THIRD EDITION

MENTAL RETARDATION

a life cycle approach

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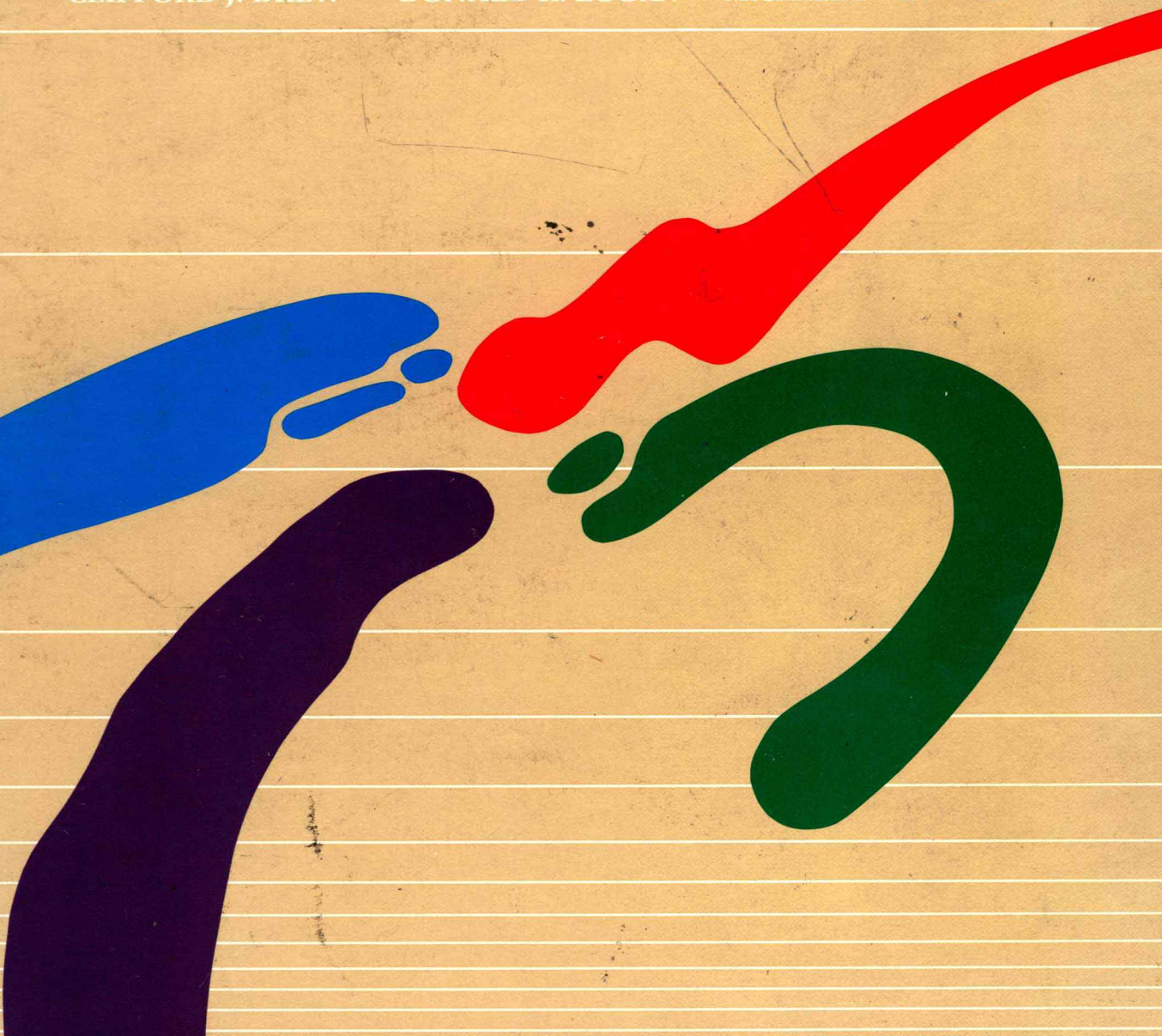

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a life cycle approach

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PREFACE

The third edition of this text has largely the same purpose as did previous editions. Our intent is to provide an introduction to the field of mental retardation that is both readable and comprehensive. The title of the book reflects the foundation concept of this volume—the developmental life cycle. It is our view that potential workers in the field may encounter mental retardation at a variety of developmental levels. Further, this volume involves many different disciplinary perspectives, since a wide variety of professions interface with the problems of mental retardation. The inclusion of different perspectives is seen as essential to provide a comprehensive presentation of the field.

This text is designed primarily for social and behavioral science students (broadly defined) who are at the upper division undergraduate or beginning graduate level. Students in psychology, educational psychology, special education, sociology, education, rehabilitation, and social work will find this text particularly relevant to their preparation. However, pre-med students and individuals anticipating professional work in nursing, law, and administration will find much that facilitates their careers.

CHANGES IN THIS EDITION

Input for the third edition emerged from many different sources. We had a great deal of reader feedback (both faculty and students) as well as reviews by many professionals in the field. All of this information was extremely valuable as we undertook the development of this edition. It is updated, and the coverage is substantially expanded in several areas from that provided by earlier editions. All chapters have been revised with regard to updated research and references. Much of this work has resulted in significant expansions and revisions, in addition to certain deletions. Important new material has been added in the areas of assessment, early caus-

ation, infancy and early childhood, aging, legislation and legal issues, and social and ethical issues. Major reorganizations were undertaken and new material presented in the areas of adolescence, adulthood, and issues related to retardation and the family. These changes and additions from earlier editions are intended to provide the reader with the most recent and comprehensive information available.

SUPPLEMENTS

To facilitate instructional use we have greatly expanded the instructor's manual to include overviews of each chapter and a pool of test items that vary in format. Most instructors will find questions that are suited to their teaching approach as well as suggestions for instructional activities. Certainly no instructor's manual can provide everything that will totally meet the needs of all faculty. However, the manual will provide a substantial head start on the development of examination preparation, which should help a great deal for all of those with frantically busy schedules.

ACKNOWLEDGMENTS

As noted earlier, many have helped us in the preparation of this volume. Listing individuals is always risky, since someone is inevitably omitted. However, that risk must be taken. First and foremost, we owe a debt of gratitude to our students who have provided feedback on earlier editions, which has been incorporated into this current one. We are also grateful for the long hours spent and helpful suggestions made by reviewers on earlier versions of this manuscript. In particular we appreciate the assistance of Louis Brown, University of Iowa; Jim Sears, University of Alabama; Gary Clark, University of Kansas; John Salvia, Pennsylvania State University; and Lyle Romer, University of Washington. Their careful review of the manuscript and cogent comments facilitated our work greatly. A special thanks also goes to our typists, who put up with our strange schedules, handwriting, and moods throughout the project; to Ellen Chandler and Ginger Danielson, once again we thank you for your superb work and putting up with us. Finally, speaking of putting up with us, we thank our families for prodding and complaining (but not too much) and generally supporting us while we were working on the project. It is indeed difficult to answer questions such as "What does your Dad do?" when all that is evident is that he sits around and writes a lot of words on yellow pads.

Clifford J. Drew
Donald R. Logan
Michael L. Hardman

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introduction # PART 1

chapter 1

CONCEPTS, DEFINITIONS, AND CLASSIFICATIONS

Individuals with physical, mental, and behavior differences have been of interest since the beginning of human existence. Many perspectives have prevailed throughout history, including religion, psychology, education, and various branches of medicine. Perceptions of abnormality have varied greatly over time and among disciplines. Definitions and concepts of abnormality still differ and will probably continue to change as our knowledge base expands and societal values shift. The history of mental retardation has followed the variable path of other disorders, as will be seen throughout this volume.

It is important to address the concepts and definitions of mental retardation at the beginning of this discussion. What is mental retardation? This is a question that would seem rather simple to answer, yet it has plagued educators and psychologists for many years. As in many areas of behavioral science, this question is deceiving in its simplicity, but an answer that is in any way complete is exceedingly difficult to articulate. In reviewing the literature related to mental retardation, one finds that the response to the question has received a great deal of attention, particularly during the past 30 years. This chapter examines mental retardation from the standpoint of concepts, definitions, and classification systems that have been used historically and those that are currently employed. Review of this material and

that found in following chapters will provide the reader with an overview of mental retardation. It will become evident that the phenomenon is multifaceted. Mental retardation presents a challenge to education, medicine, psychology, law, and society in general and always to the family. What we have attempted in this volume is to place mental retardation in its broadest perspective, squarely in the center of human existence, because above all, mental retardation is a human problem. It cannot be viewed from a narrow focus if one wishes to obtain an accurate and comprehensive perspective.

Mental retardation as a concept

An examination of the mental retardation literature suggests strongly that the conceptual issues are complex and a considerable lack of clarity still exists. Frequently professionals seem to respond to the initial question of defining mental retardation by discussing what it is not and describing causes. Refinement of the concept of mental retardation has become more complex as the many factors that were previously unknown are taken into account.

The history of mental retardation predates many of the other areas that are considered handicapping conditions. Hippocrates and Confucius provided descriptions of mental retardation that date several hundred years BC. With such a lengthy record of attention it is of some interest why confusion and vagueness remain concerning classification and definition.

A variety of factors contribute to this lack of precision in definition. It is commonly accepted that mental retardation is related to a reduced level of intelligence. The concept of intelligence perhaps more than any other factor, has played a central role in the definition of mental retardation. All of the controversy concerning the nature of intelligence has a direct impact on the field of mental retardation. As a consequence, part of the difficulty in defining mental retardation relates to the notion of permanence of intelligence.

Mental retardation has always been an area in which many disciplines have operated. This has contributed significantly to the problems of definitional and conceptual clarity. There has never been a legitimate "science" of mental retardation in and of itself. The problem of mental retardation has been addressed by psychiatrists, sociologists, psychologists, educators, anthropologists, and many others, each with a separate perspective and language. Consequently the many different definitions and classification systems often tend to focus on the constructs of a particular profession rather than on the retarded individual; thus sociologists set out to study retardation as a social problem, psychologists study it as a psychological problem, and physicians examine it as a medical problem. There are even

wide variations evident within professional areas, such as between clinical and experimental psychology. We do not intend to negate the value of a multidisciplinary attack on any problem; in fact, we strongly subscribe to such an approach. However, we are highlighting the fact that the central conceptual focus, the retarded individual, is in danger of being ignored. We intend to present mental retardation from a multidisciplinary perspective while maintaining a focus on the concept of the retarded individual.

As noted above, mental retardation has often been conceptualized from different viewpoints, depending on the purpose and discipline involved (e.g., social, administrative, medical, educational, and legal viewpoints). This is to be expected to some degree. However, the absence of a single, functional conceptualization has seriously detracted from the preparation of professionals who work with the retarded. Although a high degree of sophistication has been developed in certain technical aspects of programming for children (e.g., reinforcement procedures), the lack of an effective, generic conceptualization of mental retardation has impeded the overall progress of service delivery to these people. Professional expertise is often limited by a great deal of skill in certain areas but a deficiency in terms of a perspective of retarded individuals in their total environment. Consequently efforts are now being exerted toward formulating conceptual frameworks that will facilitate more effective professional preparation. Retarded individuals must be viewed as developing human beings with varying needs and characteristics and living within a contemporary society that has fluid and ever-changing performance standards.

More than 20 years ago Cantor (1960) identified two rather simple but important criteria for assessing abstract concepts: (1) the *clarity* of a definition and (2) its *usefulness*. The first involves how well a definition communicates; that is, Do you know what I mean by my definition? The usefulness criterion involves the degree to which a concept facilitates predictions and decisions. Using these criteria, it becomes evident that the conceptual framework is intertwined in an essential relationship with both definition and classification. Research in mental retardation clearly indicates that this is not a simple phenomenon. The problem is a fluid one both among and within disciplinary areas. The conceptual framework for mental retardation, if it is to be functional, will necessarily be complex.

Definition of mental retardation

Definitions of mental retardation have varied considerably over the years and between disciplines. Currently there is a great deal of agreement among the main definitions being used. The American Association on Mental Deficiency (AAMD) definition has basically been adopted by the American

Psychiatric Association and is also essentially intact in the proposed Federal Rules and Regulations for Public Law 94-142. The definition of mental retardation presented by the AAMD involves two main dimensions—adaptive behavior and measured intelligence. The most recent definition of the AAMD states that "mental retardation refers to significantly subaverage general intellectual functioning resulting in or associated with impairments in adaptive behavior and manifested during the developmental period" (Grossman, 1983). The following statements illustrate the similarities in current definitions:

> "Mentally retarded" means having significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. (Proposed Regulations, 1982, p. 33,485).

> The essential features are: (1) significantly subaverage general intellectual functioning, (2) resulting in, or associated with, deficits or impairments in adaptive behavior, (3) with onset before the age of 18. (American Psychiatric Association, 1980, p. 36).

AAMD has taken steps to comply with the criterion of clarity for concepts. Important terms have been specifically defined in the published manual. For convenience, the complete articulation of these term definitions has been excerpted and is presented in the Appendix to this chapter. Some professionals have viewed the inclusion of adaptive behavior in AAMD definitions as placing clarity in jeopardy (Clausen, 1972; Penrose, 1972). Despite the longevity of the idea in relation to mental retardation, *measurement* of adaptive behavior has not achieved the sophisticated precision that would be desirable. Clausen (1972) contended that adaptive behavior is representative of an " ill-defined elusive concept, the inclusion of which results in added confusion, rather than increased clarity" (p. 52). (See Symposium No. Seven in the annotated bibliography of this chapter for a detailed discussion of the issues involved in this topic.)

The inclusion of adaptive behavior in definitions represented a rather dramatic broadening of formally stated criteria for viewing mental retardation. Adaptive behavior had been largely ignored in definition for many years. This particular criterion does, however, raise certain issues that should be kept in mind for a variety of dimensions that may be relevant as attributes of mental retardation. A retarded person may be viewed essentially as one requiring some type of action on the part of the community for the protection or enhancement of the individual or others in the community. Two factors usually enter into this perception: (1) the retarded in-

dividual's deficits or level of functioning and (2) the threshold of community tolerance. When such action is taken depends on the degree to which an individual deviates from community norms—from those zones of behavior or performance that are deemed acceptable by society.

Mentally retarded people usually come to the attention of someone in the community of individuals surrounding them because their behavior deviates (or is thought to likely deviate) enough from the norm to be noticeable. This is true regardless of the degree of retardation. Identification of the more severely retarded may occur at birth or during the very early part of life. This usually happens because some anomaly, either physical or behavioral, is sufficiently obvious that it is observable. For those who are less deviant, identification may not occur until much later, as they begin to develop language or enter school. Initial suspicions of deviancy may then be further investigated through formal diagnostic evaluation and clinical observation by professional personnel. More details about diagnosis and evaluation are provided later in the text.

Incidence and prevalence of mental retardation

At the beginning of this discussion it is important to distinguish between two terms that have often been confused in the field of mental retardation—*incidence* and *prevalence*. Incidence refers to the number of new cases identified during a given time period (often 1 year). Such cases would involve a count of all individuals who were newly identified as retarded during that period, whether they are newborns or youngsters so diagnosed in school. Prevalence includes all of the cases existing at a given point in time. Prevalence thus involves newly identified cases plus those others that are *still* labeled as retarded from some earlier diagnosis. Fig. 1-1 pictorially illustrates incidence and prevalence concepts, how they differ, and how they relate to one another. Obviously these two counting procedures do not result in the same figure. However, the terms have often been used interchangeably in the literature. We will examine incidence and prevalence separately in those cases in which it is possible, although it should be noted that we are often relying on earlier literature in which the terms were employed rather loosely.

How frequently do individuals evidence sufficient deviancy to be considered mentally retarded? A precise answer to this question is difficult to obtain for a variety of reasons. Accurate accounting is neither easy nor economically feasible. The difficulty of obtaining consistent definition and classification schemes over the years has made determining actual frequency even more formidable. Estimates of the prevalence of mental retar-