

Self-determination and Social Inclusion as Priorities for Improving Quality of Life of Children with Intellectual Disability

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Goal

The importance and utility of the concept of quality of life is unquestionable; it is used throughout the world as a sensitizing notion and to inform social practices and interventions. Significant progress has been made in defining quality of life for people with intellectual disability developing appropriate measurement instruments. The psychometric properties of the instruments have however been questioned (Li et al. 2013).

There has been most progress measuring quality of life in adults with intellectual disability, while little attention has been paid to childhood and adolescence. For this reason, the main goal of the present study is to contribute to knowledge and understanding of quality of life for this population in order to provide some guidelines for developing persons-centered plans, evidence-based practices, and social and human policies to improve their quality of life.

Participants

The KidsLife Scale was applied to a convenience sample comprising 873 Spanish children and adolescents with intellectual and developmental disabilities under 21 years old. Most of them were males (65.2%). Their ages ranged from 3 to 21 years old (M = 13.8; SD = 5.2). Respondents informed that 17.3% had mild intellectual disability, while most of them showed moderate (32.8%) or severe (8.7%) levels. Only 8.7% were classified as showing a profound intellectual disability. However, respondents also declared in relation to their support needs, that 12.6% needed limited supports, 25.3% intermittent supports, 28.5% extensive supports, and 33.6% needed pervasive supports. It must be noted that many of the participants showed, besides intellectual disability, other associated verified conditions such as autism spectrum disorder (26.2%), physical disability in lower (19.2%) or higher (15.2%) extremity, Down syndrome (15.2%), cerebral palsy (13.3%) or behavior disorders (12.2%).

The assessment was carried out by 512 respondents, most of whom (76.6%) were staff working at 105 agencies that provides supports to people with intellectual and developmental disabilities located throughout Spain; the rest (23.4%) were parents (18.4% mothers and 5% fathers). Respondents had known the person whose quality of life was assessed for a mean of 5 years. The great majority (89.9%) had a frequency of contact with the assessed person of several times per week.

Instrument

The field-test version of the KidsLife Scale was a self-administered questionnaire that assesses quality of life-related personal outcomes in children and adolescents with significant disabilities (under 21 years old) who are social, educative, or sanitary service recipients. The assessment is carried out by a third party (i.e., staff, relative, proxy, etc.) who knows well and has opportunities to observe the person assessed. It is composed of eight subscales that correspond to the eight quality of life domains proposed by Schalock and Verdugo (2002), and a total of 156 items (Self-determination = 16; Emotional wellbeing = 20; Physical wellbeing = 20; Material wellbeing = 20; Rights = 20; Personal development = 20; Social inclusion = 20; Interpersonal relations = 20). The answer format is a frequency scale with four options (never, sometimes, often, and always). The scale is available in electronic and printable version and administration time varies from 30 to 40 minutes.

Cronbach's alpha was .969 for the total scale. The highest internal consistence was found for personal development (.904) while the lowest one was for rights (.809). This study is focused on the analysis of two of the eight domains: self-determination (.877) and social inclusion (.886).

Results

Self-determination and Social inclusion were the domains showing the lowest scores in comparison to the other six domains (the greatest means were found for material and physical wellbeing). The quality of life related - personal outcomes that obtained the greatest scores (i.e strengths) were related to express what they like and dislike (e.g., food, activities, clothing, plays), to ask for help from other persons when they need, and to participate in the same classes or activities as the other peers. On the other hand, the lowest means (i.e. those where greater supports are needed) are those concerning to choose clothing, to participate in activities in their community with persons outside their support group, and to participate in the development of their individual support plan.

These findings reveal that self-determination and social inclusion should be a priority for person-centered plans as well as for social and human policies addressed to improve the quality of life of children and adolescents with intellectual disability.

