ADULT EDUCATORS' ROLE IN THE REHABILITATION OF PHYSICALLY DISABLED ADULTS

Ъу

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ABSTRACT

The purposes of this study were to investigate the psychosocial needs of the chronically disabled and to determine the extent to which the adult educator could further expand the educational opportunities which could partially fulfill these needs.

Due to limited research by adult educators in this field, most of the literature investigated and consultations conducted were in other disciplines. In the chronic care field, medical personnel were visited, extended care and rehabilitation centres were inspected, disabled persons were interviewed, and facilities for the disabled at universities in Vancouver, B.C. were studied. Finally, a four-month field study was undertaken at an extended care hospital in Victoria, B.C. The field study followed "A Model for Research and Evaluation on Rehabilitation" proposed by Suchman.

The literature revealed that the number of physically disabled has increased in this century with a corresponding rise in their psychosocial needs. In previous centuries the numbers of chronically disabled were few and the medical orientation was towards the physical aspect of disease. This practice has persisted to the present day. Owing to these increases and to the fact that there appears to be insufficient time for the complete care of the patient, both physical and psychosocial, the psychosocial needs cannot be adequately met by physicians and nurses. These needs are now recognized, and they appear to be predominately social. Sociologists and adult educators should participate to prevent these needs from becoming psychological.

Three factors that may determine the outcome of rehabilitation are: Motivation, goals and integration and these aspects are illustrated in the case histories studied. The adult educators must recognize the importance of their role in achieving these factors with the disabled.

Unlike Sweden, no comprehensive effort has been made in North America to provide education for the disabled. Some universities and adult educational facilities have been modified and services supplied to the disabled but few adult educators offer services to these people outside of institutions and yet the value of education, whether it be for self-enrichment or vocational rehabilitation, cannot be overemphasized. Even in the brief field study at St. Mary's Extended Care Hospital the benefits of adult education in aiding rehabilitation were demonstrated.

It is concluded that there might be two main causes for this oversight by adult educators. The first is that there is no inclusive registry of disabled, therefore, the extent of the problem might not be apparent. The second is that there are no courses for adult educators on the medical problems of the disabled and adult educators are thereby ill-prepared to assist in rehabilitation. It is recommended that the Provincial Government register all the disabled; that the Canadian Adult Education Association familiarize its members with this problem; and that it suggest further research and study in this area. Courses should be organized by Continuing Education Departments at Universities, Colleges, Adult Education Centres or by Correspondence.

Adult Education Research Centres should further explore the role of adult educators in the field. Adult Education Departments should stress the removal of all physical barriers from educational facilities. Correspondence courses and personal contacts should be initiated and maintained in the home by the adult educator or volunteer. Counselling in regard to adult education should also be available.

The above recommendations would make it possible for adult educators to contribute to the rehabilitation of the disabled.

ACKNOWLEDGEMENTS

In appreciation for the guidance given by Dr. James E. Thornton, for the interest shown and assistance given by Miss Marilyn Dutton and Mr. Paul Thiele and to Mrs. Vera McIver R.N., Miss Margaret Hood, Doctor Peter Bunton and all personnel in the health care field who contributed to my further understanding of the problems of the physically disabled. And particular appreciation to all those physically disabled who participated in this study and whose patient and cheerful responses made the writing of this thesis a most rewarding experience:

DEDICATION

To my Mother

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CHAPTER I

INTRODUCTION

Prior to the twentieth century, the physical needs of the ill were emphasized but after the turn of the century, other needs of the ill were given increased attention, resulting in social scientists becoming active in the health care field.

During the first half of this century, their efforts concentrated on sanitation and contagious disease control. As these conditions have largely been brought under control, social scientists have directed their attention from the physical to psychosocial aspects of disease. Ling and O'Malley point out that this psychosocial concept of disease is not new, having its origin with Hippocrates, and that it has been alternatively emphasized and neglected. It appears never to have been emphasized as much as in this century because of the growing number of disabled requiring long term care.

Along with the increase in research in the psychosocial aspects of disease by sociologists, psychologists and social anthropologists, the emergence of adult educators is noted among the social scientists interested in the health care field.

At some universities physical modifications and special facilities, have made it possible for wheel-chair students and blind students to attend. At the University of British Columbia, for example, a special library for students with sight defects and perceptual difficulties makes it unique in North America.

Although some educational facilities are available in chronic care hospitals and two minor field studies in adult education have been undertaken in one, there does not appear to be a co-ordinated programme by adult educators to participate in the education of the disabled in North America.

A. PROBLEM UNDER STUDY

The physical needs of the chronically disabled appear, for the most part, to be recognized and adequately met by the medical profession but the psychosocial are not. "Even the practitioner's traditional orientation and involvement with the patient and his professional reward system may require considerable restructuring as treatment extends not only temporally, but sociopsychologically as well", Litman states. Also, the government programmes concentrate on vocational rehabilitation and employability. Therefore, the psychosocial needs of the chronically disabled appear to be overlooked and educational opportunities are not being extended on an equal basis to all who are disabled.

"In short, unless a handicapped person is capable of leaving his home, has some means of transportation, can attend a school with no architectural barriers to his mobility, has no great physical problems which render him 'undesirable' in the classroom, has no major problem in communication and has unusual drive and motivation, he is not very likely, at present, to be educated."

B. HOW THE PROBLEM DEVELOPED

In this century we are confronted with growing numbers of injuries incurred in war, industry and traffic. Advances in medicine have made it possible to survive manye accidents and illnesses. This is exemplified in the statistics that the United States population has grown by about 2.5-fold since the turn of the century but the population of older persons has grown by 7-fold in the same time and is accelerating. Among these surviving accidents and illnesses are millions of people who suffer disability. In the United States, it is estimated that there are 25,620,000 disabled and in Canada, 2,500,000.

The trend is exemplified by the total number of members (See Figure 1), the number of new injuries resulting in disability (See Figure 2) and a chart of new injuries (See Figure 3), showing major causes, in the 1972 Annual Report of the Canadian Paraplegic Association, British Columbia Division. It is to be noted that the bulk of new cases were the result of motor vehicle and industrial accidents, the former predominating. Among the members listed in 1971 were 230 non disabled and 927 disabled. Thus affluent societies often not only produce a high level of welfare resulting in improved medical and social benefits, but also an increased flow of traffic resulting in more disabled people. 8

Figure 1

Membership Graph*

Canadian Paraplegic Association

B. C. Division

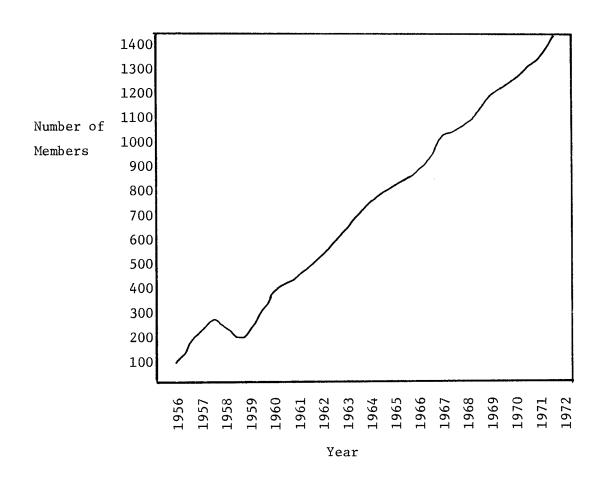


Figure 2

New Injury Growth Year*

Paraplegics and Quadriplegics
in British Columbia

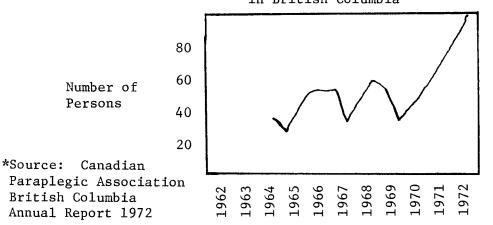


FIGURE 3

New Injuries Chart 1972*
Paraplegics and Quadriplegics

in British Columbia

TYPES OF DISABILITY	Total	Male	Female	Motor Vehicle	Industrial	Sports	Falls	Disease	Miscellaneous	
PARAPLEGICS	54	45	9	19	15	1	6	4	8	
QUADRIPLEGICS	25	22	3	13	6	4	3	-	-	
TOTAL	79	67	12	32	211	5	9	4	8	.]

*Source: Canadian Paraplegic Association

British Columbia Division

Annual Report 1972

C. THE PURPOSE OF THE STUDY

The purposes of this study are to investigate the psychosocial needs of the chronically disabled and to determine the extent to which the adult educator can further expand the educational opportunities which will partially fulfill these needs.

The study will point out how psychosocial needs often become predominant over physical and are often inadequately dealth with in the long-term disabled patients.

It will illustrate how adult educators can assist and have assisted the disabled in educational facilities, at home or in health care facilities in North America, England and Sweden. It will indicate that if adult educators are to assist competently in the rehabilitation field, they must undertake studies directed by experts such as psychiatrists, medical sociologists and occupational therapists. And it will illustrate the value of field studies for adult educators in order that they can apply the theoretical knowledge received and gain the experience necessary to understand and aid the disabled.

D. LIMITATION OF THE STUDY

There has been little research by adult educators with the disabled, therefore most of the literature investigated and interviews conducted were in other disciplines. Often the value of education in the rehabilitation of the disabled is recognized but the viewpoint of educators, in this particular area, is lacking.

E. DEFINITION OF TERMS

The following definitions are specified for this study as different connotations are suggested in the literature.

Disability:

A disability is any physical impairment which, though it may impede, will not be an obstacle to an individual's achievement of a specific goal or goals.

Handicap:

A handicap is a physical impairment which is an obstacle to an individual's achievement of a specific goal or goals.

Psychosocial

Factors

The term psychosocial includes psychological and sociological factors as a single entity which are inextricably interwoven.

Reality Orientation:

Reality orientation is a technique designed to re-educate a person who shows signs of memory loss and confusion following an accident or an illness. At its simplest form, it uses cerebral functions that are still intact. 9

Rehabilitation: Rehabilitation takes place when there is recovery

to the maximum to which a person is capable of

functioning.

F. METHODOLOGY

Personnel and disabled persons at extended care hospitals, rehabilitation centres and universities, and at home and work were interviewed. Facilities for the disabled at universities in Vancouver, B.C. were studied. A four month field study was undertaken at an extended care hospital in Victoria, B.C. There were five subjects involved in the study and three different educational processes were used as intervening variables in their rehabilitation. There were two of these people taking correspondence courses, two painting and one practicing basic printing, counting and reading. The study followed "A Model for Research and Evaluation on Rehabilitation" proposed by Suchman. 10

G. PLAN OF THE STUDY

The needs of the chronically ill, the attitude of physicians and nursing personnel, and the increasing involvement of social scientists in the care of the chronically ill are discussed in Chapter II.

In Chapter III, the study then considers some key factors and the role of education in the rehabilitation of the disabled. The importance of motivation, goals and integration are discussed and case histories are outlined.

In Chapter IV, university efforts of some universities which have modified campuses to overcome physical barriers and which have

supplied necessary services for the disabled are considered and adult educators' contribution and preparation in the rehabilitation of the disabled are assessed.

Field studies at an extended care hospital are discussed in Chapter V. Case studies about educational efforts with patients are presented.

In Chapter VI, finally, conclusions and recommendations are submitted about the adult educators' role in the rehabilitation of the chronically disabled.

CHAPTER I

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CHAPTER II

PSYCHOSOCIAL NEEDS OF

THE PHYSICALLY DISABLED

The needs of a person with a chronic disability often differ from those of a person with an acute illness. Usually the same physical and psychosocial needs are present, however, the emphasis is changed. In the care of the chronically ill the psychosocial needs are often predominant.

Physicians and nurses are mainly occupied with caring for the physical needs of the patient, however, as a result, the psychosocial needs, particularly of the long-term disabled, are often not met.

Therefore social scientists are becoming more involved in the health care field.

A. THE NEEDS OF A PATIENT WITH A CHRONIC DISABILITY

When a person suffers an illness or injury which is of comparatively short duration and has few, if any, residual effects, there is little adjustment necessary. Although the disabling factor may be painful, cause expense and worry, and dislocation from family, friends and work, it will usually be of temporary duration and the person can foresee, with a reasonable degree of surety, his return to his former way of living. This is his goal and also that of the medical team caring for him. The classic hospital model of care has its emphasis on the acute phase of an illness, on short term acute care where the patient's self reliance is not encouraged. This is the acute care

philosophy (See Phase 1 of Figure 4). It recognizes that psychosocial needs are always present in all people and increase in times of stress, such as illness or injury. But in this phase they usually do not attain the significance of physical needs. For example, at this stage, the psychosocial needs are met by visits of relatives and friends, by the knowledge he will be returning to his home and to his work. He views his present plight as only a temporary inconvenience. An illness that is of longer duration may be approaching a chronic or terminal phase and psychosocial and physical needs will often vie for importance; an awareness of loss and physical discomfort will necessitate an adjustment to both. This requires a long term acute care philosophy (See Phase 2 of Figure 34).

Finally, an illness of long duration enters the chronic phase. Except for terminal illness, Wesson explains that as the chronic phase of an illness manifests itself the emphasis should be on rehabilitative care where motivation to master disabilities must be mobilized and where the patient takes an active part in a joint endeavour with the staff. This is the chronic care philosophy (See Phase 3 of Figure 4). For the patient further adjustment is necessary and psychosocial needs may become predominant as he recognizes there will be no return to the status quo of his life prior to disability.

FIGURE 4

PHASE 1	HEALTH CARE* PHASE 2		PHASE 3
Acute Care Philosophy	Long Term Acute Care Philosophy	\longleftrightarrow	Chronic Care Philosophy
PHYSICAL CARE Psychosocial Care	PHYSICAL CARE PSYCHOSOCIAL C Care	ARE	PSYCHOSOCIAL CARE Physical Care

^{*}Categories are reversible, for an acute illness may develop into a chronic phase and chronic illness may develop an acute phase. chronic phas

If we are to achieve a balanced environment when developing psychosocial care programmes for the disabled, the emphasis must be on the social needs. Although between 34.6% and 43.7 percent of male and female claimants for disability benefits in a sample of physical disability benefits in the United States showed an elevation in the neurotic triad (hypochondriasis, depression and hysteria) and had moderate to severe psychoneuroses or personality disorders³, Wright states that the disabled do not present as many psychological problems as believed. The problems are of social origin affecting the psychological adjustment of the individual.⁴.

B. THE RELATIONSHIP OF PHYSICIANS IN THE CARE OF THE CHRONIC

For the decade 1963-1973, Dr. Szasz, the Director of the

Division of Interprofessional Education of the University of British Columbia, stated that the psychosocial needs were being recognized more by the medical profession. Buthalthough there are more disabled persons and improved rehabilitation techniques for them, most physicians are trained in the physical environment. And, in regard to patients, physicians are drawn to acute care patients, rather than chronic, in which there is more likely to be monetary reward and personal satisfaction. 5

Therefore, it would appear that there is still a considerable lag in fulfilling the psychosocial needs of patients. In the case of the acutely ill there may not be as many psychosocial needs as in the case of the chronically ill. In the United States it was found that the chronically disabled fared better physically than mentally and man's incompetence in dealing with human nature was contrasted with his ability in dealing with physical aspects.

This may account for the lack of sufficient time of most
physicians and by the attitude of some. The patterns of practice have
been changed by social changes within our society over which the
physician has little control, and by medical advances with which he must
keep up. In the first case, medical insurance for all in British
Columbia has resulted in an increased demand for hospitals' and
physicians' services. Furthermore, medical advances have resulted in a
greater portion of the physicians' time spent in study and also in the
care of the chronically ill who survive in increasing numbers. Simply

stated, today's physicians bear an increasing pressure, that of serving a larger population which is more often seeking his advice, and that of keeping abreast of medical advances and he must often place priorities on the needs of his patients. These will most often be the physical over psychosocial. In addition, the attitude of some physicians must change from that of a benign paternal image, to that of a respected adult image and, in so doing, to allow the patient to accept adult responsibility for and participate in his own rehabilitation. 8

C. THE RELATIONSHIP OF NURSING PERSONNEL IN THE CARE OF THE CHRONIC

Most nurses, like physicians, are attracted to the care of the acute patient and a large percentage of their training is in the acute hospital. Here psychosocial needs are not as significant as the physical needs and, therefore, they are often overlooked in the nurses' training with the consequence that the complete care of the patient is not realized.

In the acutely ill, psychosocial needs are usually not as evident as in the chronically ill and the lack of satisfaction by nursing staff not as damaging. However, there appears to be less personal attention paid to patients in the last decade and this aspect of care should not be neglected. For example, in 1964, at the Vancouver General Hospital, the head nurse in neurosurgery visited each patient every morning she was on duty. All patients knew her and her assistant

and there was good communication. They knew that senior nurses were aware of them and their needs. Observations in 1970-1972 disclosed that few patients even knew the names of the senior nurses on the ward; some felt the reverse must also be true. 10

This deficiency has been recognized by the nursing profession in some areas and steps have been made to rectify it. A two year programme was initiated at an American veterans' hospital in 1969 directed at improving communications among physicians, nurses and patients and to returning nurses to nursing responsibilities rather than administrative. 11

In th

In the chronically ill, psychosocial needs are significant and nurses reflect by their attitudes, that they do not always perceive this fact. In a recent study, it was observed that an orientation is needed for acute care hospital nurses to follow up in the care of cardiovascular accident patients. It states that nurses often do not train the patient in self-care and do not communicate with the patient. 12 Initially, it takes longer to train a patient in the activities of daily living than to do them for him and, it may be time consuming to try to understand and be understood in communicating with some patients. Yet training the patient to care for himself and communicate with others, even in a small way, will increase his sense of worth to himself and those around him and take him another step toward his rehabilitation. It is noted that no mention was made of physiotherapists or occupational therapists in this article.

Another study done in London by a nurse with twenty years experience, tells how a nurse rewards her favourite patients and treats the unpopular with scorn, impatience, irritation and ridicule. Among the unpopular were the unpleasant, the long-term, the mentally ill, the hypochondriacs and the dying. ¹³ It is evident that all these might require an increased degree of psychosocial care and that the nurse, familiar with the physical, does not recognize this and turns away from the unfamiliar, blaming the patient for his behaviour when it might be that his needs are not being satisfied. Vera McIver maintains for twenty-five years nurses have given psychosocial care lip service but have been unable to put it into practice. ¹⁴

D. THE INVOLVEMENT OF SOCIAL SCIENTISTS

As has been stated, the psychosocial needs of the chronically disabled are primarily social and if social needs are supplied, psychological maladjustments may not occur. But these needs are often outside the scope of services that medical personnel can supply, for example, those needs that involve socializing with others, intellectual pursuits and hobbies. Occupational therapists are engaged in many aspects of rehabilitative programmes to meet these needs, however, with the growing numbers of disabled to care for it would appear others might assist them. Occupational therapists must examine the patient's problem from every aspect, for example, find out his capabilities, aid in the selection of occupation and adapt his living habits. It is commented

that vocational evaluation and the activities of daily living should increase in importance for the occupational therapists and because of these factors concern is expressed by an occupational therapist that other disciplines may enter the field. And yet these others should contribute their skills.

The increasing involvement of social scientists in the medical field, from the initial sparce reports of the eighteenth and nineteenth centuries on disease, social and economic conditions to the reports of the twentieth are documented. It was not until the 1940's that major research was reported by sociologists, social anthropologists and psychologists in the health care field. By the 1950's attention was turned from the physical and social environment to the psychological and social environment. With this latter concern the psychosocial needs of the physically disabled were brought into focus by medical sociologists.

In 1960, a conference on "Psychological Research and Rehabilitation" was held. Modifications of behaviour resulting from the condition of disability, its implications for new learning, and relearning were discussed. Following this, in 1965, a conference on "Sociological Theory, Research and Rehabilitation" was assembled in Carmel, California, and current sociological theory and research in the field of rehabilitation were investigated. It was reported that rehabilitation, because it is a social problem, usually takes place in an unstructured environment. 18

By 1968, an Ad Hoc Committee on Disability was established and arrangements were made with the American Sociological Association's section on medical sociology to sponsor a special session on the "Sociology of Disability" at the Association's meetings in San Francisco in 1969. There are now over eight hundred social scientists engaged in research in the health field and the number is increasing. 20

Thus, social scientists, both sociologists and adult educators may be an important adjunct to the efforts of occupational therapists.

In the first case, needs in relation to the social aspect may be recognized and fulfilled; in the second, many areas of education such as commercial, technical and academic as well as recreational may be supplied. Adult educators would also be useful in vocational assessment.

E. SUMMARY

As a person passes from the acute phase of an illness into a chronic phase, his needs may differ dramatically. Most of the training that physicians and nurses receive focuses on those acutely ill which is usually physical care of short duration. As a result, when medical personnel are confronted with those chronically ill, where psychosocial care is predominant and of long duration, their needs are not adequately met.

Social scientists are now studying the psychosocial needs of the chronically disabled. The papers presented at the Carmel Conference

states that most of the rehabilitation of the disabled takes place outside of the rehabilitation system and, as such, is a social problem. ²¹

It may be theorized that if more social scientists were involved directly in the rehabilitation system itself more positive results would be achieved. In the future, sociologists and adult educators should help to fulfill the psychosocial needs of the disabled.

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CHAPTER III

FACTORS IN THE REHABILITATION OF THE PHYSICALLY DISABLED

As the numbers of disabled grow many factors are discerned among the psychosocial needs. Three of these factors are motivation, goals and integration. By recognizing the importance of these factors, the adult educator may be the means of initiating or sustaining some or all factors by educational endeavors which will aid in the rehabilitation of the physically disabled.

A. MOTIVATION IN THE DISABLED

Motivation is necessary for the disabled to be rehabilitated and the social scientist should assess that which is present in the person whom he wishes to assist. For some, motivation will be high, for others it may vary from moderate to low, or even be non-existent. Where motivation is high, adult educators may have only to counsel as to what is available, what aids can be obtained, what difficulties he may encounter and what assistance he may require in obtaining the activity of his choice. Where motivation is low the adult educator, if possible, will have to win the confidence of the disabled, stimulate his interest and encourage him in order that he may attempt a task that is new to him. Studies on the disabled showed that aspiration, learning and activity are essential to socialization. The adult educator

should be an important adjunct in this area of rehabilitation.

Case History of a Disabled Person Lacking Motivation ${\tt CASE\ I}$

He is a man in his late fifties and was employed as a milkman in 1966 when pain in his neck became severe. His physician referred him to an orthopaedic surgeon who performed a series of operations. He receives monthly payments for disability. The surgeon stated he was able to work but could not do any The government offered retraining, however, heavy lifting. the patient refused to believe the surgeon was correct in his assessment and sought another opinion which affirmed the findings of the original surgeon. He seems to have assumed the role of the invalid, having the mobile library bring books to him and spending the days reading or listening to the radio. It would appear that he can do more. When the government requested that he undergo tests in Victoria, he went by bus and ferry from Vancouver, and returned the same day by himself. He still does nothing. His background shows little education. His wife does not encourage any activity on his part but agrees with him that the doctors conspire in order to hide the fact their efforts have not been successful.

Case Histories of Disabled Persons Having Motivation

CASEIII

He is a man under thirty years of age and graduated in Economics in 1973 from the University of British Columbia. He is a paraplegic who was injured playing ice hockey while in Grade XI. He said that he was able to manage fairly well at university overcoming physical barriers and that fellow students were available when he required help. Financially, he received a pension and 12711 and 21972 grangrant mfrom the opportunities for Youth" fund to study physical barriers for disabled students at post secondary institutions. As a result, there were some improvements at his own university, such as special washroom facilities, ramps and one telephone were installed. This man is now employed as a counsellor for paraplegics.

CASE III

He is a man under thirty years of age. After becoming a quadriplegic

when he was injured while skiing during his final year at high school, he completed Grade XII then attended the British Columbia Institute of Technology for two years. Having received his certificate, he was employed as a rehabilitation counsellor.

Comments on Motivation

In these case histories, it is noted that people close to them played a prominent role. Where there was no encouragement there was no motivation. The wife in Case I could see no benefit from courses her husband was advised to take and he refused to further his rehabilitation.

Also, the age at which disability interrupted education was significant. For those whose disability did not interfere with the continuity of their education, such as the blind, or had completed much of their education, the disability presented a difficulty but not a termination to their aspirations. The rehabilitation counsellor at the B.C. Paraplegic Association confirms the fact that in this regard, therefore, there are more impediments for children than for adults.²

B. GOALS FOR THE DISABLED

Meaningful goals are necessary in programmes for the disabled. The occupational therapist or adult educator must be careful not to assign a task because he believes the task itself will aid the patient to improve muscular strength, co-ordination or concentration. The results of the task must give him a sense of fulfillment and must not

be demeaning. Early programmes for the disabled included such activities as weaving and chair caning and still exist in some programmes today. To some disabled such programmes might be useful but to others they might be harmful, as negative aspects could predominate. A formerly able-bodied individual having to face up to disability and then having to engage in activities that are possibly ego damaging in efforts to rehabilitate himself will obviously not have his psychosocial needs met. As much as possible, most activities should be similar to those in which able-bodied persons might participate. Other activities not only adversely affect the disabled's own image of himself but also influence the "normal" persons' concept of the disabled. Because of this, equipment resembling that used in industry is preferred over that used in occupational therapy projects. 3

Aids, such as car simulators used by Driving Schools to teach new drivers, could be used to practise and test co-ordination, perception, reflex and concentration. Similarly, another testing machine that could be adapted is one similar to that which can be installed in a car to test the degree of sobriety of a person before driving. The necessary numbers in correct order must be punched before ignition is turned. This could be attached to a battery operated mechanism to sound a buzzer when correct rather than the ignition of a car.

Some long-care hospitals are using methods to increase the sense of worth of the patients while they are engaged in therapeutic

procedures. For example, in some activities at Lions Gate Extended Care Hospital, North Vancouver, B.C. the patients may make items to sell at a bazaar. At St. Mary's Priory Extended Care Hospital, Victoria, B.C., they may make toys to give to the children at the Solarium.

Academic endeavours will also vary but again goals must be realized. For instance, patients might study a foreign language or paint for pleasure or profit or simply attend a course in adult education in order to socialize. Whenever suitable goals do not materialize, motivation is inhibited.

Case History of a Disabled Person Lacking Goals
CASE IV

He is a man under thirty years of age and had just graduated from high school when he was thrown off a horse. His balance is impaired, his right side is partially paralyzed and he has a double vision problem. He gets around fairly well with the help of canes. His mother wrote that her son was at the school, Council for Crippled Children and Adults at Saskatoon for two months. According to her letter, their activities consisted of packaging plastic bags, cutting wires and working ceramic articles. He would have liked ceramics but thought he was too unsteady and returned home because he didn't like to live with strangers and felt helpless. In conclusion, his mother writes, "What can a person do if he can't walk, read or write? We will have to accept his condition for what it is and make the best of an impossible situation." He dictated a letter to me and said, "I have too much time on my hands, there's simply nothing I can do."

Case Histories of Disabled Persons Having Goals
CASE V

A University of British Columbia student, under thirty years of

age, took first year Arts last year but is now continuing on in Commerce as he feels that this will be more practical. He is a paraplegic who was injured playing rugby at the age of sixteen. Like Case II he manages to get around the campus quite well owing to remodelled facilities and finds his fellow students most helpful. He plans his timetable with care, choosing time and place of scheduled lectures which are most suitable. Financially, he receives free tuition, books, and the disabled pension from the government and, hand controls for his car and a scholarship from the Paraplegic Association. Along with Case II, he also received \$90.00 per week for sixteen weeks and fifteen weeks, respectively, in 1971 and 1972 from the Opportunities for Youth Programme.

CASE VI

This man is a patient in the Pearson Hospital, Vancouver, B.C. and is under thirty years of age. He is a cerebral palsy patient and cannot sit upright or control movement in his hands or feet. With the encouragement of an aunt and the help of the occupational therapist, he is now writing short articles. He does this by the use of a stick fastened to a headband and an electric typewriter. He attended school at the Children's Hospital in Vancouver, B.C. and went as far as Grade X. He is determined to become a writer.

CASE VII

This man is a patient in the Pearson Hospital, Vancouver, B.C. and is under forty years of age. He stated he had little formal education as he worked as a logger and fisherman until he contracted polio in 1955. He was very depressed in the early parts of his illness as he is a severe quadriplegic and requires an electric wheelchair for his only self locomotion. His only accomplishments had been of a physical nature. A member of the staff, who had a doctorate in philosophy, interested him in painting by mouth. He had never done any painting before and decided to try it, by learning from those around him, especially the doctor who had initiated his interest and the occupational therapist. He sells his paintings and says it is now starting to pay. He teaches painting at night school at Vancouver City College for one or two nights a week, sells 90% of what he paints, and pays for all his own supplies. This patient said he realized that people with his type of disability, can now live many years, owing to advances in medicine, and he is pleased he can paint and teach so successfully.

Comments on Goals

Meaningful goals appeared not to have been established when Case IV attended rehabilitation school, therefore his motivation was not stimulated and he did not remain. He seems to have given up. Fraser states the disabled must concentrate on the things they can do that, therefore, the "Acceptance of the facts of a disability is the pre-cursor of all progress towards conquering it; not acceptance and resignation, but acceptance and resolve." Meaningful goals appeared to have been established for other cases in various ways. Whether they were vocational or personal satisfaction, they were persisting in their pursuits. Therefore, the chronically disabled require a positive reason for living that is not necessarily linked to monetary gain in order to be successfully rehabilitated.

C. INTEGRATIONTFOR THE DISABLED

Integration with the "normal" population is invaluable for the disabled. In our society, we have been guilty of segregating many disabled, either because of the disabilityloryofrphysicalibarriers in the environment. Sometimes good intentions may be the cause as in the move for some disabled from the Marpole Infirmary, Vancouver, B.C. to Pearson Hospital, Vancouver, B.C. The surroundings at Marpole appeared inadequate, for this was an old hotel-type building, built to the sidewalks with no grass and no view. They were subsequently moved to Pearson Hospital, back from the main thoroughfare with lawns

around the buildings. It seemed to be an ideal setting. However, some of the disabled missed sitting on the sidewalk, seeing the traffic and chatting with people passing by and were lonely in their new surroundings. Although, in this case, the move appeared to be necessary, it brought forward forcibly the point that what the non-disabled feel to be an improvement is not always what the disabled feel. 7

The protective influence of segregation is reported by the International Society for the Rehabilitation of the Disabled on the decade 1970-1980 - that we must get away from the feeling that the disabled are "different" and give more thought for the education of handicapped children within ordinary schools. Thiele, the librarian for visual disabilities at the University of British Columbia, states that if children are educated in a blind school they develop "blindisms", such habits as rocking and jumping, which become re-inforced when grouped together but seldom occur if they are educated in ordinary schools. He states that we have some blind children going to ordinary schools where special equipment is supplied. At university he follows through his integration policy by allowing the use of the Crane Library for library purposes only, thereby encouraging socializing at regular student centres.

It is also observed that with disabilities, no matter at what age they occur, the sooner integration is accomplished, the easier it is for the disabled. Thus, when it occurs with children, they should

be in a regular school when possible, and when it occurs with adults they should be returned to the regular society when possible. If kept in a protected environment too long, sometimes a person will fear leaving it.

A collection of disableds' autobiographical essays protests against the segregation of the disabled. They wish to lessen the social distance between the disabled and non disabled. Again, it is recommended that a start be made with disabled children to attend school with the "normal". 10 In this report, disabled people expressed concern with what the world calls cripples and the manner in which the "normal" sometimes patronize or write off the people who do not physically measure up, as useless. One was given the impression that many people equate mental deficiency to physical deficiency and appear embarrassed in his presence. Swedish efforts are directed to the disabled living a life as close to normal as possible and thus integrating with the members of the general community. 11 The "normal" must be made more familiar with the disabled in our population. We must see them, work with them, and live with them, from the time we are children. We must realize that almost twenty percent of our population suffers some form of disability and the chance of becoming disabled in our lifetime is increased as the complexity of our life increases. We should be familiar and accept the disabled as part of our regular culture, not as a subculture.

In our society, disabled adults appear to have difficulty

integrating unless the disability can be disguised or can be worn as a badge of honour, such as that incurred in the services of his country. In the United States, civil rights protect different races from segregation. There is little protection for the disabled. 12

Case History of a Disabled Person Lacking Integration
CASE VIII

A man, under thirty years of age, was disabled as the result of an accident. He required assistance in activities of daily living and his family wished him to live in a fraternity type of home while at college so they sought guidance and funds to establish this for their son and other disabled men on the campus. However, these other men did not wish to leave the security of their sheltered accommodation and the campus residence for them did not materialize. 13

Case Histories of Disabled Persons Obtaining Integration
CASE IX

A man, under thirty years of age, has cerebral palsy. Because he had limited physical powers, his parents encouraged him to use his mental abilities. He graduated from college with a degree in journalism. Leg braces made it possible for him to drive a specially equipped car and, after taking a course in computer programming, he was able to obtain a full-time employment. 14

CASE X

A woman, under thirty years of age, has cerebal palsy. She wants to live an adult life independent of her parents. The Handicapped Persons' Pilot Project in California found her a suitable apartment. With additional educational and social involvement she expects to keep herself mentally occupied. 15

CASE XI

A blind University of British Columbia student graduated in 1973 with

a B.A. degree. It is noted that she has a strong sense of independence and a need to be treated as just another student. 16

CASE XII

Another blind student at the University of British Columbia finished her third year in music in 1973. She left the special environment of Jericho School for the Deaf and Blind in Vancouver, B.C. after Grade III and went to public schools. At that time there were only two blind students attending classes in the regular schools. Thiele, the librarian for the blind, states that British Columbia is getting away from the idea of special schools. 17

CASE XIII

A man, under thirty years of age, is a patient at the Pearson Hospital, Vancouver, B.C. He was stricken with polio in 1953 and is a quadriplegic. He said he felt discouraged and frustrated and had no desire to take any courses until a group of employees from Canadian Pacific Air set up an amateur radio station "HAM" at the hospital. This patient, with others, took a six months morse code and radio theory to obtain an amateur ticket. He uses apstick inehisdmouth to operate the radio and telephone. took another six months study and received his advanced amateur ticket which meant he could operate with both morse and microphone. His world had been enlarged by his contacts with others on the radio but, after completion of his courses, he realized how much they had meant to him. Now he felt he was operating the "HAM" for recreational purposes only, having completed the formal instruction, and felt a void. He started to think of the education he had missed and feared he was in danger of vegetating. After all these years, his attention was turning to education. He took correspondence Biology XI. Although he thought he had missed the most interesting portion of the course, the field trips and laboratories, he stayed with it and, in spite of the obstacles presented by his condition, he completed the course in eighteen months. He is now taking English XI and Social Studies XI. Last summer he took a course on reading and study skills at the Centre for Continuing Education at the University of British Columbia.

Currently, he has been chosen as a candidate for a contemplated computer science course. As Case III pointed out, it is difficult for people who have been disabled since childhood; to undertake educational endeavours. This man has shown high motivation and determination in completing courses to date, but he obviously felt insecure when offered the opportunity of studying computer science because he requested psychological testing to determine if he would be competent.

CASE XIV

This man is a cerebral palsy case under the age of thirty and aptly demonstrates what some disabled may accomplish, given the opportunity and motivation. For ten years he attended Toronto's Sunnyview School and claims that the people in this school were not interested in finding out a handicapped person's potential. From there he went to a sheltered workshop where he did such things as folding boxes and separating nuts from bolts. Eventually, he struck out on his own, enrolled at McMaster University, got his B.A. and became a journalist. Subsequently he hashwonwa: a \$5,000.00 award on a play based on the disabled and has written another which is being produced. 18

Comments on Integration

Mixing with the "normal" population is an important phase of rehabilitation. One man was unable to attain integration for himself and other disabled on his campus because of a long delay. In different circumstances, other cases were able to integrate.

Sequential and concurrent development of the three factors, goals, motivation and integration, are exemplified in Cases XIII and XIV.

D. SUMMARY

In relation to education, case histories of the disabled illustrate that three factors, motivation, goals and integration may determine the outcome of rehabilitation.

The three factors may be interwoven and of equal importance, or one factor may be isolated and attain overall importance. Other

times, they may be in sequence. For example, motivation may be the means of seeking a goal or the goal recognized may be the means of stimulating motivation. Both may attain the integration or socialization of the individual.

It is noted that where there was encouragement, there was motivation initiated by staff, relatives and outside interested parties and integration appears to be the most significant. Yet, for the disabled, it presents many problems in our society, physical obstacles being only one. Although their physical needs may be cared for, the disabled are often placed away from the stream of "normal" living where they can be grouped together and "looked after". Without integration, motivation and goals lose much of their meaning.

FOOTNOTES

CHAPTER III

- Gary L. Albrecht, "Adult Socialization: The Effects of Aspiration upon Role Performance in Rehabilitation Settings," <u>ERIC</u> Research in Education, Vol. 6 No. 1 (January 1971): 10.
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- ³Josephine C. Moore, "Changing Methods in the Treatment of Physical Dysfunction". The American Journal of Occupational Therapy, Vol. 21, No. 1, (1967): 19.
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- ⁵Sir Ian Fraser, ed., <u>Conquest of Disability</u>, (London: Odhams Press Limited, Long Acre, 1956), p. 8-11.
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- ⁷Constantine Safilios-Rothschild, <u>The Sociology and Social</u>
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- ⁸Dorothy Warms and Susan Hammerman, "Planning for the Decade of Rehabilitation 1970-1980, New Patterns of International Service, Final Report", ERIC Research in Education, Vol. 6, No. 4 (April 1971): 39.
- ⁹Interview with Paul Thiele, Librarian, Crane Memorial Library, University of British Columbia, June 1973.
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- Richard Sterner, <u>Services for the Handicapped in Sweden</u>, (Stockholm: The Swedish Institute, 1972), pp. 1-2.
- 12 Ruth Lauder, The Goal Is: Mobility! National Citizens Conference (Washington, D.C.: U.S. Department of Health, Education, and Welfare, Social and Rehabilitation Service, 1969), pp. 51-2.
- 13Louis F. Saylor, "Residential Care Needs: A Report to the California State Legislature", <u>ERIC Research in Education</u> Vol. 6, No. 1, (January 1971): Appendix E2-3.
 - ¹⁴Ibid., p. 29.
 - ¹⁵Ibid., p. 29.
- 16_{Murray McMillan}, "We Shall Overcome", <u>U.B.C. Alumni Chronicle</u>, Vol. 27, No. 2 (Summer 1973): 5.
 - ¹⁷Ibid., pp. 5-6.
- 18 Audrey M. Ashley, "Timmy campaign called obscene", Vancouver Province, 5 August, 1971, p. 36.

CHAPTER IV

EDUCATIONAL PROGRAMMES

FOR THE DISABLED

The psychosocial needs of the chronically disabled are evident and education may be one means of partially fulfilling them. Unfortunately, many programmes only offer education to those disabled who have a chance of vocational rehabilitation. For example, in Newfoundland, financial assistance for tuition, books, fees, maintenance and transportation is available, but emphasis is placed on training or re-training of disabled persons to prepare them for the labour market. However, the value of education in rehabilitation is gaining more recognition and some programmes are available now to all disabled, regardless of future employment.

In North America, following the Second World War, the need was perceived to supply educational benefits to the disabled. Some university and college campuses were modified and services supplied. However little attention was paid to adult educational facilities.

In England, adult educators have been participating in the health care field by co-operating with the medical authorities to supply educational services. One of the most advanced centres is for the rehabilitation of spinal injuries at the Stoke-Mandeville Hospital in Aylesbury.

In Sweden, although they believe resources can still be improved, much progress has been made in the education of the disabled. Facilities and services are available at both university and adult education centres or through correspondence study for people of all ages.

A. POST SECONDARY EDUCATION PROGRAMMES

1. Universities and Colleges in Sweden

In Sweden, the same services offered to disabled students at the Folk High Schools are given at every university, school of economics or university level institute of technology and paid for by the Government. Special flats or rooms, which are adapted for students with disabilities, are built in the residences, personal assistants are supplied when required and transport is arranged. The Government is responsible for providing services such as personal help to carry books or read texts, and supply technical aids, for example, typewriters, tape recorders or wheelchairs. ²

2. Universities in the U.S.A.

University of Missouri at Columbia

In the United States, in 1959, the University of Missouri started a programme to modify its physical facilities and supply personnel to aid the physically disabled who wished to attend. The research and demonstration project was completed in October, 1966, but modifications are still carried on as needs arise. The total cost over

the six years of the grant was \$980,642.00. There are now over fifty severely disabled students in attendance.

The physical features that were modified included doorways, elevators, restrooms, telephones, desks and chairs. Housing on campus is arranged by placing one disabled person with five able-bodied people because the majority of disabled preferred to live with non disabled. Transportation is arranged by special buses. A section of the library, complete with electric typewriter, dictating machine and tape recorder is set aside for the disabled. A block model of the campus is provided for the blind and library staff assist with obtaining books.

Special counselling services are available but once a disabled student has completed registration, he is treated like any other student and is expected to meet the same academic requirements as other university students.

University of Illinois and Southern Illinois University

At these universities, there are over 750 physically disabled. Architectural barriers have been removed here but not on other campuses in the State and it is possible that many attending university might be better served if technical and occupational programmes had facilities available.

The University of California at Berkeley

A five year project, February 1, 1968 to January 31, 1973, was instituted to make a residential unit available for severely disabled quadriplegic, triplegic and paraplegic students at the university. There are eleven quadriplegics in the project, one spends sixteen hours a day in an iron lung. They require a registered nurse and an orderly to assist them. Ninety percent of the costs are funded by the Federal Social and Rehabilitation Services.

At present, two of these students have entered graduate ${\it school.}^5$

Universities in Canada

University of Alberta, Edmonton, Alberta

In 1967, a computer programming course was started at the University of Alberta Computer Centre for quadriplegics in the University of Alberta Hospital. A keypunch was placed in the polio ward. After various contract jobs, they formed their own company "Pro-Data Services Ltd."

Simon Fraser University, Vancouver, B.C.

At Simon Fraser University physical facilities appear adequate.

Five students in wheelchairs and one bland student are registered.

The project planner states that all buildings must comply with the

municipal code and new buildings must conform to the code and accommodate the disabled. Older buildings have been redesigned when necessary. 8 It is to be noted that the women's residences do not conform to the building code. 9 The planner confirmed this fact but said he knew of no request for changes. 10

There is a projected plan for the disabled from Pearson Hospital to study computer science and use facilities at the university and hospital. 11

University of British Columbia, Vancouver, B.C.

At this university, physical facilities for the disabled do not appear to be well developed. New buildings follow the National Building Code, Building Standards for the Handicapped, but most older buildings are not easily accessible for wheelchairs. There is no demand to modify the campus to be acceptable for the disabled and priorities for capital expenditure go to other needed facilities which serve the greater population. When additions were made to the Woodward Library, they conformed to the Building Standards for the handicapped. Some modifiedtaccomodation, a special telephone and washrooms have been installed in other areas of the campus. However, there is not much encouragement for the disabled with one exception.

The Crane Memorial Library on this campus is the only library in North America that is purely academic, part of an established university system and specially designed for those who are blind or

have perceptual difficulties. This library supplies both references and a qualified librarian and contains 18,000 texts in Braille and 5,000 on tape. Sixty-five persons used the library in 1973. The Crane Memorial Library has been recognized by the Library of Congress, Washington, D.C. and has established world-wide affiliations, supplying books to European countries and the United States.

Besides the books in Braille or on tapes, other services are provided. For example, there are seven paid readers and seventy volunteer readers, there is a model of the campus on which blind students can feel their way around and get to know the geography of the campus, and a ramp is located at the back of the building for easy access.

Of further interest is the fact that all materials in the library can be obtained through a public library and there are projected plans for these to be distributed through the regular mobile unit. 13

B. ADULT EDUCATION PROGRAMMES

1. North America

Participation by Adult Education Associations appears to be insignificant in the health care field in North America. Review of the literature failed to reveal any unique efforts for the disabled by adult educators, in spite of the large numbers of disabled. In one adult education publication, it mentions that there are mental and

physical obstacles to reaching adult education activities, such barriers as fatigue, weather, place to park the car, inertia, family responsibilities and social demands. A physical disability may encompass these and more and yet there is no mention of the barrier of disability or of any aid offered the disabled. It could be that adult education has turned to practical rather than idealistic purposes, that it is now a utilitarian training more than an education. 15

Or it could be that adult educators are not aware of the lack of educational opportunities for the disabled or the large numbers involved. In our society we tend to hide disabilities and often the needs of chronic patients only come to the attention of agencies such as those that are affliction-linked; therefore results are piecemeal. 16

Some disabilities are well recorded. For example, the Canadian National Institute for the Blind, keep their records updated when a report is received from an opthamologist and computerize them each year. There were 3,573 registered in the B.C. region as of January, 1974. The Canadian Paraplegic Association, B.C. Division, also maintains an accurate record and has a membership of 1,241. 18

Although the Arthritis and Rheumatism Society has files on all who are treated, because many cases are not treated or diagnosed and some that are do not wish to be registered, only an estimate of cases is possible. In B.C., this is one in twenty: In the U.S.A. one in twelve. This would make approximately 100,000 cases in British Columbia.

If the need has not been recognized, it is understandable that, at adult education centres, little concern is shown for the disabled. There are many facilities which have physical barriers and services are limited. Special transportation is expensive and not obtainable in many areas. Counselling is not available. Most adult educators are not knowledgeable of the medical aspect of disability and would find it difficult to meet the requirements of the disabled.

Away from adult education centres, adult educators do not contact the disabled as they are hard to locate outside offeinstitutions. Therefore, it appears that few educational opportunities are available for the disabled and that little encouragement is given to them if no vocational rehabilitation is possible.

However, two examples of aid to the disabled are outlined, these are both in Vancouver, B.C. One is at a chronic hospital, the other at a rehabilitation centre. In both cases, the goal is rehabilitation in its broad context, vocational rehabilitation, although it may be possible, is not the criterion for entering into any programme.

At the Pearson Hospital, there is a tutor supplied and a small special library containing text books and an encyclopaedia.

Correspondence courses are taken and an amateur radio operation was set up by some interested citizens from Canadian Pacific Air along with courses given to the patients to operate it. The radio room is lined with badges from different operators with whom they have been in contact.

Some other courses are taken outside of the hospital. For example, one patient has completed a year at Vancouver City College and plans to continue, another is taking a Certified General Accountant's course. 20

At the G.F. Strong Rehabilitation Centre, the emphasis is on the physical and the average stay for patients is indefinite--from a few weeks to over a year. When rehabilitation services are complete, the patient is moved to an appropriate residence. During their stay at the centre, they can be taught the use of many aids, such as holding devices for preparing vegetables with the use of only one arm, a head stick for typing without the use of arms and the "possum" (patient operated selector mechanism). This latter aid appears most useful as it makes it possible for the patient to operate many devices, typewriter, television, light switches, etc., but the therapist explained its disadvantages. The mechanism is not easily obtainable, there is no maintenance service in Vancouver, it is expensive and it is difficult for many people to cope with the sophistication of the "possum". The patient must also be able to manipulate his mouth to operate the device by suction and this is difficult for some patients with neurological disorders. An alternative is the "pilot") patient initiated light operated telecontrol device), which operates with a minimum amount of head movement. For educational purposes, a stick fastened to a head band can be used for persons without the proper use of arms. This has the advantages of simplicity, availability and economy to the patient but it is slow and can be used only for typing. 21,22 For those that can, they may also use a stick in their mouths for typing.

England

Adult education authorities appear fairly active in England

in the health care field. They supply facilities for pre-vocational work, advice, supervised study or practical work and tuition is available for them. If the patient is to benefit from such help, he must be identified early and the occupational therapist will not necessarily be involved. In a hospital without complete facilities the occupational therapist and social worker take the initiative and arrange for tuition through the Adult Education Authority or through the Preparatory Training Bureau of the British Council for the Rehabilitation of the Disabled. 23

A noteworthy effort is made at the spinal-cord injury centre at the Stoke-Mandeville Hospital in Aylesbury. The founder of the centre, Dr. Ludwig Guttman, was a leading neurologist and neurosurgeon in Breslau before leaving Nazi Germany in 1939. In 1944, the British Government asked him to set up the unit to rehabilitate spinal-cord war casualities of the British Forces. This has since become the largest and most famous spinal cord injury centre in the British Commonwealth and Europe. It was the first place to treat this type of injury which has been one of the most depressing and most neglected in medicine and social science. One report states that in the United States, it is still neglected and because of attitudes of some members of the medical profession and the general public, the country is the most backward and negligent of the major civilized countries in caring for civilians with spinal cord injuries. At Stoke-Mandeville, the complete person is treated, therefore, trained personnel on the rehabilitation team include,

specially trained nurses, physiotherapists, and orderlies, social workers and teachers. Radical changes and a psychological approach to the problem of paraplegia were introduced as Guttman says "...to rescue these men and women from the human scrap heap." Education plays a large part. Employment statistics show that, of 2,012 patients, 85.4 percent were employed. 27

3. Sweden

In Sweden, adult educators are very active with all ages of disabled. Some of the activities are outlined and our efforts in North America, by comparison, would appear to be far below adequate.

Hobby activities include courses in weaving, sewing, bookbinding, pottery, painting china, painting and modelling in clay. Other activities include language courses, and courses in literature, sociology, genealogy, administration and numerous other subjects. The pensioners also have groups for drama, singing and music.

Incapacitated pensioners and younger handicapped persons can use a special transport service to get to the library, or to go on private visits, theatre, etc. They also have a mobile library in 28

All ages of adult disabled are served by study circles organized by adult education associations, by an increasing number of "folk high schools" (boarding schools for adult education), by various

municipal schools and by courses for adult education. There is a library for the blind and books in Braille or "talking books" and books in large type or in simplified language are provided as well as interpreters for the deaf and special consultants working with adult education associations and organizations of the handicapped. 29

C. SUMMARY

In North America, some post secondary institutions are being modified to overcome physical barriers. Also, other services make it possible for many disabled to attend, regardless of vocational goals. However, more is being done in other countries, for example, Sweden.

The disabled must be given a motive for living not related, necessarily, to financial gain, ³⁰ and now more are seen to follow intellectual pursuits in order to compensate for physical losses. ³¹ Some educational endeavours may not be curtailed by the boundaries of physical disability and the creativity they employ may allow an outlet by which a person may escape temporarily from his disability. Also, an individual may engage in education and often gain the gratification of successfully competing with those who are not disabled.

In this field there would be numerous opportunities in adult education because there is something available for all interests. ³²

As these may be the only sources from which the disabled can draw to enlarge his environment, the importance of adult education cannot be

overemphasized for this group. Encouragement and facilities must be made available for adult education. This is being recognized and some steps taken in North America but there is still much to be done. It appears adult educators are not yet fully aware of the contribution they could be making on behalf of the disabled.

FOOTNOTES

CHAPTER IV

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CHAPTER V

CHRONIC CARE PHILOSOPHY

IN PRACTICE

Studies at St. Mary's Priory Extended Care Hospital

This thesis has discussed the problem that the psychosocial needs of the chronically disabled are often not met, but at St. Mary's Priory Extended Care Hospital, Victoria, B.C., apparently there is an awareness of these needs and sincere effort to satisfy them. At a seminar on extended care it was stated that this hospital and Mount St. Mary's in Victoria, B.C. were the pioneers in this province on extended care and have set an example of what could be accomplished. The standards for extended care were developed with the aid of several hospitals such as these. 1

From 1970, all literature about and from St. Mary's Priory Hospital was studied, four personal interviews were conducted and numerous correspondence was received from the Director of Hospital Services, culminating in a four month field study at the hospital.

A review was made of a brief study done in 1969 which used discussion groups in St. Mary's reactivation programme.

The current short study in 1973 was divided into four phases, the first, an overview of the hospital, second, familiarization of residents assigned, third, an educational process to be used in

rehabilitation and fourth, re-integration of the study group of residents with the population of the hospital.

A. FIRST STUDY IN 1969²

This short study was conducted to further the reactivation programme at this hospital. Sister Bertilla had taken a course on "Effective Leadership and Communications" and eight patients were chosen, ranging in age from sixty-four to ninety-four years, to partake in discussion groups of such topics as the news of the day, the Bible, or short stories. She was assisted by a student in order to maintain interest and give adequate coaching. Actual participation was encouraged and confidence and trust were instilled by showing interest, concern and respect. The Sister spent some time in inquiring about hobbies, interests and vocations.

During this period, some progress was noted in the patients and it would indicate this type of therapy would be of benefit in the reactivation programme.

B. SECOND STUDY IN 1973³

The second study was conducted between June 1, 1973 and September 30, 1973 and a total of five residents participated.

1. Use of Educational Process

The educational process was used as a means of replacing

a portion of lost activities and its effectiveness was observed in dealing with symptoms of withdrawal in the long-term disabled. In the case of one resident it was used simply as a diversion but with others it became a tool to stimulate awareness. Because most or all former associations, may be lost for the disabled, a partial or complete withdrawal from the world of reality may take place. Introspection enlarges to engulf many of the conscious efforts of the person and a comatose appearance may follow. It is theorized that education may be a wedge to combat withdrawal and replace some activities which are lost. It may enlarge horizons by forming new associations and new purposes or by reactivating former skills. (See Figure 5).

2. Use of a Model for Assessment

A model for research and evaluation on rehabilitation by Suchman was used, however, the preconditioning variable was not incorporated owing to the fact that it was not possible to obtain enough information prior to disability on this group of people. 4

(See Figure V6.)

FIGURE 6'I

Preconditioning Independent Intervening Dependent Variable Variable Variable Variable PRE-EXISTING DISABILITY REHABILITATION CONSEQUENCES CONDITIONS

3. Division of Study into Four phases.

Phase I Overview of the hospital, three weeks, June 1-22

- 1. General Philosophy of the Hospital
- 2. Residents and Staff
- 3. Methods of Caring for the Patients

Phase II Familiarization of residents assigned, seven weeks, June 25 - August 10

- l. Study of Medical History
- 2. Recreation Car Rides, Bowling, Planters, etc.
- 3. Reality Therapy
- 4. Mealtime in Separate Dining Room

Phase III Educational process to be added to those activities in Phase II, complying with abilities and interests of the resident, five weeks, August 13 - September 14.

- 1. Short Correspondence Course on B.C₄
- 2. Correspondence Course on Painting.
- 3. Practice on re-learning to print, read and count.

Phase IV Re-integration with population of the hospital, two weeks, September 17-30.

- 1. Recreation
- 2. Mealtime
- 3. Continuation of Correspondence Courses

D. Report on Hospital in Phase I.

General Overview of the Hospital

At the Priory Hospital an effort is made to have as "homey" an atmosphere as possible. Nursing personnel do not wear uniforms, visiting hours are not regulated, children and animals are allowed to visit and the residents are dressed in adaptable regular clothing and in the lounge or activity room as much as possible.

Mental stimulation is encouraged. All rooms have calendars and clocks and different colours are used on doors in order that the resident may identify her room. The day starts early, the resident is washed and dressed and given fruit juice. She then goes into the dining room for breakfast, followed by exercise and reality orientation

in a suitable group. In the summer there are such activities as bus rides, barbecues and bowling. At other times, those who are able make hobby items, decorations for Christmas and presents for crippled children. Community involvement is encouraged, for example, the Priory has a miniature rodeo, hot dogs and soft drinks are served and the members of the community are invited. The residents are also taken out to the highway to watch the local parade and were obviously delighted when the senior R.C.M.P. officer saluted them; thus they interact with the community.

In all these activities there is an effort to fulfill the three categories outlined in Chapter III, that of stimulating motivation, serving a purpose for activities, and making efforts at integration.

But, even with these efforts, there is some segretation. The hospital is eight miles from the city and set back from the highway.

Also, all residents are women, therefore it is not a "normal" population. Even husband and wife may be separated owing to the fact that sexes are separated or different levels of care are required. They are then placed in "appropriate" accommodation. For example, one ninety-two year old husband was at a boarding home across the road while his eight-eight year old wife was at the extended care hospital.

Residents could also be outside more often. At the present time, all outside areas are accessible only by ramp but as some residents cannot be left unattended outside, there were many fine days

when they were inside. If the large patio with umbrellas and tables were made level with the inside floor, residents could be outside and yet remain in full view from inside. This would make it easy to wheel them in to attend to personal needs and back out again.

Also, interaction between residents was not encouraged as much as it might have been. This is most important as staff and volunteers change and the residents form the stable population.

The residents were divided into two groups the first, apparently suffered little retrogression or withdrawal. They ate in a small dining room which allowed some contact during activities and mealtimes but each day they had a "happy hour" which was conducted by a volunteer or a member of the staff, reading from newspapers, conducting discussions, baking, etc. The residents were arranged in a semi-circle around the person conducting the session. Nothing was done to break up the group and have discussions among the peers so nearly all conversation was directed to her; the shyer ones never had much chance to participate.

The second group was mainly composed of residents who were suffering varying degrees of retrogression, withdrawal and confusion. There were two tables in their activity room on which eight were able to have meals. The others were placed around the periphery of the room with individual trays and therefore little chance for interaction, for the persons in their line of vision were too far away. Although it

would be less convenient to look after their needs, if the chairs were placed in small groups there would have been more conviviality and more chance for sociability even when conversation made little sense.

In summary, the positive aspects far outweighed the negative in these general observations of the first two weeks.

- 5. Report on Residents Assigned in Phases II, III & IV
 - a. General Means of Rehabilitation

The report is made on an individual bases. The means of rehabilitation which were common to all are listed.

- (i) The selected residents were seated in their own dining room for all meals, the group with its own table set with a table cloth and silver.
- (ii) They were taken on such outings as car rides, "walks", in the garden, barbecues, bowling, they set up planters with the gardener and visited at the home for the retired nearby.
- (iii) They attended general activities of the hospital which were of interest to them.
- (iv) Each day each member had a personalized orientation session. These could not be given as a group because of the disparity in levels of function and interest.
 - (v) They were often given sensory stimulation. Tactile was sometimes the only means of communication. Besides tactile, such as holding hands, putting an arm around their shoulders or giving them plants and soil to feel when arranging planters, visual and auditory means were used. It was found that speaking to them and sitting in front of them were more helpful than television or movies where they would often doze when not called upon to respond.

b. Individual Means of Rehabilitation

Phase II, III & IV (Figure 6)

Resident No. 1

History

Born in 1905.

Resident of the hospital since 1968.

Disability

Parkinson's Disease, well managed on the

medication of L-Dopa.

Able to walk but subject to faintness

and spasms of the eyes. Gets fits of depression.

Rehabilitation

Goal:

Restore self esteem, as, according to staff reports, this resident had two changes in her environment in the last few years. Her relations with her family had been strained and her position in the hospital had been changed. In prior years she had been prominent owing to her progress and capability but now was inconspicuous owing to the change in population.

Means:

Assist with the rest of the group assigned who were obviously not as capable.

Take correspondence course on British Columbia for which she would receive a

diploma.

Consequences:

Her self esteem was re-inforced in the group as she was capable of aiding the others, setting the table, helping them eat and joining them in activities, in all of which she was obviously superior.

She completed the correspondence course and received her diploma but, along with her other duties, it was difficult to assign any positive gains attributable to a definite variable, however, personal assessment would favour the first, her position as leader in the group.

Finally, she was able to re-integrate well at the end of the summer.

Resident No. 2

History

Born in 1883.

Resident of the hospital since April, 1973.

Disability

Arteriosclerosis.

Disoriented and extremely agitated much

of the time.

Rehabilitation

Goal:

To improve socialization with staff and

To control agitation and improve recollection

of relatives.

Means:

by he

Consequences:

Besides the general means of rehabilitation listed, she had many pictures of friends and relatives shown to her and discussed with her. A picture of her farm was placed by her bed.

Her socialization was improved as evidenced by the fact that many of her social graces returned. At first, at the dining table, she would take the food from others and use any utensils but at the end of two weeks, she was keeping her place tidy, folding her serviette and never touching others' food. She offered her desserts to others, enjoyed going for rides in the car and out in the garden and talked with others. Over a few weeks, in reality therapy sessions, she remembered her dead husband, asked ob about siblings and spoke of her children, but did not remember when the latter saw her. She recognized photographs of friends and relatives and a picture of her farm. She remembered her name and wished to be called by a "nickname". It is mentioned that progress in rehabilitation is made when the person assumes his identity by remembering his name. Although her mental improvement was noticeable under the personal therapy she still became extremely agitated and usually, by late afternoon, could not be consoled. At the end of July, she died from pneumonia.

Resident No. 3

History

Born in 1885. Resident of the hospital since 1971.

Disability

Unable to walk because of the effects of a stroke.

Spoke only gibberish.

Had days when she could not be aroused.

Rehabilitation Goal:

To improve socialization.

To be able to communicate intelligibly.

To be able to use utensils with which

to read and write.

To stimulate her in order that she

stayed awake each day.

To interact pleasingly with peers and

staff.

Means:

Besides the general means of rehabilitation listed, a re-educational process was used, that of reading, writing and counting.

Consequences:

In the second phase of the study, as a result of stimulation in the form of personal attention, car rides, "walks" in the garden and others, this resident became alert most of the time. She progressively improved in her speech. from the gibberish she spoke initially, to sensible and plain words, for example, by July 6, she called "nurse". The following week she spoke sensibly all the time I had her out with the group for a car ride but refused to say anything when she returned to the hospital. By July 20, she was speaking many intelligible sentences and expanding her environment by talking with other residents, their friends and relatives.

In the third phase, she continued to be alert and talkative although much was still gibberish. She was never unresponsive. She attended movies, choral groups and church services. She

commented when another member of the group appeared to be suffering and even noticed a change in hair style of another. She has been reading her name, printing, counting and even corrected me on the pronounciation of her name. In recognizing her name she evidenced the first step in her rehabilitation but in coming back to reality, the unpleasant as well as the pleasant, are recalled. At times she would remember her lifelong companion, a sister who was dead, and would cry and call her name.

In the fourth phase, she appears to be integrating well.

Resident No. 4

History

Born in 1901.

Resident of the hospital since 1968.

Disability

Stroke resulting in right sided hemiplegia and aphasia.

Heart condition.
Signs of withdrawal.

Rehabilitation Goals:

Interaction with staff, peers and others.

Hold head upright. Improve speech.

Attend group activities.

Means:

Besides the general means of rehabilitation listed, special attention was given in an attempt to gain confidence and encourage interaction, fFor example, she was spoken to often and ample time allowed for reply and repetition of reply if not understood. A halter was designed to fit over her head and used for three minutes three times a day to help her to hold her head in the correct position.

She was taken out around grounds and hospital where she would meet others rather than remain in the T.V. room by herself.

She was moved to more cheerful surroundings as all the patients in this ward were very ill.

A volunteer was approached to make regular visits to her.

A correspondence course was arranged with her permission.

Consequences:

In the second phase, since joining the group and being given lots of encouragement, she was trying to sit with her head up. She had initiated smiles and started a conversation with the nurse in which she told her all about a bus trip she had taken on the prior day. She also spoke of her husband, stating that he was dead. She had refused to admit this in a prior conversation.

In the third phase, she completed the course on British Columbia. It appeared particularly useful to this lady, not because of the course content, but for the fact it drew others into conversation while we went over the lessons in the activity room, in the ward or outside in the garden. Fellow residents, nurses and visitors inquired what we were doing. Interesting conversations followed and often the lesson was forgotten.

In the fourth phase, she appears to be integrating well. She has shown some improvement, often smiling and speaking with me. However, it is noticed that she does not interact with peers and she very rarely initiates conversation with nurses.

Resident No. 5

History:

Born in 1885. Resident of the hospital since July 26, 1973.

Disability:

Post fractured femur. Partially deaf.

Rehabilitation

Goals:

As she does nothing, encourage her to use

her latent abilities, painting and

playing the piano.

Means:

Have her play the piano in the activity room for short sessions a few times a

day.

Have her take a correspondence course on painting for pleasure, joined by another who also used to water colour as a hobby.

Consequences:

She was not with the group long, having come to the hospital at the end of July. She appeared to have pleasure with her piano playing and to enjoy her painting for shorter periods of time. Of the two,

the piano playing appeared the more

beneficial.

6. Follow-up Report on Residents Assigned.

A Report on Residents in the Study was obtained on 14 December 1973. 9

Resident No. 5 had broken her hip again in October, 1973 and had been removed to another hospital. However, Vera McIver reported that the others appeared to have maintained much of the improvement evidenced during the study.

7. Conclusion of the Second Study

There are some difficulties in arriving at a scientific assessment for any study of this type.

Firstly, it is difficult to measure behavior in times of illness, 10 therefore the study has been theoretical and descriptive, but

not analytical. Conclusions were obtained from the writer's observations re-inforced by members of the hospital staff.

Secondly, initially there was not sufficient time or opportunity to study the residents assigned before new rehabilitation measures were undertaken.

Thirdly, it was not possible to determine the pre-morbid condition of the residents as there is little record prior to disability; therefore the preconditioning variable was omitted from Suchman's model for assessment.

Fourthly, it was not feasible to isolate any positive gain and attribute it to any specific activity, such as education, as many other intervening variables were also involved such as the intense personal interest shown to these residents who were part of the study.

In conclusion, the residents appeared to benefit from the special care they received and not to form any dependency which would have to be terminated at the end of the study. Although they had to be treated with some concessions owing to their state of health, this was accomplished by respecting them and relating to them as mature people.

The discrepancies in this type of study are apparent, for example, the small sample chosen for the study and the short time engaged in the study but the positive results obtained would indicate the value of more lengthy and intensive investigation.

An observation was made of others, in the area of psychology, who attempted a study here without the necessary medical background.

As stated by Dr. Szasz, 11 educators are not utilized in the Division of Interprofessional Education at University of British Columbia because they usually lack the medical background. This could also apply to psychologists and sociologists, for in any medical field it is necessary to have some understanding of the medical aspects in order to function in a positive manner. Observations here reinforced his statement, for example, one student misinterpreted the handling of his cases as being progressive instead of evidencing dependency and depression. As a result there was retrogression in the patients under his care.

III. Summary

Knowing that many studies have shown that higher morbidity and mortality rates occur when the elderly enter institutions 12, efforts are made here to soften the trauma of dislocation. However, no studies were located comparing the length of stay of the elderly in various types of institutions, reasons for termination and indications of the kind of care which appears to result in happier and longer lives.

The summer of 1973 study was directed at the reactivation programme of the Priory and the value of psychosocial care for long term cases was exemplified by these people. Education was one variable used as there is a need for diversional activities in the field of geriatrics 13 and education and re-education can be among them. Government programmes

in the States are said to have been designed to meet vocational needs and there is need to improve and maintain the physical condition of elderly stroke patients. However, some deficiencies in extended hospital care were noted.

For instance, each hospital should have all levels of care and both sexes, more closely approximating the outside community. If at all possible, husbands and wives should not be separated. Couples who have lived together many years find themselves alone when often they need each other the most. An elderly couple visiting at the hospital said they feared some illness that would separate them. Death is inevitable but premature separation, in the name of efficiency or economy, can be detrimental.

Also, hospitals should be placed where the activities of the community may be observed by the residents, day by day, not as an excursion treat.

Within this hospital, there should also be an area reserved for residents to be alone if they wished seclusion for a short time. Now they are always with others, there is no place to display emotions or for peaceful solitude, even their rooms are shared with others. There used to be a chapel for refuge, but even this space has been utilized for dining and activity area.

As far as the staff is concerned, there was a tendency and evidence that stereotyping takes place, with resultant expectancies that a definite response was to be expected from certain types of illness. For example, one woman was in tears and both the nurse and activities co-ordinator stated that the reason was she was a stroke case. When spoken to, her depression at this time was due to the fact her husband, who was in a boarding home, had been taken to hospital. Therefore, there should be greater understanding that many reactions are "normal" in any stressful situation, depression may be caused by the results of disability, for example, by the fact of separation from loved ones, worry over them and frustration at physical disability and not necessarily attributed to the cause of disability.

Also, the staff should treat the disabled like the "normal" population. They should accept some of the responsibility for their actions and not be overindulged but does this also mean that they are not to receive little personal attentions which would be given outside an institution, take little time and make the attendant a friend rather than a custodian? For example, when a resident in the main dining room had a spasm in her eyes which made it impossible for her to eat, a wet clot was given to her to place over her eyes, then she was left alone. It was not long before she removed it, put on her glasses and finished her dinner. The nurses believed she was being spoiled, yet she was only given a little consideration and recognition that she had a difficulty and that someone cared.

Nurses should also take care not to initiate a situation that cannot be maintained. As has been explained in the case histories, Resident No. 1, had been the object of special attention until the arrival of more residents with equal capabilities dispersed this attention among others and had a deleterious effect on her.

A sociologist aware of medical problems might be useful in clarifying these issues and aiding nurses to attain a more sensitive approach and still to avoid indulgence.

In regard to the care of residents, Vera McIver 15 believes that nurses should use judgment and accept responsibility, at times, whether justified or not, for any negative behaviour of residents. By her example, she does much to preserve the dignity of the residents and maintain equilibrium among this very fragile population. She has nurses aides at this hospital trained in their philosophy and, despite the few deficiencies noted, they display an understanding of many of the problems of the chronically ill. This is most important as the problems of the elderly are often social and psychological rather than medical and technical 16 as has been demonstrated in this thesis for all longterm disabled, regardless of age.

FOOTNOTES

CHAPTER V

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CHAPTER VI

CONCLUSIONS AND RECOMMENDATIONS

A. CONCLUSIONS

As the disabled increase in numbers, it follows that their needs increase and often psychosocial needs predominate over physical. It is necessary to further differentiate the psychosocial into psychological and sociological as it is theorized that there is more immediate necessity for the social needs to be met; therefore, the emphasis on social scientists in the chronic care field is for sociologists and adult educators. Further, they should be a part of the rehabilitation team and should have courses available in order to increase their competence in this area.

Within the rehabilitation team, they could function to stimulate motivation, furnish goals and aid in the socialization of the disabled. In order to do this they would have to contact the disabled. Yet, there is no comprehensive registry of the disabled. As a result, the president of the Canadian Medical Association states that Provincial governments do not know the number of paralyzed patients or the extent of the problem. Before establishing such a registry an educational campaign would have to be directed to the population as a whole, for still today there appears to be an out-dated attitude associating disability with stigma.

The value of education for the disabled, whether for monetary gain or personal enrichment, is an important adjunct in rehabilitation. It may supply socializing influences outside the scope of the content of the activity itself, for example, the study at St. Mary's Priory Hospital illustrated how education encouraged interaction in a patient who was showing signs of withdrawal. In this regard educators must look at the overall benefit of a learning endeavour and realize that any positive by-product may be of more value than the learning experience itself and they must not overemphasize the material presented. With many adult educators, course content rather than social involvement is important yet it is often only the latter that will enhance the rehabilitative value of education for the disabled. It is experience gained in field studies that will help to clarify this issue.

Educators should also be persistent in having buildings modified and services supplied to further the integration of the disabled. For example, there has been no concerted effort here as there has been in Swedenden. In North America, some universities have been modified and a few adult education centres but little comprehensive effort has been made to communicate with the disabled and supply education if desired.

In summary, the study has indicated the significance of psychosocial needs as the numbers of chronically disabled increase in this century and, as these needs appear primarily social, their satisfaction may be partially fulfilled by adult educators. The

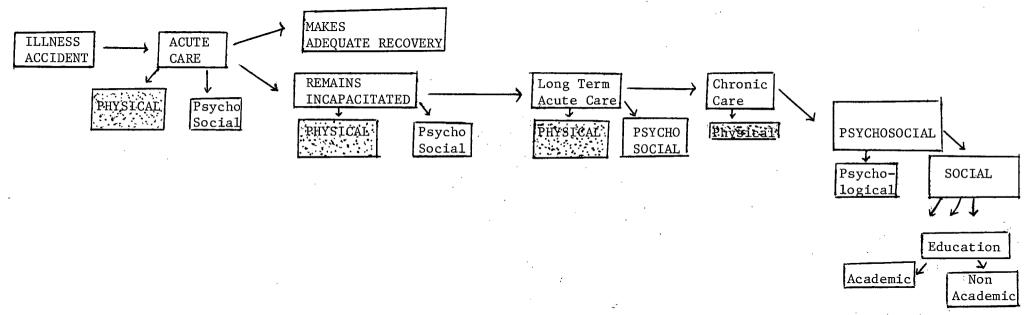
progression of these needs and the position of educators are illustrated (See Figure 7). It may be noted that, prior to the twentieth century, most care was not required past the acute care stage and, to date, it is noted that psychosocial needs of the chronically disabled appear to be greater than acknowledged by the medical profession and the medical method, therefore does not hold this view. 3

Currently, the role of the adult educator should be firstly, to establish the desire for education among the disabled, secondly, to obtain the training necessary to understand the medical aspects and thirdly, to supply the service.

FIGURE 7

PROGRESSION OF NEEDS IN THE LONG-TERM DISABLED

THE POSITION OF EDUCATORS IN THE PLAN



B. RECOMMENDATIONS

1. PROVINCIAL GOVERNMENT

That all disabled be registered by the Provincial Government and information on the disabled tabulated and made available to organizations in the health care field. Information such as medical, educational, social and financial would be included.

2. CANADIAN ADULT EDUCATION ASSOCIATION

That the association familiarize adult educators with the lack of educational opportunities for the disabled adult and suggest that they research the problems of the disabled for the purpose of furnishing educational activities to this segment of our population.

3. ADULT EDUCATION DEPARTMENTS

- a) That physical barriers be removed to enable attendance of disabled at adult education facilities.
- b) That correspondence courses be made available at home, nursing homes, hospitals, etc. and a personal contact such as an adult educator or volunteer be supplied.
- c) That volunteers, such as retired school teachers be organized for academic pursuits and lay people for hobbies and special activities. A registry of such volunteers should be set up, stating background, interest, location, transportation, times

available, number of persons they would be able to assist and number of hours they would be volunteering per week.

Also any preference in the type of person they would be assisting.

d) That counselling be given in regard to education.

4. UNIVERSITY OF BRITISH COLUMBIA

a) That the Centre for Continuing Education organize a course on campus, by correspondence or at education centres for adult educators and volunteers engaged in the education of disabled adults. This course could also be of use to sociologists and psychologists who are contemplating or are involved in the medical field. For example, courses in medical sociology are not available at U.B.C. The courses would be an overview of the needs of the disabled and obstacles encountered by them as well as aids and services available. It would be designed to interest the largest number of people in this area, not to be an in depth study and the material would be presented by adult educators, sociologists, psychiatrists, physicians in general practice, occupational therapists and counsellors.

This course would be feasible if the need were established. 5

b) That adult educators contemplating work with the disabled should engage in field studies at the University of British Columbia.

c) That the Adult Education Research Centre at the University of British Columbia should further research the role that adult educators may play in the education of the disabled.

The above recommendations would make it possible for adult educators to engage, within their expertise, in the rehabilitation of the disabled, both from the organizational and educational standpoint.

FOOTNOTES

CHAPTER VI

- ¹John Braddock, "C.M.A. head lambastes gov's, hospitals", Vancouver <u>Province</u>, 19 May 1973, p. 55.
- ²Ernest E. McMahon, Robert H. Coates and Alan B. Knox, "Common Concerns: The Position of the Adult Education Association of the U.S.A.", Adult Education Journal, Vol. 18 (November 3, 1968): 200.
- ³Interview with Peter Bunton, M.B., B.S., F.R.C.P., Social Psychiatrist, University of British Columbia, 22 May 1974.
- ⁴Pat Merchak, Assistant Professor, Department of Sociology, U.B.C., telephone communication, 30 April 1974.
- ⁵Interview with Miss M. Smith, Centre for Continuing Education, University of British Columbia, 15 February 1974.

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