CHANGING CAPABILITIES AND NEEDS OF PEOPLE WITH HANDICAPS: A TWO-YEAR FOLLOW-UP STUDY

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SUMMARY

A census-type survey of every household in the City of Canterbury identified 1,608 physically impaired people of whom 1,534 were subsequently interviewed. During the following two years the City's Social Services Department made special efforts to meet the needs of the more severely disabled people identified in the survey. At a subsequent follow-up survey, it was found that 206 people had died (13.4 per cent of those originally interviewed), 79 (5.1 per cent) had been admitted to a hospital or residential home on a more or less permanent basis, and 75 (4.9 per cent) had left the district (including 8 people who were not traced). Ninety six people refused interview, so in the follow-up survey 1,078 people were interviewed, representing 67 per cent of all those originally identified as physically impaired and 92 per cent of the original cohort who were still in private households in the City at that time. Information was obtained from the people interviewed in the follow-up survey about intervening episodes of serious illness and short-term admission to hospital, and about changes in capabilities for self-care, seeing and hearing, and from the more disabled people among them about mobility, household activity, employment and social contacts.

Two hundred and seventy five people (25 per cent of those interviewed in the follow-up) reported at least one episode of serious illness which for 250 of them necessitated admission to hospital. Two hundred and fourteen people (20 per cent) reported less difficulty with one or other of 9 self-care activities and 299 people (28 per cent) reported having more difficulty than at the time of the initial survey. Proportionately, slightly more people reported difficulty in seeing and hearing at the follow-up survey than initially.

One hundred and eleven people (23 per cent of a sub-group of 484 handicapped people)reported less difficulty in managing stairs, getting about the house and going out, but 197 people (41 per cent) reported more difficulty. Similarly, 24 per cent of these handicapped people reported less need for help with shopping, housework, cooking and gardening, but 31 per cent wanted more help. There was overall some improvement in social contacts, and some slight improvement in employment. Ninety three people had deteriorated in 2 of the functional areas examined, 16 in 3 areas and 1 person in 4 areas. Overall 61 per cent had more difficulties at follow-up.

Deterioration in personal and social activities occurred more frequently among the oldest age group (75 years or more), among those who already had difficulties in a number of self-care activities at the start of the study, among patients suffering from strokes, other diseases of the central nervous system or respiratory diseases compared with the rest of the sample. Related to these findings, more females than males became more disabled and the people that did become more disabled were more likely to be already receiving help from the social and health services.

Many respondents reported unmet needs for help and personal services at follow-up despite the considerable help that had been given between the surveys. About three quarters of the needs expressed in the initial survey had been met or ameliorated by the time of the follow-up survey, and proportionately more of the people with very severe disability had had their needs met. The majority of people with handicaps have changing needs arising from the fluctuating courses of the underlying chronic illnesses and from changes in social circumstances.

Among the group who had been considered in the initial survey as less disabled than the 'handicapped' group, it was found that 27 per cent had deteriorated during the period between the surveys to the extent that they were classified as 'handicapped' at the follow-up survey and an additional 22 per cent were so classified using somewhat wider criteria. This emphasises the difficulty of defining 'handicapped person'.

These findings indicate the magnitude of the task facing a community that wants to provide timely and relevant help for its people with handicaps. Ultimate responsibility and concern for the welfare of all disabled people should remain with social services departments, where it was put by the Chronically Sick and Disabled Persons Act, 1970. However, the remit is so wide and the needs of disabled people (in many cases for quite modest help) are so many, that fulfilment of these functions needs the cooperation and collaboration of many people and services. At present this collaboration appears to be hindered by ignorance, insensitivity and the complexity of the services.

It is necessary (i) to improve the knowledge of all groups of professional workers (and particularly those in primary care who have most contact with disabled people) about the scope of responsibilities of workers in related professions and services towards people with handicaps, and (ii) to encourage and enable disabled people themselves to use and seek the help of the various services more than they do at present. Monitored innovations and action research projects aimed at these ends are required.

INTRODUCTION

During the last decade many reports have been published of surveys of disabled people. Most of these surveys have been concerned with measuring the numbers of disabled people at home and estimating the extent and nature of their needs for social services, income support, housing and employment (Knight and Warren, 1978). There have been only a few reports of research projects which have examined changes in disability and activities of disabled people over a period of time or have attempted to measure the benefits of the help given to disabled people. An opportunity to examine some of these points occurred in Canterbury in 1974.

In 1971 the Social Services Department of the City and County of Canterbury had agreed to carry out, in conjunction with the Health Services Research Unit at the University of Kent at Canterbury, a survey of every household in the City in order to identify handicapped people needing help and to offer help to each person (Warren, 1974). The project was designed to combine research with the provision of services. Realising that the survey would raise the expectations of handicapped people for help and would find many who needed help, the City Council appointed additional staff and set up a special 'Handicap Unit' in the Social Services Department, increased the numbers of home helps, set up a Volunteer Bureau and formed a second social club for handicapped people (Wells, 1974). These actions were taken during the initial survey and the following year. Staff of the newly-formed Handicap Unit sent letters, enclosing a copy of a booklet on services available, to all of the handicapped people identified in the initial survey and subsequently visited all those who were willing (Kelly, 1974).

In 1974 the original cohort of impaired people (for definition of terms see pages 7 - 9) was followed up in order to investigate changes in their capabilities and activities, in help being received and in their perceived needs. In addition, the opportunity was taken in the follow-up study to ask additional questions about intervening illness or hospitalization, attendance of home helps, use of aids, deafness and transport for dental treatment (Warren, Knight and Warren, 1979), to examine the effects of extending the operational criteria for

defining 'handicapped person' (see pages 61 - 62) and to carry out some preliminary work for a study of people with impaired vision (Cullinan, 1977).

This report discusses the changes in activities and perceived needs of handicapped people and the effects of extending the operational definition of 'handicapped person'. It concludes with a plea for a simplification of the processes for obtaining help. People with handicaps should have easier access to help and be able to comprehend the procedures and decisions about its provision, so that they can have more control over matters affecting the quality of their lives.

METHODS AND RESPONSE

Design, Approach and Response

As a matter of deliberate policy, the definition of key terms and the basic design of both the initial and follow-up surveys were similar to those used in the national sample survey of physically impaired and handicapped people in 1968 (Harris, 1971) and, with modifications, later recommended for use by local authorities (Harris and Head, 1971).

In the initial survey, a simple one-page questionnaire was delivered to all the 10,960 private households in the City of Canterbury and completed forms were collected back from 93 per cent of them. The population living in private households was 30,085 at the census in 1971. The first stage of the survey led to the identification of 1,608 people stating themselves to be physically impaired or being so reported by a member of the household. Ninety-five per cent of these people (1,534 people) were successfully interviewed (screening interview). If it was found that the reported impairment resulted in severe disability or handicap (for definitions see page 17), a further interview (assessment interview) was carried out to obtain more details about the activities and dependence of each disabled person. Information was also obtained about the help available and about the perceived need for further help, particularly from the Social Services Department. It has been estimated that about 90 per cent of all disabled people in private households in the City were included in the survey (Warren, 1975).

In the follow-up survey, an attempt was made to interview all the survivors of the original 1,534 impaired persons who had had a screening interview in the initial survey. The interview schedules used in the follow-up survey (reproduced at the end of this report) were identical to those used in the initial survey, except for a few additional questions and other minor changes. However, there was one important change in procedure in the follow-up survey; if it was necessary to proceed to the assessment interview in the follow-up survey, this interview was carried out immediately the screening interview had been completed.

The numbers of people interviewed and of those dropping out at each stage of the surveys are shown in figure 1. In the follow-up survey 1,078 impaired people were interviewed, representing response rates of 70 per cent of those screened in the first survey and of 92 per cent of those available for follow-up. Some details about the non-responders are given on page 11.

Interviewers

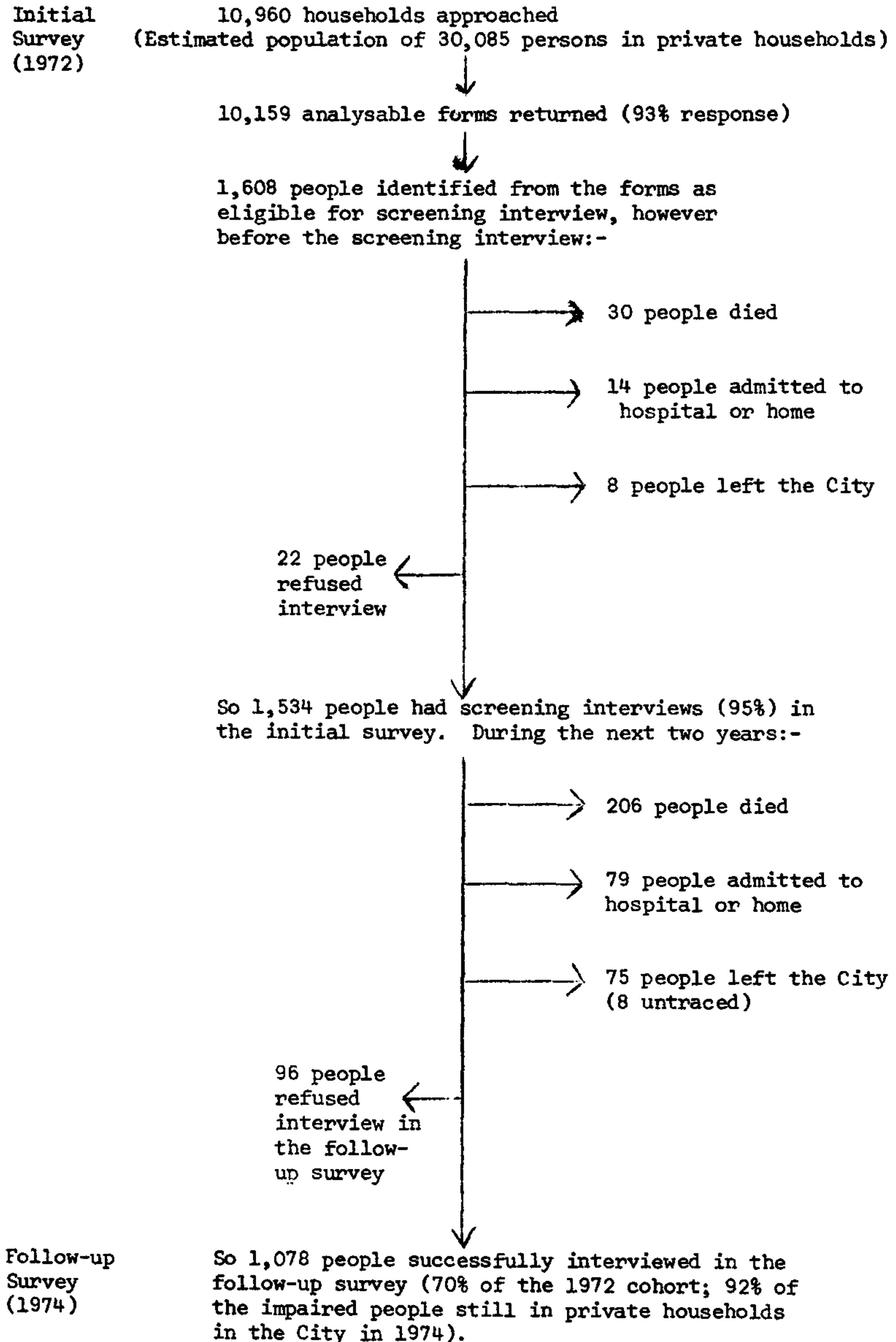
The interviewers who carried out the 'screening' interviews in the initial survey had one training session which covered such matters as the purposes of the survey and the ethics and principles of interviewing, and during which they were taken through the interview schedule and conducted practice interviews on each other. The smaller number of interviewers who carried out the 'assessment' interviews (and both interviews in the follow-up survey) received further training in interviewing, and a session in the local occupational therapy department in which aids available for disabled people were demonstrated and problems of disabled people were discussed. Of the 15 interviewers collecting data in the follow-up survey, 10 had taken part in previous surveys of a similar kind. During the follow-up survey the interviewers were not aware of, and did not have access to, the data relating to individuals from the initial survey. During both initial and follow-up surveys each interview schedule was independently scrutinised for completeness, internal consistency, correct categorisation and the eligibility of subjects for assessment interview. When necessary, complete information was ensured by interviewers making a repeat visit. In the initial survey the interviews took place between June and October, 1972, and in the follow-up survey between May and early December, 1974.

Consistency and Accuracy

There are problems of the reliability and validity of data obtained from single interviews with disabled people, in particular, the subject can be influenced by his present physical condition or recent experience and might have different perceptions of his situation on other occasions. In the present study, which combined research and service, it was not possible to guard against this source of unreliability by, for example,

Figure 1

NUMBERS OF PEOPLE APPROACHED AND RESPONDING AT EACH STAGE OF THE SURVEYS



repeat interviews. However, the accuracy of some of the interview data obtained in the initial survey was checked by examining the records of agencies reported to be helping a disabled person (Warren, 1975). It was found that 24 of the 231 people on the Social Services Department's handicap registers had not been so identified in the initial survey. Ten of these 24 people had refused interviews, 9 had returned negative replies on the initial household form and 5 had not replied at all, some of whom may have died, been admitted to hospital or left the City before the survey.

An indication of the accuracy and validity of the data is provided by experience from a study, using similar schedules and some of the same interviewers, of patients of doctors in a group general practice in Paddock Wood. In this study it was possible to check the respondent's statement about the nature of the underlying disease or injury against the records or statements of the general practitioners. Of the 311 statements that it was possible to check, 294 (94%) were corroborated by the general practitioner (Warren, 1976a).

Another indication of the levels of accuracy and validity is provided by work done by Cullinan (1977). He linked the findings, from the studies reported here, about the visual ability of the impaired people (including the recorded results of sight testing by the interviewers in the homes of the impaired people during the follow-up survey) with information about visual acuity and underlying eye disease obtained mainly from hospital notes. Cullinan found that 60 (39 per cent) of the 153 people with impaired vision who gave permission for a search of their records had attended a specialist eye clinic in the period between the surveys, and 58 of these had had the result of a visual acuity test recorded. The results recorded from the tests in the home by the survey interviewers correspond exactly with the results from the hospital tests in 34 (59 per cent) of the 58 patients, in 16 the interviewers recorded one grade lower in visual acuity (e.g. 6/36 at home, 6/24 in hospital), in 6 it was more than one grade lower, and in 2 cases it was one grade better. Bearing in mind that the lighting conditions were not always ideal in the home and that a period of up to two years could have occurred between the home and hospital tests, these results suggest that the interviewers were reasonably accurate in their assessments, and that the findings are substantially valid.

Intervening Events

Two events recorded in the follow-up survey were death and permanent admission to a hospital or residential home of any of the original cohort of impaired people. Right from the start of the initial survey the local newspapers were scrutinised and the announcement of any deaths of identified persons were recorded. During the follow-up survey statements from relatives or friends about the death or admission to hospital or a residential home of one of the cohort were accepted. In consequence of these procedures only 8 people were unaccounted for at the conclusion of the follow-up survey.

Definitions and Measures of Physical Disability and Handicap

Many personal and social factors, as well as the severity of underlying diseases and injuries, contribute to the limitation of activity and enjoyment experienced by disabled people. In order to distinguish, at least theoretically between different aspects of disablement, three terms - impairment, disability and handicap - are often used. Internationally accepted definitions of these terms are still being developed (Wood, 1979); currently they may be defined as follows:-

Impairment is defined as lacking part or all of a limb or having a defective limb, organ, mechanism or system of the body. It comprises any anatomical loss or deformity or physiological or psychological disturbance. An impairment may be so minor as not to interfere with function or it may be disabling or directly handicapping.

Disability is the loss or reduction of function or bodily activity arising from the impairment.

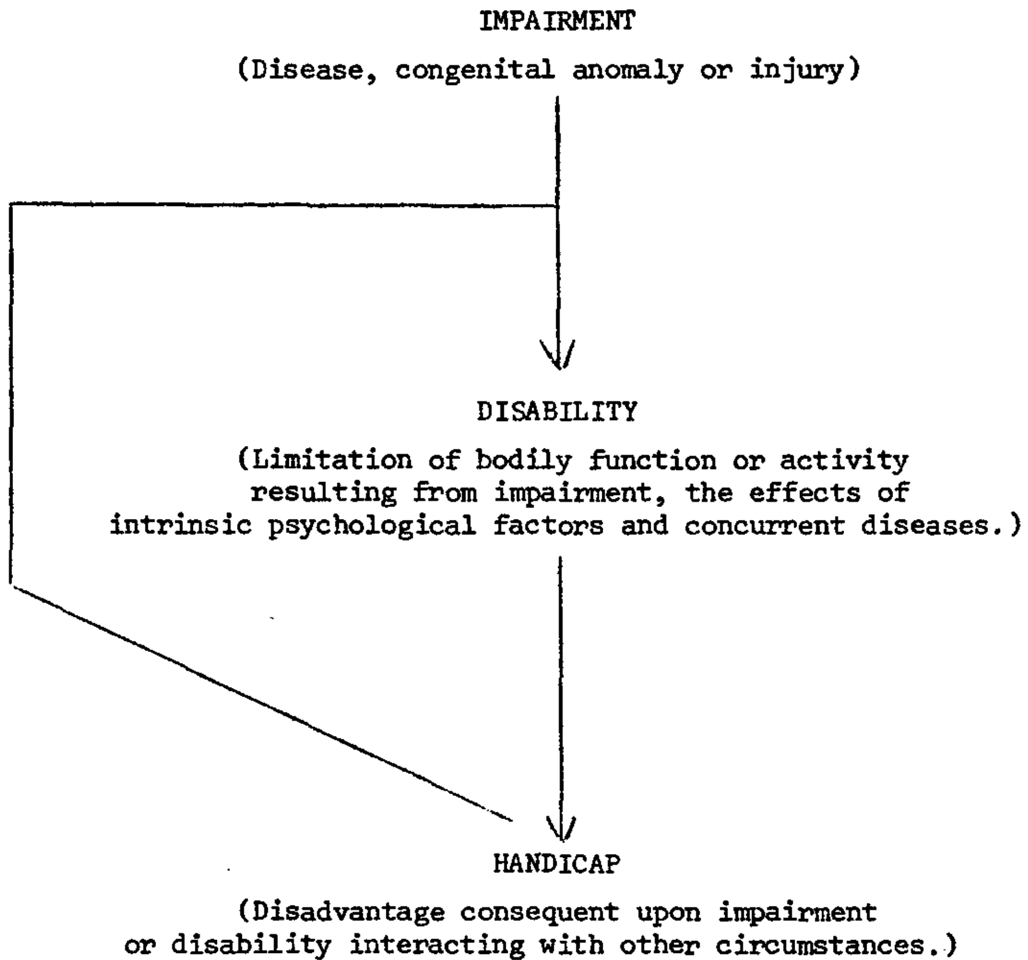
Handicap is defined as the disadvantage or restriction experienced in terms of personal and social life consequent upon disability or impairment and other circumstances. Handicap in this sense is the result of interaction between the individual's physical or mental impairment, his adjustment to this, and his physical and social environment (Wood and Badley, 1978).

Relationships between impairment, disability and handicap are shown in figure 2. Lack of motivation, fatigue at the time of testing, and additional diseases could increase the disability associated with an

Figure 2

DISABLEMENT

Complex Aggregation of Factors Producing Handicap



impairment. Many other factors in addition to the severity of disability may contribute to the degree of handicap. These factors might include the lack of facilities or services available to ameliorate the handicap (e.g. prostheses or wheelchairs), environmental factors (e.g. steps and stairs), social factors (e.g. absence of other persons in the household) and psychological factors including the attitudes of other people. Furthermore, the severity of the underlying condition may fluctuate and so affect the degree of disability or handicap present at any time. A person with an impairment may be able to cope quite well for some time with the associated disability. Eventually, however, it may happen that the loss of his spouse (for example) throws such an additional strain on him that he is no longer able to cope, and he becomes handicapped. Hence a critical point in the progression of disablement from impairment to handicap is crossing or by-passing the boundary between the categories of impairment, disability and handicap. Obviously, however, there is not a clear or narrow boundary line of demarcation between these aspects of disablement.

Attention was focussed in this study on physical impairment and handicap as defined in operational terms related to the interests and responsibilities of the Social Services Departments. No attempt was made to measure separately each of the components contributing to the states of disability and handicap. Some of the criteria used reflect the result of a summation of medical, physical, social and environmental components, although the criteria relating to vision and hearing reflect, more specifically than the other measures, loss of physiological function (i.e. disability). The activities which were enquired about were mobility, visual and hearing abilities, self-care (feeding, toilet, washing, dressing and undressing), household activities, occupation, and certain social activities.

The term 'impaired' has been applied, in this study, to all those people who were identified as having some impairment (see above) by means of the household questionnaire and subsequent

corroboration at the screening interview. 'Impaired only'* is used to describe people who despite impairment (which may or may not be disabling) were not handicapped. 'Handicapped'* is used to describe all those people with disabilities or impairments who were assessed at the screening interview as being handicapped and likely to be in need of help, and who thereby had a further interview (the assessment interview). The criteria used for eligibility for an assessment interview are given on page 17. These definitions have been used in this study in order to maintain comparability with earlier studies (Knight and Warren, 1978).

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*More descriptive, but clumsier, terms would be 'impaired only or only moderately disabled' and 'severely disabled or handicapped'.

DEATHS, PERMANENT ADMISSIONS AND INTERVENING SERIOUS ILLNESSES

In the initial survey 1,534 people had 'screening' interviews (figure 1), but before 'assessment' interviews could be given 58 of these people died, were admitted permanently to an institution, moved away or refused a further interview, so leaving 1,476 people in the study. Between the two surveys a further 266 people died or were admitted to an institution for long-term care, and 132 people had left the City, refused a further interview or could not be traced. Thus, in the follow-up survey 1,078 people were interviewed.

Non-responders

In all 171 people (11 per cent of the original group of 1,534 impaired people) had moved away, were not traced or refused interview, either during the initial survey or between the two surveys. There are no substantial relative differences in attributes between the non-responders and the remainder, except that more of them were less disabled. A slightly higher proportion of children had left the City and a lower proportion of the parents or guardians of the children refused interview. In terms of diagnoses there were slightly higher proportions among those leaving the City with diseases of the respiratory system and of the circulatory system and with 'other diseases' of the central nervous system. Those who refused interview contained a higher proportion of those without self-care difficulties (a quarter gave absence of difficulties as a reason for refusal), proportionately fewer people known to be receiving help from any of the caring agencies, and proportionately fewer with known diagnoses (table 1). However, the numbers of people in these categories were small.

Deaths

Two hundred and six people (13 per cent) died between the start of the initial survey and the follow-up survey. Of those who died 91 were males and 115 females; 118 (fifty-seven per cent) were aged 75 years or more, and 60 (29 per cent) were aged between 65 and 74 years (table 1). One hundred and twenty five people (61 per cent) had had some difficulty in self-care (19 per cent had had severe difficulty) and 31 per cent had been housebound or bedfast in 1972. Half the people who died were known to one or more of the caring agencies, in addition to the general practitioner.

Table 1

Impaired and handicapped people identified in the initial survey, those re-interviewed in the follow-up survey and those who moved, refused, died or were admitted to residential care or hospital

(by age, sex, marital status, household type, incapacity, diagnosis, etc. in initial survey)

	Moved away			Refused interview*			Died			Admitted to hospital or home			Re-interviewed			Total in initial interview	
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL	75	(100)	(4.9)	96	(100)	(6.3)	206	(100)	(13.4)	79	(100)	(5.1)	1078	(100)	(70.3)	1534	(100)
AGE Under 15	6	(8.0)	(7.9)	1	(1.0)	(1.3)	-			4	(5.1)	(5.3)	65	(6.0)	(85.5)	76	(4.9)
15 - 49	11	(14.7)	(5.6)	9	(9.4)	(4.6)	5	(2.4)	(2.5)	3	(3.8)	(1.5)	169	(15.7)	(85.8)	197	(12.8)
50 - 64	9	(12.0)	(3.0)	20	(20.8)	(6.6)	23	(11.2)	(7.6)	5	(6.3)	(1.6)	247	(22.9)	(81.2)	304	(19.8)
65 - 74	20	(26.7)	(5.0)	23	(24.0)	(5.8)	60	(29.1)	(15.0)	12	(15.2)	(3.0)	284	(26.3)	(71.2)	399	(26.1)
75 or over	29	(38.7)	(5.2)	43	(44.8)	(7.7)	118	(57.3)	(21.1)	55	(69.6)	(9.9)	313	(29.0)	(56.1)	558	(36.4)
SEX Male	26	(34.7)	(4.3)	33	(34.4)	(5.5)	91	(44.2)	(15.1)	20	(25.3)	(3.3)	431	(40.0)	(71.7)	601	(39.2)
Female	49	(65.3)	(5.2)	63	(65.6)	(6.8)	115	(55.8)	(12.3)	59	(74.7)	(6.3)	647	(60.0)	(69.3)	933	(60.8)
MARITAL STATUS																	
Married	30	(40.0)	(4.3)	42	(43.8)	(6.0)	100	(48.5)	(14.3)	19	(24.1)	(2.7)	506	(46.9)	(72.6)	697	(45.4)
Single, widowed, other	45	(60.0)	(5.4)	54	(56.2)	(6.5)	106	(51.5)	(12.7)	60	(75.9)	(7.2)	572	(53.1)	(68.3)	837	(54.6)
HOUSEHOLD																	
Alone	20	(26.6)	(4.6)	25	(26.0)	(5.7)	59	(28.6)	(13.5)	34	(43.0)	(7.8)	299	(27.7)	(68.4)	437	(28.5)
With spouse only	25	(33.3)	(5.6)	20	(20.8)	(4.5)	72	(35.0)	(16.1)	15	(19.0)	(3.3)	316	(29.3)	(70.5)	448	(29.2)
With spouse & children, etc.	4	(5.3)	(1.6)	22	(22.9)	(9.1)	27	(13.1)	(11.1)	4	(5.1)	(1.6)	186	(17.3)	(76.5)	243	(15.8)
With children only	8	(10.7)	(5.4)	11	(11.5)	(7.4)	31	(15.0)	(20.9)	12	(15.2)	(8.1)	86	(8.0)	(58.1)	148	(9.6)
With parents	9	(12.0)	(6.0)	5	(5.2)	(3.3)	1	(0.5)	(0.7)	8	(10.1)	(5.3)	127	(11.8)	(84.7)	150	(9.8)
Other types	9	(12.0)	(8.3)	13	(13.5)	(12.0)	16	(7.8)	(14.8)	6	(7.6)	(5.6)	64	(5.9)	(59.3)	108	(7.0)
SELF-CARE SCORES**																	
0	40	(53.3)	(4.5)	69	(71.9)	(7.8)	81	(39.3)	(9.2)	20	(25.3)	(2.3)	675	(62.6)	(76.3)	885	(57.7)
1 - 4	18	(24.0)	(6.3)	12	(12.5)	(4.2)	48	(23.3)	(16.7)	21	(26.6)	(7.3)	189	(17.5)	(65.6)	288	(18.8)
5 - 11	10	(13.3)	(5.6)	11	(11.5)	(6.1)	38	(18.4)	(21.1)	12	(15.2)	(6.7)	109	(10.1)	(60.6)	180	(11.7)
12 or more	7	(9.3)	(3.9)	4	(4.2)	(2.2)	39	(18.9)	(21.5)	26	(32.9)	(14.4)	105	(9.7)	(58.0)	181	(11.8)
MOBILITY																	
Housebound	11	(14.7)	(6.2)	13	(13.5)	(7.3)	51	(24.8)	(28.7)	21	(26.6)	(11.8)	82	(7.6)	(46.1)	178	(11.6)
Bedfast or chairbound	-			2	(2.1)	(9.1)	12	(5.8)	(54.5)	3	(3.8)	(13.6)	5	(0.5)	(22.7)	22	(1.4)
IMPAIRED VISION	9	(12.0)	(3.0)	26	(27.1)	(8.7)	56	(27.2)	(18.8)	31	(39.2)	(10.4)	176	(16.3)	(59.1)	298	(19.4)
IMPAIRED HEARING	11	(14.7)	(7.5)	15	(15.6)	(10.2)	31	(15.0)	(21.1)	8	(10.1)	(5.4)	82	(7.6)	(55.8)	147	(9.6)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS***																	
CVA/Stroke	3	(4.0)	(4.7)	2	(2.1)	(3.1)	24	(11.6)	(37.5)	7	(8.9)	(10.9)	28	(2.6)	(43.7)	64	(4.2)
Other central nervous system	8	(10.7)	(7.1)	1	(1.0)	(0.9)	13	(6.3)	(11.5)	6	(7.6)	(5.3)	85	(7.9)	(75.2)	113	(7.4)
Circulatory	10	(13.3)	(6.8)	2	(2.1)	(1.4)	29	(14.1)	(19.9)	11	(13.9)	(7.5)	94	(8.7)	(64.4)	146	(9.5)
Musculoskeletal	16	(21.3)	(4.5)	17	(17.7)	(4.8)	43	(20.9)	(12.2)	23	(29.1)	(6.5)	254	(23.6)	(71.9)	353	(23.0)
Fractures, injuries, operations	3	(4.0)	(4.6)	4	(4.2)	(6.1)	13	(6.3)	(19.7)	9	(11.4)	(13.6)	37	(3.4)	(56.1)	66	(4.3)
Respiratory	6	(8.0)	(7.8)	3	(3.1)	(3.9)	24	(11.6)	(31.2)	2	(2.5)	(2.6)	42	(3.9)	(54.5)	77	(5.0)
Mental disorders	2	(2.7)	(3.6)	-			2	(1.0)	(3.6)	5	(6.3)	(9.1)	46	(4.3)	(83.6)	55	(3.6)
Other diseases	6	(8.0)	(2.6)	14	(14.6)	(6.1)	25	(12.1)	(11.0)	15	(19.0)	(6.6)	168	(15.6)	(73.7)	228	(14.9)
ON AGENCY RECORDS OR REGISTERS	26	(34.7)	(4.6)	25	(26.0)	(4.5)	109	(52.9)	(19.4)	59	(74.7)	(10.5)	342	(31.7)	(61.0)	561	(36.6)

*24 stated they had no more difficulties **See page 21 for explanation of scores ***Some persons stated more than 1 main diagnosis, some gave none.

Just over 1 in every 5 impaired people aged 75 years or more in 1972 had died during the subsequent two years and just under 1 in 7 of those aged 65 - 74 years. A slightly higher proportion of males than females died, as also of people living with children only and of people living only with their spouse. A higher proportion of people with difficulties in self-care, and of people who were housebound also died. Over half of the original group of bedfast people died and just over one third of the people known to be receiving help from 3 or more of the caring agencies. About one third of people disabled by strokes died during the two years, and almost the same proportion of those disabled by respiratory diseases. About one fifth of people with disabling diseases of the circulatory system and the same proportion of those with disabling fractures, injuries or extensive operations also died during the period between the two surveys (table 1).

The number of deaths that might have been expected among the impaired group, if the same percentage of them had died as of the total population of Canterbury in 1973 was estimated. The figures (table 2) suggest that there was a higher than expected mortality among disabled persons aged between 35 and 74, average mortality among men aged 75 years or more, but lower than expected among disabled women in this latter age group. However, the expected numbers are based on death rates of people living at home _and_ in hospitals and other institutions which contain relatively more women in the older age groups.

These findings draw attention to the inclusion among the original group of impaired people of a significant number of later middle-aged and elderly people disabled by chronic disease and requiring (and many getting) help from community health and social services. There is an obvious overlap between the needs of this group labelled as 'handicapped people' and others who might be categorised as 'terminally ill' (Cartwright et al., 1973). Their needs may be extensive in variety and intensity for some periods of time (29 per cent of the impaired people who died were living alone at the time of the first survey), and continued support may be required after the death of the impaired person to help the remaining spouse adjust to the bereavement (35 per cent of this group lived with their spouse only).

TABLE 2

Expected and Observed Deaths Among
Impaired People between the Two Surveys

Age group (years)	Number of impaired people		Expected number of deaths		Observed number of deaths	
	Male	Female	Male	Female	Male	Female
15 - 24	22	11	-	-	-	-
25 - 34	22	26	-	-	-	-
35 - 44	33	32	-	-	-	2
45 - 54	60	59	1	1	5**	5**
55 - 64	104	132	4	2	10*	6*
65 - 74	155	244	18	17	31**	29**
75 or over	155	403	46	97	45	73*
Total 15 or over	551	907	69	117	91	115

Source: Expected number of deaths 1972 and 1973 from O.P.C.S. via Kent A.H.A.

Population from 1971 census with minimal adjustment.

Numbers of impaired people and numbers of observed deaths from the Surveys, excluding the 30 people who died before interview in the initial survey.

Note: *The difference between the expected and observed number of deaths is statistically significant at the 5 per cent level,
**at 1 per cent level.

For method see Bailar (1964).

Permanent Admission to Hospital or Home

In addition to the 206 people who had died, 79 people were admitted more or less permanently to a hospital or a residential home. The reasons for admission were not ascertained as no interviews were undertaken for these people. This group contained a higher proportion of the more elderly people (70 per cent were aged 75 years or more), and, related to this, of more women (75 per cent), more widowed, divorced or single people (76 per cent) and of more who lived alone (43 per cent) than the original group (table 1). Fifty nine (75 per cent) of this group had some difficulty in self-care (33 per cent had severe difficulty) and 24 (30 per cent) were housebound or bedfast at the time of the first survey. The main diagnostic categories were musculo-skeletal diseases (29 per cent), circulatory diseases (14 per cent), fractures, injuries and operations (11 per cent) and strokes, other diseases of the central nervous system and mental illnesses (9, 8 and 6 per cent respectively).

Intervening Episodes of Serious Illness and Admission to Hospital

All the 1,078 people who were interviewed in the second survey were asked: "Have you had any serious illness or been in hospital during the last two years?" Two hundred and seventy five (26 per cent) replied that they had, and all but 25 of these had been admitted to hospital. The vast majority of these, 227 (83 per cent), reported only one episode of serious illness, 28 (10 per cent) mentioned two episodes, and 20 (7 per cent) had 3 or more episodes. Of the 250 people admitted to hospital, 64 (26 per cent) stayed less than one week, 110 (44 per cent) between one and three weeks, 56 (22 per cent) more than three weeks but less than three months, and 20 (8 per cent) stayed for three months or longer. Equal proportions of both impaired men and women reported an intervening episode of serious illness, but there were differences in the age distributions between the sexes (appendix table I). Amongst the men there were proportionately more aged 50 - 64 years (35 per cent compared with 22 per cent of the other men interviewed) and fewer aged 15 - 49 years (12 per cent compared with 25 per cent). There were relatively fewer women aged 65 or more among the women reporting serious illness or hospitalisation than among the other women interviewed (53 per cent compared to 67 per cent), and, as with the men, there were proportionately more in the 50 - 64 years age group. There was little difference

in the distribution of household compositions among those impaired people who reported temporary hospitalisation compared to the others, in contrast to the findings relating to people more permanently admitted to hospital or a home.

The reasons for hospitalisation were not coded because the descriptions were mostly rather vague, and the presence of multiple conditions was common. The main cause of disability may or may not be the reason for admission to hospital; it is more likely to be so in relation to some chronic disabling diseases of the cardiovascular system or respiratory system than to disability resulting from a long-standing injury or life-long deafness or blindness. In the initial survey differences in diagnoses between persons subsequently hospitalised or experiencing serious illness and the others were few. At follow-up the following causes of impairment or disability were more prevalent among those who did report such episodes: cerebral haemorrhage, ischaemic heart disease, unspecified cardiovascular diseases, rheumatoid arthritis, respiratory diseases, endocrine diseases (mainly diabetes) and fractures. Those people with strokes, fractures, unspecified operations and injuries, arthritis, and endocrine disorders spent longer periods in hospital than those with circulatory and respiratory disorders.

The group reporting an episode of serious intervening illness or admission to hospital also contained proportionately more people assessed with higher levels of self-care difficulty in the first survey than those not reporting such episodes. Fourteen per cent of the former were assessed as severely handicapped in this respect compared to 8 per cent of the others and only 54 per cent had experienced no self-care difficulty compared to 65 per cent of the others. Although at the follow-up survey more people in both groups had become more severely handicapped (17 per cent and 10 per cent respectively) since the first survey, 14 per cent of those reporting an episode of serious illness were assessed in the follow-up survey as having deteriorated more substantially compared to under 10 per cent of the others. Those who reported one episode or more of hospitalisation or serious illness had had more contacts with domiciliary services, not only with general practitioners and nurses, but also with the home helps and social workers.

CHANGES IN HANDICAP STATUS AND CAPABILITIES

Changes in 'Handicap' Status

The initial survey classified all impaired people into two groups : those who were physically impaired or disabled without being handicapped ('impaired only') and those who were handicapped as a result of their impairment or disability and other circumstances ('handicapped'). It was anticipated that people with handicaps arising from their impairment or disability would be likely to need help, and, therefore, it was only this group who had 'assessment' interviews. Thus, in effect, the status 'handicapped' was equated with eligibility for an 'assessment' interview, rather than describing a common state of a homogeneous group of people. The criteria for an 'assessment' interview which were used in both surveys were being housebound or limited in self-care activities (based on reported difficulties when asked specific questions about self-care), having very poor vision (estimated as the equivalent of less than 6/60 Snellen even with glasses), or having poor hearing or being unable to communicate with the interviewer. Children needing special care or educational facilities were also included (Warren, 1974). In the present study, therefore, 'handicapped' and 'impaired only' are used operationally to define two sub-groups of the total number of impaired people identified in the initial household survey.

Of the 1,078 people interviewed in the follow-up survey, 517 had been categorised as 'handicapped' in the initial survey and 561 as 'impaired only'. In the follow-up survey 435 of the 517 handicapped people (84 per cent) were again categorised as 'handicapped' and 82 (16 per cent) were re-categorised as 'impaired only'. Of the 561 people originally categorised as 'impaired only', 410 (73 per cent) were similarly classified at follow-up, and 151 (27 per cent) were re-categorised as 'handicapped'. These figures are shown in table 3 together with the numbers from the initial groups of 'handicapped' and 'impaired only' who had died, been admitted permanently to an institution or had not been traced.

TABLE 3

'Operational' Status at Follow-up Compared to Status at Initial Survey

Status at initial survey	Status at follow-up Survey					Total
	Died	Admitted	Handicapped*	Impaired*	Other**	
'Handicapped'*	138	55	435	82	60	770
'Impaired only'*	61	12	151	410	72	706
Total	199	67	586	492	132	1476***

*See text for definitions of 'impaired' and 'handicapped'. In this study the following categories of people were operationally classified as 'handicapped':

1. Those with substantial restriction of mobility or with self-care scores of 6 or more.
2. Those with impaired vision of less than 6/60 with glasses.
3. Those with impaired hearing who reported difficulty in hearing conversation.
4. Children needing special care or educational facilities.
5. Persons over the age of 70 years with any difficulty in self-care.

Classification was based on the answers to questions in the first interview. For full details see Warren (1974).

**Moved out of City, refused interview, etc.

***58 people died, moved away, were admitted or refused interview during the field work of the initial survey, these people are included in the numbers in figure 1 and table 1.

Changes in Self-care Capability

In each survey respondents were asked whether they 'generally have difficulty' in performing each of the following nine basic self-care functions: getting in and out of bed; getting to or using the toilet; having an all-over wash or bath; washing hands and face; putting on shoes and stockings; doing up buttons and zips; dressing (other than difficulty with buttons or shoes); feeding; and grooming (hair for women, shaving for men). For each function, the reply was recorded as 'can perform without difficulty or supervision', 'can perform with difficulty by him or herself', or 'unable to perform without help from some other person'. In the second survey the first possibility was sub-divided into 'no difficulty without aids' and 'no difficulty, using aids', but for the purposes of comparison between the surveys the sub-division has been ignored.

Each respondent's capability to perform each of the self-care activities in the follow-up survey was compared to his or her capacity to perform that task in the initial survey. Table 4 shows for each activity the percentage of all respondents who could perform the activity with less difficulty at the time of the follow-up survey (i.e. who might be considered to have 'improved'), the percentage reporting more difficulty or who were not able to perform the task having previously been so able, and the percentage reporting no change. Obviously, those people who previously had no difficulty in an activity could not have improved on this, and equally those who had substantial difficulties or could not perform the activity at all, could not be identified as having deteriorated further, even if they had become more dependent on other people.

Except in relation to the activity of bathing and having an all-over wash, there was no change in difficulty of performing each of the listed activities in regard to about 75 per cent of more of the respondents, and for some functions almost the same number of people had apparently 'deteriorated' as had 'improved'. However, more people reported no difficulty in the initial survey than in the follow-up; in the former 289 of the men and 386 of the women reported no difficulty in any of the activities, whereas among the same group in the follow-up survey, the numbers had dropped to 269 men and 337 women. One in five of the respondents reported more difficulty in bathing or having

TABLE 4

Changes in Reported Self-care Capability at time of the Initial and Follow-up Surveys. Each Activity for all Repondents (1078 = 100 per cent)

Activity	Reported no difficulty at both surveys	At follow-up performs functions with less difficulty than initially	Same amount of difficulty at each survey	At follow-up performs functions with more difficulty than initially or cannot now perform function
	Per cent	Per cent	Per cent	Per cent
Getting in and out of bed on your own	77.0	7.7	6.5	8.8
Getting to or using the W.C.	83.6	4.0	4.1	8.3
Having an all-over wash or bathing yourself if bath used	53.5	10.3	13.7	22.5
Washing your hands and face	92.2	2.8	2.4	2.6
Putting on shoes and socks or stockings yourself	74.4	9.2	7.8	8.6
Doing up buttons and zips yourself	82.4	5.3	4.5	7.8
Dressing, other than buttons and shoes, etc.	83.3	4.0	5.2	7.5
Feeding yourself	90.9	2.6	2.4	4.1
Women and children: Combing and brushing your hair Men: Shaving yourself	87.8	4.1	4.1	4.0
One or more of the above	48.1	18.7	8.2	25.0

an all-over wash. Further analysis shows that this appears to be not only the relatively most common difficulty but also the one that comes on before other difficulties in self-care in many people.

Many disabled people have difficulties with a number of self-care activities. In both surveys points were allotted to the performance in each activity along the lines worked out by Harris (1971) in her survey. Each activity performed with difficulty scored 2 and inability to perform scored 3, except for three activities (using toilet; doing up buttons and zips; and feeding) which carried scores of 4 and 6 for difficulty and inability respectively. The total score for each person reflects the multiplicity, severity and combination of difficulties. Whilst the actual level of points allotted by Harris to each activity and the allowances that should be made for related activities can be questioned, the changes in total score should reflect improvement or deterioration between the two surveys as this system was used in both surveys. The mean score for all the 1078 impaired people in the initial survey was 3.30 and in the follow-up survey it was 3.98 (table 5). The mean self-care score was highest for impaired children at the time of the initial survey probably because parents of less severely handicapped children are reluctant to admit or recognise the existence of difficulties in activities as signs of disability. The mean score was initially higher for impaired middle-aged people than for impaired elderly people, but during the two years between the surveys, the mean self-care score had increased most for the elderly people.

The numbers and percentages of those in the cohort whose scores either increased (i.e. their functional performance deteriorated) or decreased (i.e. their functional performance improved) are shown in table 6. Changes in scores of 5 or more* would usually reflect one

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*The cut-off at 5 or more for deterioration or improvement was decided upon after careful scrutiny of the distribution to exclude minor fluctuations in capacity. It should be noted that in order to correspond to this cut-off point, self-care scores in the appendix tables are grouped 1 - 4 and 5 - 11 and not 1 - 5 and 6 - 11 as in Harris's survey and in connection with definitions of severity in this report. The difference arising from this involves only 7 people out of 1078.

TABLE 5

Mean Scores of Difficulty in Self-care by Age Groups at Initial and Follow-up Surveys

Age group in years	Number of persons	Mean scores of difficulty in self-care	
		Initial Survey	Follow-up Survey
0 - 14	65	7.88	8.31
15 - 49	169	3.18	2.82
50 - 64	247	3.34	3.63
65 - 74	284	2.75	3.45*
75+	313	2.84	4.42*
All ages	1078	3.30	3.98*

*Difference of mean scores between surveys statistically significant ($p < 0.05$).

of the following changes, (i) the loss of ability to do one of the three higher scored functions (having been able to perform this without difficulty previously), (ii) deteriorated function in at least two activities, (iii) if the score was negative, improvement in a higher scored activity or in at least two other activities. Sixty-eight people (6.3 per cent of the cohort) obtained a score at follow-up of 5 points or more below their score two years previously and might therefore be described as having improved functionally, while 117 people (10.8 per cent) obtained 5 points or more above their initial score and have, therefore, deteriorated functionally. The scores of 893 people had either not changed at all (and 519 of those people had no score in both surveys) or had changed less than 5 points in each direction.

Comparing initial attributes between these three groups ('deteriorated', 'improved', and 'little or no change'), it was found that proportionately more people aged 75 years or more and fewer aged 15 - 49 years had deteriorated, and that proportionately more people who already had difficulties in self-care, i.e. with self-care scores of 5 or more had substantial changes in their scores in one or other direction (appendix table II). Substantial changes took place particularly among patients with strokes (18 per cent of whom 'improved' and 36 per cent 'deteriorated'). One third of those who had deteriorated had been seriously ill or hospitalised between the surveys, compared to 28 per cent of those who had improved. There was also more change in both directions among those impaired people in contact with services than among those without this contact. This finding probably indicates that the services were in touch with the more severely disabled people, some of whom they were able to help and some of whom, even with help, became more disabled and dependent.

TABLE 6

Numbers of Persons Assessed with No Change or Change in Scores for Difficulties in Self-care Activities at Follow-up Survey

	Number and per cent with change in score	
	Number	Per cent
No score in both surveys	519	48.1
Same score in both surveys	46	4.3
Decrease in score 'Improvement'		
-10 or better	21	1.9
-5 to -9	47	4.4
-1 to -4	146	13.5
Total improved	214	19.9
Increase in score 'Deteriorated'		
+1 to +4	182	16.9
+5 to +9	68	6.3
+10 or worse	49	4.5
Total deteriorated	299	27.7
Total	1078	100.0

Seeing

In both surveys each impaired person (except those registered as blind or partially sighted) was asked whether he or she (wearing glasses, if appropriate) could recognise people across the street and whether he or she could usually see to read ordinary print and to write. In the follow-up study elementary tests of visual acuity were carried out by the interviewers, as part of another study (Cullinan, 1977) (see page 6). In the initial survey 176 people stated they had some difficulty in seeing, and 198 stated this in the second survey. On both occasions 77 per cent of impaired people stated that they had no difficulties with either distance or near vision and 12 per cent had difficulties with either or both. On the second occasion 6½ per cent said that they now had difficulty having previously been all right, and 4½ per cent who previously had difficulty no longer mentioned this. Some deterioration in sight among an elderly group of people is to be expected over two years, and some improvement by the recent provision of spectacles or treatment of cataracts (for example) can also be anticipated. The biggest shifts were from those who in the initial survey could read without difficulty, but who reported later that they used a magnifier (38 of the 70 with deterioration),and from those who said they used a magnifier in the first survey, said they could read without it in the second (24 out of the 48 whose vision had improved).

Over half of the group whose sight had deteriorated were aged 75 or over; three quarters were women; if anything they contained fewer people with difficulties in self-care (appendix table III).

TABLE 7

Visual Ability at Initial and Follow-up Surveys

Initial survey	Follow-up survey					
	Visual impairment				Little difficulty	Total
	Distance only	Reading* only	Both	Sub total		
Visual impairment:						
Distance only	14	4	12	30	22	52
Reading only *	2	6	4	12	13	25
Both	7	1	78	86	13	99
Sub total	23	11	94	128	48	176
Little difficulty	24	19	27	70	832	902
Total	47	30	121	198	880	1078

*Excludes children and illiterate people not known to have defects of vision.

Hearing

Changes in reported hearing ability followed a pattern similar to that of vision. On both occasions 86 per cent of the impaired people stated they could hear ordinary conversation (wearing a hearing aid, if usually worn) and 4 per cent that they could not (the numbers are presented in table 8). Sixty eight people who claimed to be able to hear in the initial survey, had difficulty at the time of the follow-up survey and 37 people who previously had difficulty then claimed to be able to hear. In the initial survey, 82 of the people stated they had difficulty in hearing and, in the follow-up survey, 113 of the group stated they had difficulty. So overall the number with difficulty in hearing had increased by 31, although as already stated, 68 people reported difficulty in hearing at the follow-up survey who had not had such difficulty in the first survey. As with those people whose vision had deteriorated, a higher proportion whose hearing deteriorated were aged 75 years or more and relatively fewer had difficulties in self-care (appendix table III).

TABLE 8

Hearing Ability at Initial and Follow-up Surveys

Hearing ability at initial survey	Hearing ability at follow-up survey		Total
	can hear conversation*	cannot hear conversation	
Can hear conversation*	928	68	996
Cannot hear conversation	37	45	82
Total	965	113	1078

*With aid, if usually worn

CHANGES IN MOBILITY, HOUSEHOLD ACTIVITY, SOCIAL CONTACTS AND EMPLOYMENT

As already mentioned, there were two stages in the interviewing. The first stage (screening interview) was designed to identify 'handicapped people' who then had an assessment interview (the second stage), in order to obtain details about their needs and difficulties primarily in relation to the responsibilities of the social services department. Seven hundred and seventy people had assessment interviews (table 3) in the initial survey. In the follow-up survey 484 (63 per cent) of these 770 people had assessment interviews made up of the 435 eligible for assessment interviews under the 1972 criteria (table 3) and a further 49 who became eligible because of the additional criteria introduced in the follow-up survey (see page 61). The data presented below in relation to mobility, household activity, employment and social contacts refer only to those 484 people who had assessment interviews on both occasions or to sub-sections of this group of handicapped people. Attributes of this group and of the remainder of the cohort are set out in table 9. In addition to the factors used in defining this group (particularly self-care scores, housebound or with impaired vision or hearing) the handicapped group contain proportionately more than the impaired-only group of the following: people aged 75 years or more, children under 15, people living alone, and people with musculo-skeletal diseases and strokes, and fewer people with circulatory or respiratory diseases.

Mobility

Enquiry was made about three aspects of mobility - getting out of the house, getting about the house and getting up and down stairs. The questions were directed at the actual experience of the disabled person, so that people without stairs or steps in their homes or for access to the garden or street would be recorded as having no difficulty with this aspect of mobility. Table 10 shows the number of people who, in the follow-up survey, either had no changes or had changes in mobility compared to their situation at the initial survey. There was a substantial number of disabled people who experienced more difficulty and this was only partly offset by the number who

TABLE 9

Persons Re-interviewed in Follow-up Survey by Type of Interview
(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

		Assessment interview in both surveys		Screening interview only in one or both surveys		Total		Percentage of total having assessment interviews in both surveys
		No.	(Col.%)	No.	(Col.%)	No.	(Col.%)	
TOTAL		484	(100)	594	(100)	1078	(100)	44.9
AGE	under 15	40	(8.3)	25	(4.2)	65	(6.0)	61.5
	15 - 49	47	(9.7)	122	(20.5)	169	(15.7)	27.8
	50 - 64	84	(17.4)	163	(27.4)	247	(22.9)	34.0
	65 - 74	129	(26.6)	155	(26.1)	284	(26.3)	45.4
	75+	184	(38.0)	129	(21.7)	313	(29.0)	58.8
SEX	Male	176	(36.4)	255	(42.9)	431	(40.0)	40.8
	Female	308	(63.6)	339	(57.1)	647	(60.0)	47.6
HOUSEHOLD								
	Alone	145	(30.0)	154	(25.9)	299	(27.7)	48.5
	Spouse only	134	(27.7)	182	(30.6)	316	(29.3)	42.4
	Other types	205	(42.3)	258	(43.4)	463	(42.9)	44.3
SELF-CARE SCORES								
	0	158	(32.6)	517	(87.0)	675	(62.6)	23.4
	1 - 4	117	(24.2)	72	(12.1)	189	(17.5)	61.9
	5 - 11	105	(21.7)	4	(0.7)	109	(10.1)	96.3
	12+	104	(21.5)	1	(0.2)	105	(9.7)	99.0
HOUSEBOUND OR BEDFAST		84	(17.3)	3	(0.5)	87	(8.1)	96.6
IMPAIRED VISION		162	(33.5)	14	(2.4)	176	(16.3)	92.0
IMPAIRED HEARING		74	(15.3)	8	(1.3)	82	(7.6)	90.2
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS								
	CVA/Stroke	24	(5.0)	4	(0.7)	28	(2.6)	85.7
	Other central nervous system	36	(7.4)	49	(8.2)	85	(7.9)	42.4
	Circulatory	40	(8.3)	54	(9.1)	94	(8.7)	42.6
	Musculoskeletal	157	(32.4)	97	(16.3)	254	(23.6)	61.8
	Fractures, injuries, operations	21	(4.3)	16	(2.7)	37	(3.4)	56.8
	Respiratory	12	(2.5)	30	(5.1)	42	(3.9)	28.6

experienced less difficulty. Improvements that took place reflect in part the provision of services; 49 people had moved house (13 from a house to a flat or bungalow) and 25 people who could not get out at the time of the first survey were able to get out by car two years later (some of this transport having been arranged by a newly established Volunteer Bureau). Deterioration clearly reflects in part the progression of the underlying medical condition and increasing frailty with age. However, greater than average deterioration was observed for those with diseases of the central nervous system and musculo-skeletal diseases, for the age groups 15 - 49 years and 75 years and over, and for those with severe self-care problems. The attributes at the time of the initial survey of those people with greater difficulties in mobility two years later are contrasted with the attributes of the others in the cohort in appendix table lV.

Thirty eight per cent of people who at the time of the first survey had difficulty getting about inside the house, but only low or no self-care scores, had self-care scores above 5 at the time of the follow-up survey, and it has already been noted that three quarters of those people admitted to a hospital or home by the time of the follow-up survey already had difficulty in self-care at the time of the initial survey. Twenty five people experienced substantial deterioration in both mobility and self-care scores (see page 40). Thus, it would appear that bathing, mobility outside the house and walking up and down stairs become limited before other aspects of self-care, and that increasing difficulty in self-care leads to increasing dependence on others and perhaps later to admission to a residential home or hospital.

Household activities

Respondents were asked who did most of their shopping, housework and cooking and whether they would like more help with these activities or with gardening. Table 11 sets out the changes between the surveys in expressed need for help in carrying out the four tasks and table 12 the numbers receiving or asking for more help compared with two years earlier for 1, 2, 3 or 4 of the tasks. The figures in table 11 show that a substantial proportion of people reported

TABLE 10

Mobility: Improvement and Deterioration at Follow-up Survey

Function	Little difficulty in both surveys	Change in difficulty at follow-up survey[4]			Total
		Less difficulty	About the same	More difficulty	
Managing stairs at home[1]	175 (36.2)	65 (13.4)	130 (26.9)	114 (23.5)	484
Getting about the house[2]	257 (53.1)	50 (10.3)	98 (20.2)	79 (16.3)	484
Going out[3]	82 (16.9)	66 (13.6)	217 (44.8)	119 (24.6)	484
Overall mobility change[5]	53 (11.0)	111 (22.9)	123 (25.4)	197 (40.7)	484

[1] Four categories were recorded: (0) No difficulty, no stairs
(1) No difficulty with rail
(2) Difficulty
(3) Can't (wheelchair, etc.)

[2] Four categories were recorded: (0) No difficulty, no aids used
(1) Uses stick
(2) Walking aids
(3) Wheelchair or chairbound

[3] Four categories were recorded: (0) Gets out on own, no aids used
(1) Gets out on own, with aids
(2) Needs someone
(3) Can't get out or only by car

[4] Change from a lower to a higher category is classed as more difficult and vice versa as less difficult.

[5] Obtained by scaling the performance of each of the three activities 0, 1, 2, 3, the change between survey I and survey II measures the combined effect.

that they received or needed less help in each of the activities, but that for some (particularly housework and gardening) a larger proportion received or wanted more help than they had stated in the initial survey. Over 30 per cent received or wanted more help with one or more of the activities and 11 per cent with 2 or more of them. The number of people receiving or wanting more help was greater than the number receiving or wanting less help. The attributes of those people wanting more help are contrasted to those of the people wanting less help in appendix table V. Further analysis of the data showed, not surprisingly, that in both surveys proportionately more of the men and women living alone expressed needs for help, but it also showed that more of the married women living with spouses or young children expressed need for help with cooking.

The changes discussed in this section and that below reflect not only changes in disability but also changes in circumstances, in expectations and in the help that was given. Thus, it is possible for a person who has become more physically disabled to be classified as 'improved' because he has less need for help with domestic tasks as he or she has given up an independent household and moved to live with a son or daughter. Conversely, a person whose physical disability has not changed, but who now receives more help because services have been made available, will be classified as having 'deteriorated'.

Social Contacts

Between the two surveys the spouses of 20 people (12 women and 8 men) died, and 2 widows remarried. Only 20 people changed to living alone (mostly as a result of bereavement) and 5 who had lived alone changed to living with others. In both surveys over three quarters of the 484 handicapped people had friends and neighbours that helped, about one third had daily visitors and a further two fifths had visitors once or twice a week. About 60 per cent had relatives living nearby and almost 70 per cent had friends or relatives on the telephone. Almost one third attended clubs or day centres. Tables 13 and 14 show the changes in the stated number of social contacts of the handicapped people. On balance more people had more rather

TABLE 11

Reported Changes in Managing Household Activities at Follow-up Survey

(per cents in brackets across rows)

Activity	Manage without help in both surveys	At follow-up survey		
		Less help received or needed	Same help required	More help received or needed
Males (n = 176)				
Shopping	76 (43.2)	35 (19.9)	38 (21.6)	27 (15.3)
Housework	77 (43.8)	24 (13.6)	53 (30.1)	22 (12.5)
Cooking	119 (67.6)	22 (12.5)	19 (10.8)	16 (9.1)
Gardening	129 (73.3)	11 (6.2)	18 (10.2)	18 (10.2)
Females (n = 308)				
Shopping	88 (28.6)	38 (12.3)	129 (41.9)	53 (17.2)
Housework	85 (27.6)	28 (9.1)	143 (46.4)	52 (16.9)
Cooking	192 (62.3)	39 (12.7)	38 (12.3)	39 (12.7)
Gardening	204 (66.2)	23 (7.5)	40 (13.0)	41 (13.3)
Males and Females (n = 484)				
Shopping	164 (33.9)	73 (15.1)	167 (34.5)	80 (16.5)
Housework	162 (33.5)	52 (10.7)	196 (40.5)	74 (15.3)
Cooking	311 (64.3)	61 (12.6)	57 (11.8)	55 (11.4)
Gardening	333 (68.8)	34 (7.0)	58 (12.0)	59 (12.2)

TABLE 12

Reported Changes in Need or Dependency on Others for Household Activities at Follow-up Survey

Changes in number of household tasks for which help was received or needed	Males		Females		Total	
Fewer tasks:- -3 to -4	5	(2.9)	6	(1.9)	11	(2.3)
-2	18	(10.2)	14	(4.5)	32	(6.6)
-1	27	(15.3)	48	(15.6)	75	(15.5)
No change, no need	48	(27.3)	38	(12.3)	86	(17.8)
No change, same amount of service or need	32	(18.2)	99	(32.1)	131	(27.1)
More tasks: +1	27	(15.3)	66	(21.4)	93	(19.2)
+2	15	(8.5)	27	(8.8)	42	(8.7)
+3 to +4	4	(2.3)	10	(3.2)	14	(2.9)
Total	176	(100)	308	(100)	484	(100)

Note: In this table a person receiving or needing less help with 1 task but more with another, would count as 'no change same amount needed', a person requiring less help with 1 task but more with 2 others would count as requiring more help with 1 task, etc.

than fewer contacts; but there were substantial numbers of people reporting a lower frequency of visiting and less contact with clubs and day centres. Some of this loss of social contact could reflect increasing frailty of the respondent and in some cases of the visitor. A smaller percentage of the people living alone (31.5 per cent) compared to those living with others (39.2 per cent) had increased the number of contacts between the surveys, but the same proportion (30 per cent) of each group reported less contacts. In the initial survey, people living alone had had more outside contacts than the others, so their opportunity for any increase was less. Of the 51 people in the initial survey who only had one social contact or none, 39 had 2 or more contacts at the time of the follow-up survey. Of the 104 people with self-care scores of 12 or more, 24 had increased the number of contacts between the surveys, for 18 the number had decreased, for the remaining 62 there had been little change (appendix table Vl).

TABLE 13

Number of Social Contacts* in Initial and Follow-up Surveys

Initial survey number of contacts	Follow-up survey - number of contacts							Total
	6	5	4	3	2	1	None	
6	22	14	5	1	1	-	-	43 (8.9)
5	18	52	21	14	5	2	1	113 (23.3)
4	5	28	26	22	9	5	2	97 (20.0)
3	5	17	27	39	19	11	2	120 (24.8)
2	-	6	11	18	16	6	3	60 (12.4)
1	-	7	5	12	7	7	1	39 (8.1)
None	-	-	2	-	6	3	1	12 (2.5)
Total	50 (10.3)	124 (25.6)	97 (20.0)	106 (21.9)	63 (13.0)	34 (7.0)	10 (2.1)	484 (100.0)

*Contacts with relatives living nearby, relatives living nearby and helping, friends and neighbours helping, relatives and friends on the 'phone, frequent visitors and contact with clubs.

TABLE 14

Overall Changes in Social Contacts of 165 Handicapped Persons Living Alone and of the 319 Handicapped Persons Living with Others

	Alone	Not alone	Total
More contacts:			
4	2 (1.2)	7 (2.2)	9 (1.9)
3	5 (3.0)	11 (3.4)	16 (3.3)
2	14 (8.5)	37(11.6)	51(10.5)
1	31(18.8)	70(21.9)	101(20.9)
Sub-total	52(31.5)	125(39.2)	177(36.6)
No change, full contact	12 (7.3)	10 (3.1)	22 (4.5)
No change, same contact	52(31.5)	89(27.9)	141(29.1)
Fewer contacts:			
1	29(17.6)	54(16.9)	83(17.1)
2	16 (9.7)	26 (8.2)	42 (8.7)
3	2 (1.2)	11 (3.4)	13 (2.7)
4	2 (1.2)	3 (0.9)	5 (1.0)
5	-	1 (0.3)	1 (0.2)
Sub-total	49(29.7)	95(29.8)	144(29.8)
Total	165 (100)	319 (100)	484 (100)

Employment

The vast majority of the survey population were above retirement age, some were children and some were housewives aged less than 60 years who were not seeking paid employment. The numbers in employment were, therefore, small. Thirty four of the 484 people were employed at the time of the initial survey and 43 were classed as permanently unfit for employment on account of disability (table 15). At follow-up, 26 of the 34 employed people were still in employment, and 1 of the 'permanently disabled' and 8 of the retired or not-seeking employment group had paid employment. Three people who had been in employment were now classed as 'permanently disabled' and 5 had retired from employment.

TABLE 15

Changes in Employment Status at Follow-up Survey

Status at initial survey	Status at follow-up survey				Total
	Employed (full or part-time)	Temporarily sick or unemployed	Permanently disabled	Retired or other	
Employed (full or part-time)	26	-	3	5	34
Temporarily sick or unemployed	5	1	1	2	9
Permanently disabled	1	1	31	10	43
Retired or other	8	-	5	385	398
Total	40	2	40	402	484

CHANGES IN COMBINED GROUPS OF ACTIVITIES

It is to be expected that, with increasing difficulty in mobility and in hearing, social activities outside the home might be curtailed. Next, as mobility and physical activity become restricted, so bathing, gardening, shopping and housework will become increasingly difficult, and then some aspects of personal care leading, in time, to some dependency on others. It is not suggested that there is always a steady progression of loss of function in the order set out above. In fact there are many exceptions, for example, an early difficulty experienced by many people in cutting toe-nails (Warren, 1974), and some disabling conditions will only limit quite defined functions and others may catastrophically and suddenly limit many activities. Because of these many exceptions it is better to look at changes in combined groups of activities as is done in this section.

It has already been seen that there were substantial numbers of people showing 'improvement' in functions within a group of activities and somewhat larger numbers showing deterioration (tables 10 - 15). To what extent did those people showing these changes within one group of activities also show them in other groups? In answering this question more stringent criteria of 'improvement' and 'deterioration' have been used. The choice of scale or score was largely determined by the number and content of the questions and their yield. The decision to include changes as substantial or minor was taken by the evaluation of questions and replies and the distribution of changes. One change or its equivalent in points of scores was mostly excluded. The exceptions were: changes in employment status, household status (living alone), and household tasks where all changes were counted. The variables and scales used are set out in appendix table V11.

Deterioration and Improvement

Table 16 shows the relationship between improvement and deterioration. Only 80 (16 per cent) of the 484 handicapped people reported no change in either direction in ability to cope in the four groups of activities; 110 (23 per cent) reported improvement only, and 172 (36 per cent) reported only deterioration. One hundred and twenty two

(25 per cent) reported improvement in some activities and deterioration in others; about half of these people reported only one change in each direction. These findings emphasise that the state of 'being handicapped' is a dynamic and not a static situation. Some of the complexities of the inter-play between the nature and course of the medical condition underlying disability and the social and environmental factors are apparent when details of those people who 'deteriorated' and of those who 'improved' in at least three of the groups of activities are examined.

Functional Deterioration

Table 17 sets out the number of people who had reported deterioration in any one or more of the groups of activities selected. Of the 484 people, 294 (61 per cent) had more difficulties in one or more of the groups, and 190 (39 per cent) had no more or fewer difficulties. The majority (63 per cent) of the 294 people whose difficulties had increased between the surveys were experiencing more difficulty in only one of the four groups of activities examined, and the majority of these related to domestic tasks. Ninety three people experienced more difficulties in two of the groups combined (the majority being in mobility and domestic tasks), 16 people had more difficulties in three groups (half being in self-care, mobility and domestic tasks) and only 1 person in all four groups. The person whose functions deteriorated in all four groups was a man aged 73 suffering from arthritis, and his arthritis had become more severe. Of the 16 people who had deteriorated in three of the groups of activities, 4 died within a few months of the follow-up survey (2 from a stroke, one from cancer and one from senility), 6 (including 2 who died subsequently) had had serious intervening illnesses between the surveys (3 strokes, 3 with cancer), one had become 'senile' (aged 83), and there were three children (one each with Down's syndrome, cerebral palsy and autism), who had become a greater burden to the family. The main diagnoses among the remainder of this group were arthritis and senility. There was one person with multiple sclerosis. In general, deterioration in terms of function tended to be associated with the onset of a new illness, or progression of a chronic condition rather than a change in social circumstances.

TABLE 16

Numbers of Handicapped Persons showing Deterioration and Improvement in Different Groups and Combinations of Activities

	Total	No deterioration	Function with deterioration in one group only				Deterioration in two groups	Deterioration in three or four groups
			Self-care	Mobility	Household tasks or employment	Social contacts or change to living alone		
TOTAL	484	190	39	36	75	34	93	17
No improvement	252	80	19	16	52	9	64	12
Improvement in one group only:-								
Self-care	28	12	-	3	3	4	6	-
Mobility	20	10	2	-	4	1	3	-
Household tasks or employment	78	37	10	9	1	11	8	2
Social contacts or no longer living alone	37	13	4	-	8	-	9	3
Improvement in two groups of activities	48	24	3	8	5	6	2	-
Improvement in three or four groups of activities	21	14	1	-	2	3	1	-

Functional Improvement

Two hundred and thirty two people stated they were managing with less help or did not want as much help as in the initial survey in one or more of the groups of activities (table 18). Only 69 (14 per cent) improved in two or more groups of activities and only 14 of these had improved in both self-care and mobility; the remainder either had more opportunities for social contacts, had changed to living with others, or were managing without help in one or other of the household tasks. One person reported 'improvement' in all of the four groups of activities. This person was a woman aged 79 years who had angina, arthritis, poor vision and difficulty in hearing at the time of the first survey. She reported the same conditions at follow-up, but her angina was less troublesome and she was more active and had more social contacts. Detailed examination of the attributes of the 20 people who had improved in three groups of activities do not show any shared consistent changes. Three of the group died within a few months of the follow-up survey from intervening illnesses, 4 of the group (including 2 who died) had had intervening illnesses between the surveys. There were, therefore, fewer deaths and episodes of intervening illness among those who improved in three groups of activities than among those who deteriorated. In the group who improved there were 2 children (both mentally subnormal with physical disabilities), 1 was attending a special school at the time of the follow-up survey having been at home at the initial survey, and the other was reported at the follow-up survey to be 'now only slightly sub-normal'; she was still attending the special school but, presumably, her parents had become more reconciled to her condition. Two other cases illustrate the impact of help given: a paraplegic man, aged 61 years, had considerable help from the social services department between the surveys and reported substantial increased activity at follow-up; in the second case a woman of 78 years had an operation for osteo-arthritis of the hip which had enabled her to become more mobile. At the same time, however, this last case illustrates some of the difficulties in evaluation, for shortly after the follow-up interview, this person died from a cerebral thrombosis.

TABLE 17

Numbers of Handicapped People showing Deterioration in Groups of Activities

(Per cent in brackets)

Deterioration in:-	Group of Activities				Total persons
	Self-care*	Mobility*	Domestic* tasks or employment	Social contacts*	
One group	39	36	75	34	184 (38.0)
Two groups:					
	14	14			14
	13		13		13
		30	30		30
	5			5	5
		8		8	8
			23	23	23
Sub-total					93 (19.2)
Three groups:					
	8	8	8		8
	2	2		2	2
	2		2	2	2
		4	4	4	4
Sub-total					16 (3.3)
Four groups	1	1	1	1	1 (0.2)
Total deteriorated	84	103	156	79	294 (60.7)
No change or better					190 (39.3)
Total					484 (100.0)

*See text for explanation.

TABLE 18

Improvements in Combinations of Different Groups of Activities

(Per cent in brackets)

Improvement occurred in:-	Group of Activities				Total persons
	Self-care*	Mobility*	Household tasks or employment*	Social contacts*	
One group only	28	20	78	37	163 (33.7)
Two groups	6	6			6
	10		10		10
		5	5		5
	6			6	6
		3		3	3
			18	18	18
Sub-total					48 (9.9)
Three groups	4	4	4		4
	3	3		3	3
	6		6	6	6
		7	7	7	7
Sub-total					20 (4.1)
Four groups	1	1	1	1	1 (0.2)
Total improved	64	49	129	81	232 (47.9)
No change or worse					252 (52.1)
Total					484 (100.0)

*See text for explanation

CHANGING NEEDS FOR AIDS AND SERVICES

The concept of need is as relative as that of handicap. For the purposes of this study the definitions of need as suggested by the World Health Organization (1971) have been used. Perceived need is the need for services experienced by the individual and which he or she is prepared to acknowledge; in this study, perceived need was need acknowledged in response to questions asked by the interviewer. Professionally defined need is the need for services recognised by a professional person concerned with the services; it may exceed or be less than perceived need. No assessments of need by professional people were made for the purposes of either survey in this study, although, of course, the professional people who visited persons referred to them as a result of the initial survey would have carried out professional assessments. The data given below refer only to perceived needs recorded in response to questions during the assessment interviews.

Provision of Services

The Chronically Sick and Disabled Persons Act, 1970 gave many special responsibilities to local authorities in respect of handicapped people. The authorities, through their Social Services Departments, can provide:-

(a) The professional services of social workers, occupational therapists and others in the home.

(b) The home-help service, meals-at-home, and help with gardening, window cleaning, etc.

(c) A range of aids, including personal aids for bathing, dressing, eating, cooking, kitchen fitments, mobility aids, hoists, and special clothing. (The health authorities can provide nursing aids and some equipment and aids concerned with daily living and incontinence, and are sometimes responsible for laundry services.)

(d) Wireless, television, library and similar recreational facilities in the home.

(e) Telephone and any special equipment necessary for its use (usually this means the cost of installation and rental).

(f) Travelling facilities.

(g) Holidays.

(h) Recreational facilities outside the home and assistance in participating in educational activities.

(i) Assistance in carrying out adaptations to the home, such as making ramps, fitting stair lifts and adapting toilets.

(j) Provision of day centres and clubs.

In addition the local housing authorities must have regard to the special needs of disabled people, and many now provide specially built houses, flats or bungalows.

The health authorities are, obviously, concerned with the medical care of disabled people, provision of artificial limbs and with all aspects of medical rehabilitation. The health authorities provide the home nurses and health visitors in the home. They supply powered vehicles, wheelchairs, hearing aids, aids to vision and some other aids (e.g. possum). They may provide domiciliary physiotherapy (Partridge and Warren, 1977).

Financial help is the concern of the Department of Health and Social Security. The main government department responsible for the employment and training of disabled people is the Manpower Services Commission.

A large number of voluntary bodies and self-help organisations assist many disabled people in a wide variety of ways, including acting in some places as the agents of the local authorities.

Perceived Needs in the Surveys

The needs enquired about in the study reported here are mainly those which are the responsibility of the social services and housing departments of the local authorities, although questions were also asked

about contacts with general practitioners, home nurses and health visitors, employment (already discussed) and services provided by voluntary organisations and direct voluntary effort. In addition to the 484 handicapped people who had assessment interviews in both the initial and follow-up surveys, a further 275 people had assessment interviews during the follow-up survey, as they then came within the criteria for such interviews (see page 61). Thus data in this section of the report refer to both groups of people who had assessment interviews, but are presented in relation to each group separately so that it is possible to distinguish between the needs of those who had originally been referred to the Handicap Unit (see page 1) and the needs of those newly categorised as handicapped in the follow-up survey.

Data about the perceived needs of the original cohort of handicapped people have been presented and discussed in detail in the report of the initial survey (Warren, 1974). In the follow-up survey, the percentages of both groups of handicapped people expressing a need for a particular service, aid or adaptation were generally lower than in the initial survey, and the percentages already having such help were generally higher, thus reflecting at least some of the impact of the efforts that had been made by the Handicap Unit and others (tables 19 and 20). Although in the follow-up survey the number of people expressing a need for most of the services is less than it was among the same group of people at the initial survey, the total numbers (taking into account the needs of the group assessed for the first time at the follow-up survey) are substantial.

Meeting Needs for Aids, Adaptations and Services

The numbers of handicapped people with particular needs recorded in the initial survey and whose needs were met at the follow-up survey are shown in column one of table 21 and in appendix tables V11l to X. Table 21 also shows the numbers of needs which were met between the surveys, but which had not been recorded at the initial survey. Some of these latter needs would be 'professionally defined needs', i.e. the need for services arising as a result of an occupational therapist or other professional person visiting in response to some other need. Some of these needs would have arisen as a result of changes in circumstances in the period between the surveys. The professional assessment for aids and adaptations by the occupational therapists had an impact

TABLE 19

Perceived Needs of Handicapped People for Personal Aids at Initial and Follow-up Surveys

	Needs assessed at both surveys (n=484)				Needs assessed at follow-up only (n=275)*	
	I Initial survey		II Follow-up survey			
	Perceived need	Already have	Perceived need	Already have	Perceived need	Already have
	(%)	(%)	(%)	(%)	(%)	(%)
Hoist	6 (1.2)	-	1 (0.2)	4 (0.8)	-	-
Support bar	20 (4.1)	1 (0.2)	6 (1.2)	5 (1.0)	4 (1.5)	1 (0.4)
Widen W.C. doors	2 (0.4)	1 (0.2)	-	1 (0.2)	-	-
Raise W.C. seat	16 (3.3)	7 (1.4)	12 (2.5)	35 (7.2)	1 (0.4)	4 (1.5)
W.C. rails	25 (5.2)	15 (3.1)	19 (3.9)	51(10.5)	4 (1.5)	7 (2.5)
Bath rails	87 (18.0)	47 (9.7)	37 (7.6)	98(20.2)	44 (16.0)	46 (16.7)
Sitz bath	4 (0.8)	1 (0.2)	1 (0.2)	1 (0.2)	1 (0.4)	-
Shower	36 (7.4)	6 (1.2)	16 (3.3)	10 (2.1)	11 (4.0)	6 (2.2)
Bath seat	59 (12.2)	37 (7.6)	17 (3.5)	104(21.5)	30 (10.9)	35 (12.7)
Shoe & stocking aid	37 (7.6)	10 (2.1)	23 (4.7)	27 (5.6)	12 (4.4)	3 (1.1)
Special clothing or advice	35 (7.2)	4 (0.8)	16 (3.3)	7 (1.4)	3 (1.1)	2 (0.7)
Feeding gadgets	10 (2.1)	2 (0.4)	15 (3.1)	15 (3.1)	-	1 (0.4)
Kitchen aids** or advice	44 (9.1)	8 (1.6)	26 (5.4)	35 (7.2)	9 (3.3)	4 (1.4)
Fit stair rail	30 (6.2)	n.a.	24 (5.0)	17 (3.5)	8 (2.9)	5 (1.8)
Ramp	26 (5.4)	6 (1.2)	9 (1.9)	14 (2.9)	1 (0.4)	4 (1.5)
Sick room equipment	16 (3.3)	11 (2.3)	9 (1.9)	29 (6.0)	4 (1.4)	6 (2.2)
Disposable pads	10 (2.1)	2 (0.4)	18 (3.7)	28 (5.8)	1 (0.4)	1 (0.4)
Laundry service	9 (1.9)	2 (0.4)	6 (1.2)	4 (0.8)	-	-

*See text for explanation.

**Change in coding in survey II.

TABLE 20

Perceived Needs of Handicapped People for Other Services, at Initial and Follow-up Surveys

	Needs assessed at both surveys (n=484)				Needs assessed at* follow-up only (n=275)	
	I Initial survey		II Follow-up survey		Follow-up survey	
	Need	Already have	Need	Already have	Need	Already have
	(%)	(%)	(%)	(%)	(%)	(%)
Chiropody - total	93 (19.2)	129 (26.7)	53 (10.9)	159 (32.8)	44 (16.0)	47 (17.1)
of which: at home	65 (13.4)	59 (12.2)	30 (6.2)	91 (18.8)	22 (8.0)	12 (4.4)
at clinic	28 (5.8)	70 (14.5)	23 (4.7)	68 (14.0)	22 (8.0)	35 (12.7)
Bath attendant	7 (1.4)	8 (1.7)	13 (2.7)	53 (10.9)	-	7 (2.5)
Day/night attendant	11 (2.3)	1 (0.2)	5 (1.0)	-	-	-
Short-term admission	15 (3.1)	1 (0.2)	16 (3.3)	7 (1.4)	4 (1.4)	-
Telephone	157 (32.4)	167 (34.5)	106 (21.9)	237 (49.0)	78 (28.4)	115 (41.8)
Friendly visit	80 (16.5)	16 (3.3)	69 (14.3)	14 (2.9)	24 (8.7)	2 (0.7)
Meet others in clubs	77 (15.9)	n.a.	48 (9.9)	92 (19.0)	21 (7.6)	48 (17.5)
Holiday	134 (27.7)	22 (4.5)	90 (18.6)	34 (7.0)	40 (14.5)	11 (4.0)
Mobile library	71 (14.7)	8 (1.7)	64 (13.2)	10 (2.1)	39 (14.2)	1 (0.4)
Transport for:				***		***
Medical treatment	30 (6.2)	134 (27.7)	14 (2.9)	108 (22.3)	7 (2.5)	67 (24.4)
Other places**	31 (6.4)	n.a.	31 (6.4)	103 (21.3)	12 (4.4)	35 (12.7)

*See text for explanation.

**Transport needs: 3 places specified in both surveys. In the follow-up four more places were mentioned; this added 28 to the need but only 5 to those who already had transport. They are not included in this table.

***"No difficulty in getting to medical treatment".

both in meeting unperceived needs and in modifying perceived needs. The impact of the work of the Handicap Unit and others in the City to meet the needs of the handicapped people identified in the initial survey was substantial. A high proportion of the needs expressed during the initial survey had been met by the time of the follow-up survey and considerable additional help had been given. An example of this provision of help between the surveys are the increases and changes in sources of help with shopping, housework and cooking (appendix tables X1 and X11). People who reported getting help from the home help service increased by over 70 per cent.

In contrast to the high proportion of needs met among those needs which are the direct responsibility of the social services department, a relatively smaller proportion of some of the other needs were met. For example, unmet needs outnumbered met needs among people wanting voluntary visitors, help with gardening and window-cleaning (appendix table X111) and a mobile library service.

The provision of a telephone raised some different issues as there were strict criteria (living alone and unable to go out) of eligibility. So although a large number of telephones were supplied during the two years, almost as many were still desired.

It is probable that some handicapped people in agreeing that they would like a certain service or form of help did not sufficiently realise the consequences whether of disturbance or costs to themselves. For example, 134 people said they would like a holiday arranged at the time of the initial survey, but at follow-up over half had changed their minds, over one third still wanted one and under one tenth had been away on holiday. Three quarters of the 94 people who had expressed an interest in sheltered housing or residential accommodation had changed their minds by the time of the follow-up survey, 18 per cent still wanted to move and only 6 per cent had been moved (table 21).

Met and Unmet Needs by Changes in Capabilities

The needs discussed in the previous pages are as heterogenous as the group of people interviewed. They also vary greatly in cost, administrative arrangements and impact. Nevertheless it is useful to take an overall view of the need for services and aids and to relate

TABLE 21

Needs Met and Needs No Longer Present at Follow-up Survey

(number of persons - n=484)

	Needs met		Needs no longer present		Needs unmet
	Perceived in I (1)	Not perceived in I (2)	No more difficulty (3)	Not wanted (4)	(5)
Hoist	1	3	-	5	-
Support bar	2	3	1	14	3
Widen W.C. doors	-	1	-	2	-
Raise W.C. seat	7	22	5	4	-
W.C. rails	7	33	9	8	1
Bath rails	31	40	6	35	15
Sitz bath	-	-	-	4	-
Shower	4	4	1	26	5
Bath seat	31	49	4	23	1
Shoe and stocking aid	9	16	7	13	8
Special clothing, etc.	2	4	7	20	6
Feeding gadgets, etc.	2	12	3	3	2
Ramp	3	10	13	9	1
Bath attendant	5	43	-	2	-
Chiropody	28	21	29	11	25
Telephone**	61	15	26		70
Sickroom equipment	4	23	11		1
Disposable pads	3	24	6		1
Laundry	1	3	7		1
Day/night attendant	-	-	9		2
Short stay in home	3	3	10		2
Mobile library	2	6	35		34
Friendly visit	9	4	37		34
Holiday	12	18	74		48
Shopping	17	79	3		1
Housework	34	67	7		4
Cooking	7	54	3		-
Needs met by L.A. home-help	63		8		n.a.
Meals on wheels	1	18	4		-
Volunteer help with: Garden*	4	15	21		30
Window cleaning*	2	12	29		13
Lighting fires	-	2	7		-
Convey laundry	-	18	4		-
Move dustbin	-	13	8		-
Housing needs: Sheltered housing	6	7	71		17
Employment: Sheltered employment	3		15		4

Notes:

*Excluding needs met in II by private paid gardener or window cleaner (not asked in I).

**Telephone needs met : those who had acquired telephone since previous survey, whether privately or through the council or with other assistance.

Col.(2):needs met in addition to those perceived, after assessment by professional worker or by other means, e.g. informal, private or voluntary effort.

Cols. (1) + (3) + (4) + (5) = Needs perceived in initial survey.

total needs to other factors. In considering the data which follow, it should be remembered that, as mentioned previously, the number of aids or services provided ('met needs') was frequently larger than the number of services in which a handicapped person had expressed an interest during the initial survey, so that the total number of met needs, unmet needs and of needs no longer present exceeded the total number of needs perceived in the initial survey.

Handicapped people, who had 'deteriorated'* and those who had 'improved'* by the time of the follow-up survey, had perceived more needs at the initial survey than people who showed little change, but the differences are not statistically significant. Those people whose capabilities had deteriorated in more than one group of activities had more needs met and also had more new needs than the people whose capabilities had not changed or had improved; the differences are statistically significant. Those people whose needs had receded were more likely to have shown improvement (table 22).

The mean numbers of needs that were expressed in the initial survey, met, unmet, not mentioned or mentioned for the first time in the follow-up survey were related to all the main variables and attributes shown in table 1 and similar subsequent tables. It was found that the mean number of needs expressed initially was highest for people aged 50 to 64 years and not for the oldest age group (probably because this age group included all people with difficulty in self-care); for those people living with spouse and children, including grown-up children; and, as might be expected, for those with severe self-care and mobility problems in the initial survey. More of the needs of these same categories of people were met between the surveys, although those living alone had more of their needs met than people in any other category. A higher number of needs were met among people with severe deterioration in self-care, intervening hospitalisation or serious illness, and people in these categories expressed more new needs. Changes in mobility were less clearly associated with met or new needs. About one quarter of the needs expressed in the initial survey were still expressed at the follow-up survey; the proportion was higher for those with little or no difficulty in self-care or mobility, but there was little variation by age or household type. (Tables are available from the authors.)

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*For definitions of 'deteriorated' and 'improved' see page 39.

TABLE 22

Met and Unmet Needs by Changes in Capabilities

	No. of people	Mean number of needs					
		Expressed needs - I initial interview	Needs met[1]	Needs no longer present	Unmet needs	New needs	Expressed needs - II follow-up interview
For total group	484	2.89	1.86	1.40	0.74	1.15	1.89
'Deterioration'[2]			*			*	*
None	190	2.71	1.36	1.39	0.74	0.84	1.58
In one activity	184	2.87	1.97	1.34	0.64	1.24	1.87
In two or more activities	110	3.22	2.54	1.49	0.91	1.52	2.43
'Improvement'[2]				**			
None	252	2.67	1.80	1.22	0.76	1.15	1.90
In one activity	163	3.10	2.07	1.55	0.74	1.21	1.95
In two or more activities	69	3.16	1.86	1.70	0.68	0.99	1.67

Notes: [1] A number of needs were met in addition to those expressed.

[2] For explanation of terms see text page 39.

F - tests not significant except for: * $p < 0.001$

** $p = 0.027$

CONTACTS WITH SERVICES

The proportions of people who had had contact with their general practitioner during the month preceding interview were similar in the two surveys and in the follow-up survey among those newly assessed. At the follow-up survey a higher proportion of people were in contact with home nurses, home helps, chiropodists, social workers and occupational therapists (table 23), and therefore in contact with people who are in a position to observe changes and offer early help. In this connection, it is interesting to note that about the same proportions of those people who were assessed as 'handicapped' for the first time in the follow-up survey had contact with at least two of the services as had been observed among the handicapped people in the initial survey. The amount of self-perceived need among handicapped people in contact with one or more of the services was remarked on in the report of the initial survey (Warren, 1974), and the need for further education and collaboration between the services was stressed. The figures presented here (table 23) suggest that there was more collaboration between the health and social services, certainly in respect of referral of people in need, following the initial survey.

TABLE 23

Old and New Contacts with Services at Initial and Follow-up Surveys

Service	Needs assessed at both surveys (n=484)			Needs assessed at follow-up only (n=275)*
	I Initial survey	II Follow-up		
		Contact maintained	New contact	
	(%)	(%)	(%)	(%)
General practitioner, within previous month	172 (35.5)	94 (19.4)	83 (17.1)	107 (38.9)
Home nurse	51 (10.5)	40 (8.3)	45 (9.3)	16 (5.8)
Health visitor	47 (9.7)	12 (2.5)	26 (5.4)	17 (6.2)
Home help	77 (15.9)**	70 (14.5)	63 (13.0)	36 (13.1)
Chiropodist	58 (12.0)	46 (9.5)	40 (8.3)	8 (2.9)
Social worker	85 (17.6)	48 (9.9)	111 (22.9)	42 (15.3)
Occupational therapist	2 (0.4)	-	10 (2.1)	-
Meals on wheels	16 (3.3)	10 (2.1)	19 (3.9)	7 (2.5)
Club or day centre	152 (31.4)	113 (23.3)	55 (11.4)	85 (30.9)
Number of services in contact with above (including G.P.)				
None	124 (25.6)	91 (18.8)		88 (32.0)
1	177 (36.6)	134 (27.7)		97 (35.3)
2	106 (21.9)	116 (24.0)		59 (21.5)
3	54 (11.2)	71 (14.7)		19 (6.9)
4	16 (3.3)	43 (8.9)		7 (2.5)
5	4 (0.8)	15 (3.1)		4 (1.5)
6	2 (0.4)	12 (2.5)		1 (0.4)
7	1 (0.2)	2 (0.4)		-

*See text for explanation.

**Home help from record linkage.

HOUSING

Between the surveys 49 (10 per cent) of the 484 handicapped people assessed in both surveys and 33 (12 per cent) of the 275 people assessed only at follow-up had changed their accommodation. About the same proportion (26 per cent) of each group rehoused were rehoused in the local authority's sheltered accommodation, but a larger proportion (53 per cent) of those assessed in the initial survey were rehoused in the local authority's houses, flats or bungalows than of those assessed only at follow-up (39 per cent), more of whom moved to private accommodation (table 24). All six handicapped people who had lacked piped cold water at the time of the initial survey had this amenity at follow-up, but only 3 out of 35 people who originally lacked piped hot water, 6 out of 37 without a fixed bath and 7 out of 38 without an inside W.C. had these amenities at follow-up (table 25). Despite the lack of amenities, many of the handicapped people did not want to move house, and this applied also to many of those people who had difficulty getting about the house. At the time of the initial survey 29 per cent of 191 people with difficulties in getting about the house already had some adaptations, at follow-up the proportion had increased to 44 per cent of 175 people with these difficulties.

TABLE 24

People Who Moved Between Surveys and Needs for Rehousing in Initial Survey

	II Follow-up survey				
	Moved between surveys to:				Total =100%
	Sheltered L.A.	Other L.A.	Private accommodation	All movers (%)	
All movers assessed both times	13	26	10	49 (10.1)	484
Movers assessed second time only	9	13	11	33 (12.0)	275
I Initial survey					
Had difficulty getting about:-					
Would consider move if adaptation impossible	2	10	1	13 (31.0)	42
Would not consider move	1	2	2	5 (5.3)	94
House already adapted	1	3	1	5 (9.1)	55
Lacked basic amenities	-	3	-	3 (6.0)	50
On housing list	5	8	3	16 (66.7)	24
Would like sheltered or residential accommodation	6	4	2	12 (12.8)	94

TABLE 25

Lack of Amenities at Initial and Follow-up Surveys

	Needs assessed both times (n=484)		Needs assessed at follow-up only (n=275)
	I Initial survey	II Follow-up survey	
	(%)	(%)	(%)
LACK OF AMENITIES:			
Piped cold water	6 (1.2)	-	2 (0.7)
Piped hot water	35 (7.2)	32 (6.6)	14 (5.1)
Fixed bath	37 (7.6)	31 (6.4)	13 (4.7)
Inside W.C.	38 (7.8)	31 (6.4)	13 (4.7)
DIFFICULTIES GETTING ABOUT INSIDE HOUSE:	191 (39.5)	175 (36.2)	72 (26.2)
Would move house	42 (8.7)	26 (5.4)	16 (5.8)
Would not move even if house cannot be adapted	94 (19.4)	72 (14.9)	28 (10.2)
Already have adaptations	55 (11.4)	77 (15.9)	28 (10.2)

PERCEIVED BENEFIT

At the end of the interview in the follow-up survey, respondents were asked whether they felt that they had had any benefit or help from the developments which arose out of the first survey. Forty two per cent of those people whose needs were recorded at the initial survey stated that they considered the survey and subsequent contact with the social services department had been of help, 40 per cent had not needed any help, and 18 per cent thought that the survey had not been helpful - including those who refused help (table 26). These figures refer only to those people in the original survey who were still living in private households in the City at the time of the follow-up study. Obviously, they do not record any benefits that might have been acknowledged by respondents or their relatives during crisis periods and periods of increasing dependency before a severely disabled person is admitted to a hospital or home or dies. These are often periods when the services are intensively involved (Cartwright et al., 1973) and no evaluation of perceived benefit can be complete without taking these episodes into account. To evaluate the benefit and impact of the services would require data obtained from a complex prospective survey.

TABLE 26

Perceived Benefit or Help Derived from Surveys
(Persons, per cent in brackets)

	Assessed in both surveys	Assessed at follow-up only
Has been of help	203 (41.9)	51 (18.5)
No help needed	194* (40.1)	174 (63.3)
Not helpful or help refused	87 (18.0)	50 (18.2)
Total	484 (100)	275 (100)

*Including 3 'don't knows'.

PREDICTORS OF INCREASING SEVERITY OF DISABILITY

Are there attributes and factors more common among those disabled people whose capabilities deteriorate markedly and whose needs increase substantially than among the remainder? In this section, the data from the surveys are examined to see if any answers can be given to this question. Unfortunately, it was not practicable to carry out assessment interviews with all people identified as impaired in the initial survey, nor with all of those still in private households at the time of the follow-up; nor at the time of the follow-up could another survey of every household in the City be carried out to find those people who had become impaired (and perhaps handicapped) since the initial survey. The resources available for the initial survey only permitted assessment interviews with about half of the original number of impaired people, and were similarly limited in the follow-up survey.

Impaired Only or Handicapped

The intention of categorising all those people, who as a result of the household survey had identified themselves as probably having an impairment, into 'impaired only' or 'handicapped' (see page 9) was to enable efforts in further interviewing and in the delivery of services to be concentrated on those people most likely to need help. How successful was the initial division? It will be remembered that the basis of the categorisation was the presence of one or more heterogeneous attributes. These attributes were those recommended by Harris and Head (1971) and were based on Harris's experience and findings in the national sample survey (Harris, 1971). The lack of data from assessment interviews with the impaired-only people (who did not have these interviews) means an answer to the question posed can only be partial. What can be looked at are the attributes of those people who at the follow-up survey had either changed from 'impaired only' to 'handicapped' or vice versa, and the attributes of those people who were classified as 'handicapped' on account of the additional criteria introduced in the follow-up survey.

The group of handicapped people clearly contained more severely disabled and ill people than the group of impaired only people, for 18 per cent of the former died during the two years compared to 9

per cent of the latter, and 7 per cent of the former compared to 2 per cent of the latter were admitted permanently to an institution (table 3, page 18). The 82 people who were no longer classified as being handicapped at follow-up (under the original definitions) included proportionately fewer people over the age of 75 years, fewer with self-care scores of 12 or more, fewer with arthritis and fewer who were already known to various helping agencies compared to those who were still classed as handicapped. The 151 people (table 3) who were classified at follow-up for the first time as being handicapped (again, under the original definition) included proportionately more people aged 75 years or more, more women, and more who were already known to the agencies than among those who were still classified as impaired only (appendix table XlV). The data support the previous findings that it is the oldest age group who have substantial disability that are most likely to deteriorate.

Extending the Criteria for Eligibility for Assessment Interviews

The criteria for an assessment interview in the initial study were substantial restriction of mobility, self-care scores of 6 or more (or any score if aged 70 years or more) being bedfast or housebound, having poor eyesight or difficulty in hearing or, for children, attending a special school. However, during the initial study some of the interviewers reported that some apparently moderately severely disabled people did not seem to qualify for an assessment interview under these criteria and yet might need help. To test this point, additional criteria were piloted in a study carried out in Paddock Wood (Warren, 1976b) and these were used again in the follow-up study in Canterbury, but they were introduced in such a way that comparisons could still be made with the data from the initial survey. The additional criteria were registration as a physically handicapped person, difficulty observed by the interviewer in the person's hearing, the use of aids in self-care even if these eliminated all difficulties, the attainment of self-care scores of 1 or more whatever the age of the respondent and any person aged between 16 and 64 who was not employed full-time because of impairment or any housewife who considered she was unable to cope with all her housework because of impairment.

Using the categorisation criteria of the initial survey it was found that 82 people previously categorised as handicapped were re-classified as impaired only at follow-up, and that 151 people previously classified as impaired only were re-classified as 'handicapped'. Using the additional criteria it was found that 49 of the 82 people who changed status from handicapped to impaired using the earlier criteria, were classified as handicapped using the additional criteria, and that 124 of the 410 people who had earlier been classified as impaired were re-classified as handicapped (table 27).

By reason of these changes in eligibility for assessment interviews a further 124 people from the 'impaired only' group had assessment interviews at follow-up, and another 151 people from that group had assessment interviews by reason of the previous criteria. So there is information about the 'needs' at follow-up of a group of 275 people who had at the initial survey been classified as impaired only, this information is additional to that of the 484 people who had assessment interviews in both surveys.

Appendix tables XV to XV111 present the attributes of the 275 persons who had assessment interviews at follow-up only, showing separately the 151 people who had such interviews by reason of the original criteria and the 124 who became eligible for these interviews by reason of the new criteria. The former group of people included proportionately more older people, more living alone, more people with lower self-care scores originally, fewer people with diseases of the central nervous and circulatory systems, fewer who were registered as physically handicapped and who were attending clubs, more with services in attendance (except for the social workers). The group classified by the new criteria had fewer perceived needs except for employment, telephones, and certain aids and adaptations (bath rails, kitchen aids and gadgets). The total needs perceived by both groups (275 people) were lower than the needs perceived by the handicapped group in the first survey. Thus, the new criteria brought into the assessment stage of the survey proportionately more younger and more active people, but nevertheless, people with needs that the services might alleviate, provided contact is made.

TABLE 27

Numbers Re-categorised by Introduction of Additional Criteria for 'Handicapped Person'

Status in Initial Survey	Status at Follow-up			Totals
	Handicapped original definition	Handicapped new definition	Impaired only new definition	
Handicapped	435*	49*	33	517
Impaired only	151	124	286	561
Totals	586	173	319	1,078

*Had assessment interviews in both surveys - total = 484.

These findings suggest that the original criteria did exclude some disabled people, who could have been helped, and that the criteria are insufficiently precise indicators although they seem to have been satisfactory in identifying the more severely disabled.

Indicators of Special Need for Surveillance

Various attributes of the 110 handicapped people who had deteriorated in 2 or more of the 4 selected groups of activities were compared with those of the 184 disabled people who had deteriorated in one group and with those of the 190 who had either not deteriorated or had fewer difficulties at the time of the follow-up survey (appendix table XIX). The attributes present at the time of the initial survey which were proportionately more common among the impaired people who subsequently showed deterioration in a number of groups of activities than among the others were:- Severe restriction in self-care capabilities, old age, living with spouse only or, if widowed, with son or daughter, suffering from stroke or other diseases of the central nervous system or diseases of the respiratory system. The differences however were insufficient to predict the subsequent events that occurred, and the same applies to predictions of less marked deterioration or improvement. Whilst 28 per cent of the younger people showed improvement, 12 per cent of the elderly also improved, and the changes in capabilities of people with musculoskeletal diseases and respiratory diseases were not mainly in one direction, some showed improvement and some deterioration.

The data for the same attributes for the 69 handicapped people who improved in two or more groups of activities or had less demand for services, for 163 who improved in one group of activities and those who showed no improvement in any group are presented in appendix table XX. The findings are complementary to those described above.

The conclusion is that whilst some attributes occurred proportionately more frequently among those handicapped people whose needs subsequently increased and whose activities diminished, the attributes examined here did not by themselves serve to distinguish them from other handicapped people.

DISCUSSION AND CONCLUSIONS

Prevalence and Incidence of 'Handicap'*

For the purposes of planning services, it is necessary to estimate not only the extent and nature of needs for the services at any one point in time, but also the likely ebb and flow of needs over a period of time. Harris's survey (1971) and the surveys carried out under the terms of the Chronically Sick and Disabled Persons Act, 1970, showed the gaps between the provision of services and the estimated needs for them at the time of each survey. Substantial expansion of all social services for handicapped people was required if the needs revealed were to be met (Knight and Warren, 1978). The nature and amount of needs to be met are relative to the number of handicapped people in the community and estimates of both needs and of handicapped people will depend in part on the definitions used. In the initial Canterbury survey 1608 people were provisionally identified as impaired and 770 of these were later classified as handicapped. These figures give prevalence rates of 58 impaired people and 29 handicapped people, per 1000 of the population, after adjustment for non-contacts and non-response and using the definitions and methods of the Harris survey (table 28). These rates are in the lower half of the middle distribution of ranges of prevalence found in other surveys (ibid).

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*Definitions of prevalence and incidence rates:
For the purposes of comparison, analysis and prediction, a statement of the number of handicapped people in a locality or community has obvious shortcomings. One locality may have more handicapped people in it simply because its population is larger. To allow for differences in population size, the numbers must be expressed in the form of rates, e.g. the number of handicapped people per 1000 of the population, either prevalence rates or incidence rates. Prevalence can be expressed as point prevalence, which is the ratio of the number of persons, with a given characteristic, to the population at a particular point in time; or as period prevalence, which is the ratio of the number known to have existed, at any time during a specific period, to the mean of the population during the same period. The incidence rate is the ratio of the number of persons, with a given characteristic, that accrue during a specified period, to the mean of the population during the same period. Period prevalence is thus the sum of point prevalence and incidence. Most estimates of the numbers of handicapped people are expressed as point prevalence rates.

Whilst the present follow-up study does not provide any figures of incidence (another complete household survey to detect new cases of impairment and handicap would be necessary for that purpose), it does provide data about 'losses' and 'changes in status' from which an estimate of incidence can be made. During the time between the first and second surveys, 236 (14.7 per cent) of the original cohort of impaired people had died, 93 (5.8 per cent) had been admitted more or less permanently to hospital or old person's home and 83 (5.2 per cent) had left the City. Thus during a period of about 2¼ years, 412 (26 per cent) of the impaired people had died or left their original private household. It is probable that the number of impaired people in the community is rising (because of the increasing number of persons aged 75 years or more, among other factors); however, on the assumption of constant prevalence, a total household survey in 1974 should have at least enumerated as many impaired people as in 1972. Thus it can be estimated that the annual incidence of impaired people in the Canterbury community is at least of the order of 6 to 8 persons per 1000 of the whole population. Therefore in a town or health district with a population of 250,000 people, it could be expected that there are 14,500 impaired people, almost half of whom are handicapped in one way or another, and that each year at least another 1,625 people become impaired, and about one third of these people will be 'handicapped'.

Definitions of Impaired Only and Handicapped

The findings from the follow-up survey suggest that the definitions of 'handicapped' and 'impaired only' do not adequately reflect the division intended into one group of people likely to require services and another group which is unlikely to require them. In addition, by extending the criteria used in defining a 'handicapped' person, this study and a previous study (Warren, 1976b) have shown that a substantial number of people with previously undetected needs for services can be brought to light. These studies have also shown that among this group there are relatively more younger people than among the group identified using the more restricted criteria. Furthermore, the present study has shown that after a period of 2¼ years, 27 per cent of the group of people originally classified as 'impaired

TABLE 28

Prevalence of Impaired and Handicapped People by Age Groups

Age group	Population in private households*	Number of all impaired people***	Rate** per 1000 pop'n.	Number of handicapped people	Rate** per 1000 pop'n.
0 - 4	2174	15	8	9	5
5 - 14	4517	61	15	40	10
15 - 29	6658	61	10	25	4
30 - 49	6691	136	23	30	5
50 - 64	5497	304	62	108	22
65 - 74	2859	399	158	200	79
75+	1689	558	373	358	240
All ages	30,085	1,534	58	770	29

*From special tabulations of the 1971 Census of Population.

**After adjusting for non-contacts and non-response.

***All impaired people includes handicapped people; for definitions see text.

Source: Warren, 1974.

only' and who had screening interviews in the follow-up survey had deteriorated in their capabilities to the extent that they were classified, on the basis of the restricted criteria, as 'handicapped' and a further 22 per cent were so classified using the extended criteria. So almost half of the original impaired only group who were re-interviewed were re-classified at follow-up. This could mean that about 70 per cent (rather than the 50 per cent or so) of the impaired people in the population should have been referred after the initial study to the social services department for assessment.

The State of Being 'Handicapped'

This study has shown that during a period of about two years, not only is there a substantial change of persons who are impaired and handicapped, but also that there are substantial changes in the capabilities of individual handicapped people and in the activities they can manage. These latter changes are in both directions. Some people can do more for themselves or their social circumstances change so that less help is required, and some people inevitably experience diminishing physical abilities and require more help. Only 80 (16 per cent) of the 484 handicapped people interviewed in both surveys reported no change in either direction in ability to cope in any of the four groups of activities (self-care, mobility, household tasks and social contacts), whilst 110 (23 per cent) reported improvement only, 172 (36 per cent) deterioration and the remaining 122 (25 per cent) reported improvement in some activities and deterioration in others. To these changes must be added the apparent deterioration of 27 per cent of the original 'impaired only' group. It could be argued that some of these changes in performing activities are reflections of transitory changes in physical condition, current circumstances, and even attitudes of the respondents. This is true, but many of the changes were substantial enough to discount this as the complete explanation. Further, services for handicapped people are aimed at improving the quality of life of such people and, therefore, presumably, at meeting their perceived needs when their physical condition relapses or circumstances alter to their disadvantage, even if such changes are transitory.

Thus the experience of 'handicap' is one of a dynamic state, rather than of a static one. The person to be helped is best thought of as a 'person with handicaps' rather than a 'handicapped person'. The aim of the help, from whatever source, is to remove or alleviate the handicap, thereby enhancing the opportunities and independence of the person. The majority of people with handicaps have changing capabilities, some improving, some fluctuating and some deteriorating. It is only the minority of people with handicaps who have a physical impairment resulting in a situation which is static over many years. These findings of changes in 'handicap' status follow, in part, from the substantial proportion of impaired people who are aged 75 years or more, and from the fluctuating course and variable recovery that are associated with the commoner underlying medical conditions - arthritis, circulatory diseases, strokes, multiple sclerosis, Parkinsonism, and diseases of the respiratory system.

Changing Needs

Changes in the capabilities of the people followed up were reflected in changes in their needs for aids, gadgets, adaptations and other help from statutory and voluntary services. Again, the changes were in both directions, some people needing more help at follow-up than they did in the initial survey and some needing less. Our findings show a reasonable consistency between change in capabilities and change in perceived needs. Although some of the needs expressed in the initial survey, and not met in the intervening period, were no longer expressed in the follow-up survey, a considerable number of the expressed needs had been met.

The main conclusions must be therefore, (i) that the initial survey uncovered a large number of impaired people who had unmet needs that could be met through the provision of statutory and voluntary services; (ii) that many of these needs when expressed were assessed by professional staff and were satisfactorily met; (iii) that some unmet needs were still of concern to the handicapped people themselves 2 years later, and (iv) that many new needs had emerged by the time of the follow-up study.

Self-care, Neighbourhood-care and Surveillance

The task facing the community which decides to help the people with handicaps in their midst is considerable. Our survey suggests that the task becomes even greater when the on-going nature of the problem and the unpredictability of many of the changes in needs and of the persons requiring help are taken into account. Responsibility to meet many of the needs of people with handicaps and to advise them about services rests with social services departments by reason of the Chronically Sick and Disabled Persons' Act, 1970. The staff of these departments cannot be expected to carry out continuous, complete ascertainment of people with handicaps and then to combine this with routine surveillance of the people so found. Not only would this require substantial increases in staff and resources, but also it would be unacceptable to many of the people concerned. Furthermore, it would involve wasteful duplication of visits to many people.

Many people with handicaps, and many people recovering from serious illness, are able to cope and want to cope with their own problems by using services appropriate to their own perceptions of their needs, but find difficulty in doing this because of the complexity of the structure and administration of the services (Blaxter, 1976; Cunningham, 1977; Lee, 1978). Furthermore, the bureaucratic structure of the services can itself generate dependency upon them. Procedures for applying for help and gaining access to advice and advocacy need simplifying (Chapman, 1979; Keeble, 1979), and even more publicity needs to be given, and given frequently, about the great variety of help that can be provided by the social services, health services, social security, employment services, education services, housing departments and voluntary organisations. A possible innovation that could be tried out to simplify the use of services and to increase awareness of their scope, would be to bring together in one place, sources for help, assessment, advice, social contacts and advocacy on behalf of individuals and groups and place the centre for these activities under the management of representatives of people with handicaps and of the major service providers (Warren, 1972). Some experiments along these lines are already underway. By simplifying procedures and increasing knowledge of the help available more people with handicaps would themselves be able to bring their needs to the notice of

those who can help, and more friends and neighbours of such people would be able to advise and assist.

However, there are some people for whom it is insufficient to rely on self-reporting and help and advice from neighbours for appropriate and timely help. Goldberg et al. (1978) in reporting the results of monitoring the work of two long-term teams in an area office of a social services department stressed the need for continuing surveillance of some people with handicaps (although not necessarily by social workers) and the frequency of unanticipated events changing the circumstances and needs of the disabled person. Our survey has shown the significance of intervening episodes of serious illness in changing needs and the existence among the whole group of handicapped people of a sub-group, often elderly, severely disabled and living alone or with an elderly spouse who over the period of two years experienced markedly decreasing capabilities and hence would not be able to take much initiative in obtaining help. Furthermore, as Goldberg et al. state, the occasional social work visit is not the most appropriate means of providing support or of anticipating approaching crises.

More effort needs to be made to obtain the cooperation of doctors and nurses and to sharpen the awareness of all staff in the health and social services of the breadth of problems that may assail handicapped people, and of the range of possible solutions. Handicaps are too readily accepted not only by some disabled people, but also by professional people in contact with them (Firth, 1975). The present study has found that over a period of two years a quarter of all the impaired people had been admitted to hospital or had a serious illness. Just over a third of those who had both assessment interviews had had contact with their general practitioner in the preceding month and almost three quarters had been in contact with one or more of the domiciliary services. Harris (1971) found that the home nurses were in contact with over 40 per cent of people with severe disability; whilst our study showed that 41 per cent of the very severely disabled were in contact with the home nurses at follow-up, and 32 per cent with the home help. In both the follow-up study and the initial study, it was found that people in contact with any one of these services had substantial perceived needs for other services. A few experiments have

taken place in which social workers were attached to general practices as members of the primary care teams (e.g. Forman and Fairbairn, 1968; Goldberg and Neill, 1972). Further experiments are required, not only with the attachment of social workers, but also monitored attempts at imparting information to all members of the primary care team not forgetting the receptionist (Firth, 1975) and at improving communication and interaction between members of interdisciplinary primary health care teams (Feiger and Schmitt, 1979). Other fruitful experiments could be in the development of domiciliary physiotherapy services (Partridge and Warren, 1977).

Monitored Innovations - Action Research

The next steps, then, are to develop and monitor imaginative local schemes designed to:-

(i) Publicise services for people with handicaps, supplementing some of the national efforts in this field, for example, the B.B.C.'s programme 'Does He Take Sugar?'.

(ii) Inform disabled people and people with serious illness in a coherent and understandable way about the problems they may meet and the services available to help.

(iii) Extend the education of many professional workers who are already in contact with disabled and chronically sick people about the scope and possibilities of help available from other professional workers. The Open University course 'The Handicapped Person in the Community' is an example of a national effort to meet the proposed objectives.

(iv) Simplify and facilitate access to help, advice and advocacy to obtain help for people with handicaps and for their relatives and friends.

(v) Develop cooperation between health and social services and between statutory services and voluntary effort, whilst retaining responsibility for achievement and overall concern with the social services department.

Research resources should be given to evaluating promising innovations so that successful efforts can be copied or modified and applied to local situations.

Responsibility

Whilst it is essential that many more people in the community should be 'listening for the sounds and symptoms of need for help' (Titmuss, 1970) it is imperative, that ultimate responsibility is not diffused ambiguously among so many people in the community that it becomes lost altogether. Ultimate responsibility for the welfare of disabled people should remain with social services departments, where it was put by the Chronically Sick and Disabled Persons Act, 1970. However, the remit of these departments is very wide and its fulfilment needs the cooperation and collaboration of very many people and services. To quote Titmuss again (op. cit.):-

> "There cannot be one unambiguous goal for social work; human needs and desires are complex, interdependent, simultaneously rational and irrational, and often in conflict. Nor is there one unambiguous objective for social services. It would be terrifying if there were and if we thought there could be. All one is left with (or all I am left with) is the philosopher's thought that increasing sensitiveness to the claims of others (and claims which cannot be wholly satisfied on the material criteria of the market) is one important element in the definition of moral progress in society."

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Appendix Table I

Persons Reporting Episodes of Hospitalisation or Serious Illness between Surveys

(by age, sex, household type, incapacity and diagnosis)

			Hospitalised or seriously ill		Others re-interviewed	
			No.	(Col. %)	No.	(Col. %)
TOTAL			275	(100)	803	(100)
AGE:	Males	Under 15	9	(8.3)	32	(9.9)
		15 - 49	13	(12.0)	80	(24.8)
		50 - 64	38	(35.2)	70	(21.7)
		65 - 74	28	(25.9)	76	(23.5)
		75+	20	(18.5)	65	(20.1)
		Total	108	(100)	323	(100)
	Females	Under 15	8	(4.8)	16	(3.3)
		15 - 49	27	(16.2)	49	(10.2)
		50 - 64	44	(26.3)	95	(19.8)
		65 - 74	41	(24.6)	139	(29.0)
		75+	47	(23.1)	181	(37.7)
		Total	167	(100)	480	(100)
HOUSEHOLD I:		Alone	78	(28.4)	221	(27.5)
		With spouse only	78	(28.4)	238	(29.6)
		With spouse and children	53	(19.3)	133	(16.6)
		With children only	16	(5.8)	70	(8.7)
		With parents	32	(11.6)	95	(11.8)
		Other types	18	(6.5)	46	(5.7)
SELF-CARE SCORES I:		0	150	(54.5)	525	(65.4)
		1 - 4	58	(21.1)	131	(16.3)
		5 - 11	28	(10.2)	81	(10.1)
		12 or more	39	(14.2)	66	(8.2)
SELF-CARE SCORES II:		0	130	(47.3)	476	(59.3)
		1 - 4	60	(21.8)	156	(19.4)
		5 - 11	38	(13.8)	91	(11.3)
		12 or more	47	(17.1)	80	(10.0)
SELF-CARE CHANGE:		Better by: 5 or more	19	(6.9)	49	(6.1)
		Better by: 1 - 4	44	(16.0)	102	(12.7)
		No change	121	(44.0)	444	(55.3)
		Worse by: 1 - 4	52	(18.9)	130	(16.2)
		Worse by: 5 or more	39	(14.2)	78	(9.7)
SELECTED DIAGNOSES I:		Stroke	7	(2.5)	21	(2.6)
		Other CNS	26	(9.5)	59	(7.3)
		Circulatory	30	(10.9)	64	(8.0)
		Musculo-skeletal	65	(23.6)	189	(23.5)
		Fractures, injuries, operations	10	(3.6)	27	(3.4)
		Respiratory	12	(4.4)	30	(3.7)
		Endocrinal, metabolic	12	(4.4)	17	(2.1)
MAJOR NEW DIAGNOSES REPORTED:		Stroke	12	(4.4)	3	(0.4)
		Ischaemic and unspecified heart disease	20	(7.3)	31	(3.9)
		Musculo-skeletal	27	(9.8)	80	(10.0)
		Fractures	3	(1.1)	4	(0.5)
		Respiratory	13	(4.7)	26	(3.2)
		Endocrinal, metabolic	7	(2.5)	15	(1.9)
SELECTED DIAGNOSES II:		Stroke	19	(6.9)	19	(2.4)
		Other CNS	34	(12.4)	76	(9.5)
		Circulatory	56	(20.4)	121	(15.1)
		Musculo-skeletal	87	(31.6)	252	(31.4)
		Fractures, injuries, operations	19	(6.9)	60	(7.5)
		Respiratory	23	(8.4)	51	(6.4)
		Endocrinal, metabolic	17	(6.2)	30	(3.7)

NOTE: I = Initial survey
II = Follow-up survey

Appendix Table II

Changes in Difficulty in Self-Care

(by age, sex, household type, incapacity, diagnosis, etc. and contact with services in initial survey)

	Self-care score less by at least 5 points			Little change in self-care score			Self-care score more by at least 5 points			Total	
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL	68	(100)	(6.3)	893	(100)	(82.8)	117	(100)	(10.8)	1078	(100)
AGE under 15	5	(7.3)	(7.7)	52	(5.8)	(80.0)	8	(6.8)	(12.3)	65	(6.0)
15 - 49	11	(16.2)	(6.5)	151	(16.9)	(89.3)	7	(6.0)	(4.1)	169	(15.7)
50 - 64	17	(25.0)	(6.9)	206	(23.1)	(83.4)	24	(20.5)	(9.7)	247	(22.9)
65 - 74	16	(23.5)	(5.6)	238	(26.7)	(83.8)	30	(25.6)	(10.6)	284	(26.3
75 or over	19	(27.9)	(6.1)	246	(27.5)	(78.6)	48	(41.0)	(15.3)	313	(29.0)
SEX Male	23	(33.8)	(5.3)	365	(40.9)	(84.7)	43	(36.8)	(10.0)	431	(40.0)
Female	45	(66.2)	(7.0)	528	(59.1)	(81.6)	74	(63.2)	(11.4)	647	(60.0)
HOUSEHOLD											
Alone	15	(22.1)	(5.0)	257	(28.8)	(86.0)	27	(23.1)	(9.0)	299	(27.7)
Spouse only	14	(20.6)	(4.4)	260	(29.1)	(82.3)	42	(35.9)	(13.3)	316	(29.3)
Other types	39	(57.3)	(8.4)	376	(42.1)	(81.2)	48	(41.0)	(10.4)	463	(42.9)
SELF-CARE SCORES											
0	-	-	-	630	(70.5)	(93.3)	45	(38.5)	(6.7)	675	(62.6)
1 - 4	-	-	-	159	(17.8)	(84.1)	30	(25.6)	(15.9)	189	(17.5)
5 - 11	31	(45.6)	(28.4)	59	(6.6)	(54.1)	19	(16.2)	(17.4)	109	(10.1)
12 or more	37	(54.4)	(35.2)	45	(5.0)	(42.9)	23	(19.7)	(21.9)	105	(9.7)
HOUSEBOUND OR BEDFAST	16	(23.5)	(18.4)	46	(5.1)	(52.9)	25	(21.4)	(28.7)	87	(8.1)
IMPAIRED VISION	11	(16.2)	(6.3)	141	(15.8)	(80.1)	24	(20.5)	(13.6)	176	(16.3)
IMPAIRED HEARING	4	(5.9)	(4.9)	70	(7.8)	(85.4)	8	(6.8)	(9.7)	82	(7.6)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:											
CVA/Stroke	5	(7.3)	(17.9)	13	(1.4)	(46.4)	10	(8.5)	(35.7)	28	(2.6)
Other central nervous system	6	(8.8)	(7.1)	67	(7.5)	(78.8)	12	(10.3)	(14.1)	85	(7.9)
Circulatory	7	(10.3)	(7.4)	75	(8.4)	(79.8)	12	(10.3)	(12.8)	94	(8.7)
Musculoskeletal	31	(45.6)	(12.2)	183	(20.5)	(72.0)	40	(34.2)	(15.7)	254	(23.6)
Fractures, injuries, operations	5	(7.3)	(13.5)	24	(2.7)	(64.9)	8	(6.8)	(21.6)	37	(3.4)
Respiratory	3	(4.4)	(7.1)	36	(4.0)	(85.7)	3	(2.6)	(7.1)	42	(3.9)
HOSPITALISED SINCE FIRST SURVEY	19	(27.9)	(6.9)	217	(24.3)	(78.9)	39	(33.3)	(14.2)	275	(25.5)
ON AGENCY RECORDS AND REGISTERS	41	(60.3)	(12.0)	242	(27.1)	(70.8)	59	(50.4)	(17.2)	342	(31.7)

Appendix Table III

Attributes of Impaired Persons who Reported Deterioration of Vision or Hearing

(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

	Deterioration in Vision			Deterioration in Hearing		
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)
ALL RE-INTERVIEWED	70	(100)	(6.5)	68	(100)	(6.3)
AGE under 15	-	-	-	2	(2.9)	(3.1)
15 - 49	9	(12.8)	(5.3)	2	(2.9)	(1.2)
50 - 64	6	(8.6)	(2.4)	10	(14.7)	(4.0)
65 - 74	16	(22.9)	(5.6)	16	(23.5)	(5.6)
75 or over	39	(55.7)	(12.5)	38	(55.9)	(12.1)
SEX Male	17	(24.3)	(3.9)	26	(38.2)	(6.0)
Female	53	(75.7)	(8.2)	42	(61.8)	(6.5)
HOUSEHOLD						
Alone	32	(45.7)	(10.7)	23	(33.8)	(7.7)
Spouse only	12	(17.1)	(3.8)	30	(44.1)	(9.5)
Other types	26	(37.1)	(5.6)	15	(22.1	(3.2)
SELF-CARE SCORES						
0	45	(64.3)	(6.7)	46	(67.6)	(6.8)
1 - 4	15	(21.4)	(7.9)	16	(23.5)	(8.5)
5 - 11	7	(10.0)	(6.4)	-	-	-
12 or more	3	(4.3)	(2.9)	6	(8.8)	(5.7)
HOUSEBOUND OR BEDFAST	9	(12.8)	(10.3)	12	(17.6)	(13.8)
IMPAIRED VISION	-	-	-	12	(17.6)	(6.8)
IMPAIRED HEARING	8	(11.4)	(9.8)	-	-	-
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:						
CVA/Stroke	1)			2)		
Other central nervous system	6)	(10.0)	(6.2)	2)	(5.9)	(3.5)
Circulatory	8	(11.4)	(8.5)	7	(10.3)	(7.4)
Musculoskeletal	20)			15)		
Fractures, injuries, operations	1)	(30.0)	(7.2)	3)	(26.5)	(6.2)
Respiratory	3	(4.3)	(7.1)	2	(2.9)	(4.8)
HOSPITALISED SINCE FIRST SURVEY	19	(27.1)	(6.9)	15	(22.1)	(5.4)
ON AGENCY RECORDS AND REGISTERS	23	(32.9)	(6.7)	23	(33.8)	(6.7)

NOTE: For percentage base of rows see Appendix Table II

Appendix Table IV

Changes in Mobility of Handicapped People

(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

		Fewer difficulties (by at least two points)			Little change			More difficulties (by at least two points)			Total	
		No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL		49	(100)	(10.1)	332	(100)	(68.6)	103	(100)	(21.3)	484	(100)
AGE	under 15	7	(14.3)	(17.5)	27	(8.1)	(67.5)	6	(5.8)	(15.0)	40	(8.3)
	15 - 49	2	(4.1)	(4.3)	33	(9.9)	(70.1)	12	(11.6)	(25.5)	47	(9.7)
	50 - 69	10	(20.4)	(11.9)	64	(19.3)	(76.2)	10	(9.7)	(11.9)	84	(17.4)
	65 - 74	15	(30.6)	(11.6)	85	(25.6)	(65.9)	29	(28.2)	(22.5)	129	(26.7)
	75 or over	15	(30.6)	(8.2)	123	(37.0)	(66.8)	46	(44.7)	(25.0)	184	(38.0)
SEX	Male	28	(57.1)	(15.9)	112	(33.7)	(63.6)	36	(35.0)	(20.5)	176	(36.4)
	Female	21	(42.9)	(6.8)	220	(66.3)	(71.4)	67	(65.0)	(21.8)	308	(63.6)
HOUSEHOLD												
	Alone	12	(24.5)	(8.3)	106	(31.9)	(73.1)	27	(26.2)	(18.6)	145	(30.0)
	Spouse only	13	(26.5)	(9.7)	91	(27.4)	(67.9)	30	(29.1)	(22.4)	134	(27.7)
	Other types	24	(49.0)	(11.7)	135	(40.7)	(65.9)	46	(44.7)	(22.4)	205	(42.4)
SELF-CARE SCORES												
	0	13	(26.5)	(8.2)	121	(36.4)	(76.6)	24	(23.3)	(15.2)	158	(32.6)
	1 - 4	8	(16.3)	(6.8)	81	(24.4)	(69.2)	28	(27.2)	(23.9)	117	(24.2)
	5 - 11	11	(22.4)	(10.5)	70	(21.1)	(66.7)	24	(23.3)	(22.9)	105	(21.7)
	12 or more	17	(34.7)	(16.3)	60	(18.1)	(57.7)	27	(26.2)	(26.0)	104	(21.5)
HOUSEBOUND OR BEDFAST		14	(28.6)	(16.7)	49	(14.8)	(58.3)	21	(20.4)	(25.0)	84	(17.4)
IMPAIRED VISION		13	(26.5)	(8.0)	120	(36.1)	(74.1)	29	(28.2)	(17.9)	162	(33.5)
IMPAIRED HEARING		5	(10.2)	(6.8)	55	(16.6)	(74.3)	14	(13.6)	(18.9)	74	(15.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:												
	CVA/Stroke	4	(8.2)	(16.7)	14	(4.2)	(58.3)	6	(5.8)	(25.0)	24	(5.0)
	Other central nervous system	6	(12.2)	(16.7)	18	(5.4)	(50.0)	12	(11.6)	(33.3)	36	(7.4)
	Circulatory	3	(6.1)	(7.5)	28	(8.4)	(70.0)	9	(8.7)	(22.5)	40	(8.3)
	Musculoskeletal	12	(24.5)	(7.6)	104	(31.3)	(66.2)	41	(39.8)	(26.1)	157	(32.4)
	Fractures, injuries, operations	-	-	-	17	(5.1)	(81.0)	4	(3.9)	(19.0)	21	(4.3)
	Respiratory	5	(10.2)	(41.7)	6	(1.8)	(50.0)	1	(1.0)	(8.3)	12	(2.5)
HOSPITALISED SINCE FIRST SURVEY		23	(46.9)	(17.3)	82	(24.7)	(61.7)	28	(27.2)	(21.1)	133	(27.5)
ON AGENCY RECORDS AND REGISTERS		28	(57.1)	(11.3)	168	(50.6)	(68.0)	51	(49.5)	(20.6)	247	(51.0)

Appendix Table V

Changes in the Need for Help with Household Activities by Handicapped People

(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

	Less need			No change			More need			Total	
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL	118	(100)	(24.4)	217	(100)	(44.8)	149	(100)	(30.7)	484	(100)
AGE under 15	8	(6.8)	(20.0)	16	(7.4)	(40.0)	16	(10.7)	(40.0)	40	(8.3)
15 - 49	15	(12.7)	(31.9)	20	(9.2)	(42.6)	12	(8.0)	(25.5)	47	(9.7)
50 - 64	17	(14.4)	(20.2)	38	(17.5)	(45.2)	29	(19.5)	(34.5)	84	(17.4)
65 - 74	27	(22.9)	(20.9)	64	(29.5)	(49.6)	38	(25.5)	(29.5)	129	(26.7)
75 or over	51	(43.2)	(27.7)	79	(36.4)	(42.9)	54	(36.2)	(29.3)	184	(38.0)
SEX Male	50	(42.4)	(28.4)	80	(36.9)	(45.5)	46	(30.9)	(26.1)	176	(36.4)
Female	68	(57.6)	(22.1)	137	(63.1)	(44.5)	103	(69.1)	(33.4)	308	(63.6)
HOUSEHOLD											
Alone	26	(22.0)	(17.9)	76	(35.0)	(52.4)	43	(28.9)	(29.6)	145	(30.0)
Spouse only	30	(25.4)	(22.4)	68	(31.3)	(50.7)	36	(24.2)	(26.9)	134	(27.7)
With parents	12	(10.2)	(19.0)	27	(12.4)	(42.9)	24	(16.1)	(38.1)	63	(13.0)
Other types	50	(42.4)	(35.2)	46	(21.2)	(32.4)	46	(30.9)	(32.4)	142	(29.3)
SELF-CARE SCORES											
0	37	(31.4)	(23.4)	69	(31.8)	(43.7)	52	(34.9)	(32.9)	158	(32.6)
1 - 4	30	(25.4)	(25.6)	51	(23.5)	(43.6)	36	(24.2)	(30.8)	117	(24.2)
5 - 11	29	(24.6)	(27.6)	50	(23.0)	(47.6)	26	(17.4)	(24.8)	105	(21.7)
12 or more	22	(18.6)	(21.1)	47	(21.7)	(45.2)	35	(23.5)	(33.7)	104	(21.5)
HOUSEBOUND OR BEDFAST	23	(19.5)	(27.4)	42	(19.3)	(50.0)	19	(12.8)	(22.6)	84	(17.4)
IMPAIRED VISION	38	(32.2)	(23.4)	73	(33.6)	(45.1)	51	(34.2)	(31.5)	162	(33.5)
IMPAIRED HEARING	19	(16.1)	(25.7)	24	(11.1)	(32.4)	31	(20.8)	(41.9)	74	(15.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:											
CVA/Stroke	4	(3.4)	(16.7)	10	(4.6)	(41.7)	10	(6.7)	(41.7)	24	(5.0)
Other central nervous system	7	(5.9)	(19.4)	18	(8.3)	(50.0)	11	(7.4)	(30.6)	36	(7.4)
Circulatory	8	(6.8)	(20.0)	21	(9.7)	(52.5)	11	(7.4)	(27.5)	40	(8.3)
Musculoskeletal	46	(39.0)	(29.3)	66	(30.4)	(42.0)	45	(30.2)	(28.7)	157	(32.4)
Fractures, injuries, operations	4	(3.4)	(19.0)	11	(5.1)	(52.4)	6	(4.0)	(28.6)	21	(4.3)
Respiratory	2	(1.7)	(16.7)	8	(3.7)	(66.7)	2	(1.3)	(16.7)	12	(2.5)
HOSPITALISED SINCE FIRST SURVEY	34	(28.8)	(25.6)	53	(24.4)	(39.8)	46	(30.9)	(34.6)	133	(27.5)
ON AGENCY RECORDS AND REGISTERS	58	(49.1)	(23.5)	107	(49.3)	(43.3)	82	(55.0)	(33.2)	247	(51.0)

Appendix Table VI

Changes in Social Contacts of Handicapped People

(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

	More contacts (by at least two) No.	(Col.%)	(Row %)	Little change No.	(Col.%)	(Row %)	Fewer contacts (by at least two) No.	(Col.%)	(Row %)	Total No.	(Col.%)
TOTAL	76	(100)	(15.7)	347	(100)	(71.7)	61	(100)	(12.6)	484	(100)
AGE under 15	15	(19.7)	(37.5)	15	(4.3)	(37.5)	10	(16.4)	(25.0)	40	(8.3)
15 - 49	7	(9.2)	(14.9)	34	(9.8)	(72.3)	6	(9.8)	(12.8)	47	(9.7)
50 - 64	15	(19.7)	(17.9)	59	(17.0)	(70.2)	10	(16.4)	(11.9)	84	(17.4)
65 - 74	13	(17.1)	(10.0)	104	(30.0)	(80.6)	12	(19.7)	(9.3)	129	(26.7)
75 or over	26	(34.2)	(14.1)	135	(38.9)	(73.4)	23	(37.7)	(12.5)	184	(38.0)
SEX Male	34	(44.7)	(19.3)	117	(33.7)	(66.5)	25	(41.0)	(14.2)	176	(36.4)
Female	42	(55.3)	(13.6)	230	(66.3)	(74.7)	36	(59.0)	(11.7)	308	(63.6)
HOUSEHOLD											
Alone	14	(18.4)	(9.7)	113	(32.6)	(77.9)	18	(29.5)	(12.4)	145	(30.0)
Spouse only	16	(21.1)	(11.9)	100	(28.8)	(74.6)	18	(29.5)	(13.4)	134	(27.7)
Other types	46	(60.5)	(22.4)	134	(38.6)	(65.4)	25	(41.0	(12.2)	205	(42.4)
SELF-CARE SCORES											
0	21	(27.6)	(13.3)	117	(33.7)	(74.1)	20	(32.8)	(12.7)	158	(32.6)
1 - 4	14	(18.4)	(12.0)	91	(26.2)	(77.8)	12	(19.7)	(10.2)	117	(24.2)
5 - 11	17	(22.4)	(16.2)	77	(22.2)	(73.3)	11	(18.0)	(10.5)	105	(21.7)
12 or more	24	(31.6)	(23.1)	62	(17.9)	(59.6)	18	(29.5)	(17.3)	104	(21.5)
HOUSEBOUND OR BEDFAST	11	(14.5)	(13.1)	64	(18.4)	(76.2)	9	(14.7)	(10.7)	84	(17.4)
IMPAIRED VISION	18	(23.7)	(11.1)	126	(36.3)	(77.8)	18	(29.5)	(11.1)	162	(33.5)
IMPAIRED HEARING	12	(15.8)	(16.2)	50	(14.4)	(67.6)	12	(19.7)	(16.2)	74	(15.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:											
CVA/Stroke	4	(5.3)	(16.7)	17	(4.9)	(70.8)	3	(4.9)	(12.5)	24	(5.0)
Other central nervous system	6	(7.9)	(16.7)	26	(7.5)	(72.2)	4	(6.6)	(11.1)	36	(7.4)
Circulatory	7	(9.2)	(17.5)	30	(8.6)	(75.0)	3	(4.9)	(7.5)	40	(8.3)
Musculoskeletal	24	(31.6)	(15.3)	113	(32.6)	(72.0)	20	(32.8)	(12.7)	157	(32.4)
Fractures, injuries, operations	2	(2.6)	(9.5)	18	(5.2)	(85.7)	1	(1.6)	(4.8)	21	(4.3)
Respiratory	5	(6.6)	(41.7)	6	(1.7)	(50.0)	1	(1.6)	(8.3)	12	(2.5)
HOSPITALISED SINCE FIRST SURVEY	34	(44.7)	(25.6)	83	(23.9)	(62.4)	16	(26.2)	(12.0)	133	(27.5)
ON AGENCY RECORDS AND REGISTERS	41	(53.9)	(16.7)	169	(48.7)	(68.4)	37	(60.6)	(15.0)	247	(51.0)

Appendix Table VII

Variables and Scales Used for Tables 16 - 18 on Multiple Changes in Capabilities

Activities	Range of scale	Distribution of changes per cent of handicapped (n = 484)			Per cent included in tables 16 - 18
		No change	Little change	Substantial change	
Self-care	0 - 36	29	41*	31	31
Mobility	0 - 9	36	32**	31	31
Household tasks	0 - 4	45	35**	20	) 59
Employment status	0 - 1	95	5		)
Social isolation	0 - 6	34	38**	28	) 32
Household status (alone)	0 - 1	95	5		)

*Equivalent to 4 points which could be two new minor difficulties or one minor activity needing help, or one major difficulty or other combinations.

**Equivalent to one point.

Note :- Alternative tables, excluding one change or 'little change' in managing household tasks, are available from the authors.

Appendix Table VIII

Met, Unmet and New Needs between Surveys

Personal Aids or Gadgets

Aid or gadget	Needs assessed at both surveys (n=484)			Needs assessed at follow-up only (n=275)*
	Needs met since survey I	Needs unmet since survey I	New needs	New needs
	(%)	(%)	(%)	(%)
Hoist	4 (0.8)	-	1 (0.2)	-
Support bar	5 (1.0)	3 (0.6)	3 (0.6)	4 (1.4)
Widen W.C. doors	1 (0.2)	-	-	-
Raise W.C. seat	29 (6.0)	-	12 (2.5)	1 (0.4)
W.C. rails	40 (8.3)	1 (0.2)	18 (3.7)	4 (1.4)
Bath rails	71 (14.7)	15 (3.1)	22 (4.6)	44 (16.0)
Sitz bath	-	-	1 (0.2)	1 (0.4)
Shower	8 (1.6)	5 (1.0)	11 (2.3)	11 (4.0)
Bath seat	80 (16.5)	1 (0.2)	16 (3.3)	30 (10.9)
Shoe and stocking aid	25 (5.2)	8 (1.6)	15 (3.1)	12 (4.4)
Special clothing or advice	6 (1.2)	6 (1.2)	10 (2.1)	3 (1.1)
Feeding gadgets or advice	14 (2.9)	2 (0.4)	13 (2.7)	-
Ramp	13 (2.7)	1 (0.2)	4 (0.8)	1 (0.4)
Nursing aids, etc.:				
Sickroom equipment	27 (5.6)	1 (0.2)	8 (1.6)	4 (1.4)
Disposable pads	27 (5.6)	1 (0.2)	17 (3.5)	1 (0.4)
Laundry service	4 (0.8)	1 (0.2)	5 (1.0)	-

*See text for explanation.

Appendix Table IX

Met, Unmet and New Needs between Surveys

Help with Household Activities

	Needs assessed at both surveys (n=484)			Needs assessed at follow-up only (n=275)*
	Needs met since survey I	Needs unmet since survey I	New needs	New needs
	(%)	(%)	(%)	(%)
L.A. help with -				
Shopping	23** (4.7)	1 (0.2)	6 (1.2)	4 (1.4)
Housework	63** (13.0)	4 (0.8)	14 (2.9)	20 (7.3)
Cooking	18** (3.7)	-	2 (0.4)	4 (1.4)
Meals on wheels	19 (3.9)	-	10 (2.1)	5 (1.8)
Volunteer help with				
Gardening	19 (3.9)	30 (6.2)	34 (7.0)	46 (16.7)
Window cleaning	14 (2.9)	13 (2.7)	34 (7.0)	30 (10.9)
Lighting fires	2 (0.4)	-	8 (1.6)	1 (0.4)
Convey laundry	18 (3.7)	-	2 (0.4)	1 (0.4)
Move dustbin	13 (2.7)	-	2 (0.4)	-

*See text for explanation

**By L.A. homehelp.

Appendix Table X

Met, Unmet and New Needs between Surveys

Other Services

	Needs assessed at both surveys (n=484)			Needs assessed at follow-up only (n=275)*
	Needs met since survey I	Needs unmet since survey I	New needs	New needs
	(%)	(%)	(%)	(%)
Chiropody	49 (10.1)	26 (5.4)	28 (5.8)	44 (16.0)
Bath attendant	48 (9.9)	-	13 (2.7)	-
Day/night attendant	-	2 (0.4)	3 (0.6)	-
Short-stay in home	6 (1.2)	2 (0.4)	14 (2.9)	4 (1.4)
Telephone	76** (15.7)	70 (14.5)	36 (7.4)	78 (28.4)
Friendly visit	13 (2.7)	34 (7.0)	35 (7.2)	24 (8.7)
Social club	23 (4.7)	23 (4.7)	25 (5.2)	21 (7.6)
Holiday	30 (6.2)	48 (9.9)	42 (8.7)	40 (14.5)
Mobile library	8 (1.6)	34 (7.0)	30 (6.2)	39 (14.2)

*See text for explanation

**Those with telephones acquired since initial survey.

Appendix Table XI

Perceived Needs of the Handicapped for Help with Shopping, Housework and Cooking and Help Received at Initial and Follow-up Survey

	Needs assessed both times (n=484)						Needs assessed 2nd time only (n=275)		
	I Initial survey			II Follow-up survey			Follow-up survey		
	Need help	Get help[1]		Need help	Get help[1]		Need help	Get help[1]	
		Adequate	Need more		Adequate	Need more		Adequate	Need more
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Shopping	21 (4.3)	219 (45.2)	13 (2.7)	1 (0.2)	240 (49.6)	6 (1.2)	3 (1.1)	129 (46.9)	1 (0.4)
Housework	14 (2.9)	203 (41.9)	31 (6.4)	7 (1.4)	252 (52.1)	11 (2.3)	14 (5.1)	119 (43.3)	6 (2.2)
Cooking	9 (1.9)	108 (22.3)	1 (0.2)	2 (0.4)	110 (22.7)	-	2 (0.7)	49 (17.8)	2 (0.7)
Meals on wheels									
Delivered at home	4 (0.8)	16 (3.3)		10 (2.1)	29 (6.0)		5 (1.8)	7 (2.5)	
At club	55 (11.4)	not asked		26 (5.4)	41 (8.5)		21 (7.6)	9 (3.3)	

(1) Help excludes tasks normally performed by other members of the household.

For sources of help see table XII.

Appendix Table XII

Sources of Help with Shopping, Housework, Cooking at Initial and Follow-up Survey

	Needs assessed both times (n=484)										Needs assessed 2nd time only (n=275)				
	I Initial survey					II Follow-up survey					II Follow-up survey				
	Total no. with help =100%	% with help from				Total no. with help =100%	% with help from				Total no. with help =100%	% with help from			
		Friends & relatives	L.A. home help	Paid pri-vate	Other*		Friends & relatives	L.A. home help	Paid pri-vate	Other*		Friends & relatives	L.A. home help	Paid pri-vate	Other*
Shopping	232	81.0	11.2	2.6	5.2	246	73.6	17.1	2.4	6.9	130	88.5	6.1	1.5	3.8
Housework	234	57.7	32.9	9.4	-	263	41.8	50.2	8.0	-	125	64.8	28.6	6.4	-
Cooking	109	89.9	2.8	5.5	1.8	110	75.5	17.3	3.6	3.6	51	92.2	2.0	3.9	2.0

*Other: From voluntary agencies, warden and miscellaneous sources.

Appendix Table XIII

Perceived Needs of the Handicapped for Help with Gardening, Window Cleaning and Other Jobs and Help Received at Initial and Follow-up Survey

	Needs assessed both times (n=484)					Needs assessed 2nd time only (n=275)		
	Initial survey		Follow-up survey			Follow-up survey		
	Need help	Get voluntary help	Need help	Get voluntary help	Paid help	Need help	Get voluntary help	Paid help
	(%)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
Gardening	60 (12.4)	32 (6.6)	64 (13.2)	27 (5.6)	26 (5.4)	46 (16.7)	12 (4.4)	9 (3.3)
Window cleaning	54 (11.2)	11 (2.3)	47 (9.7)	15 (3.1)	81 (16.7)	30 (10.9)	11 (4.0)	28 (10.2)
Light fires	7 (1.4)	3 (0.6)	8 (1.6)	3 (0.6)	1 (0.2)	1 (0.4)	1 (0.4)	3 (1.1)
Convey laundry	5 (1.0)	17 (3.5)	2 (0.4)	22 (4.5)	77 (15.9)	1 (0.4)	4 (1.4)	33 (12.0)
Move dustbin	8 (1.6)	13 (2.7)	2 (0.4)	15 (3.1)	3 (0.6)	-	3 (1.1)	2 (0.7)

Note: Paid help was not inquired into in the first survey.

Appendix Table XIV

Changes in Operational Status between Surveys

(by age, sex, household type, incapacity, diagnosis, etc. in initial survey)

		Handicapped in initial survey Status in follow-up survey:						Impaired only in initial survey Status in follow-up survey:						All with screening interviews in initial survey*	
		Handicapped		Impaired		Died, admitted, etc.		Handicapped		Impaired		Died, admitted, etc.			
		No.	(Col.%)	No.	(Col.%)	No.	(Col.%)	No.	(Col.%)	No.	(Col.%)	No.	(Col.%)	No.	(Col.%)
TOTAL		435	(100)	82	(100)	253	(100)	151	(100)	410	(100)	145	(100)	1476	(100)
AGE	under 15	40	(9.2)	3	(3.7)	6	(2.4)	6	(4.0)	16	(3.9)	4	(2.7)	75	(5.1)
	15 - 49	39	(8.9)	11	(13.4)	5	(2.0)	15	(9.9)	104	(25.4)	20	(13.8)	194	(13.1)
	50 - 64	70	(16.1)	16	(19.5)	22	(8.7)	30	(19.9)	131	(32.0)	31	(21.4)	300	(20.3)
	65 - 74	111	(25.5)	25	(30.5)	64	(25.3)	45	(29.8)	103	(25.1)	41	(28.3)	389	(26.4)
	75 or over	175	(40.2)	27	(32.9)	156	(61.7)	55	(36.4)	56	(13.6)	49	(33.8)	518	(35.1)
SEX	Male	153	(35.2)	37	(45.1)	80	(31.6)	51	(33.8)	190	(46.3)	81	(55.9)	592	(40.1)
	Female	282	(64.8)	45	(54.8)	173	(68.4)	100	(66.2)	220	(53.7)	64	(44.1)	884	(59.9)
HOUSEHOLD															
	Alone	134	(30.8)	25	(30.5)	84	(33.2)	53	(35.1)	87	(21.2)	35	(24.1)	418	(28.3)
	Spouse only	119	(27.4)	23	(28.0)	67	(26.5)	53	(35.1)	121	(29.5)	51	(35.2)	434	(29.4)
	Other types	182	(41.8)	34	(41.5)	102	(40.3)	45	(29.8)	202	(49.3)	59	(40.7)	624	(42.3)
SELF-CARE SCORES															
	0	144	(33.1)	34	(41.5)	54	(21.3)	136	(90.1)	361	(88.0)	134	(92.4)	863	(58.5)
	1 - 4	105	(24.1)	22	(26.8)	79	(31.2)	15	(9.9)	47)	(12.0)	10)	(7.6)	278	(18.8)
	5 - 11	86	(19.8)	21	(25.6)	60	(23.7)	-		2)		1)		170	(11.5)
	12 or more	100	(23.0)	5	(6.1)	60	(23.7)	-		-		-		165	(11.2)
HOUSEBOUND OR BEDFAST		79	(18.2)	6	(7.3)	89	(35.2)	2	(1.3)	-		3	(2.1)	179	(12.1)
IMPAIRED VISION		158	(36.3)	16	(19.5)	95	(37.5)	1	(0.7)	1	(0.2)	-		271	(18.4)
IMPAIRED HEARING		65	(14.9)	14	(17.1)	54	(21.3)	1	(0.7)	2	(0.5)	1	(0.7)	137	(9.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS															
CVA/Stroke		23	(5.3)	2	(2.4)	27	(10.7)	3	(2.0)	-		4	(2.7)	59	(4.0)
Other central nervous system		34	(7.8)	5	(6.1)	18	(7.1)	12	(7.9)	34	(8.3)	7	(4.8)	110	(7.5)
Circulatory		35	(8.0)	6	(7.3)	37	(14.6)	13	(8.6)	40	(9.8)	14	(9.6)	145	(9.8)
Musculoskeletal		140	(32.2)	18	(22.0)	67	(26.5)	36	(23.8)	60	(14.6)	21	(14.5)	342	(23.2)
Fractures, injuries, operations		18	(4.1)	6	(7.3)	20	(7.9)	3	(2.0)	10	(2.4)	3	(2.1)	60	(4.1)
Respiratory		9	(2.1)	6	(7.3)	21	(8.3)	8	(5.3)	19	(4.6)	11	(7.6)	74	(5.0)
HOSPITALISED SINCE FIRST SURVEY		120	(27.6)	22	(26.8)	n.a.		45	(29.8)	88	(21.5)	n.a.		n.a.	
ON AGENCY RECORDS AND REGISTERS		232	(53.3)	22	(26.8)	156	(61.7)	39	(25.8)	49	(12.0)	28	(19.3)	526	(35.6)

*Excluding 58 who died, were admitted, moved, etc. before the completion of the initial survey.

Appendix Table XV

Sex, Age, Household and Marital Status of Persons with Assessment Interview at Follow-up only

			Eligible under old definition* n=151	Eligible under new definition* n=124	Total n=275
AGE:	Males:	Under 15	3 (5.9)	-	3 (2.5)
		15 - 49	6 (11.8)	21 (30.0)	27 (22.3)
		50 - 64	12 (23.5)	29 (41.4)	41 (33.9)
		65 - 74	19 (37.3)	15 (21.4)	34 (28.1)
		75+	11 (21.6)	5 (7.1)	16 (13.2)
		Total	51 (100)	70 (100)	121 (100)
	Females:	Under 15	3 (3.0)	1 (1.9)	4 (2.6)
		15 - 49	9 (9.0)	14 (25.9)	23 (14.9)
		50 - 64	18 (18.0)	22 (40.7)	40 (26.0)
		65 - 74	26 (26.0)	11 (20.4)	37 (24.0)
		75+	44 (44.0)	6 (11.1)	50 (32.5)
		Total	100 (100)	54 (100)	154 (100)
HOUSEHOLD:	Alone		53 (35.1)	29 (23.4)	82 (29.8)
	Spouse only		53 (35.1)	38 (30.6)	91 (33.1)
	With parents		11 (7.3)	16 (12.9)	27 (9.8)
	Other types		34 (22.5)	41 (33.1)	75 (27.3)
MARITAL STATUS:	Married		67 (44.4)	67 (54.0)	134 (48.7)
	Widowed		57 (37.7)	32 (25.8)	89 (32.4)
	Others		27 (17.9)	25 (20.2)	52 (18.9)
Other handicapped person in household			10 (6.6)	4 (3.2)	14 (5.1)

*See text for full explanation.

I = Initial survey II = Follow-up survey

Appendix Table XVI

Causes of Impairment, Self-care Scores and Changes between Surveys of Persons with Assessment Interview at Follow-up only

		Eligible under old definition* n=151	Eligible under new definition* n=124	Total n=275
		(%)	(%)	(%)
Loss of limb I		4 (2.6)	12 (9.7)	16 (5.8)
New loss of limb reported		7 (4.6)	2 (1.6)	9 (3.2)
Deterioration:				
vision		39 (25.8)	-	39 (14.2)
hearing		34 (22.5)	-	34 (12.4)
mobility (housebound)		43 (28.5)	-	43 (15.6)
Self-care scores I:	none	136 (90.1)	88 (71.0)	224 (81.5)
	1 - 5	15 (9.9)	36 (29.0)	51 (18.5)
Self-care scores II:	none	58 (38.4)	69 (55.6)	127 (46.2)
	1 - 5	61 (40.4)	55 (44.4)	116 (42.2)
	6+	32 (21.2)	-	32 (11.6)
Change in self-care:	better	4 (2.6)	16 (12.9)	20 (7.3)
	same	58 (38.4)	75 (60.5)	133 (48.4)
	worse:			
	by 1 - 4	58 (38.4)	31 (25.0)	89 (32.4)
	5 - 9	20 (13.2)	2 (1.6)	22 (8.0)
	10 or more	11 (7.3)	-	11 (4.0)
Selected diagnoses I:				
stroke		3 (2.0)	-	3 (1.1)
other CNS		12 (7.9)	21 (16.9)	33 (12.0)
circulatory		13 (8.6)	17 (13.7)	30 (10.9)
musculo-skeletal		36 (23.8)	22 (17.7)	58 (21.1)
fractures, injuries, operations		3 (2.0)	2 (1.6)	5 (1.8)
respiratory		8 (5.3)	8 (6.4)	16 (5.8)
Major new diagnoses:				
stroke or other CNS		4 (2.6)	6 (4.8)	10 (3.6)
circulatory		23 (15.2)	10 (8.1)	33 (12.0)
musculo-skeletal		20 (13.2)	11 (8.9)	31 (11.3)
fractures, injuries, operations		10 (6.6)	10 (8.1)	20 (7.3)
respiratory		9 (6.0)	6 (4.8)	16 (5.8)
Hospitalised between surveys		45 (29.8)	33 (26.6)	78 (28.4)

See appendix table XV for notes

Appendix Table XVII

Service Contacts and Perceived Needs for Aids and Gadgets of Persons with Assessment Interview at Follow-up only

	Eligible under old definition* n=151	Eligible under new definition* n=124	Total n=275
	(%)	(%)	(%)
Saw general practitioner within previous month	62 (41.0)	45 (36.3)	107 (38.9)
Domiciliary visits by:			
Home nurse	11 (7.3)	5 (4.0)	16 (5.8)
Health visitor	11 (7.3)	6 (4.8)	17 (6.2)
Home help	28 (18.5)	8 (6.5)	36 (13.1)
Chiropodist	8 (5.3)	-	8 (2.9)
Social worker	21 (13.9)	21 (16.9)	42 (15.3)
Occupational therapist	-	-	-
Meals on wheels	6 (4.0)	1 (0.8)	7 (2.5)
Goes to club or day centre	42 (27.8)	43 (34.7)	85 (30.9)
On Agency records before I	39 (25.8)	30 (24.2)	69 (25.1)
Registered handicapped I	12 (7.9)	14 (11.3)	26 (9.4)
" " II	33 (21.9)	45 (36.3)	78 (28.4)
Needs perceived for:			
Hoist	-	-	-
Support bar	3 (2.0)	1 (0.8)	4 (1.5)
Widen W.C. doors	-	-	-
Raise W.C. seat	1 (0.7)	-	1 (0.4)
W.C. rails	4 (2.6)	-	4 (1.5)
Bath rails	19 (12.6)	25 (20.2)	44 (16.0)
Sitz bath	-	1 (0.8)	1 (0.4)
Shower	6 (4.0)	5 (4.0)	11 (4.0)
Bath seat	17 (11.3)	13 (10.5)	30 (10.9)
Shoe, stocking aid	9 (6.0)	3 (2.4)	12 (4.4)
Special clothing or advice	1 (0.7)	2 (1.6)	3 (1.1)
Feeding gadgets or advice	-	-	-
Special rail	6 (4.0)	2 (1.6)	8 (2.9)
Ramp	1 (0.7)	-	1 (0.4)
Kitchen aids or advice	4 (2.6)	5 (4.0)	9 (3.3)
Nursing aids:			
Sick room equipment	3 (2.0)	1 (0.8)	4 (1.5)
Disposable pads	-	1 (0.8)	1 (0.4)
Laundry	-	-	-

See appendix table XV for notes

Appendix Table XVIII

Perceived Needs for Personal Services, etc., Help with Household Activities, Volunteer Help, Housing, and other Services of Persons with Assessment Interview at Follow-up only

	Eligible under definition* old	Eligible under definition* new	Total
	n=151	n=124	n=275
	(%)	(%)	(%)
Need for other services :			
Chiropody	29 (19.2)	15 (12.1)	44 (16.0)
Bath attendant	-	-	-
Day/night attendant	-	-	-
Short stay in home	2 (1.3)	2 (1.6)	4 (1.4)
Help with:			
Shopping	4 (2.6)	-	4 (1.4)
Housework	16 (10.6)	4 (3.2)	20 (7.3)
Cooking	4 (2.6)	-	4 (1.4)
Meals on wheels	4 (2.6)	1 (0.8)	5 (1.8)
Volunteer help with:			
Gardening	27 (17.9)	19 (15.3)	46 (16.7)
Window cleaning	19 (12.6)	11 (8.9)	30 (10.9)
Lighting fires	1 (0.7)	-	1 (0.4)
Conveying laundry	1 (0.7)	-	1 (0.4)
Move dustbin	-	-	-
Housing :			
Sheltered or home	15 (9.9)	5 (4.0)	20 (7.3)
On housing list	13 (8.6)	11 (8.9)	24 (8.7)
Employment:			
Sheltered	8 (5.3)	14 (11.3)	22 (8.0)
Open	3 (2.0)	9 (7.3)	12 (4.4)
Communications & leisure:			
Telephone	42 (27.8)	36 (29.0)	78 (28.4)
Friendly visit	14 (9.3)	10 (8.1)	24 (8.7)
Social club	8 (5.3)	13 (10.5)	21 (7.6)
Holiday	21 (13.9)	19 (15.3)	40 (14.5)
Mobile library	24 (15.9)	15 (12.1)	39 (14.2)

See appendix table XV for notes

Appendix Table XIX

Attributes of Handicapped Persons by Extent of Deterioration

Attribute in Initial Survey	Deteriorated in two or more groups of activities			Deteriorated in one group of activities			No deterioration in any group			Total	
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL	110	(100)	(22.7)	184	(100)	(38.0)	190	(100)	(39.3)	484	(100)
AGE under 15	9	(8.2)	(22.5)	17	(9.2)	(42.5)	14	(7.4)	(35.0)	40	(8.3)
15 - 49	9	(8.2)	(19.1)	17	(9.2)	(36.2)	21	(11.1)	(44.7)	47	(9.7)
50 - 64	21	(19.1)	(25.0)	27	(14.7)	(32.1)	36	(18.9)	(42.9)	84	(17.4)
65 - 74	26	(23.6)	(20.2)	54	(29.3)	(41.9)	49	(25.8)	(38.0)	129	(26.7)
75 or over	45	(40.9)	(24.5)	69	(37.5)	(37.5)	70	(36.8)	(38.0)	184	(38.0)
SEX Male	37	(33.6)	(21.0)	60	(32.6)	(34.1)	79	(41.6)	(44.9)	176	(36.4)
Female	73	(66.4)	(23.7)	124	(67.4)	(40.3)	111	(58.4)	(36.0)	308	(63.6)
HOUSEHOLD											
Alone	20	(18.2)	(13.8)	61	(33.2)	(42.1)	64	(33.7)	(44.1)	145	(30.0)
Spouse only	40	(36.4)	(29.9)	40	(21.7)	(29.9)	54	(28.4)	(40.3)	134	(27.7)
Other types	50	(45.5)	(24.4)	83	(45.1)	(40.5)	72	(37.9)	(35.1)	205	(42.4)
SELF-CARE SCORES											
0	33	(30.0)	(20.9)	50	(27.2)	(31.6)	75	(39.5)	(47.5)	158	(32.6)
1 - 4	23	(20.9)	(19.7)	54	(29.3)	(46.2)	40	(21.1)	(34.2)	117	(24.2)
5 - 11	22	(20.0)	(21.0)	40	(21.7)	(38.1)	43	(22.6)	(40.9)	105	(21.7)
12 or more	32	(29.1)	(30.8)	40	(21.7)	(38.5)	32	(16.8)	(30.8)	104	(21.5)
HOUSEBOUND OR BEDFAST	21	(19.1)	(25.0)	31	(16.8)	(36.9)	32	(16.8)	(38.1)	84	(17.4)
IMPAIRED VISION	31	(28.2)	(19.1)	64	(34.8)	(39.5)	67	(35.3)	(41.4)	162	(33.5)
IMPAIRED HEARING	17	(15.5)	(23.0)	30	(16.3)	(40.5)	27	(14.2)	(36.5)	74	(15.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:											
CVA/Stroke	10	(9.1)	(41.7)	8	(4.3)	(33.3)	6	(3.2)	(25.0)	24	(5.0)
Other central nervous system	12	(10.9)	(33.3)	10	(5.4)	(27.8)	14	(7.4)	(38.9)	36	(7.4)
Circulatory	6	(5.5)	(15.0)	20	(10.9)	(50.0)	14	(7.4)	(35.0)	40	(8.3)
Musculoskeletal	40	(36.4)	(25.5)	61	(33.1)	(38.8)	56	(29.5)	(35.7)	157	(32.4)
Fractures, injuries, operations	3	(2.7)	(14.3)	11	(6.0)	(52.4)	7	(3.7)	(33.3)	21	(4.3)
Respiratory	8	(7.3)	(66.7)	1	(0.5)	(8.3)	3	(1.6)	(25.0)	12	(2.5)
HOSPITALISED SINCE FIRST SURVEY	36	(32.7)	(27.1)	46	(25.0)	(34.6)	51	(26.8)	(38.3)	133	(27.5)
ON AGENCY RECORDS AND REGISTERS	65	(59.1)	(26.3)	88	(47.8)	(35.6)	94	(49.5)	(38.1)	247	(51.0)

Appendix Table XX

Attributes of Handicapped Persons by Extent of Improvement

Attribute in Initial Survey	Improved in two or more groups of activities			Improved in one group of activities			No improvement in any group			Total	
	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)	(Row %)	No.	(Col.%)
TOTAL	69	(100)	(14.3)	163	(100)	(33.7)	252	(100)	(52.1)	484	(100)
AGE under 15	11	(15.9)	(27.5)	12	(7.4)	(30.0)	17	(6.7)	(42.5)	40	(8.3)
15 - 49	8	(11.6)	(17.0)	21	(12.9)	(44.7)	18	(7.1)	(38.3)	47	(9.7)
50 - 64	13	(18.8)	(15.5)	27	(16.6)	(32.1)	44	(17.5)	(52.4)	84	(17.4)
65 - 74	15	(21.7)	(11.6)	38	(23.3)	(29.5)	76	(30.2)	(58.9)	129	(26.7)
75 or over	22	(31.9)	(12.0)	65	(39.9)	(35.3)	97	(38.5)	(52.7)	184	(38.0)
SEX Male	33	(47.8)	(18.7)	64	(39.3)	(36.4)	79	(31.3)	(44.9)	176	(36.4)
Female	36	(52.2)	(11.7)	99	(60.7)	(32.1)	173	(68.6)	(56.2)	308	(63.6)
HOUSEHOLD											
Alone	15	(21.7)	(10.3)	36	(22.1)	(24.8)	94	(37.3)	(64.8)	145	(30.0)
Spouse only	11	(15.9)	(8.2)	49	(30.1)	(36.6)	74	(29.4)	(55.2)	134	(27.7)
Spouse and children	16	(23.2)	(24.2)	26	(16.0)	(39.4)	24	(9.5)	(36.4)	66	(13.6)
Other types	27	(39.1)	(19.4)	52	(31.9)	(37.4)	60	(23.8)	(43.2)	139	(28.7)
SELF-CARE SCORES											
0	13	(18.8)	(8.2)	47	(28.8)	(29.7)	98	(38.9)	(62.0)	158	(32.6)
1 - 4	6	(8.7)	(5.1)	42	(25.8)	(35.9)	69	(27.4)	(59.0)	117	(24.2)
5 - 11	23	(33.3)	(21.9)	36	(22.1)	(34.3)	46	(18.2)	(43.8)	105	(21.7)
12 or more	27	(39.1)	(26.0)	38	(23.3)	(36.5)	39	(15.5)	(37.5)	104	(21.5)
HOUSEBOUND OR BEDFAST	13	(18.8)	(15.5)	32	(19.6)	(38.1)	39	(15.5)	(46.4)	84	(17.4)
IMPAIRED VISION	14	(20.3)	(8.6)	49	(30.1)	(30.2)	99	(39.3)	(61.1)	162	(33.5)
IMPAIRED HEARING	6	(8.7)	(8.1)	28	(17.2)	(37.8)	40	(15.9)	(54.1)	74	(15.3)
SELECTED DIAGNOSTIC GROUPS OR CONDITIONS:-											
CVA/Stroke	3	(4.3)	(12.5)	8	(4.9)	(33.3)	13	(5.2)	(54.2)	24	(5.0)
Other central nervous system	5	(7.2)	(13.9)	14	(8.6)	(38.9)	17	(6.7)	(47.2)	36	(7.4)
Circulatory	5	(7.2)	(12.5)	14	(8.6)	(35.0)	21	(8.3)	(52.5)	40	(8.3)
Musculoskeletal	26	(37.7)	(16.6)	56	(34.4)	(35.7)	75	(29.8)	(47.8)	157	(32.4)
Fractures, injuries, operations	3	(4.3)	(14.3)	4	(2.5)	(19.0)	14	(5.6)	(66.7)	21	(4.3)
Respiratory	5	(7.2)	(41.7)	4	(2.5)	(33.3)	3	(1.2)	(25.0)	12	(2.5)
HOSPITALISED SINCE FIRST SURVEY	24	(34.8)	(18.0)	54	(33.1)	(40.6)	55	(21.8)	(41.4)	133	(27.5)
ON AGENCY RECORDS AND REGISTERS	40	(58.0)	(16.2)	84	(51.5)	(34.0)	123	(48.8)	(49.8)	247	(51.0)

The contents of this form are confidential.

CANTERBURY SURVEY OF THE HANDICAPPED

FOLLOW-UP STUDY 1974

HEALTH SERVICES RESEARCH UNIT

UNIVERSITY OF KENT

CANTERBURY.

PROXY INTERVIEWS

Someone who is responsible for looking after the subject (a proxy) should be interviewed in the following cases:

1) Where the 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).

2) Where the subject is so deaf that you cannot communicate (see notes).

3) Where the subject is a child.

NOTE *If subject is under 18 you must get the parents' permission for your interview.*

INTRODUCTION –

1. *Check that the person named on the form really does live at the address.*
2. *Introduce yourself to the person you wish to interview.*
3. *Explain the reason for your visit.*

"We interviewed you as part of the City's handicapped survey in 1972. We are anxious to know how you have been getting on. In order to make exact comparisons with the situation two years ago, we would like to ask you many of the same questions."

Name of Subject ....

Date of Birth ....

Name of General Practitioner ....

Address ....

....

If subject has moved

New address ....

....

If subject has been admitted to a residential home, to hospital or a nursing home (unless temporary)

Name of home/hospital ....

Date of admission ....

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 .... state relationship:-	3

1. **Do you have any difficulty with your eyesight, even when wearing glasses?** Yes – *ask (a)*

No – 0

If Yes

(a) **Are you registered as blind or partially sighted ?**

Registered blind 1
Registered partially sighted 2
Not registered 3
Don't know 4

2. **Do you have any difficulty with your hearing?** Yes – *ask (a)*

No – 0

If Yes (or wearing hearing aid)

(a) **Are you registered as deaf or hard of hearing?**

Registered deaf 1
Registered hard of hearing 2
Not registered 3
Don't know 4

3. **Have you lost the whole or part of an arm, leg, hand or foot by having an accident, amputation or being born like that?** Yes – *ask (a) and (b)*

No – 0

If Yes

(a) **Which limb is affected?** *Specify*

(b) **Was it an accident, amputation or birth defect?** *(Ring which applies)*

Qns. 4 – 6. Do not ask in case of young children.

4. **Have you been unable, without help, to get out of bed, or to get out of the house for the past 3 months?** Yes – *ask (a)*

No – 0

If Yes

(a) **Are you still unable to [get up] [get out of the house] ?**

Still bedfast 1
Still housebound .... *ask (b)*
No longer bedfast or housebound *ask (c)*

(b) **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 } *skip (c)*
Stays put .... 3 }

(c) **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

5. **Do you have difficulty walking without help, going up and downstairs, or kneeling and bending ?**

Yes
No

6. **Do you have difficulty in washing, feeding or dressing yourself ?**

Yes
No

7. **Do you have difficulty in gripping or holding things, or using arms, hands or fingers ?**

Yes
No

Qn. 8. Ask in case of young children only.

8. **Does your child need more help than usual for a child of the same age, in washing and dressing his/herself, walking without help or going up and downstairs etc. ?**

Yes
No

Qn. 9. Ask in case of child of school age only.

9. **Is your child unable to go to an ordinary school because of physical or mental handicap?**

Yes
No

If negative answers to all previous questions (1–9)

10 **Have you some other permanent condition * which makes it difficult for you to go to school or work, take care of yourself, or get about ?**

Yes
No

** This includes mental and physical conditions, epilepsy, etc.*

This is the end of the questions that were on the householders form.

11. Are you registered as physically handicapped ?

No 0
Yes 1
Don't know 2

This does not refer to the Disabled Persons Register; see Qn. 52.

I am now going to ask you questions many of which were asked last time in your interviews.

12. 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)*

If subject says nothing wrong

(b) **Does this mean that** *Running prompt*

[You're] [your child is] quite better now 2
or [you're] [your child is] better temporarily but the trouble might recur 4

13. Do you regularly suffer from any (other) chronic illness or condition which complicates life for you ?

No 0
Yes . . . . 1 – *ask (a)*

If Yes

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

14. Have you had any serious illness or been in hospital during the last two years ?

No 0
Yes . . . . 1 – *ask (a) & (b)*

If Yes

(a) **What was the matter ?** *(name of disease – not symptoms)*

(b) **How long were you in hospital ?**

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

15. 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 Qn. 1 – if subject is registered blind or partially sighted go on to Qn. 18.

Could we start with eyesight? –

16. 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

17. 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 0
Cannot read/write (illiterate or too young) 1
No, can't see unless uses magnifier etc. 2
No, can't see 3

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

Yes, without aid 0
Yes,with aid 1
No 2
Says yes, but difficulty observed 3
Says no, but no difficulty observed 4
Too deaf to be interviewed 5

The following panel is used to find degree of handicap. Note that the main question (19a) should be repeated every three or four items (i) – (xi). Then, for any item found difficult (needing help/supervision), ask question (19b) to sort out those who can do it even with difficulty from those who cannot.

Note. *There are two variations to main question (19a)*

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] ?**

19a **Do you generally have difficulty in ....** *(or alternative version)*	*(1)* *No difficulty or supervision*	*(2)* *No difficulty or supervision but uses aids*	*(3)* *If difficulty or supervision ask (19b)* **but can you do it yourself, even with difficulty ?**	*(4)*	*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 col. (4).*
(ii) Getting to or using the W.C.?	0	X	4	6	*If never uses W. C. because 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).*
Repeat question 19a					
(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).*
Repeat question 19a					
(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 & CHILDREN ONLY Combing and brushing your hair?	0	X	2	3	
(xi) MEN ONLY Shaving yourself?	0	X	2	3	**GRAND TOTAL** **CATEGORY**
TOTAL COLUMN SCORE					

ALWAYS CARRY OUT A FULL INTERVIEW IN THE FOLLOWING CASES

Qn. 1. *Registered blind or partially sighted – code 1 or 2.*

Qn. 2. *Registered deaf or hard of hearing – code 1 or 2.*

Qn. 4. *Bedfast – code 1 or housebound – code 2 or 3.*

Qn. 9. *Child attends special school.*

Qn. 11. *Registered physically handicapped – code 1.*

Qn. 15. *Subject of working age unable to carry out full employment or housewife unable to carry out her normal household duties because of illness or disability.*

Qn. 16. *Poor distant vision – code 1.*

Qn. 17. *Poor near vision – code 2 or 3.*

Qn. 18. *Hearing difficulty – code 2, 3, 4 or 5.*

Qn. 19. *Where there is any score in self-care OR where aids have to be used.*

YOU MAY OMIT QN. 21 – QN. 61 PROVIDING :–

Subject has adequate vision (i.e. Qn. 16 code 0, Qn. 17 code 0 or 1).

Subject has adequate hearing (i.e. Qn. 18 code 0 or 1).

Subject has no score in Qn. 19.

Subject is not housebound or bedfast.

Subject is in full employment (if of working age)

or if a housewife can carry out her normal housework.

For Office Use.

Full Interview – Eligible 1972 Criteria 0
Not eligible 1972 Criteria 1
Screening Interview only 2

Check back to Qn. 19.

Look back to see if any item on question 19 was coded in columns (2), (3) or (4). Where the subject can only manage an activity with aids (col. 2) or cannot manage an activity without help (col. 3 or 4) for which assistance or aids are available – see list below – introduce and ask WHERE APPLICABLE.

20. Introduce

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

"Would it make it easier for you to . . . ."

(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).

Item No. See Qn. 19.			
(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 Have (Hoist . . . . . . X (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?	Yes (widen doors . . . . X (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 Have (widen doors X (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

Question	Response	Follow-up	
(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 – *Specify, why not*
	No 0	*Specify, why not*	
	Already Have (Rails etc. .. A (Sitz Bath .. B (Shower .. C (Bath Seat .. D (Attendant .. E	**Who supplied ....?** Local Authority .... 3 Voluntary Organisation ...... 6 – *Specify* Other .... 9 – *Specify* 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 – *Specify, why not*
	No 0	*Specify, why not*	
	Already Have ....Y	**Who supplied ....?** Local Authority .... 3 Voluntary Organisation ...... 6 – *Specify* Other .... 9 – *Specify* 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 – *Specify, why not*
	No 0	*Specify why not*	
	Already Have .... Y	**Who supplied** Local Authority .... 3 Voluntary Organisation 6 – *Specify* Other .... 9 – *Specify* 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 – *Specify, why not*
	No 0	*Specify why not*	
	Already Have .... Y	**Who supplied ....** Local Authority .... 3 Voluntary Organisation ...... 6 – *Specify* Other .... 9 – *Specify* Don't know 9	**Do you find .... useful?** Yes .... 0 Sometimes ...... 1 No 2

Chiropody

21. 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 chiropody .... X } *ask (a) (i),(ii)&(iii).*
No difficulty, having chiropody .... Y }
Difficulty, no chiropody............... Z–*ask (b) (i).*
No difficulty........................ 0–*on to Qn. 22*

(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 } *on to Qn. 22*
No trouble, like more .... C }
No trouble, no more .... D }

Difficulty, no chiropody

(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. 22*

(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

22. 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

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

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

Meals on Wheels

24. **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
Outside household/not by member of household . . . . . 0 – *Specify*
Sometimes within household and sometimes outside . . . . 7 – *Specify*

If No

(b) **Why not?**

Specify reason

25. Introduce **There is a scheme for the delivery of hot meals 2 or 3 times a week at a cost of 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

26. **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
Not Interested – None at present 3
– Already has some 4

Specify aids etc. already supplied.

27. **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		*Specify who does it*
				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)*	1	0	2	3	

Mobility

28. *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. 29*
HOUSEBOUND - permanently	4–*ask (b)*
Housebound - temporarily, usually GOES OUT	5–*on to Qn. 29*
Usually GOES OUT	6–*on to Qn. 29*

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 } *on to Qn.35*
Can't leave bed	0 } *on to Qn.35*

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.29*
Stays in chair	0–*on to Qn. 33*

29. Introduce – **How about getting around the house?**

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

Code all that apply

Yes, wheelchair	1
Yes, tripod/frame/crutches	2
Yes, calipers, surgical footwear	3
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

30. *(Do not ask if in a wheelchair – on to Qn. 31).*

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

31. **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	*on to Qn. 32*
No,(has ramp) can manage	2	

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

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

Yes	X-*ask (a)*	
No	0	*on to Qn. 33*
Yes, but only by car, etc.	1	

If Yes

(a) **Can you usually get out**

On your own without sticks or aids and without difficulty	2	*on to Qn. 33*
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. 35).*

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

33. **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. 34*

(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

34. **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?**

		Needs special transport		Already has special transport
		Yes	No	
(i)	Dentist	1	0	2
(ii)	Church / other place of 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

35. **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*

36. We've been talking about you getting to places. In some cases the council can bring the service to people's homes. Can you 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? *[Explain - but don't make too much of it - "Some people have conditions that cause wet or dirty bedclothes"]*	1	0	2
(vi)	Disposable incontinence pads	1	0	2
(vii)	Day/night attendants *[If proxy/not talking to subject - add "to give you a chance to go out or get a good night's sleep"]*	1	0	2
(viii)	Arrange a short-term stay in residential home while the family goes on holiday.	1	0	2

Communication and Isolation

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

37. **Do you have a radio or television?**

Has radio only	1
Television only	2
Both radio and television	3
Neither	0

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

Has standard telephone	0 – *ask (a)*
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?**

39. **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

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

Yes 1
No 0

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

Yes 1
No 0

42. **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

43. **Do any of the following visit you?**

Individual prompt

Code all that apply

		Yes	No
(i)	Meals on Wheels	1	0
(ii)	District nurse/male nurse	1	0
(iii)	Home help	1	0
(iv)	Health visitor	1	0
(v)	Social worker	1	0
(vi)	Occupational therapist	1	0
(vii)	Chiropodist	1	0
(viii)	Other - *Specify*	1	0

44. **Are you alone during the daytime or night-time?**

Both 1
Day 2
Night........................ 3
Neither 0

45. **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 week 5
Within last month 6
Within last 3 months 7
Between 3 & 6 months ago 8
Between 6 & 12 months ago 9
Years ago – *Specify* 10

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

Comes to subject 1
Subject goes to him 2
Both 3

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

Yes .... 1 –*ask (a)*
No 0

(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)*

48. **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	*ask (a)*
	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. 51.*
Centre	2	*on to Qn. 51.*
No	0	*on to Qn. 51.*

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

49. *Ask of those under retirement age who are permanently disabled, off sick or unemployed (i.e. those coded 9, 10 or 11 above) – otherwise go on to Qn. 52.*

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*

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

(explain)

Yes 1
No 0

(ii) **Or work at home?**

(explain)

Yes 2
No 0

51. **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

52. **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.*

53. **Do you go to any club or Centre?**

Yes .... 1–*ask (a)*
No 0

(a) **Which one is it?** *Specify*

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

Running prompt

Code all that apply

		Yes	No	Already does
(i)	Meet other people to talk to	1	0	2
(ii)	Have a mid-day meal	1	0	2
(iii)	Have coffee or tea	1	0	2
(iv)	Pursue hobbies or interests (e.g. whist, bingo, dressmaking , handicrafts)	1	0	2
(v)	To do paid work under non-factory conditions	1	0	2
(vi)	Help handicapped or elderly people	1	0	2

Ask Qns. 55, 56, 57 only if subject has moved since 1972 survey (see p.3)

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.**

55. *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

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

.... no of years

57. **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.

ASK ALL

58. **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*

59. **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 adaptions 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 } *on to Qn. 60*
Neither .... 3 }

(i) **What adaptations have been made?** *Specify*

(ii) **Have they helped you?**

Yes .... 4 }
Sometimes........................ 5 } *on to Qn. 60.*
No .... 6 }

have difficulties

(b) **What are the problems?**

Problem	Possible solution if suggested by subject

(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?**

60. **Do you have, inside the [dwelling]**

[Establish whether sole use or with other households]			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 – *ask (a)*

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

61. **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...... 4

(a) **Why not?**

(ii) **Residential Home**

Yes 2
No .... 0–*ask (a)*

(a) **Why not?**

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

No 0
Yes, *Specify suggestions*

63. Do you feel that you have had any benefit or help from the handicapped survey in 1972 ?

No help needed 0
Refused help 1
Not helped at all 2
Has helped 3

Comments

64. Have you been visited by a member of the Social Services Department?

Yes. 1

No . . . . 0 *-ask (a)*

(a) Would you like someone to come and see if she can help you ?

Yes . . . . 1*-ask (b)*

No, *Specify reason, if possible.* . . . 0

(b) Have I your permission to give your name and address to the Social Services Department?

Yes

No

YOU MAY CLOSE THE INTERVIEW HERE EXCEPT IN THE FOLLOWING CASES:–

Where the subject is:–

1	*Registered blind*	*Qn. 1 code 1*	COMPLETE FORM B
	Registered partially sighted	*Qn. 1 code 2*	
	Unable to see to read without magnifier	*Qn. 17 code 2*	
	Unable to see to read	*Qn. 17 code 3*	
2.	*Registered deaf*	*Qn. 2 code 1*	COMPLETE FORM D
	Registered hard of hearing	*Qn. 2 code 2*	
	Unable to hear ordinary conversation	*Qn. 18 codes 1, 2, 3 or 4*	

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 they will be in the future."

Give subject letter of thanks.

Referral to Social Services Area Office

Yes . . . . 1 (Urgent/ Routine)
No 0

Comments

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