Science & Blindness:

Retrospective & Prospective

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Milton D. Graham, Editor

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This volume is dedicated to J. Alfred Leonard, one of whose last acts was to participate in this seminar. His friends and colleagues will sorely miss his dedication and sense of direction.

Foreword

SCIENCE AND BLINDNESS: Retrospective and Prospective grew out of the American Foundation for the Blind 50th Anniversary International Symposium on Science and Blindness, held in New York City in October 1971. If there has ever been any doubt that the research community is truly international, this report should settle that doubt.

It is always good to see so many different kinds of experts talking and listening to each other in their mutual concern for the welfare of blind persons. The contributors to this book run the gamut from biostatisticians concerned with the numbers of blind people and their principal characteristics to engineers concerned with lunar buggies and how they navigate. Physicists talking to psychologists and teachers talking to neurophysiologists. They worry about "diamonds," the intelligent, well-trained blind professionals, and about "pebbles," the ordinary and often untrained blind people. They ponder over training blind computer programmers in California and Denmark, selling lottery tickets in Spain, and extending the U.S. blindness service system or nonsystem to serve more blind people.

It is gratifying that there are so many different points of view on so many different topics, for underlying the differences is a serious concern for the problems that blind people face. Certainly, no final solutions are offered to many of the problems raised, but as long as there is discussion and concern there is hope that some solutions may come in time.

Let us hope that some of the ideas presented and the personal give-and-take of the scientists and technologists attending the meeting will have some positive results. This book is a record of those hopes.

Naturally, no event of the magnitude of the International Seminar on Science and Blindness happens without meticulous planning in advance. It is the synthesis of many ideas and persons and then the unstinting interest and cooperation of the participants.

In this foreword we cannot single out everyone who participated for specific acknowledgments but on behalf of the American Foundation for the Blind, we want to thank them all, especially Dr. Jerome Weisner, the honorary chairman, John S. Crowley, the general chairman, and the Foundation staff, led by Dr. Milton Graham, who did so much to design and execute the meeting.

M. ROBERT BARNETT
Executive Director
American Foundation for the Blind

Preface

Mr. M. Robert Barnett, Executive Director of the American Foundation for the Blind (AFB), opened the International Seminar on Science and Blindness on October 25, 1971 by welcoming some 60 participants and declaring his hope that the three days of meetings would result in a fruitful interchange of ideas. He then turned the meeting over to Dr. Milton D. Graham, Director of AFB's Research Department and chairman for the first day's session. He conveyed to the meeting the greetings of Dr. Edward E. David, scientific advisor to President Nixon and a onetime member of AFB's research advisory committee. Regrets were sent by:

Dr. Carson Nolan
American Printing House for the Blind
Dr. Arthur Parmelee
Medical School of the University of California at Los Angeles
Ignacio Satrestegui
Spanish National Organization of the Blind
Dr. Hans-Lukas Teuber, visiting professor
at Oxford University
Boris Zimin
All Russia Society of the Blind

All participants are listed in the appendix.

Dr. Graham also expressed profound regrets that since our last international meetings two of our most esteemed colleagues had died: the Reverend Thomas Carroll of the Catholic Guild for All of the Blind, and Mr. John Dupress of the Sensory Aids and Evaluation Center of the Massachusetts Institute of Technology. (We must note with deepest regret that since the international seminar and the publication of these proceedings, Dr. J. Alfred Leonard of Nottingham University has also died.)

Dr. Hyman Goldstein of the University of California at Berkeley began the first day's presentations. All presentations, remarks by discussants, and a short discussion by the editor of these proceedings constitute the bulk of this book.

At luncheon on Monday, October 25, 1971, Lord Fraser of Lonsdale made some remarks as did Mr. John Crowley, President of AFB, on Wednesday, October 27. These papers will be found in the appendix. Dr. Jerome Wiesner, President of the Massachusetts Institute of Technology and honorary chairman of the three-day scientific ses-

sions concluded the international seminar with a presentation to the 50th anniversary banquet. This paper will also be found in the appendix.

Readers should be aware that the format of the three-day presentations was an unusual one. Participants making presentations were asked to prepare papers in advance. These papers were circulated before the meetings as preprints to all participants. The authors were then asked to discuss their papers, not read them, before all participants in a plenary session. Discussants of the papers were also asked not to read their remarks. All remarks were recorded. This book represents the edited version of the recorded remarks.[1]

As anticipated, this form of presentation resulted in a more informal exchange of views and contributed considerably to a wider appreciation of the many complex problems and specialized vocabularies that faced the participants.

The seminar was adjourned at 5:00 PM October 27, 1971.

MILTON D. GRAHAM, Editor

[1]Original papers circulated as preprints can be obtained on request from the Research Department, AFB.

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Demography of Blindness

Dr. Hyman Goldstein

The foundation is celebrating its fiftieth birthday, and this is a momentous occasion. But fifty years is a very little time when we look at the long, thin thread of the history of blindness. It makes us all unhappy to realize that after all this time so little is known about the prevalence of blindness which can be compared from country to country. We know so little about the demographic characteristics of the blind, and the causes of their blindness.

Estimates of the total number of binocular-blind in the world have varied greatly because of differences in definition and differences in the way data are collected making comparisons almost impossible. It is urgent that a solution be found in this problem, since comparisons are the very heart of research and evaluation. Even in our country we have no factual, precise information about the number of blind and their characteristics. The number of definitions used here and abroad are legion. I for one would like to see some agreement, at least on the things that would make identification and tallying easier.

These definitions, of course, are exclusive of whatever definitions there may be now in the functional or behavioral areas. Recently there has been considerable emphasis on sensory function rather than sensory capacity, and on efficiency rather than on ability. We know that approximately 90 percent of the legally or economic blind have some residual function, some residual vision, and the problem is to determine how well they use what they have left.

We need data, good, solid, factual, and reliable information on the size and distribution of prevalence, that is, how many blind there are; and on incidence, how many people become blind year after year. We need information by demographic characteristics of age, sex, and race. This will help us to compare the resources we now have with what we need in order to give satisfactory and adequate services. It will also help us to determine which groups in the population are at greatest risk of blinding disorders so that we can direct our prevention and case identification programs accordingly.

There is general agreement among all of us on the need for such information, but not on the best methods of securing the information. This has to do with the method of collection of data, namely, survey, census, register, and estimates. I have seen situations where an estimate

is made of an estimate, and the possibilities of error in such cases are frightening.

In this country estimates of the prevalence of blindness have varied from 214 per 100,000 in 1960, based on an examination-derived distance-visual criterion for the economic blind to about 660 per 100,000, about three times as large, based on an interview-derived near-vision criterion. This latter estimate is for the severely visually impaired, including blindness.

The history of attempts to secure blindness data in this country go back to the year 1830, when the census of that year, for the first time, included efforts to determine the number of blind. These efforts were continued decennially for 110 years, up to and including the census of 1940, and then were discarded, because of the fact that the data secured were understatements, and never agreed with the data available from localities. This may be due to the fact that there was no generally accepted definition of blindness over that period of time, and there was great variation in judgment by the census innumerators. A tendency for families to be reluctant to reveal a blind person in the family also biased the data. The National Health Survey of 1935-1936 attempted to get at blindness information and this, too, was very unsuccessful, due in part to some of the same errors and problems that had been evident in the census.

The current National Health Survey of the U. S. Public Health Service conducted a nationwide household survey of a representative sample of the population during the period from July 1957 to June 1958. They made use of the functional definition of blindness that is currently used in this country; an answer to the question is there anybody in this household who cannot read newsprint, even with the aid of glasses? As you will note, there is no measurement involved of any kind. This is purely based on a behavioral characteristic as perceived by the blind themselves or by relatives. That survey estimated that there were 960,000 blind in this country at that time, and later it was amended to read *severely visually impaired* instead of blind.

Of course, this rate greatly exceeded those found by any census and by the 1935-1936 National Health Study.

There have been later National Health Surveys, one in 1959-1961 and one in 1963-1965, both of which used the same criterion, the newsprint question. They came up with estimates ranging from 5.6 per thousand to 6.6 per thousand or, from 988,000 to 1,227,000 persons.

A different type of national survey by the National Center for Health Statistics had to do with examination of a sample of the

population. In 1960-1962, an attempt was made to determine the binocular distance-visual-acuity of a probability sample of persons aged 18-79 years in this country. These were the first data to be collected on a national probability sample of the adult population. The rate of binocular distance-visual-acuity was 8-per-thousand using the criterion of blindness of 20/200 (Snellen) in both eyes.

We must note that up to that point, all the methods that have been mentioned as having been used were concerned with prevalence, that is, the number of severely visually handicapped or blind persons in the population. From the point of view of prevention, information on the newly blind or newly reported blind (including cause information) is of equal or perhaps greater importance.

With the passage of the Social Security Act in 1935 there was a new impetus for states to develop information on their blind, and in so doing perhaps to set up registers of the blind which would give certain minimum information regarding their characteristics, their visual acuity, and the causes of their blindness. The Social Security Act recommended that the 20/200 designation be set up as a criterion for economic blindness, and also recommended that examinations be given by ophthalmologists, or eye-ear-nose-and-throat men, in order to obtain more accurate, detailed, and uniform statistics on the causes of blindness.

The purpose of a register is not primarily statistical. It cannot be expected to give dependable statistical data unless the agency maintaining that register updates it periodically. Those individuals who have died in the interim should no longer be in the register. Any additional and further information on living individuals should be updated. For example, if a person regains his sight, he should be removed from the register. Furthermore, it is most essential that physicians report all of their blind patients. This assumes a certain rapport with the medical and other professions who are involved in reporting cases to a register.

The absence of uniform data on newly reported cases of blindness and on causes of blindness led, under my direction to the formation of the Model Reporting Area for Blindness Statistics (MRA) within the National Institute of Neurological Diseases and Blindness of the U. S. National Institutes of Health. This was a new endeavor, an attempt through voluntary cooperation of states to agree on a uniform definition, on uniform procedures for collection of data, on uniform procedures in updating registers, on uniform tabulations, and on a uniform classification of causes. This may not seem like much, but it was a tremendous step forward when you look back and see the

chaos that existed; it was impossible to compare the data from one state with that of another.

As of 1971, the Model Reporting area consists of 16 states and covers about 30 percent of the population in this country. The latest available estimates of incidence and prevalence rates, based on MRA data, are respectively 18 for incidence and 155 for prevalence per-100,000-population. These rates are understated for the reasons I have given. There is no reliable information available as to the degree of understatement.

What is the situation in other countries? In other developed countries, the situation is much like what we have in our country. However, in the underdeveloped countries, it is immensely difficult to conduct accurate surveys of prevalence. I will not even touch on incidence, because even in many of the developed countries incidence data are not available. In the developing countries, it is very difficult to do surveys under standard conditions to test vision, and this is particularly true in the outlying rural areas. However, it is my belief that until developing countries have services available to the blind, a survey is the best way of getting information.

I realize that a survey is expensive and would be quite difficult without assistance in these countries.

What does the future hold for us? The aging of the population is a fact of life. This means several things to us. We know that the expectancy of life has been increasing, and this foretells a growing population at risk of developing blinding disorders and ultimately blindness. Most of these people, newly blind, will be older people to a larger degree than at present. Even if the age specific blindness incidence rates remain stationary for the next four decades, there will still be an increasing number of blind since our population is increasing.

I noticed in the newspaper the other day that our fertility rate and our birthrate are dropping, and we are getting fairly close to zero population growth. However, despite this development, our population will continue to increase for at least 50-70 years. It would appear to me that now and far into the foreseeable future, medicine and society will be more and more involved in the diseases and impairments of old age, and we will find ourselves increasingly obligated to provide the necessary facilities for our ill, impaired, senior citizens.

The obligations that a society assumes toward the blind in various countries is a prime determinant of the definition of blindness which is accepted in that country. Countries who are liberal in their benefits to the blind, and who have national registers of the blind, are more apt

to get more accurate information on the number of the blind. This happens also where it is possible to make good reliable surveys of the population. In general, however, the data we have on blindness throughout the world is inadequate and incomplete.

Fundamentally, in this country, at least, there are two approaches to securing data on severe visual impairment and blindness. The *examination* approach uses the economic definition of 20/200 in the better eye with best correction (I want to underline that *best*) or an equally disabling disability in field of vision. The *survey* approach uses the functional definition, of which one example is the ability-to-read-newsprint question I mentioned before.

What are the advantages and disadvantages of each type of approach? The examination approach offers a more objective measurement and a more objective criterion for the determination of severe visual impairment based on distance vision and/or field of vision. Only when an ophthalmologist or a similar EENT specialist makes the examination can cause information be obtained. This can be of great importance in affording clues as to the degree to which various subsamples of the population, by age, sex, race, and occupation may be susceptible to various blinding disorders. This helps us to know where and for which target populations to mount programs of prevention. A test of central-distance visual acuity has been considered the single most important test of visual acuity in children.

What are the difficulties or problems in the examination approach? We know that a definition in purely ophthalmic measurements is not always accurate or fair. The Snellen chart, which is the basis of most of our examinations, measures only distance acuity, and in many cases near vision may be the critical factor in applying for admission to schools for the blind.

About 11 percent of our blind population is totally blind. The rest have some residual vision. It is important for us to know to what degree residual vision has been and can be used. This is called *visual efficiency*. The findings in the examination approach depend on the skill of the examiner and his reliability. Too often this skill is never tested. The Snellen chart, it has been noted, is deficient in the approximate region of the 20/200 line, and needs at least one additional line. It is possible that many individuals who were given an acuity of 20/200 would not have been, had there been an additional line between 20/100 and 20/200.

Standardized lighting, distance, and complete occlusion of each eye are needed. Much too often, particularly in the case of children

being measured with a Snellen chart, these standards are missing. Certainly, in making comparison from area to area, the standard lighting and distance parameters are urgently needed.

Finally, the Snellen chart does not tell us about the functioning of the individual, whether he can travel, whether he can read, and other functional details that are most important for us to know.

The survey approach also has certain advantages and disadvantages. It gives us information regarding the respondent's perception with regard to his vision, and this may be as important or more important than clinical measurements. The Snellen chart is rather artificial. It tells us what an individual can read on what line at a given distance and under given lighting conditions. It does not tell us too much about what the individual can do in his real-life situation. Because of the fact that random samples are selected in the application of the survey technique, it becomes possible for us to generalize the findings to the toal population from which the samples were drawn so that we can make estimates with a known degree of error. This possibility of using random samples or probability samples is true of both the interview and the examination approach of the National Health Survey.

What are the disadvantages of the survey approach? Although attempts are made to exclude illiterate persons, it is possible that an illiterate person may be considered severely visually handicapped with the newsprint definition. The use of low vision aids makes it possible for a person to be able to read even though he may be considered blind by the economic definition. The newsprint definition is based on near vision. The criterion of reading that is used is, in a sense, equivalent to only 20/50 if it is converted into distance vision. This is far from the 20/200 criterion used in the economic definition. The distance from the newspaper to the eye would, of course, vary from person to person, and could create considerable variation in results and in meaning.

Although some attempt is made in the survey approach to note different degrees of severity, these degrees of severity are not as detailed as data derived from the economic definition or from examination. A respondent who serves as proxy for his relatives may not have accurate information about their newspaper reading ability, since he most probably can respond a lot more accurately on his own visual limitations than he can on those of others. Accepting a statement from a respondent of his severe visual impairment without attempting to validate the information by some accepted criterion such as a reading test with standardized distance and lighting, is contrary to acceptable procedure in evaluating screening tests. It has been found