Chapter 3

Living With Intellectual Disability:

Quality of Life

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ABSTRACT

The need to understand the quality of life of people with intellectual disability is crucial as this mental disability is considered to be a major setback for any individual and his/her family. Current researches focus on creating an equal platform to understand intellectual disability in order to gain more acceptances from the masses, especially for the families who have a member suffering from intellectual disability. The age of the family member and available care taking measures are also of critical value. Models of therapy/interventions drawn from previous evidence-based practices give a bright picture.

INTELLECTUAL DISABILITY

Intellectual disability, formerly labelled "mental retardation," is defined by the Individuals with Disabilities Education Act (IDEA) as "significantly sub-average general intellectual functioning, existing concurrently [at the same time] with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance." There are two key components within this definition: a student's IQ and his or her capability to function independently usually referred to as adaptive behavior. The deficits in "adaptive behavior" cited by IDEA prove trickier to evaluate. Factors considered include the ability to comprehend and participate in a conversation, to understand and follow social norms and to perform activities such as getting dressed and using the restroom. NICHCY explains that the causes of intellectual disabilities vary from pregnancy issues and complications at birth

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to genetic conditions (such as Down syndrome and fragile X syndrome) and health problems early in life, including diseases like measles and contact with poisonous substances such as lead and mercury.

A number of traits can point to an intellectual disability. The National Institute of Child Health and Human Development (NICHD, 2016) lists the following among early indicators:

- Delay in reaching developmental milestones such as sitting up and talking
- Difficulty remembering things
- Trouble comprehending accepted social behaviors and/or understanding the consequences to actions
- Poor problem-solving skills

The term Intellectual Disability has its roots in the term ‘mental retardation’ and ‘developmental disability’ (Health Commission, 1981; Thompson & O’Quinn, 1979; Wolfe, 1992) and its epidemiology is usually developmental or subsequent to traumatic brain injury. Individuals may have mild, moderate or severe intellectual disabilities depending on the assessments of their cognitive abilities (Arthur, 1998; Hogg & Sebba, 1987).Intellectual disability could be defined as an inability to carry out everyday adaptive functions which make living simple. These deficits could result in difficulties in communication, social participation and independent living across multiple environments such as home, school, workplace and community. On more complex level, intellectual functions of reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experiences could also be hindered.

According to the DSM-V, intellectual disability is defined as a ‘‘disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains.”(DSM-V, 2013).The World Health Organization’s definitions of impairment, disability and handicap are generally regarded as authoritative, although multiple interpretations militate against a consensus (Bowe, 1978; Fulcher, 1989; Smyer, McHale, Birkel, & Madle, 1988). A very basic disagreement is whether the disability is a personal tragedy for the individual or is it more of a social problem arising because of disabling barriers within the environment (Abberley, 1987; Bickenbach, 1993; Gleeson, 1995).

Many terms, definitions and various descriptions of people with an intellectual disability see them in a ‘deficit perspective’. Such a perspective does not give much importance to the social place, humanity and abilities of people with intellectual disabilities (Bickenbach, 1993; Schalock, 2004). On the other hand, the ‘similarity perspective’ focuses on capabilities. It supports the argument that all persons can learn, irrespective of the degree or complexity of their disabilities (Oliver, 1996).

General definitions of quality of life prevail in the literature reviews. Schalock (1997) referred to perceived quality of life as satisfaction with the main areas of one’s own life. Brown (1994) stated that enhancement of quality of life was related to reduction in the discrepancy between an individual’s achieved and unmet needs. Brown (1998) also mentioned that quality of life is the extent to which individuals have increasing control of their environments. Heal (1994) described it in terms of global satisfaction with one’s lifestyle and control over resources that produced satisfaction.

A strong literature review supports the idea that conceptualization and assessment of quality of life of people with intellectual disability should be done in a manner similar to those which are done for people without such a disability. Schalock’s (1999) core dimensions of quality of life of people with intellectual disability included emotional well-being, personal development, physical well being, self-determination, social inclusion and rights. Emphasis was also put upon individual improvement rather

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