

SICKLE CELL ANEMIA AND THE BLACK MALE FROM A  
PSYCHO-SOCIAL VOCATIONAL PERSPECTIVE

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ABSTRACT

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SICKLE CELL ANEMIA AND THE BLACK MALE FROM A PSYCHO-SOCIAL  
VOCATIONAL PERSPECTIVE

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Introduction

Sickle Cell Disease is a term that refers to any inherited blood disorder where Sickle Cell hemoglobin is present. It is one of the major health problems that affects Black Americans in the United States today. People with Sickle Cell Disease usually have a chronic lifelong condition.

Statement of the Problem

The lack of familiarity with the effectiveness of vocational rehabilitation services for the treatment of selected adult Black male Sickle Cell patients.

### Statement of the Purpose

This paper will focus on the effects of vocational rehabilitation on a selected group of Black males suffering with Sickle Cell Disease. With the proper guidance, Sickle Cell patients should be able to continue vocational training, complete their educational goals, and attain gainful employment regardless of their chronic illness.

### Methodology

The methodology used to carry out this study is a Quasi-Experimental design. A pre-test and post-test were administered to twenty-two Black male Sickle Cell patients.

### Conclusions

The projected outcome of the study is that both people diagnosed with Sickle Cell Disease, and those working with the Sickle Cell patient will be better educated. It is believed that vocational rehabilitation has some positive impact on the Sickle Cell patient's overall level of functioning. Hopefully, receiving vocational rehabilitation from an understanding staff will promote a greater level of independence in the Sickle Cell patient.

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## CHAPTER I

### Introduction

The term "Sickle Cell Disease" refers to any inherited blood disorder where Sickle Cell hemoglobin is present.<sup>1</sup> Scientists are unclear on exactly when Sickle Cell Disease began, but it is believed to have originated in Africa thousands of years ago. People affected by Sickle Cell Disease are also found in the regions surrounding Puerto Rico, Cuba, Jamaica, Italy, Haiti, Greece, Turkey, Sicily, South India, and Syria. A common bond in these regions is that malaria is often prevalent at epidemic proportions.

Nature often tries to protect people from the dangers in their environments by changing their genes over the course of time. Apparently this is what happened with the sickled cell. Since Sickle Cell Disease is an hereditary disease, scientists speculate that the disease is a result of gene mutations that occurred as a survival mechanism to resist malaria. This proved to be beneficial for people who resided in regions plagued by malaria. People who developed the Sickle Cell trait appeared to have a higher immunity to the exposure of malaria.

Sickle Cell Disease is one of the major health problems in the United States today. It affects more than two million people worldwide. One out of twelve Black Americans



has the Sickle Cell trait, and one out of five hundred Black Americans has Sickle Cell Disease.<sup>2</sup> People with Sickle Cell usually have a lifelong chronic condition. The symptoms and extent of their illness vary from person to person however. People with Sickle Cell Disease face psychological, social, educational, vocational, interpersonal, financial, and physical problems. This paper will discuss some of the psycho-social, and vocational aspects Black male Sickle Cell patients encounter in our society.

Stages of Sickle Cell Disease are characterized by: (1) anemia and (2) pain crises. Since anemia is one of the many clinical manifestations of Sickle Cell, the disease is also known as Sickle Cell Anemia. The major symptom of Sickle Cell Disease is the pain crisis however. Crises are periods of severe pain which can last anywhere from minutes to days. They are unpredictable, and represent the most devastating aspect of the disease. Instead of the cells being their normal donut shape, they change into a crescent shape. These red blood cells are rigid and unable to flow throughout the body. A large percent of the sickled cells become clustered together forming "log jams".<sup>3</sup> The log jams obstruct the blood vessels, preventing adequate blood flow and oxygen from passing to the surrounding capillaries and tissue which cause pain and discomfort to the afflicted person. The shape of these rigid red blood cells greatly decreases the

life span of the cells. Both the surrounding tissue and the red blood cells are then in danger of dying due to the lack of vitally needed oxygen. It is the reduction in the number of red blood cells throughout the body that results in anemia.

The Sickle Cell pain crisis process affects all of the body organs since blood flows throughout the entire body. Many people diagnosed with Sickle Cell Disease have repeated episodes of these pain crises throughout their life's duration. The severity of these crises vary however. Preventive measures such as: (1) avoiding exhaustion, (2) avoiding environments where the oxygen levels are low, and (3) reducing their stress levels seems to reduce the frequency of painful episodes in Sickle Cell patients.<sup>4</sup>

#### Statement of the Problem

Many times emphasis is placed on the treatment of Sickle Cell Disease, instead of the total impact the disease has on the person. This is probably because some elements of the disease have been recognized as being more treatable than others. Management of the disease is primarily support and symptomatic based. The management of painful episodes has been focused on by health care professionals in the hopes of preventing disability.

Most physicians are beginning to realize the impact Sickle Cell Disease has on a person is dependent on condi-

tions other than the severity of their illness. Pain is thought to be composed of two aspects: (1) psyche and (2) soma.<sup>5</sup> The term "psychosomatic" rose out of these two aspects. They are inextricably entwined. Psyche means "soul", and soma means "body".<sup>6</sup> Together they describe the unity and interrelationship of mind and body. If a person has repeated episodes of pain, he will be affected from a psychological and symptomatic view. Some responses a Sickle Cell patient feels are organic, but others are emotional. The body reacts not only to the psyche, but upon the social situation. The symptoms of Sickle Cell Disease (pain), can usually be alleviated faster than the psychologically based problems. People diagnosed with Sickle Cell Disease are capable of leading full and satisfying lives with the proper medical treatment. The influence of the severity of the illness is dependent upon the organs affected, not necessarily the number of crises the person has.

Chronic illness can be even more devastating when there are limited resources and hopes for a better future. People with Sickle Cell Disease face problems with their own self-concepts, stigmatization from other members of society, and denial. Most people with Sickle Cell Disease are highly motivated. Since the brain is rarely affected, they are usually able to perform most routine job activities during

symptom-free periods. As long as they are feeling well, their daily routine should vary little from other people. They should receive the same treatment, privileges, respect and responsibilities as other able-bodied citizens.

Some health care specialists feel pain can be diminished by occupying the patient's time with daily constructive tasks. Employment is one of those tasks. The lack of familiarity with vocational rehabilitation centers that are designed to benefit the adult Black male Sickle Cell patient prevents them from attaining gainful employment. The utilization of vocational rehabilitation services would help prepare Sickle Cell patients for employment. Counselors working with Sickle Cell patients generally agree that there is a correlation between the patient's attitude toward disability and the success of their vocational rehabilitation. Disabled people who refuse to accept their limitations tend to be bitter, critical, unmotivated and frustrated. They in turn frustrate those who are trying to provide rehabilitation services.

Sickle Cell Disease patients should be encouraged to live up to their fullest potential. Emphasis should be placed on continued education despite the length of time involved in academic and vocational programs. The more education and skilled training they have, the easier it will be for them to qualify for jobs that do not require stressful tasks. Sickle Cell patients can perform just as well as

other individuals when placed in positions that are compatible to their health status, skills, education, and training. Most Sickle Cell patients are dedicated individuals with the capacity to be gainfully employed if given the opportunity.

People diagnosed with Sickle Cell Disease have no direct control over the onset of crises. There are times when they may appear to be perfectly healthy, but this does not mean they will not have a crisis. Therefore, occupations must leave room for intermittent or prolonged absences. American industry has begun to take a positive stand toward the employment of handicapped people. They realize that most people with Sickle Cell Disease are employable. The risks an employer takes when hiring a Sickle Cell patient are no higher than hiring a normal or handicapped person. Vocational choices that generally should be discouraged consist of jobs that require strenuous physical exertion, exposure to high altitudes, and those where extreme temperature variations exist.

#### Statement of the Purpose

Adult Black males diagnosed with Sickle Cell Disease face obstacles from the disease itself, as well as other obstacles. This paper will focus on the effects vocational rehabilitation has on a selected group of Black male Sickle Cell Disease patients. People generally think of Sickle Cell patients as being affected physically due to the com-

plications they experience. It is seldom realized that Sickle Cell patients must try to function on the same levels as everyone else. Many people affected by Sickle Cell Disease are living with a stigma of innocent ignorance. Providing people who are affected by Sickle Cell with accurate information, services, and centers will enable them to identify and deal with their problems more effectively. Patient and public education are needed regarding Sickle Cell Disease. Emphasis should be placed on educating the patient with Sickle Cell Disease, as well as the people who will be working with the Sickle Cell patient. The general population can help those diagnosed with Sickle Cell Disease by educating others about the disease. Types of intervention that appear to be effective when dealing with Sickle Cell patients include: (1) supportive counseling, (2) financial counseling, (3) vocational counseling, and rehabilitative services. Since people with Sickle Cell Disease are ordinarily capable of a normal life, vocational rehabilitation would probably promote a greater sense of independence.

The Sickle Cell adult usually cannot function well when their place of employment consists of demanding manual labor. Sedentary positions which allow them to work without physical exhaustion are usually more suitable for them. Their level of education becomes an extremely important factor in whether or not they can attain desired employment. They should seek

employment requiring mental ability or skill instead of physical ability. Many Black male Sickle Cell patients would be able to participate to a greater degree in the nation's productive enterprises if they successfully completed vocational rehabilitation.

Rehabilitation is a beneficial investment in human welfare. With the proper cooperation, Sickle Cell patients should be able to continue vocational training, complete their educational goals, and attain gainful employment regardless of their chronic illness. They should not be considered any different, or any less fortunate, because of their Sickle Cell diagnosis. Their lifetime chronic illness should be approached with a positive attitude.

Individuals with Sickle Cell Disease are capable of pursuing a variety of vocations and professions. They may need training and extra assistance to compensate for time lost from school due to illness however. This additional help is sometimes the determining factor in whether or not they are able to remain at their respective grade levels. Receiving guidance from vocational rehabilitation counselors would help people with Sickle Cell Disease explore realistic career choices. It is imperative that their goals and aspirations be assessed. This will enable the vocational rehabilitation counselor to make the appropriate referrals to community resources if needed.

The development of Sickle Cell centers has provided patients with a comprehensive team approach for health care maintenance and patient education. Patients with Sickle Cell Disease are often eligible for special services in several states. Some are provided supportive services by vocational rehabilitation agencies, and colleges. The patient's job, lack of one, or potential employment should be explored. Most physicians will provide these agencies with medical reports that document the patient's strengths and weaknesses. Emphasis should be placed on the need for people who are providing these services to have some knowledge about Sickle Cell Disease. Individuals with Sickle Cell have the potential to successfully complete these programs and become gainfully employed. The attainment of employment would discourage disability and enable more Black male Sickle Cell patients to become productive members of society.

#### Assumptions

There were three basic assumptions focused on in this study: (1) educating both the general population as well as the Sickle Cell patient will help alleviate some of the stigmatization Sickle Cell patients must face in our society; (2) occupying the Sickle Cell patient's time with constructive tasks such as employment may help diminish painful



episodes; and (3) gainful employment of Sickle Cell patients will help discourage disability.

### Limitations

There were four basic limitations related to this study: (1) funding, (2) the size of the Sickle Cell Disease population, (3) the time-frame, and (4) the geographical location. Limited funding prevents the establishment of many programs that serve special populations. The number of adult Black male Sickle Cell patients who are eligible for vocational rehabilitation services is therefore limited. Performing a longitudinal study to obtain detailed and complete information relevant to this study was not possible during the established time-frame. The geographical location of this particular Sickle Cell Disease Center tended to be a hindrance since it was the only center in the state. Sickle Cell Disease patients came from the immediate area, as well as neighboring towns and smaller cities.

### Definition of Terms

(1) Academic: Used in psychological writing to characterize experimental programs and schools of thought whose aims are theoretical as opposed to applied.

(2) Adjustment Inventory: A questionnaire for assessing the quality of an individual's adjustment. Such inventories typically consist of a large number of questions indicative of good and bad adjustment. The subject is asked to agree,

disagree, or indicate that he cannot answer the question. The pattern of answers is then scored and compared with norms based on large samples of individuals.

(3) Advantage by Illness: The gain enjoyed by the individual because of illness.

(4) Anemia: An inadequate amount of hemoglobin and red blood cells.

(5) Asymptomatic: Neither causing nor exhibiting symptoms.

(6) Disability: Incapacitation. A handicap. To weaken or destroy the normal physical or mental abilities of someone. To render legally disqualified.

(7) Gene: A functional hereditary unit that occupies a fixed location on a chromosome, has a specific influence on phenotype, and is capable of mutation to various species.

(8) Handicapped: A deficiency, especially an anatomical, physiological, or mental deficiency, that prevents or restricts normal achievement. Any disadvantage or disability. A hindrance.

(9) Hemoglobin: A chemical substance in red blood cells which carries oxygen. There are over two hundred types of hemoglobin. Some have letter names A-Z.

(10) Impairment: Any deviation from the normal which results in defective function, structure, organization, or

development of the whole or any part of an individual's faculties.

(11) Rehabilitation: The restoration of the handicapped to the fullest physical, mental, social, vocational, and economic usefulness of which they are capable.

(12) Sickle Cell Trait: Condition in which a person inherits a gene for hemoglobin "A" from one parent, and a gene for hemoglobin "S" from the other parent.

## CHAPTER II

Review of the Literature

The information contained in this section focuses on some of the basic components involved in the rehabilitation process. Many times people enrolled in vocational rehabilitation are directly and indirectly discriminated against. The Sickle Cell Disease patient is no exception. The patient involved with vocational rehabilitation is usually trying to become self-sufficient. Participating in a program that is stigmatized by society is traumatizing enough. Vocational rehabilitation programs that are unable to empathize with their participants make the experience even more traumatic.

"The Utilization of Psychological Knowledge in Rehabilitation", by Tamara Dethis focuses on handicapped people who are from different vocational backgrounds. It is believed that handicapped people have psychological problems even if they are involved in rehabilitation. Being exposed to psychological knowledge sometimes alleviates their problems. Many times handicapped people want immediate help however.

The point of view a person has depends on what position that person is in. The two positions being focused on in this study were observed and suffered. People who are pro-

viding psychological services to handicapped people must take a stand on which position they will take. Some health care professionals argue about which viewpoint is most beneficial to the handicapped person.

Sufferers or handicapped persons are the persons who need help. They do not feel they can wait until theoretical problems are solved. Since they are the closest to the problem, they feel they know what is best for them. On the other hand, the observers or health care professionals have the viewpoint they are more capable to determine what treatment approaches should be used. They feel their judgements are more objective. Since they are usually more experienced than their handicapped clients, they feel their point of view is closer to reality.

Both points of view should be taken into account when dealing with handicapped people. The handicapped person and the health care professional can correlate their theories. Treatment plans could then be derived through a joint effort. The handicapped person would be able to accurately relay his feelings from a first-hand point of view. This would enable the health care profession to accurately perceive what the handicapped person is really experiencing. Therefore, intervention strategies would be based on both the viewpoint of the handicapped person and that of the professional.

"Dependent Disabled and Dependent Poor: Similarity of Conceptual Issues and Research Needs", by Marvin E. Sussman is a paper that is concerned with the rehabilitation of the disabled poor. Impairment, disability, and handicap are all considered to affect one socially as well as physically. The dependent poor are considered to belong to subcultures which have the potential to better their condition. They are thought to have socioeconomic problems due to inadequate socialization. This in turn hampers their employment and range of mobility.

More major institutional systems are becoming actively involved with rehabilitation in our society. This is due to the variety of activities that rehabilitation now focuses on. Opportunities to examine these activities to determine their significance in the rehabilitation process are becoming more prevalent.

The phenomena of disability and poverty are socially defined and structured. There is no set criteria that establish what the exact problems of dependency are. The criteria that exist are susceptible to distortions by other members of society. The concept of dependence implies that there is a hierarchy in our society. This hierarchy consists of subordinate and superordinate positions. The basic dynamic of the dependency hierarchy is control. The superordinate group keeps the subordinate group dependent on it. This

relationship fosters a status quo that maintains a sense of order in our society.

"Understanding the Process of Adjustment to Disability", by Nancy Kerr discusses stages of adjustment permanently disabled people usually endure. Knowledge about the process of adjustment to loss is valuable to both the counselor and to those being counseled. The stages of adjustment are: (1) shock, (2) expectancy or recovery, (3) mourning, (4) defense, and (5) adjustment.<sup>7</sup> Many disabled people who go through these stages are responding to some of the difficult situations they have participated in. These stages are not concrete categories that all disabled people experience however.

Shock is usually the behavior that is seen during the early diagnostic and treatment periods of handicapped persons' lives. Psychologically they are normal people, but with specific limitations. Their psychological situation may be altered due to denial of these limitations however. They will eventually realize they have a chronic illness, which will put them into the expectancy and recovery phase. People in this phase can usually be motivated to do any work they perceive will aid in their recovery. Sometimes people in this phase experience psychological barriers. Things in their lives that others would consider to be worthwhile are no longer of great importance. They feel being disabled

disqualifies them from participating in events or activities normal people participate in. People in the defensive stage employ defense mechanisms as a means of denial.<sup>8</sup> Some people try to conceal their disability. They deny having any psychological barriers. Persons who have adjusted to being permanently disabled consider disability to be one of their personal characteristics. They are now able to continue with their lives in a satisfactory manner.

Disabled people who successfully reach the phase of adjustment are usually able to feel they are "whole" again. This feeling of being an adequate person is normally reached once employment is attained. The common belief in our society is disabled people are inferior.

"Sick-Role Retention As A Factor in Non-Rehabilitation", by Pearl Davidoff Starkey is a study based on Parson's sick-role theory.<sup>9</sup> Some disabled people are able to attain and maintain employment while others cannot. Many disabled people are caught in a sick-role which prevents them from functioning on the level they are capable of. Better use of rehabilitation resources and professional personnel may benefit those who are in the sick-role.

The individual in relationship to health and illness becomes an important factor in the formation of a disabled person's personality. Our society's value system is based on achievement which acts as a sense of motivation for those



who are trying to be rehabilitated. Once the status of being disabled is legitimized, dependency is permitted. The dependent role in our society is therefore considered undesirable. Society emphasizes active mastery over dependency.

Those who become trapped in the sick-role are sometimes considered as deviants. According to this study the role of the disabled person exhibits four distinct characteristics. These people are often unable to determine what is and what is not beyond their power to control. Therapeutic intervention is sometimes necessary to help these people recover. There are times when exempting those who are trapped in the sick-role from participating in normal roles or activities are legitimized however. Many times disabled people recognize being dependent is considered to be an undesirable characteristic in our society. These people feel obligated to become independent. They actively seek competent help and cooperation from agencies that may benefit them. These people definitely do not want to be considered dependent merely because they are disabled.

"Social and Economic Aspects of Chronic Disease" focuses on the difference between being poor and chronically ill, and being financially stable. Being chronically ill creates an immediate disruption in the daily routine of one's life. Emotional, financial, and social adjustments must be made. Chronically ill persons are sometimes a burden on themselves,

their families, and other members of society. The emotional and mental adjustments that must be made can be quite difficult. People who are from the poorer classes face social and economic catastrophes. Sometimes destitution due to the financial drain of being chronically ill is inevitable. They face the potential loss of employment, if they are employed. This usually leaves them without a means of support that can soon result in dependency.

The economic burdens that occur can also manifest other problems. The chronically ill may eventually succumb to physical and spiritual depletion. Prolonged illness can also cause strain on one's interpersonal relationships. The tolerance for the presence of the chronically ill may be limited. The demands placed on those associated with the chronically ill person may become unbearable.

Chronically ill people often become very dependent on others for financial and emotional support. The incidence of dependent chronically ill people appears to be higher among the poor. Members suffering from chronic illnesses often are forced to apply for some type of financial assistance as a means of steady income.<sup>10</sup>

"A Self-Help Workbook: Health Yourself: Become Independently Healthy", by Helen Rollins is a dissertation done to provide individuals with a conceptual framework for understanding wellness. It promotes health and disease preventive

methods as they apply to the individual's lifestyle. This dissertation provides assessment tools and change strategies. This self-help workbook was developed as a response to the disillusionment of: (1) medical technology, (2) changing patterns of disease within the American population, (3) inflation in health care costs, and (4) a renewed interest in self-care and self-responsibility.

The typical "medical model" is being challenged by many health care professionals. The current prototype for health care delivery no longer provides the innovative approaches that are needed in our society today. There is an increased awareness of the impact psychological, sociological, physiological, economical, and vocational factors have on human health. This has resulted in a more comprehensive approach to health care. A holistic approach is thought to promote a higher level of physical, psychological, and social functioning. This takes into account the individual and social support many people need. Maximum health potential is the ultimate goal of this study.

"Self-Help in Rehabilitation: Some Theoretical Aspects", by Alfred H. Katz suggests that cooperation and mutual helpfulness are important when working with rehabilitation clients. Little interest has been shown from people who are in the social welfare field regarding the self-help phenomena however. Self-help approaches can be used to understand and

work with clients who are involved in rehabilitative services.

Health and welfare programs have recently been developed that focus on problems that face those who are considered "disadvantaged" or "socially deprived".<sup>11</sup> Most of the people affected are ethnic minorities and other special population groups. Professionals are becoming increasingly aware of the potential benefits self-help principles can provide. Significant parallels between the awareness of the need for approaches to the socially deprived and disadvantaged populations and their potential use of self-help approaches with the physically handicapped have been discovered. These populations are considered to have similar characteristics. People who compose these populations are thought to be socio-psychologically deprived.<sup>12</sup> Many times these people are partially excluded from the mainstream of broader society. Some social scientists believe this partial exclusion and the resultant psycho-social behaviors must be diagnostically taken into account before effective treatment programs can be developed.

The deprivation these individuals feel can be physical, emotional, social, cultural, educational, or vocational. This in turn can create an entire series of psycho-social dilemmas. The deprived in our society will face obstacles regardless of the source of the deprivation. Society's

level of tolerance seems to be low when dealing with those who are deprived. Nurturing support from social groups is limited. Social norms in our society are such that individual achievement and competitiveness are of importance. Those who cannot perform according to those norms are often isolated.

"Cross-Cultural Rehabilitation", by D. Corydon Hammond discusses some of the problems involved in rehabilitation. The Vocational Rehabilitation Act of 1965 included the socially and culturally handicapped in their rehabilitative services.<sup>13</sup> Until that time, little had been done to provide services to this forgotten population. Living conditions consisted of extreme poverty, unemployment, and inadequate facilities to provide education or employment skills.

Rehabilitative services were sometimes discouraged. This increased the magnitude of poverty, unemployment, and educational deficiencies. These factors sometimes contribute to the reluctance of professional workers to provide rehabilitative services. Some professionals think of these factors as being culturally imposed. Cultural differences can then become a hindrance in rehabilitation efforts. Rehabilitation agencies tend to conform to the dominant culture and race. Some therapeutic principles are specifi-

cally designed to help certain cultures. These approaches then become inappropriate for other cultural populations.

In rehabilitation facilities that specialize in a variety of cultures clients are usually more successful. Otherwise the client may view the treatment strategies in an unfamiliar or inappropriate frame of reference. Communication becomes difficult for both the professional and the client. This can be frustrating for all of the participants.

"Staff Expectations for Disabled Persons: Helpful or Harmful", by Nancy Kerr discusses how being disabled alters a person's lifestyle. Disabled people are limited physically, psychologically, socially, educationally and vocationally. The physical aspects of being disabled are often the primary focus of rehabilitation personnel however. Physical limitations often prevent the disabled from participating in normal activities.

Disability affects a person's social interactions with others. The places, activities, and relationships a disabled person is restricted to or barred from entering are of particular importance. They are frequently placed in inferior status positions. The illness itself and disability experience places them in new psychological situations. Disabled people may be consciously and unconsciously questioning who they are. They may become unclear on what roles are appro-

priate for them. Many times they may become confused about what others' expectations of them are.

Hospital or rehabilitation personnel are capable of answering some of the questions critical to the disabled person's identity and role formation. Those who are disabled may have to adjust to being considered a second-class citizen. They face physical obstacles as well as social devaluation. This teaches them that they are no longer viewed by society as responsible, employable adults. Psychologically many disabled adults are still treated like children.

According to Kerr, rehabilitation clients can be treated according to two different perspectives.<sup>14</sup> Some rehabilitation personnel realize the disabled are responsible human beings who should be treated with respect. Personnel who have this perspective understand those who are disabled still like to be treated as "people". Some of the rehabilitative personnel naturally promote therapeutic relationships. Other rehabilitative personnel can be educated to promote therapeutic relationships.

"Staff Authority and Patient Participation in Rehabilitation", by Lawrence E. Schlesinger discusses the tendency for a lack of involvement or participation on the part of the patient in rehabilitation facilities. Such organizations discourage patient participation to a large extent. Disabled adults may experience major social-psychological impacts

because of this discouragement. Some of the impacts that affect those who are disabled are due to: (1) a loss of social roles, (2) a disintegration of personal identity, and (3) a loss of social relationships.<sup>15</sup> The "patient-role" is then created to move the disabled person from the "sick-role". This is deliberately done to improve the patient's level of social functioning.

The rehabilitation staff usually takes complete responsibility for the disabled patient. The roles staff play generally are encompassed in four major categories: (1) custody of the patient, (2) protection of the patient, (3) socialization of the patient regarding the rehabilitative setting, and (4) therapy.<sup>16</sup> The rehabilitative services protect the patient from self-destructive behavior. Training is provided for patients that will enable them to become "total" members of society. Therapy is provided to help the disabled patient improve his overall level of functioning.

Patients must not be allowed to passively receive treatment. They must be adequately motivated to actively participate in their treatment plans. The patient's primary job is to learn to improve his physical, personal, and social functioning. Most rehabilitation centers are based on a system of authority or hierarchy though. This means the station of command is the rehabilitation staff, which generally leaves the disabled patient without much control.



"Patient Cooperation in a Rehabilitation Center: Assumption of the Client Role", by Edward K. Ludwig and Shirley Davidson Adams is a study based on the framework of role theory. Assumption of the Client Role in rehabilitative settings involves submission of the client to those who are providing services. This generally limits the success of those who are being rehabilitated. Disabled people who assume the client role tend to be dependent or subordinate during their normal social relationships also.

The ultimate success of treatment programs depends upon whether or not clients act rationally and cooperate with the staff according to their best interest. Some clients engage in self-defeating behavior during rehabilitation treatment by failing to cooperate with their individual treatment plans. Ludwig and Adams believe the roles clients are placed in during rehabilitation influence the clients' level of performance.

Rehabilitation patients are governed by social behavioral expectations. Many of these expectations are outlined in Parson's sick-role theory.<sup>17</sup> Rehabilitation patients are sometimes exempted from certain rights, responsibilities and roles normal people are automatically included in. Rehabilitation patients have to take the initiative in attaining a more desirable position in our society.

No organized structured programs existed before 1972 which related only to the care of Sickle Cell Disease patients. Large populations of Sickle Cell patients were cared for by large metropolitan teaching hospitals. Sickle Cell patients were seen in Hematology/Oncology clinics most often. They were grouped together with leukemia patients, hemophiliacs and patients with terminal malignancies. Being treated with these people greatly influenced how Sickle Cell patients felt about themselves as well as those in the medical profession.

Congress passed the National Sickle Cell Disease Control Act in 1972.<sup>18</sup> This allowed people with authority to establish education, research, information, counseling, testing, screening, and treatment programs. At the present time very few communities have complete and adequate programs for rehabilitation. Most of them function with just some of the services usually required to facilitate workshops on vocational guidance or rehabilitation. Few have coordinated programs that utilize all of its facilities to their best advantage.

Attempts to develop specific therapy strategies that will benefit adult Black male Sickle Cell Disease patients have been unsuccessful. Many vocational rehabilitation programs do not allow room for flexibility. Sporadic school and job attendance often cause Sickle Cell patients to repeat

academic courses. This tends to have a negative impact on Black males when they become adults. Sometimes they begin to feel inadequate because they are not achieving academically. This sense of inadequateness may manifest itself in psychological problems due to: (1) delayed progress in school due to absenteeism and (2) low self-esteem.

In order to alleviate some of the stresses Black male Sickle Cell patients feel because of the lack of vocational rehabilitation programs that specialize in Sickle Cell patients, it is necessary to create additional programs. These programs should provide a well-integrated curriculum that is available to all who are in need of services. Such a program should include medical supervision, nursing, physical therapy, services for vocational guidance, and assistance from social workers. These programs cannot be established with the limited funding and resources that are available for Sickle Cell patients at the present time.

## CHAPTER III

Theoretical Framework

Vocational Rehabilitation would provide the necessary skills for disabled people to become independent. They would be able to increase their mobility while accepting the reality of their disability. Rehabilitation counselors would be available to assist the disabled with their occupational choices, training, and placement.

Disability has the potential to be very stigmatizing in our society. Rehabilitation staff have the ability to reduce some of this stigmatization. The disabled person can diminish such stigmatization through self-teaching. No professional assumes sole responsibility for promoting the social skills that are necessary for the disabled person to communicate with the nondisabled population. Many of these skills are acquired once the disabled resume full responsibility for their lives.

Rehabilitation may be analyzed advantageously as a process of socialization. A socialization model focuses on the processes individuals use to accomplish new roles. Attention is given to the disabled person's development of self, skills, activities, and associations.<sup>19</sup> The individuals

who are learning the new roles (disabled persons) interact with the individuals who are responsible for training (rehabilitation counselors.)

The concepts a rehabilitation staff member has regarding rehabilitation sometimes differs from the concepts the disabled person has. The disabled person suffers with the problems, whereas the rehabilitation staff member takes on the role of being an outsider looking in. Both are connected with the problem, but their perceptions of the problem still differ at times. The ultimate goal for those being rehabilitated would be having the rehabilitation staff on the same psychological level they are on.

Literature in the rehabilitation field tends to be very inconsistent when using the terms illness, sickness, impairment, disability and handicap. Many times these terms are used interchangeably when discussing rehabilitation issues and problems. Society uses all of these terms to refer to populations that are considered deviant. Being disabled does not mean a person is deviant however. Without the proper professional cooperation, disabled people may internalize social stigmatism into a negative self-image.

Failure without any outside assistance can become a form of disability in itself. Rehabilitation organizations that are created specifically for people with chronic illnesses can help reduce these feelings of failure. The growing

importance of chronic disease as a cause of dependency is forcing many health care professionals to focus on rehabilitative services.

Cultural biases involved in rehabilitative services can have negative impacts on those being rehabilitated. Ethnocentrism plays a dominant role in the formulation of rehabilitation techniques, goals, and therapy. Services rendered usually conform to the dominant culture in a society. Since the dominant culture is composed of non-disabled people, treatment is usually provided by non-disabled people. Those who are disabled tend to question the validity of this treatment.

If rehabilitation staff members treat disabled clients with an overall sense of respect, they will no longer feel like they are second-class citizens. This would prevent the submissive and devaluating aspects of the role of the patient from being accepted by both the patient and the staff members. The staff members would promote a sense of independence by encouraging patients to perform at their highest level of functioning. Disabled patients would then be able to attain employment in responsible organizations without the immediate fear of discrimination.

Decreasing the level of staff authority in rehabilitation agencies will encourage disabled patients to actively participate in their treatment regimen. Instead of everyone on

the staff having authority over the patient, they should try to work with the patient. The disabled patients would still be closely supervised, but a system of rewards and privileges would be used to promote a sense of conformity to the treatment plans. This would help patients develop the personal, vocational, and social skills needed to elevate their ego, status, and overall sense of autonomy.

A decreased level of staff authority would defy the classical model of medical care which automatically assumes the health care professional always knows best. This reduces the patient's situation to that of a childhood dependency status. This generates the attitude that being disabled is equivalent to being helpless. This perspective can be detrimental to the patient's psyche. This allows the patient to take a passive role in his treatment regimen. The patient is no longer able to exercise some judgement. The rehabilitation center staff should require the disabled patient to play an active role in his rehabilitation process.

Specific major theoretical principles and positions are used when dealing with those who are disabled due to chronic illness. Some of these theories focus on the impact of disablement, while others focus on constructs to explain the stigmatism the disabled face. The theories being referred to in this thesis are: (1) Psycho-analytic Theory, (2) Social Systems Approach, (3) Person-Centered Therapy, (4)

Behavior Therapy, and (5) Reality Therapy. A common bond in these theories is the focus on humanistic progress. This allows professionals to treat the disabled from an individual, institutional, and societal perspective.

The psychoanalytic theory is one of the earliest theories of personality development that is directly applicable to the disabled population. This theory was developed by Sigmund Freud in the late 1800's, to early 1900's.<sup>20</sup> A central tenet of psychoanalytic theory is that competition plays a major part in everyone's life. People who feel there is a limited amount of security or stability in their lives tend to struggle until they reach a state of equilibrium. According to Freud it is not the disabled person who has not achieved a state of balance, it is the non-disabled person.<sup>21</sup> The non-disabled person who is prejudiced toward those who are disabled is thought to consider himself as being psychologically superior to the disabled person. Psychoanalytic theorists believe the disabled experience adversely affects because of the non-disabled person's immature behaviors.

The Social System Approach comprises knowledge about people, groups of people, non-human influences, and the social behaviors that affect people.<sup>22</sup> The Social System is often thought to be the best theoretical basis for the study of human communication. This theory takes into account



the complex elements and components that both directly and indirectly affect parts of our environment. Attention is given to the dynamic parts of relatedness to parts of the whole object of an environment.<sup>23</sup> Clearly defined boundaries exist which distinguish the subunits of an environment. Since systems exist on all levels of society, Social Systems theorists usually take a holistic view of life. They realize one system affects another system which makes them inter-related in some way.

The Person-Centered Approach is considered to be a humanistic branch of the existential perspective. This non-directive counseling was a negative reaction against the traditional psychoanalytic approaches used in individual therapy. Carl Rogers challenged the basic assumption that the "counselor knows best" in the early 1940's with this approach.<sup>24</sup> The commonly accepted therapeutic procedures such as advice, counselor direction, suggestion, persuasion, teaching, diagnosis, and interpretation no longer seemed valid. The basic assumption of this theory is that people are capable of taking control of their own lives. Counseling would then be used as a means of support or guidance. Persons seeking therapy are to be considered trustworthy. They have the potential to understand themselves, resolve their own problems, and are capable of growing toward self-actualization without direct intervention from the therapist. The

attitude and personal characteristics of the therapist have a direct impact on the outcome of the therapist/client relationship. Therapists who emphasize a sense of independence will benefit the client to a greater extent.

The Behavior Approach is based on a scientific view of human behavior. This is a systematic and structured approach to counseling. The importance of the client/therapist relationship is still stressed however. Emphasis is placed on the client's potential for making mature choices. Behavioral theorists believe people are the producers and products of their environments.<sup>25</sup> Behavior modification is done to increase individuals' skills so they can maximize their options in life. Individuals are then free to select from a wider range of possibilities. They are able to overcome debilitating behaviors that restrict their choices. This increases their overall individual freedom. The capacity for these individuals to actually affect their environments in a positive way is definitely beneficial to their self-image. Since behavior theorists give greater attention to therapy being action-oriented, clients are encouraged to decrease their passivity. They are being helped to take specific actions in order to change their lives. Clients are trained to take responsibility for their behavior.

Reality Therapy has gained popularity among counselors, teachers, and rehabilitation workers. Reality Therapy

focuses on present behavior. Therapists function as teachers and role models. They encourage clients to face reality so they can fulfill their basic needs without harming themselves or others. Acceptance of personal responsibility is the basis of this theoretical concept. Emphasis is placed on what clients are able and willing to do to improve their present situation. Clients must be committed to therapy. They must be willing to change, develop a plan of action, and follow through with their treatment plans.<sup>26</sup> The therapist encourages the client to evaluate his values and morals. Personal responsibility will promote autonomy and success. This form of therapy employs a contract method that forces the client to actively participate in his treatment.

## CHAPTER IV

### Research Methodology

This study focuses on whether adult Black male Sickle Cell Disease patients who receive vocational rehabilitation are positively impacted upon. These Black males appear to be more equipped to integrate into the mainstream of society. The vocational rehabilitation provides them with the background to achieve independence and a greater sense of autonomy. A rehabilitation staff which is willing to cooperate with these patients based on their specific chronic illnesses will encourage Sickle Cell Disease patients to actively participate in the rehabilitative process.

Vocational rehabilitation encourages the Sickle Cell patient to face the problems which evolve from the stigma of disability. The vocational rehabilitation staff helps these patients increase their sense of personal worth. They may still encounter difficulties because of the labels placed on them by other members of society, but it will be easier for them to establish and maintain a positive self-image.

### Research Design

The research design used in this study is the quasi-experimental design. The design compares those who receive

treatment versus those who do not receive treatment. A pre-test - post-test nonequivalent control group was utilized so a long series of observations over a specific length of time or population would not affect the outcome of the study. A combination of the static group comparison and the one-group pre-test - post-test pre-experiment is the basis for this design. Combining both of these features makes the collected data more interpretable than using one perspective or the other. Pre-test information about the group's existing base line levels will be compared to the final results of the post-test. This helps reduce the possibility of threats to internal validity. Quasi-experiment designs are frequently used when evaluating social intervention services.

#### Sample

The sample for this study consisted of adult Black males who were diagnosed with Sickle Cell Disease. All of the participants were receiving medical treatment at a major community hospital that had its own Sickle Cell Disease Center. The participants in this study were observed from October of 1986 to March of 1987. A total of twenty-two patients were observed. The participants' ages ranged from 18 to 28 years old. They were all from lower class and lower-middle class economic backgrounds.

Nine percent of the participants were currently applying for disability as a means of income while they were enrolled

in vocational rehabilitation. The other participants were totally dependent on others for financial support.

All of the patients had been diagnosed with Sickle Cell Disease since birth except for three of them. The severity of their illness varied however. (See Table 1) Forty percent of the participants experienced frequent complications which prevented them from functioning at their maximum capacity. The others experienced complications, but not to the extent that they were incapacitated.

Eight percent of the participants were high school graduates. Nine percent of the participants had one year of college education. Four percent of the participants had some form of technical training or two years of college education. All of the participants had established some form of employment history. A majority of the jobs held by the participants had required manual labor.

Permission was obtained from the patient and attending physician of each patient involved in the study, as well as the vocational rehabilitation counselor. The results of the study can only be generalized to the population from which the participants were chosen.

#### Instrumentation

The study consisted of: (1) chart reviews, (2) interviews with the Sickle Cell Disease patient, (3) interviews with the Sickle Cell Disease staff, and (4)

TABLE 1: SEVERITY OF ILLNESS IN ADULT BLACK MALE SICKLE CELL PATIENTS

| Functioning Variables                 | MILD | MODERATE | SEVERE |
|---------------------------------------|------|----------|--------|
| Hospital Visits Due to Illness        | 31%  | 40%      | 29%    |
| Hospitalizations Due to Complications | 36%  | 59%      | 5%     |
| N = 22                                |      |          |        |

interviews with the rehabilitation staff members. A pre-test and post-test were given to all of the Sickle Cell Disease patients. The time required for each chart review and interview varied from participant to participant.



## CHAPTER V

Analysis of Data

Prior to vocational rehabilitation one hundred percent of the participants felt they wanted to live independently. Only thirteen percent could at the present time because they were usually financially unable to do so. Fifty-four percent of these participants resided with family members and friends. Seventy-seven percent of the participants felt their poor health was a factor in their dependency. Ninety percent of the participants were unemployed, leaving them without a means of financial support. Seventy-seven percent of the participants felt vocational rehabilitation would help prepare them for employment. Fifty percent of the participants currently received financial assistance from their relatives on a regular basis (often). Sixty-three percent of the participants required medical treatment for their Sickle Cell Disease on an outpatient clinic basis a majority of the time. Sixty-three percent of the participants felt others ignored them because of their disability. Sixty-eight percent of the participants felt more was demanded of them by their employers despite their disability however.

The data collected showed the level of functioning being improved to some degree after successfully completing vocational rehabilitation. Vocational rehabilitation appeared to have some positive effects on Black males diagnosed with Sickle Cell Disease. Seventy-two percent of the participants felt they would be able to live independently now that they had successfully completed vocational rehabilitation. Ninety percent of the participants felt their health had improved, and would continue to improve once they were gainfully employed. Fifty-nine percent of the participants were gainfully employed within months of finishing the vocational rehabilitation program. Eighty-six percent of the participants felt vocational rehabilitation benefitted them in general. Eighty-six percent of the participants were no longer primarily financially dependent on their relatives after they received vocational rehabilitation. Eighty-one percent of the participants began to receive medical treatment on an outpatient clinic basis a majority of the time. Ninety percent of the participants felt others began to respond to them appropriately after they completed vocational rehabilitation. Fifty-nine percent of the participants felt completing vocational rehabilitation prompted their employers to make more appropriate considerations for them.

## CHAPTER VI

Findings and ConclusionsFindings

Out of the total population studied, fifty-nine percent of the adult Black males who participated in this study felt the vocational services provided were not the sole factor that moved them toward independent living. They felt they must have some sense of motivation within themselves. Only then would the vocational rehabilitative staff be able to help them move toward a higher level of functioning. If Sickle Cell Disease patients do not feel they are emotionally and physically able to be independent, vocational rehabilitation will be futile. A positive self-image based on reactions from other members of society will help promote self-sufficiency in these participants. As long as they feel they are outcasts in society, they will not feel there is a need to show some improvement in their level of functioning.

Sickle Cell Disease patients have the same expectations as others when it comes to medical care. They want continuity of care with a clearly identified medical staff. The fact that they have a chronic disease makes this need even more important. Health care professionals have begun to

realize this fact, and try to make the appropriate referrals. Sickle Cell patients require specialized and skilled services. These professionals are beginning to encourage Sickle Cell patients to seek their own levels of activities as a means of promoting independence. Physicians feel a majority of the adult Black male Sickle Cell patients are employable.

### Summary

Most people affected by Sickle Cell Disease are Black Americans or of African descent. The sickling gene is a recessive trait, but its impact on a person's life can be quite dominant. The disease itself is marked by periods of well-being, but this does not leave the Sickle Cell patient totally unaffected. Sickle Cell Disease patients should be encouraged to assume responsibility and participate in normal activities despite their chronic illness. As long as they are feeling well, their daily living requirements should vary little from those of normal people.

Formal rehabilitation procedures should be available to all chronically ill patients as needed. The personnel who facilitate these procedures should be educated and dedicated to the rehabilitation process. Many times vocational rehabilitation counselors are vitally important figures in the disabled person's life. They are usually equipped to conduct simple psychological testing and provide light counseling. They have knowledge of industry that can greatly extend the

social worker's ideas and possibilities for the client's adjustment and usefulness.

### Conclusions

Adult Black male Sickle Cell Disease patients who successfully completed vocational rehabilitation would be encouraged by health care professionals. The Sickle Cell patient would then be able to encourage others to view them as mature individuals who are capable of understanding the facts related to their illness. Sickle Cell patients would be better equipped to accept their chronic illness the way they would accept other qualities that are unique to them.

Vocational Rehabilitation would prevent other members of society from treating Sickle Cell patients as invalids. Pity would be discouraged since they would be capable of achieving just like any other human being. The Sickle Cell Disease patient would no longer be able to use his chronic illness as an excuse for the failure to perform to the best of his ability. Rehabilitation services should be coordinated into smoothly functioning teams to encourage the independence of the Sickle Cell patient. Such rehabilitation programs would help many Sickle Cell Disease patients return to active lives. They would feel capable of self-care and independent living. (See Table 2)

Vocational rehabilitation is part of the total program concerned with preparing the disabled person for some type

TABLE 2: RESIDENTIAL STATUS BEFORE AND AFTER VOCATIONAL REHABILITATION

|                          | BEFORE REHABILITATION | AFTER REHABILITATION |
|--------------------------|-----------------------|----------------------|
| Own<br>Residence         | 13%                   | 72%                  |
| With<br>Relatives        | 54%                   | 27%                  |
| Shelter                  | 13%                   | 0%                   |
| Personal<br>Care<br>Home | 13%                   | 0%                   |
| OTHER                    | 7%                    | 1%                   |
| TOTAL                    | 100%                  | 100%                 |

NOTE: N = 22

of gainful employment. This would allow the Sickle Cell patient to utilize his talents and abilities while providing him with the opportunity of earning a living.

#### Implications for Social Work

Professional intervention can be indicated for a variety of psycho-social concerns and problems that affect Sickle Cell Disease patients. Some services are available through local social service agencies. Emphasis should be placed on the social worker's ability to deal with psycho-social problems. Individuals, groups, and family counseling can be provided by the social worker.

The integration of other professionals into health care efforts would promote a better understanding of the disease. This would facilitate learning for the patient as well as those who are working with the patient. Social work intervention would help the Sickle Cell patient develop and maintain the necessary communication habits that promote open and honest discussion of personal concerns. Patients would be able to view themselves positively which would raise their levels of self-esteem.

Those in the social work profession would be able to focus on the humanistic progress made by Sickle Cell patients. Knowledge of human behavior and the impact chronic illness has on a person would be important resources for those who are working with Sickle Cell Disease patients.

### Recommendations

Vocational Rehabilitation staff should encourage Sickle Cell Disease patients to discover their level of endurance so they can lead full and happy lives. The Sickle Cell patient should not neglect his academic or vocational obligations because of the stigmatism that society may have placed on him. In communities where guidance resources are limited, consideration should be given to linking the Sickle Cell patient with a positive role model. Someone who is employed at a job that the patient is interested in would be able to provide first hand information to the Sickle Cell patient. He may be able to observe the actual responsibilities and demands of the job that are involved with specific duties or tasks.

There is a need for professional rehabilitation teams whose members can bring together skills in the medical, psychological, social, and vocational fields. Since rehabilitation is applicable to people who are able to become employable, most Sickle Cell Disease patients would benefit. (See Table 3) Those who have realistic hopes and aspirations usually are able to seek and achieve a higher level of functioning upon completion of vocational rehabilitation. Sickle Cell patients would be able to accomplish more through the counseling and advice provided in vocational rehabilitations. Occupations the Sickle Cell patient is best suited for could



TABLE 3: LEVEL OF INDEPENDENT FUNCTIONING BEFORE AND AFTER VOCATIONAL REHABILITATION

| Functioning Variables | BEFORE |     |     | AFTER |     |     |
|-----------------------|--------|-----|-----|-------|-----|-----|
|                       | 1      | 2   | 3   | 1     | 2   | 3   |
| Medically             | 77%    | 13% | 10% | 9%    | 10% | 81% |
| Vocationally          | 90%    | 7%  | 3%  | 1%    | 40% | 59% |
| Socially              | 63%    | 18% | 19% | 4%    | 10% | 86% |
| Physically            | 10%    | 27% | 63% | 3%    | 7%  | 90% |
| N = 22                |        |     |     |       |     |     |

NOTE: 1 = POOR; 2 = AVERAGE; 3 = GOOD

be fully explored. The vocational rehabilitation staff would be able to assist with job placement also. Once gainfully employed, the rehabilitation staff would provide follow-up services to evaluate how the Sickle Cell patient is coping with steady employment.

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APPENDICES

## APPENDIX A

PRE-TEST TO DETERMINE PATIENT'S EXPECTATIONS PRIOR TO  
VOCATIONAL REHABILITATION

---

1) Where do you live at the present time?

Own residence

With relatives

Shelter

Personal Care Home

2) How do you think your health is at this time?

Poor

Average

Good

3) What is your job status at this time?

Employed

Unemployed

4) What preparations do you think you need to attain  
employment at this time?

School

On-job training

Vocational Rehabilitation

Not-applicable

5) How often do you need assistance from your relatives?

Often

Sometimes

Rarely

Never

6) What type of medical treatment plan do you usually require?

Outpatient clinic

Inpatient clinic

Routine check-up

Hospitalization

7) How do you feel others respond to you?

Overly helpful

Appropriately helpful

Ignoring

No response

8) How do you feel employers will respond to you?

Make special considerations because of their disability

Make appropriate considerations because of their  
disability

Demand more because of their disability

No response

## APPENDIX B

POST-TEST TO DETERMINE PATIENT'S EXPECTATIONS AFTER VOCATIONAL  
REHABILITATION

---

- 1) Where do you think you will live within the next year?
  - Own residence
  - With relatives
  - Shelter
  - Personal Care Home
  
- 2) How do you think your health is at this time?
  - Poor
  - Average
  - Good
  
- 3) What do you expect your job status will be with the next year?
  - Employed
  - Unemployed
  
- 4) What preparations do you think would be helpful in attaining employment?
  - School
  - On-job training
  - Vocational Rehabilitation
  - Not applicable



5) How often do you think you will need assistance from your relatives?

Often

Sometimes

Rarely

Never

6) What type of medical treatment plan do you usually require?

Outpatient clinic

Inpatient clinic

Routine check-up

Hospitalization

7) How do you feel others will respond to you?

Overly helpful

Appropriately helpful

Ignoring

No response

8) How do you feel employers will respond to you?

Make special considerations because of their disability

Make appropriate considerations because of their disability

Demand more because of their disability

No response

## APPENDIX C

QUESTIONNAIRE TO DETERMINE PHYSICIAN'S OPINION OF PATIENT'S NEED  
FOR VOCATIONAL REHABILITATION

---

- 1) Sickle Cell Disease patients need unique services.
  - a) Yes
  - b) No
  
- 2) Most appropriate living situations for Sickle Cell Disease patients.
  - a) Own residence
  - b) With relatives
  - c) Shelter
  - d) Personal Care Home
  
- 3) Primary reason for Sickle Cell Disease patients being dependent.
  - a) Need for hospitalization due to illness
  - b) Insufficient resources available in the community
  - c) Insufficient funds
  - d) Unemployment
  - e) Others impose dependency role on patient
  - f) Patient imposes dependency role on himself

## APPENDIX D

PATIENT'S PERCEPTION OF HELP NEEDED TO ACHIEVE GOALSFrom Health Care Professionals

Vocational counseling

More community based activities sponsored by health care professionals

Improved medical care

More realistic relationship between rehabilitation activities and community living demands

Improved psycho-social climate

Personal and psychological assistance

Through Social Work Intervention

Adaptive housing

Financial assistance

Academic schooling referrals

Transportation

Job placement

On-job training resources

From Community and Self

More opportunities for social advancement

More active personal participation in rehabilitation plans

Assistance from family and friends

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