Chapter 8
Quality of Life of People with Intellectual Disability

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ABSTRACT

Intellectual Disability, according to DSM-V 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.” Clinical judgment and individually administered standardized tests confirm deficits in intellectual functions such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience. Adaptive functioning is also deficit as the individual needs assistance in one or more activities of daily living such as communication, social participation and independent living across multiple environments such as home, school, work and community. 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. It needs to be highlighted here, that the families of people with intellectual disability also play a crucial role. New research reviews are required to bring policy changes and better tools.

INTRODUCTION: INTELLECTUAL DISABILITY

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.

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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). Various authors have postulated that even very disabled people are capable of making choices that are meaningful and realistic.

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 than population improvement (Brown, 1998; Cummins, 1996; Zapf, 1987). It was also argued that people with intellectual disabilities should be more involved in decision-making about policies and programs aimed at improving their quality of life (Brown, 1995; Brown, McLinden, & Porter, 1998, Goode and Hogg (1994), Nankervis (1997), Schalock (2002), and Schalock and Verdugo (2002).

Fabian (1991) identified three approaches of quality of life. The first two approaches view quality of life as an objective social indicator for specific groups and viewing it as a broad subjective measure of life satisfaction. The third approach is a measure of adaptive functioning which was identified as an alternative for individuals who were unable to self report or whose life experiences were inequitably limited.

**RELATIONSHIP BETWEEN INTELLECTUAL DISABILITY AND QUALITY OF LIFE**

People may have difficulty in “knowing” a person with an intellectual disability. It is usually difficult to understand what their feelings, interests, wants, preferences and inner life is like. Several authors have attempted to have a look at these aspects and have described that “knowing” a person with intellectual disability would emerge when a person spends more time with the disabled person. This ‘knowing’