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THE PSYCHOLOGY OF DISABILITY

STATE OF THE ART OF INDEPENDENT LIVING OF THE SEVERELY DISABLED

WORKSHOP-SEMINAR

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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 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 regretable 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 as a peer, a

colleague spirit, 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 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 some other 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 Means 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 lead 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 is 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 vast majority 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 its only reason for inclusion 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 lack of consensus for one's 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 the world 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. Feeling you owe a debt and figuring out how to pay it are two different things, and little measurable progress was made. The Watts riots in 1965 pointed

the way. Some Blacks in South Central Los Angeles engaged in crazy, self-destructed 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" attemped 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. 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 <u>politics</u> 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 society, including their own. 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 <u>different</u>. 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 of 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 a severely disabled person lacks the inner resources or misses the strokes of fortune which lead him to a job which pays enough to support his 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 he 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 person affected, the difference may be very great.

If one looks beyond materialistic values to spiritual values, the issue become 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 benefical 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 Insitute makes few references to psychological services. It points out that they were not among the services most sought after by the respondents. these 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.

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, which interviewed relatives recall, 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. 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 come down to "me", the expectations rush backwards a few decades and the individual is both inwardly and outwardly directed to handle that part of the adjustment process himself. 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 himself? Nobody else is very happy these days anyway.

Apart from any humanistic, quality-of-life concerns, it is very likely that sufficient attention to such 'soft data' of rehabilitation - from the earliest moments post-onset through the entire process, which may be life itself - could further reduce medical, welfare and other related costs to a degree barely conceived of today. People who feel badly about themselves generate needs which must be served. Unfortunately, it too often happens 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 meant 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 with a disabled person until you were both blue in the face, but at the end of it, if 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 discriminatroy hiring practices instead of counseling him to stop liking upstairs restuarants and training him to do the few jobs he would be allowed to do.

I agreed with this until about 1969. 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; 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 are 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? The remainder of this paper will be devoted to these two questions.

Current Practice

I will touch upon what is happening - or not happening - in five areas: 1) community (acute, general) 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 just previous jobs have led me to. I have not, for purposes of this paper, 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 who 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 singular 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 the explanation. 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 (eg, improved insight) to concrete behavior (eg, no longer beats wife). Unfortunately, the psychologists' status isn't helped by this as much as it might be.

The reason is still a third basis for marginal status. 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. If he serves well as therapist,

counselor, teacher, guide or guru, then the individual may be better prepared to deal with exigencies of his altered life weeks, months or years after 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 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. Let's say hospital staff acknowledge the need to deal with psychological problems before releasing the individual. They will 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 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 decision. 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; 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 wherein we thought the counselor, ideally, should have recognized any of a number of 'red flags' in the early case data to warn him: "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 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. Clearly, 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, their role was almost exclusively the administration and interpretation of vocational assessment instruments to guide counselor and client in their search for a suitable vocational goal. This was not a very fulfilling job for them, and it left significant unmet needs for the counselor. A new policy has been formulated. Their functions 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, and their consultation and training responsibilities take precedence. Excess testing demands are to be contracted out to practitioners 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 is too great. However, they

are expected to know the community resources thoroughly so they can recommend with assurance that the client will get 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 them include psychologists on their staffs. 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 this richness of psychological staffing can offer.

An experimental program for brain-injured men demonstrated that a token economy coupled with a sequentially reduced distraction-free environment made it possible for several of them to work at minimum-wage productiveness in the main shop whereas before, the stimulus impact had so disorganized them they could barely sustain half minimum-wage production levels.

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 result was having to close down on the flood of self-referrals from the college. 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; 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 aberrant 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 (eg, 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 presenting

problems call for it, the idependent 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 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 unwholesome 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 last 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 even explicitly 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 acknowledgment 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, 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 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 may require medical advice as to contraindications, such as Rolfing. 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.

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

Focussing 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. That is what this workshop-seminar is all about. 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.

Focussing on the private sector of psychology practitioners, some consciousness raising needs to be done to assure that relevant

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 the 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 poulation.