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Proposal of indexes to evaluate Family Quality of Life, Partnership, and Family support needs



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Family quality of life;
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Abstract In recent years, research on the families of persons with Intellectual Disability (ID) has focused on the factors that contribute to the improvement of their Family Quality of Life (FQoL), such as the support they get and their partnership with professionals. However, due to the complexity of the variables related to FQoL and support needs and adequacy, measuring these constructs is difficult and multidimensional. To do this, the aim of this study is to generate new indexes through a series of instruments and assess their feasibility to improve the evaluation process and not reduce the situation to single measurements. We applied 3 instruments adapted to the Spanish population – Service Inventory, Beach Center Family-Professional Partnership Scale, and Beach Center FQOL – to a sample of 202 families of children with ID and we studied the indexes. The results show that the new indexes were designed to make FQoL measurements more easily manageable and interpretable. In fact, we found a statistical significant correlation between partial indexes ($p < .001$) in relation to the total score and very high sensibility of the indexes in relation to the degree of disability ($p < .001$). They also facilitate conducting complex analyses without having to discard any relevant measurement dimension.

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PALABRAS CLAVE

Calidad de vida familiar;
Apoyo;
Colaboración;

Propuesta de índices para evaluar la calidad de vida familiar, la colaboración y las necesidades de apoyo familiar

Resumen En los últimos años, la investigación sobre las familias de las personas con discapacidad intelectual se ha centrado en los factores que contribuyen a la mejora de su calidad de vida familiar (CdVF), como, por ejemplo, los apoyos que estos reciben por parte de los servicios y

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la colaboración con los profesionales. Debido a la complejidad de estos constructos, su medición es difícil y multidimensional. El objetivo de este estudio es generar nuevos índices para una serie de instrumentos y valorar su viabilidad para mejorar el proceso de evaluación y no reducir la valoración a una única medida. Para ello, se aplicaron 3 instrumentos adaptados a la población española: el Inventario de Apoyos, la Escala de Colaboración Familias-Profesionales y la Escala de CdVF a una muestra de 202 familias de niños con discapacidad intelectual, y los índices fueron estudiados. Los resultados muestran que los índices fueron diseñados para hacer más fácil el manejo e interpretación de las medidas de CdVF. De hecho, encontramos correlaciones estadísticamente significativas entre los índices parciales ($p < 0,001$) y la puntuación total, y una muy alta sensibilidad con el grado de discapacidad ($p < 0,001$). Estos también facilitan la realización de análisis complejos sin tener que descartar ninguna dimensión de medida relevante.

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Introduction

Since the 1960s and 1970s, the interest of researchers in families of children with intellectual disability (ID) focused on the impact the disability had on the families in terms of stress and/or depression (Bailey et al., 1998; Davis & Gavidia-Payne, 2009; Turnbull, Summers, Lee, & Kyzar, 2007), thus favoring a pathological perspective of those families (Cunningham, 2000; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Summers, Behr, & Turnbull, 1989; Turnbull, 2003).

From the 1990s and 2000s onwards, a more positive vision of the families has increasingly appeared in the literature, emphasizing the possibility of positive adaptation to their child's disability as long as the family has the necessary abilities and support. It is understood that the adaptation processes and needs of those families are not always the same (Cunningham, 2000). As a result of that evolution, research has focused less on the difficulties suffered by the families, such as stress, and increasingly has been concerned with the factors that contribute to their adaptation to their situation as successfully as possible (Shapiro, Blacher, & Lopez, 1998; Summers et al., 1989).

In that context, the interest of the scientific community, and also the professionals and the families themselves, in family quality of life (FQoL) has become a goal both for research and intervention. Bailey et al. (1998), on the one hand, suggest that "overall perception of quality of life probably represents more than the sum of the other family outcomes domains" (p. 323) such as family perceptions about support system, satisfaction with the overall program, individual services, and service providers (Bailey et al., 1998). On the other hand, Mannan, Summers, Turnbull and Poston (2006) show that the FQoL is a more global construct to reflect family well-being. That is to say, FQoL has emerged as a good outcome to define the global life situation of those families that should be explored and encouraged (Brown & Brown, 2004; Mannan et al., 2006; Schalock & Verdugo, 2002; Schalock, 2004; Turnbull et al., 2004; Turnbull et al., 2007).

Zuna, Turnbull and Summers (2009) and Zuna, Summers, Turnbull, Hu and Xu (2010) have proposed that FQoL predictors are related to the following factors: (1) family as a unit (family characteristics and dynamics), (2) the

individuals who make up the family (demographic and individual characteristics, and beliefs of each family member), (3) performance (services, support, and practices), and (4) the system (the system, the policies, and the programs).

Researchers such as Brown, MacAdam-Crisp, Wang and Iarocci (2006), Davis and Gavidia-Payne (2009), Hu, Wang and Fei (2012), Summers et al. (2007), and Wang, Summers, Little, Turnbull, Poston, and Mannan (2006) have conducted research in several social and cultural contexts. In these studies, the authors attempted to measure whether the performance system, including supports (defined as services provided to family and child), and practices (defined as relationships with professionals) were meeting the family needs, and if so, whether the degree to which these needs were met predicts FQoL (Chiu, Turnbull, & Summers, 2013). This multi-level FQoL model illustrates the complexity of family dynamics. To investigate factors which may be amenable to interventions, and to determine what types of supports will have maximum results in terms of family outcome (i.e., FQoL), it is important to have efficient and effective measures of the various predictive factors.

In our case, in order to take a step forward in research on FQoL in Spain, to implement the measure to improve the practices targeted by these families, we deemed it appropriate to adapt (from previous research) three instruments to our population: the Service Inventory, the Beach Center Family-Professional Partnership Scale, and the Beach Center FQoL (Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2011).

The Service Inventory is an instrument that measures the degree to which supports and services that the family and child receive meet their needs. The Beach Center Family-Professional Partnership Scale is a measure to assess family perceptions about their family-professional partnerships. The Beach Center FQoL Scale is intended to identify perceptions of FQoL.

Those instruments require from the families that they assess the indicators according to two measurement dimensions.

1. The Service Inventory measures: (a) family perceptions of needs for services and, (b) the degree to which those needs are met. As regards these measurement

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