

historical article, meta-analysis, multicenter study, practice guideline, randomized controlled trial, review, systematic review, twin study, or validation studies. The limited search resulted in 3,651 retrievals.

The PsycInfo thesaurus term “Intellectual Disability” gave an assigned heading of Mental Retardation. A search for “Mental Retardation” or “Intellectual Disability” as keywords resulted in 47,532 articles. This search was then limited to English language, human, Childhood: birth to age 12 years, Adolescence: age 13–17 years, and the years from January 1, 1999, to January 21, 2019. The final retrieval was limited to Peer Reviewed Journal, Journal Article, or Review-Book, resulting in a final yield of 3,512 articles.

The Cochrane Database of Systematic Reviews was searched using “mental retardation” or “intellectual disability*”. The reviews were limited from January 1, 1999, to January 21, 1999, resulting in 316 reviews identified.

The CINAHL database was searched with the terms Mental Retardation or intellectual disability. Limits applied included English; Human; January, 1999–January, 2019; All child (0–18 years); peer-reviewed articles; abstract available. Medline records were excluded from this search. The search produced 552 articles.

The 8,031 articles found through this process were exported into the EndNote referencing program. A total of 44 articles identified by hand-searching or recommended by experts were added. After removing 483 duplicate references, the resulting yield from the comprehensive search was 7,590 articles. The titles and abstracts of all 7,590 articles were reviewed and 1,067 articles were included for full-text examination (Figure 1). A total of 258 publications were included in the qualitative synthesis based on their relevance to the parameter topic, weight in the hierarchy of evidence, quality of individual studies, and relevance to clinical practice.

DEFINITIONS

In this parameter, unless otherwise noted, the term *Intellectual Disability* (*Intellectual Developmental Disorder*) (ID/IDD) refers to intellectual disability as an intellectual developmental disorder. This parameter uses the term *Global Developmental Delay* when clinical severity cannot be reliably assessed in early childhood (under age 5) and the term *Unspecified Intellectual Disability* (*Intellectual Developmental Disorder*) for children over age 5 when other impairments make assessment difficult. The term *child* or *children* refers to both children and adolescents, and *parents* refers to the child’s primary caregivers, regardless of whether they are the biological or adoptive parents or legal guardians.

HISTORICAL REVIEW

Changes in the terminology used for individuals with ID/IDD reflect society’s perception of this population. In the 19th century, the now-unacceptable terms “cretin,” “idiot,” and “imbecile” were used, reflecting an era when these individuals were commonly housed in overcrowded asylums and institutions.² Many of these institutions were built during the height of the eugenics movement with the goal of preventing people with even mild ID/IDD from reproducing. Sterilization, often without consent or even the person’s foreknowledge, was practiced during the eugenic era. In 1961, the American Association on Mental Retardation (AAMR) introduced the term “mental retardation” to replace earlier terms that had become pejorative.

By the 1970s, the de-institutionalization movement began to provide community care. Social Security Income for this population became available, and it was assumed that community-based care could absorb and adequately provide for their needs. A movement to assess and to treat co-occurring psychiatric disorders in individuals with ID/IDD was underway, but, unfortunately, few psychiatrists had training. By the 1980s, instruments for assessment of co-occurring psychiatric disorders were developed. Since then, evidence-based principles for assessment and treatment have been developed, and specific training incorporated into psychiatric curricula.²

The most recent conceptual paradigm shift began in 1992, when the American Association on Intellectual and Developmental Disabilities’ (AAIDD) new definition placed greater emphasis on the disability construct by changing the earlier term “mental retardation” to “intellectual disability.” The premise is that a disability occurs when the demands of the environment exceed an individual’s ability. Thus, environmental modifications or social supports can ameliorate the extent to which a condition limits an individual’s functioning.³ This paradigm shift has helped frame intellectual disability not as a static condition, but one that can be enhanced by the provision of supports.⁴

In 2013, the American Psychiatric Association’s (APA) fifth edition of the *DSM-5*⁵ also revised the diagnostic term from “mental retardation” to “intellectual disability (intellectual developmental disorder).” However, unlike AAIDD’s focus on the disability construct, the *DSM-5* focus is on the developmental disorder construct in keeping with the World Health Organization’s (WHO) *International Classification of Diseases (ICD-11)*. In *ICD-11*, these are recognized as disorders of neurodevelopment and “described as a metasyndrome occurring in the developmental period analogous to dementia or neurocognitive