MENTAL RETARDATION: A SYMPTOM AND A SYNDROME

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Introduction

Mental retardation is an idea, a condition, a syndrome, a symptom, and a source of pain and bewilderment to many families. Its history dates back to the beginning of man's time on earth. The idea of mental retardation can be found as far back in history as the therapeutic papyri of Thebes (Luxor), Egypt, around 1500 B.C. Although somewhat vague due to difficulties in translation, these documents clearly refer to disabilities of the mind and body due to brain damage (Sheerenberger, 1983). Mental retardation is also a condition or syndrome defined by a collection of symptoms, traits, and/or characteristics. It has been defined and renamed many times throughout history. For example, feeblemindedness and mental deficiency were used as labels during the later part of the last century and in the early part of this century. Consistent across all definitions are difficulties in learning, social skills, everyday functioning, and age of onset (during childhood). Mental retardation has also been used as a defining characteristic or symptom of other disorders such as Down syndrome and Prader-Willi syndrome. Finally, mental retardation is a challenge and potential source of stress to the family of an individual with this disorder. From identification through treatment or education, families struggle with

questions about cause and prognosis, as well as guilt, a sense of loss, and disillusionment about the future.

The objective of this chapter is to provide the reader with an overview of mental retardation, a developmental disability with a long and sometimes controversial history. Following a brief historical overview, the current diagnostic criteria, epidemiological information and the status of dual diagnosis will be presented. Comprehensive assessment and common interventions will also be reviewed in some detail.

Historical Perspective

The plight of individuals with developmental disabilities has been dependent on the customs and beliefs of the era and the culture or locale. In ancient Greece and Rome, infanticide was a common practice. In Sparta, for example, neonates were examined by a state council of inspectors. If they suspected that the child was defective, the infant was thrown from a cliff to its death. By the second century A.D. individuals with disabilities, including children, who lived in the Roman Empire were frequently sold to be used for entertainment or amusement. The dawning of Christianity led to a decline in these barbaric practices and a movement toward care for the less fortunate; in fact, all of the early religious leaders, Jesus, Buddha, Mohammed, and Confucius, advocated human treatment for the mentally retarded, developmentally disabled, or infirmed (Sheerenberger, 1983).

During the Middle ages (476 - 1799 A.D.) the status and care of individuals with mental retardation varied greatly. Although more human practices evolved (i.e., decreases in infanticide and the establishment of foundling homes), many children were sold into slavery, abandoned, or left out in the cold. Toward the end of this era, in 1690, John Locke published his famous work entitled *An Essay Concerning Human Understanding*. Locke believed that an individual was born without innate ideas. The mind is a tabula rasa, a blank slate. This would profoundly influence the care and training provided to individuals with mental retardation. He also was the first to distinguish between mental retardation and mental illness; "Herein seems to lie the difference between idiots and madmen, that madmen put wrong ideas together and reason from them, but idiots make very few or no propositions and reason scarce at all (Doll, 1962 p. 23)."

A cornerstone event in the evolution of the care and treatment of the mentally retarded was the work of physician Jean-Marc-Gaspard Itard (Sheerenberger, 1983) who was hired in 1800 by the Director of the National Institutes for Deaf-Mutes in France to work with a boy named Victor. Victor, a young boy, had apparently lived his whole life in the woods of south central France and, after being captured and escaping several times, fled to the mountains of Aveyron. At about age 12, he was captured once again and sent to an orphanage, found to be deaf and mute, and moved to the Institute for Deaf-Mutes.

Based on the work of Locke and Condillac who emphasized the importance of learning through the senses, Itard developed a broad educational program for Victor to develop his senses, intellect, and emotions. After 5 years of training, Victor continued to have significant difficulties in language and social interaction though he acquired more skills and knowledge than many of Itard's contemporaries believed possible. Itard's educational approach became widely accepted and used in the education of the deaf. Near the end of his life, Itard had the opportunity to educate a group of children who were mentally retarded. He did not personally direct the education of these children, but supervised the work of Edouard Seguin (Sheerenberger, 1983). Seguin developed a comprehensive approach to the education of children with mental retardation, known as the Physiological Method (Sheerenberger, 1983). Assuming a direct relationship between the senses and cognition, his approach began with sensory training including vision, hearing, taste, smell, and eye-hand coordination. The curriculum extended from developing basic self-care skills to vocational education with an emphasis on perception, coordination, imitation, positive reinforcement, memory, and generalization. In 1850, Seguin moved to the United States and became a driving force in the education of individuals with mental retardation. In 1876, he founded what would become the American Association on Metal Retardation. Many of Seguin's techniques have been modified and are still in use today.

Over the next 50 years, two key developments occurred in the United States: residential training schools were established in most states (19 state operated and 9 privately operated) by 1892, and the newly developed test of intelligence developed by Binet was translated in 1908 by Henry Goddard, Director of Research at the training school in Vineland, New Jersey. Goddard published an American version of the test in 1910. In 1935, Edgar Doll developed the Vineland Social Maturity Scale to assess the daily living skills/adaptive behavior of individuals suspected of having mental retardation. Psychologists and educators now believed

that it was possible to determine who had mental retardation and provide them with appropriate training in the residential training schools.

During the early part of the 20th century, residential training schools proliferated and individuals with mental retardation were enrolled. This was influenced by the availability of tests (primarily IQ) to diagnose mental retardation and the belief that, with proper training, individuals with mental retardation could be "cured". When training schools were unable to "cure" mental retardation, they became overcrowded and many of the students were moved back into society where the focus of education began to change to special education classes in the community. The training schools, which were initially more educational in nature, became custodial living centers.

As a result of the disillusionment with residential treatment, advocacy groups, such as the National Association of Retarded Citizens and the President's Commission on Mental Retardation, were established in the 1950's through the 1970's. The Wyatt-Stickney federal court action, in the 1970's, was a landmark class action suit in Alabama establishing the right to treatment of individuals living in residential facilities. Purely custodial care was no longer acceptable. Concurrent with this case, the United States Congress passed the Education for the Handicapped Act in 1975, now titled the Individuals with Disabilities Education Act. This Act guaranteed the appropriate education of all children with mental retardation and developmental disabilities, from school age through 21 years of age. This law was amended in 1986 to guarantee educational services to children with disabilities age 3 through 21 and provided incentives for states to develop infant and toddler service delivery systems. Today, most states guarantee intervention services to children with disabilities between birth and 21 years of age.

Definition/Diagnosis/Classification.

According to Sheerenberger (1983), the elements of the definition of mental retardation were well accepted in the United States by 1900. These included: onset in childhood, significant intellectual or cognitive limitations, and an inability to adapt to the demands of everyday life. An early classification scheme proposed by the American Association on Mental Deficiency (Retardation), in 1910 referred to individuals with mental retardation as feeble-minded, meaning that their development was halted at an early age or was in some way inadequate making it difficult to keep pace with peers and manage their daily lives independently

(Committee on Classification, 1910). Three levels of impairment were identified: *idiot*, individuals whose development is arrested at the level of a 2 year old; *imbecile*, individuals whose development is equivalent to that of a 2 to 7 year old at maturity; and *moron*, individuals whose mental development is equivalent to that of a 7 to 12 year old at maturity.

Over the next 30 years, the definitions of mental retardation focused on one of three aspects of development: the inability to learn to perform common acts, deficits or delays in social development/competence, or low IQ (Yepsen, 1941). An example of a definition based on social competence was proposed by Edgar Doll who proposed that mental retardation referred to "social incompetence, due to mental subnormality, which has been developmentally arrested, which obtains at maturity, is of constitutional origin, and which is essentially incurable" (Doll, 1936 p. 38). Fred Kuhlman, who was highly influential in the early development of intelligence tests in the United States, believed mental retardation was "a mental condition resulting from a subnormal rate of development of some or all mental functions" (Kuhlman, 1941 p. 213).

As a result of the conflicting views and definitions of mental retardation, a growing number of labels used to refer to individuals with mental retardation, and a change in emphasis from a genetic or constitutional focus to a desire for a function-based definition, the American Association on Mental Deficiency (Retardation) proposed and adopted a three part definition in 1959. "Mental retardation refers to subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior" (Heber, 1961). Although this definition included the three components of low IQ (<85), impaired adaptive behavior, and origination before age 16, only IQ and age of onset were measurable with the existing psychometric techniques. Deficits in adaptive behavior were generally based on subjective interpretations by individual evaluators even though the Vineland Social Maturity Scale was available (Sheerenberger, 1983).

In addition to the revised definition, a five level classification scheme was introduced replacing the previous three level system which had acquired a very negative connotation. The generic terms of borderline (IQ 67-83), mild (IQ 50-66), moderate (IQ 3-49), severe (16-32), and profound (IQ <16) were adopted.

Due to concern about the over or misidentification of mental retardation, particularly in minority populations, the definition was revised in 1973 (Grossman, 1973) eliminating the

borderline classification from the interpretation of significant, subaverage, general intellectual functioning. The upper IQ boundary changed from <85 to ≤ 70. This change significantly reduced the number of individuals who were previously identified as mentally retarded impacting the eligibility criteria for special school services and governmental supports. Many children who might have benefitted from special assistance were now ineligible for such help. A 1977 revision (Grossman, 1977) modified the upper IQ limit to 70 - 75 to account for measurement error. IQ performance resulting in scores of 71 through 75 were only consistent with mental retardation when significant deficits in adaptive behavior were present.

The most recent change in the definition of mental retardation was adopted in 1992 by the American Association on Mental Retardation. "Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18" (American Association on Mental Retardation, 1992). On the surface, this latest definition does not appear much different than its recent predecessors. However, the focus on the functional status of the individual with mental retardation is much more delineated and critical in this definition. There is also a focus on the impact of environmental influences on adaptive skills development that was absent in previous definitions. Finally, this revision eliminated the severity level classification scheme in favor of one that addresses the type and intensity of support needed: intermittent, limited, extensive, or pervasive. Practically, a child under age 18 must have an IQ ≤ 75 and deficits in at least 2 of the adaptive behavior domains indicated in the definition to obtain a diagnosis of mental retardation.

Educational Classifications. While the medical and psychosocial communities were developing an acceptable definition and classification system, the educational community adopted their own system of classification. Their three level system separated school age children with mental retardation into three groups based on predicted ability to learn (Kirk, Karnes, & Kirk, 1955). Children who were *educable* could learn simple academic skills but not progress above fourth grade level. Children who were believed to be *trainable* could learn to care for their daily needs but very few academic skills. Children who appeared to

be *untrainable* or totally dependent were considered in need of long term care, possibly in a residential setting. Some form of this scheme is still in use today in many school systems across the country.

DSM-IV. DSM-IV attempts to blend the 1977 and 1992 definitions put forth by the American Association on Mental Retardation. It adopts the 1992 definition, but retains the severity level classification scheme from the 1977 definition. The upper IQ limit is 70, and an individual must have delays in at least two of the 10 areas outlined in the 1992 definition. In general, the overview of mental retardation in DSM-IV is thorough and easy to follow. However, it should be noted that comprehensive cognitive and adaptive skill assessment is necessary to make the diagnosis; it should not be made on the basis of an office visit or developmental screening.

ICD-10. ICD-10 is the tenth revision of the International Classification of Diseases (World Health Organization, 1993). It is currently in use in some countries around the world but will not be adopted for use in the United States until after the year 2000. ICD-10 differs from ICD-9 in at least two key ways. First, it includes more diagnoses and is, consequently, much larger. The second major change is the coding scheme. The diagnostic codes have been changed from numeric codes to codes that begin with an alphabet letter and are followed by two or more numbers (e.g., mild mental retardation has changed from 317 to F70).

ICD-10 characterizes mental retardation as a condition resulting from a failure of the mind to develop completely. Unlike DSM-IV and the Classification Manual of the AAMR, ICD-10 suggests that cognitive, language, motor, social, and other adaptive behavior skills should all be used to determine the level of intellectual impairment. ICD-10 also supports the idea of dual diagnosis, suggesting that mental retardation may be accompanied by physical or other mental disorders.

Four levels of mental retardation are specified in ICD-10: F70 mild (IQ 50 - 69), F71 moderate (IQ 35 - 49), F72 severe (IQ 20 - 34), and F73 profound (IQ below 20). IQ should not be used as the only determining factor. Clinical findings and adaptive behavior should also be used to determine level of intellectual functioning. Two additional classifications are possible: F78 other mental retardation and F79 unspecified mental retardation. Other mental retardation (F78) should be used when associated physical or sensory impairments make it difficult to establish the degree of impairment. Unspecified mental retardation (F79) should

be used when there is evidence of mental retardation but not enough information to establish a level of functioning (e.g., a toddler with significant delays in development who is too young to be assessed with an IQ measure).

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