



Impact of supports and partnership on family quality of life

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ARTICLE INFO

Keywords:

Family quality of life
Family-professional partnership
Family support
Early childhood intervention
Intellectual disability
Structural equation model

ABSTRACT

Background: In recent decades, Family Quality of Life (FQOL) has emerged as a decisive construct, both to improve the living conditions of the families of people with disabilities and to assess the results on the services and supports that they receive.

The aim of this research is to determine the perception of the families regarding their support needs, the quality of their partnerships with professionals, and their FQOL and then identify to what extent the supports of early childhood intervention centers have a positive impact on the families' FQOL while exploring whether the family-professional partnership has become a fundamental intervening factor of FQOL.

Method: The participants were 202 families with children aged 0–6 with intellectual and developmental disabilities. We used the structural equation model to analyze the influence that the adequacy of the supports and the partnerships exerted on FQOL.

Results: The results indicate that the families have language and speech support needs for their children and information needs for themselves, and that they are mostly satisfied with their partnerships with the professionals and their FQOL. Our results also indicate that their degree of satisfaction with the support was a good predictor of FQOL and their ratings of partnership quality was a key factor interceding on this effect.

Conclusions: This study provides professionals and public institutions with guidance when designing plans to improve early childhood intervention centers so the quality of life of these families and the progress of children with disabilities living in Spain become progressively stronger.

1. Introduction

1.1. Early childhood intervention and family quality of life

The family-centered approach has been widely recognized as an important philosophy to provide services for people with intellectual and development disability (IDD) and their families in early childhood intervention (ECI) (Davis & Gavidia-Payne, 2009; Freedman & Boyer, 2000; Law et al., 2005). The family-centered approach is the provision or mobilization of supports and resources to the families of young children from informal and formal social network members that influence and improve parent, family, and

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<https://doi.org/10.1016/j.ridd.2018.10.006>

Received 17 November 2017; Received in revised form 22 October 2018; Accepted 31 October 2018

Available online 20 November 2018

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child behavior and functioning directly or indirectly (Dunst & Trivette, 2009). Family-centered practices emphasize the importance of parents playing an active role in their child's care to build capacities based on parents strengths and helps parents make decisions that they consider important for their families and take control of their lives (Davis & Gavidia-Payne, 2009). In this manner, a richer context in opportunities for interaction and a sense of greater confidence of the parents in their possibilities is promoted and contributes to their well-being and quality of life (QOL). In this sense, improving family capacities are conceived as an early childhood intervention center outcome (Bruder, 2000).

The Early Childhood Outcomes (ECO) Center defines family outcome as “a benefit experienced by families as a result of services received” (Bailey et al., 2006, p. 228). More specifically, the ECO center proposed five family outcomes: a) knowing their rights and defending those of their child; b) understanding their child's special needs, strengths, and skills; c) helping their child's development and learning; d) having support systems; and e) being able to access the services and activities they need within their community. Bailey et al. (2006) stated that if these five outcomes are attained, family quality of life (FQOL) increases and, therefore, FQOL must be understood as a macro outcome of ECI and an indicator of service quality (Bailey et al., 1998; Brown & Brown, 2004; Dunst & Bruder, 2002; Shippers, Zuna, & Brown, 2015; Summers et al., 2007; Turnbull, Summers, Lee, & Kyzar, 2007; Wang et al., 2006).

Interest in FQOL dates back to the early 2000s (Chiu et al., 2013). At first, researchers had devoted their efforts to conceptualizing the model by means of qualitative research (Aznar & Castañón, 2005; Gràcia, Vilaseca, Balcells, Simó, & Salvador, 2010; Poston et al., 2003). With the results of these early studies, instruments were created to measure FQOL (Garcia-Grau, McWilliam, Martínez-Rico, & Grau-Sevilla, 2018; Giné et al., 2013; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Isaacs et al., 2007), which were later adapted to and validated for other contexts (Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2011; Chiu, Seo, Turnbull, & Summers, 2017; Hu, Wang, & Fei, 2012; Perry & Isaacs, 2015; Verdugo, Córdoba, & Gómez, 2005). Once these instruments were determined to be valid, reliable approaches to the construct were tested and spread, and researchers started becoming interested in exploring which factors explained the FQOL outcomes. As a result, Zuna, Summers, Turnbull, Hu, and Xu, (2010) and Zuna, Turnbull, and Summers, (2009) have proposed a theoretical model based on a thorough revision of the literature on the QOL of families with children with IDD.

The FQOL theoretical proposal by Zuna et al. (2010) and Zuna, Seling, Summers, and Turnbull, (2009) consists of four concepts whose functioning inside the family system can affect the FQOL. These factors are (a) the family unit; (b) the characteristics of the individuals composing the family; (c) the performance; and (d) the system. In this paper, we focus on the third component, performance, regarding the services and supports received by the person with disability and their family.

1.2. FQOL and family supports

From a historical perspective, the supports offered to the families of individuals with IDD were directly related to the needs expressed by these families. In this sense, Dunst and Deal (1994) already defined family needs as indicators of possible aids or services to attain a specific goal or objective. That is, family needs reveal a discrepancy between what actually happens and what they wish would happen. The supports would be the specific actions required to reduce the gap. Therefore, to respond to family needs, it is insufficient to provide supports, but we must ensure that they match the families' actual shortages.

Family supports usually include formal and informal and tangible goods that allow each family member to optimize their level of participation in different life environments (Brennan & Rosenzweig, 2008).

In the last two decades, many studies have been conducted to learn about the support needs of the families of individuals with IDD. Some authors have reported that the families need education, respite care, daily care, and therapy programs for their children (Epley, Summers, & Turnbull, 2011; Samuel, Hobden, LeRoy, & Lacey, 2012). Others assert other priorities related to the family as a whole and financial (Chiu et al., 2013; Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Samuel et al., 2012), emotional, or mental health aspects (Freedman & Boyer, 2000). One need reported by parents as the highest priority is information (Burton-Smith et al., 2009; Chiu et al., 2013).

Many examples in the literature have shown evidence of the relationship between the supports and services provided to children and their families and FQOL (Abbott, Watson, & Townsley, 2005; Davis & Gavidia-Payne, 2009; Hu et al., 2012; Mellon & Northouse, 2001; Schippers & van Boheemen, 2009), and that the supports provided can predict FQOL (Epley et al., 2011; Meral, Cavkaytar, Turnbull, & Wang, 2013; Summers et al., 2007).

1.3. FQOL and partnership

As has been described in the literature (Davis & Gavidia-Payne, 2009; Summers, Behr & Turnbull, 1989; Summers et al., 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006), the family–professional partnership is one of the most important supports that services provide to the families. Summers et al. (2007) stated that this partnership becomes a mediator for the FQOL experienced by the families.

Blue-Banning, Summers, Frankland, Nelson, and Beegle, (2004) defined partnerships as mutual support interactions between the families and professionals intended to identify the children's and families' needs, characterized by a sense of competence, commitment, equality, positive communication, respect, and trust. The partnership is one of the principles/components of the family-centered approach (Turnbull, Turbiville, & Turnbull, 2000).

In countries such as Australia, the United States, and Turkey, the adequacy of the supports to the family needs (provision supports matches the families' actual needs) and the family–professional partnership influences FQOL (Davis & Gavidia-Payne, 2009; Epley et al., 2011; Meral et al., 2013; Summers et al., 2007) but not in Spain. Therefore, this study investigated whether the adequacy of

services affects FQOL in the ECI population in Spain and attempted to determine whether partnerships between families and professionals are a universal aspect related to supporting families to achieve higher FQOL.

This study aimed to a) indicate the descriptive results of the three variables of interest: adequate supports, family–professional partnership, and FQOL; and, b) identify whether the degree to which families perceive they are receiving adequate supports and their satisfaction with their family–professional partnerships are also predictors of FQOL for families attending ECI centers in Spain.

The results of the first goal demonstrate to what extent the supports fit the families' needs, perception of their partnership with the professionals, and satisfaction with their FQOL. This information can be translated into a set of indicators on the quality of care that families receive from ECI services in Spain. The results of the second objective allow us to confirm the following hypotheses:

- (a) the provision of adequate supports for the needs of the children and families significantly influence FQOL (Abbott et al., 2005; Davis & Gavidia-Payne, 2009; Hu et al., 2012; Mellon & Northouse, 2001; Schippers & van Boheemen, 2009).
- (b) the quality of the family–professional partnership becomes a critical component in the relationship between support adequacy and FQOL (Davis & Gavidia-Payne, 2009; Epley et al., 2011; Meral et al., 2013; Summers et al., 2007); and,
- (c) the “Mediation model for family quality of life, service adequacy, and partnership” proposed by Summers et al. (2007) for the United States fits the Spanish population.

These results could contribute to the theoretical model proposed by Zuna et al. (2010) and Zuna, Turnbull et al. (2009).

2. Method

2.1. Participants

The participants of the study were 202 families of children with IDD, aged 0–6 years, attending 13 ECI centers.

As presented in Table 1, a significant majority of the participants (79.7%) were women, 78.7% were mothers, 54% were between 30 and 39 years old, and 89.6% of the participants were married or in a relationship. The data pertaining to the average monthly income of these families were quite disperse.

The characteristics of the children with IDD were as follows: 62.9% boys, an age range of 0–6 years, the prevalence of 3-year-olds was 29.2%, and 42.1% presented a moderate intellectual disability.

2.2. Instruments

The following instruments were used to measure the three variables under study (Support adequacy, Partnership, and FQOL):

A Service Inventory (Balcells-Balcells et al., 2011) was an instrument designed by the Beach Center on Disability in 2003 and later reformulated as the Early Childhood Services Survey (ECSS) (Epley et al., 2011). The Service Inventory intends to learn about the resources the families need and to what degree they receive these supports. The instrument comprises two parts. Each part has a list of possible supports the subjects may need, including *child-oriented supports* in the first part and *family-oriented supports* in the second. First, the survey asks families to rate whether they need a specified resource, and, if they indicate they need it, they are also asked to what degree they perceive they are currently receiving it (not at all, not sufficiently, and sufficiently). The Cronbach's α in the Spanish version is 0.97 (Balcells-Balcells et al., 2011).

The Spanish version of the Beach Center on Family–Professional Partnership Scale (Balcells-Balcells et al., 2011) intends to learn about the degree of importance the families assign to the partnership they keep with the professionals and to what degree they are satisfied with this relationship. This scale comprises 18 items. All the items are assessed according to their importance and satisfaction in a Likert scale (1–5). The Cronbach's α of the Spanish version is 0.96 in the dimension of importance and 0.97 in that of satisfaction (Balcells-Balcells et al., 2011).

Last, we used the adaptation of the Beach Center Family Quality of Life Scale (Beach Center FQOL) (Balcells-Balcells et al., 2011). This scale comprises 25 items that respond to five dimensions: family interaction, parents' role, emotional well-being, physical and material well-being, and supports for the person with a disability (Poston et al., 2003). As in the previous case, the items are answered through a Likert scale (1–5) twice, according to importance and satisfaction. The Cronbach's α of the Spanish version is 0.97 for importance and 0.96 for satisfaction (Balcells-Balcells et al., 2011).

The three scales have been designed to be self-administered; therefore, the participants write the answers in the protocols.

2.3. Procedure

To recruit participants, first, we requested the collaboration of two ECI associations in Spain (ACAP and DINCAT). Next, we invited 13 ECI centers to collaborate by using the convenience sampling process. Although the sample was not representative, we requested that the participants from the ECI centers account for their location (to have sample from different regions) and size.

Later, we met with a team of professionals from each ECI center to (a) explain the proposal in greater detail and the interactions to conduct; (b) increase their familiarity with the instruments; and (c) coordinate the family selection by handing out the instruments and returning them to the center.

The following two selection criteria were applied to select the participating families: at least one child attending an ECI center, and the child must present difficulties in cognitive development.

Table 1
Participant family demographics.

Variables for individuals	(n = 202)	%
Sex		
Female	161	79.7
Male	38	18.8
Relation to the child		
Mother	159	78.7
Father	37	18.3
Siblings	2	1
Other family relation	1	0.5
Age of respondent		
< 19	2	1.0
20–29	18	8.9
30–39	109	54.0
40–49	64	31.6
50–59	3	1.5
60–69	2	1.0
Marital Status		
Marriage or living with a partner	181	89.6
Single	8	4.0
Widowed	1	0.5
Divorced	4	2.0
Separated	2	1.0
Others	1	0.5
Total household income (monthly)		
Less than 600€	6	3.0
Between 600€ and 1.200€	52	25.7
Between 1.200€ and 1.800€	42	20.8
Between 1.800€ and 2.500€	47	23.3
Over 2.500€	48	23.8
Sex of child with a disability		
Male	127	62.9
Female	72	35.6
Age of child with a disability		
Less than 1 year	4	2.0
1 year	15	7.4
2 years	34	16.8
3 years	59	29.2
4 years	45	22.3
5 years	32	15.8
6 years	11	5.4
Level of severity of disability		
Mild	44	21.8
Moderate	85	42.1
Severe/very severe	43	21.3

Once the centers had selected the families, the pack of materials was provided to the professionals, and the professionals gave the materials to the participants. The materials comprised the following items: a) a letter of introduction; b) a general information document; c) a document with demographic data; d) a copy of the service inventory (Balcells-Balcells et al., 2011); e) the Family–Professional Partnership Scale (Balcells-Balcells, 2011); f) FQOL Scale the (Balcells-Balcells et al., 2011); and d) a letter of appreciation. Last, an informed consent was handed out for the participants to sign and return separately from their answers to guarantee anonymity. The informed consent procedure followed the recommendations of the Ethics Committee.

The families had 15 days to fill out the materials and return them to the centers in a closed envelope provided along with the protocols.

Out of the 250 packs of materials sent out, 202 were returned; therefore, we obtained an 80.8% return success rate.

We chose the type of analysis to conduct according to the nature of the research goals. To answer the first proposal, we analyzed the descriptive statistics for each variable of interest: Support Adequacy, family–professional Partnership, and FQOL. To respond the second goal, where we intended to determine whether an adequate provision of supports and the family–professional Partnership are FQOL predictors in Spain, we applied the structural equation model (SEM) to analyze a global structural model.

The SEMs are a series of multivariate statistical models to estimate the effect and relationships between multiple variables that represent a hypothetical theoretical model (Ruiz, Pardo, & San Martín, 2010). This hypothetical model is designed by the researcher and based on the literature. The advantage of this type of statistical model is it allows the analysis of the relationship between observable and latent variables (indicators of a supposed theoretical model). In this sense, SEMs are characterized by measurement

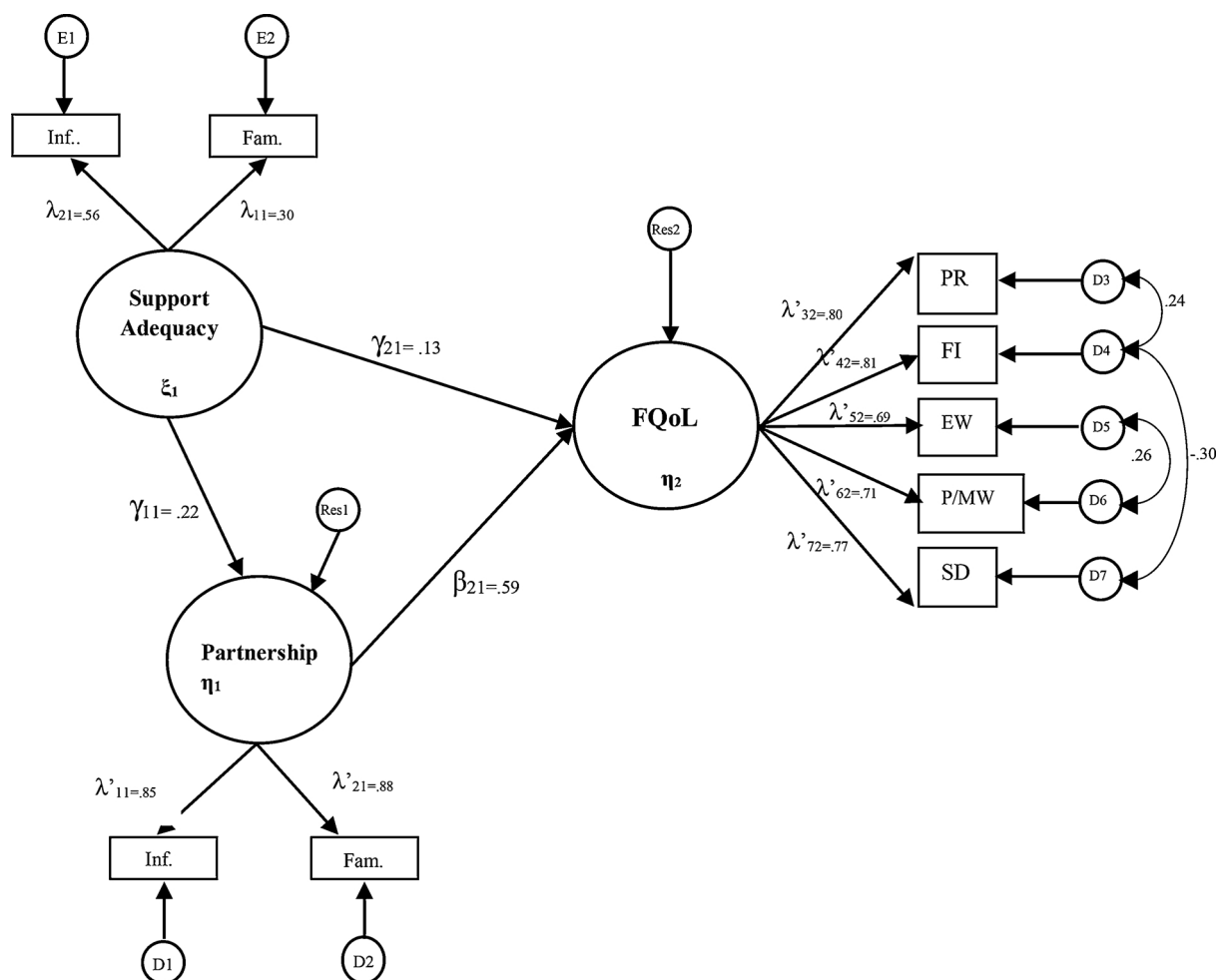


Fig. 1. Path diagram and the results of the “Mediation model for family quality of life, service adequacy, and partnership.”.

Note: PR = Parental role, FI = Family Interaction, EW = Emotional well-being, P/MW = Physical/material well-being, and SD = Supports for the person with IDD.

and structural models.

The study of measurement models has proven that certain sets of variables observed (indicators) define a latent factor or variable; in this sense, measurement models allow an assessment of the internal structure of the instruments and prove their validity. The validity results of the instruments (measurement models) used in this research were presented in Balcells-Balcells, Giné, Guàrdia-Olmos, and Summers (2011). The structural models permit the testing of hypotheses regarding the direct or indirect effects between latent variables (measurement models).

Regarding the analyses involved in SEMs, first, a series of parameters were estimated for each of the relationships in the model tested (in the measurement and structural models), and then a series of indices was obtained that reported the extent to which the theoretical proposal was reflected on the empirical data.

The name of the model we tested through the SEMs is the “Mediation model for family quality of life, service adequacy, and partnership.” This model is presented in the path diagram (Fig. 1) and consists of three measurement models, namely, Support Adequacy, Partnership, and FQoL, and a structural model featuring the direct effect that Support Adequacy has on FQoL and the moderating effect that the Partnership has on Support Adequacy.

For each measurement model involved in the “Mediation model for family quality of life, service adequacy, and partnership,” we obtained the polychoric correlation matrices on the basis of the ordinal character of the variables (items) analyzed. The model’s parameter estimation was conducted by following the maximum likelihood technique to correct for the category variables.

To analyze the data, we used the SPSS and AMOS software in their 17.0 versions.

3. Results

The results were divided into two sections according to the goals that are the impetus for the research.

Table 2
Support needs and degree of adjustment.

	Support need (N = 202)		Degree of support adjustment (to what degree is the support provided)		
	Yes	%	Not at all	Some, but not sufficiently	Sufficient
Child-oriented supports					
Speech and/or language services	154	78.6	35	57	49
Psychological services	128	67	6	44	74
Specialized health services	127	64.5	6	32	85
Specialized educational services	120	62.2	20	47	47
Attention on psychomotricity	97	51.1	14	41	37
Attention on physical therapy and/or motor rehabilitation	82	41.8	3	41	34
Service coordination	79	43.2	19	17	37
Leisure services	70	36.5	23	12	31
Frequent health attention	61	31.1	2	20	38
Accompaniment	43	22.4	18	3	18
Alternative and augmentative communication services	29	20.4	9	12	6
Attention at home	26	13.4	9	5	10
Advice and technical assistance related to visual disability	26	13.5	5	6	14
Mental health services	23	11.9	6	5	10
Technical assistance for communication	22	11.7	8	6	6
Technical assistance for mobility	15	7.8	3	3	8
Advice and technical assistances related to hearing impairment	9	4.6	2	5	2
Adapted transport	4	2.1	3	0	1
Family-oriented supports					
Information on the services and supports available for children with developmental disorders	137	73.3	44	55	33
Information on the services and supports available for the families	127	67.6	57	44	22
Training	121	62.4	37	38	35
Information on the legal rights of children with developmental disorders and their families	114	61	53	35	22
Advice on the transition from ECI centers/child education/school	112	59.6	19	27	62
Economic benefits to pay the extraordinary expenses required by children with developmental disorders	97	51.3	44	44	9
Information on specific disabilities	90	47.4	33	33	21
Family meetings	71	36.4	43	9	18
Individual psychological–emotional assistance	67	35.4	40	13	15
Parents' associations	63	33.2	38	8	15
Respite care	63	32.5	46	4	11
Support groups for parents	62	32	49	7	5
Family psychological–emotional assistance	56	29.9	35	11	10
Support to run the household	34	18.2	28	3	2
Support groups for brothers and sisters	19	10.1	17	0	1

3.1. Descriptive results

3.1.1. Support needs and adequacy ratings

Table 2 presents the number and percentage of respondents who indicated a need for support in the service inventory scale and, out of those who did, the frequency at which they believed they were receiving the support: not at all, not sufficiently, or sufficiently. This instrument comprises *child-oriented supports* and *family-oriented supports*.

The supports most requested by the families for their children with IDD was speech and/or language services (78.8%), and for the family as a unit, it was information on the services and supports for children with developmental disorders (73.3%).

The mean of supports the families claimed they needed for their children with IDD was 5.80 and 6.23 for the family in general. Therefore, the data obtained indicates that the families need more supports for themselves than for their children with IDD.

Regarding the degree of adequacy of *child-oriented supports*, two of the supports most widely needed by the families with adequate levels of service provision were “Psychological services” and “Specialized health services.” “Technical assistance for communication” was the support with the most insufficient provision for the families that required it.

Regarding the degree of adequacy of *family-oriented supports*, the support “Advice on the transition from ECI centers/child education/school” was one of the most provided to the families and also one of the most required. By contrast, the supports with the highest scores for “insufficient support” was “Support groups for brothers and sisters” and “Support to run the household.”

3.1.2. Family–professional partnerships

The total mean obtained by the participating families regarding their partnership with their professionals was 4.46 out of 5 in importance and 4.38 in satisfaction (Table 3). This result indicates that families value their partnership with the professionals.

Table 3
Family–professional partnership descriptive results.

	Importance				Satisfaction			
	<i>M</i>	<i>SD</i>	IC 95%		<i>M</i>	<i>SD</i>	IC 95%	
			Upper Limit	Lower Limit			Lower Limit	Upper Limit
Total Partnership	4.46	0.61	4.38	4.55	4.38	0.66	4.28	4.48
Child Partnership	4.53	0.64	4.44	4.62	4.32	0.73	4.21	4.43
Family Partnership	4.39	0.73	4.28	4.49	4.44	0.64	4.35	4.54

3.1.3. Family quality of life

The global mean FQOL of the families participating in the study was 4.38 out of 5 on the importance indicator, and 3.66 on satisfaction (Table 4). The families of this context have a rather high perception of their FQOL.

3.2. Relationship between service adequacy, partnership, and FQOL

In this section we present the results of the tested model “Mediation model for family quality of life, service adequacy, and partnership.”

The results obtained by all the model’s parameters were significant at the level ($p < .05$) (Fig. 1).

Regarding the three *measurement models*, the coefficients were highly acceptable for the Partnership ($\lambda'_{11} = .85$ in the child indicators and $\lambda'_{21} = .88$ in the family indicators) and FQOL model ($\lambda'_{32} = .80$, $\lambda'_{42} = .81$, $\lambda'_{52} = .69$, $\lambda'_{62} = .71$ and $\lambda'_{72} = .77$). For the Support Adequacy model, the values obtained were slightly lower ($\lambda_{21} = .56$ and $\lambda_{11} = .30$), even though still within the acceptable limits. Given that almost all the values surpassed the 0.5 threshold, statistical significance was observed, and because the values had achieved highly acceptable results in the factor analysis (Balcells-Balcells et al., 2011), they were deemed appropriate to represent the constructs they were intended for within the “Mediation model for family quality of life, service adequacy, and partnership.”

Regarding the *structural model’s* parameter estimation, all the results obtained were also coherent with the expectations because all the results yielded statistically significant values ($p < .05$).

The coefficient obtained between Support Adequacy and FQOL was $\gamma_{21} = .13$, which confirms that Support Adequacy affected the FQOL that the families experience. As for the impact of Support Adequacy on the Partnership, the value obtained was relatively higher than in the previous case ($\gamma_{11} = .22$) and sustains the hypothesis that the Partnership variable is affected by Support Adequacy. Last, we obtained a high effect of the Partnership variable on FQOL ($\beta_{21} = .59$), and this result confirms that this variable has a significant impact on the perception the families have of their FQOL.

Table 5 shows the adequacy indices as computed by the “Mediation model for family quality of life, service adequacy, and partnership.” In the chi-square statistic, the value obtained ($\chi^2 = 9.672$, $p = .983$) yielded an almost perfect adequacy. The GFI index obtained a value of .990, which surpassed .90, as recommended by the authors as Fernández (2008) and Lévy, Martín, and Román, (2006). At the same time, the value of the RMSE index (.001) was very close to 0 and not greater than .10, and this result indicates that the differences between the sample correlation matrix and the estimated matrix were unimportant.

The values obtained for the incremental adequacy indexes CFI, AGFI, BBNFI, and BBNFI yielded results greater than .90. The value for R^2 obtained by our model was .840, and this result indicates that exogenous variables explain many of the model’s endogenous variables.

The values obtained in all the parameters estimated were statistically significant, the chi-square yielded an excellent degree of significance, and the remaining adequacy indexes were also notables. We considered the model to be adequately fit for the sample data and, therefore, to properly explain the impacts that Support Adequacy and Family–Professional Partnership have on the perception of FQOL that families of children with IDD have.

Table 4
FQOL descriptive results.

	Importance				Satisfaction			
	<i>M</i>	<i>SD</i>	IC 95%		<i>M</i>	<i>SD</i>	IC 95%	
			Upper Limit	Lower Limit			Upper Limit	Lower Limit
Total FQOL	4.38	0.62	4.28	4.47	3.66	0.72	3.54	3.77
Parental role	4.38	0.70	4.28	4.48	3.80	0.78	3.68	3.91
Family interaction	4.53	0.63	4.44	4.62	3.89	0.93	3.75	4.02
Emotional well-being	4.07	0.89	3.94	4.20	2.92	1.03	2.77	3.06
Phys./mat. well-being	4.24	0.78	4.12	4.35	3.57	0.85	3.45	3.70
Supports for the person with IDD	4.49	0.75	4.38	4.60	3.85	0.88	3.72	3.99

Table 5

Adequacy indexes for the “Mediation model for family quality of life, service adequacy, and partnership” model.

Model	$\chi^2_{(df=21)}$	<i>p</i>	<i>CFI</i>	<i>GFI</i>	<i>AGFI</i>	<i>BBNFI</i>	<i>BBNNFI</i>	<i>RMSE</i>	IC 95%	<i>R</i> ²
Supports, Partnership and FQOL	9.672	.983	.945	.990	.990	.980	.980	.001	.0005-.0015	.840

Note. χ^2 = Chi-square model; *df* = degrees of freedom; *CFI* = Comparative Fit Index; *GFI* = Lisrel Goodness Fit Index; *AGFI* = Adjusted Goodness Fit Index; *BBNFI* = Bentler-Bonett Normed Fit Index; *BBNNFI* = Bentler-Bonett Non Normed Fit Index; *RMSE* = Root Mean-Square Error; *R*² = Coefficient of determination.

4. Discussion

This section is divided according to the two main goals of the research: to describe the variables and explain the relationship between them.

The descriptive results obtained through the service inventory showed that information is one of the top supports needs for families with children with IDD. Therefore, these results are consistent with the literature (Bailey & Simeonsson, 1988; Burton-Smith et al., 2009; FEAPS, 2007; Giné et al., 2011; Mas, Giné, & McWilliam, 2016) and continue to reveal that, despite living in the era of new information technologies and communication, the access to information remains the clearest need of these families.

Regarding the similarities and differences between our results and those obtained by Summers et al. (2007) and Epley et al. (2011), we confirm that speech and/or language services was the support most requested by the families for their children in the three studies. For many families attending ECI centers, their child's most evident problem was the inability to speak or not speaking in the expected manner; thus, the families indicated the need to be able to identify the early warning signs of possible developmental delays and make claims for the support provided in this field. This argument would again justify the need to inform the families about their child's actual situation and the supports available.

The demand for psychological services was substantial for Spanish families and low for families in the United States (Epley et al., 2011; Summers et al., 2007). A possible explanation may be related to the differences in the sample features of the three studies. Unlike the studies conducted in the United States, the children with IDD participating in this study presented a higher degree of severity, which might justify the greater support needs for children and emotional support for parents.

Specialized health services to fit the needs of children with IDD was also one of the resources most requested by the families from the three studies; this aspect reveals the insufficient training of the health staff to get along with the families and children with IDD.

The results of our research indicate that the participating families are happy with their relationship with the ECI professional who takes care of their child with IDD. These results are consistent with those of Summers et al. (2005) and Summers et al. (2007) but contrast with the direct experience of working with the families and other qualitative studies conducted in Spain (Giné et al., 2011). A possible reason for this discrepancy could be that parents may have smoothed out their answers because the families who usually volunteer to participate in these processes are those more open to collaborating with the professionals. We should keep in mind that the professionals contacted the families in these studies. It might also happen that, despite the assurance of confidentiality, these families felt uncomfortable providing a “negative” assessment of the professionals for fear of being identified (Bailey & Bruder, 2005).

Regarding the FQOL, the results obtained in our research indicate that the participating families are reasonably satisfied with their FQOL, although some differences are observed between the dimensions of the construct.

The results of applying the Beach Center FQOL scale in different contexts yields fairly high FQOL results that confirm the high FQOL perception that these families usually have regardless of the country where they live (Davis & Gavidia-Payne, 2009; Epley et al., 2011; Meral et al., 2013; Summers et al., 2007). In Spain, Mas, Baqués et al. (2016) revealed that the FQOL of families with children with IDD who attended ECI centers is reasonably high. Although the instrument used to measure the FQOL construct was different [the FQOL-E < 18 scale (Giné et al., 2013)], the scores obtained were very close to the results of our study.

The high FQOL perception of the families in all these studies contrasts, partly, with the results of other studies that have focused on stress outcomes, depression, or emotional well-being (Hill & Rose, 2009). We should keep in mind, as Summers et al. (2007) asserted, that the initial proposal to measure FQOL instead of other outcomes was intended to avoid focusing on the negative impact that disability has on the families and provide a new perspective, more focused on a positive perception of the child and the family. Notwithstanding, our results agree with Summers et al. (2007), that is, one of the FQOL dimensions most affected is emotional well-being and implies that the presence of a child with IDD in a family could affect psychological health.

Regarding to the relationship between variables, we confirm that the “Mediation model for family quality of life, service adequacy, and partnership” fits the population of our study and allows us to prove, just as in Summers et al. (2007), that the degree of support adequacy is a predictor of the FQOL the families experience. We affirm that the Partnership has a mediating effect between Support Adequacy and FQOL. Therefore, the degree of Support Adequacy and the family–professional Partnership become critical elements in the assessment of the efficacy of the ECI services.

Our results confirm the Partnership as a mediator between the degree of Support Adequacy and FQOL. The results are consistent with the literature: the family–professional Partnership is one of the most important outcomes for the families of people with IDD in ECI (Davis & Gavidia-Payne, 2009; Summers et al., 2005; Summers, Behr, & Turnbull, 1989; Turnbull et al., 2006).

In summary, the results obtained in this study reveal that part of the theoretical proposal by Zuna et al. (2010) and Zuna, Seling et al. (2009) has been confirmed in Spain; more specifically, services, supports, and practices for the individuals and families act as predicting variables of FQOL.

5. Limitations of the study

One of the limitations of our study, which is usual in this type of research, is the sample selection (Hoffman et al., 2006; Summers et al., 2005). Although the purpose of the research was to obtain the participation of a sample as representative as possible, the answers obtained are subject to the families' willingness to participate.

Another limitation is the dimension of Supports for people with IDD on the Beach Center FQOL scale. Conceptually, this scale was designed to assess the FQOL outcome and should, therefore, disregard indicators related to the services intended to improve the living conditions of the families and the children. In future studies, this scale should be applied by disregarding the dimension Supports for people with IDD, as in Epley et al. (2011). Zuna, Seling et al. (2009) revealed, after validating the scale for populations without disability, that the scale worked well without this dimension.

6. Conclusions and practice implications

The results obtained in this study regarding the situation of the families in each of the variables of interest lead to several conclusions. First, the professionals involved in the services and policy makers should focus on offering information about the services and supports available for children with a developmental disorder and for all the members of the family unit, and a guarantee must be made regarding the speech and/or language services for those children.

Second, the families' perception of their Partnership with the professionals who assist their children is relatively good. According to Bailey, Scarborough, and Hebbeler, (2003), the parents are usually more satisfied with the professional working directly with their child and their family than with other organizational aspects of the ECI center, for example, the amount of supports received or, as indicated by Johnson, Duffett, Farkas, and Wilson, (2002), the possibility to access other programs of the service. Finally, the case may be that families of young children may be more satisfied with the professionals working with their child because they are not yet familiar with what they should expect. This idea is supported by research that suggested that parent satisfaction with professionals declines as their children get older (Summers et al., 2005).

Third, the families who participated in the research were observed to be reasonably satisfied with their FQOL. Notably, these results, although consistent with the literature, do not match the stereotype prevailing in society and among the professionals. In this sense, a worthwhile investigation may be to confirm whether the beliefs and values of younger families have changed and whether, in opposition with the common belief, these families' FQOL is not much lower than that of families without children with IDD (Zuna, Turnbull et al., 2009).

Adjusting the "Mediation model for family quality of life, service adequacy, and partnership" to the population of our study means confirming that Support Adequacy has a direct impact on FQOL and an indirect impact on FQOL through the family–professional Partnership; and last, that the family–professional Partnership significantly affects the FQOL experienced by the families in our context.

Consequently, the need for the professionals at ECI centers and organizations to provide adequate supports is apparent, that is, the needs of the children with a disability and also those of their families, as they will, in turn, be improving their FQOL.

In this sense, we claim that the work at ECI centers and ever earlier attention to the families has positive effects on FQOL.

That the family–professional Partnership has become a mediating element between Support Adequacy and FQOL reinforces what professionals and authors have been saying about the family–professional Partnership being one of the most important supports the services can provide to people with a disability and their families. The results of our research indicate that the supports provided to the children and their families affect their FQOL. Additionally, this FQOL is particularly influenced by the manner in which the professionals provide these supports in terms of partnership.

We conclude that the manner in which the professionals provide the supports (e.g., finesse, respect, familiarity) affects FQOL. In this sense, we posit that the service professionals must understand the relevance their attitude and behavior has for the children and their families in improving their FQOL.

This conclusion strengthens the idea that, on the one hand, local governments should adopt policies so professionals have guidelines and spaces to create a partnership with the families; and on the other, that the institutions involved in higher education provide training opportunities for the professionals to acquire values and knowledge to work efficiently with the families.

Last, we conclude that the FQOL measurement is an indicator of the families' situation and a barometer of the degree to which ECI centers and other early childhood services provide adequate supports for the children and their families.

Acknowledgements

This research has been funded by the Ministry of Education and Science of Spain (BES-2007-14898/project SEJ2006-04773) and Secretary of Universities and Research of the Department of Enterprise and Knowledge of the Generalitat de Catalunya. The research would not have been possible without the contribution of the 13 ECI centers and the families who agreed to be a part of this study and to whom we are deeply grateful for their availability.

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