Chapter 4

The relation between family quality of life and the family-centered approach in families with children with an intellectual disability

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Abstract

Although family quality of life and the family-centered approach are often conceptually linked, empirical research on their relation is scarce. This study investigated the relation between the family-centered approach and family quality of life in families with a child (0-18 years) with an intellectual disability receiving home-based support in Flanders. The impact of the parental work situation and the child's support needs on family quality of life (domains) were studied too. Through the Helpgiving Practices Scale and the Enabling Practices Scale, parents of participating families ($N = 58$) reported about the family-centered approach in their families' home-based support. Using the Beach Center FQOL Scale, mainly mothers reported about their families' quality of life. The relation between the realization of the family-centered approach, parental employment, and the child's support needs on the one hand, and family quality of life on the other hand was studied via multiple regression analyses. Additionally, the best predicting model was determined for family quality of life (domains). Overall, a positive relation between family quality of life and the family-centered approach was found. Dependent on the family quality of life domain, a different relation was identified with the family-centered components. Components of the Enabling Practices Scale (i.e., comfort and parental autonomy) were better predictors than these of the Helpgiving Practices Scale. The parental work situation was a significant predictor for satisfaction regarding total family quality of life (with and without disability-related support), family interactions, and parenting. The child's support needs were a significant predictor for emotional wellbeing. As the first of its kind, this study investigated the relation between family quality of life

and the family-centered approach in detail. More, in depth, and especially long-term research is however needed to fully understand the relation between family quality of life and its contributors.

Keywords: family, family quality of life, family-centered, intellectual disabilities, survey

1 Background

By conceptualizing and defining family quality of life (FQOL), the construct of individual quality of life (IQOL) has been extended to the family system of persons with intellectual and developmental disabilities (Schalock, 2004). FQOL concerns the fulfilment of family needs, the enjoyment of family life, and whether or not the family members have the chance to do things that are important to them (Park et al., 2003). By analogy with IQOL (cf. Verdugo, Schalock, Keith, & Stancliffe, 2005b), there is consensus that FQOL is a complex multidimensional construct comprising several core domains (e.g., family interactions, physical/material wellbeing, parenting, professional support), is influenced by factors at the level of the individuals and the environment, includes both objective and subjective components, and therefore needs a methodological pluralism in assessment (Isaacs et al., 2007; Samuel, Rillotta, & Brown, 2012).

Research on FQOL has largely focused on FQOL indicators and on the development of FQOL instruments. The two main instruments are the Beach Center FQOL Scale, developed by the Beach Center on Disabilities (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) and the FQOLS-2006, developed by the International FQOL Project (Brown et al., 2006a; Isaacs et al., 2007, 2012). Recently, attention has also been paid to the construction of an FQOL theoretical framework (Zuna, Summers, Turnbull, Hu, & Xu, 2010; Zuna, Turnbull, & Summers, 2009). According to this unified structure, FQOL can be considered as the dynamic outcome of a constant interplay between factors at four levels: (1) the level of each individual family member; (2) the level of the family as a whole, including family characteristics and dynamics; (3) the level of support, services,

and practices (for both individuals and the family); and (4) the level of systems, policies, and programs (Zuna et al., 2010).

The increasing attention for FQOL goes hand in hand with a shift in vision regarding the way professional support for families with children with disabilities should be organized, namely in a family-centered (FC) way (Brown, Galambos, Poston, & Turnbull, 2007). The family-centered approach (FCA) concerns an enabling and empowering way of supporting families. Families are seen as capable actors and informed decision makers, and professionals as providers of information and promoters of existing and new skills and strengths (Dunst, Boyd, Trivette, & Hamby, 2002). More detailed, the FCA refers to a cluster of working principles including: (a) a focus on the family as the support unit; (b) a strong family-professional collaboration; (c) offering support adapted to the family's specific needs and situation; (d) attaching strong importance to the family's informed choice; (e) acknowledging and building on the family's strengths; and (f) working on and with the family's support network (Allen & Petr, 1996; Brown et al., 2007; Dunst, 1995; Dunst, Trivette, & Deal, 1994). The core characteristics of the FCA can be divided into two categories: relational practices and participatory practices (Dunst et al., 2002). Whereas relational practices refer to relationship establishment (e.g., active listening) and attitudes and beliefs about families (e.g., beliefs in parents' capacities), participatory practices include responsiveness to the family needs and offering families opportunities to be actively involved (e.g., mobilization of strengths). Particularly participatory practices are mentioned as distinguishing between 'low' and 'high' FC programs (Dunst, 2002; Dunst et al., 2002).

Research on factors contributing to FQOL in families with children with disabilities is often focused on individual family member

factors (e.g., education and employment of the responding parent; e.g., Giné et al., 2015; Mas et al., 2016) and in particular on factors at the level of the child with the disability (e.g., age, behavior problems, support needs, severity of the disability; e.g., Balcells-Balcells, Giné, Guàrdia-Olmos, & Summers, 2016; Davis & Gavidia-Payne, 2009; Giné et al., 2015; Mas et al., 2016; Wang et al., 2004; Vanderkerken, Heyvaert, Onghena, & Maes, 2018a). Some studies focused on the relation between FQOL and family characteristics as for example the parental work situation (Vanderkerken et al., 2018a), the family's income and living situation (e.g., Davis & Gavidia-Payne, 2009; Ferrer, Vilaseca, & Bersabé, 2016; Hu, Wang, & Fei, 2012; Wang et al., 2004), and religious preference and participation (Poston & Turnbull, 2004). Concerning the third level of the FQOL unified framework (cf. Zuna et al., 2010), a number of studies involved the relation between support, service, and practice factors on the one hand and (components of) FQOL on the other hand (e.g., Brown, Geider, Primrose, & Jokinen, 2011; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014; Dunst, Trivette, Hamby, & Bruder, 2006c; Ferrer et al., 2016; Friend, Summers, & Turnbull, 2009; Kyzar, Turnbull, Summers, & Aya Gomez, 2012; Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011). More specifically regarding the FCA however, empirical research on its relation with FQOL is scarce. FC professional support turned out to be an important predictor of FQOL in families with young children with disabilities (Davis & Gavidia-Payne, 2009). The family-professional partnership was demonstrated to be positively related to FQOL (Balcells-Balcells et al., 2016) and to partly mediate the association between service adequacy and FQOL (Summers et al., 2007). The FCA, and especially participatory practices, was also demonstrated to impact child, parent, and family functioning, to a greater or lesser extent through

parents' self-efficacy beliefs (Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 2006b, 2007; Trivette, Dunst, & Hamby, 2010). Because more and detailed insight in the relation between FQOL and factors at this third level can create opportunities for developing or adjusting support strategies in order to improve FQOL in families with children with disabilities, further research on the link between FQOL and support, services, and practices is needed.

The present study investigated the relation between the FCA and FQOL in families with a child (0-18 years) with an intellectual disability (ID) receiving home-based support (HBS) in Flanders. On the basis of the conceptual link between the FCA and FQOL (cf. Brown et al., 2007; Poston et al., 2003; Summers et al., 2005b; Wang & Brown, 2009), the preliminary empirical evidence for this link, and the analogy with the multiple demonstrated relation between the person-centered approach (PCA) and (components of) IQOL (e.g., Claes, Van Hove, Vandeveld, van Loon, & Schalock, 2010; Wigham et al., 2008), a stronger realization of the FCA, and especially of participatory practices (cf. Dunst, 2002; Dunst et al., 2002), was expected to be associated with higher FQOL. However, in line with results of the PCA for IQOL (cf. Robertson et al., 2005), variety in the relation with the FCA could be expected across the different FQOL domains. Next to the impact of the FCA on FQOL, also the impact of two variables at the first and second level of the unified framework (cf. Zuna et al., 2010), namely the support needs of the child with an ID and the parental employment situation were taken into account. In an earlier study, we found that a more intensive parental employment situation was associated with higher satisfaction on FQOL and on the domains parenting and emotional wellbeing in families with children with an ID receiving HBS. In addition, higher support needs of the child with an ID

were associated with lower physical/material wellbeing in these families (Vanderkerken et al., 2018a). By combining these variables with the FCA, we aimed to study the relative contribution of these three predictors on FQOL.

2 Method

2.1 Selection of participants

We aimed to include parents of families having a child (0-18 years) with an ID (intellectual disability; $IQ < 70$ and possibly additional disabilities) and receiving HBS (home-based support) monthly or more intensively for at least six months.

The present study is part of a broader survey on FQOL (family quality of life) and the FCA (family-centered approach) in HBS for families with children with an ID in Flanders. In Flanders there are about 32,500 children (0-18 year) with an ID, circa 3600 of them receive HBS¹. HBS for families with a child with an ID in Flanders is provided by specialized regional ambulatory services or by multifunctional services. HBS concerns a combination of parenting support, psychological support, early intervention, administrative support, and information and is provided by specialized regional ambulatory or multifunctional services (cf. VAPH, 2018). Family workers offering HBS typically have a psycho-pedagogical or paramedical background (e.g., special education, orthopedagogy, (applied) psychology, social work, occupational therapy, speech and language therapy; Vanderkerken, Heyvaert, Onghena, & Maes,

¹ Estimation based on data about education for children with an ID in Flanders (Petry 2015), the group of children who are not under public education law because of their disability (Maes 2015a), the group of children with an ID beneath school age (Kind en Gezin 2015; Maes 2015b), and the different types of support for children with disabilities in Flanders (Maes Noens, & Heynderickx, 2015).

2019). The five specialized regional ambulatory services for HBS in families with children with an ID as well as 43 multifunctional services and specialized ambulatory services for other target groups that often have a comorbidity with an ID (e.g., children with autism) were asked to join the broader survey study and to invite participants through a detailed selection procedure (cf. Vanderkerken et al., 2018a, 2019). In brief, participating services were instructed to randomly select 50% of their family workers having more than one year experience in providing HBS, to randomly select maximum three families per selected professional (to limit family workers' time-investment in the broader project), and invite these families and family workers to take part.

2.2 Procedure

Either a post package containing an instruction form, questionnaires, and a reply envelope or an e-mail including the instructions and links to online questionnaires (www.qualtrics.com; Qualtrics LLC, 2015) was sent to families who agreed to participate and gave informed consent. They were asked to use maximum one month to complete the questionnaires and could request for help (by phone, e-mail, or by filling out the questionnaires together with the first researcher during a home visit) in case of questions while filling out the forms. Reminders were sent when questionnaires were not returned within one month and one month before closing the survey.

2.3 Questionnaires

2.3.1 Questionnaire on the family and the child with an ID

Parents (one questionnaire per family) were asked about their family (e.g., family composition, family languages, employment of parents) and

the child with an ID (e.g., date of birth, additional disabilities, communication abilities and support needs; cf. Brown et al., 2006a).

2.3.2 Beach Center FQOL Scale

To measure FQOL in the participating families, the Beach Center FQOL Scale (Hoffman et al., 2006) was applied. This quite concise instrument is often used to get more information about people's FQOL (e.g., Rillotta, Kirby, & Shearer, 2010; Wang et al., 2004). The scale is the result of a multi-phase construction process (Hoffman et al., 2006; Park et al., 2003; Poston et al., 2003) and consists of 25 items, representing five FQOL domains: family interactions (FI), parenting (PA), emotional wellbeing (EMOWB), physical/material wellbeing (PMWB), and disability-related support (DRS). By means of a 5-point Likert scale, ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*), respondents are asked about their FQOL. The instrument demonstrated satisfactory psychometric characteristics (overall $\alpha = .88$; subscale α 's = .74-.90, strong construct validity, good convergent validity and test-retest reliability; Hoffman et al., 2006; Summers et al., 2005b). Each parent who subscribed to the study was requested to complete this questionnaire without consulting other family members. Table 1 presents some items of the applied Beach Center FQOL Scale.

2.3.3 Helpgiving Practices Scale and Enabling Practices Scale

Concerning the realization of the FCA, a number of questionnaires have been developed and used as the Family Focused Intervention Scale (Mahoney, O'Sullivan, & Dennebaum, 1990) and the Measures of Processes of Care (King, Rosenbaum, & King, 1996). This last instrument is often applied in the context of health care and rehabilitation and

several adaptations were made (cf. Cunningham & Rosenbaum, 2014). In the present study, both the Helpgiving Practices Scale (HPS) and the Enabling Practices Scale (EPS) were used. The HPS, developed by Dunst, Trivette, & Hamby (1996), was based on a literature review on support workers' competency-enhancing and empowering attitudes, behaviors, and practices. It includes 25 items and its factors represent the two core categories of the FC support style: relational helpgiving practices (RHP) and participatory helpgiving practices (PHP). The EPS was based on 12 enabling and empowering practices identified by Dunst, Trivette, and Deal (1988) and includes 24 items. Three factors were identified for this instrument: comfort (Com, referring to parents' comfort in the relationship with the professional), collaboration (Col, referring to the collaboration between parents and professionals as well as between parents and their informal support network) and parental autonomy (PaAut, referring to the level of autonomy parents experience in the relation with the professional; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009). Both instruments include a 5-point Likert scale; the HPS varies from 1 (*rarely*) to 5 (*almost always*), the EPS varies from 1 (*not true at all*) to 5 (*very true*). Psychometric properties of the HPS were demonstrated to be very good (overall $\alpha = .96$, both factor's $\alpha = .94$, strong construct validity), however two items loaded meaningful (cf. Field, 2009) and approximately the same on both factors (Dunst et al., 1996, 2002). Research on the internal consistency of the EPS revealed satisfactory results (α 's = 0.93, 0.85, 0.70 respectively; Dempsey, 1995), however the original factor structure could not be repeated in another study (Carter, Kemp, & Sweller, 2017). Parents who participated in the study (one agreed opinion per family) were asked to complete both the HPS and EPS and to indicate to what extent they experience the described

FC behaviors or situations present in their family-professional collaboration. The EPS' division of participatory practices into collaboration and parental autonomy (cf. Dunst & Espe-Sherwindt, 2006) and the combination with the HPS offers the opportunity to study the whole cluster as well as the more specific components of participatory practices. Some items of the HPS and the EPS are presented in Table 1 as an example.

With the approval of their developers, the Beach Center FQOL Scale, the HPS, and the EPS were translated into Dutch and back-translated into English to control for meaning conservation.

2.4 Participants

The current study includes the opinions of parents of 58 families on their FQOL and the FCA. Forty-three families completed the questionnaires on paper (6 of them during a home visit) and 15 families worked online. The 58 families were supported by 37 family workers, affiliated to nine services for HBS. Most families ($n = 51$) were supported by the five specialized regional ambulatory services for HBS (i.e., 16, 9, 6, 6, 14 families). Seven of the 58 families were supported by four multifunctional services and specialized ambulatory services for other target groups. More detailed information about the participating families can be found in Table 2.

In 34 of the 58 families, 2 parents (i.e., both mother and father) filled out the Beach Center FQOL Scale. In 24 families, only 1 parent (22 mothers and 2 fathers) completed this instrument. Consequently, it was not possible to include two FQOL opinions for every participating family.

Table 1

Overview of the Applied Instruments, their Subscales, and Example Items

Topic	Instrument
FQOL	Beach Center FQOL Scale ^a
	Family interactions (FI) e.g., My family members talk openly with each other.
	Parenting (PA) e.g., In my family, parents help the children learn to be independent.
	Emotional wellbeing (EMOWB) e.g., My family members have friends or others who provide support.
	Physical/Material wellbeing (PMWB) e.g., My family has a way to take care of our expenses.
	Disability-related support (DRS) e.g., The family member/family members with special needs has/have support to make progress at home.
FCA	Helpgiving Practices Scale ^b
	Relational helpgiving practices (RHP) e.g., Our family worker believes that we, as parents, know the needs and strengths of our child(ren) and family.
	Participatory helpgiving practices (PHP) e.g., Our family worker provides us with information about the resources and options that are available to us.
	Enabling Practices Scale ^c
	Comfort (Com) e.g., Our family worker accepts our family values and beliefs.
	Collaboration (Col) e.g., Our family worker anticipates our family's concerns and needs.

Table 1 (Continued)

Topic	Instrument
FCA	<p>Enabling Practices Scale^c</p> <p>Parental autonomy (PaAut)</p> <p>e.g., As parents, we make the most important decisions about our son's /daughter's support</p>

Notes. FQOL, family quality of life; FCA, family-centered approach.

^a Hoffman, Marquis, Poston, Summers, and Turnbull (2006).

^b Dunst, Trivette, and Hamby (1996).

^c Dempsey (1995).

Table 2

Characteristics of the Participating Families (N = 58)

Characteristic	<i>n</i>	Range	<i>M</i>	<i>SD</i>
Family type				
Nuclear family	44			
Reconstituted family	10			
Foster home	1			
Grandparent lives with the family	1			
Child with an ID lives with the grandparent(s)	2			
Number of family members				
2	3			
3	15			
4	24			
5	10			
6	3			
7	2			
9	1			
Language(s) spoken in the family ^a				
Dutch	56			
French	3			
English	1			
Arabic	1			
Turkish	1			
Moroccan	1			
Albanese	1			
Farsi	1			
Russian	1			
Number of parents ^b				
1	11			
Single parent: man	1			
Single parent: woman	10			
2	46			
3	1			
Educational situation of parents ^{c,d}				
One or more parents completed higher education	23			
All parents attended compulsory education	35			

Table 2 (Continued)

Characteristic	<i>n</i>	Range	<i>M</i>	<i>SD</i>
Employment situation of parents ^d				
All parents work full-time	10			
Altogether, parents work more than half-time	24			
Altogether, parents work half-time	14			
Altogether, parents work less than half-time	10			
Number of children				
1	13			
2	28			
3	11			
4	3			
5	2			
7	1			
Gender of the child with an ID				
Boy	43			
Girl	15			
Age of the child with an ID ^e		1-19	8.66	5.74
Type of intellectual disability of the child with an ID ^f				
Mild intellectual disability	11			
Moderate intellectual disability	30			
Severe / Profound intellectual disability	8			
Unknown	9			
Additional disabilities or problems of the child with an ID ^g				
Hearing disability	6			
Visual impairment	11			
Motor disability	20			
Speech or language impairment	23			
Emotional or behavioral problems	18			
Autism spectrum disorder	32			
No additional disabilities or problems	5			

Table 2 (Continued)

Characteristic	<i>n</i>	Range	<i>M</i>	<i>SD</i>
Disability-related support needs during activities in daily life of the child with an ID ^h				
No support	2			
Support during only a few activities	13			
Support during some activities	10			
Support during most, but not all activities in daily life	13			
Support during almost all activities in daily life	20			
Communication abilities of the child with an ID ^h				
Meaningful communication about a wide variety of topics	5			
Meaningful communication within a limited range of topics	13			
Meaningful communication of needs, wants and some ideas	13			
Communication of basic needs and wants	15			
Very little meaningful communication	12			

Notes ID, intellectual disability.

M, mean; *SD*, standard deviation; *n*, number of persons or families; *N*, total number of families.

^a It was possible that multiple languages were spoken in a family.

^b When grandparents were mentioned as parents, they are referred to by the word parents.

^c Foreign degrees were also included.

^d For the families in which grandparents were mentioned as a parent, their educational level and employment situation were also taken into account.

^e Calculated from 30/09/2015 using the data of birth of the child. In the period between the inclusion of participants, the distribution of questionnaires, and returning the questionnaires, two children with an ID became 19 years old.

^f Based on information of parents and if needed, checked with family workers or by means of diagnostic reports. Conservative scored; in case two levels were mentioned, the lowest level of functioning was selected.

^g Based on information of parents. For four children, the parents added the information that they had Down Syndrome. One child was mentioned as having Fetal Alcohol Syndrome.

^h Based on information of parents. Conservative scored; in case two levels were mentioned, the lowest level of functioning was selected.

Since the largest part of the participating parents were mothers, to enlarge transparency, and to facilitate replication, only the FQOL data of the mothers ($n = 56$) and 2 fathers were included in this study. Their age varied between 25 and 61 years ($M = 40.78$; $SD = 8.02$). The

advantages, limitations, and more considerations regarding this choice are further elaborated in the discussion section.

2.5 Data analysis

Data were inserted in Microsoft Excel by the first author (data on family characteristics, FQOL data) and a bachelor student (HPS data and EPS data). Within the context of previous studies (cf. Vanderkerken et al., 2018a, 2019), for every questionnaire a second person (i.e., a colleague researcher, the second author, and the first author respectively) independently re-entered at least 20% of the data to control for errors, resulting in agreements of more than 99%. Data analysis was carried out through SPSS (24.0; IBM Corp, 2016) and was executed in several stages. For all analyses, a significance level of .05 was applied.

2.5.1 Total and subscale scores

To start, for each participating family, total scores and subscale scores were determined for the Beach Center FQOL Scale, the HPS, and the EPS. To promote comparability within and between instruments as well as because of some missing data points, all total scores and subscale scores were calculated using average scores, with a maximum score of 5.

For the Beach Center FQOL Scale, a total FQOL score and subscale scores for FI, PA, EMOWB, PMWB, and DRS were calculated for the included parent. In addition, an adapted total FQOL score in which the items of the DRS-subscale were not included, was calculated (cf. Chiu, Seo, Turnbull, & Summer, 2017). We called this adapted score FQOL-. That way, we aimed to meet the concerns about the partly tautological relation between FQOL and the FCA (cf. Turnbull, Summers, Lee, & Kyzar, 2007b). More concretely, as a factor contributing to FQOL, professional support is

organized at the third level of the unified FQOL framework (cf. Zuna et al., 2010). On the other hand, professional support in general is considered as one of the core domains of FQOL itself (cf. Rillotta et al., 2010). By calculating FQOL, it was aimed to take the potential disturbing overlap between the concepts of FQOL and the FCA into account.

For the HPS, a total HP score and factor scores for RHP and PHP were computed for every participating family. One RHP item was excluded from the analyses because its negative formulation in the Dutch translation seemed to have confused some parents. The two HP items that were mentioned to load meaningful and almost the same on both factors (i.e., “trustworthiness” and “supports decisions”, Dunst et al., 1996, 2002), were solely included in the total HP score. For the EPS as well, a total EP score and factor scores for Com, Col, and PaAut (cf. Dempsey, 1995) were determined for every participating family. Likewise, the two EP items loading meaningful and around the same on two factors (i.e., “needs” and “solve”, Dempsey, 1995), were solely included in the total EP score.

2.5.2 Descriptive statistics

Subsequently, means, standard deviations, and the five-number summaries (Hoaglin, Mosteller, & Tukey, 1983) were determined for total scores and subscale scores of the Beach Center FQOL Scale, the HPS, and the EPS.

2.5.3 Intraclass-correlations and design effects

Intraclass-correlations (ICCs) and design effects (cf. Maas & Hox, 2005) were calculated to control for potential dependencies in the FC data resulting from the clustered structure of these data (some families were

supported by the same family worker; cf. Selection of Participants). Design effects of two (and smaller) were considered as small and an indication to treat the data as non-clustered units (cf. Maas & Hox, 2005; Muthén & Satorra, 1995).

2.5.4 The relation between FQOL and potential predictors

Firstly, Pearson correlations were calculated between FQOL (domains) on the one hand, and HP, RHP, PHP, EP, Com, Col, PaAut, support needs of the child with an ID, and the parental employment situation on the other hand. Support needs of the child with an ID were categorized as (1) no support needed or only during a few or some activities in daily life ($n = 25$) versus (2) support needed during most or almost all activities in daily life ($n = 33$). Employment situation of parents as well was operationalized in two categories: (1) altogether, the parents in the family work more than half-time or full-time ($n = 34$) versus (2) in total, the parents work half-time or less ($n = 24$).

Secondly, multiple regression analyses were performed to study the impact of the FCA on FQOL and its subdomains. The FCA was operationalized either by means of RHP and PHP, or by means of the factors Com, Col, and PaAut. Because both the HPS and the EPS were used to measure the realization of the FCA and Pearson correlations between both instruments ($r = .72$) and most of their domains (see Table 5) were mainly moderate to high, separate models were built to study the impact of the FCA on FQOL (domains). Afterwards, the parental work situation and the support needs of the child with an ID were added to each of these regression models. By means of adjusted R^2 (in which the number of predictors is taken into account), the predicting value of the models was investigated.

Thirdly, for each outcome variable, the best predicting model was determined out of the factors of both FC instruments, the parental work situation, and the support needs of the child with an ID. This was done by means of testing all possible regressions (cf. Myers, 1990) through the Automatic Linear Modelling procedure (SPSS 24.0; IBM Corp, 2016) and selecting the models with the best fit (based on the adjusted R^2 and AICC).

3 Results

3.1 Distribution of FQOL and FC Scores

Descriptive statistics for FQOL (family quality of life) and the FCA (family-centered approach) are presented in Tables 3 and 4 respectively. For total FQOL, total FQOL- (i.e., total FQOL without the disability-related support items) and the five domains, means were situated within the higher ranges of the 5-point Likert scales. In general, lowest scores were seen for EMOWB (emotional wellbeing), highest scores were seen for PMWB (physical/material wellbeing) and DRS (disability-related support).

For both the HPS (helpgiving practices scale) and the EPS (enabling practices scale), means were situated above 4. Except for the maxima, five number summary-scores for the EPS were situated a bit lower than for the HPS, indicating a broader range of scores for the EPS than for the HPS. Based on the ICCs and design effects calculated on the FC (family-centered) data (cf. Table 4), it was decided to treat the families as independent units in the further analysis of the data.

Table 3
Distribution of FQOL Scores

	FQOL	FI	PA	EMOWB	PMWB	DRS	FQOL ⁻
<i>M (SD)</i>	3.89 (0.45)	3.86 (0.63)	3.91 (0.51)	3.45 (0.73)	4.08 (0.43)	4.09 (0.51)	3.85 (0.46)
<i>Min</i>	2.60	1.50	2.67	1.50	3.40	3.00	2.52
<i>Q1</i>	3.56	3.63	3.67	3.00	3.80	3.75	3.52
<i>Median</i>	3.92	4.00	3.92	3.50	4.00	4.00	3.90
<i>Q3</i>	4.12	4.17	4.04	4.00	4.40	4.25	4.10
<i>Max</i>	5.00	5.00	5.00	5.00	5.00	5.00	5.00

Notes. FQOL, family quality of life; FI, family interaction; PA, parenting; EMOWB, emotional wellbeing; PMWB, physical/material wellbeing; DRS, disability-related support; FQOL⁻, family quality of life without the DRS-items.

M, mean; *SD*, standard deviation; *Min*, minimum; *Q*, quartile; *Max*, maximum.

Table 4
Distribution of HP and EP Scores, ICCs and Design Effects

	Helpgiving Practices Scale				Enabling Practices Scale		
	HP	RHP	PHP	EP	Com	Col	PaAut
<i>M (SD)</i>	4.68 (0.32)	4.68 (0.34)	4.66 (0.35)	4.46 (0.39)	4.53 (0.41)	4.26 (0.54)	4.51 (0.44)
<i>Min</i>	3.67	3.60	3.50	3.33	3.38	3.00	3.25
<i>Q1</i>	4.42	4.50	4.33	4.25	4.23	3.80	4.25
<i>Median</i>	4.75	4.80	4.75	4.52	4.54	4.40	4.50
<i>Q3</i>	4.96	5.00	5.00	4.79	4.92	4.60	4.81
<i>Max</i>	5.00	5.00	5.00	5.00	5.00	5.00	5.00
<i>ICC</i>	0.13	0.10	0.14	0.18	0.23	0.15	0.04
<i>Design effect</i>	1.07	1.05	1.08	1.10	1.13	1.09	1.02

Notes. HP, helpgiving practices; RPH, relational helpgiving practices; PHP, participatory helpgiving practices; EP, enabling practices; Com, comfort with relationship; Col, collaboration; PaAut, parental autonomy.

M, mean; *SD*, standard deviation; *Min*, minimum; *Q*, quartile; *Max*, maximum; *ICC*, Intraclass-correlation.

Table 5

Pearson Correlations between FQOL (Domains) and Potential Predictors

	FQOL	FI	PA	EMOWB	PMWB	DRS	FQOL-	HP	RHP	PHP	EP	Com	Col	PaAut	Work ^a	Support ^b
FQOL	1.00															
FI	.89**	1.00														
PA	.81**	.68**	1.00													
EMOWB	.71**	.59**	.33*	1.00												
PMWB	.75**	.54**	.62**	.32*	1.00											
DRS	.81**	.58**	.56**	.57**	.68**	1.00										
FQOL-	.99**	.91**	.83**	.71**	.73**	.73**	1.00									
HP	.23	.29*	.04	.22	.16	.21	.23	1.00								
RHP	.20	.27*	.03	.13	.17	.19	.19	.93**	1.00							
PHP	.22	.25	.03	.28*	.12	.19	.22	.93**	.74**	1.00						
EP	.30*	.31*	.16	.26*	.19	.26*	.29*	.72**	.57**	.76**	1.00					
Com	.32*	.36**	.18	.28*	.16	.25	.32*	.73**	.59**	.77**	.95**	1.00				
Col	.16	.16	.04	.23	.03	.20	.15	.56**	.38**	.66**	.88**	.77**	1.00			
PaAut	.20	.16	.19	-.02	.37**	.18	.20	.21	.28*	.10	.37**	.19	.17	1.00		
Work ^a	.28*	.28*	.29*	.21	.16	.11	.30*	-.01	.02	-.03	-.04	.01	-.08	-.02	1.00	
Support ^b	.10	-.05	-.02	.24	.19	.16	.09	-.15	-.14	-.17	-.16	-.12	-.11	-.14	.10	1.00

Notes. FQOL, family quality of life; FI, family interaction; PA, parenting; EMOWB, emotional wellbeing; PMWB, physical/material wellbeing; DRS, disability-related support; FQOL-, family quality of life without the DRS-items; HP, helpgiving practices; RHP, relational helpgiving practices; PHP, participatory helpgiving practices; EP, enabling practices; Com, comfort with relationship; Col, collaboration; PaAut, parental autonomy.

^a Parental work situation.

^b Support needs of the child with an ID.

* $p < .05$, ** $p < .01$.

3.2 FQOL and potential predictors

3.2.1 Pearson correlations

Correlations between FQOL (domains) and potential predictors ranged from small to moderate (see Table 5). For total FQOL and total FQOL-, statistically significant positive correlations were seen with EP (enabling practices), Com (comfort), and parental work situation. For FI (family interactions), in addition to the above mentioned correlations, also these with HP (helpgiving practices) and RHP (relational helpgiving practices) turned out to be statistically significant. Significant positive correlations with PHP (participatory helpgiving practices), EP, and Com were found for EMOWB (emotional wellbeing). For PA (parenting), PMWB (physical/material wellbeing) and DRS (disability-related support), a significant correlation with parental work situation, PaAut (parental autonomy), and EP respectively was seen.

3.2.2 Multiple regressions

Table 6 shows the outcomes of the multiple regression analyses. Models including RHP (relational helpgiving practices) and PHP (participatory helpgiving practices) explained very small parts of the variability in FQOL (domain) scores, ranging from 0 (PA and PMWB; parenting and physical/material wellbeing) to 6% (EMOWB; emotional wellbeing). Only in one of these HP (helpgiving practices) models, a significant predictor was found: PHP was a significant predictor for EMOWB ($t = 2.11, p = .04$). Addition of the parental work situation and support needs of the child with an ID to these HP models explained larger parts of the variability in FQOL (domain) scores, ranging from 2% (PA and DRS; parenting and disability-related support) to 15% (EMOWB). In the extended HP models, parental work situation turned out as a significant predictor for total

FQOL ($t = 2.15, p = .04$), total FQOL ($t = 2.36, p = .02$), FI (family interactions) ($t = 2.24, p = .03$), and PA ($t = 2.26, p = .03$). For EMOWB, PHP ($t = 2.55, p = .01$) as well as support needs of the child with an ID ($t = 2.19, p = .03$) had a significant impact.

Models including Com (comfort), Col (collaboration), and PaAut (parental autonomy) explained larger parts of the variability in FQOL (domain) scores than the basic HP (helpgiving practices) models, except for EMOWB (emotional wellbeing), namely from 3% (PA, EMOWB, and DRS; parenting, emotional wellbeing, and disability-related support) to 13% (FI; family interactions). Com was found to be a significant predictor for total FQOL ($t = 2.28, p = .03$), total FQOL ($t = 2.43, p = .02$), and FI ($t = 2.96, p < .01$). In addition, PaAut was a significant predictor for PMWB (physical/material wellbeing) ($t = 2.82, p = .01$). Adding the parental work situation and the support needs of the child with an ID to these EP models enlarged the explained variability in FQOL (domain) from 5% (DRS) to 18% (PMWB). In the extended EP models, both Com ($t = 2.17, p = .03$; $t = 2.30, p = .03$; $t = 2.75, p = .01$) and the parental work situation ($t = 2.06, p = .04$; $t = 2.26, p = .03$; $t = 2.11, p = .04$) turned out to be statistically significant predictors for total FQOL, total FQOL, and FI. For PA and PMWB, the parental work situation ($t = 2.16, p = .04$) and PaAut ($t = 3.14, p < .01$) respectively were significant predictors.

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Table 6
Results of the Multiple Regression Analyses for FQOL (Domains)

	FQOL			FI			PA		
HP Model	<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>	
	1.53	.23		2.30	.11		0.03	.97	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.05	.02		.08	.04		.00	-.04	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	2.41 (0.86)	2.79	.01*	1.28 (1.21)	1.06	.29	3.66 (1.01)	3.61	<.01*
Predictors									
RHP	0.10 (0.26)	0.37	.71	0.33 (0.37)	0.90	.37	0.02 (0.31)	0.05	.96
PHP	0.22 (0.25)	0.87	.39	0.22 (0.35)	0.63	.53	0.04 (0.30)	0.13	.90
HP Model+	<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (4, 53)	<i>p</i>	
	2.31	.07		2.47	.06		1.29	.28	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.15	.08		.16	.09		.09	.02	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	2.08 (0.86)	2.43	.02*	1.12 (1.21)	0.93	.36	3.54 (1.01)	3.50	<.01**
Predictors									
RHP	0.07 (0.25)	0.26	.80	0.27 (0.36)	0.76	.45	-0.03 (0.30)	-0.11	.91
PHP	0.28 (0.24)	1.15	.26	0.27 (0.34)	0.79	.43	0.08 (0.29)	0.27	.79
Work ^a	0.25 (0.12)	2.15	.04*	0.36 (0.16)	2.24	.03*	0.31 (0.14)	2.26	.03*
Support ^b	0.11 (0.12)	.95	.35	-0.04 (0.16)	-0.23	.82	-0.04 (0.14)	-0.32	.75
EP Model	<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>	
	2.96	.04*		3.85	.01*		1.60	.20*	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.14	.09		.18	.13		.08	.03	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	1.68 (0.79)	2.14	.04*	0.67 (1.09)	0.61	.54	2.12 (0.93)	2.28	.03*
Predictors									
Com	0.50 (0.22)	2.28	.03*	0.90 (0.30)	2.96	<.01*	0.43 (0.26)	1.66	.10
Col	-0.18 (0.16)	-1.07	.29	-0.36 (0.23)	-1.58	.12	-0.24 (0.16)	-1.23	.22
PaAut	0.15 (0.13)	1.19	.24	0.14 (0.18)	0.81	.42	0.19 (0.15)	1.25	.22
EP Model+	<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>	
	3.10	.02*		3.31	.01*		1.94	.10	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.23	.16		.24	.17		.16	.08	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	1.36 (0.78)	1.75	.09	0.54 (1.10)	0.49	.63	1.98 (0.93)	2.13	.04*
Predictors									
Com	0.46 (0.21)	2.17	.03*	0.82 (0.30)	2.75	.01*	0.36 (0.25)	1.43	.16
Col	-0.13 (0.16)	-0.80	.43	-0.29 (0.22)	-1.31	.20	-0.18 (0.19)	-0.95	.34
PaAut	0.18 (0.13)	1.39	.17	0.15 (0.18)	0.84	.40	0.20 (0.15)	1.31	.20
Work ^a	0.23 (0.11)	2.06	.04*	0.33 (0.16)	2.11	.04*	0.29 (0.13)	2.16	.04*
Support ^b	0.12 (0.11)	1.12	.27	-0.03 (0.16)	-0.17	.86	-0.01 (0.13)	-0.07	.95

Notes. FQOL, family quality of life; FI, family interaction; PA, parenting; EMOWB, emotional wellbeing; PMWB, physical/material wellbeing; DRS, disability-related support; FQOL-, family quality of life without the DRS-items; HP, helping practices; RPH, relational helping practices; PHP, participatory helping practices; EP, enabling practices; Com, comfort with relationship; Col, collaboration; PaAut, parental autonomy. HP model+, HP model extended with work and support needs; EP model+, HP model extended with work and support needs; *R*² *adj*, adjusted *R*².

^a The intercept refers to FQOL (domains) in families in which parents work half time or less. To know the estimated score for families in which parents work more than half of the time, the slope has to be added.

^b The intercept refers to FQOL (domains) in families in which the child with an ID needs support during most or almost all activities in daily life. To know the estimated score for families in which the child with an ID needs no support or only during a few activities in daily life, the slope has to be added.

* *p* < .05, ** *p* < .01.

Table 6 (Continued)

EMOWB			PMWB			DRS			FQOL ^c		
<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>	
2.71	.08		.85	.43		1.24	.30		1.44	.24	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.09	.06		.03	-.01		.04	.01		.05	.02	
<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>
1.27 (1.38)	0.92	.36	3.08 (0.84)	3.67	<.01*	2.54 (0.98)	2.58	.01*	2.39 (0.89)	2.69	.01*
-0.38 (0.42)	-0.90	.37	0.25 (0.25)	0.97	.34	0.17 (0.30)	0.56	.58	0.09 (0.27)	0.32	.75
0.85 (0.40)	2.11	.04*	-0.03 (0.25)	-0.13	.90	0.16 (0.29)	0.57	.57	0.23 (0.26)	0.88	.38
<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (4, 53)	<i>p</i>	
3.60	.01*		1.41	.24		1.34	.27		2.44	.06	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.21	.15		.10	.03		.09	.02		.16	.09	
<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>
0.43 (1.34)	0.32	.75	2.71 (0.85)	3.19	<.01**	2.16 (1.00)	2.15	.04*	2.06 (0.88)	2.35	.02*
-0.40 (0.40)	-1.01	.32	0.24 (0.25)	0.95	.35	0.16 (0.30)	0.55	.59	0.05 (0.26)	0.19	.85
0.98 (0.38)	2.55	.01*	0.02 (0.24)	0.10	.92	0.22 (0.29)	0.77	.45	0.29 (0.25)	1.17	.25
0.30 (0.18)	1.68	.10	0.12 (0.11)	1.06	.29	0.10 (0.13)	0.71	.48	0.28 (0.12)	2.36	.02*
0.40 (0.18)	2.19	.03*	0.18 (0.11)	1.55	.13	0.20 (0.14)	1.46	.15	0.09 (0.12)	.80	.43
<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>	
1.66	.19		3.65	.02*		1.54	.21		3.08	.03*	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.08	.03		.17	.12		.08	.03		.15	.10	
<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>
1.64 (1.32)	1.24	.22	2.00 (0.74)	2.69	.01*	2.14 (0.92)	2.32	.02*	1.59 (0.80)	1.97	.05
0.48 (0.37)	1.31	.19	0.30 (0.21)	1.45	.15	0.27 (0.26)	1.07	.29	0.54 (0.22)	2.43	.02*
0.04 (0.28)	0.16	.88	-0.20 (0.16)	-1.26	.21	0.00 (0.19)	0.01	.99	-0.21 (0.17)	-1.25	.22
-0.12 (0.22)	-0.56	.58	0.35 (0.12)	2.82	.01*	0.15 (0.15)	1.02	.31	0.16 (0.13)	1.17	.25
<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>	
2.46	.04*		3.42	.01*		1.58	.18		3.31	.01*	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.19	.11		.25	.18		.13	.05		.24	.17	
<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>	<i>β</i> (<i>SD</i>)	<i>t</i>	<i>p</i>
0.91 (1.30)	0.70	.49	1.61 (0.74)	2.18	.03*	1.76 (0.94)	1.87	.07	1.28 (0.79)	1.61	.11
0.46 (0.35)	1.29	.20	0.30 (0.20)	1.47	.15	0.27 (0.26)	1.07	.29	0.50 (0.22)	2.30	.03*
0.11 (0.27)	0.40	.69	-0.17 (0.15)	-1.11	.27	0.02 (0.19)	0.13	.90	-0.16 (0.16)	-0.96	.34
-0.07 (0.21)	-0.32	.75	0.38 (0.12)	3.14	<.01**	0.18 (0.15)	1.21	.23	0.18 (0.13)	1.37	.18
0.28 (0.19)	1.50	.14	0.11 (0.11)	1.06	.29	0.09 (0.13)	0.71	.48	0.26 (0.11)	2.26	.03*
0.37 (0.19)	2.00	.05	0.21 (0.11)	1.97	.05	0.21 (0.13)	1.56	.13	0.11 (0.11)	0.97	.33

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Table 7
Best Predicting Models for FQOL (Domains)

	FQOL			FI			PA		
Best AICC model	AICC	-99.25		AICC	-60.84		AICC	-80.00	
	<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>	
	5.98	<.01**		7.13	<.01**		3.85	.03*	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.18	.15		.21	.18		.12	.09	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	2.17 (0.61)	3.54	<.01**	1.14 (0.85)	1.34	.19	2.72 (0.66)	4.09	<.01**
Predictors									
PHP									
Com	0.35 (0.13)	2.59	.01*	0.55 (0.19)	2.97	<.01**			
PaAut							0.22 (0.15)	1.54	.13
Work ^a	0.25 (0.11)	2.26	.03*	0.35 (0.15)	2.29	.03*	0.30 (0.13)	2.35	.02*
Support ^b									
Best adjusted <i>R</i> ² model	AICC	-97.55		AICC	-60.30		AICC	-76.82	
	<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>	
	3.74	.01*		5.37	<.01**		2.31	.06	
	<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
	.22	.16		.23	.19		.18	.10	
	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
Intercept	1.42 (0.77)	1.83	.07	1.05 (0.85)	1.23	.22	2.56 (1.02)	2.52	.01*
Predictors									
RHP							-0.30 (0.24)	-1.24	.22
PHP									
Com	0.33 (0.14)	2.43	.02*	0.85 (0.29)	2.89	.01*	0.54 (0.29)	1.88	.07
Col				-0.29 (0.22)	-1.29	.20	-0.22 (0.19)	-1.15	.26
PaAut	0.17 (0.13)	1.37	.18				0.24 (0.15)	1.59	.12
Work ^a	0.24 (0.11)	2.19	.03*	0.32 (0.15)	2.11	.04*	0.29 (0.13)	2.19	.03*
Support ^b	0.12 (0.11)	1.12	.27						

Notes. FQOL, Family Quality of Life; FI, Family Interaction; PA, Parenting; EMOWB, Emotional Wellbeing; PMWB, Physical/Material Wellbeing; DRS, Disability-Related Support; HP, Helpgiving Practices; RPH, Relational Helpgiving Practices; PHP, Participatory Helpgiving practices; EP, Enabling Practices; Com, Comfort with relationship; Col, Collaboration; PaAut, Parental Autonomy.

^a The intercept refers to FQOL (domains) in families in which parents work half time or less. To know the estimated score for families in which parents work more than half of the time, the slope has to be added.

^b The intercept refers to FQOL (domains) in families in which the child with an ID needs support during most or almost all activities in daily life. To know the estimated score for families in which the child with an ID needs no support or only during a few activities in daily life, the slope has to be added.

* $p < .05$, ** $p < .01$.

Table 7 (Continued)

EMOWB			PMWB			DRS			FQOL		
AICC	-41.97		AICC	-104.84		AICC	-79.23		AICC	-97.24	
<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>		<i>F</i> (2, 55)	<i>p</i>	
4.46	.01*		6.62	<.01**		3.02	.06		6.53	<.01**	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.20	.15		.19	.16		.10	.07		.19	.16	
β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
-0.11 (1.23)	-0.09	.93	2.24 (0.54)	4.11	<.01**	2.47 (0.74)	3.34	<.01**	2.08 (0.62)	3.33	<.01**
0.69 (0.26)	2.67	.01*									
			0.39 (0.12)	3.28	<.01**	0.34 (0.16)	2.10	.04*	0.36 (0.14)	2.60	.01*
0.29 (0.18)	1.61	.11							0.28 (0.11)	2.47	.02*
0.40 (0.18)	2.22	.03*	0.21 (0.11)	2.00	.05	0.20 (0.13)	1.52	.14			
AICC	-40.68		AICC	-101.62		AICC	-78.51		AICC	-96.55	
<i>F</i> (4, 53)	<i>p</i>		<i>F</i> (5, 52)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>		<i>F</i> (3, 54)	<i>p</i>	
3.60	.01*		3.42	.01*		2.53	.07		4.90	<.01**	
<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>		<i>R</i> ²	<i>R</i> ² <i>adj</i>	
.21	.15		.25	.18		.12	.07		.21	.17	
β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>	β (<i>SD</i>)	<i>t</i>	<i>p</i>
0.43 (1.34)	0.32	0.75	1.61 (0.74)	2.18	.03*	1.79 (0.92)	1.95	.06	1.51 (0.77)	1.96	.05
-0.40 (0.40)	-1.01	.32									
0.98 (0.38)	2.55	.01*	0.30 (0.20)	1.47	.15	0.30 (0.16)	1.87	.07	0.32 (0.14)	2.34	.02*
			-0.17 (0.15)	-1.11	.27						
			0.38 (0.12)	3.14	<.01**	0.18 (0.15)	1.23	.23	0.16 (0.13)	1.23	.22
0.30 (0.18)	1.68	.10	0.11 (0.11)	1.06	.29				0.28 (0.11)	2.52	.01*
0.40 (0.18)	2.19	.03*	0.21 (0.11)	1.97	.05	0.22 (0.13)	1.66	.10			

3.2.3 *Best predicting models*

The results of the search for the best predicting models based on AICC and the adjusted R^2 (cf. Table 7) largely confirmed the results of the multiple regressions. For total FQOL, total FQOL_c, and FI (family interactions), both Com (comfort) ($t = 2.59, p = .01$; $t = 2.60, p = .01$; $t = 2.97, p < .01$) and the parental work situation ($t = 2.26, p = .03$; $t = 2.47, p = .02$; $t = 2.29, p = .03$) were significant predictors in the AICC model. The variability in outcome scores could best be explained by additionally taking into account PaAut (parental autonomy) and the support needs of the child with an ID for total FQOL (adjusted $R^2 = .16$), PaAut for total FQOL_c (adjusted $R^2 = .17$), and Col (collaboration) (which had a negative slope) for FI (family interactions) (adjusted $R^2 = .19$). The best AICC subset for PA (parenting) included, in addition to PaAut, the significant predictor parental work situation ($t = 2.35, p = .02$). To maximize explained variability (taking into account the number of predictors), it had to be completed with the other EP (enabling practices) factors (notice the negative slope of Col; collaboration) and RHP (relational helpgiving practices) (which had also a negative slope) (adjusted $R^2 = .10$). For EMOWB (emotional wellbeing), PHP (participatory helpgiving practices) ($t = 2.67, p = .01$) and the support needs of the child with an ID ($t = 2.22, p = .03$) turned out as significant predictors when combined with the parental work situation. RHP (notice its negative slope) was added to maximize explained variability (adjusted $R^2 = .15$). For PMWB (physical/material wellbeing), combined with the support needs of the child with an ID, PaAut ($t = 3.28, p < .01$) stayed a significant predictor. The predicting effect was maximized by adding the other EP factors (in which Col has a negative slope) and the parental work situation (adjusted $R^2 = .18$). Whereas Com ($t = 2.10, p = .04$) turned out as a significant

predictor for DRS (disability-related support) in a model also including support needs of the child with an ID, this variable lost its significance when combined with PaAut and support needs of the child (adjusted $R^2 = .07$).

4 Discussion

The present study concerned the relation between family quality of life and the family-centered approach in families with a child (0-18 years) with an intellectual disability (ID) receiving home-based support (HBS) in Flanders. The impact of the parental work situation and the support needs of the child with an ID were also taken into account.

In line with our hypotheses and previous research on families with children with disabilities (Balcells-Balcells et al., 2016; Davis & Gavidia-Payne, 2009; Summers et al., 2007), overall, a positive relation between family quality of life and components of the family-centered approach was identified. Moreover and also as expected, different relations with the family-centered approach were seen for the different domains of family quality of life. Hereby, in all, the factors of the Enabling Practices Scale (EPS) turned out to be better predictors than the factors of the Helping Practices Scale (HPS). This was the case for the basic models as well as for the contribution of the family-centered approach in the extended models. In the enabling practices (EP) models, Com was a significant predictor for total FQOL, total FQOL- (i.e., total FQOL without the disability-related support items), and FI, indicating higher satisfaction regarding family quality of life and family interactions when parents experienced a higher level of comfort in the family-professional partnership. PaAut turned out as a significant predictor for PMWB; higher satisfaction for physical and material wellbeing was seen in families

where parents experienced higher levels of autonomy in the family-professional partnership. Only for EMOWB, a helpgiving practices (HP) factor, namely PHP, turned out as a significant predictor, indicating a higher satisfaction concerning emotional wellbeing when a higher level of participatory practices was experienced in the family-professional collaboration. For parenting and disability-related support, no predictors related to the family-centered approach were found by means of the HP models and EP models. Nonetheless, the best AICC model included Com as a significant predictor for DRS, indicating higher satisfaction on disability-related support when a more comfortable family-professional collaboration was experienced. With parental comfort referring to relational practices and participatory helpgiving practices and parental autonomy (together with collaboration) referring to participatory practices (cf. Dunst & Espe-Sherwindt, 2016), the hypothesis that especially participatory practices are related to family quality of life (cf. Dunst, 2002; Dunst et al., 2002) was not confirmed in the current study.

In addition to the family-centered approach, which concerns a characteristic at the level of support, services, and practices (cf. Zuna et al., 2010), also the impact of the parental work situation, a characteristic at the family level (cf. Zuna et al., 2010) was investigated. The parental work situation appeared a significant predictor for total FQOL, total FQOL, FI, and PA in both the extended HP and EP models. More specifically, higher satisfaction for family quality of life, family interactions, and parenting was reported in families in which parents worked in total more than half time, compared to families in which parents worked in general half time or less. A significant impact of the parental work situation was found as well in previous analyses during which the present data set was extended with the opinions of fathers and

youngsters on their family quality of life (Vanderkerken et al., 2018a). However, in that study, the parental employment situation affected satisfaction on family quality of life, parenting, and emotional wellbeing. At any rate, and also supported by the studies of Giné et al. (2015) and Ferrer et al. (2016) that identified an effect of the responding parent's employment status on family quality of life, it can be summarized that parental occupation plays an important role in (satisfaction regarding) various facets of family life, and apparently especially in those related to emotions and interactions. This aspect might be explained by the role accumulation theory: A job offers parents the opportunity to fulfil another role (i.e., employee) besides the parent role, which can benefit their wellbeing (Sieber, 1974) and probably the whole family's welfare. Nonetheless, the support and care needs of a child with disabilities often complicate and hinder parents' employment, in particular for mothers (Parish & Cloud, 2006). A job provides also an income (and associated opportunities, cf., Parish & Cloud, 2006), a factor that was demonstrated to be related to quality of life in families with children with disabilities (e.g., Ferrer et al., 2016; Hu et al. 2012; Park, Turnbull, & Turnbull, 2002). In the present study however, no association was found between the parental employment situation and physical and material wellbeing.

In the extended HP model, the support needs of the child with an ID significantly impacted EMOWB, indicating a higher emotional wellbeing in families in which the child with an ID needed no support or only during a few activities in daily life compared to families in which children needed support during most or almost all activities in daily life. This finding was confirmed in the AICC model. In the extended EP model on the contrary, the impact of the support needs of the child with an ID on emotional wellbeing could not be identified. In several previous

studies on families with children with disabilities too, an inverse relation was found between the severity of the disability of the child (Balcells-Balcells et al., 2016; Ferrer et al., 2016; Hu et al. 2012; Mas et al. 2016; Wang, et al. 2004) or his or her support needs (Vanderkerken et al., 2018a) on the one hand and family quality of life on the other hand. In Vanderkerken et al. (2018a), including the opinions of fathers, mothers, and youngsters on family quality of life however, this relation only concerned physical and material wellbeing.

For FQOL, approximately the same results as for total FQOL were seen, with the exception of the best adjusted R^2 model. This finding indicates that adding or removing the disability-related support items did not seriously affect the study results. Nonetheless, it has to be taken into account that the tautological relation was only to some extent realized in the present study: the independent variable (i.e., the realization of the family-centered approach) was solely focused on the family-professional collaboration in the context of HBS, whereas disability-related support concerns a much broader aspect of support and services for the child with an ID.

Based on the study results, it can be concluded that the family-centered approach and especially parents' experienced comfort in the professional relation may play a part in the wellbeing of families having a child with an ID. Hence, family workers should be advised to pay and keep attention to the relation with the families they support and the climate in which the support is offered. Furthermore, according to parents, an activating and empowering support style seems to support families' emotional wellbeing. Keeping in mind that parents' feeling of making autonomous decisions and having impact on their children's lives is related to a higher physical/ material wellbeing, families could benefit

from an investment in parental autonomy in family support. During family support, it is also important to realize that the support needs of the child might hamper a family's emotional wellbeing. In addition, family workers should keep in mind that work, a factor that is potentially not considered as their first support and intervention scope, may positively impact families' lives and even parents' satisfaction about parenting. Hence, family workers should be encouraged to extend their focus from the child to the whole family, which is actually one of the core principles of the family-centered approach (cf. Allen & Petr, 1996; Brown et al., 2007; Dunst, 1995; Dunst et al., 1994).

While interpreting this study's results, four limitations have to be considered. A first constraint concerns the family quality of life data. More concretely, only one parent opinion per family and principally mother data were used to represent family quality of life in the current study and to investigate the relation with the family-centered approach. Several researchers mention the problem of solely including mothers and wonder how the family perspective on family quality of life can be grasped (Hoffman et al. 2006; Hu, Summers, Turnbull, & Zuna, 2011; Isaacs et al. 2007; Park et al. 2003; Poston et al. 2003). In addition, our study on family quality of life in families with a child with an ID (Vanderkerken et al., 2018a) demonstrated that, notwithstanding mothers did not significantly differ from fathers in evaluating their family quality of life, parents (and tout court members) of the same family had different opinions regarding family quality of life, which supports the idea of including every family member's opinion when evaluating the complex reality of quality of life in families. In the original data set on family quality of life and the family-centered approach however, not every parent of the participating families was represented by his or her family

quality of life opinion. Moreover, although we asked for the participation of every parent, in twelve two-parent families, solely the mothers gave their opinion on family quality of life. Combined with 10 single-mother families, mothers were somewhat overrepresented in our primary dataset. Dealing with these data, calculating a principal component (cf. Yong & Pearce, 2013) for the families in which two parents participated had been considered as well as randomizing between participating parents of the same family. Some exploratory attempts to randomize resulted in slightly different outcomes, further motivating the choice to present a transparent, easier to repeat, but also rather narrow subset of data. Another way of dealing with multiple, clustered opinions is by means of multilevel models (cf. Raudenbush & Bryk, 2002; Snijders & Bosker, 2012). Nonetheless, because of the small number of units per level (maximum two) in the current study, the large number of families for which only one opinion was given, and to keep the study focus on the relation between family quality of life and the studied predictors, it was preferred to apply the mother-subset.

A second limitation is related to the instruments used to measure family quality of life (i.e., the Beach Center FQOL Scale) and the family-centered approach (i.e., the HPS and the EPS) along with the way data were collected. All applied instruments are quite concise, make use of a 5-point Likert scale, and collect rather subjective information. None of them asks respondents why they tick a particular answer. Nonetheless, the current study included also objective information regarding the participating families by providing an overview of child and family characteristics and taking the parental work situation into account. Methodological pluralism in mind (cf. Isaacs et al., 2007; Samuel et al., 2012), future survey research on family quality of life and even on the

family-centered approach may ask respondents to motivate their answer on a specific question, to provide more information about their situation in each included family quality of life domain, or to write some additional comments on the realization of the family-centered approach factors in their family-professional collaboration.

Third, applying the presented survey design and not a longitudinal or an (quasi)experimental study, causal interpretations about the connection between the realization of family quality of life and the studied predictors are actually not possible (de Vaus, 2001). In addition, other variables as for example (maternal) positivity (cf. Jess, Hastings, & Totsika, 2017; Trute, Benzies, & Worthington, 2012) and parental coping style (cf. Glidden, Billings, & Jobe, 2006) might underlie and possibly explain the association between the realization, perception, and assessment of both family quality of life and the family-centered approach and influence parents' assessment of their child's support needs. Ferrer, Vilaseca, and Olmos (2017) found a positive relation between family quality of life (domains) and parents' positive perceptions to their child with an ID and their perceived control. Maybe, parents' positive perceptions and perceived control also affect how they interact with the professional and the way they experience and report on this family-professional collaboration.

Fourth and associated with this, self-efficacy beliefs of parents were not included in this study. Research demonstrated that the relation between the family-centered approach and family quality of life is rather indirect and is mediated through help receiver self-efficacy beliefs (Dempsey & Keen, 2008; Dunst et al., 2006b, 2007; Trivette et al., 2010). By means of setting up (more long-term) intervention studies and

including parents' self-efficacy, future research can attempt to meet some of the issues mentioned above.

Along with the study's limitations, its strengths have to be mentioned, starting with a core aspect of the study theme, namely the relation between the family-centered approach and family quality of life. Although the current study focusses on the parental viewpoint and sheds only light on one side of the family-centered story (cf. Jansen, van der Putten, Post, & Vlaskamp, 2018; Vanderkerken et al., 2019), it is the first of its kind investigating the relation between family quality of life and the family-centered approach in detail. Furthermore, the use of both the EPS and the HPS and especially of their factors made it possible to compare the explanatory value of both instruments for different family quality of life domains. Searching for the best predicting models and taking into account the number of predictors, especially the combination of relational practices (factors) and participatory practices (factors) reached the highest explained variability. The negative contribution (i.e., negative slope) of collaboration and relational helping practices when added on top of comfort or participatory practices to enlarge explained variability can probably be clarified by the high correlation between these variables and the possibly following - albeit limited - multicollinearity. Further research can keep this result in mind and work with the separate contribution of each HP and EP factor on family quality of life. Adding the parental work situation and the child's support needs to the HP and EP models created the chance to study the relative contribution of predictors at different levels of the unified framework to family quality of life. In general, it was demonstrated that the variability in family quality of life (domain) scores could be better explained when

also these variables at the family and individual level were added to the models.

The recruitment strategy can be considered as an additional strength of this study. Instead of working with convenience sampling and running the risk of only including immediately motivated and out-spoken Dutch-speaking families, we tried to systematically approach and invite families in the survey so that the included group of families was as representative as possible for the group of families having a child with an ID and receiving HBS. However the presented study population concerns a quite small portion of the total number of these families (circa 2%, cf. Selection of Participants), the present study did reach a participation rate of approximately 34 %¹.

We summarize that in the present study on families with children (0-18 years) with an ID receiving HBS, generally, a positive relation between family quality of life and components of the family-centered approach was identified. Different relations with the family-centered approach were seen for the different family quality of life domains. The parental work situation appeared a significant predictor of total family quality of life, family interactions, and parenting. Support needs of the child with an ID significantly impacted emotional wellbeing in the HP models and the best predicting models.

¹ Because one per two family workers (with one year experience) and maximum three families per family worker were selected, the potential sampling population was rather narrow and consisted of circa 170 families and 56 family workers (estimation based on the forms completed by the services for HBS during the selection procedure).