

# 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>

Published online: 6 February 2016  
© Springer Science+Business Media Dordrecht 2016

**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.

---

✉ 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.

**Acknowledgments** This research was funded by Spain's Ministry of Science and Innovation under the National R+D+i 2012–2014 (EDU2011-27353).

**Compliance with ethical standards**

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

## References

- Aguinis, H.: *Regression Analysis for Categorical Moderators: Methodology in the Social Sciences*. The Guilford Press, New York (2004)
- Aguinis, H., Beaty, J.C., Boik, R.J., Pierce, C.A.: Effect size and power in assessing moderating effects of categorical variables using multiple regression: a 30-year review. *J. Appl. Psychol.* **90**(1), 94–107 (2005)
- Aznar, A.S., Castañón, D.G.: Quality of life from the point of view of Latin American families: a participative research study. *J. Intellect. Disabil. Res.* **49**(10), 784–788 (2005)
- Bailey, D.B., Golden, R.N., Roberts, J., Ford, A.: Maternal depression and developmental disability: research critique. *Ment. Retard. Dev. Disabil. Res.* **13**(4), 321–329 (2007)
- Balcells-Balcells, A., Giné, C., Guàrdia-Olmos, J., Summers, J.A.: Family quality of life: adaptation to Spanish population of several family support questionnaires. *J. Intellect. Disabil. Res.* **55**(12), 1151–1163 (2011)
- Bayat, M.: Evidence of resilience in families of children with autism. *J. Intellect. Disabil. Res.* **51**(9), 702–714 (2007)
- Behr, S.K., Murphy, D.L., Summers, J.A.: *User's manual: Kansas inventory of parental perceptions (KIPP)*. Beach Center on Families and Disability, Lawrence (1992)
- Blacher, J., Baker, B.: Positive impact of intellectual disability on families. *Am. J. Ment. Retard.* **112**(5), 330–348 (2007)
- Blacher, J., Neece, C.L., Paczkowski, E.: Families and intellectual disability. *Curr. Opin. Psychiatr.* **18**(5), 507–513 (2005)
- Bradley, R.H., Corwyn, R.F., Burchinal, M., McAdoo, H.P., Coll, C.G.: The home environments of children in the United States: Part 2. Relations with behavioral development through age thirteen. *Child Dev.* **72**, 1868–1886 (2001)

- Brown, I., Anand, S., Fung, W.A., Isaacs, B., Baum, N.: Family quality of life: Canadian results from an international study. *J. Dev. Phys. Disabil.* **15**(3), 207–230 (2003)
- Brown, R.I., MacAdam-Crisp, J., Wang, M., Iarocci, G.: Family quality of life when there is a child with a developmental disability. *J. Policy Pract. Intellect. Disabil.* **3**(4), 238–245 (2006)
- Calhoun, L., Tedeschi, R.: Positive aspects of critical life problems: recollections of grief. *Omega-J. Death Dying* **20**(4), 265–272 (1990)
- Chiu, C.Y., Turnbull, A.P., Summers, J.A.: What families need: validation of the family needs assessment for Taiwanese families of children with intellectual disability and developmental delay. *Res. Pract. Pers. Sev. Disabil.* **38**, 247–258 (2013a)
- Chiu, C., Kyzar, K., Zuna, N.I., Turnbull, A.P., Summers, J.A., Aya, V.: Family quality of life. In: Weh-meyer, M.W. (ed.) *Oxford Handbook of Positive Psychology and Disability*, pp. 365–392. Oxford University Press, New York (2013b)
- Davis, K., Gavidia-Payne, S.: The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *J. Intellect. Dev. Disabil.* **34**(2), 153–162 (2009)
- Dempsey, I., Keen, D.: A review of processes and outcomes in family-centered services for children with a disability. *Top. Early Child Spec.* **28**(1), 42–52 (2008)
- Dunlap, G., Fox, L.: Parent-professional partnership: a valuable context for addressing challenging behaviors. *Int. J. Disabil. Dev. Educ.* **54**(3), 273–285 (2007)
- Dunst, C.J., Trivette, C.M.: Capacity-building family-systems intervention practices. *J. Fam. Soc. Work* **12**(2), 119–143 (2009)
- Epley, P.H., Summers, J.A., Turnbull, A.P.: Family outcomes of early intervention: families' perceptions of need, services, and outcomes. *J. Early Interv.* **33**(3), 201–219 (2011)
- Eskow, K., Pineles, L., Summers, J.A.: Exploring the effect of autism waiver services on family outcomes. *J. Policy Pract. Intellect. Disabil.* **8**(1), 28–35 (2011)
- Ferrer, F., Vilaseca, R., Bersabé, R.M.: Kansas inventory of parental perceptions: Spanish adaptation of a shortened form. *J. Phys. Dev. Disabil.* (2015). doi:10.1007/s10882-015-9456-y
- Folkman, S., Moskowitz, J.T.: Positive affect and the other side of coping. *Am. Psychol.* **55**(6), 647–654 (2000)
- Giné, C., Vilaseca, R., Gràcia, M., Mora, J., Orcasitas, J.R., Simón, C., et al.: Spanish family quality of life scales: under and over 18 years old. *J. Intellect. Dev. Disabil.* **38**(2), 1–8 (2013)
- Giné, C., Gràcia, M., Vilaseca, R., Beltran, F.S., Balcells-Balcells, A., Dalmau, M., Adam-Alcocer, A.L., Pro, T., Simó-Pinatella, D., Mas, J.: Family quality of life of people with intellectual disability in Catalonia. *J. Policy Pract. Intellect. Disabil.* **12**(4), 244–254 (2015)
- Gómez, A.: El Benestar de les famílies amb discapacitat intel·lectual i/o trastorn de l'espectre Autista [The wellbeing of families with intellectual disability and autism spectrum disorder] (2015). <http://diposit.ub.edu/dspace/handle/2445/65616>. Accessed 4 Nov 2015
- Green, S.E.: “We’re tired, not sad”: benefits and burdens of mothering a child with a disability. *Soc. Sci. Med.* **64**(1), 150–163 (2007)
- Greer, F., Grey, I., McClean, B.: Coping and positive perceptions in Irish mothers of children with intellectual disabilities. *J. Intellect. Disabil.* **10**(3), 231–248 (2006)
- Guralnick, M.J.: Family investments in response to the developmental challenges of young children with disabilities. In: Kalil, A., Deleire, T. (eds.) *Family investments in children’s potential: resources and parenting behaviors that promote success*, pp. 119–137. Lawrence Erlbaum, Mahwah (2004)
- Gupta, A., Singhal, N.: Positive perceptions in parents of children with disabilities. *Asia Pac. Disabil. Rehabil. J.* **15**(1), 22–35 (2004)
- Hassall, R., Rose, J., McDonald, J.: Parenting stress in mothers of children with an intellectual disability: effects of parental cognitions in relation to child characteristics and family support. *J. Intellect. Disabil. Res.* **49**(6), 405–418 (2005)
- Hastings, R.P., Brown, T.: Behavior problems of autistic children, parental self-efficacy and mental health. *Am. J. Ment. Retard.* **107**(3), 222–232 (2002)
- Hastings, R.P., Kovshoff, H., Ward, N.J., Espinosa, F.D., Brown, T., Remington, B.: Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *J. Autism Dev. Disord.* **35**(5), 635–644 (2005)
- Hastings, R.P., Taunt, H.M.: Positive perceptions in families of children with developmental disabilities. *Am. J. Ment. Retard.* **107**(2), 116–127 (2002)
- Helbig, S., Lampert, T., Klose, M., Jacobi, F.: Is parenthood associated with mental health? Findings from an epidemiological community survey. *Soc. Psychiatry Psychiatr. Epidemiol.* **41**(11), 889–896 (2006)
- Helff, C.M., Glidden, L.M.: More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Fam. Relat.* **36**(6), 263–280 (1998)

- Hill, C., Rose, J.: Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. *J. Intellect. Disabil. Res.* **53**(12), 969–980 (2009)
- Hoffman, L., Marquis, J., Poston, D., Summers, J.A., Turnbull, A.: Assessing family outcomes: psychometric evaluation of the Beach Center family quality of life scale. *J. Marriage Fam.* **68**(4), 1069–1083 (2006)
- Hu, X., Summers, J.A., Turnbull, A., Zuna, N.: The quantitative measurement of family quality of life: a review of available instruments. *J. Intellect. Disabil. Res.* **55**(12), 1098–1114 (2011)
- Hu, X., Wang, M., Fei, X.: Family quality of life of Chinese families of children with intellectual disabilities. *J. Intellect. Disabil. Res.* **56**(1), 30–44 (2012)
- Innocenti, M.S., Roggman, L.A., Cook, G.A.: Using the PICCOLO with parents of children with a disability. *Infant Ment. Health J.* **34**, 307–318 (2013)
- Isaacs, B.J., Brown, I., Brown, R.I., Baum, N., Myerscough, T., Neikrug, S., et al.: The international family quality of life project: goals and description of a survey tool. *J. Policy Pract. Intellect. Disabil.* **4**, 177–185 (2007)
- Jones, J., Passey, J.: Family adaptation, coping and resources: parents of children with developmental disabilities and behaviour problems. *J. Dev. Disabil.* **11**(1), 31–46 (2005)
- Judge, S.L., Burden, R.L.: Towards a tailored measure of parental attitudes: an approach to the evaluation of one aspect of intervention projects with parents of handicapped children. *Child Care Health Dev.* **6**(1), 47–55 (1980)
- Kayfitz, A.D., Gragg, M.N., Orr, R.: Positive experiences of mothers and fathers of children with autism. *J. Appl. Res. Intellect. Disabil.* **23**(4), 337–343 (2010)
- Keller, D., Honig, A.S.: Maternal and paternal stress in families with school-aged children with disabilities. *Am. J. Orthopsychiatr.* **74**(3), 337–348 (2004)
- Knox, M., Parmenter, T.R., Atkinson, N., Yazbeck, M.: Family control: the views of families who have a child with an intellectual disability. *J. Appl. Res. Intellect. Disabil.* **13**(1), 17–28 (2000)
- Lanfranchi, S., Vianello, R.: Stress, locus of control, and family cohesion and adaptability in parents of children with down, Williams, Fragile X, and Prader-Willi syndromes. *Am. J. Intellect. Dev. Disabil.* **117**(3), 207–224 (2012)
- Leal, L.: A family-centered approach to people with mental retardation. American Association Mental Retardation, Washington, DC (1999)
- Lin, J.-D., Hu, J., Yen, C.-F., Hsu, S.-W., Lin, L.-P., Loh, C.-H., Wu, J.-L.: Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. *Res. Dev. Disabil.* **30**, 1448–1458 (2009)
- Lloyd, T., Hastings, R.P.: Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships. *J. Intellect. Disabil. Res.* **52**(1), 37–48 (2008)
- Love, J.M., Kisker, E.E., Ross, C., Raikes, H., Constantine, J., Boller, K., et al.: The effectiveness of Early Head Start for 3-year-old children and their parents: lessons for policy and programs. *Dev. Psychol.* **41**(6), 885–901 (2005)
- McWilliam, R.A.: Implementing and preparing for home visits. *Top. Early Child Spec.* **31**(4), 224–231 (2012)
- Meral, B.F., Cavkaytar, A., Turnbull, A.P., Wang, M.: Family quality of life of Turkish families who have children with intellectual disabilities and autism. *Res. Pract. Pers. Sev. Disabil.* **38**(4), 233–246 (2013)
- Paczkowski, E., Baker, B.L.: Parenting children with developmental delays: the role of positive beliefs. *J. Ment. Health Res. Intellect. Disabil.* **1**(3), 156–175 (2008)
- Roggman, L.A., Boyce, L.K., Innocenti, M.S.: Developmental parenting: a guide for early childhood practitioners. Brookes, Baltimore (2008)
- Saloviita, T., Itälina, M., Leinonen, E.: Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *J. Intellect. Disabil. Res.* **47**(4–5), 300–312 (2003)
- Samuel, P.S., Rillotta, F., Brown, I.: Review: the development of family quality of life concepts and measures. *J. Intellect. Disabil. Res.* **56**(1), 1–16 (2012)
- Schreiber, J.B., Nora, A., Stage, F.K., Barlow, E.A., King, J.: Reporting structural equation modeling and confirmatory factor analysis results: a review. *J. Educ. Res.* **99**(6), 323–337 (2006)
- Shapiro, J., Blacher, J., Lopez, S.R.: Maternal reactions to children with mental retardation. In: Burack, J.A., Hodapp, R.M., Zigler, E. (eds.) *Handbook of mental retardation and development*, pp. 606–636. Cambridge University Press, Cambridge (1998)
- Spiker, D., Boyce, G.C., Boyce, L.K.: Parent-child interactions when young children have disabilities. *Int. Rev. Res. Ment. Ret.* **25**(2), 35–70 (2002)

- Summers, J.A., Marquis, J., Mannan, H., Turnbull, A.P., Fleming, K., Poston, D.J., Kupzyk, K.: Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. *Int. J. Disabil. Dev. Educ.* **54**(3), 319–338 (2007)
- Trivette, C.M., Dunst, C.J., Hamby, D.W.: Influences of family-systems intervention practices on parent-child interactions and child development. *Top Early Child Spec.* **30**(1), 3–19 (2010)
- Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphy, D.L., Marquis, J.G., Blue-Banning, M.J.: *Cognitive Coping. Families and Disability*. Paul H. Brookes Publishing Co., Baltimore (1993)
- Vilaseca, R., Ferrer, F., Guàrdia-Olmos, J.: Gender differences in positive perceptions, anxiety, and depression among mothers and fathers of children with intellectual disabilities: a logistic regression analysis. *Qual. Quant.* **48**(4), 2241–2253 (2014)
- Wang, M., Mannan, H., Poston, D., Turnbull, A.P., Summers, J.A.: Parents's perceptions of advocacy activities and their impact on family quality of life. *Res. Pract. Pers. Sev. Disabil.* **29**(2), 144–155 (2004)
- Weiss, J.A., Sullivan, A., Diamond, T.: Parent stress and adaptive functioning of individuals with developmental disabilities. *J. Dev. Disabil.* **10**(1), 129–136 (2003)
- Zuna, N., Summers, J.A., Turnbull, A.P., Hu, X., Xu, S.: Theorizing about family quality of life. In: Kober, R. (ed.) *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice*, pp. 241–278. Springer, Dordrecht (2010)