SELF-ESTEEM
AND ADJUSTING
WITH BLINDNESS

Third Edition

SELF-ESTEEM AND ADJUSTING WITH BLINDNESS

The Process of Responding to Life's Demands

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To those from whom we have learned much:
University and Hadley students,
workshop and conference participants,
parents and family members,
and, most of all, blind individuals both children and adults.

FOREWORD

If you wish to know the road up the mountain, you must ask the man who goes back and forth on it.

—Zenrinkushu

Twenty-five years ago my doctoral advisor at the University of Northern Colorado, Dr. Dean Tuttle, was assisting me in selecting a dissertation topic. At the end of our session, he asked if he could "bounce an idea off me."

He informed me he was thinking of expanding his series of lectures on the stages a person goes through in adjustment to vision loss, into a book. He asked if I thought the book would have relevance for a market outside his original intended audience—students in university programs studying to be teachers of the visually impaired, orientation and mobility instructors, and rehabilitation teachers and counselors.

He was a man who had been "on the road up the mountain" day in and day out for years—dealing with his vision loss. En route, he learned of the works of Beatrice Wright that illustrated psychosocial responses to physical disabilities with biographical sketches and Elizabeth Kubler-Ross that detailed the stages that individuals go through in adjustment to the death of a loved one or their own dying. Dr. Tuttle's idea for a book—applying Wright's and Kulber-Ross's works to blindness—was a "discovery."

He had learned from personal experience, when one encounters a "bump in the road" such was to be expected. Knowing what to anticipate, he became more hopeful knowing that soon those bumps, in due course, would be in his "rearview mirror." With predictability, he was reassured to know what lay ahead in "the trip's" next phase. Still, he wondered, perhaps, if the Wright and Kubler-Ross "road maps" would generalize and transfer to others.

At the time, retinitis pigmentosa had deteriorated his vision to the point that he was a Braille reader. His remaining vision was limited, but he still was able to use it effectively for everyday tasks. Ten years later we were eating in a restaurant and I noticed a change in his vision, or absence of any. I said, "Dean, it's all gone, isn't it." His matter-of-fact answer was, "Yes." I could tell he had traveled many miles each day on the mountain over the past ten years—and had done so successfully.

I recall that his original lectures focused on "adjustment" to blindness. When the book came out, "adjusting" with blindness was in the title. With this shifted paradigm, he took the works of Wright and Kubler-Ross and added value. From his experience, and those of the 104 case studies he used to illustrate and personalize his theory, dealing with one's vision loss is a daily process—not a quickly achieved one-time event. By using the phrase adjusting "with" blindness rather than "to" blindness, he again shifted focus. Blindness is not a detached phenomenon, but rather is a characteristic one must embrace as a travel companion.

Initially concerned that there might not be a sufficient market for his book, now twenty-five years later, the answer is crystal clear with 20/20 hindsight. As *Self-esteem and Adjusting with Blindness* is currently going into this the third edition, I now can answer my professor's question with great confidence. Yes, there is relevance, Dr. Tuttle. And, there is a market. And it has positively touched many lives in profound ways. The work has filled a gap in our field's body of knowledge. Its beauty and value is that it has made the road very clear and understandable with practical relevance for those with vision loss, their families and teachers and counselors.

His often-cited work has evolved into many unanticipated spin-offs. Hundreds of professional conference keynotes and workshops have resulted. Billy Brookshire has molded their work into a self-esteem workshop-training program for professionals called "Loving Me" published by the American Printing House for the Blind. The Hadley School for the Blind has offered a course based on their landmark work. Since 1989, 730 blind and low vision individuals, their family members, and professional service providers have benefited by taking this very popular Hadley course.

We are indebted to Dr. Tuttle who had the foresight twenty-five years ago to develop "his discovery" into a work of practical relevance and profound benefit. We likewise are appreciative of Naomi Tuttle, co-collaborator, for this the third revision. Her sensitive and insightful contribution included the medical perspective as a nurse, the parent's perspective of a special needs son, and the sighted spouse's perspective working through her own adjusting process to blindness in the family. Their work has taken on its own life. What is exciting is that consumers, family members and practitioners, all from unique, personalized travels on the mountain will further refine its evolution.

MICHAEL J. BINA, ED.D.
President, The Hadley School for the Blind

PREFACE

In the past, a great deal has been written about blind persons, their early development, educational needs, employment opportunities, and their ability in general to meet life's demands in a sighted society. Biographies and autobiographies of visually impaired persons account for more than 150 books within the available array of literature. Some of this literature is objective and factual while some is subjective and emotional; some is research-based, some opinion-based; some is fragmented and/or narrow in scope, others provide a more global and cohesive theoretical structure.

Self-esteem and Adjusting with Blindness is an attempt to analyze a vision loss within the context of two overlapping theoretical constructs: the development of self-esteem and the process of adjusting to social and/or physical trauma. The book is divided into four sections. The first provides a brief overview of blindness, essential background for subsequent discussions. Section II explores the general theoretical model for the development of self-esteem common to all persons and analyzes the impact that a visual impairment imposes upon this model. Section III analyzes the process of coping with social and physical traumas or crises, and the way in which self-esteem is affected by the adjusting process. Section IV is addressed primarily to members of the blind person's support team, especially those who have significant and frequent contact. It provides some hints and suggestions for creating a climate for optimum development of a strong and positive self-esteem in the individual who happens to be visually impaired and offers the opportunity to gain insights from students' personal responses to the concepts presented in this book.

The title *Self-esteem and Adjusting with Blindness* may be misleading. A better title would be "An Analysis of the Relationship between a Person's Self-esteem and the Process of Adjusting to Life's Demands with the Personal Attribute of Blindness," but it is obviously too long. One does not adjust *to* blindness as though blindness were some external circumstance, as when one adjusts to a new job or a new home. A visual impairment is only one of many personal attributes that make up the total person, and it is the total person who is engaged in meeting life's demands.

Although one of the authors, Dean Tuttle, is blind, he does not claim any special insights as a result of losing his vision during adolescence and young adulthood. Rather, the book grows out of the authors' combined sixty years of work in the fields of education and rehabilitation of individuals who are visually impaired.

The authors are indebted to the many capable blind persons who shared out of their own personal experiences. Although most of the biographies and autobiographies are written in retrospect, and thus subject to filtered interpretations of remembered experiences, the illustrations chosen represent a larger collection of events common to many. The excerpts cited illustrate a particular point in this text and by no means represent endorsement of any or all of the content of the biography or autobiography. These biographical sketches along with personal comments of Chapter 10 are not offered to prove a theoretical model but serve only to illustrate it. A list of the biographies and autobiographies reviewed for this book are marked with an asterisk in the bibliography.

D.W.T.
N.R.T.

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Many have contributed to the development of this book, both directly and indirectly. Both of our parents, while they were living, were a constant source of support and encouragement. Dean's mentor through graduate school in special education, Georgie Lee Abel, contributed to the basic philosophy and attitudes toward visual impairments reflected in the book.

Our appreciation is extended to Gil Johnson, Director of the American Foundation for the Blind West in San Francisco, who agreed to review the original manuscript, to offer suggestions from the rehabilitation perspective, and to write the forward to the first edition. Gil's sensitivity and insights regarding the issues under consideration have earned him national respect.

Other professional colleagues have contributed in many different ways. We are indebted to Gid Jones of Florida State University for help in the book's early development; to Dean's fellow faculty in Special Education at the University of Northern Colorado for their advice and counsel, and especially to Dave Kappan for his critique of the orientation and mobility sections; and to Jennifer Hill, an experienced teacher of visually impaired children, for her review and helpful comments.

We are also indebted to Michael J. Bina, President of The Hadley School for the Blind, for agreeing to write the Foreword to this third edition. Mike's strong vantage point in work for the blind includes leadership positions as a director of special education in the public schools, principal and superintendent at two different residential schools for the blind, and president of the International Association for Education and Rehabilitation for the Blind and Visually Impaired. Our thanks is extended to Robert Winn and Dawn Turco of Hadley for reviewing the text of Chapter 10 of the second edition and offering valuable suggestions.

Finally, we want to take this opportunity to publicly express our appreciation to each other. This revision would not have been possible without Naomi's extensive library research and her skillful editing abilities to incorporate necessary revisions, and our combined insights into the subtle and sensitive topics handled in the book. We continue to thank God for each other. The fact that we could work together so intensely on a professional project for over a year and still remain on speaking terms is a credit to both.

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SELF-ESTEEM AND ADJUSTING WITH BLINDNESS

Section I

A DEFINITION OF BLINDNESS

Chapter 1

OVERVIEW AND IMPACT OF BLINDNESS

The experience of blindness is both a physical and a psychosocial phenomenon. The medical component provides data regarding etiology, diagnosis, prescription, and prognosis. However, it is more important that the experience of living with a severe visual impairment be described in terms of the interaction among three elements: the needs and desires of an individual with little or no vision; the physical and social environment of that individual; and the common perception of blindness. In order to understand better the interactive process, one must first come to grips with the concept and dynamics of blindness.

SEVERE VISUAL IMPAIRMENT AND SELF-ESTEEM

The title, *Self-esteem and Adjusting with Blindness,* may erroneously suggest to some readers that self-esteem is a problem unique to persons who are blind or visually impaired. Of course, nothing could be further from the truth. The needs for food and shelter, for love and belonging, for responsibility and productivity, for self-acceptance and self-esteem are universal regardless of whether the individual is blind or sighted. The factors that contribute to anyone's self-esteem are the same ones that contribute to the self-esteem of a person who is severely visually impaired. The way people feel about themselves influences the way they are able to perform, and performance, in turn, affects the way they feel about themselves and the way they are perceived by others. The way others perceive them impacts on the way they feel about themselves and thus, the way they are able to perform. Self-esteem and competence are the keys to successfully meeting life's demands. However, a severe visual impairment contributes some added dynamics deserving special attention.

> The real pain I was beginning to feel was not physical, it was spiritual. It was a loss of self-esteem. That thing I call the elephant was really a big creature with

> a shriveled self-image. He did not think well of himself. He felt guilty. He felt inadequate. He felt unable to cope. Those are surefire self-esteem problems. (Kemper, 1977, p. 67)

Kemper, a recently blinded adult, described how his self-esteem was affected by his severe visual impairment. The term *self-esteem* refers to a person's sense of value and worth, a sense of competence and adequacy, a sense of self-satisfaction. "Self-esteem is the lived status of one's competence in dealing with the challenges of living in a worthy way over time" (Mruk, 1999, p. 26). For most people, the dominant role that vision plays in the performance of daily tasks is taken for granted. When sight is impaired or lost, many individuals feel particularly helpless and dependent until they can acquire appropriate adaptive behaviors and coping skills. At the same time, the minimal expectations and negative attitudes experienced by blind persons in our society contribute to lowered self-esteem. Thus, the dynamic forces that operate upon newly blinded persons make their sense of worth and competence especially vulnerable.

The development of self-esteem among those born blind is also precarious. All children growing up, especially through their teen years, wrestle with the fundamental questions: "Who am I?", "Am I lovable?", "What is the meaning of life?", "Where do I belong?", "Can I handle it?" Blind children who experience devaluating and derogatory reactions or reflections within their social environment find it more difficult to obtain satisfactory answers to these basic issues of life. When any child is made to feel strange, different, unwanted, incapable, or inadequate, self-esteem is jeopardized.

> From the other side of the road I heard the voices of little boys and the sound of something else—a ball bouncing against a wall or wooden gate. I called out, "Hello! Can I play with you? Can I come and play?"
>
> The ball stopped bouncing and there was silence. Then one of the boys answered, "No, you can't. You couldn't play if you tried. Cross-eyes!" (Hocken, 1978, pp. 1–2)

When Hocken sensed that she was unwanted and that she was different in some way from the rest of the children, her self-esteem was affected, either consciously or unconsciously. Childhood experiences that help to formulate a person's self-esteem can have long-lasting influence. Many years later Hocken was still struggling with her sense of value and worth.

> But the doubts remained. Don could see. I was blind. Therefore he could not possibly be in love with me. The logic seemed inescapable. At the same

> time I was certain, yet skeptical, of my own love for him. Love was something I had read about in braille paperbacks, and invariably concerned sighted people. How could it happen to me? (Hocken, 1978, p. 95)

Self-esteem does not need to be any more of a problem for a blind person than for anyone else in society. Many who have struggled with basic self-esteem issues of life have resolved them satisfactorily. After wrestling with life's basic questions, Geraldine Lawhorn, who is blind and also deaf, was able to express a positive outlook on life.

> When we observe as much as we can see
> There is no time for what we cannot see;
> Attentiveness to all we hear
> Leaves no room for what we cannot hear;
> If we occupy ourselves with all we can do,
> We are much too busy to fret over what we cannot do.
> (Lawhorn, 1991, p. i)

The intent of this book is to identify the factors that contribute to high self-esteem in order to capitalize on them, and to analyze the factors that contribute to low self-esteem in order to minimize their effects. When one considers that a source of self-esteem is to be found in reflections (see Chapter 3) the prevailing attitudes and feelings about blindness held by others become of utmost importance. If self-esteem is measured in terms of one's feeling of competence or adequacy (see Chapter 4), blind children and adults are frequently made to feel anything but competent or adequate. The adjusting process (see Chapters 6 and 7) describes a person's reaction to a severe trauma whether that trauma is the initial loss of vision or a confrontation with derogatory and devaluating attitudes about blindness. While the recently blinded is adjusting to a new condition, the child born blind is adjusting to initial and subsequent confrontations with the social stigma of blindness. Some of the phases of adjusting with a severe visual impairment, such as mourning or succumbing, may involve withdrawal or depression—potential contributors to lowered self-esteem.

Adjusting with blindness can be viewed as a process of adjusting to life's demands with the added complication of a visual disability for both the child born blind and the person blinded later. It is a continual life-long process in which parents, teachers, rehabilitation staff, medical personnel, and others all contribute to the individual's search for self-acceptance and self-esteem. The role of family members, friends, and professionals in the adjusting process and specific sug-