers want one thing and business wants another, it's essential for the government to be the arbitrator."

We may define such a leadership group of consumers, as does Zeigler and Peak in their book, *Interest Groups in American Society,* as an organized social aggregate which seeks political goods that it is incapable of providing for itself.

Zeigler and Peak go on to explain:

> It is important not to confuse the concepts of group interest and organized association. The former is a shared desire for a particular political good or set of political goods. Organization, on the other hand, is a manifestation of social technology; it is a means by which individuals coordinate their energies and resources toward accomplishing a common objective.

The historical existence of such special interest groups or ombudsmen in America can be traced back even beyond its earliest years as a nation. A hasty perusal of *Federalists* No. 9 and 10 reveals clearly that the founding fathers recognized their existence. Excellent

examples of such organized interest groups are the trade unions. Back in the middle of the 19th century, labor was one of the most exploited segments of our entire population. However, at that time, the unions started to organize on a national scale, until today one might even argue that the unions are too powerful.

At this moment in time, the disabled minority is at the same primitive stage of development as was the labor movement in the mid-1800's. There have been several attempts to organize the forty million disabled people on a national scale. One of the most notable of these attempts has been the Congress of Organizations of the Physical Handicapped. COPH has been in existence for approximately two decades. Its founder and executive director is Elmer Josephs, of the Chicago area. Josephs is a pharmacist by trade. He has tried to organize COPH in his spare time. COPH has suffered from a lack of funds, traveling expenses, and a paid staff. In recent years its membership has been dwindling. It used to have three state councils, but now it has only two. COPH feels that its identity is being threatened by ACCD, and it refuses to join the Coalition on the grounds that it doesn't want to be associated with the mentally retarded.

The most recent and, in my opinion, by far the most exciting attempt at organizing the disabled minority on a national basis is the American Coalition of Citizens with Disabilities, Inc. ACCD is in the second year of its existence and is attempting to incorporate all types of disabled consumers into its structure, including those with mental retardation. ACCD is struggling with all of the many problems that COPH encountered; however, by far the most serious of all problems is that of coping with the acute paranoia and suspicions of its members—both individuals and groups. Disabled people have been exploited for so long that they are literally afraid of trusting anybody, including other members of their own minority. This is what I mean when I say institutionalization of powerlessness. This is what I mean when I say disabled people are their own worse enemies.

In order for ACCD to be successful, its leadership must take the initiative and develop its creative imagination. It must go into the societal market place and actively bargain on behalf of its constituency. We must figure out what we can realistically offer society. We sure as hell know what we want from society. We want our human and civil rights! But do we know what we can offer society in return for these rights? We also must arrive at specific strategies and concrete tactics for securing these rights. Indeed, the final two sections of this paper will be devoted to formulating extremely tentative answers to these two questions.

VII. The "Responsibilities" of the Disabled Minority

Are we, the disabled people of this nation, to consider ourselves and to be considered by others as objects of pity and remorse, as poor little crippled children who hold out little tin cups for a nickle worth of charity? Or, are we mature men of value and words? If we are satisfied to remain the former, then we can remain free-loaders and sponge off society for the rest of our lives. If, however, we are to be transformed into the latter, then we must use our creative imagination to invest ways of becoming creating and productive members of society. If we want to be equal to others in the rights we receive, then we also must be equal to others in the responsibilities that we are willing to contribute to society. We must establish a quid pro quo relationship between society and ourselves. We must be willing to give something in turn for receiving something. We must be willing to exchange a responsibility for a right.

Yet, what is meant by the term responsibility? Responsibility is an answerability or an accountability under social custom or law for the proper performance of actions or duties as well as the consequences of those duties or actions. The *Dictionary of Sociology* further states that the term responsibility implies some degree of comprehension of an act or duty and the deliberate or voluntary carrying out of the act or duty. Responsibility is thus not attributable to the insane or the very young. Nor would it be ascribed to an individual who was coerced into doing something against his/her will.

With the above in mind, what are the responsibilities of the disabled minority? What can our disabled minority contribute to this society? I believe that our contribution can be an awareness of a new social reality or in the words of Rothschild:

> Unless the disabled themselves unite, thus becoming a kind of 'militant' group trying to shape their own destinies according to their own needs and demands, it is difficult to conceptualize the present state of the field as representing a social movement. A militant movement of disabled would try to create a new image of man, that of man with a disability as equally acceptable and 'normal' as man without a disability.. . . .

The image of the disabled *must* be freed from stigmatizing and stereotyping. From the very outset of this nation's history, the focus of American counselors has almost entirely revolved around the Protestant work ethic. The time has come when it would be to the advantage of our entire society to take some of the emphasis off the monetary aspects of life and place greater emphasis on the esthetic quality of living. Further, I believe that the disabled minority can be the pioneers in this esthetic revolution, and this can be the contribution of the disabled minority to our society.

Such an esthetic revolution would require a complete restructuring of our value system. A handicapped person is forced to go through this restructuring of his/her value system in the process of coming to accept his/her disability. In her book, *Physical Disability—A Psychological Approach,* B. Wright describes this process, and it will be instructive for us to briefly review it at this time. "Acceptance" of one's disability is seen as the mid-point in a continuum. One end of this continuum is the futile and vain (useless) attempt to improve the improvable disability, while the other end is total resignation. Acceptance, then, is keeping one's balance between these two extremes.

Dembo and his co-workers developed a theory of "acceptance of loss." Wright has taken this theory and expanded it. The theory involves four types of changes in a person's value system or structure. The four types of changes are: (1) enlarging the scope of values; (2) subordinating physique; (3) containing disability effect; and (4) transforming comparative values into asset values. The four types of value changes are interdependent and will be discussed below.

Regarding the first type of change in the value system: To compensate for any loss—be it the loss of a loved one, a physical ability, or something else—a person must go through a period of mourning. During this mourning period, that person realizes emotionally the existence of other values in addition to the value of the lost item. Values heretofore undiscovered come to the fore. These new and unique values add new meaning to a person's lifestyle, enriching and enhancing it.

Regarding the second change, subordinating the value of the physique: In our culture, physique is supremely valued. A disabled person must, therefore, reorder his/her priorities, so other values will be more important than (surface) appearance and performance.

The third change has to do with containing the psychological spread of the effects of the disability. A disability is often perceived as imposing a wider range of limitations than it actually should. This perceived spread often is transformed into the social reality of the situation. Social reality consists of physique, other physical environmental factors, personality traits, and interpersonal circumstances. (The objective is to limit the disabling symptoms to *only* those portions of the physique which are actually affected and not let them emotionally spread to other unrelated portions of the social reality.)

The final change is by far the most important, and it is contingent upon the first three. This change has to do with transforming a value from a comparative value to a set value. A comparative value is when the evaluation is based upon a comparison with a (social) standard. This comparison is usually made between an item and presumed average, a cultural norm (an ought), or certain formal requirements (i.e., rules for membership into a social club). An asset value is when the evaluation is based upon the qualities inherent in the object of judgement itself. The evaluation is made on how well those intrinsic qualities meet the unique needs and demands of a specific situation. *Asset* values, then, may also be termed intrinsic values or substantive values. Asset values are par excellence of human dignity.

In my opinion, it would enhance the entire society if its basic value system could be restructured in the above fashion. In my opinion, this is what the disabled minority has to offer society in toto. In my opinion, it is the responsibility of the disabled minority to be pioneers and to lead the way in this esthetic revolution.

In the course of social evolution, as a minority is assimilated into its parent society, its basic values are also assimilated, thereby enhancing and enriching the entire societal fabric. As our minority is being assimilated, let us have as our central value the basic dignity and worth of each and every human being. Let's judge each human being on his own unique merits and appreciate him or her for the potential contribution that person can make to society as a whole. Consider, for example, the following letter that I recently received from a young man who is mentally retarded. Also, consider the fact that this young man has been institutionalized all his life and he is just now learning to express himself. Under these conditions, I believe that this simple letter has the same intrinsic beauty as Milton's *Paradise Lost* or Shakespeare's *Hamlet*:

> Dear Mr. Poling:
>
> One of my major problems is last Wednesday I found out my foster mother has breast cancer. It was pretty serious to me, shocking. I went to Denver for the weekend and saw her. I was relieved to see her there where she was in good hands.
>
> Other major problems is getting out of Kelwood. It is a residential care run by the Boulder County Board. I figured I learned all I can learn in Kelwood but I don't have enough money at this point to move out. So I started eight hours doing pots and pans. I get tired of it sometimes doing pots. One major problem I hope to make my goal is to get back as an apprentice as an electricians helper cause I remember the good times in Grand Junction when I climbed up and put the wire through.

> One of my other achievements I want to learn is financing money and doing budgeting better. That's one of the biggest achievements in the outside to make money work in society.
>
> I hate the public service bus system—they stop running Sunday at two and Saturday at seven. I don't know how people can get home from the show. The mayor Pen Tate is trying to get RTD started in Boulder—public service buses are against RTD. They're dirty and not running right and half the time the windows won't open.
>
> I have a problem dating a girl—when I get up or come downstairs she asks if I want to go out. I don't have the money to take her out all the time. And she never pays.
>
> I don't like Kelwood. It's too run down and the rent is too high. I get sick and tired of the rules they've got there. Curfew—being in at ten thirty. Sitting at the table too long when we get through. I don't care for the houseparents—they're not there when you need them and are grouchy and all that. They keep medicine locked up and won't give it to you when you need it. The food should be better and the house should be fixed up. One of the good things they've done was put a sprinkler system in.
>
> Charles Dieterle

VIII. The Repertoire of the Disabled Minority

We have now defined both rights and responsibilities of the disabled minority. We also have demonstrated that the only way that we are ever going to gain our civil and human rights is by developing and offering new and unique responsibilities to society in exchange for these rights. Finally, we have demonstrated that a leadership group of disabled consumers is needed to act as an ombudsman or a mediator in the societal market place. It is extremely necessary for this leadership group to be highly skilled in the art of bargaining and negotiation.

These skills of bargaining and negotiation I refer to as the repertoire of this leadership group. In order to negotiate effectively, this leadership group must possess a large repertoire of bargaining strategies and tactics. The term "repertoire" is derived from the Latin, *repertorium,* and means inventory. However, before we partially enumerate the repertoire needed by ACCD, let us be certain that we understand precisely what ACCD is up against!

The disabled minority is just starting to find its self fulfillment and its self identity. Its dreams and aspirations are just starting to rise. Therefore, at this moment in time, the disabled minority is just about where the black minority was one or two decades ago. In other words, ACCD is sitting on a potential powder keg of dynamite; in the words of one social analyst describing the situation in Harlem 12 years ago:

> Given an increase in the positive self-image of Negro youth, based upon the realities of effective social action and demonstrated social change, there should emerge a solid basis for a new cycle of greater personal and community effectiveness. From this perspective, it can be seen that the closer the Negro community gets to the attainment of its goals—the closer it gets to the removal of the determinants and manifestations of racial exploitation and powerlessness—the more impatient individual Negroes will become for total equality.

> Success in removing some barriers feeds the idea of personal and community effectiveness and provides the strength and the motivation for increased activity. This, in turn, makes the existing barriers even more intolerable. This accelerated impatience and the lowering of the threshold of frustration for remaining inequities, paradoxically, increases the chances of racial tensions and ferment, if not explosions. This level of the cyclic relationship between increased personal effectiveness and successful community action makes careful, thoughtful, and realistic planning starkly imperative if the chances of social chaos are to be reduced.
>
> Haryou, *Youth in the Ghetto* (1964)

Today, at this very moment, a similar critical situation exists within the disabled minority. In order to diffuse this explosive situation and redirect the energies into more constructive channels, ACCD must attack the institutionalization of powerlessness from within and the imposition of power from without. In attacking the institutionalization of powerlessness, the leadership of ACCD must function as role-models. Whereas, in attacking the imposition of external powers, the leadership of ACCD must function as reference individuals. Being role-models and reference individuals are the two major components within the repertoire of disabled consumerism. Each will now be briefly discussed.

As role-models, the leadership of ACCD must be examples of the behavioral types that other disabled people desire to emulate and to copy. Furthermore, the ACCD leadership must conduct themselves in such a way as to overcome the acute paranoia and mistrust of their disabled constituency. One method of doing this is to govern ACCD as democratically as possible.

> In the early part of the twentieth century the initiative, referendum, and recall were introduced in an attempt to curb the influence of big business interests in local and state politics by giving the people a more direct voice in government.
>
> 1. Initiative. The initiative is a device by which a certain percentage of the voters (usually 5 percent) may propose a bill by petition. The proposed bill is then presented to the people for their approval or rejection. If approved, it becomes a law.
>
> 2. Referendum. The referendum, a popular form of the veto power, is a device by which a certain percentage of the voters (usually 5 percent) may petition that a law already passed by the legislature be submitted directly to the people for their approval or rejection.
>
> 3. Recall. The recall, a popular form of impeachment used largely in city government, permits a certain percentage of voters (usually 5 percent) to petition for the recall of an elected official whose services have been unsatisfactory. After the petition has been filed, a special election is held in which the voters decide whether to retain the incumbent in office or to replace him by another candidate for the position.

It is recommended that the Board of Directors of ACCD institute the above procedures. In exchange for this, their disabled constituency would render the Board of Directors of ACCD adequate authority to act decisively, to negotiate and to bargain on their behalf.

In being reference individual to the non-handicapped society, the leadership of ACCD must be examples of what disabled people can do and what they can be, *if and only if* they are

given the human and civil rights of any other citizen. Their emotional and intellectual conduct must be above reproach. Under absolutely no condition must they allow themselves to fall back into the old rut of behaving like spoiled little crippled brats; but rather, they must conduct themselves as fully mature and responsible adults at all times, for all occasions, and even under the most trying of circumstances. This is a large order indeed to fill, and I suggest the following six rules from Christopher News Notes that may serve as guidelines for disabled consumerism when dealing with the non-handicapped society:

1. Complain when necessary; in fact, if it is called for, given them hell. However, always be certain that your criticism is responsible and it can be substantiated with fact.
2. Whenever possible, do comparative shopping. In some communities, service providers offer a duplication of services. Select the one that best meets with your personal needs. Make them aware that you are evaluating them.
3. Know your rights. When you make demands, make those demands as specifically and as concrete as possible. Don't speak in generalities.
4. Give credit where credit is due. Don't be always bitching just because you are frustrated and have nothing to do. Recognize the fact that, even as no one is all right, so no one is all wrong either. Whenever possible, be positive rather than negative; be constructive instead of destructive.
5. Deal honestly. When you make a mistake, simply admit it. Don't be afraid to apologize.
6. Work at your work. When you finally obtain a position of importance, do exactly what you have been telling non-disabled professionals to do. At all costs, do not operate under a double standard: one standard for non-disabled professionals; the other standard for disabled professionals.

IX. Summary and Conclusion

This paper has attempted to address itself to the subject: "The Behavioral Science of Interdependent and Integrated Living of Disabled People." It was pointed out that this subject matter was not an art at all; but rather, it was a calculated science, a science governed by laws and hypotheses. The main objective is to integrate the disabled minority into the main stream of American life. We have defined and elaborated upon the three R's of disabled consumerism: namely, rights, responsibilities, and repertoire. We have attempted to use these concepts in explaining the basic propositions, hypotheses, and laws underlining this behavioral science.

Perhaps one of the most important sections of this paper was the suggestion that the disabled minority assume the moral leadership and be the pioneers in the esthetic revolution of this nation. This would take the disabled minority off the defensive and put them on the offensive. This would give them a positive posture rather than a negative posture. This would give them a mission and purpose in life—something towards which to work and to strive.

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"CRIPS LIB": AN OVERVIEW OF LEGAL ISSUES

Jack Achtenberg

Preface

This piece is meant to survey the recent litigational developments in the field. Many new cases are being filed daily. The problem with this type of article is that it is out-of-date even before it is published. For those who wish to remain up-to-date, the author suggests a subscription to the *Newsletter* of the recently funded *National Center for a Barrier Free Environment.* One can contact them by writing to the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

This article brings together the current legally significant developments regarding the physically disabled, but it does not contain substantial material about the Constitutional protections of the physically disabled. Those wishing a more detailed survey of these possible protections should read "Abroad in the Land: Legal Strategies to Effectuate the Rights of the Physically Disabled," 61 *Georgetown Law Journal,* p. 1501 (1973). A very recent handling of Constitutional rights is found in a publication, "Equal Access to Public Transportation: the Disabled and the Elderly" (December, 1975), by the Public Interest Law Center of Philadelphia, 1315 Walnut St., Phila., Pa. 19107.

Introduction

On July 19, 1974, the *Final Report of Wisconsin's Task Force on Problems of People with Physical Handicaps* was issued. The introduction to the extensive compendium of problem analysis and recommendations began with a quote from William Hazlitt:

> Man is the only animal that laughs and weeps: for he is the only animal that is struck with the difference between what things are and what they ought to be.

The physically disabled are presently second-class citizens. However, they are rebelling against the restraints imposed upon them by society.

Several years ago, the disabled became, in the words of the *Los Angeles Times,* a "pushy new political force." The "Crip Movement" is now expanding from the halls of the legislature to the steps of the courthouse. However, *NOW,* those steps are not going to act as barriers but rather as rampways to social integration.

In the 1960's a political and legal revolution was begun because there was a significant minority population who had to sit at the back of the bus. Today it is realized that a significant minority cannot even get on the bus.

It has been "discovered" that the disabled have been ghettoized and deprived of their humanity. Three years ago most health professionals did not realize that the physically disabled quadriplegic wants to know about his or her sexual potential. Sexuality and severe disability were assumed to be incompatible. They are not.

A few years ago, the author, returning with his attendant from an extended stay in Europe where he was able to visit almost all of the ancient European monuments, was denied the opportunity to *even attempt* to visit the relatively modern state-owned park and castle at San Simeon, California.

A person in a wheelchair may be admitted to a movie theatre. The theatre has seats, drinking fountains and restrooms for the able-bodied. However, if this person is unable to leave the wheelchair, he cannot use on a full and equal basis, these amusement facilities. His access is as completely denied as if the theatre had a sign saying, "Disabled Do Not Enter."

A series of recent law suits indicate that rapid transit districts throughout the country do not realize that narrow doorways and high stairs make it impossible for a person in a wheelchair or with severe mobility difficulties to use rapid transit, thus substantially reducing the individual's opportunity for gainful employment and a productive life.

In July, 1975, one of the first discrimination cases involving the disabled was tried.[1] This was not a case of covert discrimination, but rather it was a case of a theatre manager saying in effect, 'If you are in a wheelchair, I don't want you in here.'

Evolution of Militancy

It is almost impossible to know how many people are affected by discrimination against the disabled. There are several reasons for this phenomenon, not the least of which has been society's attitude of "out of sight, out of mind." This attitude has had two primary effects. The average person, average architect, average engineer, has built and designed for the average. The disabled person has, if his disability is not too extensive, tried to pass as "normal." On the other hand the severely disabled, the quadriplegic, the "high" paraplegic, the cerebral palsied and the epileptic have been substantially excluded from society and have been exposed to sufficient ego-destroying pressures, so that the militancy necessary for demanding legally protected rights has been slow to develop.

In the 1960's, primarily at the behest of vocational rehabilitation and health professionals, a series of laws were passed at both the federal and state levels requiring that certain accommodations and facilities be made accessible to the disabled. To date, the federal government[2] as well as all 50 states and the District of Columbia[3] have passed architectural barrier laws which require various types of newly constructed buildings be made accessible to the disabled and that certain modifications of pre-existing structures be made accessible. Several states, including California[4] and Washington,[5] have passed anti-discrimination statutes and civil rights statutes to insure the rights of the disabled. The federal government has, where federal grants are involved, also passed an anti-discrimination statute.[6]

In the early 1970's the efforts of the health professionals and such disabled groups as the Paralyzed Veterans of America were supplemented and enhanced by strong input from large

numbers of diverse disabled themselves. Spreading out from college campuses the physically disabled have begun to humanize society. The "Crip Lib" movement is afoot. Efforts are being made to integrate the physically disabled into society in every aspect.

The disabled themselves, and those familiar with their plight, are increasing the pressure on the establishment through a myriad of legislative and legal processes. This increasing pressure resulted in the landmark 1973 Vocational Rehabilitation Act and its 1974 Amendments. This Act declared that it was against government policy to allow any person receiving a federal grant to discriminate against the disabled *solely* because of their disability and further required affirmative action hiring policies by those who contract with the government (Sections 503 and 504). The 1970's also witnessed the placing of the disabled under Fair Employment Practices Acts in such states as California (Cal. Labor Code, sections 1413 and 1420).

The 1964 Mass Transit Act stated that all efforts should be made to provide transportation for the disabled. The current tentative regulations indicate, however, that no adequate effort to incorporate facilities for the severely mobility disabled will be made. The Federal Aviation Administration has issued tentative regulations for the transportation of the disabled by commercial airlines. These regulations do not seem to provide adequate facilities for those with severe disabilities. As a result, many consumer groups are contemplating or have begun lawsuits in the area of transportation.

The early 1970's also produced a legislative and legal movement in the mental health field. Legal developments relating to retarded children's education have potential for use by the physically disabled in their effort to obtain educational equality. Numerous cases were brought on behalf of parents and children in such jurisdictions as Pennsylvania[7] and the District of Columbia.[8]

Enforcement Difficulties

The disabled have found that legislation is no panacea. Constant and militant monitoring of enforcement has been necessary. The one element which runs throughout the developments of the 1960's and 1970's is that the laws and regulations which were passed have seen little or no effective enforcement.

The history of the California Architectural Barrier Statutes is indicative of the unwillingness of some governmental officials to live within the spirit of the law. The original California statute dealt with public "buildings" and "facilities" being made accessible to the disabled. Within weeks after the passage of the statute an official in Los Angeles decided that the word "facilities" did not include sidewalks around state buildings. This necessitated a return to the state legislature on two different occasions to have the word "sidewalks" specifically placed within the statute. On another occasion, one of the major building officials of San Francisco simply refused to recognize the passage of the architectural barrier laws as they applied to his city.

The disabled have had a very difficult time enforcing the laws as they exist and in obtaining recognition of their other rights. Why is this? Even when there is statutory authority there has been substantial resistance to effective enforcement. Many people claim that they are

unaware of the laws while others simply do not comply with the laws because they fear it will substantially add to the expense of building construction, or the costs of providing a usable mass transit vehicle. Moreover, until recently, there has been no effective government mechanism to oversee enforcement. The disabled themselves have been unable to bring sufficient pressure to enforce compliance. Most disabled people are poor, often unemployed or under-employed, and until very recently had no coherent organizational support. A classic example of the non-compliance with state-mandated architectural barrier laws is found in the *Smuggler's Inn* case.[9]

In late 1972, Mr. Dick Wooten, who is confined to a wheelchair, went to a restaurant in the outskirts of Sacramento, California. That restaurant had been constructed after the architectural barrier laws became operative. The entrance to the building was surrounded by stairs. The dark and narrow kitchen entrance through which Mr. Wooten was admitted led to a foyer which itself was ringed by stairs. With the help of employees Mr. Wooten, together with his wife, was able to move to a table, although they had to forego a visit to the bar which they had intended. After dinner, Mr. Wooten asked where the restroom facilities were located; he was ushered through the kitchen and employees' locker room area to a restroom used only by employees. The restroom was so small, however, that it was not possible to get the wheelchair and himself within the commode area and still close the door. In full view of all the male and female employees, and with a male employee of the restaurant standing guard at the other end of the hallway, Mr. Wooten attempted to have a normal urination.

As a result of his experience, Mr. Wooten contacted a paralyzed attorney in Los Angeles and asked him to bring suit. This attorney felt it would be better legal strategy to convince the State Attorney General's Office to commence the action because the lawsuit would be most effective if the government agency responsible for enforcing the Architectural Barrier Laws, the County of Sacramento, were forcefully reminded of its responsibility. Although the State Attorney General's Office was not opposed to bringing suit, it took two years for them to find the necessary manpower. Mr. Wooten's position in the State Rehabilitation Department was crucial in motivating this suit. Otherwise, this violation of the laws might never have been effectively challenged.

Why, in the *Smuggler's Inn* case, would Mr. Wooten need to wait for almost three years before effective and continuous legal action was possible? Why was he not able to approach a lawyer who could have taken the case on a contingency basis? Why did he not approach the American Civil Liberties Union? Why would not the average disabled person, who is poor, be able to get legal relief from the Office of Economic Opportunity Legal Aid Foundation (now a federally funded corporation)?

The answers to these questions are not simple. Most private attorneys do not have, at present, the expertise to bring these cases. Many attorneys are reluctant to involve themselves in cases where there is little judicial authority and therefore a substantial likelihood of appeals all the way to the United States Supreme Court. American Civil Liberties Union and Office of Economic Opportunity lawyers also presently lack expertise. Historically, they have been so overworked defending their black, brown and poor clients that they have not recognized the unique problems of the disabled.

Why not simply appeal to the National Center on Law and the Handicapped located at Notre Dame University? Existing limitations have thus far precluded such an appeal. The Center, founded in the early 1970's, has been acting on its own sense of priorities and has placed little emphasis on the physically disabled, the deaf and the blind; rather, it has done most of its precedent-setting work in the area of mental retardation and mental illness. More important, however, is the fact that one center, with but a few lawyers, provides insufficient staff to litigate a problem affecting one-tenth of the nation's population.

Enforcement Through Litigation

While it has been difficult to obtain the help of private attorneys and legal aid societies, it has not been impossible. Beginning in 1972 a series of suits were filed in several different states and the District of Columbia.

The courts were asked to require agencies to whom responsibility had been delegated for enforcing the rights of the handicapped to perform their duty. In these suits, as well as in strictly Civil Rights suits, the judiciary was petitioned to recognize the Constitutional and statutory rights of the disabled.

Architectural Barrier Cases

The first two cases, both in Ohio,[10] brought to vindicate the rights of the disabled were filed to gain access to courthouses. In both instances the lawyering was provided by *pro bono* lawyers (serving the public interest without charge) and law professors. Each case ended in a consent decree. The case of *Friedman v. County of Cuyahoga* involved a city councilman who was unable to use his own office because he was wheelchair confined. The building had flights of stairs but no elevators. The courthouse was built long before the effective date of the Ohio architectural barrier laws and thus the complaint and points and authorities stressed the Constitutional right to inter-state travel. It also claimed that these barriers substantially interfered with the First Amendment right to assemble and to petition the government. The plaintiff also relied on the privileges and immunities clause of the Fourteenth Amendment. The plaintiff was victorious in having the building modified, but no precedent was set for future litigation.

In the District of Columbia an action was commenced by *pro bono* private attorneys to require the newly formed Washington Metropolitan Area Transit Authority (WMTA) to adhere to the Federal Architectural Barrier Law. Transit facilities (stations, platforms, etc.) last for decades; these facilities were being built without compliance with architectural barrier laws. If the project had been built without access, the disabled would have been effectively excluded for generations to come. The defendants argued that the funds needed to make the facility accessible had to be provided by Congress, and since Congress had not done so, it was impermissible to impose upon the WMTA the added costs of building facilities accessible to all. The defendant Transit District contended that Congress' effort to place WMTA non-rolling stock under the Federal Architectural Barrier Law was, therefore, without meaning. However, a federal judge enjoined the further construction of the project. The legislation, combined with substantial pressure from numerous Congressmen and Senators, resulted in Congress voting funds to make the project accessible. This Congressional action rendered further litigation substantially moot. Since the original federal court

decision, however, the judge has had to require that specific stations be actually accessible *before* they were opened to the public. Therefore, the Transit Authority has not been able to complete certain parts of the line and put them into service until actual modifications have been made.

In 1974 a voting booth accessibility case[11] was tried. The argument was that a fundamental Constitutional right was denied a disabled person who could not physically enter a voting booth in order to cast a ballot. The case was argued on the basis of invidious discrimination under the Federal Constitution and statutes, as well as under the California State Constitution, statutes, and California Election Code. The Judge ruled that there was no irrational classification nor was any fundamental right infringed since there was an alternative—an absentee ballot. He did not accept the argument that being forced to vote by absentee ballot deprived the voter of the opportunity to consider late developing facts. The case is on appeal.

Another architectural barrier case concerns the new student union now under construction at San Francisco State University.[13] Under the California State Architectural Barrier Laws all publicly financed buildings must be made accessible to the disabled. In this suit the question is what constitutes "adequate accessibility." Large areas of the uniquely designed student union are completely available to those with mobility problems. However, the two pinnacle towers that flank the building are only accessible at the first level. These towers will contain social, study and meditation rooms. The contention of the plaintiffs is that "accessibility" means *full* accessibility and not "adequate equivalency accessibility." They say that separate but equal is not a viable concept any more.[14] As long as the towers are unique they should be open to all the public, for to deny the disabled full access is to restrict the scope of their activities and their lives. The university administration contends that they have not violated state laws nor state mandates and that they are permitted a substantial amount of flexibility in determining which parts of public buildings should be made accessible.

Although the *San Francisco State Case* has not presently gone to trial, and may never do so, it has already had three noteworthy effects. First, the Federal Housing and Urban Development Department (HUD) has cancelled the tentative loan that was to be given to help finance the student union. This was in direct response to the suit. Secondly, the design architect is being directly sued for not making the building totally accessible to the disabled. Thirdly, the halting of construction has caused a major re-evaluation of construction projects on all campuses of the nineteen-school state college and university system. As one observer ironically put it, the San Francisco suit has caused virtual panic among chancellors, deans and architects on the state college campuses. "They are almost paralyzed with fear."

Discrimination Against the Disabled

In late June, 1975, the *Edwards Theatre* case was tried.[15] This was one of the first recorded "discrimination against the handicapped" cases brought against a private defendant. The case involved an ex-Marine, Marsh, who had become a "high" paraplegic as a result of an auto accident. His disability had led to a state of depression and to a marital breakdown. His parents, in order to cheer him up, decided to take him to a motion picture theatre. Upon

arrival at the theatre he tendered the appropriate fee and at that point he was informed by the manager that unless he could sit in a regular seat he would not be allowed admittance. The manager stated that to allow him to remain in his wheelchair would violate fire regulations and, moreover, there simply was no room for a wheelchair. His parents offered to sit with him in the back of the theatre so that he could be immediately removed in case of emergency. The manager informed them that this was not acceptable. He threatened to call the police if there was any further disturbance. Marsh was so humiliated and outraged by these events that he immediately went into a state of total depression. Although three years have elapsed, he has yet to attend a theatre.

In arguing this case the plaintiff asked for, and received, jury instructions that the disabled are covered under the California general civil rights statutes. This was highly significant for two reasons. After a five year delay, the case of *In re Cox,*[16] on which the judge substantially relied, was finally used to aid the disabled. In that case the California Supreme Court held that the seemingly closed-end state general civil rights statute was not restricted to the categories enumerated therein—race, color, religion, ancestry, or national origin. It also included *any* instances of invidious discrimination by a business establishment. In *Cox* the court found that there was a violation of the plaintiffs' civil rights when two long-haired teenagers were denied access to a retail shopping center *solely* because of their appearance.

The second important aspect of *Edwards* deals with damages. California's Civil Rights Statutes for the Handicapped seemingly provide for reasonable attorney's fees in injunctive actions only when such injunctions are sought to end discriminatory activities under California Civil Code Sections 54 and 54.1 or violations of the Architectural Barrier Laws. The general civil rights statute, the Unruh Act, provides, on the other hand, for claims of plaintiff's "actual damages," as well as $250 penalty damages. By allowing actual damages, the incentive for private attorneys to bring valid suit is greatly increased. This is exemplified in the result of the *Edwards* case.

Although no actual damages were awarded, the result was in favor of the plaintiff. The jury found that there was room in the theatre for the wheelchair, that the claimed violation of the fire ordinance was only a pretense, and by a nine to three vote, decided they would have awarded $90,000 in damages, both compensatory and punitive. However, they refrained from doing so because they concluded that Marsh really wanted an injunction so that, in the future, disabled persons would not be excluded from places of public amusement. They assumed the judge would issue such a decree.

While the jury was deliberating, the judge, in the process of trying the equitable issues, decided there was a present, speedy and adequate remedy at law (damages) and refused to issue the injunction. The members of the jury, upon learning of the judge's decision, were furious.

Mass Transit Cases

> . . . Personal liberty consists in a power of locomotion, of changing situations, or removing one's person to whatever place one's own inclination may direct, without imprisonment or restraint, unless by due course of law.
>
> I.W. Blackstone, Commentaries 231

From the earliest times, it has been recognized that mobility is the key to social integration and job flexibility, and a vital ingredient in a productive and useful life. It is not surprising, therefore, that the second major target area of the disabled has been urban mass transit. The inability to use mass transit affects every aspect of a disabled person's life. Without either a private car or a very expensive van, a mobility-impaired person is often deprived of the opportunity to go to school, to recreate, or to explore job opportunities. Without sufficient education and flexibility in finding housing the disabled person may be relegated to a non-productive life.

In 1973 a suit was filed in New York City to gain accessibility to the facilities and rolling stock of the subway and urban mass transit systems.[17] It is only fitting that the first major transportation suit should be brought in New York. New York City, with only four percent of the population of the United States, accounts for almost thirty percent of the total number of people who use public transportation. The New York suit is partly based on a general constitutional attack on lack of accessibility for the disabled. Unlike some later suits, the New York case asks for retroactive modification as well as improvements in future design capabilities.

In recent months a long series of mass transit cases have been filed. In Seattle, Washington, a state court judge ruled that it was not a violation of Washington State's anti-discrimination law[18] nor of the United States Constitution to fail to provide mass transit facilities for the disabled. Suits have also been brought in California,[19] Hawaii,[20] Maryland,[21] Alabama,[22] Illinois[23] and Texas.[24] By far, the most interesting case is the one filed against the Golden Gate Bridge, Highway and Transit District in California[25] in late 1974. What is particularly interesting about this case is that the judge's memorandum opinion upheld, at the demurrer stage, two of six causes of action. After upholding the plaintiff at the demurrer stage, the judge refused to give a preliminary injunction, but the case is going to trial on the two upheld causes.

It is ironic that the San Francisco Bay area should be the home of one of the major mass transit suits. After ten years of struggle by individuals, provider groups, and handicapped consumers, the Bay Area Rapid Transit System (BART) was made accessible to the disabled. Yet when the disabled arrive in downtown San Francisco they are faced with curbs impossible to negotiate and an inability to use the Mass Transit System. Moreover, the situation is not improved when one comes in from the Marin side of the Bay. For these reasons, a suit was brought against the Golden Gate Bridge, Highway and Transit Authority. This Transit Authority, like many others, recently applied for new buses under the Urban Mass Transit Act of 1964. In that application, no special provisions were made for persons in wheelchairs or who have substantial mobility difficulties because of age, lack of sight, difficulty in hearing or lack of co-ordination. The San Rafael Indoor Sports Club brought a class action to halt purchase of the new buses by the District. The suit was brought with the help of Terry Ross, an attorney who had previous experience in the mental health movement. The grounds for the lawsuit were only tangentially Constitutional; the major thrust of the suit was statutory. First, it was claimed that lack of full accessibility to urban mass transit violated the California Handicapped Civil Rights laws. In his ruling, the state court judge found that this might state a valid cause of action since *active* discrimination by a public entity was not necessary.

Plaintiff's second cause of action was also sustained on demurrer. It was found that California Government Code Section 4500 did not cover this situation. This particular code section states that rapid mass transit system accessibility is not required on *incidental* equipment until such equipment is available from two or more sources. The judge found that the operation of buses is more than *incidental* to the operation of a bridge, highway and transportation district.

The third cause of action involved section 504 of the 1973 Rehabilitation Act. Plaintiff contended that the policy against discrimination found in this Act required that government entities make specific provisions for those in wheelchairs or with severe mobility problems. The court rejected this argument by noting that Section 502, Title 29 U.S.C. 792 mandated the creation of the Architectural and Transportation Barrier Compliance Board. One of the duties of the Board was to consider ways to meet the travel expenses of those who were not able to use mass transit systems. The court interpreted this to mean that Congress did not intend mass transit to be available to everyone, and therefore the severely handicapped could not judicially compel transportation systems to meet their needs under the Act.

Plaintiffs' fourth cause of action was based on policies enunciated in the Urban Mass Transit Act of 1964. The court said that the UMTA only declared a national *policy,* and therefore did not create a cause of action for which relief could be granted.

The Marin judge found as a matter of law that it was not unreasonable to treat the disabled as a separate class under both the California and federal constitutions. He noted that the statutes relied upon for the previous causes of action were specifically designed to promote state action which would afford the disabled special status and protection.

The last point considered by the judge dealt with damages. He found that Section 55 of the California Civil Code only allowed reasonable attorney's fees for injunctive relief. He said that neither Sections 55 nor 54 created a private right of action for *actual* damages. The *Golden Gate Transit* case represents a preliminary, partial victory for the disabled.

Two other mass transit cases illustrate the extremes in the usefulness of litigation to the disabled. A lawsuit, or the threat thereof, can produce social change. This is indicated by the consent decree entered in a Baltimore mass transit action.[26] In this case, the Mass Transit Authority of Baltimore, Maryland, the Department of Transportation for the State of Maryland, and the Federal Urban Mass Transit Administration consented to a memorandum of understanding wherein defendants, in return for plaintiffs' dismissing suit, agreed to modify the 209 new buses by installing hand rails, vertical stanchions and stepwell lights. In addition they agreed to reserve and mark three seats behind the driver in all buses for the elderly and handicapped and to purchase ten new buses specially equipped to accommodate persons confined to wheelchairs.

On the other hand, a right to transit case in the Alabama federal district court[27] was a complete disaster. The Judge ruled that section 16(a) of the Urban Mass Transit Act did not require installation of facilities for those in wheelchairs, provided that *some* effort had been made by the transit authority to make it easier on the *walking* disabled. In this instance, the bus company had included such items as stanchions, grab rails and power assisted doors. In effect the judge's ruling was that a mere *good faith* effort to implement the declared

national policy of aiding the disabled in transportation was sufficient. The judge found that there were no adequate, presently available buses designed for those with severe disability problems, even though medium sized buses are available from several companies. The judge further stated:

> Modern technology has not progressed to the point of doing more for these people than is already being done by B.J.C.T.A. (Birmingham-Jefferson County Transit Authority). In fact under the present state of available bus technology . . . it would seem inherently unreasonable to bring all new bus procurements to a halt while new equipment is being designed, developed, tested, and produced.

The federal judge stated that neither section 504 of the Rehabilitation Act of 1973 nor the equal protection clause of the Federal Constitution were offended by the actions of the Jefferson County transit Authority. The judge reasoned that the statute was not applicable since the Authority did not deny handicapped people access to buses if they were able to get on board with assistance. Therefore, a person was not being denied his rights *solely* by reason of his handicap, and there was thus no need to cut off federal funding. Moreover, in response to the equal protection arguments, the court found that there was no unconstitutional deprivation and discrimination provided that plaintiffs were not being prohibited from riding on the bus, and that any lack of equal access to the bus came rather from defendant's failure to *affirmatively* provide vehicles designed for the disabled.

A major reason for the rash of transportation suits is that the just-announced tentative regulations of the Urban Mass Transportation Administration contain no special provisions for those in wheelchairs, those who cannot get through narrow front doors or those who cannot use high steps.[28]

Another instance in which a federal agency has not made adequate provisions through rule-making for the disabled is found in the airline situation. At the present time the Federal Aviation Administration (FAA) has still not issued permanent provisions that impose a duty on all interstate airlines to serve the severely disabled.

Therefore, airlines' pilots and officers have had extensive discretion in determining whether to allow the disabled on airplanes. The theory behind this discretion is that the disabled are more likely to be hurt in a crash or will take up the valuable time of flight personnel in an emergency. This first theory disregards the disabled person's own willingness to take the risk of such danger. Each airline has instituted its own policy. This led to a famous incident in which an aide to a United States Senator was forcibly ejected from an airplane and then arrested because she was in a wheelchair, and possessed no doctor's certificate stating that she could care for herself. She filed suit claiming discrimination and false arrest.[29] This suit has been dismissed at least temporarily, because the federal judge ruled that the Civil Aeronautics Board had primary jurisdiction and that all administrative remedies had not been exhausted.

In terms of future litigation, the new proposed federal regulations may not improve the situation greatly. Under the proposed regulations, only as many disabled persons as there are emergency exits will be allowed on any flight. No disabled person will be allowed to sit near an emergency exit. Only one person confined to a litter and accompanied by an attendant

will be allowed on each plane. Another drawback of the proposed regulations is its definition of a handicapped person as "a person who may need the assistance of another person to expeditiously move to an exit in the event of an emergency evacuation."[30] As stated by Senator Tunney, this definition is "so vague and general that anyone from one's grandmother to a skier with a sprained ankle could be classed as handicapped."[31]

Education Cases

Several decades ago most states made no provision for educating the orthopedically disabled or the retarded. Then through a series of campaigns by such organizations as The Easter Seal Society and by parents themselves, a series of laws were passed which required educational programs for these persons.[32] However, in many instances these educational "advances" have resulted in "handicapped ghettos." Students often arise at 5:00 a.m. in order to be bused fifty, sixty, even seventy miles to attend school in centrally located, specially adapted institutions. In order to avoid the expense of modifying the architectural plans of local schools, many districts have decided to bus students with all types of disabilities to such special schools. Some students, of course, need intensive and constant care so that there is no practical way to integrate them into the normal school population. However, for others who are less severely disabled and only confined to wheelchairs or who have balance problems, yet are of normal or superior intelligence, this refusal to adapt the educational environment to their requirements has resulted in social and intellectual isolation.

Although there are presently no cases directly on the issue of "appropriate education" for the orthopedically disabled, analogies can be drawn to cases found in relation to the mentally retarded and the deaf. In the case of *Mills v. Board of Education,*[33] it was specifically found that the constitution required that exceptional children be publicly educated. Of course to say that one must be educated is not to say one must be educated in a certain environment. However, the implications of the black school integration cases and the federal policy of integration for the disabled would seem to be clear. A physically impaired child would presumably learn better, have less stigma, and be better socially adjusted to ultimate employment and community life if he were not exclusively in the company of those similarly situated. Just as it has been necessary that blacks come into contact with whites so that the white population may adjust to living with minorities, it is valuable for the future co-employee of the disabled person to meet him first at the childhood rather than at the adult level.

Two potential cases dealing with the educational problems of the deaf[34] also raise the issue of segregation versus integration. In the potential Utah case, it will be contended that deaf students, who must communicate in sign language, should not be put in a totally different educational tract or totally segregated from those who use the normal verbal tract. At present, the students are not even allowed to mingle at lunch time or in after-school activities. In Ohio, a legal action may evolve because of a state statute[35] which says that all students must begin school in a verbal modality. The statute also requires a testing program after the first year. However, this testing program has never been fully funded and, as a result, many deaf or partially deaf students have lost educational opportunities or have become so frustrated that they have left school.

Employment

In an earlier age the only purpose of rehabilitation was preparation for the job market.

Although there is language in the 1973 Vocational Rehabilitation Act and the 1974 Amendments thereto, recognizing the need for providing services for those with non-vocational goals, even today it is easier to justify architectural barrier modifications and special admissions procedures to schools and universities if put in terms of improved job placement opportunities. There is more resistance to these programs for the disabled when one speaks of them merely in terms of "improving the quality of life."

Many states have included the disabled under their Fair Employment Practices Acts. Many of these state statutes are so recent that there are no regulations or criteria for determining when disability in fact disqualifies someone from employment.

In the first nine months during which they were covered under the California Fair Employment Practices Act, the disabled initiated about eight percent of the complaints filed (212 out of 3110).[36] The settlement rate on these cases (44 percent) was seventeen percent higher than in all other unlawful discrimination cases. The handicapped who initiated these actions included those with limited vision, mild epilepsy, heart conditions, very severe back problems, and hearing deficiencies.

The administrative mechanism provided by the California Fair Employment Practices Commission is preferable to the situation that existed prior to the Act's coverage of the disabled. For example, before such coverage, well qualified people who were confined to wheelchairs or had difficulty standing for extended periods of time were summarily denied teaching jobs. It was necessary for disabled to go to the state legislature to lobby so that the qualified disabled could obtain teaching positions. It is a sad commentary that in the year 1974 a law must be passed which mandates that no person is to be denied the right to receive training or to practice teaching in any school *solely* because of his physical handicap or physical deformity.[37]

Even with these laws, substantial difficulties remain. For example, a co-ordinator of handicapped services at Los Angeles Valley Junior College[38] found it necessary to threaten to obtain the opinion of the Junior College's attorney to convince the Board of Trustees to allow him to hire a deaf, somewhat spastic office manager and secretary.

The 1973 Vocational Rehabilitation Act requires that those who contract with the Federal government must initiate affirmative action hiring policies. The first set of regulations were vague.[39] Many institutions, such as the Bank of America, began to develop their affirmative action hiring policy for the disabled without much assurance that their efforts would conform to the Federal regulations.[40]

In August, 1975, the Employment Standards Administration of the Department of Labor issued proposed permanent regulations.[41] These regulations are meant to provide government contractors with more detailed guidelines as well as to make the new affirmative action hiring and promotion policies conform to the broader definition of "handicap" found in the 1974 Amendments to the 1973 Act.

There is, at present, a lack of legal precedent and a dearth of authoritatively interpreted regulations at both the federal and state level. This, combined with the fact that contested

cases heard before Fair Employment Practices Commissions may take from nine months to three years before final disposition, indicates a substantial need for "watch dog" legal aid societies. Their function would be to protect the employment rights of the disabled, and to furnish input into the administrative process.

Critical Need for Ongoing Legal Expertise

Constitutional theories, case law and arguments for more stringent enforcement of presently existing laws have been around for many years. Because the disabled have long had to rely upon over-worked legal aid societies and *pro bono* time donated by socially interested attorneys, court actions have been minimal. However, times are changing. The disabled are developing a series of organizations to bring continuous legal expertise to bear.

A year ago a pilot project was begun in Philadelphia, Pennsylvania, which has resulted in the formation of a legal aid society for the elderly and disabled. On June 1, 1975, the final formation of that society was assured through a series of private grants and the financial backing of the Pennsylvania Rehabilitation Department. The head of the project, Thomas Gilhool, represented the plaintiff in one of the most famous of the mentally retarded children's education cases.[42]

In Michigan, and again at George Washington University in Washington, D.C., funding has been obtained to carry out legal projects and to institute law suits on behalf of the deaf. The National Center for Law and the Handicapped has indicated that it will soon change its emphasis from the legal problems of the retarded to those of the physically impaired.

In California there have been several developments. The San Francisco Bar Association has been approached for funding for a legal aid society for the disabled and mentally-incompetent, and the Disabled Peoples Legal Resource Center has been founded in Berkeley. This Berkeley project, still embryonic, has concentrated so far on individual case counseling at the paralegal level.

In Los Angeles, the A. Milton Miller Memorial Foundation has been funded to conduct a feasibility study for the State Department of Rehabilitation. The hoped-for result of that study will be an advocacy organization named the Western Center on Law and the Handicapped.

It is logical that legal aid societies for the disabled should develop in several states and that one of the first legal aid societies should be in California. California has over twenty million people. Its better-than-average weather combined with its reputation as a land of opportunity would lead one to believe that a disproportionately high number of the disabled live within its borders. Added to this, the Golden State has a well-developed network of private associations serving the handicapped. Recently, these associations have been joined by "consumer groups" such as the Disabled Student Unions found on each of the nineteen state college campuses. The mental health system in California, as well as the state hospital system for the mentally ill, has been very progressive and its precedents and ideas (such as California's highly developed community treatment system for the mentally ill) will provide analogies for legal actions affecting the physically disabled.

The California state court system is widely reputed to be the most progressive in the nation, making it possible to obtain for the disabled significant progress through judicial decisions. This is particularly important at a time when the attitude of the United States Supreme Court towards the rights of minorities is in substantial doubt.

California has been ahead of most states in legislating for the disabled. Enforcement, however, has been sporadic. A legal aid society is needed to help set forth enforcement criteria which presumably will be widely initiated throughout the country.

The San Francisco and Los Angeles Bar Associations have shown substantial interest in the rights of the physically disabled. The law schools at the University of Southern California, the University of California at Berkeley, University of Santa Clara, Golden Gate University and University of San Fernando Valley College of Law have expressed interest in a seminar on rights of the disabled. These institutions may well act as a valuable resource and the Center may well provide a valuable training ground for law students. Moreover, the School of Social Welfare and School of Gerontology at the University of Southern California are interested in the project.

The most important justification for any legal aid society is that it may prevent litigation and the waste of many resources. Never again will a building official of a major California city feel justified in saying, in a flippant manner, that the disabled should sue him if they don't like the way he is enforcing the architectural barrier laws.

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3. *President's Committee on Employment of the Handicapped, Analysis of Collected Data on Legislation and Standards of 50 States and the District of Columbia Concerning Laws Requiring That Buildings and Facilities be Accessible to Handicapped Persons (June 1975).* The study sets forth a chart delineating those states which have provisions for accessibility in publicly financed, publicly used and privately financed buildings. A more detailed analysis, including a notation to the relevant state code sections, is available in the latest edition of *President's Committee on the Handicapped, A Survey of State Laws to Remove Barriers,* Washington, D.C. 20210.
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24. *Might v. Briscoe,* Civil No. A 75 CA 31 (W.D.Tex. April 15, 1975).
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26. Supra, note 21.
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28. The tentative regulations are found at 40 Fed. Reg. 8314 (1975). According to an interview with Ms. Diane Bartols, law student intern and employee on Handicapped Affairs for the Southern California Association of Governments, in Los Angeles, California, September 5, 1975, the final regulations will not be issued until some time in late December.
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30. The proposed F.A.A. regulations are found in 39 Fed. Reg. 24667, 24668-69 (1974).
31. The remarks of Senator Tunney are found in Heumann, "Flying Not So High," pt. II, 2, *The Independent* 2-4 (house organ for Berkeley's Center for Independent Living) (1975).
32. E.G., *Cal. Educ. Code* Sections 895.4, 895.5 (West 1969).
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35. *Ohio Rev. Code* Sections 3323.06 (1973).
36. *Governor's Committee on Employment of the Handicapped,* Dept. of Industrial Relations, Div. of Fair Employment Practices, State of California, *News From FEPC* (May 7, 1975).
37. *Cal. Educ. Code* Sections 13168.1-2 (West 1974).
38. Interview with George Kopoulos, Coordinator for the Handicapped Student Affairs, in Sepulveda, California, April 22, 1975.
39. In 39 Fed. Reg. 20566-71 (1974), the Dept. of Labor Employment Standards Administration formally notified government contractors that they would need to have anti-discrimination clauses relating to the handicapped in all solicitations after July 11, 1974 and in all contracts executed after October 11, 1974. These interim regulations do not have specific guidelines for the contractor. The author of the regulations effectively minimized their long term impact because he requests that interested persons submit comments, suggestions, data or arguments, and specifically states that "material thus submitted will be evaluated and acted upon in the same manner as if this document were a proposal," id. 20566.
40. Interview with a Bank of America official, at a meeting of the San Fernando Valley College Employment of the Handicapped Committee, April 6, 1975.
41. The new proposed regulations are found at 40 Fed. Reg. 39887 (1975). Comments on these new criteria were to be accepted until October 13, 1975.
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SEXUALITY AND INDEPENDENT LIVING SKILLS

Neil Jacobson

Why live independently? With so much time and attention being put into teaching the physically disabled how to live independently, one rarely asks why. The reasons can be found to be the same as those which propel us to do anything. It feels good . . . it's desirous . . . it's in line with our self-image. What's my definition of self-image? The way a person perceives him/herself. To perceive is to see. In looking at ourselves, the first thing we see is a body. Is it deformed, is it revolting? Does it disturb and nauseate us, or is it handsome? Do we like what we see and do we take proper care of it? How do we want others to handle it? Do we enjoy and appreciate its existence, or is that irrelevant? These considerations are vitally important to those who contemplate living independently. When we realize that these are the concerns of a sexual being as well, we have begun to establish the correlations between sexuality and independent living.

It is my premise that independent living develops the individual's sexuality. Conversely, sexuality can propel one towards independent living skills. In examining this cycle from independence to sex and back again, a person must realize that this exchange does not describe the situation for all disabled people. Some never experience sex while enjoying independence, and still others live their entire lives in sheltered environments and are sexually active. This paper does not attempt to explain each conceivable combination, but simply addresses itself to the situations where sex may affect the independence of the physically disabled.

Independent living presumes an environment in which the disabled person has control over his/her care. It is a place which allows him to care for himself as much as he is capable of or wants to, and gives him the freedom to hire (and fire) his own attendants who do the rest. In this environment he can come or go as he pleases. A pre-independent environment is one in which the primary care for a person rests with others. Parents' home, a hospital, or a home run by a hired staff are defined as pre-independent.

Independent living also presumes the existence of role-models. Role-models are other disabled people who are living independently. They are highly important. In the course of a single day, disabled people are bombarded with stereotypes. If these are all negative, it is difficult to maintain a healthy self view. At times it is vital to have people around who have been through it to remind you who you are and what you can be. Other disabled people can best demonstrate how to better one's psychological perspective, as well as one's physical environment.

The stereotypes I'm speaking of are the assumptions made of the disabled by the public, and by disabled people themselves. Consider the following statement taken from an article written by a psychologist:

> Sexual maturity brings and symbolizes independence—to have sexual relations and intercourse and to produce children of one's own. But the severely physically handicapped can never be independent, they will always depend on others.

The same author goes on to state ". . . sex education [for the disabled] . . . for what?" In an era where the sexual attitudes of the majority are slowly changing, and at a time when people are presumably becoming more sensitive to the needs of the physically disabled, it is amazing to find statements such as these. It is frankly alarming to encounter article upon article insinuating that the disabled are sick, unhealthy, and broken facsimiles of a human being.

We still hear of parents telling disabled children that they are odd, disgusting, or ugly—or psychologists recommending to clients that they should sublimate their sexual drive, stop hoping for mates, forget marriage, children, or a "normal life." We are being made aware of institutions that punish patients for accommodating their sexuality. Patients have been placed in solitary confinement for masturbating or petting in a dark corner of the hospital. Some recommend the sterilization of physically disabled persons. Medical doctors have told some of their disabled clients that they are sterile when the truth is that nothing is wrong with their reproductive organs.

Such misinformation may be alleviated some day through the hard work and persistence of disabled people. But there are subtler stereotypes which are much more difficult to combat. Can we change the mass media's representation of beauty? By depicting Mr. America as the muscled he-man, and Ms. America as the tall, beautiful walkie, we not only exclude the wheelchair-bound person, but we imply by comparison that there is something wrong with him/her. The national passion for young athletic-looking people running hand-in-hand into the forest at sunset may be depressing to those who fall short of that description. It can be devastating to the blind or disabled person who comes to feel that sex can never be a reality. Sex, this beautiful, far out thing, isn't to be enjoyed by those who aren't "beautiful."

It is too often inferred that sex for the disabled can only be a head trip. There are counselors who tell a client that since his/her body is non-functional (a subjective point of view), he/she may imagine what sex can be like and be content with that. Again, from the previously quoted article: ". . . Sex in the head titillates without fulfilling. But to the handicapped person, the body is scarcely something that gives pleasure . . ." It is the rare and unusual person who can appreciate sex solely through the imagination. Sex includes the body as well as the mind, and if you are uncomfortable with your body, sex will probably provide little pleasure.

Other stereotypes center around the disabled as a group. Some assume that all disabled people have tactile problems. Others assume that all disabled people lack sensation in their genital areas, or have problems with their reproductive organs. In reality, with 10% of the population classified as disabled, it is impossible to draw any definite conclusions about the disabled on the whole. Still, an insidious pattern of "encouragement" emerges whereby the disabled individual is never allowed to accept himself.

For example, Cerebral Palsied people are told that being disabled is all right, but that they should work towards looking as straight as the spinal cord injured quad, while the quad is told to copy the example of the paraplegic, who is in turn made to envy the movements of a post-polio, etc. etc. This twisted hierarchy can lead to many misconceptions, and is as

counterproductive as the stereotypes held by the public. Favoritism based on this hierarchy is common in institutions, where the higher up one is on the scale of acceptability, the better care one can expect to receive. The person on the lower end of this scale is faced with more prejudice, and it becomes more difficult to achieve a good body-image and the ultimate goal of independence.

Assuming that a person does have a low body-image, it is likely that he is less concerned with his body's wellbeing. There is less to motivate the person to be well-groomed, well-fed, healthy, and otherwise well-cared for. Why worry about the possibility of bed sores, bladder or kidney infections? Who cares about getting out of bed, making money, going places? The sexually active individual does care. Just knowing that someone thinks you are attractive. Knowing that someone wants to be with you and hold you and love you—gives you a reason to get out of bed. The rest follows, for an individual is going to have to strive for independence to be with that other person. The selection of an attendant becomes important because someone else is looking at you. Mastering other skills enabling a person to get out and around and ultimately rely less on others, becomes important to the sexually active person. This situation can even stimulate the desire for a vocation and financial security, since the individual is living not only for himself, but for those who love him as well.

At this point, we are confronted with an ironic development. On one hand, the disabled person is hit by stereotypes which generally label him weird and asexual. These stereotypes indicate that his sexual desires are incompatible with his "situation," something subjectively defined by the public. On the other hand, sex may prove the inspiration behind his desire to live independently, by giving him a reason to care for his body and his needs. The disabled person comes to think better of himself, and so do others. I would like to discuss, then, several paths which lead to sexual activity and independent living.

An important step lies in sex education. One of the major obstacles to sexual activity is simply not knowing how to go about it. For the congenitally disabled, sex education is often completely ignored. Whereas the non-disabled can learn about sex from their peers, disabled people who are unable to get out are not exposed to this information. It is extremely important that sex education be available to the disabled. Apart from specific questions relating to the nature of one's own disability, and its effects or special considerations, sex education need differ little from that offered to the non-disabled. For instance, a Cerebral Palsied person may want to know what to do to reduce spasms, or what positions would be better suited than the classic missionary which might be difficult to maneuver. For these reasons, other disabled people are valuable because of their personal experience. This leads back to role-models.

For the spinal cord injured and other disabilities where the physiology might change, a special kind of sex education is in order. For those who have grown up in a society non-disabled until later in life, myriad stereotypes might be broken. Take, for example, the stereotype of Mr. and Ms. America-Beautiful, the restriction to genital sex, and the idea that sex is goal-oriented with the winner attaining the big O in the sky. Although *all* of these sentiments have an adverse effect on the populace as a whole, the need to disprove them is magnified for the newly disabled.

Similarly, limiting one's goal to the satisfaction of one's partner is another misconception. Just as we learn that there is no Santa Claus, we learn in sex that it is not just enough to give, but you need to know how to receive as well. We want to pleasure our partner, and our partner will generally want to pleasure us. So, what makes our body feel good? What are our erogenous zones? They include more than just our genitals. Both partners deserve to attain peak satisfaction, whatever that might be. With the newly disabled, as with the congenitally disabled, role-models are called for. It's one thing for a non-disabled doctor to tell a spinal cord injured person not to concern himself with the lack of sensation in the genital area, it is another thing for a disabled person to explain how he/she experiences the same orgasmic feeling from stimulation of non-genital areas as he/she experienced before his/her accident.

Sex education must also give accurate information. The era of telling women that they need only lie there is over. The era of telling disabled men and women that they are sterile because of their disability (when it isn't true) is over, and so is the denial of one's own sexuality. Imagine the doctor who tells spinal cord injured patients that the feelings of orgasm which they experience are "phantom orgasms." One must question whether if the phantom orgasm exists, why more people don't go around "phantomizing" their orgasms. The word phantom does little more than belittle the pleasure that one can achieve.

Before the disabled person can become sexually active, he must gain social confidence. This is crucial, as it is necessary to know how to approach a potential partner. For many congenitally disabled, because they have been raised in isolation, the opportunities for learning social skills are limited. Growing up in this manner, a person tends to find that they have little in common with their peers. Not being in the streets with other children, disabled people may not know the accepted means of meeting other people. Some disabled people are so afraid of being rejected, that they take no risks and remain isolated. Still others, who may really believe that they are inferior, take unnecessary risks. When they are refused, they view the refusal as rejection, or a denial, and in turn re-enforce the negative self-image that keeps them isolated. By talking to other disabled people, one can learn from the experience of others what may or may not be appropriate behavior. During one-to-one encounters, two people can share and learn from each other. Group counseling has also proven itself in teaching socialization skills.

There still remains the phenomenon of understanding intellectually the procedures in sex and socialization, and not being able to put them into practice. It's the old saw about knowing what to do, but finding that it is something else to do it.

Masturbation can be the first step in this problem. As was aforementioned, if you don't know what makes you feel good, no one else will. Masturbation and the exploration of a person's own body, without the pressure of performing, may lead one to really discover that his body does feel good. For the first time, a person may be receiving pleasure from his body instead of seeing it as an object that others are always throwing around and working on. Masturbation is sometimes felt by an individual to be the most pleasurable act in sex, even when other avenues are available. If sex is for pleasure, then there is no reason to separate masturbation from the rest and deny one's self this form of pleasure.

Another way of bridging the gap between talking about sex and taking part in it, is via the use of surrogates. For many people, disabled or not, the fear of performance breakdown is intense. Surrogates may provide that form of confidence needed before one pursues a

relationship. As was indicated before, disabled people may want to experiment with different forms of sex, positions, etc. Surrogates who may be experienced with disabled people can offer new ideas and actually give the man or woman suggestions as to how to maneuver. In this society, where sex is talked about so much, it is common for disabled people to develop grandiose ideas about what sex actually is. If these ideas grow further out of proportion, he/she may not be able to find a partner or be satisfied working under such misconceptions. Surrogates can be utilized here to put sex back into its proper perspective while showing that pleasure is indeed possible. Surrogates can be used to garner feedback on certain socialization skills as well. Although it is only one person reacting to another, it is important to receive immediate recognition of one's efforts. It is highly recommended that surrogates be used in conjunction with counseling. This assures that practical knowledge is accompanied by cognitive knowledge.

Disabled people may also learn from homosexual and bisexual individuals who have also had the courage to call society at its game. If sex is not merely a baby-producing function, with this paper presuming that it is not, then we must consider it an ignorant societal more which prohibits men from loving men and women from loving women. It is more important for people to pursue those feelings that reenforce their sense of well-being than it is for them to succumb to the same sorts of stereotypes that we have been and are continuing to fight.

It must be said that no one is advocating that all disabled people engage in any or all of the aforementioned situations with respect to sexual experiences. To feel pressured into situations where one is not comfortable (homosexuality, oral sex, etc.) merely replaces one restriction with another. Just as there are stereotypes relating to disability, a disabled person must be aware of the stereotypes relating to sex—that sex is a straightforward, missionary, heterosexual experience. The simple point is, one should not limit oneself to what others expect, either in terms of ability or sexuality.

Another avenue to sexual activity can be found in counseling. I have alluded to counseling earlier, but would like to speak of three major approaches. The predominant form of counseling available to the disabled today is that of peer-counseling, which brings us back to the use of role-models. Once again, it is my firm belief that most disabled people do not have the debilitating problems affixed to them by society, but rather lack the confidence and the simple know-how that enables them to become sexually active. A peer is the most effective and logical choice for providing the confidence and information based on accurate experience rather than second-hand stereotyped subjectivity. Of course, all sexually active disabled people are not necessarily good peer counselors. In fact, it is common that the disabled individual who has "made it" may lack the necessary empathy to make him an effective counselor. I also believe that non-disabled persons can learn to be peer counselors (insofar as age is concerned) and do a fine job as well. Groups led by one or more individuals have proven their worth. Some people feel better in situations where they can share common experiences with others. Group counseling often assures the individual that his experiences are neither as unique nor as horrifying as he may have felt. In addition, group counseling may provide the positive feedback of several people, which might prove more reassuring than the feedback from a single person. Finally, professional counseling, whether it is psychotherapeutic or behavioralist, has been valuable to some disabled people. But once again, as past attitudes have shown us on the part of professionals, there is a need for more disabled people in the professional realm.

Not all disabled people either need or benefit from counseling. Some people need time alone to figure things out for themselves, while others do need a peer counselor. Others may need the catharsis of a group in order to benefit, while still others feel most secure in the treatment of a professional. All three should be made available, even if none need be used.

The belief that positive attitudes need no reenforcement is naive. The person in the institution who is punished for sucking his finger, or the individual placed in solitary confinement, or the couple who find themselves without dinner when caught petting, may find themselves unable to sustain any positive feeling towards themselves and their sexuality. The person locked in his parents' home who is disallowed a wheelchair will very likely forget those social skills he may have learned. If a disabled person has no place or opportunity to practice what he has learned, it tends to follow that he will forget or lose his confidence in his prior ability. It is crucial that an effort be mounted to educate the professionals and the parents of the disabled.

The disabled themselves are well-suited to do just that. In the process of educating these two groups, the three major forms of counseling once again prove worthwhile. One-to-one peer counseling, group endeavors, and professionals (speaking to either parents or other professionals) can all be used. The disabled should expand their role in this area, and although programs have begun, more are needed.

In any discussion of sex, marriage and divorce can be topics of consideration. Just as marriage can be an asset to the sexually active, it can also be a hindrance. Many disabled people have married and are leading happy lives. Their sexuality is reported to be satisfactory, and each strives to give and receive. With marriage it is once again *not necessary* to follow the rules predetermined by society. Marriages following the stereotype of man-as-breadwinner and woman-as-housewife-and-child-bearer are probably in for rough times when disability is introduced into the picture.

When one of the spouses becomes disabled during the course of a marriage, one of the most important factors in determining the continued future of that marriage lies in the pre-existent conditions. Those families who have weathered crises together, have shared responsibilities, react to the introduction of disability in a more calm and realistic fashion. Reports have demonstrated that it was the couple's ability to share responsibility and the stress of crises, not the severity of disability, the lack of mobility, the lack of sensation, the inability to work, that proved most instrumental in sustaining the marriage. It was further found that just as the disabled individual needs accurate information concerning his/her sexuality, so the spouse of that person required the same information. It is important that the non-disabled marriage partner not be relegated to an attendant. I am not implying that the spouse not do any attendant-type work, but rather that a distinction be made between attendant and lover, and that the non-disabled spouse's feelings in that area be respected. A newly disabled individual can become in some respects a different person. His body may function differently, his ideas and beliefs may be altered, and his aspirations, interests, and experiences may change as a result of this change. Spouses may or may not be able to go along with these changes in the disabled lover, and divorce might (and does) occur.

The social mores that accompany divorce affect disabled people in much the same way. Divorce tends to be viewed as a failure, and one to be avoided at all costs. In some cases, divorce is the best answer, allowing for greater independence and happiness for both

partners. No one advocates divorce as a means toward independence. However, any obstacle to happiness or independence must be examined, whether it is being confined to an institution, a parent's home, a spouse's home, or whatever, less it lead to inactivity and loneliness.

Some disabled people sublimate their sexuality, and put their energy into unrelated activities. They might, for instance, become so extremely hard-working that they have neither the time nor the energy to pursue a social life. In one way, such a situation may serve to relax certain fears. Sometimes the knowledge that he/she is involved with work and doesn't have time for sex can enable a person to relax barriers and it becomes easier to meet people since there is no implied sexual desire. The mere coming into contact with other people may lead a person into sexual activity. Still, such a result of sublimating sex drives and turning to work occurs in but a minority of cases. For most, this denial of sexuality is only a self-imposed rationalization (I'm too busy) rather than an indirect approach to sexual realization.

People must definitely progress at their own rate, and for some, a period of sublimation might be needed even if it creates frustration. Everyone reserves the right to go at his own rate, and accomplish things at his own rate in his own way. What has preceded merely points out different avenues towards a certain goal—that of sexual activity.

Having discussed several ways in which disabled people approach the problem of sexual activity, and after having shown how sexuality can affect independent living (and vice-versa), there is only one conclusion to be drawn. Disabled individuals can and are becoming independent and are taking control over their own lives. Furthermore, disabled individuals can be sexually active, gaining pleasure from their bodies and giving pleasure to others. When we see this happening all around us, the question of how, why, where, and for what becomes secondary.

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CENTER FOR INDEPENDENT LIVING IN NEW YORK
A RESIDENTIAL CENTER FOR THE ELDERLY BLIND

Douglas Inkster

The New York Infirmary and the Society for the Relief of the Destitute Blind in the City of New York started the Center for Independent Living, a residential center where the elderly visually impaired individual can learn the skills necessary to live independently in the community. It opened in May of 1973 and since then, more than 100 students have received instruction and supportive services in areas such as mobility, nutrition, health, etc., which have enabled them to lead more active and independent lives in the community. The Center offers counseling in the following areas:

Aging and Blindness Counseling

Social workers at CIL provide professional help as students work through problems associated with their advancing age and loss of vision. This individual supportive therapy contributes to the student's ability to overcome depression and attitudes of self-deprecation, to affirm his/her right to be different, and to plan his/her future. At CIL there is also a group discussion program in which students compare experiences and problems and learn to appreciate their ability to help others and themselves.

Financial Counseling

Most of the CIL students were employed before they lost their vision. Yet now they are dealing with federal, state and local bureaucracies in order to secure financial support, housing and medical care. The Community Coordinator and a volunteer attorney provide help to the students as they deal with this strange, new and often frustrating circumstance. They are also developing a financial manual for the students to use as a guide through the policies and procedures of the various agencies with which they must deal and it is planned that this will serve as the basis for an education program in the use of community resources.

Medical Counseling

Most of the students referred to the Center for Independent Living have health problems in addition to their visual loss. The student may even be receiving treatment for three or four different ailments from two or three different physicians or specialists. They are rarely aware of the implications of their total medical and physical condition. Because of this situation, CIL provides counseling for students on their present physical conditions and expectations for the future. Students learn why they have dietary, physical and medical and they are taught what to do if they experience symptoms that might signal a change in their condition. Students need this kind of awareness of their medical status in order to prepare for independent living.

Volunteer Services

Any totally blind individual living alone requires a supporting group of volunteers or paid readers and attendants. They help shop for food and clothing, read the mail, provide emergency transportation, and they also informally monitor the individual's housekeeping and personal management skills. Most recently visually impaired individuals find this sudden dependency a problem. They are used to being self-reliant and are now reluctant to request the support services that they need and they feel that they are imposing on others. Recognizing this need, the Center for Independent Living provides counseling and an educational program to expose the students to the problems of recruiting, selecting, educating and using such assistants and companions.

Educational Services

Nutrition: Ninety percent of all students referred to the Center for service have dietary restrictions placed on them by their physicians. While students may be aware of the reasons for their special diets, they often do not know how to apply these dietary restrictions to their everyday living. Because of this special need, CIL offers a course in nutrition which helps students cope with dietary limitations both in planning meals at home and eating out.

Physical Conditioning: The average age of the students who are referred to the Center for Independent Living is between sixty-eight and seventy. A good number of the students have been blind for a period of five years or more. Consequently, they have been living rather sedentary lives. When they start the Center program, they find themselves in a relatively exhausting situation of attending six classes per day, five days per week. A number of students have had to adjust their schedule to alternate periods to allow their bodies to become accustomed to this new and higher level of activity. CIL has developed a prescriptive physical conditioning program to enhance the highest and best use of a student's time in training at the Center.

Sensory Development: All but one of CIL's students began having trouble with their vision late in life. The average time between onset of a visual problem and referral to the Center is five years. The fact that these individuals have had vision for the major portion of their lives means that they have a well-developed concept of the world around them. After losing their sight, it becomes extremely important to better utilize their remaining senses for interpreting what is happening in the surrounding environment. CIL offers a course in sensory development to help students to more accurately and rapidly interpret the environment through the use of sound, smell, taste and touch.

Communications: The Center for Independent Living program provides instruction in four different communications skills: Braille, typing, script and the use of electronic equipment.

Orientation and Mobility: CIL provides instruction in orientation and mobility skills, which are vital to independent living.

In order to improve the quality of instructional programs at CIL, teachers have been encouraged to clearly define educational objectives and behavioral criteria which can be used to assess each student's progress in learning course material.

These services and educational programs have given students the tools they need in order to live independently in the community. Because of the success of our residential program and also because of its limitations, we have engaged in other activities to contribute toward a future of independent living for the elderly visually impaired population. We have helped to establish and conduct training and internship programs for professionals and paraprofessionals working with the visually impaired and/or the elderly.

We have also started to develop a self-study rehabilitation curriculum for use in the home.

Self-Study Rehabilitation Program: Approximately 70% of those referred to CIL either could not or would not leave their homes to come to a rehabilitation center. According to a brief assessment, CIL students have an average I.Q. of about 120. These early findings may indicate that the Center for Independent Living is attracting those individuals who are more capable and who have less fear of facing new situations and new environments. If this is the case, a large portion of the older visually impaired population will not benefit from the CIL program because of their reluctance to come to the Center either for personal or physical reasons.

For this reason, CIL has prepared home study course materials on cassette tapes with companion large print transcripts that can be used by visually impaired individuals who will not or cannot leave their homes. The students can use the lessons on tape to learn the habit changes and new techniques required to perform adequately without vision. The large print companion manual can be used by a spouse, a volunteer, a friend or neighbor to monitor the progress of the student in learning these skills.

One such self-study course was developed by CIL and used by eleven agencies in the New England States in both metropolitan and rural areas. An evaluation of the results showed the value of this method for teaching individuals who are newly blinded.

On the basis of this early experience, the Center for Independent Living developed a self-study course in housekeeping skills which is available on a national basis. Other self-study courses will be developed in communications and mobility.

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SYSTEMS APPROACH AND THE "PHYSICALLY UNABLE"

Wallace Motloch

In this technological society we are constantly dealing with systems, e.g., political system, telephone system, digestive system, highway system, etc. The dictionary defines this word as "to combine" or "an assemblage of interdependent group of items to form a unified whole." Oh! how wonderful it would be if we could utilize the systems approach when dealing with the problems of physically impaired. For example, if faced with a mobility impairment the question would be, what set of aids would be suitable to eliminate the mobility difficulty?

When we speak of eliminating mobility difficulties for the "physically unable" we are always faced with the natural comparison to the physically able. Therefore, we must always be aware of the immense freedom of mobility that the ablebodied possess. Humans can traverse rough terrain, climb stairs, hills, even mountains; go through lots of snow, ice, change speeds, stand, walk, run, jump, swim, change positions in space, squat, kneel, sit, stand, lie, reach over and underneath, exert forces, carry things, turn knobs, ski, skate, ride bicycles, manipulate environment at close range, inspect, investigate, feel, touch, sense temperature, texture, shape, all in all basically bringing our senses, eyes, ears, hands, etc., into close proximity to the object to be dealt with. All of the above and more is what we think of when we mean mobility. Therefore, it is an extremely tall order to fill when considering severely disabled people. Most of the severely impaired need not only a wheeled transporter but a way to get in and out of a seat. They need a working surface like a lap tray and accessible utility box for their possessions. To be able to reach down to the floor, up to the shelf, a way to summon help, have their life support systems serviced . . . the list goes on and on, including endless amounts of customizing, adapting and personalizing their systems and surroundings to make their life more livable. To make their life more livable, more dignified and independent is one of the greatest challenges that face our society. We can send people to the moon and beyond, but the best we can offer to our handicapped is an ancient chair on wheels. Society has fallen behind badly in recognizing the extreme hardships and difficulty that our handicapped face.

In making life more livable we employ many tools and social structures—scientists and technology to name a few. The technology is a natural one when we speak of physically impaired. The Webster Dictionary says it so well, "Technology—the totality of means employed to provide objects necessary for human sustenance and comfort."

At the Rehabilitation Engineering Center at Children's Hospital at Stanford, we specialize in the severely disabled child and young adult. We offer our services under four categories: 1) unusual limb prosthetics, 2) unusual orthotics, 3) communication for non-oral and, 4) mobility. We pride ourselves on the fact that we provide systems to accomplish a specific task, i.e., communication system, mobility system. When a wheeled mobility system is

considered we look not only at the chair itself, but the tissue trauma management, positioning, seating, controls, trays, reachers, transfers, as well as defining a lifestyle that is consistent with the developmental needs of a child.

Developmental Aids for an Infant

In preparing a severely disabled infant to go home, the first developmental aid would probably be a carrying or "holding device." This papoose-like aid would hold and contain the anesthetic limbs, protect the back and head while enabling the family to handle the child. A spina bifida infant is often brought home from the hospital and placed in a crib face down so as not to aggravate his/her newly operated back. Relatives and friends are usually very reluctant to touch him/her and their feelings of apprehension transmit to the child. The feelings of excitement, picking-up, passing him/her from one member to another, playing with him/her, cuddling and holding him/her without fear of injury are important and stimulate the child to develop and learn in a normal way. "There are too many dimensions of normal behavior to sacrifice development of any part. Therefore, if the patient can be normalized during any period, by use of orthotic appliances, their application is justified."[1]

As the child's visual field becomes important, the need for assistance in holding up the trunk and head develops. The use of a carry seat to prop the child into a semi-reclining position is a safe, enjoyable, and developmentally beneficial activity.

We cannot emphasize enough the importance of "sitting, hands free." At this later stage (8 to 14 months) the floor is the child's world, and hands are the pedicles connecting the brain to the exciting new environment of taste, texture, shapes, and spaces. However, many spina bifida children do not have sufficient trunk balance to sit unsupported. Since they use their hands to stabilize their upper body, the interaction with environment is thereby limited to an onlooker's role—a passive observer. This child can be given a sitting jacket to enable him/her to explore his/her world, be it the floor, bathtub, or front lawn.

As we progress to the next developmental milestone we move from stationary exploration to some mobility. Crawling allows discoveries beyond the immediate visual field, around the corner, inside the cupboards. The intriguing mysteries of kitchen cupboards, the wonderful sounds of pots and pans, oh, the tastes on the floors! Do the present wheelchairs fit this need? Of course not. They're too big, too complex, and too high. When a spina bifida child loses a toy, it's gone forever; the floor is too low to reach and the tables are too high to see. We need to think more along the lines of the caster cart or similar devices close to the floor, patient-propelled, small/maneuverable, with protection for back, seat, and legs. This kind of tool allows the child to retrieve playthings from the floor with hands-free exploration, and manipulation of the environment at the child's own pace, scale, and level.

Another goal for orthotics and device design is "crutchless standing," for children 14 months and older. When we stop to consider the limitation of exploration that crutches impose on our little people, we can better appreciate the need for a "hands-free standing experience." The conventional bracing systems that tie up the hands with crutches for ambulating as well as standing are defeating the most common cause of ambulating from one point to another. That is to say, the most common purpose for going somewhere is to get there and then use one's hands to touch, pick up, or manipulate. The joy of having one's hands free for activities of play or discovery can easily be observed with the younger folk.

Developmental Aids for the Older Child and Young Adult

As we move out of the first decade of life where most Orthotic Aids could be looked upon as developmental aids, we enter a period of transition. This is a very difficult period for most patients and families, as many patients experience periods of depression. The upright ambulation in known devices is less and less attractive, spines are collapsing, pressure sores are developing and obesity compounds the problem of adjustment. On top of all these is the final realization that the best our society can offer is a frame on two big wheels. Our society has been able to solve some extremely complex technological problems and yet our disabled are left to fend for themselves. We seem to be saying that this is sufficient, this is all right; but it is not all right. The human frame was not meant to be placed in one position for 10 hours a day; there are physiological and functional reasons for stretching, moving, standing, and reclining. Imagine yourself being confined to an automobile seat for 10 hours a day, day after day.

We know that the devices we provide limit posture to a sitting position without regard to pressure on tissues, positional deformities, and a life-style which eliminates manipulation of the environment at close range (over, under, beneath, and behind). At best we consider two positions—standing and sitting—but without regard to how to get from one to the other, attendant free. We have to begin thinking about a better future for our paraplegics with a more livable life-style, including a family of their own, holding a job, running a household, being able to move into a variety of positions and undertaking a wide range of activities.

Perhaps we can borrow parts from the armamentarium for traumatic adult paraplegics and adapt it for our younger patients who have shorter stature, bigger shoulders and other peculiar problems. We have to think of individual life styles, systems approach to ambulation, urine collection, emergency handling, etc. We must not overlook the fact that, in addition to our other concerns, we soon have to address ourselves to the problems of aging with its host of new challenges. Since it will take a long time to develop, test and make available new mobility aids, it is imperative to start immediately.

Let's consider one case: a typical 16 year old young woman, obese, slow, friendly, and prone to pressure sores. It is unrealistic to expect her to push-up regularly to change her sitting position; history shows this method did not work for her. It is also unrealistic to ask her to frequently transfer from her wheelchair onto the sofa—she can barely lift herself. The work at Rancho Los Amigos clearly demonstrates that the two most important factors in tissue trauma management is magnitude of pressure and duration of time. The formula shows that if there is a great amount of pressure, the tissues can tolerate it for a short time, and we can measure this now. We can predict the length of time that a person can sit on particular areas of tissue without permanent tissue damage. In the case of this young woman, the only way to accomplish an eight hour day was to alternate the weight-bearing areas; in standing, the feet take most of the weight, in sitting the ischial tuberosities, but as we lean forward, the center of gravity line moves anterially and the weight bearing area is more forward, as we recline, the weight moves to the back. This is essentially a time sharing technique that enables us to get more ambulatory time as well as more functional positions.

Now let us consider a sample ambulation system for paraplegics. The transportation system is made up of many purpose-designed modules. These modules can be equipped with efficient patient-operated connectors which allow them to be arranged into a custom-designed system.

Module I – Short Range

Short range ambulation is most profoundly affected by spinal cord impairment. The impairment limits the person's ability to maneuver within a confined space. The fine movements which are required to locate oneself within the reach of the target, be it low, high or obstructed, are often impossible. Our concept of Module I is a crutchless standing orthosis, with a pivot-walker. Arrangement of this type allows the patient to maneuver in confined areas, narrow passageways and reaching/seeing from a standing person's level. While pivot-walking without crutches is possible in spaces like bathrooms or kitchen, on rougher terrain and longer distances it is not practical. This type of Module I is versatile in short range and offers a wide choice of connecting options, i.e., it should be possible to remove oneself from a wheeled transporter (Module II), place the transporter in the trunk of a car, and then ambulate to the seat of the car.

This kind of freedom of interconnecting to different components in the transportation system is utilized by the able-bodied all the time. We walk to our car (short range), drive the car to the airport's parking lot (long range), then walk again to the airport shuttle bus (short range). The bus moves us across the interim distance so that we end up within a walking distance of the ticket counter.

The ambulatory units should receive the human not as a static frame but as a living organism with many physiological, psychological and biological needs. The person and his/her machines should be arranged into a dynamic mobility system which facilitates such changes as alternating weight-bearing areas, exercising and just general changes in posture. This sort of consideration would play a great part in maintaining a good physical state and mental attitude.

Module II – Interim Range

The intermediate range of transport involves bridging the gap between the short and "public" transport systems. Most often Module II consists of a wheeled transporter (wheelchair, cart, scooter, etc.). Whether externally powered or not will depend on the distance/terrain to be covered. This usually limits the range to several city blocks. The barriers most often encountered are curbs, steps, narrow passages and rough terrain. The interesting point to Module II is the fact that while the distance and time to travel is relatively short, the patient often uses this module as a base from which to work or rest. Therefore, this means that he/she spends a lot of time in it and the ambulation time represents only a small portion of the actual usage time.

Module III – Long Range

Generally, it may be said that ambulation of a long range type will be by Module III (car, boat, plane, etc.) and along the existing routes of "public" transport (highways, railroads, airways). It may be necessary to standardize or even modify in some instances both "public" transport and the handicapped system to ensure their compatibility. Devising methods of connecting to able-bodied systems is of great importance; it would certainly remove many barriers to independence.

Summary

When considering physical disabilities we could render a much better service if a systems approach were used.

Also, it is my opinion that today's technology could eliminate many of the physical problems facing our disabled. It behooves us to find a way to make it available to them.

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THE IMPACT OF LITIGATION ON DE-INSTITUTIONALIZATION: A MOVEMENT TOWARD INDEPENDENT LIVING FOR THE MENTALLY DISABLED

Kathleen Ursin

The National Center for Law and the Handicapped was established in 1972 to insure or secure the constitutional and statutory rights of all disabled citizens. In working towards this goal, NCLH engages in activities which include legal assistance, research, and promoting public education and professional awareness. The broad, general areas in which NCLH activities have been concentrated are as follows: Right to equal educational opportunity; right to treatment in the least restrictive alternative; right to transportation and freedom from architectural barriers; right to equal employment opportunities; and right to equal access to medical services.

The "civil rights movement" for the disabled is a relatively new phenomenon in our society. The 1970's have been years of ever increasing organization among groups of disabled persons who refuse to remain any longer a silent minority within our society. In seeking equal treatment and the same basic rights as other citizens, disabled persons have increasingly turned to the courts to obtain the guarantees which will enhance their ability to achieve appropriate status in society. The emergence of NCLH and numerous other legal advocacy groups across the country is evidence of this growing trend. To date, a majority of litigation in this area has been brought by groups and individuals representing the mentally disabled. This is not so much a factor of greatest need among these persons, although the need is great, but a result of two other important considerations: a high degree of organization among groups representing particularly the mentally retarded; and the historical roots of the development of law in this area. Although it may seem too obvious to mention, it is important to remember that lawyers represent clients. The long and often difficult struggle to achieve equal rights through the court system will succeed only if disabled persons themselves demonstrate their willingness to become actively involved with legal advocates.

The issue of right to treatment was one of the first articulated in the courts in the legal rights for the disabled movement. NCLH, as well as numerous other legal advocacy groups such as the Mental Health Law Project, The U.S. Justice Department, The Center for Law and Social Policy, The National Legal Aid and Defenders Association, The American Civil Liberties Union and numerous statewide advocacy agencies and private counsel has participated in bringing this issue to the attention of the courts. This paper will describe briefly the history of litigation in this area as well as outlining the results of some of the court action, and pointing out future areas for consideration.

The concept of a "right to treatment" was originally formulated in 1960 by Dr. Morton Birnbaum, an attorney and physician, in an article written for the American Bar Association Journal. Dr. Birnbaum advocated in his article ". . . the recognition and enforcement of the legal right of a *mentally ill inmate* of a public mental institution to adequate medical treatment for his illness."[1] Although he recognized that the law had not established this legal right, Dr. Birnbaum felt our society had and did recognize a moral right to treatment. In his article he proposed that ". . . the courts, under their traditional powers to protect the constitutional rights of our citizens begin to consider the problems of whether or not a person who has been institutionalized solely because he is sufficiently mentally ill to require institutionalization for care and treatment actually does receive adequate medical treatment so that he may regain his health, and therefore his liberty, as soon as possible; that the courts do this by means *of recognizing and enforcing the right to treatment;* and, that the courts do this independent of any action by any legislature, as a necessary and overdue development of our present concept of due process of law."[2] (Emphasis added)

During the next ten years, the concept of right to treatment gained acceptance within the legal community and was given added attention within the larger society as a result of two reform concepts.[3] These forces were: 1) the growing move to secure mental patient's rights as part of the "rights revolution," and 2) a movement towards care in the community for the mentally ill and the mentally retarded. This second factor had as its basis the growing belief that community health care was possible and desirable for the mentally disabled. Under the Kennedy administration this concept achieved credibility and the force of law. For the mentally ill, the advent of psychoactive drugs and the skyrocketing costs of maintaining large institutional programs convinced state legislators that community care was possible and feasible.[4] With the passage of the Mental Retardation Facilities and Community Health Centers Construction Act of 1963, the Federal Government gave its stamp of approval to this movement and provided a share of construction and staffing money for these facilities. For the mentally retarded, the advent of the concept of normalization, as described by Wolfensberger,[5] was significant in establishing that the mentally retarded could and should become a viable part of the larger community. Another concept emerging at this time which gave impetus to de-institutionalization was the developmental model of disability. This idea of the potential for growth throughout a person's lifetime, coupled with the principle of normalization, set forth constructs that could be applied to the integration of other disabled persons into the community as well.

These two principles have provided a sound basis for the development of legal theories to protect the rights of the disabled.[6] The developmental model emphasizes the ability of all disabled persons as capable of growth, learning and development. Further, it is the interaction between the individual and his environment, rather than the attributes of any specific impairment, which produce development. It serves to undercut many of the assumptions upon which statutes and common law, which restrict the rights of handicapped persons, are based. Viewed with the normalization principle which calls for the provision of services to the handicapped in as normal an environment as is possible, these principles give a socio-psychological basis for the establishment of a legal right to treatment in the least restrictive alternative.

The constitutional provisions on which the right to treatment arguments are based are founded in the equal protection and due process clauses of the Fourteenth Amendment of the U.S. Constitution. This amendment establishes the obligations of the state to its citizens if fundamental rights are to be denied or curtailed. In addition to the Fourteenth Amendment, Eighth Amendment guarantees which prohibit cruel and unusual punishment and Thirteenth Amendment guarantees which prohibit involuntary servitude have been used as the basis for establishing the arguments in right to treatment litigation.

The importance of the constitutional principles involved in right to treatment litigation cannot be denied. The need for litigation to insure that these rights are protected takes on more compelling proportions when the number of disabled people potentially affected is considered. The latest figures available indicate that as of 30 June 1974, 215,573 persons were committed to institutions for the mentally ill in the United States.[7] For the mentally retarded, the January 1975 statistics indicate that 168,300 persons were committed to public state residential institution programs and 150,000 were in private programs.[8] Mental or emotional disability and its attendant handicaps can and does affect all ages and all classes of persons. It has been estimated that 20% of all Americans will, during their lifetime, require professional treatment for mental or emotional ailments.[9]

Right to treatment litigation revolves around two central issues: 1) that "when the state decides to provide a service for its citizens it must do so under conditions which are as minimally restrictive to personal liberty as possible."[10] This is the concept of the least restrictive alternative and requires state officials to examine all possible alternatives before the one most severely restrictive of personal liberty is chosen. The second component of the right states, ". . . when the state restricts a person's liberty for the declared purpose of providing a service, then it is constitutionally required to actually provide the service." [11] In the paragraphs below the cases which establish these principles are described briefly.

Initially, litigation focused on the nature and quality of treatment which a patient received once institutionalized. However, as litigation has developed in this area, the need to protect and insure the rights of mentally ill and mentally retarded persons during the entire institutionalization process have been recognized. Basically, suits have addressed issues surrounding three different phases of this process: 1) "Getting in": the commitment process itself; 2) "Treatment": what happens to a person once he is in an institutional facility and the process by which he is prepared to leave that facility; and 3) "Getting out": the complex area of community services and the appropriateness and availability of them. Each of these areas must be addressed, and adequate safeguards established, if the mentally disabled are to receive appropriate treatment and services under conditions which protect and insure their legal rights.

The commitment process itself, the process by which the mentally disabled are involuntarily confined to institutions, raises substantial questions of procedural due process safeguards. The question has been dealt with most fully in the decision in *Lessard v. Schmidt,* 349 F. Supp. 1078 (E.D. Wis. 1972). Although this very extensive case and its holdings go beyond the issue of involuntary commitment, it does address this particular issue in a most substantial way. Essentially, the decision in this case established that "no significant deprivations of liberty can be justified without prior hearing on necessity of detention. There must be adequate notice, fair hearing, right to jury trial, and the person detained must

be informed of the basis of detention, the standard on which one may be detained, names of examining physicians, etc. The standard of commitment set was an overt act of danger to others as proven beyond a reasonable doubt." In another significant case in this area, which was only recently decided, a Federal Court in Pennsylvania found that the practice of commitment to residential institutions of minors by their parents without due process safeguards was unconstitutional. This case is *Bartley v. Kremens,* CA No. 72-2272 (E.D. Pa. filed Nov. 1972). These two cases establish precedent for the adequate protection against involuntary commitment for individuals in similar circumstances.

It is important to note at this point that the articulation of a right does not necessarily guarantee its implementation. Furthermore, the recognition of a right and its affirmation in one particular locale, does not insure that other localities will necessarily implement or recognize similar rights. However, the establishment of sound precedents is particularly necessary in the area of rights for the disabled. The building of good case law enables attorneys to deal more efficiently and, hopefully, successfully with similar cases in future actions.

The protection of patient's rights once institutionalized, and the assurance of adequate treatment so that continued confinement is no longer necessary have been dealt with most extensively. In a case of *Wyatt v. Harden,* (formerly *Wyatt v. Stickney* and *Wyatt v. Aderholt*) the Alabama District Court's decision that institutionalized mentally ill and mentally retarded persons have a Constitutional right to treatment was affirmed, in part, by a Circuit Court of Appeals in November, 1974. In a series of orders relating to *Wyatt,* the Court established for the first time minimum constitutional standards for adequate care and treatment. The court held that such a right to treatment necessitates the following: 1) an individualized treatment program; 2) a humane physical and psychological environment; 3) an adequate and qualified staff; and 4) programs provided in the least restrictive manner possible.[12] Implementing this wide ranging decision in Alabama has posed considerable problems, however. The Court established standards on the basis of evidence from experts in national organizations concerned with the quality of mental health services. Although the standards established are valid, it is still questionable whether they can be implemented successfully in Alabama. The Court in *Wyatt,* disallowed the argument on the part of the State that available financial resources were inadequate to implement the standards set. The conflict has still not been resolved. Assuming the court has the ability to mandate changes in the staffing and the allocation of resources, the question still remains as to whether such standards can be reasonably interpreted and monitored, what their long term effects on minimal policy and practices are likely to be, and their bearing on the patient who wishes to refuse treatment.[13]

The court's role in establishing treatment standards is still unclear. Although the Constitutional right to treatment established in the *Wyatt* decision was upheld by the U.S. Fifth Circuit Court, a similar Fifth Circuit Court finding in the *Donaldson* case was vacated[14] by the Supreme Court in June of 1975. *O'Connor v. Donaldson* 95 S.Ct. 2486 (1975) was the first case in the area of right to treatment, and in the area of rights of disabled generally, to reach the U.S. Supreme Court. It was hoped that the Supreme Court would rule in the case on the Constitutional basis for the right to treatment. Instead, the Court decided the case very narrowly on the facts and although the principle which they

affirmed in their decision was an important one, it left many questions unanswered. Basically, the Supreme Court held in *O'Connor* that a state could not involuntarily confine to an institution a person who is not mentally ill or a danger to himself or others. This reaffirmation of the basic right to liberty was indeed significant and could, potentially, affect a great number of institutionalized persons. However, its potential affects could be devastating if patients were released without adequate planning for community living. Institutions have been characterized in the past as societal dumping grounds. It would indeed be a gross misrepresentation of the intent of the law if recent court decisions were used to sanction state administrative programs which seek to reduce hospital population and thereby reduce state expenditures.

There is growing controversy in our society around the issue of "warehousing v. dumping," institutionalization v. de-institutionalization. To characterize the issues in "either/or" terms produces fruitless debate and is a misrepresentation of what constitutes an acceptable solution to the problems raised. Recent litigation has stressed not only the need for adequate short-term training or treatment for the mentally disabled once institutionalized but also the need to develop appropriate community alternatives to which formerly institutionalized patients may return. In addition to the development of adequate facilities, however, additional problems presented by de-institutionalization are the need for budgeting for reallocation of public resources and a coordinated tracking system which will provide accountability for continuity for services. A recent consent decree in *New York State Association for Retarded Children, et al. v. Carey,* the Willowbrook case, 393 F. Supp. 715 (E.D.N.Y. 1975), 357 F. Supp. 752 (E.D.N.Y. 1973) and a recently signed settlement agreement in the *Horacek v. Exon,* No. 72-L-299 (D. Neb.) suit both provide for the states involved to develop adequate community services systems. These suits have been brought on behalf of retarded citizens in institutions and a parallel suit, requiring the development of such community alternatives for the mentally ill is being brought in the District of Columbia in *Dixon v. Weinberger,* Civ. Act. No. 74-285 (D.D.C., filed February 14, 1974). Continued pressure from the courts to move in this direction can provide the impetus for the development of innovative, creative and decent living and treatment facilities for the mentally ill and the mentally retarded both in the institution and in the community.

De-institutionalization has been articulated as National policy, and the Federal Government has made some strides in providing the necessary funding of adequate hospital programs and development of community programs. The Social Security Act, particularly title 16, which provides for supplemental security income, title 19, which provides funding for intermediate care facilities, and title 20, which provides for the development of community services, have been reflections of this policy. Some states, Michigan being a prime example, have responded to the growing trend in court decisions in this area and have substantially revised their mental health codes to conform with legally and programmatically sound practice. The response, however, has not been adequate to meet the needs of the majority of mentally disabled people for treatment or services. Although the litigation process is often a long and

arduous one, the courts can provide the necessary pressure on both Federal and State Governments to develop more viable systems for the treatment and rehabilitation of its mentally disabled.

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Footnotes

1. M. Birnbaum, "The Right to Treatment," 46 *Am. Bar Assn Journal,* p. 499.
2. Ibid., p. 499.
3. H. Santiestevan, *Out of Their Beds and into the Streets,* American Federation of State, County & Municipal Employees, p. 10.
4. D. Mechanic, *The Right to Treatment,* unpublished document, p. 8.
5. Wolf Wolfensberger and Bengt Nirge [et al.], *The Principle of Normalization in Human Services,* Natl. Institute on Mental Retardation, Toronto, 1972.
6. F. Laski, "Civil Rights Victories for the Handicapped—II," *The Social and Rehabilitation Record,* June 1974, p. 29.
7. N.I.M.H. Statistical #114.
8. National Association of Co-ordinators of State Programs for the Mentally Retarded and National Association of Superintendents of Private Residential Facilities for the Mentally Retarded.
9. Santiestevan, supra, p. 11.
10. National Center for Law and Handicapped, *The Legal Rights of the Mentally Handicapped,* unpublished manuscript, p. 2.
11. Ibid., p. 2.
12. *Wyatt v. Stickney,* 325 F. Supp. 781 (M.D. Ala. 1971), 344 F. Supp. 1341 (M.D. Ala. 1972), *aff'd in part, modified in part sub nom. Wyatt v. Aderholt,* 503 F.2d 1305 (5th Cir. 1974).
13. Mechanic, supra, p. 23.
14. A decision by the Appellate Court that the opinion of lower court is of no effect and has no precedential value.

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PRIVATE INDUSTRY AND THE VOCATIONAL REHABILITATION PROCESS

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A Role for Industry?

Does private industry have a role in the vocational rehabilitation process and in the handicapped person's quest for independent living? Although most people from both the business community and the rehabilitation community would undoubtedly answer "yes," with varying degrees of enthusiasm and conviction, there would be no clear consensus on what the role could or should be. It is not the intent of this paper to define a precise role but, rather, to present a conceptual relationship between business and rehabilitation that merits the consideration of both.

The traditional role of private industry is that of an employer of qualified handicapped people. The Rehabilitation Act of 1973 implicitly recognizes and furthers that role by requiring firms doing more than $2500 worth of business annually with the federal government to establish an Affirmative Action Program for employment and advancement of the handicapped.

A second major role or form of involvement in which industry frequently takes part is that of a provider of resources in support of a specific program or need. The resources may take any of various forms, such as loaned equipment, facilities or instructors; personnel to serve on Government committees; and sometimes money. In addition to assuming a corporate responsibility for such types of support, many of the larger firms also have programs that encourage and facilitate individual employees' participation in community projects.

A list of the various means through which industry might participate would be practically limitless. For example, it could establish, underwrite, support, provide or operate training programs, transportation systems or housing programs. Useful and necessary as such support may be, it is too frequently addressed to a single need, without sufficient regard to its place in the total process or in the rehabilitation/industry relationship. These customary roles provide little opportunity for rehabilitation and industry to understand each other's problems or to combine their unique skills and experiences to their mutual benefit and to the benefit of the handicapped. There is, however, a potential role for industry as an active participant in, and advisor to, the vocational rehabilitation process that will open lines of communication and create a cooperative environment in which each can capitalize on the unique strengths and abilities of the other. A successful model of such a partnership exists in the Computer Training Project conducted by the California Department of Rehabilitation and the Center for Independent Living (CIL) with the support and participation of an Advisory Committee of Bay Area businessmen. Similar models have been or are being established in Virginia and Chicago.

The Models

In early 1973, IBM suggested to the Virginia Department of Vocational Rehabilitation (DVR), and more specifically the Woodrow Wilson Rehabilitation Center (WWRC), that we jointly undertake a project to train and place homebound handicapped people in data processing jobs as computer programmers. Shortly thereafter, the project was initiated with the DVR and WWRC assuming lead roles and project responsibility. The IBM group committed itself to providing assistance in those areas in which their unique abilities and experience would be most relevant. Because establishment of an enduring program was desired, the IBM assistance initially focused on areas in which DVR needed to develop new capabilities such as computer programmer training. Job development, placement, and project organization were areas in which assistance was also needed and provided. The types of assistance provided included:

- Participation in the development of course modules
- Provision of training courses for the WWRC instructors to refresh and/or augment their skills
- Provision of training for counselors and others to orient them to the data processing field
- Identification of potential employers and assistance to counselors on employer calls.

The DVR and WWRC were responsible for the actual performance of the major functions of the project such as client identification and screening, training, and placement. The IBM assistance was aimed at enhancing their abilities to perform those functions, although, in some instances such as placement, it was necessary to participate as "doers" more than was anticipated.

The project has been successful in that it has trained and placed 14 handicapped persons to date and has established a new capability in the Virginia DVR. Three of the clients placed are working in their homes. The project also provided insight into some of the needs of rehabilitation and suggested ways in which industry might aid in meeting those needs.

Based largely on the experience acquired during the Virginia project, a project was started in the San Francisco/Oakland Bay Area in October, 1974. The formative stages were completed by February, 1975, and on February 10 a class of 13 students started a nine-month computer programming training course at the Center for Independent Living (CIL) in Berkeley. As in Virginia, the Department of Rehabilitation was responsible for project formation and performance, with assistance from IBM. CIL assumed responsibility for conducting the training program. In this case, however, it was decided to attempt at the start to form an advisory committee representing major local business firms to assist in the project and form the nucleus for addressing related needs, some of which had been observed during the Virginia project. (These needs are discussed later in this paper.) A committee composed of representatives from approximately 15 business firms, the Department of Rehabilitation, the CIL, and the handicapped community was established. The committee actively participates in the project rather than playing a purely advisory role. Industrial members come primarily from the Data Processing, business operations, personnel, and training departments of the participating firms. The committee, through its three sub-committees, Technical, Business, and Placement, provides assistance and guidance in a number of areas. It:

- Defines the skills and abilities a graduate of the program should possess
- Assists in developing the course to produce such a graduate
- Assists in acquainting the student with the business environment and in developing job seeking skills
- Provides a form of course accreditation by participating in the development of the program and conducting a review board of the graduates
- Assists in obtaining placements for class graduates

This is by no means an exhaustive list, but rather an identification of some of the major functions of the committee. The industrial members also provide guest lecturers and some training materials and participate in a variety of ways. It should be noted, however, that although the firms involved also fill traditional roles of providing resources and jobs, they do so as part of a coordinated effort with the rehabilitation community. The committee has also assumed certain responsibilites directed toward the continuation of the project in the Bay Area and to its expansion throughout the state, not only in the area of continued functioning, but also in recruiting new industrial members for its own and other as yet unformed committees.

A similar project has been started in Chicago. The nucleus of an Advisory Committee has been formed which has developed a description of the course content necessary to train a productive entry-level programmer. There is to be a continuing, coordinated effort between the committee and community colleges (which will conduct the training) to tailor a course to satisfy that description. The committee is also to perform other guidance and assistance functions in concert with the Illinois Division of Vocational Rehabilitation, as is being done in the Bay Area project.

Obstacles to Placement

A major objective of vocational rehabilitation is to place handicapped people in employment commensurate with their interests and abilities. Achieving that objective has become more difficult and challenging with the increased emphasis on providing services to the severely handicapped; the demands of a changing business world; and a constantly increasing case load. Before discussing the virtues of the advisory group concept as a means of supporting the attainment of that objective, it is worthwhile to examine the more significant factors that bear on its achievement.

Occupations for the handicapped have become stereotyped, and job opportunities tend to be sought in a fixed and relatively narrow spectrum of possible vocational paths. Many of the occupations targeted in years past are no longer in demand and many are not suitable for the severely handicapped. Opportunities for the severely handicapped are extremely difficult to identify for those reasons and because of client physical limitations, transportation and facility barriers, employer reluctance and a myriad of other factors. Business changes and technological advances have created a mixed blessing. Those occurrences have created new job opportunities, such as computer programming, that do not require great physical strength, mobility or dexterity but instead have a major intellectual component that may make them particularly suitable for the severely physically handicapped. They have also made it increasingly difficult to develop and maintain the understanding of the job market and job requirements needed to establish meaningful and achievable client placement objectives.

Present training programs frequently lack credibility both to the potential employer and to the potential student. Many firms contacted during the previously described projects felt that most college trained new employees were not adequately prepared to become productive programmers without additional training. In general, present training programs lack orientation to the practical aspects of the vocation, fail to include the techniques of the field felt by industry to be essential to preparing an individual for competitive employment, and do not provide orientation to business operation and the work environment, or training in job seeking skills.

Employers tend to view jobs in terms of established requirements and do not spontaneously consider possible task modifications that can make the difference between successful placement and no placement. There is also much misunderstanding, misinformation, and lack of information regarding the need for architectural changes, physical accommodations, and the productivity and absenteeism of the handicapped worker.

Many younger handicapped people lack the self-confidence and assertiveness required to obtain employment on their own. They may have little or no experience or acquired skills in job seeking and often have very limited knowledge of the occupation or job requirements. They must also contend with a disincentive to employment created by the potential loss of disability benefits, especially medical, when they take a job at a level of earned income insufficient to offset the loss.

A Rehabilitation/Industrial Alliance

There are a number of actions necessary to cope with that formidable array of barriers to employment for the handicapped. The technological advances in industry must be exploited to identify new occupational opportunities and job demand must be determined. Job descriptions must be developed and training and experience requirements defined. Existing training programs must be updated and new ones established, if necessary, to reflect current occupational demands and to include job-seeking skills and orientation to the work environment and to the actual work to be performed. The placement process must provide for active participation by the counselors on behalf of their clients and for exploring the concepts of job modification and rehabilitation engineering to augment client abilities. Means for effectively addressing the employers' concerns regarding such issues as productivity, absenteeism, and insurance rates must be developed. Above all, comprehensive client plans should be established and carried out to integrate and coordinate the required services from referral to closure, whether or not job placement is the rehabilitation objective for a given client.

To accomplish those actions and achieve the placement objective requires a wide range of skills and knowledge. Rehabilitation's special knowledge of the handicapped, and their competency and experience in humanitarian services, comprise one category of required skills. In addition, there is a need for knowledge and experience in business fields such as job market analysis, job analysis and definition, task modification, vocational training, business organization and structure, project management, and salesmanship. It has been observed that few if any counselors possess all or even most of those business oriented skills. Nor does it seem reasonable to expect counselors whose education and preparation has emphasized the social, psychological and humanitarian aspects of rehabilitation to possess, in addition, the skills normally associated with industry.

In theory, training programs could be established to provide counselors with the opportunity to acquire the necessary skills. Practically, however, there are a number of factors that mitigate against that concept on other than a limited basis. The number of counselors to be trained, number of disciplines involved, counselor absence from his or her caseload and similar considerations make the success of such an undertaking problematic. A more effective method of acquiring the required skills would be to enlist industry as a working partner to assist rehabilitation in its pursuit of improved job development, training, placement, and other vocationally oriented services. Both rehabilitation and industry would, as an adjunct to working together, acquire new skills and insight into each other's domain.

Unlike present committees for employment of the handicapped, sponsored by various levels of government, the proposed alliance would be an active working group that would jointly plan and conduct projects utilizing the unique skills and knowledge of each member. The alliance would be similar to the Bay Area Advisory Committee in both composition and function. It would include representatives from industry, the rehabilitation community, the handicapped community, and the training or educational community, and would function under the direction of a project leader. The combination of special skills and insight brought to such an alliance by each member group could foster innovative and relevant projects for, and approaches to, the training, employment, and independent living of the handicapped and benefit all by providing:

- Business with a new source of employees who possess needed skills
- Rehabilitation with assistance in orienting their vocational services to current and projected business needs
- The handicapped with new employment opportunities and enhanced services to exploit those opportunities.

The precise manner in which the alliances would function and the specific issues they would pursue would be determined by the groups themselves based on the attributes of the members and the more critical needs in their community. The general nature of the functions to be performed by the alliance and the roles of the various members are illustrated by the following brief discussion of the process as it would occur in addressing major aspects of job development.

The need for a job development effort, described above, includes a requirement for identifying and defining job opportunities that can be filled by the handicapped, and the skills and training required. To satisfy that need, a working group would seek to define occupations in demand that are suitable for the severely handicapped; the job requirements in terms of tasks, training needed, physical and intellectual requirements; and, if possible and desirable, categories of disability that are not handicapping for given occupations. Each member would contribute to such an effort based on his specific capabilities and strengths. Members from industry would be responsible for defining the demand for specific occupations in their community and defining job requirements. Members from the rehabilitation and handicapped communities would assess the applicability of the various occupations, the availability of qualified clients and support needs. The availability of the necessary training, or the effort required for its development, would be addressed by members from the educational community. The functioning of the working groups would be similar for other issues including those not necessarily related directly to employment such as architectural barriers, transportation, housing, and education. Representation from

agencies and organizations in addition to those mentioned should, of course, be sought as appropriate to the need.

Forming the Alliance

How would the alliance between rehabilitation and industry be formed to address needs such as those described? Although a specific detailed method has not been developed, there are a number of possible actions that might bring about the desired liaison. First, a national meeting of top executives from a number of leading industrial firms and leading members of the rehabilitation community, perhaps the Council of State Administrators of Vocational Rehabilitation, could be held to explore ways in which the liaison could be established, and to achieve the necessary support and pledges of participation.

A next logical step, and one to be discussed at the first meeting(s), would be a workshop attended by appropriate designates of industry and the state and federal rehabilitation community. Subgroups could address major subjects (e.g., Training, Job Development) of the program with a responsibility for developing a plan, position, and objective by the end of the workshop. Each group would address the broad factors, such as objectives and constraints, of its specific subject and the basic questions of how, when, where and who. The establishment of organizational measures necessary to create a continuing relationship and to create and conduct projects specific to the local environment and need would be a major objective of initial meetings.

The projects conducted to date provide a basis for optimism about the chances of successfully forming such a liaison. In particular, the Bay Area project has demonstrated that a partnership can be formed by industry, rehabilitation and the handicapped at the local level that is extremely effective in dealing with obstacles to the common objective. Furthermore, studies in other geographic locations regarding their ability to support similar projects revealed that a majority of the business firms contacted were receptive to participating in such projects. The experience in Virginia, Chicago, and Oakland/San Francisco indicates that receptivity to the concept may extend to active participation when the concept is implemented. It now remains to exploit the interest of rehabilitation agencies and industry in such projects in the interest of an improved quality of life for the handicapped.

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INDEPENDENT LIVING AND THE STATE AGENCY FOR THE BLIND

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Organizational systems lend themselves readily to being perfected and made more efficient as a process of growth. Feedback from staff, community, leadership and new legislation all provide cues to needed change. Unfortunately, there are no equally responsive signs or signals that the organization is out of touch with its purpose. As a result some organizations continue to do well that which they have done for many years without regard to continuing necessity, appropriateness, or the needs of those unserved and waiting "in the wings." An evaluation system, therefore, becomes a necessity.

At the turn of the century, state agencies for the blind were legislated into existence to serve the blind and ameliorate their condition. Intially, this took the form of friendly visitation, later to grow into home teaching, handwork training, and recreation. As federal legislation expanded, service programs and agencies became participants in the federal grant-in-aid process for developing vocational rehabilitation opportunities for the blind. This federal infusion of funds into the states obviously stimulated vocational rehabilitation programs so that they became more and more potent and in time the dominant services provided by the state agency for the blind. Yet, at its most optimistic only 30 percent to 35 percent of the blind can be considered employable. Another 10 percent to 15 percent are children which leaves at least another 50 percent who are elderly and whose needs differ greatly from the children and the employable group. While in recent years a number of writers have called attention to the paucity of services to the elderly, very little exact study and definition of needs for this group has been made. In New Jersey, a study[1] of 800 older blind people indicated that older blind people have four major areas of need.

1. *Isolation*—about 25 percent of the group live alone and frequently even those in family or congregate living are actually cut off from many personal and social contacts by the social attitudes around them.

2. *Lack of Information*—information systems and counseling, "a person to turn to," are considered an essential need because of the high degree of detachment from family and community prevailing among this elderly population.

3. *Increased Medical Needs*—the incidence of one or more chronic health problems is very evident.

   Among this population the following was identified:
   20 percent have Diabetes.
   20 percent have heart conditions.
   23 percent need dental care.
   26 percent have abnormal blood pressure.
   34 percent have foot problems.
   34 percent have hearing problems.

Happily, 80 percent of the group reported that they are under the care of a physician. However, one out of five do not have needed transportation, necessary funds, or someone to care for them at home if ill.

4. *Financial Needs*—New Jersey is a highly industrialized state and it is, therefore, not surprising that nearly four out of five individuals sampled have some kind of Social Security coverage. 22 percent receive Public Welfare and 5 percent employment income. However, 25 percent of the group feel their income is inadequate to meet basic living needs. A considerable number, 30 percent, do not know how to get information about income-maintenance programs and have not checked potential sources.

   Twenty-five percent said that even if they did need financial help they would not be willing to apply for public welfare because this is considered a stigma and charity. Some are willing to endure severe hardship in order to shield legally responsible relatives against routine investigation. Pride prompts others to forgo public assistance in order to cling to an insurance policy which will assure a "decent burial." Some feel strongly that being blind should not be equated or associated with welfare.

Obviously not everyone who is blind should be automatically considered a candidate for service by a social agency. Like any other citizen group they need to have the right of choice and particularly at critical times. But if services are not available, can there be any choice? This brings us then to the thesis that:

I. *State agencies for the blind need to be comprehensive agencies serving all blind people—not merely those designated as employable and in a manner consistent with current needs.*

   The government needs to expand its concept of vocational rehabilitation to just rehabilitation so that every blind citizen who can profit from retraining and life adjustment services is given the opportunity. We see no problem in having a separate title under the present rehabilitation act to make this a reality. If a fixed sum were appropriated by the Congress for this purpose the grant-in-aid system would soon stimulate study and improvements in every state to meet such a new charge without interfering with the present vocationally oriented system. We do not consider one the adversary of the other. Both are essential. Ten million dollars appropriated the first year and building up to 30 million dollars in later years would adequately provide for this program nationally.

What are some of the issues confronting this need?

1) *Comprehensive Services and the Private Agency.*
   The objective of having state agencies provide comprehensive services does not contemplate reinventing the wheel. The state agency must have a basic and residual interest in state-wide needs. Where services do not exist, the state agency must develop them. Where there are satisfactory private agencies, services can be provided or purchased on a fee for service basis. But most important the needs of all segments of the blind population need to be considered in this process.

2) *General Services vs. Specialized.*
It would seem rather obvious that a social security system of payments at age 62 or 65 to retired workers would work equally well for the blind individual as it does for the general population. The same is true for Medicare or Medicaid or general hospital services. A blind person's appendix when removed is not likely to be different from anyone else's.

On the other hand sending a blind person to a rehabilitation center serving other physically handicapped groups can be a disaster unless specialized personnel knowledgeable in serving blind people are available. The purpose of the specialized rehabilitation center or training center for the blind should be to give blind clients those personal and social tools they require to move freely within their capacities in their environment.

All of this assumes adequate planning on a state-wide basis, clarity in objectives and goals and adequate evaluation of results.

3) *The Changing Character of the Blind Population and the Social System.*
Social time lags are well-known. Perhaps the most conspicuous in work for the blind and in the social attitudes toward blindness of the general public in this country is the assumption that every blind person should be taught the accoutrements and symbols of blindness, as for example braille—this despite the fact that only about 25 percent of the blind children attending public schools or residential schools in this country are braille readers or need to be. Blind children and adults are rightly being taught to read print whenever possible. Low vision aids and ordinary refractions are making this possible because more and more of the blind population have residual vision undoubtedly due to better ophthalmological care, medical advances and effective control of a variety of inflammatory and acute eye conditions.

More and more agencies for the blind need to be involved with health problems of the blind population since it is clear that at least 50 percent of the blind are likely to have other serious or multiple handicaps. This has important overtones for program planning, service delivery systems, and is relevant to the thrust of the congressional mandate in the Rehabilitation Act of 1973 to concentrate on the service needs of the severely disabled.

It means, also, that new techniques for employment placement need to be considered since many will not be able to be placed competitively because of the severity of their handicap. In a country as committed as we are to transfers of income through such devices as Social Security, SSI, Unemployment Compensation, Medicare, Medicaid, and possible negative income tax laws in the future, it would appear to be "small potatoes" indeed to provide subsidies for employing multi-handicapped blind people as inducement to employers and to clients under controlled conditions. A system that provides millions of dollars to disadvantaged countries can surely find and support a nominal cost of this kind for its own disadvantaged. I would estimate this cost at less than 10 million dollars a year nationally. Yet it would be a remarkable investment in reducing dependency costs and an essential ingredient in giving multiply-handicapped blind people equal employment opportunities.

In addition to the personal adjustment skills, the handwork, communications and aids to daily living, agencies for the blind need to concentrate on the personal and social problems confronting blind people in our society today. They need to see to it that wherever possible blind people are not isolated and detached; that adequate needed information is reaching them; that the community organizations are including them in activities; that social attitudes which "stigmatize" blindness are brought out in the open and corrected and that staff are assigned specifically to work with these needs so that they are not ignored or forgotten.

So far we have spoken about independent living for those blind people who live in their own home, with family or by themselves. The thrust of independent living services should be made in this setting, in the home of the client and as early as possible in order to re-enforce the ability of blind people to be a part of their home and community. Organizations of the blind have properly indicated how badly advocacy programs are needed to overcome stereotypes and prejudices against blind people. And we all know of individual situations in which blind people are refused certain types of careers or plane rides, or housing, etc.

However, numbers of blind people are living in congregate centers, state and private institutions, nursing homes and the like. This raises a second thesis which we support, namely, that:

II. *Blind people should have the right to live in accommodations of their selection.* For many individuals this is fine but there are a number of issues.

1) *What if they cannot make selections?*

People, including blind people, may be so ill as to be unable to do things for themselves. Blindness deprives some who live alone of the ability to look for a new apartment. What of individuals who are psychologically dependent and have no family? What of the many deaf-blind Rubella adults?

2) *What of those who do require Institutions?*

Irving R. Dickman, Author of Public Affairs Pamphlet #522—"Independent Living: New Goal for Disabled Persons," writes, *"Institutions were not originally established for the sake of their residents."* The first asylums were created in the Middle Ages to house blind beggars, not so much to provide care for them, historians now agree, as to remove them from the sight of society.

"Institutional segregation of the handicapped took hold in the United States between 1870 and 1880, supposedly because the blind (or the retarded, or the severely disabled) are happiest with their own kind. If this was ever true most handicapped people no longer feel that way. On the contrary, many feel that if their differentness leads to their segregation, then their segregation *increases* their differentness."

Pick up a newspaper in any state having an article on the status of state mental institutions, and one is soon impressed by overwhelming conclusions that many institutions continue their original purpose of segregating unfortunate individuals away from the view of society. It is fortunate that there is a ground swell of public feeling to make institutions into treatment centers rather than warehouses for humans, or to close them.

3) *What of the severity of the handicap?*

Obviously there is a tremendous variation in severity among blind or handicapped individuals. The bedridden, the quadriplegic, the deaf-blind, the individual out of touch with reality are at a further point on the scale of disability than the ambulatory, active, blind youth. No one system can speak for all. Parents by over-indulgence may condition their blind children to dependency, frequently taking the attitude that their child will never go into an institution "as long as I live" but also seeking agency help to provide a protective, safe environment for their adult children after they die. Mr. Irving Dickman calls this "conditioned helplessness."

To quote him again: "Not all handicapped people, perhaps not even the majority, can or will ever want to live independently. But a growing number of severely-disabled young adults and teenagers are hoping, asking, planning to live not in institutions, not in homes of their parents but like other young people—in homes of their own. And new methods of government funding, new concepts of *supportive or standby services* by community and voluntary agencies, and new social attitudes, which accept the right of each individual to choose his own life style are stimulating increasing numbers of disabled people to ask, 'Why not me too?' "

It seems to this writer that the majority of the blind wish to live independently. They may need access to state and local agencies that can be supportive and provide standby services when needed without interfering with the individual's right of selection.

Alternatives to custodial care or independent living have taken a number of interesting paths. State institutions are being decentralized; group homes and halfway houses are in use; there are private apartments with two or more handicapped persons living in them. Small group living units are being tried. And of course there are senior citizen housing projects, the nursing homes and congregate homes for the aged. No perfect answer is at hand. Most people lose sight of the fact that older people are no more static than younger people. Somehow once past a certain age we tend to write off the individual and assume no growth or change. Actually older blind people, like their sighted friends, do change. Social and health hazards can become greater or less and changes in living arrangements may become necessary.

Much supportive work by agencies and families can be organized to keep older people, including older blind people, away from institutional settings. But ways must be found for compensating for lost ability to participate in community and social activities. Most of all the blind person should have the right of choice and the chance to succeed or fail at being independent.

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THE DISABLED STUDENTS IN THE COLLEGE AND UNIVERSITY SETTING

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The intent of this paper is threefold: first, to describe current issues in the education of the physically disabled; second, to outline a model support-service program in a post-secondary educational institution; and third, to attempt to identify some key issues which will need to be addressed in the continuing development of the disabled student program.

A kind of revolution has suddenly and swiftly swept through college and university systems across this country. Those who have spearheaded this sometimes spectacular movement have opened the way, in many cases, to much greater social change in the larger social systems. The development of disabled students programs is a movement in which disabled people themselves have experienced the need, attacked the problem, and led the fight in establishing equal educational rights and opportunities for the disabled individual. This element of self-leadership distinguishes the new programs at post-secondary level from those in primary and secondary schools, and from most services for the disabled.

At the elementary and secondary levels, significant change is also occurring, however, perhaps partly as a result of the post-secondary movement. The tradition of "Special Education" has come increasingly under fire. In a recent article of ICD News, Dr. Salvatore G. DiMichael succinctly described the historical dilemma of segregated classes for the handicapped. He notes:

> First, society has regarded the handicapped as different from non-handicapped people in a way that perpetuated a sense of inferiority in them; at the same time, we said, and many studies showed that the achievements of the handicapped in school and later in adult life are not inferior.
>
> Second, we built many specialized schools and facilities and organized classrooms that are essentially segregated; at the same time we said that the handicapped students had to learn to cope with the everyday problems of the "normal" world. This cultivated a sense of exclusivism justified in idealistic terms, i.e., that we were doing good for misfortunate people, and that we worked with the handicapped, understood them while other people did not.
>
> Third, we acted to unduly shield them from the problems of living while we said that the last thing we would do is to overprotect them.

"Special Education" for the handicapped has flourished at the elementary and secondary levels. But, fortunately, few, if any, public institutions at the post-secondary level have provided this type of separate educational programming. The disabled individual was fortunate to have a "non-system" at the post-secondary level rather than to have a separate

"special" system since, once entrenched, such a system might have taken years to uproot. Now that services are coming into existence at the higher education level, there is the opportunity to avoid mistakes exhibited in the past by many of the "Special Education" programs.

The Right to Education

A simplistic sounding statement is that all people should have an equal opportunity for education. The recent past, however, demonstrates that equal opportunity for education has not existed for the physically disabled individual at the post-secondary level. Not until the past five or six years has there been any significant recognition of the need for, and subsequent growth in, post-secondary educational institutions serving the physically disabled individual.

A major cause of this change is that courts have recently handed down decisions establishing the right to education for the physically disabled. The "Philadelphia Case" (1971), holding that education of the handicapped child is not an act of philanthropy, but a constitutional right; and the "Washington, D.C. Case" (1972), holding that absence of money is not a valid excuse for failure to guarantee rights to disabled people, including the right to education, were key points in the movement to provide equal educational opportunities for the disabled person.

Deterrents to Higher Education

Today, however, there still exist substantial barriers for the physically disabled individual in attempting to enter an institution of higher education. In a recent unpublished paper, Dr. Ray Jones, Director of the Center on Deafness, California State University, Northridge, California, wrote the following:

> Dr. Ray Barsch, a nationally recognized authority in the field of special education, has identified the following as major barriers which tend to limit the number of handicapped students entering higher education.
>
> (1) Attitudinal barriers of paternalism and low expectations.
>
> (2) Financial barriers—These are often erected by "professionals" who think that education of handicapped students can only be successful when carried out in a special school with unlimited funding and full complement of highly specialized personnel. Too often they discourage efforts to serve handicapped students in regular education settings.
>
> (3) Architectural barriers—These are very real and exist on almost every campus in America today. The situation is improving as new architectural standards now require that all public buildings be accessible to the physically disabled individual. However, it will be many years before all college and university buildings will be fully accessible to handicapped students.

A fourth barrier of "being educationally disadvantaged" has been identified by Leonard Eato, Poster Boy for Cerebral Palsy in 1950 who made the following statement:

> It is obvious that in giving the handicapped student separate and unequal treatment, society is saddling him with an educational disability to add to his physical one—much of the argument which led to the outlawing of racial segregation in the school could be applied in the case of the handicapped.

In addition to the four barriers listed above, another equally significant barrier bars access, or predetermines failure, for the physically handicapped in higher education.

(5) Lack of services and resources: The 1973 Vocational Rehabilitation Act mandates an emphasis on services for the severely handicapped. Many people assume that, as a result, there has been a dramatic increase in services to the severely physically handicapped, including programs of post-secondary education. That, unfortunately, is not the case. Nationwide vocational rehabilitation funding was not increased for fiscal year 1974/75 over fiscal year 1973/74. The net effect has been a *reduction* in client services due to spiraling costs. To illustrate, in Arizona, from fiscal year 1972/73 to 1973/74 to 1974/75, the average cost per client served has jumped from $1,400 to $1,800 to $2,100. The program is severely pressed to meet basic training, educational and other support services required for its present clientele. To expect the agency to fully fund all programs of post-secondary education for the severely physically handicapped is unrealistic.

In addition, there are a number of very specific problems related to the dependence of the student on Vocational Rehabilitation agency support. Dr. Jones identifies a number of these barriers:

(1) The requirement that handicapped students must have an assurance of being employed in their chosen field before a program of studies will be authorized.

(2) Requiring that the client must carry a full academic load each semester and complete his training in four years.

(3) Requiring handicapped students to obtain counselor approval before dropping courses or changing their academic objectives.

(4) Withdrawal of agency support if passing grades are not maintained.

(5) Requiring grade and attendance reports from clients.

(6) Denying clients the opportunity of attending summer school or extension classes by withholding agency support.

(7) Agency regulations which discourage students from accepting summer employment, work-study experience, or taking off a semester or two to get meaningful work experience.

The Costs of Education and Funding Sources

Since the education of handicapped clients at the university level may extend over four to six years, the total costs for all clients who could profit from higher education far exceed the funds available to the Department of Rehabilitation. The inevitable result is rationing of resources by accepting only the most promising clients (approximately one out of ten) to receive college support.

At the post-secondary level, the responsibility for meeting the excess costs of education for the severely disabled has too often been left to the vocational rehabilitation system. Jones (1974) advocates that colleges and universities be reimbursed for the excess costs of educationally-related or life-support services required by disabled students. If the states are unwilling to assume this role, then programs such as the Special Student Services Program, funded by the U.S. Office of Education, should continue to play a major role in funding programs which provide the "excess cost" services. State welfare programs and federally supported programs such as S.S.I. and vocational rehabilitation could then provide the basic maintenance support.

Staffing of Disabled Students Programs

A disturbing trend has begun to emerge in colleges and universities across the U.S. within the past two to three years: the establishment of a *single* counselor or coordinator designated to provide services to all handicapped students on a campus. Such a "program" and, hence, services to the student, are predestined to failure. Evidently, it is assumed that a single individual can develop and provide a comprehensive program of quality services to meet student needs. This is doubtful even under the best of circumstances, and too often the position carries no administrative clout and is low paying, and hence attracts unqualified or minimally qualified persons.

One can advance the argument that a program staff of one is better than none, and this is often said honestly, albeit naively. That point of view can be labelled "tokenism." A single counselor or coordinator of "handicapped services" will often be part of the traditional student services office. Many of the more successful programs that serve physically disabled students have been administered independently apart from the often tradition-bound "office of student affairs." In addition, many of the most effective program leaders are themselves disabled.

To sum up, in order to be effective, disabled students programs should (a) have adequate staffs and resources; (b) be independent agencies within the campus bureaucracy; and (c) be directed by people who themselves are closely familiar with the experience of being disabled.

Level of Education

The need for all severely physically handicapped people who are able to attain post-secondary education, including masters and doctoral level training is critical. The lifelong excessive costs of survival mean that incomes must be at a high level for the individual to be capable of self-support. If every non-handicapped member of our society were suddenly confronted with costs of $3,000 to $6,000 per year (which represents the cost of survival *before* the basics of food, clothing, and shelter) a greater awareness of the plight of the severely handicapped would probably result. Higher education for the severely handicapped is an avenue of escape from a life-long sentence to mere existence on welfare rolls or dependency on the "charitable" whims of the more affluent society.

Education for What Purpose?

An extremely sensitive current issue concerns the reasons why a disabled individual attends an institution of higher learning. The sponsoring agency almost inevitably will hang the specific vocational objective as a guillotine over the head of its client. Without the pursuit of "substantial gainful employment," support is not forthcoming. Probably the majority of all first year non-disabled students in post-secondary education programs have no set vocational objective. In order to provide truly equal opportunity to education, the disabled individual should *also* be able to enter the system with the sole objective of "higher learning" if he or she so chooses. Nondependence on the vocational rehabilitation system (in its present form) is a major first step for that individual who chooses not to be vocationally directed.

A Model Service Program in a Post-Secondary Setting

The following conceptual program model was developed as the primary objective of a U.S. Office of Education, Region IX Task Force. A number of institutions in Region IX have programs approximating this model, or have a significant number of its components operative in their programs. A number of antecedent conditions are assumed for the effective implementation and administration of a program based on the model:

(1) Support from the top administrative officials of the University is required.

(2) Involvement through all levels of the University administration is essential to develop services and to effect positive change.

(3) A basic attitudinal approach and objective of the institution should be to provide basic educational opportunities to handicapped students.

(4) A sufficient number of trained staff are required to insure a program of quality services.

(5) The program director must be in a position to work within the University structure at all administrative levels to effectively develop and direct program activities.

The model program description is divided into two sections: (1) Program Objectives, and (2) Evaluation Criteria.

(1) **Program Objectives**—Objectives of a model program involve providing supportive services to disabled students from pre-admission to post-graduation, both within and beyond the walls of the institution, ranging in kind from the provision of materials to counseling and financial support. Specifically, some key objectives are:

- To provide special orientation and assistance in registration.
- To provide classroom assistants such as notetakers, readers, interpreters;
- To provide adequate medical care and facilities;
- To make available accessible housing, parking, and transportation, both on and off the campus;
- To eliminate architectural barriers;
- To provide and coordinate general and special financial assistance;

- To make available regular and emergency attendant care;
- To provide adaptive physical education;
- To establish a mobility center for maintenance of equipment and emergency service;
- To purchase special equipment needed by particular disability groups (e.g., swimming pool lifts, rapid braille reproduction system);
- To schedule leisure time events and resources;
- To provide a resource center and services such as mobility training for blind students;
- To collect adequate follow-up data on students involved in the program;
- To employ disabled peers in the program, providing them with in-service training;
- To affect the attitudinal climate of the institution in a positive direction.

(2) **Evaluation Criteria**—Basically, the "evaluation criteria," which describe elements of a quality service, set forth key details to be included in implementing the above objectives. For example, with respect to the attendant care objective, there should be a systematic program to recruit attendants, including screening and in-service training for employer and attendant, as well as knowledge of funding sources and establishment of an emergency back-up service.

In addition, the evaluation criteria includes certain quantifiable goals, such as meeting *all* requests for notetakers and interpreters, students' successful completion of the semester, and post-graduation employment. Also included is the more subjective (though not necessarily nonquantifiable) goal, movement from dependent to independent living status, defined as autonomous management of one's own affairs.

THE FUTURE

Personal Commitment

A first consideration concerning the future of higher education for the disabled seems to me to be the kind of personal commitment that those disabled people who are involved must make to continue the movement for full participation in society for all disabled individuals. I think we can all agree that the past five years have shown great positive change for the disabled individual in our society. Many new avenues of participation have been opened, and many of those involved have had exhilarating personal experiences.

Society will praise those who have participated, especially those who have emerged as leaders. But, the corollary of "you've made it" can be, "now you are surely satisfied." Social change is a process, a continuing process. That concept needs to be reiterated as often as necessary.

Building on Present Programs

The Model Service Program outlined in the previous section must not be viewed as a static framework, but as a dynamic working outline which will require continuing re-evaluation and change as new needs become apparent. For example, it should be changed to include an "outreach" services component for reaching the unknown numbers of physically disabled individuals who could benefit from post-secondary education but have not become involved. Outreach services would appear to be particularly critical in reaching the physically disabled/ethnic minority individual. Those should become a high priority since the problems experienced by this person have been, and continue to be, overlooked.

The Program Director—An "Educational Statesman"

Strong leadership of disabled students programs is needed in order to establish their credibility within and beyond the college or university. The power structure will usually respond positively to a spokesman who represents a program perceived as being worthwhile. In order to so represent the program, the director must have full knowledge of all of its aspects. (S)he must also have a good working relationship with program staff and students in order to adequately represent their needs and in order to make and keep the program a high quality one, deserving of support.

Program Support

Financial support of education programs for disabled individuals is, of course, a primary consideration. Groups of disabled consumers and involved professionals need to develop on-going relationships with state and federal funding agencies and with key congress people and legislators to insure continuing support of disabled students programs and to provide for future expansion as court-ordered and legislatively mandated changes in education at the primary and secondary levels bring about a dramatic increase in the numbers of disabled students seeking higher education. An effective way to do this at the national level would be to develop strong ties with national professional organizations, such as the National Rehabilitation Association.

The Role of Vocational Rehabilitation Agencies

Vocational rehabilitation agencies will continue to play major roles in providing support services to physically disabled students in the post-secondary setting. A basic principle in providing these services is that clients should be provided training and services to enable them to reach the highest level of their potential. However, present priorities and statistics collecting methods of VR agencies do not encourage such attainment. Indeed, the emphasis on "successfully closing" cases tends to put a premium on finding the placement which requires the least effort and expense on the part of the agency. Changing this situation should be a primary objective of consumers and concerned professionals.

Attitudinal Considerations

The attitudes of individuals and of society toward the physically disabled have played a prominent role in the existence and life styles of disabled people. Negative attitudes or attitudinal misconceptions (by the non-disabled) may be the single most devastating factor for a disabled person. Six years after the establishment of the disabled program at the University of Arizona, we still hear the familiar phrases, "your programs" and "your

students," as if programs serving physically disabled students were not part of the total educational institution. It is clear, therefore, that *simply* establishing a disabled students program and integrating students at the university level does not bring about basic attitude change. Because attitudinal change is usually extremely difficult to effect, the issue of educating or reeducating the public is one of the toughest but most important social issues for the future.

Potential Effects of Model Post-Secondary Programs

The disabled student programs, in my view, could assume a major role in providing reeducation for elementary and secondary school systems. Existing program components will, in many instances, be directly applicable to programming at those levels. Without meaning to be unkind, I believe special emphasis in reeducating the educator should often be given to the "Special Educator." The disabled student in the post-secondary setting can also serve as a role model for the younger disabled child.

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LEGAL SERVICES BY THE DISABLED FOR THE DISABLED

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In most communities a disabled person has very limited access to the legal system. To illustrate the problem, take the case of Ms. X, a paraplegic who has been the victim of housing discrimination. She has been looking for a place to live and has found an accessible apartment, but the landlord wants a damage deposit that is three times as high as the normal deposit. He freely admits that the extra cost is because Ms. X is in a wheelchair.

In most cases, the disabled person does not know what his or her legal rights are. In this case, Ms. X feels that this special deposit is unfair, but she does not know if it is illegal or not. Some disabled people, used to second-class treatment, would simply pay the extra charge even though they don't like it. Accessible housing is difficult to find, and it can be a very frightening prospect to try and buck a system that has been imposing oppressive rules and practices for as long as one can remember. It is always difficult to do things alone, and to overcome the social conditioning, "you should be happy with what you get; don't cause trouble," that most disabled people have received.

Ms. X decides to go to a lawyer. What type of lawyer should she go to? Where does she find one? If she were to call the local Bar Association Referral Service asking for a lawyer who specializes in disability problems, she would most likely get no help or maybe the name of a lawyer who specializes in medical malpractice. That's the only type of disability-related problem the legal profession seems to be aware of. There may be a few lawyers in the community who are interested in civil rights for the disabled, but it usually is not their specialty and the Bar most likely doesn't know about it.

Ms. X decides to go to a lawyer who was recommended to her by a friend because he's the uncle of another friend. If his office is any distance from where Ms. X is staying, she's going to have trouble getting there unless she has a car. Mass transportation in most cities is inaccessible to the disabled. She does have a car, however, so she drives to his office. Unless she has called first and asked whether there are stairs at the office entrance, she may not be able to get in to see the lawyer. Even if she did call first, the secretary may have told her that the office does have a level entrance, forgetting the fact that there are two steps to get to the elevator. Unless a person is aware of architectural barriers and the problems they pose for disabled people, such details can be easily overlooked.

Assuming this lawyer has an accessible office, Ms. X next has to deal with any discomfort her presence may cause in the reception room. Her problem would be much worse if she had

any type of speech impediment. It's not comfortable to be stared at or treated with condescending helpfulness. The same problem exists when she goes in to see the lawyer; unless he's comfortable with a disabled person, his feelings of discomfort will be obvious, no matter how he tries to hide them, if he does. His own fears of disability or pain may influence him to the extent that he really pays no attention to Ms. X's legal problem, but concentrates only on how to get rid of her as fast as he can. If that were to happen, Ms. X would probably leave with the impression that she has no legal claim and will have to pay the lawyer for her waste of time.

If the lawyer is able to deal with Ms. X's presence, he may still have absolutely no idea what legal solutions are available. After listening to her story, he may decide that in his estimation the landlord is justified in asking for a higher damage deposit, and as far as he knows there's nothing to be done about it. If he doesn't know whether there's a statute dealing with housing discrimination against the disabled in rentals, he may not bother to find out. Most lawyers don't know that in many states such legislation exists.

If this lawyer does know about such a statute, or if he decides to research the problem to find out, then he has to decide whether Ms. X has a viable cause of action against her landlord. In California, the statute provides that physically disabled persons "shall be entitled to full and equal access, as other members of the general public," to housing accommodations offered for rent. (Calif. Civil Code §54.1[b]) It doesn't specifically say anything about damage deposits; therefore it's up to the judge to interpret whether such conduct fits into the language of the statute. If the attorney isn't willing to gamble that it does, then he might not want to take the case, or else will charge a large fee whether she wins or not.

If Ms. X were to go to a legal aid office, she would probably encounter the same lack of comfort and expertise in dealing with the disabled on the part of the staff. In this specific case, if she wanted to sue the landlord for damages, she would also be turned away, since legal aid offices are restricted from taking on any cases that could bring in any fees to the attorneys handling the case.

In order to protect her civil rights in this case, Ms. X has several obstacles to overcome. First she must know if she has a legal remedy; then she has to find a lawyer with an accessible office (or who will come to her), who knows how to deal with a disability-related problem. Another problem she might face is isolation. If she isn't around other disabled people, she has no way of knowing what problems are common to disabled people in general. She doesn't have the chance to find out common and simple solutions to what appear like very complex problems. She also lacks the experience of knowing other disabled people who are used to handling common problems and can act as positive role models to encourage her to take action to enforce her rights.

The Disabled People's Legal Resource Center (D.P.L.R.C.) deals with these problems by providing an intermediary between an individual disabled person and the legal system. It is a non-profit corporation that has several functions: providing paralegal counseling, training disabled people as paralegal counselors, educating the disabled in their civil rights and giving general legal information, educating lawyers in the legal aid social problems of the disabled, and researching disability law problems.

Going back to the hypothetical case this article began with, Ms. X could come to DPLRC and find out whether she has a real legal issue. Then, after finding out from a disabled paralegal counselor what the law says about housing discrimination against the disabled, she would have her case handed over to a lawyer with expertise in the area and an interest in working with disability law. The preliminary work of the case would have already been done for the lawyer (fact-finding and basic research) so he could proceed with the case faster. The DPLRC staff worker would keep track of the case progress to check on Ms. X's satisfaction with the results and to learn more about that aspect of the law.

Currently DPLRC is still in its organizational stage and dealing with finding funding sources. We managed to get some free space at the local law school to temporarily operate, but will have to vacate it soon. With no funds, space is hard to find. Members have been recruited from the local disabled community. They include law students, pre-law students, and people with a general interest in the law. We are attempting to make our services available to the general Bay Area.

Major policy decisions regarding scope of services include a limitation on client population to the physically disabled, visually impaired and deaf. This is because we have fears of spreading ourselves too thin, and the legal needs of the mentally retarded are currently being addressed by other groups. We also decided to deal only with legal problems that directly relate to the disability. Other types of problems are referred directly to attorneys or legal services that deal with that type of problem. An example of this would be referral of a divorce case where the disability of the person involved is not at issue. Another important decision is to provide services to people in their homes when necessary. Our projected budget includes a fairly generous amount for transportation. We feel that one way to give people the impetus to become more independent is to provide them with a feeling of having more control over their own lives. Being able to fight back legally or to overcome a problem that seems very complicated is one way to gain that control; we don't want to limit this to only those people who can make their way to us.

A case is generally started with an initial interview, in person or on the phone, that is conducted by a volunteer staff person. Then research is conducted by that person. It may include phone calls to people involved in the case (landlord, welfare worker), finding applicable statutes or cases, and talking to attorneys who have indicated a willingness to provide information and suggestions for further research.

Then the paralegal counselor talks about the case at weekly staff meetings and receives suggestions from the rest of the staff on where to go next. In many cases, we anticipate that either giving information or making initial contacts with persons or agencies involved in the case may bring about satisfactory results. It is not our goal to bring every case to court; going to court is not usually an expedient solution nor a pleasant experience.

If the case needs a lawyer's further attention, the paralegal will look through DPLRC's list of resource attorneys for one specializing in an appropriate area of law. Then he/she will prepare a summary of the facts and research done on the case for the attorney. A conference with the attorney, the client, and the paralegal worker will follow, with follow-up by the paralegal as the case progresses.

Training of the staff consists of weekly panels, conferences on specific problems, and on-the-job training. The weekly panels are presented by lawyers and others who have appropriate experience on a particular topic of interest to the disabled (i.e., housing or job discrimination, legal research, constitutional issues). They are open to the community. Conferences are occasionally held with interested attorneys and community members to deal with the specific problems of an individual case. The purpose of the conference is to get all the facts relating to the issue, to educate all present on that area of the law, to locate areas where research is needed, and to decide what action to take. These are usually problems that involve many people. Finally, on-the-job training is an efficient way to learn paralegal skills. Work is supervised by law students and interested attorneys. We try to make a point of informing clients that we are not lawyers and still learning ourselves.

An organization like DPLRC is an important tool for disabled people to use to gain independence. It makes it easier for an individual to receive legal information and to get referral to an attorney who can handle a disability-related legal problem with competence. This gives the individual more power over his/her life and it can provide more civil rights for disabled people as a class through successful litigation. Any civil rights movement needs a legal arm to provide legal solutions to problems that the legislature will not remedy.

DPLRC directly affects independent living because it is run by disabled people and trains disabled people in a very important skill, paralegal counseling. This training can lead to future employment and is excellent preparation for law school.

Legal battles also make good headlines. If the public sees disabled people vindicating their legal rights in court, it will quickly become aware of the specific problems facing the disabled. This kind of publicity also works to change public stereotypes about the disabled; it's an aggressive act to take a case to court, and implies a certain degree of control over one's life. If disabled people are seen as actively looking out for themselves, perhaps some of the pity people now feel for us will change to genuine respect and admiration.

It is our hope to eventually see a new area of the law develop dealing specifically with the problems of the disabled. By developing more case law and legal precedents, we can draw the attention of lawyers and law students to these problems. A major reason that these people don't now recognize such problems is that they've never been exposed to them, personally or professionally. If lawyers were familiar with the social and legal problems of the disabled, there wouldn't be as much of a need for DPLRC. It should also be noted that there is a great need for attorneys who are disabled. Hopefully DPLRC is helping to meet this need also.

A NEW KID IN TOWN

Philip H. Hatlen

There is definitely no shortage of public and private agencies serving the blind in the United States. If a blind person and his family wish to avail themselves of professional services there are programs specifically designed for blind persons from infancy through old age. At this time, as the blind person grows older, the intensity of available services decreases. But even this is being corrected by efforts in recent years to provide more professional services to the geriatric blind. The blindness system truly is a cradle-to-grave problem.

The availability of these services does not mean that all persons take advantage of them; but the fact is, they do exist. This complex, sometimes overlapping, bureaucratic array of services is awesome and impressive, particularly when one considers the fact that the population of blind persons in this country is a relatively identifiable, finite number of people, many of whom need no services from professional agencies.

Into this array came the Living Skills Center for the Visually Handicapped (formerly the Blind Adolescent Life Skills Center), in July 1972. We are just beginning our fourth year of service and are considered by ourselves and other agencies as The New Kid in Town. Why does this center exist and what service can it possibly provide that is not a duplication of existing programs of the long standing and solid professional status? This question can only be answered by devoting some time to a brief look at the development of educational services to the blind in past years.

Historical Perspective

There are two primary reasons why the Living Skills Center for the Visually Handicapped was founded. First, the past and present priorities in educational services preclude emphasis on the development of basic independent living skills. Second, existing rehabilitation services for the adult blind have not been able to establish curricula appropriate for a very heterogeneous population of congenitally visually handicapped children.

Let's examine these two points further. No population of handicapped children has so significantly affected educational services as that of the generation of retrolental fibropolasis blinded children. There is much in the literature devoted to the affect of literally thousands of congenitally blind children coming of school age in the late 1950's and early 1960's. Concurrently with and partly due to this population, there was a dramatic shift from residential schools to the local day school programs. This shift is certainly one of the most significant events in the history of educational services to the blind. Its merits will undoubtedly be debated for many generations to come. There developed a strong commitment among professional educators and parents of blind children to the development of day school programs and the "mainstreaming" of blind children.

The emphasis of these day school programs was and continues to be the placement of blind children in regular classrooms for as much of each school day as possible. Children are provided specialized instruction from resource or itinerant teachers primarily for those services which will enhance the child's performance in the regular classroom. If asked to define their positions most resource and itinerant teachers would state that their primary purpose is to facilitate the integration of blind children into regular classrooms. This they accomplish by making certain that the child has the appropriate materials and equipment to function academically. The special teacher may also take direct responsibility for instruction in some beginning braille reading skills, typing skills, use of slate and stylus, etc. All other subject matter is expected to be taught in the regular classroom.

Areas of special need for blind children such as concept development, spatial orientation, experiential opportunities, motor development, education, education in human sexuality, development of listening skills, instruction in basic living skills, socialization skills, and mobility are, for the most part, either assumed to be the responsibility of parents, or, worse yet, are not recognized as basic developmental needs of blind children.

In the early 1960's a major breakthrough regarding the recognition of special needs of blind children occurred, largely through the efforts of Georgie Lee Abel, then with the American Foundation for the Blind. This was in the area of instruction in orientation and mobility. Gradually professional educators of the blind began to understand that the need for orientation to one's environment and independent travel skills were critical and required specialized instruction. For blind children a new profession was born. Orientation and mobility specialists began to emerge from undergraduate and graduate programs in several university settings throughout the country. Resource teachers, itinerant teachers, and teachers in residential schools began to see that there was justification for a child and adolescent to spend some time during his school day on a skill (orientation and mobility) which was not required of their sighted classmates. This constituted a significant re-definition of resource and itinerant programs.

However, other non-academic skills which logic would suggest demand specialized instruction have yet to gain status in educational programs for visually handicapped children. Blind youth are graduating from high school, residential, and day-school programs with few skills in certain areas which are crucial for successful adult living. This fact might not be critical if adult services for the blind were prepared to deal effectively with the entire population of visually handicapped young adults.

When retrolental fibroplasia blinded youth began graduating from high school in large numbers, they soon became a major concern for rehabilitation counselors, social workers, and others involved in services to the adult blind. These young people were different from the newly blinded adults who until that time constituted the major caseload of rehabilitation personnel. For those blinded as adults, it is often possible, after a period of orientation to blindness, for the individual to return to his/her community, family, and a vocational similar to that which he/she had prior to losing his/her vision.

It is necessary to consider the problems related to habilitation of congenitally blind youth as compared to rehabilitation of newly blinded adults as two different and distinct responsibilities.

It has become apparent to rehabilitation counselors and agencies serving the adult blind that there are some rather large and serious gaps present in the educational development of many congenitally blind youth. While they were in school these young people functioned within a well-established educational and family social structure. As young adults in the community, the same social structure did not exist, and many blind youth who had benefitted from 12 years of integrated public school education found themselves facing serious difficulties in assimilation into the community. Further, many were seriously lacking with respect to development in skills of recreational and social behavior, independent travel, personal communication, vocational awareness, and many aspects of daily living.

One theory as to why growth and development has not occurred in these areas is that sighted children and youth learn countless concepts through visual observation which blinded students do not have the opportunity to visually observe and are not systematically taught.

The difficulty which rehabilitation services have faced in dealing with this population appears to be created by two situations. One, the level at which many young blind adults are functioning necessitates redesigning curricula for much more basic learning. The traditional curriculum of rehabilitation agencies is often not appropriate. Second, the population of retrolental fibroplasis blinded persons is a very heterogeneous one, necessitating an individualized approach which can be flexible enough to meet each person's needs at the level at which (s)he is functioning. In addition, working with these young people requires an acceptance of the fact that some may never be entirely independent and may require a certain degree of attendant care and workshop level employment.

Blind young people whose probable future is a dependent living situation with the possibility of sheltered workshop employment are no less worthy of or entitled to post secondary services than the blind young person who is functioning at a higher level and has the potential ability to be placed in competitive employment. What seemed to be needed a few years ago and still appears to be needed is a habilitative service for blind young adults which does not have a set curriculum for all its participants and which can provide services at a variety of levels, including the more severely impaired young people.

I fear that there is some truth to what some rehabilitation counselors have said to me, that public school programs are not preparing blind children and youth for adult life. This author has had many personal experiences with blind young people who have obviously been passed through school from grade to grade regardless of their academic and developmental level. If this were not true, why are there blind young people who have had several years of high school mathematics and cannot make change for a dollar? Why are there many blind young people who have extremely limited spatial awareness about their immediate geographic area, yet possess expansive verbal knowledge about world geography?

It is not my intent to be highly critical of either educational or rehabilitative services. Schools are providing the best educational services which they know how to provide. Also, there has been continual, sometimes dramatic, improvement in vocational rehabilitation services for blind and the quality of rehabilitation counselors continues to increase. I am suggesting that educators of the visually handicapped must take an immediate serious look at their priorities in education for those children whom they serve.

Just What We Need is Another New Agency

The Living Skills Center for the Visually Handicapped was born out of the frustration of teachers, rehabilitation counselors, and social workers serving the blind. It came into existence because too many blind adults were continuing to live at home after high school graduation with no plans for their adult life with respect to social, recreational, educational, or vocational objectives and activities. It was born out of the recognition that existing rehabilitation agencies were doing an outstanding job with newly blinded adults but were having difficulty adjusting their services to the developmental needs of the congenitally visually handicapped persons. It was not born to compete with any other existing agency or replace any existing service. It came into being as an alternative to existing services, particularly for congenitally visually handicapped young adults. The Living Skills Center for the Visually Handicapped has attempted some courageous high-risk approaches to the habilitation of blind youth.

The Setting

As new schools for the blind and new rehabilitation centers have been constructed over the past 15-20 years, it has continually amazed me that dormitories remain the accepted living accommodations for residential students and clients. If housing accommodations are a necessity, then why not attempt to replicate, as nearly as possible, normal living accommodations in the community? The Living Skills Center houses its participants in their own apartments in a large apartment complex. Participants occupy eight two bedroom apartments which are scattered throughout the 70 apartment complex. Two participants live in each apartment and have their own private bedrooms, and share bathroom, living room, and kitchen. They have their own address, their own mailbox, they pay their own rent to the apartment manager, they arrange for their own utilities and learn apartment living skills in their own place of residence.

The participants are encouraged to recognize that their apartment is their private living quarters although teachers do have access for instructional purposes. Only in the case of an emergency would a staff member enter a participant's apartment without permission. For many of these blinded young people this is the first opportunity for autonomy and privacy. The objective in establishing this physical setting is to provide opportunities for learning and growth in a situation which closely parallels the setting which they may live in at the conclusion of the program.

The Instructional Program

Occasionally participants receive independent living skills instruction in small groups, but primarily instruction is on an individual basis, usually within the participant's own apartment or in the surrounding community. Areas of instructional need are determined by both teachers and participants, and the curriculum is developed with the active participation of each blind young person. Sometimes it is necessary for a teacher to help a participant recognize certain needs of which he is not aware. But usually participants and teachers agree on instructional goals.

The clusters of areas of learning which are used as a general guideline are basically no different from what one might find in any rehabilitation agency. There is nothing new in providing orientation and mobility instruction, communication skills, social skills, and recreation, or instruction in personal hygiene, financial management, care of clothing, apartment cleaning, shopping and cooking. It is the manner in which the instruction is provided which makes the Living Skills Center for the Visually Handicapped somewhat different from other programs.

Individualized instruction which occurs in the participant's own living quarters, mobility instruction directly related to the social and recreational needs of participants, active student participation in the selection and objectives of goals in instruction are some of the ways in which this Center has departed from traditional approaches to teaching.

The Staff

Working at the Living Skills Center for the Visually Handicapped requires very special professional people. I have never observed a more intensive, intimate teacher-student relationship than that which occurs at the Living Skills Center. Because most instruction is individualized and because of the mutual planning of the curriculum between student and teacher, there is a shared enthusiasm and motivation for learning that adds another unique dimension to this program.

Three living skills teachers, two orientation and mobility instructors, two vocational specialists, three teacher assistants, and a director comprise the team of professionals who, at any given time, are serving up to 20 blind young adults. All major decisions regarding admission, curriculum, structure, termination, etc. are democratically made by the entire staff. Planning daily programs for each participant requires close mutual cooperation and teamwork. Yet this staff is comprised of a group of individuals who are not hesitant to disagree with one another and to discuss openly difficult topics which go far beyond the simple topics of curriculum and instruction.

Living Skills teachers are primarily responsible for teaching participants in a wide, almost endless variety of areas. Personal hygiene, care of clothing, financial management, dresser and cupboard organization, counter cleaning, cooking, dishwashing, shopping, and countless other skills learned by sighted youth through observation are taught by these instructors. They have arranged their instructional areas of responsibility in a sequential hierarchy so that no participant is expected to learn tasks that are far beyond his present functional level.

From the moment a participant is admitted, orientation and mobility instructors orient him to his apartment, the entire complex, hallways, the office, mailbox, etc. Thorough orientation to the immediate environment is followed by learning survival routes to the grocery store, the bank, local restaurants, doctor's offices, the local community college, etc. When mobility routes within the immediate neighborhood are learned well, then mobility instructors and participants take advantage of recreational and social opportunities throughout the bay area, using these opportunities to learn more sophisticated and generalizable orientation and mobility skills.

Our two vocational specialists are new to the staff as of July 1, 1975. One is a former mobility instructor who is now responsible for coordination with the Contra Costa County Regional Occupational Program. We are attempting this year to provide vocational training to a large number of participants through existing programs. Our second vocational specialist is a new staff member whose primary reponsibility is to explore with participants current knowledge of the work world and provide opportunities for job exploration through on-sight observation. We believe that the concept of providing congenitally blind young adults with opportunities to spend one or more days literally sitting next to someone performing a job in order to learn what work is like and what that specific job requires is another unique idea. The fact that blind young people have no opportunities to observe the work world, hence have extremely limited information regarding choices of vocations, and the positive and negative aspects of various jobs, is something that is often overlooked in their rehabilitation. We hope that we can demonstrate that comprehensive job exposure will better prepare the blind young person to make his own decisions about vocations.

Teacher assistants perform two extremely important tasks. First, they are on call to instructors in following-up previously taught lessons and monitoring participants in some activities under a teacher's direction. Second, they provide coverage when teachers are off duty. Because the Living Skills Center is a residential program, it is necessary to have 24 hour emergency coverage. Teacher assistants provide coverage for emergencies and in many cases enhance the program with recreational activities when teachers are not on duty.

These staff members are supervised by a sensitive and talented director who provides an atmosphere for cohesion and open exchange between teachers and participants.

The Participants

As of September, 1975 the Living Skills Center has served over 50 young people in its three year history. The length of stay for any participant is determined by need. It is possible for someone to be admitted and leave within a few months. It is also possible that some may need to stay for more than a year. There is no minimum or maximum time requirement in this program. Most participants come from Northern California, with a small number from the southern part of the state, and currently there are three participants from Illinois.

These young people have ranged in age from 16 to 27 and come from a wide variety of backgrounds. There has been an approximate equal number of participants from both day school programs and residential schools. It may be significant to note that very little difference in independent living ability has been noted between participants who have come from various educational settings. There seems to be no correlation between entry level skills and parental involvement in the educational process.

Since the Center has never involved itself in recruitment and accepts applications only from participants who themselves indicate a need for the program, no one has been admitted who has not wanted the services provided by the Living Skills Center. This does not mean that we have experienced uniformly high motivation in all participants. Indeed, some of our young people, after an initial period of enthusiasm, appear to consider placement at the Center as primarily filling a need to live somewhere. When this happens, a certain amount of gentle persuasion usually rekindles some level of motivation and enthusiasm.

When we began, we established as one criterion for admission that the applicant be functionally blind. The term functional blindness is defined in several ways. Our definition is that functional blindness implies the need to learn primarily through auditory and tactual senses. Our rationale for not initially accepting participants who have usable vision was that they have had opportunities to observe the tasks which we were teaching, hence would not need individualized instruction in order to learn. This assumption is one of the mistakes we made as a New Kid in Town. Rehabilitation counselors gently pointed out to us that many low-vision young adults do indeed need the service which we were providing, and that the integration of visual and auditory and/or tactual senses can be as difficult as utilization of only one sensory mode. Therefore, we are now willing to consider any visually handicapped applicant whose visual loss requires an instructional program.

The population has always been heterogeneous. Some participants need very little other than encouragement in order to meet their objectives, while others might never attain a level of understanding and development of skills which would allow them to be entirely independent. Whether a "graduate" leaves the Center to establish residence in his own apartment with solid potential for employment or to reside in a board and care home with the prospect of sheltered workshop employment does not reflect on the success of the instructional program offered at the Center. If progress is made in the attainment of skills, the strengthening of self-concept, the development of autonomy, who is to say which participants we have been most successful with?

The Future

Nothing would please the Living Skills Center staff more than to be needed no longer by the population it serves. It was thought that by demonstrating the necessity of the skills taught at the Center, elementary and secondary teachers would be led to revise their programs and begin to teach visually handicapped children at a very young age some of the specialized skills they will need as adults. Thus far, this has not happened; what has been learned at the Living Skills Center is not to any great degree reflected in changes of priorities in school programs.

It would appear that throughout the country residential schools have responded to the need to teach these skills much more than day school programs have. The tragedy of this is that there are many more visually handicapped children and youth in day school programs than in residential schools. So it would seem that the need for the Living Skills Center may continue for some time.

Additionally, we have learned that there are certain independent living skills which are probably best taught and best learned when they are most needed. Certain skills in financial management, apartment maintenance, cooking, etc. may not be taught effectively while students are still in elementary and high school. When they are on the brink of living on their own, blind young people are the most motivated to learn some of the skills required to live independently.

It is my feeling that, therefore, the Living Skills Center must continue to serve as a model, as an alternative service delivery system. How long it will continue in operation is difficult to determine. Funding continues to be on a year-to-year basis. If demonstrating new approaches to habilitation of blind young adults does not affect present educational and rehabilitation programs, we may be around long enough to no longer be considered "The New Kid in Town."

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Living Skills Center for
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AN ON-SITE TRAINING PROGRAM FOR PROFESSIONALS WORKING WITH PEOPLE WHO HAVE SEVERE DISABILITIES

Peter Leech, M.S.W.

C.I.L. On-Site Training Program for Professionals

The purpose of this paper is to describe a training program for professionals developed by the Center for Independent Living. This training program was funded by Federal Training Grant No. 44-P-45443/9-01. The focus of the training grant was to provide Vocational Rehabilitation Counselors with the knowledge and skill necessary to work more effectively with persons with severe physical disabilities.

It is not the purpose of this paper to debate the assumptions, but to describe our experiences of the training process based on these assumptions.

The assumptions fall loosely into two major categories, the generalized societal attitudes toward persons with physical disabilities, and the ways the usual form of professional education deals with the subject of physical disability.

With regard to the general societal attitudes, we all know what they are, and very likely would refute their validity if they were voiced openly. Unfortunately they most often operate outside of the individual's awareness and affect the relationship of counselor to client in a negative way without the counselor (and often both counselor and client) knowing why. Again, it often happens that the client becomes angry, or resistive to the counselor's efforts, and the counselor ends up believing s/he has encountered another "angry disabled person."

Some of these attitudes, and the activities that follow out of them, include the following:

- A person with a disability is a totally dependent person. It follows then, that the counselor may begin to manage the client's life and activities. These can range from grabbing client's wheelchair and pushing the client into the counselor's office with the verbal explanation being to "save the client's energy," or to "assist through these narrow halls or doorways," to deciding what might be best for a specific client and describing the client as resistant if the client doesn't agree.
- People with disabilities are "different" in all ways, therefore: there's something strange about a person with a disability desiring to be out on the street, do their own shopping, pursuing friendships and romantic relationships, wanting to drive, wanting to own a home, etc.
- People with disabilities don't want to be reminded of their limitations so a counselor must not talk about matters that would touch on these matters, such as walking out on the street, looking at or seeing things such as movies, asking the person to repeat

something the listener couldn't understand, as well as going shopping, pursuing friendships and romantic relationships, driving, owning a home, etc.

With regard to the deficiencies in professional education, let me say that I don't know of *any* professional education that adequately prepares a person to relate to the disabled experience. This includes education in medicine, nursing, the various therapies, social work as well as rehabilitation counseling. I believe that one major reason for this is that professional educators have the same societal base as everyone else, have not become aware of their attitudes, are not usually themselves physically disabled and therefore transmit the societal attitudes in the fiber of their educational process. What follows out of this is a focus on the imaginary barriers to independent functioning, rather than the real barriers, an emphasis on better physical restoration, classier assistive devices, rather than restructuring societal attitudes, reducing architectural and transportation barriers, and promoting full participation in life for persons with disabilities.

CIL's training process involves five major components which combine to provide the set and the setting within which an attitude changing awareness of the disabled experience can occur. These include the expectation that each trainee assume a disabled role; consciousness raising sessions; the experience of living with a person with a disability in the community; more traditional instruction dealing with various facets of the disabled experience; and the predominant use of faculty members who are disabled.

We begin by developing the disabled role for each training. I ask that they select out of their own life experience one of the times when they narrowly missed becoming disabled. I then ask that each trainee in turn describe what happened and the impact of the experience at the time. After they all have described an experience, they are asked to assume that the experience left them disabled, that they couldn't move because they had sustained a lower extremity paralysis. We talk a little about what this means, including that they'll be confined to wheelchairs, and then bring out the wheelchairs they'll use for the rest of the week and instruct them in transfer techniques from the chairs they're sitting in to their wheelchairs. In other words, we begin immediately to incorporate their "disability" into their life experience. We spend the next hour or so assisting the trainees in getting acquainted with the wheelchair, its use, and starting exercises useful in maintaining the role of disability while also avoiding unnecessary risks to safety and health; we use our wheelchair repair service to adjust the wheelchairs to fit each trainee as closely as possible; we instruct in manual wheelchair operation: pushing, turning, transfers to chair, toilet, car and bed, pushing up ramps and hills, jumping over bumps; we instruct in toilet activities (an immediate concern) and general bathroom and dressing techniques for the subsequent mornings; we also instruct the trainees in an exercise program to follow at least every evening in order to avoid knee flexion contractures (hamstring tightness) and ankle edema—both of which ensue very quickly when a person begins to use a wheelchair for all ambulation. Following this period of instruction we all go out to lunch in the community generally splitting up into pairs. This is the trainee's first excursion into the community in the disabled role, and always provides more than enough material for our first consciousness raising session (or reaction time) which is scheduled right after lunch.

The consciousness raising sessions are scheduled regularly throughout the training week, first thing in the morning and right after lunch. These sessions are patterned after the consciousness raising groups provided in the CIL peer counseling program and provide a specific time and place for the trainees to meet with each other and to share experiences, solutions to problems, their feeling responses to their experiences and problems so that they can begin to develop their own understanding of what living with a disability is like—including the reality obstacles, such as architectural barriers and public attitudes, as well as the common emotional responses to these.

Toward the end of the first day, the trainees are introduced to their housemates—the people with disabilities with whom they will live during the rest of their stay in the community. The housemates are selected on the basis of severity of disability, a willingness to verbalize their own experiences and responses to being disabled and demonstrate (or tolerate being observed) as they utilize assistive devices or attendants to manage their physical care, and pursue their individual lives, socialize, etc. The function of the housemate is not to "entertain" the trainee except as that flows out of their usual activities; nor is it to "help" except to give pointers about the accomplishment of activities of daily living. It is to provide a view into the daily life of a person with a severe disability who is living independently and effectively in the community.

The more traditional part of the instruction provides lectures and demonstration of assistive devices and equipment, independent living skills, wheelchair design and repair, modified transportation, barrier free design, legislative impact, emotional reactions to becoming disabled, sexuality and disability. This mode is "traditional" in the sense that it utilizes lectures, audio-visual aids and field trips as do most training programs. It is different in that the persons being trained are much more receptive to the knowledge because of their "set" as persons with disabilities eager to learn as much as possible about how to function more effectively. The setting, too, contributes to the total immersion in the training experience in that this agency's primary function is to provide services to severely disabled clients and that over two-thirds of the staff are persons with severe physical disabilities and are the people who serve as faculty for the training program. Those faculty members who are not severely disabled, have long experience in working with the disabled community, and are deeply aware of the disabled experience. The faculty contributes in several ways, each of which adds to the totality of the experience. One contribution is in the direct presentation of anecdotes about that person's experience with disability and the personal, familial and societal attitudes that he or she has encountered. Another contribution comes in the form of sharing specific knowledge of her or his own type of disability and the techniques used to maintain independent living. A third contribution develops around the use of the faculty member as small discussion group leader; the participants receive what may be the first opportunity of their lives to develop a close, sharing relationship with a person with a severe physical disability. The dialogue that develops within this format has been described by previous trainees as invaluable and combined with the assumption of the disabled role and living with a person with a disability, perhaps the most meaningful part of the training program. The overall contribution flows out of the realization that these faculty members and housemates are not particularly exceptional, and that most persons with severe physical disabilities retain the potential to be dynamic, interesting, attractive, independent individuals.

The most important question about any training program is whether or not it has been effective. I'd like to describe the results of this training program from two perspectives, my own, and the trainees.

From my own point of view, this approach to training has been the most gratifying in my experience in that I'm convinced that the trainees have really been able to "get it." No amount of the "talking at" or "reading about" forms of training can convey the perspective on disability and real understanding that assuming the role of disability has provided for these trainees. My expectation was that the experience would be important in conveying some of the lesser known but invaluable facets of the disabled experience. I had not previously anticipated the form of some of the results. One severe criticism of the format was that the assumption of the role of disability would have little value because the trainees might get "turned off" or would always know that at the end of the week they could get up and walk away, or see again, if their role was blindness. I, too, had some intellectual reservations, but decided to trust my intuition that the experience would be valuable and did not omit or shorten the role-playing experience. A second criticism, less prevalent than the first was that the counselors might not want to live with a person with a disability—that they might rather stay with a friend or family—not wanting to spend all their time in the training experience. I don't like to be in the position of making somebody do something they don't want to. I therefore decided to leave it up to the counselors to assume responsibility for opting out of any part of the experience at any time they wanted to, explaining at the same time that *my* position was a belief that they'd miss something if they did. I believe it's a tribute to the counselor's commitment to getting everything out of the training they could that they very seldom "blew their cover" as we called it.

One result which I observed was that the assumption of the disabled role very closely paralleled the phases of reaction to a real disabling illness or injury. If each day is compared to a two-to-three-month period following becoming disabled, we can see the parallel:

> The first day after assuming the role was very difficult, they found themselves confined to wheelchairs, seriously limited in their activity and mobility, running into curbs, walls, people, each other, being in the way, feeling embarrassed, slow, clumsy, angry at Peter Leech and the CIL Training Program and ready to quit, give it up, and not sure they'd make it through the week. They ended the first day with some diversion and encouragement from their housemates, but mostly exhausted, sore, and for some, depressed.
>
> The trainees awakened the second day with the same general set, finding it hard to imagine they'd be able to make it through the week; some hating the sight of the wheelchair; this was heightened by the slowness of their getting up, bathed, dressed and ready to go. During the second day they began to be able to manage the wheelchairs a little and the beginning function here sparked some hope that they'd be able to last through the week.
>
> The third day, beginning to feel comfortable in the wheelchair in public and really manage to get around fairly well. Ended the day with heightened hope and enthusiasm. Looking forward to more activities.

Fourth day, really have incorporated wheelchair into their image; one describes anxiety when transferred onto couch and someone took wheelchair away. Feeling real pride in having managed to learn how to function again and anger when people on the street come up and take that function away by starting to "help" when they don't need help.

On the fifth day almost all of the trainees expressed disappointment that the experience was ending, real pride in having managed the experience through some difficult times. When I began to work them out of the role and encourage their standing up, most were reluctant, felt strange standing, and chose to continue to sit in the wheelchair, rather than in "uncomfortable" straight chairs.

Another facet of the "disabled experience" which became apparent to the trainees were public attitudes of condescension, etc. The trainees were especially able to perceive these for what they were *because* they are able-bodied and the only difference between this week and their regular lives in public is the kind of chair they were using.

One part of our post-course questionnaire asks the trainees to list the degree of usefulness they experienced for each component with the range of response limited to low/moderate/high/very high. Rated "very high" consistently were: Assuming the role of disability; Living with a disabled housemate; Self-care techniques/preventive health care skills; and Outings in the community. Rated as "very high" by over half of the trainees were: The development of CIL; Transportation and Mobility; Communication Skills with the speech disabled; Impact on local government; Client advocacy; Sexuality; and time for reactions to what has been happening in terms of the trainees' emotional reactions.

The following is a letter by one of our Arizona trainees which was written as a report on the training and directed to the counselor's supervisors.

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THOUGHTS ON MY WEEK AT THE CENTER FOR INDEPENDENT LIVING

Mary Jane Weil – 5/24/75

When I first heard that I might be going to Berkeley, my reaction was "Great, when do I leave?" I didn't pay too much attention to what I'd have to do in Berkeley when I got there; I was too caught up in the idea of having an all-expense paid trip to California. No one knew exactly what would take place during the week, although, from a tentative agenda, it sounded like they would be "giving" us a disability to live with while we were there. I can remember even laughing a little when it said that the training was to be a "once in a lifetime experience." Sure.

Finally the departure day arrived and I found myself actually on a plane headed for Oakland. The trip was uneventful and I even found Jerry Jerome (the other counselor from Arizona) with no trouble at all. There was one slight hitch when the bus that was supposed to take us to our hotel was not running, but we found a taxi and arrived in style at the Durant Hotel. By this time, when I realized that the training was going to be starting for real, I was having a few doubts about the whole thing. I even had qualms about the premise behind the week—that of gaining better insight into what it's like to be disabled by role-playing a disability. I felt that a week, knowing that I was just acting, wasn't going to tell me much I didn't know already. I assumed, from the agenda, that our days would be fairly structured and that even the "evenings on the town" would be well-planned in advance. I also had some misgivings about my qualifications for being there. Would they expect me to be one of the two best counselors in the state? I'd been told to be ready to discuss some of my cases. What would they think if they found out that my caseload numbered in the 40's instead of being in the hundreds? By early Monday morning, I'd decided that I didn't belong there and wished I'd said "NO" when the trip was first suggested.

My first of a long list of surprises came at 8:30 a.m. on Monday. Jerry and I were in the lobby waiting for Peter Leech to show up to take us to CIL, per our instructions in the letter. I was well-equipped as a conscientious counselor, with notebook in hand. I was a little surprised to find that the lobby was relatively empty. Where were all the other counselors who were going to be involved? We didn't know what Peter Leech would look like, but I was keeping my eyes open for a "professional" looking man. Finally, Jerry and I went outside, where a "Non-professional" looking man with a beard waved at us and said, "Hi, I'm Peter Leech. Are you looking for me?" Instead of the "professional" looking van I expected, Pete was driving a ratty old Corvair convertible. I had thought he was being rude in not getting out of the car, but then I noticed the wheelchair in the back seat and realized that he was disabled himself. I hadn't expected the coordinator of the week to be in a wheelchair.

I rode over to CIL with Jean. I never learned her exact title, but soon learned that she did whatever needed to be done. On the way, she told me that she was something of a rarity at CIL, in that she wasn't disabled. I was surprised to find out that CIL was run by disabled people to help other disabled people. I think I'd been expecting a residential, occupational therapy type set-up, and it's not. I'd also expected to be taken to an impersonal conference room full of other counselors. Another fallacy. We went up to the 4th floor of an old office. building in downtown Berkeley, to a small room. We started out with introductions. There were only 4 counselors there, and I soon found out that there were only going to be 4 counselors involved. The other three included Jerry Jerome, from Arizona with a small rural caseload very similar to mine, Sandy Petta, a counselor from Las Vegas who had a SSDI/SSI caseload, and Jay Scully, from Reno who also had a SSDI/SSI caseload. We learned that Peter Leech, who was in a wheelchair as a result of polio, had an MSW and his official title was "counselor." We also found out that CIL (Center for Independent Living) was a consumer movement to help disabled people (especially those who had "fallen through the cracks" of other programs such as VR) learn to live independently. It had begun a few years ago as an off-shoot of the Physically Disabled Students Program at UC Berkeley.

After an hour or so of getting acquainted, we were given our wheel chairs. I still didn't quite take the whole thing seriously. My chair needed to have the foot pedals adjusted so Pete showed me where wheelchair repair was located. I was taken back when the wheelchair repairman started asking questions about how I wanted my chair fixed and it became obvious that he thought I was the real thing. He even picked up my legs like they were paralyzed. Pete was with me, but he didn't let on that I was really a counselor in disguise. I couldn't believe that someone thought I was a paraplegic when I felt so normal. It was scary! Although I was in a chair and for all intents and purposes a paraplegic, my mind was the same and I felt the same—I began to realize that the people who really had to be in a wheelchair were mentally O.K., but just had problems with the body. That doesn't sound profound. It sounds like something the average man on the street would agree with. But, there is a big difference between knowing it intellectually and knowing it emotionally. On paper it doesn't sound like an important moment, but it was the first of many insights I got into the disabled.

Back in the meeting room, I learned that many people even at CIL wouldn't know that we were phony and that we were supposed to act like the "real thing" and not let on that we were counselors. It was then almost lunchtime, but before we went to lunch (our first time in the outside world) we had a lesson in one of the problems of a person in a wheelchair—bathroom training. Susan (a real paraplegic) took Sandy and I down to the accessible bathroom on the 2nd floor and for half an hour we tried to learn how to transfer from our chairs. It's harder than it sounds.

Lunchtime was terrible. I was new to the business of navigating a wheelchair and I had trouble going through doorways and had to try 3 or 4 times before I could get into the elevator. Sandy, Susan and I were going to a restaurant about two blocks away, which sounds like it would be very uneventful. I barely made it. My arms were killing me by the end of the first block. When we crossed a street, I rolled back into the traffic and a little old lady had to help me to the other side. The restaurant itself was worse. We went to a carry-out restaurant (I'll never forget "Top Dog") which was small and crowded. It seemed

even smaller and more crowded because I took up so much space. I rationalized that I was probably feeling more conspicuous than I was, until the waitress told me to move because I was in the way. She even had the cook hurry up my order so I'd get out of there. I was embarrassed and angry, and was made even angrier by a man in a business suit who wanted to be helpful and handed me my order, napkins, mustard, and everything else in sight. I knew he was trying to help, so I gritted my teeth and very sweetly said, "Thank you," although inside I felt like telling him that I was perfectly able to do it myself. Now I can understand why a disabled person doesn't want to have everything done for him.

After lunch, we talked with Don Berry about Client Services and with Jeff Moyer about Blind Services. Client Services involves:

1. Attendant care: Most of the severely disabled need an attendant at least for a short time each day, since there are things they can't and will never be able to do. CIL has a roster of attendants and match clients with attendants. A very important service.
2. Advocacy: Greg Sanders of the CIL staff has spent a lot of time studying the regulations of the various state, county, and federal programs and is very successful in helping people get all the benefits they are entitled to.
3. Wheelchair repair: Trying to get a wheelchair repaired can be quite an ordeal for someone who depends on it, so CIL offers low cost, quick wheelchair repair.
4. Housing assistance: CIL helps people locate accessible housing so that they can live independently.
5. Transportation: CIL has a modified van which can accommodate wheelchairs and provide emergency transportation.
6. Counseling: Especially for the newly disabled, but also for anyone else who needs it.
7. Referral to other agencies: If CIL doesn't provide what the client needs, they are knowledgeable of other sources and are able to refer clients to the appropriate agency.

By this time, it was getting close to the end of the afternoon and the time we were supposed to meet our roommates. I'd been dreading meeting and living with someone (and a disabled someone!) who I didn't even know. Pete paired us up and put Jerry with Don Berry (a quad), Jay with Neil Jacobsen (cerebral palsy), Sandy with Jan (blind) and Charlie (muscular dystrophy), and me with Kathy Caulfield (quadriplegic). I found out that my fears about a roommate were groundless. I liked Kathy from the very beginning. She was about my age and really a lot like me. Someone decided that Kathy and I would go over to Don and Jerry's apartment for dinner. I was able to get a ride in Charlie's van, which was equipped with a lift. The evening went well. Kathy did most of the cooking, dinner was good, everyone was relaxed, and I think that we all enjoyed ourselves. By the end of the evening I'd stopped thinking of these people in terms of their disabilities and just looked on them as people. That's another statement that sounds simple; one that wouldn't take a week at Berkeley to discover, but again, just saying it is different than feeling it. Even though I was a rehab counselor and therefore an enlightened person, I learned that there had been a certain amount of feeling sorry for my clients and talking down to them. I'd been focusing on the disability rather than the ability. After being around Kathy, Don, Pete, and the other CIL folk, I realized that pity didn't even enter into my feelings toward them, even though, physically, they are a great deal more severely disabled than the majority of clients I see.

Kathy had given me some salve on Monday night because she said I might be sore in the morning. She was right—my arms were killing me. I'd never considered pushing a wheelchair to be a very physical activity until I had to do it. By Tuesday I also realized that blue jeans are much more practical for a novice in a chair than double-knits. Tuesday morning we met Edna Brean, a very articulate nurse. She talked primarily about spinal cord injuries (how they occur, different levels of injury, and capabilities at the various levels), self-care and attendants. With Pete, we also talked about the psychological effects of a severe injury on a person and how to deal with the various stages a patient goes through. On Tuesday afternoon, we spent part of the time at the computer training project, which is taught by Scott Leubking and Neil Jacobsen, both severely disabled. Neil, who had the counselor from Reno staying with him, had cerebral palsy and so had little muscular control. Until I got to know him better, I could not understand his speech. Neil, however, has a master's degree from Berkeley and was instrumental in setting up the computer program. Besides just training the handicapped, they also have established good relations with area employers and have placement opportunities at many banks and large companies.

The highlight of Wednesday was talking with Greg Sanders, Hale Zukas, and Ed Roberts. Again, they were all severely disabled, and mentioned that at one time they'd all been rehab clients who were closed as unfeasible. Greg is "the Advocate." He knows an amazing amount about SSI and welfare regulations, and all the loopholes that exist. He has also been one of the forces behind the legislative success that CIL has had. Berkeley is probably one of the most accessible cities in the country (all the corners are ramped for wheelchairs) and Hale is one of those responsible. Ed Roberts is the director of CIL and is a charismatic, articulate spokesman for the disabled. All three of them are highly motivated doers—people who get what they want.

On Wednesday evening, I went into San Francisco with Don, Jerry, Neil, Jay, and a "walkie" named Norm who drove the van. We had dinner at a small restaurant within pushing distance of Fisherman's Wharf. I had expected to cause a little stir, because, after all, you don't usually see 5 people in wheelchairs going out to dinner, but I hadn't expected the reaction we got. A middle-aged woman, who obviously had been drinking, came over to our table and began by saying, "It's so nice that they let you out once in a while to come into town." She went on to say, "I know just what it's like, because I do volunteer work with the mentally retarded at the state hospital." She lapsed into babytalk to ask Neil (who has a master's degree) if he liked his soup and then patted me on the head and asked how old I was (still in babytalk). She kept up like that for about 15 minutes and then asked Norm (who could walk) if we'd be allowed to have a bottle of wine. I was told that though most people do not behave like this when they see a person in a wheelchair, you learn to expect a certain amount of very strange behavior from the general public. I know one of my biggest gripes with the public was the patronizing attitude I'd encounter. I didn't like being treated like a mentally defective child.

All of the people I met at CIL were very open and honest regarding their disabilities. I felt that there was no question I couldn't ask them. On Thursday, we swayed from our agenda to talk about sex and the disabled. Quite often, it is assumed that when a person becomes paraplegic that he also becomes asexual. The CIL people made sure we knew that this wasn't

the case, although adjustments had to be made in this area as well as in other areas of their lives. Thursday afternoon we rode BART to San Francisco. This "most accessible transportation system in the world" is not without problems. Elevators slammed on us, the ticket machine was too high, the train doors slammed on us, and we blocked the aisles. It is better than any other public transportation, but it is far from perfect. Thursday night we had another get-together at Don Berry's (a farewell party?) and again we had a lot of fun. I know that by Thursday night I was getting used to being in a chair and caught myself getting panicky if, for example, I'd transferred to a chair and someone would move my wheelchair. Even when I was alone I seldom felt like cheating. Before coming to CIL, I hadn't expected it to be such a total, 24-hour a day experience, or that I'd get into my disabled role so deeply.

Friday was a hectic day because we were so rushed for time. We discussed what had gone into setting up the wheelchair repair shop, and also discussed what types of wheelchairs are needed for what people. Cathy Dugan, an occupational therapist, discussed assistive devices and how to fit wheelchairs, costs, etc. Then Edna Brean spoke again about health care, bed sores, catheters, and other related subjects. When it was finally time for me to re-enter the world of walkies, I had mixed feelings. Part of me didn't want to get up, I'd gotten so used to being in a chair. I think that Pete had to tell me three times to stand up or I'd miss my plane. When I try to put what I got out of the week at CIL on paper, it loses something. The important things weren't the factual ones, like hiring an attendant, setting up a wheelchair repair shop, or getting curb-cuts at all the intersections. The attitudes I came away with were the part that is going to stay with me. On the plane trip back, I thought about how my week was going to affect my work as a rehab counselor. I was reminded of the question that both Jerry and I had asked—"Sure, you people can be successful, but everyone at CIL is exceptional. What about the illiterate laborer who doesn't want to go to the city?" The answer we got was that a person doesn't need to be educated, articulate, or academically minded to make it in the world and function independently. We were amazed to find out that the CIL people hadn't always been brilliant and exceptional. Many of them had spent years in institutions, been closed out by rehab as unfeasible, and really felt that they'd never be able to do anything with their lives. They were lucky, though, and somewhere along the line got a chance. I hope I come back from Berkeley less likely to set limits for my clients and, now that I know what a person with a disability can do, more able to motivate them. Since the disabled person in Parker has few successful role models, I realize more than ever the importance of a counselor really believing in his clients and providing them with the right opportunities. Working with the disabled here is frustrating at times, but from now on, when I'm faced with an impossible client and I'm about to say that there's nothing he'd be able to do, I hope that I'll remember the people I met at CIL.

My week at the Center for Independent Living was the most valuable and enlightening training session I've been to and I hope that every person working in rehab gets a chance to spend some time there. That "once in a life-time experience" phrase that was on my travel order pretty well describes my week.