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Glasgow Theses Service http://theses.gla.ac.uk/ theses@gla.ac.uk The Young Chronic Sick at Home

and in Hospital.

Volume I.

## William Jardine MacLennan



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#### Introduction

Over the previous five years an increasing amount of attention has been given to the problems of young people suffering from chronic disease and disability. <sup>'</sup>A major landmark was the Chronically Sick and Disabled Persons Act of 1970. This contains long overdue legislation aimed at improving the lot of disabled people living at home or receiving care in hospital.

Prior to 1970 there had been much discussion, but little detailed information on the plight of the young chronic sick. Most of this was to be found in the results of three surveys conducted by Rankine and Weir (1967), Townsend (1967) and Skinner (1969).

These provided a considerable amount of data on disabled people. Included were their age and sex distributions, their marital statuses, the severity of their disability, the effectiveness of medical care, the services required and received from local authorities and voluntary organisations, the effect of disability on employment prospects, and the amount of support available from friends, relatives and neighbours. Points on which there was considerable disagreement were the main causes of disability, and the adequacy or otherwise of housing for the disabled. The problems which such people faced in travelling, following their hobbies and interests or the effect which their illness had upon relatives, received little attention.

It was decided to organise a further investigation which

would give attention to these features of disability about which there was doubt or limited information. This was tackled by selecting a group of disabled people living at home in the West of Scotland from which subjects with predominant deafness, blindness or mental defect had been excluded. The investigation included a detailed medical, social and psychiatric interview and physical examination of each patient. Most of the fieldwork was carried out between June 1970 and March 1971.

Shortly after the completion of this local investigation the results of a national survey were published (Harris, 1971). This provided a comprehensive review for most of the major problems associated with disability throughout the United Kingdom. In some respects, therefore, the present study may have merely duplicated results obtained in a much larger national investigation.

There are, however, differences in emphasis between the two surveys. Most important is the fact that the local one concentrates on adults between the ages of 16 and 59. The other covers adults of all ages. More detailed attention is given to the medical and psychological aspects of disability in the former survey. Also, this investigation alone highlights the problems facing the relatives of disabled people. A final point is that there was no collaberation in the methods of selection and investigation used in the two surveys. Their results, therefore, complement rather than duplicate each other. Prior to 1970, the only information available on the young chronic sick in hospital was contained in two reports. These contained the findings of investigations instituted respectively by the Home and Health Department in Scotland (1967) and the National Health Service (1968) in England and Wales. These only dealt with the age and sex distributions of disabled people in hospital, with the causes of their disability and with the types of unit accommodating them.

Many other important questions remained unanswered. Thus, there was no firm evidence to support the widespread view that geriatric units were unsuited to the needs of young disabled people. There was doubt as to whether or not people with organic brain disease, who were in psychiatric hospitals, were in an appropriate environment. Also, little attention had been given to the optimal size, siting, design, staffing or objectives of units specifically allocated for the care of young disabled people.

Even less was known about the residents of such institutions. Points deserving further study included the extent to which such people were disabled, the types of disability most commonly affecting them, the extent to which mental impairment affected their management, and the forms of recreational and rehabilitative therapy which were most appropriate to their needs.

It was decided to investigate these issues by performing a survey of units housing young chronic sick patients. The

range of the study was limited to hospitals within a twenty mile radius of Glasgow. Information was collected by visiting selected units and recording information from observation and from discussion with members of their staff. Attention was then directed to the patients in the units. These were given interviews and examinations similar to those used in the population living at home.

There is general agreement that long term hospital care is undesirable (Guthrie, 1968). An initial step in the prevention of this would be the identification of the causes. A review of the literature revealed little more than speculation on these.

Comparison of the two surveys already described offered a means of identifying such causes. Differences between the two populations were identified and investigated further. These included the ages, the types of disorder, the suitability and appropriateness of housing, the availability and support from relatives, and the degrees of physical and mental impairment and disability in the two groups.

#### Review

# A. <u>Definition</u>, Assessment and Identification of Chronic Sickness Definitions

Most investigations of chronic sickness make use of the terms impairment, disability and handicap. There is no general agreement about the meanings of these words. This can lead to considerable confusion when a comparison is made between the

studies of different centres.

There are a variety of opinions about the definition of impairment. The Committee on Medical Rating of Physical Impairment (1963) in the United States considered that impairment represented the effect illness had on the ability of a patient to perform normal activities. Included amongst these were self care, communication, walking and travelling.

The capacity of an individual to perform these tasks is dependent upon a wide variety of medical, psychological and social factors. Bennett, Garrad and Halil (1970) take a much more restricted view of impairment defining it as an underlying anatomical, pathological or psychological condition which may cause or be associated with inability to perform self care activities.

Different interpretations may also be given to the term, disability. It may be used synonymously with impairment. More usually it denotes limitation in the capacity of an individual to perform such everyday activities as self care, housework or the pursuit of an occupation. Attitudes of patients to their impairment and the effect which impairment has on their roles and positions in society may also be included in the definition, (Townsend, 1967).

The meanings of disability vary with the organisations and specialists using the term. Physicians involved in geriatrics or physical medicine usually relate disability to difficulty in walking and performing self care activities. (Katz, Ford, Moskowitz, Jackson and Jaffe, 1963; Wylie, 1967). These experts are primarily concerned with returning patients to an independent existence outside hospital.

The Department of Employment, on the other hand, considers disability in terms of the effect illness has upon a person's capacity to find and retain his normal employment (Disabled Persons (Employment) Act, 1944). Disability is also related to employment prospects in the definition of the American Committee on Medical Rating of Physical Impairment (1963).

The distinction between disability and handicap is vague. Harris (1971) argued that disability should be limited to "a loss or reduction of functional ability" and that handicap should describe "the disadvantage or restriction of activity caused by disability". In her survey, however, she found considerable difficulty in delineating the borderline between a reduction of functional ability and a restriction of activity. It is probably simpler to follow common usage and accept that the terms handicap and disability are interchangeable.

There is little agreement about the type of patients who should be described as being chronically sick. Rankine and Weir (1967) consider that the term should be used to embrace all people who are unable to take part in the normal activities of daily living. A much more precise definition was given by a working party set up by the Scottish Home and Health Department

(MacDonald, 1964). Here the chronic sick were described as being people "who required long periods of supervision, care, training or rehabilitation because of requirements to or deviation from normal health which are permanent or which leave residual disability". In a National Health Service survey (1968) the chronic sick were merely considered to be people who required long term hospital care.

The practical point to emerge from this review of definitions is that all are rather vague, and open to a wide range of interpretations. A study of chronic sickness will only yield useful information if the terms are explained clearly and accurately. There is little point, for example, in describing the prevalence of disability in a population without first defining disability.

For the purposes of this present study, impairment will be considered to be an underlying medical or mental condition affecting the ability of an individual to look after himself, to do housework or to engage in employment. Disability will be used to describe difficulty in performing such self care activities as walking, dressing, washing, feeding and toileting. Handicap is taken to be synonymous with disability. The definition of chronic sickness is detailed elsewhere in a description of the methods used in the present survey.

#### Assessment of Impairment and Disability

The investigation of chronic sickness in a population can

be simplified if methods are used to quantify impairment and disability. One of the crudest of these is the calculation of impairment by awarding points for partial or complete loss of vision, or the partial or complete amputation of a limb. (British Limbless Ex-Service Men's Association, 1970). This is mainly used in assessing claims for War Pensions. It has limited application in that it does not take account of cardiorespiratory disease, or dysfunction in a whole limb.

The United States Committee on Medical Rating of Physical Impairment (1958 i and ii; 1960; 1961 and 1963) has worked out an extremely detailed scheme for measuring impairment. It describes methods for quantifying and equating with each other defects in different body systems. These include the extremities and back, the eyes, the heart and lungs, the ears, and the central nervous system. The assessment, however, includes the ability of a subject to perform self care activities. Since these are partly effected by motivation and social factors, they are more appropriately considered as relating to disability rather than impairment. Despite its complexity, then, this method does not provide an accurate measure of impairment.

One of the few methods which successfully distinguishes between impairment and disability was devised by Jefferys, Millard, Hyman and Warren (1969). They do this by measuring and timing movements in the upper and lower limbs. These include hand grasp and release; wrist, elbow and forearm movements; pinch and finger dexterity; manipulation with both

hands; arm reach movements; standing; walking; stepping up and down; and bending and sitting. Experience has shown that the tests are so simple that they can be organised by a lay interviewer in a subject's own home. There also appears to be a high degree of inter and intra observer comparability in the final results.

These tests, however, were devised to investigate impairment which was likely to effect disability in self care activities. They do not measure sustained activity, and are thus of limited value in relating impairment to housework or employment. This is obvious if consideration is given to the patient suffering from ischaemic heart disease. Such a person may be able to dress and wash himself but angina may prevent him from travelling to work or engaging in strenuous physical activity once he gets there.

Various techniques for measuring the effect of illness on sustained activity have been developed. The simplest of these relies upon a grading system which is used to measure such symptoms as breathlessness, angina or intermittent claudication (Medical Research Council, 1960). More objective assessments are dependent upon such tests as the response of an electrocardiographic tracing to exercise (Simonson, 1963).

In an assessment of overall impairment it is necessary to combine the measurement of single movements with that of sustained exercises. The system described by the United States Committee on Medical Rating of Physical Impairment (1958 i and ii,

1960, 1961 and 1963) fulfils this condition. As has already been discussed, however, certain aspects of this assessment relate to disability rather than impairment.

The method used to measure disability depends upon the reason for the assessment. Investigation of basic self care activities is all that is necessary to decide whether a patient is managed best at home, in welfare accommodation or in hospital (Staff of Benjamin Rose Hospital, 1959). Where the capacity of an individual to engage in employment is under debate, a wider range of activities must be included when measuring disability (Sokolow, Silsen, Taylor, Anderson and Rusk, 1962).

Ability to cope with self care activities can either be quantified or can be studied as a profile covering different aspects of disability. An example of the first method is Barthel's index (Wylie, 1967). Points are awarded for the capacity of a subject to walk and to wash, dress, feed and toilet himself (Table 1). It has been argued that quantification of disability gives a meaningless result. Many of the basic self care activities are dependent upon the same basic movements. It may thus be irrational to add these activities together (Kelman and Willner, 1962). It is also impossible to determine the contributions which individual items have made to the final Clinical practice has, however, shown that this test score. is remarkably accurate in predicting the response of a patient to rehabilitation (Carroll, 1968). It also simplifies the investigation of disability in a large group of subjects.

The alternative is to score different aspects of disability separately. Moskowitz and McCann (1957) detail such a system. It avoids the use of an arbitrary score and describes the range of disabilities affecting the subject (Table 2). The complexity of the final result limits the usefulness of this method in epidemiological work. It has much greater value in the assessment of an individual patient.

The definition of disability can be extended to cover a much wider range of activities including mobility, domestic duties and occupation. In assessing disability Sokolow, Silsen, Taylor, Anderson and Rusk (1962) take account of factors involving the special senses, neuromuscular activity, cardio-pulmonary function, psychiatric abnormalities, the home situation, occupational capacity and ability to manage self care. These are all scored and summated to give a total picture of disability.

The main problem about this type of exercise is the difficulty involved in devising realistic and comparable scores for such a diversity of complex and unrelated factors. Evidence of these difficulties became apparent when the technique was tested by vocational counsellors in America. They found that it had little value in helping them to find the correct employment for disabled people (Sokolow and Taylor, 1967).

In considering the broader implication of disability it is probably better to concentrate on constructing profiles of the different factors in each subject. This method has been used with reasonable success by Garrad and Bennett (1971). They gave separate scores for difficulties related to mobility, self care. domestic duties and employment.

#### Assessment of Mental Function

Adult intelligence can only be accurately measured by a trained psychologist using a battery of tests (Wechsler, 1958). The most obvious limitation of this is that a trained psychologist is not always available. Another equally important but less soluble problem is that prolonged testing requires a considerable amount of co-operation, interest and endurance on the part of the subject. People with chronic ill health or severe mental impairment rarely possess these prerequisites to successful testing.

Various less accurate but less complex and less taxing tests have been devised to obviate this problem (Isaacs and Walkey, 1964; Blessed, Thomlinson and Roth, 1968; Robinson, 1970). Their value has been firmly established in the assessment of the elderly chronic sick. It is reasonable to suppose that they might be equally effective in studying the young chronic sick who often exhibit the same type of mental and physical impairment.

Various tests have been used to quantify personality traits (Vernon, 1964; Cattell, 1965; Eysenck, 1960). Attempts have been made to measure the extent to which these determine the motivation of the disabled person towards rehabilitation, (Barry, 1968). This type of work also requires the services of highly trained personnel, and considerable tolerance and co-operation on the part of subjects.

#### Identification of the Chronic Sick

Before disabled people can be studied they must first be identified. It is comparatively easy to identify old people because their names appear in general practitioner age-sex registers, or in Department of Health & Social Security records. Executive Council lists and voters' rolls are other useful sources of information (Gilmore and Caird, 1972). The value of these records is largely the result of legislation because it was necessary to identify all old people to pay them pensions. The extra payments awarded to general practitioners for pensioners made it essential that Executive Councils should list these people.

Until recently, no such legislation applied to disabled people. There is provision in the Chronically Sick and Disabled Persons Act (1970) to correct this deficiency. Local authorities now have the statutory obligation of identifying and registering all disabled people within their boundaries. This directive will benefit a large number of people if it is implemented. Local authorites, however, are faced with an extremely difficult task. It is only by studying methods of identification used in previous surveys of disability that they will find a solution to their problem.

Disabled people can be identified from a variety of sources, One of these was the register of handicapped people kept by local authorities before the 1970 Act. Such a register, however, usually only contained the names of people who had availed themselves of local authority services. It also was optional so that it was only available in certain areas (Townsend, 1967).

The Department of Employment and the Department of Health and Social Security also have records of disabled people seeking their help. These authorities, however, are legally unable to release the names of clients to outside sources. Even if this obstacle were overcome the information would be of limited value. The groups of disabled people identified would be highly selected and unrepresentative.

Rankine and Weir (1967) bought information by asking general practitioners to review their lists, and pick out all disabled people contained in these. This method is not very accurate. Unless his records are extremely detailed, the doctor may have to rely on memory in choosing suitable subjects. Some disabled people may not even come to the attention of their doctor because they do not seek his services. General practitioner lists are thus likely to be biased towards patients with mere severe illness, or people requiring regular medical certificates.

Postal surveys have been used in several studies of chronic sickness (Skinner, 1969; Harris, 1971). In the area under scrutiny a group of householders is selected at random. Each is sent a letter asking him to provide details on any disabled person living under his roof. People identified in this way can then be visited and interviewed to amplify and validate information about their disability.

Not all people reply to a postal questionnaire. Harris, 1971 reports a 85.6% response rate in a national survey. Only 45.5% of people replied in a local study at Tower Hamlets (Skinner, 1967). It is obviously difficult to determine whether the households replying are typical of the whole group. Harris (1971) considers that if there were differences in the responses of households with and without disabled people, this would be reflected in a delayed response from the latter group. There was no evidence of this in her survey, thus suggesting that the non responders were not significantly different from the responders.

The most effective method of identifying disabled people is the door to door survey. It usually yields a much higher response rate than the postal survey. Bennett, Garrad and Halil (1970) report on one of 99% and Banks, Carpenter, Hislop and Nisbet (1957) on one of 100%. The problem about this method is that it requires a large number of field workers. This is practicable in a sample survey, but could be very expensive if a whole local authority area were to be covered. A possible solution might be the use of voluntary workers directed by a Department of Social Services (Hunt, 1972).

#### B. The Young Chronic Sick at Home.

#### Prevalence

Comparison of different studies on the young chronic sick is bedevilled by the problems of defining youth and disability. This might account for the fact that though Townsend (1967) estimated that 6% of the population in Great Britain were disabled, Rankine and Weir (1967) only identified 0.26% of the population in Fife as being young chronic sick.

The survey reported by Harris (1971) provides convincing evidence of the importance of age and degree of disability on any estimation of disability. It was calculated here that 8% of people in Great Britain suffered from some degree of impairment. Only 2.6% were between the ages of 16 and 65; most of the remaining 5.4% were over 65.

#### Age and Sex

Despite variations in the definition and selection of disabled people, there is general agreement that the prevalence of disability increases with age. In their pilot study, Rankine and Weir (1967) found that chronic sickness in people between the ages of 30 and 49 was twice as common as that in those between 16 and 29. It was twice as common again in those between 45 and 59. These figures are comparable with those in the national survey described by Harris (1971). This estimated the numbers of handicapped people in Great Britain as being 89,000 between 16 and 29 years; 366,000 between 30 and 49; and 833,000 between 50 and 64.

These two studies and that of Bennett, Garrad and Halil (1970) are also in agreement that the prevalence of disability for men and women between the ages of 16 and 59 or 64 is almost identical.

#### Causes of Disability

There is much more controversy over which of various pathological conditions are the most common causes of disability. One can compare the survey of Rankine and Weir (1967) with those of Skinner (1969) and Banks, Carpenter, Hislop and Nisbet (1957). While neurological disease was found in over half the subjects in the first study it occurred in less than a quarter of those in the latter two. It is also interesting that respiratory disorders were far more common in Skinner's survey than in the other two.

#### Mental Function

The relationship between mental disturbance and certain forms of neurological disease is well established. Intellectual deterioration frequently occurs in such conditions as disseminated sclerosis, cerebrovascular disease and Parkinsonism (Surridge, 1968; Brain, 1962; Henderson and Bachelor, 1962). Some diseases may also give rise to mood disorders. Classical medical teaching, for example, has associated disseminated sclerosis with euphoria. Surridge (1968), however, found that depression was much more common in patients with this disease. This change in affect seems to be related to the terrible social consequences of the disease, rather than to any organic brain changes.

The relationship between personality changes and disease processes is poorly defined. Various authors infer that certain personality defects may lead to specific illnesses. An example of this is the "rheumatoid personality" described by certain people (Ludwig, 1955; Mueller and Leftkovitz, 1956; Cobb, 1959; King and Cobb, 1959). In this the patient with rheumatoid arthritis is considered to have difficulty in expressing feelings of hostility, and to have had a particular interest in physical activity prior to disability. Subsequent investigation has failed to confirm this hypothesis (Wolff and Farr, 1964). It is likely, however, that the distress caused by pain and disability in this disease often causes a neurosis or depression (Nalvern and O'Brien, 1964).

An equally important mental attribute in a disabled person is his motivation. It is difficult to define and almost impossible to quantify this. It is probably best considered as being a combination of these factors which determine the response of a person to disability. These include his attitude towards disability, his social background and his opportunities for activity and employment (Barry, 1968). Impending litigation or the award of damages after an injury can sometimes act as negative forces (Gregg, 1968).

### Requirements of the Young Chronic Sick at Home

#### Medical Care

The general practitioner usually occupies a key position in the provision of medical care to young disabled people living at home (Maddison, 1970). Part of his task is to diagnose illness and prescribe drugs for these people. He should also endeavour to provide a considerable amount of psychological

support to such patients. His role as a link between the sufferer and complex and poorly advertised social services may also be extremely important.

Williams (1964) gives some useful general advice on ways in which a medical attendant can provide support to the disabled in the community. Each patient should be told the extent to which his illness is likely to produce disability. He should also be encouraged to make use of all the available sources of help. It is also important that he should be encouraged to lead as active a life as possible and to play a positive rather than a negative role in society. The doctor should provide contact with the local authority social services department, with the Department of Employment's disablement resettlement officers and with the appropriate voluntary organisations. Attention should be given to the needs of other members in the patient's family who are often under considerable stress. The psychological value of providing regular treatment, even where this is of doubtful pharmacological value, is also emphasised.

It is difficult to measure the adequacy of the existing medical services to disabled people living at home. The amount of care and attention a patient requires is dependent upon the particular disease afflicting him. As a result, it is extremely difficult to build up a comprehensive picture of the situation for all disabled people in an area. Harris (1971) tried to assess this by measuring the regularity and frequency with which doctors visited disabled people, and the numbers of patients who

actually received treatment. These details, however, are of limited value in determining the medical requirements of a population suffering from a wide range of complex and unrelated disorders.

Despite the limited amount of information available, a considerable amount of thought has been given to medical care for the young chronic sick. One working party felt that the medical assessment of disabled people in Britain was grossly inadequate, (Guthrie, 1968). It pressed for the provision of facilities for earlier diagnosis. The importance of closer liaison between different specialities and between the medical and paramedical professions also received emphasis.

More detailed consideration was given to the problem by an earlier working party (MacDonald, 1964). It suggested that illness could be detected early by screening young people regularly and proposed that the services to each disabled person should be co-ordinated at a special counselling centre. This would be staffed by a doctor supported by social workers and health visitors.

#### Self Care

Some disabled people are almost completely independent, only requiring help with a few minor items of clothing. Others are totally dependent on other people for feeding, washing, dressing and toileting. In Great Britain, 1,500,000 adults under retiral age fall within the first of these categories. Only 24,000 are in the second (Harris, 1971).

Townsend (1967) investigated the plight of people requiring

help with self care in considerable detail. He found that people providing the bulk of this were either the parents or the spouses of disabled people; 15% of the subjects, however, lived alone. Though usually visited by friends and neighbours, they were largely dependent upon local authority services for help with self care. This was often inadequate. The example is cited of a woman who fell on the floor and had to lie there until someone came to her house the following morning.

The district nurse is often a key figure in the care of disabled people. Her services range from providing regular bed baths to acting as a link between the patient and other services. It is impracticable, however, for her to spend more than a short time with each of her many charges. She is not on hand long enough to be of much value to the patient who requires regular feeding or toileting.

It has been suggested that untrained people might be employed under the supervision of a district nurse (Guthrie, 1968). These would be designated nurses' aides, and would help disabled people with many of the basic self care activities. It is clear, however, that unless there were several shifts of aides to each disabled person they could not hope to provide the continuous care available to patients living with an attentive relative.

#### Equipment

Specially designed pieces of equipment are of considerable importance in helping disabled people maintain their independence.

These can be considered under the headings of "appliances", "personal aids" and "equipment". Appliances are devices fitted to patients to increase function or to correct or prevent deformity. Personal aids are small easily handled articles used to increase functional capacity. Larger articles used to increase function are classified as equipment, (BMA, Planning Unit Report, 1969).

Aids with the widest application are those which increase mobility. They include tripods, quadrupeds and various forms of walking frame (Anderson, 1967). Wheelchairs may also be of major importance. Grant (1961;) emphasises the necessity of tailoring these to the user's requirements. They should be of the correct size so that they are comfortable, and so that they can be manoeuvred through doors and round corners in the patient's house. Access to bed, table or toilet is facilitated by having folding foot-rests and removable sides.

Many aids and pieces of equipment have also been designed to help people to wash, dress, feed or toilet themselves. Examples include plates with vertical rims for trapping food, long handled shoehorns, elevated seats and arm rests for W.Cs, and overhead hoists and tracks for getting on and off beds, baths, chairs or W.Cs (Grant, 1961,ii,iii). The most comprehensive list of equipment and aids for disabled is contained in a catalogue published by the Central Council for the Disabled (Agerholm, Hollings and Williams, 1960).

Although a wide range of articles are available, their supply and distribution presents several problems. A BMA Planning Unit

Report (1969) highlighted several of these. It found that the supply of aids and appliances by the three different branches of the National Health Service gave rise to considerable delay and confusion. Another difficulty was that there were insufficient numbers of clinics available to assess the needs of people for aids. This resulted in many patients having to travel long distances.

The Planning Unit considered that these deficiencies might be rectified if the education of medical and paramedical staff in methods of rehabilitation was improved, and if there was a greater degree of team-work and co-operation between the various disciplines working in this field. Particular emphasis was given to the place of the general practitioner in such an organisation.

The Unit also recommended that different professions should co-operate in the field of research and development. A project illustrating the potential of such team work was the design of the Patient Operator Selection Mechanism (POSM). This can be used by a severely incapacitated patient to control a wide range of devices. Included in these are a bell, light, heater, radio, television, intercom, door lock and telephone (Hyde, 1969).

### Housework, Cooking, Washing and Shopping

A detailed account of the problems facing disabled housewives is contained in the report on a national survey of disabled people in Great Britain (Cox, 1971). The task which gave rise to most difficulty was shopping. This was followed by housework. Cooking appeared to cause the least difficulty. There was also

evidence that many people experiencing little difficulty with self care, could not manage household chores. This was thought to be related to the fact that more sustained activity was necessary when engaging in the latter.

Unfortunately, the study did not make a distinction between young and old people. Many of the conclusions may thus have limited validity when the problems of young idsabled people are considered. An example is that the pattern of support from relatives, friends and neighbours is likely to be different in young and old populations.

Most disabled housewives obtain the major part of their support from friends and relatives. Attention to household aids and equipment, however, can often be instrumental in reducing such dependence to a minimum. Grant (1961, iv) describes how the ingenious adaptation of ordinary household articles can allow severely disabled people to perform a wide variety of tasks. These include dusting, washing, polishing, bedmaking and sewing.

The part of the house requiring most attention to detail is the kitchen. Such features as the overall layout and height of working surfaces are extremely important. The layout should be such that the door provides easy access. Plans should also be made for the sink, stove and working surface to be within easy reach of each other. The heights of sinks, shelves and working surfaces should be such that they are suitable for a patient using a wheelchair or who is unable to stoop.

A pilot study organised by the Control Council for the

Disabled has provided a fund of information about the problems of the disabled housewife (Howie, 1967). The investigation was centred upon a work study analysis performed on 15 disabled women compared with that on a similar number of controls. This was used to construct a long list of points requiring attention in the future planning of kitchens for the disabled.

Several general principles emerged. The most important was that, while disabled women worked more slowly and for shorter periods of time, their basic patterns of activity were similar to those of controls. It was apparent from this that a bad design was bad for both healthy and disabled people. This, however, was only a source of inconvenience in the first group. It often made a task impossible in the latter. It appears, therefore, that an improvement in the general standard of kitchen design would do more to help disabled people than the provision of purpose built units. Priorities in kitchen design should include safety, elimination of distance, adoption of the best height, and attention to the ease with which equipment can be handled and manipulated.

#### Housing

Many disabled people live in housing with amenities which might be considered inadequate even for the needs of able bodied occupants. One survey demonstrated that 30% of the population investigated had no running hot water. Another 23% had no fitted bath, while 21% did not have an inside W.C. (Townsend, 1967).

Skinner (1969) found it disquieting that the proportion of disabled people living in inadequate housing was no different than

that for the whole population. This seems to reflect a failure on the part of the local authorities to support that section of the community least able to provide for themselves.

Rankine and Weir (1967), by contrast, found little evidence of disabled people having a serious housing problem. This discrepancy is probably due to a wide regional variation in the general standard of housing and accommodation (Buckle, 1971). For example, a high proportion of housing in Scotland is under the control of local authorities. In London it is much more common for furnished and unfurnished accommodation to be rented privately.

One of the most common problems facing disabled people is difficulty in gaining access to the house itself or to different parts of it (Buckle, 1971). As many as 75% of disabled people may have stairs in their homes (Townsend, 1967). Although stairs are not always a source of inconvenience, 29% of the chronic sick studied by Rankine and Weir (1967) found stairs to be a serious barrier to independence. One way of tackling this situation is to rehouse people in flats supplied with lifts. Unfortunately, social isolation or the frequent breakdown of lifts may result in this being a less than perfect solution (Skinner, 1969).

Considerable attention has been given to the desirability of providing purpose built accommodation. Grant (1962), however, suggests a house should be designed so that it is convenient for the occupants whether they are handicapped or able bodied. Such a building should be level with the outside surface, should it

consist of a single storey, its doors and passageways should be wide enough to admit a wheelchair, and the layout should be such that the occupant has to travel the minimum possible distance in carrying out day to day activities.

A great deal may also be done to modify existing accommodation to the requirements of the disabled. Ramps can be installed, the layout of furniture can be altered, and the heights of switches and windows can be adapted to suitable levels (Stewart, 1961). These tasks are the responsibility of the local authority housing department. Townsend (1967), however, complains that they are often carried out in a piecemeal fashion without any recourse to an overall plan. The situation might be improved by organising local authority work teams under the joint control of the housing and social service department.

#### Income

It is often extremely difficult to determine whether or not the income of a disabled person is adequate for his requirements. Even when the subject is willing to give details, there may be difficulty in deciding which particular financial resources should be included under the heading of income. A person may, for example, be given money by relatives. His social situation may have a considerable bearing on the adequacy of his income. Someone living with wage earners is less likely to be in financial distress than one living alone. Finally, a rapid rise in the cost of living may make estimations of income meaningless by the time the results of a survey are published.

Despite these uncertainties there is considerable evidence that many of the chronic sick suffer financial hardship. In 1967, for example, 60% of a disabled population were found to be earning less than £10 per week (Townsend, 1967). In a highly developed industrial society this seems grossly inadequate by any standards.

The situation has received considerable attention from the Disabled Incomes Group (Lancet, 1969). The organisation was formed for the specific purpose of resolving the financial plight of the chronic sick. It pressed, in particular, for such people to be given a special disablement pension.

The problem has also been considered by the working party set up by the National Fund for Research into Crippling Diseases (Guthrie, 1968). It recommended that all disabled people should receive a pension similar to those awarded for injuries sustained in war or in industrial accidents. A special attendance allowance for patients requiring continuous nursing care was also suggested.

Since these reports, legislation has gone some way towards meeting the economic needs of the chronic sick, but further provision is probably necessary.

#### Employment

Increased interest was shown in the employment of the disabled shortly after the outbreak of the Second World War. This was stimulated by the necessity of using these people in wartime industry. A committee was set up to study the problem (Tomlinson, 1943). Its report emphasised the importance of hospitals using rehabilitation techniques to restore a patient to the maximum of his potential even after definitive medical or surgical treatment had been completed. The development of industrial rehabilitation units was also suggested. These would be used to provide a convalescent patient with a period of reconditioning before he returned to work. Where people were too disabled to return to their previous occupations, vocational training courses were advocated. These would train patients in jobs within their existing physical and mental capacities.

Attention was also given to the practical problems involved in resettling people in industry. It was suggested that each firm should be legally obliged to employ a fixed percentage of disabled people, that certain jobs be restricted to disabled people, and that a register of disabled people be organised by the Ministry of Labour. Sheltered workshops were envisaged for those who were too incapacitated to work in open industry.

Most of these recommendations were implemented in the Disabled Persons (Employment) Act of 1944.

The operation of this Act was reviewed by the Piercy Committee in 1956. This concluded that existing legislation provided sufficient statutory provision for the satisfactory resettlement of people into employment. It suggested, however, that some degree of reorganisation was needed to improve the efficiency of the available services. An important aspect of this was the formation of resettlement clinics in hospitals. These would be used to assess and review the prospects of patients returning to work. They would be run by a team consisting of doctors, physiotherapists, occupational therapists, medical social workers and disablement resettlement officers. The advantages of including the general practitioner in this exercise were emphasised.

Stress was laid on the importance of close co-operation between hospital physical rehabilitation departments and Ministry of Labour industrial rehabilitation units. The practicability of combining these two centres under the one roof under certain circumstances also received attention. It was further felt that sheltered workshops could play a more active role in resettling people in open employment.

It is unfortunate that, subsequent to this report, little has been done to implement its excellent and wide ranging proposals. More recent research has shown the value and practicability of many of these. Fletcher and Wheble (1964), for example, demonstrated the value of co-operation between hospital and industrial rehabilitation units. They describe an orthopaedic unit in which a disablement resettlement officer from the Department of Employment attended the fracture clinic. Discussion between this officer and the medical staff facilitated the early identification of patients likely to benefit from industrial rehabilitation. Arrangements could then be made for admission to the industrial rehabilitation unit as soon as these people were

sufficiently fit. This prevented the delay which would have occurred had referral to the industrial unit been made on the completion of hospital rehabilitation. The end result was that patients got back to work earlier, and fewer remained off work permanently.

The value of combining medical care and industrial rehabilitation in the one centre has also been demonstrated. Tyrer (1969) describes the operation of such a unit sited in Rochdale. Patients underwent detailed medical scrutiny, and had detailed assessments made of their working capacities. The centre also maintained close links with local industries. These facilities resulted in the early and satisfactory resettlement of most patients attending the centre.

Combined centres specialising in particular disorders have also been developed. One such unit in Australia concentrates on cardiac disease (Goble, Adey and Bullen, 1963). Patients are reviewed by a team including a physician, social worker, employment advisor and psychiatrist. This results in an accurate assessment of work potential, and simplifies early resettlement in suitable employment. Many units in the United States operate on similar principles (Stein and Altman, 1965).

Co-operation from employers is extremely important in the resettlement of disabled people. Large firms are often able to operate private resettlement programmes for their employees. Lee (1968) has given an account of such a one. In this, the
person returning to work was given a job requiring a limited amount of physical activity. A time limit was set by which time he had to be able to work at full capacity. If it became apparent that this was beyond his capabilities, he was transferred to a job in which his limited abilities could be more fully utilised. People who were unable to work with normal efficiency at any job were retired prematurely.

This type of scheme is feasible in a large industry with a big work force and many different types of work. It is less practicable in a small firm where there is much less room for flexibility.

Many different factors influence the amount of ease or difficulty disabled people experience in finding work. Rankine and Weir (1967) found that middle aged patients were more likely to be out of work than their younger counterparts. This was thought to be partly due to older people being more ready to accept an adverse situation. It was also apparent that they received less encouragement from the social services or employers to seek work or undertake retraining. Buckle (1971) emphasises the plight of the child with chronic ill health. Long periods off school due to illness often result in the patient achieving a very limited standard of education. This provides yet another obstacle to the younger disabled person finding work. The level of unemployment in an area is yet another factor affecting the prospects of employment for the chronic sick (Henderson, Barr and Cowan, 1963).

## Travelling

Many of the disabled are unable to travel from home without the use of personal transport. The Department of Health and Social Security meets this problem by providing some of these people with cars or motor tricycles. There are, however, stringent regulations governing the issue of these vehicles. Tricycles are only given to people who are unable to walk at all, or to those who, though slightly less disabled, are unable to engage in fulltime employment or housework and shopping without such vehicles (Harris, 1971). The supply of private cars is restricted to exceptional circumstances. These include the situation of two disabled people living together in the same household (Lancet, 1967).

Invalid tricycles have been exposed to a great deal of criticism. A report in the magazine <u>Which?</u> (1969) detailed many of their faults. These included poor road holding, noisiness, poor suspension, inadequate heating and ventilation, and the absence of a petrol gauge. Other defects were inadequate; luggage space and insufficient safety provisions. It was discovered, however, that many people preferred such vehicles to cars. This was related to the controls being simpler, manoeuvrability being better and access being easier.

The most important disadvantage of the tricycle is that it has only one seat. Some people are only able to go on journeys if there is someone to help them out of the vehicles at their destination. Disabled housewives are unable to take their children with them when they go shopping. The solitary driver can also get into considerable difficulty if his vehicle breaks down (Harris, 1971). There are, however, impressive economic arguments against the unselected issue of adapted motor cars to disabled people.

It might be supposed that disabled drivers were more likely to cause accidents than other road users. A survey was conducted in Sweden to investigate this proposition (Ysander, 1966). This actually demonstrated that the accident rate for disabled drivers was slightly less than that for their healthy counterparts. A factor in this finding might have been the stringent motor licensing regulations enforced in Sweden. All potential drivers have to pass a medical examination. Disabled people presenting with potential risks are thus excluded (BMJ, 1966).

Evidence of the importance of medical examination in assessing the fitness of drivers was provided in a Californian survey (Waller, 1965). Here, where medical regulations were lax, the road accident rate was twice as high amongst the chronically sick than in the rest of the population.

#### Access

Even if a disabled person is able to travel he often has difficulty in obtaining access to amenities at the end of his journey. The British Standards Institution (1967) have contributed to the solution of this problem by laying down standards of access to public buildings. Most of these have been

adapted from Goldsmith's (1963) detailed study of the situation. Points covered included the approach, access and internal circulation of public buildings for both ambulant and chairbound disabled people. Emphasis was also given to the importance of adequate cloakroom and sanitary facilities.

Disabled people also face problems in town centres. They have to cope with adverse weather conditions, car parks may be a long way from shops, busy roads may have to be crossed, and public transport may be unsatisfactory. An investigation, sponsored by the Control Council for the Disabled, gave considerable attention to these problems, and produced detailed recommendations on urban planning for the disabled (Johnson-Marshall, 1969).

The Chronically Sick and Disabled Persons Act (1970) has adapted many of these proposals. It has made provision for the access of the disabled to schools, universities and public places. The provision of sanitary conveniences for the disabled in these places has also been made mandatory.

## Interests

Smith (1971) has reported on the results of a national survey dealing with the leisure activities of disabled people. He found that many people had had to give up previous interests after the onset of chronic illness. On the other hand, few of them felt that disability had curtailed leisure activities to a serious extent. Television viewing seemed to be the most popular pastime for people with all degrees of disability. This,

however, might merely have been the reflection of a national trend.

Organised activities contributed very little to the leisure of the disabled. Very few people attended local authority day centres, even where these were available. A greater proportion went to clubs for the disabled. Most in this group consisted of young rather than middle-aged people.

# C. The Young Chronic Sick in Hospital

In contrast to the detailed information available on the disabled in the community, little research has been conducted into the problems of the young chronic sick receiving long term hospital care. The National Health Service organised a census of these people in 1967. This revealed that, in England and Wales, there were 4,223 people between the ages of 16 and 59 who were receiving long term hospital care. Males and females were equally represented, but there was a striking rise in the numbers of each sex with increasing age. This is illustrated by the fact that only 502 subjects were under 35 whereas another 2,361 were over 49. It is disturbing to note that only 12% of subjects were in units designed for the care of young chronic sick patients. Another 50% were in geriatric wards. A final point was that the vast majority of subjects were suffering from neurological disease.

A similar investigation was conducted in Scotland (Scottish Home and Health Department, 1967). The situation was slightly more satisfactory here in that 37% of patients were in young chronic sick units. Again, however, almost half were to be found in

geriatric wards. The fact that 4% of disabled were in mental hospitals was rather worrying. The preponderance of neurological disease in the patients mirrored that found in England and Wales.

These investigations provided useful statistical information about the young chronic sick in hospital. They did little to throw light on the problems of the individual in this environment.

Despite the limited amount of information available a considerable amount of though has been given to the placement of young long stay hospital patients. There is general agreement that they should not be in the same ward as elderly confused patients. They should be in units specially designed for their needs (MacDonald, 1964; Brocklehurst, 1967; Guthrie, 1968). An exception to the rule is the middle-aged patient with advanced neurological disease associated with gross intellectual deterioration. There is no reason why he should not fit into the environment of a geriatric ward (NHS, 1968).

Rankine and Weir (1967) were in agreement with the principal of keeping young disabled people out of geriatric units. They went even further and stated that, with properly developed community services, it should rarely be necessary to admit disabled people under the age of 35 to hospital.

There has been considerable speculation about the size and design of long stay units. The NHS report (1968) suggested that they should contain between 25 and 50 places. This would make them large enough to support the facilities necessary to stimulate

interest, activity and a sense of purpose in the patients. At the same time, the institutional atmosphere of a larger unit would be avoided.

The report also suggested that the unit staff should have regular conferences to identify and deal with the educational and social requirements of each patient. They would be greatly assisted in this task by the active participation of local voluntary organisations. The wide diversity of tastes and requirements for each individual could be met by dividing the unit into multiple dormitory and day areas.

The siting of young chronic units sometimes presents difficulties. A place large enough to provide many of the facilities already described may have to take patients from a wide drainage area. This may result in the residents losing contact with their family and friends. The general view is that the provision of adequate facilities should take precedence over the location of a patient near his original home (Guthrie, 1968).

# D. Keeping the Young Chronic Sick Out of Hospital

Though much can be done to improve the standard of hospital care, it can never be made to match the comfort, freedom and privacy of a patient's own home. Consequently, it is essential that everything possible should be done to maintain disabled people in the community. A working party set up by the National Fund for Research into Crippling Diseases investigated this in considerable detail (Guthrie, 1968). Most of its recommendations

concerned themselves with an improvement in community care. Items covered included the incomes of the disabled, the identification of chronic sickness, the design of accommodation, the provision of day centres, publicity about available services, the arrangement of holidays, and the importance of adequate liaison between the various health and welfare services. Most of these points have been discussed earlier in this review. The working party report makes the point that attention to such a wide diversity of factors is necessary if disabled people are to be kept out of hospital.

Hostel accommodation is another useful way of supporting disabled people in the community (Guthrie, 1968). This may be designed to serve the needs of two different groups (Maddison, 1968). People may be able to work in sheltered accommodation but unable to travel long distances to and from work each day. An overnight stay in a hostel during the week may be a solution to this problem.

Accommodation may also be required for people who, though unable to look after themselves may not require nursing care. Cheshire or Thistle Foundation Homes provide possible blueprints for such places (Guthrie, 1968).

It has already been mentioned that the Piercy Committee (1956) laid considerable emphasis on the assessment of disabled people in hospital. This body was primarily concerned with the resettlement of the chronic sick in employment. Their principles, however, have a much broader application. It would seem important, for example, that there should be units designed to assess the ability of individuals to care for themselves in the community.

Goble and Nichols (1971) gave a detailed account of an experimental unit operating in the Oxford unit. Patients were assessed by a team consisting of a physiotherapist, occupational therapist, nurse, appliance technician and medical social worker. Their findings were used to plan courses of rehabilitation. These were frequently successful in restoring independence to severely incapacitated individuals. Such a success rate warrants the expansion of this type of service to meet the needs of disabled people all over the country.

## Selection of Subjects and Methods of Investigation

## A. Home Population

## Selection of Subjects

Subjects were selected from the practices of doctors working in four towns near Glasgow. These were Rutherglen, Kilsyth, Clydebank and Bearsden. There were considerable differences between the industries, housing, social amenities and age and social class structures in these four areas. They were chosen to provide subjects from as wide a range of backgrounds as possible.

Rutherglen is a burgh adjacent to Glasgow. It has a population of 25,000. There is some old dilapidated tenement property near the centre. This is privately rented. There are also sizeable areas where good quality owner-occupied housing predominates. Most of the accommodation, however, is rented from the local authority. Its age ranges from buildings recently constructed to those completed shortly after the First World War. Local industries include metal working, engineering, building, upholstering and oatcake manufacturing. The town thus contains people from all social classes, and has a wide range of industries.

Kilsyth is a town of 15,000 people about 15 miles from Glasgow. At one time most of its inhabitants worked in local coal mines. Mining has now declined. It has been replaced by several light industries including hosiery, knitwear, furniture and wallpaper manufacturing. Many people commute to work in Glasgow or Cumbernauld A very high proportion of the housing is owned by the local authority. The place thus represents a country town with a working class population employed mainly in light industry.

Clydebank is adjacent to Glasgow and has a population of 50,000. The local authority have undertaken an extensive rehousing programme since the last War. Most of the population live in this type of accomodation. Several multistorey flats have recently been built. At the time of the survey, most people were engaged in the shipbuilding and engineering industries. The town thus contained a working class population mainly engaged in heavy industry.

Bearsden has a population of 17,000. Most of its inhabitants have middle class backgrounds and commute daily to Glasgow. The bulk of housing consists of high quality owner occupied accommodation. A limited amount, however, was rented from the local authority. There is virtually no major local industry. The burgh is thus mainly a dormitory area for business and professional people.

Each doctor, who agreed to help, was asked to compile a list of young chronic sick patients in his practice. The lists were comprehensive where they were constructed from age-sex registers. In most instances, however, they were constructed from memory so that it is likely that many disabled people in the practices were omitted.

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For the purposes of the study, a young chronic sick person was defined as anyone between the ages of 16 and 59 who suffered from a disability, other than blindness, deafness or mental disease, of sufficient severity to prevent either work in open employment or the completion of housework without help.

The age range was chosen because it covered the period between the school leaving age, and the age at which women became eligible for the old age pension. It might have been more logical to extend the range for men to the age at which they could draw a pension. This would, however, have made an analysis of the results more complex.

It is obvious that a wide variety of factors other than physical impairment affect the ability of a person to find employment or engage in housework. These criteria were used because they were easy to identify. Selection based on a more accurate assessment of physical impairment could only have been achieved by using a postal or a door-to-door survey. These techniques were beyond the scope of this investigation.

Patients with blindness, deafness or mental impairment were only excluded where these incapacities occurred in isolation. Those in which these incapacities occurred as part of a more general disease process were included. Examples of such combinations were disseminated sclerosis with blindness or post-encephalitic Parkinsonism with dementia.

Since only some of the doctors in each of the areas participated, and as the lists of patients in each practice were usually incomplete, the findings of the study could not be used to estimate the prevalence of disability. They merely represented details on a sample of disabled people living at home in the West of Scotland. Table 3 gives the numbers of doctors and patients from each area who took part in the survey. These do not include three people who refused to participate when approached by the interviewer.

One was a woman in Rutherglen who, since she had no problems, saw no point in participating. Another woman in Kilsyth had similar views. A man in Kilsyth was suspicious that the information would be used by the government to look into his financial affairs.

### Methods

Social, medical and psychiatric assessments were performed on each subject. The information was recorded on three proformas (Appendix 1). Details on the social proforma included information about education, employment, visitors, housing, other members of the household, ability to manage activities of daily living, travelling, interests, income, ability to cope with housework, and sources of help. Medical information included a history of the principal disorder, details of previous illnesses, information on drug treatment, a family history, a systematic enquiry and the findings of a physical examination.

Information from the social and medical proformas was used to quantify disability. The scoring system used was Barthel's Index (Mahoney and Barthel, 1965). Activities covered were those of feeding, washing, toileting, transfer, bathing, dressing and bowel and bladder control (Table 1). The scores for total dependence and complete independence were 0 and 100 respectively.

The rating of a person on Barthel's Index is partly related to his social background and mental capacity. It was considered desirable that an attempt be made to measure physical impairment independent of these psycho-social factors. None of the methods of assessment reviewed in the literature appeared to meet this requirement. A new simple scoring system was devised, therefore, (Table 4). Partial and total losses of limb function scored 1 and 2 respectively. In arriving at a total score of limb function values for each limb were considered separately and then added together. Impaired function was considered to be present if there was a decrease in the normal range of force or movement in a limb. This might be due to muscle weakness, spasticity, incoordination, sensory loss, arthritis, shortening or an amputation.

Partial and total losses of vision scored 1 and 2 respectively. Breathlessness or angina brought on by washing or dressing scored 1. They scored 2 if they were present at rest. Points awarded for blindness, breathlessness or angina were added together with those for loss of limb function to give a final total. This was described as being an impairment rating.

Certain types of impairment were not scored. These included deafness, dysarthria and dysphasia. They might have affected the prospects of a person finding work, but would have only had a very minor influence on his ability to carry out self care activities.

The impairment rating is too crude for it to be of much use in assessing the requirements of an individual patient. It was found to be a useful tool, however, when it became desirable to group the survey population into those with varying degrees of physical impairment.

Intellectual ability was assessed using Raven's Coloured Progressive Matrices (Raven, 1965). This method was chosen because it had already been carefully standardised. It had the additional advantages of being readily accepted and easily explained to most people. The test is only considered to quantify observation and clear thinking. It does not measure overall intelligence.

A test designed to cover a wider range of mental function was desirable. A questionnaire described by Judge (1970) was used for this purpose (Appendix 1, page 2.). This measures general knowledge, ability to calculate, memory for recent and post events, and orientation for time, place and persons (Robinson, 1970). Since this test was originally used on hospital patients several of the questions had to be modified to make them applicable to people living at home (Appendix 1, page 2.). For the sake of simplicity this test will be labelled, in future, as the "IQ test". It should be recognised, however, that the test covered too limited a range to give a true measure of the intelligence quotient.

A modified version of the Tavistock questionnaire was used to screen patients for anxiety neurosis, depression or psychosis (Judge, 1970). (Appendix 1, page 3.). In practice, many patients gave misleading answers. A more accurate impression was often obtained from the demeanour and behaviour of a patient during the course of an interview.

### B. Hospital Population

#### Selection of Subjects

In this part of the study the young chronic sick were defined as being people between the ages of 16 and 59 who were receiving long term care for disabilities or illnesses other than those of deafness, visual impairment or mental illness or subnormality. Organic brain disease was considered to be an entity distinct from long term illness or mental subnormality. This definition had previously been used in surveys of long stay hospitals in Scotland, and England and Wales (Scottish Home and Health Department, 1967; NHS, 1968).

The medical superintendents of all hospitals within a twenty mile radius of Glasgow were sent a copy of the above definition. They were asked to identify all patients in their hospitals fulfilling its criteria. Information was also requested on the sexes, ages, unit numbers, dates of admission, attendant consultants and types of unit accommodating these people (Appendix 2).

These details were used to list patients occupying beds in young chronic sick, geriatric, psychiatric, post-encephalitic, or acute medical, surgical or orthopaedic wards. Patients who had been in these wards for less than three months were then removed from the lists. This was done with the object of excluding patients who had been admitted to provide temporary relief for relatives, or for the management of an acute illness incidental to chronic disability.

A stratified random sample was selected from the remaining subjects to give one-third of those in young chronic sick units, half of those in geriatric units, half of those in psychiatric units, all of those in the post-encephalitic unit and all of those in acute medical, surgical or orthopaedic units. Stratification was used to provide a reasonable balance of numbers from each type of unit. Table 5 details the numbers of patients and units involved in each part of the selection procedure.

Once the permission of the appropriate consultants had been sought and given, all of the patients on the final list were visited. They were asked whether they were willing to take part in the survey. All agreed to participate.

#### Methods

Medical, Psychiatric and social details were recorded on three

proformas. The medical and psychiatric ones were identical to those used in the community survey. There were several important differences in the social one. Information about housework and household visitors was deleted as being inapplicable to long stay hospital patients. In place of these more appropriate details were recorded. These included the reasons for admission to hospital, contact with visitors, recreational activities, outings, and treatment by occupational therapists or physiotherapists, (Appendix 3).

The subjects were usually able to provide most of the required information themselves. Sometimes details had to be gleaned from nursing staff if an individual was grossly demented. The possibility of interviewing relatives was considered. This was thought to be impracticable in a survey covering many different hospitals scattered over an area of 1,250 square miles.

### Results

## A. Home Population

In this analysis, subjects from each of the four towns are considered together. The numbers from each of the areas were too small to allow any useful comparison to be made between them.

## Sex

46 males and 50 females were included in the survey.

### Age

The numbers of subjects showed a striking rise with increasing age. There were three times as many people between 30 and 44 years

as there were between 16 and 29. Three times as many again were 45 and over (Table 6). Congenital defects and diseases acquired in childhood were uncommon causes of severe disability. Disorders causing incapacity had usually occurred during adulthood. In over half the cases this had happened after the age of 30 (Table 7).

### <u>Diagnosis</u>

A large proportion of the subjects were afflicted by some form of neurological disease. Diseases of the locomotor and cardio-respiratory systems were slightly less common (Table §). Table 9 lists the diagnoses. The most common were diss@minated sclerosis, rheumatoid arthritis, chromic bronchitis and cerebrovascular disease.

The type of disease causing disability was related to the age of a patient (Table 10). Thus, most cardio-respiratory disorders occurred in middle age. Indeed, only 2 people with this disturbance were under 45. There was a less striking change in the proportions of subjects with neurological or locomotor diseases in different age groups.

The age distribution of patients with the four most common disorders was examined (Table 11). Chronic bronchitis and cerebrovascular disease were most common intlate middle age. There was a similar though less marked trend with rheumatoid arthritis. The numbers of people with disseminated sclerosis reached their maximum between the ages of 30 and 44. Even here, however, many of the subjects were older than this.

## Secondary Disorders

Many subjects suffered from more than one pathology (Table 12). In 19 instances the secondary disorder was a cause or consequence of the main disease. Examples include a urinary tract infection in disseminated sclerosis, a fractured neck of femur in rheumatoid arthritis and hypertension in cerebrovascular disease. Another 24 people had conditions which were unrelated to the principal pathology. 9 of them had more than two of such conditions. In six instances ischaemic heart disease occurred as a secondary disorder. None of the other conditions occurred in more than three people.

Table 13 shows that there was no association between multiple pathology and age where the conditions occurring together were related to each other. There was, however, a striking rise with age when unrelated disorders were considered.

Where several diseases occurred in one person it was difficult to assess the extent to which each of them contributed to overall disability. All that could be done was to attempt the identification of patients in which the secondary disorder had an obvious effect on their ability to find employment, do housework or look after his personal needs; 14 people fell into this category.

People with partial or complete blindness were not included in the survey if this was the only defect. 8 people with other forms of incapacity, however, also had severe visual defects. 6 of them suffered from disseminated sclerosis, one from an old head injury and another from a cerebral astrocytoma. In every case, blindness was a direct consequence of the main disorder. Blindness ranged from a complete loss of vision to an inability to read normal print even with the aid of glasses.

Only two people were deaf to the extent that they were unable to follow normal speech. One had sustained a subarachnoid haemorrhage. The other suffered from a rare bone disease which had affected the base of her skull.

## Physical Impairment

Table 14 shows that there was a wide range of physical impairment. This was most marked in neurological disease, and less so in those of the locomotor system. It was least striking where the respiratory and cardio-vascular systems were involved.

### Mental Function

Visual defects, dysphasia or a reluctance to co-operate made it impossible to use both tests of intellectual ability in every subject. Raven's matrices were used in 63, and the "IQ test" in 72. Only 48 people performed both tests.

Graph 1 compares the results of the two tests with each other. There was a reasonable degree of correlation between the two methods. It was noted, however, that though a low score for the "IQ test" was normally associated with a low score for Raven's matrices, a high "IQ test" score could be associated with a wide range of values for Raven's matrices.

The values obtained for Raven's matrices in 63 subjects are

shown in Table 15. They are expressed as percentiles. Thus 25% scored 14 or less, 50% 21 or less and 75% 28 or less. These results are compared with the percentiles Raven found in 11 year old Dumfries schoolchildren (Raven, 1962). The disabled population scored less well. From this, it might be inferred that the intellectual ability of this group was more limited than that of an unselected adult population.

The "IQ test" had not been previously used in young or middle aged adults. Thus, it was impossible to draw any conclusions about the normality or otherwise of the scores in the present survey.

The difference between the results for Raven's matrices in the disabled population and those in 11 year schoolchildren might be related to the high prevalence of neurological diseases in the former. Many of these conditions were capable of causing considerable intellectual deterioration. They included disseminated sclerosis, epilepsy, Parkinsonism, old encephalitis, a cerebral tumour, cerebrovascular accidents, Little's disease, an old head injury and an old meningitis. The matrice results obtained for this group were considerably lower than those for the rest of the population (Table 15). However, when the scores of the latter were compared again with those of the Dumfries schoolchildren they remained lower.

The results of the Tavistock questionnaire, and impressions gained during interviews suggested that 12 people were depressed. Another 4 had a severe anxieity neurosis, 2 were abnormally euphoric and one man had a hysterical paralysis of his legs. Table 16 shows that these disorders occurred in a wide range of physical illnesses. The numbers were too small for any clear pattern to emerge.

## Activities of Daily Living

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Many people scored the maximum rating on Barthel's index, (Table 17). This suggests that inability to engage in employment or perform housework does not necessarily affect self care activity. A greater number of women than men had a minor degree of disability. This again is probably related to the selection techniques used in the survey. It may be easier for a disabled woman to do housework, than it is for a man with the same degree of dysfunction to hold down a job.

Walking ability was examined separately. 27 people could travel unlimited distances. Another 58 could walk a limited distance without anyone helping them. Only 3 required help in walking and only 8 were chairbound or bedfast.

When walking was related to diagnosis a pattern similar to that for overall disability emerged (Table 18). Neurological disease seemed to produce most incapacity. This was followed in turn by locomotor dysfunction and cardio-respiratory disease.

The numbers requiring help with dressing, toileting, washing and feeding were 27, 11, 10 and 5 respectively. It would thus appear that dressing was the most common barrier to independence in daily living activities. This analysis did not take account of 31 people who, though able to wash themselves, were unable to get in and out of a bath unaided. Neither did it give consideration to 16 people who could only eat certain forms of food if these had been previously cut up.

6 out of the 96 subjects were incontinent of urine. 4 of these had disseminated sclerosis, one had Little's disease and one was suffering from the residual effects of an encephalitis. 2 people with disseminated sclerosis and one with Little's disease were also incontinent of faeces.

The importance of different factors as causes of overall disability were assessed. Graph 2 shows that there was reasonable correlation between physical impairment and disability. No obvious pattern emerged when disability was compared with scores for Raven's matrices or the "IQ test". (Graphs 3 and 4). This suggested that physical impairment had a greater influence on total disability than intellectual ability.

## Medical Care

No attempt was made to quantify medical care. Such a wide diversity of conditions was encountered in the survey that any such measurement would have been completely meaningless. The frequency of visits from a general practitioner, the number of hospital attendances or the types of medicine taken could only have been interpreted in relation to specific disorders.

### Personal and Nursing Care

33 people requiring help in personal care received this from other members of their household. The amount of assistance ranged from total nursing care to dealing with relatively minor items such as tying shoelaces. Parents or spouses were usually responsible for this type of care. Friends, neighbours and more distant relatives were rarely involved to any significant extent.

Only 6 people received regular visits from a district nurse. Patients and their relatives were usually rather vague about what services the nurse provided. Most mentioned the value of being given regular bed baths,. Considerable importance was also attached to the treatment of faecal impaction with enemas. Nurses were rarely involved in broader self care activities such as feeding, dressing and toileting. Table 19 lists the diagnoses and disabilities of people visited by a nurse. All were suffering from locomotor or neurological disorders and all but two were very severely disabled.

## <u>Aids</u>

23 people had walking aids. These included callipers, tripods, zimmers, crutches and artificial limbs. 5 of the people, who were unable to walk without someone helping them, were in wheelchairs. In four instances the equipment had been issued by the Department of Health and Social Security. The other patient, a man with hysterical paralysis of his legs, had bought a chair privately. All were reasonably satisfied with their chairs though two stated that an electrical chair would have increased their independence.

Fewer people had aids for dressing, washing, toileting or feeding. Their numbers were 5, 5, 4 and 2 respectively. Gadgets included elastic sided shoes, long shoehorns, stocking suspenders on poles, stocking rings, lazy tongs, bath handles, hydraulic hoists, low level baths, commodes, elevated toilet seats, and angled drinking straws.

Table 20 details the proportions of people with different types of disabilities using aids. There was a striking discrepancy between people with difficulty in walking and those with other problems.

#### Housework

The term housework was considered to include cleaning a house, preparing meals and doing shopping. Each of these activities was given a score. O denoted that the task was not performed at all; 1 that it was performed with help; and 2 that it was performed independently. Scores for each activity were added together to quantify the amount of housework tackled by each of the women in the survey.

50 women were studied. 23 of them made meals and cleaned the house, and 1 shopped without help. There was a clear relationship between the amount of housework done and the degree of disability in the subjects (Graph 5). An attempt was made to relate performance in housework to other factors. These included intellectual ability and the presence of other women in the household. No clear pattern emerged. This may have been related to the small numbers of subjects in the various subgroups.

All but one man and all women received help with housework. (Table 21). Men usually received help from someone living within the household. Women relied more heavily on outside sources. Table 22 gives details of the people providing help. If the subject was married the principal helper usually was the spouse. Single people more often had the support of a mother or sister. They also received a lot of support from neighbours and more distant female relatives.

## Home Helps

It was difficult to assess the need for a home help. Only two households were in such a state of disorganisation and untidiness that the inadequacy of the existing domestic arrangements was obvious.

In all other cases need had to be measured in terms of undue workload on the relatives supporting disabled people. Examples of this included husbands having to work, do housework, look after children and nurse their wives; and mothers travelling long distances every day to look after disabled daughters.

These criteria were used in Table 23 to measure the number of people requiring home helps. Most single men and women requiring these services were provided with them. If men were married, home helps were rarely required. The two husbands requiring them, had wives who went out to work. Married disabled

women and their relatives were in a less fortunate position. Many of them required a home help but only two were provided with such a person.

### Housing

Table 24 details the designation and type of ownership for houses occupied by the young chronic sick. An exceedingly high proportion were rented from local authorities. Very few were rented from private landlords.

Most of the housing was of a reasonably high standard. Three exceptions were flats in dilapidated nineteenth century tenement buildings. All of them were without baths and inside W.Cs. 34 other houses, however, were unsuited to the needs of the disabled people living in them.

24 people had difficulty in negotiating stairs in their homes. In 10 instances these led up to the front door, in 13 from the front door to the main living area, and in 14 from the main living area to the W.C. and/or bedrooms. The problem was occasionally related to angina or breathlessness. More commonly it was caused by diseases of the locomotor or neurological systems, (Table 25).

17 people, though having difficulty with stairs, were able to negotiate them without assistance. Another 3 required someone to help them. The remaining 4 were unable to get up stairs even when someone was available to lend assistance. These difficulties resulted in 5 people being housebound, and in 2 being confined to the one level of their home. Only 14 of the 24 people finding stairs an inconvenience were anxious to move to another address. Reasons for not seeking a move varied and were often complex and ill defined. The more common ones included a desire to stay close to friends and familiar surroundings, the convenience of the address to other members of the family, and a reluctance to be involved in the strain and expense of a removal.

Other housing defects were less permanent and could have been rectified to meet the needs of the disabled occupants. 27 out of 41 subjects who were unable to bath would have benefited from the installation of a shower or a low level bath. 2 people, who lived alone, were unable to light or kindle a fire. As a result, they often sat in the cold. An alternative form of heating should obviously have been provided. This disability did not present the same problem to 9 such individuals who lived with relatives. In another 2 instances, doors were too narrow to allow access to a wheelchair.

There was a small group of people who requested a change in housing for reasons unrelated to disability. Two were living in flats with no baths, hot water or inside W.Cs. Both were on the rehousing list of their local authority. Another two wanted to move closer to relatives. Yet another 2 complained of the unsatisfactory state of their local authority accommodation. No obvious defects were visible but the occupants claimed that the walls were damp, and that the general standards of maintainance were unsatisfactory. Gross overcrowding was the reason for

another family wanting to move. Finally, one man had not been on speaking terms with his family for many years but they all lived under the one roof. This was obviously an unsatisfactory arrangement.

#### Incomes

Most people who were totally dependent on supplementary or sickness benefits were more than willing to provide information about their meagre resources. People with other sources of income were much more reluctant to discuss their financial affairs. This made it impossible to come to any conclusions about the financial problems of the young chronic sick in this survey.

## Employment

80 of the 96 subjects in the survey would probably have been at work had it not been for their disability. 14 of the others were women who had given up work for a variety of social reasons prior to the onset of ill health. The remaining two were of interest.

One was a girl of 16, who was severely crippled by spina bifida. She was receiving tuition at home, and had passed several 'O' level examinations. The intention was that she should continue her education and eventually go to university.

The other was a woman with chronic renal failure. She was too weak to do much housework, but felt well enough to work as a telephonist. Her husband, who was in the same firm, took her to work in his car. Only 21 of the 80 people who were unable to work because of illness had been to an employment exchange. All of these were registered as being disabled. Nobody with a Barthel rating of less than 40 had been to an exchange. Lesser degrees of disability did not seem to present a major barrier to people seeking work (Table 26).

6 out of the 21, who had attended an employment exchange, had found work in Rampley factories. Another 7 had been on industrial rehabilitation courses. One of these was on a vocational training course, at the time of the survey. Ankylosing spondylitis had forced him to give up work as an asphalt spreader. He was retraining as a machine setter. The other 6 had not derived benefit from their rehabilitation courses. Since reports from the industrial rehabilitation units were not available, it was impossible to obtain an objective assessment of the reasons for this.

2 people attended occupational centres run by local authorities. One was a mentally deficient youth who suffered from epilepsy. His capacity was extremely limited and he was probably at the right place. The other was a girl of 16 who was moderately disabled by Little's disease. She had a low normal intelligence, and should have been capable of working in a less sheltered environment.

Reasons for not working were investigated. Physical impairment played a major role in most cases. In a substantial

minority, however, social problems and mental impairment were of great importance. Examples are given of the ways in which these factors influenced the ability of a disabled person to find employment. No attempt has been made to quantify these.

A. Physical Disability

1. A middle aged man had to give up manual work in a steel mill because of severe breathlessness associated with chronic bronchitis.

2. Rheumatoid arthritis prevented a man from working as a joiner. His limited education attainments prevented him from finding suitable office work.

3. A television engineer had been sacked from several firms because his cervical spondylosis prevented him from lifting television sets.

4. Progressive physical deterioration due to Parkinsonism had forced a joiner to give up work.

5. Frequent bouts of illness following a vagotomy and gastroenterotomy two years previously had prevented a man from returning to work.

6. A woman was forced to give up her job as a shop assistant when her epileptic fits became more frequent.

7. A woman with disseminated sclerosis required total nursing care. She was obviously unable to continue working as a librarian.

8. A woman whose leg had been weakened by polio in childhood had worked in a laundry for many years. Disability due to obesity and increasing age had eventually forced her to give up work.

B. Social Problems

 A man with a tuberculous shoulder was unable to undertake heavy unskilled work. He had been offered a job as a night watchman, but had turned this down. His income from social security benefits was greater than the remuneration offered for this work.

2. A man with old poliomyelitis affecting his right leg left school during a period of mass unemployment in the 1930s. When prospects for the training and employment of disabled people eventually improved, he had become too conditioned to unemployment to take advantage of these.

3. A youth had not worked since an injury to his elbow two years previously. This was probably related to the fact that he was awaiting the outcome of litigation for compensation.

4. A man with ischaemic heart disease had originally been a general labourer. He would have been unable to continue this work. Even before the onset of his disability, however, he had been unemployed. It is unlikely, therefore, that he would have been working even if he had been fit.

C. Mental Impairment

1. Encephalitis had left a young man with severe intellectual impairment and a right hemiparesis. This, coupled with old poliomyelitis in hid left leg made him unemployable.

2. A man had been in hospital for many years as a child. This followed the onset of a septic arthritis. His limited intelligence

and immature personality were additional barriers to his employment.

3. Gross mental and physical impairment due to Little's disease had made a teenage girl totally dependent. She was obviously incapable of working.

4. A teenage boy with mental deficiency and epilepsy was only able to work at an occupational centre.

Many of the males investigated would have been too disabled to undertake their previous jobs. It should have been possible, however, for them to train in lighter work. Reasons for retraining not being available or being unsuccessful included a high rate of general unemployment in the Western Region, men in late middle age being reluctant to make a fresh start; limited educational attainments debarring people from office work; and disabled people being reluctant to engage in unskilled work where the financial incentives were very limited.

### Travelling

The frequency with which disabled people made journeys was closely related to their walking ability (Table 27). Most people who were able to walk up to 100 yards without help went on journeys more often than once a month. Those with greater disability rarely left home unless they had access to a private car, an invalid tricycle or a wheelchair.

Several reasons other than disability were advanced for subjects not getting out regularly. 7 people found that travelling was too uncomfortable. One was a man with ankylosing

spondylitis. The slightest movement caused severe pain. Another had severe breathlessness so that he had to take an oxygen cylinder everywhere he went.

Some people had no-one at home to take them out. 2 of them lived alone and 4 lived with elderly relatives who were too frail to push a wheelchair. Unsuitable housing sometimes was the main problem. 3 individuals were confined to their homes by stairs. One of them stated, however, that she would not have gone out even if there had not been this barrier.

5 were housebound because they lacked a suitable means of transport. Only one would have been able to drive an invalid tricycle. The other four could have gone out if their relatives had had access to a private car.

7 individuals used invalid tricycles. 6 of these vehicles were petrol driven while one was operated off a battery. Though all found that access to private transport was invaluable, several criticisms were raised.

3 people complained about regulations forbidding the transport of passengers in invalid tricycles. This created problems if the vehicle broke down. Drivers could remain stranded for a long time before they were able to attract help. One man found that he was unable to get out at a destination. He had to await the arrival of relatives travelling by bus.

The design of the machines was also criticised. 3 subjects found that instability in wind, rain or snow was a serious problem.

Another 3 complained that their vehicles were unreliable in that they were subject to frequent breakdowns.

The man with an electric tricycle felt safer in this than he had done in a petrol driven vehicle. The limited range of the battery created problems, however.

# Interests

Table 28 enumerates the frequency with which disabled people pursued various interests. Most of them spent a lot of time watching television. Those not doing this usually had visual defects. An exception was a man who could not afford to have his set repaired.

Two-thirds of the group read newspapers and half listened regularly to the radio. A much smaller proportion gained enjoyment from books.

36 people went on regular outings. Only 11 of these went to clubs specifically organised for disabled people. Table 29 lists the diverse range of activities the remainder were engaged in.

People going to special clubs for the disabled were not any more incapacitated than those going on ordinary outings. Indeed, they were marginally less disabled (Table 30). Special clubs seemed to cater mainly for people suffering from neurological diseases. Evidence of this is the fact that 9 out of 11 people attending such places had a neurological condition compared with only 11 out of 24 engaged in other activities (Table 31). It should be noted, however, that the difference between these two groups is not statistically significant.

Less than half the subjects took part in a hobby (Table 28). There was very little difference for the ranges of interests in men and women (Table 32). Women, however, had less leisure time to fill. They busied themselves helping in the running of the household. Most of the men had been unable to find employment and spent a lot of time doing nothing.

## Visitors

Most people had regular contact with friends and relatives from outside. 68 had visits from them several times a week. Only 16 experienced these less than once a week (Table 33). All disabled people who lived alone had contact with a visitor at least once a week. When the pattern of visits was examined in more detail it was found that 30 people only had visits from relatives, that 17 only had these from friends, and that 37 had these from both groups.

### Holidays

51 out of 96 disabled people had been on holiday at least once over the previous two years. 15 of them had gone on vacations organised by a local authority or voluntary organisation. The remainder had gone on their own or with relatives.

12 of the 45 not going on holiday gave a variety of social and financial reasons for this. The remainder stated that they were too disabled to travel. Tables 34 and 35 show, however, that there were few differences in terms of diagnosis or disability
between those going on holiday and those staying at home. Age seemed to be a more important factor in that only 10% of those over 44 went on special holidays for the disabled, compared with 43% of those who were under 30 ( $\chi^2 = 6,22$ , p< 0.05). (Table 36).

# B. <u>The Relatives and Helpers of the Chronic Sick Population at</u> <u>Home</u>.

Many disabled people were only kept at home because a relative was willing to accept a heavy burden of work and responsibility. An attempt was made to quantify this load. In this part of the investigation, the person who did most work for each disabled subject was the only one to be studied. This was done to avoid the complexity of analysing the workloads of several different members in the one household.

#### Age and Sex.

72 women and 17 men were classified as being principal helpers. Most of them were either spouses, parents or siblings (Table 37). The ages of spouses ranged from 30 to 69; those of parents from 40 to 91; those of siblings from 20 to 57; and those of children from 17 to 19. 26 helpers were over the age of 60, 6 were over 70 and 2 were over 80.

## <u>Disability</u>

Most helpers were reasonably fit. 5 of them, however, had severe cardio-respiratory disease, and one had a locomotor disorder. The following are examples of such situations. 1. A woman of 62 with chronic bronchitis and congestive cardiac failure looked after a daughter crippled by a diabetic neuropathy. The daughter could attend to her personal needs so that her mother only had responsibility for housework, cooking and shopping.

2. A man with Parkinsonism had to be dressed by his mother. She was 72 years old and suffered from ischaemic heart disease. This was reasonably well controlled by digoxin and a diuretic.

3. A woman of 48 with ischaemic heart disease looked after a teenage daughter who was completely incapacitated by Little's disease. The effect of moving her daughter made this woman extremely breathless. The result of this was that the daughter had been put on the waiting list for admission to a local young chronic sick unit.

#### Employment

3 out of the 14 husbands who were principal helpers had given up work to look after their wives. Another 2 had changed jobs at considerable financial sacrifice so that they could spend more time at home. One of them was working as a sales representative rather than a sales manager. This allowed him to work at times more suited to his disabled wife's requirements. The other had given up his trade as a butcher, and was working on a night shift cleaning buses. This allowed him to look after his wife during the day, passing on the task to his children in the evening. He was lucky if he got a few hours' sleep between the time of his coming off the night shift and that of his children going off to school.

Only 6 out of 27 women looking after disabled husbands went out to work. It was difficult to assess the extent which their husbands' disabilities had contributed to this situation. Some would have been working had they not had to nurse their husbands. Others worked to supplement the meagre financial resources of their households.

4 out of 14 women looking after siblings were out at work. It is again difficult to evaluate the social significance of this figure.

## Housework

The amount of housework done by helpers was measured using the system devised earlier to assess the chronic sick themselves. A helper doing no housework scored 0. One doing all the cooking, shopping and house cleaning scored 6.

Women invariably were the principal helpers where the disabled person was a man. They usually did all the housework themselves (Table 38). The situation was more complex where the patient was a woman. If she was married, it was her husband who did most of the housework. Single disabled women were usually supported by their mothers or sisters. Very few people helping disabled women did all the housework. The patient herself usually did some of this. Help was also forthcoming from a variety of people including neighbours, friends, home helps and other relatives.

#### Personal Care

The amount of assistance relatives gave patients with their

personal care was estimated by reversing the scoring of Barthel's Index. In this way points were given to activities of daily living for which the disabled person received assistance. 100 was thus awarded to a helper providing every item of personal care. 0 was given where he or she provided none.

This system demonstrated that wives and mothers provided most of the personal care required by disabled men. The care of disabled women was shared between husbands, mothers, sisters and daughters (Table 39).

#### Total Workload

Employment, housework and personal care were considered together in measuring the total work load of each helper (Table 40). A high proportion of the few male helpers seemed to have a particularly heavy burden in that they were forced to assume the threefold role of breadwinner, housekeeper and nurse.

Since most women helpers did not go out to work their problem was often financial stringency rather than excessive workload. The few who did work faced similar problems to their male counterparts. One worked as a clerkess. She also had to devote a great deal of energy in caring for a demented and physically disabled husband. Anxiety about leaving him on his own while she went out to work added to her problems. Another woman worked as a teacher. She relied heavily on her mother-in-law for the care of her husband. He was totally incapacitated by disseminated sclerosis.

# C. <u>Hospital Population</u>

This section deals with (a) the units accommodating young chronic sick patients and (b) the patients themselves.

## (a) The Units

The units fell into several categories. 3 were specifically designated as being young chronic sick units, 7 were geriatric units, 7 were psychiatric units, one was set aside for the care of patients with post-encephalitic Parkinsonism and 4 were surgical, orthopaedic or general medical units. The facilities available in each place are summarised in Table 41.

## Young Chronic Sick Units

Unit A consisted of an entire hospital dealing solely with the care of young chronic sick patients. It contained a physiotherapy department staffed by one full time and two part time physiotherapists. There was one occupational therapist. Her own department was under construction at the time of the survey. A chiropodist, a dentist and an optician paid regular visits. Radio and television were available, and newspapers were delivered to order by a local newsagent. The local branch of the Women's Royal Voluntary Service called with a library trolley once a fortnight.

Recreational activities included card games, draughts, dominoes, billiards and many forms of diversional therapy organised by the occupational therapist. Other provisions included a fortnightly cinema show, and summer runs in a bus owned by the hospital. The day rooms were large, but were pleasantly furnished. They created an atmosphere similar to that of a hotel lounge. Most patients slept in large uncubicalised and rather spartan dormitories. There were several single bedded rooms, however.

Although the unit had been designed for young chronic sick patients, many of its residents were over 65. This was due to the fact that many people had lived in the place for so long that they regarded it as being their home. The staff were naturally reluctant to move them once they reached an arbitrary age limit:

Unit B contained two wards in the grounds of a geriatric hospital. An occupational therapist and a full and a part-time physiotherapist were shared with the rest of the place. There was a large and well equipped occupational therapy room. Many of the patients spent a lot of time there. They were engaged in a wide range of activities. These included woodwork, ceramics, basket making, painting, sewing, knitting and typing.

Other diversional activities were organised in the day rooms by a ward hostess. This person was an auxiliary nurse who had been given some basic training by the occupational therapist. Her task was to provide stimulation and entertainment for patients throughout the course of each day (Dunn and Strang, 1970).

There was access to radio, television and newspapers. Books had been collected on an informal basis from visitors and members of the staff.

Local organisations gave concerts several times a year. Many residents enjoyed a weekly bingo session organised by local office workers. They also went on several bus runs during the summer.

The wards were divided by partial partitions into multiple sleeping areas of between two and four beds. There also was a dining area and a small day room in each ward. The unit was comfortable but had a rather clinical atmosphere in that the cubicles had glass panels, the floors had little carpeting and most of the furniture was of a standard hospital type.

Unit C was part of a small long stay geriatric unit. There was no physiotherapy and an occupational therapist only visited once a week. Radio, television and newspapers were available, but there was no library service. There were occasional concerts, and voluntary visitors called once a week to talk to patients.

The sleeping areas were uncubicalised and contained a variable number of beds. There was only one small day room. As a result, patients spent most of their time in austerely furnished corridors between the main sleeping areas.

### Geriatric Units

A, B and C were assessment or long stay units in geriatric hospital of over 200 beds; D was a long term unit in a mixed geriatric and surgical hospital; E, F and G were long stay geriatric hospitals of 100 beds or less.

A, B and C were attended by between one and three full time

physiotherapists. Only B and C had full time occupational therapists. A only received a weekly visit from one.

All three units provided radio and television, but newspapers were difficult to come by in B, and there were no library facilities in A. The only communal activities were a monthly film show in B, and very occasional bus runs from B and C.

D shared three physiotherapists and one occupational therapist with other units in the hospital. Television and radio were available. The Women's Royal Voluntary Service made regular visits with books and a food trolley. Occasional concerts and bus runs were the only other activities.

E was the only unit amongst E, F and G to have both a physiotherapist and an occupational therapist. E and F only received weekly visits from such people. All three units had television, but only E and F had radio, and only E provided access to books. There were no regular outings from any of the units.

G contained a well stocked day centre. An occupational therapist and physiotherapist treated both in-patients and day visitors here.

The ward designs of the seven geriatric units varied between the Nightingale plan and various cubicalisation arrangements. All units other than C and F had day rooms of varying size and amenity. <u>Psychiatric Units</u>

All the units had between one and four occupational therapists, and all but A had either one or two physiotherapists. All gave access to radio, television and newspapers. C was the only one without a library.

A wide variety of activities were laid on at most of the hospitals. These included sports such as swimming, football, tennis, putting and bowling. There also were socials, dances, films, bingo sessions and bus runs.

The accommodation usually was well furnished and pleasantly decorated. On the other hand, the dormitories provided little privacy, and were often large and overcrowded. Though the day areas were well stocked with furniture, books and games, they were usually large and barn like.

#### Post-encephalitic Parkinsonism Unit

This unit was part of a general hospital which employed seven physiotherapists. There were no occupational therapists. A radio, a television set and a record player were available, but books were scarce. Local organisations arranged monthly concerts and fortnightly film shows. There were several bus runs each summer.

The beds were divided between several dormitories. Each contained at least four patients. The day rooms were large, but were sparsely furnished and drably decorated.

#### Other Units

All of these units had ready access to physiotherapy and occupational therapy. Day room accommodation and recreational facilities were very limited.

## (b) The Patients

c sick -34 individuals in young chronic sick units, 25 in geriatric units, 26 in psychiatric hospitals, 10 in the post-encephalitic unit and 6 in other units were included in the survey.

#### Age and Sex

The ages of people in psychiatric and young chronic sick units ranged from 20 to 59 years (Table 6). The numbers of patients rose steeply with increasing age so that most of them were over the age of 44. None of the people in the geriatric unit was less than thirty, and more than half were over 55. Everyone in the post-encephalitic unit was over 45. There was a wide scatter of ages in the medical, surgical and orthopaedic units.

The sexes were equally represented in most of the units. In the young chronic sick units, however, there was a preponderance of women (Table 42).

## Duration of Stay

There were no significant differences in the lengths of time patients had spent in young chronic sick, geriatric or psychiatric hospitals. Mean values for these were 4, 6 and 7 years respectively (Table 43). None of the people in medical, surgical or orthopaedic wards had been in them for more than three years.

Subjects in the post-encephalitic unit had been in hospital for a particularly long time. Here, the mean duration of stay was 16 years. This was the result of many of the patients being hospitalised after outbreaks of encephalitis in the 1930s.

#### <u>Diagnosis</u>

Table 44 lists the diagnoses made in the different types of unit. These are grouped into systematic categories in Table 45. It should be noted that cerebrovascular disease was classified under the heading of neurological disorders rather than that of organic brain disease. This was done because this particular intracerebral disease often gives rise to severe physical impairment. Such a finding is less common in most other forms of organic brain damage.

The bulk of patients in young chronic sick and geriatric units suffered from neurological disorders. Amongst these, disseminated sclerosis and cerebrovascular disease predominated. Differences in the prevalence of these particular disorders for the two types of unit were not statistically significant.

The two patients in the young chronic sick unit who were suffering from cardio-respiratory disease presented with unusual medico-social problems.

One of them was a woman with chronic bronchitis who had become blind with the development of bilateral cataracts. The severity of her chest disease made surgical intervention impracticable. She was in a chronic sick unit rather than a blind welfare home, because her respiratory disorder required close medical supervision.

The other was a teenage girl suffering from Fallot's

tetralogy. On hearing of this defect, her parents had abandoned her in infancy to the care of a children's hospital. She had spent all her childhood in a residential school for disabled children. Her transfer to the chronic sick unit was arranged when she reached the age of 16. She was only mildly disabled, but there was no suitable accommodation for her outside hospital.

Most of the people in psychiatric hospitals suffered from organic brain diseases. Head injuries were particularly common as a cause of this. The two patients classified as having neurological disorders also had intellectual disturbances.

One had slight weakness in his right leg resulting from poliomyelitis in childhood. He was in hospital for the treatment of simple schizophrenia. The other had evidence of Friedrich's ataxia. He was also mentally subnormal. There was uncertainty as to whether or not the two conditions were related.

Most people in medical, surgical or orthopaedic wards were not suitable candidates for a long stay unit. The three with spinal tuberculosis were receiving prolonged bed rest as part of their treatment. Another with a cerebral tumour had come into hospital in the prolonged terminal phase of his illness. One young woman had suffered a cerebral embolism as a result of atrial fibrillation in chronic rheumatic heart disease. Her treatment with digoxin and anticoagulants required frequent adjustments. The one exception was a woman with spinal artery thrombosis. Deplorable social circumstances made the management of her quadraplegia outside hospital impossible. There was no reason why she should not have been in a young chronic sick unit. Defects of Speech, Hearing and Vision

Table 46 shows the causes of the various speech defects identified in the survey. Aphonia was rare while dysarthria and dysphrasia were common. The conditions most frequently causing speech disturbances were Parkinsonism, Little's disease and cerebrovascular disorders. In a few patients, speech was totally incomprehensible. The majority were able to express themselves if the listener showed sufficient sympathy and patience.

6 patients were deaf. Diagnoses in these were cerebral venous thrombosis, spinal tuberculosis, Friedrich's ataxia, Little's disease, disseminated sclerosis and cerebrovascular disease. In the first two, deafness was part of the disease process. It was related to streptomycin therapy in the patient with spinal tuberculosis. The other three patients had deafness unrelated to their primary disorder.

The incidences of speech, hearing and visual defects in the various types of unit are given in Table 47. Speech defects were rare in mental hospitals. They were common in young chronic sick and geriatric units and universal in wards managing post-encephalitic Parkinsonism.

## Secondary Disorders

A high proportion of subjects suffered from more than one disease. (Table 48). Table 49 lists the secondary disorders. It was difficult to assess the extent to which they contributed to

overall disability. Many, however, must have played a major part. Such disabling conditions included congestive cardiac failure, a fractured neck of femur, an amputation of a leg, angina, cerebrovascular disease, Little's disease and rheumatoid arthritis. Others including hiatus hernia, Dupuytren's contracture and peptic ulceration could have had little effect on overall incapacity.

## Physical Impairment

Impairment ratings were high for people in geriatric and young chronic sick units (Table 50). This contrasts with the minimal degree of physical impairment found in psychiatric patients. Mental Function

A comparison of scores for Raven's Matrices with those for the "IQ test" gave results similar to those for disabled people living at home (Graph 6). A low score on the "IQ test" was usually associated with a low one for Raven's Matrices. Where the rating for the "IQ test" was high, there was a wide range of values for Raven's Matrices.

Table 51 gives the scores of Raven's matrices for patients in different types of unit. These are expressed as percentiles in Table 52. Scores were similar in geriatric and young chronic sick units. In psychiatric hospitals, subjects in the 25% with lowest values scored much more poorly than those in geriatric or psychiatric units. The 25% with the highest ratings scored as well as similar groups in other types of unit.

An analysis of "IQ test" scores is given in Tables 53 and 54.

Here again, patients in geriatric and young chronic sick units achieved comparable results. On this occasion, however, people from both the lowest and highest quartiles in the psychiatric units obtained worse ratings than their equivalents in other units.

The two tests of mental function suggest that, on average, subjects in mental hospitals had less intellectual ability than those in other units accommodating the chronic sick. There was, however, a striking overlap between the two groups.

Many people exhibited mental abnormalities other than dementia or subnormality (Table 55). Depression was particularly common in geriatric and young chronic sick units. Most patients presenting with noisiness, aggression, paranoia or behavioural problems were to be found in mental hospitals.

## Disability

Inability to perform activities was investigated using Barthel's index (Table 17). There was a marked difference between patients in psychiatric hospitals and those in geriatric or young chronic sick units. The ones in the latter were much more severely disabled.

Individual self care activities were also assessed (Table 56). The most common difficulties in young chronic sick and geriatric units related to walking, dressing and toileting. Patients in psychiatric hospitals were more frequently troubled by an inability to dress, wash or toilet themselves. The pattern of disability in the post-encephalitic unit resembled that found in mental hospitals.

An attempt was made to gauge the relative importances of physical and mental impairment as causes of disability. This was done by plotting scores for physical impairment against those calculated for Raven's matrices and the "IQ test". (Graphs 7, 8, 9 and 10).

Physical impairment appeared to be a major determinant of disability. Mental impairment was much less important. It rarely gave rise to severe disability where it occurred on its own. The effect of physical impairment on disability, however, was often accentuated by mental impairment.

The patterns obtained in Graphs 7, 8, 9 and 10 suggested that patients could be divided into four groups:

A. Those with little or no physical or mental impairment.
B. Those with major physical but little mental impairment.
C. Those with little physical but gross mental impairment.
D. Those with severe physical and mental impairment.

This system was used to compare patients from different types of unit. Patients from mental hospitals predominated in groups 1 and 4. All four groups were well represented in geriatric and young chronic sick units. Thus severe physical impairment was rarely found in mental hospitals, but psychiatric abnormalities were common in units set aside for the care of the physically incapacitated.

#### Interests

Most people in all types of unit watched television and

listened to the radio (Table 57). It was more difficult to determine the extent to which patients were really interested in the programmes presented on these media. Some merely sat in a room where a radio or television happened to be switched on.

Reading was a less popular activity. Only half the subjects read newspapers and less than a third read books. There were few differences in the reading habits of people from different types of unit. Less people in psychiatric units than those in geriatric or young chronic sick ones read books but this difference was not statistically significant.

Mental ability appeared to have little effect on the reading habits of individuals. The mental test scores of many people rarely reading books or newspapers were as high or higher than many regular readers (Graphs 11 and 12). The only consistent non-readers were those with very low "IQ test" scores.

Three-quarters of patients from young chronic sick units, half of those from geriatric wards and one-third of those from mental hospitals went on regular outings. The small difference between outings from young chronic sick and geriatric units was not statistically significant.

It was thought that the difference between young chronic sick and psychiatric units might have been related to the lower intellectual ability of people in the latter. Graphs 13 and 14, however, suggest that intelligence had very little influence on the number of outings enjoyed by an individual. Another explanation for the difference between psychiatric and chronic sick units is that the former had many more facilities to offer within their own grounds. Outings may not have been of such great importance in this situation.

The term "outings" has been used to cover a wide range of activities. Table 58 provides more information about these. They included bus runs, home visits, car runs with friends and visits to places of entertainment such as the cinema or theatre. A bus run appears to have been the most populat type of outing.A greater proportion of patients from mental hospitals than from other types of unit went on home visits. It is uncertain whether this reflects a difference in administrative policy or a difference in the degree of physical incapacity for the two groups.

Physical impairment does not seem to have been an insuperable barrier to friends or relatives taking patients on outings. Graph 15 shows that some very severely disabled people went on these. The following are examples of travelling problems which were successfully tackled.

1. A man with disseminated sclerosis went on a car run with his son once a month. His limbs were paralysed and fixed in flexion at the elbows, hips and knees. Though rarely incontinent he suffered from frequency of micturition.

2. Another patient suffered from post-encephalitic Parkinsonism. This had left him with a gross tremor, and a moderate increase of tonus in all four limbs. He only had grade 3 power in his arms and

grade 4 power in his legs. His left foot was permanently fixed in inversion. These afflictions made walking or even moving a wheelchair impossible.

Despite this incapacity he went to a cinema once a week. He was taken there by a taxi driver who had known him for years. At the cinema, the driver placed him in a place reserved for wheelchairs at the back of the stalls.

Attention was next directed towards hobbies. These were considered to be either participatory or constructive. A participatory hobby was defined as being one which involved social contact with other people. In a constructive one the patient was engaged in creative activity. Though some hobbies might be both participatory or constructive, most could, in practice, be placed in one or other of the categories.

Table 59 shows that more patients from the young chronic sick units were involved in constructive hobbies than those from other units. The former group also had a much wider range of activities open to them (Table 59). The numbers in each type of unit were too small to assess the effect of age, sex, mental or physical impairment, disability or social status on an interest in hobbies.

## Frequency of Visits by Friends and Relatives

Table 60 relates the number of visits received by patients to the distances between the units and their homes. Within a maximum of 20 miles, distance had no effect on the visiting habits

of friends and relatives. Very few patients lived more than 20 miles from home. Even in this group, there was only a slight fall in the number of visits from relatives.

#### D.A Comparison of Home and Hospital Populations

This part of the survey compares many of the findings already detailed in section 1 and 3. Additional information has been used where this serves to highlight differences between the home and hospital populations.

#### Age and Sex

The numbers in both home and hospital populations showed a steep rise with increasing age (Table 6). Apart from a preponderance of women in the young chronic sick units, men and women were evenly represented in the home and hospital groups (Table 42).

## <u>Diagnosis</u>

Most hospital patients suffered from neurological conditions. There was a much wider range of disorders in people living at home (Table 45). Neurological conditions also predominated in this group, but locomotor and cardio-respiratory disturbances were common. As might be expected, organic brain disease was much more common in the residents of psychiatric hospitals than people in the community.

#### <u>Disability</u>

There was a marked difference between the self care ratings of people at home and those in geriatric and young chronic sick units (Table 17). There was, however, a marked overlap between the two groups. Thus, it was exceptional for patients in long stay units to score well, but a large proportion of those at home had low ratings. A different pattern was observed in psychiatric hospitals. Here most of the subjects were much less handicapped.

Individual self care activities were examined in more detail. This showed that most patients in geriatric and young chronic sick units were unable to walk without help. (Table 56). Only 11% of those at home and 25% in mental hospitals were disabled in this way. The majority in geriatric and young chronic sick units were unable to wash, dress, feed and toilet themselves (Table 56). Only 27% of those at home and 33% from mental hospitals were in this position.

Incontinence of urine or faeces, again, was much more common in the hospital population. One-third of people in geriatric and young chronic sick units and one-fifth in psychiatric hospitals had this problem. It was only encountered in 6 out of 96 people living in the community.

## Mental Function

Table 51 details the values obtained for Raven's matrices by people living at home or in hospital. These are expressed as percentiles in Table 52. Scores were substantially higher in the community than in geriatric, young chronic sick or psychiatric units.

Similar results were obtained when the "IQ test" was used to assess mental function (Tables 53 and 54). Differences between people at home and in geriatric or young chronic sick units were less striking, however. This may be due to the "IQ test" being less effective than Raven's matrices in differentiating between people of moderate or high intelligence. The cluster of values at the upper ends of the "IQ test" scales in Graphs 1 and 6 suggests this hypothesis.

In addition to mental impairment, other forms of psychiatric abnormality were more common in hospitals than in the community (Table 55). These included euphoria, noisiness, schizophrenia, emotional lability, aggression, paranoia and behavioural problems. Depression was common in both situations.

#### Housing

30 people had no homes to go to. Their houses had been given up for a variety of reasons.

1. In 8 instances it had become obvious that the patient was too disabled to return to an independent existence.

Houses had often been given up after the death of a relative.
 In 6 instances this had happened to a spouse, in 4 a parent and in
 1 a sibling.

3. In 3 cases siblings had sold the house when they moved off to get married.

4. The husband of one patient had sold the house after the onset of a cerebrovascular accident. He was currently receiving long term care. 5. The brother of another had also been admitted for long term care.

6. Another patient had given up her house after her husband deserted her.

7. The home of a teenage patient had ceased to exist when her parents divorced each other.

8. The wife of another patient had given up their house and had gone to live with parents.

9. A girl had been abandoned by her parents while she was in her infancy. They had subsequently left the area.

10. The house of another patient had been demolished.

11. The family of one woman had split up after her admission to hospital. Her husband had gone into lodgings, and her children were under the care of a local authority.

The majority of people in hospital had a home to go back to, but this was often unsuitable. This was even more common than for people actually living at home (Table 61). It is doubtful, however, whether such direct comparison had any validity. The patients in hospital were more disabled. They were consequently more likely to find many forms of housing inconvenient.

An attempt was made to tackle the problem by comparing groups at home and in hospital with similar degrees of disability (Table 62). People in hospital who were unable to climb stairs were more often in unsuitable housing than their counterparts living in the community.

The difference, however, was not statistically significant.

The negative result might be related to the small numbers investigated. It is also possible that poor housing does not often lead to hospitalisation. In support of the latter conclusion, is the fact that 41% of people in the community who were unable to walk lived in inappropriate accommodation.

## Assistance at Home

10% of subjects in the community lived alone. This compares with 32% of those in hospital who had no homes or who had no-one to look after them. (p < 0.05). There were also differences in the mental statuses of people in the two groups. 52% of those at home were married compared with 31% of those in hospital (p < 0.05). From this the converse follows that a higher proportion of people in hospital were single, widowed or divorced.

The relevance of marital status to hospitalisation became apparent when the availability of help to married people was compared with that to those who were single, widowed or divorced. 51 out of 52 married people in the community, and 31 out of the 32 in hospital had someone at home to look after them. Only 34 out of 44 single, widowed or divorced people at home and 35 out of the 59 in hospital were in this position.

The single, married or divorced people who had the support of relatives were considered in greater detail. 30 out of 44 in the community lived with parents. Another 14 lived with siblings, and one lived with a friend. 12 out of 31 in hospital had parents at

home. Another 18 had siblings and one had an aunt and uncle. It was thus apparent that a greater proportion of people in the community had parents at home to support them. The difference is statistically significant (p < 0.05).

There was also a difference in the prevalence of disability amongst relatives of subjects in the home and hospital populations. 5% of relatives to the home group had serious incapacity compared with 13% of those to the hospital group. The difference again is statistically significant. Table 58 lists the disorders identified in the relatives of the two populations.

## Reasons for Disabled People being in Long Stay Units

Table 63 details the reasons for disabled people being kept in long stay units. In many instances, severe incapacity was the sole reason for a patient receiving care in a geriatric or young chronic sick unit.

An example was a man of 46 who had suffered from a cerebrovascular accident. This had left him with complete paralysis in his left arm, and grade 4 power with gross spasticity in his left leg. He was able to talk without difficulty, and showed only a minor degree of mental impairment. He was chairfast, incontinent of urine and unable to wash or dress himself. His severe disability made it impossible for his wife to look after him. A geriatric unit near his own home provided him with the appropriate nursing care.

Other patients suffered from both physical and mental

impairment. An example was a youth of 22 with Little's disease. There was gross spasticity and weakness of all four limbs. Contractures held his knees in flexion and his ankles in plantar flexion and inversion. He was blind, and grossly demented. He was unable to do anything for himself, was doubly incontinent and spent most of the time screaming at the top pitch of his voice. Physical impairment made his transfer to a mental hospital impracticable. His noisiness, however, was very distressing to other disabled patients.

Some people in hospital might have managed at home if someone had been there to look after them. An example was a 58 year old woman suffering from disseminated sclerosis. She had slight weakness in her left arm and considerable weakness in her left leg. There was moderate spasticity in her left arm and gross spasticity in her left leg. Despite this severe physical impairment, she was able to walk with a zimmer and to dress, wash and toilet herself. She had been forced to come into a young chronic sick unit on the death of her husband.

Illness in a relative at home was another reason for a young chronic sick patient being in hospital. An example was a 31 year old woman with disseminated sclerosis. She had slight weakness in her left arm and leg associated with moderate spasticity. There was also a slight intention tremor in her left arm. She was able to walk with a zimmer, and to wash and dress herself. Her main problem was urgency of micturition. This resulted in her being incontinent if she did not have ready access to a commode or

toilet. She was unable to go home because both her parents were in their seventies and seriously incapacitated by ischaemic heart disease.

A small group of disabled people were in hospital for a variety of social reasons. One woman only had three brothers at home. They were unsuited to providing the intimate nursing care which she required. Other subjects had been rejected by relatives as being too much of a burden, or had been reluctant to impose a continuing load on willing relatives. In yet another instance, a personality clash between a patient and her sister made it impossible for them to live under the same roof.

Only two patients were in hospital for solely medical reasons. These were receiving prolonged bed rest in a plaster cast as part of the treatment for spinal tuberculosis.

Most people in psychiatric hospitals had been admitted because of mental abnormalities. An example was a man of 59 who had been demented for many years. This had been the result of a blow from an aeroplane propellor during the Second World War. There was no physical impairment, but the patient was unable to wash, dress, toilet or feed himself. Constant supervision was required to prevent him from wandering out of the hospital and getting lost.

A few people in psychiatric units had considerable physical impairment. They would probably have been in geriatric or young chronic sick units had they not also had gross mental disturbances. An example was a man of 44 who had been involved in a car accident.

This had left him with a mild dementia and a left sided hemiparesis. Muscle power was grade 3 in his right arm and grade 4 in his left leg. He was able to wash and dress himself but a bladder injury had made him incontinent of urine. His treatment had originally been given in a young chronic sick unit but his aggressive behaviour had necessitated the transfer to a psychiatric hospital.

### Alternative Accommodation for Patients in Hospital

Table 64 details the amount of domestic, self care and nursing support required by patients in hospital. Some of the subjects, had they been at home, would only have required help with housework. Others, at the opposite end of the scale, were unable to wash, dress, feed or toilet themselves. A proportion were able to look after many of their own needs, but were incontinent or required supervision because of mental impairment or behavioural disorders.

This information was used to speculate on whether other forms of accommodation might have been more appropriate to people currently receiving long term hospital care.

9 could have managed in their own homes with the support of a home help visiting daily to provide meals and do housework. Several of these might also have required regular visits from a nurse or nursing aide to bath them. The needs of the group could also have been provided in a hostel.

Another four required additional help with washing and dressing. This could have been provided in a hostel. Extra staff would have had to be employed to provide basic help with self care.

Most of the other people in the geriatric, post-encephalitic or young chronic sick units required help with more self care activities than washing and dressing. This degree of attention could only have been provided by staff with some training in nursing techniques. The best way of providing this was to use some form of hospital accommodation.

Many patients, particularly those in mental hospitals, were relatively independent, but required a considerable amount of supervision. 23 only required support from someone who would ensure that they did not get lost and that they dressed, washed, fed and toileted themselves. Such unskilled supervision could have been provided in a hostel. Another 8 people were aggressive or exhibited suicidal behaviour. They obviously required the services of specially trained nurses in a psychiatric hospital. Finally, there were 5 who had mild mental and physical impairment. They might have coped in a hostel where both supervision and help with self care were available.

Overall, two-thirds of patients in mental hospitals, half in the post-encephalitic unit, one-third in young chronic sick units, one-fifth in geriatric units and one-sixth in medical, surgical or orthopaedic units might have managed outside hospital. This could only have been achieved by the expansion of existing hostel accommodation and facilities for community support.

## Discussion

#### A. Disabled People in the Community

## Selection

The method used to select disabled people living at home is open to considerable criticism. One major defect is that inability to do housework or to find employment is related to many factors other than disability. These include motivation, educational background, previous employment, experience, the design of a subject's house, and impending litigation after an industrial accident. The reason for using these particular selection criteria was that they afford a simple method for identifying disability.

Selection based on inability to perform certain self care activities would have provided more accurate information. However, this could only have been achieved by analysing the results of a preliminary postal or door to door survey covering a wide area (Jefferys, Millard, Hyman and Warren, 1969; Banks, Carpenter, Hislop and Nisbet, 1957). Such a project was beyond the scope of a single investigator who did not have a staff of field workers.

Another objection to the selection technique is that its accuracy was dependent upon the memory of general practitioners. Again, a postal or door to door survey would have been more accurate had it been practicable. On the other hand, the people selected in this survey were more likely to represent a cross section of the disabled population, than subjects identified from registers of disabled people compiled by local authorities. Future surveys of the chronic sick should be facilitated if local authorities are able to meet their legal obligation of identifying all disabled people in their area (Chronically Sick and Disabled Persons Act. 1970).

#### Age and Sex

The present age distribution of subjects resembled that found by Rankine and Weir (1967) who used similar methods of identifying the young chronic sick (Graph 16). Even more striking, is the correlation between the present results and those of a national survey of disabled people where much more accurate selection techniques were used and where a much wider range of disability was covered (Harris, 1971). (Graph 16).

The rising prevalence of disability with age could be due to diseases acquired early in life causing increased incapacity as patients grow older. However, evidence from the present investigation suggests that, in most instances, disability is the result of a disease acquired in early or late middle age (Table 7).

The investigation supports the finding of others that, in youth and middle age, disability is equally common in males and females (Rankine and Weir, 1967; Skinner, 1967; Harris, 1971). This contrasts with the pattern for the aged. Here, a high male mortality produces a marked preponderance of female invalids (Harris, 1971).

#### <u>Diagnosis</u>

The pattern of disorders encountered in this study is similar

to that found by Rankine and Weir (1967) in Fife. Both show a marked preponderance of neurological disorders. Banks, Carpenter, Hislop and Nisbet (1957) and Skinner (1967) found that, in their surveys, the most common cause of disability was cardio-respiratory disease.

Geographical variation might be partly responsible for these discrepancies. Another factor might be differences in selection criteria. Evidence of this is to be found in the national survey reported by Harris (1971). Here, if all subjects including those with minor disability were included, a high proportion were found to be suffering from locomotor or cardio-respiratory disorders. When, however, only people with severe disability were considered, patients with neurological disease predominated. It appears, thus, that the prevalence of neurological disease increases with the degree of disability in the population studied.

This finding may be used to explain differences between the surveys of Rankine and Weir (1967) and the author, and those of Banks, Carpenter, Hislop and Nisbet (1957) and Skinner (1967). In the former studies, subjects were chosen because they suffered from disorders seriously interfering with such important tasks as dressing, doing housework or going out to work. Skinner (1967) investigated people experiencing even minor difficulty in performing a wide range of activities. Anyone who claimed to be handicapped was included in the study of Banks, Carpenter, Hislop and Nisbet (1957).

Another factor influencing the types of disease found in a

disabled population is its age group (Table 10). Severe disability in a young adult is usually related to a neurological disorder. This is often disseminated sclerosis. In middle age, rheumatoid arthritis, chronic bronchitis and cerebrovascular disease assume increasing importance. Despite its high prevalence in the community, ischaemic heart disease does not appear to be an important cause of moderate or severe disability.

#### Multiple Pathology

About one-quarter of subjects suffered from more than one disease. It is interesting to note that the prevalence of this phenomenon rose with increasing age (Table 12). This trend reaches an extreme in old age. Thomas (1968), for example, noted that 83.7% of patients over the age of 65 suffered from more than one disease.

In many people with multiple pathology, only one of the disorders was responsible for significant disability. 14% of all subjects, however, were afflicted with two or more diseases each of which was a major cause of incapacity. This emphasises the importance of investigating the physical condition of a disabled person in detail rather than applying a single diagnostic label to him.

There is little evidence that the practical difficulties of people with disability due to two or more disorders are any greater than those where incapacity is due to one disease. An exception is the problem of the patient in whom physical impairment is associated with blindness or deafness. Considerable skill must be exercised in coordinating the special services for blind or deaf people with those available to people with other forms of handicap. The recent reorganisation of local authority social services may simplify this task (Seebohm, 1968).

# Physical Impairment

Overall disability is related to a variety of physical, psychological and social factors. It is relatively simple to devise a method of quantifying intellectual ability or adverse social factors. The measurement of physical impairment presents greater problems. This is due to the fact that many tests of physical capacity are affected by the mental prowess or social background of a subject. Such a criticism can be directed at the system devised by the Committee on Medical Rating of Physical Impairment (1958 i and ii, 1960, 1961 and 1963).

The tests described by Jefferys, Millard, Hyman and Warren (1969) provide a more acceptable and extremely accurate method of assessing physical impairment. They do not measure sustained activity, however. Thus they are of limited value where physical impairment has to be related to ability in performing housework or engaging in employment.

The impairment system used in the present survey was comparatively crude, and the values assigned to each form of impairment were purely arbitrary. Some form of weighting system would obviously have increased the accuracy of the method. Such a system has been used to great effect in constructing diagnostic or prognostic indices (Peel, Semple, Wang, Lancaster and Dall (1962). In the present situation, there was no obvious yardstick such as diagnosis or prognosis against which the accuracy of an impairment rating system could be evaluated.

Despite its many deficiencies, the present rating system had two main advantages. Firstly, it was reasonably effective in separating physical impairment from other factors influencing disability. The other important point was that sustained effort was included in the overall assessment by the measurement of breathlessness, angina and intermittent claudication.

A large proportion of subjects had surprisingly little physical impairment. Many of these with low impairment ratings suffered from locomotor or cardio-pulmonary disorders (Table 14). It is probable that these people were able to perform self care activities, but were unequal to the sustained effort required for working in industry or doing housework. The impairment rating system might thus have been improved by increasing the weighting of signs and symptoms relating to sustained effort.

## Mental Function

The accurate quantification of mental ability was limited by the fact that the observer was not a trained psychologist, and that many of the subjects had a limited tolerance to interrogation. For these reasons the tests were short and easily performed and analysed. It was found that, in practice, Raven's matrices and the "IQ test" were complementary to each other in a disabled population. People with visual defects were able to perform the "IQ test". Those with deafness, dysphasia or dysarthria tackled Raven's matrices. Another important point was that neither of the tests was dependent upon manual dexterity. Thus, they were unaffected by the extent to which a subject was physically incapacitated.

Though there was a significant correlation between the results of the two tests the relationship was far from perfect. This might be expected in two tests which measured different aspects of intellectual ability (Raven, 1965; Robinson, 1970). The most important effect of the limited correlation was that considerable discrepancies between the tests were often found in the assessment of individual subjects. When the population was considered as a group, it became apparent that Raven's matrices were more effective in discriminating between people at the upper end of the intellectual scale. The "IQ test" was of more value at the opposite extreme.

At the start of the survey, there was concern that Raven's coloured matrices might be too easy for them to be useful in assessing mental ability in young or middle-aged adults. Raven (1965) considers that his coloured matrices should only be used for people who have difficulty in reasoning by analogy. These are usually children or old people. The fact that the majority of subjects in the present survey had difficulty in performing the test suggests that many of them had impaired intellectual ability. The unfavourable comparison made between
their scores and those of 11 year old schoolchildren reinforces this conclusion (Table 15).

The low scores for Raven's matrices was partly related to the high prevalence of neurological disorders in the disabled population. The association between mental impairment and such conditions as Parkinsonism, disseminated sclerosis and cerebrovascular disease is well recognised (Brain, 1962; Surridge, 1968; Henderson and Bachelor, 1962).

Even when such conditions were excluded, however, the scores of subjects remained low (Table 15). It is possible the withdrawal of disabled people from many of the activities of everyday life might have resulted in mental atrophy. An alternative explanation, is that more intelligent people who had been able to overcome their disability and engage in employment had been excluded from the survey. Further exploration of these possibilities would require a comparison of the present sample with a similar group who were doing housework and going out to work.

It is hardly surprising that many disabled people exhibited evidence of depression or anxiety states. There usually was a clear connection between these abnormalities, and the desperate medical and social circumstances in which many of the subjects found themselves. This impression supports the conclusion of Surridge (1968) that, in disabled people, depression is normally related to the medico-social situation rather than specific brain damage. Treatment with drugs or electricity might help some depressed disabled people. A larger number would derive greater benefit from more frequent outings, more varied interests, or more frequent social contacts. This situation would seem to be admirably suited to the skills and talents of a social worker.

# Activities of Daily Living

Less than half the people studied were so disabled that they were unable to walk without help. The numbers requiring help with other self care activities were even smaller. These figures indicate that a relatively small proportion of disabled people are in need of help with self care activities. Similar conclusions may be inferred from the national survey reported by Harris (1971). This estimated that although there were over a million disabled people between the ages of 16 and 65 in Great Britain, only 150,000 required a significant amount of help with self care. These proportions have important implications when community services for the young chronic sick are being planned.

## Personal and Nursing Care

There was little evidence that any of the patients were receiving inadequate personal or nursing care. It was noteworthy, however, that this support usually came from people within the same household as the subject. Neighbours or relatives from outside rarely played an important part in this type of care. District nurses, however, were invaluable in that they provided assistance in giving injections, dressing pressure areas, dealing with bowel and bladder problems and performing bed baths. They were rarely involved in the broader aspects of self care. This is merely a reflection of the fact that it was impossible for them to spend the whole day in the one household.

The development of a nursing aide service might provide a partial solution to this problem (Guthrie, 1968). It should be possible for a nursing aide, acting under the direction of a district nurse, to look after a disabled person for up to eight hours per day. This would be of considerable value where other members of a household had to go out to work. Such a service would be costly, but less expensive than hospital care.

# Aids, Appliances and Equipment

While many people had walking aids, a much smaller proportion had aids to other forms of activity. This is due to the fact that, in many centres, rehabilitation ceases once a patient is back on to his feet. Little attention is given to training in washing, dressing or toileting. There is also a great deal of ignorance about the range of aids, appliances and equipment available for the young chronic sick.

The National Fund for Research into Crippling Disease attempted to ameliorate this state of affairs by publishing a catalogue of equipment for the disabled (Agerholm, 1960). This can be obtained on application to the Central Council for Disabled. It is also important that more emphasis be given to rehabilitation in the curricula of nursing and medical schools. There should also be closer inter-professional co-operation in tackling the needs of the disabled (EMA Planning Unit, 1969).

## Housework

Several important points emerged when the amount of help required was related to the person who provided this. A wife looking after a disabled husband rarely experienced much disruption in her domestic arrangements. Though she often had financial problems she was often able to continue in the single role of housekeeper.

If the wife was the patient, the situation was much more difficult. This was due to the fact that her husband usually attempted to combine the duties of breadwinner, housekeeper and nurse. Inevitably this imposed a considerable strain on him. It often also affected his wage earning capacity.

Few families in this difficult situation engaged a home help. Some were inhibited by the fact that this service might have cost them a considerable amount of money. The majority, however, had simply not thought of applying for one. There is an obvious need for such families to be identified so that available services can be explained and offered to them.

## Housing

Very few subjects lived in houses which were in a poor state of repair, or lacked such basic amenities as fitted baths or inside W.Cs. This contrasts with the investigations of Townsend (1967) and Skinner (1969). A high proportion of their subjects were living in substandard accommodation. The difference is probably due to local authority housing being more readily available in the

West of Scotland than in London and the surrounding area.

A much greater problem, in the present survey, was the number of people living in inappropriate accommodation. This usually related to stairs confining people to the house or to certain parts of the house. The limited amount of local authority accommodation suitable for disabled people may partly account for this problem. It is important to note, however, that half the people in this situation tolerated the inconvenience, rather than face the problems involved in moving to a house in another area. This dilemma could eventually be solved by building all local authority houses so that they suited the needs of both healthy and disabled people (Grant, 1962).

## Employment

Inability to work was one of the criteria for people being included in the survey. It was difficult, therefore, to assess the adequacy of facilities existing for the employment of disabled people. It was apparent, however, that physical or mental impairment was rarely the sole reason for not working. Many other socio-economic factors made work impracticable or undesirable.

The most important of these was the high rate of unemployment in the West of Scotland. This point also received emphasis from Henderson, Barr and Cowan (1963) when they discussed the causes of long term incapacity for work.

The present investigation supports the conclusion of Rankine and Weir (1967) that the prospects of a disabled person finding work decrease with increasing age. Firms may be reluctant to employ older people. The unwillingness of an older patient to accept a job inferior in status to his previous one may also play a part. An additional factor is that it becomes increasingly difficult for a person to modify his working pattern as he gets older (Bromley, 1971). There is an obvious need for employers, employment services and disabled people themselves to have a more positive attitude towards the middle aged chronic sick.

Limited educational attainment was an additional obstacle in the path of many disabled people who were trying to find work. This problem is accentuated where long periods of illness in childhood prevent an individual from attending school (Buckle, 1971). Every effort should be made to seek out and remedy any defects in the existing provisions for educating disabled children.

A final reason for disabled people not working was a lack of financial incentives. Many of them were drawing as much money from various state benefits as they could have earned in such capacities as lift operator, car park attendant or sheltered workshop employee. Though not helping financially work might perhaps have provided them with more frequent social contacts, and more time spent in mentally stimulating activity. It is doubtful, however, whether all disabled people would see the validity of this argument.

Some of the most severely disabled people might have been able to perform work in their own homes. However, it is difficult to make this type of enterprise an economic proposition (Piercy, 1956). Disabled people can spend long hours on some boring, repetitive task for very little financial return. Work in the home, therefore, should only be encouraged in as far as it serves as a form of diversional therapy.

## Travelling

The sample of 7 people using invalid tricycles was too small to reach many conclusions about the adequacy or otherwise of these vehicles. One problem which was particularly evident, however, was the inconvenience of not being able to take passengers in a tricycle. This complaint also came to the fore in a national survey of disabled people (Harris, 1971). There is no doubt that many disabled people would derive considerable benefit from having an adapted car rather than an invalid tricycle. The economic arguments for and against such a proposition are beyond the scope of this investigation.

The group of people confined to their homes by lack of transport but too disabled to drive deserve special attention. A possible solution to their difficulties might be a voluntary taxi service. This might be organised along lines similar to those of existing hospital car services. Volunteers would drive their own cars, and local authorities would pay the cost of petrol and depreciation. Since the proportion of disabled people requiring this service is small, its operation should not prove to be too impracticable.

## Interests

The present investigation confirms the conclusion of Smith (1971) that the most popular leisure interest of disabled people was watching television. Help in obtaining television sets would thus do a lot to improve the quality of life in the young chronic sick. Unfortunately, provision for this, in the Chronically Sick and Disabled Persons Act (1970) does not apply in Scotland.

Only a minority of subjects engaged in social activities outside their homes. This was of little importance amongst disabled women. Most of them spent a lot of time helping in the running of their households.

A lack of outside interests was much more of a problem for men. Many had not found anything to fill the idleness enforced by unemployment. In some respects, their problems were similar to those of men reaching retiral age (Acton Society Trust, 1960). Both situations often result in a loss of status and purpose in life.

Such people might be helped if day centres for the disabled were more widely available, and if the facilities of these were widened to offer a greater range of activities (Guthrie, 1968). Such places, however, would merely occupy time, and do little to restore self esteem. They might also tend to stigmatise the young chronic sick as being people who were separate from the rest of the community. A much more satisfactory solution to enforced idleness would be an improvement in facilities for employing the disabled.

## Visitors

Most disabled people received regular visitors. Very few

suffered from the social isolation and loneliness experienced by many old people (Townsend, 1963). This was due to the fact that few of the subjects had reached a stage in life when death and disability had made serious inroads into the numbers of their friends and relatives.

## <u>Holidays</u>

The holiday pattern for subjects in the present survey resembles that recorded in a national survey (Smith, 1971). In both investigations only half of the people went on regular holidays. Disability and financial problems seemed to be the main reasons for this situation. Age was another factor. A greater proportion of young than middle-aged disabled people went on holidays.

While disability affected the ability of people to go on normal holidays, it was of little importance when the holidays were organised by local authorities or voluntary organisations. The only difference between those going and those not going on special holidays was that the one group had applied for them and the other had not. Holiday services require greater publicity if all disabled people are to benefit from them.

## Relatives and Helpers of Disabled People

One of the most striking impressions to emerge from the survey was the extent to which disabled people were maintained in the community by the efforts of their relatives. It was common to find that, in catering for the needs of such patients, relatives suffered considerable physical, mental, economic and social strains. These were particularly severe where a husband was looking after a disabled wife. He had to fulfil the threefold role of housekeeper, nurse and breadwinner. Wives were in a marginally better situation. Most, though suffering from the financial effects of their husband's unemployment, merely continued in their role of housekeeper.

The needs of relatives were often more difficult to assess than those of the disabled person himself. This was due to the fact that their strenuous efforts disguised many of the problems which faced the household. Close questioning was necessary to elicit evidence of the great stress which many relatives lived under. It is important that an increased effort be made to identify such families, and to supply them with the advice and help which they so urgently require.

Even if such families can be identified, the provision of support often presents difficulties. Home helps can certainly relieve some of the burden of housework. Many people looking after the disabled, however, find that housework is the least of their problems (Isaacs, Livingstone and Neville, 1972). Much more onerous is the task of nursing someone 24 hours a day. District nurses and their aides can provide some help with this. Day centres might also be useful if they took over the care of patients for several days each week. Both of these suggestions, however, would only provide a partial solution, and would leave relatives with a large residue of work.

The other notable feature about many of the relatives was their advanced age. This particularily applied to parents looking after disabled children. Such an arrangement was very unstable. Death or disability in the parents would lead to a crisis situation. Often the only solution would be the admission of the disabled child to an institution or hospital. It is essential that such families should be identified as soon as possible. Plans can then be made for the future and crisis decisions avoided.

## B. Disabled People in Hospital

## (a) The Units

The survey provided further evidence that geriatric units are inappropriate to the needs of the young chronic sick (MacDonald, 1964; Brocklehurst, 1967; Guthrie, 1968). Acute assessment units were unsatisfactory in that they were geared to investigating, rehabilitating and discharging patients as quickly as possible. They did not cater for the needs of people who required diversion and entertainment rather than reenablement. Long stay units often only provided nursing and medical care. They were thus not even particularly suited to the needs of geriatric patients. Such people require a considerable amount of stimulation if they are not to sink into apathy, and immobility. The problem was doubly great for any young patients who found themselves in such an environment.

Another reason for accommodating young and old patients in different places is that there are important differences in the interests and capabilities of the two groups. The young polio victim, for example, has little in common with the elderly demented hemiplegic. Psychiatric units seemed ideally suited to the needs of people with organic brain disease. They offered a wide range of recreational facilities and were staffed by nurses who were skilled in the management of mental disease. The only criticisms which could be made were that the units were often overcrowded and that the dormitories, day areas and dining rooms were usually large and impersonal.

The unit for patients with post-encephalitic Parkinsonism demonstrated some of the merits in having a specialised long stay unit. Long experience had provided medical and nursing staff with considerable expertise in dealing with problems specific to Parkinsonism. An undesirable feature was the fact that little attempt had been made to develop the wide range of activities necessary for the stimulation of a long stay patient. This was probably due to the unit being too small to warrant support from these necessary services.

Acute medical, surgical and orthopaedic units by their very aims and objectives, were unsuited to the needs of the young chronic sick.

The two larger young chronic sick units demonstrated many of the advantages to be gained in providing separate accommodation for young disabled people. Physiotherapy and occupational therapy can be directed to the needs of these patients. In this situation, disabled people are not in direct competition with more acutely ill patients for these services. An additional advantage is that it becomes possible for young people to be provided with a wide range of activities suited to their particular needs.

Many deficiencies were found in the third young chronic sick unit. There was little physiotherapy or occupational therapy and voluntary organisations did not provide much support. This may have been due to the unit being too small to justify the development of its own occupational therapy or physiotherapy departments, or to attract the attention of local organisations.

These observations suggest that a young chronic sick unit should contain at least 50 places if it is to realize its full potential. This is at variance with the figures of between 25 and 50 beds recommended in the NHS report of 1968. Though the problems involved in having a unit of less than 50 beds deserve emphasis, the dangers of a unit with more than this number should also be considered. The principle one is that the place tends to have an institutional atmosphere in which the inmate loses all sense of identity, freedom and individuality.

Another limiting factor in the size of a unit is that a large one might have to admit patients from a very wide drainage area. It has been postulated that this might result in people losing contact with their relatives (Guthrie, 1968). It was apparent, in the present study, that distance had no effect upon the visiting habits of relatives so long as the unit was not more than 20 miles from the home of each patient. A drainage area with this radius should provide sufficient patients in all but the most remote parts of Britain. Most people admitted to a long stay unit are likely to spend the most of their lives there. It is desirable, therefore, that such a place should be designed as a normal residence rather than a hospital. There should be multiple small sleeping areas rather than large dormitories; there should be adequate storage place for the patients' clothing and personal belongings; rooms should be carpeted; and there should be a domestic atmosphere about the decorations and furnishings.

The siting of a unit also requires consideration. There seems to be little advantage in having it in the grounds of a district general hospital. Few long stay patients require the costly and complex diagnostic and therapeutic facilities available in such a place, and it is possible that their special needs may take second place to more acutely ill patients admitted there. There would appear to be advantages, in building a young chronic sick unit as a separate entity.

A disadvantage of the separate unit is that its young chronic sick residents eventually become old chronic sick ones. Unless patients are transferred once they reach a certain age the unit will eventually become a long stay geriatric one. It is often difficult, however, to separate a disabled person from familiar friends and surroundings. This dilemma could be minimised by siting a geriatric ward adjacent to the unit. Transfer would then merely involve moving to another building in the same grounds. Contact could thus be maintained with old acquaintances.

# (b) The Patients

## Age

When attention was directed to the patients themselves, one of the most striking features was the advanced age of the majority. The pattern is similar to that found in a census of long stay patients conducted by the National Health Service (1968). Here, only 502 out of 4,223 people in long stay units were under the age of 35. This phenomenon is related, in part, to the age distribution of the chronic sick in the community. Various social factors detailed later in the discussion may also be of importance.

The age distribution of disability has particular relevance when consideration is given to the possibility and practicability of having a special unit for people between the age of 16 and 35 (MacDonald, 1964). The proportion of chronic sick in this category would be so small that a unit catering for their needs would have to cover an extremely wide drainage area. It may be, however, that in this situation the availability of adequate facilities should take precedence over proximity to relatives (Guthrie, 1968).

## Duration of Stay

The mean duration of stay in medical, surgical and orthopaedic units was not particularly long. This suggests that the difficulties in transferring young patients from acute to long stay areas was not very great. The impression was reinforced when an individual assessment was made in these six patients. 4 were receiving medical treatment, one was in the terminal phase of his illness, and only one was suitable for care in a long stay area. In view of the limited turnover in long stay units it is rather surprising that more young disabled people were not found in acute wards. This may be due to the fact that there are relatively few severely disabled young chronic sick people in the Community (Harris, 1971). The large amount of family support available to most of these individuals may be another factor.

It was equally surprising that the mean duration of stay for people in geriatric, psychiatric and young chronic sick units was relatively short. This was probably due to the fact that most patients had not required admission until late middle age. A high mortality in people with certain neurological diseases may also have been important.

## Diagnosis

The preponderance of patients with neurological disease in geriatric and young chronic sick units follows the pattern found in the survey by the Ministry of Health (1968). Here, 84% of diagnoses were considered to be of a neurological nature.

The similarity of diagnoses made in the geriatric and young chronic sick units suggests that admission to one or other was determined by geographical location rather than the medical or nursing requirements of a patient (Table 44).

The pattern of disease in psychiatric hospitals was completely different to that found in the other types of unit (Table 44). This provides convincing evidence that selection of mental hospital care was made on the basis of mental impairment rather than physical

incapacity. There were no instances of patients suffering primarily from the latter being wrongly placed in a psychiatric unit.

This point is of particular relevance when people suffering from the after effects of a head injury are considered. It might be expected, here, that a combination of mental and physical impairment would create problems in the organisation of appropriate long term care. In every case studied in this survey, however, it was clear that mental incapacity was the main cause of diability. These particular patients with head injuries, then, were correctly placed in mental hospitals.

## Defects of Speech and Hearing

The high prevalence of hearing and speech defects in young long stay patients deserves particular attention. Such handicaps make communication with staff and other patients extremely difficult. They thus seriously interfere with the quality of these patients' lives.

Expert help must be sought in dealing with such problems. Dysphasia and dysarthria are sufficiently common to justify the full time or part time appointment of a speech therapist to a long stay unit. Hearing defects are less common and could be dealt with by referral to an interested ENT surgeon.

# Physical Impairment

Clinical examination of subjects merely confirmed the impression that severe physical impairment was common in geriatric and young chronic sick units and rare in psychiatric ones (Table 50).

## Mental Function

The low intellectual ratings of people in mental hospitals might have been expected. It is more interesting that many of these in geriatric and young chronic sick units also scored poorly (Tables 51 and 53). This was probably due to the high prevalence of dementing neurological disorders in such patients.

There was evidence that patients with varying degrees of mental and physical impairment lived together in young chronic sick units (Graph 7). Many of these people may be mutually incompatible. Thus, the individual with mild physical but marked mental incapacity may distress the alert patient with gross physical impairment. An example might be the disturbing effect a noisy confused youth with Little's disease would have on a man in the terminal phases of motor neuron<sup>9</sup> disease. Again, someone with gross mental and physical abnormalities has little in common with the person who is alert and has only minor physical incapacity. For example, it would be extremely depressing for a young polio victim to spend the day sitting next to a patient demented and paralysed by cerebral arteriosclerosis.

A partial solution would be to accommodate some of the older people with combined mental and physical incapacity in geriatric units (Rankine & Weir, 1967). Though chronologically younger than geriatric patients, they would be as old as them, physiologically. For this reason, they would not be misplaced. This expedient, however, would only be used for middle-aged patients. It would be unsuited to the needs of the mentally deficient chronic sick in their teens and twenties. An alternative solution would be to house such individuals in special units. Considerable problems would be involved in planning and staffing such places.

A more satisfactory way of dealing with the problem would be to construct a building with multiple dormitory and day areas. This would allow the alert and moderately disabled patient to spend his time in small day areas with patients of similar aptitudes and interests. At night he could have the privacy of a single room. Mentally and physically frail people might be more conveniently housed in larger day areas and dormitories where a single nurse could provide adequate supervision. Another part of the unit could be set aside for the care of severely disabled or bedfast patients. In addition to meeting the social needs of the chronic sick this design would also lend itself to a system of graded nursing care.

As in the home population, the high prevalence of depression in long stay wards was a reflection of the hopeless medical and social plights in which many patients found themselves. This situation could only be remedied by improving the design and staffing of long stay units. Details on how this might be done are given elsewhere in this discussion.

## Interests

Television has done a great deal to stimulate and improve the quality of life for disabled people in hospital. It provides a link with the outside world, broadens interests and is a source

of entertainment in what is otherwise a rather drab and monotonous existence.

Watching television, however, is not a very exacting activity. It requires little physical or mental activity on the part of the viewer. If a long stay patient is to develop his limited potential to its maximum he must have a wider range of activities.

These are best organised by a term of physiotherapists, occupational therapists and nurses. Their aims should be to make the patient as self sufficient aspossible within the limits of his disability; to channel his skills and inclinations into activities which will provide him with a maximum of interest and sense of fulfilment; and to encourage him to establish as many social contacts as possible inside and outside the hospital.

In many long stay units, little effort is made to encourage self sufficiency. Many of the residents are too frail to have any hope of returning to a life outside hospital. It is argued that, without such a goal, there is little point in wasting the efforts of staff and patients on rehabilitation. In this situation the patient comes to accept a passive role and allows staff to provides all his requirements. He soon becomes apathetic and withdrawn, and, in extreme cases may not even bother to control bowel or bladder function.

This disastrous chain of events can be avoided by encouraging the patient to adopt a more positive approach to his disability. If, for example, he cannot walk he should be encouraged to propel himself in a wheelchair. Again, even although he may be unable to dress himself completely, he should be encouraged to put on those items of clothing which he can manage.

Self sufficiency is not developed by leaving the patient to his own devices. It requires skilled supervision by the physiotherapist, occupational therapist and nurse. For this reason, these people are indispensible in the organisation of a long stay unit.

Developing the skills and inclinations of a long stay patient requires considerable ingenuity and imagination on the part of all concerned in his care. The occupational therapist is invaluable in directing such a programme. If she is to function properly, however, she must be provided with sufficient equipment and facilities. The interests of disabled people should range far beyond those of making baskets, and playing dominoes. Table 59 suggests that some existing units had made considerable efforts to provide a diversity of activities.

A defect of many hobbies is that they failing provide people with a sense of purpose. For this reason, patients should be encouraged to participate in projects which serve their hospital or the community at large. Examples, in the present study, ranged from feeding the ward budgerigars, to editing and typing a hospital magazine. Regular employment might do a lot to improve morale. There are, however, serious problems in finding work which can be done by severely disabled people and which will also provide them with a worthwhile monetary return.

Social contacts may be fostered at several different levels.

In the ward, patients can be brought together by organising games, quizzes or discussions. It is in this situation that the "ward hostess" can be invaluable (Dunn and Strang, 1970).

Contact with the outside world can be developed where an effort is made to involve voluntary organisations in the activities of a unit. Examples of ways in which these may participate are given in Table 41. Regular outings, whether by bus or private car, are invaluable. Here again, relatives and volunteers have an important role to fulfil. On a less formal level, visits to such local amenities as libraries, cinemas, shops and pubs should be encouraged.

# C. Comparison of the Young Chronic Sick at Home and in Hospital

The preponderance of older young chronic sick patients in hospital was, in part, the reflection of a similar trend found in disabled people living at home (Table 6). Equally important factors, such as the availability of relatives, will be examined, in more detail, later in the discussion.

## Diagnosis

There was a striking preponderance of neurological disease in the hospital population. This may be due to the possibility that certain neurological diseases cause much more disability than those affecting the locomotor system. Evidence for this is provided in Table 14 where the most severe grades of physical impairment were associated with neurological disorders.

Cardio-respiratory conditions rarely resulted in admission to a long stay unit. It is probable that people severely incapacitated by angina or breathlessness do not survive long enough to require this type of care.

## Mental Function

There are obvious reasons for patients with limited intellectual ability or behavioural disorders being concentrated in psychiatric hospitals. It is more difficult to explain the finding that subjects in geriatric and young chronic sick units had lower mental test scores than those who were in the community. Chronically sick patients of low intelligence may have greater difficulty in coping with the problems of independent life than their brighter counterparts. Even more important was the high prevalence of neurological diseases associated with mental deterioration in the hospital group.

# <u>Disability</u>

People with minor disability were rarely found in geriatric or young chronic sick units. Many people with severe disability were nursed in their own homes, however. It would appear that, though disability is the main reason for admission to a long stay unit, it is not the only one. Various secondary factors are of considerable importance.

## <u>Housing</u>

A working party organised by the National Fund for Research into Crippling Diseases suggests that disabled people could often be kept out of hospital if they were given adequate housing (Guthrie, 1968). In the present investigation, inappropriate accommodation had often caused a great deal of inconvenience. It had rarely been responsible for a patient going into hospital, however. Studies in another part of Britain produced an entirely different picture (Townsend, 1967; Skinner, 1969). These discrepancies are probably related to differences in the availability of local authority property.

## Relatives

During the course of the survey it became apparent that relatives played a major part in maintaining disabled people in the community. More detailed assessment of the hospital population confirmed this impression. Many people, in this group, either had no home to go to, or had no one to look after them. The high proportion of single as compared with married subjects receiving hospital care was another striking demonstration on the importance of relatives.

The care of single disabled people usually followed a characteristic pattern. Those people, in their youth, were supported by parents. Eventually their parents died or became disabled themselves. At this stage, it often became necessary to admit the young chronic sick patient to hospital.

Some disabled people were more fortunate in that they were taken into the homes of siblings. This solution was often unsatisfactory, however. There rarely were the same bonds of duty between siblings as there were between husband and wife or

parent and child. The situation was even more unstable when the sibling was married. Here there was a division of loyalty between spouse or children, and the disabled sibling. The patient usually came off second best in such a conflict.

In some respects, the problems of the young chronic sick resemble those of the elderly chronic sick. Both are dependent upon the support of their families (Isaacs, 1972). The young group, however, are more fortunate in that their relatives are more likely to be alive and well, and able to cater for their needs.

## Alternative Methods of Care for Hospital Patients

Long term hospital care is undesirable. It deprives an individual of his privacy and independence, and isolates him from his family and the outside world (Guthrie, 1968). Consideration should be given to practical alternatives. The survey suggests that some of the people currently in hospital might have been able to live at home, Each would have required the support of a home help and a district nurse. A specially designed or adapted house would also have been necessary.

Such people might have gained privacy and independence by moving into their own homes. This might only have been achieved at the expense of considerable social isolation, however. In these circumstances, hostel accommodation might have been preferable. Here the patient would have had the support of staff and the companionship of other residents.

If hostels are to be used attention must be given to the

problems of providing privacy, freedom and a domestic atmosphere. It is easier to achieve this if the place is small, containing not more than 25 residents. Attention must also be given to the integration of a hostel into the local community. This can be done by building the place in a residential area, and by ensuring that there is easy access to local facilities for shopping, education, recreation and entertainment (Maddison, 1970).

Disabled people requiring a limited amount of help with self care might also manage in a hostel. This would be dependent upon extra staff being appointed. They would only be involved in helping with minor items of clothing, or perhaps assisting patients in and out of baths. Providing this type of care would require a great deal of patience and humanity but very little training.

Many people with organic brain disease who were in mental hospitals might have managed in hostels for the mentally frail. A discussion on the layout and staffing of such a place is beyond the scope of this study.

People with combined mental and physical abnormalities present a particular problem. They might be a source of annoyance and embarrassment to people in a hostel for the physically incapacitated. On the other hand, they might not be sufficiently robust to survive in accommodation for the mentally subnormal. Special accommodation might be allocated to them, but their numbers might be too small to make this a practical solution. It might also be difficult

to find staff willing to look after such people. The most satisfactory compromise might be to house them in one of the multiple area hospital units described already.

Most patients in geriatric and young chronic sick units required more care than could have been reasonably provided in a hostel. They were thus appropriately housed in hospital. It is important, however, that steps should be taken to minimise the many disadvantages of hospitalisation. This could be achieved by implementing some of the modifications in design and organisation suggested earlier in the discussion.

## Conclusions

## A. The Young Chronic Sick at Home

1. In youth and middle age, disability is equally common in men and women.

2. There is a marked rise in the prevalence of disability with increasing age.

3. Discrepancies in selection criteria account for variation in the prevalence of diseases in different surveys of disability.

4. Disorders of the nervous system are more likely to produce severe mental and physical impairment than those affecting other systems.

5. The average intelligence of people too disabled to find employment or to do housework is low. This is partly due to the preponderance of neurological diseases in such groups. Other factors, less easily defined, may also be important. 6. Many young chronic sick patients are depressed.

Severe disability is much less common than mild disability.
 Young chronic sick people are heavily dependent upon relatives for nursing care. District nurses have a valuable, but limited role in this area.

9. Families in which the disabled person is the housewife seem less able to attract support from a home help than other groups with disabled relatives. This might be due to difficulties involved in identifying the needs of such families.

10. There is wide geographical variation in the adequacy of housing for the disabled.

11. Inappropriate housing is a more common cause of problems than substandard housing.

12. The inconvenience and expense of a removal often outweighs the advantages of moving to "appropriate" accommodation.

13. Age, education, financial incentives and the local level of unemployment all seem to have an important influence on the prospects of a disabled person finding work.

14. There is a small number of young chronic sick patients who do not have access to private transport and are too disabled to drive. The organisation of a voluntary transport service for such people could do a lot to improve the quality of their lives. 15. Inability to work often produces a considerable hiatus in the lives of disabled men.

16. Young and middle aged disabled people rarely face the problems of social isolation often found in their older counterparts.

17. The relatives of disabled people often have an extremely heavy work load. There are problems in identifying this and in providing help where it is most needed.

# B. The Young Chronic Sick in Hospital

1. Geriatric units are unsuited to the needs of most young chronic sick patients.

 The optimal number of places in a young chronic sick unit would appear to be around 50. Validation of this conclusion would require an investigation covering a larger number of units.
 So long as a unit is within a twenty mile radus of a patient's home, distance does not affect the visiting habits of his friends and relatives.

4. Failure to transfer patients over a certain age from a young chronic sick unit may eventually result in the place developing a geriatric character.

5. Most Young chronic sick patients enter hospital in late middle age. Steps should therefore be taken to cater for the specific needs of this group.

6. The bulk of young chronic sick patients in non psychiatric hospitals suffer from neurological diseases.

7. Young chronic sick units should cater for the needs of patients with hearing and speech defacts.

8. Many young chronic sick patients have combined mental and physical impairment. Special attention must be paid to tailoring the facilities of a young chronic sick unit to people with a wide range of mental and physical aptitudes. 9. Many young people in long stay hospitals are depressed.
10. There is no evidence that patients suffering from physical impairment alone ever receive long term care in a mental hospital.
11. There is a great deal of scope for research into the organisation of the long stay patient's day.

## C. Comparison of the Young Chronic Sick at Home and in Hospital

1. Neurological disease predominates in long stay units because it is more likely to produce severe disability than other types of disorder.

2. The high prevalence of neurological disease, and the problems which people with mental impairment have in caring for themselves are the most probable causes of the high prevalence of mental impairment in long stay units.

3. Severe disability is the most important reason for people requiring long term hospital care, but it is not the only one. People with similar degrees of incapacity can be maintained at home if they have sufficient support from relatives.

4. Inappropriate housing rarely leads to hospitalisation.

5. Support from relatives is often yital to maintaining severely disabled people in the community.

6. Single disabled people at home are more likely to require long term hospital care than their married counterparts. This is due to the fact that the relatives supporting them are more often elderly and infirm.

7. It should be possible for a large proportion of people at present receiving long term hospital care to be discharged into the community.

This would be dependent upon the considerable expansion of existing local authority facilities.

## Acknowledgements

The fieldwork for this study was financed by a grant from the Research and Intelligence Unit of the Scottish Home and Health Department. The project was suggested by Professor W.F. Anderson and I received constant support and encouragement from him during its course. Dr. M. A. Heasman and Dr. W. T. Thom from the Scottish Home and Health Department provided me with a great deal of help and advice. Dr. F. A. Boddy from the Department of Epidemiology in Glasgow University gave me advice on the selection of subjects from the community and from hospitals. Dr. F. I. Caird from the Department of Geriatric Medicine in Glasgow University provided much help in the construction of the medical, social and psychiatric proformas.

Dr. N. R. Cowan and Dr. J. B. Morris, Medical Officers of Health from Rutherglen and Clydebank respectively kindly helped me to contact general practitioners in their areas. Thanks are due to the general practitioners themselves who spent a considerable amount of time in drawing up lists of subjects for the community survey. These were Drs. A. Blair, J. H. Brown, G. D. Burnett, J. Camduff, A. A. Clark, A. L. Cowan, J. W. H. Crosbie, A. C. Crowe, R. G. Dryden, R. Greenhill, A. D. K. Henderson, J. W. Junor, R. L. Low, M. MacLaughlin, M. MacLean, I. S. MacLeish, R.W.L.MacLeish, A.S. Nicholson, J. C. Rogerson, W. F. Sellar, I. C. Seymour, W. Sewell, J. R. Sutherland, R. A. Taylor, T. A. Watt and R.A. Willett.

I am also grateful for their help in compiling lists of young chronic sick subjects in hospital to the medical superintendants and physician superintendants of Bellsdyke Hospital. Coatbridge. Airdrie and District Hospitals, Dumbartonshire Hospitals. Dykebar Hospital, Gartloch Hospital, Gartnavel Mental Hospital. Glasgow Northern Hospitals, Glasgow Royal Infirmary and Associated Hospitals. Glasgow South Western Hospitals, Glasgow Victoria Infirmary and Associated Hospitals, Glasgow Western Infirmary and Associated Hospitals, Leverndale Hospital, Motherwell, Hamilton and District Hospitals, Paisley and District Hospitals. Riccatsbar Hospital. and Stoneyetts Hospital. The Matron of Broomhill produced a similar list of subjects for her hospital. I should further like to thank the consultants who granted me permission to study their patients in hospital. These were Professor W.F.Anderson, Dr. J. D. Bankier, Dr. J. K. Binns, Dr. J. Buchanan, Dr. A. Campbell, Dr. J. M. Carlisle, Dr. A. I. Cheyne, Dr. J. Crorie, Dr. J.L.C. Dall. Dr. W. L. Flannagan, Dr. M. Fletcher, Dr. I. A. Gibson, Dr.R. Good. Dr. W. W. Gordon, Dr. A. M. Gray, Dr. M. Henderson, Dr. C. C. Hosie. Mr. J. R. Howatt, Dr. J. C. Kelly, Dr. J. MacCurley, Mr.J.H. Miller. Dr. D. H. Nimmo, Dr. M. M. O'Hare, Dr. G. C. Timbury, Dr. N. A. Todd. Dr. J. L. Waddell and Dr. F. A. Walkey.

Finally, I should like to express my gratitude to the subjects themselves for their co-operation and forbearance throughout the study.

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