



UNIVERSITAT DE  
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## Les percepcions positives i la qualitat de vida familiar en famílies amb fills i/o filles amb discapacitat intel·lectual

Fina Ferrer i Vidal

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## CAPÍTOL 4. RESULTATS

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#### 4.1. Article número 1

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# The Impact of Demographic Characteristics and the Positive Perceptions of Parents on Quality of Life in Families with a Member with Intellectual Disability

Fina Ferrer<sup>1</sup>  · Rosa Vilaseca<sup>1</sup> ·  
Rosa Maria Bersabé<sup>2</sup>

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**Abstract** Families with children and adolescents with intellectual disability (ID) have positive perceptions that may raise levels of FQoL. However, little is known about what happens to these positive perceptions and FQoL when the family members with ID reach adulthood. Our main objective was to analyze the predictors of FQoL, incorporating demographic variables and parents' positive perceptions before and after the family member with ID turns 18. A sample of 861 families who had a family member with ID between 1 and 70 years old completed both the Positive Contributions Scale (PCS) in order to measure their positive perceptions and the Spanish family quality of life scale for under 18-years-old or over 18-years-old in order to assess FQoL. Firstly, a bivariate analysis was conducted to study the effect of demographic variables and PCS scores on FQoL scores. Secondly, variables whose effect was found to be statistically significant in the bivariate analysis were included in a multiple linear regression model to predict FQoL scores. Results indicated that families with higher levels of positive perceptions reported higher levels of FQoL. The predictive analysis of FQoL showed that in both groups of families with a member with ID younger or older than 18 years of

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✉ Fina Ferrer  
fferrer@ub.edu

Rosa Vilaseca  
rosavilaseca@ub.edu

Rosa Maria Bersabé  
bersabe@uma.es

<sup>1</sup> Department of Developmental and Educational Psychology, University of Barcelona, Pg. De la Vall d'Hebron 171, 08035 Barcelona, Spain

<sup>2</sup> Department of Psychobiology and Methodology of the Behavioral Sciences, University of Malaga, Av. Cervantes 2, 29071 Malaga, Spain

age, there was a significant effect from positive perceptions on the reported levels of FQoL, even when the effect of the demographic variables included in the model was eliminated. The present results provide further evidence of the importance of a positive approach toward families with a family member who have ID, reinforcing and broadening the positive perceptions in order to promote their FQoL. The practical implications of these findings are discussed, along with directions for future research.

**Keywords** Positive perceptions · Family quality of life · Families · Intellectual disability · Multiple linear regression

## Introduction

In the field of intellectual disability (ID), families are the main support for individuals with ID throughout their lives. The family assumes a very important role in their care, offering them opportunities for learning and accompaniment in their natural setting to facilitate their development (Samuel et al. 2012). However, this means that these families have to face situations of stress that are comparatively more intense and sustained over time than families who have children with normative development (Baker et al. 2010; Eisenhower et al. 2005; Hayes and Watson 2013; Oelofsen and Richardson 2006). It is even the case that greater feelings of anxiety and depression can appear in parents with children who have ID than in parents having children with normative development (Olsson and Hwang 2001; Singer 2006).

In addition, the families must cope with the diagnosis of disability and adapt to the situation, confronting a stressful experience that is lifelong in nature. However, some families show greater adaptability to the situation, presenting higher levels of individual and family well-being than others (Greer et al. 2006; Meirsschaut et al. 2010). The abilities of such families are constantly adapting to the stage of life that characterizes their family member with ID and their nuclear family (Rolland 2012).

In the last two decades, extensive study has examined the well-being of families with a family member with ID and their quality of life. Using a holistic, contemporary approach, Family Quality of Life (FQoL) is viewed as a very important element of studying and working with families who have children with ID, especially to enable fathers and mothers to interact with their son or daughter and to identify and assess any potential impact on the services and support given to these families. Indeed, several research groups have focused on the conceptualization, measurement and enhancement of FQoL in families who have a family member with disabilities (Aznar and Castañón 2005; Brown et al. 2006; Giné et al. 2013; Hoffman et al. 2006; Hu et al. 2011; Isaacs et al. 2007; Samuel et al. 2012).

The team of Zuna et al. (2010) unified various definitions put forward by different authors and proposed a definition of FQoL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 10). The authors proposed an explanatory model of the complex interactions that are generated between the characteristics and dynamics of families with a member with disabilities, the support they receive, the collaboration between professionals and families, and FQoL. Recently, this model has been reviewed by Chiu et al. (2013), who proposed giving consideration to the outcomes

generated in terms of the support received by the family and to the impact of these outcomes on the development of the individual with disability and on FQoL.

To expand what we know about which variables may account for higher or lower levels of FQoL in a family with a member who has ID, some researchers have focused on analyzing the relations between FQoL and the demographic variables (Giné et al. 2015; Wang et al. 2004) of the family itself and of the individual with ID. Differences in the levels of FQoL have been found, for example, between single-parent families and families in which both parents were present in the care of the individual with ID, with the latter group showing higher levels of FQoL (Davis and Gavidia-Payne 2009; Giné et al. 2015; Keller and Honig 2004; Park et al. 2003). This is also the case in terms of employment status. Parents who worked outside the home had higher FQoL than parents who devoted their time to the care of family members with ID (Ferrer et al. 2016). Various authors have found associations between income level and the level of FQoL reflected by the parents, with FQoL being higher when income is higher (Davis and Gavidia-Payne 2009; Giné et al. 2015). At the same time, it is necessary to take into account the influence of the characteristics of the individual with ID in these significant relations. Some studies have not found associations between the level of FQoL and the degree of disability (Lin et al. 2009), while others have observed that this may be a variable associated with lower levels of FQoL (Hu et al. 2012).

In addition, the role of the support network of families with a family member with ID in relation to FQoL has been evaluated. According to the results, families who rate their network as satisfactory, receiving real support, have a greater FQoL (Davis and Gavidia-Payne 2009). Ultimately, additional research is needed to determine how these demographic variables may be related to FQoL, given that they may be influenced by social and cultural factors. This is particularly so in the adult population, in which there are fewer studies of FQoL in these families (Boehm et al. 2015).

Few studies have found a relation between the positive perceptions that parents of children with disability have toward these children and their FQoL (Bayat 2005; Ferrer et al. 2016). These parents' positive perceptions are based on identifying the positive contributions of the child with ID within the family, finding a sense of meaning in the disability as well as benefits from having a child or relative with disability (Hastings and Taunt 2002; Hastings et al. 2005a, b; Kayfitz et al. 2010).

Researchers analyzing mothers and fathers of children with disability in different contexts have reached the conclusion that parents who had positive perceptions of their child with disability also expressed more feelings of happiness, family togetherness and personal growth (Blacher and Baker 2007; Greer et al. 2006; Hastings and Taunt 2002; Gupta and Singhal 2004; Kayfitz et al. 2010; Vilaseca et al. 2014). Zuniga (2004) found that positive perceptions and acceptance can protect families from some of the negative aspects of disability or their circumstances in life. Kuhn and Carter (2006) showed that an increase in parental knowledge about disability and more positive perceptions led to a reduction in feelings of guilt in mothers of children with autism, greater well-being and more actions by mothers to foster their children's development. However, there are fewer studies on the positive perceptions of fathers and of other relatives of adults with ID. Blacher and McIntyre (2006) reported that parental positive perceptions may be useful as a protective factor against depression symptomatology. More recently, Scallan et al. (2011) found that parents of children with Williams syndrome aged between 4 and 43 years recorded positive perceptions of the impact of their children on their families. They reported joy, a positive impact in siblings, personal development, and a sense of

family union, and lived the experience of having a child with disability as a reward rather than as a punishment. With similar results, Povee et al. (2012), in a sample of individuals with Down syndrome between 4 and 25 years of age, found that they contributed to greater family togetherness, facilitated new friendships and encouraged family members to become more empathic and understanding toward other people.

In this respect, Behr et al. (1992) devised an assessment tool on parental perceptions in families that have a member with disability. This instrument, called the Kansas Inventory of Parental Perceptions (KIPP) is the only one specifically designed to assess the perceptions of parents of children with ID (Ferrer et al. 2015). The KIPP, which included an evaluation of positive perceptions (Positive Contributions Scale; PCS), has recently been adapted for the Spanish population, specifically for families with individuals of all ages who have ID (Ferrer et al. 2015). It analyzed positive perceptions, among other kinds, while taking into account different dimensions, such as happiness and fulfilment (i.e., feelings of happiness), strength and acceptance (i.e., acceptance of life events), maturity (i.e., increased sense of responsibility), sensitivity toward disability (i.e., increased awareness of people with disability, greater understanding of people's differences), expanded social network (i.e., greater number of friendships) and purpose in life (i.e., religious beliefs).

The PCS is the only evaluation instrument designed explicitly to assess parents' positive perceptions of their family member with ID, and it has been used in several studies (Hastings et al. 2002, 2005a; Hastings and Taunt 2002; Kayfitz et al. 2010; Vilaseca et al. 2014; Singer et al. 1999) to explore the presence of positive perception in families with children and adolescents with ID. Among other variables, these studies analyzed the relationships between positive perceptions and psychological well-being and stress levels. They emphasized the importance of positive perceptions at a practical level, in the intervention with families. Especially from the perspective of empowering families and reinforcing their strengths (Dunst et al. 2014), this instrument may acquire an important role in the process of intervention with families (Ferrer et al. 2015).

Few studies have analyzed the relationship between positive perceptions and FQoL. Bayat (2005) suggested significant associations between the positive perceptions of parents of children with autism and higher levels of FQoL. More recently, Ferrer et al. (2016) has found that the positive perceptions of parents of young children and adolescents with ID are related to higher levels of FQoL. Specifically, families who had more positive perceptions of their child boosted their emotional well-being, presenting greater feelings of individual and family-level satisfaction; they expressed a better adaptation to the experience of having a child or sibling with ID; and they said they were more satisfied with their physical and mental health at the level of the individual and the family. In addition, parents who perceived that their child with ID had characteristics and abilities to contribute positively to the family attributed less importance to the child's degree of disability.

Despite the evidence on the associations between positive perceptions and levels of FQoL in families with young children and adolescents with ID, no studies have analyzed the relation between parental perceptions and FQoL at different life stages of the individual with ID, including adulthood.

In view of the above, the objectives of this study are: 1) to analyze the relation between the different demographic variables of parents (age, gender, marital status, level of education, employment status, household income, etc.) and of their children



with ID (age, gender, degree of ID, etc.) and FQoL; 2) to analyze the relation between parents' positive perceptions of their child with ID and FQoL; and 3) to predict FQoL by means of a multivariate model that incorporates demographic factors and parents' positive perceptions. All of these analyses will be conducted at two distinct life stages of the individual with ID: before and after eighteen years of age. We hypothesized that higher levels of positive perceptions would be related with higher levels of FQoL at both stages of life studied.

## Methods

### Participants

The sample included 861 family units, composed by fathers, mothers and other parent-like figures with a family member with ID. They were receiving care at early childhood intervention centers, special schools, mainstream schools or occupational therapy services affiliated to *Plena Inclusión* (the Intellectual Disabilities Association of Spain), Spain's largest association of families with people with ID, or in Catalonia, to DINCAT (the Intellectual Disability Association of Catalonia). All participating families were resident in Spain and were distributed as follows: Catalonia (51.3 %), Andalusia (23.7 %), Extremadura (14.2 %), Navarra (4.4 %), La Rioja (2.6 %), Aragon (1.4 %), Valencia (1.3 %), and Madrid (1.1 %). Spanish nationals accounted for 94.3 % and foreign nationals 5.7 %. The sample was selected using convenience sampling.

Most respondents were parents ( $n = 720$ ; 83.6 %) and 16.4 % ( $n = 141$ ) were siblings or other family members. The majority were women ( $n = 626$ ; 72.7 %) and married or living with a partner ( $n = 658$ ; 76.4 %). The age of respondents ranged between 22 and 91 years old ( $M = 50.3$ ;  $SD = 12.1$ ). A third (38.7 %) had received only elementary schooling, 30.9 % had completed high school and 24.8 % had a university degree. A third of respondents (33.4 %) were in full-time employment, whereas 36.5 % cared for their children and were fully responsible for the housework. Almost half of the sample (42.4 %) had a monthly family income between \$1319 and \$2748, considered an average income in Spain. Three quarters (75.3 %) did not receive help in their care of a family member with ID, either in the form of support from the Spanish Department of Health and Social welfare or informal help from family members or relatives, while 24.7 % did receive help.

Regarding the individuals with ID, males ( $n = 478$ ; 55.5 %) were slightly more numerous than females ( $n = 358$ ; 41.6 %). Their age ranged between 1 and 70 years old ( $M = 21.7$ ;  $SD = 13.9$ ). Slightly under half (46.9 %,  $n = 381$ ) were under 18 years, and 53.1 % ( $n = 432$ ) over 18. As regards the degree of ID (according to the Classification used by the Spanish Ministry of Health and Social Affairs) the disability was mild in 22.2 % ( $n = 191$ ) moderate in 33.9 % ( $n = 292$ ) and severe in 39.8 % ( $n = 343$ ). All of them had been diagnosed by psychologists employed by an official government agency called the Spanish Network of Care Centers for the Learning Disabled (CAD), which then issues an official certificate that acknowledges both the existence and degree of the disability. Additional conditions had been diagnosed in 91.6 % (e.g., visual impairment, hearing impairment, physical disability, autism spectrum disorders and health issues).

The individuals with ID lived with their families, except for 6.6 % who were in nursing homes. A total of 47.6 % of the sample had 1 sibling, while 13.4 % were only children.

## Instruments

A brief demographic questionnaire was used to record the parents' age, gender, marital status, educational level, employment status, level of income, and whether they received formal support or informal help at home in the care of the family member with ID, as well as the services received by their family member with ID and the parents' degree of satisfaction with these services. The same questionnaire was used to record the family member's age, gender, number of siblings and degree of ID. Positive perceptions and FQoL were assessed using two separate instruments:

### *Positive Contributions Scale (PCS)*

Parents' positive perceptions regarding their child with ID were measured using one of the scales in the shortened form of the Kansas Inventory of Parental Perceptions (KIPP; Behr et al. 1992) recently adapted to a Spanish version (Ferrer et al. 2015). The specific scale is called The Positive Contributions Scale (PCS).

The shortened form of the KIPP has a total of 59 items distributed in four scales: Positive Contributions (30 items), Social Comparisons (7 items), Causal Attributions (10 items), and Perceived Control (12 items). However, in this study we used only the first one, the PCS scale, which was explicitly designed to assess the positive perceptions that parents have regarding their family members with ID (Hastings et al. 2005b).

The PCS scale measures six dimensions: 1) Source of Happiness and Pride (e.g., "I consider my child to be a great inspiration"); 2) Family Strength and Acceptance (e.g., "Because of my child my family is more understanding about people with disability"); 3) Personal Growth and Maturity (e.g., "I consider my child to be the reason I am able to cope better with stress and problems"); 4) Sensitivity to Disability (e.g., "Because of my child I can understand better people who are different"); 5) Expanded Social Network (e.g., "I consider my child to be what gives me common ground with other parents"), and 6) Understanding of Life's Purpose (e.g., "Because of my child I know that everyone has a purpose in life"). The items were rated on a 4-point Likert scale ("strongly disagree" to "strongly agree").

For the present sample, the PCS total score had a high level of internal consistency (Cronbach's  $\alpha = .92$ ). Also, for the six positive contributions subscales, the coefficients ranged from 0.40 to 0.83: 1) Source of Happiness and Pride  $\alpha = .83$ ; 2) Family Strength and Acceptance  $\alpha = .78$ ; 3) Personal Growth and Maturity  $\alpha = .77$ ; 4) Sensitivity to Disability  $\alpha = .73$ ; 5) Expanded Social Network  $\alpha = .72$ ; 6) Understanding of Life's Purpose  $\alpha = .40$  (Ferrer et al. 2015). These results are very similar to the internal consistencies obtained by Kayfitz et al. (2010).

### *The Spanish Family Quality of Life Scales (CdVF-E)*

The Spanish Family Quality of Life Scales for families with people with ID under 18-years-old and over 18-years-old (Escala de Calidad de Vida Familiar; CdVF-E) (Giné et al. 2013) evaluates seven FQoL dimensions: a) emotional well-being, b) family

interaction, c) health, d) financial well-being, e) parents' organization and skills, f) family accommodation, and g) social inclusion and participation. It has been validated in a sample of families with a family member with ID.

This instrument has 61 items in the under-18 scale and 67 in the over-18 scale. It is self-administered and it is answered by family members, reflecting the views of the whole family. Items are rated on a 5-point Likert scale (“never” to “always”) with a “not applicable” option as well. An overall FQoL score is computed by adding the scores on each of the items of each scale. The reliability according to the Cronbach's alpha coefficient for both the over-18 and under-18 scales was .96, and the validation study results confirmed that the dimensions could be used to describe overall levels of FQoL (Giné et al. 2013). For the present sample, the overall FQoL score also showed a high level of internal consistency ( $\alpha = .92$  and  $\alpha = .93$  for the over-18 and the under-18 scales respectively).

## Procedure

Initially, *Plena Inclusión* and DINCAT were contacted by letter and telephone and informed of the study. These associations then contacted the coordinators of the affiliated centers throughout Spain to request their collaboration in recruiting families for the project. These coordinators informed us the number of families that could be candidates to participate. To preserve confidentiality, each center was given documentation for the candidate families, and each family unit was handed a sealed research pack. This allowed them to answer the questionnaires anonymously. Each research pack contained a newsletter, an informed consent form, a demographic questionnaire, and the KIPP instrument and the CdVF-E scale. In all, 1963 families were mailed questionnaire packages. Their participation was entirely voluntary and anonymous and they did not receive any incentive to participate in the study. Questionnaires were returned by 1001 family units to the respective centers, with the 51 % response rate being viewed as adequate (Schreiber et al. 2006). The coordinators then forwarded the envelope to the research team. Data collection was completed within 6–10 weeks.

## Data Analysis

The data were analyzed in several stages. First, a bivariate analysis was conducted to study the relationship between each of the demographic variables and the FQoL scores (CdVF-E). For categorical demographic variables, mean CdVF-E scores were compared via Student's t-test (for comparing two means) or Brown-Forsythe ANOVA (for more than two means), followed by post-hoc Tukey's HSD test for pairwise comparisons. Relationships between demographic continuous variables and CdVF-E scores were examined via Pearson product-moment correlation coefficients. For the bivariate analysis, effect size was calculated by Cohen's *d* and Eta squared.

Secondly, the relationship between PCS scores and FQoL scores was analyzed using Pearson correlation coefficients. Finally, variables whose effect was found to be statistically significant ( $p < .05$ ) in the previous bivariate analyses were included in a multiple linear regression model to predict FQoL scores. For variable selection, stepwise criteria were applied (probability of  $F \leq .05$  to add a predictor, and probability of  $F \geq .10$  to remove it from the model).

SPSS (version 22.0 for Windows) was used for all the statistical analyses. Missing data were handling by pairwise deletion.

## Results

### Relationship between Demographic Characteristics and FQoL Scores

Mean scores on FQoL (CdVF-E score) were compared by categories of different demographic variables. For families with a family member with ID younger than 18 (Table 1), the results showed a statistically significant effect for the “marital status” variable. In this regard, families made up of married couples or living with a partner had higher FQoL scores than single-parent families (single, divorced, separated or widowed).

There was also an effect for the “employment status” variable, where pairwise comparisons showed higher quality of life in families with full-time jobs than for unemployed parents (including household chores) ( $p < .05$ ), with no differences being found among the other categories of the variable. The “monthly total household income” variable showed effects on FQoL, and pairwise comparisons showed FQoL to be lower among families with less income (below \$660) in comparison to families with more income (from \$1979 to \$2748 or above \$2748 per month) ( $p < .05$ ).

Furthermore, the families that receive personal help (formal or informal support from a relative) to care for their child with ID had higher FQoL scores than those who do not receive help. With respect to the characteristics of the child, the degree of ID also showed an effect on FQoL; pairwise contrasts showed higher FQoL in families with a child with mild ID than in families with a child with moderate or severe ID ( $p < .05$ ). There were no differences between the other categories (moderate vs. severe).

Using Cohen’s (1988) benchmarks for interpreting effect sizes, the effect for the variables “marital status” and “personal help” can be considered as medium ( $.20 \leq d \leq .49$ ), whereas the effects corresponding to “employment status of the parent”, “monthly total household income”, and “degree of children’s ID” were small ( $.010 \leq \eta^2 \leq .057$ ).

The other demographic variables (gender and level of education of the parent who responded to the questionnaires, and gender of the children with ID) showed no statistically significant effect on quality of life in families with a family member with ID younger than 18.

For families with a family member with ID older than 18 (Table 2), it was found that families which receive personal help had a higher FQoL than those who do not receive any help to take care of individuals with ID. Also, results showed an effect that was statistically significant for the “degree of ID” variable. Pairwise comparisons showed higher quality of life in families with individuals with mild ID than in families with individuals with severe ID ( $p < .05$ ). No differences were found between the other pairs of categories (mild vs. moderate; moderate vs. severe). The effect sizes for both variables (“personal help” and “degree of ID”) can be interpreted as small (Cohen 1988).

The other categorical demographic factors studied showed no effect on the quality of life of families with individuals older than 18.

**Table 1** Differences in mean FQoL scores (for families with a member with ID under 18 years) according to demographic characteristics

		n	M	(SD)	Statistic (df)	Statistic value	Effect Size
Parent gender	Male	89	.744	(.088)	$t_{(377)}$	-0.73	-.090 <sup>a</sup>
	Female	290	.752	(.098)			
Civil status	Married/cohabitating	309	.760	(.090)	$t_{(85.1)}$	3.40 **	.531 <sup>a</sup>
	Others	67	.710	(.113)			
Level of education	Primary	120	.741	(.108)	$F_{(2364)}$	1.53	.008 <sup>b</sup>
	Secondary	136	.754	(.091)			
	Higher	111	.763	(.084)			
Employment status	Full-time job	144	.769	(.093)	$F_{(2369)}$	3.98 *	.021 <sup>b</sup>
	Part-time job	72	.741	(.087)			
	Unemployed	156	.741	(.097)			
Household income (monthly)	< \$660	34	.705	(.098)	$F_{(4351)}$	3.42 **	.038 <sup>b</sup>
	\$660 to \$1319	82	.734	(.110)			
	\$1319 to \$1979	90	.751	(.080)			
	\$1979 to \$2748	76	.766	(.085)			
	> \$2748	74	.764	(.098)			
Personal help	No	260	.737	(.097)	$t_{(371)}$	-4.43 **	-.502 <sup>a</sup>
	Yes	113	.784	(.087)			
People with ID gender	Male	226	.742	(.097)	$t_{(366)}$	-1.90	-.205 <sup>a</sup>
	Female	142	.761	(.092)			
Degree of ID	Mild	133	.768	(.097)	$F_{(2351)}$	4.44 *	.025 <sup>b</sup>
	Moderate	101	.736	(.088)			
	Severe	120	.737	(.096)			

\* $p < .05$  \*\* $p < .001$ (Effect size: <sup>a</sup> Cohen's  $d$ ; <sup>b</sup> Eta squared)

For continuous demographic variables, Pearson's correlations with CdVF-E scores were computed. For families with a family member younger than 18, statistically significant ( $p < .01$ ) negative correlations were found between FQoL scores and both the number of people who receive help ( $r = -.195$ ) and the number of siblings ( $r = -.207$ ). These negative correlations mean that the greater number the people who receive help or the greater the number of siblings of children with ID, the lower the FQoL scores are.

On the other hand, a positive correlation was found between level of satisfaction (from 0 to 10 points) with the service received by people with ID and FQoL scores ( $r = .143, p < .001$ ). That is, the higher the level of satisfaction with the service for the ID child, the better the FQoL is.

In the families with individuals with ID older than 18, the only statistically significant correlation was between the age of the parent and the FQoL score ( $r = .153, p < .01$ ). The older the parents are, the higher the quality of life of those families.

Nevertheless, the effect sizes for all the previous correlations that were found to be statistically significant can be regarded as small ( $.10 \leq r \leq .24$ ), which means that less than 6 % of the variance of the FQoL score is accounted for by any of the numerical

**Table 2** Differences in mean FQoL scores (for families with a member with ID over 18 years) according to demographic characteristics

		n	M	(SD)	Statistic (df)	Statistic value	Effect Size
Parent gender	Male	116	.808	(.090)	$t_{(412)}$	1.16	.133 <sup>a</sup>
	Female	298	.796	(.091)			
Civil status	Married/cohabitating	306	.802	(.090)	$t_{(406)}$	1.02	.121 <sup>a</sup>
	Others	102	.791	(.094)			
Level of education	Primary	184	.795	(.093)	$F_{(2385)}$	0.55	.003 <sup>b</sup>
	Secondary	113	.806	(.089)			
	Higher	91	.795	(.095)			
Employment status	Full-time job	126	.787	(.093)	$F_{(2402)}$	1.72	.009 <sup>b</sup>
	Part-time job	40	.794	(.090)			
	Unemployed	239	.806	(.092)			
Household income (monthly)	< \$660	15	.798	(.090)	$F_{(4347)}$	2.16	.024 <sup>b</sup>
	\$660 to \$1319	122	.791	(.091)			
	\$1319 to \$1979	114	.785	(.098)			
	\$1979 to \$2748	56	.818	(.088)			
	> \$2748	45	.820	(.072)			
Personal help	No	321	.795	(.091)	$t_{(397)}$	-2.14 *	-.275 <sup>a</sup>
	Yes	78	.820	(.091)			
People with ID gender	Male	220	.799	(.088)	$t_{(406)}$	0.06	.000 <sup>a</sup>
	Female	188	.799	(.096)			
Degree of ID	Mild	52	.826	(.097)	$F_{(2410)}$	3.34 *	.016 <sup>b</sup>
	Moderate	171	.800	(.090)			
	Severe	190	.789	(.090)			

\* $p < .05$  (Effect size: <sup>a</sup> Cohen's  $d$ ; <sup>b</sup> Eta squared)

demographic variables included in this study (Dunst and Hamby 2012). In both groups of families (with individuals with ID younger or older than 18), the age of the people with ID was not linearly related with FQoL ( $p > .05$ ).

### Relationship between Positive Contributions and FQoL Scores

PCS scores were correlated with FQoL scores (CdVF-E scores) (see Table 3). Statistically significant correlations were observed between most of the PCS subscales and both CdVF-E scales (under and over-18). For example, the *Source of Happiness and Pride* subscale was significantly correlated with scores on the CdVF-E under-18 ( $r = .26, p < .01$ ) and CdVF-E over-18 ( $r = .35, p < .01$ ). That is, parents or relatives who considered that their family member with ID brought them happiness and positive feelings were more satisfied with their FQoL. Scores on the *Family Strength and Acceptance* subscale also correlated significantly with scores on the CdVF-E under-18 ( $r = .17, p < .01$ ) and CdVF-E over-18 ( $r = .24, p < .01$ ); that is, parents or relatives who considered that their family member with ID helped to increase family togetherness and acceptance of life events were more satisfied with their FQoL.

Exceptions were the subscales *Sensitivity to Disability* and *Understanding of Life’s Purpose*, where the correlations with the CdVF-E under-18 scale were not significant, and the correlations with the CdVF-E over-18 scale were statistically significant but weak following Dunst and Hamby’s guidelines (2012).

Viewed overall, PCS total scores showed a significant correlation with FQoL scores both for families with individuals with ID under 18 ( $r = .16, p < .01$ ) and over 18 ( $r = .24, p < .01$ ). Therefore, those parents who perceive positive contributions because of their son/daughter with ID have a better quality of life in their families. However, the effect sizes for these two correlations can be considered as small (Dunst and Hamby 2012).

### Multiple Linear Regression Models on FQoL Scores

PCS total scores, together with the demographic variables whose effect was found to be statistically significant in the previous bivariate analyses, were included in a multiple linear regression model to predict FQoL scores.

For families with a family member with ID under 18 (see Table 4), six of the potential predictors were selected by stepwise criteria for inclusion in the model. Results indicate that high FQoL scores can be predicted by a linear combination of high PCS total scores, the marital status of the parent (married or cohabitating), whether help is being received for the ID, as well as a low number of people who receive personal help, and a high level of satisfaction with the center service.

The regression model accounts for 18.5 % of the variance of the FQoL scores (adjusted  $r^2 = .185$ ). No more variables were added to the model because their inclusion did not significantly improve ( $p < .05$ ) the model’s predictive power.

On the other hand, for families with a family member with ID over 18 (see Table 5), two of the potential explanatory variables were included in the model to predict FQoL scores: the PCS total score and the age of the parent who completed the questionnaires. Both variables showed a significant positive regression coefficient in the model to predict FQoL scores. In this group of families, the linear combination of the two variables accounts for only 8.3 % of the variance of FQoL scores (adjusted  $r^2 = .083$ ). The remainder of the potential variables was excluded from the model because their addition did not significantly improve the model’s predictive power ( $p < .05$ ).

**Table 3** Correlations between PCS scores and CdVF-E total scale scores

Subscale	CdVF-E	
	Under 18	Over 18
Source of Happiness and Pride	.255**	.352**
Family Strength and Acceptance	.194**	.247**
Personal Growth and Maturity	.109*	.256**
Sensitivity to Disability	.005	.115*
Expanded Social Network	.185**	.225**
Understanding of Life’s Purpose	-.016	.129*
PCS total score	.162**	.244**

\* $p < .05$  \*\* $p < .01$



**Table 4** Linear regression model of FQoL scores in families with a member with ID under 18 ( $n = 278$ )

Variable	B	S.E.	$\beta$	$T$
Intercept	.665	.037		
Personal help (yes)	.048	.011	.234	4.340**
Positive Contributions Scale score	.041	.012	.182	3.390**
Number of siblings	-.016	.006	-.157	-2.887**
Number of persons who need help	-.019	.008	-.134	-2.482*

\* $p < .05$  \*\* $p < .01$

It should be noted that the only predictor that was common to both models was the PCS score. In both groups of families (with a family member with ID over or under 18 years), the PCS score was found to have a significant effect on the FQoL scores, holding constant the value of the other demographic predictors included in the model. In other words, FQoL can be predicted by PCS scores, even when the effect of the rest of demographic predictors included in each model is eliminated.

## Discussion

Although previous work has explored FQoL in families with children with ID under age 18 and its relationships with different factors such as demographic characteristics, little is known about mediating variables in FQoL in families with adult members with ID (Minnes et al. 2007). Given that families are also the primary caregivers of people with ID in adulthood (Chou et al. 2009; Giné et al. 2015), it is essential to analyze this population throughout the life cycle.

As mentioned in the introduction, our first objective was to analyze the relationship between the demographic characteristics of the family unit (composed by fathers, mothers and other parent-like figures) and of the family member with ID and the levels of FQoL at two stages in the life of individuals with ID (before and after 18 years of age). According to our findings, some demographic characteristics of caregivers with a family member with ID under 18 years of age were related to FQoL (marital status, employment status, household income, personal help, number of siblings and degree of ID), while they ceased to have this importance when the children with ID entered adulthood (except personal help and degree of ID).

**Table 5** Linear regression model of FQoL scores in families with a member with ID over 18 ( $n = 381$ )

Variable	B	S.E.	$\beta$	$T$
Intercept	.579	.037		
Positive Contributions Scale score	.054	.010	.256	5.19**
Age of the parent	.001	.000	.141	2.87**

\*\* $p < .01$



Single-parent families (single, divorced, separated or widowed) in our sample had to confront the economic and emotional demands of caring for a young child or adolescent with ID without the support of a partner. As recorded in other studies (Davis and Gavidia-Payne 2009; Giné et al. 2015; Keller and Honig 2004; Park et al. 2003), this had a negative effect on their FQoL, but marital status ceased to be a significant factor for FQoL when the children entered adulthood. Another aspect related to FQoL in our study was employment status. As has been shown in previous studies (Ferrer et al. 2016), parents of a young child or adolescent with ID who worked full-time had higher levels of FQoL than parents who were unemployed or only did housework, with employment acting as a factor to protect the well-being of caregivers. In addition, families with low household incomes had much lower levels of FQoL than families with greater financial resources, because this circumstance created greater concerns for them in their daily life (Lin et al. 2009; Hu et al. 2012; Wang et al. 2004). Both of the mentioned variables, employment status and household income, were not relevant when the family member were older than 18 years of age. Families with people with ID over 18 seem to be more stable than families with children and adolescents with ID, who constantly have to make decisions regarding their development, education, treatment (Giné et al. 2015). In a regression analysis including demographic characteristics, Boehm et al. (2015) studied predictors of FQoL in a sample of families with young adults with ID and did not obtain statistically significant results.

By contrast, the help received by the family (whether formal support or informal help from a family member) was a factor that had a positive influence on FQoL, regardless of the age of member with ID (Boehm et al. 2015; Thompson et al. 2009). It was also found that families with a child with mild ID had greater FQoL than families with a child with moderate or severe ID, regardless of the age of the individual with ID. Previous studies have found similar results (Brown et al. 2010), but additional studies are needed to corroborate these findings and rule out the moderating effect of other variables, for example, any behavioral problems of children with ID (Baker et al. 2003).

The second objective of the study was to analyze the relationship between positive perceptions and FQoL as perceived by parents of children with ID at two life stages of the individual with ID. According to the findings, high levels of positive perceptions on the part of parents of children with ID of any age were significantly related to higher levels of FQoL.

Every dimension of positive perceptions presented some relation with FQoL at both life stages of the individual with ID, with the exception of *Sensitivity to Disability* and *Understanding of Life's Purpose*, which were only significant in families with adult children with ID. One possible explanation could be that these perceptions require greater reflection and elaboration. As they live longer with an individual with ID, caregivers continue learning and facing many challenges that bring them closer to, and give them greater empathy with, people who have difficulties. They are able to assimilate what disability means and some even find spiritual beliefs that give them support as they accompany an individual with ID through life (Treloar 2002), and this process appears to be related to greater FQoL.

Lastly, the third objective was to take the research a step further and analyze, by means of a multivariate model, which of the variables that have yielded significant results in the previous analyses could account for FQoL. According to the findings, the help received from others can explain the levels of FQoL in families with a young child

or adolescent with ID. This is in keeping with previous studies in which it was found that families who received support from their social network had a higher perception of their FQoL (Pozo et al. 2014), and it also concurs with other studies that found that professional help was one of the most significant predictors of FQoL (Balcells-Balcells et al. 2011; Davis and Gavidia-Payne 2009). Also, if there are more children in the family and the parents, therefore, have to take care of these additional children and satisfy their needs as well, it could generate a greater number of stressful situations and thus have a negative impact on their FQoL. These findings concur with previous studies (Giné et al. 2015; Hames and Appleton 2009; Kresak et al. 2009).

By contrast, in the analyses focusing on adulthood, we find that the age of the parents was the only demographic variable that could explain the levels of FQoL. In particular, older caregivers expressed a higher FQoL, showing that having a child with ID living with them contributed to increased feelings of personal and family-level well-being.

However, the only variable that showed a predictive value of levels of FQoL in families throughout the life of the individual with ID was the presence of positive perceptions. Based on these results, positive perceptions are not only significantly related to higher levels of FQoL, but they can also explain the levels of FQoL. That is, regardless of demographic characteristics, family members who present more positive perceptions have higher FQoL. Therefore, reinforcing these positive perceptions can enable families to achieve higher levels of FQoL. Evidently, the families' employment status, their socioeconomic circumstances, the type and degree of disability, and the formal or informal help that the family may receive are very important. As the literature has shown, they doubtless have an influence on the quality of life of families with children with disability. However, our results suggest that, despite these variables, the provision of support to families to foster their positive perceptions can predict their levels of FQoL.

These results have clearly applicable consequences for professionals and services attending to families with a family member with ID throughout their life cycle. They should include the positive aspects of having a family member with disability in their Individualized Family Service Plan (IFSP) in order to support the families' strengths (Jung et al. 2015) and promote their well-being and FQoL, regardless of demographic characteristics, employment status or socioeconomic circumstances.

### **Practical Implications**

Our findings show how positive perceptions in families with young children, adolescents and adults with ID may be related with higher levels of FQoL (Ferrer et al. 2016).

Therefore, services offered to families with family members with ID (Early Intervention Centers, special schools, occupational therapy services, nursing homes, etc.) should bear in mind the positive perceptions of parents as a key factor in well-being and FQoL. Our results increase the value of the activity of professionals whose work follows the family-centered approach (Espe-Sherwindt 2008), because positive perceptions can unquestionably have an impact on improving the perception that parents have of their own parenting abilities and of the behavior and functioning of their family member with ID, thus increasing their satisfaction with the service and family well-being. Encouraging positive perceptions in the family can also enhance its

resilience and promote the well-being of all family members throughout the life span of the person with ID, whether he/she is a child, adolescent or adult (McWilliam and García 2016).

Our proposals must go hand in hand with an alignment between the policies at a systemic level and the procedures carried out by organizations that support intervention in families with individuals with disability. Bringing about such an alignment based on more positive perceptions will not only empower family members to be effective in any contexts in which they may take part, but it also will enhance their FQoL.

## Limitations and Future Research

Our study has some limitations that we need to mention. The first one is the correlational design, which does not permit us to establish clear causality. Since this is a cross-sectional study, the term “predictor” in the regression analysis should be used with caution. It is important to make it clear that, in this context, “to predict” means to estimate FQoL scores knowing the predictor variable scores (demographic variables and positive perceptions scores) but does not imply a direct causality. Accordingly, it would be interesting to conduct an experimental study in which an intervention program is applied in relation to the positive perceptions of parents with a child with ID in order to identify any resulting effect on FQoL.

An additional limitation of the study is that the extracted results provide further evidence on the relationships between positive perceptions and FQoL in families of European culture and does not take other cultures into account. It would probably be appropriate in future research to replicate this study in different social and cultural contexts to analyze the influence on these relationships of other factors in the family’s specific environment.

In addition, research should continue to explore which specific factors of the family (for example, the role of siblings and grandparents in the care of people with ID), the individual characteristics (for example, the presence of multiple disability and behavior problems) and the social network (for example, the frequency and intensity of support, and the differences between formal and informal support) predict the levels of FQoL. The main objective should be to contribute to providing families with more tools and resources so that they can offer greater learning opportunities (Roggman et al. 2008), and ultimately foster the optimal development of the individual with ID.

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## Compliance with Ethical Standards

**Ethical Approval** Ethical approval was obtained from the Ethics Committee of the Network of Ethics Committees in Universities and Public Research Centres in Spain. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

**Conflicts of Interest** The authors report no conflicts of interest and are solely responsible for the content and writing of this paper.

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# Positive perceptions and perceived control in families with children with intellectual disabilities: relationship to family quality of life

Fina Ferrer<sup>1</sup> · Rosa Vilaseca<sup>1</sup> · Joan Guàrdia Olmos<sup>2</sup>

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**Abstract** Researchers in the field of disability are showing a growing interest in assessing the impact of having a child with disabilities on parental perceptions and family functioning. This study explores the relationships between positive perceptions, perceived control, and family quality of life (FQoL) in families of children and adolescents with intellectual disability (ID), in order to assess whether positive perceptions and perceived control are predictors of FQoL. The Kansas inventory of parental perceptions was administered to a sample of 327 Spanish families with a child or adolescent with ID completed in order to assess their positive perceptions and perceived control, and the Spanish family quality of life scale (0–18 years) in order to assess FQoL. Linear regression analysis was applied to determine whether positive perceptions and perceived control were predictors of FQoL. Results indicated that families with higher levels of positive perceptions reported greater emotional wellbeing, better health and adaptation to disability, and higher levels of FQoL. Similarly, families with higher levels of perceived control reported better levels of FQoL and greater satisfaction with the services provided for their child. With the exception of employment status, demographic variables had no bearing on these significant relationships. These results may help service providers to develop new intervention strategies for families with children with ID, fostering their positive perceptions and perceived control and ultimately promoting their FQoL.

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✉ Fina Ferrer  
fferrer@ub.edu

Rosa Vilaseca  
rosavilaseca@ub.edu

Joan Guàrdia Olmos  
jguardia@ub.edu

<sup>1</sup> Department of Developmental and Educational Psychology, University of Barcelona, Pg. De la Vall d'Hebron 171, 08035 Barcelona, Spain

<sup>2</sup> Department of Methodology of the Behavioral Sciences, Institute for Research on the Brain, Cognition, and Behavior (IR3C), University of Barcelona, Barcelona, Spain

**Keywords** Intellectual disability · Families with children with intellectual disabilities · Positive perceptions · Perceived control · Family quality of life

## 1 Introduction

Studies in the field of disability have traditionally analyzed the possible negative impact of having a child with disabilities on parents, and have sought to identify the aspects that may generate negative perceptions and high levels of stress (Blacher et al. 2005; Helff and Glidden 1998; Saloviita et al. 2003; Weiss et al. 2003). However, over the last three decades, researchers have recognized the presence of positive perceptions in families raising and educating a child with intellectual disability (ID). Some studies have found that having a child with ID can lead parents to perceive certain aspects of family life positively (Blacher and Baker 2007; Hastings and Taunt 2002; Turnbull et al. 1993). Indeed, several studies have concluded that having a child with ID may have a positive impact on a family's physical and mental health (Calhoun and Tedeschi 1990; Saloviita et al. 2003), or even promote personal growth, happiness, and family proximity (Greer et al. 2006).

Initially it was thought that the presence of, and increase in, positive perceptions would imply a reduction in negative perceptions (Judge and Burden 1980). However, Hastings and Taunt (2002) found that families of people with ID could have positive perceptions and experiences alongside high levels of stress and emotional distress. These findings were corroborated in subsequent studies (Hastings et al. 2005; Lloyd and Hastings 2008; Vilaseca et al. 2014) which confirmed that parents of children with ID presented both positive and negative perceptions. Indeed, positive and negative perceptions came to be considered as independent constructs.

Folkman and Moskowitz (2000) suggested that positive perceptions could help families to cope with stressful events. Specifically, they argued that positive family perceptions regarding the child with disabilities could help family members in the process of adaptation and accommodation.

Later authors suggested that positive perceptions might function as a mechanism for coping with the stress of caring for a child with disabilities (Lloyd and Hastings 2008), since they buffer the emotional impact and favor family wellbeing (Green 2007; Hastings and Taunt 2002; Kayfitz et al. 2010). Paczkowski and Baker (2008)'s longitudinal study found that higher levels of positive beliefs were associated with lower levels of stress in mothers of children with disabilities throughout early childhood.

Therefore, the presence of positive perceptions among parents with children with ID seems to help generate a closer and warmer parent–child relationship, thereby providing a stronger foundation for the child's development. In their study of the mother–child interaction with young children with disabilities, Spiker et al. (2002) found that parental behaviors such as a positive affective tone and attention to the signals given by the child and to his/her interests helped generate optimum outcomes. However, parents may find that engaging in these more positive behaviors represents a considerable challenge and they may require support in order to promote their child's development (Innocenti et al. 2013; Roggman et al. 2008).

In the context of parental perceptions, another key element in the wellbeing of families with children with disabilities is perceived control. This is the degree of control that parents feel they have over the information they receive from professionals about the

nature of their child's disability, treatment, and educational opportunities, and over the extent of their participation in planning and decision making regarding the present and future of their child (Behr et al. 1992), both at home and in outside services (Eskow et al. 2011).

Parents who perceive that they have some control over decisions and strategies in relation to a particular situation report better and more positive adaptation (Hastings and Brown 2002; Jones and Passey 2005; Lanfranchi and Vianello 2012). Perceived control has been reported to reduce levels of parental stress and psychological distress (Hassall et al. 2005; Hill and Rose 2009; Shapiro et al. 1998). According to Knox et al. (2000), the interventions made by services for disabled people should promote greater integrity and control perceptions among families, since this perceived control is a key element in family quality of life (FQoL). Other authors conclude that parental satisfaction with early intervention services and their perceived control will predict better outcomes in the immediate family and higher FQoL (Epley et al. 2011).

In fact, researchers have recently stressed the importance of FQoL and its conceptualization, in terms of both enabling families to interact with their child with ID and assessing the possible impact on services and the support they provide to families. Several research groups have focused on the conceptualization, measurement, and improvement of FQoL in families with children with disabilities (Aznar and Castañón 2005; Brown et al. 2006; Giné et al. 2013; Hoffman et al. 2006; Hu et al. 2011; Isaacs et al. 2007; Samuel et al. 2012).

Zuna et al. (2010) define FQoL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 262). This definition recognizes the family as the primary developmental context and underlines the importance of helping families with children with ID to improve their FQoL. Furthermore, it highlights both individual and family needs, understanding the family as a unit influenced by the dynamics between family members and their individual characteristics: for example, consistency, accommodation, decision-making, and emotional wellbeing. These characteristics are predictive of FQoL and interact with the support and services offered at individual and family level.

Several studies have analyzed relationships between FQoL and the characteristics of family members in the context of families with children with ID (Wang et al. 2004). They have focused in particular on family-centered variables such as marital status, employment situation and family income and on child-centered variables such as age and degree of disability. In relation to marital status, some studies have found that the presence of both parents and their joint participation in the care of their child with ID generates more positive family outcomes. In contrast, single parents are obliged to face economic, emotional and relational challenges without support, a situation which has a negative impact on FQoL (Keller and Honig 2004). Other studies have assessed the relationship between employment status and emotional well-being in the family (Giné et al. 2015; Helbig et al. 2006). The results showed that having a job influences emotional well-being, in so far as parents in full-time employment had fewer psychological problems and also had more income.

On the other hand, some studies suggest that the specific characteristics of children and adolescents with ID may impact FQoL (Davis and Gavidia-Payne 2009; Summers et al. 2007). Significant relationships have been reported between severity of the disability and FQoL, although not always in the same direction; while some authors have found parents of children with more severe disabilities to have the lowest levels of FQoL (Hu et al. 2012; Wang et al. 2004), others did not record a relationship between the degree of disability and

FQoL (Giné et al. 2015; Lin et al. 2009). As for the age of children with ID the results are also inconclusive. Some studies found that the age of the children with ID predicted FQoL (Meral et al. 2013), but others did not report a significant relationship between age and parental wellbeing (Kayfitz et al. 2010). So it appears that more studies are needed in order to reliably identify predictors of FQoL and the relationships between these variables.

Few empirical studies have directly examined the relationship between levels of FQoL and positive perceptions or perceived control in families of children and adolescents with ID. Bearing in mind, as we argued above, that the positive relationships between family members are predictive of lower levels of stress and overload and of greater psychological wellbeing and better parenting skills (Bailey et al. 2007; Shapiro et al. 1998), our hypothesis in the present study was that positive perceptions and perceived control among parents might predict better FQoL.

The two main objectives of this study were to explore the level of positive perceptions and perceived control, and to analyze the relationships between these two variables and FQoL in a sample of parents of children with ID aged between 0 and 18 years. We hypothesized that higher degrees of positive perceptions and perceived control would be associated with higher levels of FQoL. We also aimed to explore the relationship between FQoL, positive perceptions and perceived control and demographic variables, both of parents (marital status, employment status, income level, and level of satisfaction with service provision) and children (age and level of ID).

## 2 Method

Ethical approval was obtained from the Network of Ethics Committees in Universities and Public Research Centers in Spain.

### 2.1 Participants

The sample included 327 families with children with ID up to 18 years of age. They received care from early childhood intervention centers, special schools, mainstream schools or occupational therapy services, all affiliated either to DINCAT (the Intellectual Disabilities Association of Catalonia) or to *Plena Inclusión* (the Intellectual Disabilities Association of Spain).

All participating families were resident in Spain (in the regions of Andalusia, Aragon, Castile-Leon, Catalonia, Extremadura, La Rioja, Navarre, and Valencia), and 93 % were Spanish nationals. In 98 % of cases, the questionnaires were completed by the parents. Most respondents were married or lived with a partner (82.6 %). All children lived with their families. Table 1 shows the demographic characteristics of the parents and the children with ID.

All the children and adolescents had been diagnosed by psychologists employed by the official government agencies called the Spanish Network of Care Centers for the Learning Disabled (CAD). The majority of the children (83.5 %) had an additional diagnosis (e.g., visual impairment, hearing impairment, physical disability, autism spectrum disorder, and health issues).

**Table 1** Demographic characteristics of families and children with ID (n = 327)

Variable	n (%)	Variable	n (%)
Sex		Sex of child with ID	
Male	69 (21.1)	Male	189 (59.1)
Female	256 (78.3)	Female	131 (40.9)
Missing	2 (.6)	Missing	7 (2.1)
Age		Age of child with ID	
<29	10 (3.1)	0–5	75 (23.0)
30 a 39	93 (28.4)	6–11	113 (38.5)
40 a 59	176 (53.8)	12–18	126 (38.5)
>60	36 (11.0)	Missing	13 (4.0)
Missing	12 (3.7)		
Level of education completed		Degree of disability	
Compulsory education	194 (59.3)	Mild	125 (38.2)
University degree	99 (30.3)	Moderate	84 (25.7)
Others	34 (10.4)	Sever	102 (31.2)
		Missing	16 (4.9)
Employment status		Service received by child	
Employed full-time	129 (39.4)	Special schools	178 (54.4)
Employed part-time	64 (19.6)	Mainstream schools	49 (15.0)
Not employed	55 (16.8)	Early childhood intervention centers	56 (17.1)
Homewife	75 (22.9)	Occupational therapy	24 (7.3)
Missing	4 (1.2)	Missing	20 (6.2)
Total household income (monthly)		Satisfaction with service (1–10)	
<€1200	92 (28.1)	1–4	10 (3.0)
€1200 a €2500	149 (45.6)	5–6	27 (8.3)
>€2500	67 (20.5)	7–8	96 (29.3)
Missing	19 (5.8)	9–10	185 (56.6)
		Missing	9 (2.8)

## 2.2 Measures

A brief demographic questionnaire was used to record the parents' age, gender, country of origin, marital status, educational level, employment status, and level of income, as well as the services received by their child and the parents' degree of satisfaction with these services. The same questionnaire was used to record the children's age, gender, and degree of ID. Parental perceptions and FQoL were assessed using two separate instruments:

### 2.2.1 Kansas inventory of parental perceptions (KIPP)

Parents' perceptions regarding their child with ID were measured using the Spanish version of the recently adapted shortened form (Ferrer et al. 2015) of the Kansas inventory of parental perceptions (KIPP; Behr et al. 1992). The KIPP was translated into Spanish and then backtranslated into English. The instrument was reviewed by 12 experts in the field of

ID (four researchers and eight professionals). All the experts' comments were discussed and assessed by the research team until a consensus was reached.

This shortened form of the KIPP comprised a total of 59 items, distributed in four scales: (1) 'Positive contributions' (30 items) assesses parental perceptions regarding the positive contributions that their child makes to their personal and family life (e.g., "I believe that my son/daughter is the reason why I have met some of my best friends"); (2) 'Social comparisons' (7 items) evaluates the comparisons that parents make between their own family and/or the family member with ID and others (e.g., "I feel lucky that my son/daughter does not have more serious problems like other people with disabilities"); (3) 'Causal attributions' (10 items) explores the causal attributions made by parents regarding their child's disability (e.g., "I think my son/daughter has these special needs because of a hormonal condition"); (4) 'Perceived control' (12 items) measures parental perceptions regarding the degree of control they have over their child's management and educational activities in the present and future, and over the information they receive and planning for the child's future (e.g., "How much control do you have over your child's daily activities?").

Items are scored on a 4-point Likert scale: for the first three subscales, 1 = "strongly disagree" and 4 = "strongly agree", while on the last subscale, 1 = "no control" and 4 = "a lot of control". Internal consistency of all scales was adequate: Positive perceptions  $\alpha = .71$ ; Social comparisons  $\alpha = .71$ ; Causal attributions  $\alpha = .66$ ; Perceived control  $\alpha = .87$  (Ferrer et al. 2015).

### 2.2.2 Spanish family quality of life scales 0–18 years (CdVF-E)

The Spanish family quality of life scales for families with children with ID aged 0–18 years (CdVF-E) (Giné et al. 2013) evaluates seven FQoL dimensions: (a) *Emotional Wellbeing* (8 items) evaluates the emotional impact of disability on the family context; (b) *Family Interaction* (13 items) measures the quality of relationships between family members; (c) *Health* (7 items) explores the physical and mental health status of family members as a result of having a family member with ID; (d) *Financial Wellbeing* (11 items) examines the economic and material resources available; (e) *Parents' Organization and Skills* (8 items) explores the roles and responsibilities of parents; (f) *Family Accommodation* (7 items) assesses the degree of acceptance and family adjustment to disability; and (g) *Social inclusion and participation* (7 items) evaluates the social relations of the family and the member with ID.

The CdVF-E is a self-administered 61-item scale designed to be answered by immediate relatives of the person with disabilities, reflecting the views of the whole family (e.g., "My family is hopeful and has projects for the future"). The respondent indicates the frequency of the situation described in each item on a 5-point Likert scale (1 = never to 5 = always).

The internal consistency of the overall scale was adequate (Cronbach's  $\alpha = .96$ ), and the validation study results confirmed that the dimensions can be used to describe global levels of FQoL (Giné et al. 2013).

## 2.3 Procedure

The two associations mentioned above (DINCAT and *Plena Inclusión*) were contacted by letter and telephone, and informed of the project. The associations themselves then contacted the coordinators of affiliated centers throughout Spain to request their collaboration. Once the coordinators of centers had agreed to participate, they were asked to select

families who met the inclusion criterion, that is, having a child with ID under the age of 18. It was made clear that the participation of families would be entirely voluntary and anonymous.

Questionnaire packages were then sent by mail or personally delivered to the centers. The number of packages sent depended on the number of families that met the inclusion criterion, as reported by the coordinator of each center. Each package contained information about the study, an informed consent form, the demographic questionnaire, the KIPP, and the CdVF-E (0–18).

After a week, the coordinators monitored performance of the questionnaire. Families had between 15 and 20 days to return the questionnaires, which they sent back in a sealed envelope so as to maintain anonymity. The center coordinators then forwarded the envelope to the research team. A total of 799 research packs were sent to the families, and 41 % were returned; the response rate was considered adequate (Schreiber et al. 2006).

### 3 Analysis

Data analysis was performed using SPSS v22.0 for Windows. Before the main statistical analysis, a one-way ANOVA was conducted to assess the associations between the categorical variables of parents (gender, education level, employment status, income level) and children (degree of disability). Pearson's correlations were computed for the continuous variables such as parents' age, children's age, and level of satisfaction with the services provided. No statistically significant relationships were found between these variables.

The mean scores and SD of the KIPP and CdVF-E were calculated. Then, the Pearson's correlation test was applied for the variables positive perceptions, perceived control and FQoL scores (overall and according to dimension). A linear regression model was then used to analyze the variables that might be predictors of FQoL, such as the demographic variables of the family and children with ID as well as positive perceptions and perceived control. Some authors have concluded that the many statistical artifacts observed in applied psychology studies may create a downward bias in the observed effect size and may negatively prejudice the results; therefore, it is very important to detect the moderating effects of certain variables (Aguinis et al. 2005). Finally, we used the Spearman correlation statistical test to analyze the relationships between positive perceptions and perceived control and parents' satisfaction with the services attending their child with ID.

### 4 Results

For the analysis, the raw scores on the KIPP and the CdVF-E were converted into percentiles, as suggested by the instruments' authors. Table 2 shows the descriptive results (mean, SD, confident interval, minimum and maximum scores) for the four scales of the KIPP and the overall score and seven subscale scores for the CdVF-E.

The highest scores on the KIPP corresponded to the positive contributions scale ( $M = 85.1$ ;  $SD = 16.8$ ) and the perceived control scale ( $M = 35.8$ ;  $SD = 8.4$ ). The highest score on the CdVF-E was emotional wellbeing ( $M = 29.9$ ;  $SD = 6.4$ ), and the lowest was financial wellbeing ( $M = 30.6$ ;  $SD = 9.4$ ).

As the main objective of the study was to explore the relationships between positive perceptions, perceived control and levels of FQoL, in the light of the descriptive results we

**Table 2** Descriptive data for the the KIPP and the CdVF-E instruments

	Mean	SD	CI 95 %	Min	Max
<i>KIPPS</i>					
Positive contributions	85.1	16.8	83.2–86.9	0	159
Social comparisons	15.7	4.2	15.3–16.2	0	30
Causal attributions	18.5	6.3	17.8–19.2	0	36
Perceived control	35.8	8.4	34.8–36.7	0	48
<i>CdVF-E</i>					
Emotional well-being	29.9	6.4	29.2–30.6	0	40
Family interaction	47.0	10.3	45.9–48.1	0	65
Health	23.7	5.4	23.1–24.3	0	34
Financial well-being	30.6	9.4	29.6–31.6	0	55
Parents' organization and skills	27.3	6.8	26.6–28.1	0	40
Family accommodation	28.4	5.4	27.8–29.1	0	51
Social inclusion & participation	25.0	6.1	24.3–25.6	0	35
Total <i>FQoL</i>	209.9	35.1	206.1–213.8	0	288

Mean and standard deviation, confident interval, minimum and maximum scores (n = 327)

decided to conduct a more detailed analysis. First, Pearson correlations were calculated to examine the associations between KIPP scores (i.e., positive contributions and perceived control) and CdVF-E scores (the overall score and the scores for each of the seven dimensions).

A significant correlation was observed between positive contributions and the total CdVF-E score ( $r = .21$ ,  $p < .01$ ) (Table 3). Positive contributions were also significantly correlated with three dimensions of the CdVF-E: emotional wellbeing ( $r = .21$ ,  $p < .01$ ), health ( $r = .22$ ,  $p < .01$ ), and family accommodation ( $r = .21$ ,  $p < .01$ ).

The other significant correlations obtained, including those between perceived control and FQoL, had a low effect size ( $r^2$  between .01 and .03).

**Table 3** Pearson correlation between positive perceptions and perceived control, overall score and dimensions of CdVF-E scale

	2	3	4	5	6	7	8	9	10
1. Positive contributions	.22**	.21**	.18**	.22**	.07	.18**	.21**	.12*	.21**
2. Perceived control		.14*	.16**	.11	.02	.14*	.08	.09	.15**
3. Emotional well-being			.59*	.38**	.32**	.54**	.56**	.58**	.74**
4. Family interaction				.32**	.11	.55**	.54**	.51**	.67**
5. Health					.34**	.46*	.35**	.38**	.58**
6. Financial well-being						.30**	.17**	.27**	.59**
7. Parents' organization and skills							.56**	.52**	.76**
8. Family accommodation								.47**	.68**
9. Social inclusion & participation									.72**
10. Total <i>FQoL</i>									

\*  $p \leq .05$ ; \*\*  $p \leq .01$



**Table 4** Summary of the linear regression analysis for variables predicting FQoL

	FQoL overall score			Emotional Wellbeing			Health			Family accommodation		
	$\beta$	p	F	$\beta$	p	F	$\beta$	p	F	$\beta$	p	F
<b>Model 1</b>			2.9 <sup>a</sup>			3.24 <sup>a</sup>			3.63 <sup>a</sup>			2.5 <sup>a</sup>
Marital status	.135	.038		8.260	.127		.864	.858		8.175	.081	
Employment	.138	.044		6.730	.126		7.158	.069		4.976	.191	
Family income	-.019	.796		.282	.956		-3.299	.467		-11.583	.090	
Degree of IDs	-.141	.022		-8.528	.029		-11.553	.001		-4.915	.144	
Children's age	.038	.539		-.685	.094		.896	.115		.567	.109	
<b>Model 2</b>			6.69 <sup>b</sup>			6.57 <sup>b</sup>			4.94 <sup>b</sup>			2.14
Marital status	.112	.051		10.500	.060		-4.022	.363		2.230	.608	
Employment	.164	.005		8.716	.018		7.055	.037		.841	.800	
Degree of IDs	-.109	.057		-9.222	.110		-9.886	.300		-3.221	.319	
Positive perceptions	.199	.001		.196	.003		.172	.005		.143	.017	
Perceived control	.136	.022		.152	.019		.083	.163		.070	.234	

<sup>a</sup> p < .05

<sup>b</sup> p < .001

The relationships between demographic characteristics, positive perceptions, perceived control and FQoL were investigated using regression analyses. In order to improve the regression model and to control the effects of family and children's characteristics, these variables were entered into the regression model (Aguinis 2004). Using the variables that reached significance, we estimated first and second order interactions. The results of these analyses are shown in Table 4. FQoL was negatively predicted by the degree of ID ( $\beta = -.14$ ,  $p < .001$ ), and moderately predicted by marital status ( $\beta = .14$ ,  $p < .05$ ) and employment ( $\beta = .14$ ,  $p < .05$ ). However, other potential predictors such as family income or children's age, were not identified as significant contributors to this domain. Similar results were obtained on the other two dimensions of FQoL, emotional wellbeing and health (Table 4).

In the second step, we introduced the demographic variables which had reached significance in the first model (marital status, employment situation and degree of ID) together with the variables positive perceptions and perceived control. The results showed a higher level of significance than in the models without interaction effects and, as expected, the effects were statistically significant. Employment status was a predictor of overall FQoL scores ( $\beta = .16$ ,  $p < .05$ ) and positive perceptions ( $\beta = .20$ ,  $p < .001$ ) and perceived control ( $\beta = .14$ ,  $p < .05$ ). However, in this second step the variables degree of ID and marital status reach statistical significance.

As for the dimension emotional wellbeing, statistically significant results were obtained in the variables employment status ( $\beta = 8.71$ ,  $p < .05$ ), degree of ID ( $\beta = -9.22$ ,  $p < .05$ ), positive perceptions ( $\beta = .20$ ,  $p < .05$ ) and perceived control ( $\beta = .15$ ,  $p < .05$ ). In the health dimension, predictive variables were employment status ( $\beta = 7.06$ ,  $p < .05$ ), degree of ID ( $\beta = -9.88$ ,  $p < .05$ ) and positive perceptions ( $\beta = .17$ ,  $p < .05$ ); however, perceived control did not seem to predict the levels of satisfaction with health. Finally, on the dimension family accommodation the only statistically significant variable was positive perceptions ( $\beta = .14$ ,  $p < .05$ ).

Finally, we used Spearman correlations to examine the relationship between parents' satisfaction with the services provided for their child and both positive perceptions and perceived control. The degree of perceived control was significantly associated with the level of satisfaction with services ( $r = .25$ ,  $p < .01$ ).

## 5 Discussion

This study aimed to examine levels of positive perceptions and perceived control among families of children with ID. The initial analysis showed that the families had an average level of positive perceptions, similar to those reported in previous studies (Hastings et al. 2005; Kayfitz et al. 2010; Vilaseca et al. 2014). This corroborates the idea that parents of children with ID have positive perceptions of their child's situation within the family.

Regarding parents' perceived degree of control over the daily management of their children, the information that was available to them and their opportunities for decision making, the analysis again revealed average scores. Thus, in line with some previous studies (Brown and Anand 2003; Gupta and Singhal 2004), the families interviewed perceive that they have some control over the situations that affect them and are able to make decisions accordingly.

The study also aimed to examine the relationships between FQoL and positive perceptions and perceived control. The results confirmed our initial hypothesis that higher levels of positive perceptions and perceived control would be associated with better FQoL. Indeed,

positive perceptions were a predictor of the level of FQoL, both of the total score and of the scores on three dimensions: emotional wellbeing, family accommodation, and health. These results support the prediction based on the theoretical study by Bayat (2007), which suggested a significant association between the presence of positive perceptions and FQoL. Bayat's study of autism found that positive perceptions contributed to higher family closeness, compassion, a more positive outlook on life, patience, and personal empowerment.

Specifically, our results suggested that positive perceptions with respect to the child with ID and perceived control improve the family's emotional wellbeing: for instance, in relation to feelings of calmness, the reduction of stress, personal and family satisfaction, and the interpretation and significance of the disability for the family. In addition, in agreement with previous findings (Lloyd and Hastings 2008) positive perceptions also promote family accommodation, that is, a greater acceptance of, and adaptation to, the experience of having a child with ID. Finally, an increased presence of positive perceptions appeared to improve perceived physical and mental health among family members as a result of having a family member with ID.

However, in contrast to previous research, the present study identified the mediating effects of the degree of disability on FQoL and on parents' positive perceptions and perceived control. Disability severity appears to explain the variation in the level of FQoL; however, when other factors are introduced in the analysis, such as parents' positive perceptions and perceived control, the significance of disability severity is reduced.

Therefore, having a child with a severe ID does not appear to determine FQoL levels (Chiu et al. 2013a, b) if other aspects that can improve FQoL are taken into account such as the presence of positive perceptions and perceived control. These results highlight the importance of promoting positive perceptions and perceived control in these parents in order to raise levels of FQoL regardless of the severity of disability of their child. The results also corroborate those of previous studies, as we mentioned before, showing that the age of the child with ID is an important factor in relation to FQoL levels (Kayfitz et al. 2010).

In short, these results suggest that parents who perceive positive qualities in their child with ID, who feel that their child makes a positive contribution to their family functioning and who perceive that they have control of their everyday lives with their child will probably: (a) report higher levels of FQoL and personal and family satisfaction, (b) have a more positive view of changes in their emotions and the tasks required of them in the daily management of disability, (c) be more satisfied with their own health and that of other family members, and (d) attribute less importance to their child's disability and therefore report better family wellbeing.

As mentioned above, a sensitive family environment with positive parent-child interactions is predictive of better outcomes in the development of children with disabilities (Bradley et al. 2001; Innocenti et al. 2013; Love et al. 2005). Thus, families with higher levels of FQoL, greater satisfaction and a better emotional state are better placed to engage in a positive relationship and, therefore, to promote and optimize the development and learning process of their children.

In our study parents' employment status emerged as a covariant factor in FQoL levels. Working outside the home has a positive effect on the relationships between FQoL and positive perceptions and perceived control, as well as increasing income. Recent studies (Gómez 2015; Vilaseca et al. 2014) have already indicated that employment status was a predictor of emotional wellbeing among the parents of children with ID. Likewise, Guralnick (2004) noted that level of income contributed indirectly to increasing FQoL through improved family functioning and reduced stress.

Our results show that parents' employment status influences their perceptions of their child and their perceived control over their daily lives. An unsatisfactory work situation reduces the learning opportunities that parents are able to offer their child with ID, which would ultimately affect the latter's development. This suggests that employment status is a critical element to consider when drawing up policies for families with children with ID.

Finally, our analysis revealed a significant relationship between perceived control and parents' satisfaction with the services provided for their child with ID. Parents with a stronger sense of perceived control reported higher levels of satisfaction. These results are consistent with those of Blacher et al. (2005), who found that personal control was a key variable in terms of promoting the relationship between parents and staff at the centers attended by their children. Thus, if professionals work to promote families' decision-making skills, involving them in the intervention process and increasing their sense of control over day-to-day management of their children's lives, they will likely find that parents become more satisfied with the services offered, thereby improving collaboration and, ultimately, their FQoL (Balcells-Balcells et al. 2011).

## 5.1 Practical implications

Our results have a number of significant practical implications, since they highlight the importance of working with families with children and adolescents who have disabilities in order to promote FQoL from a positive perspective. They stress the need to build on the strengths (for example, positive perceptions) which are already present and enable parents to make choices and have more control over their child's present and future. We recommend that the intervention plans prepared by services caring for children with ID should include support for parents to improve their employment situation, and should also work on parental perceptions.

Given that the presence of positive perceptions and perceived control has been shown to increase emotional wellbeing in families, this is another aspect that could be addressed in order to improve their FQoL. These perceptions can also help the family adjust to the experience of raising and educating a disabled child whatever his/her degree of disability. In addition, attempts should be made to increase the learning opportunities available for all children with special needs.

These results may be relevant to the development of new ways of intervening with families and supporting their role as primary caregivers through programs that encourage their strengths and promote FQoL. Several authors stress that families have a responsibility in relation to their child's development and that efforts should be channeled towards helping them to improve their physical and psychological status. Whereas professionals move in and out of children's lives at different points in their development, families are a stable resource in relation to their care, education, and protection (Dunlap and Fox 2007; Dunst and Trivette 2009).

In this regard, models of family-centered practice highlight the importance of making the parental role the main focus of intervention so as to maximize the functioning of the family unit and the welfare of all its members (Dempsey and Keen 2008; Epley et al. 2011; McWilliam 2012; Trivette et al. 2010). In our view, policies need to articulate the importance of strengths-based approaches and promotion of resilience in families of children with disabilities.

## 6 Limitations and future research

The present study extends the current literature on positive perceptions and perceived control among parents with children who have disabilities, and how these aspects are related to levels of FQoL. However, the results are limited by the study's cross-sectional design, and need to be complemented by a longitudinal analysis. Another limitation is the use of self-administered questionnaires, but in future studies it would be interesting to compare the present data with those obtained from semi-structured interviews with all family members in order to extract more information and to examine their different perspectives.

A further avenue for research would be to examine other variables that may influence the relationship between parental perceived control and levels of FQoL, with a view to designing intervention in families with children with ID to improve these two aspects. According to Leal (1999), the more family-centered the focus of an intervention, the more opportunities family members will have to build on family strengths, and the more likely families are to increase their degree of control over decision-making and the situations that affect them.

The present study provides data that support the validity of previous research into positive perceptions and perceived control in western cultures. However, there is a need to determine how widespread these strategies are in other cultures and in other languages. It would be interesting to replicate studies of this kind in Asian cultures.

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**Compliance with ethical standards**

**Conflict of interest** The authors declare that they have no conflict of interest.

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### 4.3. Article número 3

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# Kansas Inventory of Parental Perceptions: Spanish Adaptation of a Shortened Form

Fina Ferrer<sup>1</sup>  · Rosa M. Vilaseca<sup>1</sup> · Rosa M. Bersabé<sup>2</sup>

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**Abstract** Previous research has highlighted the critical role of parents' perceptions of their family member with intellectual disability (ID) in family well-being and adjustment. The Kansas Inventory of Parental Perceptions (KIPP; Behr et al. 1992) was specifically designed to assess parents' perceptions of their children with disability. The KIPP is composed of four scales: Positive Contributions, Social Comparisons, Causal Attributions and Perceived Control. The goal of this study was to adapt a shortened form of the KIPP to the Spanish population. The study participants comprised 861 families with a family member with ID. An exploratory factor analysis was conducted to identify the underlying dimensions of the four scales of the KIPP. The results showed the internal consistency of the subscale scores to be good, and the correlations with Family Quality of Life measures provided evidence of the concurrent criterion validity of the KIPP scores. Theoretical and practical implications of these findings are discussed.

**Keywords** Intellectual disability · Parental perceptions · Psychometric properties · Psychological assessment · Family quality of life

## Introduction

For decades, researchers in the field of disability devoted themselves to the study of the negative impact on parents. Having a child with disability was considered as a major source of stress for the family, triggering negative experiences (Hauser-Cram et al. 2001) and high levels of emotional distress, anxiety and depression (Keller and Honig 2004; Olsson and Hwang 2002; Singer 2006).

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✉ Fina Ferrer  
fferrer@ub.edu

<sup>1</sup> Department of Developmental and Educational Psychology, University of Barcelona, Barcelona, Spain

<sup>2</sup> Department of Methodology for the Behavioral Sciences, University of Málaga, Málaga, Spain

Recently, however, researchers have recognized the existence of positive perceptions among parents with children with disability. Parents may see their child as a source of happiness and strength; his/her presence can reinforce family unity and foster the sense of compassion, patience, acceptance and respect for others (Blacher and Baker 2007; Hastings and Taunt 2002; Lloyd and Hastings 2008). Other authors consider that positive perceptions may help to mediate stress and help to give a positive meaning to the experience of having a child with disability (Folkman and Moskowitz 2000; Gupta and Singhal 2004; Tugade and Fredrickson 2004). Positive and negative perceptions may coexist: There are several studies on parents of children with disability which report both positive and negative perceptions (Gómez 2015; Hastings 2003; Kayfitz et al. 2010; Vilaseca et al. 2014).

Other parental perceptions studied by researchers include social comparisons. Parents with disabled children compare themselves to families in similar circumstances in order to obtain information and to evaluate their own situation (Davis et al. 2010). Positive effects were found in their self-esteem (Bogart and Helgeson 2000) and in their confidence in their ability to cope with raising a disabled child (Davies and Hall 2005). When compared to other families with children with disability, negative concerns about the future were often replaced by more positive perceptions (Hodges and Dibb 2010).

Parental perceptions of the cause of disability have also been studied, although the results are not conclusive. Families able to attribute a cause to their child's problems may be better equipped to cope with the situation (Weiner 2013). However, other authors found that concern with finding a causal explanation was related to poor adjustment (Dale et al. 2006; Hebert and Koulouglioti 2010; Mickelson et al. 1999).

Other researchers have focused on parents' perceptions of control; that is to say, the way they perceive their participation in planning and decision-making. Research has shown that families of children with disability who perceived the situation as controllable tend to present a better adjustment (Jones and Passey 2005). Perceived control has been found to be a positive contributor to better health status (DeVellis and DeVellis 2001) and psychological wellbeing (Grob 2000; Hassall et al. 2005; Wiggs and Stores 2001). To date, however, the kinds of perceived control that achieve the greatest benefits in the family have not been assessed in previous work.

All in all, parents' perceptions of the problem are an important predictor of their adaptation to children with disability (Pozo et al. 2014). Behr et al. (1992) carried out the pioneering studies of parental perceptions, focusing especially on positive contributions. They developed a measuring instrument, the Kansas Inventory of Parental Perceptions (KIPP), which was specifically designed to study the perceptions of groups of parents with children with disability. In fact, many subsequent studies of parents' positive perceptions have used the Positive Contribution Scale (PCS) of the KIPP (Hastings et al. 2005b; Hastings and Taunt 2002; Kayfitz et al. 2010). The study by Hastings et al. (2005a) demonstrated the reliability and validity of the PCS in a population of parents with children with ID in UK. However, they stressed the need to study the issue further in other cultural settings.

Promoting parental perceptions as strengths in families may represent an important avenue for intervention. It also ties in with the current emphasis in the field of disability on applying a family-centered approach (McWilliam 2012) which identifies and stresses the strengths and capabilities (Trivette and Dunst 2013; Trivette et al. 2010) of families to promote positive family functioning. For Guralnick (2011), supporting families in their caregiving role by designing interventions based on their strengths is likely to bring important benefits.

In this more ecological understanding of disability, in which the family is a major focus of interest, the concept of Family Quality of Life (FQoL) is taking on increasing importance. Several research groups have created instruments to measure FQoL in families caring for a person with intellectual disability (ID) (Aznar and Castañón 2005; Brown et al. 2006; Chiu 2013; Giné et al. 2013; Hoffman et al. 2006; Isaacs et al. 2007; Summers et al. 2005; Werner et al. 2009). The key role of FQoL has been acknowledged by many researchers and practitioners, who recommend that the pre-existing factors that might influence it should also be studied (Samuel et al. 2012; Shu 2009; Wang et al. 2004).

Bayat (2007) suggested a significant association between the presence of positive perceptions in families with a member with autism and higher levels of FQoL. These results were supported a study by Ferrer and Vilaseca (2015) in families with children with ID which showed that the positive perceptions variable predicted FQoL levels; more positive perceptions favored the family's emotional wellbeing and the adaptation of the various family members to the experience of having a child/sibling with a disability, and increased the whole family's satisfaction with their physical and mental health.

In view of the above, it is clear that the assessment of parental perceptions can be very useful both for research and for professionals designing intervention plans for families of children with disability. The assessment of these perceptions requires the use of a valid instrument suited to the particular social and cultural context. The KIPP is the only instrument specifically designed to assess the perceptions of parents of children with ID, but its relevance has not been studied outside the US, the country in which it was developed (Behr et al. 1992), and the UK (Hastings et al. 2005a). Therefore, there is a need to determine how widespread these strategies are in other cultures and in other languages. To date, the use of the KIPP in Spanish-speaking populations has not been assessed.

Our sociocultural context presents certain economic, legal, and educational characteristics with regard to the treatment of disabled people which demonstrate the need for a specifically designed scale for this population (Echeita and Verdugo 2005; FEAPS 2015).

On the other hand, the original KIPP (Behr et al. 1992) consisted of four scales and a total of 97 items. The scales were "Positive Contributions", composed of nine subscales (50 items); "Social comparisons", with four subscales (18 items); "Causal attributions", with five subscales (15 items) and "Perceived control", consisting of two subscales (14 items). In our view, in its original form, the KIPP was excessively long and contained too many items for effective use in clinical practice. Indeed, many families report being tired of answering excessively long questionnaires (Rillotta et al. 2010).

Therefore, one of the aims of this study was to examine the universality of parental perceptions as strategies for promoting FQoL in a large sample of Spanish families with children with ID. On second hand, another objective was to present a psychometric study of a shortened version of the KIPP adapted in order to facilitate its application in Spanish populations. We then aimed to analyze the underlying dimensions of each of the KIPP's four scales, and to assess the internal consistency of the subscale scores and their validity based on their relations to FQoL measures. We hoped that this process of validation would enable us to continue using the KIPP in our research, and this shortened version is likely to be of use to practitioners working with families of children with ID.

## Methods

Ethical approval was obtained from the Ethics Committee of the Network of Ethics Committees in Universities and Public Research Centers in Spain.

## Participants

The sample included 861 families with a family member with ID. They were receiving care at early childhood intervention centres, special schools, mainstream schools or occupational therapy services affiliated to FEAPS (the Spanish Confederation of Organizations of Families with Intellectual Disability) Spain's largest association of families with children with ID, or in Catalonia, to DINCAT (the Intellectual Disability Association of Catalonia). All participating families were resident in Spain and were distributed as follows: Catalonia (51.3 %), Andalusia (23.7 %), Extremadura (14.2 %), Navarra (4.4 %), La Rioja (2.6 %), Aragon (1.4 %), Valencia (1.3 %), and Madrid (1.1 %). Spanish nationals accounted for 94.3 % and foreign nationals 5.7 %. The sample was selected using accidental non-random sampling.

Most respondents were parents ( $n=720$ ; 83.6 %). The majority were women ( $n=626$ ; 72.7 %) and married or living with a partner ( $n=658$ ; 76.4 %). The age of respondents ranged between 22 and 91 years old ( $M=50.3$ ;  $SD=12.1$ ). A third (38.7 %) had received only elementary schooling, 30.9 % had completed high school and 24.8 % had a university degree. A third of respondents (33.4 %) were in full-time employment, whereas 36.5 % cared for their children and were fully responsible for housework. Finally, almost half of the sample (42.4 %) had a monthly family income between 1200 and 2500€.

Regarding the persons with ID, males ( $n=478$ ; 55.5 %) were slightly more numerous than females ( $n=358$ ; 41.6 %). The age ranged between 1 and 70 years old ( $M=21.7$ ;  $SD=13.9$ ). ID was mild in 22.2 % ( $n=191$ ), moderate in 33.9 % ( $n=292$ ), and severe in 39.8 % ( $n=343$ ). Additional conditions had been diagnosed in 91.6 % (e.g.: visual impairment, hearing impairment, physical disability, autism spectrum disorders

and health issues). Persons with ID lived with their families, except for 6.6 % who were in nursing homes.

## Instruments

### *Kansas Inventory of Parental Perceptions (KIPP)*

First, the KIPP was translated into Spanish and then backtranslated into English. The instrument was reviewed by 12 experts in the field of ID (four researchers and eight professionals). The experts were requested to evaluate the instructions given to the families on how to respond to the inventory statements, the clarity, suitability, and importance of the items, the adequacy of the type of response, and finally, the difficulty and the length of the instrument. All the experts' comments were discussed and assessed by the research team until a consensus was reached. Eventually the shortened form of the KIPP comprised a total of 59 items.

The Spanish version of the KIPP comprised four scales: (1) *Positive Contributions* (30 items), which assesses parental perceptions regarding the positive contributions of family members with ID; (2) *Social Comparisons* (7 items), which evaluates the comparisons that parents make between their own family or the family member with ID and others; (3) *Causal Attributions* (10 items), which explores the causal attributions made by parents regarding their family member's disability; (4) *Perceived control* (12 items), which measures parental perceptions of the control (present and future) they have over their family member's management and educational activities and over the information they receive, and of their power to influence outcomes for the family member.

The items on the four scales were rated according to a 4-point Likert scale ("strongly disagree" to "strongly agree", for the first three scales; and "no control" to 'a lot of control', for the last scale). Subscale scores were obtained by calculating the means of all the items included. [Appendix 1](#) shows a small sample of the items in the final version of each scale. Readers interested in the complete scales in Spanish should consult the Beach Center on Families and Disability.

### *The Spanish Family Quality of Life Scales (CdVF-E)*

The Spanish Family Quality of Life Scales for families with people with ID under-18-year-old and over-18-year-old (*Escala de Calidad de Vida Familiar*; CdVF-E) (Giné et al. 2013) was also administered to the same sample of participants in order to obtain evidence of the validity of the KIPP. The CdVF-E evaluates seven FQoL dimensions: a) emotional wellbeing, b) family interaction, c) health, d) financial wellbeing, e) parents' organization and skills, f) family accommodation, g) social inclusion and participation. It has been validated in a sample of families with a family member with ID.

This instrument has 61 items in the under-18 scale, and 67 in the over-18 scale. It is self-administered and it is answered by family members, reflecting the views of the whole family. Items are rated on a 5-point Likert scale (“never” to “always”) with a “not applicable” option as well. FQoL overall score is computed by adding the scores on each of the items of each scale. Internal consistency of the overall scale was adequate (Cronbach's  $\alpha=.96$ ), and the validation study results confirmed that the dimensions could be used to describe overall levels of FQoL (Giné et al. 2013).

## Procedure

First, permission to adapt the KIPP to Spain and the Spanish-speaking context was obtained from the authors (Behr et al. 1992). The Spanish version was sent to the authors after the adaptation process for use with the large populations of Spanish-speaking residents in the US.

Initially, the FEAPS and the DINCAT were contacted by letter and telephone and informed of the project. These associations then contacted the coordinators of the affiliated centers throughout Spain to request their collaboration in recruiting families for the project. Families were informed that their participation would be entirely voluntary and anonymous. In all, 1963 families consented to participate and were mailed questionnaire packages containing a newsletter, informed consent, a demographic questionnaire, the KIPP instrument and the CdVF-E scale. Questionnaires were returned by 1001 primary caregivers to the respective centers (a 51 % response rate). The coordinators then forwarded the envelope to the research team. Data collection was completed within 6–10 weeks.

## Statistical Analysis

An exploratory factor analysis was conducted to identify the critical dimensions of the four scales composing this new shortened version of the KIPP. Following the procedure applied by the authors of the original KIPP (Behr et al. 1992), data for each scale underwent Principal Component Analysis (PCA) with Varimax rotations. The optimal structure was determined via examination of the scree plot, comprehensibility of the factors, and the Kaiser criterion (Costello and Osborne 2005).

According to the results of the PCA, each of the four scales of the KIPP was organized into factors or subscales. As in the original KIPP, subscale scores were obtained by calculating the mean for items on each subscale. Cronbach's alpha coefficients were computed for each subscale to provide an indicator of internal consistency of the measures. For element analyses, we calculated Cronbach's alpha if an item was deleted, and discrimination indexes, obtained as the corrected correlation of the item score with that of the corresponding subscale.

Correlational analyses were conducted to study the KIPP concurrent criterion validity. The relationships between subscale scores of the KIPP and the CdVF-E overall scores were examined via Pearson product–moment correlation coefficients. SPSS (version 22.0) was used for all the statistical analyses.

## Results

### Dimensionality Analysis

Items on the *Positive Contributions Scale* underwent PCA. The Kaiser-Meyer-Olkin measure of sampling adequacy was .92 and Bartlett's test of sphericity was highly significant ( $p < .001$ ), indicating that the data were suitable for the analysis. Results of the PCA are shown in Table 1. Six components were identified which accounted for 54.8 % of the total variance in the sample. The names assigned to these factors described the content of the items in each factor: (1) Source of Happiness and Pride, (2) Family Strength and Acceptance; (3) Personal Growth and Maturity, (4) Sensitivity to Disability, (5) Expanded Social Network, and (6) Understanding of Life's Purpose.

On the *Social Comparisons Scale*, two components were identified which accounted for 56.5 % of the total variance in the sample. The Kaiser-Meyer-Olkin measure of sampling adequacy was .74 and Bartlett's test of sphericity was highly significant ( $p < .001$ ), indicating that the data were suitable for PCA. Two factors were identified for the Social Comparisons instrument. The target of comparison (self, family, or child) did not appear to be a salient dimension; nor was directionality, that is, the tendency to make upward comparisons (viewing others as better off than oneself), downward comparisons (viewing others as worse off), and similar comparisons (viewing others as the same). Instead, the emotional impact appeared to be the critical dimension. *Emotional impact* refers to favorable (feeling better about oneself or one's situation) and unfavorable (feeling worse) perceptions (Behr et al. 1992).

The results of the PCA are shown in Table 2. According to the salient dimension, factors were named as: (1) Favorable Comparisons, and (2) Unfavorable Comparisons. Item 8 refers to Similar Comparisons ("My family is managing about as well as other families who have children with special needs"); this item was excluded as it was not clearly related to either factor.

On the *Causal Attributions Scale*, three components were identified which accounted for 59.5 % of the total variance in the sample. The Kaiser-Meyer-Olkin measure of sampling adequacy was .70 and Bartlett's test of sphericity was highly significant ( $p < .001$ ), indicating that the data were suitable for PCA. The results of the exploratory factor analysis are shown in Table 3. Factors were named as: (1) Professional Blame, (2) Physiologic Causes/Self Blame, and (3) Fate/Chance/Special Purpose.

On the *Perceived Control Scale*, two components were identified which accounted for 62 % of the total variance in the sample. The Kaiser-Meyer-Olkin measure of sampling adequacy was .84 and Bartlett's test of sphericity was highly significant ( $p < .001$ ), indicating that the data were suitable for PCA. The results of the exploratory factor analysis are shown in Table 4. Factors were named as: (1) Professional Control, and (2) Personal Control.

### Item Analysis and Reliability of Subscales Scores

According to the results of the PCA, each of the four scales of the KIPP was organized into factors or subscales. Subscale scores were obtained by calculating



**Table 1** Principal components analysis for the positive contributions instrument

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
I consider my child to be:						
1			.348		<b>.602</b>	
2			<b>.633</b>		.329	
3	.309		<b>.497</b>			
4	<b>.686</b>					
5			<b>.630</b>	.335		
6	<b>.539</b>		.396			
7						
8				<b>.693</b>		
9	.340		<b>.383</b>			
10	.402		<b>.522</b>			
11			<b>.543</b>			
12	<b>.340</b>					.324
13	<b>.716</b>					
Because of my child:						
14					<b>.752</b>	
15	<b>.533</b>					.381
16					.344	<b>.642</b>
17					<b>.592</b>	.338
18					<b>.583</b>	<b>.630</b>
19						
20						
21		<b>.482</b>	.351			<b>.758</b>

**Table 1** (continued)

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
22 I am more compassionate			.305	<b>.488</b>		.403
23 I learned about intellectual disability		.361		<b>.495</b>		
24 My family is more understanding about people with disability		<b>.521</b>		.507		
25 I am grateful for each day	<b>.538</b>	.343				.396
26 I am more sensitive to family issues		<b>.530</b>	.340			.305
27 I have learned to adjust to things I cannot change		<b>.645</b>				
28 My other children or family members have learned to be aware of people's needs and their feelings		<b>.721</b>				
29 I have many unexpected pleasures	<b>.620</b>	.387			.319	
30 I am more accepting of things	.431	<b>.541</b>				
Eigenvalue	9.06	2.34	1.46	1.37	1.16	1.06
% of the variance	11.3	9.7	9.6	9.2	8.2	6.9

Loadings appear in bold to indicate onto which factor the items are assigned. Factor loadings lower than .30 are not reported

**Table 2** Principal components analysis for the social comparisons instrument

Item		Factor 1	Factor 2
1	It gives me hope to think about other parents who seem to manage better than I do	.608	
2	I feel fortunate that my child doesn't have as many serious problems as other children have	.705	
3	I get discouraged when I see other parents who are coping with their children's special needs better than I am		.851
4	I don't think that my family will ever be as well adjusted as other families who have children with special needs seem to be		.880
5	My child seems to be making better progress than others who have special needs	.733	
6	I seem to manage better than other people who have children with special needs	.638	
7	When I think about others with special needs who are doing very well, it encourages me to believe that my child will make even more progress	.737	
Eigenvalue		2.58	1.38
% of the Variance		33.9	22.6

Factor loadings lower than .30 are not reported

the mean scores of the items included. Therefore, all subscale scores range from 1 to 4, with higher scores indicating that the parent agreed more strongly with the items on the subscales.

Table 5 shows the number of items composing each subscale, the number of subjects who answered the items, and the mean and standard deviation of the subscale scores. Cronbach's alpha coefficient was also examined for each subscale to ensure that it exceeded an acceptable minimum of .60 (Nunnally 1978). All the subscale scores showed an acceptable alpha coefficient; the only exception was the Positive Contribution Scale *Understanding of Life's Purpose* ( $\alpha=.40$ ), which indicated poor internal consistency of the two items composing the subscale (Table 5).

The alpha coefficient of each subscale decreased if any of the items were deleted, indicating that all of them contribute to increasing the subscale's internal consistency. In addition, corrected correlations between each item and the corresponding subscale score were obtained. All showed acceptable values (discrimination index  $>.30$ ) except for the items composing the *Understanding of Life's Purpose* subscale, which had a discrimination index lower than .30 ( $DI=.253$ ).

### Validity Evidence of KIPP Scores Based on Relations to FQoL Measures

To obtain evidence of concurrent criterion validity, the relationship between the KIPP scores and theoretically related measures was analyzed. Table 6 shows the correlation coefficients between the subscale scores of the KIPP and the CdVF-E measures.

**Table 3** Principal components analysis for the causal attributions instrument

Item	Factor 1	Factor 2	Factor 3
My child's special needs are			
1		<b>.589</b>	
2	<b>.774</b>		
3			<b>.503</b>
4			<b>.816</b>
5	<b>.723</b>		
6		<b>.746</b>	
7	<b>.879</b>		
8	.329	<b>.629</b>	.303
9			<b>.850</b>
10	.300	<b>.678</b>	
Eigenvalue	2.86	1.95	1.13
% of the Variance	21.7	19.4	18.4

Loadings appear in bold to indicate onto which factor the items are assigned. Factor loadings lower than .30 are not reported

**Table 4** Principal components analysis for the perceived control instrument

Item	Factor 1	Factor 2
How much control do you personally have over:		
1	Your participation in your child's daily educational and training activities?	<b>.765</b>
2	Managing your child's activities from day to day?	<b>.777</b>
3	Your participation in your child's education or training activities in the years to come?	<b>.872</b>
4	Managing your child's activities as he/she gets older?	<b>.859</b>
5	Decisions about what will happen to and for your child in the future?	<b>.645</b>
How much control do professionals have over:		
6	Managing your child's activities from day to day?	<b>.697</b>
7	Providing useful information about what you can expect from and for your child from day to day?	<b>.741</b>
8	Your participation in your child's daily educational and training activities?	<b>.757</b>
9	Managing your child's activities as he/she gets older?	<b>.836</b>
10	Providing useful information about what you can expect as your child develops in the future?	<b>.789</b>
11	Your participation in your child's education or training in the years to come?	<b>.755</b>
12	Decisions about what will happen to your child as he/she gets older?	<b>.717</b>
Eigenvalue		2.23
% of the Variance		27.2

Loadings appear in bold to indicate onto which factor the items are assigned. Factor loadings lower than .30 are not reported

**Table 5** Descriptive statistics and alpha coefficient for the subscale scores

Instrument/scale	Factor/subscale	Number of items	Number of subjects	Mean	SD	Alpha coefficient
Positive contributions	1. Source of Happiness and Pride	7	758	2.81	0.58	.829
	2. Family Strength and Acceptance	6	803	3.14	0.48	.778
	3. Personal Growth and Maturity	6	783	2.78	0.57	.774
	4. Sensitivity to Disability	5	831	3.34	0.46	.729
	5. Expanded Social Network	4	815	2.63	0.62	.722
	6. Understanding of Life's Purpose	2	814	2.52	0.67	.402
Social comparisons	1. Favorable Comparisons	5	793	2.70	0.55	.728
	2. Unfavorable Comparisons	2	835	2.03	0.64	.697
Causal attributions	1. Professional Blame	3	737	1.88	0.84	.738
	2. Physiologic Causes/Self Blame	4	717	1.54	0.51	.605
	3. Fate/Chance/Special Purpose	3	714	1.98	0.78	.627
Perceived control	1. Professional Control	7	755	3.00	0.62	.885
	2. Personal Control	5	779	3.28	0.60	.852

Statistically significant correlations were observed between most of the Positive Contribution Scale subscales and both CdVF-E scales. For example, *Source of Happiness and Pride* was significantly correlated with scores on the CdVF-E under-18 ( $r=.26, p<.01$ ) and CdVF-E over-18 ( $r=.35, p<.01$ ). That is, parents or relatives who considered that their child with ID brought them happiness and positive feelings were more satisfied with their FQoL. Scores on the Positive Contribution Scale *Family Strength and Acceptance* correlated significantly with scores on the CdVF-E under-18 ( $r=.17, p<.01$ ) and CdVF-E over-18 ( $r=.24, p<.01$ ); that is, parents or relatives who considered that their child with ID helped to increase family togetherness and acceptance of life events were more satisfied with their FQoL. Exceptions were the subscales Sensitivity towards disability and Understanding of Life's Purpose, where the correlations with the CdVF-E under-18 scale were not significant, and the correlations with the CdVF-E over-18 scale were only moderately significant.

Regarding the Social Comparisons Scale, *Favorable Comparisons* showed statistically significant correlations with CdVF-E under-18 ( $r=.20, p<.01$ ) and CdVF-E over-18 ( $r=.30, p<.01$ ). The other factor, *Unfavorable Comparisons*, showed statistically significant negative correlations with CdVF-E under-18 ( $r=-.28, p<.01$ ) and CdVF-E over-18 ( $r=-.19, p<.01$ ). That is, the greater the tendency of parents to compare themselves with others and to have positive feelings about their child's progress, the higher their FQoL; the greater the tendency to make negative comparisons of their child's progress (that is, being discouraged when they perceive that their child is not progressing like his/her peers), the lower the FQoL.

The results on the Causal Attributions Scale presented a significant negative correlation with scores on the CdVF-E under-18: *Professional Blame* ( $r=-.21, p<.01$ ),

**Table 6** Correlations between KIPP subscale scores and the Spanish family quality of life scales (CdVF-E)<sup>a</sup>

KIPP scale	Subscale	CdVF (0–18 years)	CdVF (>18 years)
Positive contributions	1. Source of Happiness and Pride	.255**	.352**
	2. Family Strength and Acceptance	.194**	.247**
	3. Personal Growth and Maturity	.109*	.256**
	4. Sensitivity to Disability	.005	.115*
	5. Expanded Social Network	.185**	.225**
	6. Understanding of Life's Purpose	-.016	.129*
Social Comparisons	1. Favorable Comparisons	-.198**	-.296**
	2. Unfavorable Comparisons	.275**	.185**
Causal Attributions	1. Professional Blame	-.206**	-.139*
	2. Physiologic Causes/SelfBlame	-.147**	-.019
	3. Fate/Chance/Special Purpose	-.145**	.055
Perceived control	1. Professional Control	.061	.074
	2. Personal Control	.142**	.212**

\*  $p < .05$  \*\*  $p < .001$

<sup>a</sup> Computed by overall score of FQoL

*Physiological Causes/Self Blame* ( $r = -.15$ ,  $p < .01$ ) and *Fate/Chance/Special Purpose* ( $r = -.15$ ,  $p < .01$ ). This indicates that families with children with ID younger than 18 who do not attribute the diagnosis of ID to any particular cause have higher levels of FQoL.

Finally, on the Perceived Control Scale, the *Personal Control* subscale scores presented statistically significant correlations with both scales (CdVF-E under-18 ( $r = .14$ ,  $p < .01$ ) and CdVF-E over-18 ( $r = .21$ ,  $p < .01$ ), showing that family members with higher perceived personal control had higher levels of FQoL. This was not the case of the *Professional Control* factor, which was not even moderately correlated with either version of the CdVF-E.

## Discussion

As outlined in the introduction, the aim of the study was to analyze the reliability and validity of this new version of the KIPP questionnaire. We created a shortened version of the inventory adapted to the reality of families of people with ID living in Spain, for use in both research and clinical practice. With the exception of Perceived Control, we obtained a smaller number of factors on all scales.

The reliability study showed that the internal consistency of the items on each scale was adequate. On the Positive Contribution scale, all factors had an adequate Cronbach's alpha ( $\alpha = .72$  to  $\alpha = .83$ ), except for Understanding of Life's Purpose ( $\alpha = .40$ ). This factor contains two items that were not sufficiently interrelated. In addition, one of the items is related to religious beliefs; it

may be the case that this subscale is particularly sensitive to cultural differences, as Hastings et al. (2005a) already noted in their study of this scale's psychometric properties. In recent years, the importance of religion in the Spanish population has declined however there are differences in this aspect depending on the Spanish region (Sociological Research Center 2008). Therefore, although the consistency of this subscale was moderate, it was thought appropriate to keep it to evaluate this aspect throughout the Spanish territory. The Social Comparisons, Causal Attributions and Perceived Control scales showed appropriate values of reliability and internal consistency ( $\alpha=.61$  to  $\alpha=.89$ ).

In the study of the concurrent criterion validity, we found significant correlations between most factors on the Positive Contribution scale and the CdVF-E, coinciding with the literature (Bayat 2007; Ferrer and Vilaseca 2015). The factors *Source of Happiness and Pride*, *Family Strength and Acceptance*, *Expanded Social Network*, and *Personal Growth and Maturity* presented more robust results because the correlations with both versions of the CdVF-E scale were significant. Positive perceptions of the person with ID were closely related to greater perceived FQoL. The remaining two factors, *Sensitivity towards Disability* and *Understanding of Life's Purpose*, presented closer relations with FQoL when the persons with ID were older. One possible explanation is that, over the years, parents have gone through a process of adaptation to the disability and have been able to make sense of the experience.

With regard to the Social Comparisons scale, the *Emotional Impact* dimension was more important than *Directionality*. It seems that the impact of the comparison on the self is most directly linked to emotions (Smith 2000). On this scale we found significant correlations between the two factors and the CdVF-E. For example, comparing the child and the family favorably with other families with children with ID is strongly associated with a higher FQoL. In contrast, comparing one's family member with others and feeling that he/she is not making adequate progress generates more discomfort and affects FQoL, as other authors have reported (Behr et al. 1992; Buunk et al. 2013).

The results on the Causal Attributions scale show that parents who do not report being concerned with finding an explanation for the causes of their child's disability perceive themselves to be better adapted and reflect a greater satisfaction with their FQoL. In fact, the original work by Taylor (1983), which outlined the theoretical model of cognitive adaptation, argued that construing a positive meaning from the experience is related to successful adjustment, but the search for the cause is not. According to Roesch and Weiner (2001), those who actively seek the causes of their outcomes rather than the origin of their disease may have a more positive adaptation.

Finally, the Perceived Control scale confirmed the results expected in the light of previous studies, that is, the higher the parents' perceived level of personal control, the lower the psychological distress and the greater satisfaction with their FQoL (Epley et al. 2011; Knox et al. 2000). Even so, no significant associations were observed between parents' perceptions of their control over the activity of the practitioner and scores on the CdVF-E. Other variables may be at work, probably related to decision-making and the quality of collaboration between professionals and families (Balcells-Balcells et al. 2011; Ferrer and Vilaseca 2015).

The results indicate that this shortened version of the KIPP is well suited for assessing different types of family perceptions of having a child with ID and maintains



its reliability and validity in the Spanish context. It reduces the time and effort required of the practitioners and participants and is also cheaper to administer. We have shown that our version of the KIPP can be used in other Spanish-speaking countries or regions and can thus help to broaden the scope of the research carried out in this area.

The KIPP can be routinely used by professionals during standard visits with parents. As we have seen, determining parents' perceptions of their child with ID is essential to help them to adapt to the situation and to maintain their bond with their child, and it can also influence their level of FQoL. In addition, it can help to soften the impact of assessment process itself, which focuses predominantly on the difficulties and problems (Hastings et al. 2005a). In short, the administration of KIPP alongside another questionnaire to assess FQoL may provide a better balance in the evaluation of the needs of the family, as well as eliciting valuable information to guide diagnosis.

Given that parents are usually the primary caregivers throughout their children's lives, and since the professionals who attend to them have identified the need to empower them and enhance their strengths (Dempsey and Keen 2008; Dunst et al. 2014; Giné et al. 2011), the KIPP emerges as a key instrument in the intervention process. Supporting families in their positive perceptions, fostering their sense of control and helping them to take responsibility for their lives and accept disability can generate new methods and intervention strategies based on collaboration between families and professionals. The success of support services for parents is measured by improving the positive results, not just by decreasing the negative results (Hastings et al. 2005a).

A limitation of this study is the selection of the sample. Although the aim was to obtain a sample that was as representative as possible of the whole country, the fact is that the selection procedure is conditioned by the willingness of families to participate (Hoffman et al. 2006).

Another limitation has to do with the scope of the population at which the KIPP is aimed. It was adapted to provide Spanish professionals and families with a person with ID with an instrument attuned to their social and cultural characteristics. Although such contextualisation was one of the objectives, it may also be a limitation in regard to the possible use of this instrument in other countries. If they are used elsewhere, care must be taken to ensure that the social, cultural, and economic conditions, and the legislation and access to services are similar.

Future research should assess whether the dimensions found in this study are confirmed and should continue to gather evidence to support the construct validity of the KIPP. It would also be interesting to extend the analysis of the psychometric properties of this assessment tool to other Spanish-speaking countries in which its application may prove particularly useful.

### **Compliance with Ethical Standards**

**Ethical Approval** was obtained from the Ethics Committee of the Network of Ethics Committees in Universities and Public Research Centers in Spain. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Families signed an informed consent to participate in this study.

**Conflict of Interest** The authors report no conflicts of interests.

**Appendix**

**Table 7** Example of how the items are presented in the KIPP

	1	2	3	4
	Strongly disagree	Disagree	Agree	Strongly agree
Positive contributions scale				
I consider my child to be:				
What gives me common ground with other parents.				
What makes me realize the importance of planning for my family's future.				
Kind and loving.				
Responsible for my increased sensitivity to people.				
The reason I've learned to control my temper and to be patient.				
Social comparisons scale				
It gives me hope to think about other parents who seem to manage better than I do				
I feel fortunate that my child doesn't have as many serious problems as other children have.				
I get discouraged when I see other parents who are coping with their children's special needs better than I am.				
Causal attributions scale				
My child's special needs are:				
Because of heredity.				
Because of medications or medical treatments received.				
Because of God's will.				
Because of chance.				

**Table 7** (continued)

	1	2	3	4
	No control	Not much control	Some control	A lot of control
Perceived control scale				
How much control do you personally have over:				
Your participation in your child's education or training activities in the years to come?				
Decisions about what will happen to and for your child in the future?				
How much control do professionals have over:				
Providing useful information about what you can expect from and for your child from day to day?				
Managing your child's activities as he/she gets older?				
Providing useful information about what you can expect as your child develops in the future?				

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#### 4.4. Article número 4

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# Gender differences in positive perceptions, anxiety, and depression among mothers and fathers of children with intellectual disabilities: a logistic regression analysis

Rosa Vilaseca · Fina Ferrer · Joan Guardia Olmos

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**Abstract** This study explores gender differences in positive perceptions, anxiety, and depression among mothers and fathers of children with intellectual disabilities (IDs). We examined the relationship between these variables and certain characteristics of both the child (age and severity of disability) and the parents (age, educational level, and employment status). A sample of 60 mother/father couples who had children with IDs completed the Positive Contributions Scale to measure their positive perceptions, and the Hospital Anxiety and Depression Scale to assess their level of anxiety and depression. Bivariate analyses were used to determine differences between fathers and mothers as regards their positive perceptions and levels of anxiety and depression. A logistic regression model was then applied to identify which of the variables might be significant predictors of the gender differences observed among parents. Both mothers and fathers had positive perceptions of their children with IDs that co-existed with symptoms of anxiety and depression, with scores being higher among mothers. The predictive analysis of gender showed that individual variables (such as the employment status of both parents) may explain these differences.

**Keywords** Positive perceptions · Anxiety · Depression · Children with intellectual disabilities · Families · Logistic regression

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R. Vilaseca (✉) · F. Ferrer  
Department of Developmental and Educational Psychology, University of Barcelona,  
Pg. De la Vall d'Hebron 171, 08035 Barcelona, Spain  
e-mail: rosavilaseca@ub.edu

F. Ferrer  
e-mail: fferrer@ub.edu

J. Guardia Olmos  
Department of Methodology of the Behavioral Sciences, Institute for Research on the Brain,  
Cognition, and Behavior (IR3C), University of Barcelona, Barcelona, Spain  
e-mail: jguardia@ub.edu



## 1 Introduction

There is growing interest, both in society and among professionals and researchers, to understand the ways in which having a child with intellectual disabilities (IDs) can affect the life of the family across the child's life cycle (Summers et al. 2007). In the vast majority of cases, children with IDs are cared for by their parents (along with other family members), who remain the most constant and stable presence throughout the child's life. Parents therefore play a critical role in shaping the development and life experiences of the child with IDs.

Research on children with disabilities has suggested that having a child with IDs may produce negative reactions in the family, and this reduces the potential of family members to foster the child's development (Blacher and Baker 2002; Byrne and Cunningham 1985; Hastings 2003; Hauser-Cram et al. 2001). Numerous studies have examined the stresses, coping reactions, and anxiety experienced by families of children with disabilities (Dyson 1997; Keller and Honig 2004), and it has been found that parents of children with IDs generally have higher levels of anxiety, depression, and stress than do parents of children who develop normally (Dyson 1993; Olsson and Hwang 2002; Piven et al. 1991).

It is important to note that not all family members respond in the same way to being a relative of a child with IDs. Most research in this area has focused on the well-being of individual family members, especially mothers. However, very little has been published on the well-being of fathers (Glidden and Natcher 2009; MacDonald et al. 2010), and this means that the overall body of literature neglects an important element of the family structure. In general, mothers of children with IDs report more stress and poorer psychological health, such as a risk of depression, than do fathers in the same family (Gray and Holden 1992; Hastings 2003; Hastings and Brown 2002; Moes et al. 1992; Saloviita et al. 2003). In addition, some studies have found that maternal stress and well-being and the way in which the intellectual disability impacts upon family members varies according to different stages in the family life cycle; as such, it may improve over time (Glidden and Jobe 2006).

Many studies have reported no association between family well-being (measured in terms of the mother's stress, depression, and social support) and the severity of the child's disability (Skok et al. 2006). In fact, the results of some family research suggest that it is the child's behavior problems, rather than his or her intellectual disabilities, that are related to lower levels of parental well-being (Totsika et al. 2011). Interestingly, other studies have stressed that having a child with IDs may lead to the perception of positive aspects in the life of the family (Hastings and Taunt 2002; Helff and Glidden 1998; Turnbull et al. 1993). In this context, research has found that mothers of children with disabilities report more positive perceptions than do fathers (Hastings et al. 2005a,b). These findings suggest that the negative repercussions that having a child with IDs can have on the family may be offset by positive factors that help to soften the emotional impact. Positive perceptions may therefore act as strategies that help families either to adapt to or cope with the experience of raising a child with IDs (Hastings et al. 2005b; Lloyd and Hastings 2008). This could be useful in terms of developing new ways of intervening with these families, such as supporting them in the caregiving role by designing interventions based on the family's strengths (Guralnick 2001, 2005, 2006; Summers et al. 1989). Indeed, fostering positive perceptions within these families may be a way of helping them cope with adverse situations, and might therefore help to improve the quality of life of parents of a child with IDs (Folkman and Moskowitz 2000; Hastings et al. 2005a,b).

The aim of the present study was to examine positive perceptions, anxiety, and depression among mothers and fathers of children with intellectual disabilities. These three variables were assessed separately in the mother and father from each family, such that the findings

may have consequences for subsequent interventions. Based on the findings of previous studies carried out with preschool and school-aged children with autism (Hastings et al. 2005b; Kayfitz et al. 2010), we expected to find that positive perceptions and symptoms of anxiety and depression would co-exist in parents of children with IDs. In addition, we expected mothers to report higher levels of anxiety and depression, and also that the positive perceptions held by mothers would be stronger than those of fathers.

Our purpose is not only to confirm these previous results but to go further by applying a logistic regression model that allows us to identify which variables related either to the child with IDs (age and severity of disability) or his/her parents (age, educational level, and employment status) are significant predictors of the gender differences found among these parents in relation to the levels of positive perceptions, anxiety, and depression.

## 2 Method

Ethical approval was obtained from the Ethics Committee, which belongs to the Network of Ethics Committees in Universities and Public Research Centers in Spain.

### 2.1 Participants

In total there were 120 participants, accidental non probabilistic recruitment, comprising 60 married couples, mothers and fathers of children and adolescents with IDs who were attending special schools.

All of the participating families were from the northeastern regions of Spain. Most of the fathers (91.7%) and mothers (93.2%) were of Spanish origin and were living in urban areas (65%). The age of mothers ranged from 30 to 58 years ( $M = 43.7$ ;  $SD = 6.3$ ), while that of fathers ranged from 35 to 59 ( $M = 45.3$ ;  $SD = 6.3$ ). The majority of mothers (55%) had received only elementary schooling, and only 18.3% had completed high school. These proportions were reversed among fathers, of whom 50% had completed high school and 21.7% had only elementary schooling. Most of the fathers (81.6%) were in full-time employment, whereas this was the case for only 23.3% of mothers; 30% of mothers worked part-time and 36.7% cared for their children and were fully responsible for housework.

Of the 60 children with IDs, 35 were boys and 25 were girls. As regards their age, 10% were between 1 and 6 years old, 20% were between 6 and 12, and 70% were between 12 and 19. All the children lived with their families. The majority of these children (93.3%) had been diagnosed by psychologists who belonged to the Spanish Network of Care Centers for the Learning Disabled (CAD), all of which are official government agencies. In Spain the diagnosis of IDs is made by one of these centers, which then issues an official certificate that acknowledges both the existence and degree of the disability. This document is required for the child to attend a special education school, and also enables the family to apply for grants or benefits. In our sample, 31.7% of the children had mild disabilities, 35% had moderate disabilities, and 33.3% had severe disabilities.

### 2.2 Measures

Three measures were used in the present research.

#### 1. A brief demographic questionnaire

This was used to record the age, gender, cultural group, community type, educational level, and employment status of each parent. The questionnaire also covered several characteristics

of the corresponding child, including gender, age, degree of disability, and source from which the child's diagnosis was obtained.

## 2. *Positive Contributions Scale (PCS)*

The positive perceptions that the parents had of their children with IDs were measured using a Spanish translation of the Positive Contributions Scale (PCS), which is one of four subscales in the Kansas Inventory of Parental Perceptions (KIPP; Behr et al. 1992). The KIPP assesses the following dimensions: positive contributions, social comparisons, causal attributions, and mastery/control.

In this study we only used the first subscale (PCS), which was explicitly designed to assess the positive perceptions that parents have regarding their child with a disability and the family in general (Hastings et al. 2005a). The PCS comprises 50 questions that measure the following factors: a) Learning through experience with special problems in life (7 items); b) Happiness and fulfillment (6 items); c) Strength and family closeness (7 items); d) Understanding the purpose of life (4 items); e) Awareness about future issues (3 items); f) Personal growth and maturity (7 items); g) Expanded social network (5 items); h) Career/job growth (4 items); and i) Pride and cooperation (7 items).

Parents were asked to rate the degree to which they agreed with each of the 50 items on a Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The total PCS score therefore ranged from 50 to 200, with higher scores being indicative of stronger positive perceptions of their disabled children. The total PCS coefficient for the original authors showed high internal consistency for both mothers (Cronbach's  $\alpha = 0.92\text{--}0.95$ ) and fathers ( $\alpha = 0.94\text{--}0.95$ ) and for the nine positive contributions subscales, coefficients ranged from 0.30 to 0.74 (Behr et al. 1992). The total PCS score also showed to be internally consistent in several other studies that have obtained similar results (Hastings et al. 2005b; Kayfitz et al. 2010). In the present sample the total PCS score yielded Cronbach's alphas of 0.95 for mothers and 0.92 for fathers. The internal consistency values (Cronbach's  $\alpha$ ) for the nine positive contributions subscales ranged between 0.51 and 0.83 for both mothers and fathers in this study.

## 3. *Hospital Anxiety and Depression Scale (HADS)*

Levels of anxiety and depression among the parents who participated in this study were evaluated using the Spanish version (Caro and Ibáñez 1992) of the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith 1983). This measure has been widely used in community research (Hastings 2003; Hastings et al. 2005b). Although it was originally developed for residential populations it has been employed as a screening instrument to assess both emotional anxiety and depression responses in individuals who are physically ill, mentally ill, and in the general population (Terol et al. 2007). The questionnaire contains 14 four-point items, seven of which assess depression (i.e., "I feel as if I am slowed down") and seven assess anxiety (i.e., "I get sudden feelings of panic"). Raw scores of 7 or higher on each subscale indicate anxiety and/or depression in parents. Previous research on members of families in which there were children with IDs has shown that the HADS is a reliable instrument; Cronbach's alphas of at least 0.80 were found for both anxiety and depression for mothers and fathers (Hastings 2003). In the current study, both the anxiety subscale (Cronbach's  $\alpha$  for fathers: 0.86; Cronbach's  $\alpha$  for mothers: 0.88) and the depression subscale (Cronbach's  $\alpha$  for fathers: 0.81; Cronbach's  $\alpha$  for mothers: 0.85) showed high internal consistency.

### 2.3 Procedure

In order to recruit participants we contacted with seven special education schools. It is particularly active schools and which has generated several studies and projects. So they were selected because of their familiarity with the procedures developed here. The senior management teams were contacted and provided with information about the project, including an invitation for their schools to participate. Two of the schools declined to participate because they were already involved in other research projects. Once the senior management teams of the five remaining schools had agreed to participate they were asked to select children with IDs for whom both parents might be willing to take part in the research. After a meeting with the senior management team of each of the schools in which the research project was explained, the head teachers informed us of the approximate number of families that would be surveyed. To preserve confidentiality each school was given documentation for the families, and the mother and father in each case were handed an identical, sealed research pack. This allowed them to answer the questionnaires independently and anonymously. Each research pack contained an informed consent form, a demographic questionnaire, and the two questionnaires (PCS and HADS) described above. Head teachers were requested to give the research packs to the parents in person and to ask them to answer the questions individually; teachers were also instructed to ask the parents not to discuss the questionnaires until they had returned them to the head teacher. All of the research packs were returned to the school within 10 days of being given to the parents. Once the head teacher had collected the completed questionnaires from all of the parents the researcher came to collect the research packs in person, and the head teacher gave them directly to the researcher without looking at them.

A total of 150 mothers and 150 fathers were sent questionnaires, and the final response rate was 40%. This results show a sufficient level of rate response according to [Schreiber et al. \(2006\)](#). All of the families who returned the questionnaires gave informed consent for their data to be used in the research.

### 3 Analysis

Firstly, in order to assess if levels of anxiety and depression and positive perceptions among parents followed the normal distribution we obtained the Kolmogorov-Smirnov test. Demographic characteristics were analyzed by means of the Student's *t*-test, while the chi-square test was used to determine differences between fathers and mothers in terms of age, educational level, and employment status.

One-way ANOVAs were used to explore the associations among categorical variables such as gender, level of education and employment status while correlation analyses were employed to examine the associations among continuous variables such as parental age, child age and degree of IDs, that is, demographic variables related to children and their parents. Differences between the positive perceptions held by mothers and fathers, as well as between their anxiety and depression symptoms, were explored using paired-sample *t*-tests. Pearson correlation coefficients were used to examine associations between the parental variables (i.e., mothers' and fathers' positive perceptions, symptoms of anxiety, and symptoms of depression) and the child variables (i.e., the age and degree of IDs of their children).

Finally, a binary logistic regression model ([Field 2009](#); [Hosmer and Lemeshow 2004](#)), applying the principles of hierarchical modeling ([Kleinbaum and Klein 2002](#)), was used to examine whether any of these variables acted as exogenous variables predictive of parental gender. All data analyses were performed using SPSS (version 21.0) for Windows.

## 4 Results

### 4.1 Socio-demographic characteristics of parents of children with IDs

Mothers and fathers differed significantly in age ( $t_{(59)}=7.7$ ,  $p < .05$ ;  $r = .31$ ), and there were also significant gender differences as regards the level of education ( $\chi^2_{(2)} = 13.30$ ,  $p < .001$ ;  $V = .482$ ). The percentage of fathers who had completed high school was significantly higher than that of mothers (50 vs. 18.3 %, respectively), while a significantly higher percentage of mothers had only completed elementary school (55 vs. 21.7% of fathers). Significant differences were also observed in relation to employment status ( $\chi^2_{(4)} = 24.83$ ,  $p < .001$ ;  $V = .588$ ). The large majority of fathers (81.6 %) were employed full-time, whereas this was the case for only 23.3 % of mothers. Almost 40 % of mothers were full-time housewives, whereas none of the fathers were classified as a househusband.

No significant relationships, from ANOVA analysis, were found between the demographic variables referring to children (gender, age and degree of IDs) and those that described their parents (age, level of education, and employment status).

### 4.2 Psychological factors in parents of children with IDs

None of the Kolmogorov-Smirnov tests were significant, indicating that parental levels of anxiety and depression and their positive perceptions were normally distributed.

The means and standard deviations of PCS and HADS scores for both mothers and fathers are presented in Table 1, along with the corresponding  $t$  values. The results in this table show significant differences between mothers and fathers on all of the psychological variables. As regards positive perceptions, there were significant differences between mothers and fathers in terms of the total PCS score ( $p < .01$ ) and scores on three PCS subscales: Strength and

**Table 1** Means and standard deviations of scores on the PCS and HADS for mothers and fathers, as well as the corresponding results from the Student's  $t$ -test

Measurement	Mothers		Fathers		t	p	r
	Mean	SD	Mean	SD			
Learning through experience with special problems in life	21.1	4.02	20.12	3.49	1.67	.10	–
Happiness and fulfillment	17.41	4.39	17	3.64	0.46	.65	–
Strength and family closeness	20.53	4.23	19.02	4.19	2.14	.04*	.23
Understanding the purpose of life	9.86	2.48	9.28	2.42	1.20	.23	–
Awareness about future issues	8.03	2.24	7.67	1.9	1.12	.27	–
Personal growth and maturity	17.9	4.56	16.35	4.4	1.97	.05*	.20
Expanded social network	11.75	3.09	10.57	3.08	1.94	.06	–
Career/job growth	8.93	2.91	7.82	2.66	2.34	.02*	.41
Pride and cooperation	15.27	4.47	16.22	4.25	–1.29	.20	–
PCS total score	131.1	24.9	123.0	20.3	2.8	.01**	.48
HADS-A score	8.9	4.6	7.1	4.1	3.4	.01**	.55
HADS-D score	5.5	4.7	4.3	3.3	2.5	.02*	.49

PCS Positive Contributions Scale, HADS-A HADS anxiety subscale, HADS-D HADS depression subscale.  $r$  is the effect effect size for each significant contrast and \*  $p \leq .05$ ; \*\*  $p \leq .01$

**Table 2** Correlations between the mother, father, and child variables

Measurement	2	3	4	5	6	7	8
1. PCS (M)	.52**	.02	.14	-.18	-.09	.06	-.30*
2. PCS (F)		.17	.29*	-.06	.08	-.16	-.10
3. HADS-A (M)			.51**	.83**	.45**	-.09	.12
4. HADS-A (F)				.38**	.54**	-.05	-.01
5. HADS-D (M)					.58**	-.12	.07
6. HADS-D (F)						-.24	.03
7. AGE_CHILD							-.42
8. IDs_DEGREE							

*M* scores from mothers, *F* scores from fathers, *PCS* Positive Contributions Scale, *HADS-A* HADS anxiety subscale, *HADS-D* HADS depression subscale, *AGE\_CHILD* age of the child, *IDs\_DEGREE* degree of severity of the IDs. \*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$

family closeness ( $p < .04$ ), Career/job growth ( $p < .02$ ), and Personal growth and maturity ( $p < .05$ ). In the vast majority of cases the scores of mothers were higher than those of fathers. Significant differences were also found between mothers and fathers on the anxiety ( $p < .01$ ) and depression ( $p < .02$ ) subscales of the HADS. The analysis revealed that 72 % of mothers and 43 % of fathers reported clinically significant levels of anxiety, while 37 % of mothers and 27 % of fathers reported clinically significant levels of depression. Mothers generally had higher levels of anxiety and depression than did the father in the same family. These results concur with the findings of several previous studies (i.e., [Hastings 2003](#); [Hastings et al. 2005a,b](#); [Rowbotham and Carroll 2011](#)).

As shown in [Table 2](#), there were no significant correlations between the analyzed variables and the age of the children. However, a significant negative correlation was found between the positive perceptions of mothers and the degree to which their child was disabled: the more severe the child's disability, the smaller the number of positive perceptions reported by the mother.

There was a significant positive relationship, of moderate intensity, between the positive perceptions held by mothers and fathers. However, the reports of positive perceptions among both mothers and fathers were not significantly related to their respective levels of anxiety or depression, except for a significant but weak positive correlation between the anxiety levels and positive perceptions of fathers. Notably, a highly significant correlation was found between the anxiety and depression scores of mothers, and a significant positive correlation was also found between the anxiety and depression scores of fathers.

A logistic regression model was used to analyze the main effects of the following variables: employment status, educational level, presence of anxiety and depressive symptoms, and level of positive perceptions among parents, with the parent's gender being taken as a classificatory variable. [Table 3](#) shows the results obtained from this logistic regression model, with all the variables defined as categorical. It can be seen that employment status is highly significant ( $p < .001$ ), while both the level of depression ( $p = .056$ ) and educational level ( $p = .082$ ) reach significance. These results indicate that in this sample employment status clearly differs between mothers and fathers, and it therefore becomes a crucial variable. Regarding levels of depression, the results show that there is a clear trend toward depression in mothers that is somewhat more pronounced than in fathers.

The results of the logistic regression model with anxiety, depression, and positive perceptions defined as continuous variables show a loss of significance for all variables, except for

**Table 3** Logistic regression model with categorical variables

	$\beta$	SE	Wald	df	$p$	OR	OR 95 % CI
Age	-.379	.355	1.137	1	.286	.685	.341–1.374
Employment	1.644	.506	10.557	1	.001	5.177	1.920–13.956
Education	.575	.330	3.022	1	.082	1.776	.929–3.395
Anxiety	.659	.444	2.202	1	.138	1.933	.809–4.614
Depression	1.706	.894	3.640	1	.056	5.508	.955–31.781
PCS	.016	.010	2.527	1	.112	1.016	.996–1.036
Constant	-5.067	1.933	6.871	1	.009	.006	

$\beta$  estimated value of the regression coefficient, *SE* Standard error, *Wald* Wald statistic, *df* degrees of freedom, *p* level of significance, *OR* Odds Ratio, *OR 95 % CI* Odds ratio with a 95 % confidence interval, *PCS* Positive Contributions Scale

employment status, which retained the significance level shown in Table 3 ( $p < .001$ ). The estimation process was based on the usual hierarchical process to establish the univariate effects and the corresponding interactions.

According with the above criteria and with the aim of improving the regression model, we estimated first- and second-order interactions between the variables that presented significant effects. The analysis showed that none of these interactions had a statistically significant effect, and this information is therefore not included in Table 3. The general model fit was statistically significant ( $\chi^2 = 36, 77; p < .001$ ) in relation with the null model and, finally, the model was show a moderate-high level of explained variance ( $R^2 = .52$ ) with a 68 % of correct classification.

## 5 Discussion

### 5.1 Comparative study of parents of children with IDs according to gender

The first analysis revealed socio-demographic differences between mothers and fathers of children with IDs. Specifically, fathers had a higher education level and the majority of them were working full-time at the time their positive perceptions and levels of anxiety and depression were evaluated. By contrast, mothers had a lower education level than their husbands, only a minority were working full-time, and over a third (40 %) were exclusively housewives. These results confirm the findings of previous studies regarding the employment status of parents of children with IDs (Saloviita et al. 2003).

### 5.2 Comparative study of positive perceptions and levels of anxiety and depression among fathers and mothers of children with IDs

Our results confirm the hypothesis that both mothers and fathers have positive perceptions regarding their child with IDs. This is consistent with the findings of several previous studies (Hastings et al. 2005a,b; Hastings and Taunt 2002; Kayfitz et al. 2010). However, in the present study, mothers and fathers also reported high levels of anxiety and depression, although only the levels of anxiety were clinically significant. Our results therefore confirm that positive perceptions co-exist with symptoms of anxiety and depression in both fathers and mothers. This suggests that not all reactions to having a child with a disability are negative, and any negative reactions may at times be accompanied by the perception of positive aspects.



The present analysis also shows that mothers and fathers have different levels of positive perceptions, anxiety, and depression. Specifically, mothers reported having more positive perceptions of their child than fathers did, which is consistent with the results of previous research (Hastings et al. 2005b; Kayfitz et al. 2010). On most of the PCS subscales, the scores of mothers were higher than those of fathers. Mothers were more likely to report that family unity resulted from the disability, and they also indicated greater acceptance of various life events. In addition, they scored higher on the subscale referring to career/job growth. It has already been noted that few mothers worked full-time or even part-time, but those who were employed regarded their jobs as being very important. A final point to note is that a significant relationship was found between the levels of positive perceptions held by mothers and the corresponding levels of fathers.

As previously reported (Hastings 2003; Hastings et al. 2005a,b), mothers presented higher levels of anxiety and depression than did the father in the same family. A significant relationship was also found between the degree to which mothers experienced symptoms of anxiety and depression and the degree to which fathers did so. Furthermore, there was a strong correlation between the anxiety and depressive symptoms reported by both mothers and fathers. These results suggest that members of families in which there are children with IDs experience a general feeling of psychological distress, with this feeling being especially common among mothers. Most of the literature to date has emphasized that having a child with IDs is a difficult experience that can negatively affect the mental health of both parents (e.g., raised levels of anxiety, depression, and stress). The present results are consistent with the findings of several studies that examined HADS scores among their respective sample populations, and which suggested that these scores could be treated as an index of emotional distress (Herrero et al. 2003; Lowe et al. 2004; Poole and Morgan 2006).

### 5.3 Comparative study based on parent variables and children with IDs variables

The present study found a significant negative correlation between the positive perceptions held by mothers and the severity of their child's IDs, that is, the more profound the child's disability, the fewer positive perceptions the mother had. However, no such correlation was found among fathers. In our view, this has an extremely important practical implication as it suggests that as the severity of the child's disability increases, so should the amount of emotional support offered. This is especially true of the support given to mothers because it is they who carry the greatest burden in terms of caregiving and attending to the needs of people with a disability, particularly in cases of severe disability.

No correlations were found between any of the parental variables (levels of positive perception, anxiety, and depression) and the age of children with IDs. We found that both fathers and mothers had positive and negative perceptions throughout the life cycles of their children.

### 5.4 Modeling and analyzing the parents' gender

The results show that among parents of children with IDs, being in employment is a key factor in relation to their levels of positive perceptions, anxiety, and depression. Studies that have examined the association between parenthood and mental health in the general population (Helbig et al. 2006) have found that compared to part-time employment, full-time employment was associated with a lower prevalence of mental disorders among parents (especially fathers), although this relationship did not hold for non-parents. Other studies (Abele 2001) in the general population have found that employed mothers reported better



physical and mental well-being than did housewives. Employment, therefore, seems to play a very important role for parents in the general population, and we believe it should be regarded as a differential factor in parents of children and adolescents with IDs, who have an increased risk for anxiety and depression.

Mothers of children with disabilities typically take more responsibility for other domestic tasks, and they also tend to be more involved in caregiving than are fathers (Pozo 2010). In the various studies conducted in Spain (see the introduction to this paper), as well as in other studies on the quality of life of families of individuals with IDs in which the present authors were directly involved as researchers (Giné et al. 2010, 2013), many mothers reported that they had given up paid work to be with their children. Furthermore, in the majority of cases it was mothers who spent the largest amount of time caring for all the needs of the child with a disability. This caregiving role was found to generate both positive and negative perceptions among mothers of children with IDs. In the present study, significant differences were found in relation to paid work. Mothers who perform the majority of caregiving tasks may have more interactions with their children than do the fathers, and as a result they may have more opportunities to develop positive perceptions. However, the increased number of interactions with their children with IDs may also lead mothers to experience higher levels of anxiety and depression.

### 5.5 Implications for intervention

The results of this study suggest that the experiences of mothers do not occur in isolation from those of their partners. It is therefore important to work with families (including both mothers and fathers of children with IDs) to promote the mental and emotional health of all family members. An approach that focuses on family strengths assumes that the parents play a decisive role in the development and education of the child with disabilities (Turnbull et al. 2006). Working with both the mother and father of a disabled child in order to develop positive perceptions of their situation may lead to intervention strategies that enable both parents to respond more positively to the problems and challenges they face during the course of life. The value of this approach has been demonstrated in other studies (Blackledge and Hayes 2006).

Although the causal nature of the relationship between the degree to which parents have both positive perceptions and symptoms of anxiety and depression is not clear, it might be useful from a practical perspective for both researchers and practitioners to bear in mind that mothers and fathers may have different perceptions of having a child with IDs. These differences in perception might affect the emotional well-being of each parent differently, and if so the two parents might have different support needs.

Exploring the positive perceptions held by parents may be a useful method of intervention that can help the entire family. For example, it could help to attenuate the tendency to associate negative thoughts with the fact of having a child with IDs. This would be especially important for mothers of children with IDs as it is they who generally report higher levels of anxiety and depression.

An emphasis on the emotional well-being of family members is very important when working with families in which there is a child with disabilities. However, our study also shows the relevance of other settings, outside the immediate family, to the promotion of emotional health. Specifically, our results suggest that encouraging mothers to work outside the home would be one way of reducing their levels of anxiety and depression and fostering their positive perceptions. However, it is not an easy task. In order to significantly improve families' lives, professionals need to take into account social, cultural, and political context

when identifying family needs and developing action plans. Such practice usually requires an interdisciplinary and transdisciplinary approach. More studies that further explore relationships between employment and levels of anxiety and depression and parental positive perceptions are warranted to develop better intervention and supports.

## 6 Limitations and further research

The present study extends the current literature on positive perceptions of parents with children with IDs, specifically in relation to fathers. However, the findings must be interpreted with caution because we cannot be absolutely sure that the questionnaires were completed separately by mothers and fathers, despite the instructions given to head teachers and families themselves. This requires, in future research, larger sample sizes set to reduce the effect of bias and, in any case, to consider the possibility of estimating nested models to avoid the source of error attributable to non-independence of observations.

It would also be interesting in future studies to examine other variables that may be related to the levels of positive perceptions experienced by family members in relation to a child with IDs, for example, stress levels and general psychological well-being of the parents and the whole family unit (including siblings and other family members). One could then investigate differences between different types of families. In the present study we only analyzed certain characteristics among members of nuclear families, as this is the most common type of family in Spain. However, it would be useful to examine single-parent families, not least because the number of such families is on the rise. A further point to note is that few studies have differentiated between the number of children in the household when examining relationships between demographic and socio-economic variables and the parents' psychological well-being. Given that family well-being may vary with the number of children this would be an interesting aspect to consider in future research.

Finally, it would also be of value to measure both the distribution of chores within the family (i.e., between the father and mother) and the burden borne by each parent, the aim being to determine whether having responsibility for a high share of family tasks is related to increased levels of anxiety and depression in a parent. In addition, there is a need for more detailed examination of the interactions between mothers and their children (with IDs that vary in severity) so as to identify the types of positive relations and perceptions that these interactions are able to generate.

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