REPORT RESUMES

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RESEARCH IN BLINDNESS AND SEVERE VISUAL IMPAIRMENT, PROCEEDINGS OF THE SYMPOSIUM (NEW YORK, OCTOBER 19, 1963).

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ON OCTOBER 19, 1963, SPECIALISTS REPORTED THE FINDINGS OF STUDIES THEN UNDERWAY AND OUTLINED THE RESEARCH POSSIBILITIES WITHIN THEIR RESPECTIVE AGENCIES. QUESTIONS WERE RAISED ABOUT THE DEFINITION OF BLINDNESS FOR RESEARCH AND SERVICE PURPOSES. SPEAKERS DISCUSSED THE POSSIBLE USE OF SUCH DATA SOURCES AS STATEWIDE REGISTERS OF THE BLIND, THE INTERNATIONAL RESEARCH INFORMATION SERVICE ESTABLISHED BY THE AMERICAN FOUNDATION FOR THE BLIND IN 1960, AND THE REHABILITATION CODES PROJECT BEGUN IN 1956 THROUGH FUNDS FROM THE ASSOCIATION FOR THE AID OF CRIPPLED CHILDREN. TWO RESEARCH PROJECTS, THE NATIONAL HEALTH SURVEY SPECIAL STUDY OF VISUAL IMPAIRMENT 1963-1964 AND THE WAR-BLINDED VETERANS RESEARCH PROJECT, WERE DISCUSSED WHILE THE FINDINGS AND PROCEDURES OF A 1963 PILOT STUDY OF VISUAL IMPAIRMENT IN CLEVELAND WERE CONSIDERED IN DETAIL. THE RESEARCH IMPLICATIONS OF SEVERAL RECENT TECHNOLOGICAL ADVANCES WERE ALSO EXPLORED. (DF)

PROCEEDINGS OF THE SYMPOSIUM ON RESEARCH IN BLINDNESS AND SEVERE VISUAL IMPAIRMENT

MAY 1964

PROCEEDINGS OF THE SYMPOSIUM ON

RESEARCH IN BLINDNESS AND SEVERE VISUAL IMPAIRMENT

National Committee for Research in Ophthalmology and Blindness
New York, New York 19 October 1963

Chairman: Frank W. Newell, M.D., Secretary
National Committee on Research in
Ophthalmology

Moderator: Milton D. Graham, Department of
Research, American Foundation for
the Blind

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OPENING REMARKS

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I would like to make some remarks that arise out of the title of this Symposium: Research in Blindness and Severe Visual Impairment. We chose this title deliberately, very carefully, because it represents the considerable amount of thought that has gone into the question of defining blindness for research purposes and for service purposes. In our search for a more rational and a more meaningful definition of blindness many ophthalmologists have been involved, and some of us in the nonophthalmological sciences have been involved too. One such effort (unfortunately it has been discontinued) was made by a Workshop in the National Institute of Neurological Diseases and Blindness (NINDB) at the National Institutes of Health. This Workshop, on October 12, 1962, unanimously passed a resolution that reads as follows:

> "1. Blindness includes individuals with no light perception and those with no light projection;
>
> 2. Visual impairment of an advanced degree.
>
> Visual impairments may be influenced by a variety of motor, sensory, and psychologic factors which govern the performance of visual tasks and consequently may lead to visual disability.
>
> Visual impairments arise from interference with one or more of the visual functions" (4).

This resolution has many implications. I think none is more important than the fact that it requires a multidisciplinary approach. The central problem, as some of us in the Workshop saw, was not just the measurement of distance visual acuity, but the measurement of visual efficiency which requires several kinds of measurements. Let me say it another way. To those of us concerned with severely visually impaired people, the question is not merely what the patient's acuity actually is, but what he does with what sight he has. Some 90 percent of visually impaired people, it is estimated, do have some useful sight; visual efficiency thus becomes a very important matter. This puts the emphasis on performance: How does the patient use what vision he has? How does he function as a human being with his most important sense impaired? And so on.

These are questions that we nonophthalmologists can't answer without ophthalmologists' active participation. I think that this is the theme of our Symposium: How can we cooperate in a more meaningful way in the future?

The emphasis on performance is fairly recent; perhaps it has come from two now widely held premises: (1) that visual impairment (and I quote the above resolution) arises from "... a variety of motor, sensory and psychologic factors..." and (2) that some of the so-called sight-saving practices of the past do not necessarily protect eyes from damage. A comment has been made on this particularly in the field of education of children:

> "Little more than a decade ago, it was commonly believed that children with limited vision would damage their eyes if they used them to full extent for schoolwork. Special educators encountered relatively minor problems in selecting pupils believed to be in need of placement in special programs. These educators found that their practices tended to support the application to school programs of the accepted definition of 20/200. [Most state and federal laws pertaining to blind persons define blindness for various official purposes as a visual acuity in the better eye with best correction which does not exceed 20/200 or a defect in the visual field so that the widest diameter of vision subtends an angle no great than 20 degrees. The person with 20/200 visual acuity is able to recognize from a distance of twenty feet objects which those with average vision see at a distance of 200 feet. - Author's footnote]. Many applied this definition to education even though it had been developed primarily for use with adults in determining their eligibility for public assistance or for vocational rehabilitation. Similar experience was found with the visual acuity of 20/70 to 20/200 for children placed in special education programs for the partially seeing. As long as use of residual vision was believed to be associated with ocular damage, few educators or parents were concerned about the fact that many children selected <u>primarily</u> on the basis of their <u>visual acuity</u> and taught to read by means of braille, had enough vision to read print. Very few were concerned that many children placed in special programs for partially seeing students demonstrated the ability to read ordinary print with reasonable efficiency and appeared able to progress well in regular school programs"(3).

Outside of the field of education, there have been other fields that have been particularly interested in discussing the matter of visual efficiency -- the matter of performance.

With the emphasis on visual efficiency not acuity and on performance not static measurements, the question remains: Does this in any way change the role of the ophthalmologist? With these changes of emphases, does the role of the ophthalmologist need to be more clearly defined? Most importantly, can we in the other sciences contribute to a mutual attack with the ophthalmologist on the blinding eye diseases and matters of performance affected by severe visual impairment? We're not likely to answer any of these questions readily, but I think its worth raising them for purposes of discussion. We have had several points raised by ophthalmologists in the past. One of them I particularly draw your attention to: a well-known ophthalmologist recently said to a national meeting of workers for the blind:

> "A definition of blindness is complex and requires multiple subdivision. The definition of Hawaii is good but so complex that it would be most difficult for an agency to administer.
>
> "While our Workshop will continue to gather data, perhaps we could make some constructive statements.
>
> 1) Visual deficiencies from any cause should be made 'a compulsory reportable disorder.' The border line should be all cases that are based on driver's licensure cut-off point.
>
> 2) Ophthalmology societies should appoint a committee of all interested people to review the present definitions in light of present knowledge.
>
> 3) Educators should begin a longitudinal study of the children in schools for the visually handicapped.
>
> 4) All rehabilitation agencies for the blind should name a central group to work with the Department of Health, Education and Welfare and National Institutes of Health to gather data and settle misunderstandings. This could be a reactivation of the Committee on Central Statistics of the Blind.
>
> 5) Education of the practicing ophthalmologists by state agencies and national groups to give the best service for their patients" (1).

There also is a good statement on the same occasion made by the commentator of the papers of this Symposium:

> "I consider myself a special worker for the blind and so do most ophthalmologists. However most of our interests are directed to the prevention of loss of visual acuity and

the restoration of any loss through medicine, surgery, training and optics. I think I can speak for the profession and say we would in general lend our support and talents to a program of measuring visual and other characteristics on a more consistent, comprehensive and accurate basis if such data were to be used in the same accurate and constructive manner. We would certainly continue our interest and support in the improvement of visual efficiency. This we would do with continued effort in the clinic and the laboratory, as well as in our search for better optical devices, more knowledge in the use of color, etc. We shall also continue our support to education and training programs in the use of special methods, instruments and prosthetics. This is an area capable of rapid and productive expansion, e.g., in the training of the use of certain optical aids" (2).

In view of these remarks, I think we can ask ourselves what difference does all this make to the ophthalmologist? Can he help in a mutual effort to alleviate the effects of blindness and severe visual impairment? Can social science help him? Can the two work together? The following papers of this Symposium have kept these questions in mind. I hope that they will provoke discussion among ophthalmologists and nonophthalmologists alike.

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THE BLINDNESS REGISTER AS A RESEARCH TOOL

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Research is man's way of probing intelligently into the unknown for new knowledge. Whether the area of research be exploration of space, exploration of the ocean floor, or exploration of man himself, the prospect of finding meaningful answers is enhanced when the questions are meaningful and unambiguous, when the study design makes it possible to get relevant answers, when the collection of data is uniform, and when the data are reliable.

Every attack on a public health problem has as its ultimate goal the prevention and control of disease or impairment, but neither prevention nor control is possible without some evaluation first of the adequacy of community resources. This in turn depends on adequate, reliable knowledge of the magnitude of the problem; that is, precise information dealing with the number location, characteristics, and related information concerning the cases of disease or impairment in the community at any given time or developing during a given period.

Despite the fact that blindness (including severe vision impairment) is an impairment as old as history and despite the fact that the determination of visual acuity is relatively objective and easy to make, very little is known about the number of blind persons, their demographic characterists, and the causes of their blindness. In short, severe vision impairments which, depending upon the criteria for inclusion, would appear to affect from some 385,000 (6) to almost one million persons (10) in the United States have not been subjected to rigorous epidemiological investigation to arrive at causal or associational clues on the basis of the distribution of such persons by cause, age, sex, race, and other characteristics. That the blindness problem will not only remain but probably increase in size is mutely attested to by the fact that estimates of the blind population showed an increase of some 67 percent (6,9), during the period 1940 to 1960, as compared to an increase of 36 percent in the general population. The abovementioned estimates may not be too precise but do indicate crudely the trend in prevalence of blindness. A large part of the increase in blindness may be attributed to aging in the general population.

How to obtain needed information on the magnitude of the problem of blindness and the characteristics of the blind is a problem in itself. It is obvious that information dealing with this impairment could theoretically be collected by means of periodic surveys or through the operation of a routine reporting system.

A number of survey attempts have been made to get a national estimate of blindness. For eleven decennial censuses the Bureau of the Census tried vainly to get some picture of the magnitude of the problem on the basis of house-to-house enumerations. However, after the 1930 Census it concluded that "enumeration of the blind....has doubtless always been more or less inaccurate and incomplete" (1). This was no doubt, due to the problems of definition, personal judgment of the enumerators, and the tendency of respondents to conceal the presence of blindness in their relatives.

The National Health Survey of 1935-1936 attempted to arrive at a national estimate of blindness, but it, too, suffered from some of the same difficulties encountered in the census enumerations. Attempts to obtain statistics on the number of blind in the United States were made by the current U.S. National Health Survey during the period July 1957 through June 1958. With blindness defined as the "inability to read ordinary newsprint with glasses," the Survey arrived at an estimated prevalence of blindness of 960,000 persons or a rate of 5.7 per thousand population (7). The rate was far greater than rates produced by any census or by the 1935-1936 National Health Survey. This estimate of blindness prevalence is generally thought to exceed the number of blind according to the definition of economic blindness, viz. 20/200 visual acuity in the better eye with best correction (or an equally disabling loss of the visual field). Such overestimate is largely due to reliance on respondents' replies to a question embodying a rather crude definition of blindness. It should be mentioned that the term "prevalence" refers to the number of persons affected with a given disease or impairment in a community at a given time. Similarly, the term "incidence" refers to the number of new cases of such disease or impairment occurring during a given period of time in that community.

The current National Health Survey probably achieves a reasonable estimate of severe visual impairments rather than blindness as such. As a matter of fact, National Health Survey officials no longer refer to the definition as pertaining to "blindness" but rather to "severe visual impairments." The latest estimates (July 1959 through June 1961) of the National Health Survey indicate that approximately 988,000 persons in the United States suffer from severe visual impairments (10).

Periodic surveys of a representative sample of a population relate to attempts to secure information concerning the conditions, characteristics, or opinions of the population at specific points in time. This may entail interviews with specific households or respondents selected in advance by a sampling procedure adequate to the purposes of the survey. If medical conditions are being surveyed, it may, but often does not, include medical or ophthalmological examination on the specificed subsample. With a scientifically drawn sample the estimate of prevalence or incidence derived from the survey will be qualified by the error inherent in drawing a sample to represent that total population or universe. Thus by adequate survey sampling it is possible to state that the true prevalance or incidence for the universe falls within a given range based on the degree of confidence that it is desired to attach to the estimate.

The problems that enter into the derivation of an estimate of the prevalence of disease or impairment states in the community relate (a) to the drawing of an appropriate sample, (b) the actual finding and interviewing of such a sample, making provision for the substitution of households or individuals that fall into the sample but cannot be located, and (c) the elicitation of cooperation and reliable information from respondents. It is certain that in conditions such as blindness the respondent may not know that his condition falls within this category, or if he knows, may not be willing to admit it even to himself, much less to others. Where the criterion question in a survey relates to inability to read newspaper print even with the aid of glasses, a severely impaired person able to read with low vision aids only is apt to be missed. To the extent that such events happen survey prevalence is understated. To the extent that the survey picks up as severely impaired those individuals who are not blind or severely impaired but cannot read newspaper print with the aid of glasses for reasons other than visual impairment, the survey prevalence is overstated. It is quite unlikely that the extent of understatement balances that of overstatement.

Obviously the factors of memory loss, distortion, or changing conditions must be taken into account where the data are not based on recent examination. It is also obvious that in the ordinary house-to-house survey, any questions relating to impairment cannot be answered definitively in the absence of examination. Further, where a sample of respondents is called for examination, the bedridden, infirm, and institutionalized will be among the missing. Finally, surveys by their nature are time consuming and expensive. At best they furnish estimates that may be valid only for a particular time, place and population.

Routine reporting of all known cases of a given disease or impairment in a community to a register is another way of developing methods of prevention and control. Such reporting is usually of a mandatory nature. In the case of specified acute communicable diseases, the register makes it possible to take action so that the spread of disease is prevented.

Where the register is one dealing with chronic diseases, such as cancer, the reporting process may serve not only to insure the provision of services from the register agency to the patient but also to provide necessary statistics needed to plan and develop programs of prevention and control (2).

There are some 38 state-wide registers of the blind in this country. Each of these registers is maintained by a single state agency for the blind. Although the names and organizational structures of such agencies may differ from state to state, their functions remain fairly similar. In 28 of the above 38 states with registers, the registers are maintained by statute. In the 28 states with mandatory register laws, 8 also have another statute which makes the reporting of blindness mandatory. However, it might be mentioned that there are no good data to determine whether mandatory blindness reporting does in fact increase the completeness of reporting. Therefore, the best possible approach is to maintain a program of good liaison with professional reporting sources.

What are the advantages and what are the disadvantages of the register over the survey? A routine reporting system which constitutes the backbone of every register is an intricate part of a service program. Records of various types are kept in connection with every service program which are generally intended to facilitate service, and facilitate program planning and evaluation. A case register is one type of record system which readily lends itself to use in a dual capacity, both as an administrative tool in a service program and as a source of morbidity data (2).

In the field of blindness the eligibility of an individual for addition to a blindness register depends usually on the results of an ophthalmological examination which provides the history, visual measurements, cause of blindness, prognosis, and recommendations. This constitutes an official document that when approved by the state supervising ophthamologist makes available to the blind person services that he may desire. (Validation by professional examination of the visual status is something that is rarely, if ever, present in survey procedures.) Service is available for those who need and want it. Such service may be Aid to the Blind, Vocational Rehabilitation, Talking Books, Home Teaching, etc. There is no compulsion to accept service where it is not desired.

The register can be useful administratively in pinpointing specific hazards that cause blindness, and thus help to promote legislation for the control of such hazards as well as to set up programs of eduction, prevention, and control. In determining trends in caseloads, and hence in projecting the type and number of staff needed and in justifying budget needs, as well as in obtaining statistics to aid in program orientation, the register also serves specific administrative needs. In view of the fact that the uses of the blindness register as an administrative tool have been detailed elsewhere they will not be discussed further in this paper(4).

A register is a continuing mechanism and theoretically should reflect not only cases of legal blindness newly added to the register during a given period of time in the community, but also the number of legally blind in a community at a given time. If the assumption is made that new registrants are the newly blind, that there is fairly complete reporting, and that the cause data are reliable, then the register is extremely important in detecting rapid changes in incidence of blindness due to specific causes such as the chronic and degenerative diseases of old age - a consequence of our aging population. The newly blind person becomes newly registered ideally when the determination of blindness has been made on the basis of an eye examination and only when the case has been promptly referred to the state register agency. The register will also reflect changes in prevalence that may occur as a result of improvement in methods of sight restoration for specific causes of blindness and severe vision impairment (4).

The register is flexible in terms of the information to be requested on each new registrant. As the need for certain types of information not originally present on the eye report form is revealed, such information may be added to the printed form. Conversely, as the need for other types of information decreases, such information may be modified or dropped from the form. Finally, maintenance of the register is relatively inexpensive considering the uses that the register serves.

The possible disadvantages of a register relate mainly to the fact that individual state registers may not be geared to the production of uniform statistics from state to state. This is not really a disadvantage except where it is desired to compare data from state to state or to pool such data in order to arrive at national estimates. It is obvious that where states differ among themselves in the definition of blindness used for eligibility for admission to the register, in the type of data they request, and in the use of different classifications of causes of blindness and severe vision impairment (indeed, some states use no classification!), their register incidence and prevalence data are not comparable. Furthermore, when they differ in the extent of their updating and in whether or not they remove from the register fairly promptly persons who have died, who have had vision restored, who have moved out of state, or who cannot be located, there is no possibility of securing uniform statistics on register prevalence. Finally, there is no comparability among registers and their data when one state includes in its register only eligible cases that need or want services and another includes all eligibles whether or not service is to be provided. Service records alone cannot ordinarily be used as a source of information concerning the magnitude and nature of a community disease or impairment problem (2).

The register of known blind persons is a valuable <u>potential</u> source of statistics of blindness in 38 states. "But in only several of these states is the cooperation of physicians and of agencies serving the blind sufficient or the procedure of maintaining the register adequate, to give assurance that the count of names on the register does not give a quite misleading indication of the actual prevalence of the handicap" (6). In this type of operation there is no way of determining the error of underreporting except by making house-to-house surveys in communities with a valid, portable optical screener and then have those suspected of meeting the legal definition of blindness, or a random sample thereof, called in for ophthalmological examination. Comparison of results of such surveys with register data may give some idea of the number and characteristics of the legally blind who may be missing from the register. In this way it may be possible to pick up persons who satisfy the eligibility requirements for legal blindness but who have not been as yet so diagnosed as well as those who, having been so diagnosed, have not as yet been referred to the register agency. Again, however, the bedridden and institutionalized will be missing. On the other hand, unless a sample of those who are not picked up by the screener as meeting the definition are also examined ophthalmologically, it will not be possible to determine how many the screener itself misses. Therefore, the only practical solution is to continue efforts to get all reporting sources to register those that may be eligible for registration so that the unregistered eligibles represent a minimum of individuals. It is unlikely, because of the nature of the registration process, that nonblind are registered as blind except, of course, in error. Thus, it would seem that register prevalence is most often understated and rarely, if ever, overstated, unless updating of the register has been neglected.

The research value of a register is limited by the adequacy of the information it contains. There are some inherent problems in getting adequate cause of blindness data. In most cases a thorough ophthalmological examination together with a satisfactory history would be the best way of assigning a reliable diagnostic classification. In the event that the ophthalmologist is unable to examine the patient until the eye has been blind for a number of years, examination alone, in the absence of a satisfactory history may not lead to the determination of the initiating cause or mechanism. Because the eye is limited in the number of ways it can respond to insult, many types of visual disorders converge along the same final common pathway toward blindness and thus the accuracy of etiologic diagnosis is sometimes limited. If histories were more reliable some of this difficulty might be resolved but unfortunately such is not the case. Relief for problems of this type must lie in more effective education of the public by which the interval between onset of the severe vision impairment and the date of diagnosis is considerably reduced.

Delay in diagnosis is, of course, intimately related to delay in treatment. With ophthalmic disorders particularly, severe vision impairment and/or blindness may often be a direct (and sometimes abrupt) result of delayed treatment. It thus becomes evident that in such parts of the country where ophthalmological diagnostic and treatment resources are more sparse blindness might be more prevalent. These are also the locations where reporting of blind cases may be incomplete and where the ophthalmologist eventually observes the blind eye, long post-facto, with an inadequate supporting history. Thus, the circumstances that make for missed cases of blindness also make for inadequate reporting of those that are encountered. It would appear that an increase in the number of ophthalmologists and eye-ear-nose-and-throat specialists in certain areas of the country is one possible solution for inadequate coverage of the type mentioned. Even on a nationwide basis, there are currently 12,349 physicians with a specialty in ophthalmology (8) or 6.5 such physicians per 100,000 population.

The Model Reporting Area for Blindness Statistics developed under the sponsorship of the Biometrics Branch, National Institute of Neurological Diseases and Blindness (NINDB), and with the support of the American Foundation for the Blind, the National Society for the Prevention of Blindness, and the Division of Chronic Diseases, Public Health Service, constitutes at present a group of nine states with blindness registers. These states, acoounting for 14 percent of the United States population, have agreed to adopt certain standards that would improve the possibility of getting uniform, comparable data and that would permit interstate comparison of prevalence and incidence of blindness. In addition, the standards would enhance the possibility of arriving at national estimates of these magnitudes, and hopefully would stimulate the conduct of much-needed blindness research (4).

By adopting as a common definition of blindness the definition which has usually been accepted to denote economic blindness, the states have agreed to agree on the common denominator of the impairment being considered. Register incidence and prevalence will more nearly reflect true incidence and prevalence: (1) when complete reporting of the blind is achieved; (2) when all persons meeting the definition of blindness are included on the register regardless of age, race, need for service, or any other factor outside the definition; and (3) when the status of, and information on, all registrants is brought up to date annually. States in the Model Reporting Area have determined that longevity of the blind must be assured by some means other than by getting on a register that is never updated. By standardizing and classifying uniformly the recording of essential information on each new register addition, data on the causes of blindness and characteristics of the blind from different states can be more meaningfully compared or pooled. The data considered essential by the Model Reporting Area are relatively few and simple, yet they represent a good deal more than many states now routinely collect and tabulate. It should be mentioned that the National Society for the Prevention of Blindness has given great aid to this objective by developing a uniform eye report form, a Standard Classification of Causes of Blindness and Severe Vision Impairment, and by undertaking to train supervising ophthalmologists and their coding personnel in the use of this Classification. Finally, by Area states agreeing to prepare specified tabulations annually, the production of Model Reporting Area tabulations, as well as estimates for the country as a whole, is facilitated. These will be made available in published form to all those interested in the problems of blindness. It is clear that the states in the Model Reporting Area, by agreeing to common standards, have made possible not only the reality of comparability of data from state to state, but also that of comparability and replication in register research.

All Model Reporting Area states seek the fullest cooperation from ophthalmologists in order to get as complete reporting as possible. The complete, adequate, and routine reporting of all cases of blindness and severe vision impairment will not only greatly advance the cause of good statistics on blindness and severe vision impairment, but will be of great help in stimulating research studies. The data will be valuable in planning more intelligently programs of service, as well as those of prevention and control and will, of course, result in better and more accurate feedback of statistical data and explanatory text to the practicing ophthalmologist.

It is of interest to know in what way adherence to the standards of the Model Reporting Area can promote the possibility of undertaking meaningful research studies of register data. With the establishment of a common definition of blindness, comparable age/sex/race standardized incidence and prevalence rates for each state by cause, visual acuity, and other characteristics are possible. It is, of course, needless to mention that age, sex, and race specific rates also become available. Furthermore, similar rates may be computed by community and census tract, utilizing population data published by the United States Census Bureau for the decennial census. Trend information becomes more meaningful because it is based on common fundamental definitions which remain unchanged and on statistics which become comparable due to standardization procedures. For instance, good registers would lend themselves to studies of trends in incidence of blindness due to diabetic retinopathy, and the epidemiology of such incidence in relation to age, sex, and race, as well as to the age at onset of diabetes, type of treatment, etc. The comparison between trends in age/sex/race standardized incidence rates for diabetic retinopathy and for diabetes might furnish clues for more definitive, controlled studies of the determinants of diabetic retinopathy.

Although blindness statistics, classified by cause, would seem to be of great importance in assisting the allocation of research resources as well as in planning prevention programs, the fact should not be forgotten that blindness itself is not a disease but an end result or terminal stage of severe ocular disease processes or of injury. In view of the fact that a given disease may or may not result in blindness, the figures on the prevalence of blindness due to that disease do not reveal the prevalence of the disease in the population. Thus, the prevalence of blindness gives no measure of the prevalence of less severe ocular diseases which might nevertheless be sufficiently prevalent and morbid to warrant serious research attention.

The blindness registers in the Area states, by virtue of the fact that they are on punch cards in the great majority of states, become a universe of the blind from which random samples of cases and controls, on a stratified or other basis, may be drawn for research studies. Studies to test the effects of visual acuity, age, and other factors such as motivation and intelligence on visual performance may thus be encouraged. Hopefully, it may become possible to stimulate programs of measuring not only visual acuity but also what has been designated as visual versatility and visual capacity (5) so that research on the relationship between visual efficiency and performance may be more readily undertaken. It also becomes possible to select with ease appropriate subjects for studies of the effectiveness of low vision aids, studies of the problems for the blind in the adaptation to, and use of, sensory devices utilizing hearing or touch (3), etc.

The register is a most flexible medium for the collection and study of data for specific or for indefinite periods of time. It should be remembered that the number of items on a register card may be expanded or contracted as desired. It is hoped that in the near future it may be possible to include among the uniformly collected items recorded on each new addition to a Model Reporting Area register those items pertaining to hearing loss and other handicaps as well as to psychosocial characteristics such as occupation, education, marital status, etc. Although some of the states of the Area now routinely collect some or all of these items, agreement has not yet been reached on the need for reporting them for Model Reporting Area statistics.

In view of the fact that the Model Reporting Area standards require the annual updating of each registrant's status, it becomes somewhat easier to conduct cohort studies over time; that is, follow cohorts or groups of visually impaired persons stratified by such characteristics as age group, race, sex, visual acuity, and cause of blindness, in order to note their disposition, such as recovery of vision, death, etc. This information and the resultant recovery and death rates that are computed may be of interest to the ophthalmological profession. When register records are matched with death certificates in prospective or follow-up record-linked studies it is possible to secure data on life expectancy and causes of death for groups of blind persons by cause of blindness, visual acuity, age, sex, race, etc. A study of this type is under way cooperatively between the Massachusetts Division of the Blind, Massachusetts Office of Vital Statistics, and the Biometrics Branch, NINDB. In similar fashion, retrospective or follow-back record-linked studies may be made where register records of blind children are matched with birth certificates. Such matching will secure data that may be of value, for instance, in determining the relationship between the occurrence of blindness in children, of which the cause is diagnosed as hereditary, genetic, prenatal, or unknown, and specific complications in pregnancy, labor and delivery. At the present time such a study is under way on a cooperative basis between the New York State Commission for the Blind, New York State Health Department, New York City Health Department, and the Biometrics Branch, NINDB.

Follow-up studies of blind populations can furnish information that is at present sadly lacking, yet urgently needed namely, the incidence of acute and chronic disease states and of impairment of other sensory channels in a blind population. Information is not available at present concerning the risk of acquiring disease or additional impairment by such a population. Blindness agencies do not routinely receive or record on register cards information dealing with new disease or impairment beyond that recorded at the time of the original registration. Thus, special studies are needed.

The research needs of states will be better served when problems can be approached through register studies using uniformly collected data, thus making possible replication as well as comparability of research efforts from state to state. As soon as the membership in the Area appears to have greater representativeness of the country as a whole, geographically and demographically, it will be possible and desirable to make estimates of blindness nationally within the limits of error inherent in such procedure.

There is no question but that such problems as attaining uniformity in reporting, securing professional cooperation in the community, and other administrative problems pose their share of difficulties for states in the Model Reporting Area as they do for any group of political bodies that agree to relinquish some sovereignty in order to gain the benefits of union for a common cause. However, there is hardly a problem in such endeavor that can resist the strength of true dedication to its solution.

The value and meaningfulness of a blindness register depend largely on the completeness, accuracy, and reliability of its data, particularly those dealing with cause of blindness and visual acuity. In this connection the cooperation of the ophthalmologist is essential. Such data are of value not only in planning programs for clients needing service, but also in furnishing the administrator with information on all the legally blind that is needed for policy planning whether or not service is indicated. The scientist must have access to these data in order to conduct research designed to elucidate meaningful relationships pertaining to etiology and prevention. It is obvious, however, that confidentiality of the data must not be violated. One can and must serve both the causes of administration and of science without infringing on the client's privacy.

The administrator of a program of vision conservation must utilize any and all reliable data in order to arrive at a proper balance of resources and needs. The blindness register furnishes information that may assist him in setting up and evaluating certain types of prevention and control programs. In this respect the blindness register may serve as an invaluable research tool.

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THE INTERNATIONAL RESEARCH INFORMATION SERVICE

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It is not often the case, in research as in most other human endeavor, that we have the opportunity to second-guess ourselves. The opportunity is particularly meaningful when, as in our case, it arises after an exploratory investigation designed at one and the same time to amass old information and to establish ways in which new information can be used effectively. Our Department of Research now has been given this opportunity. We are grateful for the small respite it has given to consolidate our thinking, to plan rationally for the future, and to ensure the maximum usefulness of our efforts to those we intend to serve: the research community.

In 1960 the American Foundation for the Blind undertook a project entitled "An International Survey of Technical Devices Designed for the Education, Rehabilitation, and Personal Aid of Blind Persons." The title, as it turned out, was somewhat misleading. What might appear at first blush to be an international inventory of so-called "aids to the blind" quite quickly expanded to a compilation of efforts in research and development across a wide variety of disciplines in the physical sciences. Almost as quickly we became involved in gathering information over an equally broad front in basic research on the sensory processes. Yet this rapid expansion of scope and interest was not altogether unplanned and it may be useful to quote from that ancient project proposal text to illustrate what is meant. "The desired end result of this program," we said, "is:

(1) To analyze the results of existing and past avenues and basic premises on which technical research has been founded.

(2) To establish the avenues of the physical sciences through which research and development show the greatest potential for the material of technical devices for the assistance of the blind.

(3) To collect for purposes of dissemination to all present and future scientists and engineers a comprehensive library of existing research and technical devices with (insofar as possible)

objective evaluations of their respective merits and shortcomings.

(4) To provide for an intensive and concentrated exchange of scientific opinion and information through national and international symposiums and conferences.

(5) To provide a base for more effective coördination among all researchers, through a continuing system for collection, evaluation and dissemination of developments in the field, anywhere in the world."

As I was not a member of the committee which drew up this statement, I can admire freely the formulation of a program which met not only the immediate needs of the project, but also posed goals more ambitious than could be realized within its scope. Indeed we are just beginning, three years later, and with a good deal more experience behind us, to plan for meeting fully some of these original objectives.

The International Survey was also responsible for planning one major scientific conference, and the International Congress on Technology and Blindness was held in New York City in June of 1962. The Proceedings of that Congress comprise four volumes: three of them are clothbound and contain papers from all four Panels of the Congress; the fourth volume is paper-bound, contains a fairly complete inventory of devices designed to ameliorate the consequences of visual impairment, and stands as a fair summing up of our knowledge of such things at the time of its completion (in February 1963).

Within the limits set by the manpower available, the time at our disposal, and the hard flame of reason, the Proceedings comprise a "state of the art" report on technological developments applied to the problems arising from sensory impairment, with a fairly heavy emphasis on the problems of visual impairment. Because the Congress represented one point in time when time was taken to pause, to reflect on progress, and to consider what steps might be taken (if any) to multiply our effectiveness, I should like to comment further on the goals of the International Survey and on the contribution of the Congress toward reaching them.

First, the papers in Panel I (Man-Machine Systems) and Panel II (Living Systems) of the Congress have gone far toward an adequate analysis of past and present avenues of research. In the Panel I papers some attention was also directed toward the premises upon which current and future efforts will depend. In Panel II we attempted something of an exploratory survey of sensory research; I shall have more to say on this in a moment.

Second, the avenues leading from applied research in the physical sciences to the actual accomplishment of devices for the assistance of the blind have now been reasonably well mapped out. Some of the papers in Panel IV (Adapted and Special Purpose Devices) did deal in fact with practical realizations of applied research and development activity of direct utility to the visually impaired. In our technologically-oriented culture, I have no doubt that further realizations will occur as a matter of course. I shall say a word later on the unhappy fate of such applications in the majority of cases.

Third, we have initiated a collection of documents containing descriptions and evaluations of research conducted in the past and currently under way.

Fourth, the Congress itself was the initial realization of an intent to promote exchange of scientific information through symposia and conferences. A series of these has been planned for the future (see below).

Fifth, the exchange of information crystallized by the Congress have provided one basis for more effectively coordinating exchange of data among members of the research community. In common with many other efforts in this direction, we have a very long way to go before we can satisfy everyone, but at least a start has been made.

I think you can agree with me that the ambition and the foresight contained in that original formulation of what our government colleagues call our 'mission' looked several years into the future. In spite of some strenuous efforts to meet the original goals, it might not be unfair to estimate that we have come, perhaps, only halfway toward their realization. Our immediate objective is of course to 'tie up loose ends' in these several categories; I shall spell out our distal objective as well.

The 'loose ends' can be found in each of the "progress reports" for the five statements of purpose in the original design of the predecessor project. Among the necessary remedial measures I would include the following. First, a more intensive effort to collate information from many sources on the essential nature of the sensory processes. The reason for this goes much deeper than a mere need for completeness or 'closure.' It is prompted, rather, by an hypothesis: that among other reasons for the failure of very refined and well-engineered innovations developed in the past and intended to alleviate the consequences of sensory impairment, the most important has been our lack of understanding of exactly what the device was intended to accomplish.

The field of development of sensory aids is strewn with the remains of devices which operated beautifully but which did not provide information a human being could utilize, or informed him of changes in his environment at too great a rate, or used a coding which he could not interpret in real time, and so on. No one knew what parameters of the visual or auditory or kinesthetic field were essential information and what parameters were redundant, which were stored until a time-bound field pattern was developed in memory, or which were used primarily in conjunction with data from other modalities concurrently. (I have not exhausted the possible combinations of information transfer here; my intention is only to show some possibilities.) The tutorial session on Vision in Panel II of the Congress was an attempt to redress this oversight, and the relatively large number of papers was meant to highlight some salient features of the visual process in the hope that it would stimulate cross-disciplinary thinking among the participants. (We think it has done this.) Less attention was paid to the equally enormous literature on audition in Panel II by our severely restricted scope of presentation (largely the limit of time); the papers presented were meant to be outstanding representatives of current research-oriented thinking in the field of audition.

One could make similar remarks about some other areas only touched upon in the meetings, including the construction of models of neurological behavior, models of sensory information processing in the brain, electroencephalographic research, and so on. Only the limitations of time prevented us from going much further into some rather fascinating boundary crossing to consider, for example, the influence of individual differences on perception, or the relationship of character and sensation, or the possibilities in what Dr. Grey Walter so felicitously described as the "feeling-hearing space" developed by feeding in selected data from the environment to simulate or supplement visual processes.

Second, the problem of the translation of advances in basic research into suitable hardware, or programs of action, or training procedures, or still other applications, was hardly considered - beyond the almost universal complaint that there is currently in this country no suitable vehicle for translation of laboratory "breadboard" devices to the research prototype stage and to actual line production. Surely there is need for better coordination of funding and management here, and we can note the need while admitting there is little we can do in our small effort to meet it. Yet there are other measures we can develop to help, including adequate surveys of markets, incidence and prevalence studies of the sensoriall-impaired subpopulations, attitudinal studies of usage and/or predispositions toward usage (or nonusage) of devices, and so forth.

These matters begin to lead us in directions we did not consider appropriate for inclusion in the Congress, namely an intense preoccupation with what might be called behavioral research, including sociological, demographic, social-psychological, and other studies. It will also involve us in the collection, and what the Europeans call the "rationalization," of statistics of sensory impairment: standardization of data-gathering methods, the format for data collection, procedures for handling data, and consistent concensus in the interpretation of such data.

Third, the collection of documents already amassed - and which multiplies quietly and unsupervised, in my office every day - is another loose end which, I pray, we shall never be able to tie up tightly. The explosion in scientific knowledge, which has provided us with more information in a decade than all we learned previously in a century insures a continuing flow of data which must be gathered together in meaningful ways. It is our responsibility in part to help interpret these data so that progress can build on fresh turns in knowledge. The chronic situation faced in all the sciences - of a cornucopia of knowledge from which flows an endless stream of new data, much of which stimulates further work, and so on in a geometric progression - does not, we know, guarantee now that we can schedule the moments when really fundamental reshuffling of knowledge into new patterns, characterized by a small number of assumptions and a tight, theoretical calculus (something akin, let us say, to the universal law of gravitation or the Lorenz-Fitzgerald contraction) will take place. What we can do, realistically and at the moment, is to organize our knowledge with a consistent and easily understood system which is open-ended, capable of handling large amounts of material, and adapted to future modification with automatic retrieval machinery.

Fourth, the summing-up provided by the Congress helped us to limn quite clearly those areas of research and application wherein we felt secure, those we knew needed much more work, and finally those which made us uneasily aware of areas to which we _should_ pay attention but didn't _want_ to because they involve so much complication and such painful thinking-out . Although we concur with our scientific colleagues in the prejudice that the best cross-disciplinary integration occurs within the skull of one man at a time, we also believe that national and international meetings of various kinds offer an unusual opportunity for stimulating new trends of thought and for lifting us all occasionally from the well-trod paths of thought to which we become committed in working alone and relatively isolated from one another. Such meetings are also, of course, the quickest way to transmit information within the research community; the presence of a face to which one attaches a theory is still one of the best guarantees that we will remember the theory, and dispute it, and allow ourselves to attack the data with a yet better solution. There is much yet to be accomplished in a series of meetings of rather more limited scope than the International Congress, meetings which are devoted to a small range of topics and which call together a small group of specialists (within or without the context of professional societies) for common consideration of unsolved issues in sensory research and applications.

Finally, we have much to do in implementing our desire to promote the most effective exchange among researchers of actual data and documents, to keep "current awareness" current in fact as it is in intent. We must also face up to the task of finishing what we have started in some spheres already. One of the more important examples of this is the collection of data on devices contained in Volume IV of the Proceedings of the International Congress. Without intending to spoil the plot, I can reveal that this volume contains information not only on devices drawn from every supplier available to us at the time, but also descriptions of "one-offs" and other laboratory or experimental devices which never saw the light of day for common use. The examples of such latter devices are at present only a partial representation of this class of devices and we believe it is not mere curiousity or mere historical interest which prompts our desire for completeness. Indeed, those of you not in a position to greet a steady flow of enthusiastic inventors might be amazed at the number of times one or another device is discovered, invented, or adapted, found unsuitable, dropped, and reinvented - over and over again. There are also very valuable historical materials, often buried in long Teutonic exegeses or multi-volumed autobiographies, which show not only that there is very little new under the sun, but moreover that some mistakes have a very long tradition.

We have not only not finished an inventory of hardware; we have hardly begun an inventory of techniques (that is, ways of doing simple tasks in everyday life, in one's job, and during one's recreation) which may obviate the need for a special aid or appliace or device. In this area there is a simply enormous literature, most of it diffuse, prolix, widely dispersed, poorly organized, often amateurish, usually poorly written. Yet there is a desperate need for a catalog of techniques for persons who cannot afford hardware, for the developing nations with little capital, to suit the temperament of those who wish as little impedimenta as possible, and so on. We have made a start in collating such knowledge, but our baby efforts will require more sustained efforts than those devoted to the problem so far if, even within five years, we can hope to present even a stripling youthful version for public consideration in printed form.

Helen Keller once said that "...While they were saying among themselves 'it could not be done,' it was done." I am also sure (though I have not eavesdropped) that any critic of our research activities during the past five years of life of the Division of Research has never said that we embraced problems or programs that were too small in scope! (It did seem to us involved in it at the time that the International Congress was a rather bigger bite than we could hope to chew.) Perhaps it has been only the luck of the amateur - and the kindly regard of Fate upon fools - which helped us avoid any really serious blunders.

These considerations undoubtedly played some role in our decision to provide a locus within the Division of Research for a complex pattern of activities tailored to do the work implicitly and explicitly described in the preceding sections. We have now given these activities a housing, a guarantee of minimum support, and a sponsor: the International Research Information Service. (The name is abbreviated to IRIS and we rather enjoy the ambiguity in connotation with descriptive anatomy, the Species plantarum, and an occasional fashion designer.)

The activities of IRIS center around a diversified publication program, a certain amount of administration and liaison work, some documentation research, and a modest amount of interpretative and explanatory writing. Perhaps it might help simplify explanation somewhat if we were to consider the former classification of 'loose ends' once again, this time from the point of view of ameliorative efforts directed toward tying them up, or at least strengthening the knots.

As a first step, we have taken the Research Bulletin of the Division of Research as the responsibility of IRIS. Formerly the Bulletin had been an occasional publication of theses or abstracts, reprints of papers printed elsewhere, and the like; it was under the general editorship of the Director of the Division of Research, Dr. Graham. While making this journal a more frequent publication, we intend to continue its evolution. The Bulletin will try to focus on one general area of research for each issue; it will range, issue by issue, over the whole front of research under way; it will feature reprinting of valuable papers from the past to jog our memory and stimulate our thinking; and it will provide an open forum for discussion of proposals for research interest. The contents of the Bulletin will also include some of the tutorial material needed for nonspecialists in sensory research, akin to the information on Vision in Panel II of the International Congress. We hope also to incorporate a quarterly or semi-annual progress report on current research in all the fields under our purview. Finally, it will contain occasional materials relative to the continuing cataloging operation for devices as these become available; data on techniques will be similarly treated.

To supplement the information in the Bulletin, a series of separate publications will try to keep us all informed of data at hand for our use. Among these publications will be special bibliographies, each dealing with a specific area of research and/or development (the first of these was prepared by Mr. J. K. Dupress of our staff, on mobility research, and is now available). Future bibliographies will deal with the areas of reading machine research, audition, information processing in the human being, and so on. Another publication series will attempt to bring together the sets of recommendations made in the past in many conferences, symposia, congresses, and the like, regarding research needed in the amelioration of sensory impairment - together with an estimate of what has been done to meet the recommendations and what remains to be done. I should also include here the series of "state of the art" reports on several subareas of sensory, behavioral, and technological research which will keep current our knowledge of advances in the field. Finally, we shall plan the publication of the proceedings of such conferences as we become involved in from time to time on special subareas of research; the first will be the papers to be presented at the Mobility Research Conference proposed for The Hague next year.

Another area of activity of IRIS will be the refinement of classification, coding, and retrieval schemes with which we can make more accessible a wide variety of data, from information on specific devices, aids, and appliances to fundamental research information. For dealing with the actual hardware of which we must keep track we have been fortunate indeed in obtaining the cooperation of the Royal National Institute for the Blind (RNIB) for the beginnings of a joint program to consolidate this information. A duplicate information file will be kept in New York of RNIB's data, while we in turn will supply the RNIB in London with copies of material in our files of research data. It is expected that in approximately two years a revised version of Volume IV of the Proceedings (the Catalog Appendix) will be published by the RNIB which will complete the gaps left in the present volume. The matter of techniques will be a joint concern of RNIB and AFB, and we hope to have more definite word on a method of collating this information to give you within a year or so.

Research data from the technological, physical science, behavioral science, some medical, and demographic/statistical areas will be the concern of IRIS. We had already initiated a classification and coding system based on the use of Uniterm-type coding, dictionary handbooks for the coding system, the Scan-Column Index of Dr. J. J. O'Connor (University of Pennsylvania) - and several filing cabinets - during the International Survey. The multiform problems of organization of the International Congress kept us from making very much progress in this direction until quite recently, when we were able once again to turn a portion of our time over to the task. It can be expected that within the present year we will have the coding and retrieval scheme operational, and it is hoped that several small documentation and retrieval experiments can be carried out soon thereafter. I regard the successful conduct of this effort as essential to the conduct of IRIS itself, for it is on the basis of coding and classification schemes that we can hope to exert some control over a constantly increasing pool of documents. The basic principle in our operation will be to keep information flowing to those who need it and can use it, rather than making any attempt merely to have 'complete' information at some central locus.

Finally, IRIS will be intimately involved in a series of international conferences, each devoted to some special subarea of research, and scheduled one year at a time ahead. The intention here is to provide that opportunity for face-to-face contact which seems to catalyze significant advances in research through mutual stimulation among specialists. We are engaged at the moment, in fact, with the first-stage arrangements for a conference on Mobility Research to be held at The Hague in August of 1964. Each conference will seek to report on the current stage of development of laboratory devices, exchange information across lines of thought and practice to the benefit of both groups, and consider the context within which research in that particular area takes place - including the prospects for development work, and the prospects for incorporation of new knowledge into training or other action programs.

You will infer from all this - and correctly so - that our fundamental bias is that the most chronic need in the development of new departures in the amelioration of sensory impairment is for information. We hope to ensure that the information we gather and then disseminate will be <u>useful</u> information by applying the same canons of rigor, parsimoniousness, and internal consistency as obtain in any scientific work, in whatever field of science. While recognizing and accepting the chronic and pressing needs for information and for reliable data in the many areas with which we deal, we intend to make haste slowly and to learn consciously how to do our job better as we become more experienced in doing it. Our confidence is based on the marvelous cooperation given us by the scientific community, and in an exciting range of talent and capability made available to us through its selfless and generous help.

IRIS starts with a responsibility for measuring up to the very high standards established by the participants to the International Congress, and by our many consultants and correspondents; we expect no less to be asked of us, and we expect to work no less than they to meet these standards. Indeed, there is no choice in this matter, for no less an effort is required of us all if we expect to advance our ability to ameliorate the consequences of visual and other sensory impairment in the foreseeable future.

THE IMPORTANCE OF THE REHABILITATION CODES PROJECT

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I should like to thank Dr. Goldstein for laying the groundwork for my own paper. If I had a blackboard I would put his data and Mr. Clark's data at the top of the board and our records at the bottom. Our project gets down to the need for records about the human being who has a problem, and from this point we have been gradually working upward toward diagnostic data.

Our project started out as a one-year survey. Now in its seventh year, the results of the project meet with the work described by Dr. Goldstein and Mr. Clark, with so many points of common interest that I am delighted to have the opportunity of explaining to you what it is that we have been trying to do with an approach quite different from that of many clinicians.

I should explain first that the Association for the Aid of Crippled Children is not a service agency -- in spite of its name -- but rather a foundation which gives awards of money to other programs carrying on basic research on the prevention of congenital anomalies of all kinds. But since basic research has not yet made possible the prevention of all congenital anomalies, nor even the possibility of correcting them all completely, the Association has periodically found itself concerned with "rehabilitation" -- that is, the effort to pick up the pieces for the individual who has survived the first onslaught of the problem and has to go on living with it.

In the early 1950's the Association financed a clinical program in the borough of Queens. The program consisted of setting up a diagnostic and evaluation facility for handicapped children of all kinds within the general hospital. The staff soon found that when a careful record of the case was reported to the family doctor, it was quite impossible to interpret to the parents which of the several problems ought to be taken care of first. Nor did it provide the everyday language for him to say what the implications of the diagnostic report might be. Worse still, the clinical staff found that there was confusion over their own terminology as used by professional personnel dealing with different aspects of the problems of the child and the family concerned. Even the United Cerebral Palsy Association and the American Academy of Cerebral Palsy were said to group different limbs under the terms diplegia and triplegia.

This problem of interprofessional communication and also communication among the professions, the family, and the community was brought to Mr. Leonard W. Mayo, the Executive Director of the Association. The clinical staff had already constituted themselves an informal committee who wrote to other agencies in the nation to enquire whether similar problems were being experienced elsewhere, so they were able to report to him that many agencies were concerned over the confusion in terms. There was a general lack of communication and liaison among the several agencies dealing with a single patient's case. Mr. Mayo called a meeting of representatives of the National Health Council to consider the problem. A group of these representatives eventually went with Mr. Mayo to Washington to find out whether or not some federal agency might look into the situation. In consulting with Miss Mary Switzer, Director of the (then) Office of Vocation Rehabilitation (OVR), the group discovered that no federal agency was authorized to use its funds for such a purpose. She asked the Association, in turn, to undertake the sponsorship of such a special research project for one year; and to house, administer and cofinance with the OVR an investigation of the problems which direct service agencies were experiencing in the area of communications. Among these problems were the following: were there internal problems in keeping and maintaining records? in sharing information? in making referrals? in follow-up? Was there a problem of interpreting information accompanying the patient at admission or sent to the referral agency at discharge? Were agencies sufficiently concerned with their community image to cooperate in arriving at some common definition and some common lines of communication for future use?

I was engaged to carry out this one-year investigation. Toward the end of that year I had visited over 200 agencies. I sat in on case conferences during which record forms were used and I collected as many of these forms as I could secure. Back in New York, I would try to consolidate these several forms into one, in an effort to see where they differed, and to develop them further into one form in which everything was covered which would prove significant in a patient's case. Fortunately I had just completed some 15 similar follow-up studies in the previous eight years; thus a number of case histories were already collected which I had studied from several different points of view. On these studies I could base my evaluation of the effectiveness of the record forms. As I studied the forms, I began to be extremely confused about how any communication at all was carried on between and among agencies: there was great variation among forms: their emphases varied from one to the next. To me there was but one focus for a patient's record and that was the current condition of the patient himself. The records I examined emphasized the therapy, the needs of the treatment environment, the professional person filling it out, the pathology (perhaps already long past). Nowhere did I find information about the person's accustomed living environment and status; his parents; where he grew up; his points of normalcy, his past achievements, his current capabilities, or his potential for development of other capabilities as compensation for his residual disability. The impression one received was that the professions were organized to treat a person as if he had never had life prior to his disabling experience, nor was he ever to return to his family and community and take up a life of his own again.

Since our original study had encompassed not only children but persons of all ages and all types of impairments, it seemed all the more important to evaluate not only the disability and the handicap but the person's potentials as well. That is, there should be an evaluation not only of what the person could no longer count on but also the "plus" factors that might help him build his new life. I undertook, therefore, to analyze some 28,000 case records gathered in earlier follow-up studies to find out what were the significant details which aided the person in using services or which impeded his cooperation with service agencies. This analysis formed the basis for the Rehabilitation Codes record keeping system.

As a result of this one-year investigation, we were asked to extend the project for an additional two-year period. During this extension we set down the classifications of information which an agency ought to consider in arriving at decisions for services to be given. One complication here was the voluminous amount of material collected during field work, hence we had to begin an assessment of how much detail one should retain in a case record. This motive prompted a six-month field testing stage in 1959-1960 and resulted in a further one-year extension of the study to permit evaluation of the field test recommendations for revision.

In 1961 a new three-year period began during which we were to attempt making the record-keeping structure operational through additional committee work and through a twelve-month field testing program. At present we are engaged in the field work of this phase of the project.

One unexpected development in our second year, 1958, was work on a descriptive Impairment Code. The informal Queens committee had long before writted to Mr. Eugene L. Hamilton, Chairman of the Surgeon General's Subcommittee on the Physical Impairment Code of the National Committee on Vital and Health Statistics. This committee had been set up around 1950 at the request of the World Health Organization (WHO), which had been looking forward to the 1958 revision of the International Statistical Classification (ISC). Every member of WHO had been asked to set up such a data gathering agency, and each national committee had been asked to study certain special problems. One of these problems was to replace the E and N Codes of the ISC. These are residual codes concerned with the extent of injury and the nature of the impairment. Other residual codes cover such items as admission to a hospital for vaccination, checking of a prosthesis, and so on. All of these point at least in the direction of ongoing services which are commonly called "rehabilitation." This was the basis of Mr. Hamilton's interest in our project; he has served from its start on the Advisory Committee.

I had also been referred to the Surgeon General's Subcommittee on the Physical Impairment Code. I had hoped that they would provide us with a complete Impairment Code, since we were already trying to describe it in terms of "course of the pathology," and "nature of the impairment," etc. The Subcommittee, which is composed of Division heads from the various agencies of the Department of Health, Education and Welfare (HEW) decided that it could not develop the kind of descriptive code that was called for. They proposed, instead, that our project take on this added responsibility. We agreed to do so in 1959, and appointed a number of subcommittees to cover the various areas of impairment. Representatives were drawn from HEW, the Veterans Administration, the Armed Forces, professional academies, national voluntary health and welfare agencies, and some outstanding direct service agencies.

Each subcommittee took as fundamental the concept of a human being living in a family and community, experiencing both normal and occasionally disruptive incidents in his total living context. Each also attempted to define normal function in its area of impairment before any attempt to describe impairment of normal function. This proved to be the most difficult task for every subcommittee, but once it was accomplished they could proceed consistently to describe impairment in terms of (a) absence or total loss of function, (b) measurable limitation of function, and (c) those unmeasurable dysfunctions shown by persons from one occasion to another. This pattern of development has been consistent for all the areas of impairment treated in our Codes.

The classification of information about an individual living within his family and his community is but part of the problem. While developing these record forms we faced also the problem of "serializing" the format so that code numbers could be entered in parallel columns which could be dated the day of examination and encoding. A serialized format permits comparison of status through a series of contacts, as for example from preservice through accustomed status, to discharge status, and throughout whatever follow-up period the staff might feel advisable until closure of the case record. A second serial form was developed for active service status which starts with the identification of the impairment, its underlying pathology and its etiology; a description of the resulting disability or limitation of function; and the handicap (i.e., the effects on the individual's accustomed or appropriate use of his total resources in his family and community context).

The kind of forms in use in agencies throughout the country have in the past often been taken over directly from some in-patient hospital program. They were thus geared to institutional needs rather than to the needs of a person living with a problem at the moment. The new forms take into account the fact that the patient has not died, but also that he has not recovered fully. They recognize that when his life is in danger he usually submits without question to the ministrations of the professions, but once safely past that point, still alive, he must himself participate fully in the recovery process. He must, in fact, do most of the actual work himself; no person can be rehabilitated against his will. Thus if parents do not understand why a child must exercise his eye muscles or wear his glasses once he is outside the clinic, it is impossible to make a prescription work; in a similar way, a person who has never been much of a reader may not feel the need to use a device to improve his reading skills. In rehabilitation the most important and critical factor is not the impairment involved, nor the severity of the pathology, nor the treatment institution or staff, but the individual who has the impairment. In spite of this our habit is to label a person by his pathology or his lost function, as when we call patients "CP's," "TB's" "amputees," "laryngects," and so on.

The Rehabilitation Codes' approach is based on the fundamental notion that an individual, in his total personality, in his existence, in his experience, and in his conception of his own role, is more influential for the recover process than the pathology or function lost: he is more than the sum of his assorted and accumulated infirmities, for he goes on living in terms of what he <u>can</u> do, not what he can<u>not</u> do.

How can we expect a person to live in this sense when all our services, our institutions, our professions, insist upon regarding him as only an "interesting vehicle of a fascinating pathology"? If we label a group of people as "the blind" we are assuming that each person within the group is exactly like every other -- yet each is different, for in fact the only thing that they may possibly have in common is something that they can<u>not</u> do! Of course we are stereotyping when we label people in this way, but then we often proceed from this assumption to the conclusion that they can all be helped in exactly the same way; that they all have exactly the same needs; and that if programs are set up to handle the group problem, no individual problems will remain. Such labeling libels an individual's identity, all his potentials, and his normal functions. In some cases it may bar him from doing things he might well do for himself otherwise -- including taking a productive role in his group.

Record keeping with the Rehabilitation Codes reverses this process, but it is often difficult to get this point over at once to agency staff. In starting some of our field testing, for example, the staff took up the matter of classification of "community accpetance." When this was listed not as an asset but as a handicap, we call it "community nonacceptance." The response of the staff was, "Oh yes, but the patient gets along fine here - we all like him, and he takes an active role in all our programs." I must then explain what we mean, including the answers to such questions as: Does he have a social role in his community? Do his employer and he get along well together? Does he get along well with his workmates? Does he have a group of peers among whom he plays an active role? I explain that in the treatment institution, the total complex of professional personnel, therapy, and the institution itself, are together the abnormality, which takes the patient out of the general flow of life during a period when he needs specialized help. If we evaluate his responses inside the institution, without considering that he is not going to remain there forever, we are missing the important point that he has an independent status and function in his family and community.

The question must then arise, inevitably, as to whether the patient is created for the professional personnel in institutions to work on, or are the professions and institutions set up to help the individual when he needs help?

We have found it important, therefore, to exphasize first a person's normalcy, his usual way of life, his family resources, and his community role. We must know, in detail, not just what help is needed, but what the person can do to help himself. Most persons who suffer an impairment do not even come to the attention of professionals; they rehabilitate themselves with resources immediately available to them.

It is also true that living with residual disability which can be remedied unnecessarily handicaps a person's full contribution and productivity. Physical restoration is thus the first step to take whenever possible. Yet many disabled persons do not get the primary clinical services they should get. This is due in part to the stereotyping through arbitrary labels in the minds of professionals and lay public alike. This is one reason we agreed to develop the Impairment Codes to describe current function regardless of underlying pathology or etiology. It has been an impressive experience for me to hear a group composed of eminent ophthalmologists, internists, nationally known program directors, research optometrists, and government agency staff, discuss not just what diagnosis was appropriate in a case, but also how it is that some patients manage to do things their diagnoses imply are impossible. Of course we often really do not seem to know what clues a person uses even when he is <u>un</u>impaired and carrying on the ordinary activities of his day. How much less we know of the people who get around with no vision at all, or who carry on activities with which some sighted people may have trouble!

In our Subcommittee on Impairment of Visual Function we started our studies with the first hours of the child's life, and we tried to spell out what normal development of visual function might be. Note that we did not entitle the Subcommittee as a group concerned with "impairment of vision," but with "visual function." We asked what should the single organ, then both organs together, be able to do? Our definition of blindness became very narrow: "...total impairment of function (i.e., absence or total loss) in both eyes." This represents an end point of a complete range of measured function with normal visual function at the other end. We included also impairment of visual field, of ocular motility, of binocular vision, and of color vision.

The Subcommittee has consisted of some 23 members; eight of these are ophthalmologists. It includes also representatives of federal and state government services for the blind, some directors of nationally known training institutions, and some members of national research and direct service voluntary agencies. We were also able to call on such resources as the United States Navy for a demonstration of equipment to test color vision when the question was raised of the usefulness of this equipment in persons having very low vision. We have drawn upon the well documented experience of the Armed Forces and the Veterans Administration. Finally, we have drawn upon the personal experience of a number of our own Subcommittee members who are totally blind or who have very low vision. We have aimed constantly at a synthesis of understanding from the points of view of these varied professional skills, and we have specified that the record form should include precise documentation of how a person is tested and not the test results alone.

In August of 1963 the American Center for Research in Blindness and Rehabilitation organized a two-day workshop for us to test the Impairment of Visual Function Code. It was attended by their own staff; members of the staffs of the Catholic Guild for All the Blind, and St. Paul's Rehabilitation Center; the Blinded Veteran's Association; the Massachusetts Institute of Technology; the American Foundation for the Blind; Bio-Dynamics, Inc.; the Massachusetts State Department of Education, Division of the Blind; and Dr. Richard E. Hoover of the Johns Hopkins Medical Institutions. Dr. Hoover brought with him case records which he had under review to serve as material to be coded. Two days of intensive use of the code resulted in a number of recommendations. The most pressing need was felt, however, for a clinical serial record form on which the examiner could enter his usual diagnostic findings and also the instrumentation of the test procedure.

Steps have been taken already to implement this recommendation by adapting our serial record form to this need; space is provided also for our own coded entries.

The examination findings from one to another date are entered in parallel columns in the serial record with the date heading each column. The form thus shows at a glance any changes in therapy or responses to therapy from one date to the next. Multiple impairments, of visual function or of any function, are coded in successive columns any number of which may be for the same date. Whether the pathology and etiology are related or not, this procedure permits listing a cluster of symptoms from one syndrome (such as diabetes). It also permits singling out the primary impairment from the syndrome and spelling out its disabling effects separately. Similarly, multiple impairments in the same person may be entered in priority order in successive columns even if their causes and etiologies are unrelated. The form is thus flexible and responsive to the needs of the eye examiner and physicians who may be cooperating in the case. At the same time the existence of other health problems can be coded whether or not they are the subject of past, present or future treatment.

Multiple impairments require a master punch card with a listing in order of priority of need for service. Each impairment is then coded on a separate punch card, and is cross-indexed to the master punch card and to those for other serial records, the Personal History, Active Service, and so forth, by means of the same identifying data. Thus any condition affecting the visual problem can be brought into focus as service proceeds.

Further committee study has resulted in additional refinement of the Impairment Code which will eventually be placed in field testing on the serial record form.

To conduct the field tests for Impairment of Visual Function we are following a pattern already established for the Communicative Disorders section of the Impairment Code. In 1962 we received a grant from the Communicative Disorders Training Program of the NINDB to hold a workshop on that section of the Code covering impairment of voice function, hearing function, speech function (articulation only), and language comprehension and use. This grant was later extended to provide four years' additional and continuous field testing of the Code and five workshops. The first workshop will be confined to the section on impairment of language comprehension and use (the least fully worked out, especially for childhood and developmental problems). This is scheduled for January 1964. Four regional workshops will carry the Code material to potential users in the field, including directors of state services, academic training programs, and voluntary direct service agencies. These workshops will be regional in a geographic sense only, since they are aimed at persons in the position to influence policy and curriculum as much as case record keeping.

In our Subcommittee on Impairment of Visual Function Code, we have benefitted over a four-year period from participation by seven members who also were members of Dr. Braley's NINDB Workshop on Definition of Blindness. When Dr. Braley's committee did not apply to NINDB for a second year's work, one of our mutual members, Dr. P. J. Leinfelder, cleared with Dr. Braley the idea that Rehabilitation Codes might continue to study our mutual problems. We would then apply to NINDB for a workshop and field testing program which could start with a joint meeting of representatives of both committees. The least we could hope for would be some agreement on continuation of a parallel program of field testing and regional workshops. The idea has been discussed with NINDB and has met with a not unfavorable response. We are now preparing an application to be submitted before the end of 1963.

The Braley committee assignment was to consider such definitions as those for "legal blindness," and "industrial blindness." Although that point of view is at an opposite pole from our own, we have every hope that useful recommendations will result from our multidisciplinary conference -- an approach which has been shown to be successful in our 1962 Communicative Disorders Workshop and in our own Subcommittee work since April 1959. In any case our purposes are the same: to find some means of securing valid and significant data from accurately kept case records. This will allow assessment of the results of the services given; it may reveal unmet needs and thus help reduce to the minimum the costs of dependence and waste of our human resources. Only when consistent data are recorded regularly in the disparate programs at community, state, and federal level can data be merged to provide program planning and evaluation which will best meet the demands of an increasingly difficult situation. The number of persons who need help continues to grow, while the professional staff and the nation's resources cannot begin to keep pace with the needs. It is thus essential that we organize and utilize our resources more effectively. To do this we must have valid data based upon individual case records.

The past four years' experience has shown us that the Rehabilitation Codes Serial Record form is a basic tool for securing these consistent data. It has proved in actual use to be a basic training tool for staff in weighing the problems and assets an individual may have. The statistics obtained about him are essential, of course, but at the same time they are essentially a by-product of quality service carried out in terms of his own life. We know that attitudes in the community often hamper the resettlement of a disabled person, but we also know that these attitudes are too often found also among the workers for the disabled -- and among the disabled themselves.

Our record-keeping system attempts to mold attitudes by presenting individuals instead of stereotypes, by stressing assets and potentialities, by giving services to compensate for whatever liabilities individuals may have to live with. One might say the serial record permits keeping one's thumb on the pulse of the service process; it does this by establishing a base line at the first contact. Then, against this base line, successive comparable readings can be entered in parallel columns to provide visual and numerical "shorthand" clues to the trends in the response to service. Only by means of this kind of longitudinal case record can the effectiveness of services be assessed; only in this way can we reveal the needs for research and for further refinement of therapy, techniques, and aids. By computer evaluation of such records we can begin to secure clues also to an understanding of the behavior and performance of persons in spite of their liabilities (or, perhaps, because of them). With this kind of clue to guide us we may improve services and utilize both staff and resources more effectively.

Field Tests are now under way at the Perkins School for the Blind and at the American Center for Research in Blindness and Rehabilitation. Both organizations are using the Impairment Codes for Visual Function and for Hearing Function so that the clues from each can be cross-indexed. If the NINDB approves our application to continue these and other tests, and to present the code material to an ever-enlarging audience over the next four years, we may well end up with a refined record form useful to a wide variety of agencies. It would contain classifications of information to provide a corpus of knowledge about the daily lives of people with special sense impairments, and would serve equally as a research resource for both private and government programs.

I should like to end by returning to our basic activity - to bring to agencies and staff members, and to the disabled themselves, a deeper awareness that we are all a part of the general stream of life; that it is, after all, "normal" to get sick, to experience injury, to learn to live with reduced functions of various kinds (some of which may be correctable and some of which may not, some of which start at birth and some of which occur in adult life when the main period of learning may be over).

Workers for the blind appear to me, as an outsider, to be in a separate stream from workers in other types of impairment. "The blind" themselves, by statute and by service program, seem largely cut off or segregated out of the main life of the community.

This is the <u>ad hoc</u> way in which most of our services have grown. It is also the way in which most of our attitudes toward people-in-need have grown. We can only ask how appropriate and how effective it is now to carry over these old, penalizing, denigrating attitudes when our newer knowldege of human behavior permits us to demonstrate today the infinite capacity and adaptability of the individual who is given a chance to develop without the hindrance of warping social attitudes and conditions. We can also ask how realistic it is to continue to concentrate upon the abnormal to the exclusion of the many potential contributions such an individual might make through his own efforts, if we let down the barriers of "labels" and stereotypes and look at the person as a whole.

THE NATIONAL HEALTH SURVEY
SPECIAL STUDY ON VISUAL IMPAIRMENT 1963-64
and THE WAR-BLINDED VETERANS RESEARCH PROJECT

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I would like to draw your attention very briefly to two ongoing research projects which may be of interest to you. They are at the moment both within their first year of data collection and therefore not as definite in form as they might be.

The National Health Survey of the Public Health Service has been requested several times in the past to obtain estimates on blindness and severe visual impairment. As a result of several conferences with them over a period of time they have agreed to do this and have in fact been in the process of doing so since July 1, 1963. In the course of their normal household survey (which is a scientifically derived national sample) of households that are visited in the course of the year, an extensive questionnaire on all health conditions on all members of the household, health conditions, impairments, and so forth, is administered; as a subject of separate study, a supplementary questionnaire on visual conditions is being administered to those people who say that they have some problem with vision as indicated by any one of three questions. One is the old familiar question used for many years, "Can you see to read newspaper print with the help of glasses?" If the answer is No, a special questionnaire is then administered (1).

The collection of the special data on visual impairment started July 1, 1963 with the new fiscal year and will continue through June 30, 1964. The data collected over that period will take perhaps another six months to analyze after all the reports are in from the field. Probably it will be the end of 1965 before the report is published. Its importance should not be underestimated: it will be the first time we will have a survey of visual impairment based on a scientifically drawn representative national sample. This survey has one major disadvantage; it is a person's report on his own condition. This raises the question of how accurately a person can report his own visual impairment. Since the National Health Survey personnel and the Society for the Prevention of Blindness has been very interested in this question too, we have asked that some subjects who have reported their own conditions be taken for a clinical examination; then reported data and clinical data can be compared. No decision on this request has been made as yet. We hope this will be done.

The second project, which is large also, was started at the request of the Veterans Administration. The Department of Research of the American Foundation for the Blind was asked to undertake a survey of war-blinded veterans. This had been done previously by the Veterans Administration in 1952/1953 for some 3000 veterans by some 350 social workers. In planning our project we felt we needed more information than was gotten in that original survey - particularly much more extensive health information. Consequently, we give a general physical examination which is precoded for machine tabulation purposes. It is a product of a research group at Cornell Medical School. We use also the ophthalmological examination developed recently by the National Society for the Prevention of Blindness. The audiological examination is that used by the Veterans Administration. The remaining examinations include a health perception test (the Cornell Medical Index), and a psychosocial interview (2).

These individual examinations take a total of from four to six hours, depending on the complexity of the individual case. Men are called in to a VA outpatient clinic and are given the total battery of tests in a medical setting.

As a matter of interest, the ophthalmological examinations, at least in this group that we know about, are given by consultants called in for short periods of time; they do not refer to the records, know none of the background of the patient, and often don't take the time to refer to what does exist in the way of medical treatment records. In other clinics we've found devoted ophthalmologists who have followed individual cases over many years and they know the patient load as does no one else in the entire clinic. There seems to be great disparity from clinic to clinic and this perhaps reflects a national shortage of ophthalmologists.

We also find that there is a definite tendency not to prescribe low vision aids to patients who might benefit from them. Many of the ophthalmologists, it appears, don't have the latest knowledge on low vision aids. Also we do get too many "etiology unknown," and we have found one case of an ophthalmologist who thought that loss of sight from gunfire was not trauma. In general, however, it has been a straightforward matter with the ophthalmologists giving a great deal of interest to individual patients and setting the tone for the rest of the examination.

The data collection for this project will be finished about mid-1964, after which it will afford a wealth of data of importance to veteran and nonveteran blind populations alike.

REFERENCES

1. The basic and supplementary questionnaires are available from the U. S. National Health Survey, Public Health Service, Department of Health, Education, and Welfare, Washington 25, D. C.

2. The several parts of the complete protocol developed for this project may be obtained upon request from Mr. Robert Robinson, Blinded Veterans Research Project, Bender Building, Connecticut Avenue, Washington, D. C.

A PILOT STUDY OF VISUAL IMPAIRMENT

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This paper describes a study of visual impairment in Cleveland designed and conducted by the American Foundation for the Blind, in collaboration with Western Reserve University, during the winter and spring of 1963.*

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*This is a revised and extended version of my Symposium paper. The investigation was supported in part by Public Health Service Research Grant NB 04282-01, from the National Institute of Neurological Diseases and Blindness. Additional financial support for the study was provided by the Cleveland Foundation and by the American Foundation for the Blind. I wish at this time to express my great indebtedness to my three chief collaborators on the project, Prof. Marvin B. Sussman, Chairman of the Department of Sociology and Anthropology, Western Reserve University (under whose auspices the study was administered in Cleveland), Mr. Paul B. Sheatsley, and Mrs. Ann F. Brunswick -- respectively Eastern Representative and Study Director, National Opinion Research Center, University of Chicago (which was responsible for recruiting and training field staffs, collecting data, and drafting a preliminary analysis of findings on which this paper is based). The research was a joint undertaking in every sense of the phrase. I am also indebted to Mr. Seymour Sudman, Senior Study Director, and Mrs. Barbara Kimball, Area Field Supervisor -- both of NORC. Others who have offered valuable assistance and guidance at various stages of the project are Mr. Cleo B. Dolan, Executive Director, Cleveland Society for the Blind; Dr. Milton D. Graham, Director of the Department of Research, American Foundation for the Blind; Mr. Richard E. Onken, Research Assistant in the Department; Dr. Hyman Goldstein, Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness; Mr. Theodore D. Woolsey, Deputy Director, National Center for Health Statistics, U. S. Public Health Service; Miss Regina Loewenstein, Washington Heights Master Sample Survey, Columbia University School of Public Health and Administrative Medicine; and my secretary, Mrs. Edith DuVal, who is mainly responsible for the tabular presentations and for ensuring that this report has seen the light of day.

OBJECTIVES

The original suggestion for a community study of visual impairment came from the Cleveland Society for the Blind, the leading private organization concerned with the welfare of blind persons in metropolitan Cleveland. Like other agencies working with blind people throughout the country, the Cleveland Society has felt the lack of reliable information about the number and characteristics of blind persons, especially those who need but who do not presently receive medical and social services.

For its part, the American Foundation for the Blind independently had planned a comprehensive study of the physical, psychological, and sociological characteristics of a much broader group, the "visually impaired," in a large metropolitan area. An extremely diversified city in terms of industry, occupation, socioeconomic characteristics, age, and ethnic groups, Cleveland offered a suitable cross section of the population in which to conduct such a study. No less important, the idea of an impairment study received support from other leading health and welfare agencies (notably the Cleveland Welfare Federation), and Western Reserve University provided local auspices for our research.

In awarding us a research grant, however, the National Institute of Neurological Diseases and Blindness recommended that we narrow our objectives and restrict ourselves to a test of methods -- some of them unique -- which we proposed to use in a larger study. We therefore revised our plans and launched what amounted to a <u>pilot</u> study with the following primary aims:

First, to determine whether a telephone survey can effectively screen for visual impairment. That is, to what extent is a telephone sample representative -- or unrepresentative -- of households where visual impairment is present? Or put otherwise, will a telephone sample yield prevalence rates of visual impairment which are comparable to figures obtained by more traditional methods -- e.g., personally interviewing a sample of <u>all</u> households (telephone and nontelephone) as in the National Health Survey and most other household health studies?

Second, to discover whether telephone interviews produce reliable data regarding the presence of visual impairment, or whether there is underreporting of such conditions when results are compared with personal or face-to-face interviews.

Finally, to determine whether fairly reliable vision tests can be administered in homes by nonmedical interviewers -- their observations to be checked against medical records and, where necessary, clinical examinations of the same subjects.

In view of our stress on research methods, some caution must be exercised in looking at our findings regarding the prevalence and degree of visual impairment. While we have faith in our techniques, a more definitive epidemiological survey of this condition would require a far larger population sample than our pilot study permitted.

DEFINITIONS

Visual impairment is open to varying clinical, legal, and functional or behavioral definitions; consequently any study of persons with eye disorders must begin with some statement about the criteria used to identify them. Thus federal and state laws define blindness in order to determine eligibility for special education, vocational rehabilitation, financial aid, reading services, etc. In simple medical terms, legal blindness means anything less than 10 percent of "normal" vision.* According to best estimates, the prevalence of blindness in the United States is slightly more than two per thousand population -- yielding a total of nearly 400,000.** However, blindness as defined by law is arbitrary in the sense that it includes some persons who appear to function nearly as well as "normally" sighted persons and excludes others who are severely limited in physical mobility and activity because of trouble seeing. Therefore, in our pilot study we decided not to restrict ourselves to

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* In more clinical terms, legal blindness is usually defined as central visual acuity of 20/200 or less in the better eye, with correcting glasses; or central visual acuity of more than 20/200 if there is a defect in which the peripheral field has contracted to such an extent that the widest diameter of vision subtents an angular distance no greater than 20 degrees.

** Ralph G. Hurlin, "Estimated Prevalence of Blindness in the United States and in Individual States, 1960," The Sight-Saving Review, Vol. XXXII, No. 1 (Spring 1962). In this study Hurlin estimated rates of legal blindness for the states by drawing on the actual count of blind residents in North Carolina and by weighing three factors -- the proportion of the total state population aged 65 and over, the proportion nonwhite, and the infant death rate. Estimated rates were then applied to the population of states. Some variation was found among them, with Utah having the lowest rate (1.39 blind persons per thousand) and Hawaii having the highest (3.98 per thousand). In Ohio the rate was reported to be 1.94 per thousand. Hurlin's estimates have served as the primary source of information about the number of blind persons in the U. S. which in 1960 he estimated at 385,000.

the legally blind; rather, we adopted the functional criteria for studying visual impairment which have been employed by the National Health Survey. Defining "severe visual impairment" as inability to read ordinary newspaper print even with glasses, the Health Survey reports nearly a million severely impaired persons.* Our reason for including such cases is that an appreciable number of them are limited in daily activities and physical mobility precisely because of their impairment.

In addition, there are many more persons described by the National Health Survey as suffering from "other visual impairments" -- which includes those who are blind in one eye, or persons who have poor vision or trouble with seeing in one or both eyes but who can read ordinary newspaper print.** While we were primarily concerned with the severely impaired, we could not ignore those with moderate or slight impairments because (at least in theory) not all persons defined by law as blind fall into the Health Survey's definition of severe impairment -- for example, blind persons who for sustained periods of time can read ordinary newspaper print with optical aids. Some people with moderate visual impairment are also handicapped to the extent that their physical and social activities are limited -- hence our wish to include them.

In short, following the model of the National Health Survey, we interpreted "visual impairment" to include all persons who reported "serious trouble with seeing, even when wearing glasses" and "severe impairment" to include all persons who replied negatively to the question, "Can you see well enough to read ordinary newspaper print with glasses?"

PROCEDURES

In devising a strategy for locating cases of visual impair-

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* U. S. National Health Survey. Selected Impairments by etiology and activity limitation, United States, July 1959-June 1961. Washington; U. S. Department of Health, Education, and Welfare, Public Health Service, 1962. Basing its findings on interviews with a nationwide probability sample of 76,000 households (250,000 persons) the National Health Survey estimated that there were approximately 988,000 severely impaired persons in the U. S. (5.6 per thousand population).

** According to the National Health Survey, there were approximately 2,507,000 persons with "other" visual impairments (14.2 per thousand population). The total for all visual impairments is therefore about 3,494,000 (19.8 per thousand population).

ment, one of our basic assumptions was that a fairly large probability sample of households would be essential to determine the magnitude of the condition and provide a representative number of cases for detailed analysis. Without such a sample, we would have missed both the "hidden" or unknown blind and the far larger number of persons who are severely impaired but not blind as defined by law. In most states and large cities it is chiefly legally blind persons receiving public assistance or those getting special services (educational, vocational, recreational, etc.) who become known to and listed by public and private agencies. As a result, serious bias exists in such lists of blind persons, and we may assume that an important minority of the total legally blind population are unaccounted for. In Cleveland, for example, more than 2000 blind residents are known to the local Society for the Blind, but our pilot study suggests there may be at least half again as many blind persons who are unknown as such to local health and welfare agencies because the agencies have been unable to reach them, because they do not want or need to be reached, or because they do not know that they are blind. One of our aims was to test a method for getting information about this hidden element. As for the visually impaired who are not blind according to law, since no list or registration of such cases exists there was no way to reach them other than through a household sample.

In view of the relatively low prevalence of visual impairment and the large number of persons to be screened, a household sampling based entirely on personal visits would have been prohibitively expensive. An alternative approach and the one we followed was to rely chiefly but not exclusively on a telephone screening of households. This method is rapidly gaining in favor. Thus, a recent survey conducted by the California Department of Public Health shows that a considerable amount of health data can be obtained by means of telephone interviews and that with respect to validity, rate of return, and rate of completeness, the telephone method is as reliable as mail questionnaires or personal visits.*

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* Joseph R. Hochstim, "Comparison of Three Information-Gathering Strategies in a Population Study of Socio-Medical Variables," in American Statistical Association, Proceedings of the Social Statistics Section, 1962. Washington, 1962; and "Alternatives to Personal Interviewing" (a paper presented before the Annual Meeting of the American Association for Public Opinion Research, Lake George, New York, May 17, 1963). These papers report a comparison of three interviewing techniques (telephone, mail, and personal) in a health survey conducted by the California State Depart-

Sample Design

The National Opinion Research Center (NORC) selected a random sample of 3689 households from the March 1961 Cleveland Directory (the most recent available). To reduce field costs and simplify procedures, we limited our sample to the city of Cleveland. From every fifth column in the pages of this directory, the first seven consecutive listings were drawn into the sample. These names were then checked against the March 1962 Street Address Telephone Directory to identify the phone numbers of those with listed telephones. The total sample thus split into a telephone sample of 2778 households and a nonphone sample (including unlisted numbers) of 911 households. We assigned all of the telephone listings to NORC interviewers for screeing,* but for purposes of efficience we decided not personally to visit all nontelephone households in the sample and therefore drew a random subsample of approximately one-third (309) of them for screening purposes.

Screening for Visual Impairment

We used an identical screening questionnaire for both tele-

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ment of Public Health. An area probability sample of Alameda County, California was divided into three subsamples, and each was asked identical questions by means of the three interviewing strategies. The survey dealt with a fairly sensitive subject, cervical cytology, i.e., the Papanicolaou smear for early detection of cancer of the cervix. Comparing the three techniques, and particularly the telephone method with the personal interview, the author reports identical substantive findings and equally high rates of return, questionnaire completeness, and validity -- as confirmed by medical sources. On the other hand, the telephone interviews cost only half as much as the personal interviews.

* The actual telephoning was done by interviewers calling from their own homes and by teams of interviewers calling from a battery of phones which had been specially installed for us in an office on the Western Reserve University campus. Approximately 60 percent of all calls were made from this office, the remainder from interviewers' homes. No great differences were observed between the two interviewing procedures as far as completion rates and other measures of efficiency were concerned; however, the team operation permitted closer supervision of interviewers, and interviewers who had done interviewing both at home and in the office said they preferred the team arrangement.

phone households.* The questionnaire included an enumeration of all household members along with their age, sex, and usual activity (school, work, etc.); the occupation and education of the household head; the race of the respondent; and total family income. More importantly, the screening form also contained a check list of seven health items -- adapted from the National Health Survey -- for all household members. To be more specific, we asked whether anyone in the household had any of the following conditions:

1. Arthritis or rheumatism
2. Diabetes
3. Varicose veins
4. Serious trouble seeing, even when wearing glasses
5. Deafness or serious trouble hearing
6. Heart trouble or high blood pressure
7. Repeated trouble with back or spine
8. Any other ailments or conditions which have continued for a long time.

Interviewers obtained this information from any responsible household member over 16 years of age who was at home when they called or visited, and this respondent provided information for all persons living in the household. We presented the interview as a "survey of family health in Cleveland, sponsored by Western Reserve University," and at no time did we mention blindness or give any special emphasis to visual impairment.** This seemed a necessary precaution against the danger of overreporting if the respondent had become aware of our interest in eye disorders.

Personal Interviews

While our interest in visual impairment was concealed during

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* The questionnaire had been pretested by NORC in the New York metropolitan area in November 1962.

** Our plan to publicize the study as a Western Reserve University project and thereby increase the cooperation of prospective respondents was thwarted by a newspaper strike in Cleveland which did not end until after our screening operation was completed. Nevertheless, some publicity was obtained through the cooperation of a local television station and an abbreviated newspaper published during the strike period.

the screening phase of the study, we saw no need to camouflage the purpose of follow-up interviews. Consequently, letters were sent by Western Reserve University to all persons reported in the screening (either by themselves or by other family members) as having "serious trouble seeing." These letters mentioned our special interest in "the amount and kinds of visual impairments, or eye trouble, in the population" and requested the cooperation of all recipients. Shortly after the letters were mailed, NORC's field staff conducted intensive personal interviews, approximately an hour long, with all accessible visually impaired persons reported in the screening.* Our primary objective in these interviews was to obtain measures of the degree or severity of visual impairment. To achieve this objective, we asked for the respondent's personal appraisal of his "trouble seeing" and his answers to a four-item scale (which included reported ability to read newspaper print with glasses, recognize the features of familiar people when close enough, perceive moving objects, and -- if the first three items were answered negatively -- determine when a light is on or distinguish between night and day). Most important of all, our personal interviews included actual tests of central visual acuity.

To measure distance vision, we used the Good-Lite Company's electrically illuminated Visual Acuity Chart with a 10-foot Sloan letter card (see Figure 1) -- to allow for the probability that most households do not contain 20-foot living rooms. We standardized the distance at which this test was administered by equipping each chart with a 10-foot cord and instructing interviewers to extend the cord to full length between the subject and the chart.** To record near vision, we used the Lebensohn card at 14 inches for both the Snellen and Jaeger tests (see Figures 2 and 3). All tests measured best corrected vision, that is, subjects were asked to put on glasses if they used them. NORC's interviewers were trained in the use of these testing devices by an ophthalmologist recommended to us by the Ophthalmological Advisory Committee of the Cleveland Society for the Blind.

In addition to administering tests of visual acuity and

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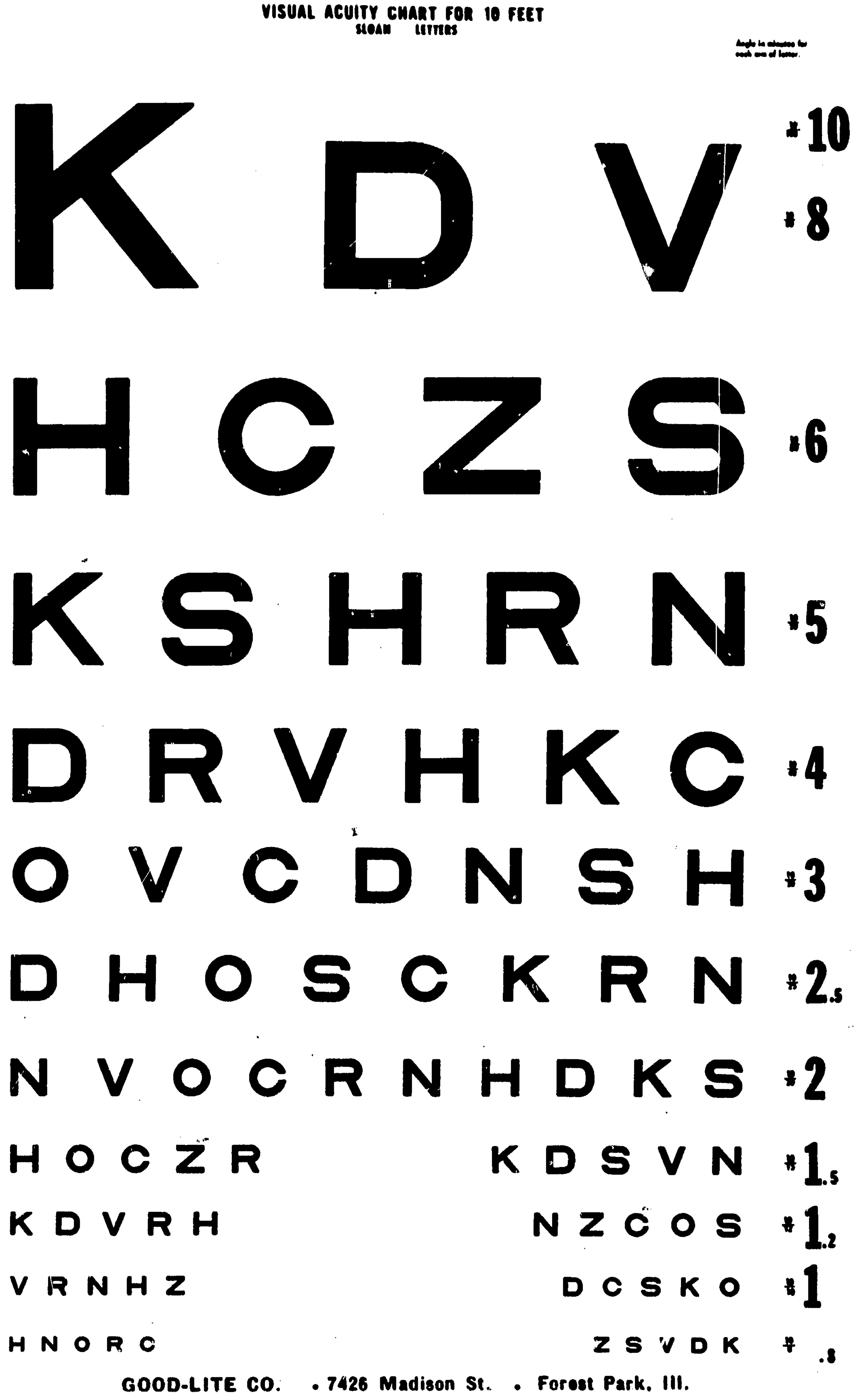
* Proxy respondents were used for children under 16 and for adults too ill to be interviewed.

** Respondents who turned out to be either illiterate or unfamiliar with the Roman alphabet were shown the so-called "Tumbled E" vision chart. This chart used no letters; instead it contains a figure resembling the letter "E" in various positions. Subjects are asked to tell the investigator the direction in which the figure's prongs are pointing. Acuity measures obtained with this chart are comparable to those derived from lettered charts.



VISUAL ACUITY CHART FOR 10 FEET
SLOAN LETTERS

Angle in minutes for each arm of letter.

K D V #10
#8

H C Z S #6

K S H R N #5

D R V H K C #4

O V C D N S H #3

D H O S C K R N #2.5

N V O C R N H D K S #2

H O C Z R K D S V N #1.5

K D V R H N Z C O S #1.2

V R N H Z D C S K O #1

H N O R C Z S V D K #.8

GOOD-LITE CO. • 7426 Madison St. • Forest Park, Ill.

Figure 1. Visual Acuity Chart - Sloan Letters (distance).

NEAR VISION TEST CHARTS

As designed by DR. JAMES E. LEBENSOHN,
Northwestern University Medical School, Chicago

The charts are to be read at 35 cm. (14 inches); (exactly 35.3 cm.; 13.9 in.) The reading visual acuity obtained from the miniature Snellen charts can be expressed in terms of distance equivalent, visual efficiency, or—as with corresponding distance charts—decimally, or in fractions. Thus "normal" reading visual acuity 1.0 can be recorded: 20/20 equivalent; 100% efficiency; 35/35; or 14/14;—reading visual acuity 0.8 as : 20/25 equivalent; 95.6% efficiency; 35/44; or 14/17. The adjoining test with point-type (Century Schoolbook) indicates what this means in practical reading ability. The left column therein is for illiterates who are simply to count the "crosses" in each group as in : oxxo oxoxx.

Decimal notation	Reading norm Cm.	Reading norm In.			Distance equivalent	Visual efficiency
0.025	1412	560	L	85	20/800	0.1%
0.050	706	280	F D	293	20/400	3.3%
0.075	471	187	E C T	8754	20/260	11.7%
0.1	353	140	L Z T D	63952	20/200	20.0%
0.2	176	70	F P	293	20/100	48.9%
0.3	118	47	T O Z	8754	20/65	66.8%
0.4	88	35	L P E D	[illegible]	20/50	76.5%
0.5	71	28	[illegible]	[illegible]	20/40	83.6%
0.6	59	23	[illegible]	[illegible]	20/30	91.4%
0.8	44	17	[illegible]	[illegible]	20/25	95.6%
1.0	35	14	[illegible]	[illegible]	20/20	100.0%
1.2	29	12	[illegible]	[illegible]	20/16	
1.5	24	9	[illegible]	[illegible]	20/13	

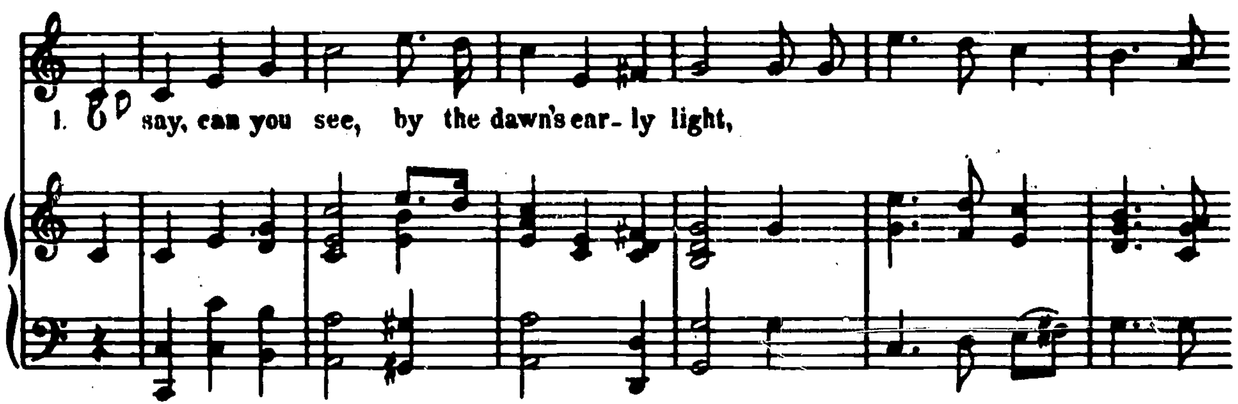
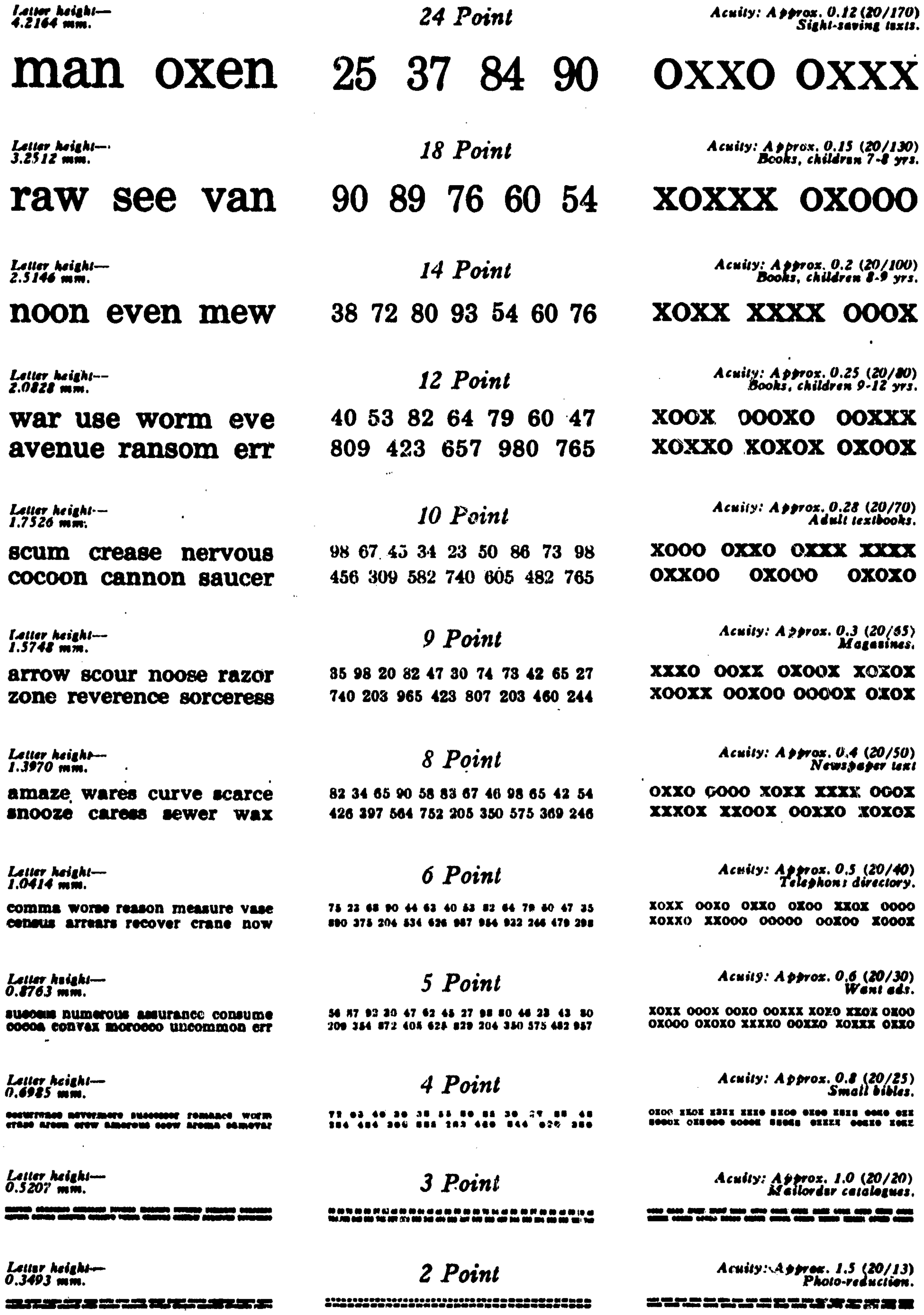



Figure 2. Visual Acuity Chart - Snellen (near). Available from Matalene Surgical Instruments Co., 125 East 46 Street, New York, New York.



Letter height— 4.2164 mm.
24 Point
Acuity: Approx. 0.12 (20/170) *Sight-saving texts.*

man oxen 25 37 84 90 OXXO OXXX

Letter height— 3.2512 mm.
18 Point
Acuity: Approx. 0.15 (20/130) *Books, children 7-8 yrs.*

raw see van 90 89 76 60 54 XOXXX OXOOO

Letter height— 2.5146 mm.
14 Point
Acuity: Approx. 0.2 (20/100) *Books, children 8-9 yrs.*

noon even mew 38 72 80 93 54 60 76 XOXX XXXX OOOX

Letter height— 2.0828 mm.
12 Point
Acuity: Approx. 0.25 (20/80) *Books, children 9-12 yrs.*

war use worm eve 40 53 82 64 79 60 47 XOOX OOOXO OOXXX
avenue ransom err 809 423 657 980 765 XOXXO XOXOX OXOOX

Letter height— 1.7526 mm.
10 Point
Acuity: Approx. 0.28 (20/70) *Adult textbooks.*

scum crease nervous 98 67 43 34 23 50 86 73 98 XOOO OXXO OXXX XXXX
cocoon cannon saucer 456 309 582 740 605 482 765 OXXOO OXOOO OXOXO

Letter height— 1.5748 mm.
9 Point
Acuity: Approx. 0.3 (20/65) *Magazines.*

arrow scour noose razor 35 98 20 82 47 30 74 73 42 65 27 XXXO OOXX OXOOX XOXOX
zone reverence sorceress 740 203 965 423 807 203 460 244 XOOXX OOXOO OOOOX OXOX

Letter height— 1.3970 mm.
8 Point
Acuity: Approx. 0.4 (20/50) *Newspaper text*

amaze wares curve scarce 82 34 65 90 58 83 67 46 98 65 42 54 OXXO OOOO XOXX XXXX OOOX
snooze caress sewer wax 426 397 564 752 205 350 575 369 246 XXXOX XXOOX OOXXO XOXOX

Letter height— 1.0414 mm.
6 Point
Acuity: Approx. 0.5 (20/40) *Telephone directory.*

comma worse reason measure vase 75 23 68 90 44 63 40 53 82 64 79 60 47 35 XOXX OOXO OXXO OXOO XXOX OOOO
census arrears recover crane now 890 375 204 534 626 987 954 932 246 479 298 XOXXO XXOOO OOOOO OOXOO XOOOX

Letter height— 0.8763 mm.
5 Point
Acuity: Approx. 0.6 (20/30) *Want ads.*

success numerous assurance consume 56 87 93 30 47 62 45 27 98 80 46 23 43 80 XOXX OOOX OOXO OOXXX XOXO XXOX OXOO
cocoa convex morocco uncommon err 209 384 872 405 628 829 204 350 575 482 957 OXOOO OXOXO XXXXO OOXXO XOXXX OXXO

Letter height— 0.6985 mm.
4 Point
Acuity: Approx. 0.8 (20/25) *Small bibles.*

Letter height— 0.5207 mm.
3 Point
Acuity: Approx. 1.0 (20/20) *Mailorder catalogues.*

Letter height— 0.3493 mm.
2 Point
Acuity: Approx. 1.5 (20/13) *Photo-reduction.*

Figure 3. Visual Acuity Chart - Jaeger (near). Available from Matalene Surgical Instruments Co., 125 East 46 Street, New York, New York.

asking respondents how they perceive their eye disorders, we questioned them at some length about the impact which visual impairment has had on their mobility and on daily activities -- work, housework, reading, recreation, etc. We also obtained information about their need for medical and social services (see Data from the Personal Interviews, below).

Validation of Vision Tests

In our personal interviews, all respondents were asked when they had last had their eyes examined by a physician. Those reporting an examination within the past three years were asked to sign releases authorizing us to approach their physicians for additional information. Respondents reporting that they had not received an eye examination within the past three years were invited to have clinical examinations -- at our expense -- by a local ophthalmologist recommended by the Ophthalmological Advisory Committee of the Cleveland Society for the Blind. These two sources -- reports from physicians who had examined our respondents in the recent past and new examinations -- provided data for checking results of our own vision tests. With the advice of the Society's Ophthalmological Advisory Committee, we developed a short form for recording clinical data (see Figure 4).* Physicians were asked for measurements of distance and near visual acuity and of the field of vision, along with brief diagnostic information about the primary and secondary conditions which had led to the impairment.

SCREENING RESULTS

Since our pilot study was designed chiefly to test research methods which we proposed to use in a larger investigation, we shall begin with an account of our sampling and screening experiences.

Completion Rates

In January and February 1963, NORC completed telephone screening interviews with 73 percent of the originally assigned household listings.** It turned out that a total of about one-eighth of the originally assigned listings were lost to

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* The model for this form was the "Physician's Report of Eye Examination" which is distributed by the National Society for the Prevention of Blindness.

** Of the remainder, 9 percent were "break-offs" or refusals, 7 percent were disconnected or discontinued numbers, 5 percent had moved with their telephones since the directory first appeared, 4 percent failed to answer after 5 calls, and 2 percent were unobtainable for miscellaneous reasons.

WESTERN RESERVE UNIVERSITY
Survey of Visual Impairment

REPORT OF EYE EXAMINATION

CONFIDENTIAL

I. Name of Patient________________________________

II. Measurements

A. Visual Acuity

	O.D.	O.S.	O.U.
1. Distant vision with best correction	________	________	________
2. Near vision with best correction	________	________	________

B. Field of Vision (Information on test of peripheral visual field is desired if visual acuity for either eye is better than 20/200.)

Greatest diameter of remaining visual field (if test was given):

O.D.____________________° O.S.____________________°

III. Diagnosis

A. Primary condition(s) responsible for vision impairment	O.D.__________ ______________ ______________	O.S.__________ ______________ ______________
B. Secondary condition if any, which led to present condition	O.D.__________ ______________ ______________	O.S.__________ ______________ ______________

Date of last examination______________________________

Name of Examiner________________________________

Ophthalmologist ☐ Other ☐

Figure 4. Physicians' Report Form.

us either because the numbers had been discontinued or because the families listed had moved since the directory (already two years old) first appeared. Relying on an old directory was clearly a handicap and it produced higher sample mortality than we would have expected from a more up-to-date listing.

The directory proved even more of a problem in our personal screening of nontelephone households. The obsolescence of its information was reflected in the fact that more than one-sixth of the originally assigned listings turned out to be vacant or demolished dwelling units. Screening interviews (conducted in February-April 1963) were completed with 77 percent of all existing households assigned.* Subsequent checking of our completed nontelephone screening interviews against the new 1963 Street Address Telephone Directory (which appeared after we had completed our field work) revealed that a third of the households contacted had obtained listed telephone numbers since 1961. Furthermore, 17 percent of the completed cases turned out to have unlisted numbers. Therefore, in looking at data from our nontelephone sample, it should be remebered that only two-thirds of these households really belonged in a nontelephone sample -- i.e., were either without phones altogether or had unlisted numbers. It is reasonable to expect different results from use of a more up-to-date directory, particularly if households which have recently acquired phones can be identified at the outset.

As noted earlier, we originally planned to personally interview all persons reported as having serious trouble seeing. Our two screenings (telephone and nontelephone) yielded 152 such cases, and of these, 127, or 84 percent, were successfully interviewed during March and April 1963.**

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* Of the remainder, 9 percent were refusals, 11 percent did not answer or were not at home, and 3 percent were unobtainable for miscellaneous reasons. An additional 16 listings turned out to have been previously contacted in the telephone screening; they therefore do not figure in the calculation of the completion rate in the nontelephone sample.

** Of the 25 nonrespondents, 15 refused to be interviewed, 2 had died, 4 had moved, 3 did not answer, and 1 turned out not to live in the household which had originally reported him. As compared with respondents, nonrespondents were disproportionately aged (63 percent were 65 years and over), more likely to be women (79 percent were women), and disproportionately white (only 8 percent were Negroes). On the other hand, only 44 percent of our visually impaired respondents were 65 years and over, less than 60 percent were women, and 34 percent were Negroes.

Screening Costs

In keeping with the experiences of other researches who have compared the two interviewing techniques, we found that the telephone screening cost only one-third as much as the nontelephone or personal screening of households. To be more precise, the average cost of approximately 2000 telephone screenings was $1.50; in contrast, the average cost of nearly 200 personal screenings was $4.50. The telephone approach offers considerable economy. Does it also provide representative data?

Representativeness of the Sample

When we compare the characteristics of individuals in our total sample with U. S. Census data for Cleveland (see Table 1), we find an identical age distribution and an almost identical distribution of men and women. Our sample had a slightly higher proportion of Negroes, but this difference may be explained by the fact that Census data were collected almost three years before our study began and hence do not reflect the greater concentration of Negroes in the city since 1960. It should be noted that we obtained information on race from <u>households</u>, and since Census data were collected only for individuals in Cleveland, for purposes of comparison we have projected household data on race onto individuals in the sample. As indicated by Table 2, which shows the racial distribution for households, our sample characteristics were almost identical to the distribution reported by the Census.

Turning to other demographic characteristics presented in Table 2, it can be seen that our sample had proportionately more persons in lower socioeconomic groups than reported by the Census. Income is the only characteristic for which our study and the Census used the same population base: the family. But while only one-quarter of Cleveland's families reported a total annual income of less than $4000 in 1960, the corresponding figure in our sample of households in 1963 was two-fifths. This difference cannot be explained solely by the passage of time between the two surveys; it may also be a result of the loss of persons and households no longer to be found at the assigned addresses or telephone numbers under which they had been listed.

In any case, the greatest differences in sample characteristics appeared not as between our total sample and the Census, but <u>within</u> our sample -- i.e., between telephone and nontelephone households and also within the relatively small nontelephone sample itself. As Tables 1 and 2 show, the nontelephone sample was younger and had disproportionately more Negroes than the telephone sample. Family income was lower in the nontelephone group, and heads of households had less education than their counterparts in families with telephones. Table 3 shows the characteristics of the three subgroups who made up the nontelephone sample: those altogether without phones, those with unlisted numbers, and those who had acquired phones since the directory had appeared. The three groups are probably too small for us to draw any firm conclusions, but they do suggest that nontelephone households are heterogeneous, particularly when we compare the characteristics of homes without phones and those with unlisted numbers.

To recapitulate, our total sample (which was made up largely but not exclusively of telephone homes) was representative of Cleveland with respect to age and sex, and it had only a slightly higher than expected proportion of Negroes -- as compared with earlier Census figures -- and also a disproportionate number of families scoring low in income and occupational skills. On the other hand, the nontelephone sample differed sharply from the telephone group.

Prevalence of Reported Visual Impairment

As noted earlier, our screening questionnaire included a checklist of chronic conditions and impairments adapted from the National Health Survey. The prevalence rates which we obtained for these conditions may therefore be compared with reports from the National Health Survey and other epidemiological studies. Table 4 shows the prevalence of seven conditions in our total sample, in our telephone and nontelephone samples, and -- for purposes of comparison -- in the National Health Survey and in Columbia University's Washington Heights health survey in New York City.* Comparing the rates in our total sample with figures reported by the National Health Survey, we observe that with the exception of heart trouble or high blood pressure, the prevalence of visual impairment (23.8 per thousand) was closest to the National Health Survey rate (19.8 per thousand).

On the other hand, the prevalence of varicose veins reported in our sample was nearly twice as high as the National Health Survey estimate. Since we were primarily interested in visual impairment, we made no effort to analyze the reported prevalence of other conditions -- e.g., by personally checking on persons who in the screening reported that they had diabetes or deafness, etc. There is evidence from the National Health Survey and other studies which suggests that the prevalence of impairments and chronic conditions may vary

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* A master sample health survey of upper Manhattan, with data obtained from household interviews and from records of health agencies. The survey is actually being conducted by the School of Public Health and Administrative Medicine, Columbia University.

between geographical regions.* Thus, the Washington Heights health survey reported a much higher rate of arthritis and rheumatism than the National Health Survey.

Regarding visual impairment ("serious trouble seeing"), Table 5 shows its prevalence in our telephone and nontelephone samples by sex, age, and race. As noted, the overall rate of visual impairment in our total sample (23.8 per thousand) did not differ significantly from the National Health Survey figure or from the rate reported by the Washington Heights health survey. But as Table 5 also shows, the prevalence of visual impairment in our nontelephone sample (37.5 per thousand) was nearly twice that reported by the National Health Survey, or by our telephone sample. What explains the apparently higher rate of visual impairment in nontelephone households? Here it should be recalled that our nontelephone sample households scored lower than the telephone group on all socioeconomic measures, and we have reason to believe that the visually impaired in general are low in socioeconomic status. Therefore, although the sampling error would undoubtedly be smaller in a larger nontelephone sample, we might still expect to find a higher prevalence rate than in the telephone group. This is a major reason for supplementing any telephone screening with a sample of nontelephone households.

Apart from characteristics of the two populations (telephone and nontelephone) which may explain variation in the prevalence of visual impairment, there remains the question whether this variation can be attributed to the use of different interviewing techniques. Here we come to the critical problem of underreporting.** A primary objective of

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* U. S. National Health Survey. Selected Health Characteristics by area: Geographic Divisions and Large Metropolitan Areas, United States, July 1957-June 1959. Washington, U. S. Department of Health, Education and Welfare, Public Health Service, 1961. Here the National Health Survey compared the prevalence of selected chronic conditions by geographic division and among certain metropolitan areas. The prevalence of visual impairment varied somewhat among the regions (e.g., from 15.5 per thousand in East North Central states to 22.3 per thousand in South Atlantic States). Data available for only four metropolitan areas showed little variation in the rate of visual impairment.

** Ray E. Trussell, Jack Elinson, and Morton L. Levin, "Comparisons of Various Methods of Estimating the Prevalence of Disease in a Community -- the Hunterdon County Study," American Journal of Public Health, (February 1956); Jack Elinson and Ray E. Trussel, "Some FActors Relating to Degree of Correspondence for Diagnostic Information as Obtained by Household Interviews and Clinical Examination," American Journal our pilot study was to determine whether telephone screening increases the danger of underreporting visual impairment. To check this, we undertook a special reliability study and randomly selected for personal re-interviews a sample of telephone respondents who had not reported any case of visual impairment in their households. A total of 220 such checks were assigned to our interviewers, and 174 or 79 percent of them were completed.* In all of these cases we interviewed the same individual who had served as our original telephone respondent and the questionnaire included the same health items that had been used in our original screening of the household -- except of course, that it was now administered face-to-face with respondents. The 174 re-interviews (providing data on approximately 550 household members) uncovered only one new case of visual impairment which had not been reported in our original screening. Further questioning about the duration and degree of the impairment revealed that it was not severe: the individual was reported as able to read ordinary newspaper print with correction. Our reliability check thus suggested, at least for visual impairment, that the difference between prevalence rates in our telephone and nontelephone samples was not caused by variation in interviewing techniques.**

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of Public Health, March 1957; Commission on Chronic Illness, Chronic Illness in a Large City: The Baltimore Study, Cambridge, Mass., 1957; U. S. National Health Survey, Health Interview Responses Compared with Medical Records, Washington, U. S. Department of Health, Education and Welfare, Public Health Service, 1961; H. William Mooney, Methodology in Two California Health Surveys, Washington, U. S. Department of Health, Education and Welfare, Public Health Service 1962. All of these studies show wide discrepancies between the number of diseases or conditions reported in household interviews and those reported by medical examination. As may be expected, the reliability of household interviews varies with the conditions being reported. For example, as Trussell, Elinson, and Levin indicate in their 1956 paper, diseases of the eye reported in household interviews are relatively well matched with clinical evaluations, while diseases of the respiratory system are poorly matched. On the other hand, in the same study relatively few of the eye disease cases found by clinical evaluation were matched with conditions reported in family interviews.

* Three-quarters of the nonrespondents were accounted for by "not-at-homes" after three calls and most of the remainder by families who had changed their addresses since the original telephone screening.

** In our pilot study, as in a number of other epidemiological surveys, there was evidence that respondents are more likely to report their own chronic conditions or impairments than those of other household members. However, we had no evidence

TESTING VISION

As noted earlier, our pilot study sought to determine whether reliable vision tests could actually be administered in homes by nonmedical interviewers. We have already described the nature of these tests. Here it should be noted that in only 10 percent of the examinations did our interviewers (all of whom had been trained in the use of three testing devices by an ophthalmologist) experience any difficulty in administering the three tests (two near and one distance). The Sloan distance test was actually given to 122 or 96 percent of the 127 visually impaired persons whom we interviewed.* Of those who took the tests, only 5 persons did so reluctantly.

However, these tests were not the only means at our disposal for determining the severity of vision impairment. In addition we had answers to a series of questions (in our follow-up interviews) about respondents' trouble seeing and, more important, reports from their physicians and a limited number of clinical examinations which we ourselves arranged for respondents who had not been examined within the previous three years. Hence we obtained a variety of measures of vision impairment and an opportunity to correlate verbal reports and actual tests of visual acuity.**

To begin with, slightly more than one-quarter (26 percent) of our visually impaired respondents replied negatively to the question, "Can you see well enough to read ordinary newspaper print with glasses?" This is the criterion by which the National Health Survey identifies the "severely impaired" population; it is worth noting that the Health Survey reports

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that this tendency was related to the interviewing technique (e.g., telephone vs. nontelephone). See U. S. National Health Survey, Health Interview Responses Compared with Medical Records, Washington, U. S. Department of Health, Education and Welfare, Public Health Service, 1961; p. 28.

* Of the remainder, three refused to take the test, one was too ill, and one was out of town (and had been interviewed in proxy).

** Since our pilot study began, the National Health Survey has begun to administer a supplemental questionnaire to persons reported in the regular household survey as having severe visual impairments. Tentative plans have also been made by the Health Survey to conduct an independent study which would compare information obtained from this supplement with clinical data. This proposed study will be conducted in a single metropolitan area (not Cleveland) with respondents drawn from the general population and from a local register of blind persons. However, results will not be available for some time -- well after we begin our own new study.

an almost identical proportion (28 percent) of all persons with visual impairment in this category.

However, since we administered our own tests of visual acuity we had a chance to compare the two sets of findings. Table 6 shows the relationship between reported ability to read ordinary newspaper print and actual performance on the Jaeger near vision test card which we administered at 14 inches. As this table shows, 38 percent of all our visually impaired respondents were unable to read 8-point (standard newsprint) or smaller type on the Jaeger near vision test. Almost one-fourth of those who said they were <u>able</u> to read newsprint could not read 8-point type. Conversely, approximately one-fifth of those who said that they were <u>unable</u> to read newsprint could read 8-point or smaller type in the Jaeger test. Table 7 shows the association between reported ability to read newsprint and performance on the distance test (Sloan letters) which we administered at 10 feet.* Nearly one-quarter of all our visually impaired respondents scored at 20/80 or less on the distance test, i.e., had 40 percent or more loss of vision (which we have arbitrarily taken as the upper limit of "severe" impairment). Fewer than half of those who said they were unable to read newsprint fell into this category. On the other hand, more than one-eighth (13 percent) of the respondents who said they were able to read newsprint tested at 20/80 or less on the distance chart.

We do not offer these results as conclusive evidence of unreliability in the National Health Survey criterion for defining severe impairment -- especially as our near vision test was administered at 14 inches, and there are no specifications for distance or type size in the Health Survey question regarding ability to read newsprint. Furthermore, we did not learn whether persons claiming they were able to read newsprint (but unable to read 8-point type on the Jaeger test) could, in fact, do so over a sustained period of time. Nevertheless, this correlation of verbal reports and test results suggests that any definition of sever impairment based entirely on what people report is subject to error.

Verbal reports, of course, are hardly adequate to identify persons who fall into the legal definition of blindness --

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* For comparison with clinical reports, the results of our distance test were converted into standard 20-foot measurements; that is, they were multiplied by two. For closer approximation of 20-foot testing, the Good-Lite Company recommends that a pair of +.25 lenses be placed over the patient's eyes or glasses when taking the visual acuity test. This we were unable to do in the pilot study.

particularly those who have more than light perception.* Consequently, to distinguish the blind we relied on our own test of distance acuity: all respondents who scored 20/200 or less on the 10-foot Sloan letters chart were considered blind. We found that 10 percent of our reported cases of visual impairment fell into this category, a figure which would have been expected from the proportion of estimated blindness (2 per thousand population) in the total universe of visual impairment as defined by the National Health Survey (19.8 per thousand population). Approximately one-third of our blind respondents were totally blind, a somewhat higher proportion than indicated by other studies of this population.**

If, as noted earlier, there was some inconsistency between what people told us about their eye trouble and what actual tests revealed, there was even greater inconsistency between the results of our own vision tests. Table 8 shows the distribution of scores (in Snellen notation) on the 10-foot distance test and the 14-inch Jaeger near vision test. While nearly one-quarter of our visually impaired respondents scored at 20/20 or more on the Sloan distance test, only 4 percent of them achieved such high scores on the Jaeger near vision test. Further analysis reveals that in only one-fifth of all cases tested did our interviewers record identical scores on the two vision tests. Similarly, Table 9 shows the distribution of scores on the two near vision tests which we administered -- the Jaeger and Snellen tests. As may be expected, there was greater convergence of results here. Indeed interviewers obtained identical scores in nearly half of the cases tested.

Finally, just as respondents' reports of vision impairment were checked against the results of eye examinations which our interviewers administered in homes, so too we attempted to check our own vision tests against reports from physicians who had examined our respondents. As noted earlier, all respondents who said they had been examined within the past three years were asked to sign releases authorizing us to obtain information about them from their physicians.*** Some 84 persons, or 79 percent of those eligible, signed the releases; medical reports were obtained on 55 persons, or nearly two-thirds of the ones who had signed. In addition, clinical examinations were arranged for nearly half (14) of the respondents who had not been examined within the previous

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* Light perception is the ability to see light but not its source (e.g., to tell whether or not a light is on, or distinguish between night and day).

** It is generally assumed that between 10 and 20 percent of the legally blind population are totally blind.

*** Physicians reporting to us -- most of them opthalmologists -- suggested that many patients underestimated the time which had elapsed since their most recent visit.

three years. As a result, we secured clinical data consisting of distance and near vision acuity measurements and brief diagnostic information on 54 percent of our visually impaired respondents.

Again, there was considerable variation between the two sets of observations, as Table 10 suggests. Thus, according to the physicians, 37 percent of our respondents had 20/20 or more distance vision; in contrast only 15 percent of them were given this score by our interviewers. At the other end of the vision scale, clinical reports indicated that only 3 percent had light percention or were totally blind; according to our own vision tests, the figure was 8 percent. Identical test results were obtained in less than a quarter (22 percent) of the cases. Furthermore, in most of the cases of disagreement, our interviewers recorded <u>less</u> distance vision, that is, more visual impairment, than the physicians.*

What explains such discrepancies? In the first place, it is important to distinguish between the problem of behavioral variation on the one hand and the question of observer reliability on the other. From a behavioral point of view, there is no reason to expect perfect correspondence between different tests, particularly when comparing distance and near vision. Thus, nearsighted persons would of course score much higher on the near vision test than on the distance test. There are even legally blind persons with extremely poor distance vision acuity who have some useful near vision; they too would obviously score "better" on one test than on the other. Hence a certain amound of inconsistency is to be expected between tests which get at different aspects of vision.

As for inconsistency between our own distance tests and what physicians reported, there is no evidence from our study that it is due to the time lag between physicians' examinations and our own tests; indeed, a surprisingly large proportion of our respondents had been examined by their physicians within a few months of our two contacts with them -- some of them afterward.** What remains to be explored, perhaps as

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* Unfortunately, since physicians' near vision tests were not uniform as to distance and since their notations varied widely, we were unable to compare them with the results of our own near vision tests.

** Although our screening questionnaire was carefully phrased to avoid placing any special stress on blindness or visual impairment, it is possible that even the fairly neutral question about "trouble seeing" triggered a response which soon after took the form of a visit to the ophthalmologist.

part of a larger study, is the general reliability of vision tests -- particularly with regard to severe visual impairment. Needed, it seems to us, is not just a study of the test/retest reliability of particular screening devices, but rather of the persons administering them.* As far as we know, this has never been attempted on a large scale. But until the attempt is made, there appears to be no simple way to establish criteria for comparing differences in test results and evaluating those differences. What this means in the case of our pilot study is that without further research we can make no definitive statement about the general reliability -- or unreliability -- of our vision testing data or of physicians' reports. However, we feel that our fairly simple vision tests achieved at least one of their objectives -- which was to provide a check against self-reported disability. But whether these tests would stand up under more rigorous clinical validation remains to be seen.

DATA FROM THE PERSONAL INTERVIEWS

While the major purpose of our interviews with visually impaired persons was to test visual acuity, we obtained a considerable amount of additional information about them -- particularly of the impact which their impairment has had on activities and mobility. Accurate measurement of visual loss is essential to any proper study of this population; no less important is the analysis of what visually impaired persons feel about their condition and how they function in everyday life. For example, how do visually impaired persons rate their disability? What effect does visual impairment have on leisure behavior? What services do the visually impaired receive? What services would they like to get? Our small sample of 127 cases permits no definitive answers to such

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* For a reliability study of testing devices, see U.S. National Center for Health Statistics. Comparison of two vision-testing devices: A study to compare visual acuity as measured by the Sight-Screener and the Sloan Letter Chart. Washington, D.C.: U.S. Department of Health, Education and Welfare, Public Health Service, 1963. This study reports a comparison of visual acuity as measured by the American Optical Company's Sight-Screener and the Sloan Letter Chart (an improved Snellen-type chart, similar to the one used in our own pilot study), controlling for fatigue and recall. The study group was nonrandom, consisting of 502 adults (age 17 through 79) with visual acuity of 20/200 or better. On the whole the scores obtained with the Sight-Screener matched those obtained with the Sloan tests; that is, no significant differences were found between them.

questions and no projections should be made from these data. Furthermore, this small sample made it impossible to present more refined breakdowns of behavioral differences -- for example, by age. What we have here then are sketches of problems which we plan to analyze more systematically in a larger study.

General Health Characteristics

In beginning our interviews with visually impaired respondents, we did not immediately broach the subject of eye trouble. Instead, our first questions dealt with general aspects of the respondent's health and hence gave him an opportunity to mention his eyes (if they were an important health problem for him) or any other condition which was bothering him. The result was a measure of the respondent's general health and of the "saliency" or importance of visual impairment to him.

In our sample few persons said that they felt well -- only a third claiming "good" or "excellent" health. As Table 11 shows, nearly three-quarters of our respondents reported chronic conditions apart from trouble with their eyes. Those with additional conditions were likely to be the more severely impaired people.* This finding is not particularly surprising in view of the fact that severe visual impairment usually accompanies old age (see Table 12). The direct relationship between age and severity of impairment is confired by the National Health Survey, which reports that two-thirds of all severely impaired people are 65 years of age or older; on the other hand, according to NHS, only slightly more than one-third of the moderately impaired are in this age group.

Visual impairment therefore is only one and not necessarily the most important of a number of chronic conditions with which some people (especially the aged) are afflicted. Our interviews in Cleveland provide evidence for this statement. Asked about their health in general, little more than a third of our visually impaired respondents <u>spontaneously</u> mentioned their eye trouble. As may be expected, the more severe their impairment, the greater the frequency with which

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* In our tabulations the "severely" impaired group comprises all respondents who reported they were unable to read ordinary newspaper print with glasses; included in it are all persons indentified by our acuity tests as legally blind -- e.g., scoring 20/200 or less in the better eye. The "moderately" impaired group -- nearly four times as large -- is made up of all other respondents, i.e., persons who said that they <u>could</u> read newspaper print with glasses.

they mentioned it; even so, however, less than half of the severely impaired respondents referred to their eye trouble before our interviewers began to question them about it. On the other hand, there is apparently an inverse relationship between people's evaluation of their health in general and the saliency of visual impairment: respondents describing themselves in poor health were more likely to mention eye conditions than persons who said they were in fairly good health.

How People Rate their Visual Impairments

In the previous Section we presented some objective measures of our respondents' visual impairments. These measures, however, do not tell us how people rate or evaluate such conditions, an important element in any study of the personal impact of serious eye trouble. In our interviews we asked respondents, "How much trouble would you say you have in seeing - a great deal of trouble seeing, some trouble seeing, or hardly any trouble at all?" Answers to this question were correlated with the visual acuity scores which our interviewers obtained (see Tables 13 and 14). More than a third of all our visually impaired respondents claimed that they had a "great deal" of trouble seeing; on the other hand, approximately one-quarter said they had little or no trouble. While persons scoring low on the Sloan (distance) and Jaeger (near vision) tests were much more likely to admit that they had at least some trouble seeing, there were exceptions. Thus, one-eighth of our respondents scoring 20/80 or less on the distance test -- an approximate equivalent of sever impairment -- told interviewers that they had little or no trouble seeing. Similarly, one-fifth of those who were unable to read the equivalent of newspaper print on the Jaeger near vision test said that they had little or no trouble seeing. In other words, subjective reports were imperfect predictors of acuity scores.

The correlation between these reports and our criteria for distinguishing "severe" or "moderately" impaired persons was of approximately the same order (see Table 15). Nearly nine out of ten severely impaired respondents and only one-quarter of the moderately impaired reported that they had a "great deal" of trouble seeing; conversely, while none of the severely impaired tended to underestimate his difficulty seeing, almost a third of the moderately impaired discounted their trouble, i.e., said they had little or no trouble. As for the association between how people rate their trouble seeing and their reported ability to read ordinary newspaper print (the criterion by which the National Health Survey distinguishes "severe" from "moderate" impairments), our study shows that almost a quarter of those who say they are able to newspaper print still consider themselves as having a "great deal" of trouble seeing (see Table 16).

Here we have additional evidence of inconsistency between what people think about their trouble seeing and the results of fairly objective measures of visual acuity. Perhaps most striking is the tendency of some severely impaired persons to discount their trouble seeing. Were visual impairment merely a medical or public health problem and not also deeply imbedded in personal and intergroup psychology, this would hardly be worth reporting. However, from the point of view of adjustment, the way people perceive their eye disorders may be just as important as what clinical measurements show.*

Age at Onset, Cause, and Treatment of the Impairment

As noted earlier, our visually impaired respondents in Cleveland were quite disproportionately old -- nearly half of them 65 years of age or over. Furthermore, the great majority were fairly advanced in years when their trouble with seeing began (see Table 17). Indeed, more than half of the severely impaired group had reached at least the sixth decade of life when their impairment "first began to make a difference" in their daily lives.** On the other hand, only about a third of the moderately impaired (chronologically a much younger group) first experienced trouble seeing in later years.

Most reports by visually impaired persons about the etiology of their condition are open to question; in our study the proportion who gave illness as the cause (77 percent) was of rougly the same magnitude as the proportion of National Health Survey respondents (68 percent) who mentioned it as the cause of their impairments (see Table 18). According to persons interviewed in our study, they have been fairly conscientious about getting medical attention for their condition. Approximately one-fifth of them claimed that they had never had their eyes examined or had not been treated for at least five years; however, a surprisingly large proportion of our respondents -- half -- said that they had been examined by their doctors at least once within the past year (see Table 19). Our study suggests no direct relationship between the severity of visual impairment and the date of the

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* In a four-state survey of 684 legally blind persons 20 years of age and over, conducted by the American Foundation for the Blind, half of the respondents said that they did not consider themselves "blind."

** In Massachusetts in 1960 nearly two-thirds of all new cases of legal blindness registered that year were 60 years of age or over; in New York State the corresponding figure was nearly three-fifths.

most recent medical examination. In this connection it is worth repeating what we heard from some ophthalmologists who sent us eye reports on our respondents, namely, that there may be a tendency for them to underestimate the time since their most recent examination. Unfortunately, we obtained no information about the kind of treatment which our respondents had received.* However, we did learn whether or not they used optical aids and if so, which aids they used (see Table 20). Our finding was that approximately one-fifth of all visually impaired persons in the study used no optical aids whatsoever and that the proportion of severely impaired who used no glasses or other aids was more than twice as great as among the moderately impaired.

Impact of Visual Impairment on Mobility and Work

Here we come to the direct impact which visual impairment has had on our respondents' lives, particularly on mobility and work. To begin with, we asked them whether trouble seeing had made any difference in other people's attitudes toward them: less than a fifth of them replied that it had made a difference. As one would expect, the more severe their condition, the greater their awareness of such attitudes. But more than a quarter (28 percent) of our respondents said that trouble seeing made a difference in their attitudes toward other people; again, the greater their impairment, the more likely they were to mention the difference.**

What visually impaired persons say about such attitudes is not the only, nor the best, measure we have of its impact on their lives. One of its most important consequences, as previous studies have shown, is to limit mobility. Our study too provides clear evidence of this effect (see Table 21). As we discovered, however, it is not always easy to distinguish the effect which trouble seeing has from the influence of other physical conditions. Thus, an appreciable number of our respondents -- more than a fifth -- reported mobility limitations for reasons that had nothing to do with visual impairment. It seems safe to assume that this is largely a function of old age and the multiplicity of chronic conditions which it often brings. Nevertheless, we found a direct relationship between severity of visual impairment and degree of mobility limitation. Four-fifths of our blind

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* In the more comprehensive study which we plan for the future, we would hope to get such information from doctors reporting to us on their patients.

** We plan a much fuller analysis of these attitudes in later studies.

respondents were confined to their immediate neighborhoods because of trouble seeing; the corresponding proportion among other severely impaired persons was nearly one-third -- at least partial evidence of the extent to which this group displays "functional" manifestations of blindness. On the other hand, only 8 percent of respondents with moderate visual impairments were confined to their immediate neighborhoods; more than two-thirds of them reported no limitation on their mobility.*

Visual impairment -- especially when severe -- limits mobility; it also restricts work. Data on the employment status of our respondents 16 years of age and over (see Table 22) shows that many are idle. Only one-fifth of them were working, a far smaller proportion than in the general population of Cleveland. The direct impact of trouble seeing is fairly clear: the percentage of persons at work among the severely impaired was much smaller than the proportion of moderately impaired persons who were gainfully employed. This, however, is not due to the fact that the severely impaired are older. When we control for age (i.e., by taking those under 65 years) we find that while less than one-eighth of the severely impaired were working, the proportion of employed among the moderately impaired was approximately one-third.

Impact of Visual Impairment on Leisure Activities

Due to their age, a large proportion of our respondents were retired. For them as well as for those at work, leisure activities assume special importance -- particularly in view of their mobility limitations. Analysis of selected leisure activities -- reading, visiting with friends, club life, television, and radio -- provides further evidence of the impact of visual impairment. For purposes of comparison we have also presented data from an earlier study of leisure behavior among legally blind adults conducted by the American Foundation for the Blind.**

Taking reading first, we find (see Table 23; that only one-third of our respondents had read any books in whole or part during the month prior to our interviews with them --

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* One quarter of the moderately impaired in our sample reported that they are presently driving cars. In addition, one severely impaired respondent said that he drove a car.

** Data were derived from interviews with 684 legally blind adults 20 years and over drawn at random from the registers of four states (Massachusetts, North Carolina, Minnesota, and Oregon). Field work on this survey was completed in 1961.

a figure approximating the estimated proportion of the general population which spends time reading books. Severely impaired persons were considerably less likely to have read a book than the moderately impaired. In sharp contrast stand the legally blind adults whom we interviewed in our earlier four-state survey: not only were they more likely to be book readers; they were also more likely to be heavy readers -- 17 percent of them having read four or more books in the month prior to our interviews with them.* However, in our Cleveland sample, visual impairment itself was not the only reason why people did not read books. Indeed, more than half of the nonreaders gave some explanation other than trouble seeing, and even among the severely impaired the proportion mentioning something other than eye disorders was nearly a third.

While relatively few of our Cleveland respondents read books, most on the other hand said that they themselves read newspapers; two-thirds reading them more than once a week. As may be expected, none of our blind respondents was able to read the papers; but two-thirds of the (15) other severely impaired persons said they read papers more than once a week -- although severe impairment was defined to include all people who had claimed inability to read newspaper print even with glasses. Here we have still another indication of unreliability in self-reported visual disability.

If reading is relatively unimportant as a leisure pursuit for our respondents, the same cannot be said of television and radio, particularly the former (see Table 23). Only 10 percent of our total sample said that they do not watch television; more than half, however, watch TV two or more hours a day, and more than a fifth watch it four or more hours a day. The greater the degree of visual impairment, the less time spent watching TV. Thus, nearly a third of the severely impaired people in our sample do not watch television at all (most of them because of their eyes) and less than half watch

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* In this survey we defined reading among the blind to include not only braille and "talking book" records, but ordinary print (in our sample 14 percent had reading vision) and reliance on sighted readers as well. The addition of this latter group gave us a higher proportion of readers than we would have obtained if we had limited ourselves to braille and records alone. Indeed, when we asked about their primary mode of reading, we found that while more than half of our readers used records, the next largest group (over one-quarter) read with the help of sighted readers. More striking still, the proportion who read ordinary inkprint materials was larger than the number who read braille (8 percent). Of course, many blind readers use more than one technique of reading.

it two or more hours a day. On the other hand, among the moderately impaired only 5 percent fail to look at TV, and three-fifths watch it two or more hours daily.

As in the general population, radio lags behind television with respect to audience interest (see Table 23). One-fifth of our total Cleveland sample never listen to the radio. But it is worth noting that severely impaired persons are more likely to be heavy listeners than the moderately impaired; more than half of the former listen to radio two or more hours a day; the corresponding proportion among the moderately impaired is little more than a third.

So far we have been considering sedentary leisure activities which can be pursued in one's home. Data regarding more active pursuits, such as visiting with friends and joining clubs, provide another picture of the impact of visual impairment (see Table 23). In our pilot study we found that relatively few (only 16 percent) have no social life with friends; at the other extreme of sociability approximately one-quarter claimed they visited with friends at least three times a week. Our data also suggest an expectedly inverse relationship between severity of visual impairment and the amount of visiting: as compared with the moderately impaired, severely impaired persons were far less engaged in social life. Further questioning revealed that approximately one out of ten in our total sample felt that trouble seeing made some difference in the amount of their visiting with friends. But while less than 3 percent of the moderately impaired expressed this attitude, the proportion among the severely impaired was more than one-third.

Most of our respondents -- nearly two-thirds -- did not belong to any of the myriad clubs or organizations in Cleveland (a characteristic which they share with most Americans). As in the case of visiing with friends, moderately impaired persons were more inclined than the severely impaired to be joiners and also more likely to belong to more than one organization (see Table 23). And again, while less than one out of ten of the moderately impaired felt that trouble seeing affected his opportunity to join clubs, more than half of the severely impaired felt this way about it. Of the few who *did* belong to community organizations, little more than half said they regularly attended meetings.

Going to the movies also involves leaving the house or immediate neighborhood -- something which less than two-thirds of all our respondents (and only slightly more than one-third of the severely impaired) can do without help. But only one out of eight reported that they had gone to the movies at least once during the previous month. At least among our severely impaired respondents, the obvious explanation for nonattendance -- trouble seeing -- was most often mentioned.

This is by no means a complete survey of visually impaired persons' leisure pursuits; it does, however, show how selected activities -- some of them conducted in the home and others outside the home -- are affected by the degree of impairment. It is safe to conclude that the more severe one's visual loss, the greater the restriction on leisure activities, particularly those interests which require a certain degree of physical mobility and independence.

The Need for Social and Medical Services

We turn now to the problem of services. What do visually impaired persons receive in the way of medical and social services and what do they need? Perhaps our most striking finding in this connection is that so many receive no services whatsoever and apparently feel no need for help (see Table 24). More than half of our respondents said they receive no medical or social services from public or private agencies in Cleveland and nearly half said they needed no services because of their trouble seeing.* It is worth noting that the degree of visual impairment made little difference as far as services are concerned: the proportions of severely and moderately impaired persons receiving and expressing a need for particular services were approximately the same. As for the kinds of assistance which our respondents get, general medical treatment was first in importance, followed by visits from social workers, glasses and optical aids, etc. Severely impaired persons in our sample were more likely to be receiving agency help of some kind, e.g., visits from social workers, or planned recreation. This group also expressed a greater need for assistance in reading, traveling, housework, and shopping -- precisely the activities in which serious visual loss is most likely to make itself felt.

In Cleveland legally blind residents are offered vocational, recreational, and other special services by the Society for the Blind. Less severely impaired persons have no such single agency concerned with problems stemming from their impairment; if they need help they may obtain it from a large number of less specialized health and welfare agencies in the metropolitan area. It is not surprising, therefore, that when asked to name "any agency or organization in Cleveland that provides services for people who have trouble seeing," the great majority of our respondents failed to mention the

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* The two figures are not mutually exclusive; that is, some who presently receive no services expressed a need for aid, while others who <u>are</u> getting help mentioned additional services they would like to get.

Cleveland Society for the Bline (see Talbe 25). More striking, half of our legally blind respondents failed to mention the Society; that is, they claimed that they did not know of any institution providing services for them. However, when we subsequently asked our sample, "Have you ever heard of the Cleveland Society for the Blind?" nine out of ten indicated that they had. In other words, it turned out that most of the people in our sample did know of this agency but only after having their memories refreshed.

The Hidden Blind

Lack of awareness (particularly among the severely impaired) of the Society's existence is related in turn to the fact that the Society itself is not familiar with all blind persons in Cleveland.* Of the 14 legally blind persons in our pilot study sample, fewer than half were known to the Society for the Blind. The remainder -- i.e., blind persons unknown to the Society -- we have tentatqvely classified as "hidden." This high proportion of unknown blind persons may well have been due to the extremely small sample of legally blind people which our household screening uncovered; in view of the fact that the Society knows approximately two out of three blind resident in metropolitan Cleveland, it is doubtful whether we would expect to find such a large proportion of hidden blind persons in a larger household sample.

Who are the hidden blind? Our limited data suggest that the hidden blind are older than known blind persons and also more likely to have first experienced blindness in middle or later years. As may be expected, our unknown blind respondents were unlikely to be familiar with the Cleveland Society for the Blind -- only half of them naming it when asked whether they knew any agency that provided services to blind residents. In contrast to the known blind, who receive many social and medical services, hidden blind persons apparently get little help; nevertheless, half of them in our sample expressed a need for such services. One kind of assistance they may need is treatment for their eyes: they were much less likely to have been examined recently than the known blind. Another problem for the hidden blind is mobility, since they were just as limited in this respect as were the known blind. Indeed, our data suggest that the health of unknown blind persons is

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* The Cleveland Society for the Blind maintains a list (for mailing purposes) of slightly more than 2000 blind residents of metropolitan Cleveland and provides services to less than half that number. The estimated total blind population of the area is well over 3000.

even poorer than that of their neighbors known to the Society -- i.e., they themselves were more likely to rate it as poor and also more likely to report a multiplicity of chronic conditions and ailments.

Again, these differences between the two groups are extremely tentative: whether a larger study would confirm them remains to be seen. In future research we hope to make detailed comparisons of the known and unknown blind, particularly their respective adjustment to blindness. Thus, we assume that some blind people remain unknown because local agencies lack the resources to find them; others, however, may conceal their condition from all but immediate family and close friends because they do not wish to be associated with "the blind." Why? Unfortunately, our pilot study in Cleveland produced too few cases of blindness, let alone hidden blindness, for systematic analysis of such problems.

Other Characteristics of the Visually Impaired

Before concluding this report, we shall briefly mention a number of other characteristics of our sample. As noted earlier (and shown in Table 1), the proportion of Negroes in our total screening sample was approximately the same as in the total population of Cleveland according to the 1960 Census; the distribution of Negroes and whites among our visually impaired respondents also matched Census figures for the city. On the other hand, the proportion of Negroes who were severely impaired was much lower than would have been expected -- only 11 percent in this category as against 26 percent among whites, and this was especially true of Negroes under 65 -- among whom only 5 percent were severely impaired as against 26 percent of the whites in this age group (see Table 26).

Educational achievement was much lower among our visually impaired respondents than among the heads of their households, all persons in our original household sample, or the city of Cleveland as a whole. Nearly two-thirds of the visually impaired in our sample reported less than a high school education. The corresponding proportions among the heads of their households, all persons in our household sample, and Cleveland as a whole were 46, 35 and 45 percent respectively. At the other end of the educational scale, the proportion of visually impaired respondents with at least some college education was only 2 percent; in the other three groups the figures were 6, 13 and 9 percent respectively. It seems safe to assume that this low level of educational achievement is due in large measure to the disproportionate number of aged persons in the visually impaired population -- the aged in general having completed fewer years of schooling than their juniors.

Finally, but by no means least important, we have data regarding the major source of income among our visually impaired respondents (see Table 27). According to our findings, social security payments represent the major source of income for one-third of our total sample and for approximately half of the severely impaired. As might be expected, the earnings of visually impaired individuals and/or their spouses are more important for the (younger) moderately impaired group than for the severely impaired. What is perhaps most striking is that none of the blind people in our sample said that they receive Aid to the Blind* -- either as a minor or as a major source of income.

SUMMARY AND CONCLUSIONS

To summarize, our pilot study sought to determine whether telephone sampling yields prevalence rates of visual impairment which are comparable to figures obtained by more traditional sampling methods; to discover whether telephone interviewing affects underreporting of the condition; and to determine whether reliable vision tests can be administered in homes by nonmedical interviewers. A random sample of 3700 Cleveland households, splitting into samples of 2800 telephone and 900 nontelephone homes, was screened by a checklist of impairments adapted from the National Health Survey; respondents reported as having "serious trouble seeing" were then personally interviewed and given simple tests of visual acuity. The prevalence of visual impairment in our total sample of households (23.8 per thousand) and in the telephone sample (19.8 per thousand) was fairly close to the National Health Survey figure (19.3 per thousand); however, in the nontelephone sample the rate was nearly twice as high (37.5 per thousand), which we believe may result from the particular socioeconomic characteristics of this group rather than from differences in interviewing techniques. Slightly more than one-quarter (26 percent) of our visually impaired respondents said they were unable to read newspaper print even with glasses (the criterion by which NHS identifies the "severely" impaired). NHS itself reports an almost identical proportion (28 percent) in this category. Approximately 10 percent of our visually impaired respondents were discovered to be blind -- a figure which would have been expected from the proportion of estimated blindness in the total universe of visual impairment; and of this small group less than half were known to the local agency serving blind residents. Low correlation between vision tests performed by our interviewers, respondents' own

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* About one-fourth of all legally blind persons in the United States receive this form of public assistance under the terms of a joint federal-state program. However, blind people who qualify for Old Age Assistance may be encourage to receive this instead, particularly if the monthly payment is higher than Aid to the Blind.

appraisals of their trouble seeing, and physicians' reports indicated that all measures of visual impairment are subject to error. Finally, personal interviews with visually impaired respondents indicated that characteristics and behavior vary significantly according to the severity of their impairment. Severely impaired persons were older, more likely to have first experienced trouble seeing late in life and to suffer from other chronic conditions, more limited in mobility, less likely to be working, and less actively engaged in ordinary leisure pursuits.

Our conclusions are that to screen for visual or other impairments, any telephone sample must be supplemented by a nontelephone sample, that directories from which samples are drawn must be up-to-date, and that, given these conditions, a telephone sample is as reliable as any other method for screening purposes and for determining gross rates of visual impairment. Two additional conclusions are that more research is needed on the general reliability of vision testing and that the degree of vision loss clearly has a significant effect on behavior and attitudes which should be more fully explored in subsequent research.

A NOTE ON SAMPLING VARIATION AND WEIGHTING IN TABLES 1 AND 2

Sampling Variation

Estimates of variability of percentages are affected by the size of the sample and the degree of cluster used to select it. For the total sample of individuals and for the telephone sample (Table 1), we can expect that percentages at about 50 percent would not vary by more than plus or minus 2 percentage points in 95 out of 100 repeated samplings. At the same confidence level, the variation from the percentages observed in the nontelephone sample of individuals would not exceed the limits of plus or minus 5 percentage points. The household data for the total sample and the telephone sample (Table 2) have an expected variation of no more than plus or minus 3 percentage points at the 95 percent level of confidence, while variation for the nontelephone household data can be expected not to exceed 8 percentage points in either direction. Data on our total sample of visually impaired persons can be expected not to exceed the limits of plus or minus 10 percentage points at the 95 percent confidence level. All figures referred to here are true for percentages around the 50 percent level. For percentages nearer the extremes, the expected variation would be somewhat smaller. Whenever greater differences are observed than referred to here, they suggest that some true difference is operating that cannot be attributed to chance sampling fluctuations.

Weighting

In all presentations of findings, nontelephone cases have been weighted by a factor of three since we subsampled one-third of the assigned nontelephone households. This weighting restores the proper balance in the overall proportion of telephone and nontelephone households.

TABLE 1

PERCENT DISTRIBUTION OF SAMPLE CHARACTERISTICS: INDIVIDUALS

		Total Cleveland City Population	All Persons Screened			Visually Impaired Persons	
			Total Sample* (7192=100%)	Telephone Sample (6499=100%)	Nontelephone Sample (693=100%)	Cleveland (152=100%)**	Total U.S.***
AGE							
Total	Under 65	90	90	89	94	57	52
	Under 45	69	69	65	80	31	25
	45 to 64	21	21	24	14	26	27
Total	65 and over	10	10	11	6	43	48
	65 to 74	7	7	8	3	24	21
	75 and over	3	3	3	3	19	27
SEX							
	Men	49	48	48	49	40	47
	Women	51	52	52	51	60	53
RACE							
	White	71	68	71	56	71	
	Negro	29	31	26	44	29	
	Other	-	-	1	-	-	
	Refused	-	-	2	-	-	

* Actual N's reporting varied somewhat from item to item. All reported N's are unweighted. Percent distributions for the total sample are based on a weighting of nontelephone cases by a factor of three.

** This is the total number of visually impaired persons identified in our household screening. Not all of them were subsequently interviewed.

*** Source: National Health Survey.

TABLE 2

PERCENT DISTRIBUTION OF SAMPLE CHARACTERISTICS: HOUSEHOLD

	Total Cleveland Population		All Households Screened			Visually Impaired Persons
	City	Metropolitan Area	Total Sample* (2197=100%)	Telephone Sample (2014=100%)	Nontelephone Sample** (183=100%)	(152=100%)***
RACE						
White			71	73	62	70
Negro			27***	25	38	29
Other			*	*	-	-
Refused			2	2	-	1
INCOME (in dollars)	(all families)		(total family)			
to 2000	10		19	16	27	36
2000 to 3999	15		21	20	25	27
4000 to 6999	39		37	38	33	22
7000 to 9999	23		12	12	9	9
10,000 +	13		5	6	4	2
Refused	-		6	8	2	4
EDUCATION	(all persons aged 25+)	(head of household)	(head of household)			
8 years or less	45	32	35	33	40	46
Some high school	25	24	26	25	33	33
Completed high school	21	24	23	25	18	13
Some college	5	9	8	8	7	4
Completed college	4	11	5	6	2	2
Other	-	-	1	1	*	2
Refused	-	-	2	2	-	*

TABLE 2 (continued)

PERCENT DISTRIBUTION OF SAMPLE CHARACTERISTICS: HOUSEHOLD

	Total Cleveland Population		All Households Screened			
OCCUPATION	City (all employed age 14+)	Metropolitan Area (head of household)	Total Sample* (2197=100%) (head of household)	Telephone Sample (2014=100%)	Nontelephone Sample** (183=100%)	Visually Impaired Persons (152=100%)***
Professional	7	12	5	6	3	2
Farm, Farm Mgr.	4	*	*	*	1	1
Prop. Mgr., Official	-	11	6	7	3	6
Clerical, Sales	22	16	14	15	10	12
Craftsman, Foreman	14	23	22	23	17	17
Operative	26	23	28	26	36	28
Service	13	6	15	14	19	19
Farm Labor, Foreman	-	*	*	*	-	-
Labor	7	5	8	7	10	14
Refused or Not Reported	7	4	2	2	1	1

* Actual N's reporting varied somewhat from item to item. Unweighted N's are reported.

** The proportion of Negro households sampled is smaller than the proportion of Negroes among all individual persons because average number of persons per household is larger among Negro families than white (see Table 1).

*** (See Table 1).

TABLE 3

PERCENT DISTRIBUTION OF SAMPLE CHARACTERISTICS: NONPHONE SAMPLE

	Total * (N=693)	No Phone (N=378)	Unlisted Phone (N=108)	Newly Listed Phone (N=207)
Individual Characteristics	%	%	%	%
Visual impairments (per thousand)	37.5	34	65	29
RACE: White	56	47	70	65
Negro	44	53	30	35
SEX: Men	49	49	49	49
Women	51	51	51	51
AGE: Under 65	94	95	93	93
Under 45	80	85	72	73
45 to 64	14	10	21	20
65 and over	6	5	7	7
65 to 74	3	3	6	3
75 and over	3	2	1	4
Average number of individuals per household	3.7	4.3	3.5	3.5
Household Characteristics	(N=182)**	(N=88)	(N=32)	(N=62)
INCOME: (in dollars)				
under 2000	27	38	19	15
2000 under 4000	25	27	19	25
4000 under 7000	33	27	39	39
7000 under 10,000	9	5	13	14
10,000 and more	4	2	7	5
Refused	2	1	3	2
EDUCATION:				
8 years or less	40	44	44	33
Some high school	33	38	30	26
Completed high school	18	13	13	28
College	9	5	10	13
Other	*	-	3	-
OCCUPATION:				
Prof., Farm mgr., Prop.	7	5	6	8
Clerical	10	10	19	7
Craftsman	17	16	10	22
Operative	36	34	39	38
Service Worker	19	22	20	15
Laborer	10	13	3	10
Refused	1	-	3	-
RACE:				
White	62	55	74	67
Negro	38	45	26	33

* Unweighted N's are reported.

** Data not available for one household.

TABLE 4

PREVALENCE RATES
PER 1000 FOR SELECTED IMPAIRMENTS

	Cleveland				
Impairment	Telephone Screening (N=6499)	Personal Screening (N=693)	Total (N=7192)	Washington Heights (N.Y.C.)*	Total U.S.**
	%	%	%	%	%
Arthritis or Rheumatism	79.1	56.3	73.6	81.3	65.6
Diabetes	17.5	11.5	16.1	10.8	9.8
Varicose Veins	40.0	37.5	39.4	21.7	19.8
Serious trouble seeing, even when wearing glasses	19.3	37.5	23.8	20.2	19.8
Deafness or serious trouble hearing	21.7	23.1	22.0	31.7	35.3
Heart trouble or high blood pressure	64.6	60.6	63.7		62.6
Repeated trouble with back or spine	42.6	34.6	40.7	33.2	28.0

* Preliminary figures.

** Source: National Health Survey.

TABLE 5

PREVALENCE OF VISUAL IMPAIRMENT PER 1000 BY AGE, SEX, AND RACE

	Cleveland			
	Telephone (N=6499)	Nontelephone (N=693)	Total Cleveland (N=7192)	Total U.S.*
All Men	12.9	41.5	20.0	19.1
Men under 65	7.3	31.3	13.6	12.0
Men 65 and over	57.9	222.2	81.2	101.2
All Women	25.2	33.8	27.3	20.5
Women under 65	11.9	30.1	16.5	10.8
Women 65 and over	118.4	86.9	114.0	114.3
All white persons	19.3	47.6	24.9	
All Negro persons	20.2	26.9	22.5	
All ages	19.3	37.5	23.8	19.8
Under 65	9.7	30.7	15.1	11.4
65 and over	92.0	146.3	99.6	108.4

Note: In more precise statistical terms, we have calculated that in a sample of this size (nearly 6500), in 95 cases out of 100 one could expect to find a fluctuation of 3.5, i.e., a range from 20.3 per thousand to 27.3. As for the observed rate in our telephone sample, 19.3 per thousand, one could expect to find a fluctuation of 3 in either direction, i.e., a range from 16.3 to 22.3 per thousand. The corresponding range for the National Health Survey's estimated prevalence rate (19.8 per thousand) is from 18.3 to 21.3. In other words, there is overlap between our figures and those of the National Health Survey. Similar considerations apply to our prevalence figures for persons under 65 and for those 65 and over -- at least for our total sample and for the telephone sample in particular. As for the nontelephone sample figure, we have calculated that in 95 samplings out of 100 one could expect to find a fluctuation of 15 in either direction, i.e., a range from 22.5 to 52.5 per thousand -- the lower figure being relatively close to the upper range of the National Health Survey rate. These calculations are based on the assumption that we drew a simple random sample.

* Source: National Health Survey.

TABLE 6

ASSOCIATION BETWEEN REPORTED ABILITY TO READ ORDINARY NEWSPAPER PRINT AND PERFORMANCE ON JAEGER NEAR VISION TEST

Point Type Read on Jaeger Near Vision Test	Percent of Total (N=122)*	Percent Able to Read (N=87)*	Percent Unable to Read (N=35)*
	Reported Ability to Read Ordinary Newspaper Print with Glasses		
	%	%	%
8-point or smaller (20/50 or more)	62	76	21
Can't read 8-point (20/60 or less)	38	24	79
	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 7

ASSOCIATION BETWEEN REPORTED ABILITY TO READ ORDINARY NEWSPAPER PRINT AND PERFORMANCE ON DISTANCE TEST

Visual Acuity (Snellen Notation)	Percent of Total (N=122)*	Reported Ability to Read Ordinary Newspaper Print with Glasses: Percent Able to Read (N=87)*	Reported Ability to Read Ordinary Newspaper Print with Glasses: Percent Unable to Read (N=35)*
	%	%	%
20/16 to 20/20	24	32	2
20/24	10	12	2
20/30	14	16	9
20/40	15	16	14
20/50	6	2	14
20/60	7	7	9
20/80	5	4	7
20/100	6	8	-
20/120 to 20/160	3	3	5
20/200	1	-	5
Light Perception	6	-	21
Totally Blind	3	-	12
	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 8

PERCENT DISTRIBUTION OF VISUAL ACUITY SCORES ON SLOAN AND JAEGER TESTS

Visual Acuity (Snellen Notation)	Sloan (10 feet) (N=122)*	Jaeger (14 inches) (N=122)*
	%	%
20/16 to 20/25	34	21
20/30	14	20
20/40	15	5
20/50	6	17
20/60 to 20/65	7	4
20/70 to 20/80	5	8
20/100	6	5
20/120 to 20/130	1	4
20/160 to 20/170	2	5
20/200 or less**	1	5
Light Perception***	6	3
Totally Blind	3	3
	100	100

* Actual N. Although the total number of persons taking each test was the same, one of our respondents took the Sloan test and not the Jaeger test, and another took the Jaeger and not the Sloan test. As a result, the two test groups are not identical. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

** This notation does not appear on the Jaeger test.

***The difference between the two scores is explained by the fact that of nine persons who reported that they could see no more than light on the Sloan test, four were able to see more than light on the Jaeger test.

TABLE 9

PERCENT DISTRIBUTION OF VISUAL ACUITY SCORES ON JAEGER AND SNELLEN TESTS

Visual Acuity (Snellen Notation)	Jaeger Near (N=122)*	Snellen Near (N=122)*
	%	%
20/16 to 20/20	4	5
20/25	17	14
20/30	20	15
20/40	5	12
20/50	17	18
20/65	4	9
20/70 to 20/100	13	6
20/130 to 20/170	9	-
20/200 to 20/800**	5	15
Light Perception	3	3
Totally Blind	3	3
	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

** This notation does not appear on the Jaeger test.

TABLE 10

PERCENT DISTRIBUTION OF VISUAL ACUITY SCORES ON CLINICAL REPORTS AND SLOAN TEST*

Visual Acuity (Snellen Notation)	Clinical Reports (N=69)**	Sloan Test (N=69)**
	%	%
20/16 to 20/20	37	15
20/25	11	14
20/30	13	18
20/40	16	13
20/50	8	4
20/60	-	12
20/70	1	-
20/80	2	7
20/100	-	5
20/120	-	1
20/160	-	2
20/200	4	1
20/300	4	-
20/400	1	-
Light Perception	2	6
Totally Blind	1	2
	100	100

* This table shows the percent distribution of distance acuity scores reported by doctors and by our own interviewers in 69 cases where data were available from both sources.

** Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 11

SEVERITY OF VISUAL IMPAIRMENT* AND OTHER CHRONIC CONDITIONS

Number of Other Conditions Reported	All Visually Impaired Persons (N=127)**	Severely Impaired Persons (N=29)**	Moderately Impaired Persons (N=98)**
	%	%	%
None	27	9	32
One or two	46	48	45
Three or more	26	43	22
Don't know	1	-	1
	100	100	100

* In this and subsequent tables, the "severely" impaired group comprises all respondents who reported they were unable to read ordinary newspaper print with glasses; included in it are all persons identified by our acuity tests as legally blind, e.g., scoring 20/200 or less in the better eye. The "moderately" impaired group is made up of all other respondents, e.g., persons who said that they could read newspaper print with glasses.

** Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

Note: The question was, "Do you have any (other) health conditions or impairments which have lasted for a long time, even though they don't bother you all the time? (What? Anything else?)"

TABLE 12

SEVERITY OF VISUAL IMPAIRMENT AND AGE

Age	Cleveland Pilot Study: All Visually Impaired Persons (N=127)**	Cleveland Pilot Study: Severely Impaired Persons (N=29)**	Cleveland Pilot Study: Moderately Impaired Persons (N=98)**	Total U.S.*: All Visually Impaired Persons	Total U.S.*: Severely Impaired Persons	Total U.S.*: Moderately Impaired Persons
	%	%	%	%	%	%
Under 65	56	43	60	52	33	60
65 and over	44	57	40	48	67	40
	100	100	100	100	100	100

* Source: National Health Survey.

** Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 13

ASSOCIATION BETWEEN PERFORMANCE ON SLOAN DISTANCE ACUITY TEST AND REPORTED AMOUNT OF TROUBLE SEEING

		Visual Acuity (Snellen Notation)		
Reported Amount of Trouble Seeing	Total (N=122)*	Totally Blind-Light Perception (N=12)*	20/200 to 20/80 (N=21)*	20/60 to 20/16 (N=89)*
	%	%	%	%
Great Deal	38	93	52	29
Some	37	7	36	40
Hardly Any/None	25	-	12	31
	100	100	100	100

TABLE 14

ASSOCIATION BETWEEN PERFORMANCE ON JAEGER NEAR VISION TEST AND REPORTED AMOUNT OF TROUBLE SEEING

		Visual Acuity - Jaeger Near		
Reported Amount of Trouble Seeing	Total (N=122)*	Unable to Read Line 20/170 (N=17)*	20/170 to 20/65 (N=33)*	20/50 to 20/20 (N=72)*
	%	%	%	%
Great Deal	38	84	49	25
Some	37	16	30	43
Hardly Any/None	25	-	21	32
	100	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 15

ASSOCIATION BETWEEN SEVERITY OF VISUAL IMPAIRMENT AND REPORTED AMOUNT OF TROUBLE SEEING

Reported Amount of Trouble Seeing	All Visually Impaired Persons (N=127)*	Severely Impaired Persons (N=29)*	Moderately Impaired Persons (N=98)*
	%	%	%
Great Deal	38	86	24
Some	36	14	42
Hardly Any/None	26	-	34
	100	100	100

TABLE 16

ASSOCIATION BETWEEN REPORTED ABILITY TO READ ORDINARY NEWSPAPER PRINT AND REPORTED AMOUNT OF TROUBLE SEEING

		Reported Ability to Read Ordinary Newspaper Print with Glasses	
Reported Amount of Trouble Seeing	All Visually Impaired Persons (N=127)*	Able to Read Newspaper Print (N=92)*	Unable to Read Newspaper Print (N=35)*
	%	%	%
Great Deal	38	23	78
Some	36	43	18
Hardly Any/None	26	34	4
	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 17

SEVERITY OF VISUAL IMPAIRMENT AND AGE AT ONSET

Age at Onset	All Visually Impaired Persons (N=127)*	Severely Impaired Persons (N=29)*	Moderately Impaired Persons (N=98)*
	%	%	%
Under 3 Years	11	9	12
3 to 13	13	6	15
14 to 29	11	14	10
30 to 49	23	14	26
50 to 59	19	14	20
60 to 69	10	14	8
70 and over	11	29	6
Don't Know	2	-	3
	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

Note: The question was, "How old were you when your trouble seeing began to make a difference in your daily life?"

TABLE 18

REPORTED CAUSE OF VISUAL IMPAIRMENT

Reported Cause	Cleveland Pilot Study (N=127)**	Total U.S.*
	%	%
Accident or Injury	12	16
Illness	77	68
Both	3	-
Don't Know	8	16
	100	100

* Source: National Health Survey.

TABLE 19

SEVERITY OF VISUAL IMPAIRMENT AND DATE OF LAST EYE EXAMINATION

Date of Last Examination	All Visually Impaired Persons (N=127)**	Severely Impaired Persons (N=29)**	Moderately Impaired Persons (N=98)**
	%	%	%
Never	5	-	6
Five years ago or longer	14	23	12
Two to five years ago	15	17	15
One to two years ago	15	20	14
Once within past year	30	23	32
Two or more times within past year	20	17	20
Don't Know	1	-	1
	100	100	100

** Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

<u>TABLE 20</u>

SEVERITY OF VISUAL IMPAIRMENT AND OPTICAL AIDS USED

Optical Aid Used	All Visually Impaired Persons (N=127)*	Severely Impaired Persons (N=29)*	Moderately Impaired Persons (N=98)*
	%	%	%
Eye glasses with strong reading additions, such as bifocals	49	43	50
One pair of glassess for both distance and reading	20	11	22
Eye glasses for reading	11	3	13
Hand magnifying lenses	8	17	5
Eye glasses for distance alone	5	3	5
Other optical aids	4	11	2
Use no optical aids	19	37	14
	116**	125**	111**

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

** Percentages add up to more than 100 because some visually impaired persons use more than one optical aid.

TABLE 21

SEVERITY OF VISUAL IMPAIRMENT AND MOBILITY LIMITATIONS

Extent of Mobility Limitation	All Visually Impaired Persons (N=127)*	Blind (N=14)*	Other Severely Impaired (N=15)*	All Severely Impaired (N=29)*	Moderately Impaired (N=98)*
	%	%	%	%	%
Confined to house, yard or neighborhood because of eyes	17	81	31	54	8
Confined to house, yard or neighborhood for other health reasons	15	6	11	9	17
Travel outside neighborhood but need help of others or cane because of eyes	2	13	-	6	1
Travel outside neighborhood but need help of others or cane for other health reasons	7	-	21	11	5
No mobility limitations	59	-	37	20	69
	100	100	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

Note: Columns 2 and 3 show the extent of mobility limitation for the two groups comprising the "severely impaired" -- namely, the "blind" (those whose visual acuity was 20/200 or less on the Sloan distance test) and "other severely impaired" (or those whose visual acuity was more than 20/200 but who said they could not read ordinary newspaper print).

TABLE 22

SEVERITY OF VISUAL IMPAIRMENT AND EMPLOYMENT STATUS

Employment Status	All Visually Impaired Persons (N=115)*	Severely Impaired Persons (N=28)*	Moderately Impaired Persons (N=87)*
	%	%	%
Working	21	6	26
Looking for work	7	3	8
Retired	32	41	30
Unable to work	17	26	14
Housewife	15	18	14
Student	1	-	1
Other	7	6	7
	100	100	100

* Actual N of persons 16 years and over. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 23

LEISURE ACTIVITIES

Activity	Cleveland Pilot Study All Visually Impaired Persons (N=127)*	Severely Impaired Persons (N=29)*	Moderately Impaired Persons (N=98)*	Four-state Survey of Legally Blind
	%	%	%	%
Number of books read in past month				(N=684)**
None because of eyes	30)67	63)91	21)60	53
None for other reasons	37	28	39	
One	15	6	18	14
Two or three	10	-	13	16
Four or more	8	3	9	17
Watching television on average weekday				(N=684)**
Don't watch because of eyes	5)10	20)31	1)5	27
Don't watch other reasons	5	11	4	
Less than one hour	10	14	10	20
1 to 2 hours	21	9	24	23
2 to 4 hours	36	20	39	18
4 hours or more	22	26	21	10
Don't know	1	-	1	2
Listening to radio on average weekday				(N=684)**
Never listen	21	20	21	7
Less than 1 hour	22	14	24	18
1 to 2 hours	17	9	19	27
2 to 4 hours	17	20	16	22
4 hours or more	22	37	19	25
Don't know	1	-	1	1

TABLE 23 (continued)

LEISURE ACTIVITIES

Activity	Cleveland Pilot Study: All Visually Impaired Persons (N=127)*	Cleveland Pilot Study: Severely Impaired Persons (N=29)*	Cleveland Pilot Study: Moderately Impaired Persons (N=98)*	Four-state Survey of Legally Blind
	%	%	%	%
Movie Attendance				
Don't attend because of eyes	16		10	
Don't attend for other reasons	55		57	
None past month	17		19	
Once or more in past month	12		14	
Visiting with friends	(N=115)***	(N=28)***	(N=87)***	(N=684)**
Do not visit at all	16	21	14	8
Less than 4 times a month	36	29	38	32
Once or twice a week	21	32	18	32
Three times a week or more	24	18	26	28
Don't know	3	-	4	-
Membership in Organizations	(N=115)***	(N=28)***	(N=87)***	(N=684)**
None	65	79	60	56
One	20	12	23	21
Two or more	13	9	14	23
Don't know, no answer	2	-	3	-

TABLE 23 (continued)

LEISURE ACTIVITIES

Activity	Cleveland Pilot Study All Visually Impaired Persons (N=127)*	 Severely Impaired Persons (N=29)*	 Moderately Impaired Persons (N=98)*	Four-state Survey of Legally Blind
	%	%	%	%
Attendance at Meetings	(N=41)****			(N=302)****
Regularly or usually	55			59
Occasionally	16			27
Never or Practically never	21			14
Don't know	8			-

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three. Figures are not shown for severely impaired group because the N's are too small.

** Data derived from an earlier (1961) survey of adults 20 years and over drawn at random from the registers of four states (Massachusetts, North Carolina, Minnesota, and Oregon).

*** Actual N of persons 16 years of age and over. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

**** Actual N of persons who belong to one or more organizations. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three. Figures are not shown for severely and moderately impaired groups because the N's are too small.

TABLE 24

SERVICE THAT VISUALLY IMPAIRED PERSONS RECEIVE AND NEED

	All Visually Impaired (N=127)*		Severely Impaired (N=29)*		Moderately Impaired (N=98)*	
Type of Service	Have Received	Would Like to Receive	Have Received	Would Like to Receive	Have Received	Would Like to Receive
	%	%	%	%	%	%
Nothing	57	47	51	49	59	47
Medical treatment other than optical aids	30	13	20	6	32	15
Visits from a social worker	18	-	29	-	16	-
Glasses, optical aids	11	30	14	34	10	10
Planned recreation	4	7	14	11	2	5
Vocational training	4	7	6	6	3	8
Other visits to a settlement house	3	2	-	-	4	2
Help in reading	2	5	9	14	1	3
Help in going to school	2	4	6	6	2	4

TABLE 24 (continued)

SERVICES THAT VISUALLY IMPAIRED PERSONS RECEIVE AND NEED

	All Visually Impaired (N=127)*		Severely Impaired (N=29)*		Moderately Impaired (N=98)*	
Type of Service	Have Received	Would Like to Receive	Have Received	Would Like to Receive	Have Received	Would Like to Receive
	%	%	%	%	%	%
Help in traveling, housework, or shopping	2	4	6	14	1	2
Other Services	6	4	11	-	5	5
	139	132	166	140	135	131

* Actual N. In computing percentages, visually impaired respondents from the nontelephone sample have been weighted by a factor of three.

Note: Percentages add up to more than 100 because some visually impaired persons receiving or desiring services mentioned more than one type of service. The questions were: A. "Have you received any of the following kinds of services from any public or private agency?" and B. "Are there any services of this kind that you would like to receive because of your trouble seeing?" All respondents were asked part B, even if they had indicated that they were already receiving services.

TABLE 25

FAMILIARITY WITH AGENCIES PROVIDING SERVICES TO THE VISUALLY IMPAIRED

Familiar with Agencies Providing Services	All Visually Impaired Persons (N=127)*	Blind (N=14)*	Other Severely Impaired (N=15)*	All Severely Impaired (N=29)*	Moderately Impaired (N=98)*
	%	%	%	%	%
No	77	50	90	71	79
Yes, mentioned Cleveland Society for the Blind	14	44	5	23	11
Yes, mentioned other agencies	9	6	5	6	10
	100	100	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

Note: The question was, "As far as you know is there any agency or organization in Cleveland that provides services for people who have trouble seeing?" (IF YES) "Can you tell me the names of any that you know?"

TABLE 26

SEVERITY OF VISUAL IMPAIRMENT BY RACE AND AGE

	White			Negro		
	All Ages (N=85)*	Under 65 (N=35)*	65 and Over (N=50)*	All Ages (N=42)*	Under 65 (N=26)*	65 and Over (N=16)*
	%	%	%	%	%	%
Severely Impaired	26	26	26	11	5	25
Moderately Impaired	74	74	74	89	95	75
	100	100	100	100	100	100

* Actual N. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TABLE 27

SEVERITY OF VISUAL IMPAIRMENT AND MAJOR SOURCE OF INCOME

Major Source of Income	All Visually Impaired Persons (N=116)*	Severely Impaired Persons (N=29)*	Moderately Impaired Persons (N=87)*
	%	%	%
Social Security	34	49	30
Own or spouse's earnings	33	26	36
Aid to dependent children	7	-	9
Savings	5	8	3
Regular contributions from anyone in the family	5	8	3
Retirement pay, pension or annuity	4	3	4
Old Age Assistance	3	3	3
Unemployment compensation	2	-	3
Veterans pension	1	3	1
Other	6	-	8
	100	100	100

* Actual N of respondents providing financial information. In computing percentages, visually impaired persons from the nontelephone sample have been weighted by a factor of three.

TECHNOLOGICAL RESEARCH AND DEVELOPMENT ON VISUAL IMPAIRMENT

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In this brief review it will not be possible to cover most of the important areas which include technological research, human factors research, the role and relation of astrospace and military research, data processing research, and their relations to visual impairment. It would also be impossible to relate these areas of research to development, long range planning, and rehabilitation services. What I shall do is mention briefly the kinds of problems which continue to preoccupy technological and human factors researchers.

The most recent trend involves the team approach with experimental psychologists, mechanical and electrical engineers, mathematicians, physicisits, bioengineers, human engineers and, where relevant, doctors engaged in research.

At the present time there are about 30 projects in the technological and human factors areas intended to work directly towards partial or complete solutions of problems which affect the blind and deaf-blind. There are approximately 50 other projects in related social science and medical areas. The majority of these 80 projects are in the United States, England, and the Soviet Union. There are a few related projects in Sweden, Canada, Poland, The Netherlands, and Australia. The 50 related projects were initiated primarily for the astrospace or military effort and for the aging population. Part of our task in the field of research for the blind is to ascertain the findings from these 50 projects, and try to apply the results to work for the blind and the deaf-blind.

What has been the background orientation of individual researchers prior to the undertaking of research? The main factor is problems which seem to be so obvious to those who have met one or more blind persons or have read about them. In addition to discussing problems of the blind with a few blind persons or their relatives, project investigators have occasionally spent some time at a rehabilitation facility. On the basis of such limited sampling of important information the design parameters for instrumentation have been chosen. One additional factor has been the state of the art of technology as of the time the project began.

The principal problems for which instrumentation has been designed are: direct and indirect access to the printed word, handwriting and other graphic forms, independent mobility, and direct access to the spoken word for the deaf-blind. In addition to these key problem areas people have looked at the innumerable simple and complex tasks which are made more difficult or impossible by visual impairment and/or hearing impairment. For these tasks specially adapted and specially designed devices have become generally available in the more highly developed countries of the world. In addition, rehabilitation specialists and friends or relatives of blind persons have found that general purpose devices intended for the sighted population become even more useful in the hands of the blind or deaf-blind.

The following list of instrumentation is representative. In the reading area one direct access machine is the British Optophone which became available during World War I. The machine converts printed data to a series of musical tones. Only one of these instruments has been in use by one blind person. The mobility problem continues to be solved for those persons desiring to travel independently by the dog guide or the cane. A number of mobility devices is under advanced development and evaluation. One example is an ultrasonic "probe" which operates very much like the bat: objects are detected and their presence made known to the blind person through a series of chirps of varying frequency and intensity. The indirect access routes to the printed word and graphic forms have been improved by research and development on braille and sound recorded media. The modern digital computer will soon become operational in a rehabilitation facility which produces most of the braille in this country. Much more needs to be done before instrumentation of sufficient diversity, sophistication, and practicality is available to remove the dependence of the blind and deaf-blind on sighted humans and special processes.

In summary, the history of research in this field is brief, extremely interesting, and generally unrewarding in terms of terminal solutions to all major problems. There was only one project of any scope prior to World War II. This was the attempt at Cambridge University in England to develop the Optophone. Beginning during World War II and continuing to the present time there has been a tremendous increase in activity. Right now, for example, there are five working prototypes of mobility devices which one should take in hand and try to evaluate; there are three reading machines available as prototypes or in advanced development; and there are innumerable examples of simple, specially adapted and designed devices for the home, the school, and the job.

A few words are in order concerning the facilities at which sensory aids research is under way. In this country there are Veterans Administration sponsored projects at Haskins

Laboratories in New York City, Bionics Instruments near Philadelphia, Mauch and Battelle Laboratories in Ohio, and at the University of Southern California. The National Institute of Neurological Diseases and Blindness is supporting projects at Peabody College in Tennessee, and the Stanford Research Institute in California. The Vocational Rehabilitation Administration is funding research at the Massachusetts Institute of Technology and the Stanford Research Institute. The Medical Research Council and other agencies in England, as well as St. Dunstan's, have sponsored projects at Oxford, Cambridge, Keele, Lanchester College, Bradford Institute of Technology, and the National Physical Laboratory.

What has limited the success of these projects? Probably the most significant factor is ignorance of the way blind people live and struggle with their problems. The researchers and research planners have frequently had very little contact either with blind people who can solve problems and blind people who are tremendously handicapped by blindness. It is only in the very recent past that an exchange of information has begun between specialists in the rehabilitation area and the research community. For the most part, there has been very little long range, coordinated research planning. No governmental or private organization interested in the problems of the blind or the deaf-blind has maintained an advisory group of scientists who meet regularly year after year. The emphasis has been on individual projects limited in time, funds, staff, and facilities. There has been no machinery to take the products of the research laboratory through preliminary evaluation with blind or deaf-blind persons, through advanced development where justified, and into the final implementation process where devices are incorporated into rehabilitation services. There has been insufficient progress in human engineering in general to provide adequate data for displays, or for the interface between an instrument and the blind user. We know too little about the analysis of the tasks which confront blind persons to asign the proper amount of processing to the machine and to the human. In some cases we have tried to build instruments when blind persons could perform the task better by appropriate training and the use of their remaining sensory channels. These are most of the factors which have limited progress.

It is my educated guess, obtained during a recent trip to England, that if we Americans fail to initiate and implement through long range coordinated planning, evaluation, and development the English may succeed.

What is the current state of the art and the short range promise? The indirect access routes to the printed word have been substantially solved. Automated braille production, the use of the computer, and new access to publishing typesetting control tapes are here or in the immediate future. Mobility rehabilitation facilities are beginning to meet the demand for independent mobility through the dog guide and the cane. A number of miniature "eyes" and sophisticated mobility devices will soon be thoroughly evaluated, and their future development accelerated. Solutions to the problem of direct access to the spoken word for the deaf-blind is still in the preliminary stages of investigation.

From the long range standpoint there is great hope and promise. The physical sciences, technology, and medical researchers will eventually be able to process and introduce information directly into the central nervous system at the appropriate level. Organ transplants will eventually become routine. We are beginning to learn through the use of advanced computer and microneurophysiological research to synthesize parts of the central nervous system including the brain.

The research program will succeed when there are no longer any blind or deaf-blind persons. How soon we arrive at that goal depends upon the effort we are willing to exert as researchers and as taxpayers.

COMMENTARY AND SUMMARY REMARKS

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Dr. Newell and Dr. Graham should be congratulated on organizing a symposium which has offered as much information as related in these papers. An article in the last Journal of the American Medical Association was a satire on the gamut of frequency and implied that doctors are allowed to use three negatives in a row; therefore, I comment it is not un-impossible to discuss these papers in five minutes - but almost.

One of the interesting highlights is that every speaker here seems to feel that the individual opthalmologist and the profession as a whole have something to offer in all these areas, and he would like to enlist our support. The question it poses to me is, just how can we best give this support? It would be nice to hear from each one how he would recommend this be done as it relates to his special interest. In general within the four areas discussed this morning, as everybody has inferred, there seems to be a broad category in which people are defined as being blind or visually impaired for purposes of prevention, collection of data, compensation, aid, services, and etc. It would be nice if we, the opthalmologists, could help define this area, interpret the data, and supply a much more accurate definition so the impaired could be directed to the propoer places for services. I would also like to know from each in his specific area of interest just how this can be altered so we can have a much more definite idea of what is needed for the definition of visual impairment and for blindness.

There are several more questions that have suggested themselves to me as the individuals spoke. I think that I shall just pose them for what they're worth, and if they're answered now so much the better - but perhaps years will pass before we get the final answers.

To Dr. Goldstein I would like to say as far as a register is concerned, we do not have at our command at this time any consistent or accurate way of measuring the visual acuity, much less the visual capacity, of children under the age of three or three and one-half. I ask what importance this might have on such a register as he proposes? I would also like to say that when we speak of blindness and of visual impairment we tend to the habit of talking about people. I wonder if epidemiologically it would be important to consider eyes, since there is little information as to the natural history of the one-eyed visually impaired or blinded individuals?

To Mr. Clark I would like to ask if he feels there are any other vehicles, for example the rehabilitation manual of the Excerpta Medica, which could be used more effectively than it is now being used to help in the International Research Information Service? I would also like to know if he feels there are enough sufficiently trained people and laboratories available that we might be able to expect this project to be effective over a long period of time?

Dr. Riviere presented a very complicated system of coding in a very simple manner with a few columns on the board, but it isn't quite that easy - as anybody realizes who has tried to code any of these impairments. I would ask of her if she feels the coding would be so complicated as to lose its effectiveness as a practical device? I would also like to know the possibility of using these codes to determine other sensory, physical, or mental impairments and if these additional impairments could be correlated to visual impairments in a meaningful way?

Dr. Josephson presented a very simple Good-Lite apparatus for checking vision and he indicated to us that this is rather accurate and gives consistent results. He then speaks about allowing two lines (which in reality means three) as a not very important variation between the clinical examination and the tester's examination. This may be correct around the 20/20, 20/30, 20/40 level, but I wonder how this holds concerning the capabilities and the abilities of individuals around the 20/400 or 20/300 level. Two or three lines here can make a difference in the population of 50 percent or more. I would also like to know about the correlation that might come from such a study as he made between near and distance acuity. Did that show some relationship? Some people feel that we shouldn't even bother measuring near visual acuity; it is common to see reports which say that it is a waste of time.

Mr. Dupress, of course, had the most time and gave us the most in the way of technological advances. He inferred that we have, and I think he is correct, machines that can detect obstacles, detect openings, detect steps-up, and detect steps-down. We can also get this information to the user either aurally or tactually. Now it seems with all this technological ability we should have something that is more practical. I wonder how the technological investigation should proceed to make these things we have usable? Do we need to do technological research in the area of technique and procedure as well as on invention and production?

There are many other questions suggested by these very erudite papers but I have only one addition to what has been said and that is; Congratulations to each of you for your contribution.

DR. GOLDSTEIN

The two items raised by Dr. Hoover are very pertinent. From some of the data we have already secured in the Model Reporting Area states, the group under five years of age has the lowest prevalence and incidence rates, and this may in turn reflect the difficulty in securing adequate visual acuity data on such a group. It is my hope that with more research and instrumentation we will more nearly approach the true figure, and I think this calls for a tremendous amount of ingenuity and drive in being able to get data that adequately reflect the condition of this young age group.

Concerning the point raised by Dr. Hoover on the possibility of considering eyes and not people, this has been under some discussion at some of our committee meetings. As you may know, in classifying a cause of blindness the general procedure has been to take the eye that becomes blind latest in time and give that cause to the record form. Where both eyes have the same cause there is no problem, but when the cause is different for the two and no information is available on time, there is a problem with what is done about this. This is still of great concern to us.

Another point is the magnitude of the one-eyed population in this country. I recently contacted the National Health Survey and they gave me some information: they estimate that there are 600,000 one-eyed persons in this country. I would think that this is grossly understated, and it brings to mind the need for us to think of prevention measures and programs that may be geared to these people, because obviously the risk of becoming totally blind for such a group is vastly higher than for the population at large.

MR. CLARK

I believe that what you've proposed for us is a matter of homework, Dr. Hoover, and I must admit that during the past three years we have come time and again upon situations in which an indexing or coding scheme has been developed (as in the Working Party for Adaptation Instruments in The Netherlands, or the Society for the Handicapped in Sweden) that has direct relevance to our own interest in ordering our data and our information. Because of our other commitments we have not yet had an opportunity to work these through. We know in most cases of their existence; I don't know whether our knowledge is as yet exhausted.

We also have yet to coordinate our own activities with those of the National Medical Library, which as you know is just fully coming into operation, and I have a feeling that there will be a good deal of mutual help here. We have been in intimate contact with abstracting and indexing services and current awareness services, both federal and private, in the United States. To a certain extent we've extended our cooperative efforts to other countries, notably England and The Netherlands so far, but this is just part of our initial task at the present time.

DR. RIVIERE

We do, on our record form, provide for coding of multiple impairments both where these are completely separate, coincidental conditions from completely different etiologies or where a visual problem might arise in the long disease process of, say, diabetes. We can code this first as one of the symptoms in the cluster that we have developed for the syndromal description of diabetes, with allowance for the precise amount of vision and visual problem diagnosed to be added in as a secondary condition, but with the same cause as etiology. In direct service programs, if the visual problem is a primary problem to be considered, it could be coded as the primary impairment and the additional impairments added on in separate columns, each of which is described for its severity, duration, response to previous therapy if any, and prognosis for response to future therapy. Also, in tabulating we provide one master card on which would be coded all impairments with gross pathology grouping and etiology, and then a separate card for the full description of each separate condition -- so that we could cross-relate any type of condition found in an individual at any date with the visual problem.

MR. DUPRESS

Dr. Hoover raised a question as to whether there was any implementation; I have already mentioned that we are trying to get a center organized to do just that. The English have, for example, one mobility device which is now being production engineered. It represents from the beginning one engineer's interest to build a prototype. He got some small support from St. Dunstan's, a private organization. Ten prototypes were built by Ultra Electronics Ltd., a commercial concern. Upon the recommendation of a scientific advisory committee to St. Dunstan's made up of medical doctors, physiologists, engineers, physicists and so on, all first-rate English scientists, the evaluation of the first prototype was done by staff members of Dr. Boadbent's group at

Cambridge. The funding for the production engineering and redesign are being provided partly by St. Dunstan's, partly by the National Development Corporation of England, which is a governmental funding group for development work, and by Ultra Electronics Ltd. Half the units will go to St. Dunstan's and half will be available to other organizations in the world to use, and after 100 prototypes are built there will be training procedures set up by the people in Dr. Broadbent's group. In other words, they have a coordinated program. We're trying to get such a program in this country: the federal government wants it; our own advisory committee wants it; the staff is prepared to join the center. The bride who is being wooed is the Massachusetts Institute of Technology, and she's rather reluctant as of the moment but she is far from saying no. If she agrees to join the marriage party, Harvard, Brandeis, and Tufts will follow in quick order. Who knows? If we don't do it here the English will do it; and if the English don't do it, the Russians will.