



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



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 plannings, 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.



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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: selfdetermination (.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 plannings as well as for social and human policies addressed to improve the quality of life of children and adolescents with intellectual disability.



Persons providing him/her supports know what he/she likes and dislikes Specific measures are taken to allow him/her to influence his/her environment He/she chooses how to spend his/her free time

Specific measures are taken to allow him/her to make choices He/she has opportunities to refuse to do things that are unrelated to his/her health issues When opportunities are provided he/she chooses the meal or part of the meal The decision to carry out an action is carefully considered when he/she experiences it as unpleasant

He/she chooses clothing that he/she wants to wear He/she has opportunities to refuse things that he/she dislikes Persons providing him/her supports take into account his/her preferences and choices He/she decorates his/her bedroom to his/her liking

Supports are provided to him/her that take into account his/her needs, wishes, and preferences He/she has a daily program of activities that reflect his/her preferences He/she participates in the development of his/her individual support plan He/she asks for helpfrom other persons when he/she needs He/she refuses what he/she does not like with gestures, sounds, or words He/she chooses who he she/spends his/her free time with His/her preferences are taken into account in his/her individual support plan

He/she enjoys holidays in inclusive environments 11,5 35.7 He/she is integrated with his/her class peers 3,6 17,6 He/she carries out leisure activities with same age peers 12,7 He/she uses community environments 2,4 26,1 Persons outside his/her support group interact with him/her 12,9 He/she receives supports and interventions in natural environments 5.3 25.4 He/she participates in family celebrations 6,3 18 19,2 He/she participates in natural groups from his/her community

He/she has opportunities to go to other environments, different from the place where he/she lives 5,5 He/she participates in activities in his/her community with persons outside his/her support group

He/she participates in inclusive activities that are commensurate with his/her physical and cognitive

He/she participates in the same classes or activities as the other peers 1,9 18

He/she participates in inclusive activities that are in line with his/her interests 14,5 He/she participates in social activities outside the place where he she/receives services or formal Specific measures are taken to strengthen his/her participation in the community 10,8 He/she participates in leisure and cultural activities in community environments



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His/her decisions are respected His/her opinion in taken into account when changes are made

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