THE EPIDEMIOLOGY OF VISUAL DISABILITY

STUDIES OF VISUALLY DISABLED PEOPLE IN THE COMMUNITY

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SUMMARY

Review of the world literature on attempts to discover how many people are disabled by poor sight suggested that estimates of prevalence and cause have been constantly hampered by differences of definition, and the difficulties inherent in equating reduced visual acuity with the hardship that it actually causes to each individual in his whole social environment. Attempts have been made to overcome these difficulties by population survey techniques using both self identification alone and self identification followed by visual acuity measurement, but they have seldom covered whole populations and have usually been constrained by the relatively low level of acuity by which most countries define their blind and partially sighted people. Other approaches, through registers and hospital records, though sometimes providing a more comprehensive picture of the diseases leading to poor sight, have not fully analysed the social and other processes leading to selection and have not therefore been able to provide population estimates of prevalence. On the other hand, purely social studies, while sometimes comprehensive, have always used a low level of sight - usually 'blindness' - as a starting point and have tended to ascribe all hardship to the single cause without exploring the possible relationships with other disabling conditions.

An attempt to overcome these difficulties was made by analysing the comprehensive data on the visually disabled from the Canterbury Survey of the Handicapped (1974). The W.H.O. definition of 'visual impairment' (visual acuity of less than 6/18 Snellen) was used as a definition of visual disability and 180 people identifying a difficulty with distant or near vision, or both, were sight tested at home. Sixty of these were already registered as blind or partially sighted. Only 71% of those identifying a difficulty were found to be within the W.H.O. definition and a full analysis of the daily problems, other disabilities, home conditions and social support of these was made. Eighty per cent of the visually disabled were over retirement age, 79% had at least one other major disability than poor vision, and

62% needed, at least, the help of another person in travelling beyond the house. Half of them, however, could manage all the daily routines of self-care without help and the difficulties experienced by the rest were probably as much caused by other disabilities as by poor sight. Forty-one per cent (mostly elderly widows) of the visually disabled lived alone - a significantly higher proportion than of all the disabled in the survey. Sight-testing suggested that the blind register underestimated the true numbers potentially eligible for registration in the community by about 30% and the partial sight register by about 20%. For those with a distance vision below 6/18 there was poor correlation between distance and near vision when tested at home. The questions used in the survey, when compared to the test results, proved to be poor indicators of who was visually impaired by W.H.O. standards but good indicators of who might qualify for registration as blind or partially sighted by U.K. definition.

Permission was obtained from all who identified a difficulty with vision to search any hospital, social service, opticians' and general practitioners' records that might be available. Diagnostic data were obtained for 67% of those who gave permission; 39% had hospital records dated within two years of the survey, 16% at an earlier date than two years, 10% had social service data only, stored on B.D.8 forms, while a remaining 1.5% had only general practitioner records of their eye diagnosis. Opticians' records did not add to the diagnostic data.

Sight tests done at home, both for distance and near vision, corresponded fairly well to sight tests done at the hospital within two years, but for the 34% for whom there was some difference in the measurement of distance vision almost all did better at the hospital than at home. Only 26 of the 60 who had recently attended the hospital had had a near vision test recorded; comparison between home and hospital tests, based on these small numbers, was approximately the same as for distance vision. Diagnostic data were found for only 65%

of the visually disabled - macular degeneration (19%) followed by cataract (18%), myopic error (13%) and glaucoma (11%) were the principle causes diagnosed. Twenty eight per cent of those who had at some time attended hospital for their eyes were attending another hospital clinic at the same time.

The survey and measurement techniques developed in Canterbury were then used to identify and follow up the visually disabled in a national survey of England and Wales mounted by the Centre for Socio-Legal Studies, Wolfson College, Oxford. Two hundred and fifteen adults from 14,866 households in a stratified clustered design identified some difficulty in "seeing to read or get about" and were interviewed in the second stage of the survey (1976-1977). Nearly half these (47.4%) proved to be visually disabled by definition (visual acuity less than 6/18) though another 20% had vision of no more than 6/18. Nearly 80% of the visually disabled were over retirement age; most lived in two person households with a spouse of similar age but nearly a quarter lived alone (13% being over 74 years).

Nearly half (48%) of the visually disabled had received a visit during the previous year from a health or social worker, but many more (87%) had at some time seen their family doctor about their main disability (not necessarily visual). Less than half (44%) of the visually disabled in fact described poor sight as their main problem and only another 12% mentioned it at all - the remaining 46% counted some other difficulty as of over-riding importance to them. Among these, the commonest conditions mentioned by name were ischaemic heart disease and osteo-arthritis, though there was no mechanism in the survey for the objective reporting of apparent deafness.

Most (70%) of the visually disabled had been out of the house within the previous week and another 12% within the previous month - only 12% were confined to the house by a physical disability. A full 74% claimed to travel, out of doors, independently without any aids at all. In the main they were

used to their home and outdoor surroundings - 66% having lived in the same house for over 10 years and 86% in the same district. Their household amenities compared well with those for the nation as a whole except, not surprisingly, in the availability of motor transport - only 21% lived in a household where a car was available. Few (7%) had been constrained from moving from their present accommodation by disability (not necessarily visual).

No data from the survey made it possible to quantify exactly any deficiency that existed in optical correction used by each respondent in performing the tests for distant and near visual acuity but there was some evidence that considerable inadequacy may have existed. Twenty two per cent of the visually disabled had no spectacles available for the distance test and 20% for the near vision test - though 8% used a low vision aid.

Most of those (80%) who considered poor sight their greatest problem had sought medical help for it and almost all had been referred to a specialist clinic. Hospital records were traced for 42% of the visually disabled and from other sources (mostly family doctors) for another 15%; it was estimated that 40% of the visually disabled had never had a diagnosis of their eye condition. All those who had been seen at a specialist clinic had a significant eye disease causing sight loss - cataract being the commonest (27% of those seen) followed by macular degeneration (15%) and glaucoma (8%). Finally, the suggestion from the Canterbury survey that many people seem to see better in a hospital clinic than they do at home was confirmed nationally - as many as 64% saw marginally or markedly worse in their own surroundings than they did in the hospital setting.

It was concluded from the study that it is no longer appropriate to regard visually disabled people living in the community as a homogenous

group troubled only by poor sight. Because of their age range many suffer other disabilities that may be of equal or greater importance to them and only by exploring the interaction of these can a true picture be gained of the help they need for their sight problems. Many have accepted increasingly poor sight as a natural concomittant of growing old and have sought no help for it, but the study showed that finding them in the community should not be difficult. Almost all have made recent contact with social and medical services and the simple definition of visual disability is within the competence of almost everybody. It was concluded that further studies should impose no questions between initial simple broadly based identification of a sight difficulty and measurement of acuity. The apparent differences between what many seem able to see at home and in the hospital were concluded to have components largely in lighting and correction but more work on this is needed. Finally, it was shown that present statutory definitions of blind and partial sight are poor indicators of who in the community needs help for their sight problems and that a wider concept such as that suggested by W.H.O. would be preferable. Estimates from the study suggest there are approximately 520 visually disabled adults per 100,000 adult home based population.

PART I

INTRODUCTION

INTRODUCTION

Clinical epidemiology is becoming increasingly involved with the problems of chronic degenerative diseases, and the disabilities they cause. These diseases, with origins more in the slow structural changes of advancing years than in the rapid changes brought about by contact with a single external agent, demand for their alleviation a less rigid adherence to purely clinical definitions than did the more precise pathological entities of epidemiology's childhood. For this definition, descriptions are needed which accommodate not only the physiological and pathological process of the disease but the whole social situation of each individual afflicted by it. This is important because, unlike diseases of quick onset, only seldom does the pathology of any chronic disease, with a course measured in decades rather than in days or weeks, adequately describe the disability it causes at any single point in its natural history, early or late. Unless the accommodation, physical psychological and social, that each individual has made to his disease with varying success over the years can be adequately described in epidemiological studies, no mere presentation of the breadth and depth of the disease in traditional medical terms will do much to enhance the alleviation of the disability it causes. Purely clinical definitions of disease, which suit all patients in all places, are no longer enough.

To the epidemiologist falls the task of reconciling the clinician's model of disease process with the social scientist's interest in the disability it causes. The difficulty lies in getting the balance right. To describe only the pathology of the disease in traditional medical terms, and to produce statements of incidence and prevalence based on them alone, is to lift the disease clear of the social and psychological effects it has had on the individual and to deny that those effects could in any way influence its natural history. But to lose all sight of the clinical and pathological definition of the disease and to describe only disability is to forfeit all chance of indicating where modern medical intervention may be most efficient and effective.

These difficulties and differences have been very pronounced over a long period in the field of failing sight. On the one hand a vast literature, indeed a whole descriptive science, has built up round the difficulties, physical, psychological and social that visually disabled people face in coping with an ever more complex society. On the other, ophthalmological techniques, ever more refined and exquisite, continue to be developed for dealing with sight threatening eye diseases whose definition and clinical measurement are not more closely related to the disabilities they cause than they were fifty years ago. Despite great progress on both sides the single tenuous link that holds them together - the largely subjective measurement of visual acuity that defines statutory disability on one hand and clinical progress on the other - is not now any stronger or more refined than it has ever been.

Our medical services are not geared to the long accurate follow-up and continued reassessment of patients with slow sight-threatening disease, or indeed any degenerative condition, and because of this singularly little is known of the natural history of most degenerative diseases. Moreover, the long term accommodation that the individual makes to them is achieved out of sight of the clinician and he has little chance of learning from them. Partly for historical reasons, and partly because modern medicine has not noisily declared itself interested, a slow deterioration in vision is accepted in all societies as a natural process of growing old and so the insidious onset of sight-threatening disease may often pass unnoticed until it has progressed beyond the point where medical science can cure or even alleviate. For this reason, no accurate estimate of the number of people who are truly disabled by poor sight can be had from the records of all those who have presented themselves for help.

On the other hand, society is used to defining as 'blind' - as in need of statutory help and therefore known and listed - only those for whom no more medical help is available, and so the records of those so defined are an

equally poor estimate of all in the community who might be helped. The epidemiologist, having reset his definitions to accommodate both clinical and social realities, must actively seek in the community for those disabled by poor sight. The most practical way of doing this is by means of a cross sectional study, for no longitudinal or cohort study would be feasible for such chronic conditions. Descriptions of two such studies - one which included every household in a single town (Canterbury) and a second, following from the first, which was based on a random survey of households in England and Wales - form the main parts of this thesis (Part III and Part IV). The conclusions drawn from the studies are presented in Part V.

A prerequisite, however, of all epidemiological work is an assessment of what has already been done in the field - not only to avoid repetition, but to learn from others' experience what tools and techniques have proved useful in the past. Such an assessment, in the form of a literature review, forms Part II of this work - it illustrates quite extensively the dichotomies already described between approaches that have depended on the quantification of clinically measured eye diseases and those that have depended on the quantification of the social and personal disabilities they cause. It becomes possible in the conclusions from the two studies (Part V) to return to some aspects of those traditional approaches and suggest ways in which definitions might be reconciled for working purposes.

The descriptions of both surveys (Part III and Part IV) are preceded by details of their design and coverage. Neither survey concerned visually disabled people alone - each was a wider study of either general or particular disabilities and therefore it is necessary to describe them in some detail to show where the visually disabled fitted in. Perhaps even more important, however, is that such details allow an assessment of the strengths and weaknesses of the epidemiolgoical methods used and, so, their refinement for the future.

Indeed it is partly a failure to analyse weaknesses of method in the past that has led to some of the repetitive and inconclusive studies described in reviewing the literature. The techniques used to find, measure and study visually disabled people and their difficulties in the national study (Part IV) were a direct result of experience gained and analysed in the local survey (Part III) and, together, presented in detail, they form some sort of validated and tested method as a starting point for future work.

If cost had been no object, then it would have been possible to mount studies in which the prevalence of the various diseases that threaten sight in the community was as fully explored as the social and demographic characteristics of those disabled by them. As it is, only estimates can be made of the prevalence of these diseases from the present study, largely because many elderly people disabled by poor sight have apparently never sought professional help for it. Clearly a true reconciliation of the clinical definitions of diseases and the disabilities they cause in terms that would make easier the alleviation of both depends to some extent on the epidemiologist's ability to present data that satisfies the needs of each side. Only then can a mutual drawing together take place that will lead to organisational changes in the arrangements of health care that will make it easier for visually disabled people, many of them elderly, to seek and obtain the continuing help they undoubtedly need. The present study goes some way towards achieving this.

PART II

REVIEW OF WORLD LITERATURE

REVIEW OF WORLD LITERATURE

INTRODUCTION

This section reviews world experience of studies of the epidemiology of partial sight and blindness, especially as it concerns populations such as that of the United Kingdom. It is not a comprehensive review of all that has ever been written; work has been selected only to illustrate the variety of approaches adopted and the difficulties in data collection and definition that have beset all attempts to establish accurate estimates of the numbers suffering from 'partial sight' and 'blindness', the aetiology of their impairments and the extent of their disabilities.

DEFINITIONS

In 1973 the World Health Organization[107] (W.H.O.) defined Public Health Ophthalmology as "a discipline that encompasses the comprehensive community approach to the promotion of eye health and particularly to the prevention of disability due to visual impairment and blindness". It was also stated that the basic tools needed for research and practice in this field, in addition to clinical knowledge, are "epidemiology and modern management procedures". Such a discipline is unlikely to progress beyond infancy, (and certainly unlikely to achieve the all-important goal of prevention) without accurate definition of the problems it is trying to tackle. Such definition, of numbers, of cause of impairment, and of extent of 'disability', has proved a constant stumbling block so far.

There are at least 67 different definitions of 'blindness' in use round the world[72]. Although most countries can agree a definition of total blindness as "an inability to perceive light in either eye", they have not agreed a definition of blindness which is less than total and which affects at least 30,000,000 people in the world with a visual disability profound enough to

amount to 'economic', 'social' or 'legal blindness'*.

Page (1974)[76] considers this an underestimate because it is based on the estimated ratios in developed countries of the 'blind' and 'partially sighted' - ratios he considers inapplicable universally, even if the estimates on which they are based were correct.

Variance in definition stems from three basic difficulties. The first of these is the perennial difficulty of collecting data in terms that will satisfy both the needs of epidemiological accuracy and those of service provision. Goldstein[29] has said that "the obligations that a society assumes towards the blind in various countries is a prime determinant of the definition of blindness which is accepted in that country". Such obligations include the provision of education, services, and financial help as well as release from social obligation; where one or all of these is thought to be impossible there is little stimulus to make an accurate and regularly updated count of the 'blind', much less the 'partially sighted'. Thus in Nizetic's (1975)[72] review of world 'blindness' (however defined) 46% of 117 countries provided figures more than 25 years out of date. Mann (1966)[64] provides several examples of 'one off' local surveys of 'blindness' in countries which had little to offer those so defined. The surveys were usually done by outsiders and the definitions, where any were cited at all, invariably came near to 'total blindness'.

The second difficulty that besets definitions is a combination of the age structure of different populations and the eye diseases which prevail. Terms which define the visual impairments of an ageing population suffering largely from macular degeneration, say, in the United Kingdom are clearly unsuited to children suffering from xerophthalmia in the Sudan, or working men with trachoma in Arabia. But even within one country, as Schon (1972)[80] has pointed out, definitions can become dated. Thus in the United Kingdom, where

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*These terms, loosely based on those adopted in 1934 by the American Medical Association[76], will be used in a general and largely self explanatory sense in this paper. 'Economic' implies loss of earning ability, 'social' loss of social function, and 'legal' entitlement to whatever provision the community offers.

an estimated 80% of the blind and partially sighted are over retirement age, registration as 'blind' still depends on an "inability to perform any work for which eye sight is essential". There is no mention of leisure enjoyment or mobility which is of far more importance to the elderly.

The third difficulty lies in distinguishing between visual acuity (i.e. what the eye and its central nervous pathways can be shown, by simple tests, to be capable of) and visual ability (what is actually being achieved, visually, with that acuity). In general those countries that have the means of measuring visual acuity (including easily available access to such measurement) use these measurements as a basis for defining and estimating their 'blind' populations (usually in the sense of 'legally blind'). Where such means are lacking, visual ability is more often used. Thus the Canadian definition of blindness is "a central visual acuity of 6/60 (Snellen) or less in both eyes, even with best correction, or reduction of the field of vision to less than 20 degrees" and the Zambian "inability to move about in unfamiliar surroundings unaided, such aid including the blind man's stick".

Neither system is satisfactory; the one because it is but a poor estimate of what each visually impaired person is actually able to achieve and the other because it must of necessity exclude a great deal of visual disability which falls short of blindness. However, even developed countries with the fiscal, service and organisational ability to offer help to visually disabled people of approximately equivalent age structure and economic status have not found it easier to come to a common concept of the measurement of need. In countries where access to help depends entirely on measurement of optical capability (e.g. Canada, New Zealand and much of the U.S.A.) the numbers of those registered as blind, however generous the definition, has always conflicted with estimates derived from self-assessment questionnaires[29], [61], [34], [25]. On the other hand, where 'legal' blindness, in an effort to make service provision more equitable, embraces both a concept of visual acuity and visual

ability (as, typically, the United Kingdom) the opportunity for internationally comparable estimates is lost, while effective registration, particularly that of the 'partially sighted', is not necessarily gained[89].

In an effort to obviate these difficulties and to provide "a generally accepted definition of blindness and visual impairment" the W.H.O. Study Group (1973)[107] devised a system of classification which views the more severe degrees of visual impairment as a continuum reaching down to total blindness (Appendix 1, Part II)

This classification encompasses all national definitions that depend on optical measurement alone but, of course, none of those that include, or consist solely of, perceived visual ability. Moreover, the inclusion of visual field as a determinant has made population screening in countries without trained personel more difficult yet. Nevertheless, international standards are clearly necessary and it would seem both feasible and sensible for each society to present published estimates, where measurement is possible, on these standards, while at the same time basing its service provision on much more society-determined estimates of need.

The W.H.O. definition of visual impairment (Appendix I), at least as it involves visual acuity and not visual fields, has been taken for the sake of the present research as a definition of 'visual disability'. That is, everyone with a measured distance visual acuity of less than 6/18 (Snellen) is considered to be visually disabled. The term 'impairment' is used in the same sense as it was in the Canterbury Survey of Handicapped People (1974)[98]; that is, as some significantly defective organ or bodily system. While all those defined for the purpose of the studies as visually disabled certainly had an impairment of vision, so also does anyone who needs no more than corrective lenses to achieve full sight. To impose an upper limit on a definition of disability, especially one that depends on a single measurement of

visual acuity, is to an extent arbitrary and there will doubtless be some in the community who consider themselves disabled by poor sight and yet are not so defined. But all epidemiological studies need operational definitions and this one not only suits internationally agreed standards, but provides a much more generous grouping than has been used hitherto.

The term 'handicap' is defined, as it was in the Canterbury survey[98], as an inability or difficulty in performing certain activities as a result of having an impairment. Thus it depends for its use not only on a detailed knowledge of the extent of impairment but on a definition of the activities to be performed - usually the activities of daily living judged with each individual's aspiration in mind.

STUDIES OF PREVALENCE OF VISUAL DISABILITY

Historically, estimates of the number of people disabled by sight problems in a community have originated from four different sources. The first has relied on the self-identification of those considering themselves visually disabled in censuses or other population surveys; the second on the actual sight testing of whole populations or of those identifying a sight difficulty; the third on the study of special groups and the fourth on the examination of registers. Nizetic (1975)[72] has summarised the use by different countries of these methods. Of the 117 countries he reviews 47 (40%) depend on census counts, 43 (37%) on 'estimates', 12 (10%) on surveys and 11 (9%) on examination of registers. These last comprise Belgium, Canada, England and Wales, El Salvador, Faroe Islands, Guadaloupe, New Zealand, Northern Ireland, Scotland, South Africa and Zanzibar - with very varied visual problems and equipment to identify them.

CENSUS RETURNS AND POPULATION SURVEYS

The National Census of the United Kingdom included Blindness Returns as a regular feature between 1851 and 1911[88] - since then no questions to identify the prevalence of 'blindness' or 'partial sight' have been included. However, questions designed to identify the 'blind' were a constant feature of the U.S.A. decennial census between 1830 and 1940. Such self reporting depends on answers to pre-formed questions and clearly these questions have very different relevance to different people. The inaccuracies to which this method gave rise first became apparent in the 1930's in the U.S.A.[29]. The census returns, when compared with local surveys and registration, seemed to be greatly underestimating the numbers of the truly (legally) blind. This appeared to be largely due to a very natural unwillingness to be identified as blind in a census return, and this seems to be a constant feature of all national censuses - and, more importantly, the under-enumeration is by no means uniform by age, sex, race, cause or degree of visual loss. Thus

Macdonald (1955)[61] reported that actual registration of the blind in Canada (based on optical measurement and admittedly using a liberal definition which includes many considered elsewhere as 'partially sighted') was double that of the corresponding census estimate.

In 1966 the W.H.O. reported that many countries had given up including questions on purported 'blindness' in their most recent population censuses. Among the countries of Asia and Europe included in W.H.O. reports between 1963 and 1972 only Kuwait[104], Portugal, Turkey, Greece and Gibralter[105] and Japan[depended on national or sample censuses for their figures. (Turkey, Greece and Japan provided no definition of what was meant by 'blindness'). Nizetic (1975)[72] cites Egypt and Switzerland as the only other large countries to have produced recent figures dependant on census counts - while among very small nations, where census counting is presumably much easier to verify, only St. Helena and Mauritius have attempted them in recent years.

Three other attempts have been made in the U.S.A. since 1940 to use questionnaire surveys to identify 'blindness'. These are the National Health Interview 'Surveys' of 1957-58, 59-61 and 63-65, which depended on interviewing a 'representative' sample of the United States population (some 21,000 on each occasion). The estimate of 'blindness' referred to a single question relating to inability to read "ordinary newsprint even with the aid of glasses". Some allowance was made for illiteracy and children under six years of age. Such a definition of blindness is a far broader concept than usually understood and all three surveys resulted in figures greatly in excess of any previous census or estimate based on local survey. Thus the 1958 figure of 570:100,000 total population was almost three times as high as any other estimate of economic blindness (6/60 or less in the best eye had been accepted by most States since 1955). Goldstein (1972)[29] criticises this survey method (depending on the answer to single or multiple questions) as being quite invalidated by measurement and based purely on a behavioural characteristic as perceived by the 'blind' themselves or by their relatives. Hasse

(1972)[34], however, defends the method on the grounds that it gives a better estimate of perceived need than do measurements of visual acuity, though he admits that the identification of underlying aetiology, incidence and the assessment of services needed, is beyond its reach. One major stumbling block in attempts to verify data derived from questionnaire surveys seems to have been the use of near-vision questions in the surveys and distance vision tests in local concurrent studies. Josephson and Sussman (1962/1963)[49] have shown that the correlation between reported ability to read ordinary newsprint and two commonly used tests of visual acuity is not high.

In the U.K., Sheldon reported in 1948[84] on a survey of old people in Wolverhampton which included questions relating to visual problems and the availability of corrective lenses. No attempt was made to verify the reported findings or to assess visual acuity but he was able to estimate that at least one third of his sample had either had inadequate correction or none at all. Seventeen per cent had never had their eyes tested and were using lenses they had either inherited, been given or bought over the counter of a general store. No other population based studies using questionnaires alone are reported from the U.K. until the general handicap survey of 1971 and no questions on vision are included in the General Household Survey.

The general handicap survey carried out by the Office of Population Censuses and Surveys for the D.H.S.S. in 1971[35] included questions relating to visual ability. Questionnaires were sent to a stratified sample of 209,335 households with a view to identifying the impaired and handicapped in the population. Of the 12,622 identified, 2,421 (19%) reported difficulty with vision; but, of these, 41% could see to read and write. This was no more than a 'census' as far as vision was concerned because no measurements were made (although they were for some aspects of motor ability); but such a comprehensive approach did at last open a way for relating visual handicap to other handicapping conditions.

This survey became a model for many of the local authority surveys carried out between 1971 and 1975 in response to Section I of the Chronically Sick and Disabled Persons Act (1970)[40]. Jaehnig (1972)[48] has pointed to the essential shortcomings of this Act and its implementation as a means of identifying all those who needed, and wanted, services. No compulsion was put upon local authorities to achieve 100% identification in any field, though it was suggested that this should be their eventual aim; and the criteria of need was to be determined by local authorities in the light of resources available (and not the needs of the handicapped themselves)". For the visually impaired, such loose constraints resulted in very varied and imprecise estimates of how many were handicapped by their impairment, let alone how many could be defined as 'blind' or 'partially sighted'. Warren and Knight (1977)[102] found that 16 of the 82 reports they examined in 1975 showed tables relating to visual disability and none had made any attempt to validate their figures beyond occasional reference to those who were, or were not, already registered. The only common thread discernible was the age grouping among the visually disabled in the seven reports where ages were represented.

Kohn and White (1976)[52] report the results of a recent international collaborative study involving twelve centres in seven countries, in which questions on the use of opticians' and ophthalmologists' services featured. Respondents (between three and five thousand in each centre) were asked questions designed to test perceived difficulties in both distance and near vision and what steps had been taken to overcome them. For near vision "seeing ordinary newsprint" rather than "reading ordinary newsprint" was used to obviate the difficulties that infrequent readers may have in identifying and understanding what is printed. No attempt was made to verify the findings of the survey by tests of visual acuity, or to carry it beyond the reported use of corrective lenses, but "a remarkable stability in the total standardized rates for persons with overall vision problems" was found. The range

between the study areas of those claiming a difficulty (uncorrected) with near vision was between 356 and 440 per thousand and with distance vision between 120 and 260 per thousand. In most of the seven countries, over 90% of those identifying a vision problem claimed to have glasses or contact lenses, though the percentage fell to between 57% and 71% in Poland and the two centres in Yugoslavia.

Gruer in 1975[33] published the results of a questionnaire to a sample of 835 elderly people (65 years and over) in the Scottish Border Area (1971-1972) which identified 1% as being legally blind and a further 23% as reporting some difficulty in seeing. This questionnaire, unlike the Harris survey , and most of the local authority surveys, related entirely to near-vision ability.

SIGHT-TESTING SURVEYS

Sight-testing surveys are here taken to mean either the sight testing of a whole or a sample of a whole, population; or the sight testing of a group thought to be at particular risk of undiscovered impairment; or the sight testing of those members of a general population who have identified themselves (by means of questionnaires etc.) as suffering from visual disability. Although the W.H.O. classification allows for measurements of visual field, only those surveys which have used measurements of visual acuity will be considered here. It is however remarkable that several surveys (e.g.[45][97][63][32]) which have taken considerable trouble over the identification and screening of fairly large populations for visual fields, tonometry and ophthalmological examination, have omitted simple measurement of visual acuity.

Sight-testing surveys of whole populations

Reports of surveys of whole populations where sight testing methods have been used for visual impairment short of total blindness are almost impossible to find. Clearly only small populations could be involved - Mann[64]

describes a few, but does not give definitions of blindness, and rarely is there an accurate population estimate to act as a denominator. Reports of sample surveys are more numerous - though sometimes the sampling method is either not detailed or open to criticism.

Bjornsson (1955)[2] describes a census and survey model used in Iceland. The decennial census identified 434 people (population 143,961) so blind as to be 'unable to find their way in places unknown to them before by means of their sight' - only 295 (68%) were known to district physicians. He examined a 1/3 sample (not random) and deduced a prevalence rate of 300:100,000 with vision 3/60 or less (W.H.O. 3, 4, 5 approximately). This is a very high prevalence rate by 'western' standards and is largely accounted for by glaucoma simplex in the elderly. Wyatt (1973)[108] describes an ophthalmic survey of an 18% population sample in Northern Canada, but gives no details of sampling technique. This survey equated visual acuity among three races (Eskimo, Indian, European) with past and present eye disease.

A very detailed and well planned survey has recently been completed by Said and his colleagues (1972) in Alexandria[79]. This compared the prevalence rates of blindness (visual acuity of 6/60 or less in the better eye, with best corrections, or more than that if the visual field was no greater than 20 degrees) in a 4% random population sample containing nearly 11,000 people of all ages and economic groups, with a self-selected sample of 144,354 people from the same area who chose to come for testing. In the first sample they found a prevalence 29.7pper 1000 examined; in the second only 12.9 per 1000. Both these prevalences, of course, are enormously high by 'western' standards, but of great interest is their analysis of who was under-represented among the self selectors. Much of the selection must have had cultural implications which do not necessarily apply elsewhere, but it was elderly men and women in both town and country, and women in general in both areas, who were statistically under-represented. The tests used were done under standard conditions of lighting, distance, etc.

Most population samples have, however, been limited by some age restriction, albeit wide. Undoubtedly the largest so far completed was the 1960-1962 National Health Examination Survey carried out in the U.S.A. on a 'probability' sample of 6,672 people aged between 18 and 79 years in the civilian home-based population[28]. The estimated prevalence of visual impairment, defined as 6/60 Snellen or less (approx. W.H.O. categories 2, 3, 4 and 5) was found to be 800:100,000 - considerably higher than the Interview Surveys, which used a near vision question alone - even though the old and institutionalised were excluded. No explanation of why this particularly vulnerable group was left out is provided and a further criticism[28] is that some of those not eventually examined may have been amongst the most severely impaired. Also 'usual' rather than 'best' optical correction was used. Clearly such results highlight once again the variance between results based on questions relating to near-vision and tests relating to distance vision.

Greve and Verduin (1972)[32] report a mass visual field screening survey of 1834 people in Holland but the very old were undoubtedly under-represented (children were excluded) and visual acuity measurements were used only as a method of exclusion from visual field testing. Lindemann and Van Leevwen (1974[57] screened 400 industrial workers for visual acuity using Landholt's rings - but clearly no population estimates for prevalence are possible here.

Among more restricted age groups - specifically the young and the elderly - much more work has been done both in community and institutional settings. The literature on visual screening in the first years of life, the pre-school child and the school child is very extensive and covers most countries with a medical system sufficiently organised to manage it. However, Nizetic's statement "in all countries, the school medical service can be relied upon to carry out the necessary screening of children of school age"[72] is over-optimistic. Gardiner (1969)[24] has advocated an 'at risk' concept to the screening of young children for myopia and sight defects and he and Sheridan (1962)[85]

have put much thought into developing suitable methods to achieve this. Sheridan has stated that "many normal children of 5-7 years, and a still larger proportion of handicapped children in this age group, cannot cope with the complexities of the ordinary Snellen chart". This has led her and Gardiner to develop various visual acuity tests suitable for most ages below school age and reports of the use of these and similar methods come from all over the world, though they all fall a long way short of complete screening of a random sample of the population of this age group. Thus Smith (1969)[87] describes a visual screening clinic for young children in Birmingham that has been running for several years. Approximately 7,000 children a year (selected entirely by attendance at infant welfare clinics) are screened by orthoptists - over half are under 2 years of age. No accurate measures of visual acuity are provided but 317 of the 7,000 children screened in 1968 were referred with an 'abnormality' - a further 176 were considered to be 'at risk' of developing a future 'abnormality'. Chase (1972)[11] however points to the dangers of letting evaluation of this age-group (and, by extension, any age group) become an end in itself; it must be allied to better provision and care. Not much is available in England at the moment for those very small children diagnosed as visually impaired (unless they have correctable strabismus) and little is known about the extra or special sensory stimuli which might mitigate their handicap[39].

The present situation with regard to visual acuity testing of school age children in the United Kingdom was summed up in 1972[41]. During 1971, 95% of the 155 local education authorities in England and Wales screened pupils for variations in eyesight within the first year of entry to school. Twenty (13%) managed annual screening between 5 and 16 years (2% omitted one or two years at either end) and another 12 (8%) screened biennially. Among the others, practice varied; only 62 (40%) of all authorities provide a visual screening test more than once during a normal school career, though many keep a special

check on those found to be impaired at entry. Clearly the need here is the provision of educational facilities suited to the peculiar needs of each child and the 1972 Report of the Committee of Enquiry into the Education of Visually Handicapped Children[17] outlines the minimum the Committee felt necessary to achieve this. Annual tests of visual acuity are recommended for all children in all primary and secondary schools, as well as special schools for other handicaps. These recommendations were endorsed by the 'Court' committee in 1976[21].

The visual acuity of youths aged 12 - 17 years was measured as part of the third cycle (1966-1970) of the United States Health Examination Survey[96]. A 90% sample (6,768 of an original 'representative' sample of 7,514) was finally examined, and nearly a third of these had featured in an earlier (1963-1965) children's survey, since the household sampling frame was the same. So changes in both visual acuity and refractive errors could be measured in this sub-set. Of the youths examined 2% fell within the W.H.O. definition of partial sight and blindness even with best correction; it is not however all that clear how many of these were already known to be visually impaired.

Myers (1975)[70] has written of an intriguing and detailed longitudinal study he has completed of 314 graduates from a school (Condover) for multipally handicapped blind and partially sighted children but apart from this and a small study of partially-sighted school leavers in North Carolina[34] nothing is written of the measurement of visual acuity in post-school age populations in specific age groups, until retirement. For the elderly and old, however, there are numerous reports, although none has so far achieved the coverage of a whole population - each has depended on membership of an institution, diagnosis of a particular disease, attendance at a clinic, etc.

In 1955 Hobson and Pemberton[43] reported on a survey of 476 old people in Sheffield carried out in 1949-50, which included a detailed eye examination

and tests of near and distant visual acuity. No analyses of acuity were, however, presented though at least 18% of the sample either had no spectacles for near vision or inadequate correction, and a similar percentage for distant vision. They did not relate the prevalence of various eye diseases found to the level of visual acuity, but of 8 people (2.5% of the sample) with a corrected visual acuity no better than 6/60, 3 were due to "senile atrophy of the retina or choroid", 2 to glaucoma, 2 to cataract and 1 to myopia. However, their sample was at least partially self-selected in that 22% of the original number contacted declined to be examined.

Miller and Stern (1974)[65] offered audiometry and sight-screening to the inhabitants of 243 apartments in a housing project for the elderly in the United States; only 115 people were eventually tested and of these only 6 (5%) came within the W.H.O. classifications. Many of the problems of mobility, multiple handicap and the attitudes of the elderly to screening were evident in the survey and undoubtedly biased the original (self) selection of those tested. No attempt was made to equate the importance of various handicapping conditions as perceived by each person, though a 'communication index' depending on hearing and sight was suggested. The authors freely admit that many severely visually impaired may have been 'selected out' of their study; an earlier (1952) survey of 1,000 inhabitants of a large Jewish old peoples' home in New York by Kornzweig and others[53] showed that over 14% and perhaps nearly 20% would have been included in the W.H.O. classification (the staging they used does not allow exact comparison).

The difficulties inherent in screening the elderly in institutional care are well described by Cohen in the U.S.A.[13] and Fenton and his colleagues in England[19]. Cohen's study in 1970 of 500 residents of a large home for the elderly in Philadelphia showed that 18% were unable to perform any visual acuity tests due to illiteracy or dementia. However, he was able to record both distance and near visual acuity tests for the remaining 409 patients and ascribe

a diagnosis to most of these. Again,his results were not directly comparable to the W.H.O. staging, but approximately 20% of those he tested would be counted as visually impaired or blind. This accords with Kornzweig's findings in New York - and indeed with the estimates Townsend made in his report on the Aged in The Welfare State (1965)[95]. Although no visual acuity tests are reported he found that 17% of the elderly living in geriatric homes (not specifically for the elderly blind) were "blind, or had a lot of difficulty in seeing".

Fenton and others (1975)[19] surveyed 221 patients in slow-stream geriatric wards in the Portsmouth Area. Although they give no actual details of visual acuity in their paper, they found that 40% of the patients examined could be helped visually by simple means such as the provision of correct spectacles, cataract operation, etc. However, these patients had to be identified by actual examination and were not accurately identified by their own assessment of their visual ability, or, indeed, the assessment of the ward sister or doctor in answer to a simple questionnaire. Clearly this was a selected population, unable for one reason or another to cope in the community - indeed a full 30% were accurately identified by the ward sister as being too confused to benefit by optical testing and help.

This inability to self-select among a purely hospital geriatric population contrasts with Rosin and Galinsky's experience with a community based population of the elderly in Israel[78]. They found a significant correlation at the .01 level between a subjective complaint of poor sight in answer to a questionnaire and a measured visual acuity of less than 6/36 (well into the W.H.O. classification). Twenty two (12%) of 186 subjects were so affected. Strangely there was no correlation between a complaint of poor sight and the wearing of spectacles - which speaks of a significant amount of unmet need.

Surveys of High Risk Groups (selected and self-selected)

In the U.K. age is the outstanding factor that places some groups more at risk of visual impairment than others; there is no evidence of a social class, occupational or geographical discriminator. Racial origins, however, play such a big part in the Southern United States, West Indies and those parts of Asia with immigrant populations in Britain, that it would be surprising if no effect were found among them.

Two reports of surveys among at-risk population based age groups in Britain have been published. Lowther and others (1970)[59] report a general health screening service offered to high risk groups of the elderly (living alone, recently bereaved, recently discharged from hospital) in Edinburgh, which included sight testing. Here initial identification of those 'at risk' was by general practitioner and health visitor - there is no evidence that it was by any means comprehensive and no sampling procedures were used. However, 300 people of 65 years and more were eventually examined (83% of those initially approached). Unfortunately no details of visual acuity were reported, but 5% (5,000:100,000) were found to be blind (within the Scottish definition of registerable blindness - approx. W.H.O. 3, 4, 5)[59]. Little can be learned, from the study, of lesser degrees of visual impairment.

Graham and his colleagues (1968)[30] used a postal questionnaire followed by examination to identify those patients of 65 years and more severely enough visually impaired to be registerable as blind. The study was based on a single group practice in South Wales. Again no visual acuity scores are reported and again the first two W.H.O. grades are missing; they only sought to validate their questionnaire as an instrument for identifying the 'blind' rather than the 'partially sighted'. Nevertheless, the questions they used were well validated ('en bloc') at subsequent examination, and 9 people in a population of 1,648 were found to be blind but unregistered. A further 23 were

already registered, giving a prevalence of 1941:100,000 in this average risk geriatric population. These figures generally accord with those published elsewhere[28].

Lastly, visual acuity testing has been included in a few general Multiple Health Screening surveys done in this country. The Social Science Research Unit of the Ministry of Health reported (1969) on the Rotherham Screening Clinic (1966)[15]. Only one third of the 3,839 people passing through the Screening Clinic (i.e. self selected) opted for a vision test - of those that did 23% were referred for further optical or ophthalmic advice. However, among the 1,300 or so people tested for vision, only 1 person came within the W.H.O. grading (although attendance at the clinic was heavily loaded towards the middle years). The elderly were under-represented by a factor of 3-4 times and undoubtedly there were other biases as well - twice as many women attended as men and over one third attended with one particular health check in mind. Clearly, as far as vision is concerned, this type of screening is offering no more, and probably far less, than the easily available optician in the High Street.

Surveys of Eye Clinic Attenders

The vision testing of that highly selected sample of the population that attends ophthalmic clinics has been reported from several countries. The Ross Foundation reports a study in the Edinburgh Royal Infirmary from 1956-58[47] in which 4.1% (605) of the attenders were registerable as 'partially sighted' (approx. W.H.O. groups 1 or 2). This rate of 4,100:100,000 is by no means an accurate estimate of the prevalence of partial sight in the general population (the report calls it 'incidence') or even among attenders in the eye clinic (again 'incidence'). But there were only 414 patients on the register of the partially sighted in the whole of S.E. Scotland (1966). Although the report presented no visual acuity data, care was taken to assess

the disability and handicap experienced by the partially sighted. This showed that, apart from ophthalmological care, 56% of the partially sighted were in real need of help of one kind and another as a result of their visual disability and that at the time of the survey "there is a large element of chance as to whether a partially sighted person is picked up and put in the way of receiving help; should, in fact, the help he needs be available in the particular area." Although there is much in the report that is obscure about the methods used in this study, it is without doubt the biggest and most comprehensive study yet done on the needs of the visually impaired who fall short of legal or even social blindness.

Another study, this time specifically disease orientated, was done by Brennan and Knox[6] on outpatient attenders in Coventry during a six month period in 1971-1972. One hundred and eleven patients with cataract had visual acuity measured and only 3 had vision of 6/60 or worse (W.H.O. stage 2, 3, 4, 5) in the 'best' eye, though a further 57% were in the range 6/36 - 6/12 which includes W.H.O. stage 1. Naturally, the elderly and old were heavily represented. Cataract was not necessarily the only cause of visual impairment in all these patients - 15% certainly had macular degeneration as well and a further 15% had other eye conditions. With removal of an opaque lens a better view of the retina might reveal still more.

Lastly, the visual acuity of 524 glaucoma patients was recorded in a single ophthalmic practice in Germany by Schuman in 1970[81]. Only 37 (7%) had at least one eye in category (W.H.O.) 3, 4, 5 and only 10 patients (2%) were bilaterally impaired to this degree. A full 63% of his patients had "full visual acuity" in both eyes. There have been several other more population based glaucoma surveys done but none has reported figures for visual acuity.

REGISTERS AS A SOURCE OF STATISTICS

Where countries register their 'blind' populations in order to provide services to them, it is tempting to regard the registers themselves as a source of prevalence data and the yearly additions to them as a measure of incidence. But, whatever the definition of 'blindness' used, registration has always proved inadequate wherever it has been tried and whether entry to the register depends on precise measurement of visual acuity or on lay estimates of visual ability. Under-registration abounds and most affects the aged and supposedly unsophisticated who may not view the benefits of being on a register in the same light as do those who administer it. In very few countries is registration obligatory at any age; in none is it obligatory for the old.

In the U.K. the use of the blind register as a source of statistics data back to 1919. The 1920 Blind Persons Act extended registration to all ages and a summary of the figures for most of the years between 1919 and 1932 was presented in 1933[67]. This showed a marked increase in the number of registered 'blind' from 69:100,000 to 154:100,000 of the whole population. This was rightly ascribed to better registration procedures and more inducement to do so (notably pensions starting at the age of 50 years). Already the preponderance of elderly and old was becoming obvious. No analysis of cause was attempted because most of those registered had not been seen by a specialist, but Fergus (1927) reported a survey of 1,206 adult registered 'blind' in Glasgow in 1926 which included aetiology[20]. At that time venereal disease was still the cause of blindness in 17% and measles in 3%. Trachoma and meningitis were also mentioned and 'senile cataract' came third to venereal disease and injury as the commonest cause of 'blindness'.

Sorsby (1966)[89] has provided the most complete analysis of 'blind' registration in England and Wales - his figures and analyses extend from 1948 to 1962. (A further report details figures for 1963 - 1968 but only for those

under 65 years[90]). Between 1948 and 1962 he analysed a total of 118,277 blind registration certificates (71% of the total of 165,606 available). The partially sighted (approx. W.H.O. 1, 2) were not included, though 27% of those counted as 'blind' were in fact in these categories; well over 50% of the total had "some useful vision". Extensive analyses are provided by age group of different aetiological causes and of the secular changes in these over the 14 years covered, both as 'prevalence' (total on register) and 'incidence' (additions to register). In 1962 58% of those registered were over 70 years of age. He makes the important point that each year some 6,000 people of pensionable age are referred for examination with a view to possible registration, by lay sources - largely because of a need for social services; among younger age groups the great majority are referred through medical agencies. From this he concludes (tentatively) that there must be a great number of unregistered elderly 'blind' - a point well substantiated by Graham and his colleagues (1968)[30] in their Welsh survey where 28% of the registerable elderly blind were unregistered. Other aspects of Sorsby's important study will be discussed later.

Gray and Todd (1965)[31] used the blind registers of a stratified sample of 30 local authorities as a sampling frame in a large survey designed to discover the mobility and reading habits of the blind; 1,174 people under the age of 80 and over 16 were eventually interviewed. Although the design was largely of the census type, simple reading tests were performed, though no concurrent measurement of visual acuity was used. Again, only those in W.H.O. groups 3, 4 and 5 were supposedly included, though 16% of the elderly could read large print and 24% of those between 16 and 64 could do so. Indeed, 11% of this younger age group were accustomed to reading ordinary print. Many questions in the very extensive questionnaire had a bearing on visual fields but these were not actually measured in any way, and the final report dealt only with the limitations in mobility and reading resulting from visual impair-

ment alone; other impairments and handicaps were only briefly mentioned. It is without doubt the most comprehensive work that has been done into the handicaps of the severely visually impaired and the report is very full. (Though, again, 'prevalence' appears as 'incidence' (page 5)). Shaw (1969)[83] used the Partial Sight Register for a sample of 288 adults and 48 children in the U.K. in 1966. Her study was specifically about reading ability and print characteristics. Her sample was by no means a random one but she was able to show that it was reasonably representative in age and sex of all those registered. Using distance vision alone (visual fields were not measured) 19% of her sample would not have been counted as visually impaired within the W.H.O. range and a further 28% would have been classed in category 2 or more (thus 'blind' and not 'partially sighted' in many parts of the world).

The deficiencies and inaccuracies in registers that spoil them as an accurate source of statistics have been well analysed by Brennan and Knox (1973)[5]. They showed that differences in prevalence (total on register) and incidence (new additions) of 'blindness' and 'partial sight' in various local authority areas of England and Wales were consistent over time and not to be explained entirely on the basis of different population age structures, though the coarse age grouping used in the register returns did not allow detailed analysis. They concluded that while differing age structures, especially of the elderly and old, certainly played the greatest part, the second major factor was probably to be found in variations of behaviour among patients, doctors and social workers. There was no correlation between the amount spent on each registered person and the proportion of the population registered in any age group and there was some suggestion that lack of opportunity for suitable employment and the need for supplementary benefits encouraged registration. A glance at the partial sight register figures for 1974 confirms that these discrepancies are even more pronounced among the 'partially sighted' than among the 'blind' - two towns with approximately the same geriatric population (Hastings and Bournemouth) have 210:100,000 and 90:100,000 respectively registered as 'partially sighted'.

There is no doubt that these are universal problems. Goldstein (1968[28]) describes the setting up in the U.S.A. in 1961 of the Model Reporting Area (M.R.A.), designed to overcome the enormous variations in registration and registration procedures that are current in different parts of America. These difficulties had been fully analysed by Hurlin (1947)[46] and Mugge (reporting in 1965)[69] - both had attempted to derive reliable statistics on prevalence and age grouping based on nation-wide figures of financial and other help given to the blind - both had found differential under-registration the main and insurmountable barrier to accuracy, although a standard definition (of 6/60 or less) was supposedly in use in all states. By identifying 3 states in which registration seemed to be nearly complete, and using weights in respect of population age-structure, non-white races and socio-economic status (as judged by infant mortality) which he had derived from his previous study, Hurlin derived figures for all states in the country. This idea of deriving 'weights' was used in reporting figures from the M.R.A. - 9 states (later 16) agreeing not only to abide by a uniform definition of blindness but to adopt the same procedures for registration and, most importantly, for keeping the registers up to date. These 16 states embraced 31% of the U.S. population and had approximately the same demographic and socio-economic stratification as the whole country; nevertheless it was decided to extrapolate national figures on the basis of three only of the states which had kept accurate records over a long period of time. Hatfield (1973)[37] produced a state map of prevalence based on the 1970 extrapolations - she discusses the weaknesses of the method as well as its logic and points out that while it serves well enough as an indication of prevalence rates in any one year it provides no accurate means of estimating changes in these rates over time. Nevertheless, extrapolation using 'weights' derived from a careful analysis of accurate figures derived in a small area is an interesting approach - unfortunately the 'partially sighted' (W.H.O. stage 1) were specifically excluded. The M.R.A., and statistics based on it, was discontinued in 1971 for economic reasons.

MacDonald (1965)[61] has used 'blind' registration to estimate Canadian statistics. The Canadian definition of 'blindness' is among the most liberal and includes those with vision of 6/60, or better than this if the visual field is less than 20°. Thus many, but not all, those in W.H.O. stage 1 will be included; certainly many classified as 'partially sighted' in England would be 'blind' in Canada. MacDonald studied the records of all 24,671 registered between 1959 and 1963 and derived tables showing age group and cause. Although the records were well completed (only 5% were deficient in information on aetiology) he acknowledges the deficiencies of the register in other fields. Some indication of possible under-registration of the old emerges in the proportion of men to women registered (51.4%:48.6%). This is contrary to all reports from other approximately similar 'western' populations. Although a later report (1974) from the Canadian National Institute for the Blind[9] reverses this ratio (49.6%:50.4%) it still seems that women may be underrepresented. MacDonald points out that examination of the registers gave a figure for the blind double that of the corresponding census enumeration. However, some evidence that registration in Canada may be more complete than in other countries comes from figures quoted in a 1960 report on Rehabilitation Services in Canada[8]:- the 1951 Canadian Sickness Survey estimated 26,800 "severely or totally blinded" and 62,000 partially disabled by visual impairment (total 89,000), while registration in 1958 gave 22,677 as 'blind' and 65,850 as 'partially sighted' (total 88,527).

Sturman (1969)[93] has performed the same exercise in New Zealand and presents tables based on registration (as at January 1st 1968) for all the 3,687 registered, by age group and aetiology but not by sex. He makes some interesting points about the different ages and degrees of visual impairment at the time of entry to the register. Thus in both England and Wales and in New Zealand 15% were totally blind or perceived light only (W.H.O. 4, 5) at the time of enrolment; while in Canada the figure was 24%. Fifty-three per cent of those becoming enrolled in New Zealand had vision better than 3/60

(W.H.O. stages 1, 2) but only half that number in England and Wales. 5.5% in New Zealand had no visual impairment within the W.H.O. range. Once again, those classified as 'partially sighted' in England might well appear as 'blind' in New Zealand, while very many classified as 'partially sighted' in Canada would not qualify for registration at all in England or in New Zealand.

Other reports of the use of registers to deduce epidemiological data come from Singapore (1958)[56], Japan (1964)[71] and Sweden (1969)[58]. Lindstedt's (1969) study in Sweden specifically excludes those who lost their sight after their 60th year and is based only on those 'blind' in receipt of public funds. He outlines all the biases that this and the use of registration figures in general introduces, and found that 87% of the 11,500 members of the Association for the Blind had a visual acuity less than 6/60 and (approx.) 55% less than 3/60 (i.e. W.H.O. 3,4,5). Again his staging does not allow exact comparison.

The same difficulties and deficiencies in registration were described for a much less 'westernised' community by McGlashan (1972)[62]. In one area of Zambia, where the definition of blindness used is "an inability accurately to count separated fingers held at a distance of six feet from the face with both eyes open" (easy enough for untrained lay personnel to apply), it was still the old, principally the rural old, who saw no benefit in registration and were therefore under-represented. However, he calculated that 93% of those in a position to be helped were located.

Lastly Damato (1960)[14] shows what can be done with a much less formalised type of registration in a small population (Malta). By asking parish priests, examining all the institutionalised aged and searching through several years attendances of blind people in the out-patient department, he was able to trace 638 people with a visual acuity lower than 3/60 (W.H.O. 3,4,5). This gave a prevalence rate of 199:100,000 - the nearest census return (1948) had suggested 124:100,000. He believed that very few people can have been left out of his survey.

Before summarising such statistics as can be distilled from such a massive variation in approaches, definitions, methods and populations, it is worth briefly touching on why registration and censuses and answers to specific questionnaires all produce such a high proportion of 'false negatives' - especially among the elderly and old.

REGISTRATION AND STIGMATISATION

In most countries registration as blind or partially sighted provides the only gateway to such help as society offers. There is an enormous and expanding literature on the typification, the stigmatisation that is implied in being declared publicly as impaired in any way - for the poorly sighted Josephson (1968)[50], Monbeck (1973)[68], Goldberg (1969)[27], Scott (1969)[82] and Blaxter (1976)[3] provide good analyses of what it means to be blind in a sighted society. The social and psychological implications of accepting the role that society expects may give rise to a natural reluctance to become registered.- "I wouldn't want to be a member of a club that would have me as a member" (Groucho Marx). This refusal to be typified as defective may be as big a barrier to registration as the perceived deficiencies in the help that is offered. The choice for the visually disabled person lies between joining the club and accepting the tragi-comic role that membership imposes as a price for the handouts it offers, or fighting a lone and alienating battle against typification which often leads to greater solitude and loneliness. It is not surprising that many find it tempting not to declare themselves disabled (register, answer censuses or surveys) but to keep it secret and thereby claim a place still in a 'normal' world, however restricted. This is obviously less hard for those with some remaining sight than it is for the truly blind; even where the fiscal benefits of registration do not discriminate between the two, as in Canada and New Zealand, the shortfall is always most marked in that group with most sight. In the U.K. where no direct financial advantage at all is gained from registration as 'partially sighted' the inaccuracies must be great indeed. Thus Page (1974)[76] estimates that there is at least a 50% shortfall in partial sight registration in the U.K. - which anyway excludes W.H.O. stage 1, unless severe visual field limitation is a factor. There is evidence in Sorsby's analyses[89] that confirms this - annual additions to the 'partial sight' register (between $4\frac{1}{2}$ and 5 thousand)

were unchanged in the years from 1953 to 1962, although they had risen to 6,727 in 1974.

Hilbourne (1973)[42] provides a very good account, from one who is 'partially sighted', of how irrelevant and even antagonistic many of the 'benefits' of registration appear to someone confronted with the real social problems imposed by visual impairment. This is because, apart from education of the young, help is offered entirely in terms of material aids and is never (and perhaps never could be) presented in terms of the help and friendly support a fully trained social worker can give. Some of Gray and Todd's (1965)[31] figures illustrate how irrelevant many of these material aids, or perhaps the way in which they are offered, may seem to the elderly - of a random sample of 420 registered blind people between the ages of 65 and 79, 323 (77%) had never had a talking book and 374 (89%) were unable to read Braille. (Of these 420, only 67 (16%) could read large print and only 29 (7%) were said to be "generally reading ordinary print". Of those without a talking book 52% were not interested or didn't like them and 35% said they preferred the wireless (these groups overlapped to a small degree). That survey clearly shows that there is only a slight correlation between degree of visual loss and mobility, use of talking books etc; Fitzgerald (1970) confirms this in a younger age group (21 to 65) in a small study of 66 newly registered blind in London[22]. He claims the use of all the help that is available only comes with acknowledgement of the reality of blindness. This reality can clearly be made easier and more tolerable by the continuing help of a trained and sensitive social worker, but this help is not likely to be assessed when a visually impaired person is weighing up the benefits and costs of registration. Moreover there is also good evidence that such continuing and sensitive help is the one major factor in the continuing successful use of mechanical aids to reading and mobility once they have been accepted - Krieger (1957)[54] shows that even in a self-selected well motivated group of 917 partially sighted

patients (U.S.A. private and 'clinic'), a sustained success rate in the use of initially accepted visual aids was directly dependent on the amount of continuing support and encouragement the person received. Only 20% achieved it.

The whole problem of stigmatisation and self-identification among the visually impaired has been very thoroughly studied by Josephson (1968) in America[50]. Interviewing 700 adults registered as blind he found that 357 (51%) did not consider themselves 'blind' (of these 121 (34%) were approximately in W.H.O. groups 3, 4 and 5). The reluctance to accept the label 'blind' and to seek such help to which that label gave entitlement was much higher among the elderly, the isolated and those with less education; financial support, which is one of the main features of statutory provision, was considered of minor importance by most respondents.

FIGURES AND STATISTICS

It is possible, even with such enormous differences in definitions and methods of collecting data to distil out from all these reports a few general statements about prevalence rates. The following statements apply only to western societies with their ageing populations and tolerable concurrence on the obligations they owe to the visually impaired; these societies are not generally affected by the trachoma, xerophthalmia and filariasis that are endemic among younger age groups elsewhere.

1. The true prevalence of 'blindness' (W.H.O. 2, 3, 4, 5) lies between 130 and 230:100,000 total population. In the U.K. it is about 190-220:100,000 total population.

2. The true prevalence of visual impairment to the extent only of W.H.O. stage 1 is impossible to estimate accurately from previously published reports. It is probably at least 300:100,000 total population.

3. Sixty five to seventy per cent of the blind, and probably of the partially sighted are over the age of 65 years. Between 65 and 74 years the prevalence of 'blindness' in the population rises to 550-600:100,000 population and over 75 reaches at least 1500:100,000.

4. Registration suffers from broadly the same inaccuracies wherever it has been tried. It is more comprehensive for the blind than the partially sighted but because the overlap is very extensive in all countries between these divisions, it is more profitable to drop them all together in favour of visual impairment as defined by the W.H.O.

5. Registration provides no accurate estimate of 'incidence' in any category of visual impairment - only of 'discovery', as much activated by economic factors as by eye disease or level of sight.

EYE CONDITIONS LEADING TO VISUAL IMPAIRMENT

The W.H.O. report which established the classification used throughout this paper also suggested that the eye condition leading to visual impairment should be listed as a dual classification by site and aetiology. This system was first adopted in 1959 by the International Association for the Prevention of Blindness, but has in fact been in use in the U.K. since 1955. For the sake of clarity only aetiology will be discussed in this paper and the preventable blinding conditions which are not endemic in the U.K. such as trachoma, xerophthalmia, onchocerciasis and pterygium will be omitted (although they account for at least 3,000,000 cases of blindness in the world).

MACULAR DEGENERATION

In ageing populations such as that of the U.K. this is almost certainly the largest single cause of severe visual disability. However it does not often lead to total blindness or the perception of light only - most of those registered with this diagnosis are in W.H.O. groups 1, 2 or 3[28][61].

No population survey yet undertaken has produced figures from which prevalence data may be estimated. Kornzweig (1957)[53] estimated the disease to be present in 24% of all those between 60 and 79 and 39% of those of 80 years and more - but his figures are based on a racially selected population of institutionalised people. The Ross Foundation's study of 605 partially sighted people (1969)[47] gave a prevalence rate of 10.7% (all ages) - but at that time only 3.3% of registered blind in Scotland had this diagnosis. There is no doubt at all that there is enormous variation between observers in making this diagnosis, which depends on retinal appearances alone - there has never been an attempt to standardise techniques or validate observations; moreover the retina may well be partially obscured by lens opacities. Sturman (1969)[93] quotes register percentages of 19% for New Zealand but MacDonald (1965) only 5% for Canada[61].

CATARACT (ALL TYPES)

Of all eye diseases, registration figures for 'cataract' are likely to be most misleading. To begin with many people visually impaired by cataract are not registered because they are thought to be waiting operative treatment; Brennan and Knox (1975)[6] have shown the apparent disparity in how many actually get treatment, between regions. Nevertheless Sorsby (1966)[89] counts the availability of this treatment as the single major factor explaining the drop in registered cases between 1949 and 1968 (83:100,000 to less than 50:1,000,000 among the 70+ age group); he also comments on the confusion that exists in the literature between 'cataract' and lens opacities[91].

Furthermore, very many people with bilateral cataract are not visually impaired (within the W.H.O. classification) and the slow progression towards it must affect the ageing person's perception of his own visual ability. Thus Wyatt in his Arctic survey (1973)[107] found that 89% of 154 people with lens opacities could not be counted as visually impaired. Even in Brennan and Knox's[6] symptomatic group of 111 cataract patients (all of whom had been referred because of 'failing vision') only 3% had a 'best eye' vision of 6/60 or less (W.H.O. 2, 3, 4 or 5). They found that on the basis of attendance at eye out-patient clinics the all-age population prevalence rate could be estimated at about 59:100,000 in men and 99:100,000 in women. The female preponderance was not explicable solely in terms of increased longevity - this has been confirmed elsewhere[28]. It would seem likely from their work that most of the elderly in the community with cataracts who are presently suffering severe visual impairment, have some other systemic disease making operation inadvisable or - perhaps more commonly - have a dual eye pathology such as macular degeneration.

GLAUCOMA

Untreated glaucoma can undoubtedly blind, and yet it is by no means established that early treatment is effective. It is not possible to diagnose

most cases of chronic glaucoma in the context of most General Practices until pronounced visual changes have occurred[23]. By then the disease has often been running several years and damage has been done. Miller (1975)[66] estimates it may be 5 - 6 years in progressive cases before field defects can be shown or the optic disc becomes cupped - even then most of the early changes are in visual fields and not in acuity and may not be noticed by the patient. Schumann (1970)[81] found that 63% of patients with established glaucoma had a full visual acuity.

In a very detailed and well validated series of studies Hollows and Graham (1966)[44] showed a prevalence rate of glaucoma of 840:100,000 in a population between 40 and 75 years of age. 91.9% (4,231) of 4,608) people were examined - each had a tonometric test and eye examination and 1 in 3 had a visual field test. All tests and examinations had previously been validated for experimental and observer error. They concluded that this prevalence rate was low compared to other studies but if so-called preglaucoma suspects (raised pressure alone) are added the prevalence rises to 9,100,000.

However, Cochrane, Graham and Wallace (1968)[12] could find no good evidence that reducing ocular hypertension affects the progressive loss of visual field or that following up all those found to have a high pressure is an efficient way of diagnosing glaucoma. Half those found, on population screening, to have visual field changes or glaucomatous disc cupping have a 'normal' tonometric reading ('false negatives'). Since there is no apparent benefit in intervention before early field changes occur population screening should probably depend on detecting such early changes - at least until more is known of the genetic and other factors that might allow a population particularly at-risk to be identified.

MYOPIC CHORIORETINAL ATROPHY

Sorsby (1966)[79] shows that although there was a marked drop in the percentage of registered blind from this cause under the age of 60 between 1949 and 1955, since then it has remained stationary. Between the ages of 60 and 69 years there has been little change and in people over 70 years of age a steady increase in registrations.

Again, there is no work on which any sort of estimate of population prevalence can be made. Like macular degeneration, variation in diagnosis must be very great. For example, Damato in Malta (1960)[12] ascribes 18.6% of all 'blindness' to myopia but he includes all retinal detachments in this group (half his cases) and some macular degeneration as well. He does not otherwise mention macular degeneration. Sorsby has some evidence that the diagnosis is more common among Jewish populations and certainly Kornzweig (1957)[49] found a prevalence rate of 2.86% (2,860:100,000) among his elderly Jewish population. Ashcroft and colleagues (1967)[1] diagnosed 0.9% of 576 Jamaicans between the ages of 35 and 70 as suffering from it (900:100,000).

DIABETIC RETINOPATHY

Diabetes is the one 'western' blinding disease that also limits life, so the analysis of time trends in incidence and prevalence of diabetic retinopathy is very difficult. There is good evidence that retinal changes are associated with the number of years the disease has been present. Goldberg (1971)[23] estimates that of young diabetics (diagnosed before their 30th year) 10% will have observable retinopathy within 5 - 9 years, 50% by 15 years, and 80% - 90% if the disease lasts over 25 years. The onset is much quicker in older age groups. For the very young diabetic (under 15 years) Leighton (1974)[51] quotes figures to suggest that 9.5% have retinopathy 15 years, 66%, 30 years and 83%, 48 years after the presumed onset of the disease. 1 in 1,000 will be totally blind by age 30 and 35 in 1,000 by 50.

Szabo (1967)[94] summarises evidence that suggests the presence of retinopathy is associated with high blood sugar levels at the time of examination - he found an overall prevalence rate of 77% among 324 diabetic patients with mean age of 62 years and mean disease duration of 17 years. Kahn and Hiller (1974[51] quote all-age blind registration from diabetes in the U.S.A. (1962) as 24:100,000 population; Sorsby's[90] are lower at 6.4:100,000 between 60 and 69 and 10.3:100,000 at 70 years and over. Neither find evidence for a reported increase in the true incidence of this condition during the last two decades convincing; moreover Kahn and Hiller point out that the overall life expectancy for diabetics in the United States has not increased at all since 1955, despite supposed advances in therapy.

The remainder of the registered blind are diagnosed as suffering from a variety of diseases of which optic atrophy, from various causes, and congenital lesions play a dominant part.

Estimates that have previously been made for this country have been derived from a population with (largely) a single racial background; now that the U.K. has a large and ageing immigrant population it cannot be assumed that prevalence rates of various diseases will be the same among them. Kahn and Hiller (1974)[51] show an interactive effect between being female and dark skinned in the United States as far as diabetic retinopathy goes; the chances of a non-white woman aged more than 45 years having diabetic retinopathy are 200% higher than a white man of the same age. Ashcroft and colleagues (1967)[1] found a similar fourfold higher prevalence of glaucoma in Jamaica (to Hollows and Graham's finding in Ferndale (1966)[45]).

AGE GROUPING

Although the W.H.O. report[107] recommends that epidemiological data be presented in an agreed form with regard to degree of visual impairment, site of eye disease, and aetiology it makes no recommendations on age grouping. Yet if different countries and different surveys continue to divide age groups largely according to local fancy, the chances of determining time trends, especially as they illustrate underlying diseases will continue to be lost. Age groups must satisfy not only the natural history of disease by the demographic characteristics and social milestones of the society they illustrate (pre-school assessment, school starting and leaving, retirement age, pensions, etc.); they must also be large enough (especially in the younger age groups) to allow something short of total population surveys to be representative. No national or local surveys have yet satisfied all these criteria - yet agreement should not be hard to reach, at least among 'western' nations with demographically similar populations and comparable causes of eye disease.

Sorsby[89] uses 0-4, 5-14, 15-29, 30-49, 50-59, 60-69 and 70+ for the analyses. Clearly the needs of the pre-school child are so important that they must continue to form a special group, as also must schoolchildren. The new school leaving age of 16 is allowed for in the latest (1974) D.H.S.S. returns on 'blindness' and 'partial sight'[16]. The childhood age groups are usually omitted from surveys of anything less than total populations because of the different techniques used in identification and measurement and because registration, or at least awareness, is fairly complete by the end of school life; this is just as well because the numbers in these age groups are small and the sample surveyed would have to be very large.

But Sorsby's analyses cut right across retirement age (at least for men) and mostly stop short at 70, which does not make a special study of the difficulties of very old people easy. Exactly the same percentage of all registered blind (26%) are aged 80-89 as are 70-79 (1964)[89]. There is very

little sense in lumping all these people together from the point of view of providing services suited to their needs, even if the major blinding diseases are not necessarily progressive to any marked extent in very late age. The picture is in no way clarified however by the 1974 D.H.S.S. presentation[16] which groups all those of 65 years and more together (as is the custom with all handicapping conditions).

Goldstein's careful analysis of American figures[28] provides some breakdown between 65 and 84 years for new additions and for degree of impairment, but most of his age/sex tables and all those listing causes, group 65 years and over together. In a later analysis (1970), however, Hatfield[37] uses the age groups 0-4, 5-19, 20-44, 45-64, 65-74, 75-84 and 85+. The Canadian National Institute for the Blind[9] uses 5 and under, 6-15, 16-19, 20-29, 30-39, 40-49, 50-64, 65-80 and 81+,but MacDonald[61] in his analyses of the Canadian figures has very different groupings (and varies them for different purposes without explanation).

With some variation round the school years the Canadian age groups seem to provide the best descriptive framework from all points of view (service provision, demographic structure, natural history of disease). Brennan and Knox[6] showed a 3 fold increase in the symptomatic presentation of cataract between 50-59 and 60-69 (76.8:100,000 and 237.2:100,000 respectively). There were large increases in each decade after that. Although most people with cataracts do not live long enough to be blinded by them, (or are treated before they are), nevertheless there were 2,305 additions to the blind register in England and Wales for this cause alone in 1960 (Sorsby[89]).

As far as it is possible to tell, glaucoma does not appear to carry the same decade-related prevalence trends, at least in this country. Thus in the Ferndale study[45] there were no difference in any five-year age group between 50 and 75, although the figures were very small. However the sample matched

the age/sex structure of the local population. No other study has applied the same exigent criteria to the diagnosis of glaucoma; intraocular pressure certainly rises with age but in no five year period after the age of 50 is the age factor as important as other factors such as diurnal variation. As far as our limited knowledge goes it would seem that incidence and prevalence of glaucoma is similar in each decade after 50.

For diabetic retinopathy, however, it is possible to be a little more dogmatic. Kahn and Hiller's analyses of additions to the M.R.A. registers[51] showed age standardised additions much higher in the 65-74 age group than any other decade before or after - clearly if ages after 65 years were all lumped together this information would be lost and the important effect of 'selecting out' among older diabetics missed. Again the figures, even for the 65-74 year group, are not large (average annual additions for this age group are 41:100,000 total population) but the preceding 20 year group has only 18:100,000. This 20 year span is too long - even with only 18 additions in every 100,000 in this age group it is important to know whether they are forming the beginning of the older population (added in the last few years) or another group (added around 45 years of age) with an early-onset type of diabetes.

These then are some of the implications in deciding the age-groups that should be used in presenting figures. It seems that the widest interests - of epidemiology, of service provision related to the particular needs of different age groups, and of possible future screening - would be served by presenting age groups for visual disability thus:-

0-2, 2-4, 5-15, 16-39, 40-54, 55-64, 65-74, 75-84 and 85+

However, if all survey data contained dates of birth, then data could be represented and regrouped for different purposes.

PART II - APPENDIX I

VISUAL DISABILITY

(DEFINITION OF VISUAL IMPAIRMENT AND BLINDNESS W.H.O. 1973)

W.H.O. Category	Maximum less than	Minimum equal to or better than
1	6/18	6/60
2	6/60	3/60
3	3/60 (or visual field $<10^{o}$ and $>5^{o}$)	1/60 (Finger counting at 1 M.)
4	1/60 (Finger counting at 1 Metre) (Or visual field $<5^{o}$)	Light Perception
5	No Light Perception	
9	Undetermined or Unspecified	

PART III

VISUALLY DISABLED PEOPLE IN CANTERBURY 1974

VISUALLY DISABLED PEOPLE IN CANTERBURY 1974

INTRODUCTION

Study of the literature (Part II) suggested that the only way of deriving adequate estimates of the number of people in a community disabled by poor sight is by means of a population survey. Examination of routinely kept hospital or other records, the use of registers and the invitation to come forward for assessment and help, have all led to deficient or biased estimates, unless the level of visual acuity to be considered is so low as to include only those who are severely handicapped. Success with surveys has not necessarily been greater because they have too often been confined only to small sections of a population, limited by age, residence or occupation, and have usually concerned themselves only with disabilities that could be directly attributable to poor vision. When attempts have been made to describe the whole social situation and other disabilities of the poorly sighted in a community, as in the Harris[35] survey, no attempt has been made to measure levels of vision by acuity testing. Nevertheless, it is possible to cull from a critical appraisal of the many survey approaches that have previously been tried, an idea of what has and has not proved successful in the past.

It seems that the initial population approach must be couched in general and not restrictive terms so that all who feel they may have some sort of difficulty in seeing are initially included for consideration. Emotive terms, such as 'blind', must be excluded. No experience has been gained of how accurately various 'closed' questions relating to distant and near vision estimate visual acuity, but the impression is that simple visual acuity measurement is a useful survey tool and can be used without too much difficulty on a population basis. Because very many of the visually disabled are of an age to experience other possible disabilities, it is inappropriate to ascribe all difficulties to a single disability and sight-surveys must be combined with an assessment of other problems.

The 1972 Canterbury Survey of the Handicapped[98] fulfilled many, but not all, of these criteria at least for a single defined community and an analysis of the data from it promised not only considerable epidemiological knowledge but a chance to test out and refine the techniques necessary for further successful survey work. Above all, there was the possibility of much more experience than was presently available about the relationship of visual to other disabilities. Moreover, among all the surveys which followed the publication in 1970 of the Chronically Sick and Disabled Persons Act[40] only that in Canterbury had used sight testing in the follow-up of those designated as handicapped by a visual problem, although this was not done until at least two years after initial identification.

The 1972 Canterbury Survey was undertaken as a joint project by the Social Services Department of the City of Canterbury and the Health Services Research Unit of the University of Kent. It had the following declared aims[98]:-

1. To identify each handicapped person who might be in need of some sort of social service, and then refer his or her name to the Social Services Department.

2. To produce estimates of the needs for the relevant services in the City by adding together the details and needs of each handicapped person, in order to plan the direction and rate of development of the City's Services.

3. To collect data which could be used as a partial evaluation of the services and combined with other data for further research into the needs for and organisation of social and voluntary services for handicapped people.

Thus the prime intention of the survey was to discover who needed what and to see that they got it, and to this end the City made extra resources available. However, the second and third aims were quite definite that the survey data were also to be used for further research into what should be rather than what is, and so in two respects the Canterbury Survey went considerably beyond the demands of the 1970 Act, as published[40] - to examine the needs for help and services in the light of what is available. In fact, the

aims of the Canterbury survey were closer to the aims of the sponsors of the original Bill, as it was first presented to Parliament[48].

Initial identification was by means of a questionnaire to all households (Appendix I). Those in each household who said they had a bodily impairment were interviewed to see if it amounted to a handicap to them and, if so, a further interview was arranged to see what help was needed to alleviate it. However, to make fulfillment of the second and third aims possible a follow-up survey was undertaken two years later, in 1974, which did not seek to reidentify the impaired and handicapped in the City but to find out what had happened to those already identified in 1972. How had their impairments and handicaps changed? How many had died, moved away or been admitted to hospital? How had their home situation changed and had they received the help they apparently needed in 1972? Did they still need the same sort of help or was it no longer appropriate?

It was during this second follow-up study two years after the initial approach that sight-testing at home of most of those complaining of visual difficulties was undertaken; a few had to wait until 1976 before testing. The addition of these sight-tests, to be carried out by the interviewers, was suggested by the Department of Health and Social Services, and there was no opportunity to do more than show each interviewer how to use the standard distance and near vision cards. No direct validation of the application of the tests was possible during the survey.

Data from the survey were linked to other data from hospital, social service, and family doctors' records in order to learn as much as possible of the epidemiology of visual disability among people living at home in a demographically defined population and, equally importantly, about the usefulness of the survey methods used to discover them and measure their disability. However, most of the survey data related to those who survived in the community

between identification as impaired (not necessarily visually) in 1972 and final assessment and measurement in 1974 (a few in early 1976) so that a true point prevalence study of the epidemiology of visual disability in the community was not possible.

During the Canterbury survey an operational definition of handicapped was applied to all those who had an inability or difficulty in performing certain activities as a result of having an impairment[98]. This was a qualification for follow-up and detailed assessment. People were considered visually handicapped if they said they were registered as blind or partially sighted, or said they were unable to read print or recognise a friend across the streeet or both; this was a purely operational definition qualifying them for further assessment and sight-testing. It will be seen that a number of those claiming to be visually handicapped were not, when tested, within the range of visual disability as defined (page 8).

The data presented in this part of the study cover only those living in private households in Canterbury in 1972-1976 and, for the visually handicapped, only those of 16 years or more; none of the sight-testing methods used in the final stage was necessarily suitable for children[85].

METHODS

DESIGN OF THE CANTERBURY SURVEY OF HANDICAPPED PEOPLE

The basic design of both phases of the Canterbury survey (1972 and 1974) was close to that used in the Harris national survey (1971)[35] and recommended to local authorities[36]; the questions used to identify the impaired and to assess the handicapped were also similar. A first simple questionnaire (Appendix I) delivered to, and collected from, as many households as possible within the City limits led, in 1972, to self, or proxy identification of impairment. Those claiming an impairment were interviewed within one to four months ('screening' interview) to see if their impairment amounted to a handicap (or if they had other impairments amounting to handicaps). For those with a handicap a second ('assessment') interview was carried out to discover in detail the extent of the handicap and the needs of the handicapped person. During this assessment full details of social and housing conditions were also obtained.

The second (1974) phase of the Canterbury survey was designed to discover how much people's impairments and handicaps, as well as their social conditions, had changed in two years and how far it had been possible to meet the needs of those identified as handicapped in 1972 by social service and other provision. Much the same questions that had been used both for 'screening' and 'assessment' in 1972 were used for 'rescreening' and 'reassessment' in 1974, though of course no new personal identification took place. Unlike 1972, the 'assessment' interview in 1974 followed, where indicated, directly on the 'screening' interview. Those who undertook the 1974 interviews had no knowledge during the interviews of the individual findings of 1972 - to this extent both 'rescreening' and 'reassessment' were 'blind'. The implications of the second phase were that some of those not handicapped by their impairment in 1972 might now be handicapped by it or have acquired another impairment, while some of those handicapped in 1972 might have been so helped that their impairments were no longer handicapping two

years later. It had to be accepted, however, that a number of those screened as impaired in 1972 would no longer be available, in the community, in 1974.

The criteria by which the impaired were considered to be handicapped by their impairment were wider in 1974 than in 1972, but the changes were made in such a way as to enable comparisons to be made with the 1972 data. Registration as physically handicapped, or an inability to follow a full-time occupation because of impairment or illness now became an automatic qualification. Also, the age restriction (70 years or more) applied to those with a lesser degree of self-care difficulty[98] was removed in 1974 so that now anyone of any age with any self-care difficulty, or needing to use aids, was considered handicapped. Included, too, as handicapped were those who, while denying difficulty, seemed to the interviewer to be substantially hard of hearing - the fact that assessment immediately followed screening, where indicated, in 1974 made this judgement by the interviewer easier than it would have been in 1972.

The categories were expanded in 1974 because it was thought that many, who were truly handicapped by their impairments in 1972, had not been designated and assessed as handicapped by the narrower criteria then applied. Figure 1 shows how many were included, in 1974, by reason only of the broader criteria; Warren[98] has described in detail all the qualifications for inclusion as handicapped in the Canterbury Survey and the effect that the changes in these qualifications had on numbers.

Apart from expanding the categories of handicap in 1974, a second difference in the assessment of the handicapped was the addition of special questions for those who had indicated a handicap of vision or hearing during screening. The special questions asked of the visually handicapped are listed in Appendix 2; it can be seen that they include two tests of visual acuity - distance and near; no such measurement was attempted in 1972. The question relating to distance vision is the same as that used in Kohn and White's international study (1976)[52].

Finally, since the criteria by which people were judged as visually handicapped (see page 47) were unchanged between 1972 and 1974 it may be supposed either that those who were fully assessed as visually handicapped in 1974 but not in 1972 had actually suffered a deterioration in vision, or that the questions used in screening had poor repeatability. Aspects of both these possibilities will be explored.

COVERAGE OF THE SURVEY

The detailed results of the Canterbury survey and discussion of the implications appear elsewhere[98]; a brief summary of the coverage achieved is presented here only as a background to a more detailed analysis of the data on the visually handicapped.

From Fig. 1 it can be seen that 1,631 people in 10,159 households were originally identified in 1972 as having some significant impairment (Appendix 2) and that 1,534 (94%) of these were subsequently interviewed. Of those interviewed, 836 (54.5%) were considered to be handicapped (usually, but not necessarily, by the impairment originally identified) according to the criteria used in 1972[98], and 770 (92%) of these 836 were available for full assessment 3 - 5 months later. Between initial identification in May 1972 and the end of the assessment interviews in October 1972, 37 (2.5%) of the original 1,631 identified as impaired had died, 26 (1.5%) had been admitted to institutional care, while others had moved from the City or were otherwise lost to the survey.

It can be seen from Figure 1 that only 1,078 (70%) of the 1,534 who had originally been interviewed as impaired in 1972 were available for the 'follow-up' phase of the survey in 1974. In the intervening years 199 (13%) of the 1,534 had died, and 67 (4.5%) been admitted to long-term care. Others

had moved and a few refused another interview. Of the 1,078 'rescreened' in 1974 759 (70.5%) were found to be handicapped - 584 (54%) by the criteria used in 1972 and 175 (16%) by the expanded criteria of 1974. Among these 759 people with a handicapping condition,were 198 (194 adults) who were assessed, by the questions used in the survey, as handicapped by their visual impairment. It is from the analysis of data on these 194 that the conclusions of this part of the study are drawn.

Table 1 provides details of the demographic characteristics of the 1972 impaired and handicapped of Canterbury compared with data from the 1971 census for Canterbury, and for England and Wales as a whole. As might be expected, the proportion of those with impairments who are handicapped by them is higher in childhood and old age than it is in the middle years, and by far the largest single group of both impaired and handicapped is that of old women aged 75 years or more. Nevertheless, even in old age a remarkable number of Canterbury citizens seem spry - nearly 70% of men and 66% of women of 75 years and more identified so significant impairment at all.

SURVEY DATA ON VISUALLY 'HANDICAPPED' PEOPLE

In both phases (1972 and 1974) of the Canterbury survey a person was considered for operational purposes to be'visually handicapped' if he or she, having originally identified an impairment of some sort (not necessarily visual), then fulfilled one or more of the following criteria at the screening interview:-

1. was registered as blind, or partially-sighted;
2. was not so registered, but said he was unable to recognise an acquaintance seen across the street (wearing glasses if applicable);
3. was not registered, but said he was unable to read ordinary print (a leaflet was shown) or see to write, without a magnifier (glasses were worn if applicable).

Thus the 194 adults identified in 1974 as visually handicapped can be grouped into five different categories - registered blind, registered partially-sighted, claiming a difficulty only with distance vision, claiming a difficulty only with near vision, and finally those claiming a difficulty with both distance and near vision (Table 2). These 194 adult visually handicapped people can be regarded as 'survivors' from initial identification in 1972 - however, they were not all identified at that time as visually handicapped (or, indeed, as handicapped at all). Figure 2 traces the different routes by which the 194 reached assessment as visually handicapped in 1974; it also illustrates why an accurate point-prevalence estimation of visual handicap is not possible from these data. The validity of the questions used both in the initial household approach (Appendix 2) to discover visual impairment, and in the screening questions (above) to ascertain handicap, is explored in a later section.

From Figure 2 it can be seen that, in 1972, only 231 (59.5%) of the 389 who identified a sight impairment were considered tc be handicapped by it, but that they were joined by another 80 (7%) of those 1,145 people who had claimed no visual impairment at the initial approach. Among these 80 were 6 who were registered as blind or partially sighted.

Two years later everybody still available from the first phase was 'rescreened' using (at least as far as vision is concerned) the same questions (above). Clearly the majority (Fig.2) of the visually handicapped still about in 1974 had been identified as visually handicapped in 1972 but they were joined by 70 who had not been so identified. Half these (35) had claimed at the initial household approach in 1972 that they were 'blind or had very bad eye-sight' (Appendix 1) but had then said, on screening in 1972, that they could read ordinary print unaided and recognise their friends across the road. Now they claimed they could not do one or both of these things. The whole number (198) who thus qualified for full assessment and sight testing as visually

handicapped in 1974 was made up of 128 (41%) of the 311 who had been assessed as visually handicapped in 1972 and 70 (6%) of the 1,223 who had not.

The visual difficulties that these 70 additional people had apparently acquired between 1972 and 1974 are outlined in Table 2 and are compared with those experienced by the 128 survivors already assessed as visually handicapped. In 2 years one of the 70 newcomers had been registered as blind, another (a child) as partially sighted, and approximately equal numbers claimed a deterioration in near vision (19), distance vision (24) and both near and distance vision (25). During the same period 4 among the 128 visually handicapped 'survivors' from 1972 had acquired a difficulty with distance vision to add to their near-vision difficulty, and 9 with only a distance vision difficulty in 1972 were now unable to read ordinary print unaided or to see to write. Ten people with a double visual handicap in 1972 had become registered by 1974 - 4 as blind and 6 as partially sighted; 3 more, with only a distance problem in 1972, had also been registered as partially sighted. This does not necessarily, however, imply a deterioration in vision - many other factors, social as well as personal, influence the process of becoming registered(5).

However, some changes for the better had also occurred. Six (16%) of the 37 who claimed a double handicap in 1972 now had, apparently, only a difficulty with distance vision and a further one only with near vision. Added to these are another 12, not shown in Table 2, who claimed in 1972 a visual handicap of one sort or another and claimed none in 1974 - these represent 4% of those originally assessed in 1972 with a visual handicap.

It must be remembered that the data illustrated in Table 2 and the apparent changes in visual ability which they illustrate were obtained purely from the responses of a largely elderly (Table 3) group, often suffering other handicaps, to two unvalidated questions about near and distance vision. Doubtless some changes in visual ability did occur (due to the natural progress of

pathological conditions, or, in the other direction, to treatment for them, or to changes in the provision or use of corrective lenses etc.) which are reflected in the differences illustrated in Table 2, but without certainty of the validity of the questions used no assessment of the extent or importance of changes in visual ability is possible. The use of sight testing during the follow-up phase in 1974 did, however, give the opportunity to examine some aspects (notably 'sensitivity' and 'specificity') of the validity of the questionnaire (see page 51), but because these tests were not applied in 1972 no full examination of 'repeatability' - clearly of importance in a follow-up survey - is possible.

Tables 3 and 4 show the age groups and sex of the 194 adults who were assessed as visually handicapped in 1974 and compares them with all those assessed as handicapped at this time. No great differences appear, for any one age group (Table 3) between the percentages of those suffering only a visual handicap and those suffering from other handicaps - except among women of 85 years and more; here sight difficulties seem to play an increased role. However, visual problems are not usually associated with mortal diseases, while some other handicaps are - and those assessed in 1974 must be regarded as a survivor group, two years after initial identification.

Of the 194 adults claiming a visual handicap in 1974, 161 (83%) had the extra sight questions (Appendix 2) asked at the same time as their assessment interview while another 23 (12%) had to wait for these until the beginning of 1976 (14 months later). These latter complained of a difficulty with distance vision alone. All who could see more than 'light from windows' had the near and distance visual acuity test, unless they were too ill for it (Appendix 2). The 10 (5%) who became 'lost' to the survey between 1974 and 1976 consisted of 2 who had died, 2 who were too ill to answer the sight questions, 1 who had moved, 1 who had been admitted to hospital and 4 who refused a further inter-

view. In total, then, 184 (95%) of the 194 adults who were eligible for the full sight questionnaire and sight tests (Appendix 2) actually received it (and 3 of these were too ill to manage the sight tests).

OTHER SOURCES OF DATA ON VISUALLY HANDICAPPED PEOPLE

In order to derive as much diagnostic data as possible to complement the data obtained from the survey, permission was sought from each of the 184 visually handicapped adults who eventually received the extra questionnaire (Appendix 2) to consult such hospital, social service, optician or G.P. records as might be available. It was also hoped that a sufficient number would have attended the hospital eye clinic to allow some comparisons to be made between the sight tests done under less than optimal conditions at home and those done under more standard conditions in hospital.

The 161 visually handicapped adults who had been assessed at home and had the sight questionnaire in late 1974 were approached for permission by post (November - December 1975) - those 23 who, though assessed in 1974 did not get the extra sight questions until January 1976, were asked at the time of their final interview. Fifteen (9%) of those approached postally had died since 1974 and 2 more were untraced; a further 14 (9%) refused permission to consult their records - many saying there was nothing of relevance available. All 23 asked during interview in 1976 readily gave permission for records to be consulted.

Thus the detailed analyses of the visually handicapped are based on 184 sight-tested adults, 153 (83%) of whom gave permission for records to be consulted; diagnostic or other data were found for 110 (72%) of these 153 (Table 5) - and the remaining 3 had some diagnostic data in their family doctor's records; this was, however, only sought for those (who had given permission) who appeared to be visually disabled (acuity of less than 6/18

Snellen - see page 8) when tested at home and for whom no other data were available. Warren has shown (1976)[100] that only in rare instances do family doctors' records contain details about eye conditions.

These details are worth stressing because they underline the difficulties in seeking cooperation for record linkage if time has elapsed since last contact and if a fresh approach has to be made postally rather than personally. A search might have been made for up to 17% more records if permission had been asked at the time of the interview in all cases - when it was, it was never refused.

HOSPITAL DATA

Only 55 (30%) of the 184 who were finally interviewed as visually handicapped said they were attending hospital about their eyes (Q.1, Appendix 2) - almost all locally. However, a decision was made to search the hospital records for notes on all the 153 who gave permission and in this way useful data were found on 30 more (Table 5). For each of these (85) diagnostic, prognostic, referral and other data were available and these hospital data have been used in preference to other diagnostic and measurement data (registration forms, opticians' records) in the very few instances where there appeared to be conflict. From Table 5 it can also be seen that 60 (71%) of the 85 for whom hospital records were found had attended within 2 years of the survey - most of these had had a visual acuity test done at the hospital (usually confined to distance vision using a Snellen chart and the patient's own correction). This provided a reference against which to validate similar tests done at home.

DATA FROM SOCIAL SERVICE RECORDS

Forty two (22%) of the 194 visually handicapped adults qualified, in 1974, because they were registered as 'blind' and 18 (9%) because they were regis-

tered as 'partially sighted''(Table 4). All were among the 184 to whom the sight questionnaire was eventually administered. However, by the time permission was sought (postally, 14 months after interview) for record search, 9 (15%) of the 60 registered had died, though relatives gave permission in respect of 3 of these. One other had moved away, and 3 declined permission, Of the 50 who gave permission, 34 had details of their eye condition and visual acuity etc. in the hospital records as well as in the social service records (Table 5); of the 16 for whom the only data were in the copies of B.D.8 forms lodged with the social service department, there were 3 with data over 25 years old. For these, the diagnostic data are probably less certain than for the others.

DATA FROM OPTICIANS' RECORDS

Each of the 184 visually handicapped who answered the sight questionnaire (Appendix 2) was asked when he had last had his eyes tested (Q.2) - unfortunately not 'where', though there was good reason to suppose that most tests would be done by one of the six opticians in practice in Canterbury. Their records provided a third possible source of data to complement and validate the survey findings and all six, when approached individually, readily agreed to search their records for those who claimed they had had an eye test within 3 years. However only 5 eventually found it possible to do so.

Despite this cooperation, these records did not prove a very fruitful source of data. Undoubtedly very many elderly people underestimated the time that had elapsed since their last eye test; 139 (75%) of the 184 said they had had an eye test within 4 years, but records were only found for 28 (18%) of the 153 who gave their permission for a search, and 17 of these had also attended hospital recently. Only 6 of the 9 who had not been to the hospital (Table 5) had apparently had a visual acuity test measured by an optician

within 3 years of the test done at home during the survey. There was nothing, of course, in the design of the study, much less its purpose, which allowed a comparison between opticians' and hospital data; such a comparison would normally concern visual acuity only. Nevertheless, the impression was gained that opticians' records could be developed into a very fruitful source of data for future studies, if they were kept with this in mind over a limited period in a defined community.

In Kohn and White's international study[52], in which Liverpool was the centre chosen for England, 31.3% of those identifying some vision problem said they had had a 'vision test' within 12 months of the survey (April 1968 - April 1969) - usually (67%) at an optician's premises. No longer period than a year was sought.

DATA FROM GENERAL PRACTITIONERS' RECORDS

It was decided to approach family doctors for details in respect only of those people for whom no hospital or social service data were available and who were truly visually impaired (less than 6/18) by W.H.O. standards when measured at home. Only 11 (7%) of the 153 who gave permission for a record search fell into this category and diagnostic data were eventually obtained for 3 of these (Table 5). For the others, there were no data in the doctors' notes (9 different doctors).

RESULTS

INTRODUCTION

The several sources of data on those claiming a visual handicap naturally gave rise to seemingly conflicting as well as complementary results. The main areas of seeming conflict arose between what individuals said they were or were not able to see in answer to survey questions and what they could actually see when sight-tested, and in the differences between sight tests done at home and those done in the hospital. The extent of the differences revealed and the possible reasons for them as well as the light that they throw on the value of survey questions and the effect that they have on estimates of prevalence are later explored. First, the social and demographic characteristics of the visually handicapped are described; for this the data come entirely from the survey.

SURVEY DATA

Age and Occupations of Visually Handicapped Adults

Table 6 illustrates the occupations of the 194 claiming a visual handicap; age-groups and sex have been presented in Tables 3 and 4. As expected, more than 80% were over retirement age (though not necessarily retired from work). Among the smaller numbers under retirement age it is not possible to trace variations in work patterns between the five different groups of visual handicap, but only 8% were in full time work without benefit of the help that registration as physically handicapped theoretically gives on the 'open' employment market. Among the 10 who were so registered (not necessarily because of sight problems) only 4 were in remunerative full time work and one in part time (not shown in Table 6).

Other Disabilities Suffered by the Visually Handicapped

Table 7 shows the additional disabilities suffered by those with poor vision - these disabilities were not all necessarily so handicapping as to qualify for assessment in their own right.

The picture presented is of a group of people more troubled by multiple disabilities than a single one - only 41 (21%) of the 194 claimed to be suffering from a visual handicap alone. The linking factor between the disabilities shown in Table 7 is age - these are the disabilities of advancing years, and none of them are, of course, exclusive. Thus 79 (41%) of the visually handicapped were deaf as well, and 47 (24%) stated they were to some degree arthritic; only 15 (8%), however, were considered to be 'senile' or confused. Warren[98] has quantified in detail the combinations and variations of disabilities that the handicapped of Canterbury were shown, by the survey of 1972, to be suffering from - the general range of disabilities suffered by the visually handicapped as a group did not differ markedly in degree or kind from those suffered by all the handicapped.

Daily Living

Such a variety of conditions as is illustrated in Table 7, with or even without the added difficulty of poor sight, is bound to have an effect on the simple tasks of daily life as well as on mobility - yet too often the disabilities of the poorly sighted have been described in terms of vision alone (see Part II). The only major study of the blind in the U.K. which has attempted quantification of other handicaps is that of Gray and Todd (1968)[31]; in their study of 1,464 registered blind adults 57% perceived no other immobilising disability than blindness. Their survey, however, excluded all those of 80 years and more - in Canterbury, where only 12% of the registered blind were aware of having no other significant disability (Table 7), 31% of the

blind and 54% of all the handicapped were in this age group. Any survey that omits the old will not provide all the basic data needed to build a clearer understanding of the comparative, additive and interactive effects of multiple and visual handicaps. Gray and Todd's survey, moreover, dealt only with immobilising conditions perceived by the blind; Josephson[50] has shown that the self-perception of the severely visually handicapped may not always provide an accurate picture of their difficulties.

Table 8 illustrates some of these points - cutting the toenails was by far the commonest difficulty perceived by the visually handicapped yet those with only a distance problem did not find this near-vision task markedly easier than those who could not see close-to. Many in both groups were arthritic (Table 7) and what might, superficially, have been considered a sight-dependent task may have as much to do with stooping and fine movements as with seeing.

None of the questions about the restrictions listed in Table 8, however, was specially directed towards any particular disability - all were designed to illustrate general aspects of daily living and to this end they were 'summed', using a scoring protocol suggested by Harris and Head[ ], to produce a self-care 'score' for each individual. Table 9 illustrates the scoring system and results achieved by the visually handicapped (foot-care and 'housebound', included in Table 8, were not scored). Ninety (46%) of the 194 adults claiming a visual handicap had no serious difficulty in day-to-day self-care and a further 57 (29%) had a 'score' of 5 or less, suggesting that they found only one or two activities difficult, or only one impossible. Without their visual handicap, such a low score would not have qualified them for assessment as handicapped in 1972 unless they were 70 years old or more; there were no restrictions in scores, or age, in 1974.

Moreover, 41% of all the visually handicapped were coping on their own at home. Table 10 compares the household composition of those claiming a visual handicap with that of the handicapped with no visual problem. Significantly ($P < .01$) more visually handicapped lived alone, and significantly fewer lived with a spouse - Table 3 has illustrated the larger proportion of old women among the visually handicapped. Most of these were widows - and those that could not manage alone, lived in the households of their children (Table 10).

On the whole, too, they were Canterbury citizens of long-standing. Only 24% of them (Table 11) had been less than five years at their present address, and the majority of these had moved from one household to another within the City limits. Table 11 also suggests that they were not, in the main, reclusive and unknown to the social service department - 54% could remember being visited by a social worker, and most of those who said they had not been didn't want to be. Only 14% thought a visit from the social services, which they could not remember receiving, might be of benefit to them.

Mobility

Just as for self-care, it is not possible to be sure how much restriction in mobility beyond the garden gate was imposed by visual, and how much by other, difficulties. Going up and down stairs, managing steps in the garden and outside, and travelling further distances from home were used as separate measures of mobility in the assessment of all the handicapped - but here (Table 12) only travel beyond the house is discussed because it implies social interaction as well as personal mobility, while circumventing different individual's attitudes to visiting clubs etc., which was also measured.

From Table 12 it can be seen that only 18 (9.5%) of the 193 visually handicapped said they were unable to got out at all, though a further 6 were

also probably too ill to move. Over half were able to leave the garden unaccompanied although half of these needed the help of a stick or walking aid. Virtually all the 28 who needed the help of a friend or relative said such help was usually available.

Among the 42 registered blind, 16 (38%) said they were able to travel about unaccompanied by another person - this is less than the 57% in Gray and Todd's[31](younger) sample of 1,464 registered blind who achieved some degree of independent travel in the week before their interview. Gray and Todd stress that only a week's diary of travel provides a reliable guide to what is actually being achieved - the answers to single questions, as asked in Canterbury, giving much less reliable results. Of all the ways of measuring mobility that they tried, ability to go out unaccompanied was the best.

The visually handicapped in Canterbury were also asked (Appendix 2) what aids they used for getting about. Seventy per cent used no aids other than an ordinary walking stick, 16% used a short white cane and 5% a long white cane. Nobody used a sonic aid and only two people a guide dog. Eight people used another person as a sighted guide when they travelled about, and not more than 10% of those who were mobile and independent admitted to any problems with parked cars or changes in traffic signals.

Conclusions

Data from the survey, then, suggest that those claiming a visual handicap comprise a group characterised by age, multiple disabilities, and relative independence. Thus, four-fifths are in their retirement years and four-fifths have some significant disability in addition to poor vision; nevertheless, almost a half can manage all the daily routines of self care without help or special aids, and another third can manage all but one or two of them. More than half can travel about unaccompanied and for those that can't the help of friends or relatives seems to be generally available; two-fifths of them live alone.

But how far is their claim to be regarded as a single group justified? It rests largely on their own individual perceptions of what they could or could not see; only a third were actually registered as blind or partially sighted. Such perceptions are immensly important to the individual and to the solution of his problems; how reliable a guide they provide, however, to the epidemiology of visual disability is explored in the next section.

SIGHT TEST RESULTS

Distance Vision

One hundred and eighty (93%) of the 194 adults who claimed a visual handicap had a test of distance vision done at home (see page 54).

Distant visual acuity was measured using a standard Snellen card (scaled down for use at 3 metres) in conditions of 'the best lighting available' - using such lens correction as each person had available in the house at the time of the interview. These are obviously far from ideal testing conditions and the tests can in no way be regarded as standardised - nevertheless they do present some measure of visual ability in a more usual setting than is the case in the hospital or optician's consulting room. It can be seen from the progression of questions asked of the visually handicapped (Appendix 2) that there was nothing that allowed a precise estimate of the visual acuity of those who, while able to see more than 'light from windows' were not able to read the top line of the Snellen chart (6/60). In the Tables dealing with visual acuity they have been included as a single group with an estimated visual acuity between 1/60 and 3/60.

Table 13 summarises the visual acuities, on home testing, of those claiming a visual handicap. While most of the very poorly sighted (less than 6/60) were registered as blind or partially sighted, 18 (30%) of them were not. The

range of visual acuities in each group was wide - especially perhaps among those claiming a double handicap (distance and near) where as many (12) were among the very poorly sighted as were among those with vision of 6/18 or better. Indeed, 51 (26.5%) of all those claiming to be handicapped by poor sight who had a home test were in this better sighted group and did not therefore qualify as visually disabled according to the definition used in this study (page 8). Among these were 3 registered as blind and 1 as partially sighted.

Table 13 also shows that those who declared only a problem with near vision did not do significantly better, when tested for distance vision, than those who claimed only a distance problem. (Ten of the latter, however, were not tested - they may have made the difference in proportions greater.) At least 20 (54%), and perhaps more, of the 37 (tested) who claimed an inability to recognise a friend across the road as their only visual difficulty had an acuity which should have allowed them to do so,and would not be counted as visually disabled (visually impaired by W.H.O. standards). Those who identified a dual problem, however, demonstrated their greater disability - at least 41 (76%) would be considered visually disabled; indeed 12 of them (22%), together with 4 of those with a distance problem and 2 with only a near problem, apparently had a visual acuity low enough to make them theoretically eligible for registration as blind or partially sighted.

Among those 60 (Table 13) who <u>were</u> registered as blind or partially sighted there was considerable variability in visual acuity ranging from 4 who could apparently see quite well to 3 who had no light perception at all. Registration as blind or partially sighted does not, however, depend on visual acuity alone - visual fields play a formal part and the wishes of the patient, and possible benefits to him of registration, an important informal one. But before anything can happen the patient must be in contact with an

eye specialist - it is estimated that about 40% of all those 73 unregistered, with a visual acuity below 6/18 on home testing (Table 13) had never had a specialist examination. This figure remains as no more than an estimate because of the way the question about hospital attendance (Appendix 2) was phrased, and the 'loss' to the survey before permission to search was obtained.

Estimate of Shortfall in Registration (based on Home Tests)

Table 13 suggests that 18 more people might be considered for registration (if they had seen a specialist and if it had been their wish) on grounds of poor visual acuity (less than 6/60) alone. If they had been registered in the same proportion of blind to partially sighted as those already registered, it is estimated that blind registration underestimates true numbers by about 33% and partially sighted registration by about 17%. This estimation is, in fact, probably too low, because 8 registered 'blind' and 10 'partially sighted' had a visual acuity above the normal level for registration and were registered, perhaps, because of contracted visual fields or some other consideration. It can also be seen from Table 13 that, although proportionally more of the registered partially sighted than the registered blind were among the better sighted, there is still a considerable overlap between the two groups, at most levels of visual acuity. The choice about which register to enter an individual on is much influenced by age, possible financial benefits and so on. So although it is possible to go some way towards establishing the validity of the sight tests done in the home (see next section), there are other factors which make estimates of under-registration based on the measurement of a relatively small number of self-selected people tested under varying conditions no more than speculations.

Validation of Acuity Tests (Distance) done at Home

Although no formal validation exercise was done at the time of the survey, enough people (Table 5) attended hospital, and had an acuity test done under

optimal conditions, within a short time of the survey to provide a measure against which to judge the accuracy of the home tests.

Sixty (39%) of the 153 who gave permission for a record search had attended a specialist eye clinic (and 58 had had a visual acuity test recorded) within 2 years of the survey (Table 5). Gray and Todd[31] have deduced that 2 years is the largest period over which it can be assumed that no substantial sight deterioration occurs, at least among the registered blind. There is no evidence that the same assumption can necessarily be made for a group containing a fair proportion with a visual disability short of registerable blindness - it may be that deterioration in visual acuity is more rapid. By chance, however, almost as many (28) of the 58 (Table 5) who were tested both at home and hospital within 2 years had the home test first, as had the home test subsequent to their last hospital visit (30). It might be supposed, therefore, that if the tests were comparable and if deterioration in visual acuity were progressive over two years, the group first tested at home would show a fair number who apparently saw better at home than at the hospital. Conversely, those first tested in the hospital would include many who saw worse when subsequently tested at home.

This, however, was not so. The pattern illustrated in Table 14, which compares home with hospital findings for the whole 58 hospital attenders, was exactly mirrored by each of the two constituent groups whether they were tested at home before or after their hospital visit. Table 14 shows that while a general correlation exists between tests of visual acuity made under far from ideal conditions at home and those made in the hospital, at least 20 (34%) of the 58 seem to be achieving less at home than would have been supposed at their hospital visit. For those 30 tested at home before they visited hospital this percentage was 30% and for those 28 tested at home after their hospital visit 39% - the differences in these percentages are not statistically significant ($p > .05$). However, both the people who apparently

saw marginally better at home than in the hospital (Table 14) were first tested at home (one 4 months and one 12 months before hospital visit).

Measurements below 6/60 were not attempted in the home and assumptions have been made for those with this level of acuity from the responses to the various questions; these assumptions have not been tested. Nevertheless it seems from Table 14 that 9 (36%) of the 25 people who would not, when measured under good conditions of lighting etc. at the hospital, be considered visually disabled (visually impaired by W.H.O. standards) are so disabled in their own surroundings and that 3 (18%) of the 17 who, though visually disabled, and no worse than W.H.O. group 1 (Appendix 1 Part II) are managing no better than group 2 or 3 at home. As for U.K. definitions, on visual acuity alone 3 who were not registered might have been considered for registration had they wished it - one as blind and 2 as partially sighted. (One of these latter was awaiting cataract surgery with the hope of vision improvement.) Those in Table 14 who <u>were</u> registered with a visual acuity apparently much above their registerable status <u>all</u> had moderate or severe contraction of visual fields; both those with 6/18 vision had severely contracted fields.

There is, of course, the possibility that the differences illustrated in Table 14 represent systematic or random observer error, but this is most unlikely - there was no evidence of systematic error among any one of the 14 interviewers and to assume random error would be to assume that the test card was held at least six feet too far away from the tested person's eyes and usually more than this. It is much more likely that $\frac{1}{3}$ of the poorly sighted actually saw better when they were tested at the hospital (where decisions about treatment and registration etc. are made) than they did at home (where the everyday difficulties in living are encountered). It needs stressing, however, that the majority of these people attending the hospital were elderly, and most of those with vision of less than 6/18 (for whom, alone, the above conclusions are drawn) were suffering from degenerative or vascular eye con-

ditions associated with advancing years - for these very little hope of vision improvement by specific eye treatment could perhaps be expected.

Theoretical Estimates of Visual Acuity 'Corrected' for Differences between Hospital and Home Measurement

The 58 who had recently attended the hospital did not differ significantly in age, sex or visual acuity (home measurement) grouping from the whole sample of 180 tested at home - if they were truly representative, the differences in the measurement of their distance acuity between hospital and home can be applied to the home-measured visual acuities of all 180 to derive an estimate of what would have happened if they had all been measured under optimal conditions in the hospital. The results of this theoretical calculation, expressed in percentages, are presented in Table 15.

Comparison of the percentages in Table 13 with those in Table 15 suggests that it is the better sighted who are not registered as blind or partially sighted who are most affected by the 'correction'; a further 14% of the 180 tested (26 people) would now escape classification as visually disabled, making a total of 77 people or 43% of all those (tested) who were considered to be visually handicapped by the criteria of the survey.

The effect on the U.K. definitions of 'blind' and 'partially sighted' is, however, much less because of the smaller estimated differences in visual acuity measurements between hospital and home for the very poorly sighted. Table 15 suggests that, on visual acuity alone, the blind register underestimates by 34% and the partially sighted by 20%; approximately the same as estimates made purely on home measurement (page 66). Graham[30] and his colleagues estimated a shortfall of 28% for blind registration on visual acuity alone, among elderly people in South Wales, which accords with the Canterbury estimates, but there is less confirmation for the partially

sighted. Page[76] estimates a 50% shortfall in registration, without stating how he arrived at his estimate. Numbers of registered partially sighted were small in Canterbury but it is interesting that 55% had a visual acuity of 6/60 or more when tested at home (Table 12) - clearly there is more than visual acuity to registration and an estimated shortfall of 20% is considerably too low.

Near Vision

Tests of near vision play no part in either national or international definitions of 'blindness', though questions relating to it have constantly featured in population surveys (see part II). Near vision is of obvious importance in day to day living and self care - perhaps even more so when mobility is reduced by other handicaps. Table 16 illustrates the near-vision reading ability of 178 (92%) visually handicapped adults on whom the test was successfully completed; the testtype used was the standard 'N' form approved by the Faculty of Ophthalmologists. In each case 'usual' reading correction was used, at the most comfortable distance, with the best lighting available.

It can be seen in Table 16 that there was a wide spread of reading acuity among all groups, except those who complained of a distance vision difficulty only, all of whom could read approximately normal print. Although no one among the unregistered who had a substantial reading difficulty had not claimed it, half those who had claimed not to be able to read ordinary print or see to write without a magnifier managed to do so on sight testing at home. It is not certain, however, from the results how many actually used magnification during the test. Two (5%) of the registered blind could read at the level of newspaper and book print and a further 5 (12%) could manage large print books - about the same percentages as Gray and Todd[31] found among the elderly members (65 - 79 years) of their sample. The implications of the results illustrated in Table 16 for survey questions about perceived ability to read will be explored in a later section.

Although the print sizes indicated in the left-hand columns of Table 16 are accurate as far as dimensions go, there is much else in printing that affects legibility. Thus Shaw[83] has shown that, for the poorly sighted, the 'weight' (approximately pigment density) of the face is of almost as much importance as size and for those with cataract may be of more importance. Even assuming adequate saccadic and other eye movements, and all the other variables that contribute to successfully comprehended reading over more than a very short period of time, it is doubtful if many with a reading vision of less than N5 could manage a newspaper with any enjoyment.

Validation of Near-Vision Tests done at Home

Unfortunately only 26 (43%) of the 60 (Table 4) who had attended hospital within two years of home testing had a near-vision measurement done there within that time, so comparisons depend on smaller numbers than for distance vision. Nor is there any evidence that two years is necessarily a suitable period over which to assume there has been no great change in near-vision ability.

Comparison between home and hospital testing are presented in Table 17. This suggests that although almost everyone appeared to do marginally better when tested at the hospital than at home, 20 (85%) of the 25 who were judged able to read (at least) clearly printed books by hospital test, could also do this at home. Most of the near vision tests were done, of course, in the range of acuity most likely to benefit from suitable lens correction.

Correlation Between Distance and Near Visual Acuity

Although the tests used to judge both distant and near vision each depend on the angle which opposite edges of the test image subtend on the retina, and the amount of resolution that the visual costex can manage, it is only in respect of test image size and density that they are truly comparable.

The rest depends too much on powers of accommodation, lighting, psychological perception and, of course, pathological or degenerative changes in any part of the eye, for the one to be used as a measure of the other. For instance, the cortex of the ageing lens may be affected more than the nucleus making near vision less distinct; but, against this, many 'high myopes' are undercorrected for distance vision. There may, perhaps, be evidence that correction for both 'near' and 'far' sight was deficient in the whole group of 194 visually handicapped - only 75% claimed to have had an eyetest within 4 years and records were traced for only 20% of these. Perhaps, too, if all had had perfect 'correction' available at the time of the survey far fewer would have complained of a single distance or near vision difficulty (Table 2). Nor were the conditions under which the tests were made necessarily similar for each test - lighting arranged in a room so that a handicapped person with restricted mobility can make the best use of near vision may not always illuminate as well as a test card held several feet away.

Table 18 compares the distance and near vision results of the survey - the 'cells' where the test image size in the two tests is, in theory, approximately the same have been boxed in. Of course the near vision test was, properly, not a test of visual acuity measured under standard conditions but a test of the smallest print that could be read in 'usual' circumstances (of lighting, distance from the eyes, etc.) - exact correlation or test image size can only be assumed if the reading card is held at 35 cms. Nevertheless the discrepancies in Table 18 are too great to be explained by any single factor; in only a small minority of cases did the two theoretical tests of image size coincide, except among the very poorly sighted (Snellen 1/60 - 3/60).

Take, for example, the 24 people who, in their own surroundings, have a measured distance acuity of 6/24 - just within the range to be considered as visually impaired by W.H.O. standards. Only one of the 24 seemed to perceive

the same angle on his retina whether tested at distance or close range; 18 (75%) seem to be able to accommodate (or to have corrective lenses available) to a near distance acuity finer than that suggested by the distance test and 11 of these accommodated to a level at which they could, theoretically, manage book print. Of the remaining 5 who did better at distance than at the near tests equivalent, 2 were so poorly sighted that they must have found almost all close work a practical impossibility. However, at all levels of visual acuity measured by the distance test, proportionally more people seemed able to read better than might be expected by their distance test, than worse - at each level of distance acuity between 6/18 and 6/60 the proportion is at least 2:1.

There is some evidence that lighting and proper correction are the factors that may explain, at least, why 40 (22%) of the 178 tested at home read worse than might have been expected by their distance test. All 26 people (Table 17) who had a near vision test at the hospital within 2 years of the survey also had a distance vision test at the same time. Nineteen of the 26 had a distance acuity of 6/18 or better - all 19 could read at an equivalent or finer level than their distance test. Of the seven whose acuity was less than 6/18 only one read at a lower level. At home, only 11% of the 19 better sighted (6/18 or more) read at a level equivalent to or better than suggested by the distance test.

There must of course be social factors as well; even supposing the best correction and visual aids (if any) available in the house were used for each separate test, much must depend, especially among the elderly and multiply handicapped, on what a person is accustomed to doing or interested in doing with his eyes. Nor do the tests, of course, provide any sort of estimate of sustained visual effort. Nevertheless, the differences illustrated in Table 18 provide a framework around which most of the difficulties, optical and perceptual, suffered by the visually disabled can be discussed.

It does, moreover, seem that neither sight test can be used as an adequate substitute for the other, either in good conditions at the hospital or in the more varied conditions at home; and that it remains essential to do both if an adequate measurement of the present state of functioning visual acuity is to be achieved, even in a 'snapshot' sense.

VALIDATION OF SURVEY QUESTIONS

How accurately did the questions used in the various stages of the survey discriminate between those who had, and those who had not, a visual impairment and between those who were, and those who were not, handicapped by it? How far did people's perception of what they could see accord with their measured visual acuity? - for to assume that the one is an accurate guide to the other is to disallow the effects of self-perception, psychological and social adaptation, dependency, habit and so on.

The questions used in the survey can be tested for their validity first by measuring the more general approach used in the initial household questionnaire (Appendix 2) with the more detailed 'screening' questions used in the second stage (page 51), and secondly by measuring the answers to the screening questions against the measured visual acuity of those answering positively. It has already been shown (Fig.2) that the initial household approach had failed to identify 80 people (6 of whom were registered as blind or partially sighted) who had a visual handicap, as well as some other impairment. Using the screening interview questions as a reference the validity of the initial approach can be estimated thus:-

Screening Interview	1972 Initial Household Approach		
	Self-identified As Visually Impaired	Self-identified As Not Visually Impaired But Having Another Impairment	Total
Found to be Visually Handicapped	231	80	311
Found not to be Visually Handicapped	158	1,065	1,223
	389	1,145	1,534

Those 80 who claimed no difficulty with vision at the original approach and were then found, operationally, to have a visual handicap do not, of course, comprise the whole number of 'false negatives' in the population - there must have been others who were not 'screened' at all because they claimed no impairment, or (3% of households) declined to take part in the survey. There is some evidence that these, truly lost to the survey, number not more than 10% at most of all the visually handicapped in the home-based population; Warren[99] showed in his examination of agency records in Canterbury that 12% of the registered blind, and 6% of the registered partially sighted, were not identified by the survey (supposing they were living in the community at the time). He estimates 10% as the upper limit for underestimation of all impairments and quotes from a pilot study done as a preliminary to the national sample study (Harris[35]) as showing that 'false negatives' were heavily weighted towards old women of over 75 years, who attributed their disabilities to the natural consequences of growing old.

It can be seen from the table above that the initial approach, when judged against the subsequent screening questions, is more 'specific' than 'sensitive' - percentages of 87% specificity and 74% sensitivity can be cal-

culated. A higher sensitivity than this should be achievable; there is evidence (see part II) that the use of the word 'blind' and 'very bad' in the initial questions (Appendix 1) may have caused some with the true visual handicaps to answer in the negative. It may be that less precise questions with minimal value connotations may well improve the sensitivity of this first approach, even at the cost of reducing specificity.

An opportunity did not arise until the application of the sight tests in 1974 to test the validity of the two 'screening' questions relating to distance and near vision - even within the constraints already discussed. Table 13 (columns 3 and 4) shows that 33 (13 + 20) of the 91 (54 + 37) who claimed not to be able to recognise a friend across the road, were not visually impaired by W.H.O. standards (distance test), and that 15 of the 29 who, claiming only a difficulty with near vision, said they could recognise a friend, were nevertheless visually impaired when tested.

Visual Acuity (measured at home)	Says unable to recognise a friend over the road	Says able to recognise a friend over the road	Total
Visually Impaired (W.H.O.) 6/18	58	15	73
Not Visually Impaired (W.H.O.) 6/18 +	33	14	47
Total	91	29	120

SPECIFICITY

= 48% (% of 'true negatives' correctly identified)

SENSITIVITY

= 64% (% of 'true positives' correctly identified)

(See Table 13)

Clearly, asking people whether they can recognise a friend across the road is but a poor discriminator between those who can and cannot be regarded as visually disabled (impaired by W.H.O. standards); moreover, the figures in the table represent only those with an actual visual handicap of some sort and are therefore by no means representative of the population from which they come.

When, however, the reference against which the validity of the question is measured is a visual acuity of 6/60 or less - approximately the upper limit for registration as blind or partially sighted - the question assumes a high sensitivity (93%) but a very low specificity - if the questions were to be used as the sole discriminator in a survey to discover who might be eligible for registration as blind or partially sighted very few would be missed, but very many who were not eligible would be included.

Similar tests can be applied to the question on near vision used in the screening interviews to decide who was to be considered handicapped by visual impairment, and who not (Table 15).

SCREENING QUESTION

	Says unable to read ordinary print or see to write without a magnifier	Says able to read ordinary print & see to write	Total
Unable to Read N '5-12'	42	0	42
Able to Read N '5-12'	40	36	76
Total	82 (53 + 29 - Table 16)	36	118

SPECIFICITY = 51% SENSITIVITY = 100%

Once again, only those with some other visual handicap are represented among the total who said they could read, so the 'sensitivity' of this test is probably exaggerated. Nevertheless, among this group at least, all those who said they could read ordinary print were shown to be able at least to manage two lines of print on sight testing, while half those who said they could not also managed to do so. On this evidence, this question may provide an excellent 'lead-in' to a study of why so many who suppose that they cannot read can

be shown to be able to do so, at least for a short period; but the question provides no adequate substitute for sight-testing as an estimate of visual acuity.

This difference in peoples' perceptions of whether they can or cannot see to read is further illustrated by the answers to the question about personal letters asked of all the visually handicapped (Appendix 2, Q.9). The results are presented in Table 19; although most claimed an ability within their measured visual acuity performance, there was a substantial minority for whom the correlation was negligible. Except for those too blind to see even the largest type, it is clear that such a question about personal letters provides no accurate measure of visual acuity. It is quite possible to imagine that many elderly and old people do not get a lot of personal letters and some time may have passed since the last one. To claim an inability to read them may have as much to do with a sense of isolation from those who are dear, as with a difficulty in the mechanics of reading.

The results of some of the other questions asked of the visually handicapped (Appendix 2, Q.4) are summed up in Table 20. Gray and Todd[31] used these questions to try to guage how far residual sight affected mobility in their sample of registered blind. They deduced that an ability to see a cyclist was approximately equivalent to a visual acuity of at least 3/60 and showed that independent mobility increases, in all age groups, with increasing residual sight from 'light perception only' to being able to see a cyclist on the other side of the road. In Table 20, however, these questions have been compared not with mobility but with measured visual acuity (distance).

The answers illustrated in Table 20 are those of the 165 who could see more than 'light from windows'; 6, however, said they couldn't answer the questions about the grass verge and the cyclist because they had not been out

for a long time and 5 of these could give no opinion about the lamp post for the same reason. It can be seen, however, that an inability to see the lamp post, the grass verge or, among the better sighted, the cyclist, did not match closely any particular level of measured acuity; only among the very poorly sighted was the number of those who could not see a cyclist greater than the number who could, and even for this select group the question provided no accurate estimate of visual acuity. It is possible, of course, that discrimination might have been more precise for one, or all three questions, had acuities below 6/60 actually been measured; but to provide a question that distinguishes solely between those with a visual acuity of 1/60 or less and those with an acuity of 3/60 or more is to concentrate on less than half the visually handicapped (Table 13).

It is no great surprise that none of the questions asked during the survey turned out to be an accurate predictor of visual acuity. Josephson[49] came to precisely the same conclusion (using different questions) in 1963, and, indeed, it is precisely the reliance on questions such as these that has so long befuddled most survey attempts to get an accurate picture of the number of visually disabled in a population, within the definitions of 'blindness' used in most 'western' countries (see literature review). It would be quite wrong to suggest, however, that because these or similar questions are useless for screening purposes, they are not worth asking in the context of deeper studies; they clearly have far more bearing on an individual's self-perception and way of life than measurements of what he or she can or cannot see on test cards devised to test visual acuity in isolation from normal habits and surroundings. Indeed, all questions asked of the handicapped, especially if they are elderly, must be asked and analysed with this concept in mind. For instance, of the 40 (Table 12) who could only go out by car, how many could genuinely not see (or move because of arthritis etc.) and how many needed the protection of a motor-car because they were afraid their disability would embarrass them or those they

met? How many of the 27 (Table 12) who needed a companion needed him or her for the social reassurance that the presence of a friend may give and how many because they were unable to manage due to physical handicap? It may be that these are more the things that are isolating than the actual extent of the disability.

RESULTS FROM HOSPITAL, SOCIAL SERVICE AND G.P. RECORDS

Introduction

Apart from the use of hospital records to validate the sight tests done at home, hospital, social service and G.P. records were used to estimate the number of visually handicapped who had had a specialist opinion, the source of referral for specialist opinion, the part played in visual handicap by restrictions in visual fields (unmeasured in the survey) and to obtain diagnostic data on as many people as possible, including other diseases treated at hospital. Initially it was also hoped to obtain data on prognosis, but records were not detailed enough for this.

Specialist Opinion

Table 21 details the numbers at each level of visual acuity who had had a specialist opinion about their eyes at some stage. Local hospital records were searched for notes on all 153 who gave permission unless they said they had been to a hospital elsewhere, in which case records were obtained from that hospital. Social service records were obtained for all those registered as blind or partially sighted and family doctors were approached where no hospital or social service data existed for all those with a visual acuity of less than 6/18. In only 2 cases (Table 21) were family doctors the sole source of useful records.

It can be seen from Table 21 that 103 (67%) of the 153 who gave permission for a record search were within the W.H.O. category of visually impaired (less

than 6/18) by home measurement, and that 23 (22%) of these had apparently never had a specialist diagnosis of their eye condition. All those (15) with no more than light perception had been seen by a specialist, but at each level of visual acuity above that (and below 6/18) between 18% and 42% had apparently never had a specialist opinion. It is, of course, possible that some of the 23 visually impaired who had no records of any sort had records elsewhere in the country that could have been used, and undoubtedly several of those who died before they could give permission had been seen in the local eye clinic. It is, however, at least likely that most of those 23 visually impaired for whom no specialist opinion was available had never had one - 80% of them had lived at the same address for at least 5 years and there were still no records with their family doctors or the local hospital.

Sources of Referral for Specialist Opinion

It was possible to trace the source of referral for most (94%) of the 102 people for whom specialist opinion was available (Table 22). Family doctors initiated, either on their own or because of referral by an optician, 47% of hospital referrals and the social services (including the medical officer of health*) 31%. Other hospital clinics referred 13% of people seeing the specialist.

Almost all the 32 referrals from the social services or local authority health department (Table 22) led to registration as 'blind' or 'partially sighted'; almost all the 13 referrals from other hospital clinics concerned patients with very poor eyesight (less than 6/18) associated with diseases known to have ocular implications (e.g. diabetes, multiple sclerosis etc.) and virtually all those with relatively good eyesight, though with definite eye disease, were referred to the hospital by G.Ps.

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*These referrals were all prior to the reorganisation of Social Service Departments in 1972.

Sorsby[89] showed in his analysis of blind registration between 1957 and 1960 that 61% of all referrals ending in certification came from 'lay' sources. In Canterbury 52% of the 33 registered blind, and 59% of the 17 registered partially sighted, for whom permission for record search was obtained, were registered as a result of lay referral; family doctors had referred another 21% and 29% respectively and the remainder had come from other hospital clinics or voluntary societies.

Visual Fields

No questions in the survey, or sight tests, were designed to estimate possible defects in visual fields, although an ability to see a lamp post at 5 paces or a cyclist over the road (Appendix 2) presumably depends partly on an adequate field of vision. Visual fields, however, play a formal part in both the W.H.O. classification as visually impaired (Part II - Appendix I) and in U.K. registration as blind or partially sighted; in order to see how important limitations of field might be to all the visually handicapped as well as those registered as blind or partially-sighted the hospital and social service records of the 100 people for whom they were available were searched for mention of visual field measurement. Unfortunately no optician in Canterbury was measuring visual fields at that time.

The results are presented, as they were recorded, for each eye separately in Table 23 in order to show such association as existed between low visual acuity and reduced visual fields. From such limited data it is not possible to deduce the prevalence of visual field defects in the whole group of 194 visually handicapped; records were available for hardly more than half the group and, for these, only 57% of their eyes had a visual field test recorded. Table 24 suggests that the likelihood of the visual field being measured is greater if the acuity is low, but this was partly because a record of visual fields is one feature of the B.D.8 form for registration as blind or partially

sighted. In all, 41 (82%) of the 50 registered who gave permission for search had visual fields recorded (for 81 eyes) and only 17 of those 103 who were not registered (15 for both eyes and 2 on one eye only).

Because, however, most of the registered blind and partially sighted had visual fields recorded it is possible to derive some estimate of the effect that reduced visual fields might have had on the process of registration. Thus 21 (64%) of the 33 registered blind whose notes were searched had a visual acuity, in the better eye, so low that even a full visual field would not have affected their eligibility, while a further 10 (30%), with an acuity of 6/60, might have been registered only as partially sighted, had they not had a greatly defective field. The remaining 2 (6%) had an acuity of 6/18 vision in the better eye, but a central field greatly contracted to no more than 10 degrees. Of the 17 partially sighted, 14 (82%) had an acuity low enough to lead by itself to registration and 2 more (12%) a low acuity and a restricted field. Only one partially sighted person appeared to have been registered because of a severely limited field alone.

These are no more than conclusions drawn from the readings of records; registration depends on much more than can be measured and, of course, visual acuity and visual fields are interactive as well as additive in effect. Also the records spanned nearly 40 years - although the great majority were clustered in the last 5 - 10 years. Nevertheless, the conclusion that 3 (6%) of the 50 who were registered, were registered by reason of visual field restriction alone is not far wide of MacDonald's[61] estimate, from an examination of 24,671 blind registration records in Canada, that 3% with a visual acuity better than 6/60 were registered only because of a defect in visual field. It may be, therefore, that any estimate (page 66) of under-registration of the blind and partially sighted based on measurement of visual acuity alone, will slightly understate the true picture.

Causes of Visual Handicap

The World Health Organization[107] suggests that the aetiology of impaired vision should be expressed for each eye separately according to underlying pathology and major site of disease. An attempt has been made to do this in Tables 24 and 25 for those 104 (68%) of the 153 who gave permission for record search, for whom diagnostic data were available. By far the greater part of these data came directly from hospital records where of course diagnoses are not entered in this dual W.H.O. form; some difficulty was experienced in translating to the dual system, especially when the patient was recorded as suffering from more than one potentially blinding condition. In general retinal disease was given priority over lens opacities, where they co-existed.

For the purposes of discussion, however, especially on a community basis, it may be easier to consider the diseases that actually caused the visual impairment of each person, rather than the pathological process in each individual eye. One hundred and thirty (72%) of the 180 for whom visual acuity (distance) was recorded at home (Table 12) had an acuity of less than 6/18 and so were truly visually disabled by definition - the diagnosis for the 84 (65%) of these, for whom it was available, is presented in Table 26 with visual acuity as measured at home. Under the heading 'no diagnosis' are included 5 of the 14 who refused permission for a record search (the other 9 all had a visual acuity of 6/18 or better) and 7 of the 15 who died before their permission could be sought, but who had a measured acuity of less than 6/18. One other visually impaired for whom no diagnosis was available claimed she was attending hospital 'for her eyes', but there was no mention of these in her hospital records. All the remaining 47 (26%) of the 180 who had acuity measured at home (Table 13), not accounted for in Table 26 had eyesight of 6/18 or better.

Such incomplete data, with a diagnosis available for only 63% of all those who were shown to be visually impaired, by W.H.O. standards, in their own homes, allow for no accurate statement about the relative importance of the various

causes. However, if the data are limited to those with an acuity of 6/60 or less, who might be considered for registration as blind or partially sighted, 63 (78%) of the 84 are included (Table 26) and comparisons can be made with other surveys using approximately the same criteria. In fact, such limitation of the data hardly affects the ordering of importance of the various causes. The predominance of macular degeneration (15%), followed by cataract (11%) is the same as that in Sorsby"s[89] analysis of the blind register (all ages 1955-60) and of Sturman's analysis in New Zealand[93]. Both, however, place glaucoma third and, although Sorsby ascribes the same percentage to myopic error (8.4%) as in Canterbury, in New Zealand it accounted for no more than 2.5% of all cases of registered blind. In contrast, Goldstein[29] found cataract (24%) the commonest reason for new registration as blind in America (1964) with 'retinal degeneration' 16% and glaucoma 14% - 'myopia' accounting for no more than 3% of all cases. MacDonald, in Canada[61], also found cataract the commonest cause for registration (15%), but this was followed by glaucoma (10%) and myopia (9%). He ascribed no more than 5% to macular degeneration.

Clearly the small numbers in Canterbury, together with the fact that 22% were undiagnosed, make detailed comparisons meaningless - it should nevertheless be said that discussion is also inhibited by the unstandardised way in which diagnoses are made and data recorded in different parts of the 'western' world. Certainly more data are needed before a definitive statement can be made about the relative importance of the causes of visual impairment (W.H.O.) in the United Kingdom.

Lastly, 29 of the 102 who at some time had attended a hospital eye clinic, were attending another hospital clinic at about the same time. In order of frequency these clinics were diabetic (8), general surgery (6), physical medicine (4), general medicine (2), radiotherapy, geriatric and nine others (1 each). In view of the elderly nature of the population of visually impaired from which this hospital sample comes, it is worth remarking that many had last attended hospital before specialist out-patient geriatric services were started there.

CONCLUSIONS AND DISCUSSION

The constraints of the Canterbury study, in which at least two years elapsed between the initial identification and the detailed visual assessment of those considered to be handicapped in their daily lives by poor sight, did not allow definitive statements to be made about prevalence, even for one community. Less than half those initially identifying a sight handicap were available for measurement two years later and, although they were joined by others already disabled for some other reason who had apparently acquired a visual handicap in the intervening years, there was no way in which the range of visual acuities could be assessed for all at, or near, the time of their first identification. Since the definition of visual disability depended on the measurement of acuity, no point prevalence estimate could be made.

Very much, however, was learned of the social and other difficulties suffered by those with poor sight and, most importantly, of the part that other disabilities played on various aspects of their ability to lead independent lives. Over eighty per cent of the visually disabled were in their retirement years and only 20% were free from some other disabling condition that hampered their daily lives. Certainly the commonest of these was deafness, but very many were also restricted by arthritis or other serious ailment and there was good evidence that the effect of these conditions often overshadowed the limitations on daily activities imposed by poor sight. There was no mechanism in the Canterbury study for judging what each person perceived as his most disabling problem but the importance of assessing the effects of all disabilities, rather than concentrating on a single one, was amply demonstrated. Visual disability, for most, is only one disability among many and to quantify its effects in isolation, will not lead to a better understanding of what poor sight means to the individual, or of his ability and success in adjusting to it.

Something, too, was learned of the use that the visually disabled in one community had made of the specialist services available to help them, of the

pattern of diseases that led to visual disability and of the differences that seemed to exist for many in the performance of simple tests of visual acuity in home and hospital surroundings. The precise origin of these differences was not resolved by the survey - probably there were components in lighting, background and correction as well as in psychological and sociological motivation. More than a quarter of those tested within a few weeks at home and hospital appeared to see moderately better in conditions of good lighting, and a further 9% markedly better. It has always been accepted that lighting, both its intensity and its diffusion, plays a major part in visual acuity, though there is recent evidence[92] that background may be at least as important. It was largely among the better sighted visually disabled, who would not qualify on visual acuity grounds for registration as blind or partially sighted, that the greatest differences lay between measurements made at home and in the hospital - clearly if these findings applied to all the visually disabled in the survey and not only to those who had recently been to hospital, much might by achieved by the simple adjustment of lighting conditions at home.

The Canterbury study suggested that less than 20% of the visually disabled had recently (within 4 years) visited an optician for assessment or reassessment of the correction they needed and that over a quarter had never had a specialist diagnosis of their eye condition. Visiting opticians is, of course, of more importance to the visually disabled than simply for the adjustment of their lenses - it is the commonest route by which those with a sight difficulty, short of registerable blindness, reach the hospital. There was some evidence for most of those who had been referred to a specialist clinic by their family doctors that referral had originated from an optician or ophthalmic medical practitioner. The barriers that exist, social, financial and physical, between an elderly and often multiply disabled person and his visit to the optician located in the busy high street are thus doubly important.

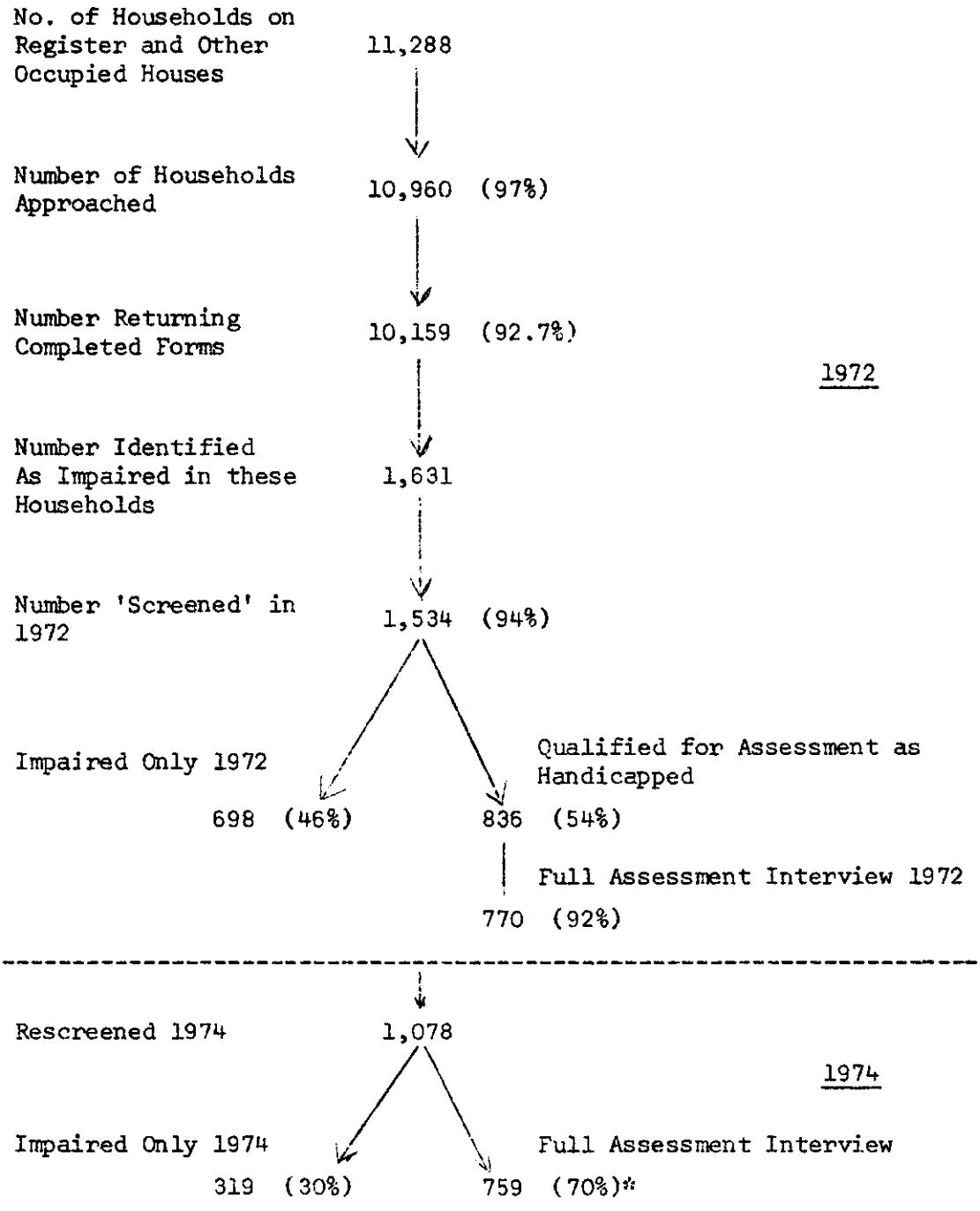
Another result of the Canterbury study was the opportunity that analysis gave to judge the validity of the methods that were used to discover those in the community with a visual disability. Review of the world literature (Part II) suggested that the number and the problems of those living at home with poor sight has never, anywhere, been adequately assessed by the study of routinely kept data, local or national, and that only survey techniques are likely to lead to accurate results. Much experience of what these techniques should consist of was gained in the analysis of the Canterbury data where it was possible to match the answers given by the poorly sighted to detailed questions about what they could or could not see with standardised vision tests. There is much, of course, that is subjective in the tests themselves, but they are the standards on which national and international definitions of visual disability are based. The Canterbury data confirmed that the most accurate results are likely to be achieved if the initial population approach is couched in the broadest possible terms and consciously avoids value laden or emotive terms (such as 'very' or 'blind'). It must allow for general concepts of both distance and near vision, or at least not exclude them, and it must impose no sort of limits. Undoubtedly many 'false positives' result from such an approach, but the use of simple tests of distant and near visual acuity which should follow initial identification as soon as possible is reasonably accurate in 'screening' them out and, if part of a general survey of disability, cheap. In Canterbury, questions related to distance vision were only useful in deciding who or who not to include if interest was confined to those with very low vision (6/60 or less), while questions on ability to read and write were not accurate predictors of acuity at any level short of an ability only to perceive light. Such questions, at least if open ended, are of undoubted value in judging the difficulties that poor sight leads to, in the assessment of each individual; but they are not useful as survey techniques and should not at any rate be used for selection between initial identification and acuity measurement.

The analysis of the Canterbury data also allowed judgement to be made about the usefulness of the W.H.O. classification of visually impaired as a description of all those disabled by poor sight. Clearly, no reading of a test card in a single moment can provide an adequate description of what a person is actually managing to do in the context of his day-to-day living, but no questions in the Canterbury survey, which was a general disability survey with closed questions on sight added, were detailed enough to determine the full disability caused by a sight problem. Certainly the Canterbury data suggested that to rely on traditional definitions of partial sight and blindness would be to exclude 63% of those who felt they had difficulty with distance vision and 37% who could be shown on testing to be unable to read anything but the largest print. Many of those with the very real possibility of being disabled for optical and not perceptual reasons in the enjoyment of their daily lives would thus be excluded. Although the W.H.O. standard of less than 6/18 still excluded 32% of those who perceived a distance problem and 14% with an apparent inability to read ordinary print, many more with the possibility of a true optical handicap were included and it thus provides a much more satisfactory framework for the examination of the relationships between perceived visual difficulties and measurable visual acuity.

Thus the analysis of the Canterbury data served not only to show the dimensions of the problems faced by visually disabled people living in the community, but the techniques that could be used for locating them and describing their difficulties, and the framework around which descriptions could be made. In this way the Canterbury study was used as a testing ground, in a sense a pilot, for the national survey - the techniques and lessons learned in Canterbury were directly applied to it.

FIGURE 1

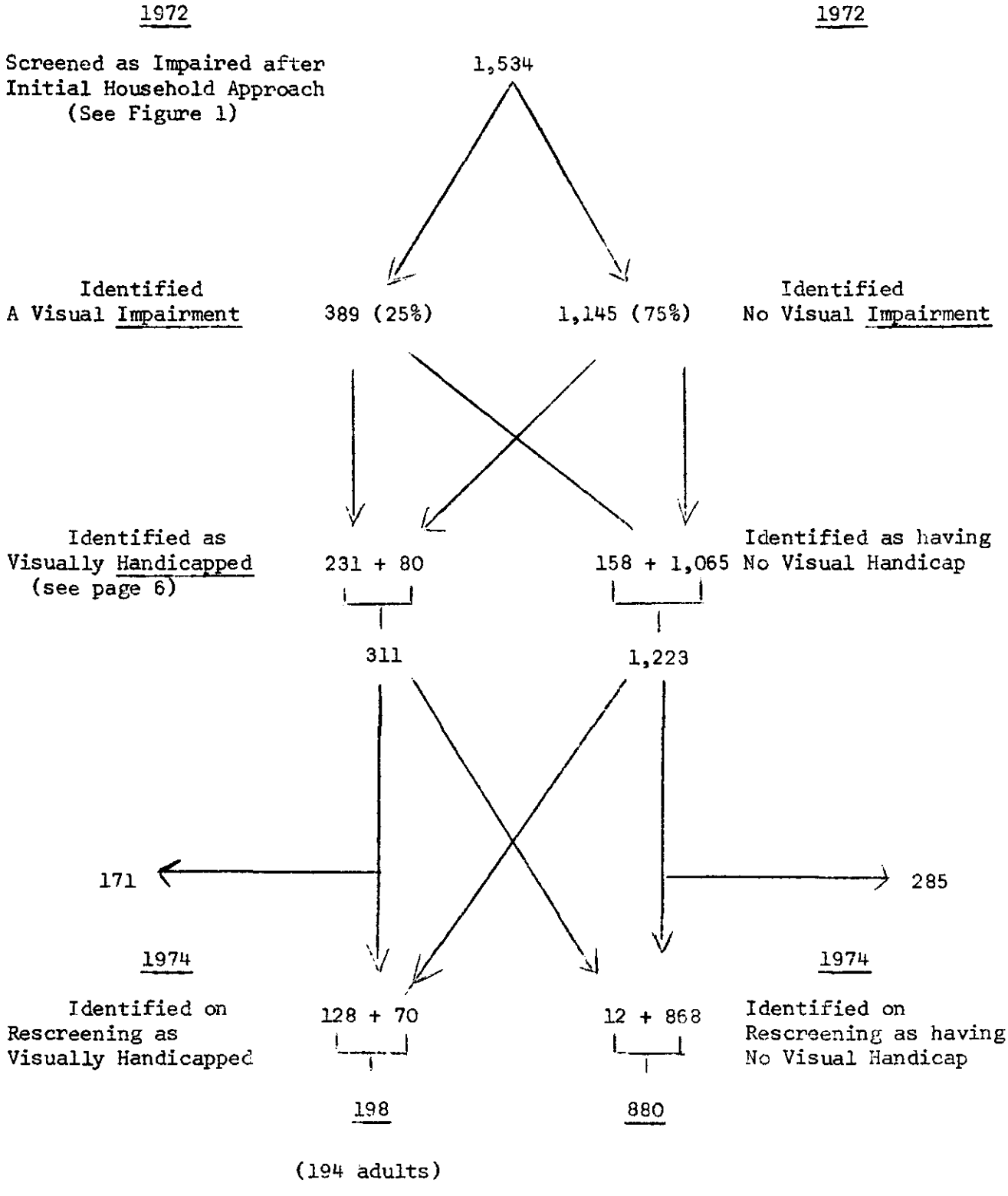
COVERAGE OF BOTH PHASES (1972 & 1974) OF THE CANTERBURY SURVEY



(*NOTE: 584 (77%) of these had handicaps in 1974 which would have qualified them for full assessment in 1972. 175 (23%) came into additional handicap categories only added in 1974.)

FIGURE 2

VISUAL IMPAIRMENT AND HANDICAP (1972 and 1974)



(Total Impaired 'Survivors' Screened in 1974 = 1,078)

(See Figure 1)

TABLE 1

DISTRIBUTION BY AGE GROUP AND SEX OF THE IMPAIRED AND HANDICAPPED LIVING AT HOME IN CANTERBURY (1972), OF THE HOME-BASED POPULATION OF CANTERBURY (1971 CENSUS) AND OF THE HOME-BASED POPULATION OF ENGLAND AND WALES (1971 CENSUS)

Age Group		Impaired living at home Canterbury 1972	Handicapped living at home Canterbury 1972	Home based population of Canterbury 1971	Home based population England & Wales 1971 Census (%)
Men	0- 4	10 (0.7)	6 (0.8)	)3,506 (11.7)	(4.1
	5-14	39 (2.5)	27 (3.5)	)	(8.2
	15-29	38 (2.5)	15 (1.9)	3,305 (11.0)	10.7
	30-49	69 (4.5)	14 (1.8)	3,124 (10.4)	12.0
	50-64	134 (8.8)	44 (5.7)	2,502 (8.3)	8.5
	65-74	154 (10.1)	63 (8.2)	1,126 (3.7)	3.6
	75+	156 (10.2)	101 (13.1)	512 (1.7)	1.5
Total * (Men)		600 (39.2)	270 (35)	14,075 (46.8)	48.6
Women	0- 4	5 (0.3)	3 (0.4)	)3,185 (10.6)	(3.9
	5-14	22 (1.4)	13 (1.7)	)	(7.7
	15-29	23 (1.5)	10 (1.3)	3,353 (11.1)	10.5
	30-49	67 (4.4)	16 (2.1)	3,567 (11.9)	11.9
	50-64	168 (11)	64 (8.3)	2,995 (10.0)	9.3
	65-74	244 (15.9)	137 (17.8)	1,733 (5.8)	5.0
	75+	402 (26.3)	257 (33.4)	1,177 (3.9)	3.1
Total (Women)		931 (60.8)	500 (65)	16,010 (53.3)	51.4
Grand Total		1,531*(100%)	770 (100%)	30,085 (100%)	100%

(*3 impaired had no age recorded)

TABLE 2

198 VISUALLY HANDICAPPED PEOPLE (1974)

Visual Handicap in 1972	Visual Handicap in 1974					Total
	Registered		Unregistered Disability			
	Blind	Partially Sighted	Distance Near	Distance* Only	Near* Only	
Registered Blind	26	3	0	0	0	29
Registered Partially Sighted	11	7	0	1	0	19
Unregistered Distance and Near Disability	4	6	20	6	1	37
Unregistered Distance Disability Only	0	3	9	14	4	30
Unregistered Near Disability Only	0	0	4	2	6	12
Claimed No Visual Handicap in 1972	1	1	25	24	19	70
Total Visually Handicapped (1974)	42	20	58	47	30	197†

*'Distance' Disability: Claims to be unable to recognise a friend across the street.

*'Near' Disability: Claims to be unable to read 'ordinary' print, or see to write, without the aid of a magnifier.

Both assume such lens correction as is usually worn.

†One person, when fully assessed, claimed no substantial sight difficulty.

TABLE 3

AGE GROUPS AND SEX OF VISUALLY HANDICAPPED ADULTS (1974) COMPARED TO HANDICAPPED ADULTS (1974) WITH NO VISUAL DIFFICULTY

Age Groups	Only Visually Handicapped	Handicapped With No Visual Difficulty
16-29	2 (1)	20 (3.8)
30-49	3 (1.6)	26 (4.9)
50-59	7 (3.6)	26 (4.9)
60-64	4 (2.1)	34 (6.4)
65-69	19 (9.8)	51 (9.6)
70-74		
75-84	19 (9.8)	42 (7.9
85+	9 (4.7)	12 (2.3)
Total (men)	63 (32.6)	211 (39.8)
16-29	5 (2.6)	11 (2.1)
30-49	6 (3.1)	23 (4.3)
50-59	3 (1.6)	31 (5.9)
60-64	4 (2.1)	33 (6.2)
65-69	28 (14.5)	99 (18.7)
70-74		
75-84	46 (23.8)	98 (18.5)
85+	38 (19.7)	23 (4.3)
Total (women)	130 (67.4)	318 (60)
Grand Total	193* (100%)	529 (100%)

*One person claimed during assessment that he had perfect eyesight.

TABLE 4

CATEGORIES OF SIGHT DIFFICULTY SUFFERED BY VISUALLY HANDICAPPED ADULTS (1974)

Age Groups	Registered		Unregistered Disability			Total
	Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
16-49	2	2	2	5	4	15
50-64	5	2	3	7	1	18
65-74	16	3	10	12	6	47
75+	19	11	41	23	19	113
Total	42	18	56	47	30	193*

*See note Table 2 and 3

(Slight variations of the total in each age group between Table 4 and 5 are caused by differences in ages recorded in 1972 and 1974.)

TABLE 5

SOURCES OF EXTRA DATA ON 153 VISUALLY HANDICAPPED ADULTS (1974)
WHO GAVE PERMISSION FOR RECORD SEARCH

Age Groups	Hospital Records (Eye Clinic)					No Hospital Records			Total Records	No Records Traced	Total
	Within 3 Months of Survey (1974)	3-6 Months	6 Months - 1 Year	1-2 Years	Over 2 Years	B.D.8 Form Only	*Opticians' Records Only	G.P. Notes Only			
16-29	1	0	2	0	1	0	0	0	4	1	5
30 49	1	1	1	1	1	0	0	0	5	3	8
50-59	0	1	0	0	1	2	0	0	4	2	6
60-64	0	1	0	1	2	2	0	0	6	2	8
65-74	5	2	8	3	9	5	2	1	35	3	38
75-84	8	9	6	2	6	4	1	1	37	17	54
85+	3	0	3	1	5	3	3	1	19	15	34
Total	18	14	20	8	25	16	6	3+	110	43	153

*Within 3 years of survey (1974)

+2 had had specialist ophthalmological opinion
1 had presumptive diagnosis only.

TABLE 6

OCCUPATIONAL PATTERN OF VISUALLY HANDICAPPED ADULTS

		Registered		Unregistered Disability			Total
		Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
	Over Retirement Age	36	14	51	34	25	160 (83)
Under Retirement Age	Full-time Work	2	1	1	2	2	8 (4)
	Housework	0	1	2	3	2	8 (4)
	Registered As Disabled	4	1	1	4	0	10 (5)
	Part-time Work	0	1	1	2	0	4 (2)
	Training Centre (Full or Part-time)	0	0	0	1	1	2 (1)
	Unemployed	0	0	0	1	0	1 (0.5)
	Total	42	18	56	47	30	193*(100%)

TABLE 7

ADDITIONAL DISABILITIES SUFFERED
BY THE VISUALLY HANDICAPPED

Disabilities Other Than Visual	Registered		Unregistered Disability			Total of Each Disability
	Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
None	5	5	10	15	6	41
Deafness	17	6	28	17	11	79
Arthritis	7	1	17	11	11	47
'Senility'	7	1	6	1	0	15
Hypertension	2	0	6	4	1	13
Other Cardiovascular Conditions	1	0	3	7	4	15
Diabetes and Other Endocrine Disorders	3	2	2	1	4	12
'Strokes'	3	1	3	0	5	12
Genito Urinary	3	0	4	3	0	10
Epilepsy	0	0	0	3	0	3
Other	12	11	17	24	12	76

TABLE 8

RESTRICTIONS IN SOME ASPECTS OF DAILY LIVING SUFFERED BY THE VISUALLY HANDICAPPED

	Registered		Unregistered Disability			Total
	Blind (42)	Partially Sighted (18)	Distance & Near (56)	Distance Only (47)	Near Only (30)	
Unable to get in and out of bed unaided	3	0	4	1	3	11
Unable to get to or use W.C. unaided	4	0	4	2	4	14
Unable to have all over wash or bath unaided	11	3	12	11	6	43
Unable to put on shoes/socks/ stockings alone	5	1	5	2	3	16
Unable to manage buttons and zips alone	4	2	5	3	1	15
Unable to dress without help	5	1	4	2	2	14
Unable to feed self	5	1	2	1	2	11
Unable to brush hair (women), unable to shave self (men)	1	2	3	1	2	9
Unable to cut own toenails	29	15	38	23	19	124
Housebound	7	2	6	2	5	22

TABLE 9

SELF CARE ABILITIES OF THE VISUALLY HANDICAPPED

Self Care Score	194 Visually Handicapped Adults		
	Men	Women	Total
0	39 (60)	51 (39.5)	90 (46.5)
2	9 (14)	22 (17)	31 (16)
3	0 (0)	10 (8)	10 (5)
4	4 (6)	8 (6)	12 (6)
5	2 (3)	2 (1.5)	4 (2)
6	2 (3)	4 (3)	6 (3)
7	0 (0)	2 (1.5)	2 (1)
8	4 (6)	3 (2.5)	7 (3.5)
9	0 (0)	2 (1.5)	2 (1)
10	0 (0)	3 (2.5)	3 (1.5)
11	1 (1.5)	2 (1.5)	3 (1.5)
Total 2-11	22 (34)	58 (45)	80 (41)
Total 12-36	4 (6)	20 (15.5)	24 (12.5)
Grand Total	65 (100)	129 (100)	194 (100)

	Can Do With Difficulty	Cannot Do Unaided
1. Getting in and out of bed	2	3
2. Getting to or Using W.C.	4	6
3. Having an overall wash (or bath if used)	2	3
4. Washing hands or face	2	3
5. Putting on shoes and socks or stockings	2	3
6. Doing up zips or buttons	4	6
7. Dressing, other than buttons and shoes	2	3
8. Feeding self	4	6
9. Combing and brushing hair (women)	2)	3)
10. Shaving (men)	2)	3)
Total	24	36

TABLE 10

HOUSEHOLD COMPOSITION OF THE VISUALLY HANDICAPPED COMPARED (PERCENTAGES) WITH THE HANDICAPPED WHO HAD NO VISUAL PROBLEM

	Registered		Unregistered Disability			Total (%)	% of 520 Handicapped Adults (Canterbury 1974) with No Visual Handicap
	Blind	Partially Sighted	Distance & Near	Distance Only	Near Only		
Lives alone	12 (28.5)	4 (22)	28 (50)	18 (38)	17 (56.5)	79 (41)	32
Lives with spouse	14 (33.5)	4 (22)	11 (19.5)	13 (27.5)	3 (10)	45 (23.5)	32
Lives with spouse and married or unmarried children	5 (12)	3 (16.5)	4 (7)	5 (10.5)	1 (3)	18 (9.5)	14
Lives with spouse and others (not children)	1 (2.5)	0 (0)	1 (2)	0 (0)	1 (3)	3 (1.5)	0.5
Lives with married or unmarried children	6 (14.5)	3 (16.5)	9 (16)	5 (10.5)	3 (10)	26 (13.5)	7
Lives with others (including parents) and siblings	4 (9.5)	4 (22)	3 (5.5)	6 (13)	5 (16.5)	22 (11.5)	14
Total	42 (100)	18 (100)	56 (100)	47 (100)	30 (100)	193 (100)	99.5 N=520

TABLE 11

RESIDENCE AT PRESENT ADDRESS AND VISITS BY THE SOCIAL SERVICES

VISUALLY HANDICAPPED ADULTS

Years Lived at Present Address	Registered		Unregistered Disability			Total
	Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
Less than 5	10	6	10	12	9	47 (24)
5 - 10	10	4	12	11	9	46 (24)
More than 10	22	8	34	24	12	100 (52)
Total	42	18	56	47	30	193 (100)
Visit by Social Services						
Not Visited Not Wanted	3	0	14	17	7	41 (21)
Not Visited Wanted	0	3	9	9	6	27 (14)
Visited	39	15	31	21	17	123 (64)
Don't Know	0	0	2	0	0	2 (1)
Total	42	18	56	47	30	193* (100)

TABLE 12

MOBILITY OF VISUALLY HANDICAPPED ADULTS

Travel	Registered		Unregistered Disability			Total
	Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
Goes Out Alone and Unaided	4 (9.5)	6 (33)	14 (25)	22 (46)	6 (20)	52 (27)
Goes Out Alone With Help of Stick, etc.	12 (28.5)	2 (11)	13 (23)	12 (25.5)	10 (33)	49 (25.5)
Goes Out Only If Accompanied (and can get help)	7 (16.5)	3 (16.5)	8 (14)	6 (13)	3 (10)	27 (14)
Goes Out Only If Accompanied (and cannot get help)	1 (2.5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.5)
Goes Out Only By Car	14 (33)	5 (28)	9 (16)	5 (10.5)	7 (23)	40 (20.5)
Cannot Go Out At All	2 (5)	2 (11)	9 (16)	2 (4)	3 (10)	18 (9.5)
Not Asked (Too Ill)	2 (5)	0 (0)	3 (5.5)	0 (0)	1 (3)	6 (3)
Total	42 (100)	18 (100)	56 (100)	47 (100)	30 (100)	193* (100)

TABLE 13

DISTANCE VISUAL ACUITY OF 180 VISUALLY HANDICAPPED ADULTS (HOME MEASUREMENT)

Definitions		Visual Acuity (Distance) Measured At Home	Registered		Unregistered Disability			Total (% of 180)
U.K.	W.H.O.		Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
		6/18 +	3 (7)	1 (5.5)	13 (24)	20 (54)	14 (48.5)	51 (28.5)
	1	6/24	0	1 (5.5)	13 (24)	7 (19)	3 (10.5)	24 (13.5)
		6/36	2 (5)	4 (22)	7 (13)	5 (13.5)	6 (21)	24 (13.5)
		6/60	3 (7)	4 (22)	9 (16.5)	1 (2.5)	4 (14)	21 (11.5)
P.S.	2	3/60	20 (47.5)	5 (28)	11 (20.5)	4 (11)	2 (7)	42 (23.5)
B	3	1/60						
	4	Light Perception Only	11 (26)	3 (16.5)	1 (2)	0	0	15 (8.5)
	5	No Light Perception	3 (7)	0	0	0	0	3 (1.5)
		Total Recorded	42 (= 100%)	18 (= 100%)	54 (= 100%)	37 (= 100%)	29 (= 100%)	180 (= 100%)
		Not Recorded	0	0	2	10	1	13
		Total	42	18	56	47	30	193

TABLE 14

COMPARISON BETWEEN DISTANCE VISION SIGHT TESTS DONE AT HOME AND IN THE HOSPITAL

	Best Visual Acuity Measured within Two Years at Hospital		Visual Acuity as Measured at Home							
			6/18+	6/24	6/36	6/60	1/60-3/60	Perceives Light Only	No Light Perception	Total
		6/18+	x 16	4	o 3	1	1			25
	W.H.O. Group	6/24	1	3	1					5
	1	6/36			x 1	xo 5	o 1			7
		6/60				xo 3	xo 2			5
U.K. Partially Sighted	2	3/60				1	xxxo 5	xo 2		8
U.K. Blind	3	1/60					o 2	xo 2		4
	4	Perceives Light Only						oooo 4		4
	5	No Light Perception								
		Total	17	7	5	10	11	8	0	58*

o Individuals registered as blind
x Individuals registered as partially sighted

* Two of the 60 (Table 5) who had attended hospital within two years had had no accurate measurement of visual acuity recorded during that time.

TABLE 15

ESTIMATED PERCENTAGE OF 180 VISUALLY HANDICAPPED AT EACH LEVEL OF VISUAL ACUITY 'CORRECTED' FOR DIFFERENCES BETWEEN HOME AND HOSPITAL MEASUREMENT

Definitions		'Corrected' Visual Acuity	Registered		Unregistered Disability			Total % in each Category
U.K.	W.H.O.		Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
		6/18 +	12%	9.5%	39%	70%	65%	43%
	1	6/24	0	5%	16.5%	11%	6%	9%
		6/36	4.5%	24%	12.5%	11%	16.5%	12%
		6/60	4.5%	15.5%	10.5%	1%	7%	7%
P.S.	2	3/60	45.5%	30%	19%	8.5%	5.5%	21%
B B	3	1/60						
	4	Light Perception Only	24%	16.5%	2%	0	0	7%
	5	No Light Perception	8%	0	0	0	0	2%
		Total % Of Each Group Tested	100% (N=42)	100% (N=18)	100% (N=54)	100% (N=37)	100% (N=29)	100% (N=180)

TABLE 16

NEAR VISUAL ACUITY OF 178 VISUALLY HANDICAPPED ADULTS MEASURED AT HOME

Approximate Print Sizes	Near Vision Measured At Home 'N' Value	Registered		Unregistered Disability			Total
		Blind	Partially Sighted	Distance & Near	Distance Only	Near Only	
Ordinary Newspaper Print (Times)	8+	2 (5)	2 (11)	9 (17)	24 (66.5)	10 (34.5)	47 (26.5)
Normal Book Print	10	1 (2.5)	1	8 (15)	8 (22)	2 (7)	20 (11)
	12	0	2 (11)	8 (15)	4 (11)	3 (10.5)	17 (9.5)
	14	1 (2.5)	0	6 (11.5)	0	2 (7)	9 (5)
Approximately Large Print Book	18	3 (7)	1 (5.5)	6 (11.5)	0	4 (14)	14 (8)
Column Headlines (Times)	24	3 (7)	2 (11)	3 (5.5)	0	2 (7)	10 (5.5)
	36	0	2 (11)	1 (2)	0	1 (3.5)	4 (2)
	48	3 (7)	1 (5.5)	3 (5.5)	0	4 (14)	11 (6)
	Can't see type	15 (25.5)	4 (22)	8 (15)	0	1 (3.5)	28 (15.5)
	Light Perception Only	11 (26)	3 (16.5)	1 (2)	0	0	15 (8.5)
	No Light Perception	3 (7)	0	0	0	0	3 (1.5)
	Total Recorded	42 (100)	18 (100)	53 (100)	36 (100)	29 (100)	178 (100)
	Not Tested	0	0	3	11	1	15
	Total	42	18	56	47	30	193

TABLE 17

COMPARISON BETWEEN NEAR VISION SIGHT TESTS DONE AT HOME AND IN THE HOSPITAL

Approximate Print Sizes	Best Visual Acuity Measured Within 2 Years At Hospital 'N' Value	Best Visual Acuity Measured at Home 'N' Value								
		5	6	8	10	12	14	18	24	Total
Newspaper Small Print	5		3	2	1			2		8
	6	1		2	1	2				6
Newspaper Ordinary Print	8		1		2	2				5
Normal Book Print	10				2			2	1	5
	12				1					1
	14						1			1
Large Print Book	18									
	24									
	Total	1	4	4	7	4	1	4	1	26

TABLE 18

COMPARISON BETWEEN NEAR AND DISTANCE MEASUREMENT OF VISUAL ACUITY (HOME)

Near Vision ('N')	Distance Vision (Snellen)										
	6/6	6/9	6/12	6/18	6/24	6/36	6/60	1/60-3/60	Not More Than Light Perception	Not Tested	Total
N.5	0	3	0	7	2	2	0	0	0	0	14
N.6	1	0	2	5	2	0	0	0	0	0	10
N.8	1	0	2	7	7	4	1	1	0	0	23
N.10	1	2	2	5	3	5	1	1	0	0	20
N.12	0	0	0	6	4	2	5	0	0	0	17
N.14	0	0	0	2	1	2	2	2	0	0	9
N.18	0	0	1	3	2	2	4	2	0	0	14
N.24	0	0	0	1	1	3	1	4	0	0	10
N.36	0	0	0	0	1	3	0	0	0	0	4
N.48	0	0	0	0	1	1	5	4	0	0	11
Unable to See Largest Print	0	0	0	0	0	0	2	26	0	0	28
Not More Than Light Perception	0	0	0	0	0	0	0	0	18	0	18
Not Tested	0	0	0	0	0	0	0	2	0	13	15
Total	3	5	7	36	24	24	21	42	18	13	193

TABLE 19

REPORTED ABILITY TO READ
PERSONAL LETTERS

Reading Test Measured at Home 'N' Value	Personal Letters			Total
	Cannot Read	Can Read	Big Writing Only	
8+	3	44	0	47
10	1	17	2	20
12	5	11	1	17
14	1	4	4	9
18	4	5	5	14
24	4	3	3	10
36	1	2	1	4
48	7	2	22	11
Can't See Type	28	0	1	28
Light Perception Only	15	0	0	15
No Light Perception	3	0	0	3
Total	72 (40.2)	88 (49.2)	19 (10.6)	178 (100%)
Not Recorded (3 too ill)				5
Not Interviewed				10
			Total	193

TABLE 20

ANSWERS TO SOME OF THE SPECIAL QUESTIONS ASKED OF THE VISUALLY HANDICAPPED

	Visual Acuity (Distance) - Home Measurement											
	1/60-3/60	6/60	6/36	6/29	6/18	6/12	6/9	6/6	Too Ill For Sight Test	Total Recorded	Not Recorded	Total
Can See Lamp-Post	23	18	22	23	35	8	5	3	1	138(86)	160 (100%) 5	165
Cannot See Lamp-Post	15	2	2	1	0	0	0	0	2	22(14)		
Can See Grass Verge	24	14	23	20	34	8	4	3	2	132(83)	159 (100%) 6	165
Cannot See Grass Verge	14	5	1	3	2	0	1	0	1	27(17)		
Can See Cyclist	14	9	19	19	32	8	5	3	1	110(69)	159 (100%) 6	165
Cannot See Cyclist	25	11	4	3	4	0	0	0	2	49(31)		
									+ No more than light from windows			18
									+ Not interviewed			10
											Total	193

TABLE 21

ACCESS TO SPECIALIST OPINION FOR 153 VISUALLY HANDICAPPED GIVING PERMISSION FOR RECORD SEARCH

	Visual Acuity (Distance) Measured at Home									
	No More Than Light Perception	1/60-3/60	6/60	6/36	6/24	6/18	6/12	6/9	6/6	Total
Hospital Notes Available	9 (60)	20 (56)	11 (65)	11 (69)	11 (58)	13	4	3	1	83
Evidence from Social Service Records of Specialists' Opinion within 10 years	2 (13)	6 (17)	1 (6)	0	0	1	0	0	0	10
Evidence from Social Service Records of Specialist Opinion more than 10 years ago	4 (27)	3 (8)	0	0	0	0	0	0	0	7
G.P. Records of having once had specialist opinion	0	0	2 (12)	0	0	—Not Sought ——				2
No Record of any Specialist Opinion	0	7 (19)	3 (18)	5 (31)	8 (42)	24	2	2	0	51
Total	15 (100)	36 (100)	16 (100)	16 (100)	19 (100)	38	6	5	1	153

TABLE 22

SOURCES OF REFERRAL TO HOSPITAL EYE CLINICS

General Practitioner	48		(47%)
Social Services	22	)	
		) 32	(31%)
Other Lay or Medical Sources (Often M.O.H.)	10	)	
Other Hospital Clinic	13		(13%)
Voluntary Societies	2		(2%)
Accident Centre	1		(1%)
No Definite Information on Record	6		(6%)
Total	102		(100%)
No Hospital or Social Service Records Found	51		
Total Who Gave Permission for Search	153		

TABLE 23

RELATIONSHIP BETWEEN VISUAL FIELDS AND VISUAL ACUITY AS MEASURED IN HOSPITAL EYE CLINIC

Visual Field (Central)	Visual Acuity Measured at Hospital								
	No Light Perception	Light Perception Only	1/60	3/60	6/60	6/36	6/24	6/18+	Total
Nil	7	9	1	1	0	0	0	0	18
Less than 5°	0	2	1	0	0	0	0	0	3
$5^{\circ} < 10^{\circ}$	0	5	4	1	3	0	1	1	15
$10^{\circ} < 20^{\circ}$ or 'Contracted'	0	2	2	2	4	4	2	1	17
$20+^{\circ}$	0	0	2	0	0	0	0	0	2
Central Scotoma	0	7	8	11	4	0	0	5	35
Hemianopia	0	1	0	0	1	0	0	2	4
Recorded As 'Good'	0	0	2	1	2	1	1	12	19
Not Recorded on Notes	0	11	13	10	9	6	3	32	84
Total	7	37	33	26	23	11	7	53	197 EYES

TABLE 24

PATHOLOGY OF EYE CONDITION

		Visual Acuity (Hospital - at time of diagnosis)								
		No Light Perception	Light Perception Only	1/60 < 3/60	3/60 < 6/60	6/60 < 6/18	6/18+	Eye Missing	No Record	Total
Degenerative	(R)	1	6	5	8	8	15	0	5	48 (R)
	(L)	1	8	7	7	11	11	0	6	51 (L)
Myopic	(R)	0	2	2	5	3	0	0	0	12 (R)
	(L)	0	2	1	3	2	3	0	0	11 (L)
'Glaucoma'	(R)	1	1	4	1	1	4	0	0	12 (R)
	(L)	1	1	1	1	4	2	0	0	10 (L)
Metabolic (Diabetes)	(R)	1	2	1	0	2	3	0	0	9 (R)
	(L)	1	1	2	0	1	3	0	1	9 (L)
Congenital	(R)	1	0	0	1	0	3	0	0	5 (R)
	(L)	0	0	1	0	1	2	0	0	4 (L)
Accidental	(R)	0	3	1	0	0	0	1	0	5 (R)
	(L)	0	1	1	1	0	0	0	0	3 (L)
Hereditary	(R)	0	1	1	0	1	0	0	0	3 (R)
	(L)	0	0	2	0	1	0	0	0	3 (L)
Irido-Cyclitis	(R)	0	0	0	0	2	0	0	0	2 (R)
	(L)	0	1	0	0	1	0	1	0	3 (L)
Amblyopic	(R)	0	1	0	0	0	1	0	0	2 (R)
	(L)	1	2	0	0	0	1	0	0	4 (L)
Other	(R)	0	0	1	0	1	1	0	1	4 (R)
	(L)	0	1	0	0	1	1	0	1	4 (L)
Unknown	(R)	0	1	1	0	0	0	0	0	2 (R)
	(L)	0	1	1	0	0	0	0	0	2 (L)
No Pathology	(R)	0	0	0	0	0	3	0	0	3 (R)
	(L)	0	0	0	0	0	2	0	0	2 (L)
Total Recorded	(R)	4	17	16	15	18	30	1	6	107 (R)
	(L)	4	18	16	12	22	25	1	8	106 (L)
No Record	(R)	0	1	0	0	2	2	1	80	86 (R)
	(L)	0	2	0	0	2	3	0	80	87 (L)
Total Eyes	(R)	8	38	32	27	44	60	3	174	386

(= 2 x 193 patients)

TABLE 25

SITE OF EYE LESION

Site Right Eye (R) Left Eye (L)		Visual Acuity (Hospital - at time of diagnosis)								
		No Light Perception	Light Perception Only	1/6 < 3/60	3/60 < 6/60	6/60 < 6/18	6/18+	Eye Missing	No Record	Total
Whole Retina	(R)	0	8	6	4	7	7	0	1	33 (R)
	(L)	2	6	5	4	5	11	0	2	35 (L)
Lens	(R)	1	1	2	3	1	11	0	3	22 (R)
	(L)	0	3	4	3	5	8	0	3	26 (L)
Macula (Central Retina)	(R)	0	3	3	7	2	2	0	1	18 (R)
	(L)	0	4	3	4	2	1	0	2	16 (L)
Optic Nerve	(R)	1	1	3	1	5	6	0	0	17 (R)
	(L)	2	2	0	1	7	2	0	0	14 (L)
Cornea	(R)	0	3	0	0	2	0	0	0	5 (R)
	(L)	0	1	2	0	1	0	0	0	4 (L)
Lens & Retina	(R)	1	1	1	0	0	0	0	0	3 (R)
	(L)	0	1	1	0	0	0	0	0	2 (L)
Uvea	(R)	1	0	0	0	1	0	0	0	2 (R)
	(L)	0	1	1	0	1	0	0	0	3 (L)
Intra Cranial	(R)	0	0	1	0	0	1	0	1	3 (R)
	(L)	0	0	0	0	1	1	0	1	3 (L)
Acquired Anophalmia	(R)	0	0	0	0	0	0	1	0	1 (R)
	(L)	0	0	0	0	0	0	1	0	1 (L)
No Eye Disease	(R)	0	0	0	0	0	3	0	0	3 (R)
	(L)	0	0	0	0	0	2	0	0	2 (L)
Total Recorded	(R)	4	17	16	15	18	30	1	6	107 (R)
	(L)	4	18	16	12	22	25	1	8	106 (L)
No Record	(R)	0	1	0	0	2	2	1	80	86 (R)
	(L)	0	2	0	0	2	3	0	80	87 (L)
Total Eyes		8	38	32	27	44	60	3	174	386

(= 2 x 193 patients)

TABLE 26

CONDITION LEADING TO VISUAL HANDICAP ('BETTER EYE')

W.H.O. Visually Impaired (Visual Acuity (Distance) Measured at Home									
Diagnosis (Hospital Notes etc.)	No Light Perception	Light Perception Only	1/60-3/60	6/60	Total 6/60 or Less	6/36	6/24 (2 with 6/18 and reduced fields)	No Acuity Recorded	Grand Total
Macular Degeneration	1	3	6	2	12 (15)	1	3	0	16 (12)
'Cataract' (Including Congenital)	1	0	7	3	11 (14)	2	2	0	15 (11)
Myopic Error	0	2	5	1	8 (10)	0	2	0	10 (7.5)
Glaucoma (All Types)	1	0	4	2	71(8.5)	1	1	0	9 (7)
Optic Atrophy	0	0	0	3	3(3.5)	1	2	0	6 (4.5)
Retinal Vascular Disease (All Types)	0	1	2	1	4 (5)	1	1	0	6 (4.5)
Corneal Dystrophies	0	2	0	2	4 (5)	1	0	0	5 (4)
'Choroiditis'	0	1	2	1	4 (5)	0	0	0	4 (3)
Diabetic Retinopathy	0	1	1	0	2(2.5)	1	0	0	3 (2.5)
Anterior Uveitis	0	0	1	0	1(1.5)	0	1	0	2 (1.5)
Detached Retina	0	1	1	0	2(2.5)	0	0	0	2 (1.5)
Retinitis Pigmentosa	0	1	1	0	2(2.5)	0	0	0	2 (1.5)
Other	0	1	1	1	3(3.5)	1	0	0	4 (3)
Total Diagnosed	3	13	31	16	63 (78)	9	12	0	84 (63)
No Diagnosis Available	0	2	11	5	18 (22)	15	14	2	49 (37)
Total	3	15	42	21	81(100)	24	26	2	133(100)

APPENDIX I

DEFINITION OF VISUAL IMPAIRMENT AND BLINDNESS

W.H.O. 1973

VISUAL ACUITY (BOTH EYES USING BEST CORRECTION)

W.H.O. Category	Maximum less than	Minimum equal to or better than
1	6/18	6/60
2	6/60	3/60
3	3/60 (or visual field $< 10^{\circ}$ and $> 5^{\circ}$)	1/60 (Finger counting at 1 M.)
4	1/60 (Finger counting at 1 Metre) (Or visual field $< 5^{\circ}$)	Light Perception
5	No Light Perception	
9	Undetermined or Unspecified	

CANTERBURY SURVEY OF THE HANDICAPPED

Name of Householder or Tenant _____

	Please write "Yes" or "No" in this column for each question	If the answer is "Yes" please write in age and name of person having difficulty
EYESIGHT		
1. Is there anyone in this household who is blind?		
2. or has very bad eyesight even when wearing glasses?		
HEARING		
3. Is there anyone in this household who is deaf, or has to wear a hearing aid?		
4. or is so hard of hearing he or she cannot hear ordinary conversation?		
LOSS OF LIMBS, etc.		
5. Has anyone lost the whole or part of an arm, leg, hand or foot by having an accident, amputation, or by being born like that?		
MOVING ABOUT		
6. Is there anyone, apart from babies, who has been unable to get out of bed, or unable to get out of the house, for the past 3 months?		
7. Is there anyone, apart from babies and young children, who has difficulty walking without help, going up and down stairs, or kneeling and bending?		
SELF-CARE		
8. Is there anyone, apart from babies and young children, who has difficulty washing, feeding or dressing themselves?		
9. Is there anyone, apart from babies, who has difficulty gripping or holding things, or using arms, hands or fingers?		
BABIES AND YOUNG CHILDREN		
10. Are there any young children who need more help than usual for children of the same age, in washing and dressing themselves, walking without help, going up and down stairs, etc.?		
11. Are there any school-age children who cannot go to an ordinary school because of physical or mental handicap?		
IF NO-ONE IN HOUSEHOLD HAS ANY OF THE ABOVE DIFFICULTIES		
GENERAL		
12. Is there anyone who has some other permanent mental or physical condition, including epilepsy, etc. which makes it difficult for them to go to school or work, take care of themselves, or get about?		
ELDERLY		
13. Is there anyone living here aged 75 or over?		
14. Do you live alone?		

APPENDIX 3

FORM B (1974)

UNIVERSITY OF KENT AT CANTERBURY

HEALTH SERVICES RESEARCH UNIT

Survey No.

Name Date of birth

1. Are you attending a hospital about your eyesight? Yes 1 (specify)
No 0

2. When did you last have your eyes tested? Less than 1 year
1 - 2 years
3 - 4 years
5 or more

3. ASK OF THE BLIND ONLY

(i) How old were you when you became blind? ..... years - ask (ii)

or blind since birth - 1

(ii) Was your loss of sight gradual or sudden? gradual - 2
sudden - 3

We should like to get an idea of how much sight you have.

4. If you are in a room in the daytime can you tell, by the light, where the windows are? Yes - ask (i)
No - 0 On to Question 6

(i) Can you see more than that? Yes - 1 (ask (ii))
No - on to question 6

(ii) Can you see a lamp post five paces ahead of you (in daylight)?
Yes
No

(iii) If you are walking along a pavement which has a grass verge can you see where the grass verge begins?
Yes
No

(iv) If you are standing at the edge of the pavement could you see a cyclist on the other side of the road?
Yes
No

5. ASK ONLY IF SUBJECT CAN SEE MORE THAN LIGHT FROM WINDOWS - i.e. Question 4, Code 1

(i) Can you tell me if you can read any of the words on this card?
(The subject must be sitting in a good light, using normal reading aids.)

Smallest type read N... Illiterate 0, Unable to see type 1

(ii) Can you tell me how far down you can read on this chart?
(The card should be held 10 ft. from subject)

Smallest line read - Illiterate 0, Unable to see chart 1

We are interested to know what help and instruction you have had in managing your everyday life and what problems you have had in getting about outside your home.

6. (This question is in two parts, for each activity you ask "Have you had instruction in .....?", followed by "Who taught you?, if appropriate)

	No Instruction	School	Home Teacher	Rehab. Centre	Self	Other Instruction
(i) Reading Braille	0	1	2	3	4	5
(ii) Reading Moon	0	1	2	3	4	5
(iii) Writing without sight -						
(a) Braille	0	1	2	3	4	5
(b) Print	0	1	2	3	4	5
(iv) Cooking	0	1	2	3	4	5
(v) Washing (clothes)	0	1	2	3	4	5
(vi) Ironing	0	1	2	3	4	5

7. Do you use any of the following?

	Yes	No
Low Visual Aid for close work	1	0
Low Visual Aid for distance	1	0
British Talking Book Service	1	0
National Library for the Blind	1	0
Large Print Books	1	0

8. Do you use any aids to help you get about?

None 0
Long Cane 1
Short Cane 2
Sonic aids 3
Sighted guide 4
Guide dog 5 - ask (i)

(i) Have you been excluded from any public places because of your guide dog?

Yes - 1 (specify)
No - 0

9. Can you read personal letters addressed to you? Yes - 1
No - 0

10. ASK ONLY IF MOBILE AND INDEPENDENT

Have you had any problems from

	Yes	No
(i) cars parked on pavements	1	0
(ii) changes in traffic control systems	1	0

11. Have you any other problems you feel you need help with?

APPENDIX 4

Estimates of National Prevalence Rates of Visual Handicap

In order to derive any estimate of the prevalence, nationally, of visual handicap in the home-based population from the data described in this report, it is necessary to make two assumptions, both of them untestable. The first is that the 193 adults assessed as visually handicapped in 1974 had the same visual acuity distribution as the adults among the 311 identified as visually handicapped in 1972. This would suppose that the 183 visually handicapped who were identified in 1972 but were not available for full assessment in 1974 (having died, moved, been admitted or improved), together with the 70 who joined the category between 1972 and 1974, had the same distribution of visual acuities as the 180 finally tested at home in 1974. Clearly this is a very large assumption and is not susceptible to any form of verification. The second, lesser, though equally untestable assumption is that the initial household approach in 1972 was virtually 100% sensitive for the truly visually handicapped; this is discussed in the text.

Given these assumptions, the following formula can be constructed:-

$$.98 \times 311 \times .72 \times \frac{100{,}000}{19{,}786} \times \frac{76.1}{77.8}$$

.98	311	.72	$\frac{100{,}000}{19{,}786}$	$\frac{76.1}{77.8}$
(Proportion of adults (16+) among the visually handicapped (1974).)	(Total declaring a Visual Handicap (1972).)	(Proportion of Visually Handicapped Impaired by W.H.O. Definition.) (1974 tests)	(Adult home-based population of sampled households.)*	(Adult age-standardisation factor between Canterbury and England & Wales.)

*Calculated as:- Total adult home-based population of Canterbury (1971 Census) x 93% household response rate x 95% screened.

1. Using this formula, the estimated private-household-based adult population of England and Wales who are visually impaired by W.H.O. standards is 1,085:100,000 adult private-household-based population.

2. Substituting, in the above formula, .333 as the proportion who had a measured visual acuity, at home, less than 6/60 and might therefore be considered for registration as blind or partially sighted by U.K. definition:- 502 per 100,000 adult private household-based population.

The latest figures available (1974) for the total registered blind and partially sighted for England[1] show 290 registered per 100,000 total population, and an adult (15+ years) prevalence rate can be calculated as 376 per 100,000 total (household and institutionally based) adult population. It must be restated however that the larger figure based on the Canterbury data is subject to untested assumptions and is set down here only as a yardstick for further studies.

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(1) Statistics of the Registered Blind and Partially Sighted Persons during the 12 months ending 31st March 1974. D.H.S.S. Statistics & Research Division 6, December 1974.

PART IV

NATIONAL SURVEY OF VISUALLY DISABLED PEOPLE
ENGLAND & WALES 1976-1977

INTRODUCTION

The analysis and presentation of the data for those found to be visually disabled during the 1972/74 Canterbury Survey of Handicapped People showed that no adequate epidemiological statement could be made on the basis of age, sex, visual acuity and causal diseases alone. Individual perceptions of ability and disability, habits of attitude and behaviour both among visually disabled people and the providers of care, the presence of other disabling conditions and the circumstances under which measurements were made all had an integral part to play both in understanding the condition and in planning ways in which it might be alleviated. Some of these factors which have been the subject of previous research work, both in this country and elsewhere (see part II) were perhaps brought together for the first time during the Canterbury Survey and shown to be so interrelated that it is no longer sensible to study them singly, especially among the elderly and old.

An important research task that follows logically from the Canterbury data is to clarify the interrelationships of the different factors which prevent the poorly sighted from making the best use of their vision, or from seeking the help they need, as well as those structural and process factors which obstruct the efficient provision of that help. To achieve these aims would need expertise in social psychology, sociological theory, applied social science, optics and lighting, as well as ophthalmology, working more or less in step with a similar multidisciplinary approach to each of the variety of other disabilities the poorly sighted so often suffer from. For some of these disabilities there is enough national data available to support deep local studies into interrelationships, but this is not so for all the components that go to make up visual disability (except, perhaps, among those who are registered as blind).

It seemed, then, that a national study was needed to assign some order of importance to the many aspects of visual disability before more detailed work could be done; a national study which would include all the different factors

found to be of importance in Canterbury, and might even suggest others, or point to areas where intervention might logically be tried, or policies changed. The cost of mounting such a study would, however, have been prohibitively high had not the chance offered itself of joining another national survey which was already well under way while the Canterbury data were being analysed during the spring of 1976.

This national survey, under the overall direction of the S.S.R.C. Centre for Socio-Legal Studies, Wolfson College, Oxford, had as its main objective "to study the social, economic and legal consequences of serious functional difficulties arising from illness, injury or handicap"[103]. The survey was planned as a two stage procedure to cover 15,000 households in England and Wales - the first stage to identify any in the household who had suffered a misfortune and the second to interview that person either directly or, if necessary,by proxy by means of a detailed questionnaire. The design and eventual coverage of the survey is outlined in Appendix A.

The immediate advantage of joining such a survey was, of course, to save the enormous cost of mounting anything nearly as comprehensive. But, as far as discovering the prevalence of visual disability was concerned, this particular survey also offered other distinct advantages. The first was that the initial screening question, asked of all in the first stage (and repeated in Stage II), referred only to "difficulties in seeing to read or get about". Experience not only in Canterbury, but throughout the history of asking poorly sighted people about their eyesight, has shown that only by using such generalisted, non-directional, non-emotive terms as these, embracing perceptions of both near and distant vision, will the greatest number of people who may have a real difficulty in seeing be included for consideration. Such wording is not, of course, very specific but its sensitivity is guarded by consciously avoding reference to terms such as 'blind' or 'poorly sighted' or 'bad eye-

sight' which have always been open to wide variations in personal interpretation. Nor does such a simple all-embracing approach seek to do what the Canterbury work has suggested may well be impossible - to devise wording that is so precise that it stands in place of visual acuity measurement as an estimate of what a person can, theoretically, see. So although there was no opportunity to alter the wording of the first screening stage of the survey by the time it was joined, the form of words used could hardly have been bettered from current knowledge.

There was ample opportunity, however, to influence both the design, and the questionnaire, of the second interview stage, and the analysis of the results from Canterbury were to hand to help with this. Sight testing by lay interviewers, which had appeared to be so successful in Canterbury, was used again but most specific questions relating to distant and near vision were omitted. In their place an attempt was made to assess what optical aids each of the visually disabled used during the sight tests. Record linkage, as in Canterbury, remained an essential feature.

The second attraction of the survey was that it explored to considerable depth very many of the aspects of daily living, use of health and social services and the presence of other handicapping conditions that had been found, in Canterbury, to be of such importance to a full picture of the epidemiology of visual disability. Because the national survey had different objectives each of these factors was not examined to the same depth or from the same starting point as in the Canterbury and other local surveys based broadly on the categorisations and weightings of the Amelia Harris survey[35]. No attempt, for instance, was made to assess mobility restriction objectively at the time of interview or to attach scores to the various activities of daily living. To this extent it was far nearer the General Household Survey (G.H.S.) than most of the surveys emanating from the C.S.D.P. Act of 1970[40], and so offered less about precise levels of physical disability than were obtained

by surveys, such as Canterbury's, based on the Harris design. But, on the other hand, it promised far more on the financial implications of misfortune, including long standing illness, than was available from any current source.

This (fourth) part of the research work on visual disability is, then, a presentation of the data on the visually disabled from the second (interview) stage of a national survey of a sample of households in England and Wales carried out between November 1976 and February 1977. The data have been linked, where possible, to hospital and general practitioner records, as in Canterbury. The report of the main survey on all disabilities will not be available for at least another year, and will then undoubtedly concentrate on the le al, financial, compensation social security and employment consequences of misfortune without any deeper insights than are already available from elsewhere into how disabilities, or combinations of disabilities, handicap people in their daily lives. In these circumstances, there seems little point in delaying this comprehensive epidemiological statement about visual disability.

The definitions of 'impairment' and 'handicap' are those used throughout the five parts of this work(p.8). However, the concept of 'handicap' as relating the extent of a person's disability and his adjustment to it to his whole physical and social environment is but little used in this fourth part because nothing in the survey questionnaire allowed anything like as detailed an examination of the activities of daily living as is necessary to establish how handicapped a disabled person may actually be. So 'visual disability' is the term preferred, and it does not in any way hamper an epidemiological statement based on visual acuity and a description of social conditions and underlying and accompanying diseases.

METHODS

The design and coverage of the national survey are detailed in Appendix A.

During the first (screening) stage, one person in each household was interviewed acting as proxy for the rest. Some estimate of the ability of various household members to describe accurately the misfortunes of others in the household during the pilot phase of the survey, has been made by Maclean[60]; the most favoured proxy was the housewife, followed by the head of household and, failing that, any responsible adult.

Every adult (16 years +) who reported (or was reported to have) any difficulty at all in 'seeing to read or get about' was eligible for second stage interview. About half of the 214 reporting such a sight difficulty were included in the second stage of the main Wolfson survey either by reason of having had an accident at some stage, or because they were selected in the "1 in 2" sample of those with a long-standing illness (Appendix A) - the remainder were included in a special 'visual survey' which, however, was identical (except for the omission of most legal questions) to the main survey, and was conducted concurrently.

During the second stage of both these sections of the survey rescreening took place using the same question about sight difficulties as had been used in the first screening stage. It was considered important to do this both to gain further knowledge about the accuracy of the original screening procedure and to limit the numbers of 'false negatives' as far as possible. It was not thought, however, that there would be many who had truly suffered a loss of sight in the 6-8 months between original screening and final interview, so no sort of incidence estimate was expected from this procedure.

The special sight questions asked of positive responders in the second stage are shown in Appendix C. These questions were not asked of those too ill, or otherwise unable (though present) to answer the main schedule for themselves - allowance for this small minority of 'proxy' responders has been made in the analysis of results. It will be seen that the greater part of the special sight questionnaire consists of actual visual acuity tests (distance and near) administered by experienced, but for these purposes lay, interviewers. In the Canterbury study, where this method was first tried, some difficulty was experienced in gaining an estimate of vision below 6/60, yet better than 'light perception only', because the scaled down Snellen charts used at 10 feet made no allowance for this. It was hoped, in the national survey, that this problem could be overcome by using full sized (6 metre) charts at 10 feet (3 metres) and translating the results appropriately, thus allowing a more accurate estimate of 3/60 vision than is to be had by the traditional counting of fingers, etc. This made it necessary to use another simple manouvre (Question 31c) to differentiate between those who could manage vision of 6/60 and those who could manage only 3/60, because the gradations of the standard Snellen chart are additive at these levels. However, it proved simple to instruct the interviewers in these techniques, which had been proved fairly accurate both in Canterbury and elsewhere[10].

The remainder of the special questions asked of the visually disabled referred to the aids they normally used for seeing to get about or to read and to seeking permission for record linkage where hospital or other records might be available. The questions referring to lens correction and low vision aids did not, of course, allow for any estimate of the accuracy of that correction or its suitability for the task being undertaken - merely whether they were actually available in the house at the time of the interview. For low vision aids, this question was referable to an earlier question in the main schedule about whether they had ever been obtained.

The remaining questions in the special 'sight' schedule (Appendix C) relate to record linkage. As a preliminary to the survey the secretary of each of the 113 local medical committees in England and Wales which had one or more of the 200 cluster points within its provenance was written to in order to explain the purpose of the survey, and the possible need to approach a few individual doctors for such details as they had of one of their patient's sight problems. Almost all the local medical committees replied, saying that they had debated the matter and giving it their unqualified blessing; in the one or two instances where some qualification was stipulated it was only because the doctors felt that information gained during the survey would be helpful to them in caring for their patients.

However there was good reason to suppose that few if any details of sight-limiting eye disease are usually available in family doctors' records[101], and much more store was put on the possibility of obtaining hospital records where they might possibly exist. Experience in Canterbury had shown that records over ten years old are usually not available, but anything more recent than that was sought, with the interviewee's permission, and with the helpful blessing of the President and Secretary of the Faculty of Ophthalmologists. A recording form, based on both W.H.O. guidelines and national recording customs, had been devised for use in Canterbury and this, slightly modified, proved suitable during the short pilot phase of the main national survey. Although it was designed for hospital specialist use, it was also sent to family doctors and to directors of social services where no hospital notes were available; on a few occasions both these sources had enough details to complete it fully. The recording form, apart from detailing site, cause, and diagnosis of disease in each eye, also allowed for record of the latest distant and near visual acuity in each eye, and visual field where it had been measured. There was also room to record the origin of referral to the specialist clinic and the presence of any concurrent disease with or without sight implications - many

but not all, of these details had some reference to answers given in the main interview questionnaire.

As the interview data came in between November 1976 and February 1977 it was edited and sorted by the staff of Social and Community Planning Research - the agency which conducted the survey for the Centre for Socio-Legal Studies at Oxford. Record linkage, coding and punching of the data were done at the University of Kent in order to maintain confidentiality and minimise costs, by simplifying the main schedule to those aspects alone which would be of interest in a comprehensive epidemiological statement. The data were analysed using the SPSS system.

As in Canterbury, every person successfully interviewed and sight-tested at home who had vision of less than 6/18 Snellen with the best glasses available (i.e. would be considered visually impaired by W.H.O. standards) was considered to be visually disabled for the purposes of this survey. Analysis of data is presented with both this description, and the traditional U.K. definitions of blind and partially sighted as a framework - they sit easily together both for analysis and comparison.

RESULTS

THE VISUALLY DISABLED

Two hundred and fourteen people, among the 2,334 successfully interviewed during the second stage of the National Survey, stated they had some difficulty in seeing to read or get about. Most of these (approximately 140) were included in the recall stage because of a specific accident, or injury, or industrial illness (23%) or as part of a 1:2 sample of those suffering from a long standing chronic illness (43%) who were used in the second stage largely as a control group for those suffering a more specific misfortune; the remaining 74 (34%) were included to make up the whole number of those claiming a sight difficulty in the 1st stage. A very few of the 214 finally interviewed as suffering a sight difficulty may not have had such a difficulty identified in the first stage. The total of 214 interviewed was 83% of those eligible for interview - there is no reason to believe that those not interviewed varied markedly from this group in visual performance. Perhaps, however, they were a little iller (4.7% of those with a sight problem were too ill to be interviewed and only 0.8% of those with another type of misfortune) and a slightly higher percentage had died between the 1st and 2nd stages (2.6% as opposed to 1.9%) but it is fairly safe to conclude that they had at least as many and varied sight problems as those interviewed. The extent and the coverage of the survey, from which population projections can be made, is detailed in Appendix A.

Table 1 illustrates how many of those who complained of a sight difficulty were visually disabled by the definitions of the survey, and the level of their visual acuity when measured at home. Only 105 (49%) of the 214 who complained of a sight difficulty were visually disabled by definition (had a visual acuity of less than 6/18 when measured at home), but a further 43 (20%) had an acuity of no more than 6/18.

Eleven respondents are shown in Table 1 as having no sight measurement. Four of these were illiterate (2 in English only) but for all four there was good reason to believe that they were severely visually impaired, and they have been counted as disabled. Five of the eleven were proxy answers and for 3 of these (two congenitally blind and mentally retarded and one 'post stroke' victim) there was ample reason for counting them among the visually disabled - for the remaining 2 there was no such reason. One more man, who refused to perform the sight test (the only one among all the respondents who did so) was registered as blind and has therefore been included.

As expected, more visually disabled women were found than men (Table 1) but this is accounted for entirely by the proportions of the two sexes among the elderly (65 - 74 years) and old (75+ years). The post retirement age groups (65 and over for men, 60 and over for women) account for 78% of the visually disabled and 59% of those claiming a visual difficulty but having an acuity of 6/18 or better. This is no surprise - the same results were found in Canterbury (see Part III) - but the difference between the two percentages is now seen to lie in the number of relatively younger people who claimed a difficulty with sight, yet were not defined as visually disabled. This is slightly more among men than women and may relate to opportunities in paid employment.

Thirteen of the visually disabled claimed to be registered as blind - all of them with a visual acuity of no more than 3/60, which would certainly suggest they met the qualifications for registration. But it can be seen from Table 1 that a further 17 met these same qualifications and were not so registered (though two of these said they were registered as partially sighted). Warren (1975)[99] showed that the Canterbury survey identified, by direct questioning, 88% of those in the community who were registered as blind. If this percentage can be applied to national figures the estimated

short-fall in blind registration judged purely on home functioning is as high as 50% but it should be stressed at this point that the technique of measurement used to distinguish vision of 3/60 from 6/60 was open to considerable error and it may be safer to regard the two measurements as largely comparable. The effect that differences in home and hospital measurement have at this level of eyesight, see page 83, is slight but the effect of both these indefinites would be to reduce the estimate of 50% somewhat, perhaps nearer the 33% estimated from home measurement in Canterbury or the 28% estimated by Graham[30] for an elderly population in South Wales. However, each of these latter estimates concerned a defined population in a small area and Brennan and Knox[5] have shown how wide are the disparities in blind registration practice between different regions and, even more so, between local authority areas.

Finally, 24 (11%) of the 214 complaining of a visual problem were registered as disabled with the Department of Employment though only 9 (4%) proved to be visually disabled (visual acuity of less than 6/18) by the definition of the survey. Forty-two (20%) of the 214 said they were registered as physically handicapped with the social service department of their local authority, but hardly more than half of these (24) were actually visually disabled. Of these 24, 16 were also registered as blind or partially sighted. It is of interest that most (11) of the 13 visually disabled who said they were registered as blind also claimed to be registered as physically handicapped, but only six of another 13 who claimed to be registered as partially sighted.

HOME BACKGROUND OF THE VISUALLY DISABLED

Table 2 illustrates the type of household in which each of the 102 visually disabled was living at the time of the survey; and, for comparison, the spread of these household types as they appeared in the 1973 General Household Survey (G.H.S.)[75]. The thinking behind these categories is explained in the introductory report to the G.H.S.[74]; each category is, of course, exclusive and so some sort of picture of dependent and independent living emerges instead of merely listing household size. The attraction of this when describing a group of disabled people largely in the elderly and old age groups is obvious, especially when a disability that increases (in prevalence) with advancing years is concerned. For the purposes of adequate description, however, and to make some comparison with other surveys[102] possible, the elderly (60+) and old (75+) have been separated. But there are, also, shortcomings to the system. It does not, for instance, distinguish elderly and old (disabled) people living in the households of their children from younger adult (disabled) people living with their parents. Neither is it possible to tell two-generation households with a disabled parent and dependent children from three generation households with a disabled grandparent (or parent). These are clearly important considerations for disability or the handicapping effect of disability, and the extent to which it may be possible to alleviate it.

Table 2 suggests that the burden of coping with visual disability falls most heavily on the shoulders of the generation in which it is most prevalent. Thus, although 70% of the visually disabled in the population live either alone (20%) as an elderly or, more likely, old householder or (50%) in a two person household in which one member at least is 60+ years, these household types make up only 30% of the national distribution. Moreover, in 41 (82%) of the 50 households with at least one elderly member, both were over 60

years - in 13 (26%) both were over 75 years. In only 9 households in the whole group of 50 were two generations represented - usually a son or daughter in the 40s or 50s was caring single handed for a visually disabled parent in the 80s.

Some inter-generational dependence is, also, of course represented in the 4th category (Table 2) where households contain 3 or more adults. These, too, were over-represented where there was a visually disabled member present but, once again, this was largely accounted for by age. Three of the 16 households in this group consisted only of elderly and old people and a further 9 contained at least one elderly (disabled) person living with a family of the next generation. The remaining 4 households in this group, as well as the sixteen in other groups (Table 2) consisted of younger adults visually disabled or older working parents supporting a visually disabled (often multiply disabled) adult child. In only two of the eight households with dependent children was a visually disabled grandparent also present.

This picture is worth painting in detail because the previous work in Canterbury suggested that it is partly the acceptance of slow visual disability as one of the penalties for growing old that inhibits people from seeking help for often remediable conditions - optical or ophthalmological. If only 20 of the 81 elderly and old visually disabled come into daily contact with a household member of a younger generation it may be that this attitude, or the ability to do anything about it, will be slow to change. For the 20% who live on their own, and particularly for the 12% who are over the age of 75, the difficulties must be great - and it is worth noting how many of these (Table 2) had a visual acuity of a level which may well be amenable to improvement by accurate correction and appropriate lighting (Table 1). It becomes important, for these reasons, to view the domestic arrangements of the visually disabled not only in relation to how much they may be handicapped by their disability

but to the opportunities, in the psychological as well as the social sense, that may be available for alleviating it.

Household incomes of the visually disabled

Stage 2 of the survey examined in considerable detail not only the total amount but also the source of household income both at the time of the survey and, retrospectively, when the misfortune occurred or the illness began. Clearly the difficulties in comparing the two, or in producing comparisons with other data sources, are considerable in a time of rapidly altering prices, incomes and pensions. Moreover, questions relating to incomes are notoriously unreliable as survey instruments[74] and this is certainly compounded by the difficulty the elderly and old visually disabled, living in their children's households, had in estimating the approximate amount of total household income. Moreover, there is no indication in baldly presented monetary figures of how much of the household income is available to or used by the disabled person for the necessities of daily living. So the only possibly useful statement that could be made on the basis of total reported incomes of the households of the visually disabled would be to compare them with all the disabled in the survey. But the value of even this is doubtful, because most of the data from the survey concentrate on the financial hardships of a generally younger population suffering a defined misfortune rather than an insidious process of increasing disability.

A fairer picture might be gained by considering the source of household income - Table 3 illustrates this. The survey questionnaire allowed for an estimate of all sources of household income, and for the main source, and although there were undoubted inconsistencies in the replies given (many elderly people were unsure, for instance, about receiving supplementary benefit) there were also indications that the overall picture was fairly accurate. Thus elderly and old people in one or two person households,

claiming to live solely off old age (State) pensions, with or without supplementary benefit, all reported total income in the appropriate ranges.

Table 3 illustrates the main source of incomes for the various households. For many of those households where an elderly member was present as well as an income earner, pensions were also declared as a source of income but have not been included in the table. Most of those in the 'other' column were dependent on a combination of state benefits (invalidity, disablement, supplementary, war pensions, etc.)

There are no recent sources which give comparable figures for the whole population - at least which can be divided into the categories used here. In 1973, 37.4% of all single people over retirement age received supplementary benefits[18] - among the visually disabled over retirement age in the survey no more than 10% claimed to do so. For married couples over retirement age the corresponding figures are 16.7% and 6%. Social Trends (1975) also quotes D.H.S.S. statistics as suggesting that 13% of single and 8% of married retired people live on incomes low enough to entitle them to supplementary benefits - among the visually disabled 18% claimed to live only on old age or widows pensions - about comparable percentages. So the overall picture is by no means one of dire poverty compared to the national picture - although some of the elderly visually disabled are probably eligible for supplementary benefit and are not getting it, their 'uptake' rate seems higher than the general one. This may well be the result of being in contact with more services, or, in a few cases, because of the extra entitlement resulting from blind registration.

Home ownership and household amenities

Table 4 depicts the type of house (and tenure) occupied by the visually disabled in the survey and Table 5 the amenities they enjoyed. No attempt

was made, as in the 1973 G.H.S. survey[75] and the Harris survey of 1969[35], to determine the age of the dwelling or to distinguish between those who owned their homes outright and those who still had mortgages to pay off.

It can be seen from Table 4 that the visually disabled do not present a markedly disadvantaged picture as far as housing is concerned; nearly half live in privately owned (including mortgaged houses) and another 30% in council accommodation. There are precisely the same proportions as for comparable household types in the 1973 G.H.S.[75], but comparisons with the handicapped in the Harris survey[35] are harder because that survey does not detail the tenure of handicapped people who were not themselves householders (usually because they lived in the households of their children). Nevertheless, 75% of all impaired and handicapped people in the Harris survey lived in a whole house or bungalow, not purpose built for the handicapped - in the present survey 73% of the visually disabled did so.

The amenities available to the visually disabled are listed in Table 5. Allowing for the smallness of the sample, they still seem to be well up to the standards suggested by the G.H.S. for all houses in the country. Thus only 2% of the visually disabled have no inside lavatory, 3% no fixed bath or shower and 4% no hot water supply. For this last there are no comparable national figures. It is not surprising, of course, that only 21% of the visually disabled should live in households with a motor car available (though only 3 claimed themselves to be drivers and to hold a current driving licence). Nor is it surprising that the 21% of households that did own a motor car should all be among the group with the youngest members. Even so, only 38% of these younger households with a visually disabled adult member had a motor car available - the Family Expenditure Survey (1975)[18] suggests that 57% of households in England and Wales own a motor car. The difference in the percentages is largely accounted for by the age of the visually disabled as well, of

course, as their disability, but the figures do suggest a considerably reduced chance of mobility.

Telephone ownership is also presented in Table 5. The Harris survey (1969) went in to considerable detail about the ability of the handicapped to use a telephone, as well as mere ownership; the present survey included none of these details. Among all the impaired and handicapped in the Harris survey 27% lived in households with a telephone (though only 24% could use it) and a further 50% had no telephone but said they would be able to use one. Among the smaller sample of visually disabled in the present survey 46% had a telephone available - for the sub-group of elderly and old living alone the percentage was the same. The Family Expenditure Survey (1974/1975)[18] lists 51% of households in England and Wales as having a telephone.

The overall picture is certainly not one of a group living in sub-standard accommodation with fewer amenities than are enjoyed by the rest of the population. This is in no way to suggest that each individual's needs are well suited - the lack of telephones among the aged visually disabled is testimony that they are probably not - but the only respect in which the group falls below comparable national standards is in the availability of motor transport, for which there is good reason.

Duration of Residence, Home Alterations and Additional Expenditure

The length of time that a disabled person has spent in one house and one neighbourhood is likely to have an effect not only on his successful adaptation to a disability, of sudden or slow-onset, but also on the mobilisation of the social and medical services designed to alleviate it. This last, of course, can work both ways - an elderly person may go slowly blind, unnoticed and unhelped much more easily in the familiar surroundings of his (or more likely, her) own lifelong home and social circle, than if the disruption of

a move to new and unfamiliar surroundings is added to his difficulties. It is not possible to explore deeply these very important aspects in a survey of the present size, but the survey questionnaire did ask for some details about duration of residence in one home and in one district, and a desire to move from it. Respondents were also asked whether they had moved since their injury or illness began, whether the fact of the injury or illness had any influence on their decision to move, and whether they now wanted to move from their present home. If they did so, they were asked if this was because of their disability or whether their disability had deterred them from doing so.

Detailed questioning of this sort allows quite extensive analysis, but to push this as far for a single group with a long standing disability as for the main survey sample suffering the economic consequences of misfortune would inevitably lead to misconceptions. To begin with, there remain all the uncertainties associated with "intensions to move" amply described in the Harris survey[35], without the additional questions needed to elucidate them, and added to this was the continuing uncertainty of just which of several disabilities were uppermost in a visually disabled respondent's mind when answering the questionnaire. Table 6, then, which illustrates some of the findings for the visually disabled should be read with these points in mind.

Approximately 66% of the visually disabled (Table 6) had lived in the same house for 10 or more years, and 86% had lived in the same district. In the 1972 G.H.S.[73] just over 40% of heads of household had lived in the same house for eleven or more years - despite the fact that the categories are not precisely comparable, it seems that the visually disabled form a more stable group than the general population. Approximately 86% have lived in the same district for ten or more years and a further 9% between

5 and 9 years; the picture is certainly not one of moving on retirement to a new and strange neighbourhood. Relatively more movement occurs, of course, in the younger households, but, even so, it is more within a single district rather than between districts. Certainly the answers to the question about whether a move had been made since the onset of disability and whether this move had been made because of the disability or for some other reason, suggested that only seldom did disability occasion a move. Thirty respondents said they had moved since their disability began but less than half these (14 in all) said they moved because of the disability.

Though Table 6 suggests that 7% of people with a visual disability had their hopes of moving in the future affected by their disability (most of them wanted to move to accommodation, single or with relatives, that they thought would be easier for them) there was another 6, not shown in the Table, whose hopes of one day making a move had nothing to do with disability. This total of approximately 13% with some desire to move is half of the figure of 26% of all impaired and handicapped people found in the Harris survey who said they would like to move.

The nearness of relatives may obviously be of importance not only to the daily life of the disabled but to their desire to make a move. Twelve (60%) of the twenty elderly and old people living alone had a relative within a mile or so and 32 (64%) of the 50 two-person households with at least one elderly member (Table 6).

Table 7 lists the structural alterations and extra household expenses occasioned by disability in the households of the visually disabled. Only eight per cent had needed structural alterations - half of these were paid for by a local authority and half arranged and paid for privately. However, over a quarter of households claimed extra heating expense as a consequence of disability (perhaps because of the immobility that goes with it); 14%

said they had extra telephone bills (30% of the households with a telephone) but only one household claimed extra lighting as an expense (though this may have featured among some of the 5 'other expenses'). Sixty eight per cent of respondents claimed their household was put to no extra expense at all by their disability. Once again, a word of caution about associating these extra costs solely with visual disability (and not with age or other disabilities) is obviously in order.

Conclusion

This picture of the visually disabled as a group in no great housing distress who live in neighbourhoods they know well and who generally have relatives nearby they can turn to for help, must not be allowed to mask the very real difficulties that individuals among the group may experience. Thus of the 20 who claimed to be living on old-age pensions alone, 7 (approximately 7% of the whole) claimed considerable extra household expenses as a result of their disability - mostly heating bills. As a group the visually disabled have markedly less access to personal motor transport than the population as a whole and no greater access to telephones.

The following chapter will deal with the social and medical support afforded by statutory and voluntary services.

THE DIFFICULTIES OF VISUALLY DISABLED PEOPLE

Introduction

During the second stage of the survey each respondent stated in his own words what it was that he thought most disabled him and how it had affected his work, and now affected his leisure and mobility. All further questions and analysis were based solely on the principal problem that the respondent identified at this stage - not necessarily the same as the disability that had been identified by proxy in the first stage. This scheme was obviously essential for the main purposes of the survey, but it naturally led to difficulties when considering a disability such as poor sight which is so often associated with other disabilities. By no means all those who were discovered on screening in the second stage to be visually disabled complained that this was their main problem, and for these much of the second stage data about hospital attendance, social service support, etc., relate to another disability. These problems were of course foreseen and steps taken to circumvent them where possible, but at the same time the arrangement did offer the promise of a good picture of how highly the visually disabled actually rate their poor sight when they are faced with other disabling conditions. This was obviously information to be prized.

The relative importance of visual problems

Table 8 shows that only 44 (43%) of the 102 visually disabled considered their poor sight as the chief difficulty in their lives, although a further 12 thought it was their second main problem. Of this total of 56 (55%), however, 5 thought they had problems with one eye only and that the other was 'good'.

Forty-six (45%) of the visually disabled did not mention poor sight as one of their difficulties - among them was one of the 13 registered blind,

5 of the 13 registered as partially sighted, and 3 of the 11 who had no more than light perception. All 3 who could not perceive light thought this their main problem, but two of the eight with hardly more than light perception (1/60 Snellen) did not mention eyesight as a difficulty. Table 8 further suggests that among the visually disabled with slightly better sight (6/48 - 6/24) well over half (63%) thought some other difficulty of over-riding importance and their problem with distant vision (if perceived at all) not worth a mention by comparison.

Clearly this has implications both for future survey work and in the assessment of individual disabled people by professionals who are not alive to the possibility of poor sight or trained in its simple measurement. In the face of other difficulties, poor sight will not necessarily be mentioned even in a fairly lengthy conversation and must be actively sought - confirming what was found in Canterbury (see Part III) in the community, and by Fenton et al[19] in the institutional setting.

Of the 56 visually disabled respondents who said that poor sight was either their major or secondary problem, 37 (66%) were able to say what it was that caused it - the remaining 19 (34%) complained of symptoms only. By far the commonest cause of poor sight among those who knew the cause was cataract (36%) followed by glaucoma (11%) and aphakia (4%). Other conditions each mentioned by one person only were diabetic retinopathy, tuberculosis, meningitis, sympathetic ophthalmitis and congenital blindness. Two mentioned herpes zoster. It did not seem, however, that when a visual problem was perceived to be the major one it was necessarily recently acquired. Although 45% said they had suffered it for less than five years, another 32% dated its onset between five and 20 years before the survey, while the remaining 23% had either had it longer than this or dated the onset from birth or early childhood. There was nothing in the survey which allowed a detailed study of adaptive procedures and this is obviously an area for further study.

It is interesting that of all 48 in the second stage of the survey who complained that eyesight was their main problem 44 (92%) were found to be truly visually disabled by the definitions used. Of these 44, 34 (77%) admitted to no other disabling condition than poor sight, and of the 10 (23%) who mentioned another condition over half suffered from diabetes or 'stroke' or some other condition with eye connotations. These last were also the commonest conditions mentioned by the 12 who complained of poor eyesight as being a secondary though definite problem to them.

Respondents were asked to state in their own words how the full enjoyment of their daily lives, including their ability to get out and to pursue hobbies and leisure activities, was affected by their self-identified disabilities. Among those 212 who claimed, on direct questioning, some difficulty in "seeing to read or get about" somewhat less than a third (31%) said the difficulty curtailed their lives; a similar proportion (30%) said their lives were curtailed only by some difficulty with mobility not related to poor sight and another quarter (27%) described symptoms only, or other disabilities such as deafness or mental illness with no sight connotations. The remaining 12% claimed no difficulties at all either with mobility or the enjoyment of their hobbies. These results are summarised in Figure 1 which should, however, be read solely as a statement of what the respondents said in answer to an open question - no opportunity to verify the statements occurred, or, of course, to test the depth of each person's perception or the meanings they attached to the words they used. It will also be noted that some of the columns in Figure 1 depend on very small numbers so that, for instance, the claim by no less than five of the eleven with apparent vision of only 6/48 that their lives were not made difficult by poor sight may be no more than a chance finding among this particular group. Figure 1 does not include those few (11) for whom no sight test was achieved, because many of them were proxy answers. Among those whose lives were made difficult by poor

sight, 25% felt it was only in close work, 22% only in mobility, while the remaining 53% found difficulty in both. Thus rather more found a dual difficulty than in Canterbury where answers were to specific questions about what could or could not be seen in the distance and close to (see Part III).

Among those 46% of visually disabled who did not identify poor eye sight among their major difficulties (though later, of course, on specific questioning confessed to a difficulty in seeing to read or get about) less than 10% mentioned a disease with obvious possible sight complications as their principle difficulty, which would, perhaps, indicate the specific need for a sight test. All the remaining 41 either mentioned diseases which had no common sight implication (among the chief of these was ischaemic heart disease, followed by osteoarthrosis) or symptoms only. It is significant that only 2 of the 102 visually disabled complained of deafness as a problem (and one of these had been born deaf) despite the age range of most of them; there was no mechanism in the survey for the interviewer to record apparent deafness as an objective observation. To do this was found to be crucial in the follow-up Canterbury study, after indications of extensive under reporting of hearing loss by respondents in the first part; eventually deafness turned out to be the commonest associated disability among the poorly sighted in Canterbury. However, the present study deals only with what the respondent perceived as his major difficulties - not what the difficulties actually were when judged by the far more precise design of the Harris-type[35] survey.

Lastly, it is fair to ask whether the same picture emerges when the sight difficulties have to do with near vision rather than distant vision, which is arguably of equal or greater importance to the elderly. Of the 48 who complained of a sight difficulty as their main - usually only - problem, 61% were unable to read N.12 (approximately very clearly printed normal print size), but among those who made no complaint about their sight only 25% were unable

to read to this level. Once again, although there is some correlation between the two, spontaneous remarks about eye sight, or the fact that it is not mentioned, as a disability, are no indication of reading ability. But the importance of near vision will be more fully discussed later.

The duration of disability

One of the features of disability (and handicap) which most surveys have, in the past, omitted is a sense of their duration. Yet most of the diseases which cause disability, including most of those that lead to poor sight, are fairly slow in onset and the hardships that they presently cause, illustrated in the details of survey results, have usually been arrived at after a long period of progressive change with consequent successful or unsuccessful social and personal adjustment. It has already been shown that over three quarters of those suffering a visual disability are in their retirement years - how much of their retirement has been affected by poor sight or did many of them notice such a deterioration in vision before they retired that it affected the last years of their working life? The present survey was by no meals ideally equipped to answer questions such as these, if only because all answers were tailored to a single predominant disability (or incident), but an attempt was made to discover when the identified disability occurred or was first noticed and, in considerable detail, what effect, if any, it had had on earning capacity. So,once again, any estimate of duration of visual disability can only be made for those who identified it as their major problem.

Table 9 presents the findings for all those who said they had difficulty with vision (not only those defined as visually disabled). This has been done because it is clearly important to take note of those whose productive life seems to have been shortened or affected by poor vision, yet who were not visually disabled, by definition, at the time of the survey. In fact, however, 10 of the 13 in Table 9 who were in full time work when they were overtaken

by a sight difficulty were truly visually disabled by the time of the survey, and 2 of the 7 who were working part time.

Table 9 suggests that almost 40% of this group of 215 adults who admitted to some difficulty in seeing to read or get about were either in full time work (34%) or in the Armed Forces (6%) at the time when their disability first became apparent, or incapacitating injury occurred. Another 25% were fully retired and 29% were housewives (though this latter group included many who were over retirement age). Only 20, 9% of the whole group, were both in full time paid work (or in the armed forces) and identified a sight problem as their main trouble, though it is of interest that 38% of those so doing were in a position to have their remunerative occupation or their prospects affected by a sight problem coming on after they had started their working lives (not illustrated in the table). In essence, then, most of those whose earnings may have been affected by disability did not count a sight problem as the disability responsible, but among those who identified it as their major present difficulty over a third entered their retirement years with an already identified sight disability.

Respondents were asked to estimate the ways in which their disability had affected their earning capacity or promotion and pension prospects. Such estimates, of course, were purely subjective and based, in some cases, on hardly more than guesswork; nevertheless, most of those (Table 10) who were in a position to have their work affected by a disability reckoned it had made little difference to their earnings in the long term. Although there is some slight discrepancy between Table 9 and Table 10 among those who did not identify their sight as a main problem and were not in full time work at the onset of the disability, the main conclusion from Table 10 that the great majority (83%) of disabilities identified by this group had not interfered with earning capacity or job prospects over the long term, is apparent. Only 6 (3%) of the whole group estimated that they were financially the poorer

because of bad eyesight and only 33 (15%) because of some other disability, or the long term effects of an accident or injury. This is, of course, a self selected group containing many elderly people thinking back over many years; undoubtedly when the main survey findings dealing with the financial consequences of misfortune are available they will paint a different (and certainly more detailed) picture. Nevertheless, although sight problems may be considerable in the retirement years, nearly three quarters of those who count them as their main difficulty had no such problem while they were in full time work, and of those who did less than half had their earnings or savings affected by it.

The mobility of the visually disabled

Although the second stage questionnaire went into some detail about each respondent's ability to leave the house, it was only on the basis of whether they had been out during the previous week, or during the previous month, and if so what aids or help they needed. Gray and Todd[31] have shown that, for the visually disabled at least, this hardly produces an adequate, or even very accurate, picture of ability in getting about and that only a week's diary of distances travelled and the purpose of the outing will suffice. In the present case, moreover, no causal association can be implied between visual disability and restricted mobility (as, indeed, it could not in Gray and Todd's survey) because of the other mobility-restricting disabilities of the visually disabled. Thus only 17% of all those complaining of some sort of visual problem thought that poor sight affected some aspect of their mobility, though another 5% were housebound or bedfast. On the other hand, 25% complained of a mobility restriction not caused by poor sight. Nevertheless, it is useful to see how visually disabled people compare with all the disabled in their opportunities for moving beyond the confines of their homes.

Tables 11 and 12 present the findings for the survey. Because the questions relating to mobility and the aids needed to achieve it, were progressive and asked only of those who admitted, at an earlier question, that they had some difficulty with mobility, there were some inconsistencies in the replies - the percentages in each column are only accurate within 5% or so each way. Approximately 70% of the visually disabled claimed to have been out during the previous week and a further 12% during the previous month. These percentages are of the same order as those in the Harris survey[35] where three quarters of all impaired people (and 71% of those with an appreciable handicap) were able to go out on their own, and in Gray and Todd's survey of the registered blind[31] where 80% had been out of the house in the previous week. At least 55% of their (somewhat younger) sample had another disability which affected mobility. In the Canterbury survey 87% of the visually handicapped claimed they could go out - though 20% could only do so by motor car. In the present survey 82% had been out within the previous month.

There is further evidence in Table 11 that successful mobility beyond the house has little enough to do with levels of sight as such. Those who saw worse actually got out more than those who saw rather better - the majority of those with no more than light perception had left the house within the week and all had done so within the month. The majority of those housebound (or bedfast) because of physical inability to go out had fairly good sight within the range described by visual disability. However, those with true visual disability were more restricted in their mobility than those who had a sight problem but were not visually disabled by definition - only 10% of these had been unable to go out in the past month, almost all because of a restricting physical or mental disability.

The aids that the visually disabled said they used, or the help they needed, to achieve mobility are listed in Table 12. It is not possible to

relate this table too closely with Table 11, because the question on which it is based was asked only of those claiming a visual problem during the survey. A previous question, asked of all who claimed any mobility restriction, was not considered detailed enough for present purposes. So although a full 9 % seemed to imply by their answers that they were capable of travel it is not to be assumed that they had all managed it within the previous month. Nevertheless, nearly three quarters of the visually disabled considered they needed no special aids or help in getting about and a further 13% only needed an ordinary stick or other form of walking aid. Only 10% needed assistance specifically geared to the poorly sighted (none used a guide dog).

It must be admitted that these percentages did not accord very precisely with answers to other questions in the schedule. Thus 35% of the visually disabled said they actually had a stick, cane or other form of walking aid (28% did not pay for it themselves) and this figure is much nearer to the 44% in the Harris survey of all handicapped having such aids, or the 62% of Gray and Todd's younger sample of registered blind. The difficulties inherent in trying to correlate what people have with what they actually use with what they have recently done merely highlight the need for detailed travel diaries rather than non-probing closed questions in estimating mobility beyond the house.

However, among those 80% or so who had been outside the house during the previous month, few turned their steps towards a day centre or handicapped club. Only 2 visually disabled people had visited a day centre (one on only one occasion), though another 8 said they attended a handicapped club (7 regularly). None went to a lunch club or sheltered workshop. Three had spent some time in a residential home.

The picture, though incomplete in many respects, complements that found in Canterbury of a largely independent group of people whose mobility restric-

tion, albeit crudely measured, has little to do with their level of measured visual acuity.

Social service, medical and other help available

As with their mobility, the contacts that the visually disabled have established with the services best able to help them with their difficulties cannot all be related to their visual problems alone. In fact there was some evidence, especially among those few who declined permission for contact to be made with the family doctor, that some elderly people deliberately keep the knowledge of their poor sight from their doctor, feeling perhaps that it is none of his business. However this is only a small minority and for the most part the importance of contact with social service and medical agencies lies not only in the help that can be given, but also in the increased opportunity for a presumptive initial diagnosis of poor sight to be made using simple tests that are within the competence of almost everyone.

Table 13 details the contacts that the visually disabled said they had made with social service and other non-medical agencies during the preceding year. It can be seen that 52% of the visually disabled could remember no visit from any agency during the year - these tended to be, proportionately, among the slightly better sighted. Further analysis, not shown in the table, suggests that the large majority of unvisited lived in households of two elderly or old people, although 5 of the 8 between 60 and 75 who lived alone claimed no visit, and 2 of the 12 of 75 years or more. These, of course, are not figures on which any sort of estimate of national contact patterns can be made; they depend very much on what is locally available, what is the local pattern of responsibility (e.g. whether health visitors undertake regular visits to the aged or concentrate on children alone) and on elderly people's ability to recall in any detail what has happened over a whole year.

However, comparison with other local surveys, such as the Canterbury Survey[98] confirms the ordering of the different services with social worker, home nurse and home help (not included in the Canterbury Survey) taking precedence over health visitor, meals on wheels, etc. These are approximately the same percentages and the same ordering as found for the handicapped in the Harris survey[35] where a similar percentage (60%) were unvisited by any service. However, Warren[99] has shown that there are weaknesses in respondent's ability to recall which services have visited, when compared to agency records, though the discrepancy is not more than 5% for any one service.

Table 14 illustrates how many of those visited by the various services identified poor sight as their major difficulty. This gets nearer the expressed needs of the visually disabled for help with the problems ensuing from poor sight alone, but still cannot be said to relate precisely to it. The figures in the table do suggest that those who identified poor sight as their main problem received slightly less social service and other support (39%) than those who considered it no problem at all (55%) but the figures are standardised neither for age, nor actual level of any disability. Thus many of the elderly and old with multiple problems were among those who did not identify a sight problem, yet who did get more support from the home help and home nursing services. Only two of the visually disabled claimed help from a physiotherapist or occupational therapist at home during the year.

Table 15 details the medical help which the 102 visually disabled had sought for their main disability. It does <u>not</u> relate, as does the previous table, to the past year only but to any help or advice ever obtained. Again, the questions dealing with medical advice were related specifically to the presenting disability, so the only clue to possible ophthalmic advice is attendance at ophthalmic outpatients. Nevertheless the majority (80%) of those presenting with poor sight had at some time sought medical help for it,

attended a specialist clinic and perhaps (52%) been admitted to hospital for it. On the other hand only a small minority (4%) of those not mentioning sight as a problem said they had attended a specialist eye clinic, although 52% had attended hospital for something else and 33% had been admitted for it. Of those who complained of sight as a secondary problem, none had been to an ophthalmic clinic. Only 5% of the 102 visually disabled claimed to have sought no medical help at any time for their principle disability.

It would seem from Table 15 that family doctors might be in possession of a great deal of information about the visually disabled - 86% of those with a sight problem having consulted them and 88% of the 58 who identified no such problem or mentioned it as a secondary one. This is however not necessarily so - in many cases among the first group the G.P. acted as no more than a referral agent to the hospital (often, probably, between the optician and the hospital) and for the other two groups it is likely that eyesight is not often discussed during consultation. Thus when it came to record linkage (see page 126) very little information on eyesight was available from family doctor records. Once again, however, the importance of many of the non-specialist contacts illustrated in Table 15 lies not in the detailed information about eyesight they give rise to, but to the opportunity to perform simple screening tests. Given that they were actually visually disabled at the time they last made contact, 95% of the 102 visually disabled have had an opportunity to have it diagnosed.

Aids available to the visually disabled

One of the most important effects of successful adaptation to visual disability is the acceptance of, and successful use of, such aids as are available to meliorate the handicap it causes[42,50,54] and yet Hilbourne[42] has shown that for elderly patients with cataract, at least, such acceptance cannot be achieved without considerable help. This is, of course, the

theoretical basis underlying the work done by social workers and teachers trained to help the blind. The present survey offered an opportunity to quantify, though not to explore in depth, the various aids used by those, less than blind, who had generally not had the benefit of special social work help in overcoming their visual disability. Kohn and White (1976)[52] found that 91.6% of those adults (15 years +) in their Liverpool sample who identified a vision problem claimed to use some sort of corrective lenses, but there was no way of estimating how suitable these were for the task being performed. However, one in 9 of these appeared not to have been specifically prescribed for the respondent by anyone qualified to do so.

Interviewers were instructed to explain carefully that distance vision and near vision correction should be used for the appropriate test and to allow plenty of time (and assist if necessary) to find any spectacles or other aids in the house that the respondent was using in his day to day life. In the Canterbury survey, where the opportunity was available to check opticians' records, respondent's estimates about the date of their latest correction proved so unreliable that no such question was included in the national survey. Nor, of course, was there an opportunity to go to opticians' records. So the present estimates are based on what was available and in daily use at the time of the interview - the lay interviewers had no special knowledge of optics.

Tables 16 and 17 illustrate the optical aids used by the visually disabled to perform the distance and near vision tests in the present survey. In the tables 'special distance' and 'special reading' lenses imply that the respondent had available more than one pair of spectacles and changed them between the tests - 'ordinary glasses' implies only one pair was available and used for both tests. Bi-focal lenses form a separate group. Those who could perceive no light were not recorded and among those whose sight was not mea-

sured were 4 who were illiterate and the 3 for whom only proxy replies were obtainable.

It can be seen that 22 (22%) of the visually disabled had no correction available for performing a test which identified them as truly visually disabled, though 7 of these had no more than light perception. Thirty six (35%) used the same lens correction as they subsequently used for the near vision test though it may be that a few of these lenses were bi-focal. Twenty three per cent had special distance glasses available. It is of interest that these percentages are not much different among the 112 better sighted (6/18+) who, while confessing to a sight difficulty, were not visually disabled by definition - 31% used no correction (somewhat higher than among the visually disabled), 32% ordinary glasses (slightly lower) and 21% special distance lenses. Of course, far fewer people approach an optician with a difficulty in distance vision than near vision[52] and perhaps not much more than 20% of them[86] can be helped in distance vision by optical means though many more are able to help themselves by adjusting their position and lighting for T.V. watching, etc. Relatively few patients will accept and make good use of telescopic lenses for distance vision[86].

The number using lenses and aids for performing the near vision test are presented in Table 17. Just over 20% of the respondents used no spectacle correction for near vision, though 8 of these used a magnifier, and 4 with no correction were able to read print of 'normal' size (approximately N10 or finer) and the great majority (75%) of all the visually disabled, whatever their correction available, were unable to do this. This is somewhat higher than the 63% found in Canterbury to be unable to do so.

Table 17 suggests that correction for near vision is in fact more common than correction for distance vision. Twenty seven per cent had special reading lenses available and a further 11% used a magnifier with or without their

ordinary glasses, whereas only 25% adopted special glasses for distance vision. It is also probable that 'ordinary glasses' were more often suited to near than distance vision. Silver[86] suggests that 50% of patients referred to a low vision clinic gain long-term benefit from the use of low vision aids and further suggests that between 39% and 58% of the registered blind and partially sighted would be visually benefited by them had they been given the opportunity to try them. Among the present sample of visually disabled only 11 (11%) were using any form of magnifier or aid, though 5 others who complained of a sight problem but were not visually disabled also used them. Two of these could read no more than N24. Lastly, it is instructive that of all those 214 in the survey who complained of a vision difficulty eighteen (8%) had at some time acquired a magnifier or other low vision aid (11 paid for it themselves, 7 had it provided) and 15 of these were still using them regularly.

Finally, some further idea of the difficulties, in seeing, of the visually disabled can be gained from comparing each respondent's acuity in distant and near vision, measured under ostensibly the same conditions. There are, of course, pitfalls in assuming that lighting, for instance, was in fact of the same order of suitability for the two procedures, and the previous two tables have implied, if not actually quantified, far from ideal correction for many of the respondents. So inferences about optics, rather than disability, cannot necessarily be drawn by comparing distance with near visual acuity. Nevertheless, some picture is gained of where the greatest difficulties may be and where help might most effectively be directed.

Table 18 illustrates the correlations. In general, those with better distance vision (6/24 or 6/36) were able to read the finest print, and only 4 people with distance vision lower than this (6/48 or worse) might have been

able to manage a book or newspaper of normal print size. Theoretically, 'N14' roughly correlates with 6/36 and 'N24' with 6/48, so it can be seen that a majority (65% of the visually disabled with better distance vision (6/24 - 6/48) could read print to a finer level than suggested by their distance visual acuity test. Eighteen per cent read as well as suggested and 17% worse. These are almost the same percentages as found in Canterbury (see Part II, where the implications are more fully discussed), and it must be concluded that lighting and proper correction are the most important factors explaining the differences. Respondents appeared to be much better equipped to deal with close work than with distance vision (where many non-optical techniques can be used to overcome difficulties). Further evidence to confirm this comes in the answers of the visually disabled to questions about how their disability affected their leisure enjoyment. Although nearly 30% of those identifying sight as their main problem said it did not affect their leisure time enjoyment, 48% said it was in close work (sewing, reading etc.) that their difficulties lay and only 22% identified any difficulty with social activities, gardening or sport, which might involve distance vision. However, no conclusions should be drawn without making full allowance for that bottom 20% or so who feature in each of the three tables (16, 17, 18) - no correction for distance vision, some uncorrected for near vision as well, unable to do the close work which they consider so important; these, among the better sighted visually disabled, may be the real losers.

RECORD LINKAGE

Introduction

The main purpose of tracing hospital records, where they existed, for the visually disabled was of course to establish the underlying cause of diminished vision, but the opportunity also arose, as in Canterbury, to verify the acuity tests done at home and to estimate the possible importance of visual field defects as a concomitant to reduced acuity. However, part of the success of record linkage in Canterbury was due to the opportunity to make a personal search of all the records of one hospital, and thereby uncover ophthalmological opinions which had been forgotten by some of the respondents when they were asked about specialist contacts. No such opportunity arose in the National Survey, of course, and so everything depended on the goodwill of family doctors, eye specialists and, on a few occasions, the directors of social services, none of whom had any personal interest in, or involvement with, the research. This goodwill was given unstintingly, and says much for future possibilities in collaborative research.

Table 19 illustrates the outcome of the record linkage. Only those who were defined as visually disabled were asked for permission to write to the hospital if they had attended an eye clinic within 10 years, or to their family doctor if they had not. For the few registered blind or partially sighted who had not been recently (10 years) to hospital, permission was sought to write to the appropriate social service department. Approximately half the visually disabled had been to a specialist eye clinic within the last ten years; for 6% no records were traced at the hospital concerned, and a further 3% refused permission to write for records.

For a few of the 49 who had apparently not been to hospital within 10 years some information was obtainable from their family doctors about their

eyes, or their sight, and a further 4, registered as blind or partially sighted, had information on their B.D.8 forms lodged with their local social service department. For the 11, however, for whom information was obtained from a family doctor, it was not usually the doctor himself who had made the assessment - for 8 it was either an optician's report or a hospital report forgotten by the respondent at the time of interview, and for only 3 was it the family doctor. Actually in one case, at least, and in five others referred to hospital, the survey itself seems to have been the reason the assessment was made. Warren's finding[100] that family doctors' records only rarely contain useful details about eyesight was certainly confirmed in this survey; indeed 5 of the respondents who declined permission to write to their family doctor did so expressly because they said he knew nothing about their eyesight (2 saying it was none of his business!).

Under such circumstances a list of diagnostic causes of visual disability is bound to be deficient - only 60% of the visually disabled had ever had a diagnostic assessment of any sort. Such a list can be taken only as a rough guide to the relative importance of the various diseases, but it is worth stressing that all those in this survey, and all those visually disabled in the Canterbury survey, who had at some time been assessed by an ophthalmologist had a demonstrable eye pathology as a cause of diminished sight - no one had a 'functional' defect only.

Table 20 lists the main diagnoses causing visual loss among the visually disabled - in a few cases additional eye pathology might well have led to added difficulties but the diagnoses were selected by each doctor (usually specialist) as the principle cause. Cataract, of all types, tops the list accounting for well over 25% of all those diagnosed, and 14% of all the visually disabled. As a cause of visual disability it came a close second to macular degeneration in Canterbury (which has an older population than the

national average) and, indeed, in Sorsby's analysis of blind registers[89] the ordering is the same. Sorsby, writing in 1966, says "The marked reduction in the incidence (sic) of cataract as a cause of blindness in recent years ... is a heartening illustration of what can be done by administrative effort in appropriate fields. It is clear that the measures taken so far ... justify further and persistent action on these lines". Table 20 suggests that the intervening ten years have not altered the importance of his message and that, as Brennan and Knox have shown[6] there is a great deal of unoperated cataract still in the community causing very real sight difficulties. The ordering of the other diseases is much the same as was found in Canterbury (see Part III) though perhaps diabetic retinopathy plays a slightly bigger part than was thought there, and myopia, without retinal detachment, a lesser one. The numbers, of course, are too small (and incomplete) for a definitive statement.

Lastly, it is interesting to compare what the respondents thought was wrong with their eyes with what the eye specialist gave as a principle diagnosis. Warren[100] has shown that for one small town group practice at least there is a high concordance between patients' statements of what conditions cause their eye trouble and broad diagnostic categories obtained from G.P. interviews. Nationally, this seems a little less so; only half of those 14 for whom there was specialist confirmation of cataract mentioned that they had it and a further 4 who did say they had cataract, in fact had other eye diseases as a predominant cause of sight loss (diabetic retinopathy, myopia, macular degeneration, optic atrophy). It must be stressed that no-one was asked specifically for a diagnosis of their disability, but nevertheless survey questions about diagnoses do not seem to promise very useful results.

Correlation between home and hospital visual acuity

As in Canterbury, it was possible to compare visual acuity measured at home and that measured at a respondent's recent visit to a hospital clinic.

Only those with defined visual disability were included, so numbers were smaller than in Canterbury. Once again 2 years was taken as the outer limit for comparison, though 20 of the 28 for whom notes of a recent visit were obtained had been seen within a year of the survey (11 within a month of the survey).

Table 21 outlines the results, and presents a picture remarkably similar to that found in Canterbury (Table 14). Except for 7 with vision no better than 1/60 either at home or at hospital, only one person saw marginally better at home than at the hospital, and for 2 others the test-reading was the same. All the remaining 18 (64%) apparently saw either marginally or markedly worse when measured at home than they did in the specialist clinic. By definition, of course, all would have been considered visually impaired by W.H.O. standards at home; but only 16 (57%) when measured in the hospital.

The differences illustrated in Table 21 probably have several components. Lighting, correction, daily variations in acuity, pathological conditions and psychological attitudes and adaptation must all play a part, but it is not possible to discount entirely the possible effect of inter and intra observer variation both in the home and hospital setting. However, the differences are almost entirely one way and to achieve an error of only one Snellen type size implies a test-distance error of at least eighteen inches in ten feet - it is unlikely that all 200 interviewers in the National Survey, as well as all the Canterbury interviewers, would have erred in the same direction. Moreover, there is separate evidence[10] that visual acuity measurements made by lay observers do achieve fairly accurate results. It must be concluded that most of the respondents for whom the measurements were different actually were seeing worse at home than they were supposed to do at the hospital.

No attempt was made during the survey to measure home lighting, though two thirds of the home tests illustrated in Table 21 were made in daylight

hours. Nor was there any opportunity to judge the adequacy of lens correction used, beyond recording what each respondent wore (i.e. had available to wear) for the distance acuity test at home. Eleven (3%) wore 'distance glasses', 9 (32%) the same lenses as they used for reading, 1 bi-focals, 1 contact lenses, and 6, all with very poor sight, used no correction at all. The differences between home and hospital measurement were not greater for those who had only one type of lens correction then they were for those who had two. Six (21%) of those in Table 21 had cataracts in both eyes, 7 (25%) were suffering from macular degeneration, 3 were aphakic, 2 had glaucoma, 2 detached retinae, and the remainder glaucoma, optic atrophy, diabetic retinopathy, etc. As in Canterbury, no one disease accounted for most of the measurement differences, though all the 6 patients with cataract had at least two Snellen lines difference.

Clearly more detailed research is needed to elucidate the various components of this problem, including just how important to the activities of daily living small variations in visual acuity actually are. This must, of course, vary with the individual, but one recent research report has accepted differences of as much as two lines of Snellen type as indicating similar vision for the purpose of judging treatment response[77] - though no group in their controlled series had an average acuity of less than 6/36. It is arguable that as sight becomes worse to the point of light perception only, especially if it happens fairly quickly, the handicapping significance of each measureable loss may well become greater, particularly among the elderly and old and that, for these, differences of two Snellen lines mean much more than they do for the better sighted. Table 21 suggests that 37% of those seen recently at hospital had at least this difference between home and hospital, and to this number must be added all 6 with an acuity of 6/24 at home, who saw at a level of 6/9 or better when measured in hospital.

Visual field defects, and other diseases recorded

Little knowledge was gained, from the survey, of the visual field defects of the visually disabled, and how much they might affect sight. Although an opportunity was offered on the recording form to set down the visual field of each eye so that it could be correlated with visual acuity measured at the same time, in almost half (43%) no record of visual field had been made. A further 17 (18%) fields were described as 'good'. Where there was a defect, a central scotoma was by far the commonest, occurring in 25% of all the eyes recorded, with contracted fields varying from 'Nil' to 10°, 20° accounting for only 12% of all recorded eyes. But these are deficient figures on which to base any judgements, and merely serve to confirm what was found in Canterbury - that reliance on hospital records for estimating the handicapping effect of diminished visual fields will not serve, and only a special study with an easily portable field screener will provide any form of adequate estimate. On such small figures as these, no attempt is made to correlate with actual levels of visual acuity, or to verify the estimation made from the Canterbury data of what effect visual fields may have on the under-estimation of those eligible for registration as blind or partially sighted.

Finally, half of those seen at specialist eye clinics were not known by the ophthalmologist to be suffering any other disease at the time; 17% had diabetes alone, 10% hypertension alone, and 2% diabetes with hypertension. A further 12% or so suffered some other illness, generally not sight threatening. As in Canterbury, diabetics were the commonest attenders at eye clinics apart from those who have no other pathology, and, as in Canterbury, the great majority of patients came to the eye clinic directly from the family doctor (69%), though many, doubtless, indirectly from opticians and perhaps social services. Only 8% were referred by other hospital departments.

THE VISUALLY IMPAIRED

This section gives some information about the 112 people who stated in answer to a direct question that they had at least some difficulty in seeing to read or get about but were not defined for the purposes of the study as visually disabled because they had a measured distance acuity in their own homes of at least 6/18. In most surveys[102], certainly those following approximately the Harris protocol[36], visual disability has been judged solely on answers to questions, and all who have answered positively have had their difficulties analysed as a single group - yet Table 1 suggests that the range of visual acuity amongst positive responders is very great, varying from practically normal vision to an inability to perceive light. Indeed, 31% of all positive responders (60% of those not defined as visually disabled) had vision apparently good enough to allow them to drive a motor-car (6/15 or better). It would seem, then, that there is logic in using a test of visual acuity in definition, but having done so to inquire how the difficulties in mobility, work,leisure enjoyment, contact with medical and other services, and the other factors which have been shown to be of importance to the visually disabled, differed among those better sighted who still perceived themselves as having a sight problem. It may be, for instance, that they suffer only a sight difficulty and therefore it is of more importance to them or perhaps that they have a more profound difficulty with near vision than their distance acuity would suggest.

It has already been shown (Table 1) that the better sighted are generally younger than the visually disabled (comparative mean ages for the groups are 61.4 years and 71.5 years) and have rather more men among them (45% compared to 34%). However, these effects are largely brought about by those in the group with vision better than 6/18 (Table 1) - those with 6/18 only compare in age structure and sex much more closely with the truly visually disabled.

Yet among the whole group of 112 only 14 (13%) mentioned poor sight as among their problems though only half these (6%) counted it as their greatest. This is far less than the 55% (Table 8) of the visually disabled who mentioned sight as a problem and it does seem that, even among the better sighted, generally younger group, the presence of other disabilities still overwhelms and perhaps obscures the fact of poor sight, just as it does for so many of those defined as visually disabled. The two groups are not, however, strictly comparable with regard to the reasons for their inclusion in the survey; 30% of those not defined as visually disabled were included because of some incapacitating injury, but only 15% of the visually disabled, so fewer among the better sighted suffered from some other chronic disabling illness than did the visually disabled. Despite this, ischaemic heart disease and arthritis continued to head the list among those who did identify a longstanding condition, and just as many (65%) of those included because of a past injury apparently saw no better than 6/18, as those with another chronic condition (61%) or those who complained that eyesight was the worst of their problems (63%).

When it came to defining, however, the effect that their disability had on the activities of their daily lives, rather more (21%) among the group of 112 claimed no effect at all on their mobility or the enjoyment of their hobbies, than among the visually disabled (16%). Moreover, those who claimed no present effect were as much to be found among the chronically disabled as among those who had suffered an injury or accident in the past, although only one of the 14 claiming a difficulty with sight denied that his life was in any way curtailed by disability. A further 5 denied that it was their sight problem that limited their activities, while the remaining 8 (7% of the whole 112) attached more importance to being curtailed in close work than in mobility, by poor vision.

The above analyses all suggest that, while those who complained of a difficulty in seeing to read or get about but had a visual acuity of 6/18 or better were a little younger and contained more men of working age than those defined as visually disabled, they were no less beset with other problems that limited and, perhaps, overshadowed their sight difficulties. It is certainly not the case that they suffered only from a sight problem and therefore found it easier to identify in answer to a direct question about it. Nor, on further analysis, did they differ in any discernable way from the visually disabled in mobility, household amenities, length of residence or income - only in household composition, which could largely be accounted for by the age effect. Although just as many lived alone as among the visually disabled (see Table 2), over twice as many (36%) lived in households of three or more adults and fewer in households of two elderly people alone.

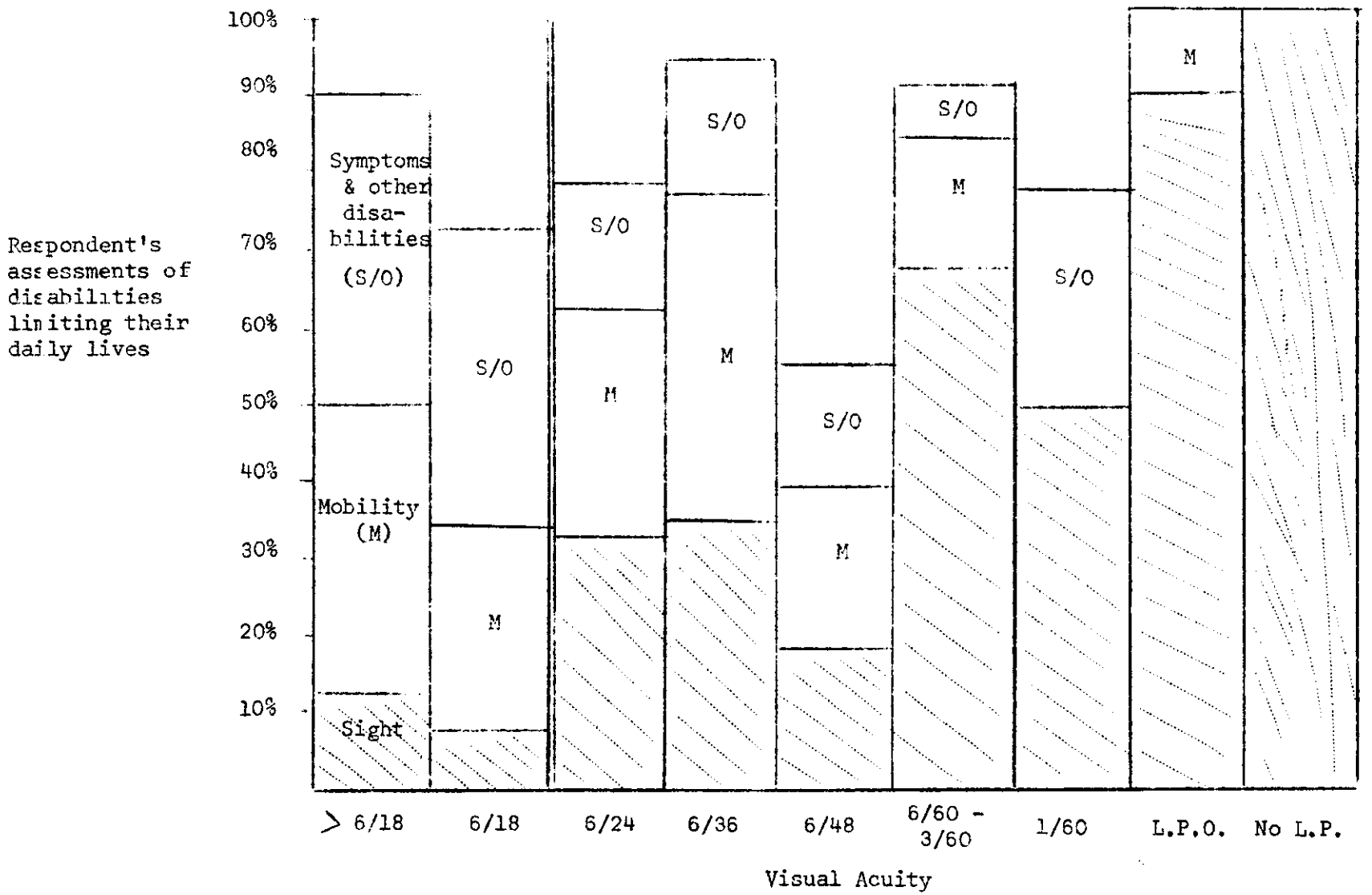
Although no attempt was made to trace hospital or other records for those who were not defined as visually disabled in the survey, all were asked what clinics they had attended in relation to their major disability. Among those not defined as visually disabled, all 14 who complained of a sight problem said they had been seen at some time by an eye specialist, together with one other who did not mention vision among his difficulties. Five (33%) of this total of 15 said they had cataracts, one was aphakic and 3 said their sight problems had originated with a 'stroke'. Of the remaining seven, 2 described eye symptoms in association with diabetes, and one each with hypertension, 'arthritis', Paget's disease, herpes zoster and 'injury' - all of which might have had eye connotations. It is of some interest, too, that the 97 who did not say they had been to an eye clinic and complained of other disabilities without mentioning poor sight as one of them, contained 9 with 'arthritis' (or various kinds), 5 who had had a stroke, 4 with diabetes, and one with herpes zoster and one with multiple

sclerosis - all had been to hospital for their condition. However, only the visually disabled were asked if they had ever been to hospital 'for their eyes', and so there may well have been some among those not visually disabled who had at some time had a specialist eye assessment but did not mention it during the survey.

In view of the above considerations it could well be argued that to draw a distinction on the basis of visual acuity alone between those to be considered visually disabled and those not is to introduce an artificial division into a largely homogeneous group. Both sides of the division show the same pattern of conditions, other than poor sight, limiting mobility and daily living and both show the same living conditions, use of medical services,etc. Moreover both have complained of a difficulty in 'seeing to read or get about'. But reference to Figure 1 suggests that there is a very real progression in the relative importance of sight problems imposing restrictions on the enjoyment of daily life as measurable sight worsens to the point of no light perception; moreover the difference in the perceptions of those defined as visually disabled and those not is obvious. Under these circumstances a 'cut-off' point of less than 6/18 vision not only satisfies the definitions of the internationally agreed W.H.O. protocol for the purposes of epidemiological data, but also seems to include 95% of those who consider that the most limiting disability that they suffer is poor sight.

FIGURE 1

The Relative Importance of Sight Problems in Limiting Daily Life



CONCLUSIONS AND DISCUSSION

From the data of the national survey, and from the earlier Canterbury data, a picture begins to emerge of the visually disabled in the community that has not been painted before. Too often, before now, the 'blind' or the 'partially sighted' or the 'visually handicapped' have been portrayed, in social, epidemiological and optical studies, as a group for whom 'poor sight' is assumed to be sufficient explanation for all their difficulties. Part I of this report, in which the literature is reviewed, describes abundant work from many countries, in which poor sight is described in isolation as if it were the only difficulty the individual suffers, the only label that sets him aside from the rest of society. Of course, this has usually been achieved by dealing either with only one age group, often excluding the elderly and old, or by asking no questions of those who have identified themselves or who have been identified as visually disabled that cannot be directly related to poor sight and the social, psychological and physical problems which supposedly emanate from it. Such restricted questions naturally preclude any concept of the interaction of visual disability with other disabilities the sufferer may have, and the ascribing of all handicaps to the one disability, merely because it is of most interest to the researcher, has led to a popular picture of the visually disabled as a group perfect in all things save for a single flaw.

If the national survey, and the work in Canterbury which preceded it have done anything, it has been to show that this will no longer do. While, certainly, in childhood or in working age poor vision may be the single disability that handicaps the visually disabled person from achieving his full potential, it is the elderly and old in retirement years who account for at least three quarters of all the visually disabled and for many of these other disabilities begin to intrude and sometimes to overwhelm. When asked to state freely what most troubled them, less than half (44%) of the visu-

ally disabled said that poor sight was their major problem and hardly more than a half (56%) mentioned it at all. Yet all said, on direct questioning, that they had at least some difficulty in seeing to read or get about. Admittedly most who had really poor vision,making them eligible for registration as blind, mentioned poor sight as a problem, but at least 10% of those not mentioning it could see no better. None of this, of course, lessens the importance of the very real difficulties caused by poor vision - it merely serves to show that poor vision can no longer sensibly be considered in isolation, especially in a largely elderly population.

The second major conclusion from the work is that poor sight, and the hardship it brings, is no longer the business only of the optician and the ophthalmic surgeon. Both the Canterbury survey and the national survey have shown that it is certainly within the competence of any trained social worker, health visitor or home nurse to administer simple non-intrusive tests which will give an indication of where help might be needed. These tests are not, and do not have to be, of the level of accuracy needed by opticians to prescribe or ophthalmologists to treat. But while for societal and psychological reasons these professionals lie outside the easy reach of many of the elderly and housebound who might benefit from their initial and continuing help, it is all the more important that those who are in contact should become familiar with the simple criteria on which action can be initiated. Over half those visually disabled who did not mention poor sight as a problem and so might not have taken action themselves, were visited during the preceding year by a social or health worker with the capability of making a simple assessment of vision. Moreover, 90% of them had seen their family doctor about their major disability, and over half had been admitted to hospital for it - yet only a very small percentage (4%) had ever had a specialist eye assessment, unless they themselves considered poor sight their major problem. This is no more, of course, than Fenton and his colleagues found

in the geriatric wards in Portsmouth[19] but the impression gained of a general medical profession both inside and outside the hospital either unaware, or unmindful, of the possibility that poor eyesight may be contributing to the difficulties faced by their disabled patients, is disturbing - especially when the tools for elementary assessment are so simple. The only drawback to the use by all health-care personel of the simple techniques needed to make an initial assessment of the distant and near visual acuity of all and any they may be caring for, is the possibility of raising hopes that cannot then be fulfilled, and of upsetting situations that may have taken years to stabilise. But the sensitivity to avoid such mistakes is part of the general, not the particular, training of the professional.

No firm conclusions can be drawn about the prevalence of the different conditions causing visual disability in the community because only half the visually disabled had ever had a specialist eye assessment; nor do further studies based either on registration data or hospital record studies promise anything more useful. Nevertheless, cataract as a diagnosis constantly appears at or near the top of every list and far outstrips all other forms of treatable sight threatening eye disease; it accounts for well over a quarter of all the visual disability of known cause in the community. It would, however, be easy to state that to operate on all cataracts that cause visual disability, given modern surgical and anaesthetic techniques, would be to make a profound difference to the number disabled by poor sight, without equally stressing that cataract remains the primary known cause of visual disability purely because the patients have been seen by specialists and decisions made not to operate. The basis on which such decisions were made, be it the patient's desire, the specialist's assessment of the importance of the disability to the patient, the backup support available to help post-operative adjustment, the presence of other conditions or whatever, was not within the scope of the survey. However, it is possible that had the surgeon

known just how much worse the patient seemed to see at home than in the hospital, he might have had other data on which to decide, and Brennan and Knox[6] have shown that the operation rate for cataracts among elderly people varies greatly between regions. It must be assumed that there remains a great deal of undiagnosed cataract among the elderly visually disabled on which no decisions have ever been made. For most of these, there can be no harm in at least finding it.

The purely optical difficulties which the visually disabled experienced in their own surroundings can only be surmised from the data in this report. It was concluded from the Canterbury data that correction and lighting as well as social and psychological attitudes probably accounted for much of the difference found between hospital and home measurement and the data from the national survey certainly reinforce this conclusion. In Canterbury, the visually disabled were not able to remember with any accuracy when last their lenses were checked and opticians' records showed how few had apparently been seen within 4 years. In the national survey there was great variability in what was available for performing the sight tests. Both findings, while not producing accurate quantitative data on which firm plans can be made, seem to point firmly to where a considerable amount might be accomplished in alleviating the day to day problems of visual disability. Domiciliary visits by opticians, prepared to advise on all aspects of optics including near as well as distance vision, and lighting, even where the patient is not housebound, could be very beneficial, but they will often be made as part of a general assessment where several disabilities co-exist and the optician must have the experience to appreciate this. Moreover, they would most logically occur after specialist ophthalmic assessment either in the home or in the hospital and after treatment is complete - all the visually disabled can be assumed to be suffering from a pathological eye condition for which specialist assessment is needed. However, no specialist advice, optical or ophthalmic, need

necessarily inhibit the simple experiments that any family doctor, social worker or home nurse can make, with the patient, by altering the lighting of the room or trying the effect of a hand held magnifying glass. No harm, and much good, can come from this as long as there is no preconceived notion of what should or should not be, other than the disabled person's own perceived benefit.

One of the other effects of the national and Canterbury surveys has been to refine the tools a local authority might use to find the visually disabled, by means of survey. Much of the Canterbury report (Part III) dealt with the effect that various traditional approaches and types of question had on the numbers of visually disabled (or handicapped) found in a community and the approach to the visually disabled used in the national survey was modelled on the conclusions drawn from these. Without repeating the arguments in detail (see Part III), it can be stated with fair confidence that:-

(a) no question, open or closed, directive or non-directive, can be used to estimate with any accuracy either distant or near visual acuity,

(b) the measurement of distant visual acuity is no accurate indication of near vision.

(c) the level of measured visual acuity, distant or near, provides no accurate guide to what can be achieved visually or to the extent of the handicap experienced - many can achieve with a little residual sight far more than others can do with considerably more.

It would seem, therefore, that the approach to any estimate of the visually disabled in a community must consist of a simple all-embracing initial question embracing concepts of both distant and near visual ability - such as "do you have any difficulty at all in seeing to read or seeing to get about?" -

followed by simple tests of visual acuity, both distant and near. No intervening questions about how much can or cannot be seen,or about what is or is not done using sight are likely to be helpful and no form of self-reporting, study of registers, or of hospital records will achieve anything like an accurate result. How much the visual disability actually handicaps depends of course on how handicap is defined (visually, socially, psychologically, etc.), but certainly it will not depend on whether registration has or has not occurred or whether the disabled person counts it as the greatest or least of his problems.

Finally, the W.H.O. definition of visual 'impairment' (here, disability) seems both useful and logical, if, and only if, distance visual acuity, together with some allowance for diminished visual fields, remains a sensible way of measuring visual disability. The method has become traditional because it is based on sound optical principles, is simple to administer and can be reasonably standardised, but the U.K. system of registration, based only partly upon it, has always recognised its weakness as the sole basis for delivering statutory help. Gray and Todd[31] showed how inefficient it is in describing where the difficulties of the very poorly sighted really lie and this must be even more so among the elderly visually disabled to whom near vision is of great importance. Genensky, in America[26] has suggested how a concept of near visual acuity as well as visual fields might be combined with distance acuity to describe those most in need of help with their vision, but its application demands an ease of access to specialist services which certainly doesn't exist in this country at present. Nevertheless, if a system largely dependent on distance acuity is to continue to be used it seems logical to use a system such as the W.H.O. one, generous enough to include most of those with a near vision problem, rather than to exclude many of them as our current concepts of partial sight and blindness seem to do.

TABLE 1

The Age and Sex of those complaining of a Visual Problem

Age Groups		Not Visually Disabled			Visually Disabled									
		6/10+	6/12	6/18+	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No Light Perception	Not Measured	Total
Men	16-29	4												4
	30-49	9		2			1				1			13
	50-59	4	1	1	2	2	1					1		12
	60-64	2	2	3	1	1	1		1					11
	65-74	5	4	6	2			2	1	1	2		2	25;
	75-84		2	3	1	3	1			1	2		2	15
	85+			1						2	1		1	5
	Total (Men)	24	9	16	6	6	4	2	2	4	6	1	5	85
Women	16-29	3	1										1	5
	30-49	5	1	2				1			1	1	1	12
	50-59	1	1	3	2	1			1				1	10
	60-64	1	1	5	3								1	11
	65-74	4	4	7	6	4	1	1	3	2		1		33
	75-84	4	5	6	6	9	4		1	2	3		2	42
	85+	1	1	4	2	4	2		1		1			16
	Total (Women)	19	14	27	19	18	7	2	6	4	5	2	6	129
Total		43	23	43	25	24	11	4	8	8	11	3	11	214

TABLE 2

The Households of the Visually Disabled

Percentage of Visually Disabled Adults in Different Households

Household Composition	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total %	Surveyed Households (1st stage)	G.H.S. Households (1972)
1 person age 16 - 59	1				1					2	5%	5%
2 persons age 16 - 59	2				1		1	1	1	6	14%	14%
Youngest person age 0 - 15	1	1	2				1	1	2	8	37.5%	38%
3 or more persons aged 16+	3	5	1		1	3			3	16	12%	12%
2 persons age 16+ one or both aged 60+	13	11	6	3	4	4	4	1	4	50	17%	17%
1 person aged 60+	3	2	1		1	1				8	12.5%	13%
1 person aged 75+	2	5	1	1			3			12		
Total = % (Base = 102)	25	24	11	4	8	8	9	3	10			

TABLE 3

Main Source of Household Income

	Earned Income (Disabled Person)	Earned Income (Other Member)	Retirement Pension from Employer + Old Age Pension	Unearned Income (Rents, Investments) + or - Pension	Old Age Pension only	O.A. Pension + Supplementary or other State Benefit	Other
1 person age 16 - 59	1						1
2 persons age 16 - 59	1	2					3
Youngest person age 0 - 15	2	3		1			2
3 or more persons age 16+		10	1		2	2	1
2 persons age 16+, one or both aged 60+		8	12	8	13	6	3
1 person aged 60+	1			1	2	4	
1 person aged 75+				3	3	6	
Total % Base = 102	5	23	13	13	20	18	10

Base 102 (=100%)

TABLE 4

Tenure of Households in which the Visually Disabled Lived

	Visual Acuity (Snellen)										
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total ≙ %	G.H.S. 1973 approx. %
Privately owned (or mortgaged) house or bungalow	16	10	3	2	3	5	4	1	4	48	45%
House or bungalow rented from council, etc.	4	4	4	1	1	0	2	1	1	18	16%
Privately rented house or bungalow	1	3	3	0	0	0	0	0	1	8	5%
Flat rented from council	3	7	0	0	3	3	3	1	2	22	17%
Flat/rooms rented privately	0	0	1	1	0	0	1	0	0	3	9%
Privately owned flat	1	0	0	0	1	0	1	0	0	3	4%
Total ≙ % Base = 102	25	24	11	4	8	8	11	3	8	102	

TABLE 5

Household Amenities of the Visually Disabled

Household Composition	Sole use inside flush toilet	Shared use of inside flush toilet	No inside toilet	Fixed bath or shower (sole use)	No fixed bath or shower	Hot water supply	Telephone	Motor car for personal use
1 person aged 16-59 Total = 2	2			2		2	1	
2 persons aged 16-59 Total = 6	4		1	5		5	3	1
Youngest 0-15 Total = 8	8			8		8	4	4
3 or more 16+ Total = 16	16			16		16	10	7
2 persons 16+ 1 or both 60+ Total = 50	50			49	1	49	19	9
1 person 60+ Total = 8	8			8		8	5	
1 person 75+ Total = 12	10	1	1	10	2	10	4	
Total ≏ % (Base = 102)	98	1	2	98	3	98	46	21
G.H.S. (1973)	84.9%	1.4% (None 1.1%)	12.6%	88.3% Shared 2.9%	8.8%			

No answer = 1

TABLE 6

Duration of Residence

	Years living in present accommodation				Years living in present district				Relatives within 2 miles	Plans to move affected by disability
	10+	5-9	1-4	Less than 1	10+	5-9	1-4	Less than 1		
1 person aged 16-59 Total = 12	1		1		1		1			
2 persons aged 16-59 Total = 6	2	3	1		3	3			3	1
Youngest person 0-15 Total = 8	6	2			7	1			5	2
3 or more 16+ Total = 16	9	1	5	1	12	1	3		8	1
2 persons 16+ 1 or both 60+ Total = 50	33	8	7	2	45	3	2		32	2
1 person 60+ Total = 8	6	1	1		7		1		4	
1 person 75+ Total = 12	9	2	1		11	1			8	1
Total = % Base = 102	66	17	16	3	86	9	7		60	7

TABLE 7

Household Alterations and Additional Expenses Directly Attributable to Disability

	No alterations or extra expense	Structural alterations	Extra heating costs	Extra telephone costs	Extra maintainance bills	Extra lighting costs	Other household expense	No extra household expenses
1 person aged 16-59 Total = 2	2		1		1			
2 persons aged 16-59 Total = 6	6		2	1				4
Youngest person 0-15 Total = 8	6	2	2	2				6
3 or more 16+ Total = 16	16		6	1			3	8
2 persons 16+ one or both 60+ Total = 50	44	6	13	8				36
1 person 60+ Total = 8	8		1			1	1	5
1 person 75+ Total = 12	12		2	2			1	9
Total ~~=~~ % (Base = 102)	94	8	27	14	1	1	5	68

TABLE 8

Relative Importance of Sight Difficulties to the Visually Disabled

Self-identified problem	Visual Acuity (Snellen)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total %
Sight presented as main problem	10	8	1	2	5	5	7	3	3	44
Sight mentioned as secondary problem	3	0	0	1	3	1	1	0	3	12
No mention of poor sight	12	16	10	1	0	2	3	0	2	46
Total % (Base = 102)	25	24	11	4	8	8	11	3	8	102

TABLE 9

Disability and Employment Activity at Onset of Disability

(All who complained of sight difficulty)

Respondents claiming a difficulty in seeing to read or get about	Retired	Full-time work	Part-time work	Full-time education	House-wife	Armed Forces	Other	Total
Sigh presented as main problem	13	13	1	1	16	7	2	53
Sight mentioned as secondary problem	7	7	0	0	7	0	2	23
No mention of a sight problem	33	53	6	1	40	4	1	138
Total	53	73	7	2	63	11	5	214

TABLE 10

Effect of Disability on Earnings

Respondents claiming a difficulty in seeing to read or get about	Effect on earning capacity							
	Not in full-time work (housewife, retired etc)	No difference to earnings	Would still be in full time work	Earning more (same job)	Higher qualifications or bett r job	Pension from work	Higher pension Higher savings	Post retirement work
Sight presented as main problem	40	7	2	1	1	1	0	1
Sight mentioned as secondary problem	18	2	1	0	0	0	0	0
No mention of a sight problem	87	25	7	5	7	1	3	2
Total	145	34	10	6	8	2	3	3

TABLE 11

Mobility of the Visually Disabled

	Visual Acuity (Snellen)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total ⌒ %
Been out within previous week	17	15	9	3	5	7	9	2	3	70
Been out within previous month	3	2	1	1	2	0	2	1	0	12
Not outside within previous month										
Housebound by physical disability	5	4	0	0	0	0	0	0	3	12
Frightened	0	1	0	0	1	0	0	0	0	2
No car available	0	1	0	0	0	0	0	0	0	1
No company available	0	0	1	0	0	0	0	0	0	1
No occasion to	0	1	0	0	0	1	0	0	0	2
No reply	0	0	0	0	0	0	0	0	2	2
Total ⌒ % (Base = 102)	25	24	11	4	8	8	11	3	8	102

TABLE 12

Aids to Mobility used by the Visually Disabled

Aids to travel	Visual Acuity (Snellen)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total %
Alone and unaided	23	22	9	2	4	5	5	1	3 3	74
Ordinary stick	1	1	2	2	0	3	2	2	0	13
Short white cane	0	0	0	0	1	0	0	0	0	1
Long white cane	0	0	0	0	2	0	1	0	1	4
Sighted guide	1	1	0	0	0	0	1	0	0	3
Guide + cane or stick	0	0	0	0	0	0	2	0	0	2
No reply (too ill to go out)	0	0	0	0	1	0	0	0	4	5
Total % (Base = 102)	25	24	11	4	8	8	11	3	8	102

TABLE 13

Social Service and Other Support of the Visually Disabled

Visited within past year	Visual Acuity (Snellen)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total %
By Home help	6	4	4	2	0	1	4	3	1	21
By Health visitor	3	1	0	0	0	1	1	0	3	9
By Home nurse	5	6	2	0	2	1	1	0	3	20
By Social worker	0	1	6	1	3	1	2	2	5	21
By Meals on wheels	3	4	0	0	0	2	0	0	0	9
By Bath attendant	0	1	0	0	0	0	0	1	0	2
Received no visits	18	16	2	2	4	4	4	0	2	52
(Base	25	24	11	4	8	8	11	3	8	102)

TABLE 14

Contact with Social Service and Other Agencies by Presenting Problem

Self identified problem	Visited with past year						
	By home help	By health visitor	By home nurse	By social worker	By meals-on-wheels	By bath attendant	Received no visits
Sight presented as main problem (total 44)	7	3	4	9	4	1	27
Sight mentioned as secondary problem (total 12)	4	3	3	5	0	0	4
No mention of poor sight (total 46)	10	3	13	7	5	1	21
Total = % Base = 102	21	9	20	21	9	2	52

TABLE 15

Contact with Medical Services

	Contact ever made					
	Ever consulted G.P.	Attended ophthalmic out-patients	Attended other department only	Admitted as inpatient	Still attending hospital	No medical contact for main disability
Sight presented as main problem (Total 44)	38	35	4	23	16	2
Sight presented as secondary problem (Total 12)	10	0	7	7	3	0
No mention of poor sight (Total 46)	41	2	24	15	5	3
Total ⩫ % Base = 102	89	37	35	45	24	5

TABLE 16

Aids used by the Visually Disabled for Distance Vision

Correction used for test	Visual Acuity (Snellen)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total ⟶ %
Special Distance Lenses	11	7	2	1	2	0	2			25
'Ordinary' Glasses	10	10	5	2	3	6	0			36
Bifocal Lenses	1	1	2	0	1	1	0			6
Contact Lenses	0	0	1	0	0	0	0			1
No Correction	2	6	1	1	2	1	7		2	22
Not Recorded	1	0	0	0	0	0	2	3	6	12
Total ⟶ %	25	24	11	4	8	8	11	3	8	102

TABLE 17

Aids used by the Visually Disabled for Near Vision

Correction used for test	'N' No on reading chart												
	5	6	8	10	12	14	18	24	36	48	Cannot see print	Not Recorded	Total ⌒ %
Special reading glasses	2	3	4	3	4	2	2	0	1	1	4	1	27
'Ordinary' glasses	0	1	4	4	6	3	4	2	3	0	9	0	36
Bifocal lenses	0	0	0	0	1	0	2	1	0	1	0	0	5
Contact lenses	0	0	0	0	0	1	0	0	0	0	0	0	1
No correction	0	1	1	2	2	1	0	2	1	1	7	1	19
Not recorded	0	0	0	0	0	1	0	0	0	0	0	13	14
Total ⌒ %	2	5	9	9	13	8	8	5	5	3	20	15	102
Magnifier or other low vision aid	0	1	1	1	1	2	2	1	0	0	1	1	11

TABLE 18

Corellation between Near and Distance Visual Acuity

Near Visual Acuity: 'N' number (Standard Reading Chart)	Distance Visual Acuity									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total
5	0	2	0	0	0	0	0			2
6	4	1	0	0	0	0	0			5
8	5	3	1	0	0	0	0			9
10	3	3	1	1	1	0	0			9
12	4	6	1	0	1	1	0			13
14	4	2	2	0	0	0	0			8
18	2	5	1	0	0	0	0			8
24	0	0	2	1	1	0	1			5
36	1	0	2	0	2	0	0			5
48	0	1	0	1	1	0	0			3
Cannot see print	2	1	1	1	2	7	6			20
Not Measured							4	3	8	15
Total ⟋ % (Base=102)	25	24	11	4	8	8	11	3	8	102

TABLE 19

Visually Disabled

Sourse of information resulting from record linkage

	Total ≏ %
Records obtained from eye specialist	42
Information on eyes/sight from G.P.	11
Information on eyes/sight from social services	4
G.P. confirmed no record eyes/sight available	14
Respondent refused permission to write to hospital	3
Respondent refused permission to write to G.P.	10
Permission not asked (proxy respondent)	3
Permission not asked (other reason)	6
No records traced at hospital	6
G.P. not traced	1
Linkage still awaited	2
Total	102

TABLE 20

Causes of Visual Disability

Principle Diagnosis Causing Sight Loss	Visual Acuity (Snellen - Home Measurement)									
	6/24	6/36	6/48	6/60	3/60	1/60	L.P.O.	No L.P.	Not Measured	Total ≐ %
Cataract	1	6	2	1	2	1	1	0	0	14
Macular Degen.	1	0	0	0	2	2	3	0	0	8
Glaucoma	0	1	0	0	1	0	1	1*	0	4
Diabetic Retinopathy	1	0	1	0	0	0	1	0	0	3
Myopia	0	0	1	1	0	1	0	0	0	3
Aphakia	2	1	0	0	0	0	0	0	0	3
Cong.Blindness	0	0	0	0	0	0	1	1	1	3
Retinal Detachment	1	1	1	0	0	0	0	0	0	3
Opticatrophy	0	0	0	0	0	0	1	0	0	1
Keratitis	0	0	0	1	0	0	0	0	0	1
Corneal Ulcer	1	0	0	0	0	0	0	0	0	1
Pan-uveitis	0	0	1	0	0	0	0	0	0	1
Eye Injury	0	0	0	0	1	0	0	0	0	1
Disseminated Choroiditis	0	0	0	0	0	0	1	0	0	1
Post 'Stroke'	1	0	0	0	0	0	0	0	0	1
Herpes Zoster	0	1	0	0	0	0	0	0	0	1
No Diagnosis on Record	1	1	1	0	0	0	0	0	0	3
No Records Obtained	16	13	4	1	2	4	2	1	7	50
Total ≐ %	25	24	11	4	8	8	11	3	8	102

*Congenital

TABLE 21

Comparison between distance Vision Sight Tests done at Home and Hospital

		Best visual acuity measured within two years at hospital	Visual acuity as measured at home							
			6/24	6/36	6/48	6/60	3/60	1/60 - L.P.O.	No Light Perception	Total
U.K. Partially Sighted		6/18 +	7	4	1					12
	W.H.O. Group 1	6/24		1	1		1			3
		6/36		1				1		2
		6/60			1	1		2		4
	2	3/60								
U.K. Blind	3	1/60						5		5
	4	L.P.O.						2		2
Total			7	6	3	1	1	10		28

APPENDIX A

DESIGN AND COVERAGE OF THE SURVEY

APPENDIX A

DESIGN AND COVERAGE OF THE SURVEY

The household survey, carried out by Social and Community Planning Research (S.C.P.R.) for the Centre for Socio-Legal Studies was initially planned to include 15,000 households. This number was necessary to provide enough 'cases' among smaller sub-groups (e.g. road accident or industrial injury victims) for subsequent detailed follow-up, but to limit costs fairly tight clustering had to be achieved. The 'design effect' which any clustering (etc.) imposes when compared to a simple random plan, has not yet been finally calculated for the survey so estimates of prevalence etc. are not now quite as precise as they may in future be. However, steps were taken to mitigate the influence of tight clustering by careful stratification using nationally known data on socio-economic grouping, urban/rural and regional population groupings and by comparing the results of the survey at each stage (pilot, 1st and 2nd stages) with data from other surveys. The sampling units were private households clustered within polling districts randomly selected within the probability constraints of the stratification - private households being defined broadly as all households not containing more than three boarders. The actual households were selected by choosing a name at random from the electoral roll of a randomly selected ward, and the following 157 names to give approximately 75 households interviewed in each of 200 'cluster points' - electors per household averaging approximately 2.1:1. Interviewers were instructed also to approach unlisted addresses which intervened in a sequence of listed addresses. By using peoples' names rather than addresses to select households a small systematic bias towards polling districts with larger than average number of named electors per address was eliminated.

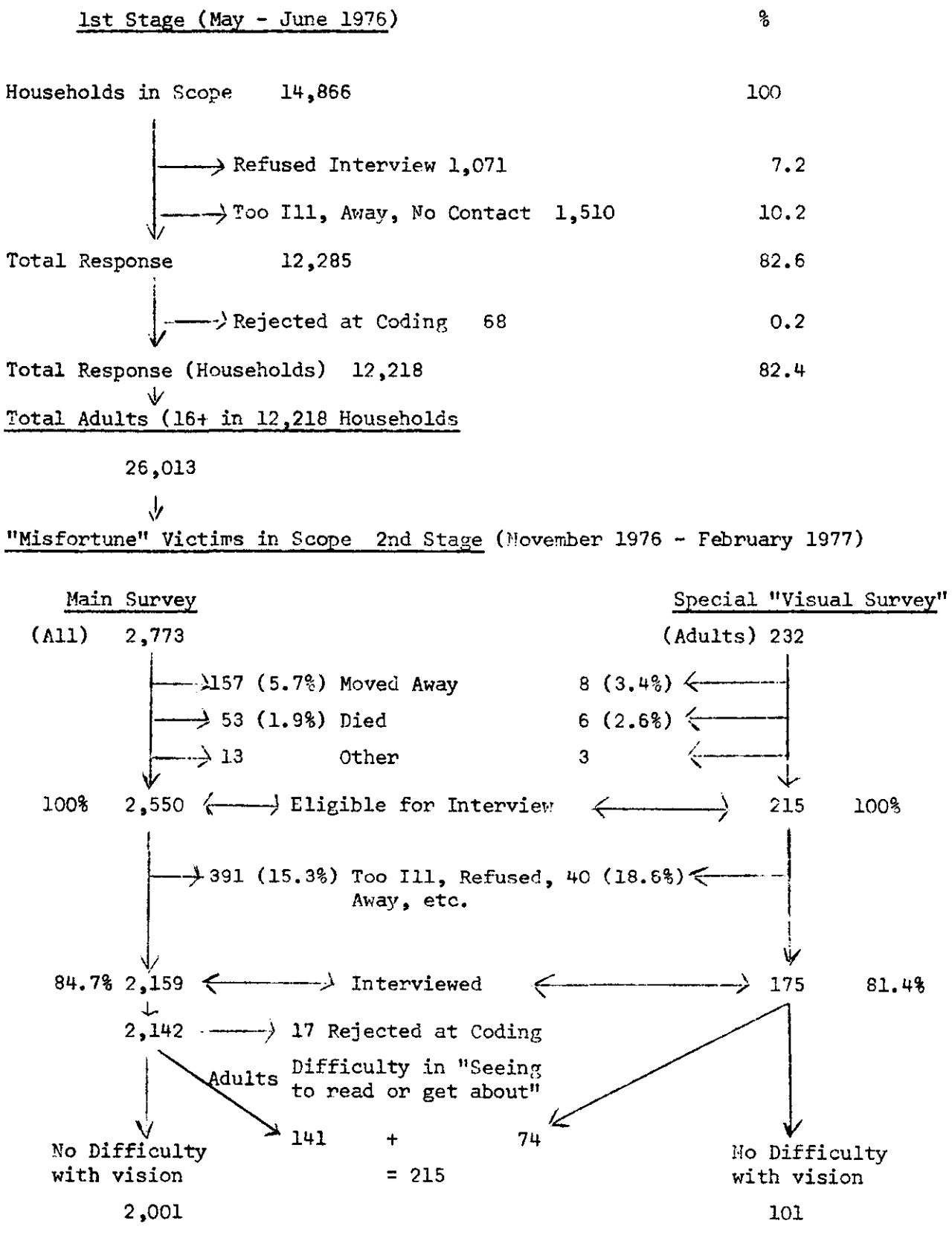
There is no reason to suppose from a study of the characteristics of the polling districts in which the finally achieved (Stage 2) response rates were lower than the average that there was anything about them that might affect final estimates of the prevalence of visual disability (basically, that they were districts with an abnormally high proportion of elderly people). However, one of the three sets of premises where access was refused (by the warden) was a sheltered housing development for the elderly - this may result in a slight downward bias to the final estimate of prevalence. The other two sets were married quarters for the armed forces where entry was restricted on security grounds.

Figure A summarises the final coverage of the survey as far as it concerned adults who said they had some difficulty in "seeing to read or get about". The regional distribution of the households was comparable to the General Household Survey findings as was the distribution of adults and children, and men and women within the households. The only obvious point where slight bias might operate is in the relatively high percentage of adults (2.6%) included in the special "visual" sample who had died before interview could be achieved. This was higher than the 1.9% of all those suffering a misfortune. Similarly (not shown in the Figure) 2.3% of adults included in the "visual" sample were in hospital at the time of interview and only 0.7% of the main sample; the differences are doubtless explained by greater age and disabling illnesses.

Finally it will be seen from Figure A that 101 adults originally included in the "visual" sample denied on requestioning in Stage 2 that they had any difficulty at all in "seeing to read or get about". Their original inclusion in the sample was due to a misunderstanding in the Stage I coding - it does not affect final estimates in any way.

FIGURE A

COVERAGE OF NATIONAL SURVEY (ENGLAND & WALES)



APPENDIX B

ESTIMATES OF THE NUMBER OF VISUALLY DISABLED PEOPLE IN THE COMMUNITY

APPENDIX B

ESTIMATES OF THE NUMBER OF VISUALLY DISABLED PEOPLE IN THE COMMUNITY

Estimates of the number of adults (16 years +) in the community visually disabled in their own surroundings, according to the W.H.O. definition of 'visual impairment' (distance visual acuity in the better eye of less than 6/18 Snellen), are based on these assumptions:-

1. That the initial household survey sample included approximately the same age ranges as exist nationally. All the indications are that this is so, but the final analyses are not yet available.

2. That non-respondents in the survey, or those 'lost' to it between identification and assessment, compare in all respects with respondents. There is no reason to suppose any significant difference for non-respondents, but there may have been a slightly greater 'loss' of visually disabled people because of age and other illness than among all the respondents. This would tend to produce a slight understatement of the true prevalence of visual disability in the community.

Given these assumptions, it is estimated that there are approximately 520 adults per 100,000 adult home-based population who can apparently see no better than 6/24 (Snellen) in their home surroundings. When measured under better conditions in hospital clinics these numbers are reduced to about 300 per 100,000 adult population. About 80% of visually disabled people are in their retirement years and up to 40% have apparently never had a specialist eye assessment of their eye condition.

The blind register underestimates by at least 40% the number of adults who might be eligible for inclusion on grounds of acuity alone (excluding diminished fields) on home assessment but this figure falls to 30% - 35% when differences between home and hospital measurements are taken into account. No similar estimate can be made of the inaccuracy of the Partial Sight register because of very varied registration practices in different parts of the country. Underestimation is not, however, likely to be less than the blind register and is probably greater.

APPENDIX C

NATIONAL SURVEY OF MISFORTUNES

STAGE II

Questions asked of those claiming difficulty in seeing to read or get about at Stage I or, on rescreening, in Stage II.

Record No. (1-4)
Card 06 (5-6)
P.423 (7-9)

PART 5 VISUAL HANDICAP

			Col./ Code	Skip to
	ASK ALL EXCEPT PROXY RESPONDENTS. IF RESPONDENT IS A PROXY SKIP TO PART 6, Q.35		(10)	
2	Do you ever nowadays have any difficulty in seeing to read or in seeing to get about?	Yes	1	
		No	2	PART 6 Q.35
	ALL WHO EVER HAVE DIFFICULTY (YES AT Q.29)		(11)	
30.a	Are you registered as blind or partially sighted?	Registered as blind	1	
		Registered as partially sighted	2	
		Neither	3	
b	Because of your sight, do you normally use any aids to help you get about?		(12)	
		Yes	1	
		No	2	d)
	IF YES AT b)		Yes	No
	c) Do you normally use ..... READ OUT	A guide dog	1	2 (13)
		A sonic aid	1	2 (14)
	CODE YES OR NO FOR EACH.	A short white cane	1	2 (15)
		A long white cane	1	2 (16)
		An ordinary stick	1	2 (17)
		Another person to guide you	1	2 (18)
	ASK ALL WHO EVER HAVE DIFFICULTY		(19)	
	d) In a room during daytime, can you tell by the light where the windows are?	Yes	1	
		No	2	Q.33
31	ASK ALL WHO EVER HAVE DIFFICULTY (YES AT Q.29) BUT WHO CAN TELL BY THE LIGHT WHERE THE WINDOWS ARE. (YES AT Q.30d) IF RESPONDENT HAS GLASSES/CONTACT LENSES, THESE MUST BE WORN FOR THIS QUESTION. IF RESPONDENT HAS SEPARATE READING AND DISTANCE GLASSES, DISTANCE GLASSES MUST BE WORN.			
		Respondent wore for this question:	(20)	
		Special distance glasses	1	
		Ordinary glasses	2	
		Contact lenses	3	
		None of these	4	
a	HOLD UP SNELLEN CHART (LETTER CHART) 10 FEET FROM EYES OF RESPONDENT. Can you see this chart?		(21)	
		Yes	1	
		No	2	Q.32
	IF CAN SEE CHART		(22)	
	b) How far down can you read this chart?	Respondent illiterate	1	Q.33
		Respondent cannot read largest letter	2	Q.32
		Respondent can read all letters correctly down to line :-	(23-24)	
			60	
			36	
			24	
		RING APPROPRIATE NUMBERS	18	
			12	
			09	ASK
			06	Q.32,
			05	THEN
			04	GO TO
		(Respondent read whole chart correctly)	03	PART 6
	IF LOWEST LINE RESPONDENT CAN READ IS LINE 36 (ND) BRING CHART FORWARD 1½ FEET TO 8½ FEET FROM RESPONDENT'S EYES AND ASK:		(25)	
	c) Now can you read the next line down?	Next line (ZHV) read	1	
		Next line not read	2	

	Col./ Code	Skip to
CHECK ANSWER TO Q.31 IF RESPONDENT COULD READ DOWN TO LINE 9 OR LOWER ON THE SNELLEN LETTER CHART, SKIP TO PART 6,(Q.35) ALL OTHERS ASK Q.33		
ALL WHO COULD NOT TELL WHERE WINDOWS ARE (NO AT Q.30d)) OR WHO COULD NOT READ DOWN TO LINE 9 ON THE SNELLEN LETTER CHART	(31)	
33 a) Have you ever attended hospital for your eyes? — Yes	1	
No	2	Q.34
IF YES AT a)		
b) When did you last attend hospital for your eyes? (32-33)		
YEAR (WRITE IN) 1 9 _ _		
IF ANSWER TO b) IS 1966 OR EARLIER, SKIP TO Q.34		
ALL LAST ATTENDING HOSPITAL FOR THEIR EYES IN 1967 OR LATER		
c) We are working with Dr. Cullinan, a medical specialist on eyesight at the University of Kent. May Dr. Cullinan write in confidence to the eye specialist at the last hospital you attended?	(34)	
Yes - he may write	1	
No - he may not write	2	PART 6 Q.35
IF HE MAY WRITE, ASK d) - f)		
d) What was the last hospital you attended about your eyes? _____		
e) What was your address at that time? _____ _____		
MARRIED WOMEN ONLY		
f) Was your name then the same as it is now? IF NO What was it? — Same name	A	
Other name (WRITE IN) _____		
NOW SKIP TO PART 6, Q.35		

PART V

CONCLUSIONS AND DISCUSSION

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Traditionally the 'blind', invested with the special awe which society has always accorded them, have been treated as a single group for the purpose of sociological and epidemiological studies. Defined by their poor sight, it has too often provided for the observer a sufficient explanation for all their difficulties. Statutory definitions, and the listings they give rise to, have provided a convenient starting point for studies; studies which have tended to deal with only one age group, often excluding the elderly and old, or asked no questions that could not directly be related to poor sight and the social, psychological and physical problems which supposedly emanate from it. Such restricted questions naturally preclude any concept of the interaction of visual disability with other disabilities the sufferer may have, and the ascribing of all handicaps to the one disability, merely because it is of most interest to the researcher, has led to a popular picture of the visually disabled as a group perfect in all things save for a single flaw.

Both the Canterbury and the national study suggest that this will no longer do. While, certainly, in childhood or in working age poor vision may be the single disability that handicaps, it is people in their retirement years who account for more than three quarters of all the visually disabled living in the community, and for many of these other disabilities begin to intrude and sometimes to overwhelm. When asked to state freely what most troubled them less than half those with a visual disability said that poor sight was their greatest problem and hardly more than half mentioned it at all. Yet all said, on direct questioning, that they had at least some difficulty in seeing to read or get about. Admittedly most of those whose vision was so poor that they were eligible for registration as blind mentioned poor sight as a problem but one in ten, even of these, did not mention it at all.

None of this, of course, lessens the importance of the very real difficulties caused by poor vision - it merely serves to show that poor vision can no longer sensibly be considered in isolation, especially in a largely elderly population.

The second conclusion to be drawn from the study is that our present definitions of 'blind' and 'partially sighted' are but poor indicators of who may be in need of the help that they give access to. Neither the Canterbury nor the national study suggested that the difficulties in getting about or managing close work that could be confidently ascribed to poor vision correlated closely with measured visual acuity, either distant or near, and that there are many people in the community not presently eligible for registration who appear to have as many difficulties as those who are. Of course, the U.K. definition of 'blindness' has always recognised the weakness of visual acuity measurements as a sure guide to who may need statutory help but the escape clauses it provides relate solely to work opportunities and have nothing to do with the social and leisure enjoyments so important to the elderly. That there is a large range of visual achievement and visual needs among the registered blind has long been recognised (Gray and Todd, Alison Shaw) but because it is the fact of registration that has provided the starting point for the studies, similar needs among those with poor sight who are not registered have passed unnoticed. To the extent that it embraces this much wider group, the W.H.O. definition of 'visual impairment' (here disability) seems more useful, but it, and all definitions used in western societies, are logical only if distance visual acuity, together with some allowance for diminished visual fields, continues to be the only practical way of measuring visual disability for administrative purposes. Gray and Todd[31] showed how inefficient it is in describing where the difficulties of the very poorly sighted really lie and this must be even more so among the elderly visually disabled to whom near vision is of great importance. Genensky, in America[25] has suggested how a concept of near visual acuity as well as

visual fields might be combined with distance acuity to describe those most in need of help with their vision, but its application demands an ease of access to specialist services which certainly doesn't exist in this country at present. Nevertheless, if a system largely dependent on distance acuity is to continue to be used it seems logical to use a system such as the W.H.O. one, generous enough to include most of those with a near vision problem, rather than to exclude many of them as our current concepts of partial sight and blindness do.

The third major conclusion from the work is that poor sight, and the hardship it brings, is no longer the business only of the optician and the ophthalmic surgeon. Both the Canterbury survey and the national survey have shown that it is certainly within the competence of any trained social worker, health visitor or home nurse to administer simple non-intrusive tests which will give an indication of where help might be needed. These tests are not, and do not have to be, of the level of accuracy needed by opticians to prescribe or ophthalmologists to treat. But while for societal and psychological reasons these professionals lie outside the easy reach of many of the elderly and housebound who might benefit from their initial and continuing help, it is all the more important that those who are in contact should become familiar with the simple criteria on which action can be initiated. Over half those visually disabled who did not mention poor sight as a problem and so might not have taken action themselves, were visited during the preceding year by someone, social worker, health visitor or district nurse, capable of making a simple assessment of vision. Moreover, 90% of them had seen their family doctor about their major disability, and over half had been admitted to hospital for it - yet only a very small percentage (4%) had ever had a specialist eye assessment, unless they themselves considered poor sight their major problem. This is no more, of course, than Fenton and his colleagues found in the geriatric wards in Portsmouth[19] but the impression gained of a general medical profession both inside and outside the hospital either unaware or unmindful, of the possibility that poor eyesight may be contributing to the

difficulties faced by their disabled patients, is disturbing - especially when the tools for elementary assessment are so simple. The only drawback to the use by all involved in community care of the simple techniques needed to make an initial assessment of the distant and near visual acuity of all and any they may be caring for, is the possibility of raising hopes that cannot then be fulfilled, and of upsetting situations that may have taken years to stabilise. But the sensitivity to avoid such mistakes is part of the general, not the particular, training of the professional.

No firm conclusions can be drawn about the prevalence of the different conditions causing visual disability in the community because only half the visually disabled had ever had a specialist eye assessment; nor do further studies based either on registration data or hospital record studies promise anything more useful. Nevertheless, cataract as a diagnosis constantly appears at or near the top of every list and far outstrips all other forms of treatable sight threatening eye disease; it accounts for well over a quarter of all the visual disability of known cause in the community. It would, however, be easy to state that to operate on all cataracts that cause visual disability, given modern surgical and anaesthetic techniques, would be to make a profound difference to the number disabled by poor sight, without equally stressing that cataract remains the primary known cause of visual disability purely because the patients have been seen by specialists and decisions made not to operate. The basis on which such decisions were made, be it the patient's desire, the specialist's assessment of the importance of the disability to the patient, the backup support available to help postoperative adjustment, the presence of other conditions or whatever, was not within the scope of the survey. However, it is possible that had the surgeon known just how much worse the patient seemed to see at home than in the hospital, he might have had other data on which to decide, and Brennan and Knox[6] have shown that the operation rate for cataracts among elderly people varies greatly between regions.

It must be assumed that there remains a great deal of undiagnosed cataract among the elderly visually disabled on which no decisions have ever been made. For most of these, there can be no harm in at least finding it.

The purely optical difficulties which the visually disabled experienced in their own surroundings can only be surmised from the data in this report. It was concluded from the Canterbury data that correction and lighting as well as social and psychological attitudes probably accounted for much of the difference found between hospital and home measurement and the data from the national survey certainly reinforce this conclusion. In Canterbury, the visually disabled were not able to remember with any accuracy when last their lenses were checked and opticians' records showed how few had apparently been seen within 4 years. In the national survey there was great variability in what was available for performing the sight tests. Both findings, while not producing accurate quantitative data on which firm plans can be made, seem to point firmly to where a considerable amount might be accomplished in alleviating the day to day problems of visual disability. Domiciliary visits by opticians, prepared to advise on all aspects of optics including near as well as distance vision, and lighting, even where the patient is not housebound, could be very beneficial, but they will often be made as part of a general assessment where several disabilities co-exist and the optician must have the experience to appreciate this. They would most logically occur after specialist ophthalmic assessment either in the home or in the hospital and after treatment is complete - all those with a visual disability as defined can be assumed to be suffering from a pathological eye condition for which specialist assessment is needed. However, no specialist advice, optical or ophthalmic, need necessarily inhibit the simple experiments that any family doctor, social worker or home nurse can make, with the patient, by altering the lighting of the room or trying the effect of a hand held magnifying glass. No harm, and much good, can come from this as long as there is no preconceived notion of what should or should not be, other than the disabled person's own perceived benefit.

One of the other effects of the national and Canterbury surveys has been to refine the tools a local authority might use to find the visually disabled, by means of survey. Much of the Canterbury report dealt with the effect that various traditional approaches and types of question had on the numbers of visually disabled (or handicapped) found in a community and the approach to the visually disabled used in the national survey was modelled on the conclusions drawn from these. Without repeating the arguments in detail it can be stated with fair confidence that:-

(a) no question, open or closed, directive or non-directive, can be used to estimate with any accuracy either distant or near visual acuity,

(b) the measurement of distant visual acuity is no accurate indication of near vision,

(c) the level of measured visual acuity, distant or near, provides no accurate guide to what can be achieved visually or to the extent of the handicap experienced - many can achieve with a little residual sight far more than others can do with considerably more.

It would seem, therefore, that the approach to any estimate of the visually disabled in a community must consist of a simple all-embracing initial question embracing concepts of both distant and near visual ability - such as "do you have any difficulty at all in seeing to read or seeing to get about?" - followed by simple tests of visual acuity, both distant and near. No intervening questions about how much can or cannot be seen, or about what is or is not done using sight are likely to be helpful and no form of self-reporting, study of registers, or of hospital records will achieve anything like an accurate result. How much the visual disability actually handicaps depends of course on how handicap is defined (visually, socially, psychologi-

cally etc.), but certainly it will not depend on whether registration has or has not occurred or whether the disabled person counts it as the greatest or least of his problems.

Inevitably studies such as this leave questions unanswered, and more work to do. This one is no exception, although it has gone some way to fulfilling its stated aim, to reconcile in an epidemiologist's statement the diverse views of the clinician and the sociologist. To complete this reconciliation more knowledge is needed, of the prevalence and the natural history of the diseases that cause poor sight in an ageing community and of the reasons why poorly sighted people apparently see less well in their own homes than they do in hospital. These are the directions in which further work is planned.

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