Part I

Introduction and background
1 What we do and do not understand about mental retardation

Compared to many of the physical sciences, the study of mental retardation is still in its infancy or early childhood. From the initial efforts of Seguin and Howe in the 19th century to the classic studies of Bayley, Spitz, and the Iowa group in the 20th, all of the advances in the mental retardation area have occurred in the past 150 years, and most within the last 50.

Thinking back to 1959 gives a sense of how recently the field has evolved. That was the year that Down syndrome (“mongolism” in those days) was found to be caused by an extra chromosome, thus leading to our present understanding of this familiar disorder. It was also the year when the American Association on Mental Deficiency (AAMD) published the first definition of mental retardation (Heber, 1959). Prior to this time workers had been guided by their own independent judgments; these judgments varied so much that mental retardation was not really a legitimate field or bona fide science. It seems only fitting that in reviewing the situation in this period, Masland, Sarason, and Gladwin (1958) should decry the lack of high-quality research in mental retardation.

Less than 20 years later, the situation had changed dramatically. In testimony before Congress, Zigler observed that “Current research in the mental retardation area is vibrant work of high quality, being carried out by methodologically sophisticated workers whose efforts are directed by a broad and rich array of theoretical formulations” (1977, p. 51). He further noted that “The general quality of America’s major journal in reporting mental retardation research, the American Journal of Mental Deficiency, has improved so much over the past 20 years that it is hard to believe this is the same spotty journal that represented the field just two decades ago” (p. 51). These recent achievements have vastly improved our understanding of mental retardation, and additional knowledge accumulates at an astonishing rate.

Still, the extent of knowledge about mental retardation is and will remain limited until some basic issues are resolved. To begin at the most basic...
level, how should we define mental retardation? Only when a consensus is reached can we more purposefully address the other big questions: How many retarded people are there? What causes mental retardation? How is it best treated? Can retardation be cured or prevented? Such issues have provoked passionate argument among professionals and laypeople alike. These rambling controversies are seen by some as a deterrent to further progress in the field. We choose to see them as catalysts to the maturation of a solid and seasoned discipline.

The purpose of this book is to examine critically the existing knowledge about mental retardation, to separate myth from fact, and to provide a unifying framework for understanding the phenomenon. In the process, we will expound ways of viewing retarded people that have helped us in our own thinking and research in the field. This is done not to impose our opinions but to encourage young workers to tackle difficult and crucial issues.

**What we know about mental retardation**

**Subnormal intellectual functioning**

The most salient characteristic of retarded people is that their intellectual level is lower than that of the average person in the society. Retarded persons are "slow" or "dull" in their abilities to learn and respond to the problems of everyday living. This is an obvious, commonsense observation, but a professional investigator must take a closer view and arrive at a more objective categorization.

What do we mean by "subnormal intellectual functioning"? Indeed, what is intelligence itself? Sternberg, Conway, Ketron, and Bernstein (1981) attempted to define intelligence from the perspective of the nonexpert, the person unacquainted with psychology. These investigators asked three groups of laypeople -- college students in a library, commuters waiting for their trains, and shoppers at a supermarket -- to list the behaviors they considered characteristic of "intelligence." Another group of nonexperts, as well as a group of professionals in the field, then rated these behaviors on the degree to which each reflects intelligence (e.g., on a scale of 1 to 9, to what degree is behavior X an "intelligent behavior")?

Results showed that people unfamiliar with research on intelligence ranked highest those behaviors falling into three general categories: practical problem solving (e.g., reasons logically and well; identifies connections among ideas), verbal ability (speaks clearly and articulately; converses well), and social competence (accepts others for what they are; displays an interest
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in the world at large). The experts largely agreed with the nonexperts; they
gave high ranks to verbal intelligence, problem-solving ability, and “prac-
tical intelligence” (e.g., sizes up situations well; determines how to achieve
goals). Only this last factor, which was less social than the social compe-
tence category of the nonexperts, differed between the two groups. The
point is that, while scholars have long argued about the definition of in-
telligence, most people have a fairly clear sense of the phenomenon.

A brief glance through several psychology texts provides a second source
of information on the nature of intelligence. Kimble, Garmezy, and Zigler
(1984) emphasize the function of intelligence as the “solving of real-life
tasks.” They note that “modern definitions of intelligence tend to empha-
size cognition, the capacity to think, reason, remember and understand”
(p. 227). In his textbook on mental retardation, MacMillan (1982) sum-
marizes the attempts to define intelligence as having three general themes:
“(1) the capacity to learn, (2) the totality of knowledge acquired, and (3)
the adaptability of the individual, particularly to new situations” (p. 170).
In the introductory chapter to Sternberg’s Handbook of Intelligence, Stern-
berg and Salter (1982) define intelligence as “goal-directed adaptive
behavior.”

Combining the above elements, we are able to compose a general defi-
nition of intelligence: Intelligence consists of those mental operations, the
accumulated knowledge, and the ability to learn that help one purposefully
to solve real-life tasks. Intellectual functioning involves such cognitive pro-
cesses as thinking, memory, and logical reasoning, and the knowledge of
general information and vocabulary; many of these skills can be either
linguistic or nonlinguistic in nature.

While this definition may seem general enough to satisfy everyone, it
does step into some controversial ground. First, it omits physical, sensory,
or personality attributes as features of intelligence, although some would
argue that these traits influence cognition. Our definition also implies that
intelligence consists of both general and specific mental abilities. Reasoning
and the ability to learn are general features; they can be used to solve any
number of problems faced by the individual. These types of processes enter
into Spearman’s g, or general intellectual factor. Accumulated knowledge
and certain types of logical reasoning, on the other hand, are more specific
in nature. These s factors involve specialized areas of knowledge and are
contingent on a person’s specific interests, environment, and experiences.

A debate has long raged over whether intelligence is a general ability
underlying all mental functioning or a set of abilities that are independent
of each other. The position that intelligence involves specific skills is based
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on the common observation that individuals have intellectual strengths and weaknesses. Someone may have superior mechanical aptitude but be illiterate, or be unable to balance a checkbook but able to do a *New York Times* crossword puzzle without an eraser. On a more scientific level, there have been some very complex and determined efforts to identify the specific skills that constitute intelligence. Guilford (1956) described no less than 120 distinct components of intellect and devised tests to measure most of them. More recently, Gardner (1983) proposed that there are separate “multiple intelligences” in the linguistic, musical, logico-mathematical, spatial, bodily-kinesthetic, and personal domains. Support for his theory comes from studies of persons who possess superior talent in one area while demonstrating little or no competence in other areas (the so-called idiot savant). The method used to isolate specific mental abilities is factor analysis, which indicates the degree of independence of the various traits. Arguments abound, however, over the appropriateness of different types of factor-analytic techniques, some of which may indicate a *g* factor while others, applied to the same data, do not.

The opposing view that intelligence is a single underlying entity also has supportive evidence. Jensen (1982), a strong proponent of *g*, writes that “Essentially the same *g* emerges from collections of tests which are superficially quite different. Unlike *all* other factors (i.e., factors found when intelligence tests are factor analyzed), *g* is not tied to any particular type of item content or acquired cognitive skill” (p. 133). Jensen also relies on evidence that people who score well on one type of mental ability test also generally score well on others, a fact that he calls “one of the most remarkable findings in all of psychology” (1981a, p. 52).

Since no resolution of this debate seems imminent at this time, our choice of definition reflects a middle-ground position: Intelligence consists of both general and specific abilities. The *g* and the various *s* factors combine to become the sum of “intelligence” for any particular individual. Our view of intelligence is similar to the “hierarchical models” of intelligence proposed by Vernon (1971), Snow (1978), and others. “In Vernon’s view, for instance, intellectual abilities comprise a hierarchy, with a general factor (*g*) at the top; two major group factors, verbal-educational ability and spatial-mechanical ability at the second level; minor group factors at the third level; and specific factors at the bottom. Hierarchical models such as this one seem to account for much of the correlational data on the structure of intelligence” (Wagner & Sternberg, in press, p. 7). This mixture of general and specific abilities allows for strengths and weaknesses in an individual’s intellectual functioning, while maintaining a basic intellectual “core” for each person.
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Our view of intelligence also acknowledges the three general outlooks that currently pervade the intelligence field: the psychometric, the Piagetian, and the information-processing perspectives. Each of these emphasizes different aspects of the phenomenon. Psychometricians stress the differences among individuals on standardized measures of intellectual functioning. Piagetians concentrate on the development of cognitive operations, and psychologists working within the information processing perspective examine the microscopic processes that underlie the performance of any intelligent behavior (e.g., attention, encoding, memory). Thus, the first view is useful in defining mental retardation (because of its focus on individual differences), while the second teaches us about development, and the third about the mental processes by which individuals come to acquire knowledge. Thus these three seemingly divergent views complement each other by focusing on three different aspects of intelligence (Wagner & Sternberg, in press).

A second issue involves the specification of “subnormal” in the phrase “subnormal intellectual functioning.” Obviously, such a determination must be arbitrary. There simply is no clear dividing line between normality and subnormality for almost any continuous human trait, and intelligence is no exception. For example, although different people will disagree about what constitutes a tall man (is it 6’, 6’2” or 6’6”?), most would agree that tallness is a meaningful concept. There is likewise nothing in the nature of intelligence that clearly distinguishes those who have “normal” endowment from those who do not.

We will save the bulk of our remarks for the discussion of individual differences in a later chapter (Chapter 3). Suffice it to say here that subnormal intelligence is usually determined statistically, by means of standardized psychometric instruments. According to the current AAMD definition, a person’s IQ score must be at least two standard deviations (SDs) below the mean of the population for that person to be considered retarded. In the 1960s the cutoff was one SD, indicating that even this statistical approach to definition is somewhat arbitrary.

It is also worth noting that intelligence tests themselves are not purely objective measures. Since there is no universal definition of intelligence, test constructors devise questions that tap processes represented in their own conception of intelligence. IQ tests were created to predict success in school (which they do quite well), but there is some doubt whether the abilities needed for academic achievement are the same as those needed for achievement in nonschool life. Other criticisms of intelligence tests are that they are too verbal in nature and that they are biased against minority and lower-class individuals, because they contain items “culture-bound”
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to middle-class, white American values. Responses to these criticisms have included attempts to develop restandardized, “culture-fair” and nonverbal tests. These efforts have to date met with only limited success. Thus, while standard intelligence tests are not perfect, they are the best we have at this time. Their use in the designation of mental retardation is justified by the view that diagnosis must be based on more objective measures of intellectual functioning than the subjective judgments of school administrators, physicians, or psychologists. Interested readers should consult Jensen (1980) and Vernon (1979) for reviews of this problem.

Some retardation involves known organicity, some does not

The typical image of a retarded person is that of a Down syndrome child with the striking features (pudgy face and limbs, protruding tongue) characteristic of the disorder. A casual observer might add that the child’s speech might be slurred, that the child might have a pleasant personality, and that heart defects are possible. The presence of organic defects, and corresponding physical sequelae, are important to this general view.

This picture of retardation might be expanded by noting that organic insults are of three kinds: (1) those occurring prior to birth, either because of genetic anomalies or problems in utero (prenatal insults); (2) those occurring at or close to the time of birth (perinatal insults); and (3) those occurring at some time thereafter during the life span (postnatal insults). Examples of prenatal insults caused by genetic anomalies include Down syndrome, Fragile X syndrome, Tay-Sachs disease, and phenylketonuria; examples of insults that occur in utero are rubella syndrome and teratogenesis (e.g., thalidomide children). Perinatal causes include anoxia at birth and postnatal factors include head trauma and childhood encephalitis. Many of these organic insults (e.g., Down syndrome) seem to occur about equally across the socioeconomic spectrum (SES); others seem to affect certain ethnic, SES, or racial groups more than others (e.g., Tay-Sachs is peculiar to Ashkenazi Jews and retardation due to complications of prematurity occurs more often in children from low-SES mothers; see Cytryn & Lourie, 1975, for a description of the many etiologies of mental retardation).

Hidden from view, however, are all of those people who do not display any obvious organic etiologies but who are nevertheless retarded. This phenomenon has variously been called retardation due to sociocultural factors, familial retardation, retardation due to environmental deprivation, nonorganic retardation, and cultural-familial retardation. This group may comprise up to 70–75% of the total retarded population (see Chapter 4
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for a fuller discussion of this issue). In general, IQ levels of this group tend to fall in the mild (IQ 55–70) and moderate (IQ 40–54) ranges of retardation.

As with many issues in mental retardation, a debate rages about the causes of retardation in these people. Have they been deprived in their early environments, are they offspring of parents with genes for lower intelligence, or do they in fact suffer from some as yet undiagnosed organic insult, an etiology that only future diagnostic procedures will discover? Or are several of the above factors working in concert to cause intellectual subnormality in this group? We simply do not know.

For now, let us say only that notwithstanding one’s position on the cause of retardation in this group, all would agree that in some retarded people (probably less than half of all cases of retardation) a clear organic etiology can be specified. In other cases (probably over half of the total), no clear organic etiology is indicated.

Motivational and personality factors play an important role in life functioning of retarded people

We have all been impressed by the degree to which motivational and personality factors affect people we have known or read about. On one hand, there are persons who have driven themselves to career success. The example of Abraham Lincoln comes to mind, learning to read and write with little formal schooling, teaching himself the law, diligently studying famous authors to improve his own style of writing and speaking (Oates, 1977). The story of Lincoln is one of the Horatio Alger tales that have long been part of American folklore. On the other hand, we have all been equally impressed, or dismayed, by experiences with individuals who have not used their talents to the fullest. Countless men and women might have become great successes in any of a thousand careers, had they only tried. And yet, for some reason, they did not.

This is not to say that motivation conquers all. It is only one of a number of factors that help to determine success. Sociologists and historians have long argued about the degree to which success is due to the circumstances of one’s birth and upbringing (e.g., social class, race) and the degree to which the individual’s own initiative is involved. For example, few would argue that a black child born in dire economic circumstances will have a more difficult time succeeding than will a white child born of upper-class parents. The so-called privileges of birth – a stable and affluent home life, good schools, special tutoring, the best colleges – may be available to one child and not to the other. Similarly, one’s historical epoch helps determine one’s chances for career success. Becoming literate in the rural Midwest
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of the early 1800s (admittedly, not an easy task) gave young Lincoln a long head start on a legal and political career. It is not so clear that current social and economic conditions in most modern societies allow for such rises in social status.

Our point is simply that an individual’s motivation and personality at least partially determine the degree of success attained. This point applies to retarded individuals as well. One retarded person with an IQ of 60 may differ greatly from another retarded person, also with a 60 IQ. The first may work, have a family, and live an independent life, whereas the other may be incapable of any of these achievements. It is unsettling to contemplate how often this simple fact is forgotten.

Similarly, those life experiences that affect normally intelligent people will also affect people who are retarded. Indeed, several negative life experiences that happen frequently to retarded persons may cause certain deficits that are falsely attributed to retardation itself. Consider the experience of failure, a common event for retarded persons (because of their lower levels of intellectual functioning). A fear of trying new tasks or a greater dependence on adults to solve problems may be more likely in retarded people not because of their lower intelligence, but because of repeated failures (Weisz, 1982). If put in situations that foster success, they may cease to show such behaviors altogether. One must also consider the effects of being institutionalized, of being labeled retarded, of being placed in a special class, and of being the lowest-functioning member of a main-streamed class – all experiences common to retarded persons.

Most experts in the mental retardation (MR) field would agree to at least the three statements about mental retardation that are presented above. Mental retardation does involve subnormal intellectual functioning, some retardation involves known organicity and some does not, and motivational and personality factors play some role in the life functioning of retarded people. Beyond these facts, however, debate continues on a number of issues. We now turn to some of these areas of disagreement.

Issues in mental retardation about which experts disagree

The role of social adaptation in defining mental retardation

The current AAMD definition of mental retardation reads as follows:

Mental retardation refers to significantly subaverage intellectual functioning resulting in or associated with impairments in adaptive behavior and manifested during the developmental period. (Grossman, 1983, p. 11)
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Three factors are involved in this definition: (1) subaverage intellectual functioning (i.e., IQ below 70); (2) impairments in adaptive behavior (as assessed by Vineland Scales or clinical judgments); and (3) impairments that are manifested during the developmental period (before 18 years of age). (For our present discussion, the third factor will be ignored, as it is in most discussions of the AAMD definition; see Grossman, 1983, p. 12.)

Disagreements arise when one considers the role of social adaptation in the definition of mental retardation. Social adaptation, as one outcome of the personality and motivational factors affecting each retarded and non-retarded person, is clearly important, but its role in defining who is and is not retarded is hotly debated.

On one side of this issue are those who argue that IQ tests discriminate against low-SES and minority groups. If one employs a definition based solely on the IQ criterion (IQ below 70) and administers IQ tests that are discriminatory, a greater proportion of minority children than nonminority children will be labeled retarded and placed in special-education classes. Indeed, the assignment of a disproportionate number of California black and Hispanic children to special-education classes led to the famous Larry P. decision (Larry P. v. Riles, 1974), forbidding California educators from using IQ tests in determining special-class placements (see MacMillan & Meyers, 1980, for a review of this issue).

On the other side of the debate are those (the authors among them) who claim that social adaptation should not be used to define mental retardation. We believe that social adaptation is not intrinsic to mental retardation (i.e., that the sole defining characteristic of mental retardation should be subnormal intellectual functioning) and that the social adaptation concept itself is not clearly defined or adequately measured. This does not imply that we are any less uneasy about the possible biases of intelligence tests, only that lower levels of intellectual functioning should be the sole criterion for defining retardation.

An important corollary to the two-factor definition of mental retardation, its effects on prevalence levels of retardation, also deserves mention. A two-factor definition in which both factors are weighted equally makes the prevalence levels of mental retardation dependent on the level of correlation between the two factors. However, Silverstein (1973, p. 380) notes that “correlations between various intelligence tests and the Vineland Social Maturity Scale (Doll, 1953), one measure of adaptive behavior, range from .00 to .90 for different samples (Leland, Shellhaas, Nihira & Foster, 1967).”

How many people are retarded, using the two-factor definition? Silver-