



Kent Academic Repository

Warren, M.D., Warren, J.L. and Woodward, S. (1976) *Studies of Impaired People in Paddock Wood*. Health Services Research Unit, 108 pp.

Downloaded from

<https://kar.kent.ac.uk/24399/> The University of Kent's Academic Repository KAR

The version of record is available from

This document version

UNSPECIFIED

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

STUDIES OF IMPAIRED PEOPLE
IN PADDOCK WOOD

M.D. WARREN

1976

H.S.R.U. Report No. 22

RESEARCH TEAM

Professor M.D. Warren, M.D., F.R.C.P., F.F.C.M., Director

Mrs. J.L. Warren, S.R.N., Research assistant.

Mrs. S. Woodward, Administrative secretary.

Health Services Research Unit,
Centre for Research in Social Sciences,
University of Kent,
Canterbury, Kent.

Copyright - H.S.R.U., 1976.

STUDIES OF IMPAIRED PEOPLE
IN PADDOCK WOOD

CONTENTS

Foreword

Acknowledgements

Identifying Handicapped People in a General Practice
Population

Interview Surveys of Handicapped People. The Accuracy
of Statements about the Underlying Medical Conditions.

Handicapped People in Paddock Wood

Forms and Questionnaires.

FOREWORD

This volume contains three reports based on a community survey of impaired persons living in and around Paddock Wood, Kent and who were registered with a general medical practice of three partners working with nurses, health visitors and ancillary workers from a purpose-built health centre. The opportunity of working with a primary medical care team enabled a number of different questions to be examined, and because some of these form discrete areas of interest the results are presented in the following three papers:-

1. Identifying Handicapped People in a General Practice Population.
2. Interview Surveys of Handicapped People. The Accuracy of Statements about the Underlying Medical Conditions.
3. Handicapped People in Paddock Wood

The first paper describes the use of the practice age-sex register for a community survey and discusses the possibility of the combined use of a diagnostic index and medical notes as a means of identifying handicapped people. The second paper describes the procedure used to check the statements of impaired people about the nature of the medical conditions underlying their impairments against the medical notes, supplemented where necessary by the doctor's recollections. The third paper gives some details about the impaired and handicapped people located in Paddock Wood and compares these details to those of impaired and handicapped people located in Canterbury during a previous survey. The paper also describes the effect of broadening the criteria used in the definition of 'handicapped person' and recommends that the new criteria should be incorporated in future surveys.

ACKNOWLEDGEMENTS

This study had considerable help from a large number of people. The late Dr. J.A. MacDonald, Dr. C.M. Warner, Dr. J.W. Baker and Dr. D.E. Whillier encouraged and cooperated with the study based in their practice and their enthusiasm was shared by the health visitors, Mrs. D.D. Blake and Miss C.M. Sparks, who in addition to assisting in various aspects of the study, also helped to meet the needs of the handicapped people as these were identified. Mrs. B. Craddock gave a lot of secretarial help within the practice.

The organisation of the fieldwork was done by Joan Warren and the interviews were carried out by Robin Dowie, Kim Downs, Ann Kennedy, Joan Le May, Jill Munday, Elizabeth Ray, Mary Rothermel, Maureen Russell, Sheila Sayers and Patricia Sutherland. Lavinia Harvey helped with the sorting of the age-sex register, Maureen Russell and Barbara Wall assisted with the computing and tabulations and Shirley Woodward carried out the administrative and clerical work at the Research Unit.

Mr. F.E. Miles, chief clerk of the Kent Executive Council kindly arranged for the executive council to supply an age-sex list of the practice and Dr. A. Elliott and Mr. R. Newnes, the County Medical Officer of Health and the Director of Social Services supported the study.

John Baker, John Bevan, John Butler, Tev Eimerl, Rose Knight and Robert Lee made many helpful criticisms of a draft of this paper.

To all of these people and to the people of Paddock Wood and the surrounding villages, I am most grateful. The study was financed by the Department of Health and Social Security as part of the programme of research of the Health Services Research Unit.

IDENTIFYING HANDICAPPED PEOPLE IN A
GENERAL PRACTICE POPULATION

M.D. WARREN

1976

RESEARCH TEAM

Professor M.D. Warren, M.D., F.R.C.P., F.F.C.M., Director,
Mrs. J.L. Warren, S.R.N., Research assistant,
Mrs. S. Woodward, Administrative secretary.

Health Services Research Unit,
Centre for Research in Social Sciences,
University of Kent,
Canterbury, Kent.

Copyright - H.S.R.U., 1976.

IDENTIFYING HANDICAPPED PEOPLE IN A
GENERAL PRACTICE POPULATION

SUMMARY

The Chronically Sick and Disabled Persons Act, 1970, placed a statutory obligation upon local authorities to collect systematic information about the needs and numbers of handicapped persons eligible for help through their social services departments. This study used the age-sex register of a group general medical practice as the population base for a postal enquiry and examined the possibility of the combined use of a practice diagnostic index and the patients' medical records for locating handicapped people. The age-sex register was found to contain deficiencies and inaccuracies despite the substantial efforts of members of the practice team to maintain it. This is not an infrequent finding of investigators using these registers. It was necessary to allocate each person recorded in the age-sex register to a household as a postal survey was to be addressed to the householder rather than to individuals to avoid the anticipated difficulties arising from multiple forms sent to one household, some addressed to infants. Structuring up the households was a formidable task. The response from the householders to the postal enquiry about the presence of an impaired person in the household, revealed further inaccuracies in the information in the practice - 13.5 per cent of the forms were returned as the addressee was unknown at the address. The 81.5 per cent of householders who responded identified 353 impaired people who were subsequently interviewed about the nature of their impairment, the underlying condition, and the range of their activities. Depending upon the answers to these questions, a proportion of these people were classified as handicapped and were asked further questions. The number of impaired people and their distribution in sex and age-groups were broadly similar to the findings from other surveys. The diagnoses of the underlying conditions given by the impaired people were discussed with the general practitioners and confirmed or otherwise by the use of the patients' notes or the recollections of the general practitioners. Using data from the national morbidity study (1970-71), estimates were made of the likely composition of a practice diagnostic index kept for one year and the feasibility of using such an index combined with the information recorded in the patients' notes was examined. It was concluded that whilst the use of a diagnostic index

would be helpful for certain conditions which usually disable people and about which general practitioners are consulted, there would remain on the one hand a substantial number of people with a disease that is potentially disabling who would have to be approached for further screening and on the other a substantial number of people (mainly with poor hearing, poor eyesight or limited locomotion) who are handicapped but would be missed. Efforts should be concentrated on defining and measuring the components of the concept of 'a handicapped person' in order to develop criteria that a number of agencies can recognise and then use. This would simplify communication between the agencies and its completion would act as a checklist for each agency. Until there is classification of the component details, it is unlikely that the records of one agency in contact with disabled people can be used as the basis of information required by another to identify who requires its help.

INTRODUCTION

Chronically Sick and Disabled Persons Act

The Chronically Sick and Disabled Persons Act, 1970, placed a statutory obligation upon local authorities to collect systematic information about the needs and numbers of handicapped persons eligible for and desiring assistance from their social services departments. In September 1971, local authorities were advised by the Department of Health and Social Security in Circular 45/71 that the findings of a national survey of impaired and handicapped people carried out in 1968-69 (Harris, 1971) could not be relied on for an accurate picture of need in any individual local authority area. As it was mandatory for each local authority to obtain accurate information about the scale and nature of local need in order to ensure the proper planning of services, it was suggested in the circular that one way of obtaining the information would be through local sample surveys, although such surveys 'would still leave local authorities with the ultimate task of identifying everyone who both needs and wants a service. The completion of this task should in any case be the authority's aim, and there will be certain authorities who will feel able to embark at an early date on a programme of identifying all these people or have already done so, whether by individual enquiries to each household in the authority's area or by bringing together information at present scattered among the whole range of statutory and voluntary services and agencies to whom handicapped individuals are known'.

Many local authorities undertook sample surveys in their areas, a number followed the procedure, with perhaps a few modifications, that had been suggested in a booklet (Harris and Head, 1971) based on experience from the national survey. Some authorities adopted different methods of surveying and some concentrated on publicising their services rather than systematically collecting information (Jaehnig, 1972, and Murray and Orwell, 1973). Variations in practices in carrying out the surveys and in defining 'handicap' have made the collation and comparison of the results of these surveys difficult; however, in so much as these methodological problems can be overcome the findings are more uniform and nearer to estimates calculated from the national survey than the Department of Health and Social Security had anticipated (Knight and Warren, in preparation). It is, therefore, being asked in a number of local authorities if the survey exercise is worth carrying out if such an elaborate, time-consuming and expensive project yields figures that are only a little more accurate than those already available (Jaehnig, op.cit.).

Use of Records and Registers already Maintained

Obtaining estimates of the total number of handicapped people for planning purposes is one thing; the identification and offering of help to individual handicapped people is another. Whilst there may be doubts about the need for further local surveys for planning, local authorities still have to identify all the handicapped people in their areas who need and want services, and must continue to do this. Furthermore it is not only local authorities that need this information; a number of statutory and voluntary services from time to time require similar but not identical information relating to persons who are eligible for their help, for example, when a new benefit or service is introduced such as the recent attendance allowance, non-contributory invalidity pensions or behind-the-ear hearing aid. Local authorities, as the agencies with the major responsibilities for identifying handicapped people, are thinking again of the possibilities of bringing together information from the main statutory and voluntary services and agencies likely to be in contact with handicapped people.

In this connection, the opportunity was taken of collaborating with the social services departments of the City and County of Canterbury (now part of Kent County Council's responsibility) and of Kent County Council to combine data from a household survey (Warren, 1974) with data from other sources in order to examine the extent to which approaches through agencies and services would yield information that could replace that obtained by the household surveys (Warren, 1975). The records of 15 agencies and 5 statutory registers of handicapped people in Canterbury were examined and it was found that about half of the handicapped people identified by the household survey were recorded by the agencies or were on the registers. However, it was not practicable to examine the records of the general practitioners in the City, so another study, which forms the basis of this report, was undertaken in the Paddock Wood area of Kent.

General practitioners are in contact with a substantial proportion of handicapped people, although not all of them may recognise the special needs of these people (Harris, 1971; Warren, 1974; Firth, 1975). Almost all handicapped people are registered with a general practitioner, even if some handicapped people have not consulted him recently and are not in regular contact. Some handicapped people are in regular contact with other members of the primary care team, especially the home nurse (elderly handicapped) and the health visitor (handicapped children). The Canterbury household survey showed that the general practitioner was the professional person most frequently reported

by the handicapped people as being in contact. Of the 770 handicapped people interviewed, 299 (39%) stated they had regular contact with their general practitioner, compared to 133 (17%) stating regular contact with the home nurse, 66 (8.5%) with the health visitor and 115 (15%) with the social worker, although it is probable that there may have been some misunderstanding by some handicapped people as to whom these last two categories referred.

To what extent can notes, records and registers available within a general practice be utilised for the identification and continuing care of handicapped people not only within the practice but also by other agencies? This paper examines a number of problems related to this question. First, the feasibility of using a practice age and sex register for the initial listing of the people to be approached in the first stage of locating handicapped people is discussed. If the object of a survey is to identify all the handicapped people registered with a general practice (rather than within a community) then the age-sex register must be the preferred source of the initial list of names and addresses. Secondly, the limitations of using a diagnostic index for the identification of handicapped people are outlined. The basis of the paper is a survey carried out in a group practice; this survey provided the opportunity to check the accuracy of the age-sex register and the results are reported here, as well as to check the reliability of statements made by impaired people about the nature of the underlying medical condition, the results of which have been reported elsewhere (Warren, 1976a).

The direct approach of attempting to extract from the various records kept by the general practitioners a list of those people who appear from the details recorded to be impaired or handicapped and those who might be named by the general practitioners and comparing this list with a separate list of impaired and handicapped people identified by a survey was not attempted. Earlier exploratory studies (Jefferys, Hyman and Warren, 1966, unpublished report) had suggested that the records kept by general practitioners were unlikely to contain adequate notes about the impairments and handicaps of patients, as distinct from details of diagnosis and treatment. A preliminary examination of the clinical notes in the practice, confirmed this impression.

METHODS

Choice of Practice

Paddock Wood was chosen as the centre for the studies based in a general practice because the Health Services Research Unit was conducting other studies in the health centre there; the general practitioners concerned, the Director of Social Services and the County Medical Officer of Health of Kent County Council agreed to the further studies; the group general practice based in the health centre and with a branch surgery in East Peckham was believed to serve almost all of the local population; and it would provide experience in and data from a rural area to contrast with that from the earlier survey in the City of Canterbury.

The general practice consists of three partners, with attached health visitors and home nurses, practice nurses, receptionists and secretaries. It is housed in a spacious health centre in the centre of Paddock Wood. During the period of the study one partner fell seriously ill and a fourth partner was brought in. The partners usually have a trainee general practitioner and periodically have medical and other students attached to them. The partners have been associated with a number of research projects. The population served is about 9,300, so it is a busy practice.

Age-Sex Register

At the time of the studies reported here (1973) the practice had set up with some financial help from a previous research project an age-sex register and the doctors were recording basic work-load data in conjunction with research concerned with the study of the move of the practice into the health centre. For these purposes the practice was re-imbursed for the part-time services of a clerical assistant from research funds. The age-sex register is a card index of each person registered with the practice; each card gives details of the name, initials, date of birth, sex, address, date of entry into and removal from the practice list, and N.H.S. number. The register was compiled from the files of medical record envelopes by the clerical assistant in 1970 and an attempt was made to keep it up-to-date, by adding new entrants to the practice population, filing departures from the practice separately and noting any change in details. The cards are filed alphabetically by year of birth and separately for each sex. The clerical work involved in setting up and maintaining a practice register is substantial,

the initial costs in Paddock Wood in 1970 were of the order of £100 and its maintenance requires about 4 hours of clerical work per month. Goodman (1975) has estimated the total costs of establishing a register at at least £50, but he did not state the number of patients to which this expenditure referred.

Identification of Impaired People

The method adopted to identify the handicapped and potentially handicapped (impaired) people was to carry out a three stage operation essentially along the lines of the recommendations of Harris and Head (1971). In the first stage each householder was approached and asked to complete a one page form containing 14 questions designed to identify (by name) any person in the household with substantial impairment of vision, hearing, locomotion, or ability to look after himself or who has lost the whole or part of the use of an arm, leg, hand or foot through accident or amputation or has a serious congenital abnormality. In the second stage, each impaired person, identified on the form returned by the householder was interviewed by a trained interviewer and asked questions about the nature of the impairment and the limitations to activities that it caused. Depending upon the answers to these questions, the interviewer decided whether to continue into the third stage and ask questions about the problems experienced and the services received by the handicapped person or to complete the interview at the end of stage 2. All people who had a stage 2 interview are referred to as impaired people and the sub-group that had a stage 3 interview as handicapped people.

The decision to approach households and not individuals was taken for two reasons. Firstly, it was thought that there would be confusion in families if each member was asked to return a form, to say nothing of the inaptitude of addressing a letter and form to small children and infants. Secondly, it was desired to use a method essentially similar to the methods adopted by many social services departments and to the survey in Canterbury so that the results and experience could be readily comparable. It was therefore necessary to sort the age-sex register of the practice into households. This was a formidable task. All patients recorded in the active files of the age-sex register were listed in alphabetical order. A new filing card was completed for each surname at the same address, and cross references made for persons with different surnames at the same address. After the completion of this operation, no new patients in the

practice were accepted into the study population. Where there was more than one card for an address the help of the doctors and the health centre staff was sought to find out if one of the families had moved, whether there were two households at the same address or the household contained people with two surnames or more. The names were also checked against the lists in the electoral registers. Where no further information was available, forms were addressed to bearers of both surnames.

On completion of the household lists, the postal and interview procedures already described were followed, after a check that each person identified was registered with the practice. The interviews were conducted by 11 interviewers during the period May - September 1973. As this study was carried out with the cooperation of the primary medical care team at the health centre and the county's social services department, it was possible to ensure that all handicapped people identified in the survey and apparently in need of any available service could be referred to the appropriate person.

Check on the Age-Sex Register

The executive council provided an age-sex register of the practice compiled from its records, so it was possible to compare the age-sex register originated in the practice with the register from the executive council and with data obtained from the postal approach to the registered householders.

Check on Diagnosis

When all the interviews had been done the research assistant interviewed each of the partners to discuss the diagnoses or nature of the condition stated by the impaired person to be the cause of his impairment. The doctor had the patient's notes available and was encouraged to supplement these, when necessary, by his own recollections of the patient's medical history. In this way data were obtained about the nature of the specific disorders underlying the impairments, and hence the prevalence of conditions found in the group identified as impaired in the survey that might have figured in a diagnostic index of the practice. Information was also obtained about the detail of impairments recorded in the patients' records, and the corroboration of the patients' statements about the nature of the causative conditions by the doctors' statements (these latter findings have been reported elsewhere, Warren, 1976).

RESULTS

Accuracy of the Age-Sex Register

The more appropriate register for the purpose of approaching householders would be a family or household register, but this was not available. Even so, problems could arise, and did, where members of one household are registered with different practices, as some members of the household would not be known to the study practice but might be included in the considerations of the householder completing the form. In the event 5 patients were reported who were not registered with the practice. The basic problems of accuracy and up-dating are even more intractable with family and household registers.

In addition to the major task of compiling households from the age-sex register, the study demonstrated discrepancies between the age-sex register and the practice list held by the executive council and revealed deficiencies and inaccuracies in the data in the age-sex register. Many of these problems have been reported by other authors (e.g. Eimerl, 1960; Goodman, 1975). Table 1 presents the numbers of men and women in eight age-groups as found in the age-sex register at the start of the study and in the age-sex register after a research assistant had checked the entries and removed duplicates and persons wrongly filed in the 'active' register (i.e. the register of the names of all persons currently registered with the practice). In all 511 names (301 males and 210 females) were removed in this way. This checking of the entries brought the numbers recorded in the age-sex register (4,645 males and 4,728 females) close to the total figures supplied by the executive council (4,594 males and 4,701 females) also shown in table 1. A 1 in 10 sample of all the patients' medical notes showed that the original age-sex register reflected reasonably accurately the age-sex structure of the practice population derived from the patients' records, but the estimate based on the sample of the notes gave an even larger total practice population of 10,320 made up of 5,140 males and 5,180 females. This total is 4.4 per cent higher than the figure derived from the original age-sex register and 11 per cent higher than the figure for the practice population derived from the executive council's list; the discrepancy probably reflects duplicate notes and the retention of notes of persons who have left the practice. A major deficiency in the age-sex register was the lack of information about the dates of birth of 459 people which even after checking could only be reduced to 409, that is 4.4 per cent of the revised age-sex register.

Comparing the revised age-sex register figures with the figures from the executive council, it appears that the majority of these deficiencies related to persons aged between 50 and 64 years (table 1). It seems also that the revised practice age-sex register did not contain all of the infants registered in the practice, and indeed it is around this age-group and their parents that the majority of inaccuracies were found, as a result of the postal survey (see below).

A one in ten sample of all of the names on the executive council's age-sex register was taken and the details on these 928 cards were compared to the information contained on the revised practice age-sex register. As a result just over 91 per cent of the names on the executive council list were found in the age-sex register. Almost 4 per cent of the names on the executive council's register referred to registrations that had occurred during the four months between the start of the study (and hence the revision of the practice register) and the despatch of the executive council's register. The remaining 5 per cent of names on the sample from the executive council's register were not recorded in the practice register. In regard to the matching of details recorded in the two registers, it was found that 779 (92 per cent) of the 848 cards that could be matched corresponded exactly in details of year of birth, sex and name, 32 (3.7 per cent) gave different years of birth, 29 (3.4 per cent) had no year of birth recorded on the practice card, 5 had different sexes recorded, 2 had different surnames (1 because of marriage and 1 following adoption) and 1 had a mis-spelling of a surname.

Postal Enquiry

The postal enquiry (stage 1 in the location of impaired people) was addressed to 3,287 householders by name, and replies were received from 2,680 (81.5 per cent). The Post Office returned 402 forms (12.2 per cent), and another 42 (1.3 per cent) were returned by others stating that the addressee had moved away or died. No reply was received from 163 householders (5 per cent). Only 6 people (among those who replied) actively refused to cooperate, so the response rate was high, and among those receiving a form comparable to that obtained in other household surveys of impaired people. However, the finding that as many as 13.5 per cent of the householders identified from the revised practice age-sex register were not known or had left the addresses recorded again emphasises the need for some formal system of enquiry within general practice to up-date information on the patients' records and on practice registers (Farmer, Knox, Cross and Crombie, 1974).

The attempt to approach householders in a large population of people through the use of a general practice age-sex register involved considerably more clerical work than an approach through the use of the electoral register and produced a lower percentage of replies - 81.5 per cent of those approached through the general practice compared to 96.1 per cent in the Canterbury survey where the initial letters and forms were delivered to and collected back from each householder by volunteers. A letter delivered to or addressed to 'the householder' cannot be returned because the addressee has left the premises, as occurred with 13.5 per cent of the letters sent out in Paddock Wood.

Estimating the Population Surveyed

Most household surveys of handicapped people have to make assumptions about the sex and ages of the people included in a survey. The assumption may be that the people are representative of the sampling fraction of the population enumerated in the census (or a more recent estimate) or of that fraction of that population which is proportional to the response rate of the first stage of the survey. Precise figures for the age and sex structure of the population approached and of all the respondents could be obtained if each person on an age-sex register was approached individually and if the ages of all of the people were known. In the present study, households were constructed from the information in the age-sex register and householders were approached and asked about members in the household collectively. The ages of 409 (4.4 per cent) of the practice population were not recorded in the age-sex register. It is not possible to know precisely whom each householder included in his considerations when completing the form; if it is assumed that each respondent householder had in mind the members of the households that had been reconstructed from the revised age-sex register then the precise population from which the impaired are drawn is that set out in table 2 (col.3).

The conclusion about the use of the age-sex register for a community study is that it complicates rather than simplifies the initial approach to householders and does not add to the precision of data about the responding population compared to experience elsewhere with the use of the electoral register. However, in most general practices, it is the only feasible register available for a practice study. The use of a general practice household or family register might have removed the need for much of the initial work, but the problems of accuracy and completeness of information would probably have still remained.

Numbers of Impaired People

As other community surveys of impaired people have had to use estimates of the composition of the respondent population, comparisons of the estimates of the prevalence of impaired people in the practice population with the results from other studies must be tentative. Table 2 shows the number of impaired people that were interviewed (and therefore the number about whom there was complete information about age), and the prevalence rates per 1,000 people in each age group based on the probable minimum population (that is the estimated population in the households that replied) and a maximum population (the current practice population as recorded by the executive council). It is probable that the majority of the persons whose ages were unknown were aged between 50 and 74 (see table 1) so that the estimated prevalence rates in column 4 of table 2 for these age groups are too high. Column 6 of table 2 shows the prevalence rates found in the Canterbury household survey and except in the older age groups the figures are similar. These similarities occurred also with the prevalence and registration rates for the number of registered blind people (1.5 per 1,000 of the respondent population in Paddock Wood compared to 1.7 in Canterbury), for the registered deaf (0.4 compared to 0.5) but not for 'difficulty in self care' (23.9 compared to 31). The lower figure for difficulty in self care in Paddock Wood may be due to the smaller proportion of elderly in the population (8.5 per cent) compared to Canterbury (14.9 per cent), among whom the proportion of impaired people rises rapidly. The needs and problems of the 353 impaired people have been described elsewhere (Warren, 1976b); broadly speaking they are of the same nature and occur in the same proportions among the impaired people as has been found in other surveys.

Possible Use of the Diagnostic Index

The diagnostic index has been developed by the Research Unit of the Royal College of General Practitioners (Research Unit, 1971) from the earlier work of Eimerl (Eimerl, 1960; Eimerl and Laidlaw, 1969). The index provides an index to practice records as it records under each diagnostic term, syndrome or symptom-complex the names and N.H.S. numbers of patients who have been so diagnosed. The diagnoses are classified in accordance with the classification based on the I.C.D. and agreed between the Royal College of General Practitioners and the Office of Population Censuses and Surveys.

The diagnostic index would be an efficient way of identifying potentially impaired and handicapped people provided that there is a close correlation between the diagnostic labels and the presence of significant impairment or handicap and provided that all impaired and handicapped people were in regular contact with the general practitioner or at least were likely to make contact at a time when in need of one or other of a variety of services. The Paddock Wood practice did not maintain a diagnostic index, but data from the present survey has been used to look at the theoretical use of such an index.

Each impaired person was asked by the interviewer what was the nature of the condition underlying the impairment, and the answer was later checked in a discussion with the general practitioner. One hundred and fifty four impaired people (44 per cent) were able to state a detailed diagnosis which the general practitioner was able to confirm either from the person's records or from his own recollection; and the general practitioner was able to add a diagnosis to a further 37 of the impaired people, so that in all 191 impaired people (54 per cent) were allotted a detailed diagnosis. One hundred and three of the remaining 162 people gave a broad label to the underlying condition (e.g. rheumatism, arthritis, deaf or poor vision) with which the general practitioner agreed but was unable to elucidate further from the notes or his recollection (Warren, 1976a). Sixty of the 191 impaired people who were allotted a precise diagnosis gave either details of injuries (34 people) or diagnoses that are included in 'other' categories in the R.C.G.P.-O.P.C.S. classification of morbidity (e.g. detached retina, ankylosing spondylitis), so that only 131 specific diagnoses are listed in table 3. The table also gives the number of persons whose names would have been added to a diagnostic index during a year in the practice if the consultation rates for the practice in Paddock Wood had been exactly the same as those for the rates reported in the 53 practices studied by the Office of Population Censuses and Surveys (1974). In addition, the table includes 4 large categories of disorders (neoplasms, refractive errors and other diseases of the eye, other deafness, and accidents and injuries). A diagnostic index would contain a larger number of people than are shown in columns 4 and 8 of the table, if the diagnostic index had been maintained for longer than one year. An impaired person's name would only be listed in the diagnostic index against the diagnosis to which the person attributes the impairment if that person had consulted the doctor about that

condition during the period of the establishment and maintenance of the diagnostic index. These qualifications must be kept in mind in discussing table 3, as well as the underlying assumption that the index will be accurate and regularly updated. Furthermore, corrections have not been made for the age and sex structure of the practice population as the table can only give an approximate indication of the composition of a diagnostic index.

There are a number of points to note from the data in table 3. For some diagnoses, the number of impaired persons identified in the survey equalled about a fifth or more of the number of patients estimated to have consulted with the declared diagnosis during the year. This applies to diabetes, multiple sclerosis, epilepsy, glaucoma, cataract, otosclerosis, bronchiectasis, nephritis, rheumatoid arthritis, spina bifida, congenital heart anomaly and other congenital anomalies, and mental retardation. However, these total only a possible 66 of the 353 impaired people. The duration of some of the impairing conditions is such that many of the impaired people may not have consulted the general practitioner during the year about the underlying condition and so would not be recorded under that diagnosis in a diagnostic index. This would apply to poliomyelitis, mental retardation, deafness, blindness, injuries and congenital anomalies. For a number of conditions the number who were identified as impaired was only a small fraction ($\frac{1}{10}$ or less) of the number estimated to have consulted. It could be that only a small proportion of such people consulting are impaired (e.g. herpes zoster, migraine, chronic otitis media, hypertension, varicose veins and injuries) within the definitions of the survey, or that the household survey missed a substantial number of people impaired by some of the conditions (e.g. anxiety neurosis, ischaemic heart disease, congestive failure, chronic bronchitis, asthma and neoplasm).

It is not possible to give accurate estimates of the yield of impaired people that might be derived from a survey based only on a diagnostic index of patients attended in a general practice from the data presented in table 3 because of the assumptions underlying the data and the qualifications already made. A rough estimate would be that to have made contact with the 1,660 persons listed under the 35 diagnostic labels would have yielded between 100 and 131 (28 to 37 per cent) of the names of the people identified in the household survey and between 50 and 100 further names might have been added if the 1,023 persons listed in the four large groups of disorders had also been approached. Perhaps, therefore, between 150 (42 per cent) and

231 (65 per cent) of the 353 people found in the household survey might have been identified in a survey based on patients with selected diagnoses recorded in a diagnostic index. A substantial number of other people, many suffering from neurosis, ischaemic heart disease, congestive cardiac failure or chronic bronchitis might have been identified in addition to those found in the household survey. Up to 35 per cent of those found by the survey might not have been identified, because many impaired patients probably do not consult during a year about the condition underlying their impairments.

An approach through a diagnostic index would involve either a detailed questionnaire to be completed by, or an interview with, over 2,500 persons compared to the postal approach to 3,287 householders followed by an interview with 353 persons. The estimated yield from an approach through a diagnostic index of between 42 and 65 per cent of the persons found in the household survey compares with a correspondence of 36 per cent of the names of persons identified in the Canterbury household survey by means of a search through the records and registers of a number of agencies (Warren, 1975). Many of the persons identified in a survey of agencies' records and registers would be the same people as were listed in the diagnostic index, for example, the general practitioner is the main source of referral of patients to the home nurse.

DISCUSSION

The experience described in this report suggests that the current notes, records and registers available within a general practice cannot be directly utilised for the location of handicapped people among the population living within an administratively-defined community or among people registered with a general practice. The major problems in locating handicapped people among a general practice population relate to the diffuseness of definitions of handicap (see below), the lack of recording either in the medical notes or registers of criteria used in defining handicap, and the lack of systematic up-dating of recorded information. It is well known that medical records are often not kept systematically in general practice or in hospital practice. The records frequently lack structure because no decision has ever been taken about the type of information that should be collected; too many records consist of vague statements and lack important details such as the current address, marital status, occupation or even diagnosis of the patient

(Cormack, 1971; Dawes, 1972; Hannay, 1972; McIntyre, 1974). The present survey has shown that some records even in a practice participating in research and teaching are deficient in details concerning hearing ability, visual acuity and locomotion; and this is not surprising as the records are kept mainly for the clinical handling of patients' problems and not the comprehensive care of disabled people.

An alternative method of locating and helping handicapped people registered with a general practice that might be investigated is the use by members of the primary care team (the general practitioner, the home nurse and the health visitor) of a check-list designed to define whether a patient with whom they are in contact is handicapped and has needs that might be met by one or other of the statutory or voluntary agencies. The O.P.C.S. National Morbidity Study reported that 67 per cent of the practices' population consulted their doctors during the year, so that it would be necessary to mount a survey of the population that had not consulted by the end of the year. Such an approach would have the advantage of spreading the load of meeting newly discovered need over a reasonable period of time and could be adapted as a means of updating information.

The problems of using general practice records and registers for locating handicapped people in a community served by a number of practices are formidable at the present time.

First, there are problems of confidentiality which were not overtly apparent in the present study because members of the research team were working as part of the team at the health centre and subscribed to the same ethics and code of conduct as the doctors and nurses.

Second, only a small proportion of general practices maintain practice registers. Goodman (1975) reported that by 1971 320 practices had requested the standard age-sex register cards from the Birmingham Research Unit of the Royal College of General Practitioners. He wrote to each of these people and found that 83 of the 246 respondents had either stopped using the register (17) or had not yet completed their preparations (66). It is not known how many practices in England have set up an age-sex register without approaching the Birmingham Research Unit. Cormack (1971) sent a questionnaire by post to 201 general practitioners in Scotland selected by taking a stratified sample from lists of principals maintained by the Scottish Home and Health Department. He found that 19 per cent of the 167 doctors who replied had age-sex registers in their practices; that 6.5 per cent had family registers and only 4 per cent had diagnostic indices.

Third, there remain the well-known problems of defining impairment, handicap and disability (Jefferys et al, 1969; Bennett and Garrad, 1970; Sainsbury, 1973). Impairment and handicap are relative concepts which are difficult to define objectively; most people, probably all, are impaired to some degree and whether or not that impairment will be included within a particular definition will depend on such factors as the proposed use of the definition, cultural and biological concept of normality, normative social behaviour, perception, personality, and the social, family and physical environment as much as and often more than the clinical findings and diagnosis. A given diagnosis may or may not result in functional impairment and if it does the impaired person may or may not need additional help such that would suggest identification as a handicapped person^{*}. These points have been recently discussed by Glaxter (1975) who points out that both medical and administrative definitions of disability have widened and loosened, but at the same time agencies, because of their need to define whom they will help, have introduced their own definitions, with a tendency for there to be a certain incompatibility of the various definitions evolved. There are too many definitions, and too little agreement about the information needed.

Progress towards better recording not only in general practice but also in all agencies concerned with disabled people, will depend upon the identification of each of the major components of the concept of handicap, both intrinsic and extrinsic (Agerholm, 1975). Many of the components are known, e.g. physical and mental impairments, multiple impairments, age, level of self-care activity, household and family support, home environment, local environment, transport, locomotion, occupation, personality and motivation, but many still lack reliable and repeatable methods of identification and recording. The introduction of such methods together with the widespread use in general practice of summary cards (Research Unit, Birmingham 1973) and special records such as those described by Woods (1974) which combine data from the health visitor and refer specifically to many of the components of the state of 'being handicapped', if combined with the use of the same definitions in the nursing, social and voluntary services could

* In this paper the terms 'impaired' and 'handicapped' have been defined operationally in relation to the stages of the survey. The term disabled is used in its colloquial sense without a precise definition.

considerably help agencies to find their clients and to follow them up where necessary. Hopefully, if a consistent system of recording was widely introduced, problems appropriate to one agency would not be overlooked by another and far fewer disabled people would fail to obtain the help they need. Such a system could form the basis of referral between agencies and be a step towards solving the problem of updating information and keeping in touch where necessary with handicapped people. Episodic surveys whether of households or of various records and registers are expensive and cumbersome means of putting a person in need of a service in touch with the provider of that service.

References - 1

- Agerholm, Margaret (1975) Royal Society of Health, Conference Papers, 1.3.
- Bennett, A.E. and Garrad, Jessie (1970) British Medical Journal, 3, 762.
- Blaxter, Mildred (1975) Disability and Rehabilitation: Some Questions of Definition. Chapter in 'A Sociology of Medical Practice'. Edited by Caroline Cox and Adrienne Mead. London: Collier-MacMillan.
- Cormack, J.J.C. (1971) The General Practitioner's Use of Medical Records. Scottish Health Service Studies, Number 15. Edinburgh: Scottish Home and Health Department.
- Dawes, K.S. (1972) British Medical Journal, 3, 219.
- Eimerl, T.S. (1960) Journal of the College of General Practitioners, 3, 246.
- Eimerl, T.S. and Laidlaw, A.J. (1969) A Handbook for Research in General Practice. London: E.S. Livingstone Ltd.
- Farmer, R.D.T., Knox, E.G., Cross, K.W. and Crombie, D.L. (1974) British Journal of Preventive and Social Medicine, 28, 49.
- Firth, Barbara (1975) Journal of the Royal College of General Practitioners, 25, 21.
- Goodman, M. (1975) Journal of the Royal College of General Practitioners, 25, 379.
- Hannay, D.R. (1972) Lancet, 2, 371.
- Harris, Amelia I. (1971) Handicapped and Impaired in Great Britain. London: H.M.S.O.
- Harris, Amelia I. and Head, Elizabeth (1971) Sample Surveys in Local Authority Areas with Particular Reference to the Handicapped and Elderly. London: Department of Health and Social Security.
- Jaehnig, W. (1972) Seeking Out the Disabled, in Year Book of Social Policy in Britain (Ed. Kathleen Jones). London: Routledge and Kegan Paul. (Reprinted in The Handicapped Person in the Community (Ed. D.M. Boswell and Janet M. Wingrove). London: Tavistock Publications in association with The Open University Press).
- Jefferys, Margot, Hyman, Mavis, Millard, J.B., and Warren, M.D. (1969) Journal Chronic Diseases, 22, 309.
- Knight, Rose and Warren, M.D. (1976). In preparation.
- McIntyre, N. (1974) Journal Royal College of Physicians, London, 8, 267.
- Murray, Joanna and Orwell, S. (1973) The Implementation of the Chronically Sick and Disabled Persons Act. Report by Social Policy Research. Horsham: National Fund for Research into Crippling Diseases.
- Office of Population Censuses and Surveys (1974) Morbidity Statistics from General Practice. Second National Study 1970-71. Studies on Medical and Population Subjects No. 26. London: H.M.S.O.
- Research Unit, Royal College of General Practitioners (1971) Journal of the Royal College of General Practitioners, 21, 609.
- Research Unit, Royal College of General Practitioners (1973) Journal of the Royal College of General Practitioners, 23, 413.

References - 2

- Sainsbury, Sally (1973) Measuring Disability. Occasional Papers on Social Administration Number 54. London: G. Bell & Sons Ltd.
- Warren, M.D. (1974) The Canterbury Survey of Handicapped People. Canterbury: Health Services Research Unit, University of Kent.
- Warren, M.D. (1975) Handicapped People in the Community. A Survey of Agencies' Records in Canterbury. Canterbury: Health Services Research Unit, University of Kent.
- Warren, M.D. (1976a) Interview Surveys of Handicapped People. The Accuracy of Statements about the Underlying Medical Conditions. Canterbury: Health Services Research Unit, University of Kent.
- Warren, M.D. (1976b) Handicapped People in Paddock Wood. Canterbury: Health Services Research Unit, University of Kent.
- Woods, J.O. (1974) Journal of the Royal College of General Practitioners, 24, 865.

TABLE 1

Distribution by Sex and Age of Persons Registered with the Practice.
Information from the Practice Age-Sex Register compared to Executive
Council Lists

Age Groups in Years	Practice Age-Sex Register		Executive Council List	Practice Age-Sex Register		Executive Council List
	Before Checking	After Checking		Before Checking	After Checking	
	<u>MEN</u>			<u>WOMEN</u>		
0 - 4	560	504	547	518	497	526
5 - 14	949	886	878	865	821	855
15 - 29	948	902	916	1081	1029	1008
30 - 49	1344	1266	1275	1269	1221	1250
50 - 64	556	541	630	570	559	614
65 - 74	200	194	224	275	268	288
75 - 84	101	96	104	127	124	126
85+	20	17	19	42	39	32
Not known	268	239	1	191	170	2
All ages	4946	4645	4594	4938	4728	4701

TABLE 2

Numbers of Impaired People Registered with the Practice Identified
by Household Survey and Estimated Age Specific Rates
Compared to Rates found in Canterbury Survey

Age Group	Number of Impaired Persons	Estimated Population in Households that replied	Rates per 1000 Population		
			Based on estimated respondent population	Based on practice population Supplied by the executive council	Rates found in Canterbury Survey
0 - 4	8	887	9	7	7
5 - 14	21	1515	14	12	14
15 - 29	16	1665	10	8	8
30 - 49	45	2160	21	18	21
50 - 64	75	973	77	60	58
65 - 74	84	421	199	164	145
75+	104	250	416	370	309
Not known	-	335	-		
All Ages	353	8206	43	38	50

TABLE 3

Number of Persons Identified as Impaired by Diagnostic Classification (following Morbidity Classification of R.C.G.P.) with the Estimated number of Persons Consulting in 1 year with Diagnosis (based on Patients' Consulting Rates, National Morbidity Study 1970-71)

I.C.D. Number	Diagnosis	Number of Impaired Persons	Estimated Number Consulting in Practice	I.C.D. Number	Diagnosis	Number of Impaired Persons	Estimated Number Consulting in Practice
040-043	Poliomyelitis	2	0	430-438	Cerebro Vascular disease	6	49
053	Herpes Zoster	1	37	454	Varicose Veins	1	83
250	Diabetes	9	42	491	Chronic bronchitis	7	107
274	Gout	1	15	493	Asthma	3	95
281	Pernicious anaemia	2	13	518	Bronchiectasis	1	5
300	Anxiety neurosis	2	316	580-4	Nephritis	3	3
300.1	Hysterical neurosis	1	16	712	Rheumatoid arthritis	9	46
303-304	Alcoholism	1	7	713.1	Spondylitis O.A.	1	66
310-315	Ment. Retardation	7	4	713	Osteo-arthritis	10	167
340	Multiple Sclerosis	3	6	725	Displaced intervertebral disc	4	54
342	Paralysis Agitans	1	9	741	Spina bifida	1	1
345	Epilepsy	5	27	746	Congenital heart anomaly	1	4
346	Migraine	1	68	749	Cleft palate	2	1
373	Strabismus	1	11	754	Cong. anomaly of bone or joint	4	7
374	Cataract	16	16				
375	Glaucoma	3	8				
381.1	Chronic Otitis Media	1	20	Total	All of the above	131	1660
386	Otosclerosis	2	4	140-209	Neoplasms	2	111
400-404	Hypertension	6	178	370-379	Refractive & other diseases of eye	26	113
410-414	Ischaemic heart disease	9	120	388-389	Other deafness	81	32
427	Congestive failure	4	55	N805-N949	Accidents etc.	45	767
				Total	Four Groups above	154	1023
				Grand Total		285	2683

UNIVERSITY OF KENT AT CANTERBURY
CENTRE FOR RESEARCH IN SOCIAL SCIENCES

HEALTH SERVICES RESEARCH UNIT

INTERVIEW SURVEYS OF HANDICAPPED PEOPLE
THE ACCURACY OF STATEMENTS ABOUT THE
UNDERLYING MEDICAL CONDITIONS

M.D. WARREN

1976

RESEARCH TEAM

Professor M.D. Warren, M.D., F.R.C.P., F.F.C.M., Director.
Mrs. J.L. Warren, S.R.N., Research Assistant.
Mrs. S. Woodward, Administrative secretary.

Health Services Research Unit,
Centre for Research in Social Sciences,
University of Kent,
Canterbury, Kent.

Copyright - M.D. Warren.

SUMMARY

The opportunity was taken during an interview-survey of impaired people, based on a group general medical practice, to check the impaired person's statement about the nature of the underlying medical condition against the general practitioner's assessment based on his notes and recollections. It was possible to check 311 statements, and 294 (94 per cent) were corroborated by the general practitioner. Specific diagnoses were established for 191 cases, of which 154 had been given accurately by the impaired people. There was a marked lack of specific diagnoses in three groups of disorders, the deaf and hard of hearing, the blind and partially sighted, and musculo-skeletal disorders. The findings are in agreement with previous studies and whilst they may not be surprising, they are reassuring in view of the large number of interview surveys of impaired and handicapped people that have been and are being carried out.

INTRODUCTION

Many social services departments of local authorities have carried out surveys of people living in private households in order to estimate the number of handicapped people in the area and the extent of their requirements for services. Some of these surveys have asked about the nature of the condition causing the handicap and of any other underlying conditions (e.g. Buckle and Baldwin, 1972; Research and Planning Section, Leeds County Borough, 1973; Warren, 1974; and Knight and Warren, in preparation), as had been done in the national sample survey during 1968-69 (Harris, 1971). The opportunity was taken during a survey of handicapped people which used the methods and definitions of many of the social services departments' surveys, and was based on a group general medical practice housed in a health centre at Paddock Wood, Kent, to check whether the medical condition stated by an impaired or handicapped person as the underlying cause of his impairment could be corroborated by that person's general practitioner. This paper reports the results of the project.

The data that follow refer to all those people registered with the group practice who were identified by means of a postal questionnaire addressed to each householder by name. The questionnaire contained 14 questions, the answers to which enabled the investigators to identify people who were stated to be impaired in one way or another and as a result might be physically handicapped. For the purposes of this study an impaired person was defined as a person with some significantly defective organ or bodily system and a handicapped person as a person who as a result of an impairment was unable to perform certain activities or, in the case of certain attributes was presumed to have difficulty in performing such activities (Warren, 1974). The data in this paper refer to all of the impaired people whether or not they were later classified into the subgroup of handicapped people. The methods used in the study are inappropriate for the assessment of mentally ill persons, except for those whose physical activities are severely affected by their mental condition.

The study was concerned with the reliability of the impaired person's statement about the nature of the underlying medical condition. Whilst data about the prevalence of certain conditions among impaired persons are presented, these data cannot be taken as reflecting the total prevalence of the conditions in the population, except in the rare instances where it can be assumed that all persons suffering from the condition are significantly impaired and will state the condition as the main cause of their impairment. Previous studies have shown the limitations of the use of general questionnaires in

estimating the prevalence of chronic illnesses in a population (Madow, 1973) and the need to develop detailed questionnaires for each condition (Medical Research Council, 1965; Rose and Blackburn, 1968).

METHODS

The survey was conducted in three stages. After identifying and listing by household all of the people registered to receive general medical care from the three medical practitioners in the group practice, the householder was sent by post a letter and the questionnaire, which has already been referred to, asking, in effect, if there was anyone in his household with an impairment that restricted the person's activity or potential activity. 3,287 households estimated to contain 9,373 people were initially approached. Two reminder letters were sent to the non-responders at three-weekly intervals. The response rate was 81 per cent of households approached (see table 1); these households were estimated to contain 8,206 (87% of the 9,373 people identified as registered with the practice. Blank forms were returned (mainly by the post office) from almost 14 per cent of the households approached, 5 per cent of the householders did not reply and only 6 householders actively refused to cooperate.

This postal survey identified 392 persons who were stated to have an impairment, living in 352 households. In the second stage of the survey each of these people was scheduled to be interviewed by a trained interviewer for the purpose of deciding whether the person could be defined as handicapped. Interviews were completed for 353 people. There were various reasons why the 39 people were not interviewed; two of the people refused an interview, 1 was considered to be too unfit for interview, 12 had been admitted to hospital or a home before interview, 1 had recovered, 1 was not contacted, and 22 were not interviewed because of misunderstanding of the original form, not being on the practice register or they had subsequently moved out of the district.

During the second stage of the survey each of the 353 persons or a proxy was asked by an interviewer the following questions:-

"What does the doctor say is the matter with you?" and if the doctor had not been seen or hadn't given any information,

"What do you think is the matter with you?" The answers to these questions are examined in this report.

The interviewer asked a number of other questions including questions about seeing, hearing and some activities of daily living. If the impaired person was finding significant difficulty in some of these activities, he or she was considered to be handicapped and the interview was continued into the third stage of the survey - the collection of data about further activities, wants, difficulties, and services in attendance upon the handicapped people. Data from this third stage are not reported here. (Warren, 1975).

After the interviews had been completed, the research assistant interviewed each of the general practitioners in the practice about those of his patients who had been identified as impaired. Each doctor, who had the medical notes of the patient in front of him, was asked to state the main diagnosis. If there was no obvious diagnosis recorded, the doctor could not recall any diagnosis, or there seemed to be disagreement, the patient's statement was revealed to the doctor and the doctor's confirmation, general agreement, or disagreement noted. One of the three partners in the practice became seriously ill during the course of the study and some of his patients had to be discussed with one of the other partners.

RESULTS

Interviews were successfully completed with 353 of the 392 people apparently eligible - that is with 90 per cent of the identified group of apparently impaired people. There is no reason to believe that the reasons, which have already been stated, for not interviewing the 39 people are related in one way or another to the reliability of answers that the people might have given.

Most of the reports of surveys of handicapped people present the data about diagnoses in groups of conditions based on the groupings used in the International Classification of Diseases, Injuries and Causes of Death (I.C.D.) and the same procedure was used in the Introductory Report of the General Household Survey (Moss et al, 1973). Table 2 shows the degree of corroboration found in the present study by each of the condition groups in the I.C.D. (Seventh Revision). Harris (1971) and many subsequent researchers into the numbers and needs of handicapped people have used an essentially similar list also based on the I.C.D. She classified poliomyelitis among the diseases of the central nervous system (Group VI) and had conditions affecting the eyes and ears in a separate group, separated fractures and sprains from other injuries (birth injuries, burns, etc.) and included the former among the

musculo-skeletal disorders. With only three exceptions (disorders of the ear, disorders of the eye and the arthritic and musculo-skeletal group) there is considerable evidence of confirmation of the patients' statements by the general practitioners. The patients are aware of, and prepared to give information reasonably accurately about which bodily system it is that is disordered.

The amount of detail given by the impaired people about their illness or impairment varied from a specific diagnosis (e.g. multiple sclerosis, chronic bronchitis, glaucoma), description of injury or operation, through a statement of disability or disease group (e.g. blind, deaf, difficulty in hearing, arthritis) to an account of symptoms (e.g. breathlessness and swollen ankles, stiff joints). In 154 cases (44 per cent) the specific diagnosis or details of an injury stated by the impaired person was corroborated by the general practitioner. The conditions are listed in table 3. In another 140 cases (40 per cent) the more general statements by the impaired people were corroborated as being compatible with the doctors' diagnoses. For example, the impaired person might say 'arthritis' and the doctor might be more specific (e.g. rheumatoid arthritis) or might merely agree that the person did have 'arthritis' without being more specific.

There was, therefore, agreement between the patient and the doctor in 84 per cent of the cases (table 2). In 12 per cent no check was possible because there were no relevant notes about the condition or the doctor could not recall whether or not the patient had the condition; the majority of these cases referred to the patients of the partner who was ill. In only 17 cases (5 per cent) were the statements from the two sources incompatible. One patient attributed her impairment to tuberculosis of the spine, which the doctor did not confirm, another to a stroke (which the doctor said was hysteria) a third to rheumatoid arthritis (which the doctor denied) and a fourth to a long-standing jaw infection which spread to the shoulder (which the doctor denied). Thirteen other patients mentioned conditions such as inflammation of the eyes, partially deaf, bad eyesight and old age, which whilst probably correct were not seen by the doctor as the major cause of impairment and handicap. Seven of these people had congestive cardiac failure, ischaemic heart disease or hypertension, one had cancer of the rectum and had had a colostomy, another was alcoholic and another had epilepsy.

In 37 of the cases where the patient had not given a specific diagnosis or where the patient had given a diagnosis with which the doctor disagreed, the doctor was able to give a specific diagnosis and these are shown in table 3.

In all, therefore, a specific diagnosis was available for 191 (61 per cent) of the 311 cases, the bulk of those cases without a specific diagnosis being among the blind and visually impaired, the deaf and hard of hearing, and those with musculo-skeletal disorders. These three exceptions to the generally reassuring findings raise interesting points. A very small proportion (7 per cent) of people with impaired hearing were able to state a diagnosis and in 33 per cent the doctors could not confirm or dispute the patients' statements. That the patients did have difficulty in hearing was confirmed by the interviewer, so the lack of corroboration by the doctors arose from a lack of recording or recalling this information. As one doctor pointed out, he did not usually record difficulty in hearing because this would be obvious from the start of a consultation. However, it does mean that if doctors do not usually make a note about deafness, doctors' records will be a poor source of information concerning the prevalence of deafness among their patients or for the identification of deaf people. An additional factor is that many patients do not consult the general practitioner about gradual deterioration of hearing. Somewhat similar but very much less marked findings are seen in relation to the visually impaired people. The findings in regard to the arthritic and musculo-skeletal group probably reflect the vagueness of the term 'arthritis' and 'rheumatism' and perhaps the too ready acceptance of one or other term as a reason for difficulty in locomotion in old age.

Statements made by elderly people were corroborated less often than statements made by younger people. About 15 per cent of the statements of people aged 65 or more could not be checked (table 4), reflecting in a large part the association of impaired hearing, vision and locomotion with old age and that the oldest (and first) partner in a practice had more elderly people on his list than the younger partners.

DISCUSSION

In a series of studies to investigate the feasibility of an enquiry to establish how many individuals in the population at any given time have motor impairments or limitations, Jefferys et al (1969) checked the reliability of the information obtained from impaired people about their conditions. With the subject's permission, comparisons were made for 65 of 89 impaired individuals between their general practitioner's diagnosis and their own description of the underlying cause of their impairment. In 24 cases (27 per cent) no check was possible. There was agreement on the cause of the disability in 61 (94 per cent) of the remaining 65 cases and in only 4 was their disagreement.

These figures are similar to those obtained in the survey reported in this paper, in that agreement on the nature of the condition was established in 294 cases (94 per cent) out of the 311 that could be checked. The reason that the present survey achieved a lower percentage of failures to check (12 per cent), was due almost certainly to the survey being based on one group practice, the partners of which had agreed to cooperate fully and eagerly with the study.

Investigators in the United States of America have compared the results of a comprehensive family interview survey and a mailed questionnaire check of physician's records and recollections (Elinson and Trussell, 1957). Among their principal findings were 'that medically attended conditions when reported in the family interview, tend to be substantially verified by replies to written inquiry of physicians attending the conditions. The proportion of overall agreement between interview reports and physician reports varied between three-fourths and nine-tenths with the lower figure representing the degree of correspondence when physicians were not informed as to the essential content of the interview report'. Madow (1973) reported on a study designed to measure the accuracy and completeness of the reporting of chronic conditions in health interviews. When the conditions were classified into 50 broad disease categories it was found that diabetes, vascular lesions of the central nervous system, heart conditions, diseases of the gall bladder and amputations were reported with a fair degree of accuracy and completeness. Neoplasms, mental illness, menstrual disorders and skin diseases were under-reported and hay-fever, asthma, tuberculosis, migraine, hypertension, bronchitis, visual impairments and hearing impairments were over-reported. In the Paddock Wood study no evidence of over-reporting of bronchitis and hypertension was revealed and some of the other conditions mentioned in Madow's report were not encountered; with these exceptions the data from Paddock Wood are similar to those reported by Madow.

CONCLUSION

It is concluded that in interview studies of impaired people reliable data can be obtained from the impaired person or a proxy about the nature of the condition causing the impairment, using straightforward and simple questions. The information will be reliable in so much as it refers to

broad disease groupings, but it is more likely to be deficient rather than inaccurate in relation to specific diseases, and especially in relation to the causes of deafness, blindness or partial sight, and musculo-skeletal disorders. These findings are not surprising as a person with a chronic disease or impairment will usually have had a number of contacts with his or her doctor. Furthermore, as has been found in a number of surveys recently, impaired people are willing to cooperate to the best of their ability in interviews about their problems. Although not surprising, the findings are reassuring in that the basic survey methods examined in this study were those that were used in the national sample survey of handicapped and impaired persons (Harris, 1971), in many of the local authorities' surveys as well as in the General Household Survey (Moss et al, 1973).

References

Buckle, Judith and Baldwin, P. (1972) Survey of Handicapped and Impaired Persons and Persons Aged 75 or Over and Living Alone in the Royal Borough of Kensington and Chelsea. The Royal Borough of Kensington and Chelsea: Social Services Department.

Elinson, J. and Trussell, R.E. (1957). American Journal of Public Health, 47, 311.

Harris, Amelia I. (1971) Handicapped and Impaired in Great Britain. London: H.M.S.O.

Jefferys, Margot., Hyman, Mavis., Millard, J.B. and Warren, M.D. (1969). Jn. Chronic Diseases, 22, 303.

Knight, Rose and Warren, M.D. In preparation. An Analysis of Local Authorities' Surveys of Handicapped People.

Madow, W.G. (1973) Net Differences in Interview Data on Chronic Conditions and Information Derived from Medical Records. D.H.E.W. Publication No. (HSM) 73-1331. Washington, D.C., U.S. Government Printing Office.

Medical Research Council: Committee on the Aetiology of Chronic Bronchitis (1965). Lancet, 1, 775.

Moss, L., Barnes, R., Durant, Mary., Birch, F. and Paley, Bobbie (1973) The General Household Survey - Introductory Report. Office of Population Censuses and Surveys. Social Survey Division. London: H.M.S.O.

Research and Planning Section, Leeds County Borough (1973) Survey of Handicapped and Impaired Persons and Persons Aged 75 or Over and Living Alone in Leeds County Borough. Leeds: City Treasury.

Rose, G.A. and Blackburn, H. (1968) Cardiovascular Survey Methods. Geneva: World Health Organization.

Warren, M.D. (1974) The Canterbury Survey of Handicapped People. Canterbury: Health Services Research Unit Report.

TABLE 1

Number of Householders Approached and
Number of Forms Returned

Householders approached	3287	(Population 9373)
Completed forms returned	2674	(Population 8206)
Incomplete forms returned by post office	402	
Incomplete forms returned by others	42	
Refusals	6	
No reply	163	

TABLE 2

Corroboration by General Practitioner of Person's Statement
about Diagnosis by Group of Conditions

Condition Group	Degree of Corroboration				Total
	Complete match	Statements compatible	Statements incompatible	No check possible	
I Infectious diseases	3	0	2	0	5
II Neoplastic diseases	0	0	0	0	0
III Endocrine, metabolic diseases	9	0	0	0	9
IV Blood, blood forming diseases	2	1	0	0	3
V Mental disorders	11 (61)	6 (33)	1 (6)	0	18
VI Central nervous system diseases	20 (77)	4 (15)	2 (8)	0	26
Disorders of hearing	6 (7)	48 (57)	2 (3)	28 (33)	84
Disorders of vision	20 (43)	17 (37)	1 (2)	8 (17)	46
VII Cardiocascular diseases	11 (44)	13 (52)	0	1	25
VIII Respiratory diseases	11 (84)	2	0	0	13
IX Digestive diseases	0	1	1	0	2
X Genito-urinary diseases	3	1	0	0	4
XI Pregnancy disorders	0	0	0	0	0
XII Skin and subcutaneous diseases	0	0	0	0	0
XIII Arthritis and musc. diseases	18 (29)	34 (55)	5 (8)	5 (8)	62
XIV Congenital malformations	6	1	0	0	7
XV Perinatal diseases	0	0	0	0	0
XVI Symptoms and ill-defined	0	1	2	0	3
XVII Fractures and injuries	34 (74)	11 (24)	1 (2)	0	46
Total	154 (44)	140 (40)	17 (5)	42 (12)	353

(Percentages in brackets)

TABLE 3

List of 154 Diagnoses named by Handicapped Person and
Corroborated by General Practitioner and in brackets
37 diagnoses added by General Practitioner

Group I	-	Poliomyelitis	2	Group VII	-	Angina	5 (4)
		Herpes zoster	1			Hypertension	3 (3)
Group II	-	Cancer	(2)			Buergers	1
Group III	-	Diabetes	8 (1)			Varicose veins	1
		Gout	1			Cong.heart def.	1
Group IV	-	Pernicious anaemia	2			Congestive failure	(4)
Group V	-	Mental handicap	7 (2)	Group VIII	-	Chr.bronchitis	7
		Neurosis	2 (3)			Asthma	3
		Hysteria	1			Bronchiectasis	1
		Alcoholism	1 (1)	Group X	-	Nephritis	2 (1)
Group VI	-	Strokes	6			Hysterectomy	1
		Epilepsy	4 (1)	Group XIII	-	Rheum.arthritis	8 (1)
		Cerebral palsy	3 (1)			Osteo-arthritis	7 (3)
		Hemi-/or paraplegia	3			Prol. interv. disc.	3 (1)
		Multiple sclerosis	2 (1)			Cervical spond- ylitis	(1)
		Parkinsonism	1			Ankylosing spondylitis	(1)
		Migraine	1	Group XIV	-	Cleft palate	2
		-				Cong. foot defect	1
		Rubella deafness	2			Cong.hand defect	1
		Otosclerosis	2			Cong.disloca- tion, hips	1 (1)
		Birth trauma	1			Spina bifida	1
		Chr.sup.otitis media	1	Group XVII	-	Fractures and injuries	34
		Cataract	14 (2)				
		Glaucoma	3				
		Detached retina	2				
		Choroiditis uveitis	(2)				
		Strabismus	1				
		Corneal scars	(1)				

TABLE 4

Corroboration by General Practitioner of Person's Statement
about Diagnosis by Age Group of Persons

Age Group in years	Degree of Corroboration				Total
	Complete match	Statements compatible	Statements incompatible	No check possible	
0 - 14	15 (52)	13 (45)	0 (-)	1 (-)	29
15 - 29	10 (62)	5 (31)	0 (-)	1 (-)	16
30 - 49	30 (67)	13 (29)	1 (-)	1 (-)	45
50 - 64	38 (51)	24 (32)	3 (4)	10 (13)	75
65 - 74	27 (32)	38 (45)	6 (7)	13 (15)	84
75 - 84	26 (35)	35 (47)	3 (4)	11 (14)	75
85+	8 (28)	12 (41)	4 (14)	5 (17)	29
Total	154 (44)	140 (40)	17 (5)	42 (12)	353

(Percentages in brackets - rounded)

HANDICAPPED PEOPLE IN PADDOCK WOOD

M.D. WARREN

1976

RESEARCH TEAM

Professor M.D. Warren, M.D., F.R.C.P., F.F.C.M., Director

Mrs. M.J.A. Russell, M.S.R., Research assistant.

Mrs. J.L. Warren, S.R.N., Research assistant.

Mrs. S. Woodward, Administrative secretary.

Health Services Research Unit,
Centre for Research in Social Sciences,
University of Kent,
Canterbury, Kent.

Copyright - H.S.R.U., 1976.

SUMMARY

Forms were posted to the 3287 households of people registered with a group medical practice in Paddock Wood enquiring about the presence in the household of any person with disability. The Post Office returned 402 forms which could not be delivered. Replies were received from 2674 (93% of eligible addresses) which identified 392 impaired people, 353 (90%) of whom were interviewed about their impairments. As a result of the interviews 216 people were classified as handicapped and were asked further questions about their use of services and their needs.

This study was one of a series of studies concerned with the identification of handicapped people in the community and the ascertainment of their needs for certain services. Additional criteria were introduced into the definition of 'handicapped person' for the purpose of this study, but this was done in such a way that comparisons could be made between handicapped people defined in the way of an earlier study carried out in Canterbury in 1972 and between the groups defined by the old and the new criteria.

The prevalence rate of impaired people in the population in Paddock Wood using the 1972 criteria was found to be 43 impaired persons per 1000 of the population compared to the figure of 50 per 1000 found in the earlier Canterbury survey. Paddock Wood has a 'younger' population and it is probable that the demographic differences account for most of the few differences found in the circumstances and needs of handicapped people in Paddock Wood and in Canterbury.

The use of the new criteria brought in another 69 impaired people into the handicapped group; these were mainly people aged between 15 and 64 years. Many were substantially disabled and had needs or were using services similar to many classified as handicapped by the 1972 criteria. The use of the new criteria appeared to bring into the definition an important group of people; their use should be incorporated in future community surveys.

INTRODUCTION

This report presents details about the age, sex, marital status, household composition, housing, impairments and the expressed needs for certain help and services of disabled people living in the community around Paddock Wood, Kent. The survey, on which this report is based, was carried out during 1973 and was one of a series of studies of handicapped people and their needs. The objectives of the study in the Paddock Wood area were:

1. to examine the problems of identifying handicapped people registered with a general practice and to see if the use of records and registers used in general practice could simplify the task of a social services department in locating handicapped people;
2. to check the impaired peoples' statements about the nature of the conditions causing or underlying their impairments;
3. to repeat the methods of locating handicapped people, which were used in the Canterbury Survey (Warren, 1974) and based on the recommendations of the Department of Health and Social Security, in order to gain experience of their use in a different situation and to be able to compare the circumstances and expressed needs of handicapped people in Canterbury with those of handicapped people in another place;
4. to examine the effect of introducing modifications into the interview schedules and widening the criteria used to identify handicapped people from among impaired people.

This report presents the results in regard to the third and fourth objectives; previous papers have described the findings in relation to the other two objectives (Warren, 1976a; Warren, 1976b).

Paddock Wood

Paddock Wood is a traditional centre for hop growing and a hop festival is still held every September. However, the old village and its neighbour, East Peckham, grew considerably during the 1950s and 1960s; both are now partly industrialised and contain large estates of new suburban-type houses and bungalows. The effects of these developments are apparent in the age-sex structure of the population in the area. Compared to the population in England and Wales there are in Paddock Wood higher proportions of children (29 per cent compared to 24 per cent) and of people aged 30 - 49 years (26 per cent compared to 24 per cent) and a lower proportion of people aged 50 years or more (20 per cent compared to 31 per cent). Paddock Wood has some of the features of a new town blended with its more traditional features.

METHODS

The survey was based on the population of people living in Paddock Wood, East Peckham and surrounding hamlets who were registered for the purposes of general medical care with the group practice centred at the health centre in Paddock Wood (with a branch surgery at East Peckham). The compilation of the list of households (and the members of each household) that were included in the survey has been described in a previous paper (Warren, 1976a). The procedure used to locate the impaired people and to identify the handicapped from among them was to carry out a three stage operation, basically along the lines of the recommendations of Harris and Head (1971) and as had been used in the Canterbury survey. In the first stage each householder was approached and asked to complete a one page form containing 14 questions designed to identify (by name) any person in the household with substantial impairment of vision, hearing, locomotion, or ability to look after himself or who has lost the whole or part of the use of an arm, leg, hand or foot through accident or amputation or has a serious congenital abnormality. In the second stage, each impaired person, identified on the form returned by the householder was interviewed by a trained interviewer and asked questions about the nature of the impairment and the limitations to activities that it caused. Depending upon the answers to these questions, the interviewer decided whether to continue into the third stage and ask questions about the problems experienced and the services received by the handicapped person or to complete the interview at the end of stage 2. All people who had a stage 2 interview are referred to as impaired people and the sub-group that had a stage 3 interview as handicapped people.

Changes Introduced

There were three important differences between the procedure in Paddock Wood as compared to that in Canterbury. First, in Paddock Wood the first stage was conducted by post; in Canterbury, volunteers delivered and collected back the initial screening form from each household. Second, in Paddock Wood the interviewers carried on, if the information so indicated, from the first to the second interview, whereas in Canterbury the decision about the need for a final interview was checked centrally and then further arrangements were made for the second interview. Third, four alterations were made in the schedule used for the first interview, designed to bring into the category of 'handicapped' persons some severely impaired people that were believed in the light of experience in Canterbury to have needs

for services, but had not qualified for a final interview in the Canterbury survey. These changes were introduced in such a way as to enable the data from Paddock Wood to be analysed separately for the group of handicapped people identified by exactly the same criteria as that used in the Canterbury survey (referred to in the tables as '1972 definition') and for the other group identified by reason of the new criteria (referred to in the tables as 'new criteria'). The changes introduced and the effects these had are discussed in a later section of this report.

Response

Forms were despatched to 3287 households. The Post Office directly returned 402 uncompleted forms as the addressee no longer lived at the address. Six householders refused to complete a form, 42 returned a blank form and 163 householders did not respond at all. Completed forms were received from 2674 householders (93 per cent of eligible addresses), after two reminders had been sent to non-responders (table 1).

It was estimated from the practice age and sex register that the 3287 households initially approached contained 9373 persons registered with the group practice; and that the 2674 households from whom a completed form was received contained 8206 persons (87.5 per cent). Proportionately fewer (79 per cent) of persons aged 85 years or more responded (table 2). This age-group is the most likely to contain people that will be admitted to hospital or to homes or to have died; it is also possible that because of infirmity, some handicapped people among this group failed to reply. However, the proportion of this age-group in Paddock Wood who were identified as impaired was higher than in Canterbury. Unfortunately the ages were not known of 4 per cent of the persons in the households; data from the executive council records of persons registered with the practice suggest that the majority of these persons belong to the age group 50 - 64 years, and some in the age group 65 - 74 and a few would be infants (Warren, 1976a).

Three hundred and fifty two of the 2674 completed forms returned mentioned the presence of 1 or more impaired person in the household. These 352 forms gave information about 392 people, of whom 353 (90 per cent) were interviewed; table 3 sets out the reasons for failing to interview the 39 others. Twelve people had been admitted to hospital or a home before the interview could be arranged, 9 had been admitted before the survey and so had been wrongly included on the household form, 5 had moved out of the area before interview, 5 were found not to be impaired, 5 were not registered with the practice, 2 refused and 1 was too ill to be interviewed.

RESULTS

The circumstances and expressed needs of the 353 impaired people in the Paddock Wood area corresponded qualitatively to those of the impaired people in Canterbury. Some of the general implications of these circumstances and expressed needs for the impaired people and for the development of services were discussed in the report of the Canterbury Survey (Warren, 1974) and so are not repeated here. The finding of general similarity in regard to circumstances and expressed needs of impaired people in the two surveys is on the one hand not surprising as the same questions were asked, but on the other the finding is re-assuring as showing that the method used in Canterbury, when repeated elsewhere gave comparable results.

Impaired and Handicapped People in Paddock Wood Compared to those in Canterbury

Impaired People

As has already been mentioned the estimated population of the households responding to the survey in Paddock Wood contained proportionately more children and persons aged 30 to 49 years and fewer persons over the age of 50 years than the populations enumerated in private households in England and Wales and in Canterbury by the 1971 Census (table 4). As assessed by the age distribution of patients registered by the executive council with the general practice in Paddock Wood, a few of the members of households whose ages were unknown were aged under 4 years, and the majority were aged between 50 and 74 years (see table 1 of Warren, 1976a). Table 5 presents the prevalence rates of impaired people by age groups and compares the rates in Paddock Wood with those found in Canterbury. Upto the age of 49, the rates in the two areas are similar, but among persons aged 50 or more, proportionately more impaired people were identified in Paddock Wood than in Canterbury. (These figures refer to impaired people, not the subgroup of handicapped people, and therefore are not affected by the changes introduced in the interviewing schedules.) Among the 353 impaired persons in Paddock Wood there were 188 (53 per cent) old people, whereas in Canterbury among the 1,534 impaired people there were 956 (62 per cent) people aged 65 years or more; 29 per cent of the impaired people in Paddock Wood were aged 75 years or more compared to 36 per cent in Canterbury. These differences in the age structures of the two populations and of the impaired populations could account for many of the differences between the figures from the Paddock Wood survey and those from the Canterbury survey presented in the subsequent tables.

The registration rates of blind people are similar in the two areas (table 6), but proportionately fewer of the people in Paddock Wood stated they were registered as partially sighted or had difficulty with distant or near vision. The registration rates of deaf people were also similar between the two areas, but proportionately more people in Paddock Wood stated they were registered as hard of hearing, but fewer of the non-registered were observed to be hard of hearing. There were more housebound impaired people and more who had difficulty in self-care or getting about per 1000 of the population in Canterbury than in Paddock Wood.

The main conditions associated with impairment in Paddock Wood (table 7) were the same as those found to be associated with impairments in other studies.

A larger percentage of the impaired people in Paddock Wood were married (54 per cent) than in Canterbury (45 per cent) and a lower percentage were widowed or divorced (28 per cent compared to 35 per cent, table 8); consequently, a lower percentage were living alone in Paddock Wood (19 per cent) than in Canterbury (29 per cent) and a higher percentage in Paddock Wood were living with 2 others or more in the household. All of these differences could be due to the younger population in Paddock Wood.

Handicapped People

The group defined as handicapped people are a sub-group of all impaired people. The distinction depends upon a number of factors ascertained in the first part of the interview; thus registration as a blind, partially sighted, deaf or hard of hearing person, attendance at a special school, scoring 6 or more points on the self-care scales (or any score if 70 years or older), being bedfast or housebound or stating to have poor eyesight or difficulty in hearing (see interview schedule in the appendix) were the indicators for a second interview in Canterbury and (with the additions) for completing the schedule in Paddock Wood. These criteria formed the '1972 definition' for the designation of 'handicapped'. Other criteria (the 'new criteria', see below) were added in Paddock Wood; but, as has already been mentioned, the analysis has been carried out so that the data from the two groups of handicapped people can be examined separately.

Using the 1972 criteria for defining the group of handicapped people, 147 of the impaired people in Paddock Wood were so defined. This forms 42 per cent of all impaired people, compared to 54 per cent in Canterbury (table 9), much of this difference can be attributed to the greater proportion of

the more elderly, i.e. in this context, aged 70 years or more, among the impaired people in Canterbury. Table 10 presents the age distribution of the handicapped people in the two areas.

In Canterbury there were proportionately more permanently housebound handicapped people (table 11). More of the handicapped people lived in bungalows in Paddock Wood, but fewer in ground-floor flats; however, this seems to reflect the differences in housing available in Paddock Wood and Canterbury, for in Paddock Wood 24 per cent of the handicapped people lived in a bungalow compared to 13 per cent in Canterbury (table 12) and 5 per cent in a ground floor flat compared to 16 per cent in Canterbury. More of the handicapped people in Paddock Wood were owner occupiers and fewer were council tenants.

Availability of relatives and friends to the handicapped people was similar in both places; this is surprising in view of the amount of new building in Paddock Wood. A smaller proportion of the handicapped people were alone day and night in Paddock Wood (table 13).

The health visitors seem to be in contact with more of the handicapped people than the social workers in Paddock Wood, whereas the reverse was the case in Canterbury (table 14). Possible explanations are that the health visitors in Paddock Wood were already concerned with many of the families, because so many still have children at home; and the integration of their work with that of the general practice at the health centre has probably extended their involvement with elderly people. A substantially smaller percentage of the handicapped people in Paddock Wood were being visited by the chiropodist; there was a chiropody service at the health centre and transport to this service was arranged by the Red Cross.

The expressed needs of the handicapped people for personal aids and house adaptations (table 15) are similar in magnitude and kind in Paddock Wood and Canterbury, but proportionately more handicapped people in Canterbury expressed needs for help from other people or services (table 16) - another manifestation of the larger proportion of handicapped people in Canterbury who were severely limited in mobility and isolated.

The Effects of Extending the Criteria Used
in the Definition of 'Handicapped'

Five new criteria were added to those used in the Canterbury survey (see p.5) in order to extend the breadth of the definition of 'handicapped'.

This was done, because a number of interviewers in the Canterbury survey had reported that quite extensively disabled people did not seem to qualify for a final assessment interview under the 'rules' then operating. The new criteria introduced in Paddock Wood were registration as a physically handicapped person, difficulty observed by the interviewer in the impaired person's hearing, the use of aids in self-care even if these eliminated all difficulty, the attainment of a score of 1 or more on the self-care assessment questions even if aged less than 70 years (previously, those under 70 years of age were only included if scoring 6 or more) and any person aged between 16 and 64 who was not working full-time because of impairment or any housewife who considered she was unable to cope with all her housework because of impairment (see attached schedule). As a result 69 impaired persons were classified as 'handicapped' by reason, only, of one or more of the new criteria (table 17). The changes that affected the definition of most people were the inclusion of people scoring any points on the self-care assessments (this added 16 men and 16 women), inability to work full-time (15 men and 9 women) and registration as physically handicapped (11 men and 1 woman). This last criteria might have a much larger yield in other areas as only 6 per cent of all impaired persons stated they were registered as physically handicapped in Paddock Wood.

In what ways did this additional group of handicapped people differ from the first group? Is this additional group an important group for services to be in contact with? Before answering these questions by examining the tabulated data, some details of 'cases' will illustrate that some of these people were extensively disabled. The most severely disabled person in this group was probably a man of 47 years who had sustained a fractured spine in a car accident. He was confined to a wheelchair, travelled by an invalid tricycle, had had his house adapted by the council, had been rehabilitated at Stoke Manderville, but was still unemployed at the time of the survey. He was registered as physically handicapped and therefore fulfilled three of the new criteria (registered, unemployed and used aids), but would not have been classified as handicapped on the 1972 definition, mainly because he was coping reasonably well despite his impairment (paraplegia) which would, of course, have been picked up. Another case was that of a woman aged 58 who because of arthritis was unable to get upstairs so she slept downstairs, she needed aids to help her use her bath and lavatory. Another was that of a man aged 43 who had had a head injury at work and was still unemployed because of mental changes. The only two cases of multiple sclerosis (stated to be such by the patients and later confirmed by the doctors) were defined as handicapped by the additional criteria.

The impact of the new criteria must be mainly among impaired people of working age, because the criteria take into account the lack of full-time employment and remove the limitation in regard to the low scores in the self-care assessments for persons under 70 years of age. Therefore, it is not surprising to find that 70 per cent of the new category of handicapped people are aged between 15 and 64 years (table 18), and that the majority are males (59 per cent) for as the females outlive the males, it is among the elderly that they increasingly form the majority of handicapped people. The new criteria had the effect of more than doubling the number of impaired people of working age classified as handicapped. The main diagnoses of the underlying conditions among the new group were injuries, arthritis, respiratory diseases, mental disorders (particularly mental handicap) and coronary disease (table 19).

Almost all of the new category could get out of their houses (table 20); if they couldn't, except for some temporary cause, they would have come within the 1972 definition. However, 41 per cent had difficulty with walking (2 had to use wheelchairs).

There were no significant differences in the housing of the people in the new group as compared to the first group (table 21), nor in their contacts with friends and relatives (table 22). Handicapped persons in the new group had proportionately less contact with most of the services, but for some of the services the differences are small (table 23). Their expressed needs for aids and house adaptations (table 24) and for various forms of personal help (table 25) were similar proportionately to the other handicapped group, although there was some less expressed need for certain services (visitor, holiday, help with housework, gardening and window-cleaning and transport).

The most striking differences between the two groups of handicapped people identified in Paddock Wood are in their employment status (table 26). Twenty-six per cent of the new group were employed, 6 per cent wanted employment and 4 per cent were temporarily unemployed, whereas only 11 per cent of the group defined by the 1972 criteria were employed, none was looking for work and only 1 was temporarily unemployed. Twenty-four (37 per cent) of the new group were or had been registered as disabled with the Department of Employment (as distinct from registration as handicapped with the local social services department), and 17 people (27 per cent) would have liked to do paid work at home, at a day centre or in a sheltered workshop, compared

to 14 (11 per cent) and 5 (3 per cent) in the other group in Paddock Wood. The table also presents the figures from the Canterbury survey which are of the same order of those of the group defined by the 1972 criteria in Paddock Wood.

CONCLUSION

The basic procedures used to locate handicapped people and to assess their conditions and needs presented no new problems when used in the different circumstances of Paddock Wood compared to Canterbury. The amalgamation of the first and second interviews used in Canterbury into one interview which could be terminated after completion of the screening part of the interview was welcomed by the interviewers, eliminated the possibility of any reduction of numbers between interviews and as far as can be seen presented no problems.

The data obtained in Paddock Wood is broadly comparable to that obtained in Canterbury; many of the differences that were found between various features of handicapped persons in Paddock Wood compared to those in Canterbury could be attributed to the differences in the age structure of the populations.

The introduction in Paddock Wood of the new criteria extending the definition of 'handicapped' increased the proportion of handicapped people among the impaired by almost 20 per cent. The vast majority of the new group were aged between 15 and 64 years. They appeared to be substantially disabled and to have needs in everyway comparable to people defined as 'handicapped' using the previous criteria, and to have more expressed needs in the sheltered employment field. Future surveys should include these new criteria in their definitions of handicapped people.

References

Harris, Amelia I. and Head, Elizabeth (1971) Sample Surveys in Local Authority Areas with Particular Reference to the Handicapped and Elderly. London: Department of Health and Social Security.

Warren, M.D. (1974) The Canterbury Survey of Handicapped People. Canterbury: Health Services Research Unit, University of Kent.

Warren, M.D. (1976a) Identifying Handicapped People in a General Practice Population. Canterbury: Health Services Research Unit, University of Kent.

Warren, M.D. (1976b) Interview Survey of Handicapped People. The Accuracy of Statements about the Underlying Medical Conditions. Canterbury: Health Services Research Unit, University of Kent.

TABLE 1

HOUSEHOLDS APPROACHED AND RESPONDING

Number of forms despatched to households	= 3287
Number of blank forms returned by Post Office	= 402 (12%)
Number of forms delivered (eligible addresses)	= 2885
Number of blank forms returned by Household	= 42 (1%)
Number of forms not returned	= 163 (6%)
Refusals	= 6
Total number of forms not completed	= 211 (7%)
Number of completed forms returned	= 2674 (93%)

TABLE 2

AGE AND SEX OF PERSONS IN HOUSEHOLDS APPROACHED AND
IN HOUSEHOLDS RESPONDING

Age Group Years	Population in households approached			Population in households approached			Percent responding
	M	F	Total	M	F	Total	
0 - 4	504	497	1001	447	440	887	89
5 - 9	517	488	1005	452	441	893	89
10 - 14	369	333	702	330	292	622	89
15 - 19	249	282	531	212	246	458	86
20 - 24	246	256	502	212	218	430	86
25 - 29	407	491	898	349	428	777	86
30 - 34	422	414	836	357	356	713	85
35 - 39	331	304	635	287	264	551	87
40 - 44	300	274	574	253	244	497	87
45 - 49	213	229	442	193	206	399	90
50 - 54	233	220	453	198	193	391	86
55 - 59	167	165	332	145	149	294	89
60 - 64	141	174	315	127	161	288	91
65 - 69	109	154	263	101	141	242	92
70 - 74	85	114	199	78	101	179	90
75 - 79	64	80	144	61	73	134	93
80 - 84	32	44	76	30	42	72	95
85+	17	39	56	12	32	44	79
Not known	239	170	409	192	143	335	82
Total	4645	4728	9373	4036	4170	8206	87.5

TABLE 3

NUMBER OF IMPAIRED PEOPLE LOCATED AND INTERVIEWED

Number of completed household forms returned	= 2674
Number of completed forms identifying 1 or more possibly impaired people	= 352

The 352 completed forms gave information about 392 possibly
impaired people; of these 392 people 353 (90 percent) were
interviewed.

Total number of persons identified on household forms	= 392
Number of persons admitted to hospital or home before survey	= 9
Number of persons admitted to hospital or home before interview	= 12
No interview for medical reasons	= 1
Moved out of area	= 5
Recovered or not impaired	= 5
Refused	= 2
Not on the practice register	= 5
Total number of persons interviewed	= 353

TABLE 4

AGE DISTRIBUTION OF THE POPULATION IN THE HOUSEHOLDS
RESPONDING IN PADDOCK WOOD COMPARED TO
CANTERBURY AND ENGLAND AND WALES

(Percentages)

Age Group Years	Paddock Wood Survey	Canterbury 1971 Census (Private Households)	England and Wales 1971 Census (Private Households)
0 - 4	11	7	8
5 - 14	18	15	16
15 - 29	20	22	21
30 - 49	26	22	24
50 - 64	12	18	18
65 - 74	5	9	9
75+	3	6	4
Not known	4	-	-
Total persons (= 100%)	8206	30,085	47,296,180

TABLE 5

PREVALENCE OF IMPAIRED PERSONS IN PADDOCK WOOD
BY AGE GROUPS, COMPARED TO PREVALENCE IN CANTERBURY

Age Group Years	Paddock Wood Survey			Canterbury Survey
	Population Responding	Number of Impaired Persons	Rate per 1000 Persons	Rate per 1000
0 - 4	887	8	9 (8) ¹	7
5 - 14	1515	21	14	14
15 - 29	1665	16	10	8
30 - 49	2160	45	21	21
50 - 64	973	75	77 (65) ¹	58
65 - 74	421	84	199(172) ¹	145
75+	250	104	416	309
Not known	335	-	-	-
All ages	8206	353	43	50

Age-standardised rates using Paddock Wood responding population

Paddock Wood = 43 per 1000 persons

Canterbury = (37)¹ " " "

¹The figures in brackets are the rates calculated after distributing the group of the population whose ages were unknown among the age groups in the proportions suggested by information from the executive council, that is 25% would be under 4 years, 55% aged 50 to 64 and 20% aged 65 to 74 years. This can only be a crude estimate, but it would add 84, 184 and 67 persons respectively to each of the age groups mentioned.

TABLE 6

PREVALENCE RATES PER 1000 POPULATION FOR IMPAIRMENTS
IN PADDOCK WOOD AND CANTERBURY

Impairment	Paddock Wood		Canterbury	
	Number	Rate	Number	Rate
Registered blind	12	1.5	51	1.7
Registered partially sighted	3	0.4	36	1.2
Difficulty in distant vision	32	3.9	170	5.6
Difficulty in reading	31	3.8	137	4.5
Registered deaf	3	0.4	16	0.5
Registered hard of hearing	14	1.7	17	0.5
Observed hard of hearing (not registered)	44	5.4	224	7.3
Housebound	24	2.9	200	6.6
Difficulty in self-care/getting about	196	23.9	945	31

TABLE 7

GROUPINGS OF DIAGNOSES. ALL IMPAIRED IN PADDOCK WOOD

Figures in brackets are percents of all 353 impaired persons

Diagnostic group	Primary condition	Total number persons with condition*
Musculo-skeletal	76 (21.5)	117 (33.1)
Central nervous	31 (8.8)	37 (10.5)
Cardiovascular	39 (11.0)	67 (19.0)
Psychological	30 (8.5)	42 (11.9)
Respiratory	18 (5.1)	45 (12.7)
Injuries	24 (6.8)	40 (11.3)
Amputations	26 (7.4)	26 (7.4)
Other	82 (23.2)	137 (38.8)
None stated**	57 (16.1)	

* Tables more than 100 percent as more than one condition may be present per person.

** Refers particularly to persons who only stated their impairments, e.g. 'blind'.

TABLE 8

MARITAL STATUS, HOUSEHOLD COMPOSITION, PRESENCE
OF OTHER IMPAIRED PERSON IN HOUSEHOLD
ALL IMPAIRED PERSONS. PADDOCK WOOD AND CANTERBURY

Factor	Paddock Wood		Canterbury	
	Number	Percent	Number	Percent
Total impaired persons	353	100	1534	100
<u>Marital Status</u>				
Married	192	54	697	45
Single	61	17	299	20
Other	100	28	538	35
<u>Household Composition</u>				
Alone	66	19	440	29
1 other person	139	39	601	39
2 others or more	148	42	493	32
<u>Other impaired person</u>				
Present	47	13	170	11

TABLE 9

PROPORTION OF ALL IMPAIRED PEOPLE CLASSIFIED AS HANDICAPPED

	Paddock Wood	Canterbury
Impaired persons	353 (100)	1534 (100)
Handicapped persons 1972 definition	147 (42)	836 (54)
By new criteria only	69 (19)	-
Total	216 (61)	-

(per cents in brackets)

TABLE 10

HANDICAPPED PERSONS (USING 1972 DEFINITION) IN AGE GROUPS

PADDOCK WOOD AND CANTERBURY

Age group years	Numbers of handicapped (1972 definition)	
	Paddock Wood	Canterbury
0 - 4	3 (2.0)*	11 (1.3)
5 - 14	10 (6.8)	41 (4.9)
15 - 29	2 (1.4)	27 (3.2)
30 - 49	6 (4.1)	31 (3.7)
50 - 59	11 (7.5)	57 (6.8)
60 - 64	9 (6.1)	57 (6.8)
65 - 74	35 (23.8)	213 (25.5)
75 - 84	48 (32.6)	289 (34.6)
85+	23 (15.7)	110 (13.2)
Total	147	836

* Figures in brackets show percentage of total in each age group.

TABLE 11

MOBILITY OF HANDICAPPED PERSONS BY DEFINITION

Category	Paddock Wood Number by Canterbury 1972 definition	Canterbury Total
<u>Getting out of House</u>		
Perm. bedfast	0	4
Perm. chairbound	0	6 (1)
Perm. housebound	34 (23)	236 (31)
Temp. housebound	5 (3)	32 (4)
Usually gets out	108 (73)	492 (64)
Total	147	770**
<u>Mobility*</u>		
Stays in chair	4 (3)	16 (2)
Wheelchair	4 (3)	26 (3)
Used tripod, crutches	13 (9)	72 (9)
Walks with difficulty	75 (51)	347 (46)
No difficulty	51 (35)	297 (39)
Total	147	758

(Percent in brackets)

* Excludes bedfast, chairbound and infants

** Tables 11-16 refer only to the 770 handicapped people in Canterbury who were interviewed in the third stage. As the same interviewer did not carry on from stage 2 to stage 3 on the same occasion, 66 people who had a screening interview in Canterbury and were assessed as handicapped did not have an assessment interview. These 66 handicapped people have been included in tables 9 and 10.

TABLE 12

HOUSING

TYPE AND OWNERSHIP OF ACCOMMODATION OF HANDICAPPED

PERSONS

Type of accommodation	Paddock Wood Number by Canterbury 1972 definition	Canterbury Total
House	94 (64)	493 (64)
Bungalow	36 (24)	98 (13)
Ground floor flat	8 (5)	123 (16)
Other flat	8 (5)	56 (7)
Caravan	1	-
Total	147	770
<u>Ownership</u>		
Occupier	72 (49)	321 (43)
Local authority	47 (32)	303 (39)
Private - unfurnished	18 (12)	105 (14)
Private - furnished	2	10 (1)
Voluntary agency	3	10 (1)
Rent free - tied	5	21 (3)
Total	147	770

(per cent in brackets)

TABLE 13

CONTACTS OF HANDICAPPED PEOPLE WITH RELATIVES AND
FRIENDS

	Paddock Wood Number by Canterbury 1972 definition	Canterbury Total
<u>Availability of relatives, etc.</u>		
Relatives nearby	84 (57)	461 (60)
Relatives able to help	76 (52)	382 (50)
Friends, neighbours able to help	128 (87)	581 (75)
<u>Frequency of visitors</u>		
At least daily	46 (31)	249 (32)
At least weekly	52 (35)	303 (39)
Less often	49 (33)	218 (28)
<u>Numbers alone during day/night</u>		
Alone day and night	28 (19)	235 (31)
Alone during day only	22 (15)	86 (11)
Alone during night only	2 (1)	10 (1)
Total number in each group	147	770

(per cent in brackets)

TABLE 14

CONTACTS OF HANDICAPPED PEOPLE WITH SERVICES

Service in Contact	Paddock Wood Number by Canterbury 1972 definition (N=147)	Canterbury Total (N=770)
Home nurse	31 (21)	133 (17)
Health visitor	23 (16)	66 (9)
Meals on wheels	7 (5)	35 (5)
Social worker	14 (9)	115 (15)
Occupational therapist	0	2
Chiropodist	4 (3)	107 (14)
Home help	13 (9)	Not asked
Clubs	38 (26)	209 (27)
<u>General Practitioner</u>		
Contact within 1 month	66 (45)	299 (39)

(per cent in brackets)

TABLE 15

EXPRESSED NEEDS OF HANDICAPPED PEOPLE FOR PERSONAL
AIDS AND HOUSE ADAPTATIONS

Aid or Service	Paddock Wood Number by Canterbury 1972 definition (N=147)	Canterbury Total (N=770)
Support bar	5 (3)	27 (3)
W.C. rails	5 (3)	29 (4)
Bath rails	21 (14)	122 (16)
Shower	9 (6)	44 (6)
Bath seat	9 (6)	84 (11)
Shoe/stocking aid	12 (8)	51 (7)
Special clothing	9 (6)	48 (6)
Kitchen aids	12 (8)	60 (8)
Stair rails	7 (5)	46 (6)
Telephone	40 (27)	235 (30)

(per cent in brackets)

TABLE 16

EXPRESSED NEEDS OF HANDICAPPED PEOPLE FOR HELP
FROM OTHER PEOPLE OR SERVICES

Service	Paddock Wood Number by Canterbury 1972 definition (N=147)	Canterbury Total (N=770)
Chiropody at home	23 (16)	110 (14)
Chiropody at clinic	13 (9)	37 (5)
Holiday Visitor	23 (16)	202 (26)
	18 (12)	141 (18)
Help with housework	10 (7)	69 (9)
Help with gardening	12 (8)	109 (14)
Help with window cleaning	15 (10)	88 (11)
Mobile library	6 (4)	126 (16)
Transport to doctor	8 (5)	33 (4)
Transport to dentist	5 (3)	Not asked
Transport to church	6 (4)	Not asked
Transport to clubs	8 (5)	85 (11)

(per cent in brackets)

TABLE 17

ADDITIONAL CRITERIA USED IN DEFINING PERSONS AS HANDICAPPED

(See the interview schedule attached)

<u>Criterion</u>	<u>Number of persons affected</u>	
Registration as physically handicapped (question 6)	12	(1F, 11M)
People of working age not working full-time or housewives unable to do all their housework (question 9)	19 5	(4F, 15M) (5F)
People <u>observed</u> to have difficulty with hearing (question 12)	7	(2F 5M)
People using aids in self-care (question 13)	3	(3M)
All people scoring any score in self-care and aged less than 70 years (question 13)	32	(16F 16M)

NOTE: A few people are included under more than one of the new criteria.

TABLE 18

HANDICAPPED PERSONS IN AGE AND SEX GROUPS
BY DEFINITION OF 'HANDICAPPED PERSON'

Age Group Years	Handicapped persons (Canterbury 1972 definition)			Handicapped persons (new criteria)			Handicapped persons (all criteria)			% of all handicapped persons due to additional criteria
	Males	Females	Total	Males	Females	Total	Males	Females	Total	
0 - 4	2	1	3	0	0	0	2	1	3	0
5 - 14	5	5	10	2	1	3	7	6	13	23
15 - 29	2	0	2	5	3	8	7	3	10	80
30 - 49	3	3	6	8	4	12	11	7	18	67
50 - 59	8	3	11	9	8	17	17	11	28	61
60 - 64	5	4	9	7	4	11	12	8	20	55
65 - 74	15	20	35	6	6	12	21	26	47	25
75 - 84	10	38	48	3	1	4	13	39	52	8
85+	7	16	23	1	1	2	8	17	25	8
Total	57	90	147	41	28	69	98	118	216	32

TABLE 19

SELECTED MAIN DIAGNOSES BY DEFINITION OF 'HANDICAPPED PERSON'

PADDOCK WOOD

Diagnosis	Number by Canterbury 1972 definition	Number added by new criteria	Total
Strokes	6	1	7
Multiple Sclerosis	0	2	2
Paralysis Agitans	1	0	1
Coronary Disease	6	5	11
Heart (unspecified)	9	1	10
Rheumatoid Arthritis	6	1	7
Osteo-arthritis	4	2	6
Other Arthritis	36	13	49
Bronchitis, Emphysema, Asthma	19	8	27
Mental disorders	13	6	19
Injuries	12	16	28

TABLE 20

MOBILITY OF HANDICAPPED PERSONS BY DEFINITION

Category	Paddock Wood		
	Number by Canterbury 1972 definition	Number added by new criteria	Total
<u>Getting out of House</u>			
Perm. bedfast	0	0	0
Perm. chairbound	0	0	0
Perm. housebound	34 (23)	0	34 (16)
Temp. housebound	5 (3)	2 (3)	7 (3)
Usually gets out	108 (73)	67 (97)	175 (81)
Total	147	69	216
<u>Mobility*</u>			
Stays in chair	4 (3)	0	4 (2)
Wheelchair	4 (3)	2 (3)	6 (3)
Uses tripod, crutches	13 (9)	4 (6)	17 (8)
Walks with difficulty	75 (51)	23 (33)	98 (45)
No difficulty	51 (35)	40 (58)	91 (42)
Total	147	69	216

(per cent in brackets)

* Excludes bedfast, chairbound and infants.

TABLE 21

HOUSING

TYPE AND OWNERSHIP OF ACCOMMODATION OF HANDICAPPED
PERSONS BY DEFINITION OF HANDICAPPED PERSON

Type of accommodation	Paddock Wood		
	Number by Canterbury 1972 definition	Number added by new criteria	Total
House	94	48	142 (66)
Bungalow	36	14	50 (23)
Ground floor flat	8	3	11 (5)
Other flat	8	1	9 (4)
Caravan	1	3	4 (2)
Total	147	69	216
<u>Ownership</u>			
Occupier	72	32	104 (48)
Local authority	47	24	71 (33)
Private - unfurnished	18	10	28 (13)
Private - furnished	2	1	3 (1)
Voluntary agency	3	0	3 (1)
Rent free - tied	5	2	7 (3)
Total	147	69	216

(per cent in brackets)

TABLE 22

CONTACTS OF HANDICAPPED PEOPLE WITH RELATIVES AND
FRIENDS BY DEFINITION OF 'HANDICAPPED PERSON'

	Paddock Wood		
	Number by Canterbury 1972 definition	Number added by new criteria	Total
<u>Availability of relatives, etc.</u>			
Relatives nearby	84 (57)	41 (59)	125 (58)
Relatives able to help	76 (52)	34 (49)	110 (51)
Friends, neighbours able to help	128 (87)	60 (87)	188 (87)
<u>Frequency of visitors</u>			
At least daily	46 (31)	19 (28)	65 (30)
At least weekly	52 (35)	32 (46)	84 (39)
Less often	49 (33)	18 (26)	67 (31)
<u>Numbers alone during day/night</u>			
Alone day and night	28 (19)	9 (13)	37 (17)
Alone during day only	22 (15)	11 (16)	33 (15)
Alone during night only	2 (1)	0 -	2 (1)
Total number in each group	147	69	216

(per cent in brackets)

TABLE 23

CONTACTS OF HANDICAPPED PEOPLE WITH SERVICES

Service in Contact	Paddock Wood		
	Number by Canterbury 1972 definition (N=147)	Number added by new criteria (N=69)	Total (N=216)
Home nurse	31 (21)	6 (9)	37 (17)
Health visitor	23 (16)	8 (12)	31 (14)
Meals on wheels	7 (5)	2 (3)	9 (4)
Social worker	14 (9)	6 (9)	20 (9)
Occupational therapist	0	0	0
Chiropodist	4 (3)	1 (1)	5 (2)
Home help	13 (9)	2 (3)	15 (7)
Clubs	38 (26)	14 (20)	52 (24)
<u>General Practitioner</u>			
Contact within 1 month	66 (45)	28 (41)	94 (43)

(per cent in brackets)

TABLE 24

EXPRESSED NEEDS OF HANDICAPPED PEOPLE FOR PERSONAL
AIDS AND HOUSE ADAPTATIONS

Aid or Service	Paddock Wood		
	Number by Canterbury 1972 definition (N=147)	Number added by new criteria (N=69)	Total (N=216)
Support bar	5 (3)	0	5 (2)
W.C. rails	5 (3)	0	5 (2)
Bath rails	21 (14)	9 (13)	30 (14)
Shower	9 (6)	5 (7)	14 (6)
Bath seat	9 (6)	3 (4)	12 (6)
Shoe/stocking aid	12 (8)	2 (3)	14 (6)
Special clothing	9 (6)	0	9 (4)
Kitchen aids	12 (8)	5 (7)	17 (8)
Stair rails	7 (5)	6 (9)	13 (6)
Telephone	40 (27)	20 (29)	60 (28)

(per cent in brackets)

TABLE 25

EXPRESSED NEEDS OF HANDICAPPED PEOPLE FOR HELP
FROM OTHER PEOPLE OR SERVICES

Service	Paddock Wood		
	Number by Canterbury 1972 definition (N=147)	Number added by new criteria (N=69)	Total (N=216)
Chiropody at home	23 (16)	6 (9)	29 (13)
Chiropody at clinic	13 (9)	11 (16)	24 (11)
Holiday	23 (16)	6 (9)	29 (13)
Visitor	18 (12)	5 (7)	23 (11)
Help with housework	10 (7)	3 (4)	13 (6)
Help with gardening	12 (8)	2 (3)	14 (6)
Help with window cleaning	15 (10)	5 (7)	20 (9)
Mobile library	6 (4)	10 (14)	16 (7)
Transport to doctor	8 (5)	0	8 (4)
Transport to dentist	5 (3)	1 (1)	6 (3)
Transport to church	66 (4)	1 (1)	7 (3)
Transport to clubs	8 (5)	3 (4)	11 (5)

(per cent in brackets)

TABLE 26

EMPLOYMENT STATUS OF HANDICAPPED PEOPLE (AGED 15 YEARS OR MORE)

Employment Status	Paddock Wood			Canterbury Total (N=770)
	Number by 1972 definition (N=147)	No. added by new criteria (N=69)	Total (N=216)	
<u>Currently employed</u>				
Full time, open employ- ment	13 (10)	15 (23)	28 (14)	26 (3)
Part time, open employ- ment	2 (1)	2 (3)	4 (2)	12 (2)
Full time, sheltered employment	0	0	0	4
Part time, at a centre	0	0	0	3
<u>Not employed</u>				
Not available	112 (84)	32 (48)	144 (72)	617 (80)
Wants work	0	4 (6)	4 (2)	4
Perm.disabled, unable	6 (4)	10 (15)	16 (8)	48 (6)
Temp. disabled	1	3 (4)	4 (2)	7 (1)
Total (aged 15 or more)	134	66	200	721
<u>Expressed Needs of the 'Not Employed' but available</u>				
Sheltered workshop	2 (1)	7 (11)	9 (4)	12 (2)
Work at day centre	0	2 (3)	2 (1)	Not asked
Work at home	3 (2)	5 (8)	8 (4)	21 (3)
Work at day centre or home	0	3 (5)	3 (1)	Not asked
<u>Registered as Disabled Person</u>				
Has been registered	9 (7)	7 (11)	16 (8)	33 (4)
Still is registered	5 (4)	17 (26)	22 (11)	47 (6)

(percent in brackets)

APPENDICES

SURVEY OF THE HANDICAPPED

HEALTH SERVICES RESEARCH UNIT,
CORNWALLIS BUILDING,
UNIVERSITY OF KENT,
CANTERBURY, KENT.

April, 1973.

Dear Householder,

We are investigating ways in which handicapped people might further be helped by developments in the health and social services and by the use of voluntary services. We are carrying out surveys of selected groups, one of which is the practice based in the Woodlands Health Centre. We have the full support of Drs. MacDonald, Warner and Baker. We also have the agreement and co-operation of the Social Services Department and the Health Department of Kent County Council.

We need to know how many people there are in each of our selected groups who may need some form of help, and how such help and support can best be provided. We are interested in people of all ages. Some children may need to have more done for them than others because of some physical or mental condition. The elderly, though accepting that their movements are a bit restricted, may not be able to do as much for themselves as they would like. There are also younger people who, because of physical handicap, may need special provisions to help them lead as full a life as possible. There are services, too, for the blind, and the deaf, as well as for those with physical and mental complaints.

We are therefore asking if you would help us by completing the attached simple form for everyone living in your household. PLEASE DO NOT pass the form on to others outside your household who may have difficulties, as this could lead to duplication.

As you will appreciate, we are anxious to get as complete a picture as possible. Even if the answer to all the questions is 'No', we should like you to tell us so on the form. You may have completed a similar form for Kent County Council last year; if so we would still like you to complete this form, as we are now aiming at a total survey in this area.

We can assure you that any information you give us on this form will be used solely for the purpose of research, and will be regarded by everyone working with us as strictly confidential. The Health Services Research Unit is staffed by experienced doctors, statisticians and social scientists, and is financed by the Department of Health and Social Security.

When you have completed the form, please put it in the stamped addressed envelope, and return it to me, as soon as possible.

Thank you for your co-operation.

Yours faithfully,



Professor Michael Warren, M.D., M.R.C.P., F.F.C.M.
Director.

SURVEY OF THE HANDICAPPED

Name of Householder or Tenant _____

Address _____

EYESIGHT

- 1. Is there anyone in this household who is blind?
- 2. Or has very bad eyesight even when wearing glasses?

1. _____
2. _____

HEARING

- 3. Is there anyone in this household who is deaf, or has to wear a hearing aid?
- 4. or is so hard of hearing he or she cannot hear ordinary conversation?

3. _____
4. _____

LOSS OF LIMBS, etc.

- 5. Has anyone lost the whole or part of an arm, leg, hand or foot by having an accident, amputation, or being born like that?

5. _____

MOVING ABOUT

- 6. Is there anyone, apart from babies, who has been unable without help to get out of bed, or to get out of the house, for the past 3 months?
- 7. Is there anyone, apart from babies and young children, who has difficulty walking without help, going up and down stairs, or kneeling and bending?

6. _____
7. _____

SELF-CARE

- 8. Is there anyone, apart from babies and young children, who has difficulty washing, feeding or dressing themselves?
- 9. Is there anyone, apart from babies, who has difficulty gripping or holding things, or using arms, hands or fingers?

8. _____
9. _____

BABIES AND YOUNG CHILDREN

- 10. Are there any young children who need more help than usual for children of the same age, in washing and dressing themselves, walking without help, going up and down stairs, etc.?
- 11. Are there any school-age children who cannot go to an ordinary school because of physical or mental handicap?

10. _____
11. _____

IF NO-ONE IN HOUSEHOLD HAS ANY OF THE ABOVE DIFFICULTIES

GENERAL

- 12. Is there anyone who has some other permanent mental or physical condition, including epilepsy, etc. which makes it difficult for them to go to school or work, take care of themselves, or get about?

12. _____

ELDERLY

- 13. Is there anyone living here aged 75 or over?
- 14. If yes, do you live alone?

13. _____
14. _____

If the answer is "Yes" please write in age and name of person having difficulty.

Please return this form after completion to:—
Professor M. D. Warren, M.D., M.R.C.P., F.F.C.M.,
Health Services Research Unit,
Cornwallis Building,
University of Kent. CANTERBURY.

The contents of this form are confidential.

Serial No.

--	--	--	--	--	--	--	--

SURVEY OF THE HANDICAPPED

HEALTH SERVICES RESEARCH UNIT

UNIVERSITY OF KENT

CANTERBURY.

TURN TO PAGE 24 TO COMPLETE DETAILS AND CHECK NAME OF SUBJECT BEFORE STARTING

INTRODUCTION – *Introduce yourself to the person you wish to interview or to the proxy (mother of impaired child etc.) and check that the person named on the postal form really does live at the address stated on the postal form. Check that the subject has not recovered from the difficulty shown on the postal form and that there has not been any error in completing the form.*

'Yes' to postal items 1 or 2

I understand you are [blind] [have very bad eyesight]

1. **Are you registered as blind or partially sighted?**
- Registered blind 1
 - Registered partially sighted 2
 - Not registered 3
 - Don't know 4

'Yes' to postal items 3 or 4

I understand you are [deaf] [hard of hearing]

2. **Are you registered as deaf or hard of hearing?**
- Registered deaf 1
 - Registered hard of hearing 2
 - Not registered 3
 - Don't know 4

'Yes' to postal item 5

I understand you have had an amputation – [the subject will correct this assumption if a birth defect]

3. **Which limb is affected . . . (SPECIFY and Code 1) 1**

'Yes' to postal item 6

I understand you have been [bedfast] [housebound] recently.

4. **Are you still unable to [get up] [get out of the house] ?**
- Still bedfast 1
 - Still housebound Ask (a)
 - No longer bedfast or housebound Ask (b)

(a) But you can get around the house walking or in a wheelchair or do you have to just stay put?

- Get around the house 2)
- Stays put 3) Skip (b)

(b) Does this mean you're quite better now, or do you still have difficulty getting about or taking care of yourself?

- Quite better 4
 - Have difficulties 5
- Close interview if no other postal 'Yes' on to Qn. 6

'Yes' to any of postal items 7, 8, 9, 10, 11, 12

Summarise from postal form to ask this question.

I understand you [your child] [has some difficulty]
[cannot go to school]

5. Is this correct?

Yes, has difficulty 1
No, incorrect 0 Ask (a)

If incorrect

(a) Is this because

RUNNING
PROMPT

[You're] [your child is] quite better now 3 If no other postal 'Yes' close interview.
or [you're] [your child is] better temporarily but the trouble might recur 2

'Yes' to postal items 5, 6, 7, 8, 9, 10, 11, 12

6. Are you registered as physically handicapped?

Yes 1
No 2
Don't know 3

This does not refer to the Disabled Persons Register; see question 47.

To all permanently impaired

7. What does the doctor say is the matter with you?

Not seen doctor/doctor doesn't say 0 Ask (a)
Doctor says (SPECIFY BELOW) . . 1

If doctor not seen or doesn't say

(a) What do you think is the matter with you? (SPECIFY BELOW)

8. Apart from [name of complaint] – do you regularly suffer from any other chronic illness or condition which complicates life for you?

Yes 1 (Ask (a))
No 0

If Yes

(a) What is the matter? [name of disease – not symptoms]

Could you just tell me who lives here with you – so I can just get a better picture of the household.

9. ESTABLISH HOUSEHOLD COMPOSITION

Relationship to subject	Sex		Age last b'day	Marital Status			Occupation		
	M	F		Md.	Sgl.	Wd.	Full-time work	Part-time work	Retired/too young housewife, i.e. not working.
1. Subject	1	2		3	4	5	6	7	8
2.	1	2		3	4	5	6	7	8
3.	1	2		3	4	5	6	7	8
4.	1	2		3	4	5	6	7	8
5.	1	2		3	4	5	6	7	8
6.	1	2		3	4	5	6	7	8
7.	1	2		3	4	5	6	7	8
8.	1	2		3	4	5	6	7	8
9.	1	2		3	4	5	6	7	8
10.	1	2		3	4	5	6	7	8

Note

1) "Lives with you" covers those living permanently at this address, and eating at least one meal together, (family, friends, boarders, etc.)

A lodger or subtenant, not sharing meals is a separate household.

2) Widowed includes separated and divorced persons.

I'd like to ask about your general health –

Check question 1 – if subject is registered blind or partially sighted go on to question 12.

Could we start with eyesight? –

10. Can you recognise people you know if you were to see them across the street (wearing glasses if applicable)?

Yes, could recognise 0
No 1

11. Can you usually see to read ordinary print (show leaflet) like this, and see to write (wearing glasses if applicable)?

Yes, can see to read and write 1
Cannot read/write (illiterate or too young) 2
No, can't see unless uses magnifier etc. 3
No, can't see 4

12. And how about hearing?
Can you hear ordinary conversation (with hearing aid if applicable)?

Too deaf to be interviewed 1
Yes, without aid 2
Yes with aid 3
No 4
Says yes, but difficulty observed 5
Says no, but no difficulty observed 6

The following panel is used to find degree of handicap. Note that the main question (13a) should be repeated every three or four items (i) – (x). Then, for any item found difficult (needing help/supervision), ask question (13b) to sort out those who can do it even with difficulty from those who cannot.

Note. There are two variations to main question (13a)

A. For Young Children (in most cases the under 12s)

Does (name) need more help than other children of his [her] age?

B. Where a proxy is taken because subject is mentally impaired

Does (name) need help and supervision in ?

Introduce Can we talk about looking after [yourself] [name of subject]

(1) (2) (3) (4)

13a Do you generally have difficulty in (or alternative version)	No difficulty or supervision	No difficulty or supervision but uses aids	If difficulty or supervision ask (13b) but can you do it yourself, even with difficulty ?		Notes
			Yes can do	No cannot do	
(i) Getting in and out of bed on your own?	0	X	2	3	If uses hoist – code 3 in column (4)
(ii) Getting to or using the W.C.?	0	X	4	6	If never uses W. C. because of bedfast – code 6 in col. (4). If incontinent - code 6 in col. (4).
(iii) Having an all over wash, (or bathing yourself if bath used)?	0	X	2	3	If subject cannot use bath, but can wash his body and limbs with difficulty code 2 in col. (3).
<i>Repeat question 13a</i>					
(iv) Washing your hands and face?	0	X	2	3	
(v) Putting on shoes and socks or stockings yourself?	0	X	2	3	If doesn't dress, wear shoes etc. because bedfast, or never goes out, code as appropriate in col. (4).
(vi) Doing up buttons and zips yourself?	0	X	4	6	If special clothing for handicapped bought, e.g. cannot do up buttons so wears "pull-on" clothes - code in col (4).
<i>Repeat question 13a</i>					
(vii) Dressing, other than buttons and shoes?	0	X	2	3	If, however, wears, say, casual shoes because he prefers them - code in col. (1) if no difficulty, or (3) if some.
(viii) Feeding yourself?	0	X	4	6	If food has to be cut up, code in col. (4)
(ix) Cutting toe nails?	X	X	X	X	
(x) WOMEN AND CHILDREN ONLY Combing and brushing your hair?	0	X	2	3	
(xi) MEN ONLY Shaving yourself?	0	X	2	3	
TOTAL COLUMN SCORE					GRAND TOTAL CATEGORY

Check back to Qn. 13.

Look back to see if any item on question 13 was coded in columns (2), (3) or (4). Where the subject can only manage an activity with aids (Col. 3) or cannot manage an activity without help (Col. 4) for which assistance or aids are available -- see list below -- introduce and ask WHERE APPLICABLE.

14. Introduce

“Some fittings or help can be supplied by the Social Services Department where things are difficult”

(Explain – Some of the aids are free but sometimes where people can afford to pay they are asked to make some contribution towards structural alterations if they are necessary).

“Would it make it easier for you to

Item No.

See Qn. 13

6.

(i) Get in and out of bed if they could fix a hoist or support bar?

Yes (Hoist X
(Support bar ... Y

If could be supplied would you like the Department to fix one?

Yes 1
No 2 -- Specify why not.

No 0

Specify, why not

Already (Hoist X
Have (Support bar.. Y

Who supplied Local Authority 3
.....? Voluntary body 6 – Specify
Other 9 – Specify
Don't know 9

Do you find useful
Yes 0
Sometimes 1
No 2

(ii) Get to and use the W.C. if they could widen doors for wheel-chairs, fit raised seats, fix handrails or wall supports?

(widen doors X
Yes (raised seats Y
(rails etc. Z

If could be supplied would you like the Department to fix one?

Yes 1
No 2 – Specify, why not

No 0

Specify, why not.

Already (widen doors X
Have (raised seats Y
(rails etc Z

Who supplied Local Authority 3
.....? Voluntary body 6 – Specify
Other 9 Specify
Don't know 9

Do you find useful
Yes 0
Sometimes 1
No 2

(iii) Having an all-over wash or bathing yourself if bath used, if they could fit bath rails, handles, rings to help get in and out of bath, sitz baths, showers, bath seats, bathing attendant (male or female)	Yes (Rails etc. A (Sitz Bath B (Shower C (Bath Seat D (Attendant E	If could be supplied would you like the Department to provide one?	Yes 1 No 2 – <i>Specify, why not</i>
	No 0	<i>Specify, why not</i>	
	Already (Rails etc. .. A Have (Sitz Bath .. B (Shower .. C (Bath Seat .. D (Attendant .. E	Who supplied Local Authority 3? Voluntary Body 6 – <i>Specify</i> Other 9 – <i>Specify</i> Don't know 9	Do you find useful? Yes 0 Sometimes 1 No 2
(v) Put on shoes and socks yourself if they could supply gadgets to help pull on shoes and stockings?	Yes X	If could be supplied would you like the Department to provide one?	Yes 1 No 2 – <i>Specify, why not</i>
	No 0	<i>Specify, why not</i>	
	Already Y Have	Who supplied Local Authority 3? Voluntary Organisation 6 – <i>Specify</i> Other 9 – <i>Specify</i> Don't know 9	Do you find useful? Yes 0 Sometimes 1 No 2
(vi) If they gave advice or on special (vii) clothing so that you wouldn't need to do up buttons and zips yourself?	Yes X	If could be given would you like the Department to help?	Yes 1 No 2 – <i>Specify, why not</i>
	No 0	<i>Specify why not</i>	
	Already Y Have	Who supplied Local Authority 3 Voluntary Organisation 6 – <i>Specify</i> Other 9 – <i>Specify</i> Don't know 9	Do you find useful? Yes 0 Sometimes 1 No 2
(viii) Feed yourself if they supplied gadgets or specially designed forks, spoons etc.?	Yes X ...	If could be given would you like the Department to provide them?	Yes 1 No 2 -- <i>Specify, why not</i>
	No 0	<i>Specify why not</i>	
	Already Y Have	Who supplied Local Authority 3 Voluntary Organisation 6 – <i>Specify</i> Other 9 – <i>Specify</i> Don't know 9	Do you find useful? Yes 0 Sometimes 1 No 2

Chiropody

15. **Introduce**

Could you tell me about your feet? Do you have any discomfort because of corns or hard skin or because you can't manage to get your toenails cut?

- Difficulty, despite chirpody X₁
- No difficulty, having chirpody Y₁
- Difficulty, no chirpody Z-ask (b) (i)
- No difficulty 0-on to Qn. 16

ask (a) (i),(ii)&(iii).

(a) (i) Do you go to a chiropodist to have your feet attended to or does he come to your home to treat you?

- Private Chiropodist, at home 1
- Private Chiropodist, at surgery 2
- Welfare Chiropodist, at home 3
- Welfare Chiropodist at clinic 4
- Red Cross/Vol. body, clinic 5
- Day Hospital 6
- Don't know home 7
- Don't know, clinic 8

(ii) How often do you have your feet treated?

Specify

(iii) Do they give you any trouble between visits so that you would like to go, or be visited, more often?

- Trouble, like more A
- Trouble, no more B
- No trouble, like more C
- No trouble, no more D

On to Qn. 16

Difficulty, no chirpody

(b) (i) Would you like to have help with your feet if it could be arranged?

- Yes W-ask (ii)
- No 9-Specify reason and on to Qn. 16.

(ii) Would you be able to go to a clinic, or would you need to be visited at home?

- At home 10-Specify reason
- At clinic 11

16. **Other**

Is there anything else you can think of that could be done to make it easier to get up, wash and dress yourself and so on? If so - what?

- Cannot think of anything 0

Specify suggestions

Housework and Shopping

17. I'd like to ask how the household chores are managed in this house.

<p>(i) (a) Who does most of the shopping?</p> <p>Subject 0 Other person in household 4 <i>Specify</i> Other 8 <i>Specify</i></p>	<p>(b) Does anyone else help? If so, who?</p> <p>No-one helps 0 Helped by 1 <i>Specify</i></p>	<p>(c) Would you like [more] help with shopping?</p> <p>No 0 Yes 2 } <i>Specify reason</i></p>
<p>(ii) (a) Who does most of the housework?</p> <p>Subject 0 Other person in household 4 <i>Specify</i> Other 8 <i>Specify</i></p>	<p>(b) Does anyone else help? If so who?</p> <p>No-one helps 0 Helped by 1 <i>Specify</i></p>	<p>(c) Would you like (more) help with the housework?</p> <p>No 0 Yes 2 } <i>Specify reason</i></p>
<p>(iii) (a) Who does most of the cooking?</p> <p>Subject 0 Other person in household 4 <i>Specify</i> Other 8 <i>Specify</i></p>	<p>(b) Does anyone else help? If so, who?</p> <p>No-one helps 0 Helped by 1 <i>Specify</i></p>	<p>(c) Would you like [more] help with the cooking?</p> <p>No 0 Yes 2 } <i>Specify reason</i></p>

Meals on Wheels

18. Do you get at least one good meal a day?

Yes X-ask (a)

No Y-ask (b)

If Yes

(a) How is this provided?

Within household by member of household 1-on to Qn. 20
 Outside household/not by member of household 0-Specify and on to Qn. 20
 Sometimes within household and sometimes outside 7-Specify and on to Qn. 20

If No

(b) Why not?

Specify reason and then ask Qn. 19.

19. **Introduce** There is a scheme for the delivery of hot meals 2 or 3 times a week at a cost of 10-15p
Would you like to have these meals on wheels delivered if it is possible?

Yes 2
 No 3-*Specify reason*
 Already have Z-*Ask (a)*

If already has

- (a) Do you find this useful?

Yes..... 4
 Sometimes 5
 No 6

20. **The Department can fix kitchen aids, carry out structural alterations or advise on special gadgets (explain, give examples) to make housework and cooking less difficult for handicapped people. Would you be interested in knowing more about this, or can you manage all right [with more help/meals on wheels]?**

Interested – None at present 1
 – Already has some 2-*Specify aids etc.*
 Not Interested – None at present 3 *already supplied.*
 – Already has some 4-*Specify aids etc.*
already supplied.

21. **There are some other household jobs people like yourself find difficult that we can sometimes get volunteers to do.**

Do you need someone to

	Yes	No	Already Have		<i>Specify who does it</i>
			Voluntary	Paid	
(i) Come in and light fires	1	0	2	3	
(ii) Do window cleaning	1	0	2	3	
(iii) Help, occasionally, in the garden	1	0	2	3	
(iv) Take or collect laundry	1	0	2	3	
(v) Move dustbins for refuse collection	1	0	2	3	
(vi) Are there any other regular odd-jobs you need help with? (If Yes, specify below)	X	Y	Z	W	

Mobility

22. *Establish whether subject is:-*

BEDFAST - permanently	X-ask (a)
Bedfast - temporarily, usually HOUSEBOUND.....	2-ask (b)
Bedfast - temporarily, usually GOES OUT	3-on to Qn. 23
HOUSEBOUND - permanently.....	4-Ask (b)
Housebound - temporarily usually GOES OUT.....	5- on to Qn. 23
Usually GOES OUT	6-on to Qn. 23

For bedfast, permanently

(a) Are you able to get up and sit in a chair or can't you leave your bed?

Can sit in a chair	1
Can't leave bed	0

} on to Qn. 29

For housebound, permanently

(b) But can you get around the house and garden (walking or in a wheelchair) or do you have to sit in a chair when you're up?

Gets around	Y-on to Qn. 23
Stays in chair	0-on to Qn. 27

23. Introduce – How about getting around the house?

(Code without asking if observed)

Do you use a walking aid or wheel chair to get about the house?

Yes, wheelchair	1
Yes, tripod/frame/crutches.....	2
<i>CODE ALL</i> Yes, calipers, surgical footwear.....	3
<i>THAT APPLY</i> Yes, stick(s)	4
No, but uses furniture, etc. as support	5
No aids used, but walks slowly or with difficulty.	6
No aids or apparent difficulty	7

24. (Do not ask if in a wheelchair – on to Question 25)

Can you get up and down stairs all right, or would it help to have a handrail fitted?

- Manages stairs using handrail 0
- Manages stairs 1
- Difficulty, handrail or extra handrail would help 2
- Difficulty, handrail or extra handrail would not help 3
- No stairs 4

25. Are there any odd steps or stairs to landings, other rooms, or leading out to the garden or street which you can't manage?

- Yes, has difficulty X-ask (a)
- No, can manage 1
- No (has ramp) can manage 2 } on to Qn. 26

If Yes

(a) Would you like to be able to get out and about more easily if the social services could fit a ramp and/or rail or handle? (explain ramp)

- Yes, ramp only 3
- Yes, ramp and handrail 4
- Yes, handrail only 5
- No, neither ramp nor handrail 6

26. Can you usually get out of the house and garden if the weather is not too bad?

- Yes X-ask (a)
- No 0
- Yes, but only by car, etc. 1 } on to Qn. 27

If Yes

(a) Can you usually get out

- On your own without sticks or aids and without difficulty 2 } on to Qn 27
- On your own but only with aids or difficulty 3
- or can you only get out if someone is with you Y-ask (b)/(i)&(ii)

(b) (i) Who usually goes with you?

Specify

(ii) Can you generally get someone to go with you when you want to go out?

- Yes 4
- No 5

Transport – Ask of all except permanently bedfast (go on to Qn. 29)

I'd like to ask you about going out to places

27. Are there any places you need to go to for medical or special treatment?

Yes X-ask (a)(b)(c)(d)
 No 0-on to Qn. 28

(a) Where do you need to go? *Specify*

(b) How often do you need to go? *Specify for each place*

(c) How do you get there? *Specify, who provides transport and how*

(d) Do you find it difficult to obtain transport to get to this treatment?

Yes 1
 Sometimes 2
 No 3

28. Some people tell us they are prevented from going to places such as clubs, centres or to the shops and so on, or only go very occasionally simply because they find it impossible or very difficult to get there.

Do you want to go to [each item separately] but could only get there if the local authority could arrange transport?

	Need special transport		Already has transport
	Yes	No	
(i) Dentist	1	0	2
(ii) Church / other place or worship	1	0	2
(iii) Centre or club for handicapped or elderly	1	0	2
(iv) School or other educational institute	1	0	2
(v) Special interest groups – like Women's Institute, British Legion, Trades Union, and so on? [Specify which group(s) below]	1	0	2
(vi) Shops (include even occasional visits, e.g. Christmas)	1	0	2
(vii) Visits to relatives and friends	1	0	2

29. Do you have any difficulty in obtaining medicines prescribed by your doctor?

No difficulty 0
 Difficulty 1 *Specify*

Services in the Home

ASK ALL – Omit first sentence for bedfast

30. We've been talking about you getting to places. In some cases the council can bring the service to people's homes. Here are some services they provide - I'll just read the whole list, even if some won't apply in your case, and you can tell me if you are interested in any of them.

	Yes	No	Already Have
(i) The mobile library	1	0	2
(ii) A friendly visitor - just someone to keep you company	1	0	2
(iii) A seaside or country holiday	1	0	2
(iv) Lend sick-room equipment	1	0	2
(v) A laundry service for incontinent people? <i>[Explain - but don't make too much of it - "Some people have conditions that cause wet or dirty bedclothes"]</i>	1	0	2
(vi) Disposable incontinence pads	1	0	2
(vii) Day/night attendants <i>[If proxy/not talking to subject - add "to give you a chance to go out or get a good night's sleep"]</i>	1	0	2
(viii) Arrange a short-term stay in residential home while the family goes on holiday.	1	0	2

Omit for Bedfast and where obviously inappropriate

31. If there were various concessions for [elderly] [handicapped] people would you be interested in them?

	Yes	No	Already Have
(i) Cheap travel on buses	1	0	2
(ii) Cheap use of swimming baths at special times	1	0	2

(a) Can you think of anything else that could be done?

Yes 1 – *Specify*

No 0

Communication and Isolation

ASK ALL – Now about your contact with the outside world?

32. Do you have a radio or television?

- Has radio only 1
- Television only 2
- Both radio and TV 3
- Neither 0

33. Establish whether there is a telephone for the use of the household, and whether it has been adapted.

- Has standard telephone 0
- Has adapted telephone 2 } ask (a)
- No telephone Z-ask (b)

If has telephone

(a) Do you use it?

- Yes, uses 3
- No, does not use 4-ask (a)/i)

If not used

(i) Why don't you use it?

If no telephone

(b) Would you personally find a telephone useful?

- Yes, useful 7
- No, not useful 8-ask (b)/i)

If not useful

(i) Why do you feel it wouldn't be useful?

34. Do any relatives [apart from those in the same household] live nearby?
(i.e. in same town or village or within mile or two in a rural area)

- Yes 1-ask (a) and (b)
- No 0

(a) How close do they live? Specify

(b) Are they willing and able to assist when required?

Yes 1
 No 0

35. Are friends and neighbours able and willing to assist when required?

Yes 1
 No 0

36. Are any of these relations, friends or neighbours on the telephone?

Yes 1
 No 0

37. How often do you have visitors?
 (relatives, neighbours etc).

At least one a day 0
 At least one or two a week 1
 Infrequently 2

38. Do any of the following visit you?

		Yes	No
<i>Individual Prompt</i>	(i) Meals on Wheels	1	0
	(ii) District nurse/male nurse	1	0
	(iii) Home help	1	0
	(iv) Health visitor	1	0
<i>Code all that apply</i>	(v) Social worker	1	0
	(vi) Occupational therapist	1	0
	(vii) Chiropodist	1	0
	(viii) Other - <i>Specify</i>	X	Y

39. Are you alone during the daytime or nighttime?

Both 1
 Day 2
 Night 3
 Neither 0

40. Do you see your doctor regularly – I don't mean just calling for a prescription – but actually seeing him?

Yes X-ask (a)
No Y-ask (b)

If seen regularly

(a) How often do you see him?

More than once a week 0
Once a week 1
Every 2 or 3 weeks 2
Once a month/4 weeks 3
Other period-*Specify* 4

If not seen regularly

(b) How long ago was the last time you saw him (for yourself)?

Within last week5
Within last month 6
Within last 3 months7
Between 3 & 6 months ago 8
Between 6 & 12 months ago 9
Years ago – *Specify*.....10

41. Does he come to visit you or do you go to see him?

Comes to subject 1
Subject goes to him 2
Both 3

42. Are there any occasions when you have had to call a doctor in an emergency during the last 12 months?

Yes 0-ask (a)
No X

(a) How many times during the last year or so has this happened? *Specify and ask (b)*

(b) Why did you need to call him in an emergency?

Employment (if some of these questions are obviously inappropriate code as required without asking)

43. I did ask you earlier about employment. Could you tell me again if you are at present doing any work for which you are paid?

Working	Full-time	0	}ask (a)
	Part-time	3	
Not working		Z	-ask (b)

(a) Is this within a local authority "Sheltered workshop" or in a local authority centre?

Sheltered workshop	1	} -On to Qn. 46
Centre	2	
No	0	

If not working

(b) Why is this?

Too young	6
Over retirement age	7
Housewife	8
Off sick	9
Unemployed (can work if work available)	10
Permanently disabled unable to work again	11

44. Ask of those permanently disabled and under retirement age (i.e. those coded 9, 10 or 11 above) - otherwise go on to Qn. 47

Would you be interested, subject to your doctor's agreement, to take a job in a sheltered workshop if it were available? [Explain what a sheltered workshop is]

Yes	X	-ask (a)
No	0	-ask (b)

(a) Would you be willing to move to another part of the county (Kent) if this meant you could then work in a sheltered workshop?

Yes	1
No	2

(b) Why not? Specify

45. (i) How about work at a Day Centre?

(explain)

Yes 1
 No 0

(ii) Or work at home?

(explain)

Yes 2
 No 0

46. Talking about work in general, not any particular job. Does your disability affect

(i) The number of hours you can work?

Yes 1
 No 0

(ii) The distance you can travel to work?

Yes 2
 No 0

47. Are you, or have you ever been registered with the Department of Employment as a disabled worker?

Yes, was 1
 Yes, is 2
 No 3

Day Centres, Clubs etc. – omit for permanently bedfast

48. Do you go to any club or Centre?

Yes 1 ask (a)
 No 0

(a) Which one is it? Specify

49. Would you be interested in going to a club or Centre where you could:-

	Yes	No
(i) Meet other people to talk to	1	0
(ii) Have a mid-day meal	1	0
(iii) Have coffee or tea	1	0
(iv) Pursue hobbies or interests (e.g. whist, bingo, dressmaking handicrafts)	1	0
(v) To do paid work under non- factory conditions	1	0
(vi) Help handicapped or elderly people	1	0

50. Can you suggest anything else that should be provided? – Specify

Housing – Introduce – Housing conditions and amenities can make a big difference to how you manage so before I go I'd like to ask you about them.

51. Please note type of accommodation (ask if necessary)

- House (i.e. more than one level of accommodation) 1
- Bungalow 0
- Flat – Ground floor 2
- Flat – First floor 3
- Flat – Above first floor 4
- Caravan 5

52. How long have you lived here (at this address)? – Specify

. no of years

53. Do [you] [your family] own (this dwelling) or rent it?

- Owned (freehold or leasehold - with/without a mortgage) 1
- Rented from local authority 2
- Rented from vol. agency 3
- Rented privately, unfurnished 4
- Rented privately, furnished 5
- Rent free 6

Note - living with relatives or friends - code which applies to relatives and note at side that applies to them not to subject.

54. Are you on the local authority waiting list for a house or flat?

- Yes (not now in Council house or flat) . . . 1 –Ask (a)
- Yes, waiting transfer for council property . 2 –Ask (a)
- No 0

If on waiting list

(a) How long have you been on the list?

- Less than 1 year 0
- No of years Specify

55. Are you able to manage to get around in this [house] [flat] [bungalow] ?

No difficulties X ask (a)
 Have difficulties Y ask (b) & (c)

no difficulties

(a) Have any adaptations been made to this house to help you manage or is it purpose built housing for disabled people?

Adaptations made Y-ask (i) & (ii)
 Purpose built 2
 Neither 3 } on to Qn. 56

(i) What adaptations have been made? Specify

(ii) Have they helped you?

Yes 4
 Sometimes 5 } On to Qn. 56
 No 6

have difficulties

(b) What are the problems?

Problem	Possible Solution if suggested by subject

If you have asked this question (55 (b)) go on and ask (c) at top of next page

(c) If it would not be practicable for your [house] [bungalow] to be altered would you be prepared to consider moving to a more convenient place to live in?

Yes 1
 No 0 *ask (i)*

(i) Why not?

56. Do you have, inside the [dwelling]

<i>[Establish whether sole use or with other households]</i>		Yes sole use	Yes shared use	No
Individual prompt	(a) Electricity	1	—	0
	(b) Piped cold water	1	2	0
	(c) Piped hot water	1	2	0
Code all that apply	(d) Fixed bath (include showers)	1	2	0
	(e) A WC (flush toilet)	1	2	X — <i>ask (a)</i>

If no inside W.C.

(a) Do you have an outside W.C. or is there no flush toilet at all?

Outside WC, sole use 3
 Outside WC, shared use 4
 No flush toilet 0

57. Would you be interested in moving to

(i) Sheltered accommodation

(explain own bungalow or flat with warden available)

Yes 1
 No 0—*ask (a)*
 Already in sheltered accommodation 2

(a) Why not?

(ii) Residential Home

Yes 2
No 0 *ask (a)*

(a) Why not?

Now just before I finish could you answer two short questions

58. Can you think of anything else that could be done to help handicapped people and the elderly?

No 0
Yes, *Specify suggestions*

59. If you were told that we could provide you with one or more of the services would you want to make use of them?

Yes 0
No 1 *ask (a)*

(a) Could you tell me why you wouldn't want to use them? *Specify reasons*

When the interview is concluded say something like

"Thank you for talking to me we will find what you've said very helpful. I would just like to stress that some of the services we've talked about may not be available at the moment, but we hope to plan for them in the future."

Name of Subject

Age Name of General Practitioner

Address

.....

Where subject is at home, but is too confused, or irrational, or too ill to be interviewed (excluding temporary illness where an interview may be carried out at a later date), someone who is responsible for looking after the subject (a proxy) should be interviewed.

Of course, for young children a proxy interview will be necessary.

If subject has been admitted to a residential home, to hospital/nursing home (unless temporary), since date of postal take a proxy, relating questions to "when you (she) filled in the postal form."

If subject is under 18 you must get the parents' permission to interview them.

If refused
Please make a note of the reason for the refusal, if possible.

Name of Interviewer

Date of Interview

Person interviewed:-

Subject 1

Subject helped by proxy 2

Proxy 3

state relationship:-

Urgent Referral to Social Services Area Office/General Practitioner

Yes 1

No 0

Comments

Please note below any additional facts or points which arose during the interview.