

Global Developmental Delay and Mental Retardation or Intellectual Disability: Conceptualization, Evaluation, and Etiology

Michael Shevell, MD, CM, FRCPC^{a,b}

KEYWORDS

- Global developmental delay • Mental retardation
- Intellectual disability • Evaluation • Etiology

CONCEPTUALIZATION

Neurodevelopmental disabilities are a common problem collectively in child health that challenge primary and specialty medical practitioners at varying levels, including (1) early recognition, (2) accurate diagnosis, (3) appropriate evaluation, (4) determination of etiology, (5) securing needed interventions, (6) just resource allocation, and (7) predicting eventual outcomes.^{1–4} Neurodevelopmental disabilities are a group of chronic clinically distinct disorders that all share a documented disturbance, quantitative, qualitative, or both, in developmental progress in one or more developmental domains compared with established norms.⁵ These domains, although not mutually independent or exclusive, include (1) motor (gross or fine), (2) speech and language, (3) cognition, (4) personal-social, and (5) activities of daily living. Neurodevelopmental disabilities are divided into various subtypes essentially functioning as “terms of convenience” that quickly capture a group of children who share

^a Departments of Neurology/Neurosurgery and Pediatrics, McGill University, Montreal, Quebec, Canada

^b Division of Pediatric Neurology, McGill University Health Center, Room A-514, Montreal Children's Hospital, 2300 Tupper, Montreal, Quebec, H3H 1P3, Canada

E-mail address: michael.shevell@muhc.mcgill.ca

impairments and mandate a common approach to diagnostic evaluation, possible medical requirements, therapeutic needs, required interventions, and individual or family challenges to participation and integration.⁶

Ideally, neurodevelopmental disabilities are diagnosed over time rather than at a single point of clinical encounter. This diagnosis occurs against a backdrop of a highly individualized developmental trajectory that may not be smooth or consistent over time. Indeed, what is “normal” may have wide variation, and establishing a clear boundary line may be difficult in a particular individual case.⁷

“Global developmental delay” refers to a disturbance in an individual child across one or more developmental domains.⁸ Such a child has limitations or delay in the widespread acquisition of skills that is directly observable and measurable in the context of the natural progression of children. The use of this term reflects difficulties in agreeing on the objective measurement of intelligence and cognition in a consistent, reliable, and valid fashion in the young child (ie, less than 5 years of age). The most recent consensus definition considers global developmental delay as a disturbance across a variety of developmental domains that is defined operationally as a significant delay (meaning 2 or more standard deviations) lower than the mean on objective norm-referenced age-appropriate testing in two or more developmental domains. Typically, there is delay across all domains.

A multidimensional approach has been used to define “mental retardation” in the most recent consensus statement put forward in 2002.⁹ According to that definition, mental retardation is conceptualized as “a disability characterized by significant limitation both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.” Thus, the definition extends beyond the traditional concept of a general subaverage level of intellectual function as captured in the measurement of an “intelligence quotient” (IQ). Adaptive behavior was envisioned to include those skills that an individual must acquire to function within the context of the expectations of his or her everyday life. Within the framework of the International Classification of Functioning, Disability, and Health (ICF) model of health and disease, mental retardation is manifested by significant problems in (1) an individual’s capacity to perform (ie, impairment), (2) the ability to perform (ie, activity limitations), and (3) the opportunity to function (ie, participation restrictions).¹⁰ The disability that is mental retardation is lifelong and originates at an early age well before the age of 18 years.

This definition for mental retardation requires the awareness of certain contextual assumptions implicit in its definition. These include the following: (1) the limitations and functions are considered within the context of an individual’s typical environment, (2) assessments used to yield a diagnosis of mental retardation are sensitive to and reflect varying linguistic and cultural diversity, (3) limitations that are necessary for diagnosis coexist with recognized strengths, (4) providing a profile of possible limitations envisions a spectrum of required supports for the individual, and (5) the quality of life for an individual with mental retardation can be improved by implementation of these envisioned supports.

More recently the term *intellectual disability* has emerged to replace that of *mental retardation*.¹¹ This change in terminology is reflected in the change in title of the American Association of Mental Retardation (AAMR) to the American Association on Intellectual and Developmental Disabilities (AAIDD). The term *intellectual disability* is thought to be synonymous with that of *mental retardation*, but its use is preferable because it reflects the recent change in our construct of disability and aligns better with the recent emerging emphasis on functional behaviors and contextual factors. A period during which both terms are used concurrently can be envisioned; however,

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