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UNIVERSITY OF KENT AT CANTERBURY  
CENTRE FOR RESEARCH IN SOCIAL SCIENCES  
HEALTH SERVICES RESEARCH UNIT

HANDICAPPED PEOPLE IN THE COMMUNITY  
A SURVEY OF AGENCIES' RECORDS IN CANTERBURY

MICHAEL D. WARREN

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RESEARCH TEAM

Michael D. Warren, M.D., F.R.C.P., F.F.C.M., Director.  
Joan L. Warren, S.R.N., Research assistant.  
Shirley Woodward, Administrative secretary.

## SUMMARY

A search was carried out of the records of 15 agencies, expected to be deeply involved in helping handicapped people and of the 5 statutory registers of handicapped people, following a three-stage survey of every household in the City of Canterbury in 1972, aimed to identify all impaired people living in the community. The objective was to see if an examination of agencies' records is a practical way of deriving a list of handicapped people in a community.

The survey of records and registers yielded a list of 907 persons as being recorded in receipt of a service (or registered) and living in the community. The household survey had identified 1608 impaired persons. The number of persons identified in both surveys was 586; this number represents 65 per cent of persons on the registers and records list, and 36 per cent of the persons identified by the household survey. Out of the 586, 402 had been assessed as handicapped in the household survey, that is 52 per cent of the 770 people identified as handicapped in that survey.

The disparity in the lists derived from the two surveys suggests that agencies' records are likely to give lists that are incomplete as many handicapped people may need a service but are not in touch with any agency and are unspecific because most agencies do not record sufficient detail for any standard criteria of 'handicap' to be applied.

Further work is required to develop an effective and efficient method of finding handicapped people in need of help and those eligible for new services. In order to do this, problems of definition and of assessment of severity of handicap must be resolved, and new ways of collecting and collating information from a community tried out. As far more handicapped people are in receipt of help from statutory and voluntary bodies than are registered, it is recommended that concern should shift from registration as a formal activity to the development of operational case-registers, for the purposes of managing the continuing care of handicapped people.

### Acknowledgements

The success of an enquiry such as the one described in this report depends upon meticulous fieldwork and the support and cooperation of a large number of people. Joan Warren carried out the fieldwork; without her hard work and sensitivity to the purposes of the study not even tentative conclusions could have been drawn. Mrs. Hetty Barber, Mrs. Mary Keith-Lucas and Miss Kay Wells enabled the study to take place and gave it unstinted help and support. Mrs. J. Amos, Miss H. Dixon, Miss A. Grey, Dr. M. Harvey, Mrs. J. Porter, Dr. J. Pritchard and Rev. T.M.F. Rogers allowed access to various registers and records and in some instances gave up much time to discussing details with the research assistant. Mr. D. Eldridge, the staff of the Canterbury Unit for the Physically Handicapped and subsequently staff in the Canterbury Division of the Social Services Department of Kent County Council gave considerable assistance and allowed access to the registers. Mrs. Shirley Woodward helped to design the layout of forms and cards and typed the forms, drafts and final report. To all of these people, and to others not mentioned, the author is very grateful and remains indebted.

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## HANDICAPPED PEOPLE IN THE COMMUNITY

### A SURVEY OF AGENCIES' RECORDS IN CANTERBURY

#### INTRODUCTION AND OBJECTIVES

Surveys of elderly and of impaired people (e.g. Townsend and Wedderburn, 1965; Harris, 1971; and, in Canterbury, Warren, 1974) have shown that substantial numbers of handicapped and of frail elderly people could be helped by the provision of services, but, for many reasons, such people do not or cannot take the initiative to seek help and so lead a more toilsome and perhaps more fatiguing, painful and restricted life than is necessary or wanted. The majority of handicapped people are elderly who have gradually and imperceptibly become less mobile, less able to see or less able to hear, and many accept their limitations too readily. Some handicapped people only require help on occasions (e.g. the occasional visit, help with window-cleaning, assistance with travel) and some require help urgently on unusual occasions (e.g. during or following a power-failure). Those providing services are faced from time to time with the tragic realisation that more could have been done to prevent distress if only they had been aware of the problems; and many health and social workers believe that planned, thoughtful, sympathetic, anticipatory care of vulnerable people could produce improvements in the effectiveness and efficiency of the services. The services that may be required by handicapped people are so diverse and are provided by different authorities and departments (e.g. social services, social security, health services, housing, employment, education and voluntary bodies) that special efforts at coordination and exchange of information are required if the service to any one handicapped person is to be comprehensive and coherent (Warren, 1972). Many of the problems might be eased by the creation and maintenance of a central list of handicapped people in an area.

Many social services departments have conducted special household surveys in order to obtain data for planning the development of their services in accordance with the requirements of the Chronically Sick and Disabled Persons Act, 1970, and some have used the survey as a means of contacting and helping handicapped people in their areas (Knight and Warren, 1976). A question that is sometimes asked is why is a household survey necessary? Could the same information be obtained by a careful examination of the records of the main agencies serving handicapped people? This study examines this proposal, because if agencies' records are a satisfactory source of information, a linkage of such records might be a cheaper and easier way of identifying impaired people than a household survey.

During 1972 the Social Services Department of the City and County of Canterbury, in collaboration with the Health Services Research Unit at the University of Kent, carried out a survey of every household in the City in order to identify all physically and sensorially impaired people (whether handicapped or not) living in private households (Warren, 1974). On completion of that survey, the opportunity was taken to examine a number of registers and lists of persons residing in the City and who were in receipt of services, in order to find out how many impaired people identified by means of the household survey were currently known to one or other of the main statutory or voluntary helping agencies; how many of the agencies were in contact with the same person; how many people in contact with the agencies were not identified by the household survey; and what were some of the practical problems involved in attempting to derive lists of impaired and handicapped people from the lists of the helping agencies.

#### METHODS

##### Agencies surveyed

The records of the 5 statutory registers of handicapped people (in accordance with Section 29 of the National Assistance Act, 1948) and of 15 agencies in the City of Canterbury were checked by a research assistant during the early months of 1973. The list of registers and agencies are presented in tables 1 and 2. The agencies chosen were those which were operating in the City and were most likely to be in touch with handicapped people. The choice of agencies was based on the findings of studies that had interviewed handicapped people about services in regular contact with them (Harris, 1971 and Warren, 1974). On this basis, three striking omissions from table 2 are general practitioner records, the records of the social services department of the City and the records of the chiropodists. As almost all of the population are registered with a general practitioner it would be necessary to separate out 'impaired' people, however earlier exploratory studies (Jefferys, Hyman and Warren, 1966, unpublished report) had suggested that the records kept by general practitioners were unlikely to contain adequate notes about the impairments and handicaps of even the majority of the handicapped people and a study in a group practice at Paddock Wood, Kent, has confirmed this (Warren, 1976). The records maintained by the social services department in 1972 concerning handicapped people in the City were mainly the statutory registers listed in table 1. The arrangements for chiropody in the City were that patients were referred to a private chiropodist, to a Red Cross clinic or made their own

arrangements; but no records could be made available to the research assistant. No usable registers or records were available for Red Cross medical loans or for one of the clubs for handicapped people which encouraged an open access policy and invited spouses and friends of the handicapped to attend functions. Lists of agencies for the mentally ill were not examined as the study was primarily concerned with physically handicapped people.

#### Population previously identified in the household survey

A special record card was made out for every person who had identified themselves or been identified by a member of their household as being physically or sensorially impaired or handicapped by means of completing a one-page form that had been delivered to every household in the City in 1972. In that survey forms had been collected or returned from 94 per cent of the 10,960 households: these identified 1,631 persons, but 23 of these had completed the form incorrectly so that the number of the people identified by the household survey in 1972 who were eligible for a screening interview was 1608. These 1608 form the population that was ascertained by means of the household survey; their progress through the stages of the 1972 survey are summarised in table 3. The 1608 people are referred to in this paper as 'the people identified in the household survey'. Although during the 1972 survey there was inevitably a reduction in the numbers reaching each stage because of death, admission to an institution, moving out of the City or refusing further interviews and assessments, the survey had at the initial stage identified the 1608 persons already referred to and it is the names in this total group that were matched with the registers and agencies' records.

#### Definitions of impaired and handicapped people

The terms impaired and handicapped have been introduced in table 3. These are discussed in the full report of the household survey (Warren, 1974). An impaired person lacks part or all of a limb, has a defective limb, defective organ or bodily system which stops or limits getting about, working or self-care; is blind or has very bad eyesight; or wears a hearing aid or is so hard of hearing that he or she cannot hear ordinary conversation. Handicap reflects the disadvantage or restriction caused by the impairment. Many factors in addition to the presence of the impairment may contribute to the degree of handicap; these include lack of facilities or services available to ameliorate the handicap, environmental factors (e.g. steps and stairs), social factors (e.g. absence of other persons in the household) and psychological factors (e.g. certain types of personality and lack of motivation).

'Impaired' and 'handicapped' are not separate categories but different points on a continuum. All handicapped people (in the context of this survey) are impaired but not all impaired people are handicapped. An individual's ranking can change with time, and in either direction. Furthermore, because so many personal, social and environmental factors are involved in the state of being handicapped, it is possible for one person to be more handicapped than another person, even although the latter person has a greater degree of severity of impairment.

In the household survey, all those persons who were eligible for a screening interview were defined operationally as impaired people and all those eligible for an assessment of their needs as handicapped people. Those who were eligible for a screening interview but not for assessment were defined as 'impaired only'. The group referred to as the handicapped people were all those in the following categories:-

1. The severely handicapped people, as assessed by the degree of restriction of mobility or of self-care activities based on the score attributed to answers to questions in the screening interview; and weighted for persons over the age of 70 years.
2. Those with very poor vision (estimated as the equivalent of less than 6/60 Snellen), or registered as blind or partially sighted.
3. Those with poor hearing and those who are not able to communicate with the interviewer due to deafness, or registered as deaf or hard of hearing.
4. Children needing special care or educational facilities.

This group of handicapped people is heterogeneous. The justification for grouping these people together is that they are the majority of handicapped people who are the concern of the social services department and the subjects of the Chronically Sick and Disabled Persons Act. Although each type of impairment has a propensity for its own related type of handicap, many of the problems are similar and many of the clients have more than one form of impairment.

#### Field Work

The research assistant completed a card for each of the 1608 people correctly identified as impaired in the first stage of the 1972 household survey. The name, address, age, sex, computer reference number, diagnosis and final status (handicapped, impaired only, interview not completed) allotted in the household survey were entered on the card. The cards were colour and symbol coded on the top left hand corner in order to facilitate handling and counting. The cards were filing cards (8" x 5" - 20 cms.x 12.5 cms.) and the whole set was carried to and used at each agency.



The checking was a straightforward operation of matching names on lists against the cards. A new card was added to the set when a person was found to be recorded by an agency but had not been identified in the household survey. This new card was checked against each of the subsequent agency lists. In this way a further group of people was identified - a group of people in contact with one or more of the helping agencies but who had not been identified by the household survey.

The detailed procedure followed with each agency had to vary depending upon the availability and contents of its records. The Social Services Department supplied copies of the blind, partially sighted and physically handicapped registers. The deaf and hard of hearing lists were obtained from the Canterbury Diocesan Association for the Deaf, who carried out the social work for the deaf as an agency for the county borough; these lists included people living beyond the city's boundaries. For the other agencies further decisions had to be taken about the duration of time during which help was given for the recipient to be included in the study. The household survey had lasted from May until November 1972; a period of six months, during which there could be (and were) changes in the conditions of people ascertained. However the 'entry' point for the household survey was the completion of the first form which had been delivered in early May 1972. It was therefore decided that the period that the agency survey was interested in ceased in June 1972. As a client may not receive regular and repeated services and may even have his or her needs met by one visit or discussion, the records over a period of time had to be examined. The final decision was to examine records covering the twelve months from July 1971 to June 1972, inclusive.

A number of difficulties arose from this type of period survey of records, in addition to the obvious ones of completeness and accuracy of the material recorded. People could have received a service during the months preceding the household survey and their total condition so improved that they did not consider themselves as impaired in the survey; their names will therefore be found on the agency's records, but, quite rightly, not on the list of people found by the household survey. Some people with non-progressive, but none-the-less severe, impairments might have received a service some time before July 1971, and have been identified in the household survey, but not on the agencies' lists. Inevitably, some people will have received a service during the months preceding the household survey and have been admitted to hospital or a home, moved out of the City or have died before the survey, in the same way that some people moved or died during the survey before the appropriate stage of the

survey had been completed in regard to them (see table 3). The agencies' records did not contain sufficient information for these points to be examined further.

A second range of difficulties arose in identifying the 'impaired' as a possible sub-group of all the clients of an agency. Not everyone being attended by the home nurse or home help is impaired within the definitions used in the household survey. Therefore, an effort had to be made to distinguish the possibly impaired clients from those who were probably not impaired. How this was done is stated in the paragraphs below in relation to each of the agencies whose complete lists were not used.

The number of people receiving a service will be effected by the adequacy, accessibility and quality of the service. The home nursing and health visiting services available in the City in 1972 were provided at a level somewhat above the national average (see table 4), but the home help service was below. No formal waiting lists for the services were maintained, but often the person in charge would have in mind the needs of recent applicants. There may therefore be a small number of people who were not identified in the agency's records but who were known to the agency and were about to receive a service.

#### The agencies' records

The home nursing service maintained a register of all patients visited during a calendar year, the ongoing cases being brought forward from the previous year. The register included the acutely ill as well as the chronically ill and apart from the inferences that could be made from the age, diagnosis and treatment given, contained no means of identifying those receiving help who were chronically sick and handicapped. The director of nursing services went through the registers and read out the name, address, age, sex and diagnosis of each patient she considered to be disabled or chronically sick. This produced a list of 538 names which was checked against the cards.

A somewhat similar procedure had to be adopted with the home help service. The home help supervisor went through her registers and read out the names and addresses of those clients she assessed as elderly or handicapped. Little additional information was given and it was not possible to separate the impaired from the elderly frail and again reliance had to be placed on a blend of subjective and objective information.

The list of patients to whom nursing aids were on loan was included in the home nursing register, and was provided by the senior nursing officer at the same time as the home nursing list was compiled. At that time equipment was also supplied by the British Red Cross Society medical loan department, but no information was recorded about the person being helped; indeed, the aid or appliance was often booked out to the person collecting it rather than to the patient.

The meals-on-wheels service was organised by the Womens Royal Voluntary Service. The director supplied a list of the recipients during the twelve month period. Like the home help service, this service was planned to be greatly expanded and the director stressed that she tried to spread her scarce resources in relation to her assessments of urgency of need and that the list could not be taken to reflect the numbers of impaired people who had been in contact with the service during the period of study.

About 200 physically handicapped and elderly patients attend the geriatric day hospital each week. The hospital serves a wider area than the City, so it was necessary to identify only persons living in the City. The list of patients who had been admitted to the geriatric department of the local district general hospital was checked after all other agencies' records had been examined, and, on this occasion only the accumulated set of cards was checked against the hospital register of patients. On all other occasions the reverse procedure was adopted. The hospital serves a wide area and the patients' cards are kept in alphabetical order of surname and not by year of admission or re-admission.

The health visitors were attached to general practices and no central case records or case registers were kept. Before the household survey the chairman of the social services committee had asked for a list to be compiled by the medical officer of health and the director of nursing services. Interestingly, this request produced only 17 names and addresses, although this probably reflected a lack of understanding and clear definition of what was meant by 'handicapped person'. The household survey found that only 66 handicapped people mentioned contact with a health visitor.

No records were kept of persons receiving the domiciliary laundry service. The laundry was cleaned at the local hospital and the list used in this study was compiled from the receipt book of the man who did the collecting and delivery.

A somewhat similar procedure had to be adopted to compile a list of persons who had had their accommodation adapted in any way to facilitate movement or daily living activities. Here, the source of information was a book of counterfoils of the work done. However the list is defective to the extent that the work was 'booked' to the tenant who may not be the handicapped person (e.g. the tenant may be the son-in-law of the handicapped person) and when an adapted house was vacated the housing department tried to move in another handicapped person (so more handicapped people could have been helped than would be recorded). No specific records were kept about re-housing the handicapped. A large number (said to be 'hundreds') of applications are made to the Housing Department every year and very many of these are supported by a medical certificate.

The attendance records at one club for the physically handicapped and at the hard of hearing club were checked; however all of the persons attending the former had to be registered so they were not counted separately. Mention has already been made of the lack of usable records maintained by the social clubs; the difficulty arose from their sensible policy of encouraging spouses and friends to participate and of not separately identifying the handicapped people from the lonely or the visitors.

The school medical officer for the county borough supplied four lists of handicapped pupils. These were of handicapped pupils at residential schools, of handicapped pupils at special day schools, of severely mentally handicapped children and of educationally subnormal children.

Finally, the list of persons attending the adult training centre was compiled by the secretary of the centre reading out to the research assistant the names and addresses of persons attending who had a City address.

#### RESULTS

This study demonstrated the complexity of the operation of searching records and registers from a number of different statutory and voluntary agencies who whilst undoubtedly helping handicapped people are also helping many other groups of people. It is possible that throughout the country, there are individual services maintaining detailed and meticulous records of patients and clients that could provide the data required in order to identify handicapped people from among those recorded. But it is unlikely that many local authority departments and local branches of voluntary bodies in one area maintain more detailed and accessible records than their counterparts in

Canterbury. The general impression of people who have worked for a number of authorities is that the standard of recording in Canterbury in 1972 was not abnormal and that because of the City's small size the quality of the subjectively recalled information and of 'grapevine' up-dating may well be better than in larger cities.

The survey of the agencies' records was far more economical of resources than the household survey, but it did occupy a research assistant for 25 hours per week for 16 weeks, to say nothing of the time of the directors and staff of the services.

#### Household Survey compared to agencies' surveys

The two surveys produced lists with substantial differences. The survey of the registers and records of the agencies yielded a list of 907 persons as being recorded in receipt of a service or registered and living in the community (i.e. outside institutions) in the City during the period from July 1, 1971 to June 30, 1972. The household survey carried out mainly in May and June 1972 identified 1608 impaired persons. The number of persons identified in both of the procedures was 586, that is 65 per cent of persons on the registers and records list were identified in the household survey, and, the other way round, 36 per cent of the persons identified by the household survey were also identified by the search of registers and records. The 1608 impaired persons were divided into three groups in the household survey - those who were classified as handicapped (770 people), those who were impaired only (706 people) and the group for whom interviews were not completed (132 people) (table 3). Of the 770 handicapped people, 52 per cent were identified on the registers and records list, of the 706 impaired only people, 21 per cent were so identified and of those with incomplete interviews 26 per cent (table 5).

#### Registers

One would expect to find close agreement between the information from the household survey and that from the statutory registers, as questions about statutory registration of the blind, partially sighted, deaf and hard of hearing were asked in the household survey and a positive answer automatically meant assessment as a handicapped person. However no question was asked about registration in the general classes (physically handicapped) category. The results are set out in table 6. For all of the registers, except the hard of hearing, between 87 and 94 per cent of those people who were registered had been identified in the household survey; for the hard-of-hearing the figure was

only 67 per cent (10 out of 15). Whilst these findings are reassuring, insofar as they go, for the validity of the household survey, they do not add any information about the completeness of the registers. During 1972 the numbers of persons registered in Canterbury per 1000 of the population were of a similar order to the numbers registered nationally. It has been found in community surveys that the numbers registered in all categories (except the blind) are substantially below the numbers that might be registered; and the 1972 household survey found that the situation in Canterbury did not differ markedly from those reported elsewhere.

#### Agencies having most contact with handicapped people

Turning now to the lists derived from the agencies' records (table 7), a striking feature is the dominance of the home nursing and home help services, followed, but at some distance, by the day hospital, meals-on-wheels and nursing aids. For all of the services for adults, almost half or more of the people listed from the agencies' records were also identified by the household study. However this means that a substantial number of people were listed that were either 'missed' by or whose condition did not come within the definitions of impairment used in the household survey. Furthermore, the findings show that no single agency was in contact with more than 15 per cent of the 1608 persons identified in the household survey (home nursing service).

The conclusions are inescapable that the agencies' records cannot be used to provide anything approaching a complete list of handicapped people in the community, and any list derived from the agencies' records will contain a substantial number of people who may not be, or do not consider themselves to be, handicapped, and will leave out an even larger number of people who would consider themselves impaired or handicapped.

#### Numbers of persons in receipt of multiple services

Table 8 sets out the number of persons identified in the household survey by the number of agencies and registers recording them, and shows the persons identified in the household survey either as handicapped or as impaired only and including those whose interviews were incomplete. One thousand and twenty two of the 1608 people identified in the household survey were not listed in the registers and agencies' records; the majority of these (64 per cent) had been classified in the household survey as impaired only. The majority of persons who were both listed by an agency and ascertained in the household survey were classified as 'handicapped', the proportion rising from 66 per cent of those recorded by one agency to 85 per cent of those recorded by four or more

agencies. As a number of people recorded by 3 or more of the agencies died between the first and second stage of the household survey it is very probable that such people would have been classified as handicapped and so the proportion would have been even higher. It appears, therefore, that the increasing number of services involved in the care of an individual is likely to reflect, among other factors, the increasing severity of the impairment. However, as the actual number of persons receiving a multiplicity of services is relatively small, the use of the utilisation of a number of services as a discriminating factor to identify handicapped people would produce a low yield.

#### ACCURACY AND REPRESENTATIVENESS OF THE RESULTS

##### Completeness of the household survey

The first question to be examined is:- Did the household survey miss substantial numbers of impaired people? The household survey depended upon an efficient delivery and collection system of the initial form and the cooperation of the householder and his identification of any person who might be impaired. The response rate was high, but the survey in 1972 did not check on the non-responders or on those who replied that there were no impaired people in the household. The agencies' survey identified 321 persons who were recorded by an agency but who had not been identified as impaired by the household survey. Contact had been made by the household survey with 293 (91 per cent) of the households at the addresses recorded by the agencies. Half of these households had returned a form which gave no indication of an impaired person being present (see table 9). A further 69 (21 per cent) had been identified in the survey as an elderly person living alone and had been referred to the health department but had not been reported as impaired. In 22 households another person was identified as impaired, so contact would have been made with the household. Twenty six of the households refused actively to complete a form. Fourteen did not respond and 28 of the people listed by the agencies lived at addresses not identified in the survey (these could be due to wrong, incomplete or out-of-date addresses in the agencies' records, or omissions from the electoral roll and its up-dating during the fieldwork).

There is therefore the possibility that 42 persons listed by the agencies were not contacted by the household survey. There is also the possibility that some impaired persons might have incorrectly completed the initial form, and a few have refused or not responded. The more reliable data refer to the registers of handicapped persons, and these are shown in table 10. If it is

argued that the 24 (10 per cent) of 231 persons registered, who returned a negative reply, refused or did not reply, and that the same percentage of other categories did likewise, then the household survey would be deficient by that percentage or 160 persons. In a small pilot study (Jefferys, Hyman, Millard and Warren, 1969) carried out as part of the preliminary work to the national sample study (Harris, 1971) 10 per cent of households who had returned a negative reply were found to contain a person who had some degree of physical impairment; but all of these people were women over the age of 75 years who had answered negatively because they attributed their difficulties to the 'natural' limitations of old age. Similar factors might have operated in the Canterbury household survey. There is no evidence to suggest that the shortfall of the household survey was greater than 10 per cent. It was probably less than this, because some of the people listed by the agencies will have died, been admitted to a home or hospital or have left the area between receipt of service and the first approach by the household survey.

No data are available about those who refused or returned a negative reply but were not in contact with any service approached. This group could contain severely impaired people who are strongly determined or unwilling to seek any form of statutory or voluntary help.

#### Accuracy of handicapped persons' statements about contact with services

This section examines the extent to which people who told the interviewers in the household survey that they were in contact with a service were found on the list derived from that agency's records. In the household survey each person was asked during the first interview whether they were registered as blind, partially sighted, deaf or hard of hearing and during the second interview whether they were in regular contact with a number of services. The home nursing service is examined here as correlation with the four registers has already been discussed. In 1972, 133 handicapped persons stated that the home nurse was in attendance, 112 of these people were also listed from the nursing services' records. Of the remaining 21 people, in 16 instances the nurse had started visiting after June 1972 (the end date for the survey of agencies' records) but still during the period of the household survey, thus whilst the handicapped person was correct in stating the nurse was in attendance, the nursing records could not have been used to identify the person as handicapped in the preceding May or June. In a further 4 cases the home nurse was recorded as visiting another member of the household and in only one case was there no apparent record. Certainly then, as far as persons answered positively about the home nursing service, they gave accurate answers to the question. However,



there were 49 people listed from the home nursing service's records who did not state they were in regular contact. It is possible that some of these people had had the service some months before the household survey and so were not in contact at the time of the survey.

#### Representativeness of the results from the agencies' survey

Accepting that the positive statements of persons interviewed are likely to be correct about their contacts with services, then the proportion of handicapped people who stated that they were in contact with a service can be compared to the proportion recorded in the agencies' survey and in the national sample survey (Harris, 1971). The results are presented in table 11. No questions were asked in the 1972 Canterbury household survey about registration in the general classes with social services departments, nor about home helps in attendance. For the home nursing, home help and meals-on-wheels services the agencies' survey yielded a greater proportion of handicapped people to be in receipt of the service than did the household survey, but it must be remembered that the record search covered a year of possible contact, whereas the household survey's figures are based on one or two contacts only. The figures from the agencies' survey are lower for house adaptations and for contacts with the health visitors. It is probable that a number of handicapped people, particularly owner-occupiers, make their own arrangements for installing hand-rails, bath rails, etc., and so would not be recorded by housing department records. The list of health visitors' contacts used in the Canterbury agencies' survey has already been stated to be defective; when interviewed 9 per cent of the handicapped people stated they were in contact with a health visitor. Bearing these points in mind, it is concluded that there is reasonable compatibility between the findings from the different studies.

#### DISCUSSION

The aggregation of information from the records of a number of agencies providing services to handicapped and other people in order to compile one list of handicapped people is a time-consuming procedure, abounding with difficulties due to incomplete information and lack of agreed definitions; and the procedure cannot identify people in need who are not already in contact with a service. The list compiled in this way in Canterbury contained the names of 36 per cent of the list of handicapped and other impaired persons identified by a household survey. Sixty five per cent of the names derived from the survey of agencies' records had been identified as handicapped or

otherwise impaired people in the household survey. Further work is required to develop an effective and efficient method of finding handicapped people in need of help and eligible for new services. Current efforts to produce agreed definitions of levels of impairment, disability and handicap will help. But a system of periodic contact with every household seems to be necessary. This could be developed by postal enquiry using questionnaires to be completed by the householder and by designing schedules to be used by trained volunteer interviewers allocated to neighbourhoods and by professional workers (e.g. home nurses, health visitors and social workers and their assistants) in contact with potentially handicapped people. The Health Services Research Unit is planning to develop such schedules based on the analyses of the schedules used in its previous studies. The objective would be to produce a reliable method of location and referral to the correct agency of potentially handicapped people.

The present study shows yet again that the majority of handicapped people are not on the registers. It is, therefore, inappropriate to use the number of persons registered as handicapped as an index of activity on behalf of and concern for handicapped people in any area or to rely on the registers as the central list of handicapped people. Help for handicapped people and the act of registration can be distinct and unconnected events as has been shown in the distribution of service provision in the surveys. What may be required in addition to an improved method of ascertainment is a system akin to that of psychiatric case registers (D.H.S.S. 1974; Wing and Hailey, 1972). The case register is an administrative device relating to events occurring in a defined area and population (so that results can be expressed as ratios) and therefore some comparability between areas can be obtained; it should aim at completeness; the information should be person-linked (rather than or in addition to event, service or diagnosis linked) so as to avoid duplicate counts and enable identification of persons with multiple handicaps and in receipt of a combination of services; the registers should be cumulative and up-dated. They should be used in the care of the registered person. Whilst the need for some form of statutory registration of handicapped people seems doubtful, the uses of case-registers based on case-records could benefit the handicapped people, by providing a basis for coordination of effort, communication, anticipatory help and follow-up. The experience from the Canterbury surveys emphasises the need to bring together information from different statutory and voluntary services, and highlights many of the difficulties, including the lack of any consistent scheme of definitions.

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TABLE 1

List of Registers of Handicapped People  
Maintained by Local Authorities in accordance  
with the National Assistance Act, 1948

Blind	Partially sighted
Deaf	Hard of hearing
Handicapped (General)	

TABLE 2

List of Agencies whose Records were  
included in the Survey

Home nursing	Housing adaptations
Home help	Hard of Hearing Club
Home nursing aids	Residential special schools
W.R.V.S. meals-on-wheels	Day special schools
Day hospital	School for severely subnormal
Geriatric inpatients	School for educationally subnormal
Health visiting	Adult training centre
Laundry service	

TABLE 3

Summary of Response to the 1972 Household Survey to identify Impaired and Handicapped Persons

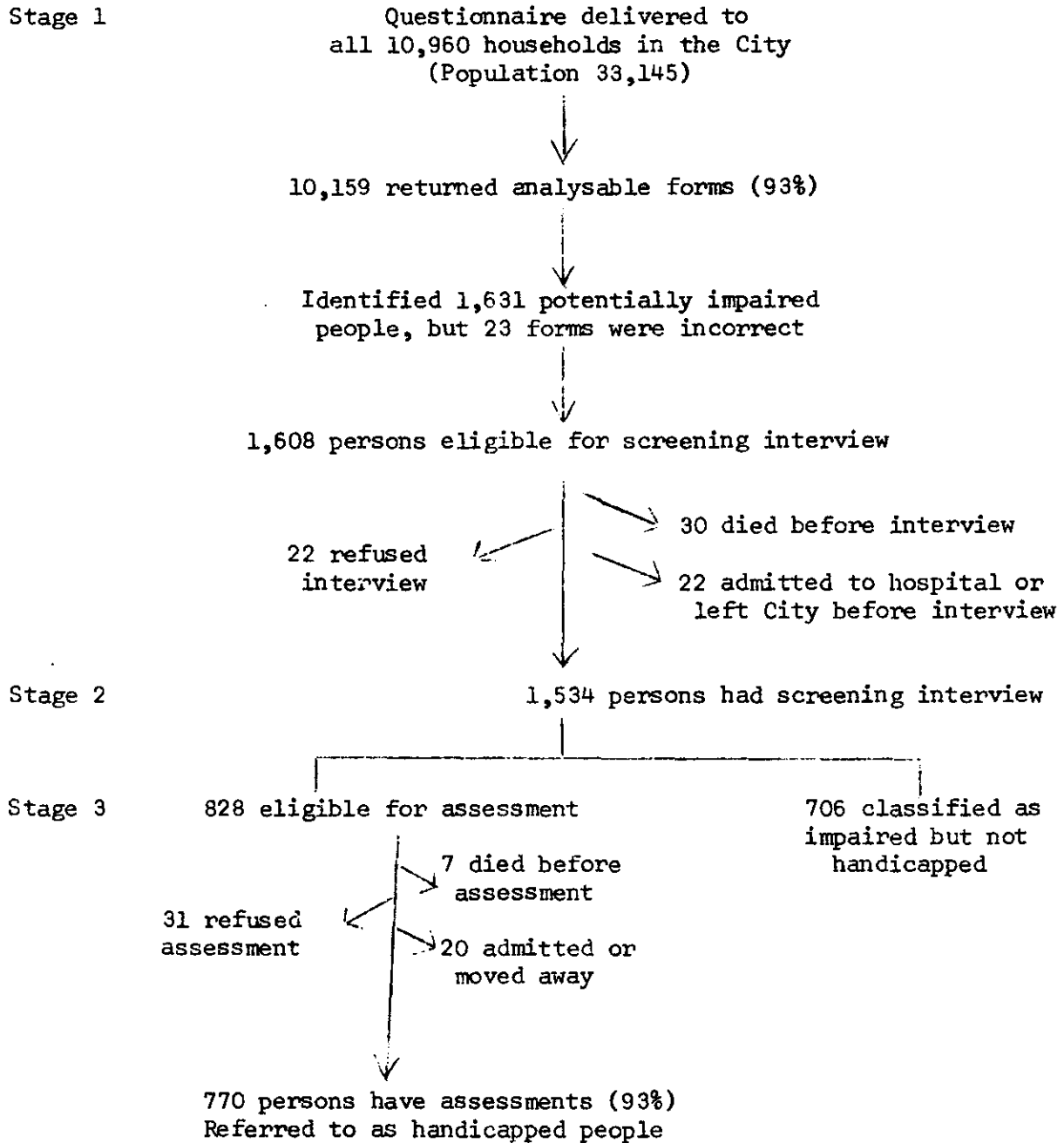


TABLE 4

Resources available in Canterbury 1972

Resource	Canterbury 1972-3 WTE/per 1000 population	National* average provision 1973
Home nursing	0.27	0.22
Home helps	0.69	0.86
Health visitor	0.19	0.13

\* D.H.S.S. 1974 Health and Personal Social Services  
Statistics for England.

TABLE 5

Numbers found in register and record search  
by category allotted in the household survey

Agencies' survey	Household survey category					Total
	Handi- capped	Impaired only	Survey stages 2 or 3 not completed but indicated	Negative form returned from the address refused or no response	Address not identified*	
Listed	402	150	34	293	28	907
Not listed	368	556	98	-	-	1022
Total	770	706	132	293	28	1929

\* See Table 9 and text for further details

TABLE 6

Numbers of people on register  
and numbers of registered people  
identified by household survey

Register	Total no. on register	Number in community*	Number on Register identified in household survey**	Percent of all in community who were identified in household survey
Blind	96	75	66	88
Partially sighted	20	16	15	94
Deaf	8	8	7	87
Hard of hearing	15	15	10	67
Handicapped (general)	119	117	109	93

\* This is the total number registered minus persons known to be residents in homes or hostels.

\*\* This column refers to the matching of the person, and not to a check of whether the person stated in the household survey that he was registered. The figures, therefore, are not the same as in Table 3.2 of Canterbury Survey Report (Warren, 1974).

TABLE 7

Numbers of people listed from each agency's records and numbers of those people identified both by the agencies' survey and by the household survey

Agency	Number of people listed from each agency	Number of people listed and identified in household survey as handicapped or otherwise impaired	Percent of all persons identified in household survey who were listed by the agency N = 1608	Percent of all persons listed by the agency who were identified in household survey
Home nursing	538	242	15	45
Home help	332	202	13	61
Home nursing aids	84	57	3	68
WRVS meals-on-wheels	92	62	4	67
Day hospital	116	63	4	54
Geriatric inpatients	*	47	-	-
Housing adaptations	58	51	3	88
Health visiting	17	12	-	70
Laundry service	30	11	-	37
Hard of hearing club	*	11	-	-
Residential special schools	24	11	-	46
Day special schools	32	12	-	37
School for severely sub-normal	13	12	-	92
School for educationally sub-normal	24	6	-	25
Adult training centre	31	19	1	61

\* Served an area beyond the city's boundaries



TABLE 8

Impaired persons by number of agencies  
and registers recording them

Identified in household survey as:-	Number of agencies and registers recording persons					
	0	1	2	3	4+	Total
Handicapped	368	209	88	58	47	770
Impaired only or interviews incomplete	654	109	42	25*	8**	838
Total (household survey)	1022	318	130	83	55	1608
Not identified as handicapped or impaired in household survey	-	239	58	17	7	321
Total (both surveys)	1022	557	188	100	62	1929

\*10    \*\* 3 died or admitted before first interview.

TABLE 9

Household returns from addresses given by agencies  
of 321 persons recorded by agencies  
but not identified as impaired by household survey\*

Household returned 'negative' reply	162
Household response 'elderly living alone'	69
Household identified another person as impaired	22
Refusal	26
No response	14
'Household' not identified in survey	28
<hr/>	
Total	321
<hr/>	

\* Some of the people listed from the agencies' records may have been admitted to hospital, moved away or died by the time of the household survey.

TABLE 10

Response of persons registered as handicapped persons

Register	Number registered in community	Number in col. 2 identified in survey	Number in households who:-		
			Returned negative replies	Refused	Did not respond
Blind	75	66	2	5	2
Partially sighted	16	15	1	-	-
Deaf	8	7	-	-	1
Hard of hearing	15	10	3	1	1
Physically handicapped	117	109	3	4	1
Totals	231	207	9	10	5

TABLE 11

Numbers and percentage of all handicapped people recorded by the agencies compared to the statements made about contacts by the handicapped people in the Canterbury household survey and the national sample survey (Harris)

Agency recording or mentioned	Canterbury agency survey 1971-72 Records	Canterbury household survey 1972 Interviews	National sample O.P.C.S. survey (Aged 16 years +) 1968-69 Interviews percent only
Register (general classes)	67 (9)	Not available	(12)
Home nursing	171 (22)	133 (17)	(14)
Home help	135 (18)	Not available	(13)
Meals-on-wheels	45 (6)	35 (5)	(4)
House adaptations	40 (5)	(Estimate 10)	(Estimate 10-20)
Health visiting	8 (1)	66 (9)	(6)
	N = 770	N = 770	N = 4529