

Research Article

Family-centered practices in home-based support for families with children with an intellectual disability: Judgments of parents and professionals



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Abstract

Background: The realization of the family-centered approach (FCA) in home-based support (HBS) for families with children with an intellectual disability (ID) in Flanders was investigated, and parents' and family workers' perspectives were compared. The relation between parents' educational level, the family worker's education, and his/her experience in HBS; and parents' and family workers' judgments on the realization of the FCA was considered. **Method:** Parents (N = 58 families) and family workers (N = 46) completed the helpgiving practices scale and the enabling practices scale. **Results:** The FCA was largely present, parents rated its realization higher than family workers. Considering family workers' answers, parents' educational level appeared an important factor for parental autonomy. **Conclusions:** The study confirms recent research on the realization of the FCA. Including different perspectives, a nuanced view on the realization of the FCA was obtained. Further research on the concrete meaning, interpretation, and elaboration of the FCA is needed.

Keywords

family-centered, survey, intellectual disability, home-based support

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Background

The present study deals with the realization of the family-centered approach (FCA) in home-based support (HBS) for families with children with an intellectual disability (ID) in Flanders. The FCA (Dunst et al., 1994) refers to a particular way in which professionals work with families who have a child with a disability. The FCA stems from changes in thinking and attitudes regarding the collaboration with parents and families that were noticeable across multiple fields of human services (Allen and Petr, 1998; e.g. social work, education, mental health, and health care). It has been generally agreed that having a child with a disability affects the whole family functioning (Turnbull et al., 2007), that, in particular, the family is the constant factor in the life of the child (Shelton and Stephanek, 1994), and that children are best supported in the context of the family (Samuel et al., 2012; Summers et al., 2005). Hence, to meet the needs of both the child and the family, a family-centered (FC) support style, referring to a more equal, dialogical, and empowering way of interacting with families, was presented (Allen and Petr, 1998).

More specifically, the FCA is characterized by (a) a focus on the family as the support unit; (b) a strong family–professional collaboration in which everyone's role, expertise, and contribution are respected; (c) an individualized approach in which support is adapted to the family's specific needs and situation; (d) the importance of the family's informed choice; (e) acknowledging and building on the family's strengths; and (f) enlarging or strengthening the family's support network and appealing to this network (Allen and Petr, 1996; Brown et al., 2007; Dunst, 1995).

FCA's core characteristics can be divided into relational and participatory practices (Dunst et al., 2002). Relational practices refer to interpersonal practices used to create effective relationships with families (e.g. empathy) and attitudes and beliefs about families (e.g. belief in parents' capabilities). Participatory practices include practices responsive to the family needs and actions that provide families with opportunities to be actively involved (e.g. information exchange). According to Dunst and colleagues (Dunst, 2002; Dunst et al., 2002), especially participatory practices differentiate between "low" and "high" FC programs.

In scholarly literature, much attention has been paid to the conceptualization of the FCA. Based on the already mentioned changes in thinking regarding collaboration with families and parents, key principles and value statements of the FCA were elaborated (Allen and Petr, 1998; Dunst and Espe-Sherwindt, 2016). Several instruments measuring FC practices were developed, as, for example, the helpgiving practices scale (HPS) (Dunst et al., 1996) and the family focused intervention scale (Mahoney et al., 1990). In the context of health care and rehabilitation, the Measures of Processes of Care (MPOC; King et al., 1996) was developed and several adaptations were made (e.g. MPOC-profound intellectual and multiple disability (PIMD), Jansen et al., 2013; MPOC-service provider, Woodside et al., 2001).

Using the FC instruments, research has been conducted on the implementation of the FCA in support for families with children with disabilities and its consequences at the level of the child, parent, and family (e.g. Cunningham and Rosenbaum, 2014; Dempsey and Keen, 2008; Dunst et al., 2007). In the health care and rehabilitation context and measured through the MPOC, "providing general information" was indicated by parents of children with disabilities as occurring least in collaborations with professionals, meanwhile "respectful and supportive care" occurred most frequently (e.g. Dickens et al., 2011; Granat et al., 2002; Wilkins et al., 2010). In several of these MPOC studies (e.g., Dyke et al., 2006; Jeglinsky et al., 2012; Raghavendra et al., 2007) and in Jansen et al.'s study (2018) on the support of persons with PIMDs, professionals' viewpoints were included as well. However, only Jansen et al. (2018) statistically compared parents' and

professionals' viewpoints regarding the realization and the importance of the FCA. Although, in that study, parents evaluated the general collaboration with all professionals involved in their child's support, making a nuanced assessment rather difficult and paying no attention to each specific collaboration (Jansen et al., 2018; Nijhuis et al., 2007). Other quite rare studies statistically comparing the viewpoints of parents and professionals on the realization of the FCA are the studies of McWilliam et al. (2000) and Murphy et al. (1995).

A meta-analysis of 18 studies in the context of a support program for families with young children with and without disabilities (Dunst and Trivette, 2005) demonstrated that, according to parents, relational practices were more present than participatory practices in their collaboration with professionals. The professional perspective was, however, not included in these studies. Additionally, differences were seen among support settings; the FCA was stronger present in HBS compared to community-based centers. According to Dunst and Trivette (2005), the one-to-one relation of a home setting facilitates FC working and focusing on the family. Furthermore, a home setting was demonstrated to increase the chance for parental involvement in early intervention (Dunst et al., 2014). Investigating professionals' judgments, McWilliam et al. (2000) also found a stronger realization of the FCA in HBS. Professionals' perspectives were also incorporated in the studies of Dunst et al. (1991), Bailey et al. (1992), and McBride and colleagues (1993), identifying a general discrepancy between the FC philosophy, its core values and ideal practices on the one hand and its actual implementation in family support on the other hand.

Summarized, the FCA has already quite a history (see Dunst and Espe-Sherwindt, 2016) and is strongly emphasized in the literature (Blue-Banning et al., 2004; Brown et al., 2007). Also, Flemish policy documents (Vandeurzen, 2010) put forward empowering, demand-driven support, informed choices, and working in the context and with the network of persons with disabilities. However, there is a lack of knowledge about the current realization of the FCA and its core components in the support for families with children with an ID in Flanders.

Additionally, parents' and professionals' judgments on the topic have been only occasionally statistically compared, leaving an important part of the complex interaction between parents and family workers neglected (see Jansen et al., 2018; Nijhuis et al., 2007). More knowledge on the extent to which parents and support workers evaluate the way they collaborate in a similar or different way is needed and will provide us with implications for a more optimal assessment and consequently also a more optimal enhancement of the FCA (see Dempsey & Keen, 2008).

Moreover, in contrast to a couple of international studies on barriers and facilitators of the FCA (e.g. Lotze et al., 2010; McWilliam et al., 2000; Wright et al., 2010), no research has been undertaken regarding the characteristics of families and family workers and other factors that influence, hinder, or facilitate its implementation in the Flemish context. Nonetheless, more knowledge on influencing factors might make family workers more conscious about possible pitfalls in their work as well as more anticipating and looking forward for chances and possibilities. Based on the international research, it can be concluded that education and training for family workers in (components of) the FCA are important for its successful implementation (King et al., 2003; Lotze et al., 2010; Raghavendra et al., 2007). Furthermore, the experience of the family worker was demonstrated to play a helping role in the realization of the FCA (McWilliam et al., 2000). Concerning parents, somewhat ambiguous results were found regarding their educational level and the link with their judgments on the realization of the FCA (Dunst and Trivette, 2005; Summers et al., 2005).

The present study firstly aimed to investigate the realization of the FCA in HBS for families with children (0–18 years) with an ID in Flanders. HBS concerns a combination of parenting

support, psychological support, early intervention, and information and is provided at the living place of the family by specialized regional ambulatory or multifunctional services (see VAPH, 2019). Considering the potential difficulties of a paradigm shift from a more professionally centered to a more FC way of helpgiving (e.g. giving up the idea of having control over the family, being a partner instead of the decision-maker, see Dunst et al., 1991; Espe-Sherwindt, 2008), it was expected that the FCA was only to some extent realized in HBS for families with children with an ID in Flanders and that relational practices would be more present than participatory practices.

Secondly, this study aimed to compare the viewpoints of parents with a child with an ID and their family workers regarding the realization of the FCA in HBS. Based on some previous research (Dyke et al., 2006; Jansen et al., 2018; Murphy et al., 1995), it can be expected that parents will indicate a higher level of FC working than professionals. However, McWilliam et al. (2000) found professionals reporting more FC practices than parents experienced.

Thirdly, this study aimed to study the impact of the parents' educational level and of the education of the family worker and his/her experience in offering HBS on the realization of the FCA according to parents and family workers. Concerning parents' educational level, lower realization scores can be expected for higher educated parents (see Summers et al., 2005). Conversely, family workers might experience putting into practice the FCA, and particularly the participatory component, more challenging when parents have a lower educational level. Regarding professionals' education, a higher level of FC working was hypothesized in collaborations with family workers who completed an education about which can be expected that the collaboration with families and (aspects of the) FCA is herein integrated (see King et al., 2003; Lotze et al., 2010; Raghavendra et al., 2007). In addition, a higher level of FC working was expected when family workers have more experience in HBS (see McWilliam et al., 2000).

Methods

Selection of participants

We aimed to include family workers with more than 1-year experience in offering HBS, and families having a child (0–18 years) with an ID (intelligence quotient < 70) receiving HBS monthly or more intensively for at least 6 months. In Flanders, HBS for families with a child with an ID is provided by specialized regional ambulatory services or multifunctional services. Families and family workers were recruited by these services through a detailed selection procedure (see Vanderkerken et al., 2018) linked to a broader research project on family quality of life and the FCA. Participating services were asked to randomly select 50% of their family workers with more than 1-year experience in offering HBS. Subsequently, for each selected professional, services were asked to randomly select the maximum three families (to limit family workers' time investment in the broader research project) and ask them to participate. Randomization was done by alphabetically listing the family workers and families and selecting the family workers/families with a specific number. The research received ethical approval by the social and societal ethics committee of the KU Leuven.

Procedure

Families and professionals who agreed to participate and gave written informed consent received questionnaires and a return envelope by post or links to online questionnaires (Qualtrics LLC, 2015; www.qualtrics.com) by e-mail. They were asked to use the maximum 1 month to fill them

out. If they had questions while completing the questionnaires, participants could ask for help (by phone, e-mail, or, for families, by filling in the questionnaires with the researcher during a home visit). Families and family workers who did not complete and return the questionnaires within 1 month received one (or more) reminder(s). One month before closing the survey, a final reminder was sent.

Instruments

To start, parents of participating families were asked to complete a short questionnaire concerning their family and the child with an ID. Similarly, family workers completed a short questionnaire on demographics and their professional experience.

Parents' (one agreed judgment per family) and family workers' judgments regarding the realization of the FCA in their collaboration were asked for by the HPS (Dunst et al., 1996) and the enabling practices scale (EPS; Dempsey, 1995). The HPS (Dunst et al., 1996) includes 25 items on professional's helpgiving practices related to empowerment outcomes in families (Dunst et al., 2006). By a five-point Likert-type scale, ranging from *rarely* (1) to *almost always* (5), respondents are asked to what extent they experience the described practices or situations in the family–professional collaboration. Factor analysis of the HPS revealed two factors: participatory helpgiving practices (PHP) and relational helpgiving practices (RHP; Dunst et al., 1996, 2002).

The EPS (Dempsey, 1995) includes 24 items based on the 12 enabling and empowering practices defined by Dunst et al. (1988). By this instrument too, respondents are asked to what extent they experience the described FC practices or situations. The EPS is completed by means of a five-point Likert-type scale, ranging from *not true at all* (1) to *very true* (5). Factor analysis resulted in three factors: comfort with relationship (Com) referring to parents' comfort during the collaboration; collaboration (Col) referring to the parent–professional collaboration and the collaboration with the families' network; and parental autonomy (PaAut; Dempsey, 1995; Dempsey et al., 2009). Com concerns relational practices, whereas Col and PaAut refer to participatory practices (Dunst and Espe-Sherwind, 2016).

In consultation with their developers, the HPS and the EPS were translated into Dutch and back-translated into English to control for meaning conservation. By changing the subject of the items from "our family worker" to "I," and changing "us" to "these parents/this family" and "my child/children" to "their children," both instruments were adapted to the professional viewpoint.

Participants

Parents. The judgments of parents of 58 families were included in this study. Forty-three families responded on paper (6 of them chose a home visit) and 15 families worked online. The families were supported by nine services for HBS. Table 1 offers more information about the participating families.

Family workers. The judgments of 46 family workers, resulting in data on 93 collaborations, were included. Most of them gave their judgment about the collaboration with three families (n = 17). Thirteen family workers reported about working with 2 families and 16 family workers responded about their work with 1 family. Twelve family workers responded on paper and 34 of them worked online. The 46 family workers worked for 11 services for HBS. More information about the participating family workers is presented in Table 2.

Table. I. Characteristics of the participating families and the children with an ID (N = 58).

Characteristic	n	Range	М	SD
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			
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				
·	11			
Single parent: Man	1			
Single parent: Woman	10			
2	46			
3	1			
Parents' educational situation ^{c,d}				
One or more parents completed higher education	23			
All parents attended compulsory education	35			
Parents' employment situation ^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			
Gender of the child with an ID				
Male	43			
Female	15			
Age of the child with an ID ^e		1–19	8.66	5.74
Type of ID of the child with an IDf				
Mild ID	П			
Moderate ID	30			
Severe/profound ID	8			
Unknown	9			
Additional disabilities/problems of the child with an ID ^g	•			
Hearing disability	6			
Visual impairment	П			
Motor disability	20			
Speech or language impairment	23			
Emotional or behavioral problems	18			
- Linotional of benavioral problems	10			

(continued)

			11
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Characteristic	n	Range	М	SD
Autism spectrum disorder	32			
No additional disabilities or problems	5			

Notes: M, mean; SD, standard deviation; n, number of persons or families; N, total number of families; ID, intellectual disability.

Data analysis

Data were entered in Microsoft Excel. Controlling for errors, a second person independently reentered 22% of the data on family and professional characteristics and 50% of the families' HPS and EPS data. Data analysis was carried out through SPSS (24.0; IBM, 2016); effect sizes were calculated by means of GPower (3.1.9.2; Faul et al., 2007).

In the first part of the analyses, parent (N = 58 families) and family worker (N = 93 judgments) data sets were treated separately and in parallel. Total scores and factor scores for the HPS and the EPS were calculated. Because some parents seemed confused by the negation in one RHP item, this item was excluded. The two HP items that were mentioned loading meaningful (Field, 2009) and almost the same on both factors (i.e. "trustworthiness" and "supports decisions," Dunst et al., 1996, 2002) were only included in the total HP score. EPS factor scores were calculated according to the factor structure mentioned by Dempsey (1995). Similarly, the two EP items loading meaningful (Field, 2009) and around the same on two factors (i.e. "needs" and "solve"; Dempsey, 1995) were only included in the calculation of the total EP score. To facilitate comparison and because of some missing data (16 data points of the 7248 and maximum 3 data points per participant per questionnaire), total scores and factor scores were calculated using average scores, with a maximum of 5.

For the parent data as well as for the family worker data, descriptive statistics (i.e. means, standard deviations (SDs), and five-number summaries; Hoaglin et al., 1983) and 95% confidence intervals (CIs) of the means were calculated for the HPS and the EPS. The subscales of each instrument were compared by means of paired t-tests. Pearson's correlations were calculated for each instrument and between the total scores of both instruments. To control for potential dependencies in the FC data resulting from their partly clustered structure (see Selection of Participants; some families were supported by the same family worker), intraclass correlations (ICCs) and design effects (see Maas and Hox, 2005) were determined. All design effects were smaller than two (see Maas and Hox, 2005; Muthén and Satorra, 1995), so it was decided to continue the data analysis considering the data as nonclustered units.

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

bWhen grandparents were mentioned as parents, they are referred to by the word parents.

^cForeign degrees were also included.

^dFor the families where grandparents were mentioned as a parent, their educational level and employment situation were also taken into account.

^eCalculated from September 30, 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 became 19 years old.

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.

gBased 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.

Characteristic	n	Range	М	SD
Gender				
Woman	44			
Man	2			
Age		26-60	39.72	9.66
Education ^a				
Educational sciences: special education (i.e. orthopedagogue and MS)	13			
Orthopedagogy (BA) ^b	12			
Social work (BA)	7			
Psychology (MS)	6			
Applied psychology (BA) ^c	3			
Speech and language therapy (BA and MS)	2			
Occupational therapy (BA)	4			
Preprimary education teaching (BA)	3			
Years of professional experience in offering HBS		I-32	9.59	7.64
Percentage employment in HBS		6-100	71.11	23.49

Table 2. Characteristics of the family workers (N = 46).

Notes: M, mean; SD, standard deviation; n, number of family workers; N, total number of family workers; HBS, home-based support; MS, master's degree; BA, bachelor's degree.

For the second part of the analyses, a data set linking the families and the family workers in pairs (N = 57) was built. Paired *t*-tests were used to investigate the differences between parents' and family workers' perceptions on their collaboration. In addition, Cohen's *ds* were calculated as a measure for the size of the effect. For all analyses, a significance level of 0.05 was used.

In the third part of the analyses, the data set with family–professional pairs (N=57) was used, but parent and family worker data were treated separately and in parallel. For parents and professionals, the separate impact of the three variables on each outcome variable (i.e. HP, RHP, PHP, EP, Com, Col, and PaAut) was investigated. Family workers' education was categorized as: (1) education expected to include collaboration with families and (components of) the FCA (e.g. social work and orthopedagogy; n=39) and (2) other education (e.g. psychology and occupational therapy, n=18). The same was done for parental education: (1) one or more parents completed higher education (n=22) and (2) all parents attended compulsory education (n=35). Family worker's experience in HBS was implemented as a continuous variable. To control the family-wise error rate for the three tests (i.e. two independent t-tests and linear regression) on each outcome variable, a Bonferroni–Holm correction (Holm, 1979) was implemented. Adjusted α 's were 0.0167, 0.025, and 0.05.

Results

Realization of the FCA

Parents. Table 3 presents means, SDs, and 95% CIs of the means for the HPS and the EPS for parents. Both for the HPS and the EPS, means were higher than 4. SDs were rather small. In

^aSome family workers completed multiple educations.

^bOne of them had also a master's degree in criminology.

^cOne of them had a master's degree in mental health sciences.

	Helpgi	ving practices	scale		Enabling pra	ctices scale	
	HP	RHP	PHP	EP	Com	Col	PaAut
Parents ^a M (SD)	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)

95% CI [4.59-4.76[=] [4.59-4.77] [4.57-4.75] [4.35-4.56] [4.42-4.64] [4.12-4.40] [4.39-4.63]

4.12 (0.36)

4.30 (0.39)

[4.05–4.19] [4.22–4.38] [3.54–3.76]

3.65 (0.53)

Table 3. Distribution of HP and EP scores for parents (N = 58) and family workers (N = 93).

4.39 (0.40)

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; 95% Cl: 95% confidence interval of the mean.

4.43 (0.33)

95% CI [4.36-4.49]

Family workers^b M (SD) 4.43

4.43 (0.37)

[4.35–4.50] [4.31–4.47]

Table 4. Comparison of HP and EP subscale scores for parents (N = 58) and family workers (N = 93).

	Helpgivi	ng practio	es scale				Enabling	praction	ces sca	ale		
		RHP-PHP	'	C	om-Co	I	Со	m-PaAı	ut	Co	I-PaAut	:
Parents ^a	t(57) 0.50	р 0.62	d 0.07	t(57) 6.02	р <0.01	d 0.79		р 0.75		t(57) -2.98	р <0.01	d 0.36
Family workers ^b	t(92) 1.03	р 0.3 I	d 0.11	t(92) 13.45	р <0.01	d 1.39	t(92) -4.3 l	р <0.01	d 0.45	t(92) -12.16	р <0.01	d 1.26

Notes: HP: helpgiving practices; RPH: relational helpgiving practices; PHP: participatory helpgiving practices; EP: enabling practices; Com: comfort with relationship; Col: collaboration; PaAut: parental autonomy; d: Cohen's d.

general, scores for the EPS were somewhat lower than for the HPS. Mean scores for RHP and PHP and for Com and PaAut were quite similar and paired t-tests showed no statistically significant differences for these subscales. The mean for Col was remarkably lower than for Com and PaAut; paired t-tests confirmed that these differences were significant (see Table 4). All Pearson's correlations for the HPS (r_{HPRHP} , r_{HPPHP} , r_{RHPPHP}) were high. For the EPS, high (r_{EPCom} , r_{EPCol} , r_{ComCol}), low ($r_{EPPaAut}$), and very low ($r_{ComPaAut}$, $r_{ColPaAut}$) correlations were found (see Table 5). Pearson's correlation between HP and EP was high ($r_{HPEP} = 0.72$).

Family workers. Means, SDs, and 95% CIs of the means for the HPS and the EPS for family workers are also presented in Table 3. With the exception of Col, all means were higher than 4. SDs were rather small. For family workers too, scores for the EPS were somewhat lower than for the HPS. Also for family workers, paired t-tests did not identify significant differences between RHP and PHP. All studied between-subscale differences for the EPS were statistically significant (see Table 4). For the HPS, Pearson's correlations were high (r_{HPRHP} , r_{HPPHP}) to moderate (r_{RHPPHP}). High (r_{EPCom} , r_{EPCol}) to moderate (r_{ComCol} , $r_{EPPaAut}$, $r_{ComPaAut}$) correlations were seen for the EPS,

^aParents of 58 families gave their judgment.

^bThe 93 judgments were formulated by 46 family workers.

^aParents of 58 families gave their judgment.

^bThe 93 judgments were formulated by 46 family workers.

	Н	elpgiving pr	actices so	ale		Enablin	g practice	s scale	
		HP	RHP	PHP		EP	Com	Col	PaAut
Parents ^a	HP	1.00			EP	1.00			
	RHP	0.93 ^c	1.00		Com	0.95°	1.00		
	PHP	0.93°	0.74 ^c	1.00	Col	0.88 ^c	0.77 ^c	1.00	
					PaAut	0.37 ^c	0.19	0.17	1.00
Family workers ^b	HP	1.00			EP	1.00			
,	RHP	0.87 ^c	1.00		Com	0.94 ^c	1.00		
	PHP	0.91°	0.60°	1.00	Col	0.71°	0.51°	1.00	
					PaAut	0.64 ^c	0.56 ^c	0.15	1.00

Table 5. Pearson's correlations for the HPS and EPS for parents (N = 58) and family workers (N = 93).

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

Table 6. Comparison between parents and family workers (N = 57).

	Helpgi	iving practice	s scale		Enabling pra	actices scale	
	HP	RHP	PHP	EP	Com	Col	PaAut
M _{Parents} (SD)	4.67 (0.32)	4.68 (0.34)	4.66 (0.35)	4.45 (0.39)	4.53 (0.41)	4.25 (0.54)	4.51 (0.45)
M _{FamilyWorkers} (SD)	4.43 (0.32)	4.43 (0.38)	4.39 (0.37)	4.10 (0.37)	4.29 (0.39)	3.63 (0.55)	4.48 (0.50)
t(56)	3.98	3.71	3.74	4.61	3.16	5.74	0.33
Þ	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	0.75
d	0.54	0.49	0.50	0.61	0.42	0.76	0.04

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; d: Cohen's d.

except for $r_{ColPaAut}$, for which a very low correlation was found (see Table 5). Pearson's correlation between HP and EP was high ($r_{HPEP} = 0.81$).

Comparison between parents and family workers

Table 6 presents the results of the comparison between parents' and family workers' judgments. Parents generally reported higher scores than family workers for both the HPS and the EPS and all subscales. For HP, RHP, and PHP, the differences between both groups were statistically significant. For the EPS, statistically significant differences between parents and family workers were seen for EP, Com, and Col. No significant difference was found for PaAut. Effect sizes (i.e. Cohen's ds) indicated very small (PaAut) to small (RHP and Com) and medium (HP, PHP, EP, and Col) between-group effects.

^aParents of 58 families gave their judgment.

^bThe 93 judgments were formulated by 46 family workers.

^cCorrelation is significant at the 0.01 level.

Relation with family and family worker variables

Table 7 presents the results of the independent t-tests and linear regressions aimed to investigate the relation between the realization of the FCA and family and family worker characteristics. As previously mentioned, a Bonferroni–Holm correction (Holm, 1979) with adjusted α 's of 0.0167 (for the smallest p-value), 0.025 (for the second smallest p-value), and 0.05 (for the largest p-value of each outcome variable) was implemented to control the family-wise error rate for the three tests on each outcome variable. By this rather strict procedure, a significant relation was seen for parental education and PaAut, in the family worker data set. Family workers reported higher parental autonomy in families where one or more parents completed higher education compared to families where all parents completed compulsory education ($M_{HigherEducation} = 4.72$, SD = 0.32; $M_{CompulsoryEducation} = 4.33$, SD = 0.53, t(55) = 3.06, p = <0.01). No additional relations were found.

Discussion

The first research question of this study concerned the realization of the FCA in HBS for families with a child (0–18 years) with an ID in Flanders. Considering the rating scales' ranges, the quite high mean scores and corresponding CIs for HP and EP show that the FCA is largely present in HBS, according to parents and family workers, which were rather unexpected. Inconsistent with our expectations, the HPS results of parents and family workers indicate that relational practices and participatory practices might be equally represented in HBS for families with a child with an ID in Flanders. Nonetheless, for both parents and professionals, the scores for Col were remarkably lower than for the other EP factors, indicating that collaboration (with the family and its network) is less present than (building) a comfortable relationship and parental autonomy. Especially, the item on encouraging families to apply to their network for advice was scored quite low (compared to the others) by both parents and professionals. Our general positive findings on the realization of the FCA correspond with results obtained in other countries and contexts (e.g. Jeglinsky et al., 2012; Raghavendra et al., 2007) and rather contrast with older studies on the topic (Bailey et al., 1992; Dunst et al., 1991). Nonetheless, the overall discrepancy between the realization of relational and participatory practices (see Dunst, 2002; Dunst et al., 2002) was not seen in our study. Considering the correlations between the scales and subscales, especially the low to very low correlations including parental autonomy are striking. Similar correlations were, however, found by Dempsey et al. (2009). These results might be partly explained by the number of items forming the PaAut subscale (i.e. 4; compared to 13 for Com and 5 for Col). The limited reevaluation of the instrument in other settings may also explain the limited connection between its parts (see Carter et al., 2016). Nonetheless, based on the present study, it seems not irrelevant to split participatory practices into collaboration and parental autonomy for a more nuanced insight in these kinds of practices.

The second research question pertained to the comparison between the judgments of parents and family workers regarding the realization of the FCA. Generally, higher scores were found for parents and paired *t*-test determined the observed differences as statistically significant, with the exception of PaAut. Hence, Flemish parents with children with an ID are more positive than family workers about the realization of the overall FCA, the presence of relational practices (both in the form of RP and Com), and especially the aspect of collaboration. Parental autonomy is equally presented in HBS according to parents and professionals. Our results are in line with Jansen et al.

Table 7. Relation between characteristics of the family and the family worker and the FCA for parents (N = 57) and family workers (N = 57).

I			<u> </u>	Helpgiving practices scale	; practic	ses scal	o l							Enabl	Enabling practices scale	actices	scale				
물	보	_			RHP	ĺ		PH			6			Com			Co	ĺ		PaAut	
β $t(55)$ ρ	t()	55)	ф	β	t(55)	þ	β	$t(55)$ ρ	ф	β	$t(55)$ ρ	þ	β	t(55) p	ф	β	t(55) p	þ	β	t(55)	ф
	-	2 07	2.07 0.04		2.12	0.04		1.73	0.09		8	0.24		1.83 0.07	0.07		-0.40 0.69	69.0		0.79	0.43
		;			! i) :)	:					?			;	<u>:</u>
I		1.07	-1.07 0.29		-0.82 0.41	0.41		<u></u>	0.24		-I.80 0.08	0.08		-1.45 0.15	0.15		-2.06	0.04		-0.85	0.40
0.00		0.36 0.72	0.72	0.00	0.62	0.54	0.00	0.22	0.83	0.00	0.07	0.94	0.00	-0.04	0.97	0.00	0.14	0.89	0.00	-0.03	0.98
		0.97 0.33	0.33		1.37	0.18		0.15	0.88		1.67	0.10		1.84	0.07		-0.90 0.37	0.37		3.06	<0.01°
		1.87	1.87 0.07		1.45	0.15		1.73	0.09		0.55 (0.59		0.62	0.54		1.20 0.24	0.24		-0.37	0.72
190 150- 000	- 1	0.51	190	0 0	-0.01 - 1.16.025	0.25	00	91.0- 00.0	88	000	000 -056 058	0.58	00	0 00 -0 73	0.47	00	000 -043 067	290	000	-0.33	0.74
				;) : :) ;	}						:		2				

Notes: HP: helpgiving practices; RPH: relational helpgiving practices; PHP: participatory helpgiving practices; EP: enabling practices; Com: comfort with relationship; Col: collaboration; PaAut: parental autonomy; FCA: family-centered approach.

^aThe judgments of parents of 57 families were used.

^bThe 57 judgments were formulated by 36 family workers.

^cA Bonferroni-Holm correction (Holm, 1979) was implemented. Adjusted x's were 0.0167 (for the smallest p value), 0.025 (for the second smallest p-value), and 0.05 (for the largest p-value of each outcome variable).

(2018) concluding that parents of people with PIMD gave higher scores on the realization of the FCA than professionals for enabling and partnership (a participatory component) and respectful and supportive care (a relational component; see Dunst and Espe-Sherwind, 2016) and with the results of Murphy et al. (1995) who found significant higher FC scores for parents than for professionals, with the exception of "respecting the family as the decision maker."

The third research question considered the impact of family and professional characteristics on the judgments about the realization of the FCA. Against our expectations, no impact was found for the education of the family worker and his/her experience. Nonetheless, we only considered the family workers' initial education. Several of them completed multiple additional trainings. A significant relation was found between parents' educational level and parental autonomy as reported by professionals: family workers experienced higher parental autonomy in families where parents had a higher educational level. This result was not found from a parental viewpoint. Hence, more research is needed considering the concrete meaning, interpretation, and elaboration of providing information and decision-making for families as well as for professionals. Hereby, the relation with empowerment has to be taken into account. Research demonstrates that the FCA benefits self-efficacy practices of parents and families (Dunst and Espe-Sherwind, 2016) but maybe this relation is more complex and even bilateral.

The first strength of this study concerns the contact with and especially the recruitment of participants. To lower the participation barrier, participants could ask for help while completing the questionnaires. When participants did not respond betimes, reminders were sent. As mentioned, parents and family workers were included through a detailed selection procedure. We aimed to include a representative group of families and family workers in HBS and to avoid convenience sampling of professionals strongly convinced of or critical against the FCA, and of immediately enthused, out-spoken Dutch-speaking families. Nevertheless, not every invited family or professional was able to or interested to participate. Taking into account the families and professionals who subscribed to the study however, response rates were 62.24% and 96%, respectively. The second strength applies to the data analysis. By means of ICCs and design effects (Maas and Hox, 2005), the impact of the partially clustered structure of the data was investigated and a motivated choice for further analyses was made. That way, the present study may inspire further research to cautiously handle (partly) clustered data.

Along with these strengths, two limitations should be mentioned. Firstly, whereas also studies outside the health care and rehabilitation context (e.g. Jansen et al. 2018) employed the very popular and widely spread MPOC, we used the HPS and the EPS, making comparison with previous research a little more difficult. After equating several FC instruments, the HPS and the EPS appeared, however, to be most directly suitable for this study and the context of HBS. Secondly, this study had solely a quantitative focus; the reason why participants ticked an answer was not asked for. Further research can explore the qualitative or mixed methods field and enrich and nuance our results by asking why parents and professionals chose a specific response. Associated herewith, the attitudes and beliefs of both groups toward the FCA in HBS must also be taken into account. (Interview) questions can include thoughts about the FCA in general (see King et al., 2003) but should also go more deeply into very concrete practices of families and professionals without explicitly mentioning the FC label. After all, the FCA refers to an umbrella concept including several core characteristics, which real meaning can only be found in daily family-professional interactions (see Blue-Banning et al., 2004).

Furthermore, two general remarks should be made. The first remark concerns the instruments. It was already mentioned why the HPS and the EPS were used and their combination can be pointed

out as a strength of our study. Nonetheless, difficulties were experienced when scoring them. Regarding the HPS, several versions of the instrument (long, short, and modified) and various ways of clustering the items into the categories RHP and PHP were found, based on multiple factor analytical studies (Dunst et al., 2006). Furthermore, also clustering of 20 slightly different formulated HP items into four subdomains was presented (Trivette and Dunst, 2007). To stay as close as possible to the instrument used (Dunst et al., 1996), we applied the classification mentioned in that article, taking into account that two items had meaningful and approximately identical loadings on both factors. For the EPS too, the classification mentioned by the author (Dempsey, 1995; Dempsey et al., 2009) was used. Nonetheless, also another factor structure has been found for this instrument (Carter et al., 2016).

The second remark is related to the overall FCA. Some of its core aspects and some questionnaire items might include a contradiction. For instance, providing support based on the family's needs might create a field of tension with focusing on the family's strengths instead of weaknesses. Similarly, the equal parent–professional partnership can be challenging to reconcile with the FC way of decision-making; by the parents as informed decision-makers. Likewise, for parents, in particular, the collaboration with the professionals and the provision of support and information can bring changes and progress at the child level. Some parents (and especially during home visits) made small remarks about these components. Areas of tension within the FCA and (priority) conflicts between the definition's elements were also discussed by Allen and Petr (1996, 1998) who formulated a modified definition in which the focus on the family, the family's choice, and the adaptation of a strengths perspective were the core elements.

Conclusion

Based on the present study, a positive conclusion can be made. According to both parents and family workers, the FCA is largely present in Flemish HBS for families with children with ID. Hence, it can be concluded that the generally agreed values regarding the support of families with children with a disability have found their translation in practice and that the principles of empowerment and of respectful and equal interaction are noticeable in this kind of family support. Regarding offering demand-driven support and especially concerning working on and with the network of families, there is still room for improvement. The fact that parents were more optimistic than family workers about the realization of the general FCA, the presence of relational practices, and the collaboration component shed light on the importance of including both perspectives for an optimal assessment of the FCA. A survey study makes use of general descriptions of behavior. Future qualitative or mixed methods research should zoom in on the daily family—professional interactions in HBS and especially on the motives of each interaction member to collaborate the way they do.

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