

Chapter 27

Intellectual Disability in the Family Context: Parents with Intellectual Disability

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ABSTRACT

Literature with regard to parents with intellectual disability is scant. On one hand, parents with intellectual disability engage in the valued social role of raising children; on the other, their parenting attracts (typically negative) attention based on an expectation of their limited capacities to parent. Available research primarily addresses the question of whether or not individuals with intellectual disability can be adequate parents or reports on methods for improving their parenting skills. There has been relatively negligible work in the Indian context with regard to parents with intellectual disability. This paper attempts to review literature on the current data available about parents and parenting with intellectual disability in the Indian context concentrating on directions for future research.

INTRODUCTION

Intellectual disability has been defined in several ways in literature. It can be described as a neurodevelopmental disorder, which has onset in childhood and leads to impaired development of one or more human capacities (Girimaji, 2015). Intellectual disability is characterized by limitations in intellectual functioning and resulting in the need for extraordinary supports for the person to participate in activities involved with typical human functioning (Wehmeyer et al., 2008). Intellectual disability, then, is a disability in which impairments to the brain (e.g., body functions and structures) result in activity limitations and participation restrictions, specifically limitations in intellectual functioning. Intellectual functioning is defined in the American Association on Intellectual and Developmental Disabilities (AAIDD) Manual (2002) on Definition, Classification, and Support Systems in Mental Retardation, as

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referring to a general mental ability that includes reasoning, planning, problem solving, abstract thinking, comprehending complex ideas, learning quickly, and learning from experience (Luckasson et al., 2002). In the past internationally and in India the term “mental retardation” was widely applied and defined as “a condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence” according to The National Trust For Welfare Of Persons With Autism, Cerebral Palsy, Mental Retardation And Multiple Disabilities Act, 1999. However, a more comprehensive definition takes into consideration the lower IQ scores on standard intelligence tests, as well as difficulties in social and adaptive functioning, occurring before the age of eighteen years. The latest mental health diagnostic publication, the Diagnostic and Statistical Manual -5 (DSM-5), replaces the term “mental retardation” and defines intellectual (developmental) disability as “a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.” These revisions bring DSM into alignment with terminology used by the World Health Organization’s International Classification of Diseases (ICD-10), other professional disciplines and organizations, such as the American Association on Intellectual and Developmental Disabilities, and the U.S. Department of Education. While suggesting that the term intellectual disability “covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type and duration of the disability and the need of people with this disability for individualized services and supports” Schalock and colleagues also recognized that the term “intellectual disability” more effectively “reflects the changed construct of disability proposed by AAIDD and the WHO” (Schalock et al., 2007). Contemporary literature uses the term “learning disability” or “learning difficulty” while discussing the same condition.

A break up of the ICD definition is as follows:

- *Deficits in intellectual functions such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience, and practical understanding confirmed by both clinical assessment and individualized, standardized intelligence testing.*
- *Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, and across multiple environments, such as home, school work and school, work, and recreation.*
- *Onset of intellectual and adaptive deficits during the developmental period. (DSM – 5, pg. 33).*

Thus one observes that individuals with Intellectual Disabilities (ID) face challenges throughout their life with regard to scholastic performance as well as in the realm of day-to-day life.

Looking at the etiology and manifestation of intellectual disability, we can regard it as one of a set of disabilities that can result from impairment to the central nervous system that manifest in limitations to general cognitive functioning. Cognition refers to the processes of knowing, including attending, remembering, and reasoning; also the content of the processes, such as concepts and memories (Gerrig et al., 2002). Other cognitive disabilities include traumatic brain injury, learning disability, and dementia associated with Alzheimer’s disease. Intellectual disability is set apart from other cognitive disabilities by factors such as scope of impairment (e.g., global) and age of onset (e.g., prior to age 18). Because intellectual disability must be manifested in the developmental period (e.g., prior to age 18), it is also a developmental disability. Developmental disability is a non-diagnostic category that refers to people with

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