

## ANALYTICAL SUMMARY

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### Rare diseases and intellectual disability: assessment of quality of life of children and adolescents

**ABSTRACT:** *Antecedents.* The main objective of this study was to evaluate the quality of life in children and young people with rare diseases and intellectual disability, as well as to determine the incidence of certain predictors (i.e., gender, age, level of intellectual disability, type of school, type of illness and autonomous community) in the criterion variable. *Method.* The KidsLife Scale was applied, a questionnaire based on the eight domain model of quality of life by Schalock and Verdugo. The sample comprised 103 participants with rare diseases and intellectual disability, aged between 3 and 21, who received supports in any organization providing educational, social, or health services. *Results.* The best scores were found in physical wellbeing, while the lowest were in social inclusion. The level of intellectual disability and support needs resulted in significant differences for the total score of the scale. Analyses by domains showed differences by gender, intellectual disability level, and type of schooling. *Conclusions.* The results argue for designing practices aimed to improve quality of life-related personal outcomes with regard to self-determination, inclusion, and interpersonal relationships.

**KEYWORDS:** rare diseases; intellectual disability; quality of life; assessment.

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## Deafblindness, its regulatory treatment and care

**ABSTRACT:** It is clear that people with dual sensory disability: deafblindness, have special needs for integration. Now, determine what supports they need to live an independent life and to be socially integrated remains a challenge. We propose here to discover what social, and family contextual factors influence the acquisition of the functional autonomy of deafblind people (PCS hereinafter), in order to get effective strategies that contribute to their integration. Given the nature of our goal, great importance is conferred to the discourse of PCS and its context. It advocates considering disability as an interaction between subject and environment, not only as personal circumstances. Indeed, the emphasis is on how the environment helps / hinders the acquisition of autonomy and integration.

This article focuses on the present state of affairs, concluding on one hand, deafblindness is a unique disability with a heterogeneous character, and secondly, the lack of attention that the PCS have received so far, largely due to its invisibility.

**KEYWORDS:** autonomy; integration; people with deafblindness; heterogeneity; attention; invisibility.

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## Construction of a Family Quality of Life Support Program for families of young and adults with intellectual disability

**ABSTRACT:** This paper is grounded on current conceptions on Family Quality of Life (FQoL) and family-centered intervention. It describes a part of the building process of a 'Program for Supporting Family Quality of Life', within the SAIOA-BBK frame –a Gorabide's information, guidance and support service for people with intellectual disability and their families. A major goal of this project is making proposals for professionals to fit the link between FQoL assessment and its improvement. The program was developed, constructed and tested through collaborative methods between professionals and university researchers, aiming to an increase of FQoL of families with sons or daughters among the youth and adulthood period. Program features, and how it was experimented in a pilot sample of families (n = 5) is presented.

**KEYWORDS:** family quality of life; family-centered intervention; program; empowerment; family routines; action-research; professional training.

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## Profile of job coaches in supported employment

**ABSTRACT:** This study analyzes the figure of the job coach in various Supported Employment services in Spain. A quality-oriented study carried out, based on the case study. Twenty-three semi-structured interviews held with professionals, along with thirty-six participant observations at different stages of Supported Employment. The results show disparity in the profiles associated with various areas of knowledge, as well as a diversity of functions related to the roles performed by the job coach depending on the number of staff taken on. The most significant competencies combined with personal

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skills and communicative abilities. It recommended that employment programs improve vocational retraining programs to make up for training deficiencies and provide professional skills for intervention in each service.

KEYWORDS: job coach; vocational skills; professional profile; qualitative research; intellectual disabilities; Supported Employment.