# LIVING WITH LOW VISION AND BLINDNESS

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# LIVING WITH LOW VISION AND BLINDNESS

# Guidelines That Help Professionals and Individuals Understand Vision Impairments

By

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and

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### PREFACE

Will Rogers is credited with the statement "Everyone talks about the weather but nobody does anything about it." We feel that, like the weather, there is a lot of discussion about education and rehabilitation services to the blind, but often there are feelings of discouragement about efforts to overcome poor quality services or the lack of services. This book is an effort to review some past discussions, suggest ways to improve and increase the amount of services available to those who are blind or who have low vision.

Hopefully, those who have been trained as educators or rehabilitation specialists in the field of work for the blind and visually impaired will find information that is new or that will remind them of issues which still need to be resolved. However, **this book is meant to be an overview of issues which need to be understood by psychologists, social workers, educators, rehabilitation specialists, therapists, families, and others who have little or no training in work for the blind and visually impaired.** Others will find information from the fields of general psychology, science, and regular education we have encountered which could prove helpful in understanding and improving services to those who are blind or who have low vision.

We have departed somewhat from traditional scholarship in that specific references are not cited. What is discussed here comes from texts, journal articles, and many years of experience in work for the blind and visually impaired. References consist of only a few books and articles listed after each chapter as "Suggested Readings." Many of these will lead readers to in-depth study of subjects of interest to them. Other sources which are listed provide a rich background for understanding the needs and complexities of providing education and rehabilitation services to this very diverse, low incident population. The population consists of children, students and adults who never have had or who have lost most or all of their eyesight. Some readings are not still used in professional training programs because of the limited time available to professors to present vast amounts of information needed to serve the array of children, students and clients. We consider most of the suggested readings to be vintage material that should be considered by those interested in serving the blind and visually impaired.

Our viewpoint is that absence of or the loss of the sense of sight makes individuals who are "blind" different to the degree that quality services are most likely to be provided by professionals and agencies that have special training and experience. This perspective seems at odds with the current general philosophy and current practices, services, and programs. For several decades, state and federal funding patterns, professional training, and public misunderstanding of the effects of vision loss have pushed services toward a "one size fits all" approach. We believe when concept development, self-concept, motivation, perception, emotions and attitudes are impacted by loss or absence of sight to the degree they are, that specialized programs and services are the most effective and efficient way to help the individual be a productive, independent and contented member of their community. We also believe that contributions from science, medicine, psychology, and sociology provide information about neurology, memory, psychological adjustment, and engineering that can be used to serve the blind and visually impaired better.

The ways individuals who are blind or have low vision accommodate, learn and perform successfully are not in any way inferior to other ways, just different. Neither are the methods of instruction, things to be learned and adaptive technology inferior, just different. Hopefully the material presented here will help bring understanding to the differences and suggest improvements professionals trained to work with the blind and visually impaired as well as those from other professions can make.

It is not expected that all will agree with what is presented here. It is hoped that due consideration will be given to the views and information. It is hoped that this book will benefit individuals wishing to provide programs and services for those who are blind or who have low vision.

> John M. Crandell, Jr. Lee W. Robinson

### INTRODUCTION

The educational and rehabilitation systems for blind and partially seeing persons (along with all special education and rehabilitation services) are in a state of great flux. There is no consensus of where the upheaval will lead, whether toward greater inclusion of these persons into the educational and vocational "mainstream" or toward more isolated programs, or toward something quite different.

There is a need to consider the progress the fields of blind education and rehabilitation have made in the centuries since Valentin Hauy began the process of preparing those without sight for participation in the broader society. There have been controversies throughout the years and, hopefully, we have learned something from the resolution of these difficulties. Several excellent books have offered some viewpoints on these difficulties (e.g. Koestler, 1986; Scholl, 1986).

This book is an attempt to summarize the findings in the fields of general education and psychology as they relate to vision loss. It makes no claims of being complete. Hopefully, it will stimulate thought and discussion on some of the issues which face us in this time of great change.

A properly made convex lens increases the apparent size and detail of an object being viewed. The greater the power of a convex lens, the larger the object appears and more of the detail is visible—as with telescopes and microscopes. There is a price which is paid for the increase of size and detail: the field of vision is decreased and the relationship of the detail to the whole is diminished or lost.

In like manner, when emphasis is placed on specific remedial and instructional techniques without the broader perspective provided by theory and principles, the professional worker may not be able to see how a specific program impacts the total life of individuals with vision loss. In the same way, if one becomes so caught up in philosophical and theoretical perspectives, practical concerns of how tasks can be performed may be lost.

A balance between general perspectives and specific intervention approaches needs to be maintained if the lives of those with whom one works are to be properly assisted. It is not enough that an individual client or student knows braille, typing, and travel skills; he/she must also know about the broader society into which he/she needs to enter and to become an independent and contributing member.

This book is designed to provide both a Gestalt or overall perspective in the field of work with the blind and visually impaired and to focus the attention of the reader on the many detailed facets examined in other sources. Vision loss does not occur in isolation from personal and environmental factors, and on the basis of theories, a worker can infer special needs. If these psychological and sociological perspectives are lost, the professional worker will find it difficult to guide the educational and rehabilitative processes for an individual. For example, one area of need for people, including those with vision loss, is to be able to access the environment. Helping a particular visually limited person in meeting this need is not a simple matter of choosing from among several options-sighted guide, guide dog, the long cane, etc. Rather, the professional needs to know about the person's history of vision loss such as age at onset; residual vision, if any; type of losscentral loss or peripheral loss-type of residential area including where the visually impaired person needs to go; family attitudes toward independent travel for their visually limited family member, physical capabilities of the person, including additional disabilities, and so forth before a choice is made. Without the broader perspective, however, there is a strong tendency to focus too narrowly on strictly technical aspects of the program. With a broader perspective, details of the plan for a specific person can be woven into the total pattern.

The book is concerned primarily with providing understanding of the many elements which must be considered before a successful rehabilitative and/or an educational program can be developed. This type of understanding will be illustrated in the pages of the book by examples drawn from experience which the authors have observed directly. Theoretical factors will be described which must be considered in the development of a suitable program for a person with specific strengths and weaknesses.

Discussions will also be included related to the meaning and implications of self-concept and self-esteem in the overall adjustment of

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### chapter title

individuals with vision loss. We will also evaluate psychological and sociological theories of "the blind" as described in writings such as Kim's, *The Community of the Blind*, and Scott's, *The Making of Blind Men*, in terms of their relevance to life adjustment. An attempt will be made to identify weaknesses in the research bases in this field and propose specific research activities which could help alleviate problems.

Another focus will be provision of explanations of the origin, development, influence, and modification of public attitudes toward blindness and the influence of these attitudes on the adjustment of individuals with blindness. We will use information–concepts and theories– in the development of specific goals and objectives for a specific person with unique characteristics in a service setting: writing an "IWRP" or "IEP."

This book is foundational, i.e., providing a framework within which to fit materials from many sources. The knowledge base for this book consists of the historical and research literature available in texts, and from the professional journals. An attempt has been made to organize this book on the basis of a systematic and reasoned outline to provide scaffolding upon which the content of theories can be place. It starts with simple ideas and moves toward more complex concepts. Suggested Readings are given after each chapter as well as at the end of this preface.

### SUGGESTED READINGS

- 1. Koestler, Francis A. (1976). The unseen minority: A social history of blindness in the United States. New York: David McKay Company, Inc.
- 2. Scholl, G.T. (1986). Foundations of education for blind and visually handicapped children and youth: Theory and practice. New York: American Foundation for the Blind.
- 3. Scott, R.A. (1968). The making of blind men. New York: Russell Sage Foundation.

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Any contribution the authors may make to help individuals who are blind or who have low vision as well as professionals in the field of work with this population is heavily indebted to many generations of leaders and dedicated teachers and rehabilitation workers who have devoted their lives to service for the blind and visually impaired. We have had the opportunity to become personally acquainted with many of these individuals and have benefitted from their efforts. Likewise, there are many current friends and colleagues who have encouraged and supported us during our many years of work. We express our deep appreciation to each and all of them.

Our families have also supported and labored along with us to see that this book has been completed. Without their support and tolerance, it would not have been possible to spend long hours of discussion and writing. We hope they will be pleased and rewarded for their consistent encouragement.

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# LIVING WITH LOW VISION AND BLINDNESS

## Chapter 1

### CURRENT SETTING

There are many speculative opinions about how individuals who are blind or who have low vision may be different from those who have normal or correctable eyesight. There are just as many opinions about how individuals with visually impairments are the same as other people. Perhaps the more important question is, "What evidence is there to support either side of the arguments?" Amidst all the questions and opinions, "What difference does it make to the person with blindness or low vision?"

Founders of programs of education and rehabilitation for the blind and visually impaired have been divided over these issues since the first schools for the blind were begun in the late eighteenth and early nineteenth centuries. Early examples of successful blind individuals seemed to point to unusual abilities which should be fostered through specialized education, training, and support. Other notable pioneers stressed that the blind should be included in the "common" schools and receive the same curricula as their sighted peers. The different philosophies have spawned controversy for over two centuries and continues today with most avid debaters shedding more heat than light on the issues.

General changes in society have had their influences on the prevalence of segregated or integrated programs for the blind. For example, during most of the 1800s only a few programs were supported outside of special schools for the blind. This reflected the general attitude of society toward all those who were disabled. Asylums, poor houses, and orphanages were the major alternatives to total support from the family, usually in an agrarian setting. Thoughts of alternative ways to provide for the blind/visually impaired shifted to more local community-based efforts as the populist movement began to advocate for services that would meet the needs of a more industrialized society. This general change split the field of work for the blind. There were those who strongly advocated for the continuation of state-supported schools and eleemosynary institutions. There were equally strong advocates who stressed the importance of being in the "world of the seeing." Each pointed with pride to the successes of those completing their programs.

One common theme through the decades of debate has been the assumption and belief that, given the appropriate education or vocational training, individuals who are blind or have low vision can be successful and happy adults who participate in and contribute to society. The success, however, has often depended upon the willingness of society to provide resources including specially trained personnel, adaptive equipment, and equal opportunities for gainful employment. Governmental funding has waxed and waned with the nation's economy and the corollary meant that the disabled were the last to be hired and the first to be fired.

As an example, during the era of post World War II, the costs of war and the influx of women into the work force as well as the return of military personnel to civilian pursuits made it difficult for those who were blind to obtain employment even when well educated and qualified. This situation was observed by governmental entities and rehabilitation programs were begun that emphasized employment in "new" occupations. Orientation and mobility programs, which were first begun to aid returning veterans, became a part of training in virtually all rehabilitation agencies. By the 1960s, the United States was in an economic position to support many more special programs as a part of the "Great Society." Many professional personnel training program were in operation. Later, as the national economy worsened, many programs lost funding and closed or were severely limited in scope.

Beginning with the Rehabilitation Act of 1973, and the Education for All Handicapped Children Act of 1975, and extending until the present, another cycle has been evident. These two public laws of the United States have entitled those with disabilities, including those who are blind/visually impaired, to education and rehabilitation with the expectation that given opportunities they would be integrated into society. In early stages of implementation, many new programs were

### Current Setting

begun and both state and federal efforts provided considerable new funding. However, again as the economic tides shifted, Congress did not fund programs as "promised" and many unfunded mandates have stretched the resources to a point where the quality and effectiveness of services being provided has come into question with a corresponding skepticism about the value of special education in general with concerns that spill-over into services for the blind. The need for unique services to the blind is especially under fire.

The laws which have generated current special education and rehabilitation programs are mostly based on an "inclusion" philosophy giving extreme preference to participation in the "general" programs. Funding patterns at the national and state level have supported this philosophy to almost the total exclusion of all other models of service. Providers of specialized services are being forced to provide evidence that there is a need for specialized services to the blind and those with severe low vision. The predominant models support generic programs even though the facts provide evidence that two-thirds of the workforce of eligible blind are unemployed or underemployed, which would indicate lack of success of the generic approach. So, the speculation and debate about whether special or generic models of service best meet the needs of individuals who are blind or who have low vision continues.

### **Blind Persons Are Different**

One factor that continues to fire debates as to whether the blind are more like than different from the sighted is the diversity of the population. As will be discussed in later chapters, the blind are found among all social and economic strata of society. It does not matter whether families are rich or poor, whether they come from a specific geographic region, whether they descend from any particular racial or ethnic background; all are touched by loss of sight. This may be from having an infant born into the family who is blind or it may be the result of disease or accident any time later in life. Fortunately, the number of those who are blind or have severe low vision is relatively small, but this, too, makes identifying and understanding the needs through valid and reliable research difficult.

Until the inventions of modern imaging techniques that allow observations of brain activity in humans, researchers could only speculate about what happens when the sense of sight is not ever present or when it is lost. From animal studies, researchers found that the brains of rats changed when eyes were removed with the visual centers becoming smaller and other areas increasing in size. Monkeys and cats placed in environments that had only one visual pattern available to them were later unable to detect other patterns. While these were interesting findings, it was not possible to confirm similar findings in humans. However, folk lore, such as blind people have a better sense of hearing or touch, seemed to make sense. These studies suggested to some how the brain of blind individuals might function in different ways from the sighted. Conclusions from these animal studies stressed the unique features blindness has on neural development.

Studies by professionals using techniques that measured the sensitivity of hearing and touch seemed to refute any notions that brain functions of the blind were different. Measured acuities of the senses did not support ideas that the blind were different except they could not see. Likewise, those with other disabilities have more characteristics like "normal" children than not. This "evidence" was used by advocates of generic philosophies to support *their* service models designed to "mainstream" students or clients.

Still, regardless of how grounded service providers are in generic services for the blind even those grounded in the generic models must recognize that some tasks such as concept formation are supported by visual stimuli. In fact, some concepts such as color, clouds, flames, and other phenomena are not possible for those with total absence of sight to understand in the same fashion as individuals with sight do. So, questions about the differences between individuals who are blind and those with sight persist. How do those who are blind form concepts? Are the same centers in the brain used to store and retrieve information? Are tactile stimuli as powerful or can they replace visual input effectively? The fact that adaptations to the learning media are needed for training make it obvious that different centers of the brain will be involved. Tactile media surely require that tactile areas of the brain be more active. Taking advantage of the brain's plasticity to learn would seem to require those who provide services to study special theories and methods unique to the blind.

In the past few years, magnetic resonance imaging which allow observation of electrical activity in the brain without surgical invasion has shown that "image centers" in the brain are different when chil-