A Concept of Rehabilitation

by Herbert S. Talbot, M.D. — Part II

The introduction to this medical feature of the month appeared in the November, 1962 issue of PN.

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Nothing better illustrates the intensely individualistic philisophy that still prevails in the United States, despite the cries of alarmists, than the resistance so frequently offered to rehabilitative efforts. This is seldom overt, being far more manifested by apathy or lack of interest than by actual hostility. But it is clearly evident that our people, even when disabled, do not take kindly to having their lives worked out for them and the patterns of their existence planned, however benevolently.

During recent years I have had the privilege of visiting a number of rehabilitation centers in this country and abroad and of meeting many foreign colleagues. It has been heartening to observe that, on the highest level of endeavor, equally fine work is being done in many nations. There is, however, one difference worth reporting. Our American patients are less docile than their European counterparts about accepting jobs to which they are directed. This is not simply a manifestation of greater independence because of more generous pensions. It is the vigorous assertion of a man's prerogative to pick his own work, a prerogative which, being based upon specific ability, may not be categorically denied because of an irrelevant disability.

The problem, of course, is to have the ability emerge and develop, to make certain that the disability is reduced to irrelevance. The fundamental choice, however, must be the individual's own, not his doctor's nor his vocational counsellor's, nor that of any of the host of people whose knowledge and skills qualify them to help but not to direct. No point needs more earnestly to by stressed than the need for being humble with those we wish to help. The absence of such humility is responsible for many of our failures. The very heart and essence of rehabilitation is self-sufficiency; it cannot be nurtured if it be denied at the outset. The greatest handicap of a disabled man is not the physical impairment itself so much as the fear that, because of it, he may be unable to follow his own bent and make his own choices. These, after all, are the prerogatives of that freedom to which we pay such constant lip service. The obligation that lies upon us is to show the patient that he can still make his own choices; it is not for us to make them for him.

This, of course, means that we must be prepared to teach, to encourage, to advise, but never to dictate. It means, too, that these men and women must be allowed to make their own mistakes, as we all have done. This may be very trying to the beholder, for it is not easy to be sympathetic with a course of action with which we disagree. Finally, it must be acknowledged that there are those who cannot be rehabilitated in the fullest sense. Some would not in any circumstances have become self-sufficient to the degree idealized in a free society, and for these we must be content with lesser achievements. It is no discredit to the whole work that not all of its results will be of equal excellence—not as long as we recognize clearly the difference between a finished job and a makeshift. It is helpful sometimes to be able to take refuge in a sense of humor. Heavy-handedness is very wearing, but every doctor knows how much comfort there may be in the appearance of casualness. Chesterton once wrote, "What can one be but frivolous about serious things? Without frivolity they are simply too tremendous." I am not quite prepared to recommend an attitude of frivolity, but a light touch causes no pain.

The economic factor has brought further confusion to the issue. While it is quite true that financial need is an important stimulus to a man's determination to rise above his disability, it is also true, now as ever, that man does not live by bread alone. The concept of self-sufficiency should not be limited to the economic sense, although that obviously must be included. There are times, in fact, when I wonder if we are not deceiving ourselves, mistaking a makeshift for a finished job, simply because a man is earning a living. I expressed this doubt some time ago in an article written for a journal in England and was interested in finding confirmation, in the next issue, in a letter from a paralyzed reader. He wrote in part: "To so many people a return to work approximating to the sort of work done prior to injury is synonymous with a return to the natural order of things. There is surely much more in life than just being cooped up in a factory or an office. Mental health is surely the primary condition, and I remain unconvinced that the only way to achieve that is by finding the patient a job. Satisfaction at being economically independent will not, I submit, compensate in the long run for an uncongenial job."

Motivation is a word glibly used—often too glibly—but it represents a complex of emotional and intellectual elements not easily identified, much less measured. Certainly, it is a reasonable assumption that most people work in order to earn money. As I write these words I am reminded of Dr. Johnson's famous remark, "No man but a blockhead ever wrote except for money." But its full significance lies not in the implication of his disinclination to write for nothing, but rather of his choice of writing as a means of earning. Incidentally, he also said, "There are a few ways in which a man can be more innocently employed than in getting money."

Among my own patients and former patients, I have observed with interest that those who receive the most generous pensions, i.e., those who became paralyzed while in service, are by no means the least assiduous in looking for, landing, and holding jobs or in engaging successfully in some form of self-employment. On the contrary, I believe that their record in this respect is rather better than that of their nonservice-connected comrades, whose pensions are adjusted to a mere subsistence level. Without speculating about the reasons for this, it is sufficient to suggest that actual need for money is not the only determinant for working, nor the amount earned the only criterion for the choice of work.

There is yet another sense in which, I believe, the economic aspect of rehabilation has been falsely stressed. It has been

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considered necessary by some to "sell" the idea of rehabilitation by pointing out that it is cheaper for the community in the long run—cheaper, of course, in a pecuniary sense. The argument goes something like this: First, when these people have been brought to the point of earning their own livings, the public treasury, be it local, state, or national, is relieved of the drain of supporting them; second, they earn enough so that the taxes they pay more than balance the costs of their rehabilitation. Statistics are brought forward to prove this, as, indeed, they can be to prove anything. But suppose that the taxes paid by these people came to only one half of the sums expended in their behalf, or one quarter, or one tenth? Is there a point at which we might decide that the return did not justify the outlay and that our endeavors were, in consequence, unjustified? Is rehabilitation, indeed, a luxury to be indulged in only so long as it pays or breaks even, or an obligation to human decency to be met at whatever cost? Perhaps it is important to be assured that we can afford to carry on this work. Can we, believing what we do believe, afford to do otherwise?

The sort of argument I have just mentioned not only does grave injustice to the spirit of our people, it is a disservice to the cause of rehabilitation because it obscures its chief purposes. These, I insist, are fundamentally humane and not economic. If our efforts are to be inspired or even chiefly encouraged by the fact that they are going to save us money, then we come off second best by comparison with our ancestors who left their disabled on a mountain top. At least, they were not expected to return a profit. If the total amount of these taxes is cause for any satisfaction at all, it must come to those who pay them, from the knowledge that they are playing their part in the community.

No one but a fool denies the importance of earning a living. But simply to do so no more constitutes the complete rehabilitation of a disabled person than it would imply a complete and satisfying life for any other individual. Like the mechanical gadgets, it is a means and not an end. Any man, disabled or not, should do something with himself — something from the doing of which he can derive satisfaction and augment the sense of his worth as an individual, something from which, also, he can earn enough money to meet his particular needs. The true criterion of successful rehabilitation is not making a living but finding a satisfactory way of life.

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Educators say of a college that its function is not so much to give its students learning as to open their eyes to the truth and teach them how it may be sought. Similarly, the process of rehabilitation must open a man's eyes to what he wants to do with himself and help him to achieve his aims. It is a process that must begin at the very onset of the disability, for it demands, from the beginning, a reasonably satisfactory adjustment by the paitent to the modifications of activity that have been imposed upon him. And it is a process that, in its most successful application, never

ends. For rehabilitation is not a sort of degree or mark of distinction granted at the end of the course. It is, rather a state of being to which one aspires, more or less approximated in various instances but never fully realized. It is a way of life.

Obviously, good health and its accompanying sense of physical well-being are highly desirable and may be set down as essential prerequisites. Despite serious gaps in our knowledge, more is possible now in this direction than ever before. With certain exceptions, most disabled persons may now except lives of reasonable comfort and normal duration. In our enthusiasm over the finer results of our increasing medical and surgical skills, however, we forgot for a time that they were doing only half the job. They were making life longer and more comfortable, but not necessarily more worth living. It was, perhaps, natural that, when the medical profession began to assume in earnest its obligation is respect to rehabilitation, it should have emphasized those physical aspects for which the knowledge and technics were at hand.

As doctors, however, we have not yet brought the best of our philosophy to bear upon the essence of the problem. It has always been our noblest aim to treat man and not disease, however we may have strayed occasionally from this high purpose. Moreover, we are more and more being urged, and urging ourselves, to treat the whole man. When a paitent presents himself, we do not stop at the chief complaint but work him up completely. We are not, nor should we be, satisfied with any course of treatment that does not meet all the needs we have uncovered, regardless of whether he was himself aware of them in the beginning. Everyone has heard of the poor chap who comes in with some minor complaint or other, gets a wonderful work-up, and leaves the hospital, some weeks and an operation or two later, with his original complaint still untreated.

(Continued on page 10)

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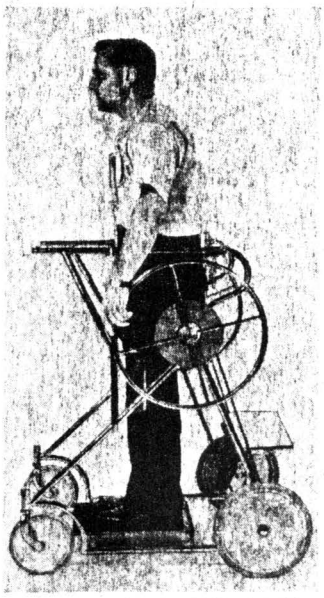

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But when a disabled patient presents himself, we find it difficult to see beyond the disability itself, the missing or paralyzed limbs, the deformity, the loss of vision or hearing. Yet this is but the presenting facet at which the physician articulates with the patient. Behind it is an organism, a personality desperately needing to regain an image of itself in which will be preserved the precious core of individuality. We must study and understand the whole organism the whole personality.

It is through no virtue of our own that a few have had this realization thrust upon us. The patient with a spinal cord injury presents, along with the obvious paralysis, such a variety of grave complications, autonomic, visceral, cutaneous, and the like, that his very survival requires the most painstaking observation and management. In fact, until the period of World War II, not enough such patients survived for more than a few months to attract general attention to their needs. Now there are probably more than 50,000 in this country, some say as many as 80,000, and those who are charged with their care must treat the whole man indeed or there will be none to rehabilitate. It has been an extraordinarily rewarding experience from which we have learned much that is applicable elsewhere in medicine and surgery. But, in particular, we have learned from these patients how to approach all the severely disabled, to recognize their particular needs, and to appreciate the almost unbelievable courage and resoucefuliness with which they face the most formidable handicaps.

Because of a variety of patients' requirements, a high degree of specialization in treatment has been inevitable. The specialties are necessary, but someone must know the whole patient and know him well. Someone must draw the varied efforts together into a master plan, be aware of everything that is going on, direct the whole undertaking. Whether or not he contributes one of the special skills himself is less important than that he should understand the right time and place for all of them in each individual case. In short, the relationship of doctor to patient must be as intimate and direct, as charged with mutual confidence as has ever been idealized as a standard of practice. There is no more essential element that this in the concept I am trying to describe. Rehabilitation cannot be turned over altogether to specialists and special clinics. They have their part to play, but the key figure is still the patient's doctor. Whether he be a family doctor in private practice, or one of the team of specialists, or a full-time doctor in a large center is unimportant, but he must be there. Whatever its other implications, rehabilitation is a medical problem, and there is an essential quality in the physician-patient relationship that cannot be delegated.

For all this, we must recognize our limitations. In problems so highly individualized as those of rehabilitation, our insights will not always be sufficient. This is not a council of despair but a reminder to be humble. Plastic surgery, prosthetic appliances, and the fine accomplishments of physical medicine have all contributed immeasurably to equipping and preparing the disabled for useful and contented lives. But in themselves they may not get down to the essence of a man, and, if he has not within himself the desire for accomplishment, his response to all these efforts will be at best mechanical. For all our methods of medical and psychological investigation, we cannot reach into the secret places of the heart. We may stimulate and persuade, but the essential response must arise in the patient himself, and the sooner this is generally realized, the sooner it is acknowledged that most of the things we have been calling rehabilitation are not that but only a means to it, the sooner we shall have the results we want. Up to now, too much emphasis has lain on processes and technics, too little upon the individuals to whom they are applied.

It is not too difficult to provide a man with a pair of artifical legs and teach him to walk upon them. The next question is where will he walk? There is no determination in the legs themselves, but the manner and direction of that determination are none the less a part of rehabilitation, concededly the most difficult part. Paradoxically, it is just that individuality which we must so sedulously cultivate and encourage that places so many obstacles in the way of success. Unless it is encouraged, however, there can be no success worthy of the name. It is possible now for many, if not most, physically handicapped persons to get gainful employment without the onus of "made work." But in any given case we must ask as well, was this the work he chose for himself, or was it chosen for him? Was he discouraged from trying something else he preferred, or was encouragement lacking for a venture he wanted to try but feared to risk? Whatever aid he got, whatever training, whatever gadgets, was he permitted to make up his own mind, to choose his own way?

In promoting the cause of their rehabilitation, many have referred to the waste to society represented by disabled persons. The real waste, however, is not of so many mechanics or scholars or artists or scientists, but of the human beings who play these parts. The greatest danger a disabled man faces is not that he may lose his earning power but that he may, in boredom, apathy, and despair, lose the awareness of his own worth and dignity. The material phases of the problem, although not fully mastered, are at least well in hand. The time is come when, if the work is to be fruitful, we must reach toward those intangible values that give life meaning and savor—toward a concept of rehabilitation that recognizes that man is, or is capable of becoming, a spiritual being. In this lies his capacity to overcome almost any physical handicap.

What, then, are we striving for? What is this concept all about? If all the things we generally call rehabilation are simply a means to an end, what is the end itself? What is it that the disabled man must recapture in order that he may fashion a new and acceptable image of himself, overcome the handicap of his disability, and achieve self-sufficiency in so far as any one can in this crowded world? If you must have it in a few words—and I do owe you some effort to be concise—I should say that our man must find restored to him a sense of the security of his own in-

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It may immediately be objected that this is inconsistent. For I have said that our undertaking must reflect the time we live in, and certainly one of the recurrent themes of life today is a lurking sense of insecurity. It is true that I cannot expect my patients to achieve a sense of security in a military or economic or political sense any firmer than that which supports most of us in these uncertain times. I may hope, as a physician, to be able to offer him security of his person to the extent of reasonable health and comfort. But the security of his individuality, drawn from an inward strength, will render him capable of standing up to any threat, at least as well as the rest of us do.

He cannot be spared, any more than we can spare our children, the trials all men must face. To each era of history comes its own problems, nurtured in the great intellectual currents that sweep across the earth from time to time. Today, we of the Western World are struggling to free ourselves from the trammels of materialism even as we must strive to make ourselves materially stronger. That is the desperate paradox we face and which we must resolve. We can do so only by reaching back and reestablishing the spiritual values that first gave us courage, confidence, and strength as a nation. This is the great problem of our generation. It is the chief problem of education: to learn the values that transcend material considerations and at the same time achieve mastery of the intricacies of our material culture. It is certainly the chief problem in rehabilitation, precisely because we have come to put so much faith in gadgets and medical skills, inadequate as they are, that there is a danger that our patients will depend upon them rather than simply use them for what they are worth.

It is, perhaps, a symbol of what I seek for the disabled, that in my general associations with most of my former patients, I am scarcely ever consciously aware of their disabilities. This is not merely a glossing over, or a matter of habit. Among those currently under treatment the same disabilities are a matter of constant preoccupation. The attitude, in fact, is not of my making but theirs. They bear their handicaps with a sort of grace that makes them unnoticeable. This also is not made up entirely of intagibles. But, in the physical realm, we have reversed the old attitude; we concentrate on the abilities that remain until the disability seems, by comparison, less significant. I honestly think that in some instances it becomes, even for the patient himself, insignificant. For he has filled his life and his mind with things to do until he no longer misses the things he cannot do.

There is a theory that no severely disabled person, however intelligent and understanding, however clearly he acknowledges his predicament on the conscience level, ever actually accepts, in his subconscious, the permanence of his dysfunction. I have discussed this with many patients and perhaps half of them think it may be so; the other half doubt it. I have no firm opinion myself, and it seems unlikely that we shall ever have sufficiently extensive psychoanalytic studies to give us much sound evidence one way or the other. But this I do know: The great majority of these people, whether or not they have accepted the permanence of their disabilities, have made good preparation for a long siege. If some day the siege is lifted, fine. If not, they will not have wasted their time.

Whatever they can or cannot do physically, however great or small their handicaps, often in spite of discomfort and poor health, most of them are sure of themselves, satisfied that life is worth living, and doing their best to live it fully according to their several abilities. Most important of all, they are living their own lives, making their own choices, enjoying their rightful heritage.

So the goals we seek in the rehabilitation of the disabled are none other than those we should choose to see established for all, handicapped or not. We have come the full circle. I began by saying that the validity of our undertakings depends upon their fitting into the pattern of our culture. Now, as I close, I hope you will agree that the concept I have tried to define fairly reflects the meaning of our democratic ideal, our Christian ethic, our American tradition.

Nothing less will do.

Reprinted from December 1961 issue of Rehabilitation Literature.

ISRD CONFERENCE REPORT

The proceedings of the conferences devoted to "The Physically Disabled and Their Environment" are available from the International Society for Rehabilitation of the Disabled. The conferences were held in Stockholm, Sweden, October 12-18, 1961, in cooperation with the Swedish Central Committee for the Care of Cripples, member organization in Sweden of the International Society.

Among the topics discussed at the conferences and reported in this 208-page volume are the planning of dwellings for the handicapped; disabled homemakers and their problems, including methods and technical aids used in laundering, cooking, dressing and the care of clothes, cleaning, caring for children, shopping; the distribution of information; individual transportation by motor vehicle and its problems; and rehabilitation services for disabled homemakers. These subjects are illustrated with pictures and diagrams.

The appendices to the proceedings include reports on community planning and the disabled; progress in rehabilitation services in individual countries; public transportation facilities for the disabled and services for disabled homemakers.

Rehabilitation specialists from 13 countries participated, including, among others, Miss Muriel E. Zimmerman, OTR, United States; Miss Susie Oosthuizen, South Africa; Dr. Castor Lindquist, Finland; and Mr. Sadanobu Kono, Japan.

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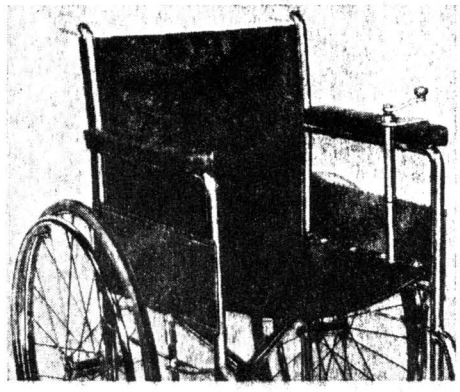

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TO: MISS BARBARA HINDS

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FROM: D. E. CURREN

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Over to you!

Don Curren,
Executive Director.

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• Paraplegic:— a person paralyzed, generally from the waist down, by injury or disease of the spinal cord.

TO: Barbara Hinds

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