## Facing the Challenge of Assessing Quality of Life of Children with Profound and Pultiple Disabilities

LINDVERSIDAD DE OVIEDA

A selection of the best valued items conformed the field-version of the KidsLife Scale. Please, find more information about the

scale and its development

and validation process in

the subsequent poster

MICO

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Significant progress has been made in the operationalization of quality of life for people with intellectual disability and subsequent development of quality of life measures. However, most of this progress has been achieved for those with the highest levels of functioning who are able to communicate their preferences, opinions, perceptions, and goals. In contrast, the operationalization for those with profound and multiple disabilities is still a pending task that has been acknowledged in the published research since more than two decades. In the same way, there are a very considerable number of instruments to assess quality of life -not so many with sound psychometric properties-, but most of them are hardly suitable for people with profound intellectual disability who may also have significant motor dysfunctions, chronic health issues, challenging behaviors, sensory impairments, or mental health problems.

To date, the only effort to operationalize the concept of quality of life for this population has been made by Petry, Maes, and Vlaskamp (2005, 2007, 2009) on the basis of the five-domain model proposed by Felce and Perry (1995, 1996). They carried out the first research in 2005 in Belgium, Holland, and Germany through a Delphi study. They achieved a pool composed of 176 items that constituted the first quality of life operationalization for adults.

Taking their studies as a starting point, our goal was to get a valid operationalization of quality of life for children and adolescents with multiple and profound disabilities in Spain. On the basis of the indicators found by Petry et al., the San Martin Scale (an instrument recently developed in Spain to assess quality of life of adults with significant disabilities), and other quality of life questionnaires, we carried out a Delphi study with the goal of identifying core indicators for the eight domains proposed by Schalock and Verdugo (2002). The starting point was a pool of 200 items (i.e., 25 per domain).

14 experts participated in a Delphi study involving 3 rounds:



Experts valued suitability, importance, observability, and sensitivity of the 200 items through a scale ranging from 1 to 4, as well as proposed new items

Experts discussed about the

observability, and sensitivity

suitability, importance,

of a selection of 27 items

among those that were

Round 1

considered "non-valid" in

Selection criteria that items must fulfill to be retained: to reach a mean score ≥ 3: and

2. to show a standard deviation < 1.5

No scale

Experts decided about the suitability of 204 selected items among those proposed in Round 1 through a Yes /

retained (80% considered them as suitable) Among the 27 discussed:

14 were reformulated, I was assigned to a different domain, and 8 were joined into 3 new ones

55 items among the new ones proposed by the experts were



Experts valued suitability, importance, observability, and sensitivity through a 1-4 scale for 77 items (the 55 new items retained and the 22 discussed in Round 2)

Selection criteria that items must fulfill to be retained: to reach a mean score ≥ 3

- and
- 2. to show a standard deviation < 1.5

57 items were (40 new: 17 reformulated)

RIGHTS

110 items

were valid

366 new

items were

proposed

The operational definition of quality of life resulting from the Delphi study (N = 167 items):

EMOTIONAL

WELLBEING

aonity / saiet nental health

PHYSICAL WELLBEING

MATERIAL

WELLBEING

SELF-DETERMINATION

PERSONAL DEVELOPMENT

SOCIAL INCLUSION

RELATIONSHIPS

INTERPERSONAL

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