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PROBLEMS OF DISABILITY FROM THE PERSPECTIVE OF ROLE THEORY*

Edwin J. Thomas†

Two general topics were discussed in this role-theoretical analysis of the disabled. The first topic involved a description of the "roles" of the disabled, in connection with which five disability-related roles were discussed (the "disabled patient," "handicapped performer," "helped person," "disability comanager," and "public-relations man"). The second topic concerned the role-related problems of the disabled. In addition to the difficulties of role discontinuity, role conflict, conflict of role definition, and non-facilitative interdependence, the special problems of role asynchrony and invalid role synchrony were elaborated, as were the conditions that determine these problems of role synchrony.

The disabled are a mixed lot; all manner of condition—psychological, sociological and economic—is to be found among them, and the impairments that medically define these individuals as disabled are also remarkably diverse.[1] In her concluding comments concerning an assessment of the field of somatopsychology, Wright has captured what is perhaps the heart of the matter for the case of the disabled; she said " . . . *somatic abnormality as a physical fact is not linked in a direct or simple way to psychological behavior*."[2] In support of this is the sobering fact that the scholars who have reviewed the scientifically reputable studies concerning the effects of disability upon adjustment have not found that there is presently any known, general, deleterious effect upon adjustment attending disablement.[3] That is, there is no evidence that an impaired physique results in any general maladjustment or that there is an association between types of physical disability and particular personality characteristics, such as tolerance for frustration or feelings of inferiority. Future research, of course, may force a revision of these observations. And, in any case, these results do not deny another equally important generalization, this one being based upon personal accounts of disabled persons, the observations of practitioners who work with the disabled, and the rehabilitation literature in general. This conclusion is that there are significant behavioral correlates of disability, for given impairments and for given individuals, and that disability often profoundly affects the person's life.[4]

One must therefore turn to the underlying psychological and social conditions responsi-

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1. Disability may be defined as " . . . a condition of impairment, physical or mental, having an objective aspect that can usually be described by a physician . . . "; in contrast, a handicap " . . . is the cumulative result of the obstacles which disability interposes between the individual and his maximum functional level." See K. W. Hamilton, *Counseling the Handicapped in the Rehabilitation Process*, New York, Ronald 1950, p. 17, quoted in B. A. Wright, *Physical Disability — A Psychological Approach*, New York, Harper, 1960, p. 9.

2. Wright, *op. cit.*, p. 373, as italicized by Wright.

3. For example, see Wright, *op. cit.*, pp. 373-377; similar conclusions are supported by the analyses of the following writers; R. G. Barker, in collaboration with B. A. Wright, L. Meyerson, and M. R. Gonick, *Adjustment to Physical Handicap and Illness: A Survey of the Social Psychology of Physique and Disability*, (second edition) New York, Social Science Research Council, Bulletin 55, Revised, 1953; and L. Meyerson, "Special Disabilities," in P. R. Farnsworth and Q. McNemar, eds. *Annual Review of Psychology*, Palo Alto, Annual Reviews, 1957, Vol. 8, pp. 437-457; E. L. Cowen, R. P. Underberg, R. T. Verrillo, and F. G. Benham, *Adjustment to Visual Disability in Adolescence*, New York, American Foundation for the Blind, 1961. An especially revealing study is that of T. F. Linde and C. H. Patterson, "Influence of Orthopedic Disability on Conformity Behavior," *J. Abnormal and Social Psychology*, 68:115-118, January, 1964.

4. For example, see Wright, *op. cit.;* H. H. Perlman, "Family Diagnosis in Cases of Illness and Disability," *Family-Centered Social Work in Illness and Disability: A Preventive Approach*, New York, National Association of Social Workers, 1961, pp. 7-21; E. Gambrill, "Post Hospitalized Disabled Children," *J. Health and Human Behavior*, 4:206-210, Fall, 1963; F. Davis, *Passage Through Crisis: Polio Victims and Their Families*, Indianapolis, Bobbs-Merrill, 1963; A. G. Gowman, *The War Blind in American Social Structure*, New York, American Foundation for the Blind, 1957; and J. Kamm, *A Study of Patients With Orthopedic Disabilities*, Ann Arbor, Univ. of Michigan School of Social Work, 1956, (unpublished Master's thesis).

ble for these different reactions in order to gain a richer understanding of the problems of disability. It is here that role theory is useful. Its concepts make possible a consistent, general description of the behaviors of the disabled and of those with whom he relates and the perspective helps predict and explain the strains and adjustmental difficulties that may attend disablement.[5]

This paper focuses upon problems of role which are linked to the behavioral changes associated with disability or to the behavioral changes deriving from the reactions of others to the disabled. The problems of role which disabled individuals share with the non-disabled and which do not therefore distinguish their condition particularly, will not be discussed here. Because of this emphasis upon the disability-linked factors, only portions of role theory will be employed.[6] Also, the problems of role associated with an individual's disability may not always create severe adjustmental difficulties. The disability-related role problem may contribute little or much to an individual's over-all adjustment, depending upon the entire complex of personal and environmental pressures in his life. This is true despite the fact that role difficulties to be treated here generally have undesirable adjustmental consequences, assuming all other factors equal.

THE ROLES OF THE DISABLED

Because of the great diversity of impairments characterizing persons designated as disabled and because of their almost infinite conditions of psyche and environment, is it meaningful at all to talk about the "roles" of the disabled? Are the behavioral repertoires, or "roles," of the disabled and the repertoires of those with whom they interact sufficiently distinct to be singled out, analyzed, and labelled? The answer is decidedly affirmative. Whether he is disabled from birth or suffers the disability later in life, the disabled person has some segment of his behavioral repertoire which is different from that of his normal fellow human. The difference may derive from any or all of the following; some responses may be lost, some regained, some substituted, or some simply different or new.

Five disability-related "roles" have been singled out for analysis: "disabled patient," "handicapped performer," "helped person," "disability comanger," and "public-relations man." The names are but convenient designations for particular aspects of the disabled person's behavioral repertoire or for the behaviors of others with whom he interacts; the behavioral repertoires so labelled are really complex clusters of conceptions, rules, and performances. The behaviors associated with each "role," however, are descriptively similar and they are different from, and independent of, the behaviors grouped as belonging with another "role." Although these "roles," hopefully, capture the essential differences between the behavioral repertoires of the disabled of those with whom they interact, all five roles are not necessarily applicable to every disabled individual; one or more of the "roles," however, should apply to every disabled person.

"Disabled Patient": At the onset of the impairment and later too the disabled individual is typically a patient, thereby exposing himself to a characteristic set of expectations. To quote from Parsons' seminal discussion of the sick role:

> The first of these is the exemption of the sick person from the performance of certain of his normal social obligations. Thus, to take a very simple case, 'Johnny has a fever, he ought not to go to school today.'
>
> . . . Secondly, the sick person is, in a very specific sense, also exempted from a certain type of responsibility for his own state . . . He will either have to get well spontaneously or to 'be cured' by having something done to him. He cannot reasonably be expected to "pull himself together" by a mere act of will, and thus decide to be all right . . .
>
> The third aspect of the sick role is the partial character of its legitimation, hence the deprivation of a claim to full legitimacy. To be sick . . . is to be in a state which is socially defined as undesirable, to be gotten out of as expeditiously as possible . . .
>
> Finally, fourth, being sick is also defined, except for the mildest cases, as being 'in need' of help . . .' He . . . incurs certain obligations, especially that of 'co-operating' with his physician—or other therapist—in the process of trying to get well (p. 613).[7]

5. I know of no analysis of the behavioral problems of the disabled from the perspective of role theory, although there have been sociological analyses of specific disabilities (such as blindness) and descriptions of the patient role.

6. For a general treatment of role theory see B. J. Biddle and E. J. Thomas (eds.), *Role Theory: Concepts and Research.* New York, John Wiley, in press.

7. Parsons, T., "Illness and the Role of the Physician: a Sociological Perspective," in C. Kluckhohn and H. A. Murray, with the collaboration of D. M. Schneider, eds., *Personality in Nature, Society, and Culture,* (second edition) New York, Knopf, 1953, pp. 609-617, reprinted by permission.

In addition, most disabled persons are also hospitalized at some point. The expectations placed upon hospital patients are partly those relating to the sick role and partly those attending the particular subculture of the hospital. King has described this particular set of expectations for the hospitalized as follows:

> The first general expectation is that of *dependence*, of compliance by the patient to hospital rules and regulations, to the daily routine, to the decisions that are made for him by physicians or nurses. The compliant patient is therefore likely to be perceived as the good patient by hospital staff, whereas the patient who tries to exert authority will be perceived negatively . . .
>
> In line with dependence, the patient is expected *not to fulfill his normal role responsibilities*. This is one of the prerequisites of the sick role . . . , and a factor that receives strong support from hospital expectations. The patient is encouraged not to worry about cares of family or job and to concentrate on the process of getting well . . .
>
> A third expectation concerns the *de-emphasis on external power and prestige* which the patient carries in his life outside the hospital. The taking away of patients' clothes is a symbol of this loss, all patients being rendered as naked as the day they came into the world, and supposedly as innocent. Indeed, there is nothing quite so deflating to an individual's sense of prestige as his own nakedness in public. A positive function is also served by this action and expectation, that of emotional neutrality and fairness. . .
>
> *Suffering and pain are to be expected* and should be borne with as much grace as possible under the circumstances, so goes the general expectation. Hospital personnel know that rarely do patients come without pain or malaise and often the suffering is intense. Furthermore, the procedures involved in curing sickness in themselves often produce pain . . .
>
> Finally, *the patient should want to get well* and do all he can to aid the process. Again, this expectation grows out of the definition of the sick role and is an aspect of the role that is subject to rewards and punishments. The faintest hint of malingering can be picked up quickly by nurse or physician and is a sign that the patient is not living up to his obligations. If malingering can be clearly established, it acts to release the hospital from its obligations and brings about attempts to get rid of the patient as quickly as possible . . . (pp. 355-357).[8]

We add to these the expectation that there be tolerance for *prognostic uncertainty*. With most medical problems, there is a period between the recognition that there may be something wrong medically and the time following a diagnosis when there is relative certainty concerning the prognosis for the individual. During this period the illness or disability must be followed to see how it develops and time is required to gather the information and to make decisions about the case. In addition to this time required to reach a medically sound prognostication, there are other factors that prolong the period of uncertainty. This is well illustrated in Davis' analysis of this problem for polio victims.

> . . . As we have seen, medically there is a pronounced shift from prognostic uncertainty to certainty after the first six weeks to three months following the onset of the disease. Yet nothing approximating a commensurate gain in the patients' knowledge of outcome probabilities occurred then or for a considerable period thereafter. Thus, 'uncertainty', a real factor at the beginning of polio convalescence, came more and more to serve social-managerial ends for treatment personnel. Instead of openly confronting the parents with the prognosis—by then a virtual certainty—that the child would be left with a disability, treatment personnel sought to cushion its impact by hedging, evading questions, and acting as if the outcome were still uncertain. Thus they tried to spare themselves the emotional scenes that outright utterance of the prognosis would probably have entailed. . .
>
> . . . we must . . . not lose sight of the possibility that in many illnesses, especially those of a chronic or permanently incapacitating nature, 'uncertainty' is to some extent feigned by the doctor for the purpose of gradually—to use Goffman's very descriptive analogy—'cooling the mark out,' i.e., getting the patient ultimately to accept and put up with a state-of-being that initially is intolerable to him (pp. 66-67).[9]

One consequence of this prognostic limbo is that the patient and those closest to him lack authoritative opinion with respect to which realistic levels of performance may be set. Without the moorings of definite expert opinion, the patient and others may easily entertain unrealistically high or low expectations.

Another expectation held for patients is that they *define themselves as sick*. This requires that the individual acknowledge the unalterable fact that he is ill, injured or otherwise impaired and that his assumptive world and actions be structured accordingly.[10] For the disabled, this of course is repre-

8. King, S. H., *Perceptions of Illness and Medical Practice*, New York, Russell Sage Foundation, 1962, reprinted by permission.

9. From *Passage Through Crisis* by Fred Davis, copyright (c) 1963 by the Bobbs-Merrill Company, Inc., reprinted by permission of the publisher.

10. Pine, F., and D. J. Levinson, "A Social psychological Conception of Patienthood," *The International Journal of Social Psychiatry*, 7:106-122, 1961.

sented by beliefs and behavior commensurate with the premise that the individual in fact has a disability. The hospitalized and non-hospitalized patient alike are expected to conceive of themselves as sick, although the entry into a hospital is likely to impress this fact more emphatically upon patients.

There will be wide variations in the forms that the patient role takes for given disabled persons, depending upon the specific nature of the disability. But to the degree that the impairment is permanent, most of the elements of the patient role are extended or made enduring. The exemption from responsibility for the impairment may be granted for the duration of the disablement; the period of prognostic uncertainty, rather than being a matter of days or weeks, may be months or even years; the exemption from ordinary social responsibilities, as it takes form for the particular person and disability, may be permanent.

The expectation that the patient should want to get well, however, is not merely extended for many disabled. Rather, it is elaborated in complex detail, as is revealed in present-day rehabilitation practice and philosophy. Thus the disabled is encouraged to make the most of his capacities, within the restrictions set by the impairment. "Motivation" is the key word and has reference to a major theme in much of the rehabilitation literature. The expectation that the disabled realize his potentialities is manifested in numerous services, these variously providing counsel, therapy, training and education, prosthetic devices, employment opportunities, and money.

This philosophy also informs us that the disabled must "accept" his impairment, the acceptance being nearly a necessary condition, one gathers, to the proper realization of his capabilities. "Acceptance" of one's disability typically requires at least that the disabled conceive his limitations and promise realistically and that rules for performance be made commensurate with his true degree of handicap, his capabilities, and the environmental opportunities. The rationale attending the idea that "acceptance" is important for the disabled is a specification, in the context of disability, of the expectation mentioned earlier that patients conceive of themselves as "sick."

"Handicapped Performer": Because of the disablement there will very probably be an attending handicapping of performance. The impairment, of course, may range from complete loss of function, at one extreme, to a very minimal loss, at the other. As a consequence, some portion—large or small—of the normal individual's behavioral repertoire is somehow circumscribed, limited, or eliminated. All this is well known, of course.

But there are important ramifications deriving from having this more limited behavioral repertoire. First, the disabled person may be less able to care for himself physically: he may not be able to feed himself, dress, or move around, to select common instances. Second, the impaired function may be one which is requisite to the performance of normal social roles. For all adults there are at least three key roles or role clusters; one is the individual's sex role, either as a female or male; another is one's occupational role; and the third the individual's family roles, as son, daughter, father, mother, or spouse. The disability may reduce the level of performance for these roles or make it variable and unpredictable; in the extreme case, of course, repertoires required for all these roles may be essentially lost, resulting in the removal of the person from the main avenues society provides for accomplishment, reward, and a sense of personal identity. A third and related point is that the disablement may preclude the fulfillment of normal responsibilities to others; thus, if disabled, the father may no longer be able to be the breadwinner or the mother may have to relinquish homemaking and child care activities. And fourth, the disabled may simply hinder others; for example, the family members of the disabled may be constrained to forfeit vacations, educational advancement, social and recreational opportunities—all because of the added drain on the family resources of time, money, and effort consequent to the impairment.

The behavioral repertoire of the disabled person is not merely less complete than that of his non-disabled counterpart; it is also a partial collection of behaviors which are substitutes for those lost due to the impairment or for those which the person never had in the first place. The blind learns to read and write with Braille, the deaf comes to read lips and use a sign language, the extensively crippled find devices to aid their physical locomotion, to mention common illustrations of essentially substitute behaviors with which disabled individuals may embellish their repertories and thereby increase their effective functioning.

It is in all of these ways that the individual with an impairment may be said to be a "handicapped performer."

"Helped Person": All persons receive help from others from the beginning of life to its end, and the amount of aid is generally much more than is generally realized or acknowledged. The individual with an impairment typically receives more help than does his normal counterpart, of course; his physical needs may have to be ministered to and the responsibilities he ordinarily shouldered may have to be taken on by others. The disabled is thus on the receiving end of helping acts, he must adjust, accommodate and respond to being an object of aid; he is thus a "helped person." The help received may be relatively small or large but it is nonetheless sufficient generally to constitute a deviation for the recipient, from cultural standards of self reliance and independence so esteemed and revered even yet in the United States. The implications of this will be discussed further at a later point.

"Disability Co-Manager": The disabled individual often becomes an active participant in the decisions and regimen of living attending his impairment and rehabilitation. Thus the disabled may participate in the selection of an artificial limb, may assume responsibility for giving himself injections, taking medication, following a diet, taking exercises, or following a schedule of rest and activity. In all these ways, the individual may thus be said to be a "disability co-manager," following Wright's terms.[11]

"Public-Relations Man": Non-disabled persons conduct a large share of the business of living in institutionalized roles and in the context of widely shared understanding relating to expected behaviors. As a consequence, it is not common that a person has to explain his role to others. How often does a man, for instance, have to explain his role to a woman, or *vice versa*? The disabled, in contrast, typically have a particular impairment, the understanding of which is not provided for others by such a widely held, common store of knowledge. The relative uniqueness of the particular individual's impaired condition and the associated ignorance of others places a burden of explanation and interpretation upon the disabled over and above that which the non-disabled carries. The necessities to educate others are of at least two sorts. The first is mainly unsolicited in which another person behaves toward the disabled so as literally to force him to account for his problem. Thus the blind individual is asked what it is like to be blind or his arm is grasped by the well-intentioned sighted person who believes that he needs to be led across the street. The other set of occasions necessitating explanation, in contrast to the gratuitous, may be regarded as the relevant and legitimate. Consider these: the blind job applicant is called upon to indicate how he would perform with this handicap; the potential mate requests information about how the marital relationship will be affected by the other's disability; the prospective student is asked how his impairment will affect his ability to perform academically.

The information conveyed ranges over many themes: explanations of the nature of the disease, injury, or birth condition; the extent of disability and handicap; the regimen of rehabilitation and disability management. All these pertain to the disability itself. There are also those features relating to the individual's attitudes, beliefs, and life philosophy developed in relationship to his condition. Rich examples are provided in the rehabilitation literature of the diverse ways in which disabled individuals handle these themes of public relations. At one extreme there is "the educator," the one who dispassionately conveys the facts pertaining to his particular disability; and at a different extreme are those individuals who perform the function more as "propagandists," "apologists," "defeatists," or "deceivers." Goffman has described a particular variant of explanation in his notion of apologia. In this respect he says:

> First, in many total institutions a peculiar kind and level of self-concern is engendered. The low position of inmates relative to their station on the outside, established initially through the stripping processes, creates a milieu of personal failure in which one's fall from grace is continuously pressed home. In response, the inmate tends to develop a story, a line, a sad tale—a kind of lamentation and apologia—which he constantly tells to his fellows as a means of accounting for his present low estate (pp. 66-67).[12]

The fact that the individual's disability is particular, if not unique, for him and because of the absence of a uniform corpus of common knowledge pertaining to that disability, great latitude is provided for person-

11. Wright, *op. cit.*, pp. 345-364.

12. Goffman, E., *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, New York, Doubleday, 1961.

al differences to shape the explanations given to others.

PATTERNS OF DISABILITY ROLES FOR INDIVIDUALS

As observed earlier, a given impairment does not necessitate all of the behavioral changes identified with these five roles, but most disabilities implicate most if not all of them. A given individual will characteristically display his particular pattern or profile, through time. Some roles may be engaged in for longer periods than others; at any moment, some persons may manifest two, three, four or all five of the roles; and the sequence of going from one role to the others may also vary from person to person.

Beyond these individual differences is the question of when the disablement occurs in the person's lifetime. If the individual has an impairment from birth or one acquired early in life, he must learn the behavioral patterns associated with these five roles in the course of growing up, where these behavioral patterns—with the possible exception of portions of the patient role—are not common with those of the population at large. The socialization of such a disabled person is therefore partially deviant. The individual disabled later in life also has to learn these new behaviors, but in addition he must "unlearn" other behaviors no longer possible or appropriate. For these persons the task is that of re-socialization into a deviant social category and, of course, this may be gradual or rapid. A large proportion of disabilities occur relatively suddenly and this therefore poses the occasion for rapid re-socialization.

PROBLEMS OF ROLE

We turn now to the problems of role which attend disability. These difficulties arise partly because of role changes just described and partly because of general societal conditions, to be referred to shortly.

Role Discontinuity: Benedict introduced the concept of role discontinuity to characterize the lack of order and smooth sequence in the cultural role training of the life cycle.[13] She documented how various primitive cultures provided for more continuity in the training for responsibility, dominance and sexuality than was characteristic in the United States. The "storm and stress" of adolescence so often attributed only to physiological changes, she concluded, was in fact due to the particular discontinuities resulting from prior role training.

This seminal conception is sufficiently important to merit elaboration and extension. First, although Benedict used the term in connection with age-graded transitions universal for all mankind, it is but a simple step to realize that discontinuities may occur also for specific groups and individuals whenever there is a transtion from one position to another in which the role behaviors associated with each are different. Such is the case with large numbers of the disabled.

Second, the elements requisite to continuous role training need specification. There are at least these five: (1) there should be congruence of the expected behaviors between the new and the old positions; (2) the individual should have the capacity to acquire the new behaviors; (3) he should be properly motivated for the transition; (4) he should have been socialized in anticipation of the impending transition through prior rehearsal—either imaginative or actual—of the new behaviors; and (5) the rate of change in moving from one position to the next should not be too rapid.

On most of these counts a disability that occurs later in life involves discontinuity. An abrupt, sudden change probably serves to exacerbate the effects of the other factors. And even a gradual, progressive change may never eliminate a basic incongruence of expected behaviors, or never rectify the possible absence of capacity to perform the new and different behaviors, or achieve proper motivation to change. A gradual rate may make possible anticipatory socialization, but not necessarily. Thus even disabilities that involve gradual deterioration are mainly discontinuous role transitions, considering all of the requisites of role continuity here proposed.

Role discontinuity may result in confusion, anxiety and stress for the individual and we assume that these effects will be more probable to the extent that there are many rather than few discontinuous junctures.[14]

Role Conflict: Whether or not the individual's disability is attended by role dis-

13. Benedict, R., "Continuities and Discontinuities in Cultural Conditioning," *Psychiatry*, 1:161-167, 1938.

14. However plausible these effects may appear to be, their postulation must still be considered as hypothesized rather than as clearly demonstrated. The same conclusion pertains to the effects of role conflict, conception conflict and non-facilitative interdependence, to be discussed.

continuity, there are various conflicts of expectations which are disability related. An expectation is a statement which defines given behavior as obligatory, forbidden or permitted. Role conflict exists when there are two opposing expectations held for the behavior of an individual such that he cannot perform consistently with both at the same time. Role conflict may take many forms. Others may hold different expectations for you as compared with those which you hold for yourself; thus the child with a heart disorder may hold expectations for himself as if he were normal, whereas his parents may hold expectations requiring restriction of activity and rest. Another variant of role conflict occurs when others who prescribe behavior for the individual disagree between themselves; for instance, a parent, in attempting to deny a child's disability, may prescribe expectations for his behavior which do not take into account the disability, whereas the child's physician may advocate expectations more commensurate with the degree of impairment. A more subtle variant of role conflict occurs when the two conflicting expectations reside within the same skin, that is, are held by the same person for his own behavior; consider the father who has had a heart attack and who experiences conflict between his understanding of the doctor's orders that he care for himself properly and the expectations he has learned as a middle-class male that he be achieving, hard working, and successful in his work. Conflicts of expectations may result in stress for the individual, particularly to the extent that the conflicts are strong, enduring, or numerous.

Conflict of Role Definitions: Role definitions are in conflict when contradictory role conceptions are held for the same person. In the case of disability, the conceptions most likely to be conflicting pertain to ideas that the disabled person is normal or disabled. Thus the individual may view himself appropriately as disabled in a given area whereas selected others may view him as normal. More specifically, conceptions that the disabled hold for themselves may disagree with the conceptions others hold for them in any or all of the five disability related roles described earlier. Consider, for instance, the youth with a serious heart condition, the visability and significance of which is not apparent to the casual acquaintance. When meeting such a person for the first time it is not likely that others will conceive of him as disabled. The parallel problem involving the possible conflict of conceptions for the individual with a highly visible disability, such as blindness, is that the casual acquaintance is likely to conceive of him as more handicapped than he in fact may be. Conflicts of role definitions, at the very least, result in confusion and asynchronous behaviors of individuals *vis à vis* one another; more seriously, such conflicts may result in anxiety and stress, again to the extent that they are strong, recurring, or numerous.

Non-facilitative Interdependence: Because of the impairment and the resulting inability to care for himself, the disabled is typically less able to facilitate others, yet, others are constrained to act facilitatively toward him. This helplessness and non-facilitative relationship with others departs from the dominant cultural emphasis upon self reliance and independence; the individual may have been well trained to be self reliant, autonomous, and independent in the course of his social learning prior to the advent of the disablement. Williams, in his perceptive analysis of the values and beliefs in American society, has described achievement—success and activity—work as major value orientations in America;[15] and he has noted further that Americans esteem active mastery more than passive acceptance. The psychological needs for achievement and autonomy may be regarded as individual dispositions which derive in part from these highly esteemed cultural values.[16] The disabled may depart from this cultural standard of self-reliance and independence on many counts, and as a consequence, there may be various psychological effects. First, the individual may experience what Bertha Reynolds called the poignant "hurt" associated with the receipt of assistance when he is unable to repay others for the help received;[17] second, the individual may experience a drop in his self esteem;[18] and third, the help

15. Williams, R. M., *American Society: A Sociological Interpretation,* (second edition), New York, Knopf, 1960.

16. Murray, H. A., *Explorations and Personality,* New York, Oxford Univ. Press, 1938.

17. Reynolds, B., *Social Work and Social Living,* New York, Citadel Press, 1951.

18. See D. Landy, "Problems of the Person Seeking Help in our Culture," *Social Welfare Forum,* New York, National Conference on Social Welfare, 1960, pp. 127-145; and J. R. P. French, Jr., "The Social Environment and Mental Health," *J. Social Issues,* 19:39-56, October, 1963.

offered is likely to be apprehended ambivalently or even negatively.[19]

Role Strain: All these role problems—role discontinuity, role conflict, conflict of role definitions, and non-facilitative interdependent relationships—conspire, either singly or in complex combinations, to create role strain, i.e., to affect the experienced difficulty that an individual has in performing his role.[20] This strain differs from anxiety and stress in general only by virtue of its particular association with the problems attending one's social role.

SPECIAL PROBLEMS OF ROLE SYNCHRONY

In addition to the role difficulties already discussed, there is a special set of problems relating to the synchronization or meshing of the behavior of the disabled with that of others with whom he interacts. Because the problems of role synchrony are subtle and complex, they deserve more extended comments.[21] Let's begin with an example.

Consider the blind person about the catch a train in a subway. Through practice and the use of the cane he has become proficient at navigating steps and turnstiles and knows the correct moves required to get on and off subway trains and, as a consequence, he is able to locomote relatively independently from one section of the city to another. In only one respect is this person unable to be totally self reliant in his travels; he must inquire of others concerning whether the forthcoming train is the one he wishes to board. As he hears the distant roar of a forthcoming train, he asks this question: "Pardon me, is this an E train?" "Oh, yes!," comes the startled reply, "I've got you—" and the man to his left takes a firm grasp on his arm. In attempting to free himself, the blind person says, "That's all right, I can make it . . ." "It's no trouble at all," he protests, and then taking the blind man's arm, the other says "This way," and the train is boarded. Although the blind man is now able to fend for himself, his guide announces that there doesn't seem to be any seats, in a distinctly audible voice, whereupon one of the passengers looks up and says "Here, he can have my seat." After the blind man is seated the guide inquires shortly after, in a voice louder than is required by the roar of the train, "Where are you going?" Pausing briefly, the blind individual replies, "I'm getting off at Forty-second." "Oh," says the guide, "Well, I get off here. Good luck. Maybe someone else will help you."[22]

All that the blind individual needed was information regarding which train was coming, yet by virtue of the unsolicited help provided by the guide, he was treated as more handicapped than he was. The excessive handicap that was presumed was thus invalid. Furthermore, the blind person went along with the guide, this presumably being the course of least resistance, and he thereby fictitiously feigned a handicap that he did not have. The role behaviors of each were synchronic, however; the behavior of each meshed with that of the other, both sets of behaviors apparently being based upon the same behavioral assumptions. Thus in this example we have *role synchrony* between the disabled and the other, but it was essentially invalid because the behavior of both presumed a handicap that in fact was not present—a *fictitious handicap* as it were.

Now for another example. Fred is a ten year old boy with a mildly handicapping heart disorder. He does not choose to recognize his disability, however, and consequently he does not rest appropriately and, when he plays with others, he participates altogether too vigorously. Fred does all of this in spite of the admonitions and advice of doctors, parents and even his friends.

In this example Fred has ignored his disability and consequently he behaves essentially as if he were not handicapped; his behavior is thus invalid with respect to the true degree of handicap. Others behave toward him much more realistically, however, in that their behavior is commensurate with the true degree of handicap that exists. Because Fred's behavior does not mesh with that of others in respect to the degree of handicap, we may say that there is *role asynchrony* between him and others. The

19. Wright, *op. cit.*, pp. 224-229.

20. For an elaboration of this concept and of the conditions that may give rise to it in general, see W. J. Goode, "A Theory of Role Strain," *Amer. Sociological Rev.*, 25:483-496, August, 1960.

21. Problems of role synchrony have not been treated systematically in the literature, although related problems of marginality and so-called reciprocity and complementarity of role behavior have been discussed. For insightful discussions of the problem of marginality and of inter-action problems of the disabled, see especially Barker, *op. cit.;* Wright, *op. cit.;* and Gowman, *op. cit.* For a discussion of reciprocity and complementarity see A. W. Gouldner, "The Norm of Reciprocity: A Preliminary Statement," *Amer. Sociological Rev.*, 25:161-178, April, 1960.

22. Gowman, *op. cit.*, quoted and paraphrased from pp. 120-21.

Table 1
Varieties of Synchrony of Repertoires of Role Behavior for Self and Others

Behavioral Options of Self	Behavioral Options of Others: Behaviors Appropriate for a Handicapped Self	Behavioral Options of Others: Behaviors Appropriate for a Normal Self
Handicapped Behaviors		
Correct for Self	I. True Handicap	II. Imposed Normalcy
Incorrect for Self	III. Fictionalized Handicap	IV. Autistic Handicap
Non-Handicapped Behaviors		
Correct for Self	V. Imposed Handicap	VI. True Normalcy
Incorrect for Self	VII. Autistic Normalcy	VIII. Fictionalized Normalcy

source of the asynchrony is *self originated,* for Fred has chosen essentially invalid behavioral options. This particular variety of role asynchrony, in the context of disability, might be termed *autistic normalcy.*

Valid Role Synchronies: The significance of role asynchrony and of invalidity is highlighted by considering the typical role relationship characterizing the interactions of most persons, namely, that of valid role synchronies. The non-disabled person typically behaves in a normal fashion with others, and he thus may be said to be performing validly; and others relate to him on the assumption that he is normal, and their behaviors *vis-à-vis* him are appropriately complementary. This might be called *true normalcy* and is a valid role synchrony which characterizes the large majority of the normal interaction encounters of non-disabled individuals and, of course, it is characteristic for non-disabled persons prior to their disability (see Table 1). The problem posed by the advent of disability is that the valid role synchrony of true normalcy becomes less common and, in certain cases, is virtually ruled out.

The ideal interaction encounter, from the perspective of role theory, is the valid role synchrony. Because the synchrony we have called true normalcy is generally precluded for the disabled individual, the appropriate valid role synchrony for the disabled is therefore that which might be called *true handicap.* This is defined by behavior on the part of the disabled individual commensurate with the true degree of handicap and by related behavior of others also commensurate with the actual degree of the disabled person's handicap (see Table 1).[23] Interaction contexts in which this form of valid role synchrony is most likely to occur are the hospital, where the disabled person is on a ward with similarly disabled individuals cared for by a perceptive and competent staff, and in the disabled person's own family, assuming of course that he and his family members behave realistically. Interaction encounters outside of these more protected contexts have a greatly increased likelihood of being either asynchronous or invalid synchronies.

Invalid Role Synchronies: There are two varieties of invalid role synchrony to which the disabled are peculiarly subject. The first is characterized by a form of mutual denial of the disability in which the disabled performs in a manner implying or indicating less handicap than truly exists, coupled with the behavior of others toward him which analogously is appropriate for the absence of handicap (see Table 1). This might be called *fictitious normalcy.* In his analysis of polio victims and their families, Davis has described an extreme case of what he termed "normalization."[24] This was the case of six-year-old Laura Paulus, the most handicapped child in his group of nine study participants. Laura wore full-length braces on both legs, a pelvic band, high orthopedic shoes and had to use crutches. From a purely physical standpoint, she was extremely limited in what she could do. Her energetic mother was determined, however, to make Laura "normal." She was registered in the school that she attended before her illness, and took a regular city bus to school; parties, games and other festivities were held for her and she was enrolled in a Brownie troop. By joining willingly with her mother in this "normalization," Laura was entering into fictitious normalcy. If the situation of fictitious normalcy is enduring and his health and rehabilitation depends upon how well he cares for himself, the disabled may of course expose himself to unnecessary haz-

23. The "true" degree of handicap is difficult to assess because it requires judgments about the individual's impairment and his capabilities to perform with that impairment. The fact that professionals working with diability often have difficulty making these judgments is one of many factors which is conducive to generating either asynchronous or invalid role synchronies.

24. Davis, *op. cit.,* pp. 149-152.

ards. The excessive striving, in any case, may greatly increase role strain.

The second invalid role synchrony is the *fictitious handicap*. This, too, involves a pluralistic deception, for the disabled and others jointly adopt invalid behaviors in terms of the disabled person's true degree of handicap; but fictitious handicap also involves behavior on the part of the disabled and others which exaggerates the actual degree of handicap. Many of the examples of so-called overprotection cited in the literature on disability would be illustrative here (see Table 1).

LD was a 40-year-old insurance salesman married to an aggressive, strong-willed woman at the time of his first heart attack. The attack proved to be a mildly disabling condition which left the patient with shortness of breath when performing physical labor over an extended period of time. Thorough medical examination revealed he was able to continue with his work on a reduced schedule. Mrs. D, however, was fearful that continued work of any nature would result in further attacks, or even death, in spite of medical reassurance to the contrary. She earned an adequate income to support both herself and her husband, and convinced him without difficulty that he should not return to work. Both refused repeated offers to help (p. 35).[25]

The difficulty with fictitious handicap, clearly, is that as long as such a situation exists the disabled person will perform at a lower level than is necessitated by his disability.

Role Asynchronies: Role asynchronies occur when either the disabled person or the other adopts invalid behavior with respect to the true degree of the disabled person's handicap. We have already made reference to autistic normalcy in our example of Fred. Another self-originating asynchrony is *autistic handicap*. Here the individual displays more handicapped behavior than the disability actually warrants while others behave toward him in a fashion commensurate with the true degree of handicap (see Table 1). This is a variety of hypochondriasis for the disabled, as it were.

HB, a 35-year-old married Southern Missouri sharecropper with five children, had a brain infection five years prior to being referred for social case work help. The infection left him with a mild shuffling gait and general slowed ability to move hands and arms. Formerly an unskilled laborer, he quickly settled into apathy and developed a passive attitude toward various rehabilitative efforts which were attempted with him. His wife was unable to convince her husband that he should take more responsibility in helping himself since he believed he had a more serious and incapacitating illness than the doctors advised. The patient and his wife went on public assistance, and subsequent efforts toward re-employment became feebler with the patient finding numerous reasons why he could not work (p. 34).[26]

Both autistic handicap and autistic normalcy are self originating, i.e., they derive from invalid behaviors and assumptions on the part of the disabled person himself. All manner of personal and environmental condition may generate these particular autisms, as the clinical examples in the rehabilitation literature amply demonstrate. Emotional difficulties are most patently likely to be operative in such cases.

In contrast to these asynchronies, there are two others that arise from the invalid behaviors of others. For this reason these have been called the imposed role asynchronies. The first, an *imposed handicap,* occurs when others behave toward the disabled person as if he were more handicapped than he actually is, while the disabled behaves validly (see Table 1).

Joe was a 19-year-old plumber's apprentice when he was critically injured in an automobile accident resulting in what was at first considered severe brain damage. Gradually and unexpectedly, he improved to the point where he was considered medically capable of continuing in his previous occupation in spite of some clumsiness and a slight tendency to lose balance. Although both the patient and his employer were eager for him to resume work, his parents vigorously resisted and successfully interrupted his return to work. They had nursed him back from a critical illness, 'protected' him to the extent of doing for him needlessly, and were fearful he would 'get hurt' on the job and that it would be their 'fault' if anything further should happen to him (p. 35).[27]

An enduring imposed handicap may clearly eventuate in a fictitious handicap; in response to the extreme solicitousness, in other words, the disabled individual may succumb, lowering his performance to a level less than that of his true handicap.

The second asynchrony is that of *imposed normalcy*. Here the others who relate to the disabled person behave toward him as if he were less handicapped than he truly is, while the disabled maintains valid behavior (see Table 1). The case of Laura Paulus cited earlier would illustrate imposed normalcy

25. Breedlove, J., "Casework and Rehabilitation," *Social Work,* 2:32-37, October, 1957.

26. *Ibid.*
27. *Ibid.*

had Mrs. Paulus foisted the normalization on Paula against her wishes. An imposed normalcy probably exists early in the development of fictitious normalcy, especially when the disabled are children. One apparent difficulty with imposed normalcy is that the disabled person is constrained to perform above the level appropriate to the true degree of his handicap.

These are the eight varieties of role synchrony for the disabled. The details of their exposition should not obscure the two basic points. The first is that disability generally restricts the possibilities for valid role-synchronic encounters, and the second is that the particular problems of role synchrony chracteristic of the disabled appear either as an invalid role synchrony or as a role asynchrony. The particular problems of synchrony may be complexly patterned in the life of any given disabled person. The more enduring contexts of human encounter, such as home, school and work, may involve one or more varieties of synchronic difficulty; and the more fleeting, casual encounters may involve different and possibly highly diverse confrontations.

Underlying Conditions: A basic condition which gives rise to these problems of role synchrony is that society has not provided a social niche for the disabled that is as clear, predictable and as guiding as that which the non-disabled enjoys. There simply are not uniform, clear rules for disabled persons in the same way that there are rules for the performance of non-disabled persons; and the rules and conceptions that are held for these persons are generally diverse and lacking in agreement. Furthermore, an uncommon ignorance pervades the situation for the disabled. There is a widespread lack of public knowledge concerning the various types of disabilities, and there are many stereotypes concerning the disabled which substitute for genuine knowledge and operate along with ignorance. And contributing to the uncertainty is the disabled person himself; unless he is known rather well, he presents an ambiguous stimulus, as it were, in human form. The individual encounter with a disabled person is fraught with uncertainty about the conditions of his particular impairment, combined with ignorance of the individual personality and of how he has coped with his disability.

This lack of tradition, consensus, and knowledge—of institutionalization in general—surrounding the social niche of the disabled, has a singular consequence: the customary social moorings which control the choice of behavior in human encounters are weakened. The disabled and those who behave toward them consequently have more choices of behavioral alternatives. Speaking more generally, there is *role optionality,* a condition that is defined by the existence of two or more behavioral repertoires, each of which (1) attaches to a different social position, (2) has different implications for the person behaving and for the others with whom he interacts, and (3) lacks definition by the society and culture as preferred over other alternatives.

The main axis with respect to which the optionality exists for the disabled concerns that of normalcy *versus* disability, these being the central, opposing behavior repertoires. The disabled may behave so as to imply a greater or lesser handicap than he has, or he may behave consistently with the true degree of handicap. If he behaves consistently with the true degree of handicap, he may be said to be performing validly, as we have observed. And the other person (or persons) who interact with him may behave in analogous terms; i.e., they may perform so as to imply a greater or lesser degree of handicap than actually exists, or consistently with the actual degree of handicap. And if the other (or others) behave toward the disabled commensurate with the actual degree of his handicap, then the performance may be said to be valid. Without a condition of role optionality for the disabled or for those with whom he interacts, problems of role synchrony would not exist.

Now, given these behavioral options the question is what factors determine which choices will be made. In short, what conditions determine whether the disabled will choose valid or invalid options and analogously, what affects the selection of options when others behave with a disabled person? There are a few conditions that immediately come to mind.

The first is the very *degree of disablement.* The non-disabled person obviously has little occasion to perform as if he were handicapped, and others are most unlikely to relate to him as if he were handicapped. Also, the person who is nearly totally handicapped in all areas of functioning is going to have little role optionality with respect to performing as a non-disabled person. Others, however, may or may not perform

toward him as if he were as severely handicapped and thus even the totally disabled may face problems of role synchrony. Thus we see that occasions for invalid role options—and the consequent difficulties of synchrony—are more likely to be posed for persons who are partially rather than more extensively disabled.

Visibility of the disability also affects the behavioral options, especially those of the others who relate to the disabled person. The casual encounter with an individual with a visible impairment may cause others to behave toward him as if he were more disabled than he actually is, thus creating the occasion for what we have called an imposed handicap and possibly fictitious handicap as well. The situation is different for the disabled with an essentially non-visible impairment, for cues are generally not present to signify disablement and, for that reason, others frequently behave toward him as if he were normal. Under these conditions, for for the non-visibly disabled, we would therefore anticipate that there would be problems of role synchrony involving either fictitious or imposed normalcy.

The disabled person's *acceptance* of his disabled condition is still another factor which influences behavioral options. If the individual fails to acknowledge his impairment and he behaves accordingly, his denial clearly increases the probability that his encounters with others will involve the particular asynchrony called autistic normalcy. Analogously, if the person "accepts" his disability with resignation and denigration his behavioral options may well be biased toward excessive handicapping, thus creating the conditions for the particular asynchrony called autistic handicap. Only when acceptance involves a realistic appraisal of one's impairment along with behavior commensurate with this viewpoint on the part of the disabled person are the conditions established for averting asynchronies which derive from invalid, self-originated behaviors. Although the proper acceptance of the disability by the disabled person does not guarantee, of course, that others will adopt valid options in their encounters with him, the disabled person's genuine acceptance of his impairment, when communicated to others, may greatly increase the chances that they will similarly adopt valid behaviors when interacting with him.

The *society and culture* also shape the choice of options, directing them mainly toward normalization. The design of society is based on the premise that its members are not disabled. As many writers have observed, the society has been created and is run for the benefit of the normal individual. Also, the cultural values in the United States, stressing self reliance, independence and autonomy as they do, bias choice toward behaviors that would be designated as normal. Independence is esteemed and there is still some stigma, generally covert and subtle, which attaches to most every disability.

These pressures toward the normalization of behavior are to be pitted against essentially countervailing conditions which constrain the disabled to select the invalid options of excessive handicapping. I am thinking particularly of the factors that give rise to self pity, to secondary gains from disability, and to the solicitude of others in general. Humanitarian mores constrain others to err generously rather than niggardly in the public treatment of the disabled, and the pain and stress of disablement conspire, along with various personality factors, to make the disabled accept and sometimes to exploit these opportunities for attention, love and care.

SUMMARY

The perspective of role theory was employed in this analysis of the disabled. Two general topics were discussed, the first being that of the "roles" of the disabled. Five disability-related "roles" were described: the "disabled patient," "handicapped performer," "helped person," "disability comanager," and "public-relations man."

The second topic concerned the problems of role that may attend disablement. These problems were those of role discontinuity, role conflict, conflict of role definition, nonfacilitative interdependence, role strain, and the special difficulties of role synchrony. In addition to the synchronies of true normalcy (precluded for the disabled by virtue of the impairment) and true handicap (an ideal and sometimes uncommon encounter), the asynchronies of imposed normalcy and imposed handicap and of autistic normalcy and autistic handicap were discussed, as were the invalid synchronies of fictionalized handicap and fictionalized normalcy. Defining conditions and clinical examples were elaborated.

The conditions underlying the various problems of role synchrony were discussed, among these being role optionality, the extent of disablement, the visibility of the impairment, the acceptance of the disability, and selected societal and personal factors.

OPTIMISM, PHYSIQUE AND SOCIAL CLASS IN REACTION TO DISABILITY*

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The relationship between social class and the reaction to disability is examined. It is hypothesized that both optimism-pessimism, and the emphasis attached to physique, vary inversely with social class position, the lower the class level the greater the somatic emphasis, hence the more pessimistic the reaction to disability, and vice versa. Parents of 58 disabled children were examined, by questionnaire and interview. The results indicate a generally optimistic attitude toward disability, combined with a general depreciation of physique. In all, neither the reaction to disability, nor the emphasis attached to physique, showed any distinction by social class. Nevertheless, the anticipated relationship between the variables remains valid, the devaluation of physique facilitating the optimistic attitude toward disability.

Recent investigations by Richardson, *et al*,[1] suggest a uniformity of reaction to physical disability. Both children and parents, of different socioeconomic backgrounds, showed a uniform preference pattern in the ranking of various drawings:

Rank 1. A child with no visible physical handicap.
Rank 2. A child with crutches and a brace . . .
Rank 3. A child sitting in a wheelchair . . .
Rank 4. A child with the left hand missing.
Rank 5. A child with a facial disfigurement . . .
Rank 6. An obese child.

The question is, whether these findings are indicative of a general cultural uniformity in the total reaction to disability, or whether they are not.[2] Certainly, the general development of social class research would lead one to anticipate that the phenomenon of disability, like so many other conditions, would be differentially defined and reacted to by the several social classes.[3] On the other hand, it may be that somatic impairment evokes a universal response, which transcends social class lines. In an attempt to resolve this question, the following research was conducted.

Families of 58 disabled children[4] were studied, in the hope of discovering parental reaction to this problem. The following hypotheses are advanced to indicate the expected content and direction of this reaction: (1) That the reaction to disability is determined by socioeconomic position; (2) That this reaction will be progressively more pessimistic as one moves down in the class structure, and progressively more optimistic as one moves up; and (3) That there will be a progressive emphasis upon physique as one moves down the socioeconomic ladder, and a progressive de-emphasis of this same factor as one moves up.

The theoretical rationale behind these hypotheses contains the following points: (1) There is a universal need for status, prestige, self respect, etc.;[5] (2) In our society the most common and the most approved way of meeting this need is economic success;[6] (3) The legitimate paths to this goal are, however, more open to the middle and upper classes than to the lower classes;[7]

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1. See S. A. Richardson, N. Goodman A. Hastorf, and S. Dornbusch, "Cultural Uniformity in Reaction to Physical Disabilities," *Amer. Sociological Rev.*, 26:241-247, April, 1961; and "Variant Reactions to Physical Disabilities," *Amer. Sociological Rev.*, 28:429-435, June, 1963.
2. That is, does a uniformity of preference suggest as well a total uniformity of reaction to the concept and actuality of disability?
3. See R. Bendix, ed., *Class, Status and Power*, Glencoe, Free Press, 1953, for a general symposium on differential social class reaction, and B. Farber, *Family Organization and Crisis*, Yellow Springs, Antioch Press, 1960, for specific social class distinctions in the reaction to mental retardation.
4. The subjects, at the time of the study, were patients at Children's Seashore House, which is a private hospital. Their disabilities were largely orthopedic in nature.
5. See E. H. Bell, *Social Foundations of Human Behavior*, New York, Harper, 1961, pp. 130-140.
6. See R. K. Merton, *Social Theory and Social Structure*, Glencoe, Free Press, 1957, pp. 166-167.
7. Merton, *op. cit.*, p. 146.