

# IMPACT OF THE INTELLECTUAL DISABILITY SEVERITY IN THE SPANISH PERSONAL OUTCOMES SCALE

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## Abstract

### Background

The interest in measuring Quality of Life (QoL) in persons with intellectual disability (ID) has brought about a number of QoL measurements for this population. These measurements need to address two issues that have contributed to enhancing the current instruments. First, the necessity to develop measures with adequate psychometric properties, which has been discussed in recent studies; and second, the agreement between experts in analysing objective and subjective perspectives, as well as the use of self-report to include the participation of the person with ID. The question that we set out to investigate in this paper is whether the measurements function properly for the person with ID, independent of their level of severity. We used the Spanish version of the Personal Outcomes Scale (POS), as it is a psychometrically sound instrument and includes three sources of information (the person with ID, a professional, and a family member).

### Method

The sample was composed of 529 persons with ID (296 men, representing 55.95% of the total sample, and 233 women; with  $M_{\text{age}}=35.03$ ,  $SD=10.82$ ) from several regions of Spain, along with their professional of reference and a family member. The severity variable was estimated for each item based on estimations of differential item functioning (DIF).

### Results

The results showed that several items were undervalued by the assessments if the severity of the ID was greater. Mainly, this difference was observed in the assessments

by professionals and in the dimensions of rights, personal development and self-determination.

## **Conclusions**

This paper focuses on the uses and interpretations of the results of the QoL measurements in the POS. The results indicate that, in our sample, the people with high levels of ID, some items are affected by the severity of the ID in the person being assessed. For correct use, these items must be interpreted on the basis of the results obtained. Additionally, it is necessary to thoroughly review the QoL indicators for persons with severe or profound ID.

**Key Words:** Intellectual Disability, Quality of Life, Personal Outcomes Scale, Differential Item Functioning

## **Introduction**

Research has shown that the quality of life (QoL) model generated by Schalock & Verdugo (2002) provides a framework for person-centred planning and is a useful guide for practices and policies concerning persons with intellectual disabilities (ID) (Schalock & Verdugo 2012; Schalock & Verdugo 2013). The measurement of QoL is achieved through the assessment of personal outcomes, described as “person-defined and valued aspirations. Personal outcomes are generally defined in reference to QoL domains and indicators” (Schalock *et al.* 2007, p. 14). Personal outcomes reflect the core domains of the Schalock & Verdugo QoL model that have been cross-culturally validated (Jenaro *et al.* 2005; Schalock *et al.* 2005) and have subsequently been identified as having three second-order factors (Wang *et al.* 2010). These factors are independence (composed of personal development and self-determination), social participation (composed of interpersonal relations, social inclusion, and rights), and well-being (composed of emotional, physical, and material well-being).

The substantial interest in measuring QoL in persons with ID is reflected by the large number of instruments on the topic. Nevertheless, based on a systematic review, only six instruments have psychometrically acceptable properties that provide empirical and useful data (Townsend-White *et al.* 2012). The development of these scales has revealed two issues that have been widely discussed in the literature. The first issue is the need for psychometric properties that guarantee sufficient reliability and validity to provide consistent data. The second issue is that different perspectives or sources of

information must be included in QoL measurements. This issue refers to whether individuals with ID and their proxies should participate.

Regarding the first point, the current scales show substantial advantages, as they have been developed through deep and detailed statistical analyses, i.e., the Personal Outcomes Scale (POS) (van Loon *et al.* 2008) and its adaptation to Spanish (Carbó-Carreté *et al.* 2015) and Portuguese (Simões *et al.* 2015), the Integral Scale (Verdugo *et al.* 2009), the INICO-FEAPS Scale (Verdugo *et al.* 2013), the Personal Wellbeing Index (PWI-ID) (Cummins & Lau 2005) and the Evaluation of Quality of Life Instrument (EQLI) (Nota *et al.* 2006). All these scales and their adaptations prove the increasing interest in the QoL of persons with ID, which are considered one of the most socially excluded groups (Ali *et al.* 2012; Werner *et al.* 2012).

The second point has been widely discussed, and the latest studies justify the involvement of the participants in QoL measures. The use of self-reported data has been widely addressed (Bonham *et al.* 2004; Li *et al.* 2013; Verdugo *et al.* 2005), but authors generally agree that allowing people to talk about themselves is essential in the QoL measurement process (Cummins 2005; Schalock *et al.* 2002; Stancliffe 2000). Although some authors disagree regarding whether the objective or subjective perspective should be evaluated (Schalock & Felce 2004; Schalock *et al.* 2007), the most sound proposal is based on a combination of these two perspectives (Cummins 2005; Schalock & Felce 2004; Schalock *et al.* 2007). This view has been affirmed in more recent studies involving the active role of participants, which justifies the necessity of including the person with ID, a professional, and/or a family member (Balboni *et al.* 2013; Claes *et al.* 2012; Janssen *et al.* 2005; Perry & Felce 2002, 2005; Schmidt *et al.* 2010; Schwartz & Rabinovitz 2003; Simões & Santos 2016).

Separate from the two issues mentioned above, we consider a new question regarding the severity of the participants' ID. Personal outcomes are interpreted as a result of a process wherein the person's individual support needs have been evaluated and minimised thanks to the provision of adequate support (Schalock & Verdugo 2012; van Loon 2015). This approach to persons with ID originates from the latest publications in the ID concept (Luckasson *et al.* 2002; Schalock *et al.* 2010), which argues that the focus of an ID on the person's "defect" is increasingly outdated and should shift towards an understanding centred on the person and their environment. This altered viewpoint is reflected in the incorporation of support needs assessments by support services as well as the design of Individualised Support Plans to enhance QoL.

Thus, in Spain, services for persons with ID are undergoing a transformation towards a procedure based on this more recent conceptualisation of ID, although at varying paces (Verdugo 2018).

Part of the evidence of this ongoing service transformation is the relevance now given to personal outcomes and their assessment (Schalock & Verdugo, 2013). However, the same scales and procedures have also been used for all people treated by the service. This is the crux of our research question: Can QoL scales be used without taking into account the severity of the ID? This shortcoming has been addressed, for example, in the conceptualisation and measurement of QoL for people with severe ID proposed by Ouellette-Kuntz & McCreary (1996) and the work of Petry *et al.* (2007), who showed the utility of the five-domain QoL model by Felce & Perry (1995) for persons with profound ID. Another relevant work is that of Gómez *et al.* (2015), who elaborated a series of QoL indicators for persons with severe ID based on the QoL model of Schalock & Verdugo (2002). Moreover, specific scales and procedures have been developed with a focus on persons with severe or profound ID (Lyons 2005; Petry *et al.* 2009; Ross & Oliver 2003; Verdugo *et al.* 2014; Vos *et al.* 2010).

In light of these contributions, we sought to examine whether QoL scales are influenced by the severity of ID. Because these scales have significant psychometric properties and comprise different perspectives (i.e., self-reporting and reporting by others), we questioned whether the severity of the ID of the person assessed could modify the QoL results. The rationale for conducting this study was that if the severity of ID affects the QoL assessment, the scales or certain items should be adapted to guarantee a valid and reliable assessment. Therefore, the purpose of this work was to analyse whether the severity of ID could affect QoL measurement, particularly in light of our sampling possibilities. To examine this question, we used the Spanish version of the POS (Carbó-Carreté *et al.* 2015) and estimations of differential item functioning (DIF). More specifically, DIF estimates were used to assess whether an external variable could affect the observed distribution of the items, i.e., to determine whether there was possible bias. In our case, these techniques were used to reveal the possibility of bias in one or several items to assess in more detail the total score derived from administering the Spanish version of the POS in a Spanish-speaking sample population. For further development of these techniques in the field, please see Jones & Amtmann (2016) and Baker & Kim (2004).

## Method

### Participants

The sample comprised a total of 529 persons with ID (296 men and 233 women, with  $M_{age} = 35.03$ ,  $SD = 10.82$ , age range: 16-66 years) who resided in seven Autonomous Communities in Spain: Andalusia (20.9%), Aragon (4%), Catalonia (25%), Castile and León (6.6%), Castile-La Mancha (14.8%), Madrid (17.4%), and Galicia (11.7%). Relevant professionals ( $N=522$ ) and family members ( $N=462$ ) also participated.

In this study, accidental, non-randomised sampling was performed in every Autonomous Community. Spanish law assigns a “handicap” percentage to every person with a disability to reflect the severity of the disability. The law stipulates that those with a percentage of 33% or higher receive an economic subsidy or support to facilitate everyday life. The disability percentage is assigned administratively based on all types of impairments (e.g., intellectual, physical, or sensorial, among others). Half of the participants (51.2%) were scored at 65-74% (high level of dependency). The second largest group (36.8%) were scored at 75% (very high level of dependency), and the smallest group (12.1%) of participants were scored at 33-64% (moderate level of dependency). The ID was evaluated using the following psychometric scales: the Wechsler Intelligence Scale for IQ and the ICAP (Inventory for Client Agency and Planning) for adaptive behaviour. Several Autonomous Communities have used other scales, but both domains were assessed to determine the ID. In our sample, the participants predominantly had a moderate (47.3%) or mild level of ID (33.3%), whereas the smallest groups consisted of individuals with severe and/or profound ID (11.3%) or borderline ID (8.1%).

Table 1 shows the main descriptive data regarding the individuals with ID. Additionally, Tables 2 and 3 show the descriptive data of professionals from support service organizations and family members, respectively.

Table 1

*Descriptive data of participants with ID (n=529). Observed distribution percentage (%) for each autonomous community*

	Andalusia	Aragon	Catalonia	Castile and León	Castile-La Mancha	Madrid	Galicia
Gender							
Male	58.6	61.9	53.8	62.9	52.6	56.5	53.3
Female	41.4	38.1	46.2	37.1	47.4	43.5	46.7
Area of residence							
Rural	21.1	14.3	4.5	37.1	19.2	3.3	16.7
Semi-urban	34.9	85.7	34.1	-	46.2	17.4	41.7
Urban	44.0	-	61.4	62.9	34.6	79.3	41.7
Intellectual disability level							
Borderline	10.8	14.3	5.3	2.9	19.2	4.3	1.7
Mild	31.5	23.8	36.4	62.9	33.3	30.4	20
Moderate	50.5	57.1	46.2	31.4	44.9	52.2	45
Severe and/or profound	7.2	4.8	12.1	2.9	2.6	13	33.3
Day care							
Special work center	1.8	9.5	22.7	5.7	3.8	12	1.7
Occupational therapy services	76.1	81	73.5	85.7	88.5	59.8	45
Day center	8.3	9.5	3.8	2.9	3.8	17.4	43.3
Educational center	5.5	-	-	5.7	-	5.4	5
Others	8.3	-	-	-	-	5.4	1.7
Place of residence							
Residence	8.7	9.5	5.3	17.6	6.6	8.7	3.4
Supervised flat	-	-	22	23.5	10.5	-	6.8
Family home	86.5	81	68.9	58.8	81.6	88	89.8
Independent home	4.8	9.5	3.8	-	1.3	3.3	-

Table 2

*Descriptive data of professionals (n=522). Observed distribution percentage (%) for each autonomous community.*

	Andalusia	Aragon	Catalonia	Castile and León	Castile-La Mancha	Madrid	Galicia
Type							
Direct care (day)	75	47.6	79.5	-	66.2	49.5	76.7
Direct care (night)	-	-	2.3	-	-	-	-
Direct care (physical activity and sport)	6.7	-	-	-	13	29.7	5
Technical staff of service	13.5	42.9	17.4	100	20.8	6.6	11.7
Others	4.8	9.5	-	-	-	8.8	3.3
Educational level							
Secondary education	22.1	9.5	9.1	-	17.9	6.6	16.7
University degree	58.7	42.9	64.4	94.3	51.3	42.9	41.7
Higher university degree	1.9	-	11.4	5.7	14.1	5.5	21.7
Others	17.3	47.6	15.2	-	16.7	45.1	20

Table 3

*Descriptive data of family members (n=462). Observed distribution percentage (%) for each autonomous community.*

	Andalusia	Aragon	Catalonia	Castile and León	Castile-La Mancha	Madrid	Galicia
<b>Relation with person with ID</b>							
Parent	72.4	42.9	66.4	54.5	81.2	83.1	74.6
Sibling	21.8	52.4	21.8	36.4	15.9	12	22
Other family member	4.6	4.8	2.7	-	1.4	4.8	3.4
Legal tutor	1.1	-	9.1	9.1	1.4	-	-
<b>Educational level</b>							
No studies	19.8	4.8	6.4	-	20	12.2	6.8
Primary education	41.9	23.8	42.2	60	47.1	20.7	52.5
Secondary education	18.6	38.1	26.6	30	15.7	24.4	18.6
University studies	16.3	14.3	18.3	10	11.4	32.9	15.3
Others	3.5	19	6.4	-	5.7	9.8	6.8
<b>Place of residence</b>							
Rural	19.5	14.3	14.5	23.3	21.4	3.6	16.9
Semi-urban	43.7	85.7	36.4	3.3	42.9	15.7	45.8
Urban	36.8	-	49.1	73.3	35.7	80.7	37.3

## **Instrument**

The Spanish version of the POS (Carbó-Carreté *et al.* 2015) aims to assess QoL in Spanish-speaking persons with ID on the basis of the eight dimensions of the Schalock & Verdugo's (2002) model, which were arranged into three higher-order factors: independence, social participation, and well-being (Wang *et al.* 2010). As noted above, this scale is divided into three information sources: (a) a self-report, where the individual answers questions on his/her own, which assesses the subjective perspective of QoL; (b) a professional report, which assesses the individual's experiences and circumstances from the viewpoint of direct care staff or a service technician; and (c) a family report, which indicates scores from a family member's perspective. Every dimension has 6 items, for a total of 48 item responses for the scale as a whole. Every item is assessed on a 3-point Likert scale. Scores were obtained through an interview conducted by an interviewer who had previous training in the theoretical model and the proper administration of the scale. Outcomes were obtained for every dimension and for the three factors. For every dimension, the sum of all the scores from the 6 items was obtained by using the following calculation: (3) = *always*, (2) = *sometimes*, and (1) = *rarely or never*. After the dimensions of each factor were summed, a final score was calculated. The Spanish POS adaptation (Carbó-Carreté *et al.* 2015) is consistent with the multidimensionality of the QoL construct and with the three second-order factors.

Moreover, the construct validity analysis provides an adjustment of the theoretical model with regards to the three sources of information, particularly the professionals' assessments (Table 4).

Table 4

*Adjustments and factor loading of the three measurement models*

	Self-report Model	Professional Model	Family Model
<i>Adjustments</i>			
$\chi^2$ ( $df = 1052$ )	1346.34 ( $p < .001$ )	973.09 ( $p = .04$ )	1067.43 ( $p < .001$ )
Ratio ( $\chi^2/df$ )	1.28	0.93	1.02
GFI	.943	.981	.940
AGFI	.951	.979	.941
BBNFI	.955	.980	.942
BBNNFI	.952	.979	.940
TLI	.956	.979	.944
CFI	.949	.978	.941
SRMR	0.04	0.02	0.05
95% CI	0.02 – 0.06	0.01 – 0.03	0.03 – 0.07
AIC	-1323.12	-1533.12	-975.19
BIC	-1346.71	-1608.11	-1011.71
<i>Factor Loading</i>			
First-order factors			
Personal development	.645 to .743	.545 to .623	.477 to .623
Self-determination	.721 to .812	.511 to .523	.389 to .532
Interpersonal relations	.546 to .743	.577 to .645	.523 to .578
Social inclusion	.601 to .723	.611 to .746	.431 to .449
Rights	.599 to .689	.487 to .834	.412 to .507
Emotional well-being	.602 to .822	.697 to .723	.467 to .521
Physical well-being	.433 to .728	.743 to .892	.477 to .502
Material well-being	.577 to .720	.677 to .812	.439 to .601
Second-order factors			
Independence	.322 to .478	.771 to .841	.501 to .534
Social Participation	.458 to .542	.699 to .802	.602 to .699
Well-being	.377 to .412	.578 to .671	.599 to 6.28

GFI: Goodness of Fit Index; AGFI: Adjusted Goodness of Fit Index; BBNFI: Bentler Bonnet Normed Fit Index; BBNNFI: Bentler Bonnet Non Normed Fit Index; CFI: Comparative Fit Index; TLI: Tucker Lewis Index; SRMR: Standardized Root Mean Standard Residual; CI: Confidence Interval; AIC: Akaike Information Criteria; BIC: Bayesian Information Criteria.  
All significant ( $p < .001$ )



The reliability analysis demonstrated appropriate values for the first-order domains and, importantly, for the second-order factors, with values higher than .82. (Table 5)

Table 5  
*Cronbach's  $\alpha$  values for every factor and source of information*

	Self-report ( <i>N</i> = 529)	Report of Professional ( <i>N</i> = 522)	Report of Family ( <i>N</i> = 462)
First-order factors			
Personal development	.734	.796	.802
Self-determination	.775	.855	.788
Interpersonal relations	.707	.856	.839
Social inclusion	.800	.625	.627
Rights	.629	.854	.776
Emotional well-being	.758	.685	.696
Physical well-being	.636	.703	.672
Material well-being	.680	.755	.723
Second-order factors			
Independence	.823	.877	.841
Social Participation	.878	.892	.854
Well-being	.865	.891	.866

## Procedure

Organizations that provide services were asked to participate by the Spanish Confederation of Organizations for the Persons with Intellectual Disability (named *Plena Inclusión*) and by logistic support teams from the delegations in every Autonomous Community.

Before starting with the training sessions and the POS administration, informed consent forms were prepared for each source of information in accordance with the instructions of the *Universitat Ramon Llull* Ethics Committee. These informed consent forms were read by all of the professionals, family members and persons with ID who participated in the project. When individuals with ID did not understand the document, the interviewer or an appropriate proxy (i.e., member of the family or professional) provided assistance.

In every Autonomous Community, specific training regarding the administration of the POS was provided to the professionals who would participate as interviewers. Thus, we were able to guarantee that application of the instrument would be consistent with the

original authors' guidelines. Once a person with ID was identified, a family member and a professional of reference were also identified.

The professionals who acted as interviewers administered the POS to 670 participants, 529 of whom provided complete responses to all of the items and scales across all three sources. The majority of the records that were discarded (141 in total) were removed due to the low participation of family members, who did not adhere to the registration protocol. In some of these cases, the parents were of advanced age and had difficulties reaching the service, or the relatives had little knowledge of the participants' lives in most of the environments assessed.

Following the POS instructions, the scale was administered through an interview in all cases. Respondents were required to have known the individual with ID for at least 3 months and to have had the opportunity to observe him/her in one or more environments over a period of 3 to 6 months. For the ID sample, if the person evaluated showed some communication difficulties, a support professional was present to facilitate the communication procedure.

Finally, the present study is part of a group of investigations focused on analysing the psychometric properties and the functioning of the items of the Spanish version of the POS.

### **Statistical Analysis**

To assess the effect of the variable severity on the observed distribution of the items in each dimension, we used DIF estimations, which are commonly used in these situations. Generally, logistic models are adequate for these cases, and they allow us to identify and estimate parameters showing the effects of one or several variables exogenous to the measurement system in relation to each of the items proposed. There are numerous studies showing this application (Gómez-Benito *et al.* 2013; Demir & Köse 2014). We found a derivative of these procedures in the use of Mantel-Haenszel's estimations, which we used to estimate effect sizes related to DIF effects. Both procedures have been generated from the same perspective, estimating logistic parameters and transforming them into impact measures by means of indicators of the effect size or similar data. In our case, we opted for structural equation modelling (SEM) to estimate the effects of an exogenous variable on a confirmatory factor analysis (CFA). Several psychometric studies have used similar procedures to those

proposed here (Anderson *et al.* 2016; Jones *et al.* 2015). The procedure used is shown graphically in Figure 1.

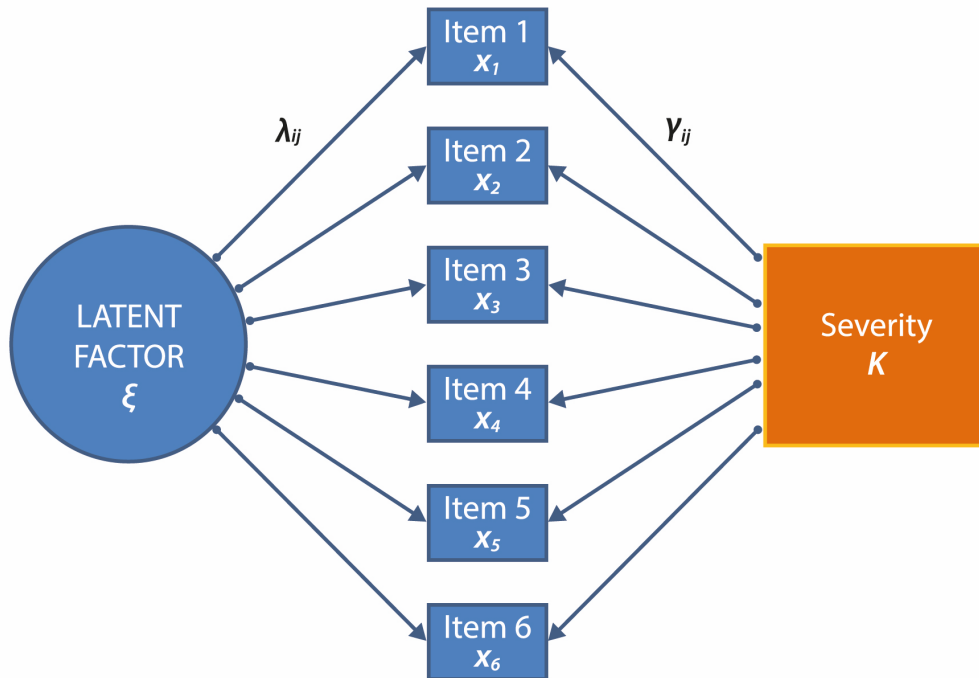


Figure 1. Structural equation model used to estimate the DIF parameter in each latent variable.  $\gamma_{ij}$  represents the DIF parameter, and  $\lambda_{ij}$  represents the factorial coefficient.

This model involves a system of simultaneous equations that can be described as follows: i)  $X_i = A_x \cdot \xi + \delta$  for the estimations of the confirmatory model, where the matrix  $A_x$  comprises the values of  $\lambda_{ij}$ , which represent the factor loadings and were secondary in this project as they were already addressed in previous studies (Carbó-Carreté *et al.* 2015); and ii)  $X_i = \Gamma \cdot K$  where  $K$  represents the exogenous variable that generates DIF, in our case, the severity of diagnosis in persons with ID, and the matrix  $\Gamma$  comprises the values of each parameter  $\gamma_{ij}$ , representing the specific impact of the exogenous variable on each item. We have therefore generated 24 models corresponding to the 8 dimensions that compose the Spanish adaptation of the POS scale for each of the three information sources.

## Results

In each model, we applied the maximum likelihood (ML) estimation; in all cases, the model fit was acceptable. The model had non-significant  $\chi^2$  values, Comparative Fit Index (CFI) values over 0.96, and Tucker Lewis Index (TLI) values over 0.94. Accordingly, the parameter estimation table is summarised in Table 6.

Table 6  
*Parameter estimation of the structural equation model procedure applied to the DIF structure*

	SELF-REPORT	PROFESSIONAL	FAMILY MEMBER
<b>Personal Development</b>			
Item1	-0.613	-0.935	-0.230
	0.252	0.193	0.205
	0.015	< 0.001	0.262
Item2	-0.657	-1.296	-0.743
	0.161	0.153	0.168
	< 0.001	< 0.001	< 0.001
Item3	-0.158	-0.579	-0.075
	0.129	0.138	0.141
	0.220	< 0.001	0.594
Item4	-0.174	-0.413	-0.180
	0.145	0.138	0.145
	0.232	0.003	0.213
Item5	-0.956	-2.053	-0.702
	0.203	0.371	0.189
	< .001	< 0.001	< 0.001
Item6	-1.330	-1.381	-0.703
	0.202	0.193	0.188
	< .001	< 0.001	< 0.001
<b>Self-Determination</b>			
Item1	-0.955	-1.767	-0.684
	0.194	0.229	0.218
	< .001	< 0.001	0.002
Item2	-0.843	-0.751	-0.182
	0.193	0.182	0.175
	< 0.001	< 0.001	0.300
Item3	-0.177	-1.506	-0.590
	0.148	0.229	0.141
	0.232	< 0.001	< 0.001
Item4	0.003	-0.727	-0.235
	0.146	0.148	0.176
	0.982	< 0.001	0.183

Item5	-0.613 0.129 < 0.001	-1.456 0.172 < 0.001	-0.923 0.140 < 0.001
Item6	-0.742 0.180 < 0.001	-0.699 0.163 < 0.001	-0.325 0.191 0.089
Interpersonal Relations			
Item1	-0.157 0.213 0.460	-0.739 0.198 < 0.001	-0.130 0.231 0.574
Item2	0.001 0.141 0.993	-0.736 0.253 0.004	-0.055 0.230 0.811
Item3	-0.598 0.163 < .001	0.079 0.145 0.585	0.463 0.149 0.002
Item4	-0.122 0.154 0.430	-0.838 0.252 0.001	-0.140 0.268 0.601
Item5	-0.237 0.272 0.383	0.252 0.184 0.172	-0.001 0.225 0.997
Item6	-0.140 0.206 0.498	-0.037 0.162 0.822	0.230 0.175 0.190
Social Inclusion			
Item1	0.238 0.145 0.102	-0.144 0.221 0.514	0.006 0.214 0.976
Item2	-0.069 0.134 0.608	-0.566 0.192 0.003	-0.027 0.183 0.884
Item3	-0.338 0.179 0.059	-0.383 0.138 0.006	-0.295 0.157 0.060
Item4	-0.370 0.139 0.008	-0.529 0.129 < 0.001	-0.531 0.165 0.001
Item5	0.360 0.135 0.008	-0.247 0.155 0.111	0.002 0.162 0.992
Item6	-0.289 0.151 0.056	-0.249 0.151 0.099	0.014 0.158 0.929
Rights			

Item1	-0.299 0.176 0.089	-0.446 0.157 0.005	-0.010 0.176 0.953
Item2	-1.265 0.322 0.000	-3.098 1.485 0.037	-1.127 0.489 0.021
Item3	-0.348 0.130 0.007	-0.328 0.116 0.005	-0.338 0.143 0.018
Item4	-0.745 0.148 < .001	-0.936 0.122 < .001	-0.837 0.208 < .001
Item5	0.040 0.128 0.755	-0.168 0.117 0.153	-0.050 0.144 0.728
Item6	-0.469 0.125 < .001	-0.571 0.121 < .001	-0.629 0.138 < .001
Emotional Well-Being			
Item1	-0.088 0.152 0.561	-0.156 0.134 0.246	0.242 0.153 0.115
Item2	-0.043 0.217 0.841	0.051 0.150 0.732	-0.093 0.160 0.558
Item3	0.363 0.152 0.017	0.396 0.186 0.033	0.399 0.210 0.057
Item4	1.017 0.282 < .001	0.528 0.289 0.068	1.130 0.358 0.002
Item5	0.374 0.175 0.033	0.602 0.267 0.024	0.219 0.231 0.344
Item6	0.283 0.192 0.141	0.281 0.180 0.119	0.373 0.185 0.044
Physical Well-Being			
Item1	0.178 0.167 0.284	-0.116 0.189 0.538	-0.113 0.160 0.479
Item2	0.111 0.128 0.387	0.093 0.139 0.503	0.118 0.134 0.377

Item3	0.305	0.078	0.353
	0.181	0.158	0.234
	0.092	0.623	0.132
Item4	0.398	0.342	0.506
	0.136	0.163	0.199
	0.004	0.036	0.011
Item5	0.080	0.070	0.021
	0.121	0.122	0.120
	0.510	0.570	0.864
Item6	0.236	0.110	0.579
	0.159	0.154	0.208
	0.138	0.474	0.005
Material Well-Being			
Item1	0.115	-0.140	-0.033
	0.214	0.158	0.204
	0.593	0.374	0.870
Item2	-0.156	-0.314	-0.207
	0.188	0.132	0.143
	0.406	0.017	0.149
Item3	0.099	-0.563	-0.045
	0.132	0.137	0.146
	0.452	< .001	0.760
Item4	-0.138	-0.384	-1.026
	0.122	0.130	0.174
	0.259	0.003	< 0.001
Item5	-0.736	-0.961	-0.773
	0.138	0.142	0.146
	< .001	< .001	< .001
Item6	0.014	-0.018	0.226
	0.175	0.156	0.184
	0.935	0.909	0.218

In each cell, the first value is the ML estimation of the DIF parameter, after the Standard error value, and the third is the p value significance.

As shown in the table, the professionals' assessments were the most affected by the variable 'severity'. Based concretely on the scores of the professionals, the item scores on the dimensions of 'personal development' and 'self-determination' were all influenced by the severity of the person assessed, as were most items from the 'rights' and 'material well-being'. From the other information sources (i.e., the person with ID and family members), the behaviour of the items was quite similar in most dimensions, even though severity was less of a determining factor.

In the 'rights' dimension, we detected the need to review a large number of the items, as three sources coincided with lower scores in four items. The second dimension requiring additional attention was 'personal development'. Even if the professionals always provided the lowest scores, item 6 ("How often does the person use assistive technology?") appeared to be the item most affected by the individual's severity of ID in terms of the three informants' responses, particularly those of the person with ID and the professional. In the dimension 'self-determination', we also found two items that the three informants tended to undervalue: item 1 ("To what degree does the person have control over what to wear, what to eat, places to go, etc.?"), where the person with ID gave the second-lowest score after the professional, and item 5 ("To what degree does the person control at least some portion of their money?"), where the family was the second source with a clear tendency to provide values lower than expected.

In addition to these highlighted dimensions, we found three items in three different dimensions that were affected by severity, whereas the other items showed minimal or no influence of severity. We are referring to item 4 in 'social inclusion' ("Does the person volunteer to help others in the community?"), item 4 in 'physical well-being' ("How would you evaluate the nutritional status of this person?"), and item 5 in 'material well-being' ("Does the person have the key for his/her home?").

It should be noted that only one item from the entire scale was influenced by severity solely in the assessment by the person with ID: item 5 in 'social inclusion' ("Do people from the community do things for you - including visiting you and taking you places?"). Similarly, only two items were affected solely by the family assessment: item 6 in 'emotional well-being' ("Does the person show that he/she trusts others by sharing feelings or being comfortable when around others?") and item 6 in 'physical well-being' ("How would you evaluate how the person looks upon waking and getting up?").

## **Discussion**

The current paper contributes complex, detailed information concerning the psychometric properties of the Spanish version of the POS. Specifically, we studied whether the interpretation of the results of the POS is influenced by the severity of ID. Thus, the variable severity was examined to determine whether it may affect the functioning of each item assessed.



Close attention to the obtained results reveals the need to interpret certain assessments cautiously, given that the scores of a significant number of items were affected by severity. There is no doubt that the professional assessments require the most attention, as they tend to lower scores for persons with higher degrees of severity. These data could be explained by the change in roles of the professionals mandated by the ongoing transformation period of the services in Spain. Currently, professionals have to promote opportunities in natural settings, providing support using the community environment and not focusing their work on the activities organised by the service (Verdugo, 2018).

Based on the data obtained, a logical first question is whether severity affects the score distributions of all three informants. In this sense, the 'rights' dimension stands out, as all three informants tended to provide lower scores on four out of the six items assessed. These results can be understood in the context of previous studies showing that persons with ID are highly conditioned by prejudices and stigmas that seriously affect their human rights (Ali *et al.* 2012; Werner *et al.* 2012).

The scores with the highest severity-related impact might be explained by the context in which the item is placed. In a previous study of persons with multiple profound disabilities (Petry *et al.* 2009), it was noted that each source of information had their own specific experiences with the person being assessed, which influenced their judgement of the items. For example, in the 'social well-being' subscale, the family member knows the capacities of the person in environments with and without support. As a consequence, item 2 in the 'rights' section of the POS ("Does this person have control over the key to his/her home/apartment?") had the lowest scores from the professionals. This item was challenged by multiple professionals during the study because they considered it to be an inappropriate indicator of QoL. Although they admitted the importance of having keys to their home, this item could seriously affect persons with ID, as they may wonder why they do not have keys to their home (some persons with ID had to wait at work for their colleagues who finish later in the day, because only the professional who was living with them had a key to the home). Likewise, it is easy to understand that item 3 in 'interpersonal relationships' ("How often does the person generally interact with or visit his/her family?") and item 4 in 'emotional well-being' ("How often have you seen the person show signs of happiness (e.g., smiles, grins, laughs)?") were affected in only the assessments provided by the person with ID and the family member. These data could be interpreted that persons

with severe level of ID tend to consider that they have little relationship with their family. Moreover, the severity of the person with ID do not let them identify expressions related to positive feelings. Probably, the families of persons with high severity of ID tend to think they have little interactions with them. These results are consistent with those from a study that used t-tests to analyse paired samples (Claes *et al.* 2012). This work found significant differences in assessment scores between persons with ID and their families and professionals within the domain of ‘interpersonal relations’ as well as between families and professionals within the domain of ‘emotional well-being’.

Undervaluing these items might lead to a broader discussion of whether the definitions of QoL dimensions and indicators are adequate for the whole spectrum of individuals with ID. A suitable answer to this question has been discussed in previous studies (Gómez *et al.* 2015; Ouellette-Kuntz & McCreary 1996; Petry *et al.* 2007), and we suggest that future studies on QoL scales carefully consider the different levels of severity in the populations examined. The existence of scales for persons with profound ID is well accepted; however, establishing scales for all the levels of ID may be a challenging task. Identifying those items influenced by the severity of ID guarantees the use of valid scales and minimises errors in the interpretation of the results of QoL measures.

We call attention to the data presented in the current paper and sample population are critical when considering the correct interpretation of the Spanish version of the POS, as the scores may be undervalued according to the severity of ID. Treating professionals must be cautious when assessing the QoL of persons with moderate or profound levels of ID due to their observed tendency to score certain items at a lower level. Moreover, the data we obtained show the need to review in detail those items influenced by the severity of ID.

Although highly relevant to the field, the results obtained in this project are subject to certain limitations. The first limitation is related to the size of the sample. The group with severe or/and profound ID was small; for this reason, futures studies must include more persons with this profile. The second limitation was the assumption that all professionals and services are involved in the QoL model and the current assessment procedures to the same extent. Although all of the assessing professionals received the same training sessions, some of them were not as familiar with these materials as others.

Finally, the results obtained in the present paper allow us to affirm once again that the studies based on the DIF estimations are essential for a correct administration and interpretation of psychometric data. Researchers working on translations of original scales into other languages and countries will know well that not only is it a mere translation, but a thorough and in-depth study of the necessary adaptations derived from the context conditions are required. For example, the degree of familiarization about the quality of life model and the support paradigm observed in the phase of data collection was different in the different regions of Spain. Although we have not currently examined the data according to each region, it would be an interesting future proposal to study these possible differences in more detail.

Finally, we would like to emphasise that quality of life scales aimed at the population with intellectual disabilities cannot be useful instruments if only translation and psychometric adaptation are carried out. Based on the work presented, our suggestion is that these scales require an additional study based on the differential estimates according to the severity categories that we have shown. The original versions, usually in English and/or generated in an English-speaking social context, should not only be adapted psychometrically. They should be the purpose of more specific studies, such as those presented here, for a better understanding and quality of the scores obtained and their interpretation.

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